

Special Article - Community Healthcare

Treating Women with Genito-Pelvic Pain/ Penetration Disorder: Influences of Patient Agendas on Help-seeking

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Abstract

This study sought to investigate the help-seeking experiences and motivations of women seeking treatment for Genito-Pelvic Pain/Penetration Disorder (GPPPD) that are important for coping with this chronic health condition in community health care settings. Genito-Pelvic Pain/Penetration Disorder (GPPPD) is a common chronic genital pain condition, affecting anywhere from 3-18% of women in the general population, that can cause significant personal and relational burden. Twenty-six Australian women with GPPPD (50% with provoked and localized vulvodynia; age range 19-43 years) participated in either two interviews or an on-line survey designed to gather information about treatment seeking for GPPPD. Data was thematically analysed using grounded theory and phenomenological methods. The women reported treatment support from a variety of community health care professionals (HCPs), and which support they perceived as not always helpful. Three consultation expectancies were identified. First, that the HCP would validate the reality of their symptoms to comprise a treatable condition, second that an HCP who was knowledgeable about GPPPD likely would be patient centered, and third that a strong treatment alliance with the HCP was important for the successful management of GPPPD. GPPPD can cause significant personal and relational burden, and those afflicted require responsive community health services for health related quality of life.

Keywords: Genital pain; Penetration disorder; Community health care; Treatment experiences; Help seeking expectations; Patient agendas

Abbreviations

GPPPD: Genito-Pelvic Pain/Penetration Disorder; HCP: Health Care Provider

Introduction

Women with Genito-Pelvic Pain/Penetration Disorder (GPPPD) typically seek treatment support from community health care providers [1]. While women often consult community or family doctors, research indicates that they may consult with other allied health professions. For instance, women with GPPPD may consult general practitioners, gynecologists, sex therapists, psychologists and physiotherapists [2], who may be working in primary or community health care settings. Women with GPPPD are a hidden population of patients in that many may not seek consultation from not recognizing their health condition as treatable, not being believed in their claims to be with a health need, or from fear of being socially stigmatized [1]. As a hidden population, women with GPPPD are at risk for poor or suboptimal health care by community health care services.

There is increasing interest by community health service providers to collect and use data on patient experiences for quality care improvement [3-6], and include data important for the quality care of hidden community women with GPPPD. If untreated, GPPPD can negatively impact personal well-being or health related quality of life [7]. Patient self-reported experiences of health care data are also useful for determining whether there are service quality gaps in patient-oriented care and what service qualities would bridge identified gaps as part of quality care improvement. This study sought

to address this research gap by exploring the factors that influence treatment uptake and adherence for women who are seeking treatment for GPPPD.

Genito-Pelvic Pain/Penetration Disorder

A GPPPD diagnosis requires a six month history of at least one of four symptoms (see DSM-5): 1. difficulty with vaginal penetration, 2. marked genital or pelvic pain during attempted or actual intercourse, 3. significant fear of pain as a result of vaginal penetration, and 4. tensing or tightening of the pelvic floor muscles during attempted vaginal penetration [8]. GPPPD is a new diagnosis that subsumes a number of diagnoses, including vulvodynia and vaginismus [9, 10]. Vulvodynia is defined as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder" [11]. It can be further classified as [11]:

- Generalised (affecting the entire vulva),
- Localised (affecting only one area of the vulva),
- Provoked (where direct pressure on the vulva causes pain),
- Unprovoked (where the pain appears spontaneously and can be unrelenting),
- Primary (where the pain has always been present), or
- Secondary (where the pain has developed after a period of time without pain).

Vaginismus was defined as “recurrent or persistent involuntary spasm of the vagina’s musculature making intercourse painful or even impossible, despite the woman’s expressed wish for penetration” and could also have been classified as primary or secondary [9]. The ‘spasm’ of vaginismus could not be reliably measured leading to the removal of the diagnosis of vaginismus from the DSM-5 [12]. The omission of the diagnosis of vaginismus occurred after the data collection phase of this study, therefore the diagnosis of vaginismus will be maintained.

Given the fact that GPPPD is a newly documented diagnosis, its prevalence is still to be ascertained [13]. However, prevalence studies for vulvodynia and vaginismus can give some guidance. Prevalence of vulvodynia varies from 3-18 % of the general population, and up to 46% in a clinical population [14-18]. Researchers estimate that 1-6% of women worldwide have vaginismus [9, 19-21], with prevalence in clinical settings being between 5-17% [19, 22].

Between 6% and 54% of women with genital pain symptoms seek treatment [14, 18, 23-25]. Women who seek treatment report that receiving a diagnosis and finding effective treatment can be elusive and lead to significant personal distress [26, 27]. Unmet patient agendas may be a contributing factor in this distress, although no studies have examined the treatment-seeking agendas of women with GPPPD.

Women with GPPPD are at risk for suboptimal health care in that the condition is often contested by health care professionals (HCPs) and people in the woman’s social network [26, 28,29]. For instance, women with GPPPD perceive to be disbelieved by HCPs as to the nature and severity of their symptoms [26]. The intimate nature of GPPPD and the fear of such judgement and stigma [30] could delay or interrupt treatment-seeking. Treatment-seeking can impose a subjective burden on women beyond the physical, as the person’s sexuality, relationships and self-perceptions as a sexual partner [7, 30, 31] are exposed to external threat. Women may also experience relationship burden when attempting to protect their intimate relationship with little to no social support from significant social others. These burdens may lead to delay or interruption of treatment seeking for GPPPD. For those who do seek treatment, the quality of their interactions with HCPs, as well as their history of consultation, may impact their access to the care services they need and deserve [32].

Consultation Agendas for Treatment Seeking

Patient agendas, or the implicit and explicit perceptions people bring to the medical consultation, include the patient’s expectations, feelings and fears about their health status [33]. These consultation expectancies are in part influenced by their treatment seeking history and important to understanding patient responses to treatment uptake and adherence [34]. Yet, eliciting patient expectancies or agendas is often neglected by HCPs [35]. Unmet patient agendas are associated with poorer health outcomes [36] and lower patient satisfaction [37-40]. For the community HCP, the cost of unmet patient agendas includes more demanding consultations [41] and avoidable patient drop out [34, 42-44].

Patients often overlay multiple consultation expectancies, with

some of these agendas unvoiced [40]. HCPs may believe that patients come to them for a specific action (e.g., prescription, test or referral) [40], however the literature suggests there may be other agendas at work. Surfacing patient agendas requires that HCPs provide information and clinical expertise [39, 45, 46], explore psychosocial needs [47, 48], take physical symptoms seriously [48], and listen to and empathise with patient concerns [27, 45, 49].

One way of meeting the health care needs of women with GPPPD is to understand and address their consultation expectancies or agendas [34]. Community HCPs who are able to discern and address their patients’ agendas are more likely to effectively address patient concerns [33]. Although previous qualitative research has explored the treatment seeking experience of women with GPPPD e.g. [26], specific consultation agendas have not been elucidated. Therefore, the aim of this research was to characterise patient agendas important for the successful treatment of GPPPD. The study was guided by the following questions: (1) What are the consultation agendas of women patients with GPPPD? and (2) How do these agendas vary according to GPPPD symptoms and treatment seeking history? The findings may be of clinical significance in guiding and supporting patient oriented care by health care providers with woman with GPPPD.

Method

Research design

Qualitative inquiry was used to explore the lived experiences of women seeking treatment for GPPPD; specifically, a grounded theory approach [50, 51] within the context of a phenomenological exploration of the woman’s experience of treatment seeking for GPPPD. A lived experience approach is able to best characterise treatment seeking agendas in community health care settings from the perspective of the woman by capturing the common meanings and features for these women [52].

Participants and setting

Participants were 26 community women with GPPPD - 13 women (50%) with provoked and localised vulvodynia, 9 (35%) with unprovoked and generalised vulvodynia and 4 (15%) with vaginismus. The average age of the participants was 27, with a range of 19-43 years. Nineteen of the women (73%) were in long-term relationships (see Table 1 for a summary of the demographic information).

Data collection

Data were collected on the women’s help-seeking experiences and motivations, as well as trajectories. The women also provided personal demographic data including age, diagnosis and relationship status. Data were collected in Australia from participants living in Australia and North America.

Help seeking experiences

Data on help-seeking experiences and motivations of the women were collected utilizing face-to-face interviews (n=4), phone interviews (n=7) or an on-line survey comprising of open-ended questions (n=15) (see Appendix 1 and 2 for copies of the interview schedule and the online survey, respectively). The interviews and on-line survey collected demographic information and information about the women’s symptoms, diagnosis, and treatment seeking history and experiences. If the woman had sought treatment, this experience

Table 1: Demographic information.

Part. #	Age	Relationship status	Diagnosis	Length of time with symptoms
P001	22	Single (in short term relationships with both men and women]	U/G vulvodynia*	10 months
P002	26	LTR, heterosexual	P/L vulvodynia*	60 months
P003	19	LTR, heterosexual	U/G vulvodynia*	60 months
P004	33	LTR, heterosexual	P/L vulvodynia*	72 months
P005	23	LTR, heterosexual	U/G vulvodynia *	18 months
P006	26	LTR, heterosexual	Vaginismus*	120 months
P007	25	LTR, heterosexual	P/L vulvodynia**	60 months
P008	23	LTR, heterosexual	U/G vulvodynia **	108 months
P009	30	LTR, heterosexual	P/L vulvodynia *	144 months
P010	23	LTR, heterosexual	P/L vulvodynia*	96 months
P011	19	LTR, heterosexual	P/L vulvodynia**	9 months
P104	28	LTR, heterosexual	Vaginismus *	48 months
P106	43	Single^	U/G vulvodynia **	"years ago"
P108	30	LTR, heterosexual	P/L vulvodynia **	120 months
P111	24	Single^	P/L vulvodynia*	60 monts
P112	24	Single^	U/G vulvodynia *	168 months
P117	19	Single^	U/G vulvodynia**	96 months
P118	36	LTR, heterosexual	U/G vulvodynia **	4 months
P121	32	LTR, heterosexual	Vaginismus*	36 months
P122	36	LTR, heterosexual	P/L vulvodynia **	144 months
P125	33	Single^	P/L vulvodynia*	Not stated
P126	27	LTR, heterosexual	Vaginismus **	Not stated
P129	27	LTR, heterosexual	P/L vulvodynia **	108 months
P132	22	Single^	U/G vulvodynia **	12 months
P133	27	LTR, heterosexual	P/L vulvodynia **	144 months
P134	33	LTR, heterosexual	P/L vulvodynia**	84 months

Note: LTR: Long-Term Relationship; ^=sexual preference not stated; U/G vulvodynia: Unprovoked and Generalised vulvodynia; P/L vulvodynia: Provoked and Localised vulvodynia; *=diagnosis from doctor; **=no diagnosis from a doctor, description of symptoms used to assign a diagnosis.

was explored in-depth to ascertain what they sought to benefit from consultation and how their experiences from the consultation influenced their motivation for further treatment-seeking. As data credibility and trustworthiness checks, we triangulated the interview and the survey data for coherence. In addition, we utilized member checks to confirm and clarify analysis. This was implemented by writing a summary of the main findings and requesting confirmation and clarification of the themes from the participants.

Treatment seeking trajectories

The women self-reported on their consultation trajectory. A trajectory has both duration and shape [53-56]: immediate or delayed, and continuous, episodic or discontinuous. Trajectory duration is expressed in time frames (i.e. immediate or delayed), while the shape of the treatment seeking trajectory is defined by the nature of treatment seeking, i.e. continuous, episodic or discontinuous. An immediate trajectory is defined as treatment seeking within two months of symptom development and a delayed trajectory is defined as more than two months. A continuous trajectory is when a participant seeks treatment on a consistent basis. An episodic trajectory is characterised by significant periods of time (more than two months) without

participating in treatment seeking. A discontinuous trajectory is characterised by no contact with a HCP or participation in treatment strategies at all. Discontinuation of treatment seeking could be due to either 'giving up' on managing symptoms, or satisfactorily managing symptoms and having no need for professional health care.

Procedure

This study was approved by the University of Sydney Human Research Ethics Committee in December 2009. Participants received an explanation of the research aims and procedures (see Appendix 2 "Information about this research" for details of the information the women received) and they granted individual written consent. Participants were recruited and data was collected between January 2010 and March 2012 by contacting Australian HCPs who treat women with genital pain and through placing an advertisement in the University of Sydney e-newsletter. Participants for the online survey were recruited by placing advertisements on a number of women's health websites and in clinic waiting rooms. Women self-selected in to either the interview or the online survey. None of the women who expressed an interest in participating and met the selection criteria dropped out of the study, although one of the interview participants

did not complete a second interview due to poor health.

Analysis

Interviews were recorded and transcribed verbatim. Data was thematically analysed by the first listed author following the procedures outlined by Strauss and Corbin [57] and Charmaz [58]. Data analysis was iterative and progressive, in that data was collected and analysed at the same time. Furthermore, the analysis considered the self-reported treatment seeking experiences and expectancies taking into account consultation trajectory. Data were initially analysed by the first listed author using the grounded theory processes of coding (initial, word-by-word, line-by-line, focused, axial and theoretical coding), memoing, sorting and theory development [58]. The analysis was interpreted with the assistance of the second author listed author who also supervised the research project. The third listed author then independently audited the data transcription and interpretation for trustworthiness or credibility. N Vivo software was used to aid in data storage and organisation. The data presented here are de-identified with participants coding ‘P’ with randomly assigned case number to ensure confidentiality of participants. GPPPD condition and relationship status are also reported on in each case.

Results

Twenty (77%) of the women identified agendas for their health care consultations, which in part also explain their expectations: (1) Validation agendas, (2) Informed HCP agenda, and (3) HCP-patient alliance. These identified expectations were not always met in the first consultation and for some of the participants they were never met. When an agenda was met hope, relief and motivation to manage symptoms were often experienced. However, when they were not met the women often experienced distress, doctor shopped or discontinued treatment seeking. Table 2 shows a summary of the common characteristics of the women according to agendas.

Expectation for symptoms to be validated

When meeting with the HCP, some of the women in this study expected to receive validation that their pain symptoms were significant. If the woman perceived that her pain and the impact of the pain was minimised she felt invalidated, leading to significant distress. Nine of the women (35%) reported feeling invalidated by their HCP. One woman came to her doctor with the hypothesis that she had vulvodynia, only to have her pain minimised:

I had seen a gynaecologist and stopped seeing her because even though I told her about my symptoms she was way, way too

rough with me. It hurt heaps and she said, “*You definitely don’t have vulvodynia because if you did I wouldn’t be able to insert my fingers inside you.*” ... I just felt that we were on two completely different planes, so I was like I am not going to keep seeing this gynecologist. (P005, 23yo, GV, long-term relationship)

Another woman stated:

[The doctor] made some comment like, “*It will be interesting to see what happens after you have a baby because your pain threshold changes.*” And I thought...I can’t even have sex...It sort of made me feel like I was hypersensitive to the pain or that I couldn’t cope (P009, 30yo, PV, long-term relationship).

Conversely, when the women received a diagnosis or felt the HCP understood the significance of their symptoms (i.e. the validation agenda was met), most experienced hope and a decrease in their distress. For example, one woman had seen numerous doctors over a number of years before she found her current gynecologist. The woman described her first appointment as follows, “The consultation went well, I felt that he listened to me and took my condition seriously” (P007, 25yo, PV, long-term relationship). She then saw another specialist on his suggestion and said:

[She] had an intuitive grasp of what was going on with me... She understood that what was happening to me was terrible, both psychologically and physically...Put in the simplest terms, she understood that it was not my fault...The improvement in my quality of life is hard to quantify – I feel like I have been set free (P007, 25yo, PV, long-term relationship).

Four women experienced validation from their first consultation and all but two of the women who initially experienced invalidation went on to find HCPs who they felt validated their condition, either through diagnosis or through their symptoms being taken seriously.

Sixty-seven per cent of the women whose validation agenda was not met were diagnosed with provoked vulvodynia and 78% of them were in long-term relationships. All of the women whose validation agendas were met from the first consultation had provoked vulvodynia and were in long-term relationships, while 75% were over 25years of age.

Experience based perceptions of HCP competencies

The women expected their HCP to be well informed about their condition and its treatment. When this agenda was not met the women often looked for another HCP. Seventeen of the women (65%) had seen HCPs whom they thought did not have

Table 2: Common characteristics relating to help seeking agendas.

Agenda	Trajectory	Diagnosis	Age	Relationship status
Validation: Not met at initial consult (n=9)	IC and DC (88.9%)	PV (66.7%)	n/a	LTR (77.8%)
Validation: Met at initial consult (n=4)	DC (75.0%)*	PV (100.0%)	75.0% were >25yo	LTR (100%)
Informed HCP: Not met (n=17)	IC and DC (70.6%)	PV (58.9%)	n/a	LTR (76.5%)
Informed HCP: Met (n=2)	IC and DC (100%)	n/a	n/a	n/a
HCP alliance: Not met (n=11)	IC and DC (63.3%)	GV (54.5%)	n/a	LTR (72.7%)
HCP alliance: Met (n=13)	IC and DC (81.8%)	PV (76.9%)	n/a	LTR (69.2%)

Note: IC: Immediate and Continuous; DC: Delayed and Continuous; GV: Generalised Vulvodynia; PV: Provoked Vulvodynia; n/a: not a noteworthy characteristic; LTR: Long-Term Relationship.*One participant who did not have a continuous trajectory had only sought treatment between interviews one and two so her trajectory is not able to be determined.

the appropriate knowledge to treat their genital pain. One woman felt that “doctors don’t know (about genital pain) and just guess (at how to treat it)” (P118, 36yo, GV, long-term relationship). Another woman said, “No one knew anything [about vulvodynia] except for my last gynecologist” (P003, 19yo, GV, long-term relationship). The experience of seeing an HCP that they felt was uninformed led some of the women to discontinuing treatment. For example, one woman stated:

The number of people who have looked at me in the face and said, “*You know, you should really just stop wearing tight clothes*” or “*you should really just stop having baths*”. I don’t wear tight clothing. I’m not having baths...there needs to be more wisdom. I didn’t really see the point of continuing to seek treatment for it (the pain). I hadn’t really got very far with [treatment-seeking]. (P007, 25yo, PV, long-term relationship).

Three other women ‘doctor shopped’ because they thought their doctor was uninformed about genital pain. For example, one woman said:

I think in that early period (of having pain symptoms) I shopped around [for a doctor who was knowledgeable] and I think that was possibly the wrong thing to do because it made it hard for them to start establishing a pattern of when the pain was happening (P007, 25yo, PV, long-term relationship).

Two of the women (8%) reported that their HCP was informed about their pain condition from the first consultation and ten of the women (59%) who initially felt their HCP was not informed about their pain felt that they eventually found a knowledgeable doctor, who brought relief to their distress. The women described positive outcomes when the HCP could clearly explain why she was having pain and how the treatment addressed her pain. For example, one woman explained:

He (the HCP) really helped me by explaining [my symptoms]. It’s quite good because now I’m not as emotionally involved with it, it’s more of an, ‘*OK it’s a physical thing and I’ll get over it*’...I’ve been noticing a lot of progress (P002, 26yo, PV, long-term relationship).

Another participant contrasted the frustration of seeing an HCP that she perceived to be uninformed, with the relief of seeing a knowledgeable HCP. She said, “It wasn’t until I saw the physio that I was like, ‘*OK now I am speaking to someone who has dealt with this before*’” (P001, 22yo, GV, single).

The majority of the women whose informed HCP agendas were not met had provoked vulvodynia (59%) and were in long-term relationships (77%). There were no other characteristics specific to an informed HCP agenda being met or not.

Valuing of HCP-patient alliance

Many of the women in this study expected to develop an alliance with their HCP that was characterised by a reciprocal exchange of information, with the woman being the expert about her pain and the doctor being the expert about treatment. Eleven women (42%) experienced a poor HCP alliance resulting in distress. One woman summarised her experience of seeing specialists, “I would feel like they are not listening, or they don’t understand, or you said your story again and they didn’t get it” (P008, 23yo, GV, long-term

relationship). Another woman stated, “I wasn’t really happy with that gynecologist...I just found it frustrating because I had always been quite aware of my body yet he didn’t seem to listen to what I was saying to him” (P009, 30yo, PV, long-term relationship).

Thirteen of the women (50%) reported a strong alliance with their HCP resulting in more consistent and less distressing treatment seeking. One woman summed up her alliance with her HCP by saying, “She [is] really empathic and she is very knowledgeable and she, you know she cares, she listens to every aspect...of the problem” (P009, 30yo, PV, long-term relationship).

Of the women with a poor alliance with their HCP the majority (55%) were diagnosed with generalised vulvodynia, as opposed to the group of women with a satisfying alliance with their provider, where the majority were diagnosed with provoked vulvodynia (77%). The majority of the women with agendas that were met and not met were in long-term relationships (72.7% and 69.2%, respectively).

Recalibration of expectations in the context of treatment experience

Two of the women (8%) reported to negotiate and modify their agendas when they felt they had a strong HCP alliance, resulting in more positive management of their pain. This involved the HCP listening to and supporting the woman, resulting in the women modifying specific treatment agendas. One woman, who felt she had been previously misdiagnosed as having thrush, said this about her current HCP:

They (sexual health clinic) were really good, but they still did all the tests [for thrush] again...I kind of said to her, ‘*Look they’ve done the test you know, it’s gonna come back negative*’...and [then] she (the doctor) made the suggestion of vulvodynia...The doctor, she listened to me when I was like, ‘...*what happens when [the thrush tests] come back negative?*’...that was the first time I felt like [someone listened to me] (P001, 22yo, GV, single).

Another woman said:

I was skeptical (about what her current HCP was suggesting). I felt like I had been told a number of times that thrush was the cause of my troubles only to have the doctor do a back flip when the swabs came back negative...But at the same time I felt that, unlike previous specialists I had seen, [this doctor] had an intuitive grasp of what was going on with me. She knew which questions to ask and she provided clear and detailed answers to my questions. Most importantly, she understood that what was happening to me was terrible. (P007, 25yo, PV, long-term relationship).

Discussion

The data suggest that women with GPPPD have consultation expectations or agendas that influence their experience of treatment seeking. These are (1) the expectation of validation of the reality of their experience of symptoms, (2) that the treating HCP be well informed about GPPPD conditions, and (3) the importance of an alliance with the HCP for successful management of their GPPPD condition. Rather than being three separate expectations, the agendas seem to interact in their effect on consultation experiences and expectancies. For example, a strong HCP-patient alliance was often reliant on the woman feeling her experiences were validated and that

the HCP was knowledgeable about GPPPD. The women in this study were more successful at accessing health care and actively engaging in their treatment when they felt their consultation agendas were met.

Findings suggest positive outcomes for women with GPPPD are partly dependent on validation of symptoms, which involves mutual respect of the HCP's professional knowledge and the woman's lived experience knowledge. When there is not mutual respect of both the HCP's knowledge and the woman's experience, the consultation may become strained, leading to distress for the woman and possible doctor shopping. Conversely, when both professional and lived experience knowledge are respected, the woman feels safe to fully disclose her symptoms, making correct diagnosis and effective treatment more likely. When the woman experiences effective management of symptoms, respect for the HCP's knowledge ensues improving the chance of patient engagement and activation. There is a recent focus on patient engagement and activation in health care [59]. Patient engagement is the involvement of patients in their health care based on the concept of shared responsibility, while patient activation involves the willingness and ability of the patient to take active and independent steps to manage their health and care [59]. When the women's consultation agendas were met and they were engaged in their health care, the women with GPPPD experienced a balance of power in their relationship with their HCP.

The women in this study valued appropriately balanced HCP-patient power, as evidenced by their identification of the HCP-patient alliance as an agenda for their health care consultations. An alliance between the patient and the HCP involves negotiation, mutual respect, and reciprocity [34], suggesting a balanced power relationship. Previous research found that effective HCP communication of knowledge, good HCP listening skills and HCP empathy are important to a balanced HCP-patient relationship [60], further supporting the assertion that the three identified agendas are interdependent.

The specific GPPPD diagnosis appeared to be associated with patient self-reported strength of the treatment alliance with the HCP. For instance, the majority of women whose HCP-patient alliance was not met had been diagnosed with generalised and unprovoked vulvodynia, while the majority where this agenda was met had localised and provoked vulvodynia. Both provoked and generalised vulvodynia [11] are neuropathic pain conditions, however the pain is differentially elicited. The pain of provoked vulvodynia is experienced when pressure is applied to the vulva, whereas women with generalised vulvodynia can experience pain without an obvious trigger. Furthermore, the pain of generalised vulvodynia can be unpredictable and unrelenting [11]. The unpredictable pain of generalised vulvodynia may have led to feelings of helplessness and hopelessness leading to feeling that their HCP was ineffectual and lacked knowledge. As was stated earlier, feeling the HCP lacked knowledge negatively influenced the HCP-patient alliance. He treatment-seeking trajectory did not seem to differentiate among the women in their consultation expectancies, with all of the women who identified consultation agendas having a continuous trajectory, regardless of whether their agendas were met or not. The reasons for this finding are unclear. However, given the complex nature of treatment-seeking it is likely to be another factor that was not explored in this study, e.g., pain levels or relationship quality. Further

research is needed to confirm this finding.

Implications for clinical practice

The findings of this study have implications for patient oriented care practices with women with GPPPD seeking treatment from community health care providers. For instance, HCPs may be able to support women with genital pain more effectively with requisite knowledge on GPPPDs and also by communicating patient-centeredness in their practices. Patient oriented HCP skills necessary for successful care of women with GPPPD are knowledge of GPPPD, empathy and listening. Because of the chronicity of GPPPD these skills are all the more important as the woman requires a strong and supportive alliance with her HCP as she navigates this condition throughout the various stages of her life. For instance, a woman who is at the stage of life where she may be dating in order to find a life partner may require interventions that support assertive communication with potential partners. A woman who is of childbearing years may need fertility support. Furthermore, the complexities of treating women with GPPPD are such that it is a condition that not only affects women physically, but may also significantly impact upon sexuality, relationships and self-perceptions. Treatment may be further complicated by the stigma and shame that can be experienced by women with GPPPD.

Findings suggest HCP communication skills to be important for enhancing a supportive relationship: the provision of relevant information [61, 62], positive and supportive talk [61, 63], and a friendly, warm and sympathetic approach [61, 64-68]. This study extends the sexual health practice literature on HCP-patient relationships in that it identifies the specific HCP interpersonal skills necessary to supporting women with GPPPD. Although the identified necessary HCP skills include many of the skills any HCP needs to provide quality care (e.g. empathy, active listening, and patient empowerment), there are also skills specific to treating women with GPPPD. These are HCP knowledge about GPPPD and its treatment, and the ability to address the sexual impact of GPPPD in a sensitive manner.

This study emphasises the need for more HCP education around identifying and addressing patient agendas. With regards to GPPPD, specific training should include information about diagnosing and treating GPPPD, as well as the development of skills so that validation of symptoms is communicated and a strong working alliance can be developed.

This research highlights one of the ways (addressing patient consultation agendas) community HCPs can support women with GPPPD to encourage them to actively engage in management of their symptoms. As clinicians gain a more complete understanding of the consultation agendas of this community of women, outcomes will improve.

Strengths and limitations of the study

There are several strengths of this research. By taking a lived experience approach, the phenomenon studied was investigated holistically, rather than from the predefined parameters of a quantitative survey [69]. The lived experience data are closer to actual patient experiences than those from categories imposed by researchers.

There are also several limitations worth mentioning. First, the study cannot be considered representative of the GPPPD population because it was a self-selecting sample [70]. Another limitation of this research is that the interview schedule was researcher-developed, and therefore may be limited in the topics covered. Finally, the interview schedule was not piloted.

Research is needed that further investigates the relationship between patient consultation agendas and the various symptoms of GPPPD, and in women from other cultures and socio-economic backgrounds. Research is also needed to gain a better understanding of the interaction between HCP agendas and patient consultation agendas, and the impact of this interaction on outcomes for this community of women.

Conclusion

This study sought to identify the consultation agendas that influence the treatment-seeking trajectory of women with GPPPD utilising a lived experience approach. It identified the HCP qualities that are of particular salience to the treatment experiences of women with GPPPD, namely the ability to diagnose and validate the woman's experience of symptoms and the ability to develop a strong alliance with the woman. On the basis of this research, significant effort should be invested in educating community HCPs about GPPPD. This can be achieved through HCP pre-service and continuing education program participation as well as community oriented women's health outreach programs.

References

- Reissing ED. Consultation and treatment history and causal attributions in an online sample of women with lifelong and acquired vaginismus. *J Sex Med.* 2012; 9: 251-258.
- Groisman V. Vulvodynia: new concepts and review of the literature. *Dermatol Clin.* 2010; 28: 681-696.
- Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med.* 2005; 20: 953-957.
- Davies E, Cleary PD. Hearing the patient's voice? Factors affecting the use of patient survey data in quality improvement. *Qual Saf Health Care.* 2005; 14: 428-432.
- Swenson SL, Buell S, Zettler P, White M, Ruston DC, Lo B. Patient-centered communication: do patients really prefer it? *J Gen Intern Med.* 2004; 19: 1069-1079.
- Institute for Healthcare Improvement. Person- and Family-Centered Care Cambridge, MA: Institute for Healthcare Improvement; 2015 [cited 2015 4 May].
- Arnold LD, Bachmann GA, Rosen R, Kelly S, Rhoads GG. Vulvodynia: characteristics and associations with comorbidities and quality of life. *Obstet Gynecol.* 2006; 107: 617-624.
- Lawson AK, Wright CV, Fitzgerald LF. The evaluation of sexual harassment litigants: reducing discrepancies in the diagnosis of posttraumatic stress disorder. *Law Hum Behav.* 2013; 37: 337-347.
- Binik I, Bergeron S, Khalif S. Dyspareunia and Vaginismus. So-called Sexual Pain. In: Leiblum S, editor. *Principles and Practice of Sex Therapy.* 4th ed. New York: The Guilford Press; 2007: 124-177.
- Amarraj P, Kelly S, Bachmann G. Historical Perspective of Vulvodynia. In: Goldstein A, Pukall C, Goldstein I, editors. *Female Sexual Pain Disorders.* Oxford: Blackwell Publishing Ltd.; 2009: 1-3.
- Haefner HK. Report of the International Society for the Study of Vulvovaginal Disease terminology and classification of vulvodynia. *J Low Genit Tract Dis.* 2007; 11: 48-49.
- Reissing ED, Binik YM, Khalifé S, Cohen D, Amsel R. Vaginal spasm, pain, and behavior: an empirical investigation of the diagnosis of vaginismus. *Arch Sex Behav.* 2004; 33: 5-17.
- Meana M, Maykut E. Painful Intercourse: Genito-Pelvic Pain/Penetration Disorder. In: Hertlein KM, Weeks GR, Gambescia N, editors. *Systemic Sex Therapy.* 2nd ed. New York: Routledge; 2015.
- Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Am Med Womens Assoc.* 2003; 58: 82-88.
- Graziottin A. Dyspareunia and vaginismus: Review of the literature and treatment. *Current Sexual Health Reports.* 2008; 5: 43-50.
- Laumann EO, Paik A, Rosen RC. Sexual dysfunction in the United States: prevalence and predictors. *JAMA.* 1999; 281: 537-544.
- Pitts MK, Ferris JA, Smith AM, Shelley JM, Richters J. Prevalence and correlates of three types of pelvic pain in a nationally representative sample of Australian women. *Med J Aust.* 2008; 189: 138-143.
- Nguyen RH, Turner RM, Rydell SA, Macle hose RF, Harlow BL. Perceived stereotyping and seeking care for chronic vulvar pain. *Pain Med.* 2013; 14: 1461-1467.
- Lahaie MA, Boyer SC, Amsel R, Khalifé S, Binik YM. Vaginismus: a review of the literature on the classification/diagnosis, etiology and treatment. *Womens Health (Lond Engl).* 2010; 6: 705-719.
- Kadri N, Mchichi Alami K, Mchakra Tahiri S. Sexual dysfunction in women: Population based epidemiological study. *Archives of Women's Mental Health.* 2002; 5: 59-63.
- Weijmar Schultz W, Basson R, Binik Y, Eschenbach D, Wessellmann U, Van Lankveld J. Women's sexual pain and its management. *J Sex Med.* 2005; 2: 301-316.
- Crowley T, Richardson D, Goldmeier D. Recommendations for the management of vaginismus: BASHH Special Interest Group for Sexual Dysfunction. *International Journal of STD & AIDS.* 2006; 17: 14-18.
- Danielsson I, Sjöberg I, Stenlund H, Wikman M. Prevalence and incidence of prolonged and severe dyspareunia in women: results from a population study. *Scand J Public Health.* 2003; 31: 113-118.
- Donaldson RL, Meana M. Early dyspareunia experience in young women: confusion, consequences, and help-seeking barriers. *J Sex Med.* 2011; 8: 814-823.
- Ogden J, Ward E. Help-seeking behavior in sufferers of vaginismus. *Sexual & Marital Therapy.* 1995; 10: 23-30.
- Buchan A, Munday P, Ravenhill G, Wiggs A, Brooks F. A qualitative study of women with vulvodynia: I. The journey into treatment. *Journal of Reproductive Medicine.* 2007; 52: 15-18.
- Connor JJ, Robinson B, Wieling E. Vulvar pain: a phenomenological study of couples in search of effective diagnosis and treatment. *Fam Process.* 2008; 47: 139-155.
- Heckathorn DD. Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems.* 1997; 44: 174-199.
- Marriott C, Thompson AR. Managing threats to femininity: personal and interpersonal experience of living with vulval pain. *Psychol Health.* 2008; 23: 243-258.
- Ayling K, Ussher JM. "If sex hurts, am I still a woman?" the subjective experience of vulvodynia in hetero-sexual women. *Arch Sex Behav.* 2008; 37: 294-304.
- Brauer M, ter Kuile MM, Laan E. Effects of appraisal of sexual stimuli on sexual arousal in women with and without superficial dyspareunia. *Arch Sex Behav.* 2009; 38: 476-485.
- Gulliford M, Figueroa-Munoz J, Morgan M, Hughes D, Gibson B, Beech R,

- et al. What does 'access to health care' mean? *J Health Serv Res Policy*. 2002; 7: 186-188.
33. Butler NM, Campion PD, Cox AD. Exploration of doctor and patient agendas in general practice consultations. *Soc Sci Med*. 1992; 35: 1145-1155.
 34. Chewning B, Wiederholt JB. Concordance in cancer medication management. *Patient Educ Couns*. 2003; 50: 75-78.
 35. Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda: have we improved? *JAMA*. 1999; 281: 283-287.
 36. Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. *BMJ*. 2000; 320: 1246-1250.
 37. Brody DS, Miller SM, Lerman CE, Smith DG, Lazaro CG, Blum MJ. The relationship between patients' satisfaction with their physicians and perceptions about interventions they desired and received. *Med Care*. 1989; 27: 1027-1035.
 38. Kravitz RL, Callahan EJ, Azari R, Antonius D, Lewis CE. Assessing patients' expectations in ambulatory medical practice. Does the measurement approach make a difference? *J Gen Intern Med*. 1997; 12: 67-72.
 39. Kravitz RL, Cope DW, Bhrany V, Leake B. Internal medicine patients' expectations for care during office visits. *J Gen Intern Med*. 1994; 9: 75-81.
 40. Rao JK, Weinberger M, Kroenke K. Visit-specific expectations and patient-centered outcomes: a literature review. *Arch Fam Med*. 2000; 9: 1148-1155.
 41. Bell RA, Kravitz RL, Thom D, Krupat E, Azari R. Unmet expectations for care and the patient-physician relationship. *J Gen Intern Med*. 2002; 17: 817-824.
 42. Becker MH, Maiman LA. Strategies for enhancing patient compliance. *J Community Health*. 1980; 6: 113-135.
 43. Marquis MS, Davies AR, Ware JE Jr. Patient satisfaction and change in medical care provider: a longitudinal study. *Med Care*. 1983; 21: 821-829.
 44. Ware JE Jr, Davies AR. Behavioral consequences of consumer dissatisfaction with medical care. *Eval Program Plann*. 1983; 6: 291-297.
 45. Guise J, McVittie C, McKinlay A. A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *J Health Psychol*. 2010; 15: 426-435.
 46. Sanchez-Menegay C, Stalder H. Do physicians take into account patients' expectations? *J Gen Intern Med*. 1994; 9: 404-406.
 47. Gross K, Schindler C, Grize L, Späth A, Schwind B, Zemp E. Patient-physician concordance and discordance in gynecology: Do physicians identify patients' reasons for visit and do patients understand physicians' actions? *Patient Education and Counseling*. 2013; 92: 45-52.
 48. Newell S, Sanson-Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from a survey of five oncologists. *Cancer*. 1998; 83: 1640-1651.
 49. Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. Focus group study of endometriosis: struggle, loss and the medical merry-go-round. *Int J Nurs Pract*. 2003; 9: 2-9.
 50. Donovan MO. Implementing reflection: insights from pre-registration mental health students. *Nurse Educ Today*. 2007; 27: 610-616.
 51. Goulding C. Grounded theory, ethnography and phenomenology: A comparative analysis of three qualitative strategies for marketing research. *Journal of Marketing*. 2005; 39: 294-308.
 52. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res*. 2007; 17: 1372-1380.
 53. Glaser B, Strauss A. *Time for Dying*. Chicago: Aldine Publishing Company; 1968.
 54. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. *Sch Inq Nurs Pract*. 1998; 12: 33-41.
 55. Halcomb E, Davidson P. Using the illness trajectory framework to describe recovery from traumatic injury. *Contemp Nurse*. 2005; 19: 232-241.
 56. Henly SJ, Wyman JF, Gaugler JE. Health trajectory research: a call to action for nursing science. *Nurs Res*. 2011; 60: S79-82.
 57. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: SAGE Publications, Inc; 1998.
 58. Brossoie N, Roberto KA, Barrow KM. Making sense of intimate partner violence in late life: comments from online news readers. *Gerontologist*. 2012; 52: 792-801.
 59. Gessert C, Waring S, Bailey-Davis L, Conway P, Roberts M, VanWormer J. Rural definition of health: a systematic literature review. *BMC Public Health*. 2015; 15: 378.
 60. Venetis MK, Robinson JD, Turkiewicz KL, Allen M. An evidence base for patient-centered cancer care: A meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Education and Counseling*. 2009; 77: 379-383.
 61. Pawlikowska T, Zhang W, Griffiths F, van Dalen J, van der Vleuten C. Verbal and non-verbal behavior of doctors and patients in primary care consultations - how this relates to patient enablement. *Patient Educ Couns*. 2012; 86: 70-76.
 62. Beck RS, Daughtridge R, Sloane PD. Physician-patient communication in the primary care office: a systematic review. *J Am Board Fam Pract*. 2002; 15: 25-38.
 63. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ*. 2001; 323: 908-911.
 64. Paasche-Orlow M, Roter D. The communication patterns of internal medicine and family practice physicians. *J Am Board Fam Pract*. 2003; 16: 485-493.
 65. Mercer SW, Reynolds WJ. Empathy and quality of care. *Br J Gen Pract*. 2002; 52 Suppl: S9-12.
 66. Price S, Mercer SW, MacPherson H. Practitioner empathy, patient enablement and health outcomes: a prospective study of acupuncture patients. *Patient Educ Couns*. 2006; 63: 239-245.
 67. Eide H, Frankel R, Haaversen AC, Vaupel KA, Graugaard PK, Finset A. Listening for feelings: identifying and coding empathic and potential empathic opportunities in medical dialogues. *Patient Educ Couns*. 2004; 54: 291-297.
 68. Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. *Ann Intern Med*. 2003; 139: 907-915.
 69. Yin R. *Case Study Research: Design and Methods*. 4th ed. Bickman L, Rog D, editors. Thousand Oaks: Sage Publication, Inc; 2009.
 70. Liamputtong P. *Qualitative Research Methods*. 3rd ed. South Melbourne: Oxford University Press; 2009.