

**Women's experiences of vulvodynia: a Meta-Ethnography of  
existing literature and an Interpretative Phenomenological Analysis  
of the journey towards diagnosis**

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Oct 2015

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Submitted in partial fulfilment of the doctorate of clinical psychology,

The University of Liverpool

## Acknowledgements

*To all the women who gave their time and told their stories for this research,  
thank you.*

This thesis is dedicated to my friend. She knows who she is. Thank you for Fergus and for everything.

Thank you to Dr Gundi Kiemle, you have been a great source of support and help not only whilst writing this thesis, but throughout my years of clinical training. Dr Joanne Dickson, your advice and attention to detail has been invaluable, thank you.

Thanks also to the Vulval Pain Society, Kathrine McKenzie, Dr David Nunns and Dr Winston DeMello for all their help in the production and dissemination of this thesis.

I am extremely grateful to all my lovely course mates. What would this time have been like without you? Thank you. In particular, thank you to Dr Rob Dinwoodie and Dr Jody Etheridge for their generosity of time reviewing papers.

Finally, Charlie Hearnshaw. You are now, and have always been my mountain.

Thank you, once again for your unrelenting support, love and guidance through the completion of yet another doctorate. I promise this is the last...for a while.

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Total Word Count    23,789

## **Thesis overview**

Vulvodynia is a common idiopathic pain experienced by women, in the external female genitalia (or vulval) area. Despite being encountered by around 16% of women, research relating to vulvodynia is limited. This thesis focuses on qualitative research pertaining to women's experiences of vulvodynia, with particular attention paid to any psychological sequelae. The thesis is comprised of two papers; the first paper is written in preparation for submission to Archives of Sexual Behaviour and the second paper for submission to Qualitative Research in Psychology.

Paper 1 uses systematic search strategies and meta-ethnography in order to identify, analyse and summarise the existing qualitative literature pertaining to any aspect of women's experiences of vulvodynia. Reciprocal and refutational analysis of the papers is used to draw together the key findings of the papers, comparing and contrasting in order to develop a line of argument, moving beyond the sum of the parts of the original texts and providing fresh interpretation for the reader. The line of argument is considered in relation to the clinical implications for women with vulvodynia and potential future research is discussed.

Paper 2 uses Interpretative Phenomenological Analysis (IPA) in order to conduct original research aimed at exploring women's experiences of their journey towards a diagnosis of vulvodynia, addressing a gap in the research identified by the literature review. In line with IPA methodology, the researcher adopts a critical realist position in order to understand the experiences of women with vulvodynia within the context of the healthcare system, itself set within the wider societal context. The findings are summarised into three over-arching master themes, which

are further discussed in relation to existing research while also considering clinical implications.

## What are women's subjective experiences of living with vulvodynia? A systematic review and meta-ethnography<sup>1</sup>

**Objective:** To answer the question: What are women's subjective experiences of living with vulvodynia?

**Design:** A systematic search strategy and meta-ethnography have been employed as a means of identifying, synthesising and analysing all relevant literature.

**Results:** Four key concepts were identified: 1.) *Social Constructions: Sex, Women and Femininity:* Women experienced negative consequences of social narratives around womanhood, sexuality and femininity including the prioritisation of penetrative sex, the belief that it is the role of women to provide sex for men and media portrayals of sex as easy and natural. 2.) *Seeking Help:* Women experienced the healthcare system as dismissive, sometimes being prescribed treatments that exacerbated the experience of pain. 3.) *The Psychological and Relational Impact of Vulvodynia:* Women experienced feeling silenced, isolated, shame and guilt, which in turn lead to the experience of psychological distress, low mood, anxiety and low self-esteem. Moreover, women's heterosexual relationships and their peer relationships were also affected. 4.) *A Way Forward:* Women found changing narratives as well as group and individual multidisciplinary approaches helpful in managing vulvodynia.

**Conclusion:** Interventions aimed at both the individual level as well as interventions aimed at equipping women to challenge social narratives may be helpful for the psychological well-being of women with vulvodynia.

**Key Words:** vulvodynia, vulval pain, qualitative, systematic review, meta-ethnography

### Introduction

The term *vulva* refers to the external female genitalia, made up of the mons pubis, clitoris, labia majora, labia minora, and perineum (a glossary is provided in Appendix 2). Vulval pain is the experience of pain in the form of burning, soreness or throbbing in the vulval area (Nunns & Murphy, 2012). It has been classified by the International Society for the Study of Vulvovaginal Diseases (ISSVD) into two

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<sup>1</sup> Manuscript prepared for submission to Archives of Sexual Behaviour. No specified word limit. See Appendix 1 for author guidelines.

categories, namely pain caused by specific, identifiable and underlying disorders and idiopathic pain in the absence of identifiable underlying disease (Harlow & Stewart, 2003; Nunns & Murphy, 2012). The term *vulvodynia* refers to the latter classification and is the focus of this review. Further, vulvodynia is classified into *generalised* or *localised* categories; *primary* (onset upon first penetration or tampon use) and *secondary* (previous pain free penetration for a considerable period prior to onset of pain) categories; and can be both *provoked*, by use of tampons or upon penetration during coitus, and/or *unprovoked* in nature.

Estimates of the prevalence of vulvodynia vary from four to sixteen percent (Goetsch, 1991; Harlow & Stewart, 2003; Reed et al., 2012). Vulvodynia may affect women of any age (Nunns & Murphy, 2012), however the rate of first onset of vulvodynia is greatest before the age of 25 (Harlow et al., 2014). Prevalence of symptoms is similar for African American women and white women; however Hispanic women are around 1.4 times more likely to experience symptoms of vulvodynia (Harlow et al., 2014; Harlow & Stewart, 2003; Reed et al., 2012). The reasons for this are unknown.

Despite the relatively high prevalence of vulvodynia, little is known about the underlying aetiology, with several causative factors likely. Research has explored possible contributory factors including embryology, neuropathic pain, infection, inflammation, genetics, hormonal influences, dietary influences, anatomic pelvic floor dysfunction and psychosocial influences, which may contribute to the experience of pain differently for different women (for a review of this literature see Eppsteiner, Boardman, & Stockdale, 2014). Further, research examining the possible causative experience of a history of sexual abuse produces inconsistent findings, with methodological flaws (correlational and cross-sectional designs) making firm



conclusions difficult to draw (Harlow & Stewart, 2005; Plante & Kamm, 2008; Reed et al., 2000).

Obtaining a diagnosis of vulvodynia is often time-consuming and difficult, most likely due to the complexity of giving a concrete diagnosis as well a lack of awareness among healthcare professionals, which was demonstrated by Toeima and Nieto (2011), who explored junior doctors' (5 staff grade, 4 GP trainees, 2 Foundation Year 1-2, 27 ST1-ST5 (junior), and 14 ST6-ST7 (senior) doctors) understanding of vulvodynia. They concluded that there is a lack of training among junior gynaecologists, with no difference found between those at the junior end of their specialist training (ST1-ST5) and the senior end of specialist training (ST6-ST7), especially regarding knowledge of ISVVD classification, receiving teaching sessions on vulvodynia, and knowledge on drugs used for treatment (Toeima & Nieto, 2011). It must be noted, however, that the findings cannot be generalised to consultant grade doctors, as they were excluded from the study.

Furthermore, treatment has tended to have a bio-medical focus based upon expert opinion, clinical experience and observational studies, as very few randomized control trials exist (Ayling & Ussher, 2008). Current treatment includes skin care guidance, topical treatments, oral medications, surgery, physiotherapy and psychotherapy, with a multidisciplinary approach often needed for successful treatment (Eppsteiner et al., 2014).

Despite the challenges surrounding aetiology, diagnosis and treatment, the physical experience of vulvodynia continues to impact upon women in a range of idiosyncratic ways, ranging from the experience of discomfort to the experience of severe pain. Practically, this pain may impact on a variety of activities including

using tampons, engaging in penetrative sex, wearing tight clothing or sitting for long periods of time. Furthermore, the experience of pain also impacts upon psychosocial functioning, with women who experience vulvodynia suffering from increased rates of anxiety, depression, sexual dissatisfaction and reduced self-esteem (Gates, 2001; Gates & Galask, 2001; Sackett, Gates, Heckman-Stone, Kobus, & Galask, 2001).

Major methodological considerations of research into women's experiences of vulvodynia include the quantitative nature and methodological limitations such as lack of control groups, or vague inclusion/exclusion criteria (Marriott & Thompson, 2008). Quantitative methodology, by its nature, requires the reduction of phenomena to numerical values in order to carry out statistical analysis. Qualitative methodology, on the other hand, aims to explore, describe and interpret the personal and social experiences of participants (Smith, 2007), offering broader insights into how women may experience vulvodynia, unconstrained by an often over-simplified, positivist perspective of quantitative methodology. Therefore the current review aims to develop a broader understanding of vulvodynia by reviewing and analysing the existing, yet limited, qualitative literature regarding women's experiences of vulvodynia, and thus developing an understanding of women's personal and social experiences of living with vulvodynia.

There are numerous ways to synthesise qualitative literature (see Appendix 3) including thematic synthesis (Thomas & Harden, 2008), meta-study (Paterson & Canam, 2001), and grounded theory (Kearney, 2001), all of which reflect different epistemological stances including critical realism, subjective idealism and objective idealism respectively. Meta-ethnography, another method of synthesis, uses techniques such as reciprocal analysis (how studies relate to one another), refutational analysis (how studies refute one another) and lines of argument to

synthesise qualitative studies in order to go beyond the original studies and produce new third order interpretations (interpretations above and beyond those made in the original studies (Centre for Reviews and Dissemination, 2009). It was the synthesis of choice for the current review as it is the most well developed (Ring, Ritchie, Mandava, & Jepson, 2011; Thomas & Harden, 2008), is clearly from an interpretative (object idealism) paradigm from which most methods of primary qualitative research evolve (Campbell et al., 2003), and most importantly aims to move beyond the original data to provide a new and fresh interpretation (Barnett-Page & Thomas, 2009).

## **Method**

### **Aim**

The current review aims to explore, analyse and summarise the experiences of women in relation to any aspect of living with vulvodynia in order to further understanding by answering the question: What are women's subjective experiences of living with vulvodynia?

### **Design**

A systematic search strategy and meta-ethnography have been employed as a means of identifying and synthesising respectively, all relevant literature in order to address the aim outlined above.

## **Search Methods and Inclusion Criteria**

Scoping searches were performed using the University of Liverpool database DISCOVER. The search strategies used both keywords and controlled vocabulary, where appropriate, to identify relevant papers. The following on-line databases (and interfaces) were then searched using the developed search strategies (see Appendix 4): MEDLINE (Ovid); CINAHL plus (EBSCO*host*); Scopus (SciVerse); PsycINFO (EBSCO*host*); Social Sciences Citation Index (SSCI; Thomson Reuters). Experts in the field were contacted to ask if they could identify any missing papers. Six experts replied, two suggesting potential missing papers which did not meet the inclusion criteria for the study. References from included papers were hand searched (which produced no further papers for inclusion) and lastly, literature referenced on the Vulval Pain Society (VPS) website was examined for possible inclusion, with no further papers identified. The inclusion criteria are outlined in Table 1.

Table 1. Outline of Inclusion and Exclusion Criteria

Inclusion Criteria
The qualitative method of interviews (interviews; semi structured interviews)
Qualitative analysis (e.g. thematic analysis; Interpretative phenomenological analysis; discourse analysis etc)
Views of women with a diagnosis of idiopathic vulval pain (vulvodynia, vestibulodynia, vulvar vestibulitis)
English language
Publication of full article (published abstracts excluded) in a peer reviewed journal
Exclusion Criteria
Qualitative methods including questionnaires only or analysis of medical records
Quantitative methods of data collection and/or analysis
Joint interviews with significant others
Interviews of significant others
Theses, magazine articles, book chapters

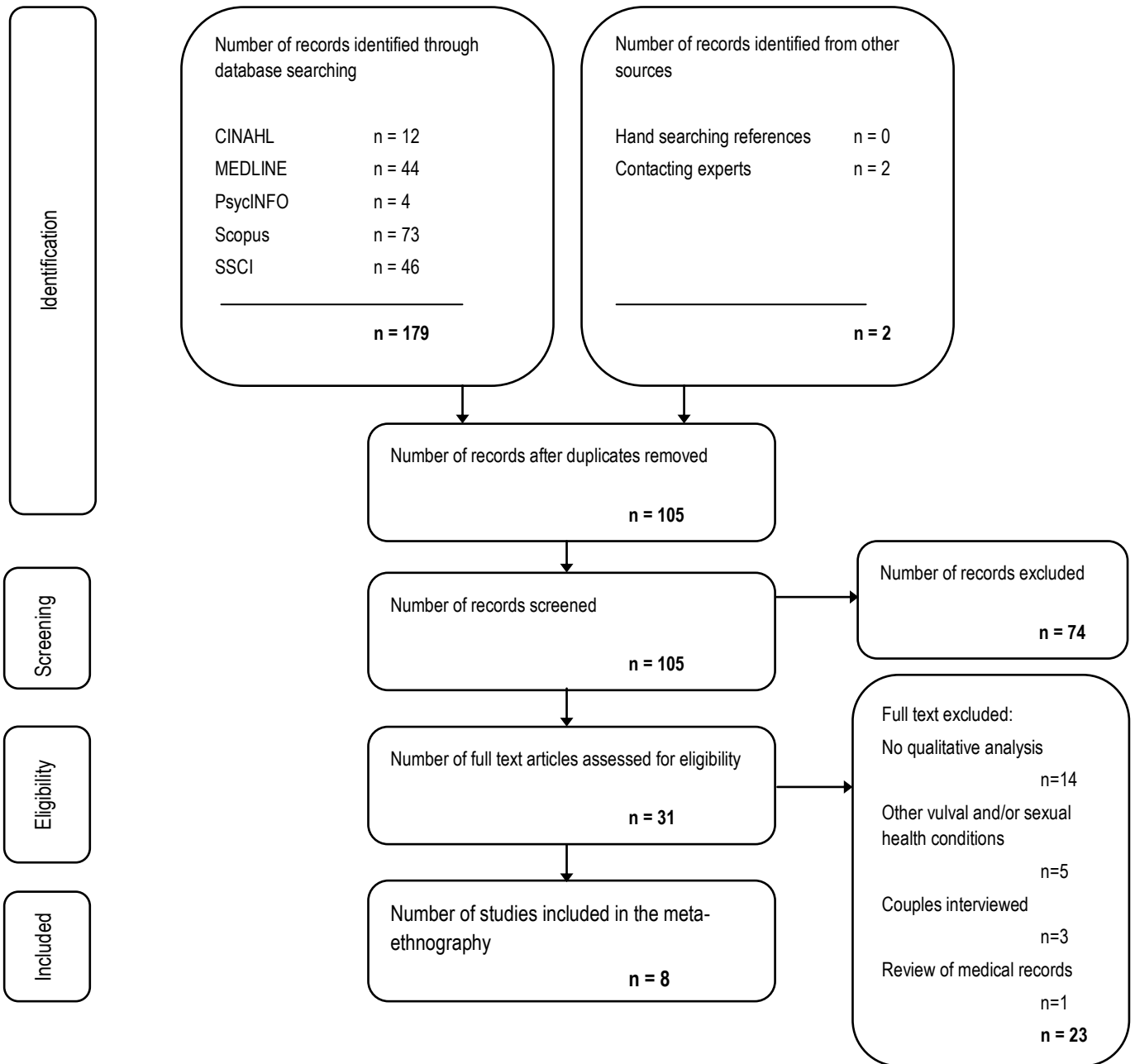
The current paper excluded research whereby women had been interviewed with their partners, for several reasons. Firstly, women interviewed in the presence of a partner may feel unable to give true and accurate accounts of their experiences, either consciously or unconsciously. Secondly, the experience of partners was not the focus of this review. For these reasons, the experience of couples would be better served by a separate review.

### **Search outcome**

The results of the search strategies were exported to referencing software whereby duplicate articles were deleted. One hundred and five papers were identified and all abstracts and titles were screened for relevance. Following the initial screening, 31 papers remained and the full manuscripts were obtained. The study

inclusion/exclusion criteria were applied to each remaining paper by author RS. The remaining 31 papers were also independently rated between a further two researchers RD and JE (see acknowledgments). Initially the researchers agreed on all but 2 papers, however, following discussion, it was agreed that eight papers should be included in the current literature review based upon the inclusion/exclusion criteria outlined. The following Figure 1 outlines the stages of the search process and Table 2 details the included studies.

Figure 1 Identification of Papers Flow Diagram<sup>2</sup>



<sup>2</sup> Adapted From: Moher, Liberati, Tetzlaff, Altman and The PRISMA Group (2009).

Table 2. Included Studies

No	Author	Date	Title
1	Ayling & Ussher	2008	"If sex hurts, am I still a woman?" : The subjective experience of vulvodynia in hetero-sexual women.
2	Brotto et al	2013	Impact of an integrated mindfulness and cognitive behavioural treatment for provoked vestibulodynia (IMPROVED): A qualitative study.
3	Buchan et al	2007	A qualitative study of women with vulvodynia. I. The Journey into Treatment.
4	Kaler	2006	Unreal women: Sex, gender, identity and the lived experience of vulvar pain.
5	Marriott & Thompson	2008	Managing threats to femininity: Personal and interpersonal experience of living with vulval pain.
6	Munday et al	2007	A qualitative study of women with vulvodynia. II Response to a multidisciplinary approach to management.
7	Sadowink et al	2012a	Provoked vestibulodynia: A qualitative exploration of women's experiences.
8	Sadowink et al	2012b	Provoked vestibulodynia – women's experience of participating in a multidisciplinary vulvodynia program.

### Quality Appraisal and Critique of Papers

No paper was excluded on the basis of the quality assessment, so as not to limit the potential for new insights to be found. However, the Critical Appraisal Skills Programme (CASP, 2014) tool for qualitative research was utilised in order to structure critique of the papers included, and to inform on the strengths and limitations of any such insights.

Table 3 provides an overview of the quality of each paper included in the study. The eight papers identified relate to six cohorts of women, with papers by Buchan, Munday, Ravenhill, Wiggs, and Brooks (2007) and Munday, Buchan, Ravenhill, Wiggs, and Brooks (2007) reporting one cohort of women, and papers Sadownik, Seal, and Brotto (2012a, 2012b) reporting another. Whilst papers were



appraised separately, due to their identical methodologies they were placed together as a cohort in the table to avoid repetition. Any differences between papers within a cohort are highlighted within the table, e.g. in the conclusions drawn.

All cohorts reported on findings from qualitative research which involved both qualitative methods of data collection and analysis, with all the research relevant to the synthesis topic. All cohorts outlined their aims of the study, with the exception of one (Brotto, Basson, Carlson, & Zhu, 2013), whereby the aims of the review were not explicitly stated. One cohort (Buchan et al., 2007; Munday et al., 2007) did not justify the research design of the study, whereas all other cohorts did. All cohorts used an appropriate recruitment strategy, however two cohorts (Brotto et al., 2013; Marriott & Thompson, 2008) did not discuss specifically why some people did not take part. Moreover, one cohort (Buchan et al., 2007; Munday et al., 2007) did not explain why the participants were most appropriate to provide access to the type of knowledge sought in the study. Data were collected in a way that addressed the research question across the cohorts; however, two cohorts (Brotto et al., 2013; Buchan et al., 2007; Munday et al., 2007) did not justify the methods chosen. Only one cohort adequately described the relationship between the researcher and the participants (Ayling & Ussher, 2008), with the remaining cohorts failing to critically examine their own role, potential bias and influence throughout the research process. Ethical issues were taken into consideration across all cohorts, however four cohorts did not provide sufficient detail of how the research was explained to participants (Brotto et al., 2013; Buchan et al., 2007; Marriott & Thompson, 2008; Munday et al., 2007; Sadownik et al., 2012a, 2012b), two did not state whether approval from an ethics committee was sought (Brotto et al., 2013; Kaler, 2006) and two did not state how consent and confidentiality were addressed (Marriott & Thompson, 2008;

Sadownik et al., 2012a, 2012b). In the majority of cohorts, the data analysis was sufficiently rigorous (Ayling & Ussher, 2008; Brotto et al., 2013; Sadownik et al., 2012a, 2012b). However in two cohorts there was not an in-depth description of the analysis process or how the data were presented (Brotto et al., 2013; Kaler, 2006). Further, one (Kaler, 2006) did not describe how the themes were derived from the data, whilst the way in which contradictory data were taken into account was not addressed by another two cohorts (Brotto et al., 2013; Marriott & Thompson, 2008). All papers had a clear statement of findings, with the exception of one cohort (Buchan et al., 2007; Munday et al., 2007) which did not present an adequate discussion of evidence for and against the researcher's arguments, nor discussed the credibility of their findings.

Finally, a question relating the epistemological and ontological standpoint of the author(s) was added to the CASP criteria as it was deemed an important consideration in quality assessing qualitative literature. Only three cohorts provided information pertaining to the epistemological standpoint of the authors (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008), the remaining authors failed to adequately discuss this. Overall, all the cohorts contribute to the existing knowledge and posit the findings in relation to the existing literature.

Table 3 Quality Appraisal Based on the CASP Tool

	Ayling & Ussher (2008)	Brotto et al., (2013)	Buchan et al., (2007); Munday et al., (2007)	Kaler (2006)	Marriott & Thompson (2008)	Sadownik et al., (2012 a & b)
Screening Questions						
Does the paper report on findings from qualitative research and did that work involve both qualitative methods of data collection and data analysis?	✓	✓	✓	✓	✓	✓
Is the research relevant to the synthesis topic?	✓	✓	✓	✓	✓	✓
CASP questions						
Was there a clear statement of the aims of the research?	✓	✗	✓	✓	✓	✓
Is a qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓
Was the research design appropriate to address the aims of the research?	✓	✓	✗	✓	✓	✓
Was the recruitment strategy appropriate to the aims of the research?	✓	✓	✓	✓	✓	✓
Was the data collected in a way that addressed the research issue?	✓	✓	✓	✓	✓	✓
Has the relationship between researcher and participants been adequately considered?	✓	✗	✗	✗	✗	✗
Have ethical issues been taken into consideration?	✓	✓	✓	✓	✓	✓
Was the data analysis sufficiently rigorous?	✓	✓	✗	✗	✓	✓
Is there a clear statement of findings?	✓	✓	✗	✓	✓	✓
How valuable is the research?	Valuable	Valuable	Valuable	Valuable	Valuable	valuable
Modified Question						
Do the researchers consider and adequately discuss their epistemological stand point?	✓	✗	✗	✓	✓	✗

### **Data Abstraction and Synthesis**

Data were abstracted and synthesised using a meta-ethnographic method outlined in Noblit and Hare's seminal work "Meta-ethnography: Synthesizing Qualitative Studies" (Noblit & Hare, 1988). Further, a worked example of meta-ethnography was employed as a guide to the practical application of Noblit and Hare's methodology (Britten et al., 2002; Ring et al., 2011).

Meta-ethnography aims to produce a synthesis that demonstrates how original studies included in a given review relate to one another. Moreover, meta-ethnography produces a synthesis that moves beyond a simple narrative summary towards conceptual advancement and new interpretation, furthering understanding in the area of interest (Britten et al., 2002; Noblit & Hare, 1988; Ring et al., 2011). In essence, the key concepts (stand-out ideas, themes, and interpretations within the original study) are treated as data. The key concepts are analysed to determine whether they are reciprocal across studies (do they have similar concepts that support one another) or refutational (do they differ and refute each other). A table is constructed to facilitate this process. Finally, from this process, a "line of argument" is developed which represents novel third order interpretations, which further contribute to the existing literature above and beyond the summation of the concepts from the original papers.

Practically, the following steps were employed in order to produce the current meta-ethnography (for examples of analysis see Appendix 5):

### 1.) Reading the studies

Each paper was read and re-read and initial notes about concepts were made.

Important study characteristics (participant demographics, inclusion criteria etc.) were noted to provide important contextual information.

### 2.) Determining how the studies are related

The initial notes were then re-read and a list of the concepts within studies was produced. Each concept, for each paper, was then considered individually and was grouped into overarching key concepts across the studies. As such, each initial concept, within each paper, was accounted for within the key concepts.

### 3.) Translating the studies into one-another

In order to be explicit about how the key concepts across the studies compare, or translate into one another, a table was created (see Table 4), which also incorporated the information gathered from the papers pertaining to outlining the study characteristics.

The table was then used in order to aid the translating of studies into one another. Each column represents a paper, and each row represents a study characteristic or a key concept. The cells within the table detail concepts identified within individual papers and demonstrate how the key concepts were derived from the original studies. "Thus, by completing the grid, it was established that each concept, in each paper, was encompassed by one of the key concepts in the grid" (Britten et al., 2002, p. 211). Blank cells in the paper highlight which papers had no data relating to that particular key concept.

#### 4.) Synthesising translations

Creating the table made it easier to perform reciprocal analysis, describing how the studies key concepts were similar to each other and refutational analysis, describing how the studies key concepts refute each other in the context of the study characteristics. Finally, the key concepts were read and re-read in order to develop a line of argument, that is to develop a third order interpretation based on the key concepts, the reciprocal and refutational analyses and the study characteristics.

#### 5.) Expressing the synthesis

The analysis is synthesised using a narrative summary, which details the reciprocal analysis and refutational analysis before finally presenting the line of argument or third order interpretations which justify the claim that the synthesis is a meta-ethnography.

## **Results**

### **Description of Included Papers**

All studies had a majority white sample, with only 10% of participants across the samples identifying as from a different ethnic background (East Asian = 2%; South Asian = 6%; South Asian = 2%). Furthermore, all studies were conducted in “western countries”; Canada, America, Australia and UK which could be argued to have relatively similar cultural, economic, spiritual and political influences. In terms of the socioeconomic background of the women, the studies are somewhat vague, with a general trend towards participants being “educated”. Fifty nine percent of the women across the papers were in relationships, however, only three cohorts (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008) detailed the sexuality of

the participants. The average age of women across the studies ranged from 27 – 40, with two papers explicitly excluding post-menopausal women.

Despite the similarities in the participants, the methods of analysis and aims of each study were different. Ayling and Ussher (2008) used a material discursive analysis and aimed to investigate the subject positions that women take up in relation to their sexuality when coitus is painful. Similarly, Kaler (2006) also used a discursive analysis as she aimed to “take up the lives of women with persistent vulvar pain” (p. 50), hoping to understand more about the enmeshment of gender and (hetero)sexual practices. In complete contrast to this, Brotto and colleagues (2013), Buchan and colleagues (2007), Munday and colleagues (2007) and Sadownik and colleagues (2012a; 2012b) all used thematic/content analysis in order to evaluate the experiences of women before and after participating in various multidisciplinary group interventions. Finally, Marriott and Thompson (2008) used Interpretative Phenomenological Analysis (IPA) to explore the meaning women make of their experiences with vulvodynia. It may therefore be expected that the outcomes of the papers may differ due to the differing, albeit qualitative, methodologies.

### **Reciprocal Analysis**

Table 4 was produced in order to outline important information from each paper and aid reciprocal analysis. Four key concepts were identified: 1.) *Social Constructions: Sex, Women & Femininity*, 2.) *Seeking Help*, 3.) *The Psychological and Relational Impact of Vulvodynia* and 4.) *A Way Forward*.

Table 4 Study Characteristics

Study Characteristics	Ayling & Ussher	Brotto et al	Buchan et al & Munday et al	Kaler	Marriott & Thompson	Sadowink et al (a & b)
Sample size	n=7	n=14	n=29	n=20 face to face interviews; n=70 open ended web based interactions	n=8	n=19
Average Age	27 (18-41)	40 (21-68)	36 (22-58)	Late teens to mid-50s; with the majority mid 20s to mid-30s.	27 (18-41)	31 (20-54)
Diagnoses	Vulvodynia	Provoked Vestibulodynia	All had provoked, localised vulvodynia and some also had unprovoked generalised vulvodynia	Primary and secondary vulvodynia	Vulvar vestibulitis	Provoked vestibulodynia
Length of symptoms (range)	n3 = 2-5 years; n4 = 5-10 years; all had a diagnosis <6months previously	n=6 lifelong; n=8 acquired (2 years -26 years)	-	-	Mean 3 years (8 months – 14 years)	Mean 65.24 months (6 months-240 months)
Relationship status & sexuality	n6 = currently partnered (4 of which cohabiting); n1 = recently been in heterosexual relationship	n=9 partnered (mean duration 7.2 years).	-	63% of web participants were either married or living with a long-term male partner. 2 interview and 2 web participants identified themselves as bisexual and 1 web participant identified herself as a lesbian	n=7 heterosexual relationship; n=1 single	n=10 married; n=5 common law; n=1 divorced; n=3 single
Socioeconomic details	n5= tertiary educated	All post secondary education with two having graduate degrees	Educated	A variety of socioeconomic background with 37% of web participants with a post secondary education	n=4 employed; n=1 full time mother; n=3 students	n=18 post secondary education; n=1 high school education
Ethnicity/nationality	n7 = Anglo Saxon-Australian	n=9 European Ancestry; n=2 East Asian	White British or White European	White American	n=8 Caucasian, British	n=11 Euro-Canadian; n=6 South Asian; n=2 Middle Eastern
Data Collection (sample and setting, interview/focus group)	Recruited from a vulvar pain clinic in Sydney, Australia Semi-structured face to face interviews and demographic questionnaire	Recruited from a large metropolitan west coast city, Canada. Face to face or telephone semi-structured interview	Vulvar pain service, Watford, UK Semi-structured in-depth interview Home/clinic/university	Newsletter of national vulvodynia association and vulvodynia related websites. Also through "sympathetic" medical professionals Interviews or web-based interactions	NHS specialist vulval pain clinic, Britain Semi-structured interview in clinic or home	Recruited from a multidisciplinary vulvodynia program in Vancouver, Canada Semi-structured interview in clinic or home



Inclusion/Exclusion Criteria	No gynaecological surgery unrelated to vulvodynia No diagnosed chronic pain unrelated to vulvodynia	Completed the IMPROVED study Diagnosis of provoked vestibulodynia	-	Women with primary or secondary vulvodynia	Pre-menopausal Diagnosis of vulval vestibulitis	Premenopausal/reproductive age No differential diagnosis Able to speak sufficient English
Theoretical perspective/epistemological standpoint	Critical realist epistemology	-	-	Feminist efforts to theorize gender	Assumption that it is possible to access an individual's cognitive inner world	-
Qualitative method of analysis	Thematic analysis/ material discursive approach	Content Analysis	Thematic Coding	Discursive Analysis	Interpretative Phenomenological Analysis	Thematic
Aims & hypotheses	To investigate the "psychologic symptomatology" of women with vulvodynia from a discursive perspective: 1. what subject positions do heterosexual women with vulvodynia take up in relation to their sexuality when coital sex is limited or painful 2. in what ways do these subject positions impact upon women's negotiation of material discursive aspects of vulvodynia with a heterosexual relationship	To explore the qualitative experiences of women taking part in group treatment program that integrates mindfulness principles along with cognitive behavioural therapy	To evaluate women's experiences of accessing help and treatment for vulvodynia (Buchan et al) To evaluate the response of a group of women with vulvodynia who were participating in an integrative multidisciplinary management programme comprising of medical evaluation and treatment, psychotherapy, physiotherapy and dietary advice (Munday et al)	To take up the lives of women with persistent vulvar pain for what they can reveal about the enmeshment of gender (hetero)sexuality and bodily practices	Explore the meaning women make of their experiences of having and being treated for vulval pain Explore the impact of vulval pain on their relationships	To explore the quality of our patients' lives and the quality of their interactions with the healthcare system prior to enrolment in the Multidisciplinary Vulvodynia Programme (Sadownik et al a) To explore the experiences of women who participated in the Multidisciplinary Vulvodynia Programme in order to identify the perceived benefits of this programme (Sadownik et al b)
<b>Key concept 1 : Social Construction: Sex, Women &amp; Femininity</b>						
<i>The Coital Imperative</i>	Belief that real sex = coitus Imagining scenarios with no [sex] sex Coitus in a sexual relationship is "normal" Continue to have [real] sex despite pain	-	Penetrative sex still attempted Stopping any physical contact for fear that it may lead to [real] sex	Belief that real sex = intercourse Belief that biologically we are supposed to be having sex Belief that men only want "real sex"	Continuing to have painful sex Avoidance of any intimacy which may lead to sex Centrality of sex within relationships (how relationships "should" be)	Avoidance of physical intimacy
<i>The One Thing that Men Really Want</i>	My partner is more understanding than other men would be (because other men just want [real] sex).  Men have a biological need for coitus which is prioritised	-	Most women described their partner as supportive (but still worried they were unable to give them [real] sex)	Envy of men: A good man is hard to find Sex as a commodity that men want (and women with vulvodynia cannot offer) String along, feeling like a tease (because men expect [real] sex)	Prioritisation of male partners Perceived male want/biological need for [real] sex Men who are understanding should be applauded	-

<i>Not [a] Real [Woman] &amp; Loss</i>	(loss) of identity for attracting men Putting up with/not hurting a man's feelings being a good (real) woman	-	Loss of sexual desire Social isolation - (loss of) self esteem - (loss of) confidence	The "male gaze" (women's authenticity comes from their relation to men) Not a "real" woman Not having children in the "right" way/expectation that babies follow marriage Not a "real" marriage – absence of a 'real' first time Robbed of motherhood No anger at heteronormative ideologies Women as sex objects Media portrayal of femininity / heterosexuality / normality	Loss of femininity: -Femininity analogous with sex -Pain not central -Loss of previous enjoyment -How sex should be	-
<i>Media Portrayal of Women</i>	Media portray women as wanting of sex Media portray sex as easy  Young people should be having lots of sex	-	Media representations of "normal" sex lives reminding women of what they cannot achieve		Perception that for others sex is fun and easy (in the media)	-
<b>Key concept 2: Seeking Help</b>						
<i>latrogensis</i>	-	No improvement or worsening of symptoms	Recurrent treatment which impacted on psychological wellbeing Amitriptyline: - weight gain and subsequent mood and self esteem difficulties - drowsiness (could generally be managed)	-	Repeated thrush treatment	Repeated visits with same treatment
<i>Experience of the Medical Model</i>	-	Alienation of single women	Attitude of physicians left women feeling emotionally disturbed / self-questioning Relief of diagnosis / feeling of being believed / not going mad Feels like a more credible diagnosis if given information Despair at no cure	Anger at medical profession Told by physicians: - need to relax -neurotic -stop fretting	"have a glass of wine" Judgement from the medical profession "silly woman" Prioritisation of a medical diagnosis Uncertainty around diagnosis / the importance of being believed	The neurotic woman / not a valid complaint Diagnosis only did a little
<i>The Mind/Body Split</i>	-	A concern that if vulvodynia is psychological then it's not "real"	-	Feeling of the body "knowing" and trying to communicate (lesbian or previous abuse) A desire to detach self from the body – my body is not me	Psychological aspect hard to think about Medical = external & removable Psychological = something "wrong" with a core aspect of myself "all in my head"	Made to feel that the pain was "all in my head" and therefore "not real"
<b>Key concept 3: The Psychological and Relational Impact of Vulvodynia</b>						
<i>Psychological Distress, Shame &amp; Guilt</i>	Shame, despite partners understanding	Guilt at not practising suggested techniques	Shame / embarrassment	Feeling of "otherness"	Fear of rejection Humiliation and shame	Psychological distress

<i>Silencing of Women</i>	Non-communication was barrier for exploring other ways of having sex	-	Inability to talk to others about vulvar pain Need to hide sexual problems Unspoken collusion (to avoid sex) became the norm	Difficulty bonding with "real" women (difficulty communicating)	-	-
<hr/>						
<i>Key concept 4: A Way Forward</i>						
<i>A Practical Difference</i>	-	Normalisation from groups - community and healing - increases psychological wellbeing - hope & acceptance Self efficacy Control Empowerment Increasing communication in partnered women	Empowerment: - given a choice of treatment - make own decisions Individual Psychotherapy - less hopeless - less anxious - more confident Regaining Control - physiotherapy allowed for feelings of self efficacy over improvement, whereas drugs do not. Feelings of safety created by the way women are treated by professionals	-	-	Empowerment: - Increased knowledge via information - Learning tools and skills (mindfulness/CBT) - Validation/ support (leading to improvement in psychological wellbeing) Good experiences with specialists: - good appropriate referrals - listen / acknowledge - say "this is beyond me" and facilitate specialist referral
<i>A Different Narrative</i>	Focusing on other "womanly" qualities (caring / nurturing etc.), without [real] sex Feminist and egalitarian discourse opens up space for women to question the position of "inadequate woman"	-	-	Adopting other "traditional" woman qualities i.e. caring and a good listener	-	-

As can be seen from the table above, the studies all related to one another through contribution to the following key concepts:

### **Key concept 1: Social Constructions: Sex, Women and Femininity**

The first key concept identified was *Social Constructions: Sex, Women and Femininity*, within which four sub-concepts were identified: 1.) *The Coital Imperative*, 2.) *The One Thing that Men Really Want*, 3.) *Not [a] Real [Woman] & Loss* and 4.) *Media Portrayal of Women*. This key concept refers to experiences that women described in their interviews, which authors of the original papers identified and labelled as constructions that were unhelpful to women experiencing vulvodynia.

#### **Sub-concept 1: The coital imperative**

The women discussed all acts of physical intimacy in relation to the 'coital imperative' (McPhillips, Braun, & Gavey, 2001; Potts, 2002), which posits that 'real sex' equals coitus: penetration of the vagina by the penis (Ayling & Ussher, 2008 p. 298).

Five out of six cohorts described a theme surrounding the notion of the "coital imperative" (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008; Sadownik et al., 2012b). Women with vulvodynia across the studies held the view that sex was only "real", "proper" or "normal" if it involved coitus (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008), with several studies describing that many women believed penetrative sex was central to a "proper" heterosexual relationship (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008; Sadownik et al., 2012b). These beliefs impacted upon women who "grieved over their inability to engage in sexual intercourse" (Sadownik

et al., 2012b, p. 25). Indeed, the narrative around what constitutes “real” or “normal” sex was so powerful that some women continued to engage in penetrative sex and “believed they were expected to accept it” (Buchan et al., 2007, p.18). As Kaler (2006) suggests, “intercourse has a normative role in defining (heterosexual) sex” (p. 59), which is supported by Ayling and Ussher (2008) who suggest that it is a “perceived pressure for coitus” and “a desire to be normal” which is “a critical factor in hetero-sexual women’s experiences of vulvodynia” (p. 298). Moreover, the notion of the “coital imperative” excluded “any positive positions for heterosexual women who cannot, or who choose not to, participate in coitus regularly” (Ayling & Ussher, 2008, p. 301).

### **Sub-concept 2: The one thing that men really want**

The subject position of ‘inadequate sexual partner’ was associated with adherence to the ‘male sex drive’ discourse, which defines man’s ‘need’ for coitus as a biological drive which his female partner must accommodate (Holloway, 1989; Nicolson & Burr, 2003; Potts, 2002) (Ayling & Ussher, 2008, p. 298).

This sub-concept was identified in four of the six cohorts (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008). It refers to a theme noted by the authors that refers to women’s beliefs that men had a “need” for sex and “would be upset by lack of sex” (Marriott & Thompson, 2008, p. 249). Furthermore, authors reported that these women held the belief that it is a woman’s ‘duty’ or ‘role’ to satisfy that need (Ayling & Ussher, 2008; Marriott & Thompson, 2008). As such, women “privileged” or “prioritised” their partner’s “need” for penetrative sex over their own “need for, or right to, pain-free sex” (Ayling & Ussher, 2008, p. 299), and “were more concerned with the effect that the vulval pain

had on their partner rather than with their own loss of enjoyment from sex” (Marriott & Thompson, 2008, p. 251).

Despite this, many authors described how the women in their studies “positioned their current partner as more supportive and understanding than they imagined other men might be” (Ayling & Ussher, 2008, p. 299). Kaler (2006) reported that women described partners as a ““good man”, the man who would love and stay with a woman with vulvodynia even though she could not qualify as a “normal” woman’ (Kaler, 2006, p. 68). Despite many women across the majority of cohorts reporting that their partners were “supportive” and “understanding” (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008), women continued to hold the contradictory belief that these understanding men were “rare and difficult to find” (Kaler, 2006, p. 68), leading women to believe that men should be “applauded” for this supposedly “rare” quality of understanding (Marriott & Thompson, 2008, p. 249). Therefore, authors used this contradiction to challenge women’s perceptions of their partner’s “need” for coitus, and as such suggested that women’s perception that they are unable to provide “The One Thing that Men Really Want” could be challenged (Kaler, 2006, p. 60).

### **Sub-concept 3 : Not [a] real [woman] & loss**

In response to the question ‘Does vulvodynia affect your sense of self as a woman?’ women expressed a sense of themselves as ‘degendered’ and ‘defeminised’ by vulvodynia (Kaler, 2006, p. 60).

Four out of six cohorts (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008) reported themes relating to a sense of “loss of femininity” (Marriott & Thompson, 2008, p. 248) or an “inability to claim

womanhood as an identity” (Kaler, 2006, p. 62), and the authors found that this sense of a loss of womanhood was specifically linked to women’s inability to engage in intercourse.

Moreover, authors reported that women’s sense of femininity was inextricably linked to the ability to “attract and keep a man” (Ayling & Ussher, 2008, p. 299). As such, authors reported that women’s sense of femininity was defined by whether men would view them as desirable. Whilst problematic in general, this capacity of women to see themselves as feminine only in relation to a man, becomes particularly problematic for women with vulvodynia who, the authors report, see themselves as “something no man would desire if he knew what he was getting himself into” (Kaler, 2006, p. 64). Kaler (2006) further postulates heterosexuality as a “set of market relations and transactions in which men ‘contracted’ for sex with women” (Kaler, 2006, p. 71). As such, women may perceive (consciously or unconsciously) a loss of “currency” (sex), due to their inability to both perform coitus and the perception that vulvodynia had taken away their “sexiness” (Marriott & Thompson, 2008, p. 249). Authors therefore describe that women worried about “false advertising” regarding sexual intercourse (Kaler, 2006, p. 64), risking “punitive consequences, such as the derogatory labels of ‘frigid’ or ‘prick tease’ or a diagnosis of sexual dysfunction” (Marriott & Thompson, 2008, p. 301), perhaps further contributing to women’s feelings of being “fake” or “pseudo-women” and confirming themselves as “unreal women” (Kaler, 2006, p. 63).

#### **Sub-concept 4: Media portrayal of women**

This was exacerbated by media representations, especially in women’s magazines, of what constituted ‘normal’ sex lives. It reminded them of

what they could not achieve and perpetuated the feeling of failure (Buchan et al., 2007, p. 17).

Four of the six cohorts referred to themes relating to perceived societal or cultural norms regarding sex, often perpetuated by media representations of how sex and relationships “should” be (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008). These societal norms and perceptions cultivated negative self-evaluations in women with vulvodynia leading to a sense of alienation in comparison to “other ‘healthy’ heterosexual women” for whom sex was perceived to be “easy and natural”, further leaving women with a feeling that “I’m having all these problems” and “the rest of the world isn’t” (Marriott & Thompson, 2008, p. 249).

In particular, there seemed to be a link between the portrayals of young women in the media that was highlighted across these studies; a sense that young women should be “skilful”, “eager” (Ayling & Ussher, 2008, p. 229) and “‘even more’ sexually active because of their youth” (Marriott & Thompson, 2008, p. 249). Furthermore, Marriott and Thompson (2008) noted that for young women in particular, there appeared to be a perception that the quality of sex was directly related to the quality of the relationship, perhaps contributing to the finding by Ayling and Ussher (2008) that young women with vulvodynia in particular felt “inexperienced”, “immature” and “constrained by the material limits of their vulval pain”, especially in comparison to media portrayals of young women and sex (Ayling & Ussher, 2008, p. 229).



## **Key concept 2: Seeking Help**

Five cohorts described themes relating to the key concept of *Seeking Help*. This key concept is comprised of three sub-concepts; 1.) *Iatrogenesis*, 2.) *Negative Experiences of the Medical Model* and 3.) *The Mind/Body Split*, all of which relate to women's experiences of Seeking Help for their vulvodynia.

### **Sub-concept 1: Iatrogenesis**

"Iatrogenesis" or an "iatrogenic effect" refers to an "illness caused by medical examination or treatment" (oxforddictionaries.com). Three cohorts (and four papers) presented findings relating to this sub-concept (Brotto et al., 2013; Buchan et al., 2007; Marriott & Thompson, 2008; Munday et al., 2007).

All three cohorts described how women reported being repeatedly prescribed thrush treatment in the absence of candida (yeast) infections (Brotto et al., 2013; Buchan et al., 2007; Marriott & Thompson, 2008). At best, women described how this repeated treatment had no effect on their experience of pain, but served to delay referral to specialist services (Marriott & Thompson, 2008), and at worst, women described a worsening of symptoms following repeated treatment (Brotto et al., 2013; Buchan et al., 2007).

Furthermore, women described side effects of certain medications, such as weight gain, which led to the experience of iatrogenic psychological difficulties affecting their self-esteem and sexuality (Munday et al., 2007). Moreover, women also attributed delays in treatment/referrals as having a direct causative detrimental effect on women's levels of distress and mental health (Buchan et al., 2007).

### **Sub-concept 2: Negative experiences of the medical model**

Like most women in the study, Sue directed her strongest emotions against medical professionals and institutions which women believed had belittled and misdiagnosed vulvodynia, rather than at the more nebulous and hard-to-pin-down targets of hegemonic norms of gender and sexuality (Kaler, 2006, p. 69).

Five cohorts outlined themes relating the Experience of the Medical Model.

Women had seen multiple healthcare professionals and felt that healthcare professionals had very little knowledge about vulvodynia (Buchan et al., 2007; Marriott & Thompson, 2008; Sadownik et al., 2012a, 2012b). Moreover, women felt they were mistreated by healthcare professionals because of their gender, often experiencing the suggestion that they were “neurotic”, “frigid”, needed to “relax” or that sex was just painful for women (Kaler, 2006; Marriott & Thompson, 2008; Sadownik et al., 2012b).

Furthermore, the authors report that women experienced distress caused by their experiences with healthcare professionals, leaving women “feeling emotionally disturbed and self-questioning” (Buchan et al., 2007, p. 17) and experiencing feelings of “anger”, “shame” and “stigma” (Marriott & Thompson, 2008, p. 254 - 255).

### **Sub-concept 3: The mind/body split**

Some women felt that there was more hope of overcoming the pain if it were physical in origin, but that it was almost hopeless if it were psychological. It seemed that a medical condition could be externalised and hopefully removed, but that a psychological aspect of the pain indicated something wrong with them ‘internally’, in the core aspects of themselves (Marriott & Thompson, 2008, p. 252).

Four cohorts outlined themes that pertained to women's distress at the implication that it was "all in their head" (Brotto et al., 2013; Kaler, 2006; Marriott & Thompson, 2008; Sadownik et al., 2012b).

Kaler (2006) theorizes about this, suggesting that women "expressed a yearning" for the "mind/body split", suggesting that women "wanted a way to disconnect the troubled body from the real, essential self, an assurance that our bodies, to twist the well-known phrase, are not ourselves." (Kaler, 2006, p. 67).

### **Key concept 3: The Psychological and Relational Impact of Vulvodynia**

Women described both interpersonal effects of vulvodynia (relationships with others) and intrapersonal effects of vulvodynia (relationship with themselves). The key concept of *The Psychological and Relational Impact of Vulvodynia* was found within all six cohorts and is comprised of the sub-concepts: 1.) *Psychological Distress, Shame & Guilt* and 2.) *Silencing Women*.

#### **Sub-concept 1: Psychological distress, shame & guilt**

Participants reported negative changes in their mood, including frustration, anxiety, stress and depression (Sadownik et al., 2012b, p. 25).

Psychological distress was a prevalent theme across all six cohorts. Buchan and colleagues (2007), Sadownik and colleagues (2012a) and Brotto and colleagues (2013) all report psychological difficulties in the cohort of women they interviewed, including low self-esteem, anxiety, frustration, an altered self-image and "depression that varied from low mood to clinical depression requiring antidepressant

medication” (Buchan et al., 2007, p. 17). Furthermore, Buchan and colleagues (2007) also make reference to experiences of “inadequacy, guilt and shame” in women in response to their perceived “sexual failure” (Buchan et al., 2007, p. 17).

However, whilst also noting the experiences of these psychological difficulties in their cohorts of women, Ayling and Ussher (2008), Kaler, (2006) and Marriott and Thompson (2008) all move beyond the identification of these difficulties in the women, suggesting that these experiences are not solely brought about by the experience of pain or the inability to have sex per se, but rather as a result of social narratives and discourses (outlined in key concept 1) that contribute largely to the negative psychological experiences of women with vulvodynia. For example, Marriott and Thompson (2008) postulate that women with vulvodynia experience shame due to the social contextualisation of their evaluation of themselves, as they perceived others to see them (i.e. abnormal or “other”), which in turn leads to the experience of low mood and anxiety (Gilbert, 2006). Similarly, Ayling and Ussher (2008) noted that women reported experiences of “shame” in spite of support from partners. They suggest that this contradiction occurs due to significant discourses around coitus establishing heterosexual relationships as normal, regardless of the material context of an intimate partner who is supportive and non-pressurising. Moreover, they found that women who did position themselves as an “inadequate woman/sexual partner” experienced “guilt, shame, and a decreased desire for sexual contact”. In contrast, one woman, through use of egalitarian discourse, was able to challenge these unhelpful discourses and as such reported being “confident” and “happy” (Ayling & Ussher, 2008). Finally, Kaler (2006) specifically addresses the experience of guilt that women with vulvodynia experience, suggesting that the objectification of women as sexual objects leads them

to feel a sense of inauthenticity or guilt; “from the outside world, they might be mistaken for a proper sexual object, being attractive and desirable, but on the inside they were ‘bad’ or ‘spoiled’” (Kaler, 2006, p. 64).

Moreover, as discussed in key concept 2, the authors of the papers report iatrogenic medication, negative interactions with the healthcare system and the notion of The Mind/Body Split also exacerbated the experience of psychological distress in these women with vulvodynia. As such, it is likely that the experience of socially contextualised shame, based upon social narratives of what constitutes “normal” gender and sexuality, as well as interactions with the healthcare system, may play a key role in moderating the psychological difficulties experienced by women with vulvodynia.

### **Sub-concept 2: Silencing of women**

Shame is highly disempowering and can result in self-silencing and isolation (Seu, 1995). Combined with the taboo associated with female genitalia and the discussion of sexual practices, this can act to constrain women from seeking professional help for their symptoms, or from communicating honestly with their partners and experimenting with alternative forms of intimacy (Ayling & Ussher, 2008, p. 301).

Three authors, reporting on three separate cohorts, discussed the difficulty faced by women in communicating openly about their experiences of vulvodynia (Ayling & Ussher, 2008; Buchan et al., 2007; Kaler, 2006). Women seemed to understand that they needed to remain silent about their vulvodynia, a necessity that Ayling and Ussher (2008) attribute to the taboo surrounding sex, particularly women and sex. Indeed in one cohort, some women had not talked to anyone about their pain (Buchan et al., 2007), highlighting the pressure experienced by women to

remain silent about their experiences. In relation to this, in one study the author describes how the lack of communication would lead to a “Mexican standoff”, where the “women were in fear of experiencing pain and so avoided sex, and partners were fearful of causing pain, and therefore an unspoken collusion to avoid sex became the norm” (Buchan et al., 2007, p. 17).

The self-silencing that women engaged in rendered them socially isolated and thus unsupported, and as such, vulvodynia modified women's relationships with other women, as well as their relationships with men (as discussed above). Kaler (2006) observed that women with vulvodynia often reported finding themselves excluded or separated from communities of women, whereby “if a woman had no heterosexual to talk about, she could find herself an outsider in communities of women structured by heteronormative discourses” (Kaler, 2006, p. 65).

The action, or rather inaction, of women remaining silent about their vulvodynia has serious psychological consequences, with Buchan and colleagues concluding that women's need to hide their vulvodynia from peers and social networks “exacerbated their feelings of abnormality, social isolation and difference; that further eroded their social identity, self-esteem and confidence” (Buchan et al., 2007, p.17). Moreover, previous literature suggesting that self-silencing is linked to increased rates of depression (Jack, 1991), is used as evidence by Ayling and Ussher (2008) to explain, to some degree, why women with vulvodynia experience psychological difficulties including, “in extreme cases, suicidal ideation” (Ayling & Ussher, 2008, p. 301).

#### **Key concept 4: A Way Forward**

The final key concept, *A Way Forward* was referenced in four cohorts (Ayling & Ussher, 2008; Brotto et al., 2013; Buchan et al., 2007; Munday et al., 2007; Sadownik et al., 2012a), and is comprised of the sub-concepts 1.) *A Practical Difference* and 2.) *A Different Narrative*.

##### **Sub-concept 1: A practical difference**

Women reported that there were some practical changes that allowed them to “move forward” in relation to their vulvodynia, which focused on two main areas: increasing communication with partners, and empowerment & control.

Women who attended Brotto and colleagues' (2013) IMPROVED group reported that the information provided at this group around vulvodynia enabled women to “open up a dialogue” with partners through sharing the information and helping them to define and talk about the vulvodynia, which women reported impacted upon the quality of their relationships by increasing understanding and “relationship cohesiveness” (Brotto et al., 2013, p. 10). In support of this, addressing feelings of shame in therapy and providing women with information was also found to facilitate communication with partners in other studies (Buchan et al., 2007; Munday et al., 2007).

“Another major theme that emerged was the ‘sense of empowerment’ that women gained from the programme” (Sadownik et al., 2012a, p. 1091). Sadownik and colleagues (2012a; 2012b), Buchan and colleagues (2007) and Brotto and colleagues (2013) all reported that their intervention groups, which consisted of multidisciplinary approaches including physiotherapy, psychotherapy and

mindfulness, “increased confidence” (Sadownik et al., 2012a, p. 1091), “improved sense of self-efficacy” (Brotto et al., 2013, p.11-12) and “empowered them and gave them control of the condition” (Munday et al., 2007, p. 21), which in turn “served to lessen the emotional and psychological burden of their disease” (Brotto et al., 2013, p.12). Further, the authors reported that following the intervention groups “the theme of normalisation was evident: women described a sense of relief in learning that they were not alone in their suffering and they directly credited this normalisation to some of their subsequent improvements” (Brotto et al., 2013, p. 12).

### **Sub-concept 2: A different narrative**

Women, including lesbians, celibate women and women who simply do not like intercourse, offer alternate narratives of the relationship between sexual practices, sexuality and gender. Their narratives have the power to short-circuit the fusion of sexual practice and gender which has caused so much pain to many women with vulvodynia (Kaler, 2006, p. 71).

In two cohorts (Ayling & Ussher, 2008; Kaler, 2006), the authors reported that if women were able to adopt different narratives, this in turn minimized experiences of “anxiety, fear, resentment, guilt, shame, isolation, and the positioning of both the body and self as ‘faulty’” (Ayling & Ussher, 2008, p. 301). The changes that were reported centred on adopting different and more helpful narratives around sex and finding new narratives of “how to be a woman”.

Firstly, the one woman who was able to adopt “an egalitarian relational discourse”, which did not “privilege one partner’s needs or concerns over the others”, allowed her, and her partner, to “dismiss the ‘coital imperative’ and experiment with other sexual practices”, which in turn freed this woman from the “physical and psychological pain” which had previously been linked with painful



coitus (Ayling & Ussher, 2008, p. 299). However, it must be borne in mind that in only one woman across the cohorts reported adopting a more helpful egalitarian discourse.

Secondly, some women rejected the notion that intercourse made them a woman, and instead adopted other behaviours, particularly those associated with a traditional view of “womanhood”, such as mothering and caring, which enabled women to maintain the concept of “essential womanhood” (Kaler, 2006, p.68). Similarly, Ayling and Ussher (2008) found that women attempted to renegotiate the construct of womanhood, instead emphasising “caring qualities” and a “nurturing nature”.

### **Refutational Analysis**

Overall, the studies do not refute each other. Despite this apparent lack of contradiction across the studies, papers which actively described and acknowledged the authors' epistemological standpoint, utilising methods of analyses in keeping with their epistemologies, tended to place the difficulties experienced by these women with vulvodynia within the context of (often unhelpful) cultural ideologies around sex, gender and womanhood (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008). In contrast, papers using content/thematic analysis, with no reference to epistemological standpoint, tended to place the difficulties within the individual, moving away from understanding within a cultural context and moving towards the individualised treatment of women from a variety of perspectives. These ranged from physiotherapy, including self-massage to “desensitize the area” (Munday et al., 2007; Sadownik et al., 2012a), medication or local aesthetic products

(Munday et al., 2007), psychotherapy, mainly in the form of CBT or mindfulness aimed at challenging women's cognitive distortions (Munday et al., 2007; Sadownik et al., 2012a) or acceptance of thoughts (Brotto et al., 2013) and dieticians promoting the low oxalate diet (Munday et al., 2007).

In this way, the studies comprised two groups, which (although sometimes over-lapping) do not directly refute each other, but rather complement and mutually support each other:

- "Experience Papers" primarily concerned with critical realist, feminist and phenomenological perspectives (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008).
- "Intervention Papers" primarily concerned with categorisation and theming of qualitative data as a way of evaluating interventions (using a pre and post methodology), not situated with a specified epistemological framework (Brotto et al., 2013; Buchan et al., 2007; Munday et al., 2007; Sadownik et al., 2012a, 2012b).

This may explain the different foci of conclusions each group of papers draws, with experience focused papers centring on the helpfulness of changes in narrative, whilst the "intervention papers" focus on the helpfulness of individualised multidisciplinary approaches. Interestingly, despite the differences, both changing narratives and individualised approaches allowed women to open up communication with others, which women resoundingly reported as being helpful and improving the feelings of shame, stigma and associated low mood and anxiety.

### **Line of Argument**

Ninety-seven women were interviewed across eight papers consisting of six cohorts of women. Following this review, we can more firmly conclude that the women in the included studies experienced negative consequences of social narratives around womanhood, sexuality and femininity, including the prioritisation of penetrative sex, the belief that sex is the role of women to provide for men, and media portrayals of sex as easy and natural. These discourses affected women's relationships, both intimate heterosexual relationships and relationships with other women, from whom the women with vulvodynia felt excluded. Moreover women experienced the healthcare system as dismissive, sometimes being prescribed treatments that exacerbated the experience of pain. These experiences left women feeling silenced and isolated and experiencing shame and guilt because of the social taboo, especially around female sexuality, which in turn lead to the experience of psychological distress, low mood, anxiety and low self-esteem.

However, the review also suggests that educating women about vulvodynia, empowering them to gain a sense of control over their experience of pain in the form of multidisciplinary group work (grounded within a individualistic approach) is also helpful for women (Brotto et al., 2013; Buchan et al., 2007; Munday et al., 2007; Sadownik et al., 2012a, 2012b), although the long term outcomes of these groups are yet to be measured. It may be that incorporating discussions around unhelpful social constructs may mitigate the danger that interventions based solely on psycho-education and interventions to "fix" women, may unwittingly place blame on women, holding them and them alone responsible for the management of their pain and the psychological consequences of vulvodynia, which seem to be, in fact, context related.

Overall, the review demonstrates that hetero-normative ideologies play a significant role in how women experience vulvodynia. Most importantly, it highlights the psychological impact of living with pain in an intimate area so inextricably tied up with sexuality and gender, in a culture that conflates sex with penetration and penetration with womanhood.

### **Discussion**

The current review identified eight empirical papers pertaining to women's experiences of living with vulvodynia. Using systematic review and meta-ethnographic methodology, the papers have been explored in order to summarise what we know about women's experience of vulvodynia, and have been analysed in order to gain new insights above and beyond the summation of the original studies. Reciprocal analysis revealed four key concepts were identified: 1.) *Social Constructions: Sex, Women and Femininity* 2.) *Seeking Help* 3.) *The Psychological and Relational Impact of Vulvodynia* and 4.) *A Way Forward*. Refutational Analysis revealed experience focused papers tended to place the experiences of women within the socio-cultural context, whereas intervention focused papers tended to place the difficulties within the individual. A line of argument was developed which surmised that hetero-normative ideologies and discourses affect women's relationships, sense of womanhood and psychological wellbeing, which is further exacerbated by some encounters with the medical model. The main psychological experiences included: frustration, depression, anxiety, low self-esteem, shame and guilt, experiences that have also been well documented in other idiopathic pain literature (Gamsa, 1994).

Vulvodynia, by its nature, is the experience of pain in a part of the body that is also inseparably linked to sex. Moreover, Tiefer (2001) has reported that the difficulties that women repeatedly tell researchers are their primary areas of sexual distress are: the desire for intimacy, wishes to please a partner, and wishes to avoid offending, losing or angering a partner (Tiefer, 2001). As such, the psychological difficulties associated with vulvodynia may be seen as two-fold; the psychological consequences of pain per se (as also reported in other pain disorders (Gamsa, 1994)) as well as the psychological consequences associated with the inability to perform, as desired, (hetero)sex. It is therefore of the utmost importance that models for the treatment of vulvodynia acknowledge both the impact of living with the experience of pain, as well as the impact of pain in an area inextricably linked to gender, femininity and (hetero)sexuality.

Overall, the studies, which in total incorporate the views of 97 women with vulvodynia across four different countries, report similar, mutually supporting insights into the experience of being a woman living with vulvodynia. However, despite this, the following must be borne in mind. Qualitative research by its nature seeks to find a purposive sample (in this case, women with vulvodynia). However, the studies reviewed only offer insights gained from predominantly young, white, educated, heterosexual women living in westernised, English speaking cultures, accessing services. Therefore, the outcomes of this review cannot be assumed to apply to other groups of women (see below).

### **Implications for Clinical Psychology**

This review highlights that women suffering from vulvodynia may be at particular risk of developing psychological difficulties, including depression, anxiety, low self-esteem and shame, which is supported by previous quantitative research (Gates, 2001; Gates & Galask, 2001; Sackett et al., 2001). By reviewing the papers included here, we can begin to understand what interventions may be helpful for women, especially in relation to preventing or treating psychological difficulties.

For example, the review highlights the importance of prioritising the psychological wellbeing of women with vulvodynia, not attempting to treat the pain solely from a medical perspective. The current review highlights shame as a particularly predominant psychological difficulty that arose for many of the women within the reviewed literature. Thus, it could be postulated that models of shame may be particularly helpful in understanding the psychological experiences of women with vulvodynia, which conceptualise shame as “the underlying desire to be valued and seen as a talented, deserving, desirable individual” (Gilbert, 2006, p. 87). Gilbert’s model conceptualises shame in the context of socio-cultural rules and beliefs of what constitutes pride and honour as well as what constitutes shame and stigma. It postulates that we experience shame in the context of internal shame (self-devaluation, depression, anxiety) and external shame (devalued by others, excluded, criticised), which is moderated by the way we experience stigma and/or rejection from the community/society. Formulating vulvodynia using models of shame, and intervening, using for instance, compassionate mind therapy, may be one helpful way to begin to alleviate psychological difficulties in women with vulvodynia.

Similarly, the importance of changing narratives was highlighted across the studies reviewed as an action that was particularly helpful for women with vulvodynia. Therefore, it could also be tentatively concluded from this review that narrative therapy (White & Epston, 1990; a therapy grounded within social constructionist epistemology) may also be a particularly useful therapy for women with vulvodynia, as a way of helping them recognise and challenge unhelpful narratives developed within a cultural context (Harper & Spellman, 2006).

More broadly, the recommendations that are drawn from the findings of this review are that interventions should not solely be aimed at the individual level (i.e. challenging women's negative (implied faulty) thinking, or working on their pelvic muscles, or learning how to have pain free intercourse), based on the notion of "fixing" women, but rather using psychological perspectives to help women (their partners, healthcare professionals and any further important others) understand and begin to deconstruct unhelpful narratives and reconstruct more helpful ones around vulvodynia, gender and sexuality that begin to challenge ingrained societal scripts. Clinical psychologists are able to draw from a wealth of different therapeutic models, including cognitive behavioural therapy, narrative therapy and models of shame. This ability, along with their training from a bio-psycho-social perspective, best places them to deliver psychological interventions, such as one-to-one therapy, facilitation of groups and consultation within relevant healthcare, for women with vulvodynia.

## **Methodological Considerations**

There are several limitations to the current research. Although systematic review guidance was utilised in order to ensure the rigorous searching procedures outlined above, it is possible that not all relevant literature was identified. Further, the review only included studies published in English and in peer reviewed journals, excluding any research in other languages or research in other sources such as theses/dissertations, the inclusion of which would have been beyond the scope of the current review.

Despite these limitations, the current review has several strengths, including the utilisation of a strict and rigorous systematic searching in line with PRISMA guidance (Moher et al., 2009). The CASP tool (2014), a well recognised and widely used quality assessment tool, was utilised in order to quality assess papers to provide context for the included papers. Finally, in-depth analysis of the data was undertaken, rather than simple categorisation of the findings, allowing the current review to contribute new insights, furthering our understanding of vulvodynia, and allowing reliable and useful implications for clinical practice to be drawn.

## **Future Research**

Following this review, several areas warrant further investigation in order to begin to improve this under-researched and under-recognised health condition:

- 1.) Future research should aim to include women of colour, women from different cultures, asexual, bisexual and lesbian women and women who are post menopausal, and should focus on the psychological wellbeing of these groups.



- 2.) The journey towards diagnosis was mentioned consistently throughout the papers as being particularly problematic for women with vulvodynia, impacting upon psychological wellbeing. Despite this, only one paper focused on this specific topic. Unfortunately, due to methodological weaknesses (see quality appraisal and critique of papers), it is difficult to draw conclusions about how and why this journey is particularly problematic and distressing for women. Therefore, further research into women's experiences of the journey towards diagnosis and its impact upon the psychological wellbeing of women is warranted so that reliable and firm conclusions can be drawn in order to improve this process for women with vulvodynia.
- 3.) Finally, research into devising, implementing and evaluating psychological interventions, based on the observations made in the current review, is warranted. It would be helpful to review existing research into the effectiveness of psychological interventions for women with vulvodynia as a starting point for developing both one-to-one therapy and group therapy for secondary psychological difficulties suffered by these women.

### **Conclusion**

Authors of qualitative literature pertaining to the experiences of women with vulvodynia consistently report psychological difficulties. From reviewing the literature it seems that interventions aimed at helping the individual women's experience of pain, as well as interventions aimed at equipping women to challenge social narratives, may be helpful for the psychological well-being of women with vulvodynia.

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## **Women's experiences of vulvodynia: An interpretative phenomenological analysis of the journey towards diagnosis<sup>3</sup>.**

**Objective:** To explore the experiences of women diagnosed with vulvodynia, specifically their journey towards diagnosis.

**Design:** Women were recruited from the Vulval Pain Society. Eight women, aged between 23 - 70 years, all with a diagnosis of vulvodynia, were interviewed. Interpretative phenomenological analysis was used.

**Results:** Following analysis, women's experiences were interpreted into three Master Themes 1.) *The Journey is a Battle*, 2.) *"What is Vulvodynia?": Ambivalence Towards Diagnosis* and 3.) *Patriarchy, Women & Sex*.

**Conclusion:** Overall, the women interviewed perceived a healthcare system which was dismissive and shaming, with an inadequate knowledge of vulvodynia. This in turn impacted upon women's psychological wellbeing. Clinical Psychologists, working in vulval pain services that provide individual and group work for women with vulvodynia, as well as consultation and training to other healthcare professionals, may go some way to improving the psychological wellbeing of women with vulvodynia.

**Key words:** vulvodynia, vulval pain, qualitative, interpretative phenomenological analysis, journey towards diagnosis

### **1 Introduction**

Vulvodynia is the experience of idiopathic pain in the form of burning, soreness or throbbing in the external female genitalia referred to as the vulva (Nunns & Murphy, 2012), and is experienced by 4-16% of the population (Eppsteiner, Boardman & Stockdale, 2014). Research has explored several causative factors including neuropathic pain, psychosocial influences and infection; however the aetiology remains unknown, and successful therapy often involves a multidisciplinary approach (Eppsteiner, Boardman & Stockdale, 2014). The impact of vulvodynia is idiosyncratic, but common difficulties include using tampons, sitting, engaging in penetrative sex or exercising, which in turn impacts on women's

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<sup>3</sup> Manuscript prepared for submission to the Qualitative Research in Psychology. See appendix 6 for author guidelines



day-to-day functioning, including both employment, leisure and caring activities. Vulvodynia also impacts upon intimate relationships and psychological well-being, including increases in depression, anxiety and lowered self-esteem (Gates, 2001; Gates & Galask, 2001; Sackett et al., 2001). Social Constructions around sex and womanhood also exacerbate psychological difficulties by increasing shame, silencing and guilt at not being able to “perform as a woman”, which in turn leads women to feel de-gendered and no longer “a real woman” (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008). As such, the psychological impact of vulvodynia should be understood in the context of individual experiences, but also within a societal context and experiencing pain in an area intrinsically linked with sex, gender and femininity (Shallcross, Dickson, Nunns, McKenzie & Kiemle, in preparation).

Previous research into women’s experiences within the healthcare system suggests that around 35% of women attend more than 15 appointments and wait more than 36 months between the onset of symptoms and receiving a diagnosis (Connor, Brix & Trudeau-Hern, 2013). Moreover, only half of women experiencing symptoms consistent with a diagnosis of vulvodynia seek help, with less than 2% obtaining a diagnosis (Reed et al., 2012). The reasons for this are unknown, but research into women’s experiences within the healthcare system might provide some answers. Several qualitative papers have explored the experiences of women living with vulvodynia, with the majority focusing on the impact upon intimate relationships, sexual functioning (Ayling & Ussher, 2008; Kaler, 2006; Marriott & Thompson, 2008) or the effectiveness of interventional multidisciplinary groups (Brotto et al., 2013; Munday et al., 2007; Sadownik, Seal & Brotto, 2012a). Within these papers, the impact of the journey towards diagnosis within the healthcare

system is often alluded to. Authors report that side effects of medication (Munday et al., 2007), delays in treatment (Buchan et al., 2007) and the implication that the pain was “all in their head” (Brotto et al., 2013; Kaler, 2006; Marriott & Thompson, 2008; Sadownik, Seal & Brotto, 2012b) left women “feeling emotionally disturbed and self-questioning” (Buchan et al. 2007, p. 17). One paper in particular focused on the “journey into treatment”, concluding that “vulvodynia is poorly recognised, and the delay to diagnosis adversely affects patients, exacerbating the severity of their symptoms” (Buchan et al. 2007, p.15). However, this paper had several methodological shortcomings, including a failure to critically examine the authors’ own influences in the research process, no in-depth description of the analysis method and a failure to discuss the epistemological and ontological standpoints of the authors (Shallcross et al., in preparation).

As such, previous research fails to offer sufficiently detailed, explanative and robust insights into how women experience their journey towards diagnosis within the healthcare system, and how this impacts upon their pain, functioning and well-being. Therefore, the current paper aims to explore the experiences of women diagnosed with vulvodynia within the UK healthcare system, specifically their journey towards diagnosis. In order to do this, qualitative methodology and Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was used, as a way of getting close to the participant’s personal worlds (Frost et al., 2010), whilst recognising that meanings are constructed within a social context (Smith, Harré & Van Langenhove, 1995).

## 2 Method

This research was developed with members of the Vulval Pain Society (VPS)<sup>4</sup> who identified a need for their experiences of the journey towards diagnosis to be researched further. Support and advice has been sought throughout the research process from an *expert by experience* and *service user*. As the study did not involve NHS staff, NHS sites or sampling of participants through NHS systems, ethical approval was sought from and granted by The University of Liverpool Committee of Research Ethics (RETH000625).

### 2.1 Participants

In keeping with IPA methodology, a purposive sampling procedure was utilised. The study aimed to recruit between four and ten participants, allowing for detailed analysis of individual accounts as well as the development of meaningful cross-case analysis for patterns of similarity and difference (Smith, Flowers & Larkin, 2009). Members of the VPS living in the North West of England were asked if they would like to take part in the study via advertisements placed on the VPS website and via VPS emailing lists (see Appendix 7). Women were eligible for the study if they had a medical diagnosis of vulvodynia (i.e. diagnosed by a qualified medical practitioner), were over 18 years of age, able to speak and understand sufficient English to be able to participate in the interview, and if they had received their diagnosis no less than 6 months ago and no more than 7 years ago. Eligible women wishing to take part in the study were sent the study information sheet (see

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<sup>4</sup> The Vulval Pain Society (VPS) is a nationwide UK charity organisation supporting its members who are women with vulvodynia, service users and experts by experience.

Appendix 8), following which an interview was arranged and fully informed consent obtained (see Appendix 9).

Twenty women contacted the researcher. Of these, two women subsequently decided not to go ahead with participation in the study, two women were not contactable following the initial contact, eight women were not eligible to participate (no formal diagnosis (n=1), living outside of recruitment area (n=1), diagnosed more than 7 years ago (n=4)) and two women contacted the researcher after recruitment was closed on the VPS website. Therefore eight women, aged between 23 - 70 years, all with a formal medical diagnosis of vulvodynia, were interviewed. Five women were interviewed in their own homes and three women were interviewed at the University of Liverpool. Table 5 outlines the demographic information of all included participants.

Table 5 Demographic Information of Participants

Pseudonym	Age	Other Relevant Diagnoses	Relationship status
Lilly	33	MRI revealed some scar tissue	Single
Amy	24	Spastic paraplegia	Boyfriend
Vicky	48	Lichen Sclerosus	Complicated
Laura	23	Vulval eczema	Recently Single
Clara	57	Urethral syndrome & fissures	In a relationship
Liz	58	N/A	Married
Bessie	67	Varicose vein	Married
Josephine	70	Pudental Neuropathy	Married

## **2.2 Procedure**

The interview was conducted in a flexible manner, using a semi-structured schedule designed to facilitate an enabling interview for participants to tell the story of their experience (see Appendix 10). The aim of the semi-structured interview schedule was to use open-ended and non-directive questions to facilitate in-depth and at-length dialogue on the part of the participant (Smith, Flowers & Larkin, 2009). Questions (and possible prompts) were developed that aimed to suspend, as far as is possible, prior assumptions about the participants and their experiences, covering the following areas: onset of symptoms, contact with services, the role of diagnosis and the experience of the journey. The mean length of the interviews was 78 minutes (range 53-109). Interviews were transcribed using the University of Liverpool transcribing services that adhere to confidentiality contracts, with the exception of Amy's transcript which was transcribed by the researcher (RS). In order to protect participant anonymity, all identifiable information was removed from transcriptions and pseudonyms are used throughout the thesis. The qualitative data analysis software QSR-NVIVO 10 (QSR International Ltd, 2012) was used in order to aid storage and retrieval of the data.

### **2.2.1 Analysis**

IPA (Smith 1996; Smith, Flowers & Larkin 2009; Smith, Harré & Van Langenhove, 1995) has been widely used in health research, specifically sexual health (Flowers, Hart & Marriott, 1999), women's sexuality (Lavie & Willig, 2005) and vulvodynia (Marriott & Thompson, 2008). It aims; "to understand how people make sense of events, relationships, and processes in the context of their particular

lifeworlds” (Larkin, Eatough & Osborn 2011, p.330). It is influenced by the philosophical underpinnings of phenomenology, hermeneutics and idiography<sup>5</sup>.

IPA is phenomenological in its detailed examination of the personal, lived experience of participants, exploring how participants make sense of these experiences (Smith, 2004). IPA methodology aims to get close to the participant’s personal world (Smith, 2007), as far as is possible, by adopting an “insider perspective” (Conrad, 1987; Smith, 1996). However, IPA recognises that this is not directly and completely possible, as access to the participant’s personal world is complicated by the researcher’s own conceptions (Smith, 1996). As such, IPA recognises that the research process is dynamic; acknowledging the “double hermeneutic” or “two-stage interpretation process” whereby the participants seeks to make sense of their world, and the researcher seeks to make sense of the participant’s sense making (Smith, 2007).

Moreover, IPA is idiographic, acknowledging that individual interpretation takes place within the context in which the phenomena transpires (Larkin, Watts & Clifton, 2006) and is informed by the theoretical perspective of “symbolic interactionism” (Smith, 1996); how meanings are constructed by individuals within both a social and personal world (Frost et al., 2010; Smith, 1996; Smith, Harré & Van Langenhove, 1995). As such, IPA takes account of individual differences in meaning-making within a social context, and thus is well suited to studying the intimate personal nature of the experience of vulvodynia within context of the healthcare system, itself set within a wider social context.

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<sup>5</sup> **Phenomenology** is the philosophical study of the structures of subjective experience and consciousness. **Hermeneutics** is the theory of interpretation. **Idiography** is the effort to understand the meaning of contingent, unique and often subjective phenomena of individuals

Guidelines for the process of analysis were followed (Smith, Flowers & Larkin, 2009). Each transcript was analysed individually before moving to the next case, following the procedure outlined by Smith, Flowers and Larkin (2009). Each transcription was read, re-read and highlighted for phrases and paragraphs of particular interest. The transcript was then subjected to a detailed analytical reading whilst also coding the text at descriptive, linguistic and conceptual levels in the right-hand margin. Following this, the initial coding was translated into emergent themes which were recorded in the left-hand margin (see Appendix 11). The emergent themes were then scrutinized and clustered to create subordinate themes, in turn clustered into superordinate themes (see Appendix 12). This procedure was then completed with all subsequent transcripts. Following the analysis of individual transcripts, the tables of super and subordinate themes were examined to detect patterns across cases, with attention paid to both convergent and divergent themes, in order to identify higher order concepts, resulting in a table of Key Master Themes, with Sub Themes nested within each (see Appendix 13). See Appendix 14 for further description of the analysis process.

### **2.2.2 Reflexivity and validity**

As discussed, IPA recognises the role of the researcher as an active participant in the process of the research. As such, it is important to acknowledge and reflect upon the potential influences that the researcher brings to the research process. The author (RS) conducted the research. She is a 29-year-old, female psychologist of white, British background. Her previous and current research is in the area of women's health and mental health and she has worked clinically within psychosexual health services. The author identifies as a feminist and as such believes that both men and

women suffer the repercussions of patriarchal and misogynistic attitudes that are subtly and sometimes not-so-subtly ingrained in society. My reading of feminist sexology literature (Moynihan, 2003; Tiefer, 2000, 2001) has informed my thinking about sexuality, specifically around the medicalisation of women's sexuality, which promotes a universally generic, function-focused and heteronormative sexuality, ignoring the areas of sexuality that women find most distressing, such as loss of intimacy and inability to fulfil the desire to please their partners. As such, the author believes that professionals should look to non-medical frameworks, which have been promoted by academic, feminist, gay/lesbian and political writers (Tiefer, 2001).

The author does not have first-hand experience of idiopathic vulval pain; however she has been allowed an insight into the experience of vulvodynia through a close friend who shared some of her experiences with the researcher prior to the commencement of this research, and throughout the research process. The author rejects both the extreme positions of naive realism (or positivism) and extreme relativism (or radical constructionism), and adopts a critical realist epistemological and ontological position, in keeping with where IPA is commonly positioned (see Appendix 15 for a more detailed description of the ontological and epistemological position of IPA).

Supervision sessions and a reflexive diary were used in order to recognise the potential biases of the researcher and to acknowledge and curtail their impact upon the research process (see Appendix 16). Moreover, supervision was used in order to insure the validity and quality of the research; all transcripts, initial coding, individual analyses and final over-all analyses were shared with the research supervisor (GK), and support was provided at every stage of the research process from formulating the interview schedule to the development of master themes. Two



supervisors (JD & GK) reviewed the final written analysis.

### 3 Results

The aim of the analysis was to examine women's experiences of the journey towards a diagnosis of vulvodynia. Following analysis, three Master Themes emerged, each containing between two and three Sub Themes, outlined in Table 6.

Table 6 Table of Master Themes and Sub Themes and Recurrence Across Participants

	Lilly	Amy	Vicky	Laura	Clara	Liz	Bessie	Josephine
<b>The Journey is a Battle</b>	YES	YES	YES	YES	YES	YES	YES	YES
On a Journey with No Direction	YES	YES	YES	YES	YES	YES	YES	YES
The Status and Power of the Medical Model	YES	YES	YES	YES	YES	YES	YES	YES
The Psycho-Social Impact of the Journey	YES	YES	YES	YES	YES	YES	YES	YES
<b>“What is Vulvodynia?”: Ambivalence Towards Diagnosis</b>	YES	YES	YES	YES	YES	YES	YES	YES
“Vulvodynia is a Bit of a Cop Out”: Limitations of a Diagnosis	YES	<b>NO</b>	YES	<b>NO</b>	YES	YES	YES	YES
The Value of Diagnosis	<b>NO</b>	YES	YES	YES	YES	YES	<b>NO</b>	YES
<b>Patriarchy, Women &amp; Sex</b>	YES	YES	YES	YES	YES	YES	YES	YES
Narratives Around Womanhood: A Barrier on the Journey	<b>NO</b>	YES	YES	<b>NO</b>	YES	YES	YES	<b>NO</b>
Female Sexuality, Shame & Stigma	YES	YES	YES	YES	YES	YES	<b>NO</b>	YES
“The Old Boys Brigade” & The Medical Profession	YES	YES	YES	<b>NO</b>	YES	YES	YES	YES

KEY: Sub Themes; **master themes**

### **3.1 Master Theme 1. The Journey is a Battle**

You've got to fight...mmm, yes, so if you want me to fight, standing up for vulvodynia, I'm here (Josephine)

Above, Josephine describes her journey as a “fight”, and several women employed language such as “I fought for three years” (Amy); “It’s so hard trying to fight for yourself” (Liz); “It’s this constant battle of feeling believed” (Laura); or metaphorical language such as “It gives you very conflicted feelings” (Lilly), suggestive of an inner state of conflict created by battling or fighting throughout the journey. The use of the metaphor of a battle, fight or conflict suggests a journey towards diagnosis that is similar to partaking in a battle; long, hard, laborious, harmful and traumatic, both physically and psychologically.

The following three sub-themes highlight particular areas that contributed to the overall sense of the journey as a battle.

#### **3.1.1 Sub theme 1: On a journey with no direction**

Participants often reported a sense that “GPs haven’t got a clue” (Amy) or “can’t/don’t understand” (Josephine/Bessie), with the majority of women describing how this left them feeling lost (“who do you turn to?” Liz), “dismissed” (Clara) or that they should “just get on with it” (Liz). GP’s limited knowledge was the first barrier faced by women on their journeys, which prevented GPs offering proactive and forthcoming help. Poor medical knowledge surrounding vulvodynia led to women being inappropriately referred, wrongly diagnosed and prescribed iatrogenic or unhelpful medication, such as repeated prescription of thrush cream which

“actually makes the skin around your vulva worse” (Amy), all of which contributed to the exacerbation of vulvodynia.

In turn, lack of GPs’ knowledge meant that women researched the internet for information on vulvodynia (Bessie; Vicky; Liz), support networks (Clara; Vicky), appropriate clinics to request referrals to (Clara; Bessie), different interventions to try (Liz; Bessie), or different “tests” to have done (Vicky), further highlighting the lack of GPs’ knowledge regarding appropriate, specialist services to refer on to. Barriers that prevented navigation of the “fragmented system” (Vicky) included; lack of continuity of care, a need to chase referrals, a lack of on-going support, long waiting times to be seen by specialists once a referral had been secured (often between 6 – 18 months), a feeling of being “in the dark” (Liz) and a sense of going “back and forth” (Amy):

It’s just, it’s horrible, it’s horrible, the amount of times that I’ve just been shooed off, and being passed from pillar to post and erm, I don’t, I don’t really know how to explain it, erm, I’ve just got this, this massive fear that, of being unbelieved (Laura).

Laura uses three interesting phrases in the passage above: “shooed”, “passed from pillar to post” and “unbelieved”. The use of the word “shooed” brings to mind a small animal or child, who is being frightened away, and thus forced to leave, for being a nuisance. It creates a sense of Laura being treated as a nuisance by doctors; feeling forced out and perhaps frightened to return to ask again for help. The phrase “passed from pillar to post” is thought to derive from punishment (the flogging post and the pillory), a punishment designed to both cause pain and public humiliation. Laura may therefore be understood to feel like a nuisance, and to experience a sense of being punished, and of being forced to remain in pain through being dismissed. Finally, Laura uses the present tense to describe her “fear” of being “unbelieved”,

creating a sense that her “battle” to obtain a diagnosis has left her still currently experiencing fear and anxiety (much in the same way a battle might leave lasting “scars”), that at any moment, the belief and validation Laura has acquired through diagnosis could be taken away; she may have to return to being no longer believed, she may have to return to the battle.

Overall, the experience of the journey within the healthcare system left six women (Lilly, Amy, Laura, Liz, Bessie and Josephine) considering treatment privately, in order to gain a sense of direction and help (access adequate knowledge to diagnose and treat vulvodynia in an acceptable time frame), as Bessie states “I wouldn’t hesitate, that's the only thing I would say: pay for it”.

### **3.1.2 Sub theme 2: The status and power of the medical model**

They can be very domineering, can’t these consultants, think they're gods (Josephine)

Josephine uses the word “domineering”, suggesting a sense of feeling subjugated and oppressed. The use of “gods”, suggests that Josephine believed that the consultants considered themselves “god like”; something to be worshipped, with ultimate power over “life and death” (Josephine), illustrating the enormity of a power imbalance experienced by Josephine.

This perception of a power imbalance was echoed by other women who reported experiencing instances where their knowledge and expertise was undermined and ignored by silencing actions. For example, Vicky had her hands “slapped away” by a professional, when trying to show them where the pain was. Similarly, Liz experienced “you’ve come to see me to find out what’s the matter with you and you’ve come and told me what’s the matter with you” from her consultant

when she showed him a booklet on vulvodynia, suggesting that maybe this particular physician wanted to retain his power of knowledge, and as such, was not open to the research Liz had done, despite his incorrect diagnosis and unhelpful prescribing. The perceived need for power to be maintained by the professionals in these instances hindered the progress of both Vicky and Liz's journeys.

Three participants (Laura, Lilly, Clara) reported instances whereby they felt violated by vaginal examinations which produced significant psychological distress: "it actually felt like I'd been assaulted...I felt really violated" (Lilly). At the age of 23, Laura had counted over 50 consultants that had examined her. Here she recounts one such examination:

and he was like, right I want to examine you, so it was a case of right, OK, you know, and so he tried to examine me, bearing in mind that he's a urologist, so why, why would he need to do anything with my vagina? without warning me, bearing in mind that he's just read that I can't have penetration, he just shoves, and that is the only word that I can describe, his hand into, like into my vagina, and I screamed and almost fell off the bed, and... where was the compassion? Where was the consideration?...so I've got, I've just go no trust in doctors, I, I'm angry, I just, I just, I hate them (Laura).

This extract can be seen as illustrative of the power of the clinician and Laura's vulnerability. Overall the extract is a difficult read, which left the researcher with a sense of assault and violation, for several reasons. Firstly, Laura recounts that the clinician stated "I want to examine you". This is a statement, and not a question, and as such cannot be aimed at gaining consent for examination from the patient. In this way, the examination feels non-consensual. Secondly, Laura is not given information about why the examination is necessary, instead she experiences being treated as an object to be examined, rather than a patient wanting to gain knowledge about their condition. The use of the words "shoved" and "screamed" within the same sentence produce a sense of the experience as violent, painful and abusive.

Overall, the experience feels non-consensual, objectifying and leaves Laura, unsurprisingly, with “no trust in doctors”, feelings of “anger” and “hatred”, and yet still reliant on remaining in the healthcare system to move forward.

In contrast to this experience, other participants viewed examinations as positive and a necessary part of the journey towards diagnosis (Liz, Bessie, Vicky).

Well I took it as par for the course; because it's necessary...I was glad to have an examination (Liz)

Overall, women’s encounters with some professionals who were experienced as prioritising the maintenance of their power and keeping patients as passive, led to five of the eight women to speak of their desire to complain (Lilly, Amy, Vicky, Laura and Liz). Despite this, only Liz wrote to Patient Advice and Liaison Services (PALS) to make a complaint, but did not wish to pursue it. Women cited fear of their future care being compromised as reasons why they did not complain, believing a need to keep on the good side of health professionals and administrative staff alike in order for their care to proceed in a productive way, further illustrating the perceived power of the health care system.

### **3.1.3 Sub theme 3: The psycho-social impact of the journey**

Women described a variety of psychological consequences which they associated with the process of journeying through the healthcare system, including; “isolation” (Clara; Josephine), “panic” (Laura) “depression” (Amy, Liz, Laura, Josephine), “anxiety” (Laura; Lilly), “low self-esteem” (Laura); “hopelessness” (Vicky) “rage” (Josephine), “fear” (Laura; Lilly), “humiliation” (Laura); which all impacted upon sex and relationship difficulties (Laura; Lilly), work/education (Bessie; Liz; Amy; Clara) and sleep difficulties (Vicky; Josephine). Moreover, some

women recognised the impact of psychological triggers exacerbating pain, connecting “stress” with “flare ups” (Lilly).

Despite the recognition of psychological triggers and consequences of living with vulvodynia, women described feeling angry when it was suggested that the pain was “all in my head/mind” (Liz, Bessie, Laura, Vicky, Josephine). Women did not identify with the suggestion by health professionals that vulvodynia had a psychological cause, instead perceiving this suggestion as another barrier on their journey. As such women became “desperate” (Amy) to find a cause with a physical biomarker. The importance of having a concrete and physical cause was so great that Lilly resorted to surgery (against medical advice) in an attempt to externalise and remove the pain from her-self:

I thought all the pain was stemming from the fact that maybe there was something erm [laughs] like physically wrong with my labia, so I thought maybe I should get my labia removed [laughs] God, it’s so awful’... ‘so actually when I was [laughs] when I was erm, not [sighs] when I was 32 I did have labiaplasty (mmm), cause I was just so convinced that was why I was in pain (mmm) and actually it hasn’t helped, it hasn’t made any difference whatsoever, [laughs] (Lilly).

Women’s consistent non-acceptance of a psychological cause - in the context of their acknowledgment that their pain was exacerbated by psychological triggers and their recognition that being in the healthcare system had had psychological consequences - suggests that the notion of a psychological cause for their pain did not make sense to women.

Finally the experience of persisting on the journey within the health care system became too much for Lilly “I don’t, honestly don’t have the energy for it”, and she removed herself from the system by no longer engaging with it, in a similar way to those who sought private healthcare. This halting of the journey

demonstrates that for women like Lilly, the experience of living with chronic vulval pain and the detrimental impact that entails was preferable to being within an iatrogenic healthcare system.

### **3.2 Master Theme 2. “What is Vulvodynia?”: Ambivalence Towards Diagnosis**

Some participants felt very strongly that diagnosis was the key to moving forward (Amy; Laura), whilst others felt strongly that diagnosis was just a name (Vicky; Bessie; Lilly), with little or no validity, reliability or predictability. Others showed some uncertainty about the role of diagnosis, acknowledging both its helpfulness and its hindrance (Clara; Vicky; Liz; Josephine). Thus, overall there was a sense of group ambivalence towards diagnosis. The following two sub-themes demonstrate the polarization of views on diagnosis, as well as the ambivalence both within individuals, and across the group:

#### **3.2.1 Sub theme 1: “Vulvodynia is a bit of a cop out” (Clara): Limitations of a diagnosis**

Six participants raised concerns regarding the limitations of the diagnosis vulvodynia (Vicky, Bessie, Lilly, Clara and Liz). First and foremost participants were unsure about what the term vulvodynia meant. Moreover, women felt that vulvodynia was “only a name” (Bessie) which “just means vulval pain” (Clara) and as such, was unable to explain the pain, or predict “a cure” (Clara). Some women felt that health professionals told them it was vulvodynia “because they don’t know what it is” (Bessie), perhaps suggesting that women felt that being given a diagnosis, in part, served a purpose; to prevent doctors from having to say “I don’t know”;



perhaps a way of maintaining the idea of medicine as a panacea. Further, women felt that they had been misled by professionals who had given the diagnosis as though it had explanatory and predictive power, only to later find out that it did not.

Well I think it's, if, if they'd have said, 'it is only a name and it just means a pain', but it was as if 'oh, it's vulvodynia', and you think 'oh, got a name, vulvodynia', and then you realise it, it's not going to help anything cause there's no answer to it (Bessie).

Women also described a sense of losing faith in the diagnosis:

It's hard to believe that that's what you've got, when what they're given you isn't making it any better, but, however you want the treatment to start making an impact...or else you start doubting that diagnosis...(pause) that tells you something doesn't it? When you've tried everything (Liz)

Liz uses a rhetorical question "that tells you something doesn't it?", forcing the listener/reader to think more about the limitations about the diagnosis of vulvodynia. Both Liz and Bessie's quotes above illustrate their expectations of what a diagnosis should provide; firstly, Bessie had hopes and expectations that receiving a diagnosis of vulvodynia would provide "answers" as to the cause of the pain. Secondly, Liz had an expectation that a diagnosis should predict an effective treatment. The term vulvodynia fails on both counts. Both women believe the notion of the medical model as a panacea, and both begin to realise their expectations are not going to be fulfilled by a traditional medical model approach of examine, diagnose, treat and cure.

For Vicky and Clara, the need for a "name" lessened throughout the course of the journey, and instead these women emphasised the need to be treated as a "whole person and not just a set of symptoms" (Clara) and for sense-making over labelling:

Having a name doesn't matter, having some (pause) I think having a kind of narrative about what's gone on what it's all about what's, what's the story of it 'cause I think people do need to make sense of what's going on (Vicky)

Overall, some participants felt that a diagnosis of vulvodynia did not offer validity, reliability or predictability, making it useless and leaving them to speculate that the purpose of a diagnosis was more for the benefit of health professionals.

### 3.2.2 Sub theme 2: The value of diagnosis

Despite these reservations, some participants saw the benefit in a diagnosis; providing “relief” (Clara, Laura and Amy), confirming a sense of what they had “known all along” (Clara), allowing professionals to communicate that they had “a grasp of it” (Clara), providing peace of mind that there was not something “seriously wrong” (Liz), “putting some sense” to how they were (Liz) and facilitated professionals to “point me in [the right direction]” (Laura).

I've got pain, you know, at least, if you can call it something, it's kind of given me the confidence to tell people' ... 'But I have, in the last, only in the last six months or so, bearing in mind I've lived with this for years and years, erm, told my close friends about it, and they've, they've been absolutely amazing, much better than I ever imagined them to be, to be honest and I think this is all contributing to me feeling a lot better, and being in a better place (Laura)

As the quote from Laura illustrates, some women also found that having a diagnosis afforded them the vocabulary which facilitated communication with their family and friends about their pain, in turn allowing these women to test out their fears that rejection and stigma would follow if they disclosed their secret. When these fears were not realised following disclosure, women felt less isolated and more supported by significant others in their experience of the pain (Laura, Amy). In

particular, both Laura and Amy conveyed a sense of having a diagnosis as paramount to their journey, and both quoted experiencing the diagnosis as alleviating blame. Interestingly, both women, who were in their early 20s, were repeatedly referred to sexual health clinics, which they experienced as stigmatising. Their sense of relief at receiving a diagnosis could suggest that, rather than actively providing anything meaningful (an explanation, an effective treatment), a diagnosis was important to them because it removed a sense of stigma and shame that was perhaps felt most acutely by young women fearful of being labelled negatively as “sexually promiscuous” due to repeated referrals to the sexual health clinic; “No more STI clinic for me” (Amy).

Moreover, although Vicky was sceptical regarding the use of vulvodynia, she did also note the importance of diagnosis in gaining “respect”, perhaps also commenting on the ability of a diagnosis to remove any stigma surrounding pain and sex and as such provide relief:

Maybe that is the difference between being respected and not, to a doctor giving it that name is the difference between a patient being respected and a patient not being respected (Vicky)

### **3.3 Master Theme 3. Patriarchy, Women & Sex**

I'd like to know where it's [the term 'vulvodynia'] come from, whose put that name to...I bet it's a man (Bessie)

The women interviewed often used words and phrases suggesting that they had encountered patriarchal attitudes within their journey, such as Bessie's statement above. Bessie believed the term vulvodynia had been thought up by “a man”, suggesting a sense that the term does not make sense to her and/or is not a useful term for her as a woman. The use of this phrase might suggest that for Bessie, the

very name vulvodynia may embody a sense of men controlling her experience by creating a name that fails to adequately capture her experience and expectations. The following three sub-themes outline women's experiences of the medical profession as male dominated, with entrenched patriarchal attitudes.

### **3.3.1 Sub theme 1: Narratives around womanhood: a barrier on the journey**

Women experienced suggestions from medical professionals that they were “neurotic” (Clara and Vicky), “mithering” (Liz), “pestering” (Liz; Amy), and/or “hysterical” (Vicky). This language, often specifically directed towards women (Romaine, 2000), communicates a sense that the women often felt dismissed and that their concerns, distress and experiences were belittled and unimportant. Further, Lilly and Vicky described how they received advice that was experienced as patronising, such as “have a glass of wine and get into the bath” and gendered, such as “do things like knitting to take your mind off it”, which communicated a sense that professionals were not understanding or taking their pain seriously. Moreover, there was a sense that this lack of understanding and patronising treatment was down to their gender:

A lot of doctors just (pause) perhaps they don't even realise it but perhaps they have these preconceptions about females and even female doctors, erm, and they, it affects how they are with women and I, I can't speak for all women, but, it was strange that when I've talked with other women, they've kind of said yeah I've had that kind of experience (Clara)

In the above quote, Clara is talking about feeling “fobbed off” (Clara) by doctors. She describes how she believes that the perception doctors have of women, (which is that they make “mountains out of molehills” (Clara)) leads them to dismiss

women's concerns as not serious. Clara directly links this feeling of not being taken seriously to being a woman, and she recounts how the "other women" she has talked to have also had "that kind of experience", suggesting Clara believes that some women are routinely treated differently to their male counterparts by doctors simply because they are women.

Further, the participants often described difficulties asserting themselves, perhaps for fear of being labelled as "neurotic" etc., or perhaps due to their experiences of repeatedly being dismissed. As such, participants described the need to be obedient ("Whatever anybody tells me to do, I do it" (Liz)), not challenging incorrect hypotheses of doctors ("But I didn't want to upset him [consultant] by telling him it wasn't my cough cause he was delighted with that" (Bessie)), and continuing to be "nice" (Liz).

### **3.3.2 Sub theme 2: Female sexuality, shame & stigma**

Having sex is either for the benefit of men or, or for having babies and (hmm), and and it's erm a little bit unseemly for women to openly admit that they might just do it for the fun of it (Vicky)

By its very nature, vulvodynia was associated with sex. This quote from Vicky illustrates her sense of the un-importance placed upon female sexuality for women within the healthcare system. This was echoed by Laura and Lilly and suggests the women experienced a prevailing belief within the healthcare system that the purpose of women's sexuality is to function only as a "performance" (Laura) for men, and not for the purpose of their own enjoyment. In essence, there was a sense that women believed they were viewed only as baby-makers or pleasure-givers within the healthcare system, removing a sense of women's ownership over their

sexuality. This was in contrast to how women perceived men's sexuality was viewed by the healthcare system:

What I honestly feel about this is, erm, if I was a guy, and I was saying, like I can't get erections, I'm not able to ejaculate (mmm) something like that (hmm mmm) then it would be taken really seriously (Lilly)

Moreover, women reported a sense of stigma associated with sex, which served to delay progression of the journey. Whilst all the women talked about stigma and shame attached to experiencing pain, the pre-menopausal women seemed much more vulnerable to experiencing shame and stigmatisation through being referred, often repeatedly, to sexual health clinics, themselves consistently associated with shame and stigma by all the women who visited them (Vicky, Amy, Laura).

being just sent down and in actual fact I waited four I just had to go down and wait four hours (hmm), walk in off the street and wait for four hours and so that in itself I think was disrespectful (hmm), to instead of referring [02.04] erm and it's it's a pretty horrible place (hmm), it's a pretty horrible place and erm it's a nice building but the whole process of it is quite dehumanizing (Vicky)

Vicky's quote above alludes to shame, stigma, whilst Laura referred to being made to feel "dirty"; and Amy worried about being labelled as a "trollop" or a "skank". The above quote is suggestive of powerful negative narratives around female sexual health and its potential impact upon women's sense of feeling shamed. Interestingly, Vicky, who identified as a feminist and was able to analyse her experience within a feminist framework, was critical of the system, which she felt had been specifically set up to create shame around sex. Amy and Laura on the other hand, were not critical of the system, but rather distanced themselves from the stigma attached to sexual health by using language to stigmatise others to create a "self" and "other" narrative, with "self" referring to somebody who is "clean as a whistle" (Amy) and "other" referring to women who have sexual health problems viewed as

“vulgar” and “green” (Amy). Moreover, both Amy and Laura use the phrase “I’m not like that” in order to distance themselves from the perceived negative labels attached to women attending sexual health centres. This experienced stigmatisation of women’s sexuality is highly influential on a journey on which women report feeling judged, stigmatised and shamed, all of which has potential implications for the well-being and mental health of women with vulvodynia (see Master Theme 1, Sub Theme 3: The Psycho-Social Impact of the Journey).

### **3.3.3 Sub theme 3: “The old boy’s brigade” (Josephine) & the medical profession**

All women described instances whereby they had experienced patriarchal attitudes in the system, such as; being patronised and dismissed; treated without dignity or compassion; or had their difficulties belittled and instead attributed to female “neuroticism”. However, one woman in particular, Vicky, was particularly eloquent and passionate about her views on why women encounter such experiences, supported also by the views of Josephine and the encounters described by the other women.

Vicky explicitly described her experiences as “misogynistic” (Vicky), and Clara described her surprise that she encountered “preconceptions about females” from both male and female doctors. Moreover, Josephine compared her experiences with medical professionals to other systems including “politics” and “religion” (Josephine), describing the medical profession as “the old boy’s brigade”.

It’s about the essential misogyny of the health profession, I’m afraid... the medical profession, it's about...you know this profession that’s erm (pause) even though women are in it, incredibly male dominated and hierarchical and erm you know dominated by people from public schools and so it it it's

erm (pause) it's a profession that's full of very old idea and I think women come on the receiving end of that all the time I think doctors frequently, male doctors especially, frequently patronise women (hmm hmm), erm and treat women's problems as... lesser (Vicky).

This notion, of women's difficulties being treated as "lesser" was further supported by Lilly, who felt that "women's health isn't taken seriously at all" (Lilly). Moreover, Vicky in particular moved her interpretation of her experiences to encompass a general, collective view of women as unimportant because they are not seen as valuable contributors in a society whereby importance is based upon economic value:

erm... I think [sighs] I think it's terms of of of of kind of NHS priorities I think the fact that erm vulval pain is something that is suffered by people who are often not a big part of the earnings makes it a low economic priority in in terms of kind of research and treatment you know we don't, a lot of the women concerned are sort of middle aged, maybe not working (Vicky)

Throughout this extract, Vicky talks about "earnings" and "economic priority", suggesting that she believes that her experiences within the healthcare system may have been influenced by a cost-benefit analysis of treating women with vulvodynia. She is suggesting that care within the healthcare system is influenced by notions of patient importance, and that importance is based upon economic earning power, which on the whole is less for women than for men for a variety of reasons (e.g. pay gap inequality; larger percentage of women engaged in unpaid domestic work). As such, Vicky implies that there is inequality within the healthcare system, to the detriment of women.

The notion of a "misogynistic" healthcare system may go some way in explaining the experience of women described in Master Theme 1, Sub Theme 2: *The status and power of the medical model*, such as being violated, silenced and



dismissed during their journey. Overall this interpretative analysis highlights the potential detrimental impact (psychological and physical) of a health care system experienced as patriarchal upon women with vulvodynia. This suggests that changing both implicit and explicit detrimental attitudes towards women and sex within the healthcare system, may go some way to improving the journey towards diagnosis for women with vulvodynia.

#### 4 Discussion

The aim of the current study was to gain further understanding of women's experiences of the journey towards a diagnosis of vulvodynia, using IPA methodology. Overall the women interviewed encountered a lack of knowledge within the healthcare system, feelings of being dismissed, shame and stigma, and some described encountering "old fashioned" and "misogynistic" attitudes. Women attributed experiences of the journey as directly impacting upon their psychological wellbeing. Women were ambivalent towards the diagnosis of vulvodynia, with some expressing doubt regarding its usefulness, whilst others found it helpful.

The suggestion that women's pain was "all in their head" has previously been described (Brotto et al., 2013; Marriott & Thompson, 2008; Sadownik, Seal & Brotto, 2012b). However, whilst Marriott and Thompson (2008) suggest that women "felt that a 'medical condition' could be externalised and hopefully removed, but that a psychological aspect of their pain indicated something wrong internally, in a core aspect of themselves" (Marriott & Thompson 2008, p. 252), the current study found that women were open to psychological *aspects* of their pain, but strongly resisted the notion that their pain had a psychological *cause*, which did not make sense to

them, and therefore was not felt to be accurate. Both the finding by Marriott and Thompson (2008) and the findings of the current research suggest that caution should be exercised when communicating with women about psychological aspects of pain, making clear distinctions between *psychological triggers* (such as stress events, bereavement, pressure), which may exacerbate pain; *psychological consequences* (low mood, anxiety, anger) which may occur due to the experience of the pain or due to encounters within the healthcare system; and *psychological causes* (trauma, abuse, neglect) of vulvodynia, a notion that was rejected by the women in the current study as not relevant to them, serving only as a barrier on their journey to understanding and treating their pain.

Whilst no previous literature exists pertaining to women's views on the usefulness of the term "vulvodynia", previous literature has highlighted the ambivalence associated with other diagnoses, such as *fibromyalgia*, *bipolar* and *obstructive sleep apnoea* where the diagnosis may be poorly defined and/or difficult to diagnose (Dennis, Larkin & Derbyshire, 2013; Inder et al., 2010; Zarhin, 2015). Within the current study, some women found the term helpful (especially in gaining "respect" from doctors), but there was also a sense from some women that it was "just a name", and as such was of limited benefit. Indeed, the complexity of other idiopathic disorders, such as chronic pelvic pain, has led some authors to suggest that exhaustive pursuit of a precise diagnostic label may not necessarily be productive (Selfe, Matthews & Stones, 1998). As such, the strengths and limitations of the label vulvodynia should be acknowledged and discussed with women when the diagnosis is given, in order to prevent creating a false impression that the diagnosis of vulvodynia leads to immediate and curative treatment. Moreover, it is important to recognise that the "journey towards diagnosis" is only part of the journey, and as

noted by the women interviewed here, does not necessarily secure the patient appropriate care and effective treatment. Indeed, future research should focus upon what women have found most helpful following diagnosis.

The women interviewed reported lack of knowledge by medical professionals (particularly GPs) about vulvodynia to be a barrier on their journey. This is of particular importance when GPs act as a gateway to other, more specialist services. In the current study, women's subjective perceptions of doctors' lack of knowledge, is supported by quantitative data examining the knowledge of junior doctors regarding vulvodynia (Toeima & Nieto, 2011) which found that more than 60% underestimate the prevalence of vulvodynia, more than 80% had never attended an educational session or training course on vulvodynia, and more than 70% were not aware of the new ISSVD classification, (ISSVD, 2003). Further, the authors note that despite dedicated vulval pain clinics in the UK, women were frequently referred by their GP to general gynaecology clinics (Toeima & Nieto, 2011). As well as medical professionals' limited knowledge of vulvodynia, some women also described how they felt belittled, dismissed and violated following encounters with them, which is supported by previous research into the experiences of women with a variety of chronic pain disorders (Åsbring & Närvänen, 2002; Johansson et al., 1996; Werner, Isaksen & Malterud, 2004). Interestingly, previous research has reported that in women with chronic pelvic pain, favourable assessment of the medical consultant, by the patient, in the first consultation, predicts resolution of pain (Selfe, Matthews & Stones, 1998). The authors suggest that the consultation style of individual doctors may be important, especially in the context of "chronic and ill-defined conditions, where patients are distressed and hostile and an immediate curative intervention is elusive" (Selfe, Matthews & Stones 1998, p. 1047).

In terms of some women experiencing the health care system as “misogynistic”, previous literature suggests that doctors may sometimes perceive female patients as “inherently dependent” and “lacking in common sense”, a view that rationalizes “paternalistic attitudes and advice” (Gannon 1998, p. 295); which may go some way to explaining why some women in the current study experienced being given “patronising advice” from doctors. In a similar way, previous literature suggesting that physicians may instruct women patients on values, morals and sexual behaviour (Foster, 1995; Gannon, 1998; Miles, 1991) is further supported by the experiences of women in the current study, who reported experiencing shame and stigma surrounding sexual health in the context of the health care system and, in some cases, suggestions that their sexuality was unseemly, for the purpose of child-bearing, or for the pleasure of men only. Finally, the concern of women in the current study that they would be labelled as “neurotic” or “hysterical” (labels historically reserved for women (Tasca et al., 2012)), illustrates the detrimental and silencing impact that these labels still hold over women today.

The current study supports previous literature which has outlined the psychological difficulties experienced by some women with vulvodynia (Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008; Sadownik, Seal & Brotto, 2012b). Moreover, this study suggests that encounters with the healthcare system during the journey towards diagnosis may be experienced as actively harmful to women’s psychological wellbeing, resulting in secondary vaginismus, anxiety and depression. This may help to explain why only around half of all women experiencing symptoms consistent with vulvodynia seek treatment (Connor, Brix & Trudeau-Hern, 2013), and only around one per cent will receive a diagnosis, perhaps in part due to women removing themselves from a health care system that was, in

some cases, experienced as iatrogenic.

#### **4.1 Implications for Clinical Psychology**

Clinical psychologists are best placed to offer one-to-one psychological work for women who have suffered in their journey towards diagnosis, addressing secondary sexual difficulties, such as vaginismus, and other psychological difficulties such as anxiety and depression, as well as addressing feelings of shame and stigma. Moreover, group work facilitated by clinical psychology may also be helpful in addressing psychological difficulties arising in women with vulvodynia.

Apart from individual or group work with clients, clinical psychologists could also provide education, training, supervision and consultation for medical and other healthcare professionals, addressing issues such as the power imbalance between women with vulvodynia and medical/ healthcare professionals, and how this serves as a barrier to treatment; the psychological impact of vaginal examinations, which has the potential to be experienced as an assault, due to the actions of medical professionals; the psychological impact of inappropriate referrals, or repeated referrals to areas already explored (such as sexual health clinics) and delay in referral to a specialist vulval clinic; and education about the nature of vulvodynia and the differences between psychological causes, triggers and consequences and how to discuss these with women.

#### **4.2 Methodological Considerations**

The current study included both pre and post-menopausal women, which may be deemed to breach the homogeneity needed for the conduct of IPA research.

However, the decision to exclude women based on pre or post-menopausal status in previous research (Marriott & Thompson, 2008; Sadownik, Seal & Brotto, 2012a, 2012b) was viewed as unhelpful, given that both pre and post-menopausal women suffer with vulvodynia. There were some differences noted in the results between pre and post-menopausal women, particularly in relation to the impact of vulval pain upon sexual relationships. The pre-menopausal women were more distressed by this in general than the post-menopausal women, with the exception of Clara, who did note the impact of vulvodynia upon her sex life. However, this is within a very small sample and the women, whether pre or post-menopausal, recounted similar experiences in their journeys toward diagnosis.

Moreover, seven women had a co-morbid diagnosis, contributing to the complexity of their case and potentially further hindering their journeys toward a diagnosis of vulvodynia. However, the co-morbidities presented here are reflective of a population of vulvodynia patients (Arnold et al., 2006). Whilst some women made reference to coexisting conditions sometimes exacerbating their experiences of vulvodynia and their journey towards a diagnosis, this was not a strong occurrence throughout the interviews and therefore does not appear in the analysis.

Finally, as with all previously identified studies examining women's subjective experiences of vulvodynia (Ayling & Ussher, 2008; Brotto et al. 2013; Buchan et al., 2007; Kaler, 2006; Marriott & Thompson, 2008; Munday et al., 2007; Sadownik, Seal & Brotto, 2012a, 2012b), the current study includes only white, British women who referred to being in heterosexual relationships only during interviews. This is a limitation of the current study and previous studies, and future research should aim to explore the experiences of lesbian, bisexual and transgender women, and women from a variety of ethnic backgrounds. Moreover, it could be

argued that women who have had negative experiences with the health care profession may be more likely to volunteer to participate in qualitative research, creating a further bias.

Despite these limitations, the current research has several strengths including consultation throughout the research process with members of the VPS, addressing an issue that was deemed to be important by women, use of empirical guidelines for collection and analysis of data, and an adequate sample size for the purpose of the study.

### **4.3 Future Research**

Future research could focus on women's experiences of specialist vulval pain clinics (as well as the effectiveness of such services), experience of health care following diagnosis, as well as the effectiveness of psychological therapy and/or group work upon improving women's mental health following the journey.

Moreover, research could explore the clinical outcomes linked to training health professionals regarding the psychological aspects of the journey towards a diagnosis of vulvodynia, and whether such training has a positive perceived impact upon women's experiences within their subsequent consultations.

## **5 Conclusion**

The current research illustrates that diagnosis is not the end of the journey for women with vulvodynia, nor is it predictive of an effective cure. Instead, diagnosis is only part of the journey for these women and as such, further research should focus on what women find helpful, above and beyond a diagnosis.

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## **Appendices**

### Appendix 1 Author Guidelines for Archives of Sexual Behaviour

#### **Manuscript Style**

There is no specified word limit. Type double-spaced and left-justified in 12-point Times New Roman font in 12-point font using 1-inch margins on all sides. Number all pages (including table pages and figure-caption page), except the title page, consecutively with Arabic numerals placed in the upper right-hand corner. In order to facilitate masked (previously termed “double-blind”) review, leave all identifying information off the manuscript, including the title page and the electronic file name. Appropriate identifying information is attached automatically to the electronic file. Upon initial submission the title page should include only the title of the article.

An additional title page should be uploaded as a separate submission item and should include the title of the article, author’s name (including highest degree received), and author’s affiliation. Academic affiliations of all authors should be included. The affiliation should include the department, institution, city, and state (or nation) and should be typed as a numbered footnote to the author’s name. The title page should also include the complete mailing address, telephone number, fax number, and e-mail address of the one author designated to review proofs.

An abstract, preferably no longer than 250 words, is to be provided as the second page.

A list of 4–5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

#### **Illustrations**

Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals and cited in numerical order in the text. Photographs should be high-contrast and drawings should be dark, sharp, and clear. Artwork for each figure should be provided on a separate page. Each figure should have an accompanying caption. The captions for illustrations should be listed on a separate page.

Tables should be numbered consecutively with Arabic numerals and referred to by number in the text. Each table should be typed on a separate page and should have a descriptive title. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

#### **References**

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order): last names and initials of all authors, year published, title of article, name of publication, volume

number, and inclusive pages. The style and punctuation of the references should conform to strict APA style.

**Footnotes**

Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

**Style Guide**

The 2009 Publication Manual of the American Psychological Association (Sixth Edition) should be used as the style guide for the preparation of manuscripts, particularly with respect to such matters as the citing of references and the use of abbreviations, numbers, and symbols. Manuscripts departing significantly from the Sixth Edition style will not be reviewed until a corrected manuscript has been received.

## Appendix 2 Glossary of Terms

<b>Mons pubis</b>	The rounded mass of fatty tissue lying over the joint of the pubic bones.
<b>Clitoris</b>	Female sex organ. In humans, the visible button-like portion is near the front junction of the labia minora (inner lips), above the opening of the urethra.
<b>Labia majora</b>	The larger outer folds of the vulva.
<b>Labia minora</b>	The smaller inner folds of the vulva.
<b>Perineum</b>	The area between the anus and the scrotum or vulva.
<b>Embryology</b>	The branch of biology and medicine concerned with the study of embryos and their development.
<b>Idiopathic</b>	Relating to or denoting any disease or condition which arises spontaneously or for which the cause is unknown.
<b>Spastic Paraplegia</b>	Progressive stiffness and contraction (spasticity) in the lower limbs.
<b>Lichen Sclerosus</b>	A long-term skin disorder that most commonly affects the skin around the genitals. The skin develops severely itchy or sore white spots.
<b>Urethral Syndrome</b>	No signs of a clear cause resulting in abdominal pain and frequent, painful urination.
<b>Fissures</b>	A cut or tear (fissure) is a painful split, crack or break in the mucous membrane inside the vagina, on the inner of outer labia, on the perineum or around the clitoral hood.
<b>Peudental Neuropathy</b>	An uncommon source of chronic pain, in which the peudental nerve (located in the pelvis) is entrapped or compressed.



### Appendix 3 Deciding on a Synthesis

Type of Synthesis	epistemology	Description	Decision and why
Narrative Synthesis		<ul style="list-style-type: none"> <li>- involves the chronicling and ordering of evidence to produce an account of evidence<sup>3</sup></li> <li>- can range from simple recounting to reflexive accounts<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>- does not seem to 'go beyond the data'<sup>1</sup></li> </ul>
Thematic analysis		<ul style="list-style-type: none"> <li>- identifies prominent or recurrent themes in the literature and summarises them under thematic headings<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>- offers little to develop higher order thematic categories beyond those identified in the literature<sup>3</sup></li> </ul>
Meta-ethnography (Noblit & Hare)	Objective idealism	<ul style="list-style-type: none"> <li>- makes explicit the context and characteristics of each study<sup>1</sup>, makes transparent the heterogeneity of the included studies<sup>1</sup>, most well-developed method<sup>2</sup></li> <li>- based in an interpretative paradigm of which most methods of primary qualitative research has evolved<sup>2</sup></li> <li>- it encourages the researcher to understand and transfer ideas, concepts and metaphors across different studies<sup>2</sup> and is explicit in how studies are compared and contrasted (although there are few examples of refutational synthesis)<sup>1</sup></li> <li>- seeks to push beyond the original data to a fresh interpretation of the phenomena being studied<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- 'third order interpretations allow reviewer to 'move beyond' the simple categorisation of themes identified<sup>4</sup></li> <li>- most well developed<sup>5</sup></li> <li>- Clearly from an interpretivist paradigm from which most methods of primary qualitative research evolve.<sup>5</sup></li> </ul>
Grounded Theory (Kearney)	Objective idealism	<ul style="list-style-type: none"> <li>- matches 'like with like' using the same methods that have been used in the original research<sup>1</sup></li> <li>- can only synthesise papers that originally use grounded theory methodology<sup>1</sup></li> <li>- seeks to push beyond the original data to a fresh interpretation of the phenomena being studied<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- can only synthesis grounded theory papers</li> </ul>
Thematic Synthesis (Thomas & Harden)	Critical realism?	<ul style="list-style-type: none"> <li>- adapts approaches from meta-ethnography and grounded theory<sup>1</sup></li> <li>- addresses questions re: need, appropriateness, acceptability and effectiveness<sup>1</sup></li> <li>- codes the entire 'findings' section (data) line by line<sup>1</sup></li> <li>- organises data into themes<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- more appropriate when a specific review question is being addressed.<sup>4</sup></li> </ul>
Textual Narrative Synthesis (Lucas)		<ul style="list-style-type: none"> <li>- arranges studies into a homogenous group<sup>1</sup>, focus on describing and summarising primary data<sup>1</sup>. focus on informing policy and practitioners<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- does not 'go beyond' the data</li> </ul>
Meta-study (Paterson)	Subjective idealism	<ul style="list-style-type: none"> <li>- no absolute truth and believes that primary research is a construction and that synthesis is therefore a construction of a construction.<sup>1</sup> it takes into accounts social, historical and ideological context<sup>1</sup></li> <li>- involves scrutiny of methodology (and the outcomes in relation to the methodology), as well as the philosophical and theoretical assumptions of the included research papers, as well as the wider context in which new theory is generated.<sup>1</sup></li> <li>- iterative, interpretative and reflexive<sup>1</sup></li> <li>- seeks to push beyond the original data to a fresh interpretation of the phenomena being studied<sup>1</sup></li> <li>- process is laborious and time-consuming<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Whilst this method was considered a possibility after reading various examples of this technique it was decided that this would be beyond the scope of a time limited DClin thesis</li> </ul>
Framework Synthesis (Brunton)	Critical realism?	<ul style="list-style-type: none"> <li>- is a highly structure approach to organising and analysing data, highly specified approach to quality assessment<sup>1</sup></li> <li>- utilises 'a priori framework' – informed by team discussions and background material</li> <li>- iterative in literature searching<sup>1</sup></li> <li>- limited problematizing of the literature<sup>1</sup></li> <li>- focus on describing and summarising primary data<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- don't have a team for team discussions</li> <li>- have already done literature search – I only want a method of synthesis/analysis</li> <li>- focus on describing rather than analysing data</li> </ul>
Content analysis Meta-interpretative		<ul style="list-style-type: none"> <li>- text is condensed into fewer content related categories</li> <li>- ideographic rather than predetermined approach to the development of exclusion criteria, focus on meaning in context</li> <li>- interpretations of original research is what is synthesised - iterative approach using theoretical sampling of studies</li> </ul>	<ul style="list-style-type: none"> <li>- new and not much guidance on the 'how to'</li> <li>- have already searched for papers</li> <li>- not widely used and therefore not much guidance</li> </ul>
Qualitative meta-summary		<ul style="list-style-type: none"> <li>- is aggregative in nature with findings accumulated and summarised rather than transformed</li> <li>- reflects 'quantitative logic'- the higher the frequency of a finding the more valid it is</li> </ul>	<ul style="list-style-type: none"> <li>- too 'quantitative in methodology</li> <li>- perhaps not much guidance for a novel synthesiser.</li> </ul>
Critical Interpretive synthesis (Dixon-Woods)	Subjective idealism	<ul style="list-style-type: none"> <li>- adaptation to meta-ethnography<sup>1</sup></li> <li>- adaption needed so it could be applied to quant and qual aswell as large bodies of literature (ie 119 studies)<sup>1</sup></li> <li>- it is the whole process rather than just the synthesis<sup>1</sup>. iterative approach to refining the research question<sup>1</sup>. has a particular approach to appraising quality<sup>1</sup>. quality is judged on the extent to which the study informs theory.<sup>1</sup></li> <li>- seeks to push beyond the original data to a fresh interpretation of the phenomena being studied<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>- I have already done part of the review and I am just looking for a method of synthesis</li> <li>- I'm not using quantitative and qualitative</li> <li>- the body of literature I'm exploring isn't large enough</li> <li>- useful to apply to the review process in hindsight?</li> </ul>

<sup>1</sup> Barnett-Page & Thomas 2009; <sup>2</sup> Britten, Campbell & Pope et al., 2002; <sup>3</sup> Dixon-Woods, Agarwal & Jones et al., 2005; <sup>4</sup> Thomas & Harden, 2008; <sup>5</sup> Campbell et al., 2003

## Appendix 4 Example Search Strategies

The following databases were searched with the following search terms. All databases were searched on the 19th February 2014.

### Ovid MEDLINE 1948 to February week 3 2014

- 1 vulvodynia.tw.
- 2 vulva\* disease.tw.
- 3 vulva\* pain.tw.
- 4 (vulvar vestibulitis syndrome.tw. OR vestibulitis.tw.)
- 5 (provoked vestibulodynia.tw. OR vestibulodynia.tw.)
- 6 1 OR 2 OR 3 OR 4 OR 5
- 7 adult.sh.
- 8 female.sh.
- 9 7 AND 8
- 10 pain.sh.
- 11 sexual dysfunction.hw.
- 12 dyspareunia.sh.
- 13 vulvar diseases.sh.
- 14 10 OR 11 OR 12 OR 13
- 15 9 AND 14
- 16 15 AND 6
- 17 interview.tw.
- 18 experience.mp.
- 19 qualitative.mp
- 20 17 OR 18 OR 19
- 21 16 AND 20
- 22 english.lg.
- 23 22 AND 23

Total papers found 45

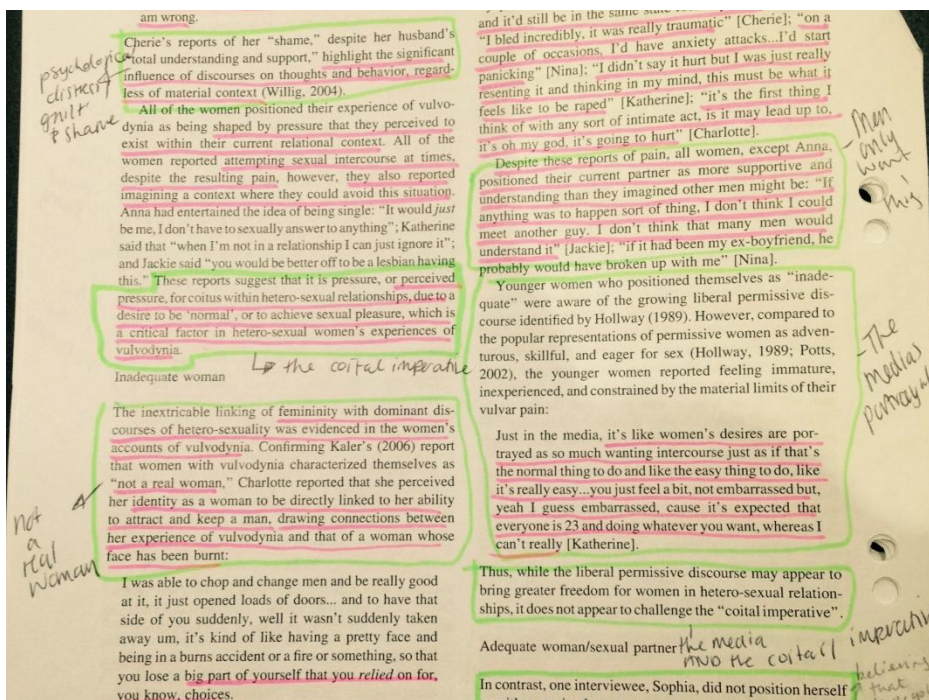
### SciVerse SCOPUS 1823 to February week 3 2014

- 1 TITLE-ABS-KEY vulvodynia
- 2 TITLE-ABS-KEY vulva\* pain
- 3 (TITLE-ABS-KEY vulvar vestibulitis syndrome OR TITLE-ABS-KEY vestibulitis)
- 4 (TITLE-ABS-KEY provoked vestibulodynia OR TITLE-ABS-KEY vestibulodynia)
- 5 #1 OR #2 OR #3 OR #4
- 6 TITLE-ABS-KEY interview\*
- 7 TITLE-ABS-KEY qualitative stud\*
- 8 TITLE-ABS-KEY audiorecording
- 9 #6 OR #7 OR #8
- 10 #5 AND #9
- 11 english.lg
- 12 #10 AND #11

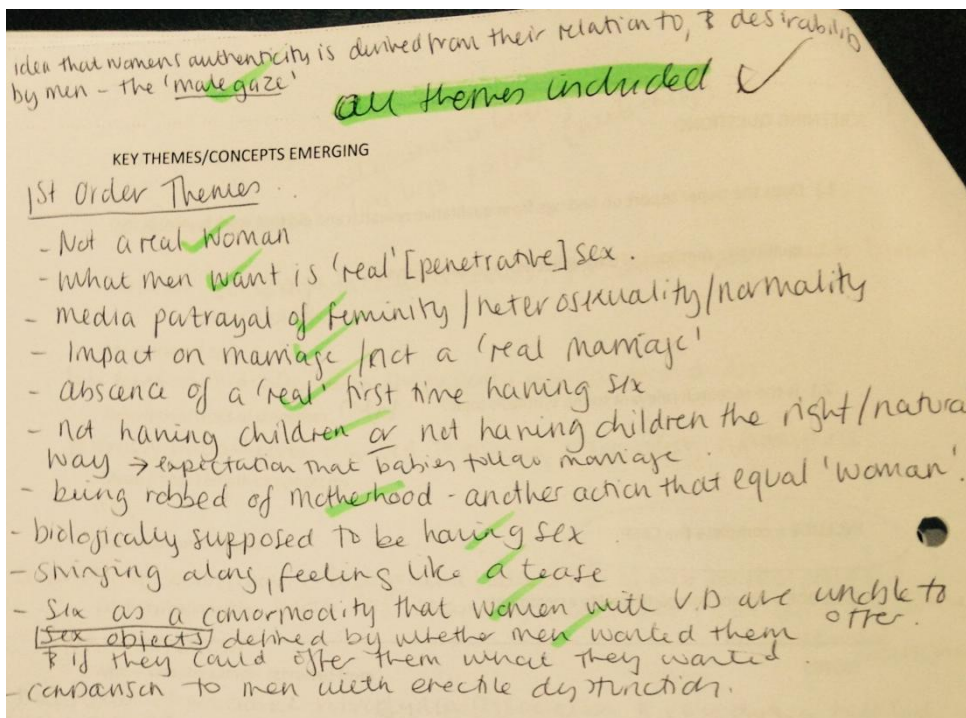
Total papers found 73

## Appendix 5 Examples of Analysis

### 1.) Reading and identifying of concepts within each paper



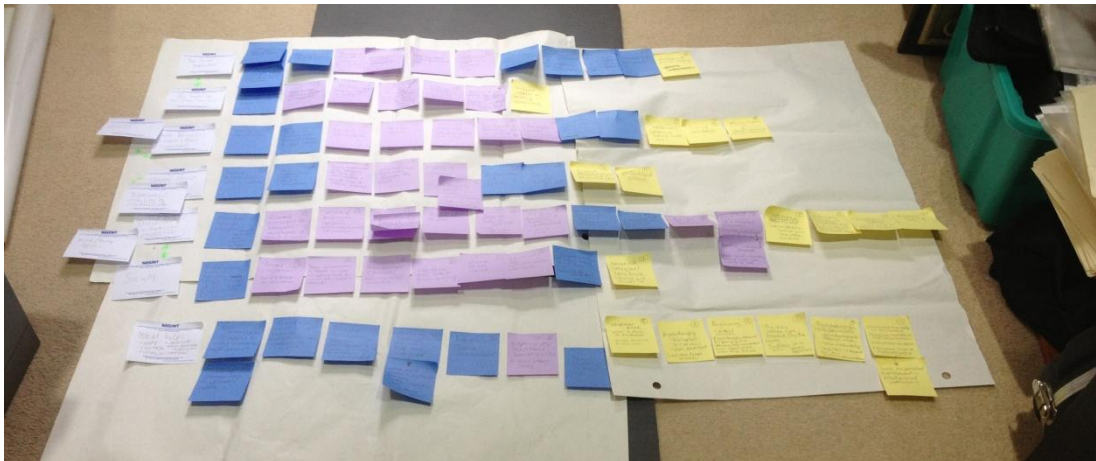
### 2.) Initial list of concepts within each paper



### 3.) An initial List of key concepts Across Papers

- a. Psychological distress
- b. Shame/guilt
- c. Non communication with partners/others (taboo; isolation)
- d. Supportive partners
- e. The assumption of the male want/need for penetrative sex
- f. Attitude of physicians
- g. Delay in diagnosis exacerbating problems
- h. Not a real woman/loss of femininity
- i. Media representations/role of society
- j. Impact on sex and relationships
- k. The Coital Imperative
- l. "Not normal"

- 4.) Finalising the key concepts : key concepts down the left hand side (white "post-it" notes) with each concept from each paper going across (blue, purple, yellow "post-it" notes).....



.....This method was used to re-work the key concepts in order to produce Table 4: Data abstraction to aid analysis.

## Appendix 6 Author Guidelines for Qualitative Research in Psychology

### Submission of Manuscripts

There is no specified word limit. Manuscripts should be double-spaced throughout, especially the references. Pages should be numbered in order. The following items must be provided in the order given:

#### 1) Title Page

*Authors and affiliations:* Authors should include their full name and the establishment where the work was carried out (if the author has left this establishment, his/her present address should be given as a footnote). For papers with several contributors, the order of authorship should be made clear and the corresponding author (to whom proofs will be sent) named with their telephone/fax/e-mail contact information listed.

*Abstract:* Please provide an abstract of approximately 150 words. This should be readable without reference to the article and should indicate the scope of the contribution, including the main conclusions and essential original content.

*Keywords:* Please provide at least 5–10 key words.

*About the author:* Please provide a brief biography to appear at the end of your paper.

#### 2) Text

Subheadings should appear on separate lines. The use of more than three levels of heading should be avoided. Format as follows:

1 Heading

1.1 Subheading

1.1.1 Subsubheading

Footnotes should be avoided. If necessary, they should be supplied as end notes before the references.

#### 3) References

The Harvard style of references should be used. The reference is referred to in the text by the author and date (Smith, 1997) and then listed in alphabetical order at the end of the article applying the following style:

For a book: Hollway, W & Jefferson, T 2000, *Doing qualitative research differently: free association, narrative and the interview method*, Sage, London.

For an edited book: Brown, LM 2001, 'Adolescent girls, class, and the cultures of femininity', in MJ Packer & MB Tappan (eds.), *Cultural and critical perspectives on human development*, SUNY Press, Albany, NY, pp. 219–240.

For a journal article: Madill, A, Jordan, A and Shirley, C 2000, 'Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies', *British Journal of Psychology*, vol. 91, pp. 1–20.

#### 4) Acknowledgements

Authors should acknowledge any financial or practical assistance.

#### 5) Tables

These should be provided in a separate file from the text and should be numbered in sequence. Each table should have a title stating concisely the nature of information given. Units should be in brackets at the head of columns. The same information should not be included in both tables and figures.

#### 6) Figure captions

These should be provided together on a page following the tables.

#### 7) Figures

Figures should ideally be sized to reproduce at the same size. All figures should be numbered consecutively in the order in which they are referred to in the text. Qualifications (A), (B), etc., can only be used when the separate illustrations can be grouped together with one caption. Please provide figures at the end of your paper on a separate page for each figure. Once accepted, you will be required to provide a best quality electronic file for each figure, preferably in either TIFF or EPS format.

## Appendix 7 Study Advert

### Advertisement

#### **Dr Rebekah Shallcross & Dr Gundi Kiemle, The University of Liverpool**

**Study:** The aims of the current study are to explore the experiences of women on their journey to obtaining a diagnosis of vulval pain, and to gain a greater understanding of the role diagnosis plays in the presentation, course and experience of the condition for the sufferer. Furthermore, it is hoped that the research will provide information to improve the experience of the diagnostic journey for women with vulval pain.

**Background:** Vulval pain (vulvodynia, vestibulodynia or vulval vestibulitis), where there is no known cause, can be provoked (pain caused by touch, e.g. during sexual contact, tampon insertion or sitting), unprovoked (pain not specifically caused by touch), localised (pain confined to one area of the vulva) or generalised (pain spreading over and sometimes beyond the vulva). The existing research is limited and often has weaknesses. Most importantly, there are very few studies that have looked at the experience of vulval pain for the sufferer. By asking women about their experiences, it is hoped that the quality of the diagnostic process experience can be improved.

In 2011, the Vulval Pain Society (VPS) asked the members of the London Vulval Pain Support Group which areas they would like research to focus on. Many of the women who responded were keen for research to be conducted into the journey towards obtaining a diagnosis, mainly resulting from their experiences of the diagnostic process. More specifically, they wanted to know what were women's experiences of undergoing the diagnostic process from first becoming aware of their vulval pain, to seeking professional help and finally, obtaining a diagnosis of vulval pain ('The Diagnostic Journey').

**Study Details:** The study is taking place in the Northwest of England (Cumbria, Lancashire, Merseyside, Manchester, Greater Manchester and Cheshire) and interviews may take place at the University of Liverpool or at your home. Women will be asked to talk about their experiences of obtaining a diagnosis of vulval pain, from their experience of first symptoms to receiving the diagnosis. These experiences will be kept confidential and can be positive, negative or neutral experiences or a mixture of these. The study will involve an interview with the researcher (Rebekah) where you will have the opportunity to talk about the aspects of the diagnostic journey that were/are important to you. The interview will last approximately 1 hour, and up to 1.5 hours. You will be reimbursed for travel costs.

**Requirements:** The inclusion criteria will include women who have a confirmed NHS medical diagnosis of Vulvodynia (vulval pain with no known underlying cause), who are over 18 years of age, and who reside in the Northwest of England. The pain can be provoked or unprovoked or a mixture of the two. For the purpose of participation, you may or may not still experience vulval pain symptoms. Women must have received their diagnosis at least 6 months ago and no more than 7 years ago. Participants will need to speak and understand English sufficiently well to be able to participate in a 1 hour - 1.5 hour interview.

**Contact Details:** If you wish to take part in the study outlined above or require any further information then please do not hesitate to contact me using the following details:

**Rebekah Shallcross,**  
mob: 07841470225,  
email: [r.shallcross@liv.ac.uk](mailto:r.shallcross@liv.ac.uk)

## Appendix 8 Participant Information Sheet

### Participant Information Sheet

You are invited to take part in a research study carried out by the University of Liverpool, in conjunction with the Vulval Pain Society. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please feel free to ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

***Thank you for taking the time to read this.***

#### **What is the purpose of the study?**

In 2011, the Vulval Pain Society asked the members of the London Vulval Pain Support Group for suggestions concerning research into vulval pain. One of the possible research areas identified involved looking at women's experiences of the diagnostic journey. Therefore the purpose of the current research is to gain an in-depth understanding of a small group of women's experiences of the diagnostic process, from first becoming aware of their pain, to seeking professional help and finally, obtaining a diagnosis of vulval pain.

#### **Why have I been chosen to participate?**

We are looking to recruit women who have a confirmed NHS medical diagnosis of vulval pain, vulvodynia or vestibulodynia (vulval vestibulitis), described as burning or throbbing pain or soreness on the vulva, where there is no known cause. You are being sent this invitation to participate as you have requested further information regarding this specific study. The study will aim to recruit between four and ten participants for an in-depth study to gain a rich and interpreted understanding of a small group of women who have shared a similar experience (i.e. experiencing the journey of receiving a diagnosis of vulval pain).

#### **Do I have to take part?**

You do not have to take part in this research. Participation in this research is entirely voluntary. You must only take part if you want to. Furthermore, if you agree to take part you are free to withdraw from the study at any time without explanation and without incurring any disadvantage.

#### **Who is organizing the study?**

The study is being organized by Rebekah Shallcross, a Trainee Clinical Psychologist currently studying at the University of Liverpool (contact details listed below). The Vulval Pain Society has kindly agreed to publicise the study to all relevant contacts in order to ask whether they would like to take part in the study.

#### **What will happen if I take part?**

If you agree to participate in the study, then you will be contacted by Rebekah Shallcross (Trainee Clinical Psychologist) to arrange a time to meet for the interview, which is convenient for you. You have two options for where you would like the interview to be conducted:

- 1.) At the University of Liverpool.



The University provides a quiet and confidential place for us to meet. You will be reimbursed for any travel expenses occurred.

2.) At your home.

Your home may be a more convenient place to meet. However, please bear in mind that if a home visit is preferred the environment needs to be quiet and confidential, and free from any disturbances (such as family, children, pets, T.V. landline and mobile telephones etc.), for the duration of the meeting/interview.

The interview will be kept as relaxed as possible and will follow a semi-structured format. You will have the opportunity to tell me about your experiences, and I will also ask you some questions about your journey to getting a diagnosis of vulval pain, from your first experience of symptoms right through to receiving your diagnosis. Any information you give me will be kept confidential. The interview will last around 1 hour and up to 1.5 hours.

You may be asked if you would agree to take part in a follow-up interview at a later date, whereby the analysis of your data will be fed back to you in order to check whether it is an accurate reflection of your experience. However, only about one third of participants will be required for this 'validation' interview. If you do not wish to have a second interview, please tell the researcher and indicate this on your consent form. This will not affect your eligibility to take part in the first interview.

The interviews will be recorded on a Dictaphone and transcribed by a University approved transcriber. Only your first name will be used in the interview process, therefore you will not be identifiable on the recordings. All recordings and transcripts will be stored in accordance with the Data Protection Act (1998). Recordings will be destroyed after they have been transcribed and checked. Transcriptions will be destroyed after publication of the study.

The data you provide and the data of others in the study will be analysed using a qualitative methodology called Interpretative Phenomenological Analysis (IPA). This will allow us to gain an in-depth understanding of experiences which are similar as well as difference in women's accounts of the diagnostic journey. It is intended that the research will be published in an academic journal which will not identify any of the participants involved.

### **Expenses**

Participants will be reimbursed for any travel expenses incurred, travelling to the University of Liverpool. Standard public transport rates will be reimbursed, if using public transport. Mileage by car will be reimbursed at the University of Liverpool mileage expenses rate.

### **Are there any disadvantages or risks in taking part in this study?**

There is a risk that you may become distressed when talking about your experiences during the interview. If this should happen, this will be managed by Rebekah in the session and you will be informed that you should contact Rebekah following the interview, should distress continue. You will be provided with a leaflet following participation in the study, providing useful information on who to contact, should you wish to speak to someone following the study. If at any time during the interview you do not wish to answer a question, you may refuse to answer that question. If at any time you wish to stop the interview, you may do so. If at any time you feel uncomfortable during the interview, this should be made known to Rebekah immediately.

**Are there any benefits in taking part?**

You will not necessarily benefit directly from the research. Potential benefits include the opportunity to voice your experiences of undergoing the diagnostic process for vulval pain in a confidential and non-judgemental setting. Furthermore, it will be an opportunity for you to make a valuable contribution to the research area benefiting similar, future groups of women with vulval pain.

**What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Gundi Kiemle on 0151-794 5530/5534 and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer on 0151 794 8290 ([ethics@liv.ac.uk](mailto:ethics@liv.ac.uk)). When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researchers involved, and the details of the complaint you wish to make.

**Will my participation be kept confidential?**

Yes. All audio data will use your first name only. All transcribed information will be kept using a study number. Participants' first names will be changed in any subsequent presentation, write up or publication. Anonymised quotes will be used in any subsequent presentation, write up or publication. Data collected will be stored in accordance with the Data Protection act (1998).

**Will my taking part be covered by an insurance scheme?**

All participants taking part in University of Liverpool ethically approved studies will be covered by insurance and indemnity.

**What will happen to the results of the study?**

It is intended that the research will be published in an academic journal which will not identify any of the participants involved. We will be unable to provide participants with copies of the published article as copyright will be with the publisher. However, we will write to participants outlining the main findings of the study.

**What will happen if I want to stop taking part?**

The participation in the current research is entirely voluntary; you are free to withdraw yourself and your data from the study at any time. However, requests for withdrawal of data after a month prior to the submission of the doctoral thesis and/or publication will not be possible. You may request that your data is withdrawn from the study and destroyed up until this point.

**Who can I contact if I have further questions?**

Dr Rebekah Shallcross (Researcher)  
Trainee Clinical Psychologist  
the University of Liverpool  
D.Clin. Psych. Programme,  
The Division of Clinical Psychology,  
Institute of Psychology,  
Health and Society  
[r.shallcross@liv.ac.uk](mailto:r.shallcross@liv.ac.uk)  
07841470225

Dr Gundi Kiemle (Principal Investigator)  
Senior University Clinical Teacher  
the University of Liverpool  
D.Clin. Psych. Programme,  
The Division of Clinical Psychology,  
Institute of Psychology,  
Health and Society  
[gkiemle@liv.ac.uk](mailto:gkiemle@liv.ac.uk)  
0151-794 5530/5534

## Appendix 9 Consent Form

**CONSENT FORM****Title: A Qualitative Study Exploring Women's Experience of Vulval Pain: The Diagnostic Process****Researchers:** Dr Rebekah Shallcross, Dr Gundi Kiemle, Dr Joanne Dickson

- |     |   |                          |
|-----|---|--------------------------|
| 1.  | I confirm that I have been given a written explanation of the study by the investigator named on this form. It includes details of any potential risks, my rights as a participant and what is to be done with the data collected at interview.   | <input type="checkbox"/> |
| 2.  | I confirm that I have read and understood the information sheet provided, had time to consider the information and have been given opportunity to ask questions and have had these questions answered satisfactorily.   | <input type="checkbox"/> |
| 3.  | I understand that my interview will be recorded using electronic recording equipment and I consent to this.   | <input type="checkbox"/> |
| 4.  | I understand that any identifiable data will be seen only by the named investigators and a transcriber.   | <input type="checkbox"/> |
| 5.  | I give consent for my anonymised data to be used in the forms of quotes in publication of this study's results  | <input type="checkbox"/> |
| 6.  | I understand that confidentiality will be broken only if there are significant risks to myself or others perceived by the researcher and that this will be discussed with me wherever possible.   | <input type="checkbox"/> |
| 7.  | I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving reason and without my health care or legal rights being affected.   | <input type="checkbox"/> |
| 8.  | I understand that my data will kept electronically for 5 years and during this time under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. I understand that following 5 years my data will be destroyed. | <input type="checkbox"/> |
| 9.  | I consent to being contacted for a second interview if I am selected.   | <input type="checkbox"/> |
| 10. | I consent to receiving written communication regarding the findings of the current study  | <input type="checkbox"/> |
| 11. | I agree to take part in the above study   | <input type="checkbox"/> |

Participant Name	Date	Signature
------------------	------	-----------

Name of researcher	Date	Signature
--------------------	------	-----------

**The contact details of Lead Researcher (Principal Investigator) are:**

Dr Gundi Kiemle, Senior University Clinical Teacher,  
D. Clin. Psych. Programme, The Division of Clinical Psychology  
Institute of Psychology, Health and Society,  
Tel: 0151 794 5530/5534 email: gkiemle@liv.ac.uk

## Appendix 10 Interview Schedule

### Interview Schedule

#### **Demographics and Background Information**

Confirmation of name and age?

Pre/post menopausal

Relationship status?

Type of diagnosis? *Provoked or unprovoked? Generalised or localised?*

Length of pain symptoms? *Years/months?*

Approximate date of diagnosis? *Where? Who by?*

Are you currently attending NHS vulval pain facilities or clinics?

#### **The Onset of Symptoms**

What symptoms did you experience in the beginning?

What were your Initial reactions to symptoms?

What made you decide to seek medical advice?

What expectations did you have prior to seeking medical advice?

#### **Contact with Services**

How did you experience your initial contact with services?

What happened next? (Referral to specialist services?)

What happened next? (Tests/Investigations?)

#### **The role of diagnosis**

How did it feel to receive a diagnosis?

For you, what was the value/role of receiving a diagnosis?

What were your expectations of a diagnosis? What did/does a diagnosis mean to you?

Now you have a diagnosis, how important is having a diagnosis?

What has been your experience of having the diagnosis?

#### **Post Diagnosis**

What happened after diagnosis? *Treatment? Interventions? Support? Comparison between having a diagnosis and not?*

#### **Current situation**

If you are still accessing services, what are your thoughts/feelings/experiences of service provision available for you now?

If you are not currently accessing services, why not?

#### **Ending**

Is there anything else that I have not asked you about, which you feel you would like to tell me about the experience of your journey to obtaining a diagnosis of vulval pain?

## Appendix 11 Example of Detailed Analytic Coding and Emergent Themes (Vicky)

Emergent themes	Line	Transcript (Vicky) <span style="background-color: yellow;">area of rich data</span> ; <span style="background-color: green;">stand out words or phrases</span>	Descriptive; <i>Linguistic</i> ; <i>Conceptual</i>
Complaint against NHS staff/service	209	at the *names centre*, *names doctor* <span style="background-color: green;">after I'd made this</span>	<i>use of phrase – ‘Well I'd not made a complaint’ – implication that she was contemplating or felt that she would have been within her rights to</i>
	210	<span style="background-color: green;">after well I'd not made a complaint (hmm hmm) and he he</span>	<i>make a complaint</i>
iatrogenic self treatment	211	<span style="background-color: green;">started to do more tests and... erm he asked me,</span> because I	<i>Self treating with iatrogenic medication- due to lack of information/knowledge from healthcare professionals – not knowing what else to do</i>
	212	think I must have still been treating it occasionally for thrush	
Lack of understanding of the impact of the pain	213	and he said well <span style="background-color: green;">stop treating it for thrush for a month,</span> well	<i>Here there seems to be a lack of understanding of the impact of the pain</i>
	214	it was actually six weeks, and come back after Christmas, and	<i>Impact on everyday life – sense of being alone with it over Christmas when specialist services typically shut down</i>
Patronising advice	215	I said I can't do that, <span style="background-color: green;">I cannot go through Christmas feeling</span>	
Neurotic woman – focusing on genitals (it)	216	<span style="background-color: green;">like this erm I think that was the point</span> <span style="background-color: yellow;">he told me it was not</span>	<i>Something here about self blame – implications that her pain is because she is focusing on her genitals – is there an implication that she is a</i>
	217	<span style="background-color: yellow;">very healthy to be thinking about my genitals all the time</span>	<i>neurotic woman – something about it being unseemly for a woman to think about her genitals?</i>
	218	<span style="background-color: green;">[laughs] he also suggested I take up knitting [laughs]</span>	<i>Patronising advice – take up knitting – undermining of the pain and belittling of the seriousness of the problem</i>
	219	<b>Rebekah:</b> he suggested, can you say that again just so it's	
Neurotic woman – focussing on genitals (it)	220	clear for the tape	
	221	<b>Vicky:</b> no <span style="background-color: yellow;">actually he'd already seen me knitting in the, and</span>	<i>It is suggested that she needs distraction from ‘focusing on her genitals’ – implication that it is her focus and attention (and therefore her fault?) that she is experiencing pain?</i>
Lack of understanding of the impact of the pain	222	<span style="background-color: yellow;">he said that's what you should do things like knitting do</span>	<i>The level of pain is undermined by healthcare professionals.</i>
	223	<span style="background-color: yellow;">things like knitting to make your mind off it, and I don't think</span>	<i>Repetition of fire metaphor ‘I'm on fire’ x 2 and ‘sitting on coals’ – this is also shouted – she repeats, uses metaphor and shouts in order to try</i>
Shouting for help (not be heard)	224	<span style="background-color: green;">anybody had any concept of the level of pain</span> (hmm) <span style="background-color: green;">I think</span>	<i>and get her point across. Shouting ‘fire’ is also a way of getting people's attention - we are told to do it in any situation as it gets peoples</i>
	225	<span style="background-color: green;">they thought I was just it was just a bit uncomfortable</span> (hmm)	<i>attention the most – she is having to shout for help because no one is listening or taking her seriously.</i>
A man cannot understand	226	and I'm like <span style="background-color: yellow;">I'm on fire, I really am on fire</span> it's like <span style="background-color: yellow;">sitting on</span>	<i>There is something here about being treated by males (because they have different genitals) that leads to a lack of understanding – but also</i>
It more than sex	227	<span style="background-color: yellow;">coals</span> ... and the other thing that they don't seem to get is that	<i>something about it being linked to sex that makes the problem</i>

## Appendix 12 Example of Analysis from Quotes, to Subordinate Themes, to Superordinate Themes; within Case Analysis (Vicky).

Example Quotes	Subordinate themes	Superordinate Themes
eventually, I'd moved to another GP and I just said right you know I don't think you're doing anything my GP didn't do I'm, I'm signing myself off and send everything back to my GP	Stuckness	Silenced & Disempowered
I couldn't get anybody to believe anything was wrong with me,	not listened to or believed	
he didn't understand that this would be something that might be upsetting to me... that it hadn't crossed his mind that this is something distressing (hmm)... erm and in fact at one point when I cried he kind of just, he erm... he shrugged and looked away and then the nurse gave me some tissues, it's kind of like he wasn't going to engage with any, with anything like that so and I think that's where some of the feeling came from that... he kind of yeah, he felt that I was being sort of hysterical, and making a fuss about nothing and all those sorts of things	making a fuss about nothing	
I think one of the overwhelming feelings was of helplessness actually erm 'cause it was like there was nowhere else to go (hmm) erm that my GP kind of really wasn't prepared to deal with this that the place I'd been sent to wasn't sent up to do it, you know, just weren't responding to my needs at all erm (pause) so [sighs] I, I just at that point I wasn't doing anything except just kind of erm salt water baths and waiting for it to go away	isolated and helpless	
women come on the receiving end of that all the time I think doctors frequently, male doctors especially, frequently patronise women (hmm hmm), erm and treat women's problems as... lesser	being patronised	
there is a specialist in the area and nobody mentioned it, nobody thought to send me to the	anger and frustration	
she was the one that slapped my hand and did the AIDS test without my consent [laughs]	The Power Imbalance	An Iatrogenic Journey
they are just going to keep trying putting something in your way, until something works, they will just keep trying something until you stop bothering them (hmm), but I think patients need a sense (hmm), it's kind of it's patients that need that making sense of things (hmm), erm so it did become kind of a quest,	Persistence with the Medical Model	
everybody assumes it's your vagina, even doctors, they just I'm going no it's not there (shouts) , it's not there 'cause they are just poking things in your vagina (shouts) [laughs] it's not my va....you know it's very specific, very specific where the pain was and it wasn't in my vagina.	Non-Consensual and Assaultive Assessment	
after treatment with Canesten I was still in pain I was diagnosed with erm bacterial vaginosis which I'm absolutely sure I didn't have erm and it was the it was the point of taking the antibiotics for that that the pain really kicked in	Iatrogenic Treatment	
that problem with the constipation was also caused by the Amitriptyline so it may be that the cause of the pain later on is different from the cause originally		

### Appendix 13 Outline of Across Case Analysis for the Master Theme 1: The Journey is a Battle, Sub Theme 3: The Psycho-Social Impact of the Journey

Re-worked sub/superordinate Themes by Participant	Sub Theme	Master Theme
<b>Lilly</b> being alone Feeling abnormal/other A hidden secret Abandonment of the journey Frustration with the system Helplessness and hopelessness Fear, shame, unhappiness The role of psychological factors Impact upon intimate relationships/fear of sex	The Psycho-Social Impact of the Journey	The Journey as a Battle
<b>Amy</b> The role of stress in the onset of pain Wanting a physical cause Unnecessary psychological suffering Emotional distress		
<b>Vicky</b> Mind body split Desire for a 'root' physical cause Isolated and helpless Anger and frustration		
<b>Laura</b> Feeling Abnormal Isolation Feeling upset and let down by the system Anger & Hatred of doctors Emotional cost: broken and drained Psychological consequences of the journey: depression, fear, anxiety, panic, hopelessness Don't tell me it's all in my head Fear of being labelled mentally ill Development of vaginismus		
<b>Clara</b> Mind Body Continuum Emotional distress: grown woman seeking maternal comfort		
<b>Liz</b> Being reduced to tears Needing strength and resource for the journey Implication: 'It's all in the mind' Mind/body continuum Psychological consequences accepted Psychological explanation is not accepted		
<b>Bessie</b> A psychological cause does not make sense Implication that it's all in your head Stigma of a psychological cause All consuming of the mind Vulvodynia causes psychological problems Desire to fit the medical model		
<b>Josephine</b> All in my head Distress caused by examinations Anger Feeling abnormal Impact upon mental health and social life Isolation, hopelessness, suicidal ideation Journey takes your energy and resource Desire to have a concrete cause		

## Appendix 14 Analysis of Data

The researcher moved between the individual (idiosyncratic) level, staying close to the data, developing interpretations at different levels (social comparison, metaphor and micro-analysis), as well as taking a theoretical stance taking an overview of the data, refining themes at every level throughout the analytic process using abstraction, subsumption, polarization and contextualisation as ways of looking for patterns and connections both within and across cases and thus continuing the hermeneutic circle<sup>6</sup>. As such the analysis was not solely concerned with moving from the individual (raw data) to the whole (a master table of themes), but rather through analysis, and the writing process, there was opportunity to move in the other direction also. For example, having analysed the whole transcripts, the researcher switched analysis to the parts by conducting deeper and more detailed readings of particularly resonant passages, which then informed and enlightened the whole analysis, and so on, thus moving the analysis to a deeper level of interpretation (Smith, Flowers & Larkin 2009). As is consistent with the iterative and dynamic nature of IPA, it is important to note that analysis did not stop here, but rather continued to develop during the writing up of themes, illuminating, strengthening and thickening the narrative emerging from the analysis. Furthermore, drafting and re-drafting also allowed the author to become clearer in, and deepen, her analysis and argument (Smith, Flowers & Larkin 2009).

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<sup>6</sup> The **Hermeneutic Circle** describes the dynamic and iterative nature between the part and whole of the text. For example, the meaning of a word becomes clear in the context of the sentence, and the meaning of the sentence is reliant on the cumulative meanings of the individual words. In the same way, the researcher using IPA moves from the parts (an individual word, extract or interview) to the whole (an overall interview or the overall analysis) in a 'back and forth' fashion, each informing on our interpretation of the text (Smith, Flowers & Larkin, 2009).



## Appendix 15 Epistemological and Ontological Position of IPA and the Author RS

There are several ontological (what is the nature of ‘reality’) and epistemological (the nature of knowledge; how and what we can ‘know’) positions outlined below.

Relativist (Constructionist)	Subjective idealism	there is no shared reality independent of multiple alternative human constructions
↑	Objective idealism	there is a world of collectively shared understandings
↕	Critical realism/contextual constructionism	knowledge of reality is mediate by our perceptions, beliefs and prior learning
↓	Scientific realism	it is possible for knowledge to approximate closely an external reality
Realist (Positivist)	Naive realism	reality exists independently of human constructions and can be known directly

IPA offers flexibility by bridging the gap between realist (or positivist) and relativist (or constructionist) approaches (Bailey, 2011). As such, IPA acknowledges that there is a reality that exists without being perceived (ontology) *and* that one’s experience of reality is constructed within a social world (epistemology; Nightingale & Cromby, 1999). Thus, research using an IPA methodology is often positioned between a critical realist and a contextual (or mild) constructionivist position. **Critical realism** adopts principles of a social constructionist epistemology (that is, how we ‘know’ is influenced by social, historical and cultural processes and that human knowledge cannot be objective or neutral), but is grounded in a realist ontology (the conviction that an external ‘reality’ exists) (Jacoby, 2012). **Contextual constructivism** is derived from Piagetian research and adopts the epistemological view that knowledge is built or constructed in the context of prior knowledge. As such ‘new knowledge’ is influenced by ‘prior knowledge’ which is replaced, added to or modified by extant knowledge. Further, this construction takes place within contexts such as religion, social economic status, geographical location, ethnicity and language (Williams, 1991). As such the author RS adopts the critical realist framework (realist ontology and mild constructionivist epistemology) throughout the current research, which is in keeping with IPA research.

## Appendix 16 Extract from Reflexive Diary

### Reflections following an interview

- Laura called me before the interview to discuss the motives behind the research. She wanted to know if I would be telling her that it was ‘all in her head’. Laura told me that her experience with psychologists had been negative and that they had told her the pain was not real. Laura was close in age to me and I reflected that this may impact upon my identifying more with the participant. The interview felt more emotional than others and her story had a traumatic feel to it. She used the word traumatic.
- I feel disappointment that Laura had had such a bad experience with psychologists. I remember wanting to give Laura a different impression of what psychologists are ‘like’ and needing to be aware that I remained in my researcher role and not the role of empathetic clinical psychologist.

### Reflections during analysis

- I had very strong feelings of irritation/frustration when analyzing Amy’s transcript. Upon reflection perhaps these were feelings experienced also by Amy during her journey.
- A lot of the language that Amy uses is actually quite misogynistic in its own right – she fights the misogyny she experiences with misogyny towards other women – preservation of self, defense against the stigma – ‘it’s been misplaced on me – it must have been meant for those other women who are ‘like *that*’ (whatever ‘that’ is).

### Reflections during write up

- Something about the very nature of asking the question using the word ‘diagnosis’ – as if the diagnosis exists as a concrete and well defined entity – but also implying that that is the end point – the goal – after which everything becomes clear. But by asking the question we begin to understand that diagnosis has different implications for individual women but that for many it is a point along a journey that doesn’t really have much benefit and perhaps leaves the professional satisfied but the woman with yet more unanswered questions.
- The process of writing up for thesis, by its very nature forces me to condense and sum up into a manageable chunk the research – which is hugely complex – to some extent the process of condensing this research into a paper is also iatrogenic – it will miss so much of the complexity.