

**Women's Experiences of Vaginismus and its Treatment: An Interpretative
Phenomenological Analysis**

Thesis submitted in partial fulfilment for the degree of Doctorate in Clinical Psychology
at the University of Leicester

by

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Declaration

I, Sarah Louise Johnston, can confirm that this thesis and its contents is my own original work. It has been written and submitted as part fulfilment of the Doctoral degree in Clinical Psychology. I also confirm that this thesis and its contents have not been submitted for any other degree or academic qualification.

Women's Experiences of Vaginismus and its Treatment: An Interpretative

Phenomenological Analysis

Sarah Louise Johnston

Abstract

Female sexual pain is a common problem affecting women worldwide yet remains a poorly researched area of women's sexual health. Dyspareunia and vaginismus are two types of sexual pain disorder each having psychological and physical health consequences for women and their partners.

Part 1:

A literature review of the qualitative research literature exploring women's experiences of sexual pain disorders and their treatment was conducted adopting a narrative synthesis approach. Searches of psychological and medical electronic databases highlighted the paucity of research exploring women's experiences of sexual pain disorders. Ten studies met the inclusion criteria for the review. The type of qualitative method and quality varied. Findings highlighted the complexity of women's experiences of sexual pain. Positive experiences of treatment identified alternative benefits of treatment in addition to the traditional outcome of vaginal penetration and penetration without pain. Existing literature has focussed on dyspareunia, and further research is needed on vaginismus.

Part 2:

The research study used an Interpretative Phenomenological Analysis (IPA) of women's experiences of vaginismus. Three women were interviewed about their experiences of vaginismus and the treatment they received. Interview transcripts were analysed using IPA. The findings identified the complexity of experiencing vaginismus, the struggle the women faced when trying to make sense of their vaginismus and the wider impact of these experiences on their identity. The findings highlight the value of psychological therapy with this client group and of the need to raise awareness amongst primary care professionals whom women with vaginismus are likely to consult in the first instance.

Part 3:

A critical appraisal of the research process is presented with focus on the experience of conducting qualitative research as a trainee clinical psychologist. A discussion of the findings is presented in the context of critical reflections on both the strengths and limitations of the study.

Key words: Sexual pain disorders; vaginismus; dyspareunia; vulvodynia; vestibulodynia; narrative synthesis; literature review; qualitative research; critical appraisal.

Acknowledgements

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Part 1: Literature Review

**Women's Experiences of Sexual Pain Disorders and Their Treatment: A
Systematic Narrative Synthesis of the Qualitative Findings.**

Submitted in April 2013

by

Sarah Louise Johnston

To the School of Psychology, Clinical Section, University of Leicester

In partial fulfilment of the degree of Doctorate in Clinical Psychology

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Systematic Narrative Synthesis of the Qualitative Findings

Sarah Louise Johnston

Abstract

Background

Vaginismus and dyspareunia are sexual pain disorders affecting women worldwide. Each can have debilitating effects on the lifestyle, fertility and psychological wellbeing of the woman and her partner. Despite such profound implications for health and wellbeing, sexual pain remains a relatively misunderstood and under-researched area of women's sexual health. Few studies have explored the experiences of these women, and research investigating the effectiveness of treatment rarely asks women about their experience of treatment. More recently, studies adopting qualitative methodologies have attempted to address this gap.

Purpose

The present review aims to synthesise the findings from qualitative research investigating women's experiences of sexual pain and its treatment. In addition, studies included in the review were assessed for quality and rigour.

Methods

Searches were undertaken for qualitative research investigating experiences of sexual pain and its treatment using the electronic databases of PsycINFO, Medline, Scopus and ISI Web of Science. Studies that focussed on sexual pain in the context of cancer, surgery and those that had a specific focus on endometriosis or general pelvic pain, were excluded.

Results

Ten papers met inclusion criteria for the review. A thematic analysis of the findings identified the complexity of the experiences of women with sexual pain. Findings were organised into the following themes: psychological impact and consequences; beliefs about causes; impact on perception of self-identity; impact on relationships; coping strategies. Women's narratives of their experiences were embedded within a heterosexual power/gender discourse. Experiences of treatment were both positive and negative. Themes of education, validation and psychological gains were associated with positive treatment experiences.

Conclusion

Further UK based research adopting a phenomenological approach to explore the experiences of women with sexual pain is required and should include experiences of women from ethnic and sexual orientation minority backgrounds. Women with vaginismus also require further consideration.

Keywords: Sexual pain; vaginismus; dyspareunia; vulvodynia; vestibulodynia; qualitative research; narrative synthesis; literature review.

Women's Experiences of Sexual Pain Disorders and Their Treatment: A Systematic Narrative Synthesis of the Qualitative Findings

1. Introduction

1.1 What is sexual pain?

Vaginismus and dyspareunia are currently defined as sexual pain disorders under the category of sexual dysfunction within the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) and International Classification of Diseases (ICD-10; WHO, 1992). According to the DSM, vaginismus is characterised by a recurrent or persistent involuntary spasm of the vagina muscles that interferes with or prevents vaginal penetration. For some women, penetration has never been possible which is referred to as primary vaginismus. For others, intercourse or penetration, although previously achieved without difficulties, are no longer possible (e.g. following traumatic childbirth or other traumatic event involving the genital area). This is known as secondary vaginismus. Dyspareunia is characterised by a recurrent or persistent genital pain before, during or following sexual intercourse in which penetration is possible but painful and is sometimes referred to as painful sex. Vulvodynia (pain in the vulvar region) and vestibulodynia (pain specific to the vulvar vestibule) are two subtypes of dyspareunia and are also implicated as causes of dyspareunia and vaginismus (LoFrisko, 2011). Neither, vulvodynia or vestibulodynia are referenced in the current DSM (for a detailed description of the female sexual pain disorders and subtypes, please see Appendix B).

1.2 Prevalence of sexual pain disorders

Prevalence rates of female sexual pain disorders range between 12 and 28 per cent of women attending sexual health clinics (Shepherd et al., 2009; Shepherd et al., 2010), women attending for couples psychosexual therapy (Roy, 2004), and among women presenting at their general practitioners (GPs) (Nazareth et al., 2003; Mercer et al., 2003; Read et al., 1997). General population estimates suggest between 0.5 and 6 per cent of women worldwide have experienced sexual pain (Burri, 2011; Schultz et al., 2005; Simons & Carey, 2001). Variance in prevalence may be due to the range of definitions for sexual pain disorders used and the absence of measures for severity and duration in some studies (Hayes et al., 2008).

1.3 Aetiology of sexual pain disorders

The literature pertaining to aetiology of sexual pain is problematic (e.g. inadequate controls, variation in definitions of sexual pain, small sample sizes, and insufficient sample sizes for statistical analyses for assessing aetiology; Reissing et al., 1999) and despite several years of research it remains inconclusive. Physiological, psychological and social explanations have all been documented. Abnormalities of the hymen, vaginal infections, factors related to genital surgery, and oestrogen deficiency have all been associated with difficulty in allowing vaginal penetration (Schultz et al., 2005). Anxiety, fear of pain and avoidance behaviours have been documented among women with dyspareunia and vaginismus (although more so in women with vaginismus) as have negative sexual attitudes or beliefs and a lack of sexual knowledge (Reissing et al., 2003). In particular, heightened levels of catastrophic pain cognitions were found among women with vaginismus (Borg et al., 2012). A religious background or upbringing and conservative values pertaining to sex may also be a risk factor in the development of sexual pain (Binik, et al., 2007; Borg et al., 2011), and sexual aversion

has been found to be higher in women with vaginismus than in women with dyspareunia (De Jong et al., 2007). Childhood sexual abuse has been reported among women with sexual pain (Reissing et al., 2003), however whether the prevalence of sexual abuse is higher among women with pain than no-pain controls remains inconclusive (Meana et al., 1997). Additionally, relationship satisfaction and partner characteristics may also contribute to the development and maintenance of sexual pain (Davis & Reissing, 2007), however research is inconclusive and in some studies, relationship satisfaction was found to be higher among women with vaginismus when compared with controls (Reissing et al., 2003).

1.4 Treatment approaches

Treatment in the UK for sexual dysfunction, including female sexual pain, is largely an overlooked and underfunded area (BPS, 2006). In order to allow pain free intercourse, treatment has largely been embedded within a medical model approach to sexual health (e.g. surgery, pharmacology including topical creams, physical therapies such as pelvic floor physiotherapy, biofeedback and pain management therapies; Binik et al., 2007). Sex therapy (Hawton & Catalan, 1990), psychoanalytic therapy (Coppini, 1999), and cognitive behavioural therapy (CBT; van Lankveld et al., 2006) have all been used in treating vaginismus and dyspareunia and often comprise elements of education, goal setting, challenging unhelpful beliefs, managing pain, and reduction of anxiety. Invariably within the treatment literature vaginismus and dyspareunia are treated as separate problems. Success rates as high as 75 to 100 per cent have been reported for vaginismus (Engman, 2010; Kabakci & Batur, 2003). However, problems with methodology including lack of follow-up and poor controls mean these findings are questionable. In a randomised controlled study of outcomes among women with lifelong vaginismus, success rates were found to be much lower at 21 per cent after a 12-month follow-up (van Lankveld et al., 2006). The definition of ‘success’ is also

questionable in terms of whether it is based solely on achievement of penetration, or should include pain free penetration.

Clinical Psychologists are seen as well suited and cost effective in their treatment of female sexual dysfunctions (Goldmeier et al., 2004) and there is growing consensus that a multi-disciplinary treatment approach is most effective in treating sexual pain (e.g. incorporating physical and psychological therapies; Bergeron & Lord, 2010; Bergeron et al., 2010). Further controlled research is required to assess the effectiveness of this combination. The exclusion of population groups (e.g. single women, ethnic and sexual minorities and older post menopausal women) from the treatment literature has also led to problems with a generalisation of the findings. Owing to the nature and location of the pain, barriers to treatment, associated taboos, lack of awareness, and difficulty in understanding symptomatology are likely to exist, all of which may impact on how and if women seek and access treatment (BPS, 2006). Of those women who have sought help for sexual pain, their experiences were variable and are discussed in more detail in the results section (Ogden & Ward, 1995; Reissing, 2012). In comparison to the treatment literature on removing the barrier to penetration or pain, relatively few studies have explored how women with sexual pain actually experience the treatment received at the idiographic level.

1.5 Sexual pain or genital pain?

The current conceptualisation of vaginismus and dyspareunia as sexual pain disorders has long been viewed as controversial and for some, reflective of an attempt to over medicalise female sexual problems (Tiefer et al., 2002; Kaler 2006) based on inaccurate nosology (Basson, 2002). It is argued that these disorders (currently the only pain problems dealt with by the DSM outside of ‘pain disorder’) should be classed as pain disorders that interfere with sexual activity rather than painful sexual problems (Binik et al., 2002; Payne et al., 2006), thus bringing the central feature of pain back

into vision. Arguments against this proposition suggest that reclassification would not benefit the diagnosis or treatment of sexual pain and that the available data does not fully support dyspareunia being better classed and managed as a pain disorder rather than a sexual one (Carpenter & Anderson, 2005). For a detailed report of peer commentaries on this debate see Binik, 2005.

Additionally, some argue against the retention of sexual pain in the DSM altogether and see sexual pain disorders as a labelling of sexual abnormality or failure, a legacy from a 'less enlightened era of medicine' and an unhelpful concept for those women who experience this type of pain (Kaler, 2005). Classification systems used for diagnostic purposes arguably represent a medical view of women's sexual pain and artificially remove them from the cultural, social, and gender based paradigms in which they are inevitably experienced. Whilst a proposed 'genito-pelvic pain / penetration disorder' for the forthcoming DSM-V may overcome some of the issues with the current nosology, it may also mean that these disorders become lost altogether.

1.6 The bio-psychosocial impact of sexual pain

In addition to physical pain and discomfort, sexual pain disorders have psychological and physical health consequences for women and their partners. For example, vaginismus is a major cause of unconsummated marriages (Ozdemir et al., 2008) and is likely to lead to infertility and a higher risk of caesarean delivery (Goldsmith et al., 2009). Psychological distress, low self esteem and difficulties in relationships have all been identified among women with sexual pain (Bond et al., 2012; Dunn et al., 1999). Despite these implications for psychological and physical wellbeing there is a paucity of research addressing the bio-psychosocial consequences of sexual pain. Research addressing how sexual pain is experienced and understood by the women themselves was largely non-existent prior to the last fifteen years and is still

rare. More recently qualitative methods have been applied in an attempt to address this gap.

1.7 Aim of the current review

The present literature review aims to systematically review the findings of published qualitative research that has addressed women's experiences of sexual pain and its treatment. Qualitative methodologies allow a more in-depth approach where women can express the complexity of how they experience sexual pain and its treatment, rather than focussing on a narrow essentialist categorical outcome of whether vaginal penetration was achieved. The review aims to facilitate understanding of recent qualitative findings by summarising and organising themes identified in the literature into a useful format for both clinical and research purposes.

2. Method

2.1 Review approach

In conducting the present literature review a Narrative Synthesis (NS) approach was selected. Guidance on NS published by the Economic and Social Research Council (ESRC; Popay et al., 2006) was consulted and used to guide a systematic and transparent approach. The approach essentially relies on a qualitative analysis to present and synthesise findings from multiple studies (e.g. Miller et al., 2007). In the context of the present review, NS facilitated the storytelling of how women experience sexual pain and its treatment.

2.2 Constructing the Review Question

In a review of literature examining treatment of vaginismus previously undertaken by the author, a lack of research pertaining to the lived experience of vaginismus and its treatment was noted. Only two studies were found meaning that a review solely focussing on experiences of vaginismus would be based on very limited data. An exploratory search of the general sexual pain literature found evidence of recent qualitative research examining women's experiences of dyspareunia. It was therefore decided that the current review would explore and investigate the qualitative findings pertaining to women's experiences of sexual pain disorders, including vaginismus and its treatment.

2.3 Search strategy

The search strategy was informed by guidance on finding qualitative research published by Shaw et al. (2004). Searches of the electronic databases of PsycINFO, Medline, Scopus, and ISI Web of Science were conducted in order to identify research from both medical and psychological backgrounds, recognising the multidisciplinary interest and involvement in treating sexual pain. Search terms were chosen by using the CHIP tool, used for searching for qualitative studies (Shaw, 2010), and from the

author's previous readings in the area of sexual pain in an attempt to capture the many ways to which sexual pain had previously been referred to (see Appendix C for CHIP tool and search terms used in the current review). Search terms were entered into each of the databases with the parameters of all dates, peer reviewed journal articles only, and articles published in English language. Manual searches of the reference sections of relevant identified journal articles were also undertaken to ensure that all relevant and available studies were identified (details of the searches undertaken can be found at Appendix D). All searches were conducted at regular intervals between December 2011 and February 2013 to ensure the inclusion of any recently published research relevant to the review.

2.4 Inclusion and exclusion criteria

All studies that used a qualitative methodology, either as a single method or part of a mixed-method approach to investigate the experiences of women with sexual pain or treatment for sexual pain, were included in the current review. Sexual pain was defined according to the current classification in the DSM-IV (DSM-IV; APA, 2000) and included vaginismus, dyspareunia and subtypes of dyspareunia. Studies using terms to indicate sexual pain generically were also included (e.g. painful sex, sexual pain, coital pain). Studies were excluded if the main focus was cancer and sexual pain, pain following genital surgery or childbirth, endometriosis and generalised pelvic pain. The author decided a separate review would be required to fully explore these areas. Owing to the scarcity of the available qualitative research, no stipulations for inclusion were made concerning a type of qualitative method or theoretical stance. Where mixed-method studies were included, only the qualitative findings were of focus of the present review. Studies from all countries were included if they were written in English language.

2.5 Quality appraisal and data abstraction

Papers were assessed for research rigour based on available guidelines for assessing qualitative research (Meyrick, 2006). These guidelines suggest that qualitative research studies are assessed for transparency and systematicity. Transparency refers to the extent to which research processes are disclosed within the write-up and systematicity refers to the extent to which methods of data collection and analysis are outlined in addition to any deviations to such methods used. Included studies were read and data was extracted to examine the level of transparency and systematicity (see Appendix E for a copy of the data extraction form based on the guidelines by Meyrick, 2006). The quality of the included studies varied, however all were deemed good enough to make a useful contribution to the review. Papers were deemed good enough if a qualitative approach to data collection and analysis had been adopted and if there was sufficient detail allowing the reviewer to ascertain the process by which the findings had been obtained. It is acknowledged that the level of detail varied among the studies included and issues regarding quality are discussed further in the results section.

2.6 Method of synthesis

Qualitative findings pertaining to experiences of sexual pain and its treatment were extracted from each study and managed in table format. Thematic analysis was used to identify dominant and recurrent themes. In order to guide this process, guidelines on conducting thematic analysis were consulted (Braun & Clarke, 2006). The guidelines suggest that decisions concerning what constitutes a theme, the method of theme identification and the level at which themes are identified, should be made explicit when adopting a thematic analysis approach (Braun & Clarke, 2006). Owing to the recent addition of qualitative research findings pertaining to sexual pain combined with the author's particular interest in the lived experience of sexual pain and its

treatment, a combination of inductive and theoretical thematic analysis was undertaken. A semantic level of thematic analysis was applied in theme identification. Findings were initially organised into appropriate categories to which the data related (i.e. experiences of sexual pain and experiences of treatment). Arising themes were highlighted within each category and where available, direct quotes from the results of included studies were used to exemplify these themes.

2.7 Author's position

Throughout the review the author was aware of the potential for personal and professional bias to influence the review process (please see Appendix F for the author's statement of epistemology). The author is a trainee clinical psychologist familiar with the research literature and has worked therapeutically with women presenting with sexual pain. Whilst undertaking the present review the author was involved in her own Doctoral research which involved using an interpretative phenomenological approach (IPA; Smith, 1996) to explore women's experiences of vaginismus. Similarly, the author recognises the complexity of simultaneously undertaking a literature review and an IPA research study and the possible impact on her capacity to 'bracket off' presuppositions from prior engagement with the literature, in terms of both her own research data and findings from previous research. This was addressed by discussing the literature review and research analysis in supervision and documenting thought processes in a reflective journal. IPA is explicitly interpretative but still has a requirement for themes to be appropriately rooted in the data and this was borne in mind throughout.

3. Results

3.1 Results of searches

In total 1,592 titles and abstracts were screened for relevance to the review between December 2011 and February 2012 (only abstracts of relevant looking titles were screened). Following the exclusion of non-relevant papers and duplications, a total of seven papers remained and were deemed relevant to the review question (studies 2, 4, 5, 6, 8, 9, and 10). An additional four papers were found by searching the references cited in the studies retrieved electronically (studies 1, 3, 7 and Kaler, 2006). Of the 11 papers deemed to be relevant at this stage, one paper was excluded owing to an unclear outline of data collection and analytical methods used, however this paper is referenced in this review owing to its relevance to the review question (Kaler, 2006). Ten studies met the inclusion criteria and are outlined in Table 1 below (please see Appendix G for a flow chart of the search process outlined above). It should be noted that the review findings are based on data from eight studies, rather than ten, as four papers were generated from two data collections (studies 4, 5, 7, and 8).

Table 1. Summary of the characteristics of the studies included in the review

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
1	Sackett et al., (2001) Psychosexual aspects of vulvar vestibulitis. USA	Mixed method questionnaire (quantitative and qualitative). Open-ended questions concerning the impact of vulvar vestibulitis. Content analysis used to analyse data.	69 women diagnosed with vulvar vestibulitis, aged 19-60 years, White background, recruited from a vulvar/vaginal disease clinic.	Data organised into the following predetermined themes: Impact on daily life (interference in daily activities, changes in mental health, decrease in sexual interest, sleep / fatigue problems, changes in interpersonal relationships); concerns about sexual activity (Pain, decrease in sexual activity, inability to satisfy sexual partner, fear relationship will not return to normal, impact on fertility); impact on relationships (sexual changes, relationship stress, strengthening of relationship, changes in emotionality, decrease in	No reference to epistemology / theoretical stance or researcher's reflexivity to the data. No details concerning sampling strategy adopted or administration of questionnaire. Does not use participant quotations to support themes presented. Difficult to assess whether themes are borne out of data. Process of analysis is outlined and qualitative themes are transformed into qualitative measure (i.e. frequency) and therefore depth is superficial. Two researchers were involved in data analysis.

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
2	Ayling and Ussher (2008) If sex hurts, Am I still a woman? The subjective experience of Vulvodynia in Hetero-sexual Women. Australia	Adopted a material-discursive approach 'embedded within a critical realist epistemology'. Semi-structured interviews adopted and 'positioning theory' used to interpret the data.	7 Anglo-Australian women aged 18-41. All women had experienced symptoms >12 months, all had a medical diagnosis of vulvodynia.	Dominant themes / subject positions included 'inadequate sexual partner', 'inadequate woman', one woman positioned herself as 'adequate woman/sexual partner', and experiences of 'resisting the inadequate woman/ sexual partner' position were presented.	Provides detailed account of researchers' positions to the data (insider / outsider contrast as one researcher had experienced vulvodynia), sampling strategy and detailed demographics. Uses excerpts to illustrate and support themes. A pilot interview was conducted and themes arising were discussed between research team. Provides sufficient detail to consider findings in context of sample population.
3	Elmerstig et al., (2008) Why do young women continue to have sexual intercourse despite pain? Sweden	Semi structured interviews. Constant comparative method from Grounded Theory is described.	16 Swedish women, aged 14-20 years, variable levels of 'coital pain'. Duration of symptoms 1 month-3 years.	Core category identified as 'striving to be affirmed in their image of an ideal woman'. Sub-categories included 'resignation' 'sacrifice' and 'feeling guilt'.	No explicit detail concerning author's position to the data. Sample demographics are provided, provides details of interview location and protocol, and analysis undertaken. Multiple researchers, however there is no information pertaining to quality and

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
					consistency checks. Data analysis protocol does demonstrate theme audit trail.
4	Ogden and Ward (1995) Help-seeking behaviour in sufferers of vaginismus. United Kingdom	Mixed method approach, postal questionnaire sent to current sufferers and ex-sufferers of vaginismus. Open-ended questions for experiences of professional contact in treating their vaginismus. 'Free comments' were categorised into themes.	67 sufferers and 22 ex-sufferers completed the questionnaire. Respondents mean age of 33.6 years. Average duration of vaginismus was estimated as 14 years due to missing data.	Subjective comments given on the questionnaire were organised as either positive or negative comments and presented in the following categories; Positive: a) experiences of a traditional directive professional centred approach (receiving information, having a problem diagnosed, being normalised and problem solving); b) experiences of a patient centred-approach (emotional support, doctors accepted feelings and problems, showed empathy, gave confidence and security, were kind, were understanding, did not apply pressure, were patient, and	Does not address reflexivity / objectivity to data. No details for how 'free comments' categorised into themes. Minimal details concerning structure and development of questionnaire used. Data is managed at a descriptive level only, providing only single word quotations, so therefore loses context somewhat and difficult to gauge picture of raw data.

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
				<p>encouraged talking about experience / feelings, being listened to).</p> <p>Negative: a) professional centred approach (imposed a physical examination, impatient, unsympathetic, no discussion offered, mechanistic approach taken, seen as hysterical, responses not meeting their needs, doctors had insufficient understanding, being fobbed off); b) patient centred approach (inappropriate psychological analyses). Same approach was viewed positively by some and negative by others.</p> <p>Help seeking was influenced by prior negative experiences and included worries of pending treatment (fear of examination, being seen as a nuisance, being offered inappropriate treatment, finding no cure possible, fear of</p>	

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
				discovering repressed memories and being misunderstood.	
5	Ward and Ogden (2010) Experiencing Vaginismus: sufferers' beliefs about causes and effects. United Kingdom	As in study 4. This paper focused on the free comments given concerning women's beliefs about causality, effects of vaginismus on their self-perception, and important relationships. Discourse analysis is used to analyse the data.	As in study 4.	Free comments from open-ended questions were organised into the following categories. 1. Beliefs about causality (trauma, need for self protection, beliefs derived from upbringing); 2. The effects of vaginismus on the sufferer's self-perception (low self esteem, feelings of isolation, incomplete as a woman, unfeminine, angry with self, anxious about being close to others, helpless, hopeless, suicidal, feeling cut off from others); 3. The effects of vaginismus on relationships with other women (feeling ashamed, embarrassed, inferiority, feelings of difference and alienation, excluded from female discussions); 4. The	Brief example of survey questions provided. There are no details pertaining to the amount of 'free' comments received for open-ended questions. Provides examples of excerpts and terminology used by participants. Difficult to ascertain how much the quantitative part of the questionnaire influenced the choice of words used by participants in the free text part of the questionnaire.

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
				<p>effects of vaginismus on relationship with sexual partner (partner did not try to help, partner wanted to leave relationship, partner dissatisfaction, erection problems, marriage delayed, angry with partner); 5. The effects of vaginismus on family relationships (feelings of anger and mistrust towards family, emotional distance, sexual/physical/emotional abuse, confused feelings, low self confidence, family's disbelief, disappointment).</p>	
6	<p>Sadownik et al. (2012)</p> <p>Provoked Vestibulodynia: Women's experiences of</p>	<p>Described as a qualitative retrospective study utilizing semi-structured interviews.</p>	<p>19 women, age 20-54 (30.8 mean age), all had completed the multidisciplinary treatment</p>	<p>Themes outlined included 1. Increased Knowledge, 2. Gained tools/skills, 3. Perceived improved mood/psychological wellbeing, 4. A sense of validation and support, and 5. An enhanced sense of</p>	<p>No reference to the researcher's position to the data. Outlines the aims of the study clearly and provides details of interview schedule and 'pre-defined' questions. Provides examples of</p>

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
	participating in a multidisciplinary vulvodynia program. Canada	Content analysis used to examine interview transcripts.	program.	empowerment.	themes and corresponding excerpts from the transcripts. All interview transcripts were analysed independently by three researchers and discussion between them led to development / agreement of themes presented.
7	Munday et al., (2007) A qualitative study of women with vulvodynia: response to a multidisciplinary approach to management and experiences of the treatment. United Kingdom	Described as an in-depth retrospective qualitative interview study. States that interviews were 'transcribed using thematic analysis'.	Twenty-nine women aged 22-58 years, white educated British or European origin.	Themes are not explicitly stated in the write up. Results section is organised into sections referring to women's experiences of the different aspects of the multidisciplinary treatment programme such as medication, physiotherapy, and psychotherapy.	Research team is stated as being separate from clinical team. No indication of author's position to the data. Outlines the aim of the study. Minimal demographics provided and minimal details concerning interview schedule; would be difficult to replicate based on level of detail provided. Qualitative data appear to have been managed quantitatively. No audit trail and therefore difficult to assess findings.

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
8	Buchan et al., (2007) A qualitative study of women with vulvodynia: the journey into treatment. United Kingdom	As in study 7. Describes using thematic coding, themes managed into initial and higher codes.	As in study 7.	Themes are not explicitly stated, however findings are organised around the following areas: Route to diagnosis; Impact of delay to diagnosis; Attitudes of partners; Response to diagnosis.	As above. With the exception of: provides central themes covered by interview schedule. Themes are presented with supporting excerpts. Difficult to differentiate between higher and initial coding. States that searches were made across the raw data for disconfirming cases. All transcripts were independently coded.
9	Donaldson and Meana (2011) Early Dyspareunia experience in young women: confusion, consequences and help seeking barriers. USA	Used semi structured interviews. Qualitative method described as being 'broadly' based on Grounded Theory.	14 young women, mean age 19.07 years, nine were European-American, 3 were African-American, one was Hispanic, 1 was Asian – American.	Core processes emerging from the data were outlined in a cognitive behavioural model of early dyspareunia and suggested a sequence of experiences beginning with a) confusion about the onset of pain and search for causal attributions, b) followed by personal pain management strategies, c) impact on sexual / interpersonal	No details concerning researcher's position to the data. Outlines aims of the study clearly. Outlines procedure undertaken and by whom. Outlines that percentage agreement on 'second-order themes' was 84%. States process undertaken when disagreements arose, however, does not provide detail of themes subject of disagreements. Representative

Study I.D	Reference & study country of origin	Qualitative methodology & analysis	Sample population	Themes / qualitative findings presented within paper	Comments
			Participants had been sexually active for an average of 34 months.	functioning and well-being, and finally, d) professional help seeking decision point, and barriers to help seeking.	quotes are provided for each aspect of the model.
10	Sutherland (2012) Qualitative Analysis of Heterosexual women's experience of sexual pain and discomfort. Canada	Semi structured Interviews, described as adopting an empirical phenomenological method.	9 heterosexual Caucasian women in long-term relationships, all married for an average of 11.68 years, mean age was 35.3 years.	Outlines 42 themes organized into four phases a) Preconditions, b) the experience of sexual discomfort and pain, c) coping strategies, and d) aftereffects.	Discusses the impact of reflexivity and relationship to data, mentions author's 'presuppositions' but no details about what these were. A follow up interview was also undertaken over the telephone, no details of when this was undertaken or particular purpose. Does not make reference to quality checks being made. There are some supporting quotes used, however these are not consistent across the four phases. For example, latter phases are not accompanied by supporting quotes.

3.2 Overview of included papers

Of the ten papers included in the review, the type of sexual pain experienced varied, as did the terminology used to refer to sexual pain. A scan of the research titles highlighted the following terms in use; sexual pain, early dyspareunia, vulvodynia, provoked vestibulodynia, vaginismus, coital pain, and vulvar vestibulitis. Studies either explored experiences of sexual pain only (studies 1, 2, 3, 5, 10); experiences of sexual pain and of professional intervention (study 9); experiences of professional intervention only (studies 4, 6, 7) and experiences of accessing treatment services / help seeking (studies 4, 8, 9). Countries of origin included Canada (studies 6, 10); USA (studies 1, 9); Australia (study 2); Sweden (study 3) and the UK (studies 4, 5). The age of participants ranged from 14-71 years, with the majority of studies indicating the woman's mean age to be in her thirties. Sample sizes ranged between seven and 89 women. Where documented, the duration of symptoms ranged between one month and 20 years, the latter being the exception. Most studies drew their samples from a clinical population of women attending for treatment at a specialist sexual pain clinic. Women were predominantly described as being from white backgrounds and in long-term heterosexual relationships, although in some studies reference was made to alternative demographics (e.g. five participants were of African American and Asian American origin (study 9); two participants described themselves as bisexual (study 5)). Finally, women who had given birth, and both nulligravida and nulliparous women were included among the studies.

3.4 Epistemological and theoretical stance

According to Meyrick (2006), good qualitative research embraces and clearly states the epistemological and theoretical stance of the researchers themselves. This is either by demonstrating their objectivity or distance from the data or by stating their relationship i.e. having prior experiences of the subject under study. Thus, it is seen as good practice for a researcher to be open about their relationship to the data and openness to biases, which is arguably an unavoidable aspect of doing qualitative research. Being reflexive is a fundamental component of the qualitative research process. Among the ten papers reviewed, the majority of the studies included did not provide any information concerning the author or researcher's relationship to the data (studies 1, 3, 4, 5, 6, 7, 8, 9). Only two papers satisfied this requirement. One study stated an epistemological stance with a material discursive approach embedded in a critical realist perspective (study 2) and provided details concerning their positions to the data. Another study stated an interpretative phenomenological perspective and discussed the potential impact of the author's 'presuppositions' on the data, however no details were provided of what these might be (study 10). Owing to eight out of the ten papers seemingly omitting to address and detail epistemology, theory and relationship to the data, it was difficult to examine the potential impact of author bias on the findings presented.

3.5 Transparency and systematicity

In addition to being open about epistemological and theoretical stance, good qualitative research is able to demonstrate clearly the methods and processes used (Meyrick, 2006). Thus the processes and procedures applied in sampling, data collection and analysis, should be clearly outlined. A clear and transparent audit trail

should be accessible to the reader in order for judgements to be made about the findings and the closeness to the data themselves with reference to the people on which they are based. Among the ten papers reviewed, the extent of transparency and systematicity was variable. A range of qualitative methods were documented as being implemented and included constant comparative method of grounded theory, thematic deconstruction, empirical phenomenology, 'broadly based' grounded theory, thematic coding and discourse analysis. Most studies stated some form of thematic analysis or coding had been applied to the data in order to identify themes and frequency. The majority of the studies made reference to who was undertaking the analysis and how themes were managed and identified. However, for some studies, detail concerning questions asked of participants and qualitative raw data (e.g. quotes and words used by the participants themselves) was lacking (Studies 1,4,5, &10).

3.6 Narrative account of the evidence

A thematic analysis of the ten papers identified that the findings pertaining to women's experiences of sexual pain could be organised and understood in terms of the psychological impact and consequences of sexual pain; beliefs about causes of their sexual pain; impact of sexual pain on perceptions of self and identity; impact on relationships and the coping strategies used. Additionally, positive and negative experiences of treatment were reported. In relation to positive treatment experiences, recurrent themes of education, validation and psychological gains were identified. The discourses of the experiences of sexual pain were associated with gender and power imbalances within a heterosexual context.

3.6.1 Women's experiences of sexual pain

3.6.1.1 The psychological impact and consequences of sexual pain

The women experienced a range of emotions including anger, fear, shame, guilt, anxiety and frustration. Women expressed a reduction in their sexual drive, sexual desire, arousal and sexual satisfaction. Depression, suicidal ideation, fear of abandonment, insecurity within intimate relationships, feeling unsafe and trapped, powerlessness and a sense of inner pressure to engage in sex and to meet their partner's sexual needs over their own, were all documented. For some women, the emotions experienced were related to an inability to provide or achieve a sexual connection in their relationships and led to feelings of inadequacy. There was also reference to the locus of blame being situated within their body.

'It makes me a little short tempered sometimes or frustrated and that just puts me in a bad mood. It puts the people around me in a bad mood.'

(P8: study 9, p819)

"I just feel like a general melancholy or disappointment not in myself because it's not my fault but just kind of like, god! Sometimes it depresses me"

(P9: study 9, p819)

'I get, like, a bad conscience or something like that...I feel guilty, you know...I am so...why does it never work or so...why can I never have sex...it's only my fault that I hurt all the time'.

(Study 3, p360).

'The impact of vulvodynia has been far greater than physical pain. Over time, my feelings of inadequacy have grown'

(Cherie: study 2, p294)

3.6.1.2 Women's beliefs about the causes of sexual pain

Previous trauma including physical and sexual abuse, negative prior experiences of sex and negative beliefs about sex were all documented as beliefs held by women concerning causality of their sexual pain. For some women, multiple and conflicting beliefs were held simultaneously and there was evidence of working through different beliefs about causes and perspectives of their sexual pain. For some women sexual pain brought about negative side effects. For others, in addition to the negative side effects of their sexual pain, they viewed it as functional at some level, including seeing pain as a barrier against the outside world and as a protective defence from being hurt. Notably these women were drawn from a sample who had previously received a psychoanalytic form of therapy (study 5). Also in the findings was a recurrent theme of women regarding themselves as ‘faulty’. Some women believed there was something wrong with their vagina and that this was causing the pain or preventing them from having penetrative sex. A lack of knowledge about their pain and their anatomy, unhelpful thinking and beliefs and confusion were evident.

‘I don’t know if it’s because the inside of me just gets smaller or if the penis is too big or things like that, but I just think it could be something in the canal way’.

(Study 9, p818).

‘I’ve been kinda just sitting around waiting for it to fix itself. Like, I think it goes to ignorance. I don’t know enough about it. I haven’t really been educated about it to know what is going on and why I have the pain and it if is normal, like if everybody has it, if it goes away, if there is a certain point, why it happens.’

(Study 8, p818).

3.6.1.3 The impact of sexual pain on the perception of self / identity

There was evidence that sexual pain resulted in negative self-appraisal. Many women viewed themselves as abnormal and had varying levels of self-dislike. Sexual pain and the impact on women's sexual self and relationships resulted in a negative view of self identify. One study found that women with sexual pain positioned themselves as inadequate women and inadequate sexual partners because they were unable to perform what they perceived as a vital female role in a heterosexual relationship (study 2). The sexual pain affected how they viewed themselves and their perceptions of how their partner, family and other women may view them. Words such as 'inadequate', 'incomplete', 'abnormal' and 'faulty' were used as self-descriptions. Much of this narrative was within a heterosexual and androcentric discourse in which their needs came second to those of their male partners. Furthermore, many women disclosed continuing with sexual intercourse despite experiencing pain in order to continue to strive towards meeting their perceived image of an ideal woman (study 3).

'I felt inadequate as a wife, inadequate as a woman. I began to resent my body and the fact that it was 'faulty', feelings of ugliness grew also.'

(Cherie: study 2, p294)

'I was just so like, there's no point in being with you, there's no point because I can't fulfil my role as I said, there's things you want, there's things I want to give you and I can't do that, and then there's a lot of pressure...'

(Anna: study 2, p298)

‘But this feeling of not being a good enough girlfriend...and not being a good woman at all in a way...feels like...that you are...less good than someone else...that you are not capable of something that you should manage...’

(interview O: study 3, p361)

“I have noticed since I’ve been experiencing the pain, I don’t dress as sexy as I used to (P9: study 9, p819)

3.6.1.4 Impact of sexual pain on relationships

The impact on relationships was evident. Narratives of avoidance of sex and of concern for their partners’ dissatisfaction featured. Fears concerning abandonment, infidelity of their partners and conflict due to decreased sexual activity were all documented. Additionally, the loss of a sexual identity was described by some women as not seeing themselves as being ‘a part of sexual interaction’ with their partner or having ‘normal’ sexual interactions (study 10, p235).

Notably, it was not just intimate relationships that were affected. Women with vaginismus expressed feeling isolated and different to their female peers (study 5). These women expressed a level of social withdrawal or feeling less of a woman in comparison with their female peers. There was also strain on familial relationships, in particular, women felt pressured in explaining why they had not started a family. When sexual pain was disclosed, reactions of friends and family were variable. For many women, communication about their sexual pain with others was either avoided or found to be a source of embarrassment.

'I still count periods of time between having sex and you know...I'm still very aware of how much can he take...you're letting him down and why would you stay with someone who's inadequate in some way'

(Charlotte: study 2, p298)

'I just kind of get angry with myself because I feel like it's holding the emotional part of the relationship back a little bit compared to if I wasn't in pain and I was able to do it on call'.

(P11, study 9, p818)

'I feel different from other women, and I feel inferior...'

'I feel that I can't open my heart to even the closest of female friends, because if I told them about my vaginismus they would de-value me as a person...I feel that if I told my friends they just wouldn't or couldn't understand'.

(No name, study 5, p442)

3.1.6.5 Coping strategies adopted in managing sexual pain

The use of self-talk, both positive and negative, hiding pain, avoidance of sexual encounters, engaging in compensatory behaviours including alcohol consumption, and continuing with sexual intercourse despite pain, were all documented as ways in which women attempted to manage their pain and the impact on themselves, their relationships, and their lives. There was evidence that for some women, sexual pain became part of their 'normal' existence and daily life. Findings highlighted how women resigned themselves to being 'that way' (study 10, p.234) or accepting that painful sex, or an absence of a sex life, was going to be the norm for them and that there was no hope of a cure.

'Grin and bear it. Get it over with. Do it for him, it's all going to be fine soon, try to be into it, pretend you are into it.'

(examples of self talk used by women, no names attached: study 10, p235)

'I can continue...with sexual intercourse although I'm in pain...I do...because I think it will somehow...he thinks it's nice...you don't want to interrupt it for his sake...'

(Interview E: study 3, p360)

3.6.2 Women's experiences of sexual pain treatment

Of the studies included, four focused on women's experiences of seeking help and treatment (studies 4, 6, 7 and 8). Among these, three studies investigated experiences associated with participating in a multidisciplinary treatment programme; two studies referred to a UK-based treatment programme (studies 7, 8) and one study was based on a Canadian programme (study 6). Treatment offered comprised a mixture of medical, psychological, physiotherapy and dietary advice. Study 6 assessed the experiences of women enrolled on to a specially designed vulvodynia programme which included the input of gynaecologists, psychologists and physiotherapists offering a range of education, physiotherapy, medication, and mindfulness-based cognitive behavioural therapy over a 16-week period. Studies 7 and 8 referred to a UK-based programme offering a similar format within the UK's National Health Service. Finally, study 4 did not identify a specific treatment programme but instead surveyed sufferers and ex-sufferers of vaginismus on their previous experiences of treatment. Findings from the four studies suggested women's experiences varied.

3.6.2.1 Positive experiences

The following recurring themes were evident in the positive experiences highlighted.

Education

For many women treatment offered a learning experience in which they received vital information concerning their sexual pain, including learning about the possible causes of their pain, improving awareness and knowledge of their own bodies and anatomy and pain management strategies. Treatment offered a problem solving approach that, for some women, provided hope of a cure and acquisition of techniques that could be used away from the treatment room. The knowledge, skills and tools gained to manage pain were found to be useful. Women outlined that through treatment they had become more aware of themselves physically and psychologically and of the treatment options available to them.

'I thought that I knew a lot already but I learned so much more from all three aspects of the program'.

(No name: study 6, p1089)

'It gave me some skills to try and overcome it and I am finding that they are quite helpful'

(No name: Study 6, p1089)

'The knowledge has really improved my life...'

(No name, study6, p1090)

Validation

Treatment was found to be beneficial in providing validation. Women found having their problem named, being listened to and being understood as positive

experiences. For many women receiving a diagnosis and the accompanying treatment provided a sense of ‘normalisation’ and physical proof their pain was real and not in ‘their head’. Their experiences of interactions with professionals at the more positive end served to validate their experiences as real and credible and provided reassurance they were normal, both psychologically and physically. Treatment challenged previously held unhelpful beliefs for example, having a faulty vagina or anatomy or that they were alone in their experience. Thus, with validation women felt less isolated. Often however, this sense of validation came after visiting many different health professionals in their search for explanations and treatment, as illustrated in the final narrative excerpt below.

‘Overall it has made me realize...that it is a very real thing so I don’t have to beat myself up over it.’

(No name: study 6, p1090)

‘I actually would hear other women have the same experiences...sort of a validation. It made me feel a lot more like this is something, but it is okay and I am not the only one’.

(No name: study 6, p1091)

‘it’s just this unbelievable sense of relief that someone understands...then says you have a recognizable condition, there’s no definitive treatment plan and it’s difficult to cure’.

(No name: study 8, p18)

‘It means I was only dealing with the real thing and not imaginary terrors’.

(No name: study 8, p18).

'It was validating to finally get that diagnosis. It just wants to make me take the diagnosis and go to every gynaecologist and GP I have ever seen and staple it to their forehead'.

(No name: study 6, p1090)

Psychological benefits / improvement

As a result of education and validation many women commented on how their emotional wellbeing had improved. Relief was experienced as a result of being able to express some of their more difficult emotions associated with sexual pain. Women felt more empowered, more confident, less isolated, less abnormal and commented on taking control or regaining control over a difficult situation. For many women being able to express themselves in treatment services also opened up communication channels between themselves and their partners and thus in turn resulted in relationship benefits.

'It helped me tremendously to feel more valued as a woman'.

'I feel optimistic for the first time in a long time'.

'It made me feel so much better, more confident'.

(Study 6, Sadownik et al., (2012), p1090)

3.6.2.2 Negative experiences

Negative experiences were generally contextualised in terms of the process of accessing and receiving treatment. For example, a delay in getting a diagnosis and an incongruence between the treatment offered and the woman's experiences, needs and understanding of her sexual pain, were all examples of negative experiences. Whilst it was difficult to identify any less favourable type of treatment approach over another,

sources of negative experiences included the sense of the time taken to reach a diagnosis, dissatisfaction with the outcome after diagnosis and general interactions with GPs. For some women treatment was accompanied by feelings of being misunderstood, ridiculed, fobbed off, and in some cases, associated with fear of forced examinations, having hopes of a cure dashed and of discovering repressed traumatic memories. Not all women found the offer of psychotherapy helpful or appropriate for their sexual pain and some women declined the offer of psychotherapy altogether (study 8).

Where there had been considerable delay in reaching a diagnosis and a reference to seeing more than one professional with less than favourable outcomes, there was indication of how these experiences had exacerbated and prolonged already existent negative effects on wellbeing and intimate relationships.

'I really think if this was caught early on, then there wouldn't be the psychological problems you end up with'. (No name: study 8, p17)

'I lost faith really, and I put up with it – at this stage I was so depressed- then I got separated and divorced.'

(No name: study 8, p17.)

For some women the realisation that there was no 'definitive cure' left them feeling worse than before.

'I felt slightly more suicidal than I had before'.

(No name: study 8, p 18)

4. Discussion

4.1 Summary of the findings

The findings from the present review highlight both the complexity and the bio-psychosocial nature of women's experiences of sexual pain disorders. Much of the discourse related to the impact of the disturbance to sexual intercourse and of the psychological consequences associated with this. Thus, supporting that sexual pain is not just about physical pain but rather a complex psychosocial experience as suggested by Ogden and Ward (1995). Findings related to experiences of treatment highlighted a range of benefits in addition to achieving vaginal penetration. Education, validation and psychological gains were found to be important benefits of treatment for women with sexual pain. These may serve as suitable aims and outcomes of treatment programmes in addition to traditional outcome measures of achieving penetration or pain-free sexual intercourse. Evidence of the psychological impact of sexual pain (e.g. range of

emotional responses and challenges to self) is also indicative of how clinical psychology has a role to play in the treatment of women with sexual pain disorders. However, for many women this was not a treatment option they had considered and the suggestion of seeing a psychologist was sometimes experienced as initially daunting and incongruent to their beliefs and causal attributions.

In reviewing the papers included it became apparent that certain population groups were missing from the research literature. In particular, as with the sexual pain treatment literature, there was a majority focus on white heterosexual women aged in their early twenties to mid thirties. Women were mostly in long-term heterosexual relationships and type of sexual pain tended to include dyspareunia, only two studies focussed on women with vaginismus (studies 4, 5).

Additionally, older women and women from minority backgrounds both in terms of ethnicity and sexuality were also predominantly absent from the included studies. Thus, findings are largely framed within a white heterosexual context and may not reflect sexual pain for lesbian and bisexual women. Indeed, the research literature is yet to address the existence and extent of sexual pain disorders among non-heterosexual women.

4.2 Limitations of the review

A number of limitations were associated with the current review and therefore care should be taken when considering the findings. Owing to the focus on qualitative research, the review did not take in to account findings from quantitative methodologies and the mixed method studies included in the review were only assessed on their qualitative methods and findings. It is recognised however, that these complemented each other. Furthermore, it should be acknowledged that synthesis was based on the pooling of data derived from different methodologies and underlying epistemologies.

As aforementioned the findings from the current review and the studies included are limited due to the included sample populations largely being based on white heterosexual females in long-term relationships and the fact they rarely included non-clinical populations, other sexual orientations or women from other minority backgrounds. Additionally the studies were conducted in a number of different countries and therefore cultural factors are possible, for example cultural factors pertaining to sexual roles, views about sex, the values placed on sex, variations in treatment approach, stigma attached with accessing treatment for a sexual problem, and differences in health service; are of which are likely to have contributed to the findings reviewed.

Arguably the fact the review incorporated studies that addressed varying types of sexual pain (including different severities) and based on a mixture of clinically diagnosed pain and self-report / self-diagnosed, may be a critical flaw. However, this was practically unavoidable due to the scarcity of the available qualitative sexual pain literature. Despite these differences, there did seem to be similarities in how women were experiencing the different types of sexual pain (e.g. problems with getting diagnosed, emotional impact, and impact on relationships and identity).

4.3 Concluding remarks

The aim of this review was to synthesise the qualitative findings pertaining to women's experiences of sexual pain, including their experiences of treatment. In addition the review aimed to assess the quality of the studies included based on available guidelines for assessing the rigour of qualitative research (Meyrick, 2006). Ten papers were included and ranged in quality, type of sexual pain investigated, and the type of qualitative methodology applied. The review identified the complex nature of experiencing sexual pain and the variable experiences of treatment.

Multidisciplinary treatment approaches were found to be beneficial in educating, validating and improving the psychological wellbeing of women presenting with sexual pain. Despite these positive and encouraging findings, research exploring the experiences of women with sexual pain, both in terms of how they make sense of their pain, the impact of this pain, and in terms of how they experience treatment offered, continues to be in short supply, especially among women from ethnic and sexual minorities and women presenting with vaginismus. Further in-depth qualitative research exploring the experiences of sexual pain among these groups is required.

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Part 2: Research Report

**Women's Experiences of Vaginismus and its Treatment: An Interpretative
Phenomenological Analysis**

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by

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Women's Experiences of Vaginismus and its Treatment: An Interpretative

Phenomenological Analysis

Sarah Louise Johnston

Abstract

Purpose

The present research study aimed to explore women's experiences of vaginismus and its treatment using an Interpretative Phenomenological Analysis.

Method

Semi-structured interviews were undertaken with three women who had presented with vaginismus and received treatment from a department of medical psychology. Interview transcripts were analysed using an interpretative phenomenological approach to analysis.

Results

Analysis identified the bio-psychosocial impact of vaginismus for each of the three women interviewed. Two main superordinate themes of 'What's going on, why's it not happening?' and 'It's not just about sex and pregnancy' highlighted the struggle involved in the women making sense of their experiences and of the many ways in which vaginismus impacted on the women.

Conclusions

This study has begun to address the experiential gap in the vaginismus research literature. The findings illustrate the complexity of experiencing vaginismus, including the social, interpersonal and psychological impact of vaginismus in addition to the impact and experience of receiving treatment from a clinical psychologist. Recommendations included the importance of raising awareness of vaginismus and in providing a patient centred approach to treatment to enable the expression of the diverse ways in which it is experienced. Further research among larger sample populations of women currently marginalised by the current literature is recommended.

Key words: vaginismus, interpretative phenomenological analysis (IPA), qualitative research.

Women's Experiences of Vaginismus and its Treatment: An Interpretative Phenomenological Analysis

1. Introduction

1.2 What is vaginismus?

Vaginismus according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Society, 2000) is a sexual pain disorder classified under the category of female sexual dysfunction, in which sexual intercourse is prevented by a persistent and involuntary spasm of the vaginal muscles. Recent conceptualisation of vaginismus acknowledges that women may also have difficulty in allowing other types of vaginal penetration (e.g. tampon use and successful gynaecological examination), despite wanting to do so (Basson et al., 2004). Women with vaginismus may also experience pain, fear or anticipate pain upon penetration and as a result may avoid attempts at vaginal penetration completely.

Prevalence rates in clinical settings (e.g. sexual and primary health clinics and relationship counselling) vary between 4 and 42 per cent (Crowley et al., 2009; Shepherd et al., 2009; Roy, 2004) and between 1 and 6 per cent of women worldwide are estimated to have experienced vaginismus (Schultz et al., 2005).

1.2 Causes of vaginismus

Sexual and physical abuse, a lack of knowledge and awareness about one's body and sexuality, relationship difficulties, partner characteristics and negative attitudes towards sex have all been implicated in the aetiology of vaginismus (Reissing et al., 2003). It has been documented in cultures in which sex is viewed as taboo (Yasan and Gurgen, 2009), however whether prevalence is higher among strict religious societies compared with more liberal Western societies, is unknown.

Establishing causes of the problem is confusing, distressing, and often an isolating experience for many women with vaginismus (Ogden & Ward, 1995). Commonly held causal attributions among women with vaginismus include fear of pain, being brought up to view sex as wrong and painful, fear of intimacy, hearing frightening talk about sex when younger and beliefs that something happened to them as children (Ward & Ogden, 2010; Reissing, 2012).

1.3 Treatment approaches

Historically, treatment has focussed on the removal of the vaginal spasm to allow normal heterosexual practices to resume (e.g. early cases of vaginismus were treated using surgery; Sims 1861; cited in Reissing et al., 1999). Medical based treatments include botulinum toxin (Pacik, 2011), anxiolytic medications (Plaut & Bieisel, 1997), and progressive dilation of the vagina under anaesthesia (Pacik, 2011). Physical therapies such as physiotherapy of the pelvic floor have also been applied (Rosenbaum, 2011).

Psychological and behavioural treatment approaches have included sex therapy (Hawton & Catalan, 1990), psychoanalytic therapy (Coppini, 1999), cognitive behavioural therapy (CBT; van Lankveld et al., 2006), cognitive hypnotherapy (Roja & Roja, 2010), bibliotherapy (van Lankveld et al., 2006), eye movement desensitisation and reprocessing (EMDR; Torun, 2010), mindfulness based therapy, vaginal dilation

using vaginal dilators (Smith & Gillmer, 1998), therapist aided exposure using vaginal dilators (ter Kuile et al., 2009), group psychotherapy (Gehring & Chan, 2001), progressive relaxation and psycho-education (Crowley et al. 2009; McGuire & Hawton 2003).

Recent research has focussed on the effectiveness of CBT in removing the fear and anxiety cycle related to penetration attempts (e.g. Wijma & Wijma, 1997, ter Kuile et al., 2007, van Lankveld et al., 2006). Reported success rates (i.e. percentage of women achieving vaginal penetration) vary between 13 and 100 per cent (Kabakci and Batur, 2003; Munasinghe et al., 2004; van Lankveld, et al., 2006; ter Kuile et al., 2007; Engman, 2010), although rates are significantly lower for successful intercourse in controlled studies (Van Lankveld et al., 2006). A Cochrane review of interventions for vaginismus highlighted the problematic nature of the treatment literature (e.g. small sample sizes, uncontrolled design, and lack of long-term follow up; Hawton & McGuire, 2012). The definition of successful treatment is also questionable in terms of whether it is based solely on achievement of penetration, or should include pain-free penetration. Multi-disciplinary approaches offering a combination of psychotherapy, physiotherapy and pain management with pharmacology, are seen as the way forward in treating sexual pain disorders (e.g. Sadownik et., 2012; Hawton & McGuire, 2012) and further studies specifically focussing on vaginismus are required.

The authors of a UK-based study, Ogden and Ward (1995), found that accessing help could be difficult and experiences of professional help were variable. Findings indicated general dissatisfaction with interventions and general practitioner (GPs) were rated as the most unhelpful amongst the professionals considered. In a recent Canadian survey of women with lifelong and acquired vaginismus (Reissing, 2012), gynaecologists and GPs were the most frequently consulted practitioners, followed by

psychologists and sex therapists. All practitioners with the exception of GPs were rated as helpful. Women with acquired vaginismus were more likely to receive pharmacological treatment, whereas women with lifelong vaginismus were more likely to receive vaginal dilatation, sex education and physiotherapy.

1.4 Sexual dysfunction, sexual pain, or genito-pain disorder

The classification of vaginismus as a sexual dysfunction and as a sexual pain disorder within the current DSM (DSM-IV; American Psychiatric Association, 2000) has received criticism. Current classification does not inform how vaginismus is experienced or what it means to experience it, and is based on questionable sex research originally carried out by Masters and Johnson during the 1960s (e.g. much of the original research was based on early thinking that male and female sexual response was the same, and that sexual response was universal; Tiefer, 2004).

Furthermore, overemphasis of the vaginal spasm and sexual context has marginalised other important aspects of vaginismus, such as the role of the fear of pain, avoidance behaviours and problems with vaginal penetration in gynaecological examinations and tampon use (Reissing et al., 2004). Indeed few studies have actually investigated the vaginal spasm and recent conceptualisation of vaginismus has called for more emphasis on the fear of pain and avoidance behaviours that prevent a woman from achieving all types of vaginal penetration. For the forthcoming fifth edition of the DSM, a combined genito-pelvic pain and penetration disorder (combining dyspareunia and vaginismus) replaces the existing nosology to incorporate pain and fear of vaginal penetration (Binik, 2010). Additionally, in response to the universal reductionist view of female sexual pain and general sexual problems, a new view of women's sexual problems is also proposed, taking account of women's socio-cultural realities (Tiefer et al., 2002).

1.5 The bio-psychosocial impact of vaginismus

Vaginismus causes distress, relationship problems and impacts upon sexual health and health behaviour among its sufferers (e.g. poor adherence to attending regular pap smear tests). Given that sexuality is implicit in psychological wellbeing, quality of life and interpersonal satisfaction (Bancroft, 2009), it is not surprising that vaginismus and sexual pain impact on the psychological and interpersonal wellbeing of women and their partners. It has been documented as a leading cause in the number of unconsummated marriages and infertility (Ozdemir et al., 2008).

Women experiencing sexual pain may experience a range of emotions in relation to their symptoms (e.g. shame, guilt, anxiety, fear, hopelessness, loneliness, and anger; Sutherland, 2012). However, there is a shortage of research that addresses the psychological functioning among women with vaginismus. Available studies indicate that women with vaginismus have low self-esteem and poor self worth (Ward & Ogden, 2010). Delays and barriers to accessing and receiving treatment may exacerbate or prolong these emotions.

1.6 Summary

Vaginismus is a relatively under-researched area of sexual health. Further in-depth qualitative research exploring women's experiences of vaginismus and how they make sense of their experiences, symptoms, causes and treatment, is required. This may assist in informing treatment approaches and raising awareness among women and health professionals.

1.7 The current research study

Given the paucity of research investigating the lived experience of vaginismus, an interpretative phenomenological analysis of the experiences of women presenting

with vaginismus is valuable in its contribution to the current research literature and to inform clinical practice.

The research asked how women with vaginismus

- experience and make sense of their symptoms and diagnosis;
- seek help for their symptoms;
- experience psychological therapy for treating their symptoms;
- experience vaginismus, their symptoms and overcome vaginismus during and after psychological therapy has ended.

2. Methodology

2.1 Study Design

The present research study used interpretative phenomenological analysis (IPA; Smith, 1996) to explore women's experiences of vaginismus and its treatment using semi-structured interviews.

IPA was first used in health psychology research in the mid 1990s and has a relatively short history. Yet in this short time, IPA has enabled the investigation of people's experiences of a number of physical and mental health conditions, their treatment and associated behaviours, and the decision-making processes involved in living with those conditions (e.g. Holt & Slade, 2003; Rhodes & Smith, 2010). IPA has also been used to explore people's experiences of sexuality and sexual health behaviours (e.g. Lavie & Willig, 2005; Free et al., 2005).

IPA is concerned with the examination of 'human lived experience' i.e. what it is like for the individual. In using IPA, the researcher is attempting to make sense of how others make sense of their own experiences, also known as the 'double hermeneutic' (Smith et al., 2009. p.3). IPA was chosen to explore what vaginismus and

its treatment are or were like for each participant and how they made sense of their experiences. As so little research has been done investigating how women experience vaginismus and its treatment, IPA was deemed to be best suited to allow each participant's account to be analysed in its own right. Alternative qualitative research methodologies such as Grounded Theory, would largely be concerned with data at the macro level across a social group, thus losing the diversity and complexity of the experiences of the individual women concerned. The ideographic aspect of the IPA approach, where each transcript is analysed individually with no pre-conception that there will be similarities across cases, retains the different ways in which the women experience vaginismus

2.2 Participants

A purposive sample of women with vaginismus was drawn from a clinical population of women who had received psychological therapy for the treatment of vaginismus from a department of medical psychology in an NHS Mental Health Trust within the United Kingdom. The final sample intended to meet IPA's commitment to using a homogeneous sample that represents a perspective or shared experience rather than that of a population. For the present research study, vaginismus was the shared experience.

In relation to sample size, the guiding clause is a commitment to obtaining in-depth detailed accounts of individual experiences, rather than seeking numerous participants. A sample size of between four and ten participants is suggested as appropriate for providing in-depth, rich quality data for this type of study. A sample size of N=3 is suggested as reasonable for allowing depth and divergence in a Masters' level dissertation (Smith et al., 2009) and is seen as a useful sample size for researchers using IPA for the first time (Smith, 2008, p.57).

Inclusion / exclusion criteria

The inclusion criteria for this study stipulated that participants had received a clinical assessment of vaginismus (primary or secondary), and psychological therapy as treatment. This included women who dropped out of treatment, to enable exploration of less positive experiences of treatment and the reasons behind drop out. Women were excluded from the final sample if they were known to the researcher, stated they did not wish to be contacted by written mail, or if the department deemed they were inappropriate for contact due to existing complex mental health difficulties that could be worsened by taking part.

Not all potential participants received a formal diagnosis of vaginismus according to criteria outlined in the DSM-IV, which requires confirmation of the existence of the vaginal spasm. For many women in the available sample the diagnosis of vaginismus was either based on the judgement of the clinician who made the referral or the clinical psychologist undertaking the initial assessment for psychology, both of which are dependent on self-reported information from the woman herself. Anecdotally, this form of diagnosis is not unusual considering that in order to have physical confirmation of a vaginal spasm, a woman must undergo a vaginal examination, a procedure that for many women with vaginismus is a source of distress and anxiety often avoided.

2.2.1 Final sample

The final sample, outlined in Table 1 below, comprised three women. Seven women were excluded on the basis of the exclusion criteria above, 15 were invited to take part in the study, but only three were willing to participate. The sample was smaller than planned, but does reflect the difficulty of recruiting participants to discuss such sensitive topics. However, the sample is consistent with postgraduate IPA study

samples and published IPA studies (e.g. Shaw, 2011). Rich data was obtained from the three interviews, therefore the sample was deemed sufficient to give an in-depth exploration of the phenomenon studied.

Table 1. Demographics of final sample

Participant Pseudonym	Age	Ethnicity and Relationship Status	Type and Duration of vaginismus	Treatment History / Pathway
1. Asmara	30	British Muslim, married with one child and pregnant for second time.	Primary and secondary; since first relationship / attempts at intercourse	GP, gynaecologist and referral to clinical psychologist. CBT approach with graded exposure with vaginal dilators.
2. Emily	31	White British, married with one child.	Secondary; since age 19	GP, GUM clinic (STIs), referral to clinical psychologist. CBT approach with graded exposure with vaginal dilators, and relaxation

				techniques. Some couple / joint sessions.
3. Nisha	33	British Muslim, married with one child.	Secondary; since first sexual encounter	GP, gynaecologist and, referral to clinical psychologist. CBT approach with graded exposure with vaginal dilators. Additional focus on preparation for pregnancy and managing anxiety through labour.

2.3 Research context

The Department of Medical Psychology located within a UK NHS hospital, provides psychology services to patients presenting with a range of physical and sexual health conditions. Referrals relating to vaginismus are mainly received from hospital sexual health and fertility clinics; direct GP referrals are not accepted and referral is via a hospital consultant specialist. The psychological therapy provided for vaginismus is tailored to the client's needs and generally consists of short-term therapy based on a cognitive behavioural approach. Psycho-education, relaxation and graded exposure with the use of vaginal dilators are incorporated.

2.4 Procedure

2.4.1 Ethical approval

Ethical approval and permission to access participants from a UK NHS trust was obtained in March 2012 (relevant documentation and correspondence with ethics

committee can be found at Appendix G). As part of the ethics application process the researcher attended an ethics review and completed all necessary training (certification of relevant training can be found at Appendix H). The research proposal documented issues concerning the prevention of harm, research versus therapy, data management and storage, all of which were discussed with the participants prior to their consenting to take part.

2.4.2 Raising awareness of the research

Initial feasibility discussions with clinical psychologists working in the department took place during the application for ethical approval process. Once ethical approval had been obtained, further discussions concerning the procedure and recruitment took place between the researcher, head of medical psychology and the field supervisor.

2.4.3 Recruitment

Recruitment took place between April and December 2012. The researcher and field supervisor identified an available sample of women who met the inclusion criteria. Letters were sent out to prospective participants on department-headed paper. Included with the letters were participant information leaflets detailing the research and why they had been invited to take part (for copies of recruitment documents please refer to Appendix I). Participants were asked to reply using an enclosed reply slip and stamped addressed envelope to the department of medical psychology. The researcher then made telephone contact with those women who responded to answer any questions they had about the research. If the participant was happy to proceed, a provisional interview date was arranged at a suitable time and place allowing a cooling-off period of 48 hours.

A total of 15 women were invited to take part in the research and three replied, all of whom agreed to take part.

2.4.4 Data collection method and interview schedule

Data was gathered via semi-structured interviews. Each interview lasted approximately one hour and was based on a schedule designed as a guide with interviews evolving according to the participant. (A copy of the interview schedule used can be found at Appendix J). The most convenient location for the interview was discussed and agreed individually with each participant. The appropriate safe working procedures were implemented during home visits.

In carrying out the interviews the researcher ensured that all appropriate steps were taken to avoid harm to either herself or her participants. All of the interviews were audio recorded and undertaken by the researcher. Appropriate informed consent was obtained from each participant prior to the interview commencing (see Appendix I for copy of consent form). Participants were also informed they could request a break or to end the interview at any time if they wished to do so. Participants were provided with details of support services and briefed of the procedures to be taken in the event of them becoming distressed. Participants were reminded they could withdraw at any time during the interview and have their data withdrawn and destroyed up until the point of transcription when the data was made anonymous. Each participant was assigned a pseudonym and any data that could potentially point to identity was changed or removed (i.e. names of children and psychologists). Participants were asked if they would like to receive a copy of the research report when available and were reminded that anonymous verbatim extracts may be published in the final research report. All data was stored securely and demographic data was stored in written form only and separately from typed interview transcripts and audio files.

2.4.5 Analysis of data

Following each interview the researcher listened to the audio recording and transcribed the content verbatim highlighting pauses, laughter or difficulty with the subject matter. This allowed for immersion into the raw original data. IPA suggests a flexible process of six stages of data analysis with the initial stage involving reading and re-reading of the interview transcript followed by a second stage of initial noting of the content and use of language, thus allowing increasing familiarity with the data. The outcome of this stage of the analysis is to provide a set of notes and comments on the data in a manner that aims to identify the participants' meanings. It is important to note that there are no set rules on what to comment upon, but for this stage of the analysis to allow an in-depth and comprehensive analysis of the participants' experience and sense-making to be obtained (Smith et al., 2009). The third stage concerns the development of emergent themes by noting how the exploratory coding may be repeated or form clusters of meaning. During the fourth stage the researcher is concerned with assessing how the identified themes fit together. Step five is a repeat of this process with the next participant's transcript and allows for new themes to develop ensuring a commitment to the data at the idiographic level is maintained. The final stage involves noticing any patterns that may feature across the cases already analysed in steps one to five, whilst retaining the themes that maybe specific to individuals.

2.5 Reflexivity and neutrality

The researcher was familiar with the research literature surrounding sexual pain and had previously held a trainee clinical psychologist position within the department from which the sample was drawn. She had prior experience of working with women presenting with vaginismus and had listened to their experiences within a clinical

setting (a statement of the researcher's epistemological position can be found at Appendix F). The researcher's position to the data can be viewed as useful to the data analysis, the sense making. IPA invites an interpretative and reflexive approach to the data in order to make sense of the participants' 'sense making', recognising and embracing the inter-subjective realm in which research is carried out, the messiness of human relationships, history and culture from which it [research] simply cannot escape' (Shaw, 2010). Without such involvement, participant's experiences would not be made sense of.

Being reflexive allows continual reflections upon the interpretations made concerning the experiences of the researcher and that of the phenomenon being explored (Shaw, 2010). To maintain a reflexive relationship with the data in this study, the researcher used the peer review and supervision process to facilitate reflexivity and to ensure interpretations made were free from inappropriate bias as much as was possible, and instead were borne out of a trustworthy interpretation of the data themselves. In addition, and as supplement to this process, the researcher kept a reflective journal in which she documented her own preconceptions about vaginismus and experiencing vaginismus. These documentations, combined with supervision, were used to track and challenge the robustness of the analysis made.

3. Results

Two superordinate themes of *‘What’s going on, why’s it not happening?’* and *‘It’s not just about sex and pregnancy’* were identified and originated from corresponding subordinate themes shown in Figure 1 below.

Figure 1: Superordinate themes and corresponding subordinate themes.

Superordinate Theme	Corresponding Subordinate Themes
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<p><u><i>What's going on, why's it not happening?</i></u></p> <p>Relates to the attempts of the women to make sense of their vaginismus and illustrates the different ways in which they attempted to do this, including aspects that led to further confusion and their frustrations with not getting answers or solutions.</p>	<ul style="list-style-type: none"> • Hypothesising • Normalising • It doesn't make sense • When it becomes a problem • Something seriously medically wrong • Not getting anywhere • So this is actually something • By the way I'm pregnant
<p><u><i>It's not just about sex and pregnancy</i></u></p> <p>Relates to the various impacts of vaginismus in addition to loss of sex and fertility, including the impact of not finding a cure, impact on identity as a woman and the psychological consequences associated with their experiences.</p>	<ul style="list-style-type: none"> • Not cured • Not a full woman • Miserable place

The subordinate themes represent the culmination of the first four steps of analysis outlined in the methodology section. Following the analysis of each interview, a higher-level analysis led to the development of the two superordinate themes, in which the disparate and homogenous ways of experiencing vaginismus and its treatment were encompassed (for examples of initial coding and theme development please see Appendix K).

3.1 What's going on, why's it not happening?

This theme depicts how, for all three women, not being able to achieve vaginal penetration (be that during a gynaecological examination or sexual intercourse), was a confusing, stressful, and emotional experience. All women discussed and reflected on their attempts to make sense of why penetration was difficult, impossible, or painful.

This sense making was a struggle both conceptually and emotionally and often proved a lengthy process both prior to and after receiving a diagnosis. Two of the women described not reaching an acceptable explanation. The following themes illustrate the various ways in which the women attempted to make sense of their vaginismus.

3.1.1 Hypothesising

During the course of the interview each woman reflected on possible explanations for their vaginismus. In the excerpt below Nisha is reflecting on how she had previously thought of herself as sex-aware. She is looking back on her experiences and how her 'not knowing' or her and her husband's sexual inexperience may have contributed to the problem. After an appointment with a gynaecologist it became apparent to Nisha that she had not had full intercourse despite her thinking she had.

'I hadn't had any sexual partners prior to getting married (...) I did think that I was relatively educated in terms of erm...I don't know, in terms of text book...we had experimented sort of but obviously both of us didn't really know, we didn't have anything to compare it to and because of that I think what had happened is we'd just assumed this is just how it is.'

(Nisha)

Earlier in her interview Nisha also reflected on how she felt her home life may have made it hard for her to relax and how not being able to relax had made her 'spasm', leading to her difficulties with penetration. In the excerpt below she goes on to talk about the pressure she experienced to have a child once she was married. The beginning of the excerpt highlights her difficulty in trying to make sense. Her hypothesising was very much related to how her own circumstances, her inexperience

and her busy life, may have led to her vaginismus. Here she reflects on a multitude of contributory factors but also describes how she '*wasn't really sure*', hence the hypothetical nature.

*'I just thought oh maybe it's that or I wasn't really sure and I weren't really I think everything was so busy, everything my life was so busy and I was so like, we sort of had a lot of pressure to have a child'.
(Nisha)*

Another example of hypothesising comes from the interview with Emily who similarly reflects on her 'inexperience' and the fact that she lost her virginity at an older age compared to her perceptions of when her peers may have lost their virginity. Emily reflects on her early life experiences and whether there may have been abuse. She describes initially how she was certain there had not been any such experiences. Her use of words highlight the desperation she is feeling in her hypothesising in trying to explain and find a cause. Initially she is certain that nothing '*like that*' had happened to her however she goes on to describe how she moves to a position considering the possibility that something may have happened and at one point emphasises how she began to doubt herself. Her doubts and over- thinking about whether something had occurred in her childhood stem from an appointment with a GP and from what she has read about causes of vaginismus. This extract highlights the emotional aspect of this process and the confusing nature of the problem.

'...and I started thinking oh I wonder if something did happen in my childhood because ninety percent of the stuff that I read about it erm went back to child

abuse, rapes, that sort of thing...and I was thinking well was there anything in my past and I was desperately racking my brains and trying to think if anything had happened in my past that maybe I've pushed so far to the back of my head I've forgotten... '.

(Emily)

Asmara also demonstrates her attempts to make sense through her hypothesising. She reflects on whether her vaginismus was due initially to her having had an arranged marriage. However, as her problems continue she rejects this hypothesis, demonstrating how different hypotheses make sense at different time periods. Her initial hypothesis made sense in the beginning but not as the problems progressed in duration and following her first pregnancy.

'Initially it was just...because I'd had an arranged marriage anyway, so I was just thinking okay it's going to take a while...maybe this is just be-because we're newly married, bit nervous and anxious'.

(Asmara)

Similar to Emily, Asmara also considers the possibility that something happened to her in her past that she has since forgotten. In the excerpt below she is talking about how she thought seeing a psychologist might assist her in finding the answer to this. This, and Emily's excerpt, highlights the lengths these women are going to in order to try and understand what is happening to them and essentially they are both questioning their version of their pasts. Asmara is considering the possibility that she has overlooked something that may have contributed to vaginismus.

'...I thought okay I know it's not a cure but I thought maybe if you get talking about it, maybe there is something [pause] that will come out that I've not, I don't know maybe there's something that I've not realised...'

(Asmara)

So far, for all of the women, sexual inexperience and relationship factors have represented possible causes. And for Emily and Asmara the possibility of forgotten past experiences are considered.

3.1.2 Normalising

The women in the study also demonstrated their attempts to normalise their experiences, as we have seen briefly with Asmara, in which she outlines her arranged marriage and how it would be normal for her to experience problems at first in an arranged marriage. Similarly, when Nisha is asked how her vaginismus had left her feeling she describes her attempts to normalise. She goes on to reflect on her explanations and how she is then unsure about her initial theory.

'...my understanding was that it would hurt it would hurt in the beginning and then like after a year it would stop hurting, but I don't think that's quite how it is [laughs] so that's, that's what I, that's what I had in my mind that it might just hurt sometimes.' (Nisha)

In response to a question enquiring how she made sense of why she had vaginismus, Nisha goes on to conceptualise her vaginismus in the context of her busy,

stressful life. She attempts to normalise it, however, towards the end of this excerpt she acknowledges that this only explains part of the problem.

‘...so therefore I thought it must be because I’m stressed out and because I’m stressed out this is happening, I need to learn to sort of relax and be calm and all of those things, which I think was part of the issue, not totally, but part of it.’
(Nisha)

Emily attempts to normalise with the help of her psychologist by focussing on her first experiences of intercourse with a partner whose penis she describes as small, leading to occasions when his penis would slip out of her vagina. She uses words like ‘stab’ and ‘jab’ to describe the experience of his penis banging against her vulvar region.

‘we came to the conclusion that maybe it came from my first sexual relationship because erm he wasn’t [pause] particularly big, it wasn’t particularly long erm...but he used to sort of you know go for it and because he wasn’t that long he would come out and then kind of stab me with it and so that was really painful and I’d kinda tense up...’
(Emily)

3.1.3 It doesn’t make sense

This theme represents the confusion and associated emotional impact for these women when their vaginismus ‘doesn’t make sense’ despite all of their struggles to find an explanation. As various hypotheses are considered, accepted and rejected, it became apparent that making sense was a struggle. This is illustrated by Asmara who attempted to make sense of it by reflecting on her ‘newly wed’ and ‘arranged married’ status. Prior to adopting this hypothesis she talks about the confusion associated with the unexpected nature of the problem. We also witness how she then rejects the original hypotheses as they no longer make sense. This demonstrates how her perception of the problem is dynamic and related to the context, duration of the problem and her relationship. The fact that she could not see a reason for the pain makes it harder for her to accept and fathom.

‘I just couldn’t understand why I was having so much pain...it just threw me completely because it wasn’t something I was expecting’.

(Asmara)

‘I think I’d been to see the doctor and they just said you know you’ve got to try relaxing...but sort of 6-7 months down the line you think hang on a minute this doesn’t feel normal anymore...you know it’s pain but there’s no reason for it to be there.’

(Asmara)

Similar to Emily in her excerpt regarding her reflection about whether something had happened to her in her childhood, Asmara reflects on a question by a doctor in which for her this explanation does not make sense.

'...they were saying things like ya know are you associating it with something, have you had a bad experience or anything and I [pause] couldn't think you know I didn't know that I'd had and I couldn't think what it was linked to.'
(Asmara)

For Asmara she demonstrates how suggestions from health professionals did not make sense or explain her vaginismus, yet it seem to have caused her a similar scenario to that experienced by Emily, in that she over-thinks about whether there had been something. She describes that she 'couldn't think'. Her repetition towards the end of the above excerpt highlights the difficulty and struggle this poses in searching for answers.

Emily she is expressing how she might never make sense of her vaginismus and in the second excerpt below she goes on to demonstrate the sheer confusion she experienced and emphatically, the lengths she has gone to in order to try and make sense.

'...it's a strange thing to understand (...) if there's a very specific reason like erm sexual abuse or something like that, I think that it is far easier to understand where it comes from erm but from my experiences not really being that bad in comparison to other women's experiences erm, I don't see that there is one particular defined root cause of why I got it.'
(Emily)

‘...and you know having experiences of thinking why on earth can he not penetrate me when I am lying here wanting to have sex, it’s a really difficult thing to get your head around...so no I don’t think I will ever understand it, not from my point of view anyway’.

(Emily)

Emily finds it particularly confusing in the context of previous relationships in which she did not experience any problems with penetration. The very fact that penetration worked with some partners and not others leaves her with more confusion. This gives the impression that if the problem had been consistent with all partners then it would have been easier for her to understand or accept.

‘I have had two other sexual relationships where I hadn’t had any problems at all. Which has made the whole process even more confusing because why’s it happened with some partners and not with all of them is a bit strange [laughs]’.

(Emily)

Both Emily and Asmara go through a series of statements in which they are essentially saying ‘it would make sense if’. Asmara, talks openly about how she would be able to understand it if her circumstances had been different to her own, as illustrated in the excerpt below. This gives us insight in to how Asmara makes sense of why women might have problems with penetration and how because of this view, she struggles to make sense of vaginismus in her own life.

'...it wasn't like I was just dumped with a stranger for the first time and it was expected that...that would happen straight away cos then I suppose you'd understand it...'

(Asmara)

'I'd never had to you know well to put it bluntly you know, sounds a bit horrible but I'd never been luckily never been raped or attacked or anything like that you know obviously I would understand if somebody had been attacked and then that would make them very reluctant you know.'

(Asmara)

For Nisha, the concept of vaginismus was confusing, rather than why it was happening, and she talks about the confusing experience of being told she had got vaginismus. As a couple she and her partner believed they were having intercourse and had originally sought treatment for infertility and not vaginismus. Her narrative begins after describing her experience of a failed smear test and of the response by the gynaecologist. Her surprise and confusion in trying to make sense of it in the context of her previous perceptions of her sex life is evident in the excerpt below. For Nisha, it was not just confusion as to why penetration was not happening, but also confusion with whether or not full intercourse had taken place.

'...she said you have something called vaginismus, and that was the first time I'd heard the term...and I didn't understand, I really didn't understand what it was. And I said to her, I was like so you're trying to say that me and my husband have never had intercourse but we been married for two years...I

remember her, she said you're not very used that's what she said to me if you know what I mean...and I was just like I don't get it.'

(Nisha)

3.1.4 When it becomes a problem

Of particular interest was how each of the women adapted to their circumstances with regard to their sexual lives. This gave some insight into when the problem became a problem and each of the three women talk about their concern of the impact vaginismus had or could have had on their wish to start a family. Nisha describes how her level of concern increased when she and her husband decided to have a child. Prior to this she talks about how she *'just used to think forget it'* and how she *'got into the habit of just providing and giving him'* and discounted her own sexual needs. She provides a description of her sex life in which penetration became less of the norm. However in the excerpt below in response to a question about whether she was concerned that penetration was not working she describes the point at which she became more concerned.

'...I think only when I decided to have a child and I suddenly, we decided that we wanted a child (...) that's when I started thinking well yeah this might be a problem...'

(Nisha)

For Emily she describes how she was single for a year and how during that time *'it didn't matter'*.

‘But then I was single for a probably a year after that so again it didn’t matter because I wasn’t having to deal with the situation anyway because I was single and I’m not promiscuous so I wasn’t sort of going out for one night stands or anything like that. So it didn’t matter.’

(Emily)

3.1.5 Something seriously medically wrong

In their attempts to normalise and hypothesise the causes of their experiences, two of the women also experienced concern and fear that there was something seriously medically wrong with them. For example, Asmara talks about how over time, she had considered the possibility it was something else rather than vaginismus.

‘I always wondered if there was something else seriously wrong in the back of my mind...I’d always thought you know maybe there’s something that like I’d go and see different doctors thinking is somebody going to pick up or are they going to do a test and somebody going to do something and say actually [pause] you know there might be a growth or there’s something there that’s stopping you-you know there’s something blocked.’

(Asmara)

The word ‘always’ signifies that it had always been a possibility in the back of her mind when visiting different doctors. The pause is poignant and highlights the seriousness of the news that could have been broken by a doctor.

Asmara goes on to describe how she never really thought it was vaginismus, further indication of how she believed it was something else more serious. For Asmara, experiencing the level of pain she describes was an indication to her that something was seriously wrong and because it did not make sense, i.e. there was no reason for it to be happening to her according to her circumstances, this made it more probable that something was wrong.

'...and I never actually thought it was vaginismus you know what they said in the end you [intake of breath] I was thinking it's gotta be something else, it's gotta be something wrong because [pause] you know it's the pain but there's no reason for it to be there... '.

(Asmara)

Later in the interview she reflects on how at one point she had wondered if her vagina was sealed owing to their lack of progress with achieving penetration and of the pain she experienced.

'...and I think for a split second, for one day I vaguely remember thinking you know I wonder if there is such a thing as it's [pause] sealed, is it sealed? Is it you know there must be something majorly wrong if it's not happening at all... '.

(Asmara)

Similarly for Emily, she reflects on her thoughts about the possibility of being something physically wrong, her experience of attending for tests at her GUM clinic and of her disappointment that the tests did not reveal anything. In contrast, she also

expresses how at the same time of wishing for a physical cause, she also had felt afraid of having the tests done and of the stress and worry she experienced in the process.

'I had a smear and all of the tests for STDs...but I mean all the tests were negative and everything was fine...in a way I almost feel like I went through all of that [pause] stress and worry, I mean I didn't think I had an eh infection erm but I thought it might bring something to light and it didn't and so I was kind of hopeful that it would bring something to light and really really scared having never had something like that done before'.

(Emily)

3.1.6 Not getting anywhere

For all three women it was evident that their symptoms had lasted longer than a year and they each talked about their experiences of their interactions with health practitioners ranging from GPs, gynaecologists, and psychologists. Experiences varied between positive and negative and most of the negative experiences centred around visits to their GP, with most of the positive gains from treatment being associated with interactions with their psychologist. The frustration with responses from different GPs is particularly evident for Emily in the excerpt below. Here she is describing how she felt she had not been taken seriously by her GP and how the advice given did not improve her situation. Her use of 'every time' highlights the frequency of her visits to her GP.

'...every time I went to the GP and tried to speak to them they..they sort of brushed it off. They didn't take it very seriously, they didn't really do any tests

other than I think I had two..two smear tests where I was tested for STIs erm and the rest of the time I was just told you know use more lube and that kind of thing and so I was trying to do that but it didn't actually you know it didn't improve, the situation didn't improve at all. '(Emily)

Later Emily talks about an experience in which she again visits her GP who gave her the impression that she is thinking something 'untoward' has occurred in Emily's life to make her 'concerned about things down below'. Emily just wanted help but the reactions of the GP left her feeling she was not getting what she needed and that the views of the GP did not correspond with her view of the problem.

'I just wanted a bit more help and so I kind of felt a bit like I couldn't go back again because she sort of told me a lot about lubrication and all this kind of thing but it never really went any further than that..'
(Emily)

In the above excerpt Emily is talking about the mismatch between what she was being advised and what she needed from her GP. She goes on to express how after a couple of times getting the same advice concerning lubrication, she felt she could not return and as a result she never got any further with finding out the cause or solution to her vaginismus.

For Asmara, although she is expressing a level of satisfaction with her GP, placing him/her as the professional who know best, her narrative highlights the repetitive process of attempting to find out what was happening. In the excerpt below she is talking about the process of seeing a number of different GPs before actually

being given a diagnosis. Again, like Emily, Asmara is reflecting on how she had taken the advice given but how the problem for her had persisted, remarking how she felt she was repeating herself on each visit and a sense of never moving past a certain point. Her comment regarding whether it is worth going back to the doctor indicates her frustration and her loss of faith in whether visiting the GP was going to change or resolve her situation.

'I went through quite a few of them and obviously initially we left it a bit and then I went and then they said you know [pause] it is this and try and breathe and relax and things and we did all that and I just kept thinking after a while you think urm I'm going back and saying the same things and they are gonna say the same thing is there any point in keep going back.'

(Asmara)

This continuous and often repetitive process of explaining their problem to health professionals in the hope of a cure led to distress, frustration and eventually a loss of faith of finding the answers.

3.1.7 So this is actually something?

What was evident for all of the women interviewed was the level of confusion, anxiety and fear experienced in acknowledging they had a problem and difficulties with penetration. Of particular note was how each woman tried to make sense and understand what was happening to them and in doing so how this was experienced in isolation often with minimal discussion with their partners.

The relief experienced when told that they had a recognised and common sexual pain complaint is particularly reflected in Asmara's account below. This excerpt occurs

towards the end of her interview when at this point she is reflecting on how she felt about finding out she had vaginismus.

'...I think I felt more [pause] normal when I went to the doctor and she didn't turn around and say oh you're the first person I've ever heard of with this...I suppose a big relief in the sense that actually [pause] yeah there are people...if you feel like the only person with something that can be a big issue and be a big impact so it always helps to know there are other people...'

(Asmara)

The fact that other people had also experienced these difficulties and that Asmara was not the first person the doctor had seen with the problem was a huge relief to her. This relief further illustrates the level of isolation she had experienced.

3.1.8 By the way I'm pregnant

At the time of their interview, all three women had previously given birth. The different and similar ways in which pregnancy impacted on their experiences of vaginismus and their sense making are presented. The overriding finding was how, for these women, pregnancy did not solve the problem of vaginismus or painful intercourse and this in itself led to confusion and in some cases made accessing help more difficult.

In Asmara's account below she illustrates her surprise at getting pregnant following her experiences with finding penetration difficult and painful. Her description of it being 'the strangest thing' is a further example of her struggle to understand the inconsistent and confusing nature of the problem.

'But the then the strangest thing was to me you know I was obviously saying I can't have sex and it's painful and then it suddenly happened.'

(Asmara)

She goes on to describe how after conceiving she experienced difficulties with penetration again and how the on/off state of the problem left her in a situation in which she found it difficult to know how to explain the problem to the doctor.

'...but then after I conceived again that was it [pause] no I couldn't again for the next obviously until my daughter was born, we tried a few times while I was early pregnant you see and I couldn't and that was [pause] the bizarre thing for me but now what are you going to say to a Doctor, I could have sex, now I have had I'm pregnant, I'm pregnant and I can't again, you know I'm struggling again...'

(Asmara)

Asmara describes how she felt silly trying to explain she was still having the problems even after she had given birth.

'...you just think god it sounds really silly because urm it's happening but only certain times now.'

(Asmara)

Similarly in Nisha's excerpts below, she describes how she was pregnant by the time she received an appointment with a psychologist. Her description of this

enlightens us to her surprise and confusion about how she got pregnant in the context of her difficulties with penetration.

‘...and strangely enough during that time, it was only, I think [pause] I actually fell pregnant around that time, I don’t know how [laughter] ...’.

‘So when I fell pregnant afterwards I was like, I still went to the sessions because of, I don’t know how, I don’t know how I got pregnant [laughs] to be honest.’ (Nisha)

Emily talks about the worry she felt at the prospect that she may not be able to have children because she could not tolerate penetration. Here she outlines how not being able to achieve penetration impacted on her ability to ‘live out’ the mother role and how this in the context of her ‘strong maternal instinct’ caused her worry. Here she is talking about a potential loss to her identity as she outlines the strong importance that being a mother has for her.

‘...I was worried that I would...I wouldn’t be able to have children erm because if you can’t have sex you can’t get pregnant so you can’t be a mother and you can’t live out that role and I’ve always had a really strong maternal instinct...’.
(Emily)

3.2 It’s not just about sex and pregnancy

This theme relates to the ways in which vaginismus impacted on the women themselves. The title of the theme is illustrative of how even when sex and pregnancy were possible for women this did not mean that the problem had been resolved. This theme also depicts how vaginismus does not only prevent sex and pregnancy for some

women but has an incredible impact on identity as a woman, lifestyle and psychological wellbeing.

3.2.1 Not cured

The women had varying levels of success following their treatment, however none of them described having been completely cured. The discourse of finding a cure and the realisation of there possibly not being a cure featured for all three women. There was also narrative of how experiencing problems with penetration and painful sexual intercourse became part of their normal routine.

For Asmara, following discussion of her beliefs of there being something seriously medically wrong, she talks about how something medical might have been less ‘scary’ and would have a cure in comparison to her difficulties with penetration. Her frustration with not having a cure is apparent and emphasised by her sigh towards the end of the excerpt.

‘...if it would have been something, if it had been a [pause] medical sort of problem, not a condition but you know like I said, like a growth or something blocked then I’d think I’d probably been less scared cos I would have thought there’s a cure, there’s a definite cure, there’s a fix for the problem you know, like if you go to the Doctors with an ear ache and get antibiotics it stops your ear ache so urm [sigh] ...’.

(Asmara)

In the excerpt below Asmara is talking about how she still suffers with pain despite having visited a number of GPs, her pregnancies and seeing a psychologist. She talks about learning to adjust with techniques that she has learnt.

'...I don't know because [pause] for me it's still on-going to a certain extent and I still have the same issues urm obviously [laughs] I am pregnant again now... Yeah I mean I do still suffer with pain, I still suffer [pause] but I think I've learnt to [pause] with the breathing and with thinking about the relaxing... '

(Asmara)

She goes on to describe how the problem has become part of her life and how she will probably need to use lubrication for the foreseeable future highlighting aspects of her sex life that are not completely pain free.

'It's a pain, I think now, I'm obviously just used to it now compared to the grief we went through at the beginning I think now it's just [pause] it's just routine... '

(Asmara)

In the excerpt below Asmara is referring to how she is still using the skills she learnt in her work with the psychologist including how she still has the dilators, adding that she has learnt to adjust and adapt to the situation rather than there being a definite cure or solution.

'...I haven't forgotten, I'm still using what I was taught and I've still got the dilators and things if I ever sort of get into that situation but I'm hoping [pause] I don't need to because the one thing we do now is before [pause] it was obviously because of the pain, because of the discomfort it was very irregular so now I find it if I try and keep with it a bit more, keep it regular...I think if you

leave it two months then it's like oh no I've not done it for two months is it gonna work...'

(Asmara)

And finally in the extract below she illustrates how she is more relaxed about the problem now despite the fact that she still has difficulty at times.

'...I guess I think it will probably never go away if its stuck with me for, it will be five no four and a half years now so [pause] you know dealing with it for four and a half years I think that's probably why I am a bit more relaxed about it now and I can talk about it and laugh about it.'

(Asmara)

Similarly, Nisha talks about how she sometimes still finds having a smear test problematic but that her view on this has changed and the impact lessened now she has the confidence and skills to control the spasms. Her excerpt depicts a more relaxed sense about the situation and yet acceptance that she might experience problems in the future.

'...sometimes there's uncomfot...I might not always have a successful cervical smear that goes perfectly but it's, its given me the indication that I am able to control the spasms.'

(Nisha)

Nisha describes feeling in more control of her life issues and she sees this as tantamount to improving her sex life, as these were the issues for her that were causing

the problem. For Nisha, her home life situation seemed to make sense as the cause of the problem.

Emily describes how she felt prior to visiting her GP for the first time in which her previous optimism of hoping to find a solution from her doctor had then turned into disappointment.

'I felt quite optimistic I think that first time because I expected to go and say it's hurting and they would say well try this or we will change your pill...erm so I just expected to be given some kind of solution erm so I was quite optimistic...and then disappointed a week later...'

(Emily)

3.2.2 Not a full a woman

This theme relates to the many ways in which the women talked about how their difficulties with penetration left them feeling they had lost part of what they described as being a 'full' or 'complete' woman. In the excerpt below, Emily describes her feelings of inadequacy and how she did not view herself as a 'full' woman. In the second excerpt she goes on to describe how this view impacted on her meeting men.

'I felt like you know I was this [pause] I don't know you know it all looks perfect on the outside but underlying problems in and just made me feel a bit inadequate and a bit like, you know not..I wasn't a full woman almost erm and quite frightened I suppose...'

(Emily)

'I felt frightened to get to know men too well because you know if you get to know someone and you like each other and you go on dates and all the rest of it, it does eventually lead to the start of a relationship, you've then got to cross that barrier of saying well actually I can't always have sex and it doesn't always happen...'

(Emily)

Asmara reflected on how she struggled with not being able to have a normal marriage and do the things that she felt normal newlyweds do and this impacted on her view of herself, describing feelings of inadequacies. She goes on to talk about these feelings and how her difficulties impacted on her identity as a person and as a wife. Her particular concern about how her husband might be making sense of the problem is apparent in the last line.

'you feel, I guess you do feel inadequate cos you're just basically, it's something that obviously you do as a couple and you feel a bit inadequate as a person...'

(Asmara)

'Initially, I think that was a big thing cos it you know cos you're newly married and every husband expects that from his wife really and that was a big that and that was why I think I felt more, I was a lot more upset back then, a lot more upset at the time. I kept thinking you know this is supposed to be a normal thing between newly married couples, well between married couples full stop and it's not happening so what's he thinking.'

(Asmara)

Emily reflects on how she ‘felt womanly’ at being able to use tampons, something that she had previously found difficult due to her problems with penetration. This excerpt highlights the loss of this feeling and regaining things she views as important in her life. In her delight and relief in being able to use a tampon and access a basic aspect of being a woman, she actually sends a text message to her mum and sister.

‘...and I can use Tampons now as well which is which is, I don’t, I felt quite [pause] womanly about that I suppose. It’s felt like you know I’ve hit that point now where I can do that whereas before the thought of using tampons frightened me as well because I thought oh well if I can’t have sex then I can’t use tampons because that’s gonna hurt as well so I never used tampons erm...the first time I used one [laughs] cos it was the first time I’d used a tampon I actually text my mum and sister [laughs] ‘I’ve used a tampon’.’

(Emily)

3.2.3 Miserable place

In their narrative, all the women expressed and illustrated a range of emotions in their attempts to make sense and in their experiences of the impact of vaginismus, including their interactions with practitioners and the impact on their sense of self and intimate relationships. This theme relates to the specific talk about those particular emotions and the psychological impact of their experiences.

In Nisha's opening account of why she became interested in taking part in the research she outlines the benefits gained in receiving treatment, and in the excerpt below she captures the essence of a place where she felt she was prior to treatment.

'I just think about how it would be if I hadn't had the session and I would be in the same sort of miserable place that I was in like a year and a half ago urm not really knowing much about it, not really having anyone to support me through vaginismus...'

(Nisha)

Her description of a 'miserable place' for her was the period in her life in which she knew very little about vaginismus and had no one to support her. Her description captures this sense of isolation and confusion and the sheer 'miserable' aspect of her existence at that time. Her use of the word 'place' is interesting and denotes a place in time at the beginning of her concerns and prior to receiving treatment.

Asmara captures the extent of the impact of her vaginismus, on her wellbeing, her sleep and how it occupied much of her thinking time.

'It was a hard time because I guess you know you're evenings you'd spend thinking about it, you'd go to bed and maybe you know try...so it was hard, it was hard on us [pause] just simply because to me [pause] by the stage after I had my daughter and we were going through the same thing again and I kind of thought this isn't normal, this isn't how most married couples lead their life.'

(Asmara)

Asmara continues to describe how it was difficult for both her and her husband and how, when she experienced vaginismus after her first pregnancy, she found it confusing in the context of having the problem again. This appeared to be compounded by her own comparisons of her married life with what she thought was the norm and her perceptions that ‘most couples’ do not have the problem. When asked about her feelings concerning this comparison she goes on in the excerpt below to describe how it left her with feelings of inadequacies as a person and in her married life. Her view that other couples did not have these problems increases the impact of the experience. This is related to her talk later in the interview when she refers to her relief that there were other women who had similar problems.

‘...you feel, I guess you do feel inadequate cos you’re just basically, it’s something that obviously you do as a couple and you feel a bit inadequate as a person, you’re thinking I’ve only been married a year you know and I’m still having these problems...’.

(Asmara)

Next, in the excerpt below, she voices her concerns about how the duration of the problem is impacting on her relationship with her husband, in particular she is concerned with how long her husband will ‘put up with it’. Her reflection on this gives the sense of her worry and concern over the possibility of losing her husband. For Asmara, her experience of the problem is confounded by the possibility of further loss. Interestingly she does not make reference to her loss of sex life but rather the focus is on her husband’s needs.

'...how long is he gonna put up with it. Which there was a phase where we did cross that and I kept thinking there's only so long somebody's gonna put up with not [pause]...there's only so many times that a man will I guess do with out a sex life, and then in the end he was really good to be fair but then there's only so many times you can expect somebody to sort of say ok that's fine.'

(Asmara)

Later in the interview she revisits how she felt stressed and upset due to her perceived lack of control over the problem and of the difficulties this caused in her relationship with her husband.

'...he did used to get annoyed and that used to be quite stressful cos at night times you know you'd get really upset and you couldn't sleep...I'd be thinking, lying there what's going on, why's it happening you know, I don't know why it's happening to me, it's so painful and I can't do anything to stop the pain...'

(Asmara)

Fear and anxiety were apparent for Emily, who in her extract below, describes the 'terrifying' nature of the pain and what it is like to experience vaginismus in the context of her beliefs about what sex should be like. For Emily her preconceived views of what sex should be like increased the impact of the problem, because for her sex was opposite and in contrast to these views.

'...erm it's horrible, really really horrible erm because the pain is so terrifying because you know sex is supposed to be such an enjoyable pleasurable thing...'

(Emily)

Later in the same interview, Emily goes on to talk about how she is left with a difficult situation in which she either goes through with painful sex or she hurts her husband's feelings. She ends the excerpt by expressing how she would rather not have sex at all in order to avoid both the pain and the difficult emotions accompanying this scenario. This excerpt highlights the cognitive level at which Emily is operating. Here Emily illustrates how she feels responsible not only for her own emotions but also, at some level, for those of her husband.

'You know I'd either had to try and grin and bear it and pretend that it wasn't hurting when it was erm or to get to the point where I say right stop I don't want to do it anymore...just thinking I've either gotta go through with it and accept that it's really gonna hurt or I've got to hurt my husband by saying no. So it's either way I'm having to deal with the emotional side of it which was really difficult so to not deal with that I didn't want to do it at all.'

(Emily)

When asked to describe the particular emotions she was experiencing in those occasions, Emily talks about guilt and of not providing her husband with a normal sex life. Again the term 'normal' is used and it would seem that in not meeting this 'normal' state, her guilty feelings arise.

'Because I felt guilty for not being able to give my husband a normal sex life erm to not be able to do it...'

(Emily)

Among the women interviewed, control or lack of control over the pain and their sex lives was mentioned. In the excerpt below, Emily is talking about how she didn't have control over her sex life and how this contrasted to other areas of her life and led to feelings of frustration and confusion. This excerpt depicts how for Emily the problem is preventing her from having an intimate relationship with her husband.

'you know I wasn't sort of lying there thinking (...) I don't want to be doing this, I wanted to be doing it and so that was I suppose frustrating in that sense because I didn't have the control over it and you know I have control over everything in my life and to not have control over that such a nice intimate thing to do with your husband it was, it was horrible to feel like I couldn't control that...'

(Emily)

Asmara reflects on the early days of the problem below and her choice of comparison gives us insight into how she felt emotionally.

'...it made me very aware of how people with a mental illness might feel [pause] because it, again as with stuff they say with employers and things...you've got a broken leg they can see it, they know you're not putting it on...'

(Asmara)

This excerpt highlights some of the conceptual and emotional struggles Asmara faced, namely that no one else could see her pain or recognise the impact it was having. She likens this to a mental illness and its comparison with something she sees as being more tangible, a broken leg. Throughout her interview Asmara demonstrated concerns about being taken seriously by her partner and health professionals. She goes on to say below how women might be less likely to inform their employers because of the sensitive nature of the problem despite the likely impact on their wellbeing and therefore ability to function at work. This provides insight into the level of the impact of vaginismus for Asmara. Despite her pain and emotional distress she is describing a sense of suffering in silence.

'...obviously this isn't something you might have time off work with, this is something that you're not going to turn round to somebody and say (...) I'm not sleeping at night because I'm having pain and I'm struggling to have sex so I can't have sex. It's not something you do drop in to conversation so.' (Asmara)

Finally in the excerpt below, Asmara captures the aspects of the experience that cause the distress described. Essentially, her view of her isolation in experiencing the problem and of how it prevents her from having a 'normal' sex life and marriage lead to feelings of anger and feeling scared.

'(...) like it was for me initially, daunting you know you're scared, you're angry...cos [pause] I suppose there is that part of you in not the same seriousness cos [pause] I imagine if you suffer with something in the serious illness you probably would feel why me, but there is a degree of

that, there was a degree of why me, why is it happening when it doesn't happen to anybody else, everybody else [pause] seems completely normal you know to put it that way everybody else seems normal and you're just thinking well I'm not normal because what's happening with me isn't happening with everybody else... '(Asmara)

4. Discussion

The aim of the current study was to explore women's experiences of vaginismus using IPA. Whilst the experiences were disparate there were also similarities in the issues that the women faced, namely the impact of vaginismus on their self-identity, their relationships and the struggle of trying to make sense of their vaginismus. In this section the findings are summarised and discussed in relation to the wider research literature and clinical implications. The limitations of the current research study and future research opportunities are also discussed.

4.1 Summary of research findings

Each of the three women's experiences illustrated the psychosocial nature of what it means to experience vaginismus (Ward & Ogden, 2010). The current research identified the confusion and struggle that each woman faced in making sense of vaginismus and how this was related to their social realities. All of the women faced challenges to their female identity, psychological wellbeing and relationships.

4.1.1 What's going on, why's it not happening?

The search for explanatory causes as to why they were having difficulty with penetration was a source of psychological stress and confusion, for all of the women in the study. It also posed a long exhaustive process that did not actually result in a completely satisfactory explanation of why they had the problem, or indeed, in the achievement of a 'cure'. Instead the women described adapting to their circumstances and changing their perceptions of the problem. Evidence of women resigning themselves to living with sexual pain without an available cure has previously been found in the literature (Elmerstig et al., 2008). Making sense of their vaginismus was a dynamic process that evolved in the context of the women's development and understanding of the problem and themselves. Their interactions with health professionals and internalisation of medical messages, relationships, the duration of the problem, and their reflections in the moment, all contributed to their understanding or confusion concerning vaginismus. The narratives associated with attempting to make sense and the difficulty in doing so, is consistent with the sexual pain literature and research that has addressed women's experiences of chronic pelvic pain (e.g. Grace & Stewart, 2007).

Problems were encountered when advice and explanatory causes suggested by health professionals did not fit with the women's own understanding of their problem.

Incongruence between health professionals and women's understandings of vaginismus has previously been found to be a source of stress and confusion resulting in dissatisfaction with treatment offered (Ogden & Ward, 1995). The process of seeking help and advice was experienced as 'lengthy' by two of the women interviewed. Lack of solutions and a cure added to their stress and confusion and impacted on their view of self and perceptions of treatment services. Similar experiences have been documented among women presenting with dyspareunia (Munday et al., 2007; Buchan et al., 2007).

4.1.2 It's not just about sex and pregnancy

The current findings highlight the impact of vaginismus on identity, lifestyle and psychological wellbeing for the three women interviewed. Normal versus abnormal sex lives were implicated in the discourse and each woman compared her sex life with her perceptions of a norm within a heterosexual andro-centric framework, emphasising the needs of her partner over her own and often experiencing guilt in not providing a 'normal' sex life for her partner. This was evidenced by a willingness to 'grin and bear' painful sex rather than hurt a partner's feelings or deprive them of 'normal sex'. In particular, the women's experiences of extreme emotions and threats to self-identity were expressed in relation to their difficulties in engaging in 'normal' intercourse and thus 'normal' heterosexual practices. These experiences are consistent with those identified in the wider sexual pain literature, including research that has explored experiences of vaginismus (Ayling & Ussher, 2008; Ogden & Ward, 1995; Ward & Ogden, 2010; Sutherland, 2012; Kaler, 2006). Narratives around view of self as 'not normal' and 'faulty' in comparison with views of a heterosexual norm, demonstrates the impact of the idealised view of sexuality often portrayed in the media as something natural and easy, on the women's view of self (Tiefer, 2004).

From an essentialist medical model approach the women in the present study might each have been considered a ‘success’ in that they were all able to achieve penetration and pregnancy. This is perhaps not surprising when much of the DSM measure of success is symptom reversal and in the case of vaginismus, achievement of penetration (Tiefer, 2004). However, all of the women in the present study were, at some level, still living with problems with penetration even after treatment and successful pregnancies. For one woman, her concerns about penetration had turned to concerns about pushing out and that she might in some way interfere with the pregnancy in an adverse way. This experience supports findings that indicate women who have experienced vaginismus may also experience a phobia of childbirth (Bansal, 2007) and complications in labour (Goldsmith et al., 2009).

All of the women interviewed described feeling disenfranchised after pregnancy despite continuing to experience difficulties with penetration. They described the confusing aspect of the persistent nature of their difficulties even after pregnancy and how this impacted on their engagement with treatment. One woman highlighted experiences of how she found it more difficult in explaining her problems to a health professional during and following her first pregnancy. Despite their success in pregnancy, all of the women described experiencing challenges to their female identity and psychological wellbeing as a result of continued difficulties with penetration.

4.2 Methodological issues

A limitation of the present research study relates to the small sample size employed. The aim was to recruit between six and ten participants to the study, however owing to a reduced available sample this proved difficult. A smaller sample of three women allowed for greater depth and exploration at the idiographic level and this

study has begun to address the paucity of qualitative research that has focussed on vaginismus.

Additionally, all three women were married and in heterosexual relationships, had given birth, experienced primary then secondary vaginismus, and had engaged in treatment services. Whilst these are not necessarily limitations, the impact of these experiences on their reflections and sense making should be borne in mind when considering the findings and may not reflect women with primary vaginismus who have yet to seek professional help. Furthermore, two of the women identified as British Muslim and one woman as White British. It is possible that cultural differences between researcher and participant may have affected access to the lived experience of these women and the sensitive nature of the study may have prevented the sharing of certain experiences in detail.

Finally, it is possible that the researcher's preconceptions and prior experiences of working therapeutically with women with sexual pain may have led her to misinterpret or 'be blind' to other meanings within the data. The data is seen as experience close rather than a representation of actual events and experiences and is dependent on the interpretative lens and the context of the interview. It is possible that new understandings and meanings may come to light from further analysis of the data.

4.3 Clinical implications and suggested recommendations

The findings from the current research study are relevant for those health professionals who may come into contact with women who are experiencing or have a history of vaginismus (clinical psychologists, gynaecologists, midwives, GPs and practice nurses, to name a few), be that in relation to an assessment, intervention, or for other aspects of physical and psychological health (e.g. birth plans; gynaecological examination, or general practice). The fact that the experiences of the three women

highlighted the psychological aspects of the experience of vaginismus and its treatment has demonstrated the contribution that clinical psychology can offer to this area of clinical practice (e.g. a safe environment in which to address the impact of sexual dysfunction on mental health, relationship issues and addressing anxiety and fear of penetration). Notably each of the three women experienced positive gains from their work with their psychologist. These included similar themes to those already documented in the literature that has explored women's experiences of treatment for sexual pain (e.g. education around sexual pain, sex and female anatomy, and a sense of normalisation and acceptance; Sadownik, 2012).

The approach of the present study allowed for the diverse and complex experiences of each of the women interviewed to be heard. The findings are not therefore, attempting to generalise across larger groups of women, but rather to highlight the individuality in these experiences. The implications of these findings are that diverse and patient-centred approaches to understanding and treating vaginismus are likely to result in greater success and patient satisfaction. It is also important not to assume that a woman who has achieved pregnancy has 'solved' all of her problems with penetration.

In addition, the findings point to experiences of delays, repeat visits and the impact of certain views of health professionals on both women's sense making and impact of vaginismus. These findings implicate the role of primary care services in facilitating the disclosure and appropriate care pathways for women presenting with vaginismus.

4.3.1 Clinical recommendations

1. Awareness of sexual pain disorders appears to be minimal among women until they experience them. General health and sexual health clinics could

promote awareness of sexual pain disorders, in particular, among young women early in their sexual lives.

2. Treatment should be bio-psychosocial rather than bio-medical and focussed on additional outcomes in complement to achieving vaginal penetration. These could include education, validation, improvement in psychological well-being, and ensuring congruence between the woman's and the professional's perceptions of the problem.
3. A patient-centred approach is important to allow women to express the diverse ways in which they experience vaginismus. It is important to listen to these experiences in order to identify the problems for the individual, not making assumptions (e.g. that a woman who has conceived and given birth no longer has a problem).

4.4. Conclusions and further research

The findings from the present research study highlight the psychosocial impact, intense associated emotions and challenges to self-identity and psychological wellbeing, associated with experiencing vaginismus. Given there are very few studies that have specifically focussed on vaginismus, further research exploring women's experiences of vaginismus in the UK, among larger sample populations and women currently marginalised by the literature (e.g. older post menopausal and women from ethnic and sexual minorities), is recommended. Further research of this kind may provide insight into the lived experience of vaginismus across the lifespan and within different social and sexual realities.

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Part 3: Critical Appraisal

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by

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Critical Appraisal

1. Introduction

The purpose of this section is to reflect critically and with candour on my experiences of carrying out an independent piece of doctoral research and on the findings of this research. The experiences described are based on those recorded in a reflective journal consisting of my written memos and electronic dictations of decisions, feelings, thoughts and reflections.

2. On beginning my clinical training

I was not prepared for the anxiety I felt during my first month of training but with support and self-determination I survived. Nevertheless, it took a while to think of myself as a trainee clinical psychologist, something that until mid-way through my final year, I had not had the confidence to acknowledge. It could be changing careers that prompted these feelings. Before starting my clinical psychology training I worked as an investigator in a major crime unit in the UK Police Service. Discussing my change in role and the associated feelings during clinical and research supervision enabled me to reflect on these experiences. The impact of career transitions among teachers on their identity and psychological wellbeing has been documented (Wilson & Deaney, 2010) however, research exploring experiences of clinical psychology trainees who enter training from different professional backgrounds appears to be non-existent. Additionally, throughout my three years of clinical psychology training I have experienced what is sometimes known as the imposter syndrome, ‘an internal experience of intellectual phoniness’, in which the person doubts their abilities in a particular role or ability and believes they have fooled people (e.g. employers, universities) into believing they are more able than they actually are (Clance & Imes, 1978). Having spoken with my cohort on the clinical psychology doctorate, I know I am not alone in this experience. As I have progressed through my training my confidence has grown and I am feeling more settled within the role and the NHS. These

early training experiences directly affected my research experience and I will now discuss each stage of the research process in chronological order.

3. On doing qualitative research

3.1 Choosing the research question

I found choosing a research topic quite stressful and confusing. I was aware the expectation that research would be published after qualification and I was keen to conduct research that could ‘add something’ to clinical psychology literature. Initially I attempted to stay within my comfort zone. Having completed an MSc in Forensic Psychology I was aware of forensic literature and thought the combination of the domains of policing, forensic and clinical psychology might provide an obvious research opportunity. Following consideration of the reasons behind my initial choice and my failed attempts to conjure a research question, I decided to step out of my comfort zone and embrace wider clinical psychology research.

This decision was facilitated by my first year clinical placement within a health psychology department in which I worked psychologically with men and women experiencing a number of physical and sexual health concerns. I found this work both enjoyable and interesting. I felt privileged to be able to practice clinical psychology and give credence to a person’s sexual identity within the ‘work’ of therapy, recognising the impact and importance that sexual health plays in a person’s mental health and vice versa (e.g. Wylie et al., 2002). This is something that resonated with my personal life in which I had experienced difficult emotions in relation to my own sexuality and reactions from different areas of society. It is often noted in clinical training that some trainees may find the topic of sex and sexuality taboo, and difficult to address in therapy. The experiences gained on my first placement provided me with the

confidence to think about sex and talk about sex in my other clinical placements. This also reinforced my belief in the importance of sexuality to wellbeing.

In my first year placement, I was particularly interested in work with women who presented with the sexual pain disorder, vaginismus. I was struck by the impact of this disorder on their psychological wellbeing and self-identity. For some of the women, the psychological impact on both their mood and self-esteem was evident and in turn affected the success of treatment. I undertook a scoping review of vaginismus treatment literature to assist with informing my clinical practice. I was surprised by the paucity of available research. There was a distinct lack of controlled treatment studies (at the time teaching emphasis was on controlled clinical trials) and only two research studies claimed to have explored what it was like to experience vaginismus or receive treatment. With the assistance of both clinical and research supervision I was able to mould my ideas into a suitable and relevant research question.

3.2 Choosing the methodology

The research question naturally led me to using qualitative methodology in order to explore the experiences of women at the individual level and to obtain rich in-depth data. The next step was to choose which type of qualitative methodology I was going to use. Before choosing my research question, I had envisaged using a quantitative methodology. I had reservations about using qualitative methods, borne mainly from concern over not being taken seriously. This is reflective of the time period in which I completed my undergraduate degree, at which point attention given to qualitative methods was minimal. The more I read about qualitative methods including published research, the more my presuppositions began to fade and it is pleasing to see that qualitative methods are now recognised for their obvious contributions to healthcare research and practice. The learning I took from this process was to ensure that the

research would choose the method and not vice versa as well as a greater appreciation of the contributions qualitative research has to offer clinical inquiry. I initially thought grounded theory would be the method of choice. In part this was about trying to conform to an epistemology perhaps more in tune with quantitative methodology, to say 'look, I have a theory'. It was useful to discuss this with my supervisor and we both felt that because of the lack of qualitative research, we first needed to add to the pool of literature by examining women's experiences in more detail. So, this led me to interpretative phenomenological analysis (IPA; Smith, 1996). I had never used IPA before and I knew that this method would place me outside my comfort zone. I therefore enrolled on an introductory course for IPA data collection and analysis. It is interesting that many of the challenges to my self-belief and confidence throughout training have been about 'not knowing' and the feelings this provokes. IPA, its history, epistemology and 'how to do' were confusing. And flexible in that there are no set rules as such, something in stark contrast to my police investigative experience in which there were specific ways of collecting evidence and of ensuring minimal influence of the investigator. With IPA, my position to the data was important. Thus, without a set rigid structure, I felt lost and this forced me to rely on my beliefs, my capabilities and ways of working. Nevertheless, I was enthused by the prospect that IPA would allow me to get close to the participant's experiences and provide me with an opportunity to make sense of their 'sense making'.

3.3 Ethics Application

The next step was to apply for ethical approval and I found this process (which included obtaining approval from local NHS Trust research and development department) both a rewarding and valuable developmental process. My previous experiences of presenting strategic and tactical information to senior police officers

provided me with a suitable grounding in preparing my research proposal for scrutiny at an NHS research committee. This process provided me with experience in presenting clinically related information, including supporting evidence justifying the research being proposed, to a range of health professionals and lay people.

3.4 Recruitment

Having worked in the department from which the sample was to be drawn, I was aware that the available sample would be relatively small but would suffice for a good in-depth IPA study (Smith et al., 2010). Two women responded within a short time of the first batch of recruitment letters being sent in May 2012 and I was delighted. However, I did not receive further replies until December 2012. This latter stage of recruitment was particularly stressful and a de-motivating experience. Supervision provided a space for me to think and reflect on the recruitment process and to remind myself that depth rather than breadth was key to good quality IPA research. Upon reflection there were a number of factors I had not anticipated which reduced my available sample (e.g. patient request for no correspondence by mail and the transient nature of referrals from the student population). Additionally, administrative issues due to department resources also added to the delay.

When my third participant responded I was delighted and wanted to conduct the interview as soon as possible. I was careful to ensure that my keen attitude did not translate into pressuring the woman to take part. I followed the same steps I had taken with other participants and an interview date was arranged.

3.5 Interviewing women with vaginismus

As a clinical psychologist and as an investigator I am used to developing rapport and finding out about the person in front of me, so the idea of using interviews to collect data was familiar. I found the interview process an enjoyable and rewarding process.

This gave my research ‘life’ and served to rejuvenate my motivation levels. I was touched and inspired that women had responded to my research and listening to the reasons for doing so, namely their belief that the research would enable their voices to be heard, made me more determined to work towards publication. The stories that unfolded during the three interviews were a testament to their bravery in speaking out about difficult and sensitive personal experiences. Hearing these stories justified the research that I was undertaking.

Initially, the challenge was in knowing what a ‘good enough’ in-depth interview might look like. My previous research and clinical practice helped me to shape the interview schedule and, with the assistance of my field research supervisor, I was able to conduct a pilot interview to test out the suitability of questions. This resulted in a comprehensive schedule designed to explore the experiences and impact of vaginismus and treatment. After the first interview I became more confident in allowing the interview to flow rather than feeling too anxious about rigidly adhering to the original interview schedule. Being able to listen back to the interview and to read the transcripts also allowed me to reflect on my style of questioning and to recognise learning opportunities.

I was also aware of the potential similarities between the research interview and therapeutic settings and related issues of boundary blurring in qualitative health research (Dickson-Swift et al., 2006). Certainly for two of the women, who preferred to be interviewed on hospital premises, my concern was about how returning to the department in which they received their treatment, might impact upon them. When arranging the interviews I checked with each woman as to whether they were comfortable in being interviewed there and provided alternative location options. All of the women stated they had found the interview positive and were pleased someone was

undertaking research in this area. They remarked on how the research experience had provided an opportunity to reflect on their experiences and in some cases had triggered recall of memories previously forgotten.

Throughout the interviews I was conscious of how my gender (female) enabled me to develop rapport with the women. However, I was also keen to avoid the assumption that my gender allowed me any special understanding and ensured I used prompts where possible to obtain the participants' meaning and avoid assumptions on my part. Upon reflection, it is possible my gender may also have hindered the disclosure, as I am aware that vaginismus is often an unspoken and embarrassing problem, even among women. It is possible that the interviewee may have positioned me as 'complete' woman as opposed to her view of herself as 'incomplete' or 'dysfunctional'. I was careful to think about how my responses may suggest a level of judgement on the subjects being discussed (e.g. sexual practices, sexual identity, religious and cultural beliefs regarding sex and sexuality).

3.6 Transcription and Analysis

Owing to IPA's commitment to the data and advice that suggests the researcher becomes immersed in their participant's worlds, words, lived experience and meanings, I transcribed all three interviews verbatim. This was a very time consuming and at times a less interesting aspect of the research process. However, I believe the process was vital in providing me with an additional view of the person I had just interviewed and in providing me with an opportunity to reflect on my interview style. Listening back to the audio recording provided an opportunity to notice the different elements in the participants' speech. As a result, I became far more immersed in the data and thus avoided introducing another researcher's interpretation.

Once the transcription of each interview was completed I moved on to the analysis of the transcript itself. This was a daunting stage of the research process. It was also very time consuming and I remember becoming overly concerned with ‘doing it right’ and adhering to guidance I had read on IPA analysis (Smith et al, 2010). Although I followed the six stages outlined by Smith et al., (2010), conversations with my supervisor, who is well published within the qualitative research field, helped me to become more relaxed and as a result more involved and reflexive with the data.

4. On writing the thesis

Whilst writing my thesis I had ‘publication anxiety’, having mistakenly understood my work needed to be of publication quality at the point of submission. This translated into scrutiny of every word and made the writing of the report an extra long and at times, stressful and stagnated process. Writing the thesis in my final year of training was a challenge in time management but also in switching between a research and practitioner focus. At times it was difficult to devote thinking time to each. Although I set targets and tried to break down each section into smaller units of writing, each unit invariably took longer than I had anticipated. Inevitably, I felt overwhelmed and anxious about the whole process. I was surprised I was struggling, having been used to writing important professional reports to the Chief Constable and ACPO (Association of Chief Police Officers) in the police service. Now here I was, barely able to put together a paragraph. At times I felt very distant to the research topic despite having read widely on the subject. I found the use of supervision invaluable in discussing the format and content of the thesis and my associated anxieties. My main concerns about the research process were ‘knowing enough’, and ‘speaking from evidence’, important facets within the police service and the NHS.

5. On limitations and quality issues

5.1 Finding my epistemological position

Initially, I found the concept of epistemology confusing and the process of stating and understanding my own stance quite daunting. However, upon reflection the process was a useful informative journey of learning and an obvious one to take when venturing into research and clinical practice. I have long regarded myself as an open-minded person and practitioner, someone who would look to many different theoretical perspectives to solve a problem. I did not want to put myself in one category yet I suspect the process of stating my epistemological position made me feel like I had to do just that. After reflection, a social constructivist position seemed to best reflect my viewpoint on knowledge and the experiential world. Experiences of sexual pain are, in essence, coloured by one's sense making within a particular social context and time period (Foucault, 1990). I believe strongly that sex and sexuality is experienced within, and influenced by, the social construction of gender, 'normal' sexual practices and in particular the medicalisation of sexual dysfunction (Tiefer, 2004). Reflecting on this process has also helped me to come to understand personal experiences of 'being different' with regard to sexuality.

5.2 Reflections on the limitations of IPA

Whilst every effort was made to ensure that the accounts obtained and subsequent themes identified reflected the experiences of the women interviewed, the issue of how well the language used actually represented their experiences and sense making is worth noting here. Given that two of the three participants had a second language raises the question of whether access to experience in those languages would have provided alternative / additional meanings. The debate over whether language describes, constructs or both should be borne in mind when considering the findings of this research study.

Connected to the use of language is the issue of how well participants can recall, reflect upon and describe their experiences in the context of the research interview. It is possible that the sensitive nature of the subject and variances in abilities of articulation may have impacted upon how accessible their experiences were to them, and the researcher.

The question of reflexivity to the data is also relevant here. Whilst there is no right or wrong in terms of the researcher knowing too much or too little, IPA's explicit use of the researcher's interpretation of the data means that different interpretations and understanding of the data are possible. This is supported by taking a social constructionist position where multiple perspectives on the same phenomenon may all be valid and of use in providing a broader understanding of a complex experience.

Finally, IPA's commitment to reality as perceived by each participant can provide rich illumination of how sexual pain is experienced and made sense of, what it cannot do is address the question of 'why' these women experienced it a certain way or even which factors caused them to experience sexual pain. What IPA does offer is a view into the complexity of a phenomenon and how it may be experienced by different individuals in diverse ways, however it does not seek to develop general theories that could be applied across a population.

6. On personal and professional development

6.1 Development as researcher and practitioner

At the beginning of my training I was keen to consult research to inform my clinical training and to approach my clinical practice with evidence based principles. I was also keen to undertake and to be involved with clinically relevant research. I am certainly inspired now, to go and conduct further research in this area and have applied

for a clinical psychologist post working in psychosexual services. I would welcome the opportunity to undertake further research in this field.

6.2 Practicing and undertaking research in changing climates

Undertaking both research and clinical training in a time of conceptual and political change within sexual pain literature and the NHS, has been an interesting and challenging experience. The last decade has seen a number of published papers in which the essentialist and universal nature of the DSM conceptualisation of female sexual dysfunction including sexual pain has received criticism and opposition (e.g. Kaler, 2005 & 2006; Tiefer, 2002). At present we await the publication of the fifth edition of the DSM. In the new edition a revision of sexual pain disorders classification is expected and is likely to continue to stir debate about what is normal, natural and universal about sex.

These changes and polemics have caused me to reflect on my first year placement in psychosexual health and of the medical terminology used when working with sexual pain and how certain ‘givens’ such as the human sexual response cycle and associated phases, were seen as the norm from which comparisons were made. Equally on reflecting on my own assumptions about sex, I considered how my own judgements led to certain formulations and approaches being taken. While I feel strongly about the current over medicalisation of sexuality, this feeling is juxtaposed with concerns that the removal of sexual pain, including vaginismus, from the DSM psyche may also mean these conditions are given less importance within resource-challenged services. For example, in the recently published Sexual Health Framework for England minimal reference is made to sexual pain disorders (DoH, 2013). Yet as the current research study and the wider literature have demonstrated, experiencing sexual pain can have

adverse bio-psychosocial impacts (e.g. infertility, poor adherence to cervical screening, decrease in psychological wellbeing, and relationship breakdown).

Similarly, since beginning my training in October 2010, many changes have been proposed and witnessed in the NHS, including changes in how services are commissioned, and the increasing challenges faced by healthcare services in providing care with minimal resources. With this in mind, I feel I will face great challenges as a clinical psychologist working in psychosexual health, most specifically in tackling essentialist thinking both on the couch and systemically within the NHS to ensure other health professions are aware of the psychological impact of sexual dysfunctions.

6.3 Personal impact of the research process and findings

I experienced a range of emotions throughout the research process and I was surprised by how writing the thesis impacted on my emotional wellbeing. At times I felt disempowered and struggled to write and have confidence in what I was writing. At other times I was really inspired and engaged in the process. This experience in the research process on clinical training courses has been documented before (David, 2006) and there is both research and anecdotal evidence illustrating the stressful nature of clinical psychology training (Cushway, 1992). In attempting to manage the stress associated with competing aspects of clinical training (e.g. research and clinical practice) I made sure that I took regular breaks, planned in fun activities and took regular exercise, including cycling from London to Paris with a fellow trainee for charity. My emotions did fluctuate but I was able to regain composure and perspective by making appropriate use of supervision and support networks. I have become much more adept at using a compassionate mind approach to my self-care. These experiences

have provided me with valuable insight into my limits and my ability to be resilient in times of stress. This self-awareness and understanding will serve me well in ensuring I stay healthy and fit for practice in my clinical psychology career.

7. Closing comments

Undertaking an IPA study of women's experiences of vaginismus and its treatment has been a rewarding and enriching learning opportunity, from which I have gained valuable research experience and insight into a specific area of psychosexual clinical practice and research methodology. I am confident that the experiences discussed in this section will inform my future practice as a clinical psychologist and I would welcome the opportunity to undertake further clinically-relevant sexual health research utilising an IPA approach.

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Appendices

Appendix A

Guidelines to Authors for Target Journal for Literature Review

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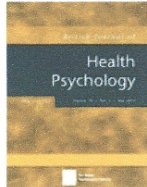
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Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via **Editorial Manager** (<http://www.editorialmanager.com/bjhp>). You may like to use the **Submission Checklist** ([BJHP Submission Checklist.docx](#)) to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the **terms and conditions of submission** ([BPS Journals Terms and Conditions of Submission.doc](#)) and the **declaration of competing interests** ([BPS Journals Declaration of Competing Interests.doc](#)).

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#) ([Sample Manuscript Title Page.doc](#)).
- **Statement of Contribution:** All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. The 2-3 (maximum) sentences for each point should identify existing research knowledge relating to the specific research question/topic and a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
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Appendix B

Description of Female Sexual Pain Disorders and Subtypes

DSM-IV-TR Diagnostic Criteria for Vaginismus (DSM-IV; APA, 2000)

- A. Recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse.
- B. The disturbance causes marked distress or interpersonal difficulty.
- C. The disturbance is not better accounted for by another Axis 1 disorder (e.g. Somatisation disorder) and is not due exclusively to the direct physiological effects of a general medical condition.

Specify Type: Lifelong / Acquired

Specify Type: Generalised / Situational

Specify Due to: Psychological Factors / Combined Factors.

DSM-IV-TR Diagnostic Criteria for Dyspareunia (DSM-IV; APA, 2000)

- A. Recurrent or persistent genital pain associated with sexual intercourse in either a male or a female.
- B. The disturbance causes marked distress or interpersonal difficulty.
- C. The disturbance is not caused exclusively by vaginismus or lack of lubrication, is not better accounted for by another Axis 1 disorder (except another sexual dysfunction) and is not due exclusively to the direct physiological effects of a substance (e.g. a drug of abuse, medication) or a general medical condition.

Specify Type: Lifelong / Acquired

Specify Type: Generalised / Situational

Specify Due to: Psychological Factors / Combined Factors.

ICD-10 Diagnostic Criteria for Dyspareunia and Vaginismus (ICD-10; WHO, 1992)

F52 Sexual dysfunction, not caused by organic disorder or disease

Includes:

F52.5 Non-organic vaginismus

Spasm of the muscles that surround the vagina, causing occlusion of the vaginal opening. Penile entry is either impossible or painful. Vaginismus may be a secondary reaction to some local cause of pain, in which case this category should not be used.

Includes: psychogenic vaginismus

F52.6 Non-organic dyspareunia

Dyspareunia (pain during sexual intercourse) occurs in both women and men. It can often be attributed to a local pathological condition and should then be appropriately categorized. In some cases, however, no obvious cause is apparent and emotional factors may be important. This category is to be used only if there is no other more primary sexual dysfunction (e.g. vaginismus or vaginal dryness).

Includes: psychogenic dyspareunia

Dermatological (skin) conditions

Lichen sclerosus, lichen planus, eczema, psoriasis

There are also a number of skin conditions that can affect the vulva – a few are listed above. They are usually characterised by itchiness; the skin may be red and inflamed, or white patches may be visible, as in Lichen Sclerosus. Initial treatment is usually with a steroid cream. Diagnosis needs to be made by a vulval specialist or dermatologist.

Interstitial cystitis (IC)

IC refers to chronic symptoms of urinary urgency and frequency, pain and burning, in the absence of a bladder infection.

Some women with vulvodynia also experience bladder symptoms, and it is possible to present with more than one vulval condition simultaneously.

What unprovoked vulvodynia and vestibulodynia are NOT

They are not sexually transmitted infections and cannot be passed on to a partner. IC and the skin conditions listed above are also non-infectious.

They are not forms of vaginismus (involuntary tightening of the vaginal muscles), though vaginismus can develop as a response to pain in the vagina or vulva.

They are real physical conditions and do not have a psychological cause. Psychological distress may develop as a consequence of ongoing pain or discomfort and in this instance women (and their partners) may benefit from seeing a psychosexual counsellor.



Vulval Pain Society

The Vulval Pain Society is a UK registered charity, No. 1118118, providing support and information to women with vulval pain and their partners. It was set up in 1996 by gynaecologist Dr David Nunnis and nurse Diane Hamdy.

Please visit the VPS website for details of local support groups, workshops and treatment options.

To obtain further copies of this leaflet free of charge, please email or write to the VPS at the address given below. Alternatively, you can download a PDF copy and an MP3 audio recording from the VPS website under 'Downloadable info'. You may freely photocopy or copy the leaflet in any of these formats provided authorship of VPS and LVPSG (the London Vulval Pain Support Group) is clearly acknowledged.

Contacts:

The Vulval Pain Society (VPS)

Web: www.vulvalpainsociety.org/vps

Email: info@vulvalpainsociety.org

Post: VPS, PO Box 7804, Nottingham, NG3 5ZQ.

Worldwide Lichen Sclerosus Support

Web: www.lichen sclerosis.org

Tel: +44 (0)7765 847599

UK Lichen Planus (UKLP)

Web: www.uklp.org.uk

Your local Vulval Pain support group is:

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Vulval Pain

Women -

Do you have unexplained genital pain?

If all tests for infections come back negative but you still experience discomfort, burning or soreness, you may have vulval pain:

- **Unprovoked vulvodynia** is characterised by continuous burning, stinging, or soreness of the vulva.
- **Provoked vulvodynia (vestibulodynia)** refers to pain experienced when pressure is applied to the vestibule (the entrance to the vagina), such as during sex and on insertion of tampons.

Vulval pain affects around 16% of women. It can be distressing but treatment and support are available.

Vulvodynia

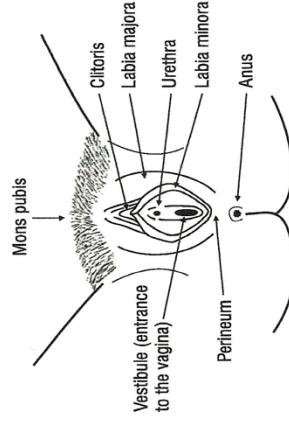
Vulvodynia is the term used to describe the sensation of vulval burning, soreness or pain in the absence of any obvious skin condition or infection. Symptoms may be constant (*unprovoked vulvodynia*) or only evident on touch (*provoked vulvodynia*, also referred to as *vestibulodynia*).

Unprovoked vulvodynia was formerly known as *dysaesthetic vulvodynia* and **vestibulodynia** replaces the term *vulval vestibulitis*.

Diagnosis must be made by a doctor knowledgeable about vulval problems. If you think you may have vulvodynia ask your GP, or local Genito-Urinary Medicine (GUM) clinic, for a referral. Ideally, you should do this as soon as possible, since a delay in getting an accurate diagnosis and treatment could lead to the pain becoming much harder to treat successfully in the long term.

Some doctors may not be familiar with the new terminology, or even with the condition itself. This leaflet provides information, support and advice for women with vulvodynia and members of the medical profession.

An illustration of the vulva, showing which areas may be affected:



Unprovoked vulvodynia

What is it? The condition is characterised by vulval burning and soreness, usually as a consequence of irritation or hypersensitivity of the nerve fibres in the vulval skin.

Symptoms are often constant and intensity may vary from mild discomfort to severe constant pain, which can interfere with sleep and sexual activity, and even prevent one from sitting or wearing trousers. Some women also experience related pain around the inside of the thighs, the upper legs and the anus. The burning sensation may be generalised over the entire genital area, or localised to just the clitoris (*clitorodynia*), or one side of the vulva only (*hemivulvodynia*). Itching is not generally a feature of the condition.

Usually there is nothing to see on examination as the problem lies with the nerve fibres themselves, which are not visible to the naked eye.

For a minority of women with vulvodynia, back problems can cause spinal nerve compression and referred pain in the vulval area. In the majority of cases, however, the precise cause of the nerve damage, irritation or misfiring remains unknown.

How is it treated? Pain that originates from nerve fibres is best treated with drugs that alter the way the nerve fibres send their impulses to the spinal cord and create the sensation of pain. Tricyclic antidepressants act in this way and have been used extensively to treat vulvodynia. (Note that they are *not* prescribed to treat depression in this case, but to dampen down the pain signals travelling along the nerves, and thus 'retrain' the nerves to function normally, i.e. without producing chronic vulval pain). Tricyclic antidepressants are available from your doctor and examples include amitriptyline, nortriptyline and dothiepin. Sometimes anticonvulsant drugs such as gabapentin or pregabalin are also used in the treatment of vulvodynia.

Complementary treatments such as acupuncture and homeopathy may help relieve symptoms and bland emollient creams and vaginal lubricants may also be of benefit. See the Vulval Pain Society's website (details overleaf) for more information.

Be wary of applying non-prescribed creams to the vulva as some can cause irritation.

Provoked vulvodynia (vestibulodynia)

What is it? In 1987, American gynaecologist Edward Friedrich described a group of women who experienced severe pain and discomfort of the vestibule area at the entrance of the vagina.

The pain experienced by women with vestibulodynia is variable; some are able to tolerate penetrative sex, whilst others find that even light touch or wearing trousers can be excruciating.

Often on examination of the vestibule there is tenderness to light touch. There may be red areas at the site of tenderness, but frequently the findings are 'normal'. Tests should be done to rule out infections and vulval skin conditions that may cause similar symptoms. Some doctors are unaware the condition exists and can often mistake it for thrush. Repeated use of topical anti-thrush treatments can make the condition worse.

It is likely that a number of factors cause vestibulodynia, but often no identifiable cause can be found. Some women have a sudden onset of symptoms following a specific event; commonly a severe attack of thrush followed by anti-thrush treatment, or after giving birth.

How is it treated? Women with vestibulodynia often benefit from a multidisciplinary approach - local anaesthetic creams/gels, vaginal dilators, pelvic floor muscle physiotherapy (biofeedback), psychosexual counselling, and sometimes surgery (vestibulectomy).

Appendix C

The CHIP Tool

The CHIP Tool (Shaw, 2010) as applied to the present review search strategy

C	Context	Experiences of women with sexual pain	Is this study investigating women's experiences of sexual pain (and / or its treatment)? Clinical and general populations included.
H	How	Qualitative & Mixed methods	Has this study used a qualitative methodology? (Including mixed method studies)
I	Issues	Experiences of sexual pain and its treatment	Is this study asking women about their experiences?
P	Population	Vaginismus & Dyspareunia, sexual pain according to DSM	Does this study have participants who have experienced sexual pain? (Studies to be excluded if in context of surgery, cancer, endometriosis, chronic pelvic pain)

Appendix D

Details of Searches Undertaken

Electronic Database	Search Date Periods	Search Terms	Total Results	Total No. of Relevant Studies
PsycINFO	December 2011 – February 2013	Sexual Pain AND qualitative research AND experience; Sexual Pain disorders AND qualitative research AND experience; Vaginismus AND qualitative research AND experience; Dyspareunia AND qualitative research AND experience; Painful sex AND qualitative research AND experience; Painful intercourse AND qualitative research AND experience; Genital Pain AND qualitative research AND experience; Vulvodynia AND qualitative research AND experience; Female sexual dysfunction AND qualitative research AND experience; Unconsummated AND qualitative research AND experience; non-consummated AND qualitative research AND experience; Vulvodynia AND qualitative research AND experience; Pelvic pain AND qualitative research AND experience; Vaginal dilators AND qualitative research AND experience; Vulva AND qualitative research AND experience; Vulvar pain AND qualitative research AND experience; Vaginal pain AND qualitative research AND experience; Vestibulodynia AND qualitative research AND experience; Vestibulitis AND qualitative research AND experience.	302	7
Medline	December 2011 – February 2013	As above	232	3
ISI Web of Science	December 2011 – February 2013	As above	200	2
Scopus	December 2011 – February 2013	As above	858	3

Appendix E

Quality Appraisal Data Abstraction Form

Data Abstraction Form (Based on Guidelines by Meyrick, 2006)

Study title, Country of origin, study reference and Id	
Epistemological / theoretical stance (objective / reflexive)	
Method	
Sampling / final sample	
Data Collection	
Data Analysis	
Qualitative Audit Trail (data to conclusions)	
External / Internal Validity	
Results (Themes)	
Conclusions	
Comments / Observations	

Appendix F

Statement of Epistemological Position

Statement of Epistemological Position

For the current study an interpretative phenomenological approach was adopted in order to access meaning at the idiographic level, essentially to explore the lived experience of vaginismus for the three women interviewed.

Women's experiences of vaginismus were interpreted through a social constructionist lens in which sexuality is viewed by the researcher as a socially constructed phenomenon, relative to time and culture (Foucault, 1990; Tiefer, 2004). Therefore the lived experience of vaginismus is seen as influenced by the social construction of sexuality and each woman's social reality that is embedded within a cultural, historical and political context. IPA subscribes to a lesser form of social constructionism proposed by Mead (1934) who argues that humans may be initially formed by the influence of culture, but at an individual level they are able to 'rework' this through symbolic and cognitive processes, thus making their own sense of things (Smith et al., 2010, p.196).

Additionally, the researcher disagrees that sex and sexuality are universal (e.g. the same for everyone across contexts) or natural (solely a biological function that all individuals will perform in the same way). Sexual dysfunction is seen as one example in which a universal and essentialist view of female sexuality has been used to ascribe normal and abnormal labels irrespective of the social paradigms and forces likely to impact on female experience and expression of sexuality (Tiefer, 2004).

Finally the interpretative role of the researcher (including her presuppositions from a social constructionist view, sexuality, cultural, and previous psychosexual practice as a trainee clinical psychologist) is understood to have inevitably influenced the findings through the double hermeneutic in making sense of the participants' sense making. To ensure that this influence does not result in inappropriate bias, reflexive practices were used to challenge the trustworthiness of the analysis. It is also acknowledged that 'pure experience' is not fully accessible and therefore the data contained in the present study is viewed as 'experience close' (Smith et al., 2010, p.33).

Appendix G

Flow Chart of Search Process

Flow Chart of Search Process

Results from all databases & search terms combined
N=1592



Titles & abstracts (only those with relevant titles) screened
N=1592



Excluded non relevant titles (quantitative methods, non-experiential focus i.e. impact of medication, and duplicates of these) N = 80



Excluded qualitative studies with nonsexual pain focus i.e. cancer, endometriosis, chronic pelvic pain. N= 62



Excluded remaining duplicates N = 7



Full text papers consulted N = 7



Further 4 papers identified via manual search of references of full papers consulted N= 11



Paper excluded due to absence of research format (i.e. details concerning data collection and analysis omitted) N = 10



Final papers included for review N = 10

Appendix H

Correspondence with Ethics Committees

NRES Committee East Midlands - Northampton

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839425
Facsimile: 0115 8839294

23 December 2011

Miss Sarah Louise Johnston
Trainee Clinical Psychologist



Dear Miss Johnston,

Full title of study: A Qualitative Analysis of Women's Experiences of
Vaginismus and its Treatment
REC reference number: 12/EM/0033

Thank you for your application for ethical review, which was received on 21 December 2011.
I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 19 January 2012.

Meeting arrangements

The meeting will be held in the Hothorpe Hall, Theddingworth, Leicestershire, Telephone: 01858 881500 on 19 January 2012. The Committee would find it helpful if you could attend the meeting to respond to any questions from members. Other key investigators and a representative of the sponsor are also welcome to attend. This may avoid the need to request further information after the meeting and enable the Committee to make a decision on the application more quickly.

If you have a disability and need any practical support when attending the REC meeting you may wish to contact the REC office so appropriate arrangements can be made if necessary.

If you are unable to attend the meeting the Committee will review the application in your absence.

The review of the application has been scheduled for 11.20. Would you please let me know whether or not you would be available to attend at this time. Please note that it is difficult to be precise about the timing as it will depend on the progress of the meeting. We would kindly ask you to be prepared to wait beyond the allocated time if necessary.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Covering Letter		21 December 2011
Interview Schedules/Topic Guides ✓	2	20 December 2011
Investigator CV ✓		20 December 2011
Letter of invitation to participant ✓	1	20 December 2011
Other: CV - Academic Supervisor ✓		
Participant Consent Form ✓	1	20 December 2011
Participant Information Sheet ✓	1	20 December 2011
Protocol ✓	4	20 December 2011
REC application ✓	80426/277544/1/42	20 December 2011

No changes may be made to the application before the meeting. If you envisage that changes might be required, we would advise you to withdraw the application and re-submit it.

Notification of the Committee's decision

You will receive written notification of the outcome of the review within 10 working days of the meeting. The Committee will issue a final ethical opinion on the application within a maximum of 60 days from the date of receipt, excluding any time taken by you to respond fully to one request for further information or clarification after the meeting.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

Guidance on applying for R&D approval is available at <http://www.rdforum.nhs.uk/rdform>.

There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for Leicestershire Partnership NHS Trust. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

12/EM/0033

Please quote this number on all correspondence

Yours sincerely

Miss Jessica Parfremment
Committee Co-ordinator

Email: jessica.parfremment@nottspct.nhs.uk

Enclosure: Further information about REC membership and meeting arrangements

Copy to: Sponsor/R&D Contact - Mr David Clarke



Health Research Authority

NRES Committee East Midlands - Northampton

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839425
Facsimile: 0115 8839294

27 January 2012

Miss Sarah Louise Johnston
Trainee Clinical Psychologist

[Redacted address]
[Redacted]
[Redacted]
[Redacted]

Dear Miss Johnston,

Study Title: A Qualitative Analysis of Women's Experiences of Vaginismus and its Treatment
REC reference: 12/EM/0033

The Research Ethics Committee reviewed the above application at the meeting held on 19 January 2012. Thank you for attending to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter		21 December 2011
Interview Schedules/Topic Guides	2	20 December 2011
Investigator CV		20 December 2011
Letter of invitation to participant	1	20 December 2011
Other: CV - Academic Supervisor		
Participant Consent Form	1	20 December 2011
Participant Information Sheet	1	20 December 2011
Protocol	4	20 December 2011
REC application	80426/277544/1/42	20 December 2011

Provisional opinion

- ✓ The committee stated that the layout of the Participant Information Sheet could be improved for instance the title should be at the top of the document, and the heading should be on the same page as the accompanying paragraph.
- ← The committee queried whether there was a certain point in which participants would not be able to withdraw from the study, as it is stated participants can withdraw any time during the study. You explained that this had been discussed and it would be at the point of publication of the results in which participants cannot withdraw their data, but will make this explicit in the Participant Information Sheet.

Should this be earlier?

- The committee asked you whether participants GP's would be informed of their participation, as it states in the Participant Information Sheet that as part of the support mechanism GP's would be informed.
- ✓ • The committee queried if participants become distressed during the study, the researcher can organize support via their department. You stated that this would be looked into as unforeseen.
- ✓ • The committee commented that not all participants may have had a diagnosis, and that the title indicates that this is already known, the committee felt that the title should be re-worded not to indicate anything. You explained that they were aware they should not mislead participants in any way and would consider changing the title to eliminate this assumption. *Response*
- ✓ • The committee felt that a definition of vaginismus should be given in the Participant Information Sheet for those who do not have a clear understanding of the illness.
- ✓ • The committee noted that the reply slip had not been included in the submission for ethical review. You apologised for this being missed out of the submission and would submit the document for review.
- ✓ • The committee asked you why additional consent would be taken if the interview ran over the period of one day. You explained that because it may take more than one day that additional consent would need to be taken. The committee went on to say that it is not necessary to take additional consent if it is made explicit in the Participant Information Sheet that the interview may be over a two day period.
- ✓ • The committee explained that an example of when confidentiality may be breached should be listed in the Participant Information Sheet.
- ✓ • The committee stated that the Consent Form would need amending to include a point for participants to consent to the interview being audio recorded.

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

1. The following amendments should be made to the Participant Information Sheet:
 - a) The title should be at the top of the document. ✓
 - b) A complaints paragraph should be included. ✓ *but check with Justice?*
 - c) Point 12 should include the Northampton Research Ethics Committee and remove the 'Leicester Research Ethics Committee Proportionate Review'.
 - d) Examples of researches breaching participant's confidentiality should be listed.
 - e) The withdrawal process should be explained fully.
 - f) A definition of vaginismus should be included. ✓
2. The reply slip needs to be submitted. ✓

3. The following amendments should be made to the Consent Form:

- a) The point 'I agree for the interview to be audio recorded' should be included.
- b) The point 'I agree for my GP to be informed of participation in the study' should be included.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from the Committee Co-ordinator, you are welcome to contact Miss Jessica Parfremment on 01158839425.

- ✓ When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 26 May 2012.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

12/EM/0033

Please quote this number on all correspondence

Yours sincerely

JP J. Parfremment

**Mr Ken Willis
Chair**

Email: jessica.parfremment@nottspct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to: *Sponsor/R&D Contact - LPT*

NRES Committee East Midlands - Northampton
Attendance at Committee meeting on 19 January 2012

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr John Aldridge	Senior Lecturer in Nursing	Yes	
Ms Elaine Blackshaw	Clinical Trial Manager	Yes	
Mr Alan Caswell	Lay Member	Yes	
Dr Geoff Dickens	Research Manager	Yes	
Ms Elizabeth Gibbons	Senior Research Officer	Yes	
Mr Mike Newman	Consultant Gynaecologist	Yes	
Mrs Yael Vinciguerra	Lay Member	Yes	
Mr Clive Wilkinson	Lay Member	Yes	
Mr Ken Willis	Medical Devices Manager	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Georgia Copeland	Assistant Committee Co-ordinator
Miss Jessica Parfremment	Committee Co-ordinator

Written comments received from:

<i>Name</i>	<i>Position</i>
Mrs Lorenza Francescut	Research Technician



Health Research Authority

NRES Committee East Midlands - Northampton

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839425
Facsimile: 0115 8839294

14 February 2012

Miss Sarah Louise Johnston
Trainee Clinical Psychologist

~~Nottinghamshire NHS Partnership Trust~~
~~101, 102, 103, 104, 105, 106, 107, 108, 109, 110, 111, 112, 113, 114, 115, 116, 117, 118, 119, 120, 121, 122, 123, 124, 125, 126, 127, 128, 129, 130, 131, 132, 133, 134, 135, 136, 137, 138, 139, 140, 141, 142, 143, 144, 145, 146, 147, 148, 149, 150, 151, 152, 153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 164, 165, 166, 167, 168, 169, 170, 171, 172, 173, 174, 175, 176, 177, 178, 179, 180, 181, 182, 183, 184, 185, 186, 187, 188, 189, 190, 191, 192, 193, 194, 195, 196, 197, 198, 199, 200, 201, 202, 203, 204, 205, 206, 207, 208, 209, 210, 211, 212, 213, 214, 215, 216, 217, 218, 219, 220, 221, 222, 223, 224, 225, 226, 227, 228, 229, 230, 231, 232, 233, 234, 235, 236, 237, 238, 239, 240, 241, 242, 243, 244, 245, 246, 247, 248, 249, 250, 251, 252, 253, 254, 255, 256, 257, 258, 259, 260, 261, 262, 263, 264, 265, 266, 267, 268, 269, 270, 271, 272, 273, 274, 275, 276, 277, 278, 279, 280, 281, 282, 283, 284, 285, 286, 287, 288, 289, 290, 291, 292, 293, 294, 295, 296, 297, 298, 299, 300, 301, 302, 303, 304, 305, 306, 307, 308, 309, 310, 311, 312, 313, 314, 315, 316, 317, 318, 319, 320, 321, 322, 323, 324, 325, 326, 327, 328, 329, 330, 331, 332, 333, 334, 335, 336, 337, 338, 339, 340, 341, 342, 343, 344, 345, 346, 347, 348, 349, 350, 351, 352, 353, 354, 355, 356, 357, 358, 359, 360, 361, 362, 363, 364, 365, 366, 367, 368, 369, 370, 371, 372, 373, 374, 375, 376, 377, 378, 379, 380, 381, 382, 383, 384, 385, 386, 387, 388, 389, 390, 391, 392, 393, 394, 395, 396, 397, 398, 399, 400, 401, 402, 403, 404, 405, 406, 407, 408, 409, 410, 411, 412, 413, 414, 415, 416, 417, 418, 419, 420, 421, 422, 423, 424, 425, 426, 427, 428, 429, 430, 431, 432, 433, 434, 435, 436, 437, 438, 439, 440, 441, 442, 443, 444, 445, 446, 447, 448, 449, 450, 451, 452, 453, 454, 455, 456, 457, 458, 459, 460, 461, 462, 463, 464, 465, 466, 467, 468, 469, 470, 471, 472, 473, 474, 475, 476, 477, 478, 479, 480, 481, 482, 483, 484, 485, 486, 487, 488, 489, 490, 491, 492, 493, 494, 495, 496, 497, 498, 499, 500, 501, 502, 503, 504, 505, 506, 507, 508, 509, 510, 511, 512, 513, 514, 515, 516, 517, 518, 519, 520, 521, 522, 523, 524, 525, 526, 527, 528, 529, 530, 531, 532, 533, 534, 535, 536, 537, 538, 539, 540, 541, 542, 543, 544, 545, 546, 547, 548, 549, 550, 551, 552, 553, 554, 555, 556, 557, 558, 559, 560, 561, 562, 563, 564, 565, 566, 567, 568, 569, 570, 571, 572, 573, 574, 575, 576, 577, 578, 579, 580, 581, 582, 583, 584, 585, 586, 587, 588, 589, 590, 591, 592, 593, 594, 595, 596, 597, 598, 599, 600, 601, 602, 603, 604, 605, 606, 607, 608, 609, 610, 611, 612, 613, 614, 615, 616, 617, 618, 619, 620, 621, 622, 623, 624, 625, 626, 627, 628, 629, 630, 631, 632, 633, 634, 635, 636, 637, 638, 639, 640, 641, 642, 643, 644, 645, 646, 647, 648, 649, 650, 651, 652, 653, 654, 655, 656, 657, 658, 659, 660, 661, 662, 663, 664, 665, 666, 667, 668, 669, 670, 671, 672, 673, 674, 675, 676, 677, 678, 679, 680, 681, 682, 683, 684, 685, 686, 687, 688, 689, 690, 691, 692, 693, 694, 695, 696, 697, 698, 699, 700, 701, 702, 703, 704, 705, 706, 707, 708, 709, 710, 711, 712, 713, 714, 715, 716, 717, 718, 719, 720, 721, 722, 723, 724, 725, 726, 727, 728, 729, 730, 731, 732, 733, 734, 735, 736, 737, 738, 739, 740, 741, 742, 743, 744, 745, 746, 747, 748, 749, 750, 751, 752, 753, 754, 755, 756, 757, 758, 759, 760, 761, 762, 763, 764, 765, 766, 767, 768, 769, 770, 771, 772, 773, 774, 775, 776, 777, 778, 779, 780, 781, 782, 783, 784, 785, 786, 787, 788, 789, 790, 791, 792, 793, 794, 795, 796, 797, 798, 799, 800, 801, 802, 803, 804, 805, 806, 807, 808, 809, 810, 811, 812, 813, 814, 815, 816, 817, 818, 819, 820, 821, 822, 823, 824, 825, 826, 827, 828, 829, 830, 831, 832, 833, 834, 835, 836, 837, 838, 839, 840, 841, 842, 843, 844, 845, 846, 847, 848, 849, 850, 851, 852, 853, 854, 855, 856, 857, 858, 859, 860, 861, 862, 863, 864, 865, 866, 867, 868, 869, 870, 871, 872, 873, 874, 875, 876, 877, 878, 879, 880, 881, 882, 883, 884, 885, 886, 887, 888, 889, 890, 891, 892, 893, 894, 895, 896, 897, 898, 899, 900, 901, 902, 903, 904, 905, 906, 907, 908, 909, 910, 911, 912, 913, 914, 915, 916, 917, 918, 919, 920, 921, 922, 923, 924, 925, 926, 927, 928, 929, 930, 931, 932, 933, 934, 935, 936, 937, 938, 939, 940, 941, 942, 943, 944, 945, 946, 947, 948, 949, 950, 951, 952, 953, 954, 955, 956, 957, 958, 959, 960, 961, 962, 963, 964, 965, 966, 967, 968, 969, 970, 971, 972, 973, 974, 975, 976, 977, 978, 979, 980, 981, 982, 983, 984, 985, 986, 987, 988, 989, 990, 991, 992, 993, 994, 995, 996, 997, 998, 999, 1000~~

Dear Miss Johnston,

Study title: A Qualitative Analysis of Women's Experiences of Vaginismus and its Treatment
REC reference: 12/EM/0033

Thank you for your letter of 10 February 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		21 December 2011
Interview Schedules/Topic Guides	2	20 December 2011
Investigator CV		20 December 2011
Letter of invitation to participant	2	13 February 2012
Other: CV - Academic Supervisor		
Other: Reply Slip	1	23 January 2012
Participant Consent Form	2	08 February 2012
Participant Information Sheet	2	13 February 2012
Protocol	4	20 December 2011
REC application	80426/277544/1/42	20 December 2011
Response to Request for Further Information		10 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/EM/0033

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project


Yours sincerely



**Mr Ken Willis
Chair**

Email: jessica.parfremment@nottspct.nhs.uk

Enclosures:
Copy to:

"After ethical review – guidance for researchers"
R&D Contact/Sponsor – 

DIRECTORATE OF RESEARCH & DEVELOPMENT

Director: **Professor D Rowbotham**
Assistant Director: **Dr David Hetmanski**
R&D Manager: **Carolyn Maloney**

Research & Development Office
Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Direct Dial: (0116) 258 8351
Fax No: (0116) 258 4226

15/03/2012

Miss Sarah Johnson
University of Leicester
Trainee Clinical Psychologist

Dear Miss Sarah Johnson

Ref: **UHL 11114**
Title: **A Qualitative Analysis of Womens Experiences of Vaginismus and its Treatment**
Project Status: **Project Approved**
End Date: **30/04/2013**

I am pleased to confirm that with effect from the date of this letter, **A Qualitative Analysis of Womens Experiences of Vaginismus and its Treatment** now has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust. The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed with the Sponsor. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&D Office.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Description	Version
Consent Form 08.02.2012	V2

PIS 13.02.2012	V2
Invitation Letter 13.02.2012	V2
Reply Slip 23.01.2012	V1
Protocol 20.12.2011	V4

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

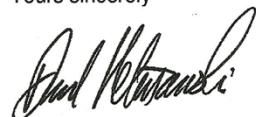
Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.

Documents listing the roles and responsibilities for all individuals involved in research can be found on the R&D pages of the Public Website. It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting www.leicestershospitals.nhs.uk/aboutus/education-and-research

The R&D Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office. Our contact details are provided on the attached sheet.

We wish you every success with your research.

Yours sincerely



Dr David Hetmanski
R&D Assistant Director

Encs: .R&D Office Contact Information

Please note that some of the documents may not apply to your study.

Appendix I

Relevant Certification Pertaining to Undertaking Research

Certificate of Achievement

This is to certify that

Sarah Johnston

successfully completed

Good Clinical Practice Training for Research (eLearning)

Date: Monday 28th November, 2011

Valid for: 24 months



Consent Assessment Certificate

(Univer

Sarah Johnson

*For study:
Women's Experiences of
Vaginismus and its Treatment*

UHL 11114

*On
23rd March 2012*



Jayna Mistry

Appendix J

Participant Information and Recruitment Documents
(Research Invitation Letter; Participant Information Sheet; Consent Form)

Dear prospective participant

Re: Research Opportunity

We are writing to invite you to take part in a research study which is being undertaken by a Doctoral degree student of Clinical Psychology at the University of Leicester. According to our records you have been identified as someone who could offer an experiential perspective relevant to the research. The title of the research study is **A Qualitative Analysis of Women's Experiences of Vaginismus and its Treatment**.

The research is interested in the experiences of women who have experienced symptoms that have prevented or made vaginal penetration difficult. This may have involved difficulties in having a smear test, using tampons and / or sexual intercourse. When a woman is unable to achieve vaginal penetration owing to tightness in her vaginal area, this is known medically as vaginismus. You may or may not have been formally diagnosed as having vaginismus or even have heard of this term before. Additionally the research is interested in exploring women's experiences of the psychological therapy received in treating these symptoms.

Please read the enclosed Participant Information Sheet as this provides further details about the research, why it is being undertaken and what you can expect if you were to participate. If after reading the information sheet you decide that you may wish to take part in this research study then please return the reply slip in the stamped address envelope provided. The researcher, Sarah Johnston, will then contact you to discuss the research study and your taking part.

Participation is entirely voluntary and this means that you will be able to withdraw from the study at any time and to have your data removed up to the point of publication if you change your mind without having to give an explanation.

It is hoped that the research will help to raise awareness of these difficulties and treatment. Thank you for taking the time to consider participating.

Thank you.

Yours sincerely

Department

Study Title

A Qualitative Analysis of Women's Experiences of Vaginismus and its Treatment.

Ethics Number: [12/EM/0033](#)

Researcher: Sarah Johnston, Clinical Psychologist Trainee, University of Leicester

Contact: Email. Sj177@le.ac.uk Telephone. 0116 223 1648

We would like to invite you to take part in a research study that is being undertaken by a postgraduate Clinical Psychology student as part of her doctoral degree course at the University of Leicester. In order to help you decide whether or not you would like to participate in this study it is important that you understand why the research is being carried out and what your involvement would be. Please take the time to read the following information in order to help you decide whether or not you would like to take part. If you have any further questions after reading this document, please do not hesitate to contact the researcher on the contact methods provided.

1 What is the purpose of the study?

This study aims to explore the experiences of women who have experienced difficulty in achieving vaginal penetration, be that sexual intercourse, smear test and / or use of tampons, and how they made sense of these experiences. When a woman is unable to achieve vaginal penetration owing to tightness in her vaginal area, this is known medically as vaginismus. You may or may not have been formally diagnosed as having vaginismus or even have heard of this term before. Additionally the research is also interested in how women experienced the psychological therapy that they received in treating these difficulties.

2 Why have I been invited to take part?

You have been invited to take part in this research because you have been identified as someone who has received psychological therapy to overcome difficulty with vaginal penetration and we would like to talk to you about your experiences.

3 Do I have to take part?

It is completely up to you whether or not you take part in this study. If you do not want to take part then it will not affect any future or current care or treatment. If you choose not to respond to this letter you will not be contacted about the research again.

4 What will you be asked about if you agree to take part?

You will be asked about your experiences and impact of your symptoms and the psychological therapy received. You will not have to talk about anything you do not wish to talk about.

5 What will happen if I agree to take part?

If you are interested in taking part you will have the opportunity to talk directly to the researcher about the research and what taking part will involve; there will be an opportunity to ask any questions you may have. Next, If you still wish to take part you will be asked for verbal consent to arrange a provisional interview date. A period of at least 48 hours will be given between arranging the date and taking part in the interview. On the day of the interview prior to it commencing, and if you are happy to still take part, you will be asked to sign a written consent form. If you choose to participate, you still retain the right to withdraw from the study at anytime and to have your data removed and destroyed up to the point of publication.

During the interview you will be asked to talk about your experiences of the physical symptoms related to your difficulty with vaginal penetration often referred medically as vaginismus.. This will either take place at the Leicester Royal Infirmary or in your home. This would be your choice. The interview will be recorded using a small digital recorder and will last approximately one hour. Should you or the interviewer feel there is more to say and if you agree then the interview may take longer than an hour or an additional interview could be arranged on another day in order to capture your experiences fully. This will be up to you and will be discussed with you at the time should this be necessary.

6 What are the possible disadvantages and risks of taking part?

During the interview you will be asked to talk about your experiences of vaginismus and the impact of these. This may stir up some emotions for you that may be difficult to talk about. You will not be pressured into talking about anything that you feel uncomfortable with and you are in control of how much information you wish to disclose. You do not have to answer all of the questions asked of you if you feel uncomfortable doing so. However, people often find it helpful to talk about experiences they have been through.

7 What are the possible benefits of taking part?

While there are no guaranteed benefits of taking part in this study you would be contributing to a piece of research that will hopefully enable healthcare professionals to learn more about how women experience and make sense of vaginismus. This may in turn also contribute to learning about ways that may help patients to get the most out of their treatment. Furthermore, as mentioned above, people generally find it helpful to discuss their experiences.

8 What happens when the research stops?

Once all of the interviews have been completed the researcher will write up the findings in a report. The information contained within the report will keep the identity of all participants anonymous. You will be offered a copy of this report if you would like one. The original recordings of your interview will be deleted from the audio recording machine as soon as they have been transcribed. Transcripts of your interview will be kept on a password-protected computer for the duration of the research in a secure file and will only be accessible to the researcher and the University research supervisor. After the research has stopped all electronic transcripts will be deleted and anonymous paper transcripts will be kept in a

secure location at the University of Leicester for 5 years. After this period all paper transcripts will be shredded by the University.

9 What will happen if I don't want to carry on with the study?

You will be able to withdraw from the study at any time. This will not influence your care in any way and you will not be contacted again by the researcher. Any interview data already provided will be destroyed upon your request up to the point of publication.

10 Further Support

If during the interview you become upset, depending on the nature and cause of your distress support from a psychologist in the department of Medical Psychology may be arranged. Alternatively if you did not wish to do this we may advise you to contact your GP. Alternatively the researcher will be able to provide you with information on where to access other sources of support. These include local counselling services and an online support group/ forum for women who have experienced vaginismus, and their partners. For further information visit <http://www.nhs.uk/Conditions/Vaginismus/Pages/Introduction.aspx>. The Leicester Counselling Service is a confidential service for people seeking emotional support and can be contacted on 0116 2558801 or visit www.leicestercounsellingcentre.co.uk.

11 Will my taking part in the study be kept confidential?

All of the information that you provide will be kept strictly confidential. No information that could identify you will be presented within the written report of the findings. However, there are limits to confidentiality which may have to be broken if the researcher becomes concerned about your wellbeing / safety or that of another. For example if you disclosed some information that suggested that you were at immediate risk of harm, or that you might act to put another at risk of harm. In these rare cases, the department of medical psychology would contact your GP. Wherever possible this will be discussed with you first.

All personal data will be stored and managed securely and will not form part of the final analysis or written report. Identifiable personal data will not be held electronically and all transcripts of interviews will be anonymised at the point of transcription i.e. your name will not be attached to your interview transcript or audio recording, instead a unique code will be used for each transcript and this will be known only by the researcher. This will help the researcher to identify your transcript in the event of you wishing to withdraw from the study.

All audio recordings will be deleted when the study and write up of the research report is completed. Raw transcribed and analysed data used during the research process will be held by the University of Leicester in a secure location for up to five years following the trainee's completion of the Clinical Psychology Doctorate.

12 What will happen to the results of the research study?

It is anticipated that the data obtained will raise awareness of vaginismus and its treatment and how women experience and make sense of their symptoms and access and experience psychological therapy. In particular the aim will be to raise awareness amongst women with vaginismus and those health professionals responsible for diagnosing, referring, and treating vaginismus. It is also anticipated that the findings from the proposed research study will lead onto and influence future research in this area.

The findings will be written up and presented in a research report format in part fulfilment towards the Doctorate of Clinical Psychology at the University of Leicester in April 2013. In addition a summary of the research study and findings will be presented in poster format and written up for submission to a relevant peer reviewed journal to be decided at a later date (e.g. the Journal of Sex and Marital Therapy or Sexual and Relationship Therapy, both of which are peer reviewed journals that feature scientific research concerning sexual dysfunction and therapeutic treatment techniques); this will take place during July – September 2013. A copy of the final report will be available from the researcher in Autumn 2013, if you wish to receive a copy please notify the researcher.

Additionally findings will be disseminated to the (details removed) Trust involved in the research and where possible presented to clinicians at psychology, gynaecological and medical departmental meetings for practitioner development purposes. In order to achieve the aim of raising awareness amongst women with or who have experienced vaginismus relevant service user forums such as the online vaginismus awareness network will also be contacted with a view to providing a summary of the research findings.

13 Who is organising and funding the research?

This study is being organised by the University of Leicester and will be funded by Leicestershire Partnership NHS trust.

14 Who has reviewed the study?

This study has been reviewed and approved by several people at the University of Leicester and by the NHS Northampton Research Ethics Committee.

15 Further information and contact details

For further information please contact the lead researcher, Sarah Johnston, at sj177@le.ac.uk or telephone 0116 223 1648.

16 Who do I contact if I have a complaint about this study?

If you feel that you would like to make a complaint about something to do with this study then please contact the following person: **Dr Sheila Bonas, Clinical Psychology, University of Leicester, 104 Regent Road, Leicester, LE1 7LT. Tel: 0116 223 1648 Fax: 0116 223 1650**

17 What to do next?

If after reading this information you are interested in taking part please send back the reply slip in the stamped addressed envelope (both enclosed). The researcher, Sarah Johnston, will then contact you via your preferred method to arrange a suitable time to discuss the study further and answer any of your questions.

Many thanks for taking the time to read this information.

Participant Identification Reference:

CONSENT FORM

Title of Project: **A Qualitative Analysis of Women's Experiences of Vaginismus and its Treatment**

Name of Researcher: Miss Sarah Johnston, Clinical Psychologist Trainee, University of Leicester

Thank you for agreeing to take part in this research project. Please read this consent form carefully.

Please initial box

1. I confirm that I have read and understand the **Participant Information Sheet Version 2 dated 13th February 2012** for the above study. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without being required to give a reason. ☐
3. I understand that relevant sections of my medical notes and/or study data may be looked at by responsible individuals from the study team, the sponsor, NHS Trust or from regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to access my records. ☐
4. I understand how the information I give is going to be stored and used by the researcher named above and I give my permission for this. ☐
5. I agree for the interview to be audio recorded. ☐
6. I agree for my GP to be informed of participation in the study. ☐
7. I understand that confidentiality may have to be breached if I disclose information that suggests that I or another person is at risk of harm. ☐
8. I agree to take part in this study. ☐

Name of Participant

Date

Signature

Name of Person taking Consent

Date

Signature

Appendix K

Copy of Interview Schedule

Semi-Structured Interview Schedule

Overall topic area: participant's experience of vaginismus and psychological therapy as treatment for their symptoms.

Range of Topic Areas to be covered:-

First knowledge of the problem / symptoms

Description of symptoms and experiencing them – can you tell me what having these symptoms means to you?

Impact & experience – were there some other aspects of your life that these symptoms affected?

Their understanding of what it meant and why they thought they had it, what they thought about it?

Seeking help / telling someone – experiencing this

Did they receive a diagnosis – experiencing this and making sense of it. Was the term vaginismus used / explained? What were they told about these symptoms? If they heard the term vaginismus – was this a new term to them? How do they think of it? Did they talk to anyone about it? How did that go? What term or way of describing their symptoms do they prefer?

Referral to a psychologist – experiencing this

Receiving psychological therapy & experiencing this

Impact of psychological therapy on symptoms and making sense of Vaginismus/ symptoms after therapy – what do they think about the therapy now? How was it for them? How do they feel about it? Has it had any lasting effects? What are these?

In order to allow the participant to tell their story and prompting them to sense make in addition to telling their story the following prompts will be used where appropriate such as:-

Why is that?

How?

What was it like for you?

Please can you tell me more / describe to me more about that

Can you tell me what you were thinking / feeling at the time?

Can you explain that a bit more?

The researcher will also avoid over use of medical terms and adopt terminology used by the participant. It is acknowledged that vaginismus may not be a term with which participants are familiar.

Appendix L

Examples of Analysis; Initial Coding and Theme Development

Example of Initial Coding For The Transcript From Interview One With Asmara

In the left column early emerging themes are noted and in the right column descriptive and exploratory comments are referenced.

<p>Something is not working.</p> <p>Searching for the answers.</p> <p>Why me? I shouldn't be experiencing this.</p> <p>It's in her head. Relaxing might help.</p> <p>The problem doesn't make sense.</p> <p>Thinking back to the past for answers.</p> <p>Regularity of the thinking, searching for answers. Always on her mind. Consuming.</p>	<p>the baby and everything [pause].</p> <p>91. R: What were your thoughts about why it was happening?</p> <p>92. [in take of breath] again all I would think about all that would go through</p> <p>93. my head is relax relax and ya know we got into such a he [husband]</p> <p>94. used to get so used to saying to me 'just relax, relax, breathe' and you find</p> <p>95. yourself holding your breath and things that you know you shouldn't be</p> <p>96. doing but I don't know I guess I just couldn't relax and the more I thought</p> <p>97. about it the more I couldn't you know and [sigh] I can't remember exactly</p> <p>98. when it was I went to counselling but she taught me all this you know</p> <p>99. breathing and close your eyes and think of things and you just try and do</p> <p>100. all that but that then was all way after my daughter was born</p> <p>101. anyway the counselling so</p>	<p><i>sighs - (frustration, disappointment?)</i></p> <p>relaxing wasn't working for her, she couldn't relax.</p> <p>Feeling examined. Wanting to find answers.</p> <p><i>skips between different timeframes.</i></p> <p>Sense that she shouldn't be experiencing this. It didn't make sense to her and in her eyes it didn't make sense to the nurses either.</p> <p><i>pause (thinking about the trigger question?)</i></p> <p>She would regularly think about the question about past events and possible triggers to the vaginismus.</p>
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<p>Something seriously wrong. Something medically wrong.</p> <p>Giving all perspectives, explanations some thought.</p> <p>Being told different things by different professionals.</p> <p>Relaxing versus tense.</p>	<p>that was a lot later on but at the time ya know in labour and things 102. you just think why does it why do I feel 103. so uncomfortable there's nothing and it kept going [pause] I kept 104. going back to when they had ol something's triggered it something 105. must have triggered it at some point your life. 106. R: and what was it like hearing that? 107. Well to be fair they are trying to give you an answer am't they 108. really they're trying to think of all possible options so it's not ya 109. know medically I don't think [pause] I always wondered if there 110. was something else seriously wrong in the back of mind apart 111. from [ok did that stay with you?] yeah I'd always thought you 112. know maybe there's something that like I'd go and see different 113. doctors thinking is somebody</p>	<p><i>pause, (thinking whether to say the next sentence?) is this about the rapport at this stage in the interview?</i> <i>'to be fair' - thinking about the experience with the GPs.</i> Describes the on-going nature of searching for answers, explanations. Describes giving this idea some thought, revisiting it. <i>'always thought' - emphasises the longstanding of this theory.</i> Idea that something seriously wrong appears more palatable than finding sex hard. <u>A sense that sex should be easy.</u></p> <p>Possibility that a different doctor might tell her something different. A sense that the answer was going to come from an external source and not herself. Believed it was a medical problem or a growth. A sense that it was not linked to relaxing or feeling tense but that there was something wrong with her.</p>
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Emerging Subordinate Themes from Participant 1 + relating final themes

① Making sense of it...

- Something seriously medically wrong (1A)
- Others ok, I'm not normal (2B)
- Would be normal if... (sexual abuse, rape, trauma) (1A)
- Unexpected and not normal (1A)
- Sometimes ok sometimes not = confusing, doesn't make sense (1C)
- Where is the problem (1D)
- Searching for explanations (1A) + (1F)
- Not having the answers (1F)
- Normal for newly weds at first... (1B)
- Were not like other couples (2A)
- Change in view of normal
- It's become normal routine
- This isn't a problem I should be having, I'm now in labour (1C)

① + ② Experiences of treatment + seeking Treatment

- Repetition - not getting the answers \ cure (1F)
- Feeling silly, embarrassed (2B) (2C)
- Communicating the problem to others \ disclosure \ not talked about (1F)
- Doing her own research on the internet (1A)
- Not a counselling issue (1A)
- Benefits of counselling (2A)
- No time pressure
- Doing something about it (1D)
- Pain becomes manageable (2A)
- It's not just me, there are other women (1G)
- Exhausting available options (1F)
- Resigning oneself to there being no cure (2A)

① + ② Psychological / emotional consequences

- Isolation
- Rumination
- Guilt
- Frustration
- Anger
- Stress
- Embarrassment
- Confusion
- Lack of control

(2C) → ① + ②

- Inadequate woman / wife (2B)
- Problem is within her (2B)
- View of self as faulty / faulty vagina (2B)

Making sense of it...

	Page/Line
Something seriously medically wrong	10:109-111 11: 115-117 35:420-430 49:596-602
Others ok, I'm not normal	70:855-860
Would be normal if... (sexual abuse, rape, trauma)	36:438-442 37:445-450
Unexpected and not normal	1:9-13
Sometimes ok sometimes not = confusing, doesn't make sense	4:45-49 22:254-256 44:535-539 44:542-544 45:550-552
Where is the problem \ pain	55:672-673 59:725-731
Searching for explanations	10:102-105 40:478-480 16:179-189
Not having the answers	3:33-35 15:164
Normal for newly weds / arranged marriage	2:21-24 17:190-193
We're not like other couples	19:223-227
Change in view of normal	3:27-31 19:223-227 70:862-870

It's become normal routine	64:780-784 72:876-877 50:616-619
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This isn't a problem I should be having, I'm now in labour	8:89
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Experiences of treatment

Page/Line

Repetition – not getting the answers \ cure	12:134-137 13:142-147 15:164-166
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Feeling silly, embarrassed	42:515-519
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Can't ask for help I'm pregnant	6:58-64 42:515-520
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Communicating the problem to others \ disclosure \ not talked about	4:39-40
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Not a counselling issue	39:466-475
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Counselling might make sense of it	23: 273-276
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No time pressure	26:313-314 29:352-354
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Doing something about it/ progress	40:488-492 53:652-661
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Pain becomes manageable / self managing	63:766-771
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It's not just me, there are other women	31:379-386
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Resigning oneself to there being no cure	49:608-610 62:760-765
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Psychological / emotional consequences

	Page/Line
Isolation	17:196-198 19:223-226 66:807-813 71:871-875
Rumination	18:212-214 47:571-575 55:674-678
Guilt	54:659-661
Frustration	13:149-151
Anger & Fear	69:850-854
Stress	46:568-571
Embarrassment	
Lack of control	47:573-574
Inadequate woman / wife	20:229-238 46:558-562 54:664-667 56:688-693 57:698
Problem is within her	54:668-673
View of self as faulty / faulty vagina	

Final superordinate and corresponding subordinate themes across cases

Superordinate Theme	Corresponding Subordinate Themes
<p><u>1. What's going on, why's it not happening?</u></p> <p>Relates to the attempts of the women to make sense of their vaginismus and illustrates the different ways in which they attempted to do this, including aspects that led to further confusion and their frustrations with not getting answers or solutions.</p>	<p>A. Hypothesising</p> <p>B. Normalising</p> <p>C. It doesn't make sense</p> <p>D. When it becomes a problem</p> <p>E. Something seriously medically wrong</p> <p>F. Not getting anywhere</p> <p>G. So this is actually something</p> <p>H. By the way I'm pregnant</p>
<p><u>2. It's not just about sex and pregnancy</u></p> <p>Relates to the various impacts of vaginismus in addition to loss of sex and fertility, including the impact of not finding a cure, impact on identity as a woman and the psychological consequences associated with their experiences.</p>	<p>A. Not cured</p> <p>B. Not a full woman</p> <p>C. Miserable place</p>

Appendix M

Chronology of Research Process

Chronology of Research Process

January 2011	Submission of three initial research ideas to University of Leicester
March 2011	Allocation of research Supervisor
March 2011	Development of research question
March – May 2011	Development of research proposal and initial submission of proposal to University of Leicester for peer review
May 2011	Begin Literature review
May 2011 – Dec 2012	Liaison with NHS Trust department from which proposed sample to be drawn
July 2011 – Dec 2011	Amendments to research proposal & finalisation of proposal
Dec 2011	Submission to Ethics committee and liaison with local R&D
Jan 2012	Attend Ethics committee
Jan 2012	Amendments to protocol following ethics committee
Feb 2012	Ethical approval awarded
Feb 2012	Submission to local R&D
March 2012	R&D approval awarded
April 2012- Oct 2012	Recruitment
June 2012- Dec2012	Interviews
June 2012 – Feb 2013	Transcription and analysis
Jan-April 2013	Finish write-up of thesis
April 2013	Submission of thesis

