Making Sense of Relationship and Sexual Adjustment in Heterosexual Couples Living with Vulvodynia: An Interpretative Phenomenological Analysis

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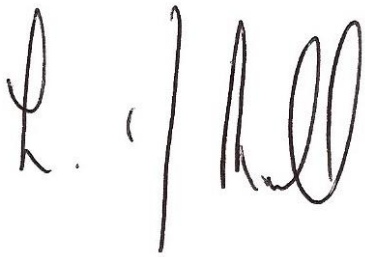

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Abstract

The significant impact of vulvodynia on women has been acknowledged increasingly within research. However, the role of gendered and sexual cultural discourses shaping construction and embodied experience of sexuality in mixed sex couples' coping vulvodynia has received minimal attention. This research investigated the lived experience of couples with vulvodynia, their navigation of gendered and hetero-normative discourse, and relational and sexual adjustment. The aim was to identify what, if any, changes and renegotiations took place whereby women with vulvodynia and their partners could find alternative ways of relational and sexual expression and diversity of pleasures.

The research was undertaken with 14 participants, in 7 heterosexual couples using a qualitative methodology: interpretative phenomenological analysis underpinned with a feminist phenomenology episteme. Four overlapping superordinate themes emerged (1) Gendered Identity (2) The Relational (3) The Sexual (4) Burden. Women did not report vulval pain as being the central issue, rather they felt the idiopathic condition of vulvodynia affected their sense of self, body and gendered identity, which was perceived in many ways as analogous to loss of self, sexual identity and sexual pleasure. Men however, reported that the vulval pain experienced by their partner was a central issue, because it affected their own sense of self and for some, loss of sexual function and maleness.

The research shows that adjustment is often avoided and defended against in repetition due to difficulties in developing the capacity for adjustment confounded by socio-cultural norms and beliefs. The analysis identifies, and uniquely explains with feminist phenomenology concepts and hermeneutic circles of understanding, the effects of cultural norms of gender, sex and sexuality in couples with vulvodynia, invoking repetition, which threatens; yet can open up possibilities for adjustment. The analysis from the study indicates a need for healthcare professionals and psychosexual therapists to acknowledge socio-cultural discourses of gender and sex that shape the possibilities and constraints for women with vulvodynia, and their partners in the couple sexual relationship. Moreover, the analysis indicates an

importance of changing the experience of women with vulvodynia of their own bodies and pleasures; and the experience of couples to re-negotiate their unique sexual relationship with attunement and re-embodied desire to develop the coherence needed for the emancipation of the imprisoned body and mind. This research gives emphasis to healthcare professionals and psychosexual therapists working with sexualities: bodies, desires and imagination; in clinical practice to support couples to re-negotiate their unique sexual relationship and adjustment to vulvodynia.

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1.0 Introduction

Vulvodynia is the experience of idiopathic pain characterised by burning, soreness, or throbbing in the external female genitalia or vulva (Nunns and Murphy, 2012). Localised provoked vulvodynia is a subset of the condition that refers to pain localised to a particular area of the vulva and provoked by touch (Lev-Sagie and Witkin, 2016). Vulvodynia is experienced by 4-16% of the female population in the U.S. (Eppsteiner, Boardman, and Stockdale, 2014), with no UK population estimates available. Reed (2012) suggests however, that vulvodynia affects approximately 8% of women at any one time. The rate of first onset of vulvodynia in women is greatest before the age of 25 (Harlow et al., 2014). Prevalence is similar in African-American women and white women however; Hispanic women are 1.4 times likely to experience vulvodynia (Harlow et al., 2014).

Research has explored several causative factors including neuropathic pain, psychosocial influences, and infection; however, etiology remains definitively unknown (Harlow and Stewart, 2003). Research shows that women see an average of five healthcare practitioners before receiving a diagnosis (Nguyen et al., 2016), leading to many to report feeling judged, disbelieved or dismissed (Lepage and Selk, 2016; Shall-Cross et al., 2018). Successful therapy involves a multidisciplinary approach (Eppsteiner et al., 2014), which is often not available in mainstream healthcare services for this complex and not fully understood condition. Some studies have found that women and their partners are interested in including sex therapy as part of their treatment, (Lepage and Selk, 2016; Piper, et al., 2012).

The subjective impact of vulvodynia is idiosyncratic, but common difficulties include using sanitary products, sitting, wearing trousers or tights, engaging in penetrative sex, or exercising, which in turn impact on women's day-to-day functioning, including work, leisure and caring activities. Vulvodynia also impacts on intimate relationships and psychological wellbeing, including increases in depression, anxiety, and low self-esteem (Gates, 2001; Gates and Galask, 2001; Sackett et al., 2001). Social

constructions around sex and womanhood also exacerbate psychological difficulties by silencing, and increasing shame, and guilt at not being able to “perform as a woman,” which often causes women to feel de-gendered and no longer “a real woman” (Ayling and Ussher, 2008; Kaler, 2006; Marriott and Thompson, 2008; Frith, 2013; Bond, 2015; Webber et al., 2020).

Vulvodynia is associated with female sexual pain and relational consequences. These may include negative relational dynamics such as frequent arguments, sexual communication difficulties, less intimacy, less closeness and relationship dissatisfaction between women and their partners (Meana, 2012). Given vulvodynia pain occurs mainly during partnered sexual activities and has effects on both members of the couple, its intimate interpersonal context represents a significant aspect of the pain experience (Bois et al., 2016). Studies on the experience of vulvodynia within couple relationships are very limited. Most have focused exclusively on the associations between behavioural partner responses to pain and women’s sexuality, relied on self reports measures, and often included only one member of the couple, limiting their ability to capture the complexity of couples’ intimate interactions (Desrosiers et al., 2008).

This paucity of research is surprising, given that the couple relationship is considered to be an important factor in individuals’ sexual and relational adjustment to persistent pain (Cano and de C. Williams, 2010). Furthermore, there is minimal empirical evidence about relationship and sexual adjustment in couples coping with vulvodynia from a qualitative research methodological perspective (Connor et al., 2008; Sheppard et al., 2008). There exist a number of couple studies using quantitative methodology but with variable design and sample limitations, with the majority of studies emanating from North America, specifically Canada (Smith and Puckall, 2011). The interpretative understanding of relationship and sexual adjustment in individuals within couples coping with the unique features of vulvodynia has received very little empirical attention to date.

Sex and sexuality with its perceived centrality to human experience, has always been a prime focus of clinical and theoretical debate, as well as controversy. Sexual desire and behaviour can reflect attachment style, be affected by loss, trauma and health conditions and is influenced by neurobiology. Assumption about, expectations of, and even enjoyment of sex, are shaped by gender identity that is itself often an unconscious product of a historically binary and normative socio-culture. We live in

western society that seems both obsessed with, and yet ashamed of, sex; a paradox that extends to the clinic room where healthcare professionals and therapists can often find themselves uncertain about, and avoidant of, working with patient's sexualities, sex, most intimate desires and the erotic aspects of transference, in their coping and adjustment to health conditions. Working with sexualities, bodies, desires and sexual practices are important when supporting couples with vulvodynia towards adjustment, combined with an in-depth knowledge of ones own sexuality and ethical responsibilities towards individuals and couples.

1.1 Statement of the Problem

Living with vulvodynia, and with vulval pain in heterosexual couples, are primarily subjective experiences. Little is known about the personal framing and meaning making of the lived experience of women with vulvodynia and their partners in couple relationships. Extant research has not fully conceptualised the ways in which the lived experience of subjectivity, (hetero) sexuality, gendered identity, and sexual pleasures are affected by vulvodynia in couple relationships. Furthermore, there is scarcity of research about couples living with vulvodynia and the intra and interpersonal influences likely to mediate the trajectory for coping with, and adjusting to vulvodynia.

Therefore, in making sense of the relational and sexual adjustment, or otherwise, in couples with vulvodynia, there is a strong argument for a qualitative (interpretative) research methodology to be used to fully explore and give meaning to the individual underlying subjectivity, sexuality, and gendered identity, within the intimate couple relationship. Given the limited research studies reported about couples living with vulvodynia, this study will illuminate original thinking and contribute a new unique body of work to inform clinical practice and equip healthcare professionals and psychosexual therapists to work more confidently with the complex condition of vulvodynia. This important study addresses the gap in research in the important area of relational and sexual adjustment in couples living with vulvodynia. Adjustment for the purposes of this study refers to the psychic and behavioural processes of balancing needs, and needs challenged by obstacles in the environment.

Before addressing the research problem specifically, it is helpful to explore current

contemporary sexology in clinical practice, and relevant feminist philosophical and phenomenological literature, to provide a contextual backdrop to the historical and socio-cultural experience of women and sex in western society. Feminist theorists and philosophers have demonstrated substantial insight into socio- cultural constraints on women, and, as a consequence, understand the important, yet problematic of woman's sexuality and sexual pleasure, gendered identity, subjectivity and lived body. Feminist phenomenologists have made an invaluable contribution in illuminating the gendered dimension of lived embodiment and made visible the irreducibly situated and contextual nature of (gendered) bodily subjectivity. Exploring the work of feminist theorists, philosophers and phenomenologists has relevance to this study because it will highlight the constraints, which may impede the development of women's agentic sexual subjectivity (through the lived body), but also their capacity for resistance and re-negotiation in adjusting to vulvodynia with their couple partner. This chapter presents the contextual landscape in sections as follows: Contemporary Sexology in Clinical Practice; Sexuality; Gendered Identity; Subjectivity; and The Lived Body.

1.2 Contemporary Sexology in Clinical Practice

Nicholson (1993) a feminist psychologist has identified three prevalent discourses operating within contemporary sexology. These include the biological imperative, the coital imperative, and the orgasmic imperative. The biological and coital imperatives dictate that penile - vaginal intercourse is a 'natural' and 'normal' sexual activity between women and men, as it serves procreative purposes for the species. The orgasmic imperative posits that all sexual activity culminates most healthily; and most pleasurably, in orgasm. The prevalence of a teleological and hydraulic model of sex is associated with male centred versions of sexual pleasure. Sexological discourse has been criticised by feminists for its masculine ideology. A further feminist criticism of sexological discourse is that it produces gendered modes of understanding and experiencing the sexual that restricts both female and male sexual pleasure, which are pertinent to this study.

Feminist sexology literature reveals that the medical profession has been characterised by phallocentrism and constructed within androcentric views of sexuality (Maines, 1999). This is particularly in regard to sex whereby "real" sex equals penetration of the vagina by the penis (coitus), placing this particular sexual act as central to "normal" heterosexuality (McPhillips et al., 2001; Maines, 1999). As well

viewing penile erections as the essence of male sexuality and satisfaction, and the expectation of female submission to provide pleasure and meet the sexual as well as the emotional needs of men (Du Plessis, 2015). As such, feminist sexology literature demonstrates how these factors impact upon women's experience of sexuality by restricting her sexuality to a framework that is inflexible and limited in possibilities to penetration. From a political and cultural perspective, sexology and sex therapy's inattention to factors like social and cultural context, gender construction, and hetero-normativity; its reliance on limited and intercourse-centred diagnoses; and its neglect of preventive sex education, mark it as still narrow and politically conservative (Irivine,1990).

There are many challenges in the treatment of vulvodynia and the optimal espoused model is a concurrent interdisciplinary one (Bink and Meana, 2009). The model advocates for a treatment team (e.g. Dermatologist, pain specialist, gynaecologist, psychosexual therapist and physiotherapist) working concurrently and collaboratively on the individual's presentation of difficulty. This co-ordination is complicated by the variable availability of such healthcare professionals, their training and education in sexuality, inter-disciplinary communication, and funding. A second challenge is that partners are not routinely invited to clinical consultations and when they are invited, often partners decline to attend. Given vulvodynia triggers pain in the intimate sexual relation, involving the partner in clinical consultations is important. One member of the couple may consider lack of pain to be a treatment aim, while another may consider the treatment aim to be a certain frequency and spontaneity of intercourse and orgasm. A checking on the expectations of both members of the couple in the clinical consultation is helpful, although it does not always result in agreement. A third challenge is the use in clinical practice of assigned 'home-work' exercises (e.g. pelvic floor stretches, mindfulness exercise, vaginal dilators, sensate focus) and client feedback, for these can lead to feelings of disappointment, avoidance, resistance and even perceived failure. Assigned exercise can also reinforce normative sexual performance and leaves out pleasure, and the immeasurable joys of erotic connection in the individual and couple. A fourth challenge is medicine's binary and dominant model of sexual dysfunction with diagnosis conferred according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). The DSM -5 has a four-category classification of dysfunctions, it embraces medical language, and specifies

which sexual problems are legitimate, namely desire, arousal, orgasm, and pain dysfunction, and ignores everything else, namely causal influences. Furthermore, it categorises sexual dysfunctions in a universal, reductionist, standardised, and normative "healthiest" model of sexuality, the "human sexual response cycle" of desire, arousal and orgasm, ignoring innumerable historical and cultural permutations of sexual meaning, priority, and script (Tiefer, 2012,p.26).

An important, but often overlooked clinical consideration is that 'unlike most pains, the unique pain associated with vulvodynia occurs in the context of a gendered and socio-culturally valued activity- sexual intercourse' (Weeks, 2015, p.206). Moreover, vulvodynia involves sexuality, which is likely to be significantly influenced by intra-psychic, lived body, interpersonal, and societal-cultural factors (Weeks, 2015, p.207). Women often lack sexual knowledge, anatomical knowledge, knowledge of general sexual functioning, which can reinforce traditional female ideologies of passivity, compliance, concern for others and agreeableness (Tolman et al., 2006; Webber et al., 2020). Women's body self consciousness and body surveillance can undermine sexual pleasure and sexual functioning (Curtin et al., 2011). There is a multiplicity of issues to consider, including relational, that can affect a woman's sense of sexual agency and embodiment, and which need to be taken into consideration, alongside the complex and enduring presentation of vulvodynia, in order to facilitate adjustment.

Central for this study's exploration is the lived experience of women of sexual genital pain within the intimate couple sexual relationship arising from vulvodynia; a Genito Pelvic Pain/ Penetration Disorder (DSM- 5) (APA, 2013), which is intrinsically linked with sexuality, gendered identity, subjectivity and the female body. This critique of contemporary sexology and its prevailing dominant and constraining hetero-normative discourse has relevance to this study when considering alternative clinical approaches and interventions provided by healthcare professionals and psychosexual therapists going forward, in connection with relational and sexual adjustment in couples with vulvodynia. It is my assertion that the concurrent interdisciplinary working model must go beyond a diagnostic and treatment approach, which focuses primarily on the management of pain and a treatment goal of pain free sexual intercourse, which inevitably privileges the genital tie.

1.3 Sexuality, Gendered Identity, Subjectivity and Lived Body

This section critically and comparatively discusses how European philosophy and post structuralist feminist writers understand the important, yet problematic of woman's sexuality and sexual pleasure, gendered identity, subjectivity and lived body. This contextual landscape gives insight into women's historical and contemporary position in western society, which is pertinent to women with vulvodynia, specifically given the multitude of pressures and expectations they face as individuals and in relation. The approach taken begins with the developmental intertwining of the historical and social, with the mind and lived body, in the field of sexuality, without reducing it to either.

1.3.1 Sexuality

Woman's sexuality and sexual pleasure has always been conceptualised as problematic. The regulation, control and measurement of female sexuality and sexual pleasure, in particular the careful distinction between normality (healthy sexuality) and abnormality (dysfunction/disorder) has a long and chequered history. These approaches have laid the foundations for a reductionist view when conceiving a woman's sexual pleasure. If a woman does not feel sexual desire, achieve orgasm or is unable to have penetrative sex- there is sexual dysfunction. If there is sexual pain of unknown origin she is making it up, and hysterical, or worse still, unstable and mentally ill (Lepage and Selk, 2016).

Western knowledge about female sexuality prior to the nineteenth century has been attributed mainly to the ancient Greeks, specifically Aristotle, fourth century philosopher. Aristotle attempted to explain human reproduction, arguing the different roles for females and males, with the female being "passive" and the male being more significant ("effective" and "active"). For Aristotle, women were perceived as being cooler than men, and therefore less perfect. A second century physician, Galen asserted that women were physiologically inverted, hence less perfect men. He argued the vagina was "an externally, precariously, unborn penis, the womb a stunted scrotum" (Laqueur, 1990,p.28). Until the mid eighteenth century women's bodies were perceived as 'fundamentally' similar to men's, "not a different sex, but a lesser version of the male body" (Oudshoorn, 1994,p.6).

Lacqueur (1990) suggests the shift from a one- sex model to a two- sex model

coincided with the socio-political unrest of the French Revolution. In an attempt to restore social order, scientists at the time assigned social roles to men and women, justified by the 'natural' bodily differences between sexes. As Lacqueur (1990, p.149) posits: "sometime in the eighteenth century sex as we know it was invented". The biological and physiological difference between females and males provided assumptions about the nature of 'heterosexuality', positioning women as weaker, passive and inferior, and men as more active, stronger, superior, and positioning penile-vaginal penetration as 'natural' and central to all conception of human sexuality. Notwithstanding the shift to the two-sex model, the insistence on the normativity of male anatomy and, by association, the masculine sexual role- persists into twenty first century accounts of sexual pleasure.

Within theological discourse again, males maintained their superior active position; sexuality was "essentially male", a biological instinctual drive, while women were positioned as either passive: "the asexual pure Madonna" or, if active, as seductive and dangerous, the whore or witch (Ussher, 1993 pp.10-11). In the eighteenth century sexual pleasure was in general problematic, particularly for women, who were constructed as maternal rather than sexual. Women who enjoyed sex, deemed a licentious lust stimulated by the devil were categorised as ill, mad or 'imperfect' (Bullough, 1994). Women manifesting desire for men outside wedlock, or sex during menstruation, pregnancy or old age undoubtedly would have been contained, controlled and certainly not understood.

For Foucault (1978) French philosopher, sexuality is constructed in social discourse. In his theory, discourse involves a relationship between knowledge expressed in a certain language; and power (Dreyfus and Rabinow, 1982). Discourses are "ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations, which inhere in such knowledge and the relations between them"(Weedon, 1987,p.108). Within the particular discursive field of sexuality there may be numerous competing ways of, "giving meaning to the world" (Gavey, 1989,p.464). These multiple discourses cohere or contradict as they create meaning. Dominant discourses are those that are more powerful within a society; they have firm institutional bases, and are so ubiquitous that they appear to be natural, universal and inevitable (Weedon, 1987).

For Foucault, language is not transparent, reflecting any actual reality. Further it is not possible to gain ‘pure insight’ into a given field of knowledge, for example sexuality, because any “perception is always structured by existing discursive arguments” (Crowley and Himmelweit, 1992,p.237). If “ sex has no essential nature” (Weedon, 1987,p.119) then sexual meanings cannot be thought of as neutral or objective; rather they harbour important relations of power (Weeks, 1985). Discourses of the sexual can thus be thought of as playing a crucial role in the social control and measurement of sexual practices in western society (Pringle, 1992).

In regulating our perceptions of the world, discourses also construct our perception of our self: our body and subjectivity. For Foucault, there cannot be any access to a ‘natural ‘ body; to a fundamentally stable, essential physical being, which exists prior to or apart from family, social, political and cultural influence and practices (Bordo, 1988). Subjects, then, are governed through the deployment of the body within sexual discourses, which “constitute the ‘nature” of the body, unconscious and conscious mind and emotional life of the subjects they seek to govern” (Weedon, 1987,p.108). For Foucault, sex is the most speculative, most ideal, and most internal element in a deployment of sexuality organised by power in its grips on bodies and their materiality, their forces, desires, sensations, and pleasures (Foucault, 1978,p.155).

Gavey (1992,p.329) uses the term social technologies and effects of (hetero) sexuality coercion, which includes the media, advertising, novels and magazines, television and cinema, pornography, medicine and of course, psychosexual therapy, each of which produces its own discourse of both hegemonic and non-hegemonic sexualities and so called ‘normal and ‘abnormal sexual practices. The idea of sex as a natural act permeates through this medium ensuring women; their sexual pleasure and desire are understood according to this paradigm (Tiefer, 1995). Consequently one can see how a woman will come to understand her sexual subjectivity, make meanings about sexual pleasure, and be saturated within the dominant cultural and social discourses. Ussher (1992), influenced by both de Beauvoir, existentialist philosopher, and Foucault, comments that ‘the female body is at the centre of the discourse, which defines and controls women. To speak of woman is to speak of the body, as femininity has been located within the body, and is constructed by the body. There is a physical, sexual, fertile body, which houses women’s danger, women’s power and women’s

weakness. Women, do not own this body, for it has been taken away from them by the phallocentric, hetero-normative discourse which represents women as ‘the Other’, as the not ‘I’, as somehow lacking- as the second sex’ (p.31).

In The Three Essays on the Theory of Sexuality (1986), Freud described his foundational project about psychosexual development and asserted that sexual identity was psychically constructed, not merely anatomically determined. For Freud the Oedipus complex offers a concept which gives form to the sexual identity and sexuality of a woman and man, albeit more controversial and ambiguous in the former. The Feminist poststructuralist philosophers and phenomenologists, which include Karen Horney, Julia Kristeva, Luce Irigaray and Iris Marion Young, variously critique the masculinist prescriptions of female sexuality showing how binary configurations, for example active/passive, body/mind and phallic/castrated - exist to delimit woman, her sexual pleasure and expression.

Horney (1885-1952) was a source of inspiration; she made an early and unique feminist psychoanalytic contribution about woman and woman’s sexual pleasure in her theory and clinical work within the prevailing social and cultural context. Indeed, her work on Inhibited Femininity (1993:1926) holds relevance to some of the current presentations of women seeking help with sexual difficulties, such as vaginismus, a condition often comorbid with vulvodynia, associated with anticipation of, or actual, experience of vulval pain.

Julia Kristeva feminist philosopher in her descriptions about the positionality of woman refuses to define ‘woman’ commenting: to believe that one “is a woman” is almost as absurd and obscurantist as to believe that one “is a man”. She continues, “I therefore understand by “woman”, ‘that which cannot be represented, that which is not spoken, that which remains outside naming and ideologies”. Kristeva does not have a theory of female sexuality, nor of womanliness but a theory of marginality, subversion and dissidence. Woman can thus be defined as marginal by patriarchy, the same for other struggles against a centralised power structure. “Call it ‘woman’ or ‘oppressed classes of society’, it is the same struggle, and never the one without the other” (La Femme, 1974).
This is interesting because it allows an assumption that, if Kristeva had a theory of

female sexuality and womanliness it would be that, which is marginalised by patriarchy. Her emphasis on marginality allows viewing the woman in terms of positionality rather than of essence, so what is perceived as marginal depends on the position one occupies, inside or outside, and a border passable in both directions. In her work there is a sense of misogyny, a sense of disgust of, and revulsion with the essence of “woman”. Her descriptions written in Power of Horrors: An Essay on Abjection (1982) potentially illuminates this. There appears contradiction in the essence of her work, which is sometimes unfathomable, limitless and unbounded. However, this may be the salient point she is making about woman, her sexuality and sexual pleasure.

Luce Irigaray, feminist philosopher and psychoanalyst has been one of most major contributors in providing a different and most influential proposition about woman, her sexuality and sexual pleasures. Irigaray’s argument is that woman is outside representation; woman is the negative required by the male’s ‘specularization’. Woman is not only the other, as de Beauvoir discovered, but is quite specifically man’s other: his negative or mirror image (1985b). For Irigaray, woman’s form is repressed by patriarchal phallocentrism, which denies woman access to her own sexuality and sexual pleasure.

Irigaray in her attempt to establish a theory of sexuality and sexual pleasure, describes the woman’s morphology, which she rather obscurely takes to be different from her anatomy (2011, pp.163-164). She positions femininity as plural and multiple: woman’s economy is not specular. Her sexuality is inclusive: she does not have to choose between clitoral and vaginal pleasure but can have it both ways and more. Irigaray argues in, This Sex which is Not One (1985a) that woman’s sex is not one: her sexual organs are composed of many elements and her jouissance is therefore multiple, non-unified, endless: “A woman ‘touches herself’ constantly without anyone being able to forbid her to do so, for her sex is composed of two lips which embrace continually. Thus, within herself she is already two, but not divisible into ones, who stimulate each other “ (1985a p.24).

Irigaray does not privilege the vagina; instead she gives privilege to, the sense of touch, as the following illustrates: "So woman does not have a sex organ? She has at

least two of them, but they are not identifiable as ones. Indeed, she has many more. Her sexuality, always at least double, goes even further: it is plural ... Indeed, woman's pleasure does not have to choose between clitoral activity and vaginal passivity, for example the pleasure of the vaginal caress does not have to be substituted for that of the clitoral caress. They each contribute, irreplaceably, to woman's pleasure. Among other caresses ... Fondling the breasts, touching the vulva, spreading the lips, stroking the posterior wall of the vagina, brushing against the mouth of the uterus, and so on" (1985a.pp.63-64). "To evoke only a few of the most specifically feminine pleasures. Pleasures which are somewhat misunderstood in sexual difference as it is imagined - or not imagined, the other sex being only the indispensable complement to the only sex." (1985a.p.28).

In this section one can see the problematic historical and contemporary position of woman, her sexuality, desires and sexual pleasures. This has significant relevance to the women (and men) in this study because socio-cultural norms and beliefs operating powerfully and repetitively define how women should live their sexualities. This can prove difficult to navigate, when a phenomenon, which is intimately bound up with the territory of sexuality exists, such as vulvodynia, disrupting normative and compulsory heterosexuality. How this is navigated and negotiated in heterosexual relationality is critical to adjusting to vulvodynia in the couple sexual relationship.

1.3.2 Gendered Identity

Butler, feminist philosopher sees gender as a historical, binary construct in modern western society: a two-binary construct of femininity and masculinity. Gender is a regulatory power of coherence in the social and operates within the set of powerful discourses within the institution of sexuality. Gender is an affect of the discourses. For Butler in her work (1990; 1993; 2004) the subjection of our bodies to such normalising practices becomes viewed, not only as a way in which already sexed bodies seek to approximate an ideal, but as the process whereby sexed subjects come into existence at all. Butler builds on de Beauvoir's claim that we *become* differentiated as women and men, rather than being born as such. De Beauvoir's comment " One is not born a woman, but rather becomes one" indicates that it is civilisation as a whole that elaborates this intermediary product between female and the male. Butler critiques de Beauvoir stating, that at the most basic level, one is perhaps born a given sex with a

biological facticity, but that one becomes one's gender that is, one acquires a set of cultural and historical significations, and so comes to embody an historical idea called "woman". Butler goes on to assert, that if one becomes a woman, according to de Beauvoir then one is always in the process of becoming a gender, and the process itself has no teleological end. In this sense, then gender is a project (1990).

Butler posits the theory that, one does not become a gender through a free unrestrained choice, for gender identity is governed by a strict set of taboos, conventions, and laws. There is shame when we are told we are somehow doing our gender wrong, that we have failed in some way to measure up to the cultural norms and expectations. If one becomes one's gender, one does it within a network of gender rules and relations. From birth, the body is culturally signified by a language and a set of institutions that immediately classify the infant as either female or male even before naming- in a sense Butler says, "we are bodies in culture" (1990).

Butler's performative account of gendered subjectivity in Gender Trouble (1990) has dominated feminist theory. She rejects the view that gender differences, with their accompanying presumptions of heterosexuality, have their origin in biological or natural differences. She explores by what means a unity of biology, gendered identification, and heterosexuality comes to appear natural. Butler views discourses as productive of the identities they appear to be describing. The effect of repetition of acts, for example gendering infants at birth, makes it appear that there are two distinct natures, female and male. These gendered performances are ones which we act out ourselves and which others act out in relation to us. They are acted out in accordance with social scripts prescribing ideals, which are unrealisable, but which nonetheless provide the framework for our everyday activities. These dominant ideals reinforce the power of certain groups; e.g., men and heterosexuals, over others. These others: women, gay people, trans and gender non-conforming people, those with differently abled bodies, or bodies differently shaped from the dominant ideal, are treated socially as outsiders, "the abject", and subject to social punishments.

"Indeed, the performance is affected with the strategic aim of maintaining gender within its binary frame – an aim that cannot be attributed to a subject, but, rather, must be understood to found and consolidate the subject" (1990, p.191). Butler emphases

the way in which gendered performances incorporate a presumptive heterosexuality, which she rejects. She asserts that gendered identity and performance is precarious and open to destabilisation.

Vulvodynia is an example of a destabilising affect on the normative links between gender and heterosexuality arguably because gender has become over-determined, and the social field is so rigid and concrete about gender. Women and men have become so narrowed down in contemporary western culture because of the fixivity of gendered hetero-normative practices. Given that gender is imposed, assigned and navigated we must take up a position in the social. The problematic is gender incites the life of sexuality and this impinges negativity, more often than not for women; particularly women who are unable or unwilling to engage in penile-vaginal intercourse due to vulvodynia.

In the context of the women (and men) in this study one must consider gender as a defence due to the precarity of fully inhabiting one's gendered subjectivity which is already hunkered down in the grip of binary, reduced-down hetero-normative constraint; and further destabilised and impinged by the presence of vulvodynia in the couple sexual relationship. Conceivably, the clinical imperative is to loosen gender so women with vulvodynia (and their partner), can be freed from the constraints of gender that is repeated and fortified in its performance in the social.

1.3.3 Subjectivity

This section explores feminist philosophical and phenomenological theory about woman's lived experience, meanings and consciousness at a bodily intra- subjective and inter-subjective (relational) level. In their accounts feminist philosophers provide a critique of normalisation, subjectivity and subjugation, and in doing so offer ways for women to redefine themselves on their own terms. This is highly applicable to the contemporary moment and particularly this study because women, as subjects take on ways of bodily being in the world in order to comply with social norms, including relational and sexual norms. Accordingly, women's bodily subjectivity can often become vulnerable to the expectations of the normative when coping with vulvodynia, making attempts to effect change difficult, leading to subjugation (Butler, 1997; Foucault, 1979).

Since Plato, western socio-culture only recognises one form of subjectivity, the male subjectivity. The male is the subject and the woman as the object of desire, the so called Other. This position is invariably challenged and critiqued by feminist thinkers in this section. De Beauvoir, feminist philosopher asserts in The Second Sex (2011) that man views himself as a universal subject and that women are only seen in relation to him. He is the subject, the absolute, woman is the Other. De Beauvoir was troubled by this recognising in the social that women do not positively posit themselves as subjects. Her project was, 'What is a Woman?' and… 'Why do women acquiesce in male dominance?' Her answer was, for women to choose freedom and to develop ones self. 'Humanity is male, and man defines woman, not in herself but in relation to himself, she is not considered an autonomous being.....A man's body has meaning by itself, disregarding the body of the woman, whereas the woman's body seems devoid of meaning without reference to the male. Man thinks himself without woman. Woman does not think herself without man. She is nothing other than what man decides.....she determines and differentiates herself in relation to man, and he does not in relation to her: she is the inessential in front of the essential. He is the Subject. He is the Absolute. She is the Other' (pp.5-6).

De Beauvoir said that men are at an advantage in a society that 'Others' women, not just for the benefits they reap, but also 'within' themselves. Men, from boyhood onwards, can enjoy their vocations as human beings without anyone telling them their vocation contradicts their 'destiny' as a lover, husband or father, or that their success lessens the likelihood that they will be loved. But for a woman, she must renounce her claims to what de Beauvoir calls 'sovereignty', to have a vision for her life, to pursue her own projects, because this is perceived to be unfeminine. This places women in a lose-lose situation: should she become herself that, means becoming unlovable. De Beauvoir wrote about the 'feminine condition' 'that women were condemned to feel divided, to become a 'split subject'. The root of the problem is that 'the individual is not free to shape the idea of femininity at will' in patriarchal socio-cultural western society.' Every subject posits itself as a transcendence concretely, through projects.....there is no other justification for present existence than its expansion towards an indefinitely open future. Every time transcendence lapses into immanence, there is degradation of existence into 'in-itself ', of freedom into facticity; this fall is a moral fall if the subject

consents to it; if this fall is inflicted on the subject, it takes the form of frustration and oppression; in both cases it is an absolute evil' (2011, p17). She continues; 'every individual concerned with justifying his existence experiences his existence as an indefinite need to transcend himself. But what singularly defines the situation of woman is that being, like all humans, an autonomous freedom, she discovers and chooses herself in a world where men force her to assume herself as Other; an attempt is made to freeze her as an object and doom her to immanence, since her transcendence will be forever transcended by another essential and sovereign consciousness. Woman's drama lies in this conflict between the fundamental claim of every subject, which always posits itself as essential, and the demands of a situation that constitutes her as inessential' (2011, p 17).

De Beauvoir had made a philosophical argument about the oppression of women, drawing on the lived experience of women, to say that many women's situations must be changed if they were to be truly 'human'. She said that women's desires should shape sex; that their projects should shape life; and that their agency should shape the world.

Luce Irigaray Feminist Essentialist Philosopher and author of Speculum of the Other Woman (1985b), stressed the necessity of a language to "speak ourselves" as women. She said if there are two subjects, there is more opportunity for relationship. Irigaray's project was finding a way to female subjectivity. She wanted to change the culture of patriarchy to a female subjectivity, which is defined in its own terms in the social. Irigaray in her work, two lips touching and re-touching (1985a) sought to recover woman's irreducible difference, to define woman in her own terms, rather than in terms of the being of the male.

She described the constitution of the male subject as dependent on the unity of self-identity. Thus male sexuality has typically been organised around the idealisation of a single, visible sex organ, in ways that reflect and reinforce the model of self-identical unity (e.g. the 'Phallus'). Irigaray contrasted this with the multiple sites of women's sexual pleasure, the breasts, pubis, clitoris, labia, vulva, vagina, neck of the uterus, womb, which are suggestive of the way the female body does not conform to the bounds of male identity. The difference she argued is clearly revealed in the different

ways women and men touch themselves to give themselves pleasure. Man is identified with a self-contained form (be it the penis, the phallus, or simply the bounded ego), he needs an external instrument with which to touch himself: a hand, a woman, language, or a self-representation. In contrast, Irigaray argued woman needs no mediation for, ‘a woman touches herself constantly without anyone being able to forbid her to do so, for her sex is composed of two lips which embrace continually. Thus, within herself, she is already two – but not divisible into one(s) – who caress each other ’(1985a, p.24). Thus, Irigaray adds to the male principle of the’ phallus’, the female principle of two lips touching and re- touching. The lips refer both to the labia and to the mouth.

Irigaray positions a perspective, ‘what can only be seen as a ’hole’ or lack if the male body is taken as the standard, becomes a spacing between lips which allows them to touch on each other, closing without becoming sealed into one, opening without losing all contact, continually taking up different forms without becoming formless. The lips through which a woman touches herself as they touch on each other are neither one nor two, nor do they relate as (active) subject to (passive) object. In ‘that contact of at least two (lips)’ there is no possibility of distinguishing ‘what is touching from what is touched’ (2011, pp.163-165). Each moves and is moved by the other such that they mutually define each other without need for division or rupture. Instead they are held together by a spacing, which allows each to touch on the other while remaining distinct. In the movements that flow between them, they remain in contact without being the same, shape one another while taking on their own form’ (2011,p.165).
Irigaray argued that, as ‘strangers to dichotomy and oppositions’, the lips offer an alternative model to that in which subject and identity is secured via opposition to the other (or via a constitutive separation from the other) (2011,p.164). Irigaray asserted, that things would be different if a re-imagined female or maternal body were taken as the starting point instead of the male body, imagined in phallic terms. Irigaray’s project is to re-construct an inter-connected imaginary and symbolic of the female body where her subjectivity is liveable, visible and positive. Irigaray’s account describes how subjectivity intersects with body parts, sexuality and sexual pleasures, offering an alternative way of being for women.

Foucault (1979) and Butler (1997) describe their view of subjectivity as: decentred,

constituted in relation to others' identities, constituted in relation to dominant power structures and powerful disciplining discourses and a number of other subject positions. Foucault, in particular enables, us to understand the way dominant ideologies express themselves materially in and on the body, as a subject and a developing subjectivity in the powerful normalising discourses of western socio-cultural society (1997,p.89). Foucault argued the process of subjection takes place centrally on the body. That subjection is a kind of power, disciplinary power that unilaterally 'acts on' a given individual as a form of domination, but also activates or forms the subject. The subjection designates a certain kind of restriction in production, a restriction without which the production of the subject cannot take place. Foucault argued the subject produced, and the subject regulated is one, and the compulsory production is its own form of regulation. This, for the subject, becomes the inculcated normative ideal, which is what Foucault called an imprisoning frame (1997,p.86). Foucault insisted this is the way in which the subject becomes the principle of her/his own subjection. Foucault suggested bodies are embodied into social systems and institutions and these structures can colour and shape aspects of embodied life. The subject takes on ways of bodily being in order to comply with social norms and forces.

Butler (1997) invariably critiques Foucault's theory asserting that, 'one cannot account for subjectivation, and, in particular, becoming the principle of one's own subjection without recourse to an unconscious account of the formative or generative effects of restriction or prohibition' (p.87). She builds on Foucault's work suggesting the unconscious offers; 'how we become to understand, not merely the disciplinary production of the subject, but the disciplinary cultivation of an attachment to subjection' (p102). Butler maintains the attachment to subjection is produced through the workings of power, and that part of the operation of power is made clear in this conscious and unconscious effect, one of the most insidious of its productions (1997,p.6). For Butler, the subject who is at once formed and subordinated is already implicated in the place of the social: that woman must take up a position of activist and resistance in the social.

Merleau- Ponty, philosopher of traditional phenomenology contrasts with the proposition of subjectivity from existentialism and constructivism. He speaks of the interrelatedness of mind and body. For him the mind and subject, thus subjectivity is

always embodied, always based on corporeal and sensory relations. For Merleau - Ponty, although the body is both object (for others) and a lived reality (for the subject), it is never simply object nor simply subject. It is defined by its relations with objects and in turn defines these objects as, "sense bestowing" and "form giving," providing a structure, organisation, and ground within which objects are to be situated and against which the body subject is positioned.

He claims to reveal a subject as a "being-in -the -world" (1962, viii) "a subject committed to the world", a subject of perception and behaviour, as well as cognition and reflection. His account of the embodied subject, which is both responsive and receptive in its 'being-in the world' offers a notion that the body subject can be agentic in its negotiated being, despite appearing to never exist in an ontological mode that is distinct from its historical situation, with the body always managed, permeated and penetrated by the other. This will be developed further in the section on lived body.

In essence, sexuality, gendered identity and embodied subjectivity can be explained as having a formation made up of our experiences, histories and biography in the social. When applying the literature, particularly to women with vulvodynia, I contend contemporary feminists, philosophers, and phenomenology advance powerful ways to be free of the constraints of the social, and specifically how to navigate the relational and sexual. They speak of resistance, activism, agentism and positionality as concepts for change that would have utility when exploring relational and sexual adjustment in couples living with vulvodynia.

1.3.4 The Lived Body

This section focuses on the lived body and explores feminist phenomenology, which has its roots in traditional phenomenology. Feminist phenomenology plays an invaluable role in combining and illuminating the gendered dimension of lived embodiment and women's experience of their bodies (Bartky 1990; de Beauvoir 2011; Weiss 1999; Young 2005). More broadly, feminist phenomenological scholarship highlights the ways in which identity categories affect our ways of being in the world and having this recognised by others. In keeping with phenomenology's rejection of naturalistic reductionism, feminist phenomenology makes visible the irreducibly situated and contextual nature of (gendered) bodily subjectivity. It extends and

vitalises traditional phenomenology's unique concern for the centrality of human embodiment. Feminist phenomenology approaches to embodied experience thus work against a 'universalising view' and offer up instead our concrete situation in the world as a privileged starting point to probe the meaning of our lived experiences.

Along with other phenomenologists, particularly Merleau-Ponty, de Beauvoir recognised that "to be present in the world implies strictly that there exists a body, which is at once a material thing in the world and a point of view towards the world" (Beauvoir, 1982, p.39). The self, for phenomenologists, is necessarily corporeal, the body constitutes the self. It is not a separate entity to which the self stands in relation. The body, however, is not simply what biology offers an account of. The body, which gained attention by feminist phenomenologists, was the body 'as lived', as yielding the sensory experiences and lived intentionality of a subject negotiating its world. It is also a body, which is encountered by others whose response to it mediates our own sense of being. 'What is central to de Beauvoir's account is that such bodily existence, the point of view it provides, and the response it garners, is different for women and men. Her account provides a complex and non-reductive picture of the intertwining of the material and the cultural in the formation of our embodied selves' (Kruks, 2010).

The way in which the young girl and then the woman experiences her body is, for de Beauvoir, 'a consequence of a process of internalising the view of it '*under the gaze of others'*. For example, through compliments and punishments, through images and words, she discovers the meaning of the words beautiful and ugly; she soon knows that to be pleased is to be beautiful (2010,p. 304). Here is the beginning of the way in which women live their bodies as objects for another's gaze, something, which has its origin not in anatomy but in "education and surroundings', in effect in the social (de Beauvoir, 2010,p. 304). De Beauvoir's highly influential account of the way in which women live their bodies in such an objectified way, internalizing the gaze and producing their bodies as objects for others, has been one of her most important contributions to a phenomenology of female embodiment.

Iris Marion Young, feminist phenomenologist continues the concept of the lived body as that, which we live in, with, and through in the social. She says, 'the lived body is a unified idea of a physical body acting and experiencing in a social context, it is a body-

in-situation. The person always faces the material facts of her body and its relation to a given environment. Her bodily organs have certain feeling capacities and function in determinate ways: her size, age, health and training make her capable of movement in relation to her environment in specific ways. Her specific body lives in a specific context – crowded by other people, anchored to the earth by gravity, surrounded by buildings and streets with a unique history, hearing particular languages, having food and shelter available, or not, as a result of culturally specific processes that make specific requirements on her to access them. All these concrete material relations of a person's bodily existence and her physical and social environment constitute her facticity' (Young, 2002,p. 415). Her concepts are essentially non- phallic and are founded on the body, its motility, positionality and spatiality. The essays in On Female Body Experience (2005), with her phenomenological descriptions and feminist approach about experiences of living in female bodies, make a unique contribution; and sit well alongside the psychic. In her work, Young intertwines and overtly links the unconscious, the self and Other expressed in language and the lived experience of the materiality of the body impacted upon by the social.

Young's feminist phenomenological approach has utility and relevance for this current study when exploring the experience and meaning making of woman, as a sexual being, and her partner coping with vulvodynia in the couple sexual relationship. The body as lived with sexual embodiment is central to the understanding of the particular of change from merely coping with, towards acceptance and adjustment to vulvodynia. Three of her essays that are important in this regard include; Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility and Spatiality (1980), Breasted Experience: The Look and the Feeling (1990), and Pregnant Embodiment: Subjectivity and Alienation (1983), (Young, 2005). 'Throwing Like a Girl' theorises socially constructed habits of female body comportment in male dominated society, and their implications for the sense of agency and power of persons who inhabit these body modalities. Young, in her descriptions of woman relies, on the work of Merleau – Ponty, Phenomenology of Perception (1962) and the work of de Beauvoir, Second Sex (1953) to inform her bodily descriptions that is, the body as lived in, is always layered with social and historical meaning. It does not replace or exclude the essence of the unconscious. In Throwing Like a Girl, Young relies on de Beauvoir's account of woman's existence in a patriarchal society, 'the culture and society in which the female person dwells defines woman as Other, as the inessential correlate to man, as a mere

object and immanence' (2005, p.31). Woman, she asserts is 'both culturally and socially denied the subjectivity, autonomy, and creativity that are definitive of being human and that in patriarchal society are accorded the man' (2005, p.31). Young suggests, therefore that women live a contradiction and their 'situation 'is one of oppression where, for the most, women are not given the opportunity to use their full bodily capacities in free and open engagement within the world (pp.42-43). Young questions, whether this contradiction and conflict get represented in the unconscious of women as a manifestation of inexplicable anxiety, doubt, and foreboding. An interesting and most relevant matter when considered in the context of women's lived bodily experience of vulvodynia.

In critiquing the problematic of woman's sexuality and sexual pleasure I now turn to Young's essay, 'Breasted Experience' to understand the modalities of a woman's experience of her body in its sexual being. Young highlights a dominant objectification of, and extreme focus on women's breasts in western cultural society. For the woman, and for others, her breasts are the daily visible and tangible signifier of her womanliness on which she is judged in terms of size, shape and the phallic erection of her nipples (2005, p.76). Young attempts in her essay to move away from the phallo-centric objectification of women's breasts, and suggests what matters for the woman is her 'breasts, their feeling and sensitivity, rather than how they look, that while active heterosexual sex is the erect penis; the real sex; she, the woman can derive the deepest sexual pleasure from touch and her breasts; a greater pleasure than man can provide through penetrative sex' (2005,p.82).

Young relies on Luce Irigaray's description of fluidity and womanliness, in The Mechanics of Fluidity in This Sex Which is Not One (1985a) and Merleau -Ponty 's description of touch, to argue a phallo-centric construction of sexuality and sexual pleasure denies and represses the sensitivity of breasts, and thus woman's sexual pleasure. Young explains, 'the breasts, for many women, are places of independent pleasure. Deconstructing the hierarchical privilege of heterosexual complementarity, giving equal value to feelings of the breast diffuses the identity of sex' (2005, p.83). Irigaray (1985a,pp.23-33) contributes further that, woman is 'plural and heterogeneous; has sex organs all over her body, in many places, and perhaps none are privileged. Woman experiences eroticism as flowing, multiple, un-locatable, not

identical or in the same place'.

Irigaray's approach is similar to the postmodern philosophers, Deleuze and Guattari (1987) who explore radical ways of disrupting hegemonic modes of understanding and experiencing the sexual. Their description of the body without organs is a field for the production, circulation, and intensification of desire, the locus for the immanence of desire and source of multiple pleasures, particularly from the movement and flow of intensities that it allows or produces on its surface: in the context of sexuality, a woman with her own desires and pleasures.

Lastly, I turn to Alcoff (2006). She offers a phenomenological identities account, which integrates social identity with people's experiences of the bodies of themselves and others. She says that sex is " most definitely physical, marked on and through the body, lived as a material existence, visible as surface phenomena and determinant of economic and political status (2006, p.102). She argues, that the sense of our own body reflects, as was described by de Beauvoir, the way it is perceived by others. The material features of the body are foundational to our sense of our sexed identity and used by others to position women in patterns of social interaction. The phenomenological identities account by Alcoff is valuable when developing thinking about the identity and positionality of women in western society, their sexuality and sexual pleasures in the context of this study.

To sum up the feminist approaches contribute an analysis of the entanglement of bodies in structures of power, and its normative implications for the oppression of (bodily) difference. A feminist perspective stresses the importance of women's bodily subjectivity, relationships and the meaning attributed to a sexual act or feeling (White, Bondurant and Travis, 2000). Additionally, women derive meaning through interactions with their partners thereby influencing their choices in sexual behaviour (Daniels, Zimmerman and Bowling, 2002). A phenomenology approach gives emphasis to the importance of lived bodily experience and sexual embodiment for our understanding of how and why we incorporate and reproduce taken-for-granted ways of being in the world. This concern brings feminist and phenomenology approaches in deep accord. This productive tension between the study of shared features of feminism, and the facticity and particularity of bodily difference is at the core of contemporary feminist

phenomenology.

1.4 Conclusion

After broad reading of different thinkers with different concepts, and extensive consideration of the published research and literature in order to gain an understanding of what may unfold in my clinical research encounter. I have clarified more exactly and narrowly, and sharpened my own epistemic position for my research. Consequently a feminist phenomenology epistemological stance is deemed the most coherent and relevant to explore this study's research aim and question within an Interpretative Phenomenological Analysis (IPA) research methodological framework. The study approach could ignite the epistemologic desire of women with vulvodynia, which could open up new thinking about heterosexual body politics and women taking full possession of their own body subjectivity, sexual desires and pleasures. The inclusion of male partners in this study represents a relational and feminist view; and because partners are not well studied in couple relationships with vulvodynia.

1.5 Research Aim

The research aim is to explore and interpret the lived experience of relationship and sexual adjustment in women with vulvodynia and their partners' in the heterosexual couple relationship, to mitigate the impact of vulvodynia on sexual and couple relationships. The study is about women's and their partners' intra subjective and inter-subjective negotiation of sexual and gendered discourse, the materiality of embodied sexual pain and suffering, and impact on sexual embodied subjectivity and the relationship context. Moreover first person experiential accounts about such could be enhancing to the clinical third person perspective, often limited to biomedical facts of disease, observation of symptoms and treatment, which is generally unfit to account for everyday experiences of our own bodies (Carel, 2016)**.** This study could make an important preliminary contribution to informing and developing new therapeutic approaches and interventions in healthcare and psychosexual therapy practice. At the moment healthcare professionals and psychosexual therapists cannot base their interventions on empirical evidence and clinical data because of the paucity of qualitative research in the context of couples coping with vulvodynia. It is hoped the research findings can make a positive contribution to filling the gap in the literature.

1.5.1 Research Question

What is the impact of socio-cultural meanings of gender and sex for heterosexual couples negotiating relational and sexual adjustment to vulvodynia, and the implications for transforming clinical practice?

This question will be explored with particular reference to: (1.) the materiality of embodied sexual subjectivity; (2.) women's and their partners' psychic and relational negotiation of sexual and gendered discourse; and (3.) the re-negotiation of couple sexual practices in the context of sexualities, desires and sexual pleasures.

Chapter 2. Models, Approaches, and Theories: Bringing Feminist Phenomenology into Clinical Practice

2.0 Models, Approaches and Theories

2.1 Introduction

Research about sex has lacked a strong theoretical base, from Kinsey's interviews (1948; 1953), to Masters and Johnson's essentialist research assumptions (1966; 1970) to the present day. Furthermore, there is ongoing tortuous deliberation about diagnosis, sexual function/dysfunction and unifying theories, thus a theoretical and research void exists. Different theories have their different emphases and they are often, not readily transferable to clinical practice. There seem however, to be three identifiable themes in recent attempts to provide unifying accounts of how sexual problems may arise and be maintained in both women and men. (1) diversity of sexual experience, (individual /gendered differences), (2) integration of mind and body, and (3) multi-determined nature of sexual function, (biological, psychological, socio-cultural and economic factors). It is however, highly problematic that theories to date are weak in determining causal pathways, and distinguishing between etiological and mediating factors. In essence there exists a paucity of research, and a lack of adequate testing of theories and models concerning sex and sexuality (Meana, 2012). The following represents a summarised and selective review of recent theoretical models and approaches.

2.2 Barlow's Cognitive –Affective Model

A negative feedback loop was a central concept in Barlow's original cognitive-affective model of how sexual dysfunctions develop, which was focused only on men (Barlow, 1986) Barlow indicated that sexual situations automatically represent demand on sexual performance. Consequently, in the sexually dysfunctional individual, this demand triggers a process of anxious apprehension whereby attention shifts away from erotic cues to negative, internal self-evaluative ones, which in turn interfere with performance and result in even greater apprehension and anxiety. The centrality of the impact of distraction from erotic cues towards attention on anxiety provoking cues remains clinically relevant today. This model is associated with the development of

cognitive and behavioural clinical interventions that are now mostly empirically supported in the treatment of sexual problems and delivered by clinical psychologists and psychosexual therapists. Barlow's model has empirical support, however for women there are questions about the meaning of sexual performance and phallocentric nature of sexual performance. This is a model about a sexual performance sequence, the body as a whole is not mentioned, nor the factors influencing it.

2.3 Dual – Control Model

The dual control model suggests that the sexual response in any given individual and any given situation is contingent on two systems with neurobiological substrates: the sexual excitation system and the sexual inhibition system (Bancroft and Janssen, 2000). Both are adaptive in that excitation propels to sexual activity (procreation) while inhibition reduces the likelihood of the sexual response when it may not be in the individual's best short or long- term interests (perceived risk). While acknowledging the influence of relational, social, and contextual factors on the sexual response, the dual control model proposes that the effects of sexual stimulation will ultimately depend on an individual's neurobiological characteristics. Research data suggests that there are individual and gender differences in the propensity for excitation and inhibition (Milhausen et al., 2010).

In this model, sexual problems might arise when there is an imbalance in either the excitation or the inhibition systems, or in their relationship to each other. The indication of gender differences in propensities for excitation and inhibition brings to attention that determinations of whether an imbalance exists would have to be made relative to gender (Meana, 2012, p.22). Epidemiologically women report lower sexual desire, arousal and orgasm frequency than men. The issue is, of course whether these lower levels are a sexual problem or the product of discrepancy in frequency in hetero-normative sex, where the male desire and demand is mostly privileged.

2.4 The Tipping Point Model

This model uses the concept of balance to delineate the development of sexual dysfunction (Perelman, 2009). It suggests that at any given point for any one individual, there will be a threshold for the expression or triggering of any phase of the

sexual response cycle, from desire, to arousal to orgasm. Meana (2012) explains 'that the excitatory physiological, relational, and cultural factors weigh in against the parallel inhibitory ones. Depending on the relative weight of the positive and negative factors, the balance will tip in favour of a sexual response, a neutral response, or a sexually inhibiting response.' Perelman asserts that multidisciplinary treatment might be even more important for sexual dysfunction in women, as psychological and relational factors may carry more weight and thus have more potential to enhance and disrupt sexual function. Meana (2012) identifies that no research study has directly tested this model. This model is highly complex and reductive, primarily due to the fact that it is conceived as a dynamic model, whereby a combination of factors that will be causal in tipping in favour of a positive or negative response will vary across situations and life span. It also appears to pathologise women with a suggestive link with sexual dysfunction, and psychological and relational factors compared to men, when indicating multidisciplinary treatment for women. The tunnel vision continues to neglect many variables important to women and the denial of issues of power in medicine and heterosexuality.

2.5 The Intersystem Approach

This model conceptualises the possible causes and mediators of sexual problems focusing on the interrelatedness of three systems; individual, interactional, and intergenerational (Weeks & Cross, 2004). The intersystem approach involves the integration of various models of psychotherapy (family, couple and sex therapy) bringing together specific theoretical foundations and techniques. In balancing the individual and relational concerns, the model proposes five intersystem domains, which are relevant to conceptualisation and treatment of sexual problems (1) individual /biological/medical, (2) individual/ psychological, (3) dyadic relationship/couple dynamics, (4) intergenerational influences, and (5) society/culture/religious/history.

The intersystem approach was developed because the focus on cognitive-behavioural interventions and medical/biological approaches are too narrow. The medicalisation of sex therapy has promoted the view that sexual problems should be treated in a medical framework, virtually ignoring the importance of recognising and treating psychological factors. The value of the intersystem is the introduction of a fundamental systemic methodology. The aim of the intersystem approach is the development of a

unified case formulation, which then leads to an integrative approach to treatment, and a more comprehensive perspective on sexual problems and psychosexual therapy (Weeks & Gambescia, 2015). The strength of this model is that it uses a theory of interaction that serves as one set of integrational constructs. Grounded in a social-psychological model, the theory of interaction posits that there are intra-psychic and interactional components. Unfortunately, research data supporting the intersystem model is sparse as research design is particularly challenging with such complex and holistic frameworks.

2.6 The New View Approach

The New View Approach emerged from concerns about reductionism in the study and treatment of sexuality, the medicalisation of sexual variation, and the perceived failure of sexology to account for the socio-political pressures on women's sexuality. The New View proposed a non-symptom focused classification for women's sexual problems (Tiefer, 2001). Rather than defining sexual difficulties through a normative definition of what should be experienced, the New View Approach allows the woman (or man) to decide what is normal for her, what is, or is not a problem and what the potential 'causes' of the sexual problem may be.

A social constructivist view of sexual experience was adopted that avoids any universal blue print for successful or normal sexual experience (Tiefer,1987). Within this depathologising framework, sexual problems can be attributed to (1) socio-cultural, religious, political, or economic factors, (2) partner or relationship, (3) psychological factors, and /or (4) medical factors. This model shares with others the perspective that sexual problems are multi-determined. However, the true signature of the New View Approach was its resistance to the imposition of definitions of sexual dysfunctions on individuals, specifically women. While the non-symptom classification was tested and received support for the model, more research, as with other models is needed (Nicholls, 2008).

2.7 Feminist Phenomenology and Medicine

A number of feminist theorists have shown that phenomenology offers a valuable resource for approaching issues concerning the lived experience of marginalisation, invisibility, and oppression. This is evidenced in recent and particular

phenomenological accounts of embodiment, focusing on the lived experience of the body, which have provided a useful beginning in examination of how the singular body, that is, the body as unique and different from other bodies, with a particular sex, of a particular age, race, ethnicity and ability, can form and inform our embodied selves and influence our ways of interacting with others in the social world (Alcoff, 1999; Weiss, 1999;Fisher, 2000;Diprose, 2002; Heinamaa, 2003; Young, 2005; Ahmed, 2006; 2007; Kall 2009a, 2010; Al-Saji, 2010;Heinamaa and Rodemeyer, 2010; Zeiler,2013a).

Kall and Zeiler (2014) claim, 'this research demonstrates the value of bringing together phenomenology and feminist theory; both reveal and scrutinise taken- for- granted and in this sense 'hidden' assumptions, beliefs and norms that we live by, that we strengthen by repeated actions and that we also resist, challenge and question. Furthermore, and beyond a feminist application to phenomenology, feminist phenomenology provides ways of deepening the phenomenological framework by asking questions of how experiences of, for example sexuality, sexual difference (Alcoff, 2000; Oksala, 2004; 2006; and Heinamaa, 2012) inform phenomenology as a philosophical project' (p.2).

Phenomenological studies have, also provided relevant analysis to inform clinical practice, such as analysis of experiences of pain, depression, illness and bodily alienation (e.g. Zaner, 1981; Leder, 1990; Toombs, 2001; Svennaeus, 2009; Carel, 2008; and Bullington, 2009.) and offered analysis of clinical encounters (Toombs, 1993,2001). Zeiler and Kall (2014) advance that the integration of feminist phenomenology and phenomenology of medicine has value for more comprehensive analyses of concepts such as bodily self-experience, normality and deviance, incorporation and excorporation, loss, self- alienation, bodily doubt and objectification that are central to both fields. They identify the relevance of feminist phenomenological perspectives to the field of medicine and health by highlighting difference, vulnerability, and volatility as central dimensions of human experience rather than deviations. Furthermore, Zeiler and Kall assert the integration of feminist phenomenology and phenomenology of medicine 'takes into consideration and examines normative cultural practices and structures of meaning that situate different bodies in different ways and with different conditions, and seek to lay bare the constitutive conditions of experience'

(p. 2). As yet, feminist phenomenology is a developing but important area. Integration with the phenomenology of medicine holds potential for informing clinical practice, research, and education in the field of sexual problems, but as yet is not fully tested.

2.8 Summary

Scientific method is generally driven to isolate specific causal factors. Sex and sexuality are rarely amenable to that narrow a strategy. The fact that a multitude of factors affect sex and sexualities is unsurprising and determining their relative importance in sexual problems is complex. Models supporting the integration of multidisciplinary practice, research and training are beneficial for the coordination and delivery of a spectrum of clinical interventions for sexual problems.

Feminist phenomenology situated at the intersection of an integrated and multidisciplinary clinical model with psychosexual services could provide a more comprehensive description and analysis of sexual pain conditions, the embodiment and situatedness of subjective life and experience, and a way to understand the experience of more expansive sexualities, genders, desires and pleasures. Feminist phenomenology applied into a psychotherapeutic frame for working clinically with women with vulvodynia and partners could make a significant contribution to the current practice context.

2.9 Bringing Feminist Phenomenology into Clinical Practice

In this research I am concerned with the experience of lived bodies with their particular markings of sex, and importantly their socio-cultural, political and psychological self-formation. The lived body is foundational to how we live our life, consequently my attention, as a practicing psychosexual therapist and psychotherapist, is drawn to the lived embodied experience of women and their partner coping with vulvodynia, and their adjustment in the heterosexual couple relationship. In this section I shall illuminate a method and a selection of key analytical concepts from feminist phenomenology, which has its roots in traditional phenomenology, for its application in this study with a view to making a valuable contribution to current clinical practice.

2.10 Phenomenological Method and Concepts

2.11 Method

The phenomenological method is a study of human experience. It is not a variant form of scientific enquiry but an analytical and descriptive method for examining pre-reflective subjective human experience as it is lived. Phenomenological inquiry can mutually inform and interact with scientific work while remaining independent from it. Phenomenology has an important relationship with empirical psychology, neuroscience, cognitive science and other domains that study human consciousness in an empirical manner. As a discipline it can provide a comprehensive, systematic and descriptive account of interrogation for the instructive understanding of human experience. There are a number of branches of phenomenology however; central to this study is that of Feminist Phenomenology.

2.12 Analytical Concepts

(i) Embodiment

Merleau- Ponty (2012) emphasises that woman's body is both an object for others and her lived reality. And she exists neither only as a thing nor only as consciousness. This is highlighted with the concept of the lived body: the lived body is a mind-body unity, acting and experiencing in a specific situation. It is her lived relationship, as an embodied being, to a world immersed in meaning that she constantly interprets and makes meaningful to herself through interaction with others. As an embodied being, her experience of her own body is often pre-reflective and practical as becomes evident if we consider how the body, in movement, co-ordinates its different parts for the sake of action.

When walking or performing other skills, we seem to act on the basis of a tacit, bodily know-how that makes it possible for us to engage in various activities without thinking about how to do so. Merleau- Ponty uses the concept of the body schema in order to highlight this bodily know-how that makes the correspondence between embodied subjects and their situations smooth and seamless. The body schema is an implicit, practical awareness of her body, motion and space. It is a system of practical and pre-reflective sensory- motor skills that enables action since it makes possible the tacit and seamless co-ordination of different bodily parts in relation to space. The

phenomenological concept of embodiment could offer insight into the lived experience of women with vulvodynia and their partner, their sense of self and sexual embodiment.

(ii) Orientation

As highlighted by de Beauvoir 2010; Heinamaan 2003; and Ahmed 2006, it is not sufficient to consider the body without further clarification. She is a particular body of a sex, ethnicity or physical ability and this matters for, but does not determine, her being-in-the-world. Inter-subjectivity is also crucial to this reasoning. She is born into a world already inhabited, shaped and made familiar to us by others. The familiar is both that which is given to us by others and that 'which, in being given, 'gives' the body the capacity to be orientated in this way or in that' (Ahmed, 2006). The familiar is an effect of how others have already inhabited and continue to inhabit this world, and there is a body dimension to this. Ahmed (2006) asserts, that to be orientated is to be in line. It is to follow lines others have already drawn and that others already follow. "We are in line ", says Ahmed, "when we face the direction that is already faced by others. Being 'in line' allows bodies to extend into spaces that, as it were, have already taken shape" (2006, p 15).

This has implications for what we can be or do: certain acts or ways of being and thinking will be very difficult, or indeed impossible for us, because of our orientation and what is "in line" with our orientation. We may not wholly be aware that we are orientated in a particular way until something happens that makes us lose our orientation. Ahmed's term "orientation" is the lived body's sexuality and gendered identity. This phenomenological concept has potential relevance for this study and clinical practice when exploring the meaning of vulvodynia on the bodily gendered and sexual being of women (and their partner) in couple sexual relationship. Particularly the impact whereby the heterosexual woman with vulvodynia may not be straight enough, thus 'not in line' for her male partner, in that she avoids painful sex or that she has to stay 'in line' to pass as a heterosexual woman despite painful sex; both being examples of culturally normalising disciplinary production of sex and sexuality in women.

(iii) Touch

The body, for Merleau- Ponty, has a dual role as subject-object, a unique being that can be experienced both from a first- and third person point of view. He developed the example of two hands touching, from Husserl (1988), of two hands touching each other. Each hand is touching, active and sensing the other hand but also being touched, passive, and sensed by the other hand. This simple action demonstrates the duality of the body. This view of the body as both an active touching subject and a passive touched object posits it as unique in nature. The body is recognised as having the power to give rise to these 'double sensations: the sensibility of the active touch and of the passive being touched. An active touch yields sensations that relate to the qualities of what she touches and the sensations that relate to the hand that touches. A passive 'being touched,' on the other hand, gives rise to a simple sensation that a surface of her body feels when it is touched (Bernet, 2013). Bernet describes the philosophical significance of these double sensations as expressing the intimacy of bodily sensations and the body's insertion in the world (2013, p.64). Touch is a key phenomenological concept, which has utility potentially for both clinical practice and this study about women with vulvodynia and their partner in the context of touch and being touched in the intimate couple sexual relationship.

(iv) Intentionality

Merleau-Ponty claims that bodily intentionality is primary to, and the foundation of, mental intentionality (Merleau-Ponty 2012, p140). He sees motility as basic intentionality. There can be no mental intentionality without bodily orientation in a world. Motor intentionality is embedded within the intentional arc, a term Merleau-Ponty uses to describe our relationship with the world. This relationship includes motor intentionality but also a temporal structure, a human setting, and a moral and existential situation. These capture the unique relationship a human being has to the world: a relationship that is not only physical, but also embedded in cultural and social meaning. The intentional arc brings about the unity of the senses, cognition, sensibility, and motility; in essence the unity of experience. As Merleau-Ponty indicates, it is the intentional arc itself that 'goes limp', in the body with illness or health problems (2012, p 137).

(v) Loss

The time of diagnosis is the point when a woman's symptoms become known as a medical condition. Diagnosis turns symptoms into a less subjective entity, symptoms are now organised in an explanatory pattern that explains, predicts and turns attention to treatment and adjustment. While there may be some relief with a diagnosis, this is tempered with despair and a loss of subjectivity. Toombs's (1987) speaks of five losses that capture the experience of newly diagnosed conditions, loss of wholeness, certainty, control, freedom and familiarity. With a health or sexual problem, the biological body comes to the fore, as it often ceases to cooperate with the individual's desires. Loss of subjectivity is highly relevant to this study and clinical practice when working with people, their adjustment to health or sexual problems.

(vi) Objectification

The natural process secondary to experiencing the lived body is experiencing the body as an object amongst objects. In receiving a diagnosis for a health problem this process takes on a new dimension, as medicine and the sciences underpinning it view the body as a physical object. This objectification takes place under the dual experience we have of our bodies. The body is experienced both as a lived, pre-reflective body; through the first person experience of and through it; and as an objectified, observed, spatial object; through the third person perspective of it (Merleau-Ponty, 2012). In health problems, objectification gives rise to a distance between oneself and one's body, which is now reified into an object of medical examination and treatment. This is particularly relevant to women who have to undergo regular and ongoing medical examination for vulvodynia and review of intimate bodily areas.

(vii) Bodily Doubt

A sense of body trust or confidence is so tacit that, at least for young healthy persons, its very existence goes unrecognised. This is a point that is fundamental to lived body phenomenological foundations; we are typically oblivious to aspects of our bodily existence. A key analytical concept in phenomenology is the tacit sense of bodily trust and its breakdown, owing to a health or sexual problem, into a feeling, a strong sense

of bodily doubt (Carel, 2016).

The sense of certainty is primarily to be found in the tacit confidence with what we do each day with taken-for-granted confidence. Bodily certainty serves as the ground on which we base many of our assumptions and expectations. An analysis of it reveals goals and assumptions are based on a bodily feeling of ability giving rise to an existential sense of possibility. This certainty, lack of the need to attend to our bodies, is core to our being. A tacit existential feeling of trust, familiarity and normalcy underlies our everyday activities and actions. With a health or sexual problem the sense of certainty and confidence we have in our own bodies is deeply disturbed. Basic tacit beliefs about bodily abilities, that were previously taken for granted are suddenly, and somewhat acutely, made more explicit and thrown into question. The bodily feelings of confidence, familiarity and continuity are profoundly disrupted and our values and sense of what is important in life affected. Carel (2016) describes bodily doubt, as being not just a disruption of belief, but a disturbance on a bodily level. It is a disruption of one's most fundamental sense of being in the world. Bodily doubt gives rise to an experience of unreality, estrangement, and detachment. From a feeling of inhabiting the familiar and expected world, one is thrown into uncertainty and anxiety. Her attention is withdrawn from the world and focused on her body. She feels isolated from others, who maintain their connection to the world, and may become detached from both physical and social environments. The natural confidence, in bodily abilities is altered, by a feeling of vulnerability, distress, and distrust in her body.

There are different degrees of bodily doubt. It may vary in duration, intensity, and specificity. It may be all pervasive or related to a specific aspect of bodily functioning. Bodily doubt has additional features that make it phenomenologically significant (Carel, 2016, p.93). Firstly; bodily doubt can descend any moment. It can appear gradually or by complete surprise. The body's precariousness and unpredictability make it more threatening and render the individual less capable of incorporating experience of it into their familiar world. Second, the feeling of bodily doubt invades the normal sense of things. It results in feeling exposed, threatened. It is uncanny and may give rise to a kind of anxiety. It is unlike normal kinds of bodily failures for example, falling over. This failure is incorporated into one's current existential feeling, which is often an undifferentiated background feeling. One may be embarrassed but one

remains immersed in the task and in the world. Bodily doubt can cast one out of immersion and into suspension. The phenomenological concept of bodily doubt has relevance to this study and clinical practice in the context of bodily confidence and trust in the process of adjustment to vulvodynia in the couple sexual relationship.

(viii) Uncanniness

When in acute or chronic pain associated with health problems, one's sense of comfort and familiarity may be displaced by alienation and a sense of 'not being at home' (Svenaeus, 2000a; 2000b). The body becomes an obstacle and a threat, instead of one's home, a familiar place inhabited. A change to one's body is a change to one's sense of being at home in the world. The body ceases to be the 'null centre' of one's orientation towards the world (Smith, 2003 p.221) and instead becomes the source of negative experiences. Pain can suspend the familiar setting and feelings that underpin normal everyday actions, giving rise instead to an experience of 'unhomelike being in the world' (Svenaeus, 2000a, p.9). Uncanniness arises most forcefully from the disruption of this background, which happens as a result of changed embodiment. Uncanniness arises from a new, negative focus on one's body, a sense of this body becoming alienated. This key phenomenological concept, along with alienation, may have relevance for women's lived experience of vulvodynia given the condition is painful and disruptive.

(ix) Bodily Alienation

Feminist phenomenologists have a particular interest in the experience of bodily self-alienation, and experience of oneself as other to oneself as normative for women's way of being- in- the- world (Arp, 1995;de Beauvoir, 2010; Young, 2005). Building on Beauvoir's insights that "woman is her body as man is his, but her body is something other than her" (2010, p.41), feminist phenomenologists have continued interrogation of the various ways in which women's bodily alienation comes to articulation at intersections of different categories of identity and structures of power and privilege.

The issue of bodily self- alienation is, as mentioned above is a relevant concept in phenomenological accounts of experiences of health or sexual problems. Some accounts target the interrelation between the illness/disease experience and gender

(Svenaeus, 2014; Wilkerson, 2014). The analysis of Svenaeus of anorexia as an experience of the body uncanny bears out the different gendered dimensions of the illness by situating it in a coercive cultural context involving norms of successful femininity. Wilkerson, too, targets the interrelation between bodily alienation and gender in her discussion of the impact of social power dynamics on body resonance in depression. There are further examples of accounts of the experience of one's own body as other to one's self in the work of other feminist phenomenologists (Kall, 2014; Shildrick, 2014). The phenomenological concept of bodily self- alienation has relevance to women with vulvodynia and cultural norms of sex and sexuality if one questions: what is it about the construction of female sexuality and power in heterosexual relations that mean women are having pain in sex?

(x) Incorporation, Excorporation and Resistance

Incorporation takes place, when objects or skills can be experienced as part of the individual's experience of her/his body, for example using a stick, wearing glasses, riding a cycle. Malmqvist and Zeiler (2010) have suggested that it makes sense to think of some culturally shared and bodily expressed beliefs and norms as incorporated, in a similar way to the incorporation of objects and skills. Their rationale is based on the notion that objects, skills to cultural patterns of understanding and behaviour can become parts of our taken-for -granted being, pre-reflective domain of bodily experience "in the domain of the 'habitual", and can form and enable our bodily existence and relational-existence. Furthermore their rationale is that we enact expectations of female and male embodiment, and that such expectations involve beliefs and norms about female and male bodies, and about sexual difference. Zeiler (2013) comments that gendered patterns exemplify such enactment. For Malmqvist and Zeiler (2010) the 'repetition' and 'sedimentation' of this enactment translates into incorporated sexed embodiment in the form of the lived body. Excorporation is explained as the reverse of incorporation. Excorporation is often abruptly and unexpectedly initiated and also can be aggravated over time. It is described as something that has been a part of one's lived body on a pre-reflective and practical level becoming majorly to one's attention. Zeiler (2013) suggests excorporation is unwanted, typically emotionally, and painful resulting in a breakdown in orientation and the lived body becomes object one cannot but attend to. Over time this results in

bodily alienation, implying a deeper, more pervasive wound of the lived body, impacting on embodied agency and disrupting intentionality. Embodied resistance is the resistance to continuous excorporation. Such resistance, Zeiler explains, takes place when individuals attempt to find new ways of expressing herself or himself and new ways of living as bodily beings. In relation to beliefs and norms about sexed and sexual embodiment, this can take place when individuals try to express their bodily selves in other ways than stereotypical female or male ways and actively question these beliefs and norms in interaction with others, discursively and through ways of being in relationship (2013). The phenomenological concepts of incorporation and its reverse, excorporation and embodied resistance have application to this study, and also to clinical practice.

2.13 Summary

In summary, the application of feminist phenomenology with its method and key analytical concepts could lay the ground for an understanding of vulvodynia in situatedness, which involves the intimate interaction and connection between two embodied selves in couple relationship with vulvodynia both in this study, and for transforming current clinical practice.

Chapter 3. Literature Review

3.0 Definition and Purpose

This literature review, including a systematic search, was undertaken to identify the available literature, which addresses the meanings and experiences of adjustment for couples living with vulvodynia in the relational and sexual context. It was also extended to identification of studies with clinical interventions to address couples' psychic and relational negotiation of sexual and gendered discourse; sexual pain and suffering, the impact on sexual embodied subjectivity; and the re-negotiation of couple sexual practices in the context of sexualities, desires and sexual pleasures in the context of vulvodynia.

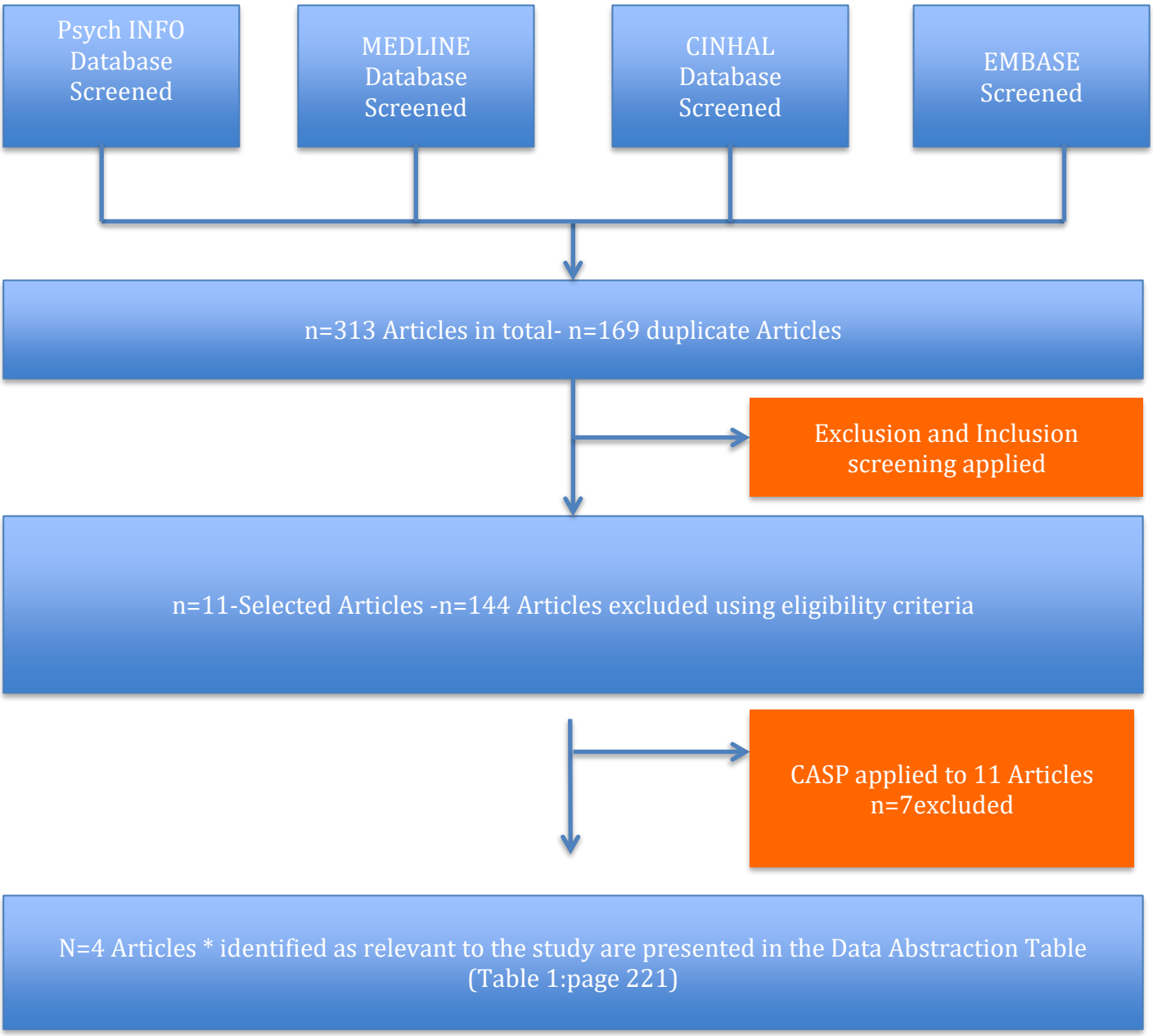
Greenhalgh (2014) recommends a systematic search when identifying a knowledge gap, arguing that it is, "…conducted in a way that is explicit, transparent and reproducible", (p.116). This limits risk of bias and ensures that any conclusions are reliable and traceable. The Data Abstraction Table (attached at List of Tables: Table 1 p.222) presents studies subject to CASP quality appraisal and selected, which address adjustment to vulvodynia in the (hetero) sexual couple relational and sexual context.

In the introduction section, I argued that there is minimal empirical evidence exploring the meaning and experiences of adjustment to vulvodynia in couples in the context of their most intimate interactions from a qualitative and quantitative research methodological perspective. I noted that there exist a number of studies using quantitative methodology, which primarily explored cognitive behavioural approaches, with the majority of studies emanating from North America, specifically Canada. The interpretative understanding of relationship and sexual adjustment in couples coping with vulvodynia has received very little empirical attention to date, with only two studies involving couples, one originating in the United Kingdom (UK) (Sheppard et al., 2008) and the second the United States of America (USA) (Connor et al., 2008). These both lie in the interpretivist paradigm, where a qualitative research methodology was used. This literature review, including a systematic search, confirmed the issues, which were identified above. The review also helped with the conclusions made regarding the research and identified the theoretical, knowledge and clinical practice gaps.

3.1 Methods of Data Collection

Electronic database searches were carried out at two systematic search points in the literature review, when looking for papers between 2000-2020. The initial search point was undertaken in August 2017, and the second search point was in November 2020, to ensure the literature review systematically captured recently published studies, since the initial search. To complement the database searches, I also used Scopus, a literature search tool, which uses author surnames to link any scholarly writers who referenced the paper and had written on the same subject. Alerts were also placed on Google Scholar and other databases to identify newly published papers. The combination of systematic electronic and manual screening was undertaken in order to be as comprehensive as possible. The PRISMA (Moher et al., 2009) flowchart was used to assist with the systematic screening process. Figure 1 below shows the PRISMA flowchart, which demonstrates the systematic review process followed.

Figure 1. Prisma Flowchart



3.2 Electronic Search Strategy

The databases CINHAL, MEDLINE, Psych INFO, EMBASE and Thesaurus were searched using the key terms vulvodynia, vestibulodynia, sexual pain, couples, communication and relationship*. The key terms and the or/and combining process for each database interrogated was to maximise the search and yield of results. The systematic search strategy consisted of an online search of English language

publications in peer-reviewed journals and books published between August 2000-November 2020. The title search terms, identified above were added. These terms were entered into the Thesaurus of each database to ensure that relevant terms were identified. 313 articles were identified, 169 articles were de-duplicated by the Reference Manager system, leaving a total of 144 articles. The studies were independently extracted and screened by myself with studies rejected if they did not meet the eligibility criteria, which resulted in a total of 11 articles, in full text published in English, in peer reviewed journals. All 11 articles were also independently rated by an academic researcher; the Cohen Kappa score was, Po= 0.818, K=0 (Kappa of 0 indicates agreement equivalent to chance), and provided the level of agreement that the selected articles were suitable to undergo quality appraisal (Cohen Kappa calculation at List of Table: Table 2 p.225). The 11 articles were subsequently quality appraised using the relevant Critical Appraisal Skill Programme (CASP) 2018, assessment tool. The final number of articles selected as having relevance to my study was 4. No article was excluded on the basis of the quality appraisal, so as not to limit the potential for new clinical and theoretical insights to be found. The relevant Critical Appraisal Skills Programme (CASP, 2018) tool was utilised in order to structure critique of the articles included and to inform on the strengths and limitations of any such insights. The 4 selected articles are presented in the Data Abstraction Table (List of Tables: Table 1 p.222) for information.

3.3 Inclusion and Exclusion Criteria

The criteria for this search are identified below at Table A. PECOS Inclusion and Exclusion Criteria. Exclusion criteria included women with vulvodynia only articles, and partners of women with vulvodynia only articles; women and men under age 18; mixed sex or same sex couples with vulvodynia in a couple relationship for less than a year and not cohabiting; couples with vulvodynia currently pregnant or planning a pregnancy; mixed sex or same sex couples with vulvodynia, and a major medical condition; mixed sex or same sex couples with vulvodynia, and a major mental illness. Individuals with lack of capacity to give informed consent. Only full text, published and peer-reviewed articles were selected, to enhance reliability, credibility, and relevance to the research question.

Table A. PECOS Inclusion and Exclusion Criteria

Research Aspect		Inclusion Criteria	Exclusion Criteria
Participants	P	Women with a diagnosis of Vulvodynia in mixed sex or same sex couple relationships for at least a year and cohabiting. Over age 18	Under age 18 Lack of capacity Pregnancy; Major mental illness/ medical condition
Exposure	E	Sexual/genital pain; socio-cultural and relational factors	
Comparator	C	Not applicable	
Outcome	O	Relational and sexual adjustment in couples	
Study design	S	Quantitative, qualitative and mixed.	Case Studies
Other Aspects:			
Publication Language		English Language	
Cultural and linguistic characteristics of participants		Studies carried out in any cultural groups. Humans only	
Time frame		2000- 2020	
Types of publications		Peer-review journals and dissertations. Full text only	Publication in non-peer review journals; commentaries to articles; books; case studies; theoretical papers; abstracts.

3.4 Critical Appraisal of the Search: Strengths and Limitations

From the database searches it is clear that there is a paucity of research activity on couples living with vulvodynia in the United Kingdom (UK). However, a developing interest emerging in North America, specifically Canada was evidenced by the proliferation of research studies returned in the systematic database searches. The significance of the under-research in UK is not wholly understood, however it indicates that it is a fertile area for research. Given the search results mainly produced studies, which had their origin in North America, there may be subtle population, cultural and societal characteristic differences, and nuances in biomedical and scientific discourses about gendered roles, sex and sexuality from this study. These are not necessarily overtly observable when screening the selected papers however, I think caution is warranted regarding the cross cultural applicability of findings, despite penile-vaginal intercourse being the most common partnered (hetero) sexual behaviour in North America.

Careful scrutiny has been given to the diagnosis and description of vulvodynia used in returned articles and whether the women had actually received a formal specialist medical diagnosis of vulvodynia when I selected or deselected articles. The changes to the American Psychiatric Association (APA), (2013) Diagnostic and Statistical Manual of Mental Disorders, (DSM) 5th edition, with the introduction of the Genito-Pelvic Pain/Penetration Disorder (GPPPD) as a new diagnostic category, also required careful attention when selecting and deselecting articles. GPPPD is an umbrella diagnosis for a cluster of conditions that can disrupt sexual functioning and result in sexual pain. Vulvodynia and relevant subsets are included in the new GPPPD diagnostic category but also vaginismus, which is an entirely different condition but nonetheless falls within the GPPPD diagnostic category (Appendix 1 p.174).

Many of the articles returned by the databases purported to be about vulvodynia when in fact they were about vaginismus. Consequently these were de-selected because vulvodynia is the focus of attention of this study. Articles using terms like sexual pain, genital pain disorder and dyspareunia interchangeably with vulvodynia also complicated the search and for the sake of clarity were deselected. A further limitation of the search was the majority of the articles returned from the electronic databases search involved women with a reported diagnosis of provoked vulvodynia. The clinical

profile of women with generalised vulvodynia, are more likely to be sexually inactive and can differ on the basis of severity and complexity from women with provoked vulvodynia; these women do not appear to be accounted for in the articles returned from the electronic database search. The intensity, duration and level of service input, and interventions may, differ for women with provoked vulvodynia, compared to those with generalised vulvodynia.

Many articles initially appeared as couple studies, but on scrutiny the analysis involved only one partner. Again these were deselected. In keeping with previous study findings, referred to in the introduction chapter, which address the constructions delimiting women with vulvodynia (Kaler, 2006; Ayling and Ussher, 2008; Marriot and Thompson, 2008) and alternative ways of gaining sexual satisfaction and pleasure; the articles returned from the search not only, delimit women, but delimit couples too. There was minimal focus on socio-cultural factors impacting on couples, adjustment issues and little room given to alternative ways of gaining sexual satisfaction and pleasures in the couple context - which is an important focus of this study.

The couple experience is important because the couple brings into focus widespread understanding and meaning of gender, sexuality and sexual practices, according to which gender, identity proceeds from and is produced by sexuality and normalising socio-cultural sexual practices.

The majority of the articles selected, after the exclusion criterion had been applied, used quantitative methods underpinned with psychological theory, predominantly adopting a cognitive behavioural paradigm. This was deemed a strength in that one study in particular was piloting a couple cognitive behavioural therapy treatment (CCBT) (Corsini-Munt et al., 2014), examining for relevance and efficacy for couples living with provoked vulvodynia, as a first level intervention treatment option. The remaining articles using quantitative methods were predominantly focused on examining psychological interventions about communication, empathy and disclosure in the couple relationship to develop relational couple adjustments to minimise pain and improve relational and sexual satisfaction. These have relevance to this study when considering clinical interventions, and the training and education of healthcare professionals and psychosexual therapists when working with couples coping with

vulvodynia. However, socio-cultural factors relevant to sex, genders and sexualities were unaccounted for in these articles. Moreover, sex and sexual satisfaction are a subjective experience, which quantitative studies keep trying to find ways of objectively measuring. This is a highly problematic area because of the socio-culturally constructed gender-based sexual gap in partnered (hetero) sex.

3.4.1 Quality Appraisal of Literature–Critical Appraisal Skills Programme (CASP)

Quality appraisal in qualitative and quantitative research has intensified in recent years, in order to enhance rigour, partly due to the debates on the reliability and credibility of such research. CASP (2018) tool for quality appraisal was developed to ensure that as a researcher one critically examines one's role, potential bias and design, influence and affect on the analysis and outcome of the research. Included in the debates on qualitative and quantitative research, one of the areas of contention is on whether the same construct should be used to assess quality in qualitative and quantitative research, as they are different epistemological paradigms (Spencer and Ritchie, 2012). CASP is one of the most popular, reliable and effective quality appraisal tools in qualitative and quantitative research. The relevant CASP (2018) checklist tool was used to evaluate individual studies identified from the database literature search. CASP ratings of strong, moderate and weak were given to the selected papers. A score of 20 = strong quality, 16-19 = moderate quality and < 15 weak quality. Appendix 4 p.182 shows an example of the CASP quality appraisal tool used for qualitative methods. In addition, analysis was undertaken to allow the contribution of new insights, furthering understanding of vulvodynia in the couple relational and sexual context, and to allow reliable and useful implications for clinical practice to be drawn.

3.5 Literature Review Findings

The number of studies for quality appraisal was 11.The majority were quantitative studies, which use questionnaires with self-report measures, for example daily diaries; surveys; numerical scales; only as their method of investigation Charonneau-Lefebure et al. (2019); Rancourt et al. (2017). A few quantitative studies reported a cross sectional method, utilising an observational approach with self- report measures, which strengthened the study and findings (Rancourt et al., (2016); Rosen et al.,

(2016); Gauvin et al., (2019); Bois et al., (2016); Rosen et al., (2016). There was a paucity of qualitative studies, only 2 studies; one of which uses a Transcendental Phenomenology paradigm (Connor et al., 2008). However the methodological detail is sparse and rated overall weak. The second study uses a qualitative method with a thematic analysis design (Sheppard et al., 2008). Methodologically, the analysis is undeveloped, hence rated weak. The remaining studies include a systematic review (Smith et al., 2011) and a small feasibility study piloting couple cognitive behavioural therapy (CCBT), (Corsini-Munt, 2014). Recruitment practices, sample sizes and methodological weaknesses must be addressed in future research, because of the difficulty to draw conclusions.

Overt epistemology articles primarily concerned with feminist phenomenology related to couples were limited. All authors of the 11 articles quality appraised fail adequately, if at all, to discuss an epistemological standpoint. Where there is no reference to epistemological standpoint, the studies tended to place the difficulties within the individual. The quantitative studies did not take account of social and cultural factors and individualised multi -disciplinary approaches. There was little in the way of research in the articles that highlights the psychological impact of living with pain in an intimate area, which is so inextricably tied up with sexuality and gender that conflates sex is penis in vagina penetration and penis in vagina penetration with womanhood. Research emphasis needs to be about targeting changing cultural narratives and examining the negotiation of alternatives in sexual practices and pleasures.

From a clinical perspective there is a need for more couple therapies to be studied to ascertain effectiveness and benefit with this couple client group. Provoked vulvodynia appears to be associated with some unique cognitive, behavioural and interpersonal features and while the feasibility for CCBT is a positive development (Corsini-Munt et al., 2014), it may be that current psychological treatments focused on communication, disclosure, and empathy, may not equally translate to improved outcomes in vulvodynia without appropriate tailoring to address these.

Several gaps in research are evident from this literature search. All 11 articles constitute valuable research and as such contribute to existing knowledge. In essence, however, the literature review shows that relationship and sexual adjustment in

couples with vulvodynia is rarely mentioned in research and there are very limited qualitative and quantitative couple studies. There is also a clear need to promote research activity with improved methodological design in order to begin to improve the research potential for this under-researched and under-recognised health condition which impacts detrimentally on women's and their partners sexual relationship.

Of the 11 articles, 4 are selected as having relevance to my study; two quantitative articles; Rancourt et al. (2016) and Rosen et al. (2016) and two qualitative articles; Connor et al. (2008) and Sheppard et al. (2008). The study of Rancourt et al. (2016) is a quantitative cross -sectional design study addressing multiple interpersonal relationship factors in dyadic sexual communication. The study has a large sample size of 107 couples, and self-reports and measures with bivariate correlation analysis. The findings suggest integrating sexual communication skills training into couples' interventions may have the capacity to influence couples' adjustment. Limitations include lack of generalisability because of the sample and the cross -sectional design of the study means that alternative explanations for the results are possible. A strength of the study is the sample size, which allows for statistical significance of smaller effects. Overall the study is of moderate quality. The findings have relevance to this study because of the concept of integrating sexual communication skills training into couples' interventions as an approach to influence couple' adjustment to vulvodynia. Developed sexual communication in couples is possibly one of the most important tools they can use in navigating discourses and the stressors associated with the condition, and also for negotiating adjustment towards alternative sexual practices and pleasures.

The study by Rosen et al. (2016) uses a quantitative method with observational, self-reports and cross sectional design with a sample of 50 mixed sex couples. The study aims to examine observed and perceived disclosure, and empathy associated with better relationship adjustment in couples with provoked vulvodynia. The findings indicate increasing disclosure and empathic responses might be a valuable target for enhancing the efficacy of couple -based interventions for vulvodynia. This study is of moderate quality and compares favourably with the Rancourt et al. (2016) study in that it stresses that improved couple communication is important when considering the

development of clinical interventions to promote adjustment in intimate relationships impacted by vulvodynia.

The study by Connor et al. (2008) uses a qualitative method with transcendental phenomenology design to explore the experiences of couples in which women have vulval vestibulitis syndrome, a subset of vulvodynia. Sixteen in-depth semi-structured interviews were conducted with 13 heterosexual couples and 3 women whose partner was not available. A reported biopsychosocial and feminist episteme informed the study. Four essences emerge; (1) the medical journey requires extensive searching for knowledgeable and respectful practitioners to provide treatment; (2) the process of developing a personal understanding of this condition led many couples to question their role in causing and maintaining vulval pain; (3) developing strategies for coping with painful intercourse led to three strategies: becoming non-sexual, using alternatives to vaginal sex, and altering or enduring painful intercourse; (4) Finally, feelings of isolation were experienced, as adjusting to this condition was often a lonely process. Recommendations include: treating the couple, not just the woman with vulvar pain; encouraging couples to broaden definitions about the importance and primacy of vaginal intercourse and suggest alternative sexual activities less likely to cause vulvar pain; developing shared meaning as a couple, and assisting couples in locating health professionals and resources.

This study is methodologically weak, firstly because of the nature of the transcendental phenomenological design was inadequately articulated and, secondly, because the sample includes three women, without partners. There may also be population and socio-cultural differences due to the study origin being the USA. Nevertheless it has relevance for my study because it offers some important information about subjective experience and couple adjustment strategies, service provision and clinical interventions.

The study by Sheppard et al. (2008) uses a qualitative method with grounded theory thematic analysis design. It involves a small sample of eight women with a diagnosis of vulvodynia or vulval vestibulitis, a subset condition of vulvodynia; and their partners. The couples were interviewed in semi- structured interviews prior to commencing couple sex therapy. The quality of the study is weak owing to the data analysis being

insufficiently rigorous and lacking of coherence. The article highlights the problematic journey couples, and particularly the individual women with vulvodynia, encounter with a whole range of healthcare professionals before finally being referred for sex therapy because the condition does not respond to various medical and physical treatments. Women aged 18-60 are recruited into the study if a diagnosis of psychosexual difficulty on at least one subscale of the Golombok Rust Inventory of Sexual Satisfaction (GRISS) (1986) was confirmed after screening.

The analysis identifies five themes: (1) the concept of emotional distress; (2) issues of failure and loss; (3) a specific damaging effect on the couple relationship; (4) emotional isolation; and (5) feeling uncared for by the medical profession who had "sent them" for therapy. The article identifies the work of Charmaz (1983), who proposed that loss of self is exacerbated by four conditions; living a restricted life, existing in social isolation, experiencing discredited definitions of self as a sense of self becomes both altered and diminished; and becoming a burden.

Sheppard et al. (2008) suggest that the aim of therapy must be seen as acknowledging that the pain is real; seeking to understand the pain and its effects on the self; understanding the effects on the couple relationship; and developing coping strategies to manage the pain. There is an acknowledgement that psychotherapy or medical intervention alone are not sufficient; with a suggestion for integrated or combined clinical interventions. This study highlights that, for some women, medical approaches to treatment have not been useful and this may have consequences for the couple relationship and their sexual life. There is an interesting conclusive comment in the study: that 'the difficulties seen in a couple may need assessing carefully as they may be the result, rather than part of the etiology, of the problem', which resonates with my study in terms of relational and sexual adjustment.

3.6 Conclusion

There exists quantitative research on vulvodynia; however, it is focused largely on treating women, not couples and often based on "achieving" pain free vaginal intercourse. There continues to exist a paucity of qualitative research studies. More qualitative interpretative research may provide insights into how vulvodynia impacts couple relationships in aspects that current quantitative measures have not yet

captured. Quantitative methodology, by its nature, requires converting social phenomena to numerical values in order to carry out statistical analysis. Qualitative methodology, on the other hand, aims to explore, describe, and interpret the personal and social experiences of participants (Smith, 2007), offering potentially much broader insights into the lived experiences of couples with vulvodynia.

The evidence from this literature review, including a systematic search, shows that relational and sexual adjustment in couples with vulvodynia is a fertile topic for research. The literature review demonstrates that the couple research is limited in that it does not examine the couple meanings and experiences of vulvodynia, nor does it address the psychic and relational negotiation of gendered and sexual discourses, the materiality of embodied sexual pain and suffering, and the complex re-navigation of relational and sexual adjustment. Clinicians and researchers ought to consider the needs and potential benefits for couples beyond facilitating pain-free intercourse, by sexual practices and pleasures through sexual activity other than intercourse. Qualitative research in the important area of relational and sexual adjustment in couples with vulvodynia could provide valuable insight and potentially optimise women's sexualities, sexual practices and pleasures.

Chapter 4. The Methodology

4.0 Epistemology

Epistemology is defined as “the study of the nature of knowledge and the methods of obtaining it” (Burr, 2003, p. 202). Taking a more robust stance in addressing the meaning of epistemology, Langridghe and Hagger-Johnson (2009) declare that epistemology is concerned with how we understand construct and validate our understanding of the world. A slightly different angle of describing the same thing is given by Bager-Charleson who argues that; “epistemology asks the questions about the bedrock and ultimate foundations of belief “(2010, p.73).

There are numerous and complex debates on epistemology and philosophical standing of qualitative research methodologies. Common to all qualitative research methodologies is the identifying of emerging themes as part of understanding the material and enabling a robust inquiry. Essentially, this study is embedded in social science domain as it concerns meaning making, which is a qualitative inquiry**.** The exploratory questions asked in this study seek to convey experiences of the participants and the meaning attached to them. The study used IPA as a data analysis method, which would naturally align it with phenomenology, which again lends it to realism - relativism epistemology (Harper, 2012). However, considering the nature of the study aimed at generating knowledge through the personal and social accounts of experiences, which is negotiated and claimed, a Feminist Phenomenology stance was adopted with a lived body perspective as a theoretical position.

4.1 Research Strategy and Design

Gleeson and Frith (2011) identify the importance of adaptability in research design to ‘fit’ the method to the adopted epistemological position, to the research question, to the researchers skills and experience, and to their participants and the scope of knowledge they aim to produce (p.56). A feminist phenomenology epistemic standing with a lived body perspective, together with an IPA qualitative interpretative analytical methodology, is compatible and entirely appropriate for thoroughly addressing the research question in this study. Central to this study is an in-depth understanding about relational and sexual adjustment in couples with vulvodynia in their life situation and intimate relationship.

The rationale for IPA is that it takes into account the participants' subjective experiences, therefore in this study, the separate couple partner's subjective experience of vulvodynia, intimacy, (hetero) sexuality, gender, pain and relationship. IPA is concerned with an individual's personal perception of a phenomenon and not with an objective statement about the phenomenon itself. IPA holds a symbolic interactionism position; it recognises that meanings are negotiated within a social context, for example the individual in relationship. It also assumes that the researcher has an interpretative role, in exploring the participants' meaning of what is happening to them, for example adaption and adjustment, or otherwise in the couple relationship (Willig, 2009).

A continual reflexive approach is incorporated as part of the research method to address the dual interpretative nature inherent in the analytic process with IPA, recognising that the researcher's perspective and position shape the research (Willig, 2001). Spencer and Ritchie (2012, p.230) maintain that rigour can be demonstrated through careful documentation of the research process. As a reflexive researcher, I used journaling together with Boud's triangular reflective model of experience, reflection and learning, throughout the research journey (2005). The examples identified in Chapter 5, section 5.3: Reflexivity and Researcher Positionality; Chapter 8: Discussion; and Chapter 10: Limitations, Strengths and Future Study, show how my reflexive practice informed the knowledge produced. These examples variously describe experiences, impacts, reflections, learning, decision-making and action to maintain rigour during the research process. They also importantly describe my role, presence, held values and thoroughness of conduct as researcher, which guided this research, together with my approach to the researcher-participant relationship.

A relevant issue to highlight in this study is the use of IPA in couples. While IPA has not been used extensively to study perspectives on shared experiences as in this research study, it is an appropriate methodology for such an endeavor as detailed in a number of studies (Robinson, (2004); Clare, (2002); Boland et al., (2012) and has been used effectively to explore experience of chronic health conditions (Smith (2010). Importantly too, a study selected in my literature review in chapter 3, namely Connor et al. (2008) used phenomenological methods in a couple study inquiring into vulvar vestibulitis syndrome, which is one of the subsets of vulvodynia. There is, therefore, a

precedent for using IPA in couples.

McLeod (2007) asserts phenomenology and hermeneutics possess significant areas of convergence; they both assume an active, intentional, construction of a social world and its meaning by reflexive human beings. This is an important statement considering the hermeneutic (meaning making) of this study as well as the phenomenological standing of IPA. From the on-going debates on epistemology, it has also been argued that qualitative research methodologies that are epistemically interpretative, concerned with meaning making, are most appropriate to use in both process and outcome of therapy practice (McLeod, 2011; Harper and Thompson, 2012). This study is indeed hermeneutic in nature and adopts IPA, a qualitative research methodology as it is deemed useful, appropriate and relevant.

4.2 Alternative Qualitative Methods

Other qualitative methods were considered. Grounded theory approaches (Charmaz, 2006; Glaser & Strauss,1967) could have been used to develop a theoretical account of relationship and sexual adjustment. The language and social constructionist focus of discourse analysis would have provided an understanding of participants' discourse, for example in relation to power (Kendall & Wickham,1998) or hetero-normativity (Potts, 2002; Kaler,2006). Thematic analysis (Braun & Clarke, 2006) would have led to the generation of themes pertinent to the participants' experiences. Narrative analysis (Crossley, 2000; Gergen & Gergen, 1988) could have been used to provide a greater understanding of story structures used by participants rather than participants' idiographic experiences and sense-making. All of these approaches were relevant. However, IPA was chosen to enable a focus on, and give voice to, participants' experiences and sense making, which would be grounded in their experience but linked to relevant psychological factors (Larkin & Thompson, 2012).

4.3 Sample

Research participants and their partners, were drawn from referrals from members of the Vulval Pain multi-disciplinary team in a NHS hospital, which comprises a Sexual Health Consultant, a Pain Consultant, a Consultant Dermatologist, a Physiotherapist for Women's Health, a Consultant Gynaecologist and a Psychosexual Therapist. Participants were eligible for the study if they met all of the following criteria; (1)

women with a medical diagnosis of vulvodynia ; (2) a reported minimum pain duration of 6 months; (3) women with vulvodynia and their partner to have been in a committed monogamous relationship for over one year and co-habiting;(4) women with vulvodynia to be in a mixed sex or same sex couple relationship, and (5) participants must be age 18 or over. The criteria for length of relationship, is used because important changes seem to occur very early in the relationship experience (Kurdeck, 1991). Exclusion criteria include couples currently pregnant, planning a pregnancy and couples with a diagnosis of a major medical disorder or major mental illness. Individuals lacking capacity to give informed consent.

Participant socio-demographics and related health condition information were collected pre-interview; Table B. below identifies the socio- demographic and health data.

Table B. Socio-Demographic Data of Participants

Participant	Age	Sex	Ethnicity	Relationship Status	Years in Relationship	Employment Status	Other Related Health condition
P1	25-49	Woman	White British	Cohabitation	1-5 years	Employed	Yes
P2	25-49	Man	White British	Cohabitation		Employed	
P3	25-49	Woman	White British	Cohabitation	1-5 years	Employed	Yes
P4	25-49	Man	White British	Cohabitation		Employed	Yes
P5	18-24	Woman	White British	Married	6-10 years	Employed	
P6	25-49	Man	White British	Married		Employed	
P7	25-49	Woman	White British	Married	6-10 years	Volunteer	
P8	25-49	Man	White British	Married		Employed	
P9	65-69	Woman	White British	Married	10+ years	Employed	
P10	50-64	Man	White British	Married		Employed	
P11	18-24	Woman	White British	Married	6-10 years	Employed	Yes
P12	18-24	Man	White British	Married		Employed	
P13	25-49	Woman	White British	Married	1-5 years	Employed	
P14	18-24	Man	White British	Married		Employed	

Note:

1.Participants' self identified as: cis-gender woman or man, and heterosexual.

2.All women met the Genito- Pelvic Pain/ Penetration Disorder (GPPPD) -Vulvodynia diagnostic criteria DSM-5 (American Psychiatric Association, 2013).

4.4 Patient Involvement

The views of the local Expert Patient Group (Vulval Pain) hosted by a NHS hospital were sought and incorporated into the study methodology, recruitment process, and participant information and interview schedule. A pilot interview was undertaken prior to embarking on the main interviews. Feedback from the pilot interview was used to tailor my research questions and to refine my interviewing skills specifically; active listening, and asking open-ended questions without imposing my views on the participants, which is important in IPA (Smith, et al., 2009).

Following patient involvement feedback and the pilot interview I discussed the structure and questions for the proposed interview schedule with my supervisor, after which the schedule remained unchanged. The interview schedule is attached for information at Appendix 5 p.183.

4.5 Recruitment

Participants with vulvodynia and their partners were recruited through a vulval pain service in an NHS hospital in the south west of England, using a purposive sampling method, between November 2018 and June 2019. Treating clinicians, members of the vulval pain multi-disciplinary team (MDT) from the participating vulval pain service identified eligible patients. The treating clinicians acted as gatekeeper to the study and provided participants with the Participant Information Sheet (Appendix 2 p.175) about the NHS research study. The treating clinicians sought verbal consent from the interested participants to be contacted by myself, as the researcher.

The treating clinicians notified me about the interested participants giving contact details in order that arrangements for the follow up telephone call could be made. I contacted those participants who gave permission by telephone after approximately seven days, to answer any queries or questions they had about the study. If the participant was happy to proceed with the study, I arranged a couple meeting to consent and to be interviewed on the hospital site. I used the Participant Information Sheet as a guide and the formal Consent Form (Appendix 3 p.180) to obtain consent from participants prior to interview. This included consent for the digital audio-recording of interviews with participants too. All participants were given sufficient information concerning the research project and had the right to withdraw at any time

without giving reason.

4.6 Method of Data Collection

Fourteen recruited and consented participants, (seven diagnosed with vulvodynia and seven being their couple partner) were interviewed. This enabled a detailed understanding of each participant's experience, whilst providing sufficient cases to enable the identification of meaningful differences and similarities between them. Important to phenomenology is less the study of a large number of instances than the intuitive and deep understanding of a few individual cases. I interviewed the couple participants separately using a prepared interview schedule (Appendix 5 p.183) developed to guide me, ensuring that a detailed account of the relevant topics was obtained about the individual experience of, and the meaning given to coping with, and adjusting to, vulvodynia in the relational and sexual couple relationship. In the interview schedule the first stage before starting the interview was a reminder about the nature of the study and obtaining the socio- demographic and health- based context of the participants'. Pietkiewicz & Smith (2012) describe this initial process as crucial in reducing tension and preparing the participants answering questions that might be quite sensitive to them.
In keeping with IPA approach, the interviews were conducted using an open ended, semi structured interview style, framed around the research question with identical questions for both partners of each couple. This was arranged at mutually convenient times with the participants and in an environment conducive to a comfortable and safe interview experience. The interview schedule was made up of semi-structured questions, which enabled in- depth exploration of the study questions (Smith, et al., 2009, p.60).

A one-to-one interview allows the researcher to engage with the participants in real time, which enables exploration in detail and further questioning, where appropriate (Pietkiewicz & Smith, 2012). Core questions included exploring the intra and inter-personal subjectivity of the impact of vulvodynia, reflecting on participants' experience of sexual pain, enquiring about any change before the diagnosis and coping strategies/problem solving approaches used in their relational and sexual relationship, enquiring about any change following the diagnosis in their relational and sexual relationship, and examples, with descriptions, of coping and problem solving strategies

adopted and to what effect and how they think their strategies may change going forward. Questions were open and expansive, enabling participants to talk at length about their experiences. I used these questions flexibly, altering the sequence and wording to fit with the participant's account. Additional prompts were used, where necessary, to gain clarification and elicit more information. Interviews ranged from 45-70 minutes in duration. Both participants in the couple relationship were consented together, and interviewed sequentially on the same day. Additionally, both participants in the couple relationship were debriefed together after completing their interviews, to check on wellbeing, obtain feedback on the process, and to ask if they had any questions or queries. They were also advised on accessing the final study.

The interviews were audio recorded using a digital audio recorder. This enabled me to undertake a contemporaneous transcription and analysis of the data after each couple had been interviewed. For confidentiality purposes, the recorded data was anonymously labeled and kept in secure storage conditions.

4.7 Resources

A private therapy facility was identified on a hospital site in the southwest to conduct the research interviews with participants. Resources identified for the study included a digital audio tape recorder and confidential, safe and secure storage for the audio recorded interviews and transcribed interviews.

4.8 Ethical Considerations and Consent

This study was approved by the NHS Health Research Authority in collaboration with the North West (NHS) Research Ethics Committee due to the involvement of NHS patients recruited into the study. Appendix 6. A-D pp.187-202 provides the correspondence relating to approval. The College of Life and Environmental Sciences (CLES) Psychology Ethics Committee at the University of Exeter also approved the study. Appendix 6. E p.203 provides the correspondence relating to the approval. Appendix 6. F p.204 identifies the university Lead Sponsor and appendix 6.G p.206 the Confirmation of Capacity and Capability to deliver the study at the NHS site. The study was performed in accordance with the ethical standards laid down in the

Declaration of Helsinki (1964) and later amendments.

Following ethical approvals, recruitment to the study commenced. Recruitment was, however, problematic as referrals from the treating clinicians acting as Gatekeeper following the originally agreed recruitment pathway were few. On investigation and discussion with the Gatekeepers it was discovered, firstly that the partners of the women with vulvodynia often declined to participate in the study, and secondly that potential participants were thought to be known to me in a clinical capacity and consequently not referred by the Gatekeepers. Recruitment was also disappointing in that same sex couples were not forthcoming through the recruitment pathway.

Despite more time and additional promotion about the study, recruitment was only moderate in numbers. I approached my supervisors and sponsor about opening recruitment to potential participants who may be known by me in a clinical capacity (but not as a researcher) and to seek formal ethical opinion and approval. This was agreed and I sent a notice of amendment and supporting documentation to the HRA North West- Preston Research Ethics Committee. The amendment was to open the study to potential participants who may be known by the researcher in a clinical capacity who have been identified by the treating clinicians as Gatekeeper following the originally agreed recruitment pathway. The Committee gave a favorable opinion of the amendment on the basis as described in the notice of amendment form and supporting documentation (Appendix 6. C p.199).

Verbal and written consent was sought from each participant before starting the interview process and they were given the right to withdraw their consent at any time. The signed consent forms were safely and confidentially kept as part of the information governance. Laptops and memory sticks were password protected to ensure patient confidentiality. All participant data was anonymised and I adhered to General Data Protection Regulations 2018 (GDPR) to protect participants' personal data.

The venue for conducting the interviews was professional and discreet to ensure patient privacy and confidentiality.

A history of sexual, physical, and psychological abuse is more common in women with symptoms of genito-pelvic pain/penetration disorder (GPPPD), of which vulvodynia is a diagnosable condition, although the vast majority report no abuse

(Reissing et al., 2003). Additionally, it is essential to assess for other comorbid psychological conditions in the women and, their partners as these individual factors can complicate the clinical picture. I was alert to disclosures of domestic violence, sexual and emotional abuse requiring a vulnerable adults referral. Such disclosures and dilemmas are part of being a psychosexual therapist (and clinical researcher), and can be quite difficult to resolve. There are those who still do not wish to accept that rape and /or domestic violence is a crime, and others who do not report for a myriad of reasons, despite recognising that it is a crime. I exercised vigilance and sensitivity during this study and held a robust understanding of local resources, reporting processes and signposting. I was also alert to the presence of any concerning active mental illness and /or self- harm behaviours requiring urgent referral for support and intervention. I was compliant with my professional code of conduct and the legal and ethical framework concerning duty of care and accountable practice as a clinical researcher (and registered clinician) throughout this study.

Chapter 5. Data Analysis Strategy

Interpretative Phenomenological Analysis (IPA)

5.0 Introduction

Philosophically, IPA has its origins in the work of phenomenologist, Edmund Husserl (1859-1938) who argued that we all have “intentionality” to describe the process occurring in consciousness and the object of attention for that process (Smith et al., 2009 p. 13). Husserl saw phenomenology as involving careful examination of human experiences, how one accurately knows one’s experience and identifies the qualities of the experience. Phenomenology concerns the philosophical approach to study of experience, capturing individual perspective and meaning attached to the experience. Hermeneutics concerns theory of interpretation while idiography, concerns the particular, by focusing on specific details of specific people (Smith et al., 2009).

Husserl’s work influenced philosopher, Martin Heidegger (1889-1976) who believed that we live in an interpretive and interpreted world. He brought the hermeneutic element to phenomenology by questioning the possibility of having any knowledge outside the interpretative stance (Smith et al., 2009, p.16). The ‘idiographic’ element was developed by Merleau-Ponty (1908- 1961), a phenomenologist who built on the work of Husserl but argued that we see and view ourselves as different to everyone and everything else in the world, believing that subjectivity and embodiment are inseparable. Subsequently, IPA was developed as an analytical methodology to investigate the in-depth (idiographic), lived experience (phenomenology), the meaning making though interpretation of the participants’ material by the researcher (hermeneutics). Psychologists, Jonathan Smith, Michael Larkin, and Flowers pioneered the use of IPA in the mid 1990’s, showing it to be one of the most accessible qualitative research methodologies in psychology, psychotherapy and psychoanalytical based studies.

5.1 Rationale for Using Interpretative Phenomenological Analysis

The philosophical approach of IPA is essentially interpretivist. Interpretivism is concerned with contribution of localised or idiographic knowledge in generating rich data through human experience and meaning making in the discovery of multiple realities (McLeod,2007p.61). IPA was developed from debates between

phenomenology, hermeneutics, and idiography; these essential elements are foundational for this study.

5.1.1 Phenomenology

Phenomenology is the philosophic study of experience. IPA attempts to idiographically capture particular experiences of particular people. It focuses on the individual's perspective and meaning, unique to their embodied experience of, and relationship with, the world. The researcher interprets these experiences, focusing on how the individual makes sense of them, being mindful that the person is embedded with a world of relationships, culture and language.

5.1.2 Hermeneutics.

Hermeneutics is the philosophical theory of interpretation, concerned with the nature of interpretation and its potential impact on the original intentions or meanings of the author. IPA particularly draws on the work of Heidegger (1962) and Gadamer (1989). Heidegger (1962) highlighted the importance of acknowledging how the fore-conceptions of the interpreter shapes the interpretation, and that, usually the process of interpretation itself brings relevant pre-conceptions to the fore. Gadamer (1989) proposed that interpretation itself enables the comparison of various pre-conceptions, which are modified and compared throughout the sense making process. The authors stated that the focus of the interpretation was on the meaning of the account, which would be influenced by the context in which the interpretation was made. The use of the hermeneutic circle, which to understand the whole one needs to look at the parts and vice versa, is central to the iterative process of IPA. Gadamer (1989) viewed understanding as a matter of negotiation between oneself and one's partner in the hermeneutical dialogue such that the process of understanding can be seen as a matter of coming to an 'agreement' about the matter at issue, which is appropriate for this study.

5.1.3 Idiography.

Idiographic refers to a concern for the particular. IPA does this in two ways: focusing on 1) the specific details of an experience, and 2) specific experiences of specific people. Any generalisations are, therefore, made cautiously and are located in the particular experience. The phenomena being studied were not seen as solely the

property of the individual, but rather their unique perspective on their relationship to them.

IPA was considered the most appropriate methodology for this study; the rationale being that it is a structured, consistent, and robust framework for the research process to be undertaken. This was from designing the research question, sampling, designing interview schedule, interviewing, and most importantly, data analysis. IPA was also chosen due to its in-depth, meaning making, and interpretative nature, which helps with generating a deep understanding of the experiences individually of women and men, and across all couples. Smith (2008) apprises the inductive and iterative nature of IPA, as well its interrogative nature, which makes it unique compared to other methodologies. By being inductive, it means IPA takes a bottom- up approach and is not concerned with hypothesis testing, or testing existent literature, but creating theory from the data given by participants.

Smith states that the inductive approach of IPA enables themes to emerge during analysis where the researcher sets aside (Smith et al., 2009) her or his own perceptions. IPA as a data analysis methodology allows the exploration of the participant's perspective, whilst acknowledging the impact of the researcher's world view, and the interaction between the two, upon the interpretation (Willig, 2001). This is a very important tenet, considering the complex relationship the clinical researcher has with the researched in qualitative studies. One of the key elements of IPA, which made it appropriate for this study is the IPA notion of the double hermeneutic, where the researcher, is trying to make sense of what the participant is attempting to make sense of, creating a double hermeneutic angle of meaning making. Hermeneutics bring out richness to the data through interpreting it, so the finished product from the analysis is not just the participants' interpretation of their own experiences but the researcher adding an additional layer of interpretation, grounded in the participants' material (Smith et al., 2009) and bringing depth to the process of analysis.

Following the idiographic nature of IPA, this seeks to give a detailed examination of individual participants followed by a cross analysis of all women participants and all men participants to identify any convergence or divergence of themes (Smith, 2004, p. 41). Smith et al., (2009) assert that IPA is concerned with nuances of the human lived experience and posit "experience can only be understood via an examination of the

meaning which people impress upon it...” (p. 34). This captures the aims of this study, which is about meaning-making hermeneutics and exploring in detail participants lived experiences and how they make sense of them. IPA focuses on the understanding of phenomena and gathering “perceptions and views” (Smith et al., 2009, p.46), which is the aim of this study.

The questions asked in this study sought to gain an understanding of lived experiences of vulvodynia, in particular relational and sexual adjustment, which aligns well with IPA, which is concerned in mostly answering “how” questions and understanding phenomena (Smith et al., 2009). IPA data collection methods from a homogenous sample of participants, also aligns this study with IPA. The data collection methods, in the form of one-to-one interviews where semi structured questions were asked also aligns with the IPA research methodology. Smith et al. (2009, p. 45) demonstrate the type of research questions better answered by IPA, suggesting that IPA is suitable for questions that focus on “personal meaning and sense making in a particular connect for people who share a particular experience”. The hermeneutic element of IPA was met through the double interpreting of myself, as researcher while the idiographic commitment of IPA was met through in-depth analysis of individual participants, working though the hermeneutic circles of the whole to the part, and then the part to the whole. IPA therefore allowed a detailed and nuanced analysis of data, coupled with feminist phenomenological lived body meaning making, which generated rich findings.

5.2 Analysis Approach

Data was collected following a diagnosis of vulvodynia from individual semi-structured interviews with fourteen participants (N=14), totaling seven hetero-sexual couples to explore the lived experience of the condition, and to understand the way a couple system changes in response to vulvodynia, specifically relational and sexual adjustment. I transcribed the data collected verbatim. Quotes that seemed important or contained information relevant to the research question were marked and themes identified. The quotes were then sorted into headings and sub headings, all according to the recommendations of IPA (Smith et al., 2009; Willig, 2009). There was a search for themes that emerged from the analysis at an individual level (Self) for each woman and man participant, then at the level of ‘all men’ and ‘all women’ (Self). This was

followed with analysis at individual level for each woman and man participant about their sense of their partner (the Other), and finally at an individual level with all men and all women (totaling seven couples) about their meaning making of relational and sexual adjustment in the couple relationship followed by the final stage, the write up of the findings.

Table C. IPA procedure below summaries the six stages of IPA data analysis (Smith et al., 2009) I adhered to. This is followed with a brief summary of the process undertaken.

Table C.

IPA procedure (Smith et al., 2009)

Stage number	Stage title	Description
1	Reading and re-reading	Listening to the audio and reading the transcript, author notes anything of interest or significance.
2	Initial noting	Producing a detailed set of notes and comments on the data (descriptive, linguistic and conceptual).
3	Developing emerging themes	Looking for emerging themes and attempting to reduce the volume of detail whilst maintaining complexity.
4	Moving to the next case	Moving onto the next transcript and repeating the process.
5	Searching for connections between emergent themes	Drawing together the emerging themes and exploring a spatial representation of how they relate to each other (including abstraction, subsumption and polarisation).
6	Looking for patterns across cases	Measuring recurrence across cases using a table of themes, which may include re-labelling and reconfiguring of themes.

5.2.1 Phase 1.

Phase one involved conducting the interview with participants within approximately one month of diagnosis. Demographic information about each participant was collected at the first interview, and all interviews were audio-recorded and transcribed verbatim. Interviews were conducted separately for women with vulvodynia and their couple partner. The interviews were conducted using an open ended, semi structured interview style framed around the research question, with identical questions for both members of each couple. Core questions included exploring the experience, understanding and impact of vulvodynia, reflecting on their experience of sexual pain prior to and after diagnosis; exploring about any change prior the diagnosis and coping strategies/problem solving approaches used in their relational and sexual relationship, exploring any change following the diagnosis in their relational and sexual relationship, and about examples with descriptions of coping and problem solving strategies adopted and to what effect. Participants were also asked how they thought their strategies might change going forward, and in what ways.

Where possible, the participants' led the interviews and I used prompts to encourage them to consider and discuss their experiences. All interviews were audio taped with the participants' written permission. Each interview was completed in one interview session; an average of 60 minutes in duration. Audio taped interviews were transcribed and analysed concurrently following interviews with each couple.

5.2.2 Phase 2.

IPA Thematic Analysis Within Couples

The 14 interviews were transcribed verbatim from the audio -tape recordings to provide transcripts for analysis. Analysis was conducted using Smith et al. (2009) guidelines, which advocates using a layered inductive approach. This involved starting with a line-by-line analysis where quotes, which seemed important or contained information relevant to the research question, were noted. As the study progressed preliminary themes were collated and categorised into groups under headings representing clusters of initial themes (Smith, 2004 and Willig, 2009). Next there was a search for emerging themes from the analysis of interview data. Reliability and validity checks were carried out in the first and second stages of IPA analysis to ensure consistency by an additional researcher.

I was immersed in the participants meanings, making notes about significant content related to how participants described experiences relevant to their self, partner and couple i.e. how vulvodynia, and relational and sexual adjustment was experienced, as well as what sense they had made of these experiences. After each reading of the transcript, observations were noted, as well as any recollections from the interview itself and my reflections of their influence on the coding. This helped gain a coherent sense of the account as a whole, areas of contradiction, ambivalence, resistance or incoherence.

The initial transcript comments were divided into discrete chunks of transcript. This allowed the identification of patterns, inter-relationships and connections between themes, notes and participant experiences. Themes that were not related to vulvodynia, relationship and sexual adjustment or meaning making were discarded, for example past medical history. A group of three independent health professionals located across the South of England were asked to externally validate the data analysis at this stage before proceeding to the next level of analysis. Super-ordinate themes were initially identified through abstraction, grouping together similar emergent themes, for example burden, suffering, negative emotionality. Groups of emergent themes focusing on opposite ends of the same concept or continuum were collapsed into super-ordinate themes through identifying and compartmentalising commonly related themes. Numeration was used to identify common themes. Some emergent themes were grouped based on their function, for example rejection, argument or confession were functions of compartmentalising negatives. A photograph of Data Analysis of a Participant Transcript is attached at p. 241.

In accordance with IPA, the analysis involved a layered, iterative and refining approach, which allowed emergent overarching themes, sub-themes and integrative themes to develop, providing substantial depth to the interpretative process (Larkin et al., 2006). The themes were mapped out on cards and grouped into superordinate themes and spatially positioned to represent relationships between themes. Themes were then checked against transcript excerpts to check the fidelity of the theme to the participant's specific experiences. This process was repeated for each participant, and the thematic mapping was amended as necessary. The map of themes was then reviewed against individual participant experiences and transcript excerpts. This

enabled the identification and removal of poorly evidenced interpretations, retaining an idiographic focus.

QSR International's Nvivo 12 software (2019) was initially used to conduct the analysis, but it was replaced by manual analysis, coding transcripts, keeping process and reflexivity notes, identifying emergent themes and then checking themes across participant accounts. External validation of the manual analysis of coding transcripts and the identification of emergent themes was obtained from health professionals to add objectivity to the analytic approach.

5.2.3 Phase 3.

IPA Thematic Analysis Between Couples

The second stage of the analysis was a search for relationship within and between couple/s relationship themes, noting any alignment, comparison and contrast.

5.2.4 Phase 4.

New Thinking and Original Findings

This phase included capturing and conceptualising new thinking and original findings arising from the IPA analysis and continual researcher reflexivity, which is identified in section 5.3 below and within later chapters of this thesis.

5.3 Reflexivity and Researcher Positionality

5.3.1 My Study Experience of Phenomenology

Phenomenology is the study of human experience itself, and the meanings that are given in experience. Working from a feminist phenomenology research position with women and men talking about their lived experience of their couple relationship, gender, sexuality, sex life and adjustment in the context of vulvodynia was a form of listening: uncovering and exploring meanings, against a constant background of not knowing and wonder. I found a wondering reflection gave me insights that possess, not empirical certainty, but phenomenological plausibility; a probing aletheia of the affectivity of life that surges through existence of being, particularly a woman consciously and unconsciously affected by the Other, and western socio-culture. For me a phenomenological influence does not eclipse the unconscious, it compliments it. For phenomenology is bound up with lived experience; it explores a manifold of

recognisable experiences in order to gain insights into human phenomena that may be evoked by them. Merleau-Ponty (1962) said: " we have no right to level all experiences down to a single world, all modalities of existence down to a single consciousness" (p.338). It is about exploring all the possible meanings without reducing experiences to our own.

I experienced working with the phenomenological as a researcher, as gaining understanding, which encompassed more than expressible propositions, statements, or facts. There were meanings to participant experiences that were, on occasion ambiguous, indistinct, or simply resistant to articulation in language; an observation similarly expressed by Ricoeur (1966,p. 208). As adults we can reflect on an experience of a moment of pain or distress, happiness or pleasure, yet find it difficult to describe such lived experience even if the experience is our own. 'There always remains a difference between the lived and the articulated, which represents a challenge to reflection and bringing the lived meanings of lived experience to language', commented Merleau-Ponty (1962,p.393).

I found listening, uncovering and exploring meanings with the women and men in this study from a feminist phenomenological epistemic stance an absolute privilege. It opened up a new way to work clinically with my clients going forward, specifically relating to the effects of repetition, and gave me wonderful insights into the experiential life of women and men suffering, yet striving to cope with the presence of vulvodynia in the couple relationship with all its meanings and impacts. As a result of this study the territory of repetition has opened up many questions for me in my clinical work, for example: What is being repeated, why and how? What are the forces and mechanisms at play in repetition?

5.3.2 Reflexivity

A continual reflexive approach was adopted to address the dual interpretive nature inherent in the analytic process with IPA, recognising that the researcher's perspective and position shape the research (Willig, 2001) as elaborated above. IPA particularly draws on the work of Heidegger (1962), who highlighted the importance of acknowledging how the fore-conceptions of the interpreter shape the interpretation

and that usually the process of interpretation itself brings relevant pre-conceptions to the fore.

Gadamer (1989) proposed that interpretation itself enables the comparison of various pre-conceptions, which are modified and compared throughout the sense making process; and further, that the focus of the interpretation was on the meaning of the account, which would be influenced by the context in which the interpretation was made. The use of the hermeneutic circle, that to understand the whole one needs to look at the parts and vice versa, is central to the iterative process of IPA.

Adopting a reflexive position as a researcher and attending IPA workshops, on-line seminars and, reviewing research studies using IPA methodology served to enable the nuances of participants meaning making about their experiences to be helpfully distilled and interpreted.

From the very beginnings of developing a research idea and proposal, l used a reflective journal as a helpful part of the research process and as aide- memoire of my research journey. As a reflexive researcher, I found the practical application of Boud's triangular reflective model of experience, reflection and learning, useful particularly at times of problem solving, decision making and learning (2005). The reflective journal was a place where I noted my experiences, thoughts, feelings, dreams and decision-making associated with my position as researcher, an inquirer, who was situated within the research process. I also captured my doctoral supervision and feedback, the feedback from the pilot interview, relevant seminars and workshops on IPA, and continuous practice development (CPD) events attended. Together with meetings with key people involved in my research, for example recruitment Gatekeepers, or a felt sense noted during a participant interview. The reflexive process enabled me to reflect critically, it served to ground me at critical times; and enhanced my research confidence, approach, ability and learning during the research journey.

The following examples are representative of how reflexivity enhanced my position as reflexive inquirer, situated within the research, therefore adding rigour to the research process.

5.3.3. Identity

Spencer and Ritchie (2012) maintain, that reflexivity is a process whereby the researcher assesses how their subjectivity, identity, and role might affect the research process. Importantly then, it is vital that any researcher reflects on their subjectivity, identity, role and relationship they may have with the research subject. I am a woman, who self identifies as a feminist woman; and professionally as a psychosexual therapist and psychotherapist. It was important therefore to reflect on the effect of my sex, feminist and professional position being very close to the research subject; thus demanding reflexivity. Also critically, some participants may have known me in a prior clinical capacity. This was an ongoing feature throughout the research process, where I remained critical to any assumptions I might have, in order to avoid contaminating the research process with my own beliefs, preconceptions and biases. Pazella, Pettigrew, and Miller-Day (2012) assert that since research is a co-creation of knowledge by the researcher and the participants, reflexivity must be central to the process in order to minimise bias.

Specifically, to minimise the biasing influence of pre-existing ideas, I reflexively journaled on my personal reflections before interviews began. For example, one pre-existing idea uncovered through reflexive journaling was the belief that women would choose to engage in methods of sexual intimacy that caused pain, such as penile-vaginal intercourse, only out of a desire to please their partner. This did arise in the interviews with women, however with reflexivity it enabled the exploring of alternative sites of sexual pleasure during the interviews. A second example, involved a couple I had seen months earlier for a clinical assessment that were subsequently referred for couple therapy. I reflexively journaled before the individual interviews began about the couple interactions I had previously observed and my different role and relationship as researcher. This enabled me to fully take up my position as researcher during the interviews and to focus on each partner individually to idiographically capture their particular experience of vulvodynia, relational and sexual adjustment. During interviews and analysis, attempts were made to put aside any pre-existing beliefs as much as possible, to mitigate bias and influence of the researcher on the research.

5.3.4 Couple Participants

During the research design stage I reflexively journaled about a pre-existing conception that women and men may not speak frankly about their embodied

experience of vulvodynia, relational and sexual adjustment in the presence of their partner in the couple interviews. Consequently, to ensure a robust research design and process I decided to interview partners within the couple individually, and therefore the analysis of the data was also conducted and presented separately for women and men.

A separate example of reflexivity was reflecting on how I conceptualise a couple, their context and aspects of intersectionality, especially gender, power, patriarchy and oppression, given my identity as a feminist woman researcher in the research process. As a consequence, for the interviews, analysis and interpretation my approach was to hold in mind 'the couple as passionate bond figures' bringing their own histories and biographies formed in the socio-cultural context they inhabit. I found the description of a couple state of mind and the creative couple by Tavistock based psychotherapist, Mary Morgan, a good touchstone when viewing the couple with vulvodynia in this study. She describes the couple state of mind is part of the separate individual's psychic development, which is the foundation for a healthy adult couple relationship. In a healthy relationship there is room for love and hate, for interest and curiosity in the other and in one's self, for relating and for non relating, for misunderstandings as well as understanding that can lead to a creative outcome, something 'new' between them, that neither could have discovered alone, (Morgan, 2019,p. xxiv).

For all participant interviews as a researcher I adopted a position of neutrality with multi-perspective partiality. It was important to come alongside each couple partner to come alongside each other to manage multiple alliances. Through my own couple and psychosexual therapy training and clinical practice I know not to take a side, but to be translating, meaning making and to be mindful to where I put myself. I place great importance on adopting a position of partiality to enable the opening up and curiosity in each participant, about themselves and as a partner in couple relationship.

I am aware and was vigilant in the participant interviews to becoming ethically compromised given the complexity of the issues that can come to the fore. I was continually mindful that the gender of the researcher is significant in the context of the couple, especially given the sensitive topics of vulvodynia, relationship, sex and vulvar pain; and what may be brought up for both, the woman, and the man.

5.3.5 Ethics and Recruitment

Another reflexive example is the ethics approval application process, which was encountered as complex and at times stressful. My study required both Health Research Agency (HRA) Ethics approval because recruited participants were NHS patients; and University of Exeter Ethics approval. Preparing the HRA ethics application and supporting documentation was time consuming, complicated and frustrating. This was further compounded by the HRA regional Ethics Committee meeting structure, their timescales and processes, alterations following feedback and resubmissions; all requiring my utmost intense care and attention. In comparison, the subsequent University of Exeter ethics approval process was easier to navigate. My journaling was helpful in grounding me, giving me a confidential space for expression, including the relief, happiness and feeling of achievement, when all the required ethics approvals were finally secured. Appendix 6 A-E pp.187-203 provides evidence of Health Research Agency (HRA) and University of Exeter ethics approvals.

Recruitment into my study was slow from the outset. On investigation with Gatekeepers I discovered there were a couple of barriers they were experiencing in referring potential participants for the study. Firstly, participant partners frequently declined to become involved with the study even if the participant herself expressed interest. Secondly, on occasions Gatekeepers had thought some potential participants may be known to me in a clinical capacity, therefore did not refer into the study.

Journaling assisted my decision-making process. My initial response was to ask Gatekeepers to continue recruiting. I provided them with additional resource materials to draw attention to the study and I meet them weekly to monitor recruitment and address any concerns they may have. Unfortunately, recruitment continued to be frustratingly slow. Journaling provided me with thinking space to develop, research and plan my next steps, and to express confidentially my feelings of increasing disappointment with the research process.

My plan involved accessing supervision to discuss the situation and to outline a proposed plan of action to seek an amendment to my original HRA Ethics approval to open up recruitment to potential participants who may know me in a prior clinical capacity. After obtaining support for this approach from my supervisors I embarked on

preparing and submitting a notice of amendment for HRA Ethics approval. Appendix 6-C p.199 provides evidence of the amendment approval to widen recruitment. Subsequently, on examining the final data set, as part the overall checking and governance process, two participants (one couple) were identified to have been in relationship and cohabiting for longer than the criteria of 1-10 years in the approved Participant Information Sheet (PIS). On informing my two supervisors and expressing concern about the viability of the study sample without the data; a Health Research Agency (HRA) ethical opinion was sought to include the two participants' data in the final data set. The positive ethical opinion subsequently received is included at appendix 6-D p.202.

From the problematic recruitment process, I reflexively learned how to navigate successfully the ethics approval process in two major institutions; the NHS/HRA and the University settings and to seek and secure further approvals to benefit recruitment and to ensure robust ethical practice as part of the overall research process.

This research process has been challenging for me at times. However, I have maintained my intense passion for the overall study throughout. I have gained a lot of insight and learning into processes that I knew very little about. My ongoing commitment to reflection throughout the research process has enabled me to stay on track, cope with disappointments, to acknowledge and deal with my frustrations, and importantly to notice my proud moments and achievements gained on the research journey, as I became a resilient clinical researcher.

Chapter 6. Data Presentation For All Women Participants' and Summary Interpretative Analysis

6.0 The data and interpretative analysis for women and men are presented in separate chapters, commencing with women participants'. The combined data for all women and all men in each of the seven couples is presented in Appendix 7 p.207 Couple Data: The Undoing of Vulvodynia.

The data and interpretative analysis for women is presented in three distinct sections titled: (1) Self, (2) Partner (sense of) and (3) Relational and Sexual Adjustment. Each section identifies key Superordinate Themes* and Sub Themes.

Key Superordinate Themes and sub themes with numeration for 'Self' for All Women participants' is shown below in Table D. The specificity of Women participants' –Self with extracts of meaning and lived experience is attached in the List of Tables at Table 3 p.227**.** Table D. below provides an overview only for ease of reference.

Table D: Table of Key Themes All Women Participants'- Self

Superordinate themes* (Number of participants)	Sub Themes (Number of participants')
1.Gendered Identity (7)	1.1 Failure as a Woman (7) 1.2 Failure as Sexual Partner (7)
2.Relational (7)	2.1 Confession to Maleness (4) 2.2 Concealment (4) 2.3 Couple interactions (7)
3.The Sexual (7)	3.1. Loss of Sexual Desire (7) 3.2. Loss of Kisses and touch (7) 3.3. Disembodiment (6)
4.Burden (7)	4.1 Menstruation (5) 4.2 Loss of Womanhood (6) 4.3 Suffering (7)

Table D. All Women Participants', above illustrates the results of the lived experience of women of Self with four superordinate themes*, Gendered Identity, the Relational, the Sexual and Burden, together with sub-themes. The following analysis provides interpretation of the women's lived experiences and the sense they made of them evidenced by extracts from each participant's reported experience. There is a profound sense of a troubled bodily being in the women's descriptions.

6.1 Analysis: All Women Participants' Lived Experience of Self

6.1.0 Gendered Identity (Superordinate 1.)

A central theme in many women's lived experience of vulvodynia in the couple was the meanings they attached to gendered identity in their subjective experience of being a woman within a heterosexual relationship. There were two sub-themes identified; failure as a woman and failure as a sexual partner, which challenged their gendered identity.

6.1.1 Failure as a Woman and a Sexual Partner (Sub- themes)

(i) Failure as a Woman

Participants talked about feeling a sense of failure and feeling unable to function and perform as a woman in everyday life. They expressed that there was a profound effect on living their life; certainly more widespread and beyond the sexual. Participants spoke about losing themselves as a woman; a sense of things falling apart and disintegrating as a result of living with vulvodynia.

"It's (vulvodynia) has literally affected my whole life, because of the way it's made me feel about myself, my work, my social life, my relationships and about sex. I can't even watch TV ". P1

"I don't feel like a complete woman because of it. P3

"I have lost me, my sense of sexuality and femininity". P13

“…..it affects my whole sense of self”….. “I don’t feel that I can have the natural thoughts and feelings that other women have”. I feel lesser, different; it gives me a sense of very low self worth. ” P1

“It affects me as a woman….”P13

“I can go down the dark rabbit hole”. P1

“I’m so upset and beginning to question who I am.” P3

(ii) Failure as a Sexual Partner

Participants reported experiences of feeling a failure as a sexual woman and in the performance of being a sexual partner as a consequence of living with vulvodynia.

“I try not to think about penetrative sex never happening… that I’m going to lose my partner, things falling apart and everything disintegrating. I try not to think about it.” P1

“I can’t do the one thing a woman is meant to do”…“I can’t have sex like normal women do”. P3

“I had a breast enlargement to make me feel better about myself, but I don’t feel better about myself”. “My body wouldn’t do what I wanted it to do”. P1

“I’m not right. My body is not right”. P11

6.1.2. Gendered Identity (Superordinate 1.) Interpretative Summary

The women in the study seem to have experienced the negative consequences of social narratives and cultural norms around womanhood, sexuality, and femininity, including the prioritisation of penetrative sex. Moreover, the belief that it is the role of women to provide sex for men and that penetrative sex is easy and pleasurable. Sex can be detected here as a technology produced by a cultural heterosexuality, which privileges vaginal penetration and masculine subjectivity. The participants expressed

shame about, and disappointment in their body, which they perceive as hindering their role as a sexual partner.

Women's descriptions like "my body is scared of my mind" can relate to ontology; a woman's existence, the distressed emotional nature of her being, and her direct relation to being, manifesting in woman's intolerance to touch, anxiety and panic attacks. Women resorting to the social technology of sexuality, for example, a breast enlargement to affirm her lived body, however creating the artificial divide between the breasts and desire. Desire, being a problem, as breasts are erotised objects, invoking the male gaze. The ample breasts are to show she is a woman, a woman who wants to be desired, to invoke the male gaze, to satisfy the man but part of her cannot tolerate being the subject of desire, for her body is scared of her mind. She cannot mobilise the desire, panic attacks occur in response to her felt anxiety and disappointment. There is mastery, deep control over the desire in order to manage distress, disappointment, her desire being to be a real woman.

There is a deep sense of bodily loss experienced by the women of their female identity and sexual identity, which results in significant distress and shame. The identity which society has offered the women with vulvodynia has catastrophically collapsed. So deep and painful is the narcissistic fragility that for one woman, ample breasts from breast enlargement to show she is a woman, a woman who desires and wants to be desired sexually is insufficient to soothe the suffering of the precarious essential self.

Descriptions like "down the dark rabbit hole" can be interpreted as the alienated sexual and femininity that creates their darkness. Falling into the darkness, the abyss of their sexual being; the melancholia of life, a perceived asexual life. Women in the study are caught up in the over determination of sex in the western world, their inability to have penetrative sex rendering them genderless, not real women. This finding builds on the concept of the lived body that is a unified idea of a physical body acting and experiencing in a specific socio-cultural context. The women describe a body-in-situation, a female bodily existence impaired by vulvodynia; shamed and disturbed by the very same heterosexual social processes that contributed to their formation.

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6.1.3 The Relational (Superordinate 2.)

A central theme was the meanings women attached to their relational experiences as a woman in heterosexual relationship. The women disclosed several different relational experiences in connection with vulvodynia and their inability to have penetrative sex with partners. It seemed common for the women to start avoiding or managing situations where they potentially risked experiences or had actual experiences, of rejection, stigma and abandonment. The couple relational field was often reported as tense, emotionally difficult and at times disconnected, and argumentative. The social field beyond the couple with friends and family was equally experienced as problematic for women. There were three sub-themes identified; confession to maleness; concealment, and couple interactions.

6.1.4 Confession to Maleness, Concealment and Couple Interactions (Sub-Themes)

(i) Confession to Maleness

Several of the participants talked about their decision to tell their potential or new partner about their inability to have penetrative sex very early on in their relationship, despite previous unpleasant experiences, associated with the vulvodynia of rejection, hostility and aggression in men and the potential risk of losing their new partner.

“When we first met, I told him about it (vulvodynia) and he didn’t believe he could be in a relationship like this (without penetrative sex) because he needs to have sex in a relationship. He was taken aback and just sat with his hands on his head for a good three to four hours. I gave him the opportunity to leave but he never did…….”.P1

“After two dates I had to tell him what the situation was, otherwise we were going to waste our time here, which was really hard. I thought I was going to scare him off, but it didn’t.” P3

“I have been left before because of it. So, if you’re going to leave …. you’re going to leave. That might sound hard, but it’s like, if that’s all you want me for.” P7

(ii) Concealment

Women expressed felt relational pressure to conceal, tell (little) lies or give fake excuses about what is going on for them to family and friends enquiring about children and social events, because of shame and stigma associated with vulvodynia and the inability to have penetrative sex.

“It affects me as a woman, the shame and embarrassment of not having sexual intercourse. His family don’t know, they ask about us having children, it makes it very hard. We agreed to say, we’re not ready”. P11

“I have lost me, my sense of sexuality and femininity. I feel uncomfortable about things on TV. I feel a different person. I don’t feel myself anymore. I can sometimes brush it off, put on a happy face at work. … It’s like a situation I can’t control.” P13

“I can’t socialise, I can’t go to people’s houses in case they have the television on and what may come on. It makes me feel tense and immediately think about my problems. So I can’t socialise properly because of it. I can’t visit friends and family because of the way people talk. It’s literally affected my whole life, my work, my social life and my relationships”. P1

“I don’t talk about it to family and friends. Sex is private”. P5

(iii) Couple Interactions

Nearly all participants reported the couple relationship as being in distress at times as a result of vulvodynia. This involved reports of negative emotions and behaviours circulating in the couple relational field. These were expressed as examples of conflict, disagreement, argument, rejection, misunderstandings, avoidance and insecurity. Such emotions and behaviours were perceived by some women as having a disabling effect on the couple relationship, creating traumatic disconnections and an exaggerated sense of vulnerability and feelings of worthlessness.

“I feel the pain between us is unbearable.” P3

“We’ve lost each other as a couple.” P9

6.1.5 The Relational (Superordinate 2.) Interpretative Summary

Women expressed that they felt unable to mix and socialise with friends, family and work colleagues resulting in loneliness, social isolation and exclusion. Avoidance of difficult questions in conversations and of situations where sex may come into the relational field resulted in participants feeling unable to mix and socialise with friends, family and work colleagues. The lived experience of this avoidance creates and exacerbates feelings of being different from other women.

There is embarrassment and guilt about not being wholly honest. Participants seem to fear discovery by the ‘other’ that they will be found to be a fake woman, an incomplete woman and concurrently they experience an overwhelming sense of failure and disappointment in self. Importantly, there is a sense for many of the women participants of relational shame associated with the vulvodynia. For several participants this was initially expressed as a sexual ‘confession’ to their new partner, which seemed like a confession to maleness or the privileged heterosex male.

The sense of relational shame seems to go beyond the initial sexual confession of the women with couples feeling forced jointly to collude to conceal or tell ‘little’ lies about the difficulties they experience associated with vulvodynia to avoid stigma, shame and embarrassment when faced with the threat of cultural expectations of western hetero-normativity. It is almost as if the truth the couple carry cannot be spoken in case they are “outed”. For some woman there was ‘leaning on’, a reliance on the man because he would affirm her as a woman, he would confer her feminine gendered identity because she is feeling precarious; like a failure as a woman and as a sexual partner. There was for some an unrealistic reliance on their partner for their own personal wellbeing.

6.1.6 The Sexual (Superordinate 3.)

A further central theme was the sexual with all women in the study reporting experiences of loss of the sexual self and, sex and intimacy with their partner. For the majority of women there was a sense of a troubled bodily being: an alienated self.

There was a negative relationship with the body and sex, and for some a turning away from their sexual self and their partner. There were three sub-themes identified; (1) Loss of Sexual Desire; (2) Loss of Kisses and Touch; and (3) Disembodiment.

6.1.7. Loss of Desire, Loss of Kisses and Touch, Disembodiment

(i) Loss of Sexual Desire

Most women participants reported experiencing low sexual desire. Their lack or reduced frequency or intensity of interest in sexual activity was directly attributed to intense genital pain they experienced associated with vulvodynia. For many women this had led to conscious avoidance, non-initiation or complete withdrawal of sex and intimacy with their partner. Some women added that while they had thoughts of sexual intimacy, they were reluctant to engage in any sexual activity because of the anticipation of pain and fear of actual pain.

"I can't talk about sex because I get defensive about not wanting sex". P13
"I push through". P5

(ii) Loss of Kisses and Touch

Women reported the loss of kisses and touch in the couple relationship and a few women spoke of perceived pressure for penetrative sex by their partners. Some expressed sadness, distress and guilt about the effect on the couple relationship as a result of their avoidance or withdrawal of affection and intimacy. There was a sense that kisses and touching of bodily flesh could lead to partner misunderstandings leading to an anticipation of sex, false hopes, and disappointment. The withdrawal of intimacy in the form of kisses and touch seemed to be a way the women managed the perceived pressure of penetrative sex from the partner. Giving and receiving kisses and touch seem to punctuate the lives of women in the couple relationship as a perceived threat and a dangerous allure. In this context the kiss is the signature of the erotic, a rehearsal for hetero-normative sex, penetrative sex; real sex. The impossibility of the intensely evocative pleasure of kissing and bodily touch wanted yet

withdrawn was experienced as a loss in the couple relationship, exacerbating experiences of rejection and disconnection.

“I have not been giving affection because I am avoiding sex because it hurts so”. P5

“I don’t always kiss him in case it leads on a bit. He notices”. P5

“I don’t want to do other things, I worry he might want more”. P13

(iii) Disembodiment

Descriptions of feeling different from other women were reported by many participants as a consequence of being caught up in the over determination of sex in the western world. Their sexual identity is shaken to the core; a catastrophic collapse under the hetero-normative pressure about the expectation of what it means to be a woman. Some participants spoke with a significant amount of distress that the identity which society has offered them as women had collapsed. The women in the study seem to relate to signifiers that affirmed their sexual identity. However, it is the very same signifiers which are persecuting them as women; that is women not having sex; not able to marry; not able to have a baby; thus not real women. This injurious identity for some has contributed to alienation of parts of the body specifically the disembodiment of vagina and breasts, alongside a disavowal of heterosexuality.

“I have an unnatural illness. I look like a woman, I have a woman’s body, feminine like a woman but I don’t have sex. I am a criminalised woman”. P1

“My vagina doesn’t work properly”. ~~P3~~

6.1.8. The Sexual (Superordinate 3) Interpretative Summary

The difficulties with sexual intimacy, arousal, orgasm and, painful touch and sexual intercourse had a profound physical, psychological, social and relational impact on the participants in the study. Their experience of being a sexual woman with vulvodynia is

akin to erotic fatality; a sense of disembodiment, a troubled disengagement with the feminine body and disavowed sexuality.

Touch is a contact sense; it is the most difficult and complex of all the senses because it is composed of so many interacting dimensions of sensitivity, involving different functions (touch, pressure, texture, frequency, pain, and heat). Touch is overlaid and constituted through transcriptions, re-tracings, modes of dimensionality that involve a kind of cultural writing which both separates the senses but entails the possibility of their realignments and re-transcriptions into other terms. Touch has many sense receptors, including the body's surfaces and its flesh. The presence of vulvodynia commands attention when touched. Touch and being touched is troubling for woman with vulvodynia. The mind and body cannot hold together, it becomes unconnected and not combined. The undoing of touch is problematic both for women with vulvodynia and their partner.

The women with vulvodynia in this study appear to increasingly and determinedly to project, an existential barrier closed around them and discontinuous with the other there, in order to keep her partner at a distance. The women in this study seem to live their space as confined and closed around them, I was witness to their bodily presentation during the interviews as researcher.

6.1.9 Burden (Superordinate 4)

The fourth central theme identified was that of a felt sense of burden. All the women talked about the lived experience of burden and the weight of expectation they carried associated with vulvodynia. Menstruation was experienced as a particular burden; it was a monthly reminder of the normal functionality of the feminine body. The felt loss of womanhood and the concurrent weight of expectation about the role of woman in western hetero-normative society were reported as a daily heavy burden to bear. Three sub themes were identified; (1) Menstruation; (2) Loss of Womanhood, and (3) Suffering.

6.1.10 Menstruation, Loss of Womanhood and Suffering

(i) Menstruation

The experience of menstruation and social significance of their cyclical body brought to the fore more acutely the women's ambivalence with their body and feminine sexuality in addition to the burden of vulvodynia. Not only is there a sense of distancing between self and vulvodynia; but also each month brings to the fore the dread of the menstruating body and the meanings associated with this situation, specifically the expectation of womanhood.

"I can't wear tampons because of it (vulvodynia)". P3

"I'm battling with it". P5

"I bleed everyday". P3

"My time of the month pain". P1

(ii) Loss of Womanhood

A key sub-theme reported by participants was a loss of womanhood, expressed as a felt sense of failure as a woman, a sexual partner, a married woman and a potential pregnant woman and mother.

"I can't do the one thing a woman is meant to do". P3

"I can't really get married because of the law about consummating the marriage before it's real". P1

"….can't have babies".

"My friends are settling down and having children. I get the pity looks." P3

"… but I know a man would want to have sex with his wife". P5

(iii) Suffering

The women all talked about the unpleasant and often unbearable nature of their suffering associated with physical, psychological and social pain. Many described the lived experience of vulvodynia as feeling psychological and social pain, sadness, low mood, panic stricken, hypersensitive, shamed, guilty and vulnerability. They also expressed fear and anxiety; the anxiety associated with the anticipation of pain and fear of actual pain when touched. The feelings of physical pain associated with vulvodynia were described as intensely painful, electrified, lacerations, burning and friction. For some participants, the pain was acute and continued for hours after an attempt at sexual intercourse with their partner. For a few participants it stopped them functioning effectively in their daily life, vulvodynia being experienced as an illness.

"My unnatural illness"….."My body is scared of my mind" …."I used to be panicked about it but now there's a lot of sadness around it." P1

"I used to feel really rubbish about it…because it's not a known thing, so I felt not normal". P11

"I have to stop him thrusting as it feels like lacerations, cut all the way up inside; tears"….." its really sore and I feel bruised the next day". P7

6.1.11 Burden (Superordinate 4) Interpretative Summary

The monthly bleeding body seemed to throw the women further into an inferior and defective state. It increased the sense of alienation from the woman's body. The disengagement of the selfhood of women with vulvodynia from their debilitating body and biology becomes more apparent with the appearance of each cycle of menstruation and its symbolic significance. Vulvodynia is out of their control, as is menstruation. There is a sense of sadness and despair about the heterosexual feminine self, the dysfunctional sexual body and yet the cycling body indicating fully functional reproductive capacity remained unfulfilled and beyond their happiness.

Each cycle of the feminine body of women with vulvodynia served to combine with and deepen this felt experience of pain, embarrassment and need for social concealment. The risk of exposure of menstruating womanliness and a feminine body with

vulvodynia compounded further the lived experience of shame, of not being a real woman; only a false woman.

Social relations of abjection and forms of misogyny continue to have hold over women in some circumstances; the threat of being 'outed', shamed as menstruators and shamed as women who do not give men "real sex" sometimes with serious consequences to their self esteem and sexual meanings of selfhood. Whether it be vulvodynia or menstruation, threat and exposure of the womanly body is dealt with by concealment to keep ones self intact in the social field.

The loss of womanhood was experienced as a massive burden for the participants in the study. For many it was a significant threat to their couple relationship, their personal wellbeing and what they experienced as the meaning of life. The suffering of physical, psychological and social pain associated with vulvodynia was experienced by participants as burdensome as it had negative consequences for their wellbeing, their intactness and stability, and functioning in day to day life.

For healthcare professionals the importance of assessing a woman seeking treatment for vulvodynia is the attentiveness to the body but also everything beyond her body. Healthcare professionals need to be sensitive to the variety of ways the woman may experience her life, and what might this experience be like for them, for the body is how we live ourselves.

6.2 Women Participants' Lived Experience of Their Partner

Tables 4 Women Participants' Lived Experience of their Partner- (Attached in the List of Tables at p.230) illustrates the results of the lived experience and meanings of women of their partners. There are four central Superordinate themes, namely Gendered Identity, the Relational, the Sexual and Burden.

6.2.1. Partner: Gendered Identity (Superordinate theme 1)

Only two participants express encountering overt maleness in the context of the couple relationship with vulvodynia. Women however, seemed to sense maleness and place expectation onto themselves about what they thought their male partners would expect in a hetero-normative relationship.

“When he’s in man mode, he feels rejected then and thinks I don’t find him attractive”. P5

“ ..he sometimes raises it (sex and intimacy). Its not an easy conversation to have.” P9

“ …a man would want to have sex with his wife”. P5

6.2.2. Partner: The Relational (Superordinate theme 2)

Most women described their partners as supportive, thoughtful, affectionate, undemanding, communicative and loving in the couple relationship. Most women also reported occasional tension and relational difficulties, specifically related to the impact of vulvodynia on the couple relationship. A few women reported arguments, conflict and instability in the couple relationship when attempting to resolve differences and difficulties associated with vulvodynia.

“I feel anxious. Our communication is really quite poor to be honest. We’re both guilty and it just builds up and it explodes sometimes”. P3

“I get upset because I think he’s having a go at me”. P13

“I have told him I feel I’m going to him to make up more than he does”. P3

6.2.3. Partner: The Sexual (Superordinate Theme 3)

There were disclosures from some women about the sexual impact of vulvodnia on their partner in the couple relationship. This included loss of kisses and touch due to withdrawal and avoidance, loss of erections, retarded ejaculation and use of pornography. Two women expressed feelings of guilt and insecurity in their couple relationship with a perceived threat to their future together as a consequence of the vulvodynia and their partner’s sexual difficulty for which they felt responsible.

“I don’t feel like a woman, especially when he’s pushing me away”. P3

“His libido has gone down and he is depressed”. P3

“I found he had been looking at porn, where I had never had that worry before”. P13

6.2.4. Partner: Burden (Superordinate Theme 4)

Many of the women spoke of their partner’s suffering, fears and guilt associated with their perceived responsibility for causing pain during attempted or actual intercourse. The women in some cases felt this led to their partner experiencing depression, low mood and anxiety.

“He fears hurting me”…..“He carries a lot of guilt because he thinks he, hurting me when he’s meant to be giving me pleasure.” P7

“He struggles with it”……..“He feels responsible for giving me pain”. P7

“He has depression….the pain affects us…. more so him ”. P3

“He say’s -if you’re suffering then I’m suffering alongside you”. P1

6.2.5. Women Participants’ Lived Experience of their Partner- Interpretative Summary

The lived experience of women in this study is stark given the difficulties of first, the inexpressibility of their felt pain, (physical, psychological and social) associated with vulvodynia; second, the perceptual and actual complications that arise with trying to cope with vulvodynia in the couple relationship; and third, the perceptual and observed impact on their partner, (his sexual difficulties). The burden and suffering of both woman and partner is immense because to be at the centre of any one of these is to be, simultaneously, at the centre of all three difficulties.

6.3 Women Participants’ Lived Experience of Relational and Sexual Adjustment

Table 5. Women Participants’ Lived Experience of Relational and Sexual Adjustment (attached in the List of Tables p.232) illustrates the results of the lived experience and meanings women make of relationship and sexual adjustment to vulvodynia. There are

two central Superordinate themes identified; (1) Relational Adjustment, and (2) Sexual Adjustment.

6.3.1. Relational Adjustment (Superordinate Theme 1.)

Captured within the relational superordinate theme there were many issues circulating for the women, which reflected the impact on the couple relationship where they were making attempts to mediate and stabilise the couple relationship to make space for relational adjustment. These are identified as sub-themes namely; communication, acceptance, trust, and connection.

(i) Communication

There is less empirical evidence for the links between relationship discord and the sexual pain disorders like vulvodynia than for other sexual dysfunctions (Davis & Reissing, 2007). Yet it is hard to imagine that there would not be negative effects of sexual pain on couple relationships. Women spoke of tension and argument in the relational field. They also spoke positively about the relational characteristics of their partner. Some participants spoke about the importance of their being able to improve communication and to communicate a positive way of being with their partner to aid adjustment.

“It’s best to talk about the things you can do, rather than those you can’t do”. P1

“Talking with my partner, involving him and telling him about the pain. Don’t do it alone.” P11

“We talk about anything and everything now.” P11

“I’ve had to learn to stay calm and talk.” P1

(ii) Acceptance

Several women spoke about their (in part) acceptance of, and adjustment to vulvodynia, both in self and in the couple relationship. A strong motivating factor was a focus on recalibrating self to alleviate negative affect, suffering and battling in a highly

valued relationship. But for the majority, there was negligible experience of felt acceptance and adjustment seemed an impossible notion.

“There has to be some acceptance of it…otherwise you’d drive yourself mad.” P7

(iii)Trust

There was a sense of felt trust in self, the partner and relationship expressed by some women, enhanced by improved open communication, acceptance of, and desire for adjustment and new learning about what is possible and how. This approach seemed more successful and highly receptive by the partner when women initiated a change and assumed the relational lead in the couple relationship.

“Your partner has to work through you, so you can learn to trust them”….“I trust him more with my body, than myself”. P1

(iv) Connection

Positive forward change and adjustment were experienced as beneficial for a few women in terms of feeling more secure, understood and connected with their partner in the couple relationship.

“Talking together and opening up to your partner, making time to touch to maintain connection, expanding on things that we find pleasurable”. P1

“…..finding the richness in your relationship and not the undoing of vulvodynia”. P1

“It’s about adapting and understanding each other”. P11

6.3.2. Sexual Adjustment (Superordinate Theme 2.)

Captured in the sexual superordinate there are the lived experiences of two women giving examples of sexual adjustment in the couple relationship. The remaining women seemed traumatised by the perceived devastation of vulvodynia on their couple sexual relationship. Also lack of comprehension of what sexual adjustment might mean due to their fixivity on penetrative vaginal intercourse and their sense of

failure as a woman and as a sexual partner. There are two sub-themes identified namely;(1) new ways and (2) pleasure.

(i) New Ways

For a few women acceptance of and adjusting to vulvodynia in the couple sexual relationship meant new ways; of experiencing sexual intimacy and reconnecting with their sexual sense of self.

“A new vibrator”. P1

“Everything is about trying”…“ We just tried different things and became more experimental”. P11

“We find other ways, we do more foreplay, mutual masturbation and stimulate each other in different ways”. P7

(ii) Pleasure

For the same few women, embracing problem solving and adjustment in the sexual relationship, the outcome was a different experience of pleasure achieved with their partner. The erect penis symbolic of penetrative sex, previously signifying sexual pain seemed, now the erect penis being symbolic of male desire validating alternative sexual satisfaction, signifying sensual and sexual pleasure.

“Sexually we’ve learned lots of ways to give each other pleasure, so in a way, it’s been a positive thing.” P1

6.3.3. Women Participants’ Lived Experience of Relational and Sexual Adjustment -Interpretative Summary

Most women were caught up in a grotesque dance of perceived failure and degrees of inner suffering and distress relationally and sexually. The people we touch, and are touched by become a material support for, or extension of ourselves. Some women were attached to their relational and sexual suffering; as yet there was seemingly little

contemplation of acceptance and adjustment, as if for them, it was just too painful to touch and be touched relationally and sexually.

It is hugely difficult for women with vulvodynia to go astray of the troubled bodily being, injurious identity and erotic fatality they may experience until they can fully understand the position they occupy, the formation of it and how they are attached to it. It is essential for healthcare professionals and psychosexual therapists to take account of this when working with women and couples living with vulvodynia. The structure of how a woman is formed, how she is impacted upon by hetero-normativity, combined with the specificity of the woman with vulvodynia before us is very challenging.

6.4 Discussion: All Women Participants': the Application of Feminist Phenomenology Concepts and a Hermeneutic Circle of Understanding

This discussion section serves to compare and contrast the emerging themes with existing literature and to provide an analysis using feminist phenomenology concepts; and a hermeneutic circle as a way of understanding the barriers and challenges to relational and sexual adjustment for women with vulvodynia in this study.

Unpacking the hidden meanings in women's accounts of self, revealed many feelings of guilt, shame, embarrassment, failure, being damaged, and broken. These feelings compare with the study findings of Marriott and Thompson (2006); Ayling and Ussher (2008); Connor et al. (2008); and Sutherland (2012). Furthermore, these women experienced themselves as being "not right" and fragmented, thus concurring with the studies of Ayling and Ussher (2008); Sheppard et al.(2008); Donaldson and Meana (2011);Kaler, 2006; and Sutherland (2012). The women in this study spoke about a negative bodily experience, which they seem to generalise to their own genitalia, specifically the vagina, which they viewed as "not working" or as an "unnatural" part of their body. This accords with Carel's (2016.p.92) phenomenological descriptions about bodily doubt in the context of a condition affecting of the materiality of the body, creating a sense of loss of confidence in its normal bodily functioning.

The women's experience of vulvodynia meant they were not only faced with vulval pain and an inability to engage in penile-vaginal sex, they are also challenged to maintain a valued and positive sense of their genital bodily area and sexual self. This was because the genitals, specifically their vagina, was experienced as dysfunctional and as a strongly negatively charged part of their female sexuality, which fostered feelings of inadequacy as a sexual partner and a sense of an abject genital self-image. This felt sense of negativity and inadequacy compares with the findings of the studies of Sheppard et al. (2008); Donaldson and Meana (2011).Vulval pain combined with cyclical natural female flows of menstruation, resulted in a preoccupation with bodily fluids adding further to the women's sense of an abject, de-personalised womanly body. This finding of a sense of abjection aligns with the work of Kristeva (1982).

Many of the women kept the reality of the level of sexual pain away from their partners, whether they were new partners, long-term partners or spouses. Some men reported that they only became aware of their partner's vulval pain during penile-vaginal sex by witnessing the pain in her face. Omissions and concealments in the realm of intimacy and sexuality, are interpreted as mechanisms women resort to in order to feel more accepted by a partner, and society out of fear of rejection, shame, and exclusion. This is interpreted as women's response to a patriarchal society that privileges men's sexual pleasures over women's desires and pleasures.

The women highlighted the effect that vulvodynia had on their couple and sexual relationship, and on their feelings about themselves. In particular, women felt that the experience of vulvodynia negatively affected their sense of self, their femininity and sexuality, which was viewed analogously to the loss of gendered and sexual identity as a woman. This has symmetry with, and builds on the existing evidence of Ayling and Ussher (2008); Kaler (2006); and Marriot and Thompson (2008) about vulvodynia having a substantial impact on women's self, gendered identity and sexuality.

The women prioritised the sexual needs of their partners over their own, and had clear ideas about the normative expectations of being a woman partner in a heterosexual relationship. This concurs with the evidence of Du Pless (2015) of female submission and women meeting the needs of the male. They had concepts of normal relational,

and sexual functioning in heterosexual couple relationship, and felt a failure, not a real, or proper woman, in comparison to these concepts. This sometimes left them feeling excluded from a perceived 'normal' couple sexual relationship and social life. This finding is in line with the evidence of Tiefer (1995); Butler (1990; 1993; 2004): that normalising practices result in women believing they are 'doing their gender wrong', seeking gender identification and heterosexuality approximate to an ideal and incorporating the notion that penile-vaginal sex is the natural act.

This study provides a new insight about women confessing to men, specifically a new or actual partner, very early on in the relationship about their inability to engage in penile- vaginal sex due to vulvodynia. This is interpreted as women's existence of anxiety and bodily doubt; and felt obligation to confess about their embodied dysfunctional sexual self; so 'he' could choose to be with her or not. This has echoes of patriarchal, hetero-normative, phallocentric regulatory processes of power circulating in western socio-cultural society where women are lesser, oppressed, and marginalised as described by de Beauvoir (1982). In patriarchal formation, for a man penetration of a woman's vagina demonstrates his right to be a real man. For a woman inability to engage in penile-vaginal penetration means she is not a real woman. Patriarchal formation in men can lead to women feeling and being pathologised. This finding resonates with the work of Ussher (1993), when she comments, 'tragically because of the powerful subjugation of patriarchal and medical knowledge claim; women, often believe in their own pathology".

The women in this study experience their lived body as problematic with penile-vaginal penetration (and resultant pain) associated with vulvodynia. The women, however, had a tendency to be unaware or fail to acknowledge their social situatedness, specifically the cultural value, normalising and repetitive hetero-normative representation placed on the penis and penetrative vaginal intercourse, which delimits and constrains them as women, let alone as women with vulvodynia. Butler (1990) says: "we are bodies of culture…" and argues that the "body is culturally signified……gendered identity and the performativity of sex is precarious and open to destabilisation". (p.65). The finding of women's unawareness or failed acknowledgment support the assertions of Butler (1997) and Foucault (1979) who assert that we are saturated by dominant and constraining hetero-normative discourse

and these create meanings for us. In essence, women become gendered subjects in the social by unknowingly bowing to culture; this shapes her body and incites the life of sexuality.

Feminist phenomenologists Zeiler (2013) and Malmqvist et al. (2010) theorise that culturally shared and bodily expressed beliefs and norms are incorporated. Their reasoning is based on the concept that cultural patterns of understanding and behaving can become parts of our taken- granted for-being-in-the world, and form and enable bodily existence and co-existence. Their theory rests on the idea that women (and men) enact culturally determined expectations, for example expectations of female and male embodiment, and that such expectations involve beliefs and norms about female and male bodies, sexual difference and bodily sexual practices. Zeiler (2013) reasons that sexed embodiment is translated into materialities in the form of the lived body, thus the subject's bodily grasp of the world.

Adapting their work to the context of this study, it is therefore argued that women in the study have incorporated beliefs, norms and expectations of their female sexed body, their gendered identity and (hetero) sexuality. Furthermore, their gendered identity and sexuality has become taken-for-granted and embodied by the women pre- reflectively to enable their bodily existence and co-existence. Through embodiment habituation and repeated action, gendered and sexual patterns of behaviour recede from reflective awareness and attention. The women have become that through which they have incorporated, engage with and repeat. Once incorporated, beliefs and norms about sexed difference, female and male bodies and sexuality are embodied and unproblematic, particularly if sexual partners have incorporated the same beliefs and norms. In the context of this study both women (and men) can be thought of as having 'incorporated' dominant and powerful beliefs, norms and expectations about embodied gendered identity, sexuality and bodily sexual practices.

Women (and men) are not explicitly aware of the norms, beliefs and cultural assumption incorporated unless it is brought into their awareness, for example with the onset of vulvodynia and vulval pain associated with penile- vaginal sex. For Foucault, sex is the most speculative, most ideal, and most internal element in a deployment of sexuality organised by power in its grips on bodies and their materiality, their forces, desires, sensations, and pleasures (Foucault, 1978,p.155). The idea of sex as a

natural act permeates through this medium ensuring women, their sexual pleasure and desire is understood according to this paradigm (Tiefer, 1995). Consequently, one can see how a woman will come to understand her sexual subjectivity, make meanings about sexual pleasure, and importantly become saturated within the dominant cultural and social discourses. However, a woman with vulvodynia, becomes tormented and persecuted by the very same social technologies and discourses as she fails to achieve the ideal; invoking narcissistic collapse in her sexual subjectivity. A few women in the study describe the effect that television and pornography have on them; their prohibition of which leads to partner relational discord.

The experience of vulvodynia is an example of a destabilising effect on the normative links between gender and heterosexuality, arguably because gender has become over-determined, and the social field is so rigid and concrete about gender and heterosexuality. Women (and men) in this study have become so narrowed down in contemporary western society because of the fixivity of gendered hetero-normative practices. Given that gender is imposed, assigned and navigated we must take up a position in the social. The problematic is that gender incites the life of sexuality and this impinges with negativity, more often than not for women; particularly women who are unable or unwilling to engage in penile-vaginal sex due to vulvodynia. In the context of the women (and men) in this study one must consider gender as a defence due to the precarity of repeated attempts to fully inhabit one's gendered subjectivity, which is already hunkered down in the grip of binary, reduced down hetero-normative constraint; and further destabilised and impinged by the presence of vulvodynia in the couple sexual relationship.

More importantly, some women seem to be unaware or unknowing, with these patriarchal notions on femininity, masculinity and sexuality, as described in this study. Women seem to choose to believe in their own sexual failure rather than, challenge the proposition on which measure of normality is conferred. Unless they fit the so-called norm of the heterosexual feminine within the social processes of real sex being penile vaginal penetration, they are sexually inadequate or not proper women. This accords with the literature, namely Holland et al. (2000) who highlights that penetrative penile-vaginal sex is recognised as a lived bodily experience, which is both gendered and gendering, an experience that makes people into hetero-gendered women and

men. Holland et al. (2000) describe ‘having sex’ as a moment of gendered self-recognition as feminine or masculine.

Potts (2002) in her work on concepts of interiority in women’s description of sex and their bodies, shows how even people who recognise the social formation and contingent nature of the penile-vaginal penetration imperative still have difficulty thinking of ‘sex’ without it. The findings of this study accord with Potts (2002) and, the work of Butler (1997) who builds on the work of Foucault (1979) in which Butler, maintains that**:** “the attachment to subjection is produced through the workings of power, and that part of the operation of power is made clear in this conscious (and psychic) effect, one of the most insidious of its production” (p.6). This has substantial implications for healthcare professionals and psychosexual therapists when working with couples, and for women with vulvodynia and their partners in contemplation of relational and sexual adjustment in their couple relationship.

An essential part of the situation of being woman is that of living with the ever- present possibility that she will be gazed upon as a mere body, as shape and flesh that presents itself as the potential object of another’s intentions and manipulations. Bartky (1979) comments: “this objectified bodily existence is in the attitudes of others, but the woman herself often actively takes up her body as a mere thing”. Young (1980) further adds, “this objectified bodily existence accounts for self- consciousness of the feminine relation to her body and resulting distance she takes to her body; an existence in discontinuity with her body. The objectifying gaze ‘keeps her in her place’ and can also account for the spatial modality of being positioned and for why women frequently tend not to move openly, keeping their limbs closed around themselves to prevent social invasion of gaze and inappropriate bodily touch”.

Accounting for both the work of Bartky (1979) and Young (1980) I suggest the internalised objectified bodily existence, combined with gendered instability and a failed sense of self as a sexual being and woman, lead the women with vulvodynia in this study, to increasingly and determinedly to project, an existential barrier closed around them and discontinuous with the other there, in order to keep her partner at a distance. The women also described withdrawing, from touching and kissing, for it is too painful to touch relationally and too painful to being touched sexually. To touch her

partner or encounter his touch gives a sense, not of comfort but a reminder of sex, a sense of inviting sex, an invasion, a threat to her already broken body, her painful vagina unable to tolerate penetration. For women in the study there was somatic hypervigilance about genital pain and an attentional bias towards their bodily sensations. This finding has symmetry with the research of Meana (2012) about pain catastrophisation (p.34). This sense of the lived body described by the majority of the women in the study can be accounted for as excorporation, as described by Zeiler, (2013). She comments excorporation is unwanted, typically emotional, and painful, resulting in a breakdown in orientation and the lived body becoming object that one cannot but attend to.

The women expressed a situatedness of unstable and decentred female gendered identity and heterosexuality, indicating they experience a sense of not being 'in line' to draw on Ahmed's (2006) reasoning. When women with vulvodynia feel they are not 'in line' with their heterosexual orientation, the norms and beliefs of sexual practices and activities of penile-vaginal sex from others, who have incorporated the same norms and beliefs, this is experienced as very difficult in interactions and relationship. Women's prior knowledge of heterosexuality becomes increasingly difficult to set aside. They are already in possession of an interpretation that exists for their gendered identity and (hetero) sexuality in couple relationship. For the majority of the women in the study there is a finding of a fixivity and repetition of that, which had been incorporated: the familiar, the taken-for-granted penile-vaginal hetero-sex that they as female gendered women, were unable to engage in.

In the majority of study interviews, the acknowledgement and confirmation of this was a very difficult if not, impossible moment, with the women feeling they could not escape it, nor be free of it, as it is. They were in their own vicious and repetitive hermeneutic circle of incorporated meanings, interpretations of self and expectations of staying within the hetero-normative lines of their sexuality. Women's lived experience of vulvodynia is preoccupying and demanding their continual bodily attention resulting in self-objectification, excorporation and distress. This supports the assertion of Bartky (1990,p 20) who argues that, " a variety of cultural discourses have brought it about that (women) inhabit an " inferiorised body". Bartky adds: "…women experience their bodies as the enemy; I am defective, not just for others, but for

myself. I habit this body, yet I live at a distance from it as its judge, its monitor, its commandant" (p.21).

Our lived bodies literally come up against surfaces, contours, margins, edges and all manner of plans by way of our fingers, lips, hands, arms, legs, and trunk. Whether we lie prone, crouch, sit, stand, walk, or run we are always in feeling contact with the world. We also feel the world through our eyes, ears, and mouths. Merleau-Ponty refers to this as our "perceptual world", emphasising that our perspective of the world is anchored in our bodily being-in-the-world (1968, p.170). From a bodily being-in-the-world, we feel the world such that not only do we grasp the world, but the world also grasps us in contact. We find ourselves touched in a particular way that reflects not only the original intent of our touch but also the manner in which we experience the touching, suggests Merleau-Ponty (1962).

To give interpretation to the women's accounts in this study it is essential to reflect on the modalities, intentionality and perception of women's experience in their being, their sexual being in situation (Young, 2005). For the women participants' in this study the touch and kiss from their partner, the familiarity of the erect penis unexpectedly touching their flesh or a gentle stroke across their breast cause negative emotions to arise within and give rise to bodily states that can be described as flinching, withdrawal and resistance to touch; turning from him, making their body seem smaller, and boundaried. The boundary between body and environment cannot be sharply drawn (Merleau Ponty,1968). We are open onto the world, embedded within it and of it, such that sound, light, heat, taste, and touch constitute our very bodily being. When something goes wrong with the body and it does not function in the familiar, homelike way, it draws attention. The individual descriptions of the majority women in the study can be compared with characteristics and degrees of excorporation as described by Zeiler (2013) and 'limp' intentionality by Merleau-Ponty (2012).

Overtime, continual excorporation results in bodily alienation, implying a deeper more pervasive injurious wound of the lived body impacting on embodied agency and disrupting intentionality (Zeiler, 2013). Intentionality, Merleau Ponty describes, as a way of being-in-the-world, in relationship, that is not just physical but also embedded in cultural and social meaning too. Zeiler's (2013) speaks of disrupted intentionality as

having resonance with Merleau Pony's description of 'limp intentionality', as sense of not feeling one's self; a sense of not being orientated. For the women in the study continual limp intentionality and excorporation associated with repeated attempts at penile-vaginal sex, or rejection of penile- vaginal advances, increase experiences of felt pain, a sense of failure, shame, distress, relational disconnection, a turning away and withdrawal into self. This compares with, and is characteristic of, alienation as described by Svenaeus (2014) and Wilkerson (2014) and is suggestive of a bodily sense of uncanniness, as highlighted further in the work of Svenaeus (2000a).

Most women's described experience of bodily subjectivity was akin to that of continual excorporation and, for a few women, more akin to alienation. This bodily disruption in women gave rise to a feeling that, 'her body is something other than her', as described by de Beauvoir (2010) and Young (2005). Excorporation and alienation are qualitatively different, Zeiler suggests. Alienation implies 'a more thorough and deeper breakage of the subject's lived body where the self can become to experience and even identify with a passivity imposed on her by others'. The women in the study, in varying degrees, described the lived body as suffering and mourning the loss of self, gendered identity and sexuality. They experienced intense psychological and social pain; and bodily disturbance associated with the loss of connection with, and the negative impact on, interpersonal relationships, in particular their partner but also family and friends. Women described experiencing shame and social isolation with friends and family and threats of other women, that they will be discovered as a fake woman: so some did not mix or socialise. The study finding of phenomenological shame in women aligns with the research of Marriot and Thompson (2006) and that of Kaler (2006).

For some women in the study, the conscious meaning of vulvodynia is expressed as a physical ailment that prevents them from having sex; and for one woman, vulvodynia was referred to as 'my unnatural illness'. The women's ailment or unnatural illness, precludes them from having sex, with the coital imperative, which states that mature heterosexual sex always involves intercourse and with the male sex drive discourse which states that men need and want intercourse to be sexually satisfied, leads to the view that real sex is penis in vagina sex. This study shows these socially inscribed,

normalising beliefs and expectations can lead to significant distress in women, accompanied with shame, guilt, depression and grief about loss of sexual identity.

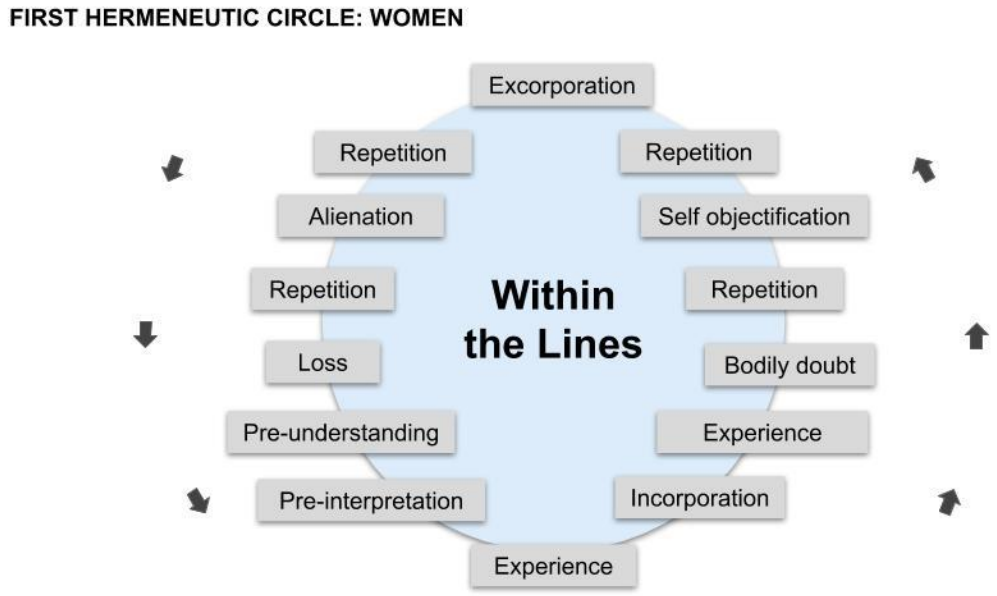
For the women in this study, there is a deep sense of loss of female and sexual identity, loss of penetrative sex, loss of womanhood, and for some the loss of pregnancy, which intensify their psychological and bodily suffering. They were trapped in their lived body and being dragged along by biology - in their unmarked body- for there is no physical evidence of their pain. The women were despairing, distressed and had a damaged way of being, which can be attributed to vulvodynia; but more so to the constraining and saturating powerful regulatory social and cultural norms of heterosexuality. The meaning of the women's substantial felt sense of loss has symmetry with the characteristics of loss Toombs (1987) describes as: loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world they inhabit.

Gadamer (1989) suggests the hermeneutic circle describes the process of human understanding hermeneutically. Understanding being a circular movement from the whole to the part and back to the whole again. He conceptualised the hermeneutic circle as an iterative process through which a new understanding of a whole reality is developed by means of exploring the detail of existence. He viewed understanding as operating, through conversations with others in which reality is explored, and an agreement reached that represents a new understanding.

Figure 2. below: First Hermeneutic Circle: Women; theoretically conceptualises the vicious and repetitive hermeneutic circle of women trapped in an imprisoning frame of body and mind, by repetitively trying to keep "in the lines" of the idealised gendered and (hetero) sexual orientation and demanding interpellations. The hermeneutic circle starts with a pre- understanding and pre-interpretation of their embodied bodily existence of, (who they experience themselves to be) having incorporated the normalising and regulatory processes of subjugation in the social. With the onset of vulvodynia, all women in the study expressed versions of their sense of bodily doubt, self-objectification and excorporation, with a majority of women describing degrees of an embodied sense of alienation and loss of gendered and sexual identity. The first

hermeneutic circle is the meaning of vulvodynia and; the meaning of vulvodynia that is difficult to grasp- hence the repetition- there is no transparency of meaning and understanding for women in this study, which prevents emancipation from their imprisoned body and mind of socio-cultural meanings of gender and heterosexuality, and thus adjustment to vulvodynia.

Figure 2.



Excorporation and alienation are qualitatively different: Zeiler (2013) explains that alienation implies '… a more thorough and deeper breakage of the subject's lived body where the self can become to experience and even identify with a passivity imposed on her by others' and previously held beliefs or norms become problematic. Importantly Zeiler adds, that incorporation and excorporation are not static, that a reversal is possible, which she terms as re-incorporation with some important adjustments. Re-incorporation builds on the subject's psychic capacity to reverse, refuse, and oppose as a form of resistance, which opens up possibilities, in the context of this study, of new 'gendered 'body-world-relations' with new sexual meanings for women.

In conclusion, the hermeneutic meaning of vulvodynia for women, is that of a wounding of the essential self, because women intrinsically link the experience of the body, gender, sexuality and self: thus their lived embodied subjectivity and sexuality, is experienced as suffering and broken. Such is the intensity of embodied pain and

suffering combined with a psychic defence of gendered identity and heterosexuality, that only two women in the study seemed to reverse and re-orientate their position towards relational and sexual adjustment. Resistance, and its agentic importance to relational and sexual adjustment to vulvodynia in the couple context, will be further discussed in Chapter 8: Discussion.

Chapter 7.

Data Presentation For Men Participants' and Summary Interpretative Analysis

7.0 This chapter presents the data and interpretative analysis for men. The combined data for all women and all men in each of the seven couples is presented in Appendix 7 p.207 Couple Data: The Undoing of Vulvodynia.

The data and interpretative analysis for men is presented in three distinct sections titled: (1) Self, (2) Partner (sense of) and (3) Relational and Sexual Adjustment. Each section identifies key Superordinate Themes* and sub Themes.
Key Superordinate Themes and sub themes with numeration for 'Self' for All Men Participants' is shown below in Table E. The specificity of Men participants'-self with extracts of meaning and lived experience is attached at Table 6, in the List of Tables p.234. Table E below provides an overview only for ease of reference.

All Men Participants'

Table E: Table of Key Themes all Men Participants'-Self

Superordinate themes* (Number of participants)	Themes (Number of participants')
1.Gendered identity (7)	1.1 Unstable maleness (7) 1.2 Fear of humiliation (4)
2.The Relational (7)	2.1 Joys (2) 2.2 Hurtful feeling's (5) 2.3 Arguments (5) 2.4 Rejection (4)
3.The Sexual (7)	3.1.Loss (7) 3.2.Touch (6) 3.3. The Male Body (7)
4.Burden (7)	4.1 Weight of expectation (4) 4.2 Leaning on (3) 4.3 Negativity emotionality (7)

Table E. above illustrates the results of the lived experience of men of Self with four superordinate themes*, (1) Gendered Identity, (2) the Relational, (3) the Sexual and (4) Burden together with sub-themes. The following analysis provides interpretation of the men's lived experiences and the sense they made of them evidenced by extracts from each participant.

7.1 Analysis All Men Participants' Lived Experience of Self

7.1.0 Gendered Identity (Superordinate 1.)

A central theme in many men's experience of vulvodynia in the couple was an account whereby there was a masculine gendered sense of self that was experienced as weakened. There are two sub-themes identified; unstable maleness and fear of humiliation.

(i) Unstable Maleness

The interior life of the gendered identity of masculinity did not initially show its face in the interviews with the men. There was an early male display of taking up space with the body spreading on the sofa; a kind of strength and rational firmness in their replies to my questions about vulvodynia and their sense of self as if to be seen by one's self and by me as male. The majority of men did want to talk about self discursively unravelling as they did so. Some men expressed a sense of bodily doubt; of loss of power; and a lack of strength and virility in the couple relationship with vulvodynia. Their maleness was defended and represented by the exemplification of the penis, their frustrated desires and difficult sex life; and for some gendered identity references, to the partner of failure to provide.

"Intercourse is impossible". P2

"I value penetrative sex and it's important to me. I have always been highly sexed, so… it's difficult". P2

"There are things she's capable of doing but she's scared to try them". P14

“It makes me self conscious about myself”. P14

(ii) Fear of Humiliation

Three participants were distressed and appeared to be experiencing vulvodynia in the couple relationship as equally painfully as their partner. There was a sense of their maleness being fatally wounded with loss of sexual power. The self was experienced as a desire-less man, which was somehow attached to the wounding.

“ … the physical side has been like a shot in the foot, like being dead in the water”.P4

There seemed to be a concern about privacy and an accompanying fear of humiliation that if non-penetrative sex and loss of genital potency were known about, it would rob the man concerned of the status of maleness and the prospect of manhood.

“I can get annoyed about family asking about kids. It’s too private to tell them about this.” P12

7.1.1. Gendered Identity Summary Interpretative Analysis

Some men in the study appeared defended in their maleness relying on their anatomical difference, prioritisation of penetrative sex, social position, function and roles ascribed to them by western society and cultural norms to shore them up. The defence of misogyny confers the subject of failure is women and not man, to think any other would render man as wounded and humiliated. While some men in the study wrestle with their maleness, many seem to prioritise the relationship, love and dependency.

7.1.2. The Relational (Superordinate theme 2.)

The majority of the men appeared to have a very particular way of being which seems to enable them to stay in relationship with their partner. This may rest with the masculine and feminine functions in self, these being interchangeable and the male unconscious experience privileging the feminine within the male. There seems to be a distinct desire and capacity for the men to fulfil the demands of their internal feminine nature, and by implication nurturing and caring roles of relating, moving beyond the sexual. However, there was significant instability in the relational field attributed to

vulvodynia by some men. There were two sub-themes identified joys and hurtful feelings.

(i) Joys

Many men shared their positive emotions about being in relationship with their partner.

" …really good, strong together, have lots of fun together, good times". P12

"I love her". P2

"I've known her a long time, it's almost like we know what the other is thinking. I can't imagine anything different really". P8

(ii) Hurtful feelings

Some participants disclosed negative emotions and displayed their felt upset and distress about relational dynamics and behaviours in the couple relationship. Examples of tension, argument, male pain and hurtful feelings of rejection were prominent when sharing their felt experience of vulvodynia embedded in the intimate relationship with their partner.

"My experience is pain and rejection with a relationship that is distant; lonely; with separate lives." P10

"It's the hardest thing we face …umm like yesterday we had an argument, well disagreement about it." P6

"I suppose it does cause issues, rows and arguments because for a long while I felt rejected."P14

"I struggle with really feeling rejected." P6

"I am open with her about how I feel. It doesn't get received well and causes lots of arguments". P14

“It’s difficult in the relationship because it makes her very paranoid. She thinks I can’t get what I want from her. That I’m going to go off with someone else. It makes things very difficult”. P1

7.1.3. The Relational Summary Interpretative analysis

The unhappiness of men in relationships, the distress men feel about the failure of love, intimacy and sex, often goes unnoticed in our western society precisely because the patriarchal culture really does not care if men are unhappy. Patriarchal mores teach a form of emotional stoicism to men that says they are more manly if they do not feel, but if by chance they should feel, and the feelings hurt, the manly response is to deny, suppress, to forget about them; to hope they go away.

In supporting a patriarchal culture that socialises men to deny feelings, we construct a culture where male pain can have no voice, where male hurt cannot be named or healed. Many women cannot hear male pain about love, intimacy and sex because it sounds like a female failure; that she is at fault; that she is to blame. This is particularly so for women carrying the endless burden of vulvodynia and the perceived failure of heterosexuality for she carries sexuality and desire. For men the burden can take its form in misogyny. The combined partner effect of hurtful feelings, a sense of failure and ineffective communication circulating in the relational field can destabilise, de-centre resulting in couples barely coping, destroying their passionate bond. Argument is the best hiding place for couples seeking to conceal pain, unstable gendered identity or distress. Unfortunately it is a perverse form of connection, which replaces true intimacy.

7.1.4. The Sexual (Superordinate Theme 3.)

All men in the study shared their experience of loss: loss of sex, loss of intimacy and loss of touch. Some men disclosed the impact on their body and sexual self. There were three sub-themes identified; loss, touch and the male body.

(i) Loss

Men expressed the experience of loss of penetrative sex, sexual intimacy, kissing and touch. For one man a sense of disconnectedness and a feeling of distance

accompanied by loss. Importantly, the majority of men disclosed that they did not want to cause their partner pain with attempts at and actual penetrative sex because it caused them to be anxious, to worry and to feel guilty. This was explained in the context of the knowledge and understanding that their partner is often engaging in penetrative sex, but is pushing through the pain of vulvodynia.

“I have given up, I do my own thing”. P10

“I don’t want to cause her pain, so our sex life has taken a back seat over the past couple of years.” P4

“As time has passed, I have become more distant from her”. P10

“And I don’t want to hurt her. It’s affected me massively”. P14

“I can see the pain in her face and we stop”. P6

(ii) Touch

Some men reported intimate touch with their partner being highly problematic and confusing for them.

“When I touch her, she jumps. It puts me off. There is difficulty in reconnecting again, it depends because it affects my erections.” P2

“When I touch her clitoris and vagina it’s sometimes ok, sometimes not- its confusing cos the pain changes, it’s sometimes this and sometimes that.” P8

“I touched her one day. She jumped out of bed. I thought what have I done! ? Have I hurt her? … I was worried about it because it was an extreme reaction to the extent I don’t try and touch her in that way. You feel like you’re hurting her. It’s not good”. P8

(iii) The Male Body

Several men in the study disclosed that their experience of vulvodynia is to cause low sexual desire, to lose their erection, have difficulties with orgasm and delayed

ejaculation. These difficulties with their male sexual body and their maleness were experienced as shameful, embarrassing and distressing. The men reporting they had not sought professional advice.

“My libido has dropped.” P4

“It affects my erections.” P2

“I couldn’t orgasm and ejaculate because I need to thrust, which caused her pain”. P12

7.1.5. The Sexual Summary Interpretative Analysis

The male sexual self, the male body and its potency seemed weakened; inhibited and lacking by loss of heterosexual intimacy and penetrative sex. Weakened by worry, anxiety, guilt and male embodied pain, the men’s suffering appeared equal to that of their partner, albeit different in nature. It was, nonetheless excruciatingly hurtful pain; sometimes acute, sometimes chronic. Moreover, several men developed sexual difficulties co-morbid to their partner’s condition; they experienced low sexual desire, erectile difficulties and delayed ejaculation, further exacerbating their anguish.

There seems to be a forced disruption of their expectations and sometimes their practices, especially in the sphere of penetrative sex. There is a sense of distress and nostalgic loss at what they believe they have lost or are missing out on. It seems the over -valuation of penetrative sex by some may not allow for a new perspective to emerge.

7.1.6 Burden (Superordinate Theme 4.)

A key theme was burden; most men spoke of their lived experience of negative emotionality, and weight of expectation from their partner to provide reassurance and hope in the on-going, sometimes raw relational interaction. There were two sub-themes; weight of expectation and negative emotionality.

(i) Weight of Expectation

Some men carried enormous despondency about penetrative sex. Others carried the weight of expectation to reassure their partner 'leaning on' them in seeking optimism and hope. Most men experienced upset, which they feel cannot seemingly be heard and responded to at times by their partner.

"Makes me feel like it's (penetrative sex) never going to happen". P2

"I worry about hurting her. I try not to over analyse it or talk about it- make it a big issue because it can make it worse". P8

"Vulvodynia and being unable to have pain free penetrative sex upsets me". P12

"I reassure her, reassure her, and reassure her. I sometimes get fed up. You can only reassure someone so much, and it gets me down. But at the same time I love her". P2

(ii) Negative Emotionality

The words and statements used by men were sufficiently descriptive to convey their negative emotionality about their lived experience of vulvodynia.

"It's affected me massively". P14

Some words used by men about their subjective experience of vulvodynia to describe their experience and the burden they were wrestling with include; depression; humiliating; anxiety; anger; shame; hurt; loss; and rejection.

7.1.7 Burden Summary Interpretative Analysis

The men participants' spoke of their sense of felt burden; it is likely the intensity of burden and suffering was equal to that of their partners, and certainly it was for a few, externally defended with a form of misogyny. It is not true that men are unwilling to change or adjust. It is true that many men fear vulnerability because patriarchy keeps them from knowing themselves, from being in touch with their feelings and giving voice to them in the intimate couple relationship. Misogyny and other defences can deny

male access to full emotional wellbeing and support in couple relationship, leaving them stuck in their suffering and sense of burden.

7.2 Men Participants' Lived Experience of their Partner (sense of)

This section of the analysis captures the participants lived experience of their partners with vulvodynia in the couple relationship. There were four Superordinate Themes* identified; (1) Gendered Identity, (2) the Relational, (3) the Sexual and (4) Burden. Table 7 p. 237 attached in the List of Tables, provides the extracts from the interviews about how the men experienced their partner with vulvodynia.

7.2.1. Partner and Gendered Identity (Superordinate Theme 1.)

Some men in the study described a significant change in their partner associated with vulvodynia that distressed them. The participants' obvious distress and upset at the perceived change in the partner is suggestive of the inevitable inter-dependencies between self and other, but also phenomenologically, the lived experience of missing and desiring the feminine lustre and gendered closeness of the embodied female.
"She is a shell of what she was. She's not the same". P14

"She was someone who was very open minded and open to new experiences…..it was nice to have someone you could trust and do things with". P14

"She's normally a very happy person, but this gets her down and gives her anxiety". P12

7.2.2 Partner: The Relational (Superordinate Theme 2.)

Many male participants' reported their lived experience of their partner in the relational field to be difficult, argumentative and excluding. Communication and resolving difficulties and differences associated with vulvodynia in the couple relationship seem to be experienced as highly problematic.

"She's a bit shut down about it (vulvodynia). I can tell she doesn't want to talk about it and wants to forget it". P4
"I'm open with her about how I feel. It doesn't get received well and causes lots of arguments, She'll put it down to me wanting to be single… she'll kick off". P14

“I tell her to open up about it because I want to be involved”. P4

“It makes her paranoid. She thinks I’m going to go off with someone else. It makes things really difficult.” P2

“She’s very set in her ways and closed down about it (vulvodynia)”. P8

7.2.3 Partner: The Sexual (Superordinate Theme 3.)

There were disclosures from some of the men about the sexual impact on their partner in the couple relationship, which gave a sense of felt rejection and frustration combined with an edge of misogyny.

“I’d say, she doesn’t ever want to do it (penetrative sex)”……“She knows it’s (penetrative sex) important for our marriage”. P6

“There are things she’s capable of doing but she’s scared to try them”. P14

“My wife doesn’t enjoy being intimate with me because of it (vulvodynia)”. P6

7.2.4 Partner: Burden Superordinate theme 4.

A few men in the study spoke of their partner’s suffering associated with vulvodynia, pain responses and the female sense of self. The participants also expressed how deeply this affected them, as they felt unable, somewhat impotent to protect and minimise their partner’s suffering.

“… she feels embarrassed. It shouldn’t be like this. She’s different to other people”. P12

“My main issue with it (vulvodynia), is how she is …. affected by something I can’t do nothing about. That upsets me.” P14

“She’s afraid to have sexual intercourse. It’s heart breaking and frustrating that she can’t live a normal life”. P4

“She’s scared of pain”. P14

7.2.5. Men Participants’ Lived Experience of their Partner- Interpretative Summary

The lived experience of men in this study is stark given the difficulties of first, their own pain and anguish being unheard; second, the perceptual and actual complications that arise with trying to cope with vulvodynia in the couple relationship; and third, the lived experience of bearing witness to the negative impact and lived bodily experience of their partner with vulvodynia. The burden and suffering of both men and partner is immense because to be at the centre of any one of these is to be, simultaneously, at the centre of all three difficulties.

7.3 Men Participants’ Lived Experience of Relational and Sexual Adjustment

This section of the analysis captures the men participants’ lived experience of relationship and sexual adjustment in the couple relationship with vulvodynia. Table 8 p.239 attached in the List of Tables, identifies two Superordinate Themes* (1) Relational Adjustment and (2) Sexual Adjustment, emerging from the analysis and provides the data extracts from the men given in interviews.

7.3.1. Relational Adjustment (Superordinate Theme 1)

Captured in the Relational Adjustment superordinate theme* are the many difficulties experienced by men at varying levels of coping with vulvodynia in the couple relationship. These are three sub themes identified: bereft; stoicism, and “it works”.

(i) Bereft

For two men their lived experience implied they felt deprived of a normal couple relationship and had negligible optimism of relationship and sexual adjustment, despite love for their partner. They were distressed, hurt, barely coping and had been questioning whether they were a real couple.

“My experience of vulvodynia is it’s awful, f**king horrible. It’s ruined our life. It’s not there anymore”. P14

“We’ve drifted apart with our ‘child’ in the middle, keeping us together”. P10

(ii) Stoicism

Several men expressed a sense of stoicism and a striving to cope rather than adjustment to the burden of vulvodynia on the couple relationship.

“Vulvodynia is inconvenient but not the end of the world”. P8

“The physical side is like a shot in the foot, like being dead in the water. I don’t want to give up though”. P4

“I see my role as a man in the relationship is to support my wife whatever comes our way.” P6

(iii) It Works

For two men in the study there was expression of positive experiences of relationship adjustment. They explained that, despite the presence of vulvodynia in the couple relationship, the relationship was positive and strong.

“It’s hard, but it works”. P2

“The couple relationship is really good; strong together; have lots of fun together, and good times. It just seems to work”. P12

7.3.2. Sexual Adjustment (Superordinate Theme 2.)

Captured in the Relational Adjustment superordinate theme* are the lived experiences of men of sexual adjustment to vulvodynia in the couple relationship. There are two sub themes identified; experimentation, and connection.

(i) Experimentation

A few men gave examples of sexual adjustment with their partner, assisted by experimentation, touching and pleasuring. It appears a few men developed a problem solving approach with a desire to experiment, change and transform. They promoted a shared language of intimacy, understanding and agreement together with their partner.

They have a joint relational understanding of relationship and sexual adjustment built on a stable partnership of trust and support.

“We do everything that a normal loving couple would do, except penetrative sex”. P2

“We don’t have the experience of regular sexual intercourse like everyone else. We just do everything else.” P12

“It was a decision that we stopped penetrative sex because of the pain but the touching and pleasuring carried on. We experiment.” P12

(ii) Connection

A small number of men indicated a coping with, rather than sexual adjustment to vulvodynia in the sexual relationship. Reports of connection and closeness with their partner were suggestive of valued intimacy and relationship.

“Penetrative sex isn’t the be all and end all. For me it’s the closeness.” P8

“Vulvodynia makes me feel frustrated that I can’t do anything about it, yet in many ways it’s brought us closer together.” P6

7.3.3 Relational and Sexual Adjustment Summary Interpretative Analysis

The quality of couple relationships seem to be the most obvious risk factor for sexual difficulties, after all, sexual function difficulties can play out primarily in a relational context. In this research it appeared a more stable harmonious relationship concurrently enables sexual adjustment. What has become apparent from the participants in couple relationship is the difference between reaching the state of adjustment versus barely coping with relational breakdown. For many participants sexual adjustment was frustrating, problematic and experienced on a continuum involving non-intimacy and non-penetrative sex; to sexual intimacy and penetrative sex; to experimental sexual intimacy and non-penetrative sex. Men who engaged in experimental sexual intimacy and non-penetrative sex expressed embodied pleasure with touch and phenomenological closeness. Men reaching this level of sexual adjustment seemed to have acquired a level of acceptance over time about non-

penetrative sex with their partner as a shared endeavour, although with an air of nostalgia.

7.4 Discussion: All Men Participants': the Application of Feminist Phenomenology Concepts and a Hermeneutic Circle of Understanding

This discussion section serves to, compare and contrast the emerging themes with existing literature, and to provide an analysis using feminist phenomenology concepts; and a hermeneutic circle as a way of understanding, the barriers and challenges, to relational and sexual adjustment for men, in relationship with a partner with vulvodynia in this study.

The lived body of men as sexual beings corresponds to the erect, firm penis; the 'hard on' being the very essence of male sexuality. The concept of potency is central to hegemonic masculine identity with virility permeating the idea of bodily manliness, Buchbinder (2013). For men in the study sex was a serious matter, with some describing at the beginning of their relationships they did not feel they could remain in a relationship without the ultimate 'natural' act of heterosexual penetration. For others, it was the repetition of attempts at penile- vaginal penetration with their partner that culminated in relational tension and sexual difficulties.

Men in the study felt their partner's 'vulval pain' had negatively affected their lived body, their sense of masculinity and sexual functioning. Vulval pain was solely described as having affected their feelings about themselves, often leading to a sense of loss of sexual power and desire, which was somehow vitally attached to their lived body. This was expressed by a few men as helplessness and being bodily fatally "wounded", '"dead in the water'", submitting the men to powerlessness and a sense of fatality. This finding aligns with the work of Merleau- Ponty about the interrelatedness of mind and body and his notion of the 'limp' intentional arc resulting from a distressed bodily being (2012).

Men described experiencing anxiety associated with a fear of hurting or harming their partner, which was invoked in the couple sexual activities during attempts of vulvar touching or vaginal penetration. Men were affected by the avoidance of sexual contact, or inability to engage in intimacy with their couple partner, as a partner, and as a man. Men suffered feelings of rejection, shame, humiliation and anxiety in the couple sexual

relationship with minimal ability to regulate their negative feelings and senses, leading to overwhelming distress in the lived body. Men in the study described relational difficulties with less closeness, difficulties with sexual communication, argument and sometimes-interpersonal conflict; this finding is consistent with the research of Meana (2012.pp. 38-39.). More exploring of these difficulties revealed them to be fueled by misunderstandings, confusion and men shoring themselves up in non-relational ways. For men in the study, their lack of understanding about vulvodynia, the silence about pain, shame, distress and bodily doubt, and not feeling heard and understood by their partner, contributed to despair and a destructive cycle of communication and intimacy breakdowns. Relational conflict for a few men veiled; hurt feelings and perceived rejection.

Men's subjectivity, or sense of self, as for women is produced in the social, through the intersection of such social discursive processes involving the sexed body, gender and sexuality. Girls and boys, women and men in their formation in the social are required to shore up the tenuous relationship between anatomical sex and cultural gender. Butler (1993) refers to this as the iteration of gender. The category of 'sex ' is, from the start normative; it is what Foucault has called a 'regulatory ideal'. In this sense, 'sex' not only functions as a norm but it is part of a regulatory practice that produces the bodies it governs, whose regulatory force is like a productive power; the power to produce, demarcate, differentiate the bodies it controls. One is socially compelled to behave in a feminine or masculine way in order to be taken for female or male. For a heterosexual man, it is important to 'pass' as a heterosexual man in the social. Not to perform 'like a man', nor penetrate 'like a man' gives rise to a sense of being feminised like a woman. For the man, the restoration of his stability and solidity corrects the self-perception, re-positioning him to his proper upright place as an identifiable 'real' man. Butler (1990) explains that we only come into being by the desire of the 'other', with vulvodynia at the centre of the couple relationship some men experienced precarity in fully inhabiting their own gender. However, for most men in the study their gender was defended, fortified, gripped and hunkered down.

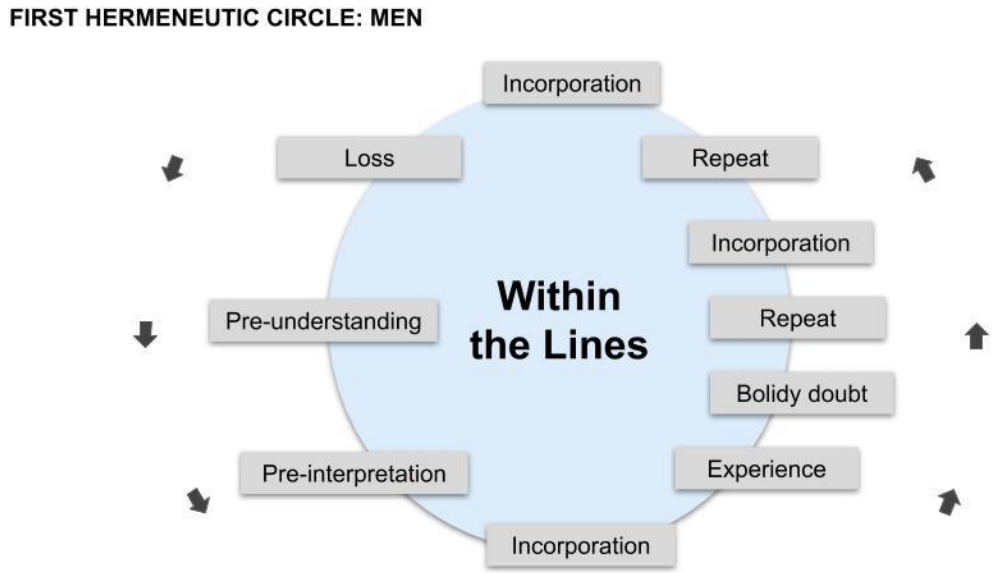
For some men in the study seeing and experiencing the vulnerability and dependency of their couple partner was problematic. It was as if their partner's vulnerability was an undesirable state, that they could not bear the precarity of her bodily being: as if too

much vulnerability and dependency was too much to accept. A few men suffered with anxiety and distress when they felt shame and guilt related to the pain they were causing their partner through sexual activity resulting in bodily doubt and experiences of low sexual desire, erectile, orgasmic and ejaculatory problems. For men in the study, the experience of unreliable erections, low sexual desire, orgasmic and delayed ejaculation, albeit episodic and can be attributed to the interloper of partner pain associated with penetrative vaginal sex, giving rise to anxiety about their partner engendering a parallel difficulty in them, which unsettled their maleness.

The lived body of bodily doubt aligns with the work of Carel (2012); in this case when the men's reliance on their past gendered performance is broken by anxiety, shame and a dysfunctional sexual bodily. Leder (1990) comments: 'while in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterised by absence', however to be a distressed body, is to have a disrupted body. For men loss of erectile, orgasmic and ejaculatory function is profoundly destablising to their maleness. The male gendered body is certainly not absent, but comes acutely into conscious bodily awareness with devastating effect to their masculinity. The men's felt sense of loss compares with the work of Toombs (1987). She describes the features of loss as: loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world they inhabit. For most men the perceived loss of their sexual partner was disorientating and impenetrable.

Figure 3. below :First Hermeneutic Circle: Men, theoretically conceptualises the hermeneutic circle starting with pre-understanding, pre-interpretation, incorporation, which is interrupted and disrupted by their partner's pain associated with vulvodynia in the repetitive or attempted act of penile-vaginal sex enacted to keep 'in line' with gendered identity and heterosexuality (Ahmed, 2006). The first hermeneutic circle is the meaning of sexual pain (associated with compulsory heterosexuality and vulvodynia) that is difficult to grasp. There is no transparency of meaning and understanding for the men, as with their couple partner- hence repetition, albeit with minor modifications and circularity (Gadamer, 1989). This repetition is the possibility of a re-embodying of the subjectivating norm that can redirect its normativity (Butler, 1997, p.99).

Figure.3



Using the feminist phenomenological concept developed by Zeiler (2013) of incorporation and applying it to the situation of men in the study, it is the case that for most men there was an engagement in the continual process of repetition with minor ongoing modification to new situations as we do in every-day life. This can be distinguished from re-incorporation after excorporation and alienation. For the majority of men, they modified and engaged relationally to support and understand their partner and to make small changes in sexual practices, which their partner acknowledged. For a few men, however relational modifications were highly problematic and the loss of their sexual partner and her vulnerability was too difficult to bear.

In conclusion, men in this study gave meanings and interpretations of their experience of vulvodynia in the heterosexual couple relationship and in doing so, the materiality of embodied sexual, gendered, relational burden was apparent often leaving them feeling powerless in their maleness. Men experiencing comorbid erectile, orgasmic, ejaculatory difficulties felt they were not fulfilling their role as a sexual partner too, and described a loss of masculinity. The majority of men remained psychically defended in their gendered identity, heterosexuality and sexual practices, such that only a few men

embraced relational and sexual adjustment with their partner. Resistance, and its agentic importance to adjustment in the couple context will be discussed further in Chapter 8. Discussion.

Chapter 8. Discussion

Couples Caught up in an Imprisoning Frame of Gender and Hetero-normativity, Power and Regulation: Resistance and the Hermeneutic Circle of Understanding.

8.1 Introduction

In this discussion chapter, I focus on relational and sexual adjustment in couples with vulvodynia building on the data, interpretative summaries and discussions in chapters 6 and 7. In these chapters the discussions for women and men illuminated the significant impact of constraining socio-cultural meanings about gender and sex; and resultant embodied pain and suffering with little orientation towards adjustment. I turn now to women and their partners' psychic and relational negotiation of powerful gendered and (hetero) sexual norms and beliefs; and re-negotiation of couple sexual practices.

This study explored how fourteen participants, in seven heterosexual couple relationships, experienced and gave meanings to vulvodynia, specifically in their sense of relational and sexual adjustment. A feminist phenomenology epistemology stance was adopted to give meaning to participants experience, generated from data collected and interpreted, using interpretative phenomenological analysis (IPA) methodology. The research question and underpinning areas generating this study's data analysis was:

What is the impact of socio-cultural meanings of gender and sex for heterosexual couples with vulvodynia negotiating relational and sexual adjustment, and the implications for transforming clinical practice? This question was explored with particular reference to: (1.) the materiality of embodied sexual subjectivity; (2) women's and their partners' psychic and relational negotiation of (hetero) sexual and gendered discourse; and (3.) the re-negotiation of couple sexual practices in the context of sexualities, desires and sexual pleasures.

In this discussion chapter I have given prominence to the theories of feminist phenomenologists and philosophers identified in earlier chapters, namely Luce

Irigaray, Judith Butler, Sara Ahmed, Iris Marion Young; and Kristin Zeiler. In bringing together their salient theories with the phenomenological insights and richness of data gained in this research study; it is hoped women with vulvodynia and their partners will benefit from the new knowledge produced. In addition a feminist phenomenology analysis, with key concepts and a second hermeneutic circle: a double hermeneutic circle of human understanding, is included for application to clinical practice. The rationale for this is, to open the way for a comprehensive analysis of the experience of vulvodynia, which includes couple meanings, social aspects of sexual and gendered embodiment, heterosexuality, and bodily practices as well as their mutual intertwining when addressing adjustment.

8.2 Women and Men as Couple

The couple experience is important because the couple brings into focus widespread understanding and meaning of gender, sexuality and sexual practices, according to which gender identity proceeds from, and is produced by sexuality and normalising socio-cultural sexual practices. In other words, one's sense of self as authentically gendered as 'real woman' and 'real man' is derived in significant measure by certain activities, such as penile- vaginal intercourse, which is culturally defined in western society as 'real sex' (Kaler, 2006; Potts, 2002; Mc Phillips et al., 2001).
During individual interviews, the women and men spoke mainly with strong feelings and distress. I reflexively attended to the images, feelings, and bodily sensations invoked in me so as to enter into their inner world. I listened experientially and with freedom of judgement. For me this presupposes putting the individual's phenomenal reality front and centre instead of placing at the fore front assumptions about how a woman or man ought to be or ought to change sexually in coping with, or adjusting to vulvodynia.

For me listening experientially gives dignity, a process of being heard. It is affirming to feel heard fully, accurately and deeply, particularly when the bodily phenomena is acute vulval pain or disturbing bodily sensations of an unwanted limp penis. I listened, probed further while simultaneously attending to these images, emotions and bodily sensations in the interviews. I experienced the excitement of two women and their partners that had found new ways of being sexually experimental, but also the despair of others, feeling defective, broken or rejected. Journaling post interview enabled me

to reflexively capture my felt experience of each woman and partner held in mind as a couple. This helped to inform the new knowledge about couple relational and sexual adjustment as part of the research journey detailed in this study.

The following provides an interpretation of the couples experience towards adjustment, or otherwise; a feminist phenomenological analysis with key concepts and a second hermeneutic circle of couple adjustment**.**

Women and men expressed a diversity of meanings and lived experiences of vulvodynia; some participants experienced minimal emotional distress, and relationship and sexual tension, while the majority experienced significant emotional distress, and profound relationship and sexual difficulties. For women, distress often took the form of low mood, anxiety and loss, disembodiment, disavowal, shame and feeling a failure as a woman, culminating in a troubled bodily being with precarious gendered and sexual identity. For men, there was confusion, rejection, hurt feelings, and unstable maleness and sexual dysfunction. Clearly, women and men experienced the impact of vulvodynia and vulval pain in the couple relationship in markedly different ways and to varying degrees, with implications for relational and sexual adjustment individually, and as a couple.

The ambiguity of etiology, lack of understanding about vulvodynia with no visible bodily markings, a hidden and unknown condition and the lack of effective treatments, left a gap for many misunderstandings, conflict and blame within the couple relationship for many of the participants; also found in the work of Meana (2012). This was further compounded by felt importance and primacy of penile-vaginal sex, and destructive self-evaluations of not being “in line” with societal beliefs and norms of hetero-sex. Couples supported each other in a variety of ways; some worked well together as a couple and some clearly struggled more in working through couple relational conflict and sexual difficulties. Most couples experienced difficulties with contemplating and moving towards a position of joint adjustment to the impact vulvodynia in the couple sexual relationship. The burden and suffering of both women and men appeared immense because for some there was no shared language of understanding, agreement and intimacy.

The combined effect of hurtful feelings, a sense of failure, absence of touch and ineffective communication circulating in the couple relational field served to destabilise and de-centre, resulting in the majority of couples barely coping, destroying their passionate bond: an erotic fatality as the participant experiences and meanings in this study indicate. Lack of adjustment was intimately linked with the female imprisoned body of self, unstable maleness, relational mis-attunement in the couple relationship and joint fixivity on heterosexual penile- vaginal penetrative sex, with different meanings and starting points for women and men in the couple relationship combined with problematic communications. Some women in the study were unknowingly attached to their relational and sexual suffering; as yet there is seemingly little contemplation of acceptance and adjustment, as if for them, it is just too painful to touch and be touched relationally and sexually. These are new findings, which have implications for healthcare professionals and psychosexual therapists' education and clinical practice.

The hermeneutic meanings gained from understanding relational and sexual adjustment in couples with vulvodynia, taking account of women and their partner's psychic and relational negotiation of sexual and gendered social norms and beliefs, was more often than not, the existence of an inability to recognise, understand and engage with the other's emotional and embodied bodily state, leaving the couple relationship critically emotionally unregulated for most women and men. For two women, however there was agentic capacity, a holding of a position with embodied resistance, combined with a stable couple relationship and positive communication, which enabled tentative venturing along the journey of adjustment.

8.3 Point of Understanding: Embodied Resistance and Emancipation of the Imprisoned Body and Mind

Zeiler (2013); Butler (1997) and Foucault (1979) introduce a theme of reversibility in their work; a form of psychic resistance as a solution to opening up possibilities. For the two women in the study there was epistemological curiosity about their own body and the sexual, which incited resistance that can be thought about as a point of new understanding and re-orientation towards sexual adjustment.

Adapting Butler's work this can be understood as follows: if one understands that certain kinds of interpellations confer identity, then those very same interpellations can become persecutory and injurious to women with vulvodynia and will constitute identity through an imprisoning frame of injury as a failed sexual women and likely passionate attachment, in the phenomenological sense, to subjugation, that is the injury and associated suffering. Butler asserts; "This is not the same as saying that such an identity will remain always and forever rooted in its injury as long as it remains an identity, but it does imply that the possibilities of resignification will re-work and unsettle the passionate attachment to subjection without which subject formation-and re-formation-cannot succeed" (Butler, 1997.p, 105). For a woman with vulvodynia, it can be understood as the essentiality of agentic agency and resistance, recasting the power that constitutes her, as the power she opposes, giving new meanings to stabilise her gendered and sexual identity, and new possibilities to her sexuality, desires and sexual practices. Importantly for the two women with vulvodynia in this study, it is to be free of constraints of the social, with embodied resistance and positionality, to act on their own desires on their own terms in the couple relationship towards relational and sexual adjustment (Irigaray, 1985a; 1985b; Young, 2005; de Beauvoir, 2011).

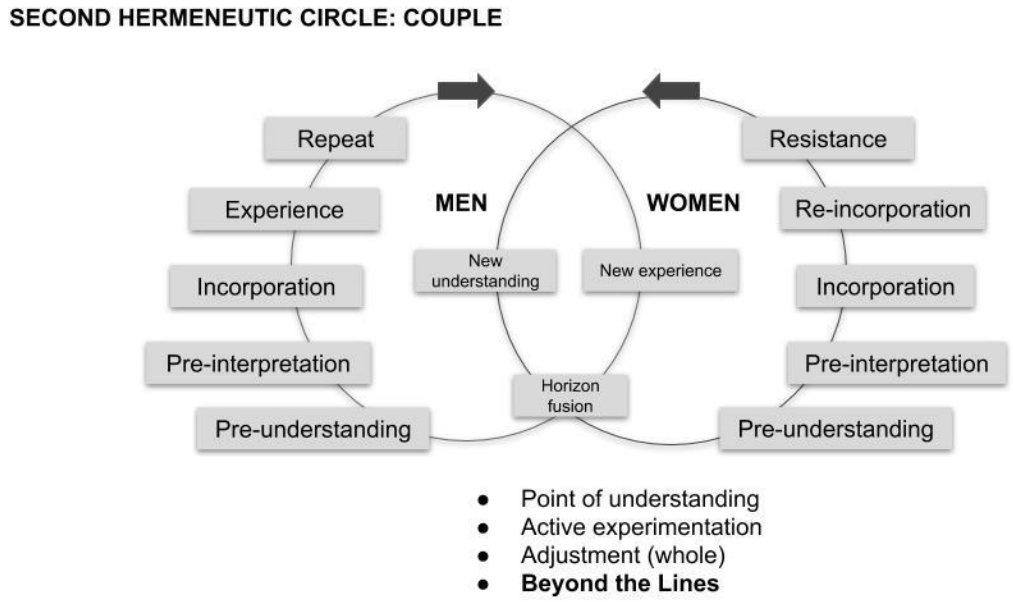
Zeiler (2013) refers to embodied resistance, which implies resistance to the continuous excorporation that eventually leads to bodily alienation. Such resistance takes place when women try to find new ways of expressing their bodily selves, new ways of living as bodily beings, even if this is done in ways that others implicitly or explicitly question. In relation to beliefs and norms about the gendered lived body, (hetero) sexuality and sexual practices; embodied resistance can be thought about as taking place when women with vulvodynia actively seek to question these beliefs and norms in interaction with their partner and they navigate and renegotiate their relational and sexual relationship 'beyond the lines' of normative penile-vaginal heterosex together. Embodied resistance was detected in the descriptions given by women and men in the two couples in the study during the interviews (Table 5 p. 232 and Table 8 p. 239).

Figure 4. below: Second Hermeneutic Circle: Couple, theoretically conceptualises the hermeneutic process of embodied resistance leading to point of transparent understanding (horizon fusion) with new meanings and experiences, and by active

experimentation and adjustment: ‘beyond the lines’ of heterosexuality, (Gadamer, 1989).

The second hermeneutic circle is the couple understanding of the powerful regulatory forces of heterosexuality that, which keeps them attached to penile- vaginal penetration, and what can be done about it. For two women and their partners navigating adjustment, this can be thought about as their becoming interested in the meaning and grounds of penile- vaginal penetrative sex in its normative sense. Their epistemologic curiosity generating interest in the regulation of heterosexuality and attached suffering.
In the second hermeneutic circle there is an overlapping, a doubling back and forth, from the part to the whole and back to the part, or better, an iterability of transparency of meaning for the couples, particularly the women, combined with resistance, agency and positionality. It can be thought about as the couples going through a hermeneutic act or process of communication and understanding, which penetrates the meaning of what is emerging in the couple sexual relationship. For example, penile-vaginal sex gives her pain: he does not like giving her pain: we, as a couple, can stop the pain by ceasing vaginal penetration, followed by mastery in understanding the subject matter by experimentally trying different things together sexually. This results in new understanding, new experiences and an awareness that it does not have to be a vicious circle but that the way out of the circle can be constructive. For other women and men in couples in the study, they appear to be caught up in the imprisoning frame of limited and constraining heterosexuality that keeps them in the act of repetition and circularity of the first hermeneutic circles (see Figure 2: Women at p.114 and Figure 3:Men at p.132).

Figure 4.



8.4 Couple Adjustment

All couples adjusted their sexual lives to some extent, to cope with vulvodynia and vulval pain; also to the associated comorbidities where they developed, specifically low sexual desire, erectile, orgasmic and ejaculatory difficulties. For couples in the study sexual adjustment was experienced as frustrating and highly problematic with all couples describing, at least one of the following sexual adjustment approaches: involving non-intimacy and non-penetrative sex, to sexual intimacy and penetrative sex; to experimental sexual intimacy and non-penetrative sex, Connor, Robinson & Wieling (2008), reported a similar outcome, albeit with limited description. All couples searched for ways to achieve sexual intercourse at some earlier point before seeking some form of adjustment.

The following describes the couple adjustment strategies that emerged in the study.

8.4.1 None Intimate and Non Sexual Couples

For couples in the study becoming non intimate and non sexual, this was not a fully collaborative, nor jointly agreed and accepted decision, leaving difficult and divided

relations. The avoidance of sexual contact, or inability to engage in intimacy, left the women feeling that they were not fulfilling their role as a sexual partner, or as a woman. Negative feelings, emotions and pain pervaded both their relational and non-sexual experiences. Communication was highly problematic and some couple partners were in relational distress and teetering on the edge of relationship breakdown. Some women and men in the non intimate and non- sexual couples however, were sexually active using solitary masturbation, which indicated they were positively managing their own sexual pleasures, albeit in a non relational way. These couples may benefit from sequential couple relationship and psychosexual therapy for opening up new relational and sexual meanings, and collaborative forms of sexual expression to be shared together.

8.4.2 Sexual Intimacy and Penile –Vaginal Penetrative Sex Couples

For the couples in the study, which engaged in sexual intimacy and penile-vaginal penetrative sex, women often did so because they seemingly prioritised the needs of their partners over their own. Despite preparations with lubricant, positioning, localised analgesic gel and for some women oral medication, the couples more often than not experienced the substantial and negative impact of painful penetrative vaginal sex. Women were acutely aware of their lived bodily sensations and, mostly but not always, communicated when they were experiencing pain to their partner. Women described acute “lacerating”, “tearing” pain on penile thrusting and prolonged chronic pain post coitus. Some men were psychologically and physically affected by their partner’s pain, with intense anxiety, and bodily loss of erections or inability to orgasm and ejaculate. Women described the intensity of pain fluctuated in their lived body, specifically the genitalia, resulting in unanticipated painful interruptions in their experience of penile - vaginal penetrative sex. Women were often surprised, experiencing more intense burning, or lacerating pain than anticipated, which resulted in suddenly discontinuing vaginal intercourse. Couples experienced considerable disappointment, relational distress and frustration with repeating unsuccessful attempts of penile- vaginal penetration. Attempts were, however repeated due to a fixivity on heterosexual vaginal penetrative intercourse to re-affirm their gendered identity and because anything less than penetrative sex was unacceptable substitution and/or perceived to be a threat to the couple sexual relationship. These couples may benefit from psychosexual therapy

to assist them to re-negotiate their couple sexual relationship and to navigate their adjustment through greater experimental pleasures beyond the genital relation of heterosexuality.

8.4.3 Experimental Sexual intimacy and Non-Penetrative Sex Couples

The two couples in the study, which engaged in experimental sexual intimacy and non-penetrative sex reported embodied pleasure with touch and phenomenological closeness. Women and men reaching this level of sexual adjustment seemed to have acquired a level of understanding and agreement over time about non-penetrative sex with their partner as a shared endeavour. The women in the experimental sexual intimacy and non-penetrative sex couples had embodied resistance, positionality and agency within a stable and supportive couple relationship with positive sexual communication. This compared with the research findings of Rosen et al. (2016) and Rancourt et al. (2016), which highlighted the importance of empathic partner responses and positive sexual communication patterns. Vaginal penetrative intercourse seemed still desired by both women and men, and there was a sense of nostalgia at what they believe they have lost or missing out on. However, this was successfully incorporated into shared erotic imaginary. The couples engaged in a variety pleasures for example, oral sex, mutual masturbation, role-play and dressing up, erotic fantasy, breast play, sexual expression; and use of a range of sex toys, and women produced and directed pornography. Touch, deep kissing and stimulation to orgasm, enhanced excitement and bodily pleasure in experimental sexual intimacy had brought relational closeness in the couple relationship.

The embodied resistance and agency of the women generated change, specifically that of heightened arousal, pleasure and embodiment, eroticism, choice and awareness of choice, notwithstanding the material existence of vulvodynia. The women's lived experiences resonate with the theories of Irigaray (1985a) ; Grotsz (1994); Young (2005): Ahmed (2006) and Zeiler (2013) about women taking full possession of their own body subjectivity, sexual desire and pleasures. Young reminds us that," the woman can derive the deepest sexual pleasure from touch and her breasts; a greater pleasure than a man can provide through penetrative sex" (2005, p.82).

From this study it seems a more stable harmonious relationship with positive communication and empathic partner responses concurrently enables sexual adjustment, which compares with the studies of Rosen et al. (2016) and Rancourt et al. (2016). Furthermore, all women in this study disclosed experiences that show that attitude of their partner is central to her experience of vulvodynia as a woman and as a sexual partner. This compares with the research of Witting et al. (2008), which identified, it matters how secure a woman feels in a relationship. This throws light on the meanings of relational and sexual adjustment to vulvodynia in heterosexual couple relationship. It specifically exposes the tight weave between gender, sexuality and bodily practices and the necessity for relational and sexual adjustment to vulvodynia through epistemological curiosity, embodied resistance, and agency to emancipate the imprisoned frame of body and mind from the powerful regulatory practices of heterosexuality. Moreover, this emancipation 'beyond the lines' of heterosexuality means a technology of freedom towards experimental sexual pleasures, beyond the level genitality, and the confines of the heterosexual genital relation (Irigaray,1985a; 1985b; Butler, 1997; Ahmed, 2006).

8.5 Research Question

Ultimately, this discussion aims to evaluate whether the study has answered the research question and underpinning areas under exploration; and to posit imperatives to transform clinical practice. This study answered the research question and underpinning areas explored using an interpretative phenomenological analysis (IPA) method; thus making a unique contribution to knowledge, reducing the gap in research relating to relational and sexual adjustment in couples with vulvodynia, and posits a new paradigm to expand current clinical practice.

The study reveals meanings and interpretations of a certain kind, which cause, vulvodynia to have a sustained and significant adverse relational and sexual impact on both partners of the couple living with vulvodynia. The data and interpretative analysis suggests couples are caught up in an imprisoning frame of gender and hetero-normativity in body and mind, which is defended by both women and men. Moreover, the analysis highlights precarious gendered identity, passionate attachment, subjugation and erotic fatality, which are concealing a resistance to women and men's

own heterosexuality that limit and narrow adjustment, instead of radicalising choices and broadening horizons. The study illuminates, particularly for women, the constraints, which impede, the women's agentic sexual subjectivity (through the lived body), and also their capacity for a liberating form of resistance, which enables a re-negotiation in the adjustment to vulvodynia with their couple partner. Further, the study importantly identifies areas for transforming current clinical practice, as follows.

8.6 Clinical and System Imperatives

This study invites healthcare professionals and psychosexual therapists to move beyond the diagnosis and treatment of vulvodynia solely at the level of genitality, and instead to work with couples to undo the forces of erotic fatality, to develop a relation with their own desires that distances themselves from the constraining and narrow lines of heterosexuality to a new bodily intensity of pleasures and sexual practices (Irigaray,1985a). There is a singular view of pleasure in western culture and this needs unsettling and opening out to enjoyment of sex without vulval pain.

8.6.1 Conceivably, the first clinical imperative for healthcare professionals and psychosexual therapists is, to loosen gender and sexuality so women with vulvodynia and their partners, can be freed from the constraints of gender and hetero-normativity that is repeated and fortified in its performance (Butler, 1990; 1997). Stimulating epistemologic curiosity in women about their lived body is essential, using questioning like: 'How difficult is your body to live with?' From there, exploring the body she wants, opening up a space for defences and meanings of normative heterosex, gendered expectations, sexualities, desires and pleasures; to find new meanings, altering perspectives and redefining sex, sexuality, pleasures and sexual practices (Irigaray, 1985a). Putting her resistance to work, by supporting her to make the changes she wants, to begin to move beyond the normative lines of heterosexuality as described by Ahmed (2006) and to start to explore sensual touch and the sexual in a completely different way. Breaking away from the loss and shame, syncing her body and mind and, loosening the repetition, thoughts and beliefs, exploring fantasy, pleasures and her own body. Importantly, the clinical imperative is also, for women and men to be jointly encouraged and enabled to open up their issues and, their selves, to face vulvodynia together in the couple relationship.

What has become apparent from the participants in couple relationship is the substantial difference between reaching the state of relational and sexual adjustment versus barely coping with relational breakdown. The findings show that we become, in no small part, from the materiality of our bodies, which constrain or enable the discourses in which we are able to participate, as well as constraining or enabling our participation in the western socio-cultural society we inhabit. Whether that participation when living with vulvodynia is a form of pleasure or a form of psychological suffering or pain depends, in turn, on the tight weave between gender, sexuality and bodily practices and the body which we live in, with and through in the social and, agentic psychic capacity and embodied resistance to adjust individually and in relation with the other.

This study finds a solution to adjustment in couples living with vulvodynia that involves curiosity, women's psychic resistance, agency and positionality to change their understanding and experiences of their own bodies and pleasures beyond the lines of normative hetero-sex. Holland et al. (1994, pp.61-62) comment the possibility for women to negotiate sexual relationships with men that destabilise the gender hierarchy will only exist when " women embody their own desires…. are informed about their bodies… know the possibilities of desires and passions and recognise what these feel like, and are able to value them". In Foucault's terms, this involves activating the female body as a site of resistance rather than maintaining it simply as a target of power. The lived experience of embodiment of an alternative, more active female sexuality can therefore only occur simultaneously with a concomitant shift within male heterosexuality, resulting from a radical destabilisation of those social processes, which privilege the so-called male sex drive and its associated imperatives.

Couples in this study, as a consequence of vulvodynia impacting their lives have been forced to disrupt their expectations and sometimes their practices, in the sphere of the sexual. In Irigaray's terms radical adjustment to vulvodynia only occurs, when a more active female sexuality and an autonomous female, and when transformations are also actively sought and affirmed by women; only when men themselves are willing and desirous of making positive and expansive changes to their own sexual horizons that they will be able to meet women half way in the transformation of sexual bodily pleasure (1985a). Grosz (1994, p.201) asserts that for men, this means a radical

transformation in the kinds of sexual practices they engage in and an even more difficult transformation in the structure of desire whereby they are not weakened as men, and do not see themselves as feminised, in their willingness to take on a passive position; to explore the rest of their bodies, as well as women's, taking on pleasure of a different order; but are able to reclaim, reuse, re-intensify, body parts, erotic zones and functions that have been phallicly disinvested. In sum, both women and men in couple relationships attempting to adjust to vulvodynia should be encouraged to adopt a collaborative point of view of establishing an experimental desire- a desire to experiment, change, and transform ones sexual behaviours and practices.

8.6.2 The second clinical imperative is, for healthcare professionals and psychosexual therapists, to adopt alternative approaches and interventions in their clinical practice that go beyond not only diagnosis and treatment of vulvodynia, but also go beyond gender and the level of genitality, so to expand sensual and sexual desires and pleasures, which are not confined to the heterosexual genital relation.

8.6.3 The third clinical imperative is, for healthcare professionals and psychosexual therapists to resist being tethered to the espoused oedipilisation of sexuality, which inevitably privileges the genital tie. Clinically it is helpful to turn towards dreams, expressions of symptoms, slips in language as revealing unconscious desire, which is not confined to the heterosexual genital relation, and getting really interested at the moment in which identity as woman or man or as heterosexual begins to break down.

8.6.4 The fourth clinical imperative is, for healthcare professionals and psychosexual therapists, to adopt a feminist phenomenology position in their clinical practice, working with mind and body descriptions expressed by couples with vulvodynia. Utilising feminist phenomenological analytical concepts to open up a situated understanding about the representation of sexual pain. More importantly, working with and getting under psychic defences to open up genders; sexualities, desires and bodily sexual practises, to avoid neglecting the specificity of the sexual bodily being in clinical practice.

Bringing feminist phenomenology into clinical practice when working with couples living with vulvodynia is the application of phenomenological inquiry to everyday life

concerns “ to contribute to more thoughtful practice”, (van Manen, 2001, p.458). Inquiry into the topic of individual and couple, their relational and sexual adjustment increases our understanding of the experiential life of couples struggling with vulvodynia, what might this experience be like for them and what attentively we may offer to help. Use of a feminist phenomenological approach, key concepts and hermeneutic circles of understanding may be a helpful tool for analysis when clinically assessing couples with vulvodynia and encouraging a collaborative point of view of establishing an experimental desire- a desire to experiment, change, and transform sexual behaviours and practices. The aim for healthcare professionals and psychosexual therapists, working with couples with vulvodynia is, to go beyond gender and the level of genitality to pleasures and practices, which are not confined to the heterosexual genital relation.

8.6.5 A fifth clinical imperative is, that clinical teaching and education about the diagnosis, treatment and management of vulvodynia should be broadened to raise awareness that vulval pain associated with vulvodynia is primarily caused in the most intimate act of penetrative sex. More critically, for clinical teaching and education to extend understanding that penile- vaginal penetration in heterosexual relation is socio-culturally produced, and that gendered power relations can operate. Treatment goals should not privilege the achievement of penetrative sex; instead loosen up the centrality of penetrative sex, the very thing that cause women pain in attempted, and actual sex with a view to opening up discussion alternative sexual practices from the very beginning.

8.6.5 A system imperative involves the fostering of working in an inter- and multi-disciplinary way with integrated treatment resources as indicated by Sheppard et al. (2008); Bink and Meana (2009); Eppsteiner et al. (2014). This should include the availability of short-term psychological and relational interventions and more long-term analytical psychotherapy as part of a collaborative treatment pathway. Individuals and couples seeing more than three clinicians for treatment at any one time should be case managed and regularly reviewed by the multidisciplinary team. Where appropriate to do so, a woman with vulvodynia and her couple partner should be invited to attend clinic appointments together.

In sum, the meaning gained from understanding relational and sexual adjustment in couples with vulvodynia in this study, taking account of the re-negotiation of couple sexual practices: sexualities, desires and sexual pleasures is, critically one of epistemological curiosity, agentic autonomous women and embodied resistance; and men meeting women half way in shared meanings, understandings and joint endeavours in expansive changes 'beyond the lines' of heterosexuality to fend off the forces of erotic fatality in the couple relationship. Healthcare professionals and psychosexual therapists have a significant role to play in transforming current clinical practice in the diagnosis, treatment and management of vulvodynia for women and their partners to navigate adjustment with possibilities and options.

8.7 Conclusion

This study answered the research question and underpinning areas using an interpretative phenomenological analysis (IPA) method and a feminist phenomenology episteme, key concepts and a model of hermeneutic circles thus making a unique contribution to knowledge, reducing the gap in research relating to relational and sexual adjustment in couples with vulvodynia. This study also addresses the implications for transforming current clinical practice by identifying clinical and system imperatives.

In a western culture where (hetero) sexuality is synonymous with 'self identity', resolution of the impact of vulvodynia becomes, therefore, of urgent concern. For the woman and man who experience themselves as failed sexual partners, the restoration of her and his solidity and stability corrects negative self evaluation, re-positioning them in their proper embodied place as an identifiable sexual woman and sexual man. For some couples, adjustment to vulvodynia may improve over time with the gaining of new perspectives, a loosening of gender, and embodied resistance, with a broader definition of heterosexuality combined with options in their sex life to be experimental, with collaborative choice to refrain from penile- vaginal penetrative sex.

In terms of experimentation, two couples in the study said they became able to explore a sex life without penetrative sex discovering together the different versions of

sexual pleasure and the closeness of other intimate interactions, namely the benefit of phenomenological touch (Bernet, 2013). The couple context illustrates how embodiment is shared and particular and adjustment to vulvodynia is to transcend a culturally determined meaning of penile-vaginal penetration with the closer connectedness for a more immediate body-to-body connection in the couple relationship. This reveals that life with vulvodynia in couple relationship does not have to be more negatively experienced than a life without.

Chapter 9. Clinical Implications

9.1 Contribution of Healthcare Professionals and Psychosexual Therapists

Healthcare professionals and psychosexual therapists meeting couples newly diagnosed with vulvodynia can contribute by considering the following;

Vulvodynia affects the relational and sexual dynamic in couple relationships, even for those considering themselves in a secure passionate bond. There is a strong argument for healthcare professionals and psychosexual therapists to work with both partners in couples; or individually, or concurrently if determined by assessment.

Encourage the couple to use the therapy space to address both partners' feelings of anxiety, shame and a sense of brokenness. The acknowledgement of the couple situatedness, and giving hope is important.

Work with the couple to stabilise dysregulated emotions, ameliorate and adjust relational dynamics and communications, specifically sexual communication and pain. Introduce approaches to assist with interpersonal processes, coping behaviours and emotional intimacy.

Provide anatomical and psychosexual education about vulvodynia to both partners so they develop a joint understanding about the condition.

Healthcare professionals and psychosexual therapists could consider the couple's state of readiness to acceptance, change and adjustment. Encourage an initial stage of intimacy with kisses and giving, and receiving touch. Tune into anticipation of, or fear of actual pain, and desensitise.

Vulvodynia impacts on actual sexual practices in ways, which limit the likelihood of vaginal penetration. Healthcare professionals and psychosexual therapists could explore with couples the meaning and importance of vaginal penetration. Healthcare professionals and psychosexual therapists could help couples to think about what they

would like or dislike in their sexual interactions, encourage experimentation and explore a language of sexual expression.

Expand the couple's repertoire for collaborative and experimental broadening of desires, pleasures and sexual practices by getting under their defences.

For healthcare professionals and psychosexual therapists meeting a couple under considerable stress, distress and displaying vulnerability, careful consideration needs to be taken about any mental health needs and being prepared to refer to services offering support, for example couple and specialist psychosexual therapy (genital pain conditions).

Healthcare professionals and psychosexual therapists should be aware that negative and destructive relational dynamics are a risk factor in couples with vulvodynia, consequentially an awareness of vulnerable adult protocols and domestic violence local resources are useful for signposting individuals as appropriate.

Healthcare professionals and psychosexual therapists are encouraged to access continuous practice development (CPD) on working with erotic transferences in the clinical setting.

9.2 Bringing Feminist Phenomenology into Clinical Practice.

Prevailing scientific approaches and clinical models for sexual pain problems have totalizing tendencies, and arguably neglect attention to the specificities of conditions, which collectively fall under the diagnostic umbrella of Genito- Pelvic Pain/Penetration Disorder (GPPPD). Vulvodynia, in particular with its unique pain presentation associated with the socially constructed sexual act of vaginal penetration can be neglected with devastating consequences for women, and their partners.

Healthcare professionals and psychosexual therapists are invited to embrace feminist phenomenology theories, method and key analytical concepts in clinical practice (Irigaray, 1985a; 1985b; Young, 2005; Ahmed, 2006; de Beauvoir, 2011; Zeiler, 2013).

To focus on embodied, situated meaning making and everyday sexual practices with women with vulvodynia, and their partners to, bring into awareness, the location of painful sex is in socio-culturally produced penetrative hetero-sex. Further to broaden understanding, and open up possibilities through the practice of reciprocity, in the couple sexual relationship, to alternative pain-free sexual pleasures and activities, as part of a jointly negotiated adjustment to vulvodynia.

Chapter 10.

Limitations, Strengths and Future Study

A limitation of the current study is that the sample is homogeneous given the participants were treatment-seeking couples with vulvodynia. A further limitation was the sample was entirely heterosexual in sexual orientation, thus it lacked diversity of genders and sexualities. This limits findings, as well as those of most studies, to this particular of all those in a population suffering from the problem. The sample was more heterogeneous in other aspects as well; for example education level and place of residence were quite similar. It is probable that a study with similar design among heterosexual couples seeking help for vulvodynia in a similar cultural context would yield similar results. A further limitation was the recruitment difficulty associated with men declining to participate and availability of same sex couples. However, Interpretive phenomenological analysis is a very suitable research method for inquiry with small samples.

From a reflexive researcher perspective and proactively learning from the limitations encountered in this research study namely (1) men declining to participate in the study; and (2) lack of same sex couples, there are improvements to the study design and method that can be made in similar circumstances going forward. For example, consulting organisations with expertise in engaging with hard to reach/ declining populations to seek examples of good practice to utilise. Another example is, to develop targeted information in a variety of forms, specifically for potential participants of differing genders, sexualities, race, ethnicity and class to stimulate their interest and encourage their participation in future couple/partner studies about vulvodynia.

A strength of this study is, that it suggests women and men's sense of gender and sexuality, and the importance they attach to penile- vaginal penetration is something that mediates between their experience of vulvodynia and self-perceived 'closeness' in the couple relationship between self and other; and consequently the trajectory of adjustment for couples. A second strength is, the study's application of feminist phenomenology theories, method, the use of key analytical concepts and interpretations with hermeneutic circles of understanding for application to clinical

practice for example, women's embodied resistance, as a critical tipping point towards adjustment within a supportive relationship (Irigaray, 1985a; 1985b; Young, 2005; Ahmed, 2006; de Beauvoir, 2011; and Zeiler, 2013).

A further strength of this study is the use of interpretative phenomenological analysis (IPA) qualitative methodology and a feminist phenomenology episteme for application to the couple context. This study furthers psychological understandings of vulvodynia in the couple relationship, and for incorporating into clinical practice. The existing research into vulvodynia is predominantly quantitative, and interpretation of the findings is restricted to the methodological limitations, for example lack of control groups, or vague inclusion/exclusion criteria. Additionally, the existing studies have been largely atheoretical, not drawing on the large body of psychological and philosophical literature that has been developed. Given that sex is an interactive activity, influenced by history, socio-cultural norms beliefs and expectations, it seems that to study vulvodynia that is so intrinsically linked with problematic sex would need a level of sophistication that has thus far been lacking. The results of existing couple research endeavours are of limited value when trying to further psychological understandings of this condition and for incorporating into clinical practice.
Based on the findings of this study, further research is recommended for studies with samples including a diversity of genders, sexualities and women of colour, and their partners living with vulvodynia in the couple relationship. Consideration should also be given to studies with couples with vulvodynia, about their adjustment accounting for the intersectionality of race, ethnicity, gender, sexuality, and class.

I have discovered from this study that IPA is a creative and flexible research methodology. As a reflexive researcher I shall, when using IPA in future research studies, endeavour to incorporate more creative approaches into the research design. For example with data collection, utilising discussion groups/ workshops/on-line interviews.

Finally consideration should be given to (1) a study examining the application and utility of the feminist phenomenology method and concepts for all conditions that fall under the DSM 5, diagnostic umbrella of the Genito-Pelvic Pain/Penetration Disorder (GPPPD). (2) a follow up study with the couples involved in this current study, to follow

their journey of adjustment (hopefully) having embraced insights and applied such findings this study has identified about radically transforming their sexual practices and pleasures in the couple sexual relationship and finally (3) a study to evaluate the prevalence of vulvodynia in the United Kingdom (UK) and the design and effectiveness of service delivery models operating for the diagnosis, treatment and management of vulvodynia (and subset conditions).

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Appendix 1.

Vulvodynia and Treatment

In 2013, a new diagnostic category of sexual dysfunction was established in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), known as Genito-Pelvic Pain/Penetration Disorder (GPPPD). This disorder encompasses two previously separate disorders, dyspareunia and vaginismus, into one single diagnostic category defined according to the DSM-5 by persistent or recurrent difficulties in the following criteria:

• Vaginal penetration during intercourse;

• Marked vulvovaginal or pelvic pain during vaginal intercourse or penetration attempts;

• Marked fear or anxiety about vulvovaginal or pelvic pain in anticipation of, during, or as a result of vaginal penetration; and

• Marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration.

Any one of the above criteria must be met for a diagnosis of GPPPD, with at least six months duration and the presence of clinically significant distress. The condition may be lifelong (since the individual became sexually active) or acquired, and is classified as mild, moderate, or severe depending on the extent of functional impairment. While persons with GPPPD may have a broad range of clinical presentation, the defining features of the condition is pain, or fear of pain upon sexual genital contact, or vaginal penetration. Penetration may refer to entry of a penis but it can also refer to any other object, making insertion of tampon or medical examination difficult, if not impossible.

Vulvodynia may be primary or secondary in onset, generalised or localised to specific areas, and provoked by contact, or unprovoked (i.e., spontaneous). There are two main subtypes of vulvodynia : provoked vulvodynia , characterised by localised provoked pain in the introitus; and generalised vulvodynia characterised by unprovoked, diffuse burning pain throughout the whole vulva.

A diagnosis of vulvodynia can be made by a comprehensive medical assessment of clinical presentation and a positive Q-tip test. The Q- tip test involves a systematic evaluation clockwise, starting at the clitoris and continuing on the inner side of the labia minora, vestibule and hymenal ring. A □positive Q-tip test is confirmed if pressure triggers pain.

The aim of treatment is two-fold:(1) to reduce sexual and genital pain, and (2) to restore or improve sexual function. Treatments may include: systemic and or topical medication, skin care, biofeedback and physiotherapy (pelvic floor), botulinum toxin injections, acupuncture, body orientated therapy, clinical hypnosis, cognitive behavioural therapy (CBT), psychosexual therapy; vestibulectomy.

Appendix 2.

Participation Information Sheet

Study Title: The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia: An Interpretative Phenomenological Study.

Researcher- Lesley Boswell

This study is the final part of a Doctorate in Clinical Research at the University of Exeter.

Introduction

Thank you for your interest in participating in the above entitled research study. The purpose of this Participant Information Sheet is to give information about the aims of the research study, the nature of your involvement as a participant, your rights and any potential risks, harms or benefits.

Aim of the Research Study

This research study aims to explore the subjective experience of individuals in a couple with vulvodynia to gain in-depth understanding of their experience of and meaning given to relational and sexual adjustment in coping with sexual pain in the intimate couple relationship.

Possible Benefits of You Taking Part

There are no direct personal benefits in taking part in the study. It is hoped that this study may make a positive contribution to filling the gap in the literature by gaining a better understanding of the couple's experience with vulvodynia, thereby enabling other couples with vulvodynia to cope better with adapting and adjusting to their life situation and unique intimate relationship.

Your Involvement and Rights

We are seeking to invite up to 10 couples diagnosed with vulvodynia into the research study. Eligibility to join the study includes couples with vulvodynia with a reported experience of sexual pain for a minimum of six months. Couples will have been in a committed heterosexual or lesbian relationship for one to ten years and currently co-habiting. Exclusions include couples who are currently pregnant or planning a pregnancy. Couples who have a diagnosis of a major medical condition and/or major mental illness. For the purposes of this study a major mental illness includes diagnoses, which typically involve psychosis, for example schizophrenia for which active treatment is required.

The partners of each couple eligible and consented to join the research study will be individually invited to participate in a 60-minute semi structured open interview with a researcher on the main Royal Cornwall Hospital site. This location has been selected to ensure your privacy, comfort and confidentiality.

Individuals participating in the research will not be asked at any time to have a physical examination, undergo diagnostic tests or undertake any exercises. The 60-minute interview will consist of open questions to understand the lived experience of relational and sexual adjustment with vulvodynia.

The research is completely voluntary**;** participants are at liberty to withdraw from the study at any time without reason, prejudice or negative consequences. To withdraw inform the researcher using the contact details given below and your collected data will be withdrawn from the study. Non-participation will not affect an individual's rights/access to other NHS services and treatment.

You will reimbursed for your reasonable travel expenses of £ 20 per person (£40 per couple) for attending for consenting and interview.

Confidentiality and Security of Information

Confidentiality is complete in the context of the study except for; confidentiality would be breached if you disclosed information that suggests that you may be vulnerable or at risk of harm.

The researcher will take notes during the interview and to assist with note taking the interviews will also be audio recorded. You have the option to pause, rewind or erase the audio recording. You will be asked to consent to the interview and the interview being audio recorded in advance. To ensure confidentiality your information and audio recordings will be pseudonymised with a unique code and anonymised and will be maintained in a locked cabinet and stored in a secure and locked room on NHS hospital property. Access to the notes and audio recordings will be strictly limited to the researcher and research team only. No identifiable information will be passed to a third party. The information you give will be used solely for the purposes of this research study, academic publication and training of healthcare and therapy professionals. You will not be identifiable in the published research study report, academic publications and educational material.

At the end of the study anonymised research data will be archived for a period of up to five years should any need arise to access the data for verification. The anonymised data will be archived in the University of Exeter institutional repository managed by the Research Data Management Service. Contact: rdm@exeter.ac.uk. After the five years has expired the data

will be responsibly destroyed in accordance with the NHS Trust Retention and Destruction policy.

Due to recent regulatory changes in the way that data is processed (General Data Protection Regulations 2018 and the Data Protection Act 2018) the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is what is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the researcher, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data is controlled and managed for this study then you can also contact the Sponsor Representative, Pam Baxter, Senior Research Governance Officer, whose details are at the end of the information sheet.

Potential Risk or Harm

Steps will be taken with due care and attention to minimise potential risk and harm as is reasonably practicable. Because there exists a residual low risk that insufficient couples may be recruited into the research study, we hope to minimise this risk by offering flexible interviews on Saturdays and evenings, face to face and telephone interviews to participants.

The researcher may have previously seen you as a psychosexual therapist and this will be established during your appointment with your treating clinician, who will act as Gatekeeper for the research study. The treating clinician will only act on you providing your permission to share your contact details with the researcher, to enable the researcher to contact you for consenting and interviewing purposes.

On contacting you the researcher will establish at the outset that participation in the research study will need to be kept separate from any previous treatment provided to you, by the researcher, when in her capacity as a psychosexual therapist. In the event of a clinical matter arising while you are participating in the study, the researcher will remind you of the need to keep the research participation separate to any clinical needs. If you have a clinical concern then the researcher may recommend you seek advice from your General Practitioner (GP), or to return to your treating clinician to obtain an appointment as soon as possible. The reason for this is to separate the role of researcher from that of psychosexual therapist and to keep the ethical integrity between clinical practice and research activities. The researcher will not have access to your healthcare records written by your treating clinician at any time during the research.

Given the intimate nature of the research study it is possible you may become slightly embarrassed or upset while being interviewed. In such circumstances the researcher will be attentive and supportive and may suspend the interview for a short time until you are able to continue. Where appropriate, the researcher may recommend contact with, for example your GP, treating clinician or counselling service.

The Next Step for You

We have provided you with as much information as possible to help you to make an informed decision about taking part or not and your right to withdraw. In addition as a research participant, you also have the right of access, rectification, or erasure of your data and the right to restrict processing. Please let the researcher, know if you have any queries about this or would like more information, the contact details are identified below.

The next step is for you to inform your treating clinician that you want to become involved in the research study. Your treating clinician will record your permission for your contact details to be shared with the researcher who will then make arrangements for you to give consent to become a research participant and be interviewed. Should you decide to consent you will be given a copy of the Participant Information Sheet and a signed consent form to keep.

Thank you for your interest and time in reading this Participation Information Sheet, it is hoped that you will participate in the study. Participants will be notified when the research is published and given an electronic link to the university's open research website to access the final study report. Feedback will be made available to the Expert Patient Group and the final study report will also be made available in the NHS Trust's Vulval Pain Clinic.

Raising any Concerns

If you have any concern or complaint about the study which has not been resolved by the researcher or supervisor you can contact the independent Patient and Family Experience Team (formerly the Patient Advice and Liaison Service (PALS). Your concern or complaint will be treated in confidence, with courtesy and sensitivity. The Patient and Family Experience Team can be contacted by e-mail: rcht.patientexperience@nhs.net or by telephone :01872 252793.

Contact details

Should you require further information, please contact the researcher or the supervisor for the research study identified below.

Researcher: Lesley Boswell, The Hub, Sexual Health Service, Royal Cornwall Hospital, Treliske, Truro, Cornwall TR1 3LJ Telephone: 07582030224. E-mail: lesleyboswell@nhs.net

Supervisor: Dr Ian Frampton, The College of Life and Environmental Sciences, School of Psychology, Exeter University, Perry Road, Exeter. Devon. EX4 4QG.Telephone: 01392 722420

Sponsor Representative: Pam Baxter Senior Research Governance Officer, Research Ethics and Governance Office, University of Exeter, Lafrowda House, St German's Road, Exeter, Devon EX4 6TL. Telephone: 013927 23588

Appendix 3.

Participant Identification Number:

CONSENT FORM

Study Title: **The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia: An Interpretative Phenomenological Study**

I. ……(Print Name) in giving my consent I acknowledge that; *(please initial each box.)*

1. I confirm that I have read the Participant Information Sheet dated 25/02/2019 (version 1.2 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and I am at liberty to withdraw from the study at any time without reason and without my rights being affected by contacting and informing the researcher who will withdraw my collected data from the study. ☐
3. I understand confidentiality is complete in the context of the research study except for; confidentiality would be breached if I disclose information that suggests I may be vulnerable or at risk of harm. ☐
4. I understand that relevant sections of the anonymised data collected during the study, may be looked at by members of the research team, individuals from the University of Exeter and the Royal Cornwall Hospitals NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my anonymised data. ☐
5. I understand that data, including hard and electronic copies of transcripts and audio recordings will anonymised with a unique code and stored in a locked cabinet in a secure locked room on the NHS hospital site and archived for a period of up to five years. ☐
6. I understand that while information gained during the study may be published in academic publications and training materials, I will not be identified and compliance with the General Data Protection Regulations (GDPR) will apply. ☐
6. I understand that I may contact the researcher or supervisor if I require further information about the research study, and that I may contact the Sponsor Representative at the University of Exeter, if I wish to make a complaint relating to my involvement in the research. ☐

7. I agree to take part in the above project

Name of Participant	Date	Signature
Name of researcher taking consent	Date	Signature

When completed: 1 copy for participant and 1 copy for researcher/study file

Contact details

Researcher: Lesley Boswell, Psychosexual Therapist The Hub-Sexual Health Service, Royal Cornwall Hospitals NHS Trust. Treliske, Truro , Cornwall TR1 3LJ. Telephone: 07582030224 E-mail: lesleyboswell@nhs.net

Supervisor: *Dr Ian Frampton, The College of Life and Environmental Sciences, School of Psychology, Exeter University, Perry Road, Exeter EX4 4QS. Telephone :01392 722420*

Sponsor Representative: Pam Baxter, Senior Research Governance Officer, Lafrowda House, University of Exeter, St German's Road, Exeter EX4 6TL. Telephone: 01392 723588

Raising Concerns: The independent Patient and Family Experience Team (formerly the Patient Advice and Liaison Service PALS) Telephone:01872 252793. E-mail: rcht.patientexperience@nhs.net

Appendix 4.

CASP Appraisal Tool

Was there a clear statement of the aims of the research?	Yes	Can't tell	No	Comments
Is a qualitative methodology appropriate?	Yes	Can't tell	No	Comments
Was the research design appropriate to address the aims of the research?	Yes	Can't tell	No	Comments
Was the recruitment strategy appropriate to the aims for the research?	Yes	Can't tell	No	Comments
Was the data collected in a way that addressed the research issue?	Yes	Can't tell	No	Comments
Has the relationship between the researcher and the participants been adequately considered?	Yes	Can't tell	No	Comments
Have ethical issues been taken into consideration?	Yes	Can't tell	No	Comments
Was data analysis sufficient and rigorous?	Yes	Can't tell	No	Comments
Is there a clear statement of findings?	Yes	Can't tell	No	Comments
How valuable is the research?	Yes	Can't tell	No	Comments

Appendix 5.

DRAFT Interview Schedule and Semi-Structured Questions (non validated)

The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia: An Interpretative Phenomenological Study.

Researcher –Lesley Boswell

This interview schedule will be used to guide the interview process for the above entitled research study .Up to 10 couples, 20 participants in total will be invited take part in individual semi –structured interviews.

Each interview of about 60 minutes duration will have three main components (1) the opening; (2) the body; (3) the closing. This is to ensure standardisation and consistency.

The Opening

The opening is an opportunity to make the participant feel welcome, relaxed and to establish a rapport. The researcher's introduction may be as follows-

"Hello I name is Lesley. I am carrying out research into the lived experience of couples with vulvodynia, their coping strategies and relationship and sexual adjustment. As part of the research I am carrying out face-to-face interviews with couple partners. The information given in this interview will be used to inform the research study, which may contribute new insight into how couple's cope with vulvodynia, the preliminary development of couple (sex) therapy, new clinical services and interventions targeting couples with vulvodynia.

Please be assured you will not be named in the report and nothing will be linked back to this interview. Therefore everything you tell me will be anonymised.

In the event of you mentioning something that leads me to believe that you and/or someone else is at risk of serious physical and /or emotional harm, I am required to raise this with my supervisor.

The interview will take up to 60 minutes. Are you still happy to take part in the interview today? You are, of course free to withdraw from the interview at any point you wish to. Just to help me with my notes is it still acceptable to record the interview? This was highlighted in the

consent form. Do you have any questions before we start? If you want to pause at any time let me know.

The Body (please note: further work is required with the Expert Patient Group (vulval pain) on the development of questions as part of the early research activity before concluding this section.)

The start of the body of the interview will involve asking basic demographic type questions, such as age, length time in relationship, employment, children, religion, relationship status, sexuality, how would you describe yourself followed by more open questions (with probing techniques as required by asking participant's to expand further) for example;

1. When did you (your partner) receive a diagnosis of vulvodynia?
2. Can you tell me how you view your present situation?
3. What is the history of your relationship?
4. What attracted you to each other?
5. How would you describe yourself?
6. How would you describe the couple relationship?
7. How would you describe the sexual side of the couple relationship?
8. How do you resolve differences/ difficulties in the couple relationship?
9. How did your parents handled differences/difficulties in their couple relationship?
10. How did you feel when you (your partner) was diagnosed?
11. Can you explain what meaning vulvodynia has for you?
12. Has vulvodynia affected the way you think of yourself as a man/woman?
13. How has vulvodynia affected your sense of self as a woman/man in the couple relationship?
14. Can you describe any impact vulvodynia has had on you, your couple relationship and the intimate sexual part of your relationship?
15. How did this make you feel? (Prompt- as a woman/man/ identity)
16. How would you describe your (Partner's) experience of sexual pain (Prompt: individually and as a couple partner) before diagnosis, after and now?
17. How has this affected you and your partner and in what ways? (Prompt: what happens?)
18. What kind of things can you/can you not talk to your partner about? (Prompt: relationship/sex/pain)

19. What kind of things has your partner talked to you about? (Prompt: relationship/sex/pain)

20. Do you ever wish you could talk to your partner more? (Prompt: now and in the past)

21. Can you be open and honest about your feelings, hopes and expectations with your partner?

22. How do you feel about sex in general with vulvodynia in the couple relationship? (Listen for: frequency,affection, touch ,foreplay, masturbation, orgasm, penetrative sex, pain, rejection, avoidance, fear, low sexual desire)

23. How do you relate to your own sexual desires?

24. How do you maintain sexual closeness with your partner?

25. How has intimacy changed with vulvodynia?

26. How much do you enjoy/avoid affection and intimate touching?

27. How has the couple relationship changed with vulvodynia? (Prompt: motherhood/fatherhood/children/loss if appropriate.

28. What would it take for you to cope well with vulvodynia? (Prompt: explore cope well

29. Moving on to relationship and sexual adjustment, from recollection were there times when you/ you and your partner tried using (any coping strategies or) problem solving approaches before diagnosis to cope with sexual pain experienced?

30. any change in the couple relationship? (prompt : describe the change)

31. and/or change in the sexual intimate part of the relationship? (prompt: describe the change)

32. What did you/ you and your partner try, how and to what effect?

33. Did these (coping strategies or) problem solving approaches change after diagnosis?

34. What did you/ you and your partner try, how and to what effect?

35. How do you feel these (coping strategies and) problem solving approaches may change going forward and in what ways?

36. On reflection what sort of things may have helped you to know earlier about vulvodynia, with regards to the couple relationship and intimate sexual part of your relationship?

35. What type of things do you think you may need going forward?

36. What information, gained from your own experience would you wish to share with other couples with vulvodynia to help them?

37. What are your views on couple (sex) therapy to assist couples to adjust and adapt in coping with vulvodynia and sexual pain?

38. What in your view would constitute a successful therapy/treatment outcome for vulvodynia for you personally? (Prompt -and why?)

39. Finally please complete these two sentences: My lived experience of vulvodynia is…? And

40. The couple lived experience of vulvodynia is…..?

The Closing

To end the interview the researcher will conclude as follows;

" Thank you very much for participating in this research today. Would you like to see the research study once it is published? If yes, I will send you a link to access a copy. Finally, is there anything else you think would be helpful for me to know?

Thank you again and I have appreciated the time you have given today. Offer payment.

Appendix 6. A i

Mrs Lesley Boswell
Psychosexual Therapist and Clinical Researcher
Royal Cornwall Hospitals NHS Trust
The Hub
Royal Cornwall Hospitals NHS Trust
Penventinne Lane, Truro, Cornwall
TR1 3LJ

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

05 November 2018

Dear Mrs Boswell

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia-An Interpretative Phenomenological Study**
IRAS project ID:	**243810**
Protocol number:	**171834**
REC reference:	**18/NW/0677**
Sponsor	**University of Exeter**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Pam Baxter
Tel: 01392723588
Email: p.r.baxter2@exeter.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

IRAS project ID	243810

Your IRAS project ID is **243810**. Please quote this on all correspondence.

Yours sincerely

Andrea Bell
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Pam Baxter – Sponsor contact*
Ms Alison Andrews, Royal Cornwall Hospitals NHS Trust – Lead NHS R&D contact

IRAS project ID	243810

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Confirmation of Scheme Cover (NHS)]	1.0	01 April 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Exeter Insurance]	1.0	21 November 2017
Interview schedules or topic guides for participants [Interview Schedule]	1.0	01 September 2018
IRAS Application Form [IRAS_Form_06092018]		06 September 2018
Letter from sponsor [Sponsor Letter]	1.0	05 September 2018
Other [Response to NW Ethics Committee]		27 October 2018
Participant consent form [Participant Consent Form]	1.1	27 October 2018
Participant information sheet (PIS) [Participant Information Sheet]	1.1	27 October 2018
Research protocol or project proposal [Research Project Plan]	1.0	01 September 2018
Summary CV for Chief Investigator (CI) [Chief Investigator Curriculum Vitae]	1.0	01 September 2018
Summary CV for supervisor (student research) [Curriculum Vitae (Supervisor 1)]	1.0	02 March 2018
Summary CV for supervisor (student research) [Curriculum Vitae (Supervisor 2)]	1.0	18 March 2018

IRAS project ID	243810

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The NHS organisation has confirmed that they do not require a SoA or SoE as they have received all of the information that they require in the pre-HRA application stage.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	There no funds or resources being provided to the participating NHS organisation by the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type. The organisation will undertake the activities as detailed in the IRAS application and protocol.

If this study is subsequently extended to other NHS organisation(s) in England, an amendment should be submitted to the HRA with a Statement of Activities and Schedule of Events for each site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS or on the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net, or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A Local Principal Investigator is required for this type of study, and has been identified at the participating NHS site. GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 6. A – ii

From: hra.amendments@nhs.net <hra.amendments@nhs.net>
Sent: 08 March 2019 09:23
To: lesleyboswell@nhs.net; p.r.baxter2@exeter.ac.uk
Cc: rch-tr.cornwallresearch@nhs.net
Subject: IRAS Project ID 243810. HRA Approval for the Amendment

Dear Mrs Boswell,

IRAS Project ID:	243810
Short Study Title:	Relationship and Sexual Adjustment in Couples with Vulvodynia. V 1.0
Amendment No./Sponsor Ref:	1
Amendment Date:	21 February 2019
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Mrs Alka Bhayani
Amendments Coordinator
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.hra.amendments@nhs.net
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

Appendix 6. B

Health Research Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 02071048234

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 November 2018

Mrs Lesley Boswell
Psychosexual Therapist and Clinical Researcher
Royal Cornwall Hospitals NHS Trust
The Hub
Royal Cornwall Hospitals NHS Trust
Penventinne Lane, Truro, Cornwall
TR1 3LJ

Dear Mrs Boswell

Study title:	**The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia-An Interpretative Phenomenological Study**
REC reference:	**18/NW/0677**
Protocol number:	**171834**
IRAS project ID:	**243810**

Thank you for your letter of 27/10/2018 , 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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk 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 management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will

be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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).

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).

Non-NHS sites

Approved documents

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

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Confirmation of Scheme Cover (NHS)]	1.0	01 April 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Exeter Insurance]	1.0	21 November 2017
Interview schedules or topic guides for participants [Interview Schedule]	1.0	01 September 2018
IRAS Application Form [IRAS_Form_06092018]		06 September 2018
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Summary CV for supervisor (student research) [Curriculum Vitae (Supervisor 1)]	1.0	02 March 2018
Summary CV for supervisor (student research) [Curriculum Vitae (Supervisor 2)]	1.0	18 March 2018

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

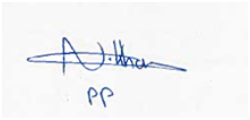
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

18/NW/0677	**Please quote this number on all correspondence**

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

Yours sincerely



On Behalf Of
Professor Carol Haigh
Chair

Email:nrescommittee.northwest-preston@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Appendix 6. C

Health Research Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 02071048234

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

05 March 2019

Lesley Boswell
Psychosexual Therapist & Clinical Researcher
Royal Cornwall Hospital & University of Exeter
Penventinne Lane, Truro,
Cornwall
TR1 3LJ

Dear Mrs Boswell,

Study title:	**The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia-An Interpretative Phenomenological Study**
REC reference:	**18/NW/0677**
Protocol number:	**171834**
Amendment number:	**1**
Amendment date:	**21 February 2019**
IRAS project ID:	**243810**

- The amendment proposes to open the study to potential participants who may be known by the researcher in a clinical capacity who have been identified by the treating clinicians as Gatekeepers following the originally agreed recruitment pathway.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The sub-committee did not raise any ethical issues.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP) [Amendment Form]	1	21 February 2019
Participant consent form [Consent track changes]	1.2	25 February 2019
Participant information sheet (PIS) [PIS Final Amend]	1.2	25 February 2019
Participant information sheet (PIS) [PIS track changes]	1.2	25 February 2019
Research protocol or project proposal [Protocol track changes]	1.1	25 February 2019
Research protocol or project proposal [Protocol final amend]	1.1	25 February 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

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.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/NW/0677:	**Please quote this number on all correspondence**

Yours sincerely

On Behalf Of
Professor Karen Wright
Chair
E-mail: nrescommittee.northwest-preston@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

North West - Preston Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 28 February 2019

Committee Members:

Name	*Profession*	*Present*	*Notes*
Professor Carol Haigh	Professor of Nursing	Yes	
Professor Karen Wright (Chair)	Professor of Nursing	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Nafeesa Khanam	REC Assistant

Appendix 6. D

Response to a Request for an Ethical Opinion about Data.

Received by e-mail on 23rd December 2020

Hello Pam and Lesley,

Thanks for laying out the details in your November letter and thanks for your patience here. There would be no problem, as far as the committee is concerned, if you were to include the data for the couple who've been in the relationship longer than 10 years. It would seem an unnecessary waste to exclude that data in these circumstances.

Kind regards,
Mark

Mark Thompson
Approvals Officer
Health Research Authority
3rd Floor, Barlow House | 4 Minshull Street | Manchester | M1 3DZ
T. 02071048206
E. mark.thompson@hra.nhs.uk
W. www.hra.nhs.uk

Appendix 6. E

Lesley Boswell e-Ethics Application outcome decided (eCLESPsy000858 v2.1)

ethics@exeter.ac.uk <ethics@exeter.ac.uk>
Tue 13/11/2018 21:14
To: Boswell, Lesley <lb537@exeter.ac.uk>
Cc: Frampton, Ian <I.J.Frampton@exeter.ac.uk>

Dear Lesley Boswell,

Application ID: **eCLESPsy000858 v2.1**

Title: **The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia - An Interpretative Phenomenological Study.**

Your e-Ethics application has been reviewed by the CLES Psychology Ethics Committee.

The outcome of the decision is: **Favourable**

Potential Outcomes

Favourable:	The application has been granted ethical approval by the Committee. The application will be flagged as Closed in the system. To view it again, please select the tick box: View completed
Favourable, with conditions:	The application has been granted conditional ethical approval by the Committee providing certain conditions are met, as detailed below. Please resubmit any requested changes for approval before beginning the research.
Provisional:	You have **not** been granted ethical approval. The application needs to be amended in light of the Committee's comments and re-submitted for Ethical review.
Unfavourable:	You have **not** been granted ethical approval. The application has been **rejected** by the Committee. The application needs to be amended in light of the Committee's comments and resubmitted / or you need to complete a new application.

Please view your application here and respond to comments as required. You can download your outcome letter by clicking on the 'PDF' button on your eEthics Dashboard.

If you have any queries please contact the CLES Psychology Ethics Chair:
Nick Moberly n.j.moberly@exeter.ac.uk

Kind regards,
CLES Psychology Ethics Committee

Appendix 6.F

RESEARCH ETHICS AND
GOVERNANCE OFFICE

Lafrowda House
St Germans Road
Exeter
Devon
EX4 6TL

Telephone +44 (0)1392 723588
Web www.exeter.ac.uk

05 September 2018

Project title:	'The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia – An Interpretative Phenomenological Study.'
Sponsor's Reference:	1718/34
IRAS ID:	243810
Chief Investigator:	Lesley Boswell, The Hub, Sexual Health Service, Royal Cornwall Hospital, Treliske, Truro, Cornwall TR1 3LJ

Dear Lesley,

I confirm that the University of Exeter will act as lead sponsor for the above study, undertaking its responsibilities as outlined in Health Research Authority's 'UK policy framework for health and social care research' (v3.3,07/11/2017). The University will ensure that the necessary insurance cover for professional indemnity and public liability are in place before the study commences.

Before participant recruitment commences, the appropriate HRA, ethics and NHS R&D approvals must be in place; please ensure that I have received copies of any correspondence or approval letters.

As Chief Investigator, you are responsible for the management and conduct of the study and are expected to deliver the project in accordance with the University's Code of Good Conduct in Research (http://www.exeter.ac.uk/research/inspiring/about/goodpractice/).

The primary responsibility for the following lies with the Chief Investigator:

- Establishing and maintaining a Master File and Site Files as appropriate throughout the life of the study. Please find a suggested index attached for information.
- Ensuring that the researchers, students or others involved in conducting the project have the necessary training, experience, qualifications, support and supervision to carry out their tasks.
- Ensuring that all amendments to the study have received appropriate ethical review and R&D approvals. In cases where it is unclear if the amendment is minor or substantial, I will be responsible for making the judgement. Please contact me to discuss potential amendments at the earliest opportunity.
- Providing annual, progress or end of project reports to Research Ethics Committees, funders and others as required. Please ensure that I receive copies of all reports.

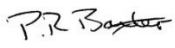
- Reporting adverse events or breaches of protocol or good practice, should they occur (a template adverse event report form is available at http://www.hra.nhs.uk/resources/during-and-after-your-study/progress-and-safety-reporting/ . You must ensure that I am informed of adverse events or breaches as soon as possible after they occur and **always within 24 hours** of the incident. If required, I will take responsibility for ensuring that the event or breach is reported to the NHS REC, funder or other appropriate organisation within 15 days of the incident.
- Appropriate dissemination of the findings

- Satisfactory storage of any personal data and archiving of study material

Please note that announced or unannounced monitoring visits may be conducted either as part of the University's routine research governance audit process or in response to a specific concern or incident. The University reserves the right to withdraw sponsorship and take any action necessary to ensure the safety of participants if it believes that the Chief Investigator is not fulfilling their obligations.

Please do contact me at any time if you have queries or concerns, for additional support or to discuss any aspect of your project.

Yours sincerely,



Pam Baxter
Senior Research Ethics and Governance Officer

Direct line: 01392 72(3588)
Email: p.r.baxter2@exeter.ac.uk

Appendix 6.G

To: BOSWELL, Lesley (ROYAL CORNWALL HOSPITALS NHS TRUST); i.j.frampton@exeter.ac.uk; j.smithson@exeter.ac.uk; p.r.baxter2@exeter.ac.uk
Cc: CornwallResearch (ROYAL CORNWALL HOSPITALS NHS TRUST)
Subject: Vulvodynia Project (IRAS: 243810) - Confirmation of Capacity and Capability at Royal Cornwall Hospitals NHS Trust

Dear Lesley

RE: IRAS: 243810 - Confirmation of Capacity and Capability at Royal Cornwall Hospitals NHS Trust

Short Title	Relationship and Sexual Adjustment in Couples with Vulvodynia.
Full Title	The Lived Experience of Relationship and Sexual Adjustment in Couples with Vulvodynia-An Interpretative Phenomenological Study
MREC No.	18/NW/0677
RCHT R&D No.	2018.RCHT.80
Site confirmed date:	7th November 2018

This email confirms that Royal Cornwall Hospitals NHS Trust has the capacity and capability to deliver the above referenced study. We agree to start this study on a date to be agreed when the sponsor gives the green light to begin.

Please copy the Study Set up Team (rch-tr.CornwallResearch@nhs.net) in to the confirmation of **green light** for our records. If you wish to discuss further, please do not hesitate to contact me.

Kind regards
Alyson

Alyson Andrew
Study Set Up Manager
RD&I Dept, F35, Level 2,
The Knowledge Spa
Royal Cornwall Hospital
Truro
TR1 3HD
Tel: 01872 256423
RD&I Website
RD&I Facebook Page
Research, Development & Innovation Department.
Providing expert assistance for research in Cornwall

Appendix 7

Couple Data: The Undoing of Vulvodynia

Couple 1 (P1 and P2)

“I don’t feel like a complete woman. I don’t feel like I can do what other woman can do. I can’t have babies. I can’t really get married cos of the law about consummating the marriage before its real. I don’t feel that I can have natural thoughts and feelings that other woman have.” “ I feel lesser, affects my whole sense of self” “I used to be panicked about it….it causes a lot of anxiety, but now there’s a lot of sadness around it” “Its affected my whole life, the way I feel about myself, about my relationships, about sex, about my work and social life ” “ I used to think I had to do it (penetrative sex) as it’s necessary to be a real woman. Otherwise I wouldn’t have a real relationship without it. Otherwise other women would see me off”. “I can go down the rabbit hole.” **(P1)**

It (Vulvodynia) sometimes makes me feel like its (penetrative sex) is never going to happen. So I get despondent, a bit down but I come back up again”. **“**I am just dealing with things in a different way. It doesn’t affect the way I am. It’s just something else I’m having to deal with”. **(P2)**

Couple 2. (P3 and P4)

“I can’t have sex because I’m in pain. I don’t feel like a woman, if I’m honest especially when he’s pushing me away. It’s really hard. I can’t do the one thing a woman is meant to do.” “ I still want to so much but…” his libido has gone down, he is depressed. “I am so upset and beginning to question who I am”. **(P3)**

“My libido has dropped. I have depression and anxiety. So over the last year it’s got so bad. I don’t tell her what’s going on for me and she’s not telling me what’s going on for her.” **(P4)**

Couple 3 (P5 and P6)

" As a wife I feel like I'm letting him miss out on having sex with his wife" I feel it has affected me, but I don't let it get too much in my head as it takes me down too far"**. (P5)**

"I struggle with really feeling rejected when she doesn't necessarily want to (have sex) , and isn't really in it." " I see my role as a man in the relationship to support my wife whatever comes our way. The struggle has been the whole rejection thing, it doesn't feel great. But whether it's pain or something else in our life, like we're in it together, does that make sense?" (**P6)**

Couple 4. (P7 and P8)

"I have had problems with not giving him as much as I should, but to be honest, I am what I am". " As much as I love and adore him, and will do as much as I can for him, I have been left before because of it. So if you're going to leave…. you're going to leave. That might sound really hard, but it's like, if that's all you want me for… I am not frightened to be on my own. I came out of it stronger "**. (P7)**

"I worry about hurting and try not to over analyse it or talk about it -make it a big issue because it can make it worse." **(P8)**

Couple 5. (P9 and P10)

" I had pain for years and years. After the baby came along we may have tried sex once or twice for a few years- it was a problem having sex. The job was done after the baby arrived so my energy went into bringing up our child well". **(P9)**

"I have given up. I do my own thing." " As time has past I have become more distant from her. We've drifted apart with our daughter in the middle, keeping us together." **(P10)**

Couple 6. (P11 and P12)

“ I feel rubbish having it (vulvodynia). I feel not normal, I am not right, my body is not right. At the beginning of our relationship I felt it wasn’t fair on me and not fair on him. I think I have said for him to leave me in the past. I was very insecure and worried about being abandoned by him”. “ It affects me as a woman, the shame and embarrassment of not having sexual intercourse. His family don’t know, they ask about us having children, it makes it very hard. We agreed to say, we’re not ready.” **(P11)**

“ I can get annoyed about family asking about having kids. It’s too private to tell them about this. She feels embarrassed, it shouldn’t be like this, she’s different to other people.” “ Vulvodynia and being unable to have pain free sex upsets me” **(P12)**

Couple 7. (P13 and P14)

“ I have lost me, my sense of sexuality and femininity. I feel uncomfortable about things on TV. I feel a different person. I don’t feel like myself anymore. I can sometimes brush it off, put on a happy face at work. It feels like a loss, not like before. If my husband tries to talk with me, I get upset because I think he’s having a go at me. Its like a situation I can’t control.” **(P13)**

“ Its difficult and … I suppose it does cause issues, rows and arguments because for a long while I felt rejected a bit. There were times when she was feeling bad and then there were times when she said she was feeling ok and didn’t want to or try anything, which makes me think it’s me. As much as she says’ she’s scared to try anything it leaves a bit of doubt in your mind that it could be you.” “ It makes me feel self-conscious about myself” “ My main issue is with it, is how she is … affected by something that I can’t do nothing about…. that upsets me. And I don’t want to hurt her.” “ It’s affected me massively. To be honest I feel a lot lower in mood**”. (P14)**

(Sense of the) Partner

Couple 1. (P1 and P2)

"He really struggles with dealing with my anxiety which comes along with the vulvodynia, He'll go quiet on me". He struggles with the vulvodynia but it doesn't stop him saying what his wants and needs are"**. "** He says he thinks I'm saying it's your fault and you're causing me to be ill"**. (P1)**

" I reassure her, reassure her and reassure her. She has good and bad weeks. I sometimes get fed up because you can only reassure someone so much and it gets me down. But at the same time I love her". **(P2)**

Couple 2. (P3 and P4)

"…..his libido has gone down, he is depressed". **(P3)**

"She's a bit shut down about it (vulvodynia). I can tell she doesn't want to talk about it and wants to forget it. I tell her to open up about it because I want to be involved." " Its heart breaking and frustrating that she can't live a normal life". **(P4)**

Couple 3. (P5 and P6)

" He's supportive, affectionate and loving but I know in my head there is something lacking" . He says, " you've just got to imagine how good it will feel eventually. But my mind doesn't work like that. I could just not do it (sex).".". We talk about the sexual pain and he gets it. Except when he is in his man mode, he feels rejected then and thinks I don't find him attractive" " He plays the victim and it's a challenge for me. I ignore him, and then I will tell him, I do find him attractive and I do want it (sex). It takes him a while to come around"**. (P5)**

“ She is anxious about being intimate with me because she might get hurt. So there’s always the fear that she’s going to be in pain during and after we’ve been intimate” “ I’d say she doesn’t ever want to do it , its because she knows its important for our marriage, for both of us.” **(P6)**

Couple 4. (P7 and P8)

“ He’s always been as good as gold. He says, it doesn’t matter we will find other ways. He’s never been unkind, he’s thoughtful and not demanding.” “ I think he worries about hurting me. I think he worries about it because he wants it more than I do, but doesn’t pressure me. But I think it could become a psychological problem for him because he worries he’s hurting me” “ He carries a lot of guilt because he thinks he’s hurting me when he’s meant to be giving pleasure. I tell him, its not your fault, I wanted you to do those things and he replies, how would you feel if you were responsible for giving me pain. I say; it is what it is. He struggles with it. There has to be some acceptance of it, otherwise you would be in a state about it, you’d drive yourself mad”. **(P7)**

“ She is very set in her ways and closed down about it (vulvodynia) so I respect that.” **(P8)**

Couple 5. (P9 and P10)

“ He sometimes raises it (intimacy and sex). Its not an easy conversation to have.” “ He backs off because he’s really a really nice person”. **(P9)**

“ She was afraid to have intercourse, then her sex drive went altogether. And then after that she’s had loads of problems down there. So it’s never happened.” **(P 10)**

Couple 6. (P11 and P12)

“ I would become emotional about the pain. Then he would become stressed and feel bad because he put me in pain. He knew I was just doing it to make him happy and he began to feel guilty about it”. **(P11)**

“She’s normally a very happy person, but this gets her down and gives anxiety. I’m always trying to boost her mood if possible with cups of tea and little jokes“. **(P12)**

Couple 7. (P13 and P14)

“ He’s been good. There are some blokes out there that wouldn’t stick around. Its hard on him because I freeze and panic about sex” “ I worry about my partner, his wellbeing. I have a thing about porn and cheating on me.” **(P13)**

“Its awful…. F**king horrible, she’s a shell of what she was, she’s not the same person”. “I try to be involved as much as I can because it’s a big deal for her. The issues it creates for me aren’t nice or easy but it’s nowhere near like what’s happening for her. I’m not sure how much I understand what’s going on but I see how it affects her. She’s scared of the pain”. **(P14)**

The Relational

Couple 1. (P1 and P2)

“ I’ve had a lot of aggression and violence in relationships because of it (vulvodynia) in the past, because of it I wanted him to know about it.” “When we first met I told him about it and he didn’t believe he could be in a relationship like this (without penetrative sex) because he needs to have sex in a relationship. He was taken a back and just sat there with his hands on his head for a good three to four hours. I gave him the option to leave but he never did so…..its been three years now. I do worry about him leaving sometimes, I tell him and he just says that’s not going to happen and gives me lots of love and hugs ”. **(P1)**

“Difficult in the relationship because it makes her very paranoid. She thinks I can’t get what I want from her. That I’m going to go off with someone else. It makes things very difficult.” **(P2)**

Couple 2. (P3 and P4)

I’ve never been able to have intercourse. Ummm because this was happening before I met him. After two dates I had to tell him what the situation was, otherwise we were going to waste our time here, which was really hard. I thought I was going to scare him off but it didn’t. He’s older than me. He said he’s more ready to settle down and have kids but if we couldn’t, he’d be happy just to love me. Which was lovely but sometimes I think he should just get on with his life, but obviously I don’t want that really”. “Things are strained and sad, but I know we love each other,” Our communication is really quite poor. I find it hard to talk to him about it. I don’t want to make him upset, so I just avoid it and don’t tell him how I feel about it. “ The relationship is…. arguments, less communication, pushing away and troubled” “ We ‘re both nervous to say how we feel. I don’t like to argue with him, he just thinks I want a perfect relationship”. “I am so upset and beginning to question who I am**”. (P3)**

“It’s had an impact on our relationship, fortunately we are still strong as a couple, but the physical side is next to nothing. We get to a certain point but she’s in pain, so it’s really hard. I get nervous about hurting her”**. (P4)**

Couple 3. (P5 and P6)

“I was a virgin when I was married”. “I don’t talk about it to family and friends. Sex is private”**.**“ Vulvodynia is frustrating and dealing with it is frustrating” “It affected how I feel about myself and our couple relationship”. **(P5)**

“ It’s the hardest thing we face. Umm… like yesterday we had an argument, well disagreement about it (penetrative sex and pain). “ **(P6)**

Couple 4. (P7 and P8)

“We’re a team, we talk and we have fun”. **(P7)**

“I’ve known her a long time, its almost like we know what the other is thinking. I can’t imagine anything different really”**. (P8)**

Couple 5. (P9 and P10)

“I think we lost each other. Yes we lost connection as a couple. No, not even touch”. **(P9)**

“My experience is pain and rejection with a relationship that is distant, lonely and separate lives”. **(P10)**

Couple 6. (P11 and P12)

“ We have a good couple relationship, we talk about everything, and we’re open about things”. **(P11)**

“ The couple relationship is really good, strong together, have lots of fun together, good times, really happy , it just seems to work”. **(P 12)**

Couple 7. (P13 and P14)

“Vulvodynia is a huge barrier in the couple relationship”**. (P13)**

“ I am open with her about how I feel, it doesn’t get received well and causes lots of arguments. She’ll put it down to me wanting to be single, even though that’s not the case.” “ She could try and explain what’s going on but no one would see the affect/influence it has on the partner” **(P14)**

The Sexual

Couple 1. (P1 and P2)

" I used to think I had to do it (penetrative sex) as it's necessary to be a real woman. That I wouldn't have a real relationship without it. Otherwise other women would see me off". " The pain is awful, it's like being electrified down there." **(P1)**

"Intercourse is impossible, very painful for her". " I value penetrative sex and it's important to me. I have always been highly sexed, so…its difficult" " She is so sensitive….when I touch her she jumps. It puts me off because I don't want to hurt her" " I don't like to cause her pain. I back off. I don't want to hurt her."' There is difficulty in re-connecting again, it depends because it affects my erections" **(P2)**

Couple 2. (P3 and P4)

" Me and my partner can't have sex. I feel like the intimacy has gone. Its painful if, if we try. The pain affects us, sometimes more so him. It affects foreplay and sex. It doesn't follow a pattern, sometimes its when he touches me and sometimes not, sometimes when we have foreplay and sometimes not". **(P3)**

"She's having a lot of pain, so it's having a massive knock on affect on our sex life. I don't want to cause her pain, so our sex life has taken a back seat over the past couple of years". **(P4)**

Couple 3. (P5 and P6)

" It burns and it's very sore". "I know it's going to hurt and I'm really struggling with my sex drive" " I obviously want to be intimate with him but I obviously just going off sex. So I'm battling with that, and I'm still trying to have intercourse" " He is very patient and fine with foreplay but I know a man would want to have sex with his wife" " So its like something I'm dealing with in my head because it makes me disappointed and not sexy". " I don't always kiss him in case it leads on a bit and he notices it" " I have not been giving affection because I'm avoiding sex because it hurts so. He thinks it feels

great so wants it". " I don't tell him about the pain because I want to please him. So I push through" **(P5)**

" We're still struggling to have sex. She's still getting a lot of pain. Her sex drive is really low as well." " I say … I feel even when we're intimate, you're not really can't really go there". " I'm quite happy to not have penetrative sex. I just want her to enjoy it. My wife doesn't enjoy being intimate with me because of it (vulvodynia)" " I can see the pain in her face and we stop"." I say I feel even when we're intimate, you're not really into it, like being in the moment, you're not really there" " It's (vulvodynia) 100% taken away the spontaneity, It has to be controlled because its painful, she can't really go there." **(P6)**

Couple 4. (P7 and P8)

"It hurts so much, it's almost easier to just not do it. I don't have much of a sex drive; I can take it or leave it. But that's not fair on the other person so we find other ways". " Sometimes I have to stop him thrusting as it feels like lacerations, cut all the way up inside, tears " **(P7)**

"I touched her one day, she jumped out of bed and I was taken a back. I thought what have I done, have I hurt her? I had to adjust to realise that was her norm. It wasn't what I was use it. I was worried about it because it was an extreme reaction to the extent I don't try as of now to touch her in that way. You feel like you're hurting her, its not good". **(P8)**

Couple 5. (P9 and P10)

"I had pain for years and years. After the baby came along we may have tried sex once or twice for a few years- it was a problem having sex and low sexual desire. The job was done after the baby arrived so my energy went into bringing up our child well". " He sometimes raises it (the sexual relationship). It's not an easy conversation to have". **(P9)**

“ We tried once or twice but it hurt her, so we stopped”.“ There is no intimacy in the relationship. I do mention it at times but no, nothing happens.” **(P10)**

Couple 6. (P11 and P12)

“ It’s difficult…..the vaginismus is like hitting a brick wall whereas the vulvodynia is like burning”. “I have a fear of pain too.” “ We are intimate together. It’s better than nothing at all **“. (P11)**

“ Its been going on a long time, we don’t have the experience of regular sexual intercourse like everyone else. We just do everything else.” **(P12)**

Couple 7. (P13 and P14)

“ Vulvodynia is awful, it doesn’t just affect me physically but emotionally too”. “ My libido is so low I don’t really want to do other things. “ “ I worry he might want more. It ‘s a bit like whoa!!” “I can’t talk about sex because I get defensive about not wanting sex”. **(P13)**

“I have said that there’s stuff we can do, but you don’t want to and for me that’s really hard. I’ve said I don’t think you realise how this is affecting me”. **(P14)**

Relational and Sexual Adjustment

Couple 1. (P1 and P2)

“ Its best to talk about the things you can do, rather than the things you can’t do. That’s definitely worked for me”. “Its been so difficult facing it (Vuvodynia) and being vulnerable….it was necessary to face it to feel stronger” …”face the demon, so to speak”.“ The diagnosis allowed me to think its not my fault, it took the blame away from me” “ I have had to learn to stay calm and talk.”

” Sexually we’ve learned lot’s, lot’s of ways to give each other pleasure so in a way, it’s been a positive thing”. “We’re constantly trying new things and pushing the boundaries.. it’s kind of made us stronger together” “ I did a lot of researching about what I had to do, I felt a bit like a science project back the.
The pelvic floor drop exercises helped, also the new vibrator and clinical hypnosis. Finding ways off shutting off the pain. Not associating with the pain so much, just going with what’s pleasurable and enjoy that. Also to stop sometimes and do something different, push through it in different ways.” “ My body was a bit scared of my mind as I always want to do more, so I have had to teach my mind to gentalise a bit and work with my body” “ Everything is about trying and not punishing yourself” “ He knows I need to be in control to be safe. When you have vulvodynia, you can want to push past the pain just to please the other person and you can get hurt over and over again. Your partner has to work through you, so you can learn to trust them and for your mind and body to work together, otherwise it gets confused.” “ Talking together and opening up to your partner, making time to touch to maintain connection, expanding on things that we find pleasurable”. Yoga stretches, meditation, clinical hypnotherapy, being calm, walking to get positive energy and taking medication all massively help”.“ You may not be able to fix it (no penetrative sex) in the conventional sense but you can face it together”. “ You’re not alone in facing this, don’t give up on it, find the richness in your relationship and not the undoing of vulvodynia”. **(P1)**

“It’s about trying different things and finding out what she likes, and keep doing it”. “Its about not giving up on everything. We do everything that a normal loving couple would do except penetrative sex”. “ We chat a lot about what happened in previous weeks that has been difficult. Its really good because it helps us to connect more” “ Clinical hypnotherapy was good and physio, it needs multiple approaches”. **(P2)**

Couple 2. (P3 and P4)

“Couple therapy”. **(P3)**

“It’s positive in the sense that we have become mentally stronger together but negative in that the physical side has been like a shot in the foot, like being dead in the water”. I don’t want to give up though. “ **(P4)**

Couple 3. (P5 and P6)

“I’m doing the yoga baby pose, and use dilators with lubricant to desensitise the pain”. I am blessed with my husband; if I’m worried he’ll try and get it out of me. Before like my parents I would just bury it. He just gets it out. He’s very patient”. **(P5)**

“ We talk about stuff and deal with our emotions 100%”.” She’s had to learn to communicate well and I’ve learned to communicate more direct with my emotions and be more precise. I don’t think we’d be where we are now without talking.” Vulvodynia makes me feel frustrated that I can’t do anything about it yet in many ways it’s bought us closer together.” **(P6)**

Couple 4. (P7 and P8)

“We find other ways…we do more foreplay, mutual masturbation and stimulate each other in different ways”. **(P7)**

”Penetrative sex isn’t the be all and end all. For me it’s the closeness.”” Vulvodynia is inconvenient but not the end of the world”. **(P8)**

Couple 5. (P9 and P10)

“To be honest I don’t know how to put it (relationship and the sexual) back together again, its been too long, nothing is going to change” “But I am sad”. **(P9)**

(Intimacy)…”yes of course, but its not going to happen sadly”. **(P10)**

Couple 6. (P11 and P12)

“It was about two years before I really opened up to him about it and he began to really get involved. We can talk about anything and everything now, it’s about adapting and understanding each other.” “ Dilator programme to help with the vaginismus and desensitise the pain helped”. **(P11)**

“ It was a decision that we stopped penetrative sex because of the pain but the touching and pleasuring carried on. We experiment. I wait, so not to put pressure on her. It’s taken a long time but its ok”. **(P12)**

Couple 7. (P13 and P14)

“ They can’t cure it, but help me to cope with it (with medication)”. “ So its very difficult”. **(P13)**

“ There are things she’s capable of doing but she’s scared to try them” **(P14)**

Appendix 8

Dissemination Statement

The study will be disseminated by publishing in academic publications and on the University of Exeter ‘Open Research Exeter’ (ORE) website. The findings of the study will be disseminated to the Patient Expert Group (Vulval Pain) by attending a Group meeting or via study newsletter. Participants will be directed to the University of Exeter ‘Open Research Exeter’ (ORE) website for the final study report. The final study report will also be made available in the Vulval Pain Service for healthcare professionals to use as a resource and education.

Table 1. – Data Abstraction Table

Author/s and Year	Title and Source	Sample and Methodology	Geographical Context	Summary of Findings	CASP Rating
Rancourt,K. Rosen,N.O., Bergeron,S,. Nealis, L.J. (2016)	Talking About Sex When Sex is Painful; Dyadic Sexual Communication is Associated with Women's Pain and Couples' Sexual and Psychological Outcomes in Provoked Vestibulodynia Journal : Archives Sexual Behavior	Quantitative method with dyadic design and analytical approach- bivariate correlations N=107 Couples	North America	A study examining sexual communication patterns in couples. It elaborates on the existing models of sexual communication (instrumental and expressive pathways). Findings suggest that integrating sexual communication skills training into provoked vestibulodynia treatment may have the capacity to positively influence multiple domains of couples' adjustment (biological, psychological and sexual). For couples coping with provoked vestibulodynia sexual communication may be one of their most important tools in navigating the stressors associated with the condition and reducing impairment.	Moderate Score: 16

Rosen, N.O, Bois, K., Mayrand, M., Vannier, S., Bergeron, S. (2016).	Observed and Perceived Disclosure and Empathy are Associated with Better Relationship Adjustment and Quality of Life in Couples with Vulvodynia Journal: Archives of Sexual Behavior	Quantitative method with observational and self -reports cross sectional design. N=50 Couples	North America	Study results concluded disclosure and empathic responding may help women maintain their quality of life and help couples maintain their overall relationship adjustment while coping with the challenges vulvodynia poses to their relationship. The findings suggest increasing disclosure and empathic responses might be a valuable target for enhancing the efficacy of couple based interventions for vulvodynia.	Moderate Score: 16
Connor, J., Robinson, B., Weiling, E. (2008).	Vulvar Pain: A Phenomenological Study of Couples in Search for Effective Diagnosis and Treatment. Journal: Family Process	Qualitative method with transcendental Phenomenological design using interviews. N=13 Couples	United States of America	The study focused on couples and identified issues relevant to sexual adjustment in the couple relationship with vulvodynia. The study finding suggested that the treatment approach with couples is to encourage them to broaden definitions about the importance and primacy of vaginal intercourse and to consider alternative strategies that may be less likely to cause vulvar pain.	Weak Score: 10

Sheppard,C., Hallam-Jones,R., Wylie, K. 2008	Why have you both come? Emotional, relationship, sexual and social issues raised by heterosexual couples seeking sex therapy (in women referred to a sexual difficulties clinic with a history of vulval pain. Journal: Sexual and Relationship Therapy	Qualitative method with semi structured interviews and thematic analytical review N= 8 Couples	United Kingdom	The study involved women diagnosed with vulvodynia, the majority having a subset of vulvodynia; and partners. Five themes were identified as experienced by most couples. The concept of emotional distress; issues of failure and loss; a specific damaging effect on the couple relationship; emotional isolation; and feeling uncared for by the medical profession who had “sent them”. The findings of the study indicated the need for inter- and multi-disciplinary approaches with integrated and attached psychological and relational therapies. The areas of loss and couple assessment were specifically identified for consideration, not only a focus on sexual and relational impacts.	Weak Score: 10

Table 2. Cohen Kappa Calculation

DATA

		Rater 1	
		Yes	No
Rater 2	Yes	9	2
	No	0	0

BASIS OF FORMULAIC CALCULATION

		Rater 1	
		Yes	No
Rater 2	Yes	A	B
	No	C	D

We know that **K = $\frac{\textbf{Po – Pe}}{\textbf{1 – Pe}}$**

First calculate Po (relative observed agreement)

$$Po = \frac{A + D}{A+B+C+D}$$

So Po = 9 divided by 11, -so Po **= 0.818**

Next calculate Pe (hypothetical probability of chance agreement)
Pe = PYes + PNo

First calculate P Yes, then P No

$$PYes = \frac{A+B}{A+B+C+D} \text{ multiplied by } \frac{A+C}{A+B+C+D}$$

$$\text{So } PYes = \frac{11}{11} \text{ multiplied by } \frac{9}{11} = 1 \times 0.818 = \textbf{0.818}$$

$$PNo = \frac{C+D}{A+B+C+D} \text{ multiplied by } \frac{B+D}{A+B+C+D}$$

$$\text{So } PNo = \frac{0}{11} \times \frac{2}{11} = 0$$

Pe = PYes + PNo

So **Pe = 0.818 + 0 = 0.818**

So returning to the formula for Kappa: $K = \frac{Po - Pe}{1 - Pe}$

$$K = \frac{0.818 - 0.818}{1 - 0.818} = \frac{0}{0.182} = 0$$

So **K = 0**

When K = 1, perfect agreement exists. When K = 0, agreement is the same as would be expected by chance. When K is less than 0, agreement is weaker than expected (rare).

Limitation

Kappa is an index that considers observed agreement with respect to a baseline agreement. However, researchers must consider carefully whether Kappa's baseline agreement is relevant for the particular research question. Kappa's baseline is frequently described as the agreement due to chance, which is only partially correct. Kappa's baseline agreement is the agreement that would be expected due to random allocation, given the quantities specified by the marginal totals of square contingency table. Thus, Kappa = 0 when the observed allocation is apparently random, regardless of the quantity disagreement as constrained by the marginal totals. However, for many applications, researchers should be more interested in the quantity disagreement in the marginal totals than in the allocation disagreement as described by the additional information on the diagonal of the square contingency table. Thus for many applications, Kappa's baseline is more distracting than enlightening

Table 3. Women Participants' lived experience of Self (Superordinate themes*)

Themes *	Gendered Identity	Relational	Sexual	Burden
Self	Failure as a woman "I have lost me, my sense of sexuality and femininity".P13 "Don't feel like a complete woman".P3 "It affects me as a woman".P13	Confession to Maleness "When we first met I told him about it and he didn't believe he could be in a relationship like this because he needs sex in a relationship". P1 "After two dates I had to tell him what the situation was, otherwise we were going to waste our time here, which was really hard". P3 "…if that's all you want from me".P7	Loss of Sexual desire " I can't talk about sex because I get defensive about not wanting sex." p13 Loss of Kisses and Touch " I don't always kiss him in case it leads on a bit. He notices". P5 "I have not been giving affection because I'm avoiding sex because its hurts so".P5 Pressure of penetrative sex	Burden of Menstruation "I can't wear tampons because of it". P3 "I bleed everyday". " My time of the month pain". "I'm battling with it" Loss of womanhood "Can't do the one thing a woman is meant to do"

	"…affects my whole sense of self". P1 "I'm so upset and beginning to question who I am." P3 "..go down the rabbit hole".P1 *Failure as a sexual partner* "I had a breast enlargement to make me feel better about myself, but I don't feel better about	Concealment " I don't talk about it to family and friends. Sex is private". P5 Lying "It affects me as a woman, the shame and embarrassment of not having sexual intercourse. His family don't know, they ask about us having children, it makes it very hard. We agreed to say, we're not ready". P11 Stigma Rejection Abandonment	"I don't want to do other things, I worry he might want more". P13 "I push through". P5 Disembodiment "I look like a women, I have a woman's body, feminine like a woman but I don't have sex. I am a criminalised woman". P1 " My vagina doesn't work properly". P3	"I can't really get married because of the law about consummating the marriage before its real". P1 Loss of pregnancy and children "…can't have babies". P1 "My friends are settling down and having children. I get the pity looks". P3 Suffering "My unnatural illness".P1 "My body is scared of my mind". P1 " I used to be panicked about it but now there is a lot of sadness around it". P1 "I have to stop him thrusting as it

	myself". P1 " My body won't do what I want it to do". P1 "I'm not right. My body is not right". P11 "I can't have sex like normal women do". P3 " Can't do the one thing a women is meant to do" P3	Avoidance Insecure "We've lost *each* other as a couple" P9 Arguments " I feel the pain between is unbearable". P3 Leaning on		feels like lacerations, cut all the way up inside, tears" P7

Table 4. Women Participants' Lived Experience of their Partner (Superordinate themes*)

Themes *	Gendered Identity	Relational	Sexual	Burden
Partner	"When he's in his man mode, he feels rejected then and thinks I don't find him attractive" P5 '" ..he sometimes raises it (sex and intimacy). Its not an easy conversation to have." P9 " …a man would want to have sex with his wife".P5 Maleness	Supportive Thoughtful Affectionate Undemanding Loving Understanding Communicative Argumentative "I feel anxious. Our communication is really quite poor to be honest. We're both guilty and it just builds up and it explodes sometimes". P3	Loss of erections "His libido has gone down and he is depressed". P3 Retarded ejaculation Loss of kissing Loss of touch " I don't feel like a woman, especially when he's pushing me away." P3 "I found he had been looking at porn, where I had never had that worry before". P13	"He fears hurting me".P7 "He carries a lot of guilt". P7 " He struggles with it".P7 "He feels responsible for giving me pain". P7 Depression P3 "He says -If you're suffering then I'm suffering alongside you" P1

		“I get upset because I think he’s having a go at me”. P13 “ I have told him I feel I’m going to him to make up more than he does”. P3		

Table 5. Women Participants' Lived Experience of Relational and Sexual Adjustment (Superordinate themes*)

Themes*	Relational	Sexual
Relational and Sexual Adjustment	Communication "Its best to talk about the things you can do, rather than those you can't do". P1 'I've had to learn to stay calm and talk". P1 Acceptance "There has to be some acceptance of it… otherwise you'd drive yourself mad". P7 Trust " Your partner has to work through you, so you can learn to trust them".P1 Connection	New Ways "A new vibrator".P1 "Everything is about trying…experimental". P11 **"** We find other ways, we do more foreplay, mutual masturbation and stimulate each other in different ways". P7 Pleasure "Sexually we've learned lots of ways to give each other pleasure, so in a way, its been a positive thing". P1

	“Talking together and opening up to your partner, making time to touch to maintain connection, expanding on things that we find pleasurable”. P1 “….finding the richness in your relationship and not the undoing of vulvodynia”. P1 “It’s about time, adapting and understanding each other”. P11	

Table 6. Men participants' Lived Experience of Self (Superordinate theme*)

Themes *	Gendered Identity	Relational	Sexual	Burden
Self	Unstable Maleness "It makes me self conscious about myself" P14 I value penetrative sex and it's important to me. I have always been highly sexed, so..its difficult". P2 "Intercourse is impossible" P2	Joys "The couple relationship is really good, strong together, have lots of fun together, good times, it just seems to work" P12 Hurtful Feelings 'My experience is pain and rejection with a relationship that is distant, lonely, with separate lives".	Loss "I can see the pain in her face and we stop." P6 "I have given up, I do my own thing". P10 "I don't want to cause her pain, so our sex life has taken a back seat over the past couple of years". P4 "As time has past I have become more distant from her". P10 Touch "When I touch her she jumps. It puts me	Weight of expectation "Makes me feel like it's (penetrative sex) never going to happen". P2 "I worry about hurting her. I try not to over analyse it or talk about it- make it a big issue because it can make it worse". P8 Leaning on " I reassure her, reassure her, reassure her. I sometimes get fed up you can only reassure someone so much and it gets me down. But at the same time I love her". P2

	Fear of humiliation ..”like being shot in the foot, dead in the water” P4 “I can get annoyed about family asking about kids. Its too private to tell them about this”. P12.	P10 “It’s the hardest thing we face..umm like yesterday we had an argument , well disagreement about it”. P6 Arguments “ I suppose it does cause issues, rows and arguments because for a long while I felt rejected.” P14 Rejection “I struggle with really feeling rejected.” P6	off. There is difficulty in reconnecting again, it depends because it affects my erections”. P2 “….its sometimes this and sometimes that…”.P8 “I touched her one day, she jumped out of bed. I thought what have I done, Have I hurt her” …”I was worried about it because it was an extreme reaction to the extent I don’t try now to touch her in that way”. P8 The Male Body ‘My libido has dropped”. P4 “It affects my erections”. P2 ‘I couldn’t orgasm and ejaculate because I need to thrust and it caused her pain”	Negative Emotionality Shame Humiliation Depression “It’s affected me massively”. P14 Anxiety “I get despondent, a bit down but I come back up again”. P2 “Vulvodynia and being unable to have pain free sex upsets me”. P12

		“I am open with her about how I feel, it doesn’t get received well and causes lots of arguments”. P14	P12	

Table 7. Men participants' Lived Experience of their Partner (Superordinate Theme *)

Themes*	Gendered Identity	Relational	Sexual	Burden
Partner	"She's a shell of what she was. She's not the same". P14 She's normally a very happy person, but this get's her down and gives anxiety". P12 " She was someone who was very open minded and open to new experiences, it was nice to have	"I tell her to open up about it because I want to be involved". P4 'She's a bit shut down about it (vulvodynia) I can tell she doesn't want to talk about it and wants to forget it". P4 "It makes her feel paranoid, she thinks I'm going to go off with someone else. It makes things really difficult". P2 "She's very set in her ways and closed down about it	" I'd say, she doesn't ever want to do it (penetrative sex)."…"She knows it's (penetrative sex) important for our marriage". P6 "There are things she's capable of doing but she's scared to try them". P14 "Its 100% taken away any spontaneity"…. " My wife doesn't enjoy being intimate with me because of it (vulvodynia)". P6	" …she feels embarrassed, it shouldn't be like this, she's different to other people". P12 " My main issue with it, is how she is ..affected by something I can't do nothing about, that upsets me" P14 'She 's afraid to have intercourse. Its heart breaking and frustrating that she can't live a normal life". P4 "She's scared of the pain". P14

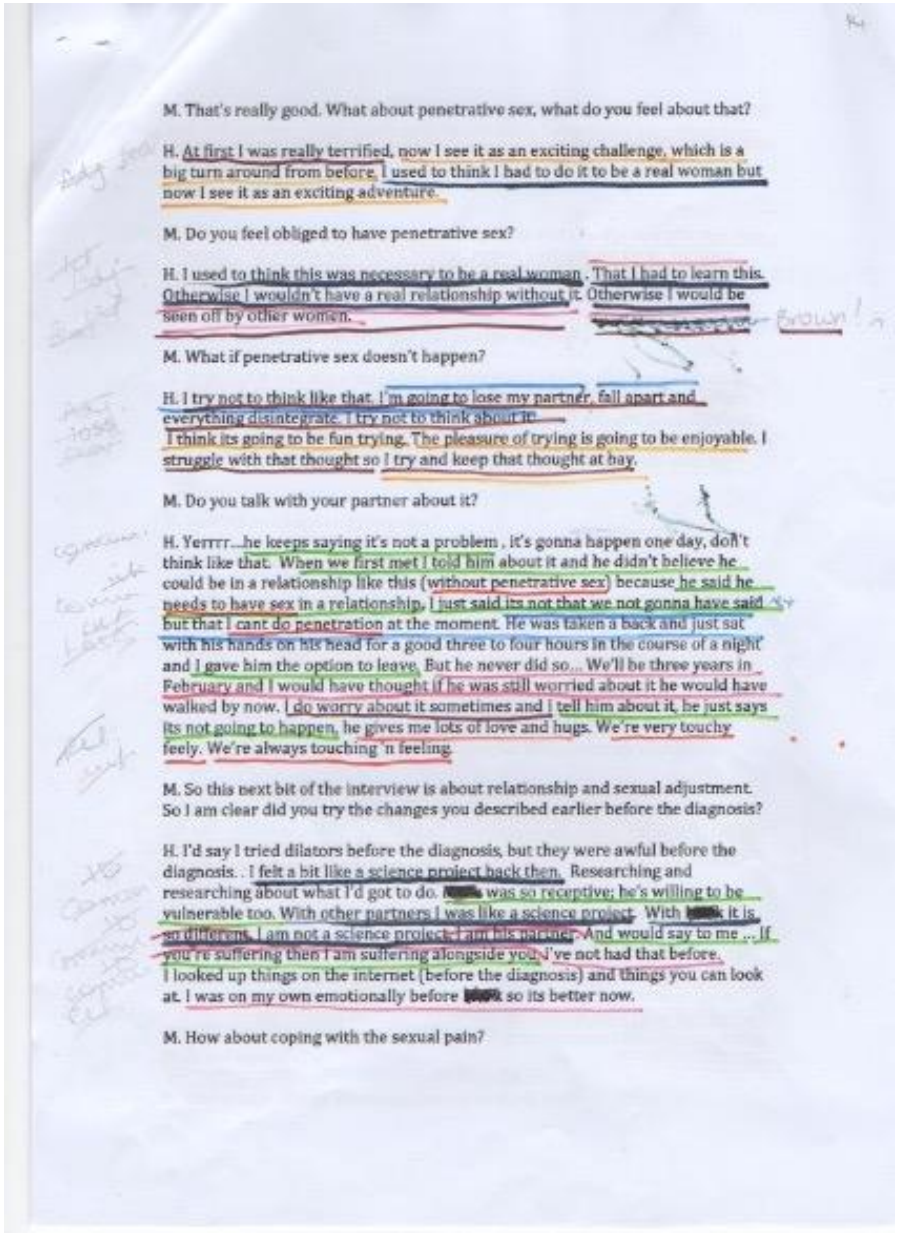
	someone you could trust and do things with". P14	(vulvodynia)." P8 " I'm open with her about how I feel, it doesn't get well received and causes lots of arguments. She'll put it down to me wanting to be single….ummm she'll kick off." P14		

Table 8. Men Participants' Lived Experience of Relational and Sexual Adjustment (Superordinate theme*)

Themes*	Relational	Sexual
Relational and Sexual Adjustment	Bereft " My experience is, its awful, f**king horrible. It's ruined our life, its not there anymore". P14 "We've drifted apart with our 'child' in the middle, keeping us together." P10 Stoicism "…the physical side is like a shot in the foot, like being dead in the water. I don't want to give up though". P4 "Vulvodynia is inconvenient but not the end of the world". P8	Experimentation "We don't have the experience of regular sexual intercourse like everyone else. We just do everything else". P12 "We do everything that a normal loving couple would do except penetrative sex." P2 "It was a decision that we stopped penetrative sex because of the pain but the touching and pleasuring carried on. We experiment". P12 Connection "Penetrative sex isn't the be all and end all. For me it's the closeness". P8

	“I see my role as a man in the relationship to support my wife whatever comes our way”. P6 “It’s hard but it works”. P2 “The couple relationship is really good, strong together, have lots of fun together, good times, it just seems to work”. P12	“ Vulvodynia makes me feel frustrated that I can’t do anything about it, yet in many ways it’s brought us closer together”. P6

Photograph : Data Analysis of a (partial) Participant Transcript



M. That's really good. What about penetrative sex, what do you feel about that?

H. At first I was really terrified, now I see it as an exciting challenge, which is a big turn around from before. I used to think I had to do it to be a real woman but now I see it as an exciting adventure.

M. Do you feel obliged to have penetrative sex?

H. I used to think this was necessary to be a real woman . That I had to learn this. Otherwise I wouldn't have a real relationship without it. Otherwise I would be seen off by other women.

M. What if penetrative sex doesn't happen?

H. I try not to think like that. I'm going to lose my partner, fall apart and everything disintegrate. I try not to think about it.
I think its going to be fun trying. The pleasure of trying is going to be enjoyable. I struggle with that thought so I try and keep that thought at bay.

M. Do you talk with your partner about it?

H. Yerrrr...he keeps saying it's not a problem , it's gonna happen one day, don't think like that. When we first met I told him about it and he didn't believe he could be in a relationship like this (without penetrative sex) because he said he needs to have sex in a relationship. I just said its not that we not gonna have said but that I cant do penetration at the moment. He was taken a back and just sat with his hands on his head for a good three to four hours in the course of a night and I gave him the option to leave. But he never did so... We'll be three years in February and I would have thought if he was still worried about it he would have walked by now. I do worry about it sometimes and I tell him about it, he just says its not going to happen, he gives me lots of love and hugs. We're very touchy feely. We're always touching 'n feeling.

M. So this next bit of the interview is about relationship and sexual adjustment. So I am clear did you try the changes you described earlier before the diagnosis?

H. I'd say I tried dilators before the diagnosis, but they were awful before the diagnosis. . I felt a bit like a science project back then. Researching and researching about what I'd got to do. [redacted] was so receptive; he's willing to be vulnerable too. With other partners I was like a science project. With [redacted] it is so different. I am not a science project, I am his partner. And would say to me .. If you're suffering then I am suffering alongside you. I've not had that before.
I looked up things on the internet (before the diagnosis) and things you can look at. I was on my own emotionally before [redacted] so its better now.

M. How about coping with the sexual pain?

Glossary

Terms

Adjustment –refers to the behavioural process of balancing needs, and needs challenged by the obstacles in the environment.

Gender Identity- refers to one's own understanding of personal identity of gender.

Healthcare Professionals-in the context of this study includes, doctors, nurses, therapists, health educators and clinical teachers.

Psychosexual Therapists - commonly work in the private sector and/or in NHS multi-disciplinary and integrated psychosexual services providing targeted counselling, or longer- term psychotherapy to address sexual problems. They are typically registered with the College of Sexual and Relationship Therapists (COSRT), which is a member of the United Kingdom Council for Psychotherapy (UKCP). Academic research is published in the international Journal of Sexual and Relationship Therapy overseen by COSRT.

Sexual Orientation –has little to do with one's gender identity, instead it refers to, who one is attracted to; it is fluid.

Abbreviations

APA American Psychiatric Association

CCBT Couple Cognitive Behavioural Therapy

DSM Diagnostic and Statistical Manual of Mental Disorders

GPPPD Genito Pelvic Pain/Penetration Disorder

NHS National Health Service