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Emily Weil McCann
University of Iowa

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TOWARDS A BETTER UNDERSTANDING OF THE LIVED EXPERIENCE OF
VULVODYNIA AND ITS IMPACT UPON GENDER IDENTITY: AN
INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

by

Emily Weil McCann

A thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Psychological and
Quantitative Foundations
in the Graduate College of
The University of Iowa

August 2015

Thesis Supervisor: Professor John Westefeld

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Graduate College
The University of Iowa
Iowa City, Iowa

CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

Emily Weil McCann

has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
degree in Psychological and Quantitative Foundations at the August 2015
graduation.

Thesis Committee:

John Westefeld, Thesis Supervisor

Elizabeth Altmaier

Cassie Barnhardt

Megan Foley-Nicpon

Valerie Keffala

To Andy. I could never have done this without your love, support, encouragement, and never-ending faith in me.

ABSTRACT

The purpose of this study was to develop greater understanding and insight as to the ways in which vulvodynia impacts women's gender identity. Interpretative Phenomenological Analysis was used to address the research questions. Data were obtained through the use of semi-structured interviews with four heterosexual women diagnosed with vulvodynia within the past two years. A total of twelve interviews were analyzed and interpreted in order to determine the most salient themes. Results of this study revealed the following four superordinate themes and seven subordinate themes: 1) *critical time periods* (i) initial adjustment to vulvodynia after first sexual intercourse was the most difficult time period, (ii) diagnosis was a turning point, and (iii) acceptance of vulvodynia and development of healthy coping strategies; 2) *alienation and isolation* (iv) feeling inherently different from other women and (v) feeling misunderstood, dismissed, and not believed by others, especially by medical professionals; 3) *positive impacts upon life* (vi) finding my voice and (vii) reclaiming and renewed appreciation for my body and my physical self; and 4) *personalized definitions of womanhood based on individuals' lived experiences and social contexts*. In conclusion, implications for healthcare providers and future directions of research are offered.

Keywords: vulvodynia, gender identity, vulvar pain, womanhood.

PUBLIC ABSTRACT

Vulvodynia is a chronic pain condition in which women experience extreme discomfort and pain during sexual intercourse. Although widely misdiagnosed and underdiagnosed, many women suffer from vulvodynia, with prevalence rates estimated as high as 16% within the United States (U.S.) However, very little is known as to what causes this chronic pain condition, resulting in inconsistent and varied treatment protocols. In turn, women with vulvodynia often report experiencing multidimensional levels of distress, particularly psychological, sexual, and relational in nature. It is also evident that vulvodynia can negatively impact women's gender identity, especially the working definition of womanhood. The purpose of this qualitative study was to utilize Interpretative Phenomenological Analysis to develop greater understanding and insight as to the ways in which the lived experience of vulvodynia impacted four heterosexual women's gender identity. Results of this study revealed the following four superordinate themes and seven subordinate themes: 1) *critical time periods* (i) initial adjustment to vulvodynia after first sexual intercourse was the most difficult time period, (ii) diagnosis was a turning point, and (iii) acceptance of vulvodynia and development of healthy coping strategies; 2) *alienation and isolation* (iv) feeling inherently different from other women and (v) feeling misunderstood, dismissed, and not believed by others, especially by medical professionals; 3) *positive impacts upon life* (vi) finding my voice and (vii) reclaiming and renewed appreciation for my body and my physical self; and 4) *personalized definitions of womanhood based on individuals' lived experiences and social contexts*. In conclusion, implications for healthcare providers and future directions of research are offered.

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Chapter 1: Introduction

The International Society for the Study of Vulvovaginal Disease (ISSVD; 2004) defines vulvodynia as, “vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder” (Haefner et al., 2005, p. 41). Frequently, women with vulvodynia describe the associated pain as severe irritation, burning, and stinging, with some individuals reporting a feeling of rawness, knife-like pain, or a constant searing sensation (Edwards, 2003; Groysman, 2010; Lotery, McClure, & Glasek, 2004). While some women report experiencing pain intermittently, others may describe the pain as enduring and never-ending (Groysman, 2010; Lotery, McClure, & Glasek, 2004). Furthermore, there may be variability in whether reported pain is localized to a specific vulvar region or wholly dispersed to the pelvic floor (Edwards, 2003; Groysman, 2010).

National estimated prevalence rates of vulvodynia are wide ranging (three to 16%) reflecting the fact that this condition is poorly understood by not only health professionals but afflicted women as well (Arnold, Bachmann, Rosen, & Rhoads, 2007; Groysman, 2010; Harlow & Stewart, 2003). Some researchers believe that current prevalence rates are underestimates, purporting that nearly 14 million women in the U.S. experience chronic vulvar pain during the course of their lifetime (Goldstein & Burrows, 2008; Harlow & Stewart, 2003). In part, these rates are likely a result of women underreporting symptoms to their physicians, as well as the fact that vulvodynia can be difficult to diagnose and often goes undiagnosed or misdiagnosed (Bachmann, Rosen, Rhoads, Pinn, Utian, Ayers, et al., 2006; Groysman, 2010).

Another important factor contributing to misleading prevalence rates and high rates of diagnostic error is the lack of understanding regarding etiology (Farage & Galask, 2005; Groysman, 2010; Lotery, McClure, & Galask, 2004). There is no known cause of this condition.

Researchers have studied various hypotheses as to the causal agents of vulvodynia, but the current consensus among medical professionals is that vulvodynia is likely a result of multiple biological characteristics and predispositions (Farage & Galask, 2005; Goldstein & Burrows, 2008; Groysman, 2010), all of which will be discussed in more detail in the next chapter.

Despite the poor understanding surrounding how and why vulvodynia develops, the psychological and psychosocial impacts of this chronic pain condition are well documented. Given the marked discomfort associated with this condition, many women with vulvodynia report symptoms of depression, anxiety, and sexual dysfunction as a result of their chronic pain condition (Bachmann et al., 2006; Gates & Galask, 2001; Farage & Galask, 2005). Currently, there remains some uncertainty as to whether women with vulvodynia experience increased rates of depression and anxiety compared to women in the general population, with some studies finding that to be the case (Masheb, Wang, Lozano, & Kerns, 2005; Nunns & Mandel, 1997; Schmidt, Bauer, Greif, Merker, Elsner, Strauss, 2001; Stewart, Reicher, Gerulath, & Boydell, 1994;) and others suggesting that women with vulvodynia are at no greater risk (Masheb et al., 2005; Meana, Binik, Khalife, & Cohen, 1997; Van Lankveld, Weijnenborg, ter Kuile, 1996).

Furthermore, it may be difficult to approximate comorbid psychological disorders in women with vulvodynia as a result of errors in diagnosing and underreporting psychological distress. This may, in part, be due to some physicians being more prone to diagnose women with vulvodynia with a psychological disorder (e.g., genito-pelvic pain/penetration disorder or other sexual dysfunction) or psychogenic pain rather than a medical condition in light of the lack of physical findings (Metts, 1999). It is also possible that women with vulvodynia may be less likely to seek psychological treatment due to embarrassment and frustration at being told their vulvar pain is only “in their head” (Farage & Galask, 2005).

Nevertheless, most individuals with chronic pain conditions, regardless of the location of the pain in the body, tend to report increased psychological distress (Bond et al., 2012), because the nature of chronic pain can be very disruptive to an individual's life. For example, chronic pain can impact one's ability to perform work-related tasks, therein posing significant risk to financial stability (Bond et al., 2012). Furthermore, chronic pain can also interfere with one's ability to engage in activities of daily living (e.g., housework, cooking, driving), often leaving individuals feeling dependent upon others for the completion of seemingly simple tasks (Bond et al., 2012). Chronic pain can also impact one's sense of self-worth and self-efficacy, often manifesting as sleep disturbances, anxious and depressive symptoms, social isolation, and even suicidal ideations (Bond et al., 2012).

More specifically to the ways in which vulvodynia proves disruptive, women have reported impaired ability to not only engage in heterosexual, penile-vaginal penetrative intercourse, but also greatly limited in clothing choices, types of exercise, choices around soaps and detergents, and occupation related activities that require prolonged sitting (Arnold, Bachman, Rosen, Kelly, & Rhoads, 2006; Friedrich, 1987; Lotery et al., 2004; Ponte, Klemperer, Sahay, & Chren, 2009; Shah & Hoffstetter, 2014). For example, some women with vulvodynia have reported exacerbated vulvar pain as a result of wearing tight pants, especially jeans, often opting to wear garments that are loose or forgoing slacks and shorts all together. Many women with vulvodynia have also reported extreme vulvar pain and discomfort around such activities as riding a bicycle, running, or even walking. Here again, the recurring pressure and friction tends to result in chafing and inflammation, further exaggerating vulvar pain and dermatologic irritation. With respect to hygiene products, women with vulvodynia may be more likely to experience increased skin irritation from some soaps or laundry detergents that include certain

dyes, fragrances, or other chemicals. Thus, women must be diligent in choosing such products, often relying on natural and organic alternatives, which may be more expensive and harder to find. Lastly, women with vulvodynia may find occupational activities that require prolonged periods of sitting difficult to perform in light of increased discomfort and pressure: occupational examples include administrative and computer science work that require sitting at a desk or in front of a computer as well as work that requires extensive traveling via plane, truck, or car. Thus it is clear that women with vulvodynia suffer not only from chronic vulvar pain, but impaired ability to engage some activities of daily living, much the same as most other chronic pain conditions (Arnold, Bachman, Rosen, Kelly, & Rhoads, 2006; Friedrich, 1987; Lotery et al., 2004; Ponte, Klemperer, Sahay, & Chren, 2009; Shah & Hoffstetter, 2014).

Another area in which vulvodynia proves highly disruptive to women is sexual functioning. Women with vulvodynia tend to avoid or limit sexual intercourse as a direct result of the marked level of pain they experience upon attempted and/or repeated vaginal entry. Not only does the act of intercourse itself become very adverse, but non-sexual touch can become adverse as well (Ayling & Ussher, 2008; Kaler, 2006). For some women, any type of touch, whether intended to be sexual or not, is interpreted as being sexually provocative, and thus, a threat to physical integrity (Ayling & Ussher, 2008; Kaler, 2006). However, many women with vulvodynia who are partnered in heterosexual relationships will often still try to engage in sexual intercourse with their male partners due to the immense guilt they feel around their perception that they are not meeting their partners' sexual needs (Ayling & Ussher, 2008; Kaler, 2006). In other words, the experience of guilt is often more painful than the act of intercourse itself. Moreover, the emotional pain at not being able to engage in intimacy with male partners can be devastating (Ayling & Ussher, 2008; Kaler, 2006).

There is also a significant body of research investigating the relationship between vulvodynia and relational distress (Ayling & Ussher, 2008; Bond et al., 2012; Elmerstig, Wijma, Berterö, 2008; Kaler, 2006) For instance, Ayling and Ussher (2008) found that some heterosexual women with vulvodynia in relationships characterized themselves as being inadequate sexual partners, stating that it would be easier to be single or in a same sex relationship, rather than face disappointing their male partners. Ayling and Ussher, also found that no matter how supportive their male partner, heterosexual women with vulvodynia still experienced increased guilt and shame around their perception of not being able to sexually satisfy their partners.

It is this sense of shame and guilt at not being able to satisfy another's sexual needs that has led many heterosexual women with vulvodynia to feel less feminine, characterizing themselves unreal women (Kaler, 2006). In their study, Ayling and Ussher (2008) found that some heterosexual women considered themselves to be inadequate women, due to their inability "to fulfill normative (or desired) functions of heterosexuality" (p. 301). It seems that to be considered a real, or ideal, heterosexual woman by both society and self, heterosexual women must be able to engage in sexual intercourse with their male partners in order to fulfill their natural gender role as women in relationships, regardless of their experience of pain and discomfort (Ayling & Ussher, 2008; Bond et al., 2012; Elmerstig et al., 2008; Kaler, 2006).

Because of the many important issues surrounding vulvodynia, the many unanswered questions around the nature of this condition, and my clinical experience as a counseling psychologist conducting therapy with heterosexual women with vulvodynia, I was inspired to conduct this study. I wanted to know more about the ways in which vulvodynia impacts heterosexual women's lives and how we as treatment providers can better serve this population.

My hopes for this study were to not only enhance and better inform my clinical work with women with vulvodynia, but also contribute to the existing body of literature on this issue in such a way that might also inform and enhance other medical providers' understanding and subsequent treatment as well. Thus the purpose of this study was to build greater understanding of the ways in which vulvodynia impacts women's sense of gender identity by seeking the personal experiences of women with this chronic pain condition. I hoped to learn more about the lived experience of vulvodynia and what factors, if any, might serve to put women at greater risk or protect against negative gender evaluations. In order to study this phenomenon and enhance my understanding of what it is like to be a woman with vulvodynia, I conducted three semi-structured interviews with four heterosexual women diagnosed with the condition.

By utilizing a qualitative framework, I hoped to not only gain a richer understanding of these women's experiences but tailor clinical implications and/or suggestions for treatment and future research based upon this information. I am hopeful that this research endeavor will not only serve to enhance my own clinical work with this population but provide a means and language by which to engage health providers and women with vulvodynia to initiate conversations, engage in advocacy, and work towards social transformation in the ways in which we diagnose, treat, and conceptualize this condition and its potentially devastating effect upon women's sense of womanhood.

Chapter 2: Literature Review

The following chapter will present the existing research literature on heterosexual women's experiences with vulvodynia, specifically in regards to how this chronic pain condition has impacted mental health, sexual functioning, and interpersonal relationships. Additionally, predominant theories of gender identity development will be presented in order to provide the reader a context within which to understand meaning making processes around gender identity. Lastly, research related to vulvodynia's impact upon certain aspects of identity, including gender identity and identity as heterosexual partner, will be presented.

This literature review will include quantitative and qualitative research studies as both methods shed light on the myriad ways in which vulvodynia impacts the lives of heterosexual women. Quantitative studies tend to focus on treatment efficacy and effectiveness of those psychosocial stressors known to co-occur in women who have vulvodynia (e.g., depression, anxiety, sexual functioning, and pain management.). The qualitative studies tend to focus on the subjective experiences of heterosexual women with vulvodynia, providing detailed and rich descriptions of the ways in which this condition has affected various aspects of their lives (e.g., self-esteem, partner in relationship, sexual functioning, and identity).

The articles included in this literature review were obtained from the following databases: PsycINFO, PubMed, Web of Knowledge, SpringerLink, and Wiley Online Library. The search terms used in these databases included ("vulvodynia" AND "femininity"), ("vulvodynia" AND "women"), ("vulvodynia" AND "sexual pain"), and ("vulvodynia" AND "distress"). Articles were also located in the reference lists of initially obtained articles.

Terminology

Before introducing a review of the current body of literature, it is first necessary to provide a brief overview of terms and definitions, as they will be referenced throughout this chapter. The following descriptions are intended to be working definitions for the reader in order to provide clarity when discussing various types of vulvar pain conditions and symptom sequelae.

“Vulvodynia,” “vulvar vestibulitis,” “vulvar vestibulitis syndrome,” and “vestibulodynia” are all terms that can be used interchangeably to describe pain that is confined to the vulvar vestibule that occurs upon vestibular touch or attempted vaginal entry (Farage & Galask, 2005; Goldstein & Burrows, 2008). Although I will consistently use “vulvodynia” to describe the phenomenon, it is important for the reader to recognize that all four terms are interchangeable, when reviewing the literature. Additionally, “dyspareunia” is used to describe pain that occurs during intercourse and is associated with several pelvic pain syndromes including vulvodynia (Bond, Weerakoon, & Shuttleworth, 2012; Driver, 2002). However, I will refer to pain associated with vulvodynia as vulvar pain since pain exists for some heterosexual women well after and/or in the absence of intercourse.

Other terms that will be referenced throughout this dissertation include the following: vaginismus, vaginitis, lichen sclerosis, and pudendal neuralgia (Stewart, Reicher, Gerulath, & Boydell, 1994; Wylie, Hallam-Jones, Coan, & Harrington, 1999). Vaginismus, now referred to as Genito-pelvic pain disorder/Penetration disorder in the DSM-V, is a condition characterized by involuntary tightness of the vagina during any attempted penetration, including sexual intercourse or tampon use. In this case, the pelvic floor muscles surrounding the vagina involuntarily contract upon penetration or attempted insertion and cease contraction once the

threat of penetration/insertion no longer exists. Vaginitis is an inflammation of the vagina that can result in itching, irritation, pain, and discharge, most commonly manifested as yeast infections. Lichen sclerosis is a dermatological condition occurring in both men and women, in which skin becomes patchy, thin, and white, resulting in itching, bleeding, blistering, and wrinkling. Most often, lichen sclerosis develops on the skin of the vulva, foreskin of the penis, or the skin around the anus. Lastly, pudendal neuralgia is a pain condition, experienced by both men and women, as a result of damage or inflammation to the pudendal nerve. Pain occurs in the lower central pelvic areas, including the anus, perineum, scrotum, penis, or vulva, resulting in pain and discomfort upon sitting or voiding the bladder/bowels. (Stewart, Reicher, Gerulath, & Boydell, 1994; Wylie, Hallam-Jones, Coan, & Harrington, 1999)

Overview of Vulvodynia

There are two types of vulvodynia: (1) vulvar vestibulitis, or provoked type, and (2) dysaesthetic vulvodynia, or unprovoked type. Provoked vulvodynia refers to the experience of vulvar pain following some sort of physical provocation, including: 1) the application of pressure to the vulva, such that might occur during a gynecological exam, walking, running, or even sitting; or 2) vaginal insertion, such as sexual intercourse, tampon insertion, or digital self-stimulation. (Friedrich, 1987; Lotery et al., 2004). Unprovoked vulvodynia occurs when vulvar pain exists continuously and spontaneously without provocation (Groysman, 2010; Lotery, et al., 2004; McKay, 1988). Unprovoked vulvodynia presents differently than provoked vulvodynia in that pain tends to extend beyond the vulva to the “labia majora and sometimes the inner thighs and anus” (Lotery et al., 2004, p.1056).

Prevalence

Prevalence studies have shown that vulvodynia, once considered a predominately Caucasian affliction, affects women from all ethnic backgrounds (Harlow & Stewart, 2003; NVA, 2012). National prevalence rates of vulvodynia vary widely, from an estimated three to 16% in women between the ages of 18 and 64, with symptom onset reported occurring most often between the ages of 18 and 25 (Arnold, Bachmann, Rosen, & Rhoads, 2007; Harlow & Stewart, 2003; Reed, Harlow, Sen, Legocki, Edwards, Arato, & Haefner, 2012). However, many researchers believe that these prevalence rates may be a gross underestimate (Groysman, 2010; Harlow & Stewart, 2003).

Vulvodynia is not a well-understood condition by medical and healthcare professionals and is often considered more of a psychological concern than a biological problem (Groysman, 2010). In many ways, vulvodynia may be a contemporary version of hysteria, in that vulvar pain and discomfort are thought to be physical manifestations of some emotional disturbance. The term 'hysteria' was once used to describe a constellation of nonorganic physical symptoms in women, indicating mental disease or disturbance, with purported etiologies being a wandering uterus, masturbation, promiscuity, abstinence, and sexual repression (Chodoff, 1974; Satow, 1979)

Further compounding prevalence rates, many women with vulvodynia tend to underreport their symptoms to physicians as a result of embarrassment, lack of information surrounding their symptoms, and/or fear of being ignored or not taken seriously by medical professionals (Groysman, 2010). In fact, Bachman, Rosen, Pinn, Utian, Ayers, Bassoon, et al. (2006) found that the type of vulvar pain associated with vulvodynia resulted in increased levels

of perceived defectiveness, most likely due to negative interactions with health providers and failure to meet societal gender norms and expectations.

Hypothesized Etiological Correlates

To date, there is no consensus among medical and health professionals as to what causes vulvodynia. However, several hypotheses exist regarding possible etiological correlates and combinations of causative components that guide the diagnostic and treatment procedures. One of the most common correlates associated with the development of vulvodynia is a history of chronic yeast infections (Groysman, 2010). However, physicians and researchers have not yet been able to determine just how such a history impacts the onset of vulvodynia. In other words, “it is not clear whether the culprit is the yeast itself, the treatments undertaken that can sensitize the tissue, an underlying sensitivity present in the tissue,” (Groysman, 2010, p. 681), or perhaps the fact that diagnosing women with yeast infections tends to be a common practice when faced with this symptom cluster (e.g., vaginal burning, stinging, and raw skin).

A second hypothesis relates to the influence of genetics. Gerber, Bongiovanni, Ledger, and Witkin (2003) found that “women with vulvar vestibulitis syndrome have an increased prevalence of less common alleles of both the polymorphic interleukin-1 β and interleukin-1 β receptor antagonist genes” (p. 76). These alleles are integrally associated with the body’s inflammatory responses (e.g., commencement, maintenance, and termination). Therefore, women who possess either allele may have diminished ability to mediate and/or terminate vulvar inflammation, regardless of what caused the original inflammation. In such cases, these women are more at risk for developing heightened and protracted vulvar inflammation (Gerber et al., 2003; Groysman, 2010), which may further increase risk for negative and detrimental physiological events, such as increased sympathetic nervous system activity (Glazer, Rodke,

Swencionis, Hertz, & Young, 1991), thereby perpetuating existing inflammation and heightened sensitivity to pain.

Thirdly, similar to the impact of genetics upon inflammatory responses, there is evidence to suggest that hormones, namely estrogen, may contribute to prolonged vulvar inflammation (Groysman, 2010; Straub, 2007). Researchers have found that inadequate amounts of estrogen, often characteristic of menopausal women, can result in vulvar dysfunction comparable to symptoms of vulvodynia, such as burning, increased dryness, itching, and irritation (Straub, 2007). However, there is some concern that increased estrogen delivered via oral contraceptives can actually lower vulvar pain thresholds (Harlow, Vitonis, & Stewart, 2008), thereby increasing vulnerability and susceptibility towards developing vulvodynia and resultant vulvar pain and discomfort. Unfortunately, other studies investigating this phenomenon found slightly different results, in that women who took oral contraceptives prior to age 18 were at greater risk for developing vulvodynia than women who started taking oral contraceptives after age 18 (Groysman, 2010). Additionally, there are methodological concerns in studying oral contraceptives and the relationship to vulvodynia since there is variation in how the contraceptives are prepared, proving problematic in ensuring variables can be controlled for (Groysman, 2010). Currently, researchers acknowledge that estrogen plays both anti- and pro-inflammatory roles in chronic pain syndromes, including vulvodynia, and that a wealth of other factors also contribute to the type of resultant inflammation response (Groysman, 2010; Straub, 2007).

A fourth hypothesized etiological correlate is the presence of pelvic floor irregularities in women with vulvodynia. According to Groysman (2010), “Most women with vulvodynia exhibit pelvic floor abnormalities” (p. 682). Pelvic floor muscles support the pelvic organs in the body

and are responsible for bowel and bladder control, as well as sexual function. In most women with vulvodynia, pelvic floor muscles are overactive, resulting in protracted and excessive tightening of vaginal muscles (Bergeron, Brown, Lord, Oala, Binik, & Khalifé, 2002). This tightening can contribute to women's experience of pain not only in the vulva, but in the lower abdomen and back (Bergeron et al., 2002). Fortunately, research suggests that physical therapy for pelvic floor dysfunction in women with vulvodynia can result in improved pelvic floor function and reduced vulvar pain and discomfort (Bachmann, Rosen, Pinn, Utian, Ayers, Basson, et al., 2006). However, what is yet to be determined is whether or not these abnormalities are a precipitating factor in the development of vulvodynia or whether they are an outcome of onset.

Lastly, a fifth hypothesis, and the predominant etiological theory, is that vulvodynia is a neuropathic disorder characterized by aberrant pain perception as a result of increased sensitization of vestibular nerve fibers and the development of pain loops perpetuated by the sympathetic nervous system (Farage & Galask, 2005; Graziottin, Castoldi, Montorsi, Salonia, & Maga, 2001; Pukall, Strigo, Binik, Amsel, Khalifé, & Bushnell, 2005). In large part, most women with vulvodynia demonstrate a markedly amplified perception of aversive tactile and pain stimuli of the genitalia, especially within the vulvar region (Giesecke, Reed, Haefner, Clauw, & Gracely, 2004; Grant, Friedman, Yarnitsky, & Zimmer, 2002; Gunter, 2007). In their functional magnetic resonance imaging (fMRI) study, Pukall, Strigo, Binik, Amsel, Khalifé, and Bushnell (2005) demonstrated this increased sensitization to pain and found that women with vulvodynia exhibited "genital sensory processing" comparable to that associated with other chronic pain conditions, including low back pain, peripheral neuropathy, and fibromyalgia (p. 118). Researchers posit that some unknown physiological event or trigger stimulate and maintain protracted sympathetic neural activity of "Type C nerve fibers responsible for transmitting

noxious chemical or thermal stimuli to the brain” (Farage & Galask, 2005, p.11). This activity causes the brain to respond with increased pain sensitization and likely develops into the chronic pain condition, vulvodynia (Cox, 1995; Farage & Galask, 2005).

Despite the unknown origin of vulvodynia, many researchers believe that this chronic pain condition occurs as a result of a complex combination of numerous biological and environmental factors (Farage & Galask, 2005; Groysman, 2010). However, this lack of etiological understanding has important implications for diagnosis.

Diagnosing Vulvodynia

Vulvodynia is considered a diagnosis of exclusion, in that all other medical conditions with similar symptomatology have already been ruled out. The two most important components in making an accurate assessment and eventual diagnosis of vulvodynia are the clinical interview, in which thorough medical and psychosocial histories are taken, as well as the gynecological exam (Groysman, 2010). It is essential that gynecologists carefully inspect and examine inner and outer genitalia in order to assess for signs of inflammation, alterations in pigmentation, changes in structural integrity, and muscular irregularities of the pelvic floor, such as involuntary contractions (Graziottin et al., 2001). Regrettably, evaluations of pelvic floor muscle function are not currently part of routine gynecological exams (Graziottin et al., 2001; Reid, 1996). This physician oversight has implications for patients, as they tend to be reluctant to discuss their symptoms given the fear of and all too common likelihood of stigmatization and dismissive attitude of some providers, thereby perpetuating underestimated prevalence rates, lower rates of accurate diagnoses, and increased rates of misdiagnoses (Bachmann et al., 1996).

Treatment

Ideally, the treatment of vulvodynia would echo the complexity and multidimensional

nature of the chronic pain condition itself. The most common treatment approaches target symptoms of irregular pelvic floor function, neuropathic pain, and psychological comorbidities (Groysman, 2010) through a variety of methods, including the use of pharmaceuticals (both oral and topical), physical therapy, biofeedback, psychotherapy, and potentially even surgery in which affected vestibular tissue is excised (Driver, 2002; Farage & Galask, 2005).

However, a standard treatment protocol does not yet exist (Driver, 2002), with treatment delivery most often including one or some combination the following: oral analgesics (usually opioids, Gabapentin, or Amitriptyline), topical analgesics (lidocaine or methylprednisone) physical therapy of the pelvic floor muscles, antidepressants and/or anxiolytics, and cognitive behavioral driven therapy (Driver, 2002; Farage & Galask, 2005; Groysman, 2010). In her review of vulvodynia, Groysman (2010) describes two essential approaches to treatment and labels them as, “nonspecific activities” and “specific therapy” (p. 685) for treating vulvodynia. Nonspecific activities include both (1) prophylactic measures, such as applying lubrication prior to attempts at sexual intercourse or digital stimulation, indefinitely suspending use of certain hygienic products that may cause or exacerbate irritation (e.g., laundry detergents and body washes), and applying analgesic creams or ointments prior to attempts at vaginal insertion, and (2) remedial measures, including applying analgesic creams or ointments following attempts at or actual sexual intercourse, applying heat or cold compresses to ease pain and discomfort, and acknowledging and validating symptoms as real experiences of pain rather than manifestations of emotional disturbance or dysfunction (Driver, 2002; Groysman, 2010; Smart & MacLean, 2003). Another important non-specific treatment measure includes providing psychoeducation to not only the patient, but to her family and partner as well, in order to maximize understanding and the importance of effective treatment and management of this condition (Groysman, 2010).

Standard therapies or approaches to treating vulvodynia are those that specifically target some abnormality or irregularity through more precise interventions (Groysman, 2010). These methods are most often implemented when treating infections, dermatological irregularities, and muscular dysfunction and include physical therapy, trigger point injections, oral medications for both pain and psychosocial stressors, electromyography, biofeedback, vestibular surgery, and psychotherapy (Driver, 2002; Farage & Galask, 2005; Groysman, 2010; Smart & MacLean, 2003).

Psychosocial Stressors Associated with Vulvodynia

Chronic Pain and Depression

Researchers have found that co-morbid depression is common amongst individuals suffering from chronic pain conditions (Banks & Kerns, 1996). In their review, Banks and Kerns (1996) characterized the experience of chronic pain as consisting of constant, aversive, and often inescapable pain symptoms; real or perceived physical disability and/or impairment; significant secondary psychosocial losses; and frequent, frustrating encounters with medical professionals. Given that, by definition, chronic pain is an enduring, pervasive condition, in which individuals experience pain and discomfort nearly all the time, it is no surprise that these individuals may be at greater risk of developing depressive symptoms. Banks and Kerns likened chronic pain patients to Seligman's (1975) experiment with dogs and learned helplessness.

In his study, Seligman placed dogs in circumstances in which they could not escape an aversive stimulus (i.e., an electric shock). The dogs learned that, no matter their attempts to escape or avoid the shock, their attempts were futile. They soon became resigned to the fact that they had no control over the unpleasant outcome, so much so, that when the opportunity to escape the shock was presented, the animals did not attempt it. Chronic pain patients may also

feel that, no matter the measures they take to reduce or cease pain, they have no control over their pain, and thus, will continue to suffer (Banks & Kerns, 1996). This way of thinking can contribute to negative and distorted thought processes (i.e., “The accident was my fault, so I deserve to suffer”), which can manifest as depressive symptoms, such as low mood, social withdrawal, and depleted energy. Furthermore, studies have shown that individuals with chronic pain who tend to align with an internal locus of control often report more depressive symptoms as a result of feeling less control over their ability to manage pain levels (Banks & Kerns, 1996; Keefe & Williams, 1990; Skevington, 1983).

Additionally, individuals with chronic pain are faced with multiple psychosocial stressors that can result in the development or aggravation of depressive symptoms. With respect to physical disability or impairment, individuals with chronic pain may not be able to perform or engage in significant occupational and social activities that once brought them feelings of accomplishment, pride, and enjoyment. However, what tends to be among some of the most important factors in the onset of depression as a result of disability or impairment are the individual’s attitude, perceptions, and cognitions regarding their ability status (Banks & Kerns, 1996; Jette, 1994). In other words, the more severe the perceived status, the more depressive symptomatology reported by individuals, thereby suggesting perception of physical disability or impairment as an important mediating variable of depression.

Furthermore, concomitant with negative cognitions related to pain and ability status, individuals with chronic pain have reported marked increases in stress related to relationships, financial stability, and occupational status (Banks & Kerns, 1996). Researchers have investigated the impact chronic pain can have upon relationships, finding that the experience of chronic pain can pose significant threat to individuals’ ability to maintain relationships with romantic

partners, family members, and friends (Bond et al., 2012). It is possible that individuals with chronic pain may feel discarded by the people in their life, especially when the pain remains intact despite various treatment attempts (Bond et al., 2012). Furthermore, the nature of chronic pain is not one easily captured on MRI or X-ray images, given that the pain is often a result of soft tissue damage or other muscular abnormality (Banks & Kerns, 1996). Researchers have also found that it is common for individuals with chronic pain to feel defensive about their subjective experiences of pain due to the lack of objective, physical evidence, such that would appear in the case of a herniated disc or spinal fracture (Bond et al., 2012; Banks & Kerns, 1996). These feelings of defensiveness and/or disbelief can contribute to individuals experiencing self-doubt, feeling mistrustful of medical professionals, frustration, and a sense that no one can, or cares to, understand their experience of pain (Banks & Kerns, 1996; Goldman, 1991).

Chronic pain can also prove disruptive to occupational status, especially when individuals cannot perform their work related duties, as a result of ability status or having to take excessive time off for medical visits or procedures (Banks & Kerns, 1996). As a result, individuals may find that they have to take unpaid time off or are at risk for losing their job. The resultant financial concerns can be very difficult for individuals to cope with, here again, often exacerbating existing symptoms of depression. For those individuals who can no longer maintain employment, “feelings of social isolation, of meaninglessness and purposelessness of life, and of uncertainty about the future” (Banks & Kerns, 1996, p. 104) can negatively impact their sense of self-worth, sense of self-efficacy, and perceived ability to cope with their pain.

Depression and Psychological Distress in Vulvodynia

Women with vulvodynia are no exception when it comes to the negative impact of chronic pain upon overall functioning. As with other individuals who suffer from chronic pain,

they also appear to experience considerable distress related to ability status, and not only within the context of their ability to engage sexually with their male partners. There are also reports of occupational and social distress in light of impaired ability to maintain seated positions for extended periods of time or engage in certain physical exercises or activities that require repeated running, walking, or bicycle riding. Thus, despite the robust body of evidence supporting the finding that many individuals with chronic pain struggle with comorbid depression, research specific to co-morbid depression and vulvodynia appears inconclusive.

Some of the current literature appears to indicate that women with vulvodynia may experience more psychological distress than women without it (Jantos & White, 1997; Khandker, Brady, Vitonis, MacLehose, Stewart, & Harlow, 2011; Masheb, Kerns, Lozano, Minkin, & Richman, 2009; Masheb, Wang, Lozano, & Kerns, 2005; Stewart, Reicher, Gerulath, & Boydell, 1994). For example, in their study on medical, psychosexual, personality, and relationship dynamics in women with vulvar vestibulitis syndrome, Jantos and White (1997) found that 60% (n = 30, N = 50) of participants had co-morbid depression, with 57% (n = 29, N = 50) reporting suicidal ideations or suicidal intent. Similarly, Stewart, Reicher, Gerulath, and Boydell (1994) conducted a study on psychological distress in women with vulvodynia and other vulvar pain conditions, such as vaginitis, lichen sclerosis, and pudendal neuralgia. Eighty-two women participated in this study which consisted of completion of the following measures: the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983), a self-report measure assessing for overall level of psychological distress, symptom severity, and total number of psychological symptoms self-reported; the Centre for Epidemiologic Studies – Depression scale (CES-D; Radloff, 1977) a self-report measure assessing for major depressive symptoms and episodes; the Barsky Somatosensory Amplification Scale (BSAS; Barsky, Whyshak, & Klerman, 1990), a self

report measure of “heightened attention to normal bodily sensations: (Bond et al., 2012, p. 51); and the Whiteley Index (WI; Pilowsky, 1967), a measure of hypochondriasis. Additionally, prior to participation in the study, a gynecologist examined each woman to determine eligibility and confirm diagnosis. In the end, Stewart et al. (1994) found that women with vulvodynia reported more psychological distress than women with other vulvar pain.

Masheb, Wang, Lozano, and Kerns (2005) investigated the “rates and correlates of depression in a sample of women with vulvodynia seeking psychological treatment” (p. 786). Women who met eligibility requirements met with gynecologists who performed exams in order to confirm a diagnosis of vulvodynia. Once a positive diagnosis was determined, the participants took a battery of validated measures to assess for pain (Kerns, Turk, & Rudy, 1985; Melzack, 1975), presence of depressive symptoms (First, Spitzer, Gibbon, & Williams, 1996), severity of depressive symptoms (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), general functioning (Kerns, Turk, & Rudy, 1985), sexual functioning (Rosen, Brown, Heiman, Leiblum, Meston, Shabsigh, et al., 2000), and quality of life (Ware & Sherbourne, 1992). Of the 53 women with vulvodynia who took part in the study, 33 were clinically depressed, nine of whom were depressed prior to onset of vulvodynia, and 24 who experienced their first depressive episode following onset. The authors determined that those women with co-morbid depression occurring after the onset of vulvodynia rated experiencing more severe depressive symptoms and lower overall quality of life. In other words, Masheb et al. (2005) found that co-morbid major depressive disorder was positively correlated to pain severity and negatively correlated to social and occupational functioning.

Khandker, Brady, Vitonis, MacLehose, Stewart, and Harlow (2011) investigated how premorbid depression affected risk of onset of vulvodynia in adulthood. The Structured Clinical

Interview for DSM-IV Axis I Disorders (SCID; First et al., 1996) was utilized as the means of assessment by which the authors determined age of onset of either major depression or anxiety in “240 case control pairs of women with and without vulvodynia” (p. 1445). Additionally, the authors gathered information on historical events (age at first menses, age at first use of a tampon, and age at first sexual intercourse) as a means of determining the temporal relationship between onset of vulvodynia and onset of depression or anxiety (Khandker et al., 2011). The authors found that a diagnosis of vulvodynia increased women’s risks for new and recurrent onset of major depression or anxiety, and that comorbid psychiatric diagnoses also increased risk for onset of vulvodynia.

In a later study, Masheb, Kerns, Lozano, Minkin, and Richman (2009) conducted a randomized controlled trial with women with vulvodynia regarding differential treatment efficacy of cognitive behavioral therapy (CBT) and non-specific, supportive therapy. Utilizing an extensive battery of inventories and indices of pain (Kerns, Turk, & Rudy, 1985; Melzack, 1975), sexual function (Rosen et al., 2000), emotional function (Beck & Steer, 1987; McCracken, Zayfert, & Gross, 1992), and treatment acceptability (Borkovec & Nau, 1972), Masheb et al. found that a CBT based approach emphasizing pain management strategies, resulted in greater treatment satisfaction and improved treatment outcome on all measures compared to a less active, non-directive approach.

However, there are some researchers who have found that women with vulvodynia may not experience increased levels of depression compared to the general population (Bond et al., 2012). For example, Van Lankveld, Weijnen, and Ter Kuile (1996) found that women with vulvar vestibulitis did not report higher rates of psychological problems compared to women in the general population. In their study, Van Lankveld et al. (1996) utilized four assessment

instruments in order to determine and compare psychological profiles among 43 Dutch women with vulvodynia. The Questionnaire for Screening Sexual Dysfunction was chosen to measure frequency of sexual problems and related distress; specifically “sexual desire and aversion, frequency of sexual interaction and masturbation, problems with sexual excitement, lubrication, reaching orgasm, sexual pain, and negative emotions associated with sex, during both masturbation and sexual interaction” (Van Lankveld, Weijenborg, & Ter Kuile, 1996, p. 66). The authors chose the Symptom Checklist to assess for psychological and physical problems, to which comparisons were made between study participants and a normative population consisting of 1,026 Dutch individuals. Four subscales of the Minnesota Multiphasic Personality Inventory, Short Dutch Version (shyness, extraversion, psychopathology, and somatization) were included in the assessment battery to measure personality traits, with 809 Dutch individuals serving as the normative population for comparisons. Lastly, participants completed the marital satisfaction subscale from the Maudsley Marital Questionnaire in order to determine satisfaction in heterosexual marriages.

Van Lankveld et al. (1996) not only found comparable rates of psychological distress between study participants and women in the normative population, but also that they did not differ on measures of personality. They did find that Dutch women with vulvodynia more often responded on ratings of somatization and shyness than Dutch women without vulvodynia. What may be misleading about this study, though, is that study participants reported experiencing more distress around sexual intercourse, leading Van Lankveld et al. to purport that women with vulvodynia might be more apt to experience “situationally defined sexual dysfunction” (p. 65) with resultant distress unique to the act of sexual intercourse itself.

In their study on the prevalence and severity of psychological distress in women with vulvar vestibulitis, Brotto, Basson, and Gehring (2003) conducted a retrospective chart review of 50 women with vulvodynia who sought treatment at a specialty clinic of sexual medicine. These 50 women all had medically confirmed diagnoses of vulvar vestibulitis and had completed various measures of psychological distress related to sexual intercourse and personality traits during a two-year treatment period. Through their analyses, Brotto et al. found that a small subset of women demonstrated “clinically significant broad based psychological distress” (2003, p. 195). However, the authors also found that, when compared to healthy controls, the women’s charts reviewed in this study, reflected markedly higher rates of fear and anxiety upon attempted or actual vaginal touch or penetration.

Limitations and critiques. It should be noted that some of the studies that did not find associations between higher levels of depression and vulvodynia suffered from methodological and sampling issues that may have affected the findings (Bond et al., 2012). For instance, Arnold, Bachmann, Kelly, Rosen, and Rhoads (2006) found comparable rates of depression in both the control and vulvodynia groups, but noted that one of the limitations of their study was using a non-validated measure of depression and stress. Also, Arnold et al. recruited study participants from “an academic medical center in New Jersey, an area characterized by high rates of depression and stress following the 2001 terrorist attacks” (p. 623). Therefore, it is possible that the normal controls used for comparison in this study may have overrepresented rates of stress and depression within the general population.

Another important consideration for interpretation is that the women who participated in these studies were seeking medical and/or psychological treatments for vulvodynia. The fact that participants may more accurately reflect treatment-seeking populations impacts generalizability

to non-treatment seeking women with vulvodynia. Furthermore, the current body of research is highly skewed with an overrepresentation of Caucasian, heterosexual women. Here again, generalizability is greatly limited, given that prevalence rates of vulvodynia indicate that it is a condition all women can develop. Although much of the literature recommends conducting future studies with women of different ethnic backgrounds and sexual orientations, no such studies yet exist.

Lastly, as can be the case when using self-report measures, it is possible that the authors' findings may reflect recall biases as a result of respondents' endorsements. Khandker et al. (2011) specifically acknowledged this fact stating that they could not "rule out that women with vulvar pain may have differentially recalled their psychiatric history compared to matched controls" (p. 1450). Overall, no such study exists to date that has been able to demonstrate directionality, causality, or temporality between vulvodynia and psychological distress, or more specifically, major depression. In other words, there is no indication as to whether psychological distress is actually an outcome of vulvodynia (e.g., situational depression) or an important precipitant to onset and development.

What researchers have been able to demonstrate is that some women with vulvodynia experience psychological distress, while other women with vulvodynia do not report experiencing any distress, and that manifestations of psychological distress can vary widely across women with vulvodynia. Researchers have also found that some variables, such as more severe ratings of vulvar pain, can negatively affect mood, serving as risk factors for the development of co-morbid depression or psychic stress.

Sexual Functioning Distress

Impairments in ability to perform and enjoy sexual intercourse are common occurrences in women with vulvodynia, often contributing to distress around sexual functioning (Bond et al., 2012; Derogatis, Clayton, Lewis-D'Agostino, Wunderlick, & Fu, 2008; Masheb, Lozano-Blanco, Kohorn, Minkin, & Kerns, 2004). In fact, women with vulvodynia experience greater rates of sexually related distress compared to women with other forms of female sexual dysfunction (FSD; Bond et al., 2012). In their study on sexual functioning in women with vulvodynia, Masheb, Lozano-Blanco, Kohorn, Minkin, and Kerns (2004) found that heterosexual women with vulvodynia reported markedly reduced sexual functioning more often than women without sexual dysfunction. For this study, the authors utilized the Female Sexual Function Index (FSFI; Rosen et al., 2000), a self-report measure of perceived sexual functioning with subscales including sexual desire and arousal, lubrication, pain during intercourse, ability to achieve orgasm, and sexual satisfaction. Not only did Masheb et al. (2004) find that heterosexual women with vulvodynia suffered from diminished sexual functioning compared to healthy controls, but they also reported greater pain levels during sexual intercourse when compared to women with female sexual arousal disorder.

The current body of literature on female sexual dysfunction (FSD) and sexually related distress appears to illustrate a negative correlation between sexual functioning and sexually related distress. Sexually related distress is defined as “negative and distressing feelings that a woman may experience about her level of sexual function” (Hayes, 2008, p. 216). In order to more accurately assess sexual distress as a result of sexual dysfunction, researchers developed the Female Sexual Distress Scale (FSDS; Derogatis, 2008). This validated scale measures

specific constructs related to perceptions of sexual functioning including embarrassment, guilt, frustration, and anger regarding the sexual dysfunction.

Dennerstein, Guthrie, Hayes, DeRogatis and Lehert (2008) utilized the FSDS, along with the Short Personal Experiences Questionnaire (SPEQ; Dennerstein, Lehert, & Dudley, 2001) in their longitudinal study on sexual function, dysfunction, and sexually related distress. Although the SPEQ does not specifically measure sexually related distress, this measure assesses sexual functioning, specifically as it relates to dyspareunia, as well as factors regarding one's sexual partner and relationship. Through the use of these two complimentary assessments, Dennerstein et al. found that 81% of participants ($n = 166$, $N = 204$) reported low sexual functioning, with 17% ($n = 34$, $N = 204$) reporting sexual distress. Those 34 women who reported sexual distress endorsed lower ratings of sexual functioning, decreased ratings of health and wellbeing, and higher rates of major depressive symptoms. Over the course of 11 years, Dennerstein et al. found that, with respect to predictive factors of sexually related distress, decreased feelings for one's sexual partner and overall decline in FSDS sex score were the most significant variables in predicting presence and degree of sexual distress.

In their investigation of factors associated with sexual functioning and sexually related distress, Hayes, Dennerstein, Bennet, Sidat, Gurrin, and Fairly (2008) conducted a cross sectional, population based study in Melbourne, Australia. In order to assess for sexual dysfunction and sexual distress, the Sexual Function Questionnaire (SFQ; Quirk, Heiman, Rosen, Laan, Smith, & Boolell, 2002) and FSDS were used. The SFQ is a validated, self-report measure of sexual function over the past two months, in which respondents report their experiences of pain during sexual intercourse, sexual arousal and desire, and ability to achieve orgasm. Furthermore, the authors incorporated the CES-D in order to determine whether

participants met criteria for major depression or not. Of the 276 women who participated in the study, Hayes et al. found that more than half of participants reported low sexual functioning.

However, this study demonstrated the impact age, relationship satisfaction, mood, hormone therapy, and sex education may have upon ratings of sexual function and resultant sexually related distress. For example, Hayes et al. found that women in their thirties, or women who more highly valued sexual intercourse, reported higher rates of orgasm achievement. The authors also found that women in their thirties and forties who were undergoing hormone therapy, were well informed about sex, or considered sexual intercourse of high value reported greater levels of arousal. Furthermore, sexually related distress was more likely to occur in women with depression or women who had difficulty expressing sexual desires or needs to their partners.

In 2008, Shifren, Monz, Russo, Segreti, and Johannes conducted a prevalence study of sexual function and distress in the United States. Shifren et al. recruited 31,581 women across 50,002 households in this cross-sectional, population based epidemiological study. Each participant completed the female version of the Changes in Sexual Functioning Questionnaire short form (CSFQ-14; Clayton, McGarvey, Clavet, 1997), a self-report measure of problems with sexual desire, arousal, and orgasm achievement, as well as the FSDS to assess for sexual distress. For purposes of their study, Shifren et al. (2008) operationally defined the phrase “sexually distressing problem” as self-reporting at least one sexual problem and sexual distress, as well as a score of 15 or higher on the FSDS. The authors found that, even though 40% of participants reported experiencing at least one sexual problem (primarily decreased sexual desire), many fewer women in the U.S. were experiencing sexual distress. In fact, Shifren et al. found that only 12% of women were considered sexually distressed, most commonly occurring

in women aged 45-64 years. However, Shifren et al. did find that women reporting current depressive symptoms reported more sexual distress than their non-depressed counterparts. It is possible that, despite experiencing increased sexual problems in older adulthood, there is less sexually related distress due to more significant health problems or declined value of sexual intercourse within relationships (Shifren et al., 2008). Unfortunately, these suppositions were not explored in the study, and serve purely as hypothetical explanations or hypotheses for future research.

Limitations and critiques. One of the greatest strengths of the literature described in the previous section on distress related to sexual functioning is the utilization of validated measures. Through the use of psychometrically sound instruments, many of the studies came to consistent conclusions regarding the relationship among low sexual functioning, low mood, and high sexual distress. Another clear strength within this area of research is the high statistical power related to larger sample sizes and random sampling. Furthermore, as a result of their findings, most researchers provided clinical implications as to the importance of assessing for depression when treating women with vulvodynia or low sexual functioning as a means of mediating or treating sexually related distress. However, there are a few shared limitations within this body of literature.

First, authors most often relied on self-reports to classify or qualify participants as experiencing sexual distress, since the large sample sizes did not easily lend themselves to interviews or clinical evaluations. Furthermore, elements of sexual functioning that might be deemed by medical professionals as functional or dysfunctional could not be corroborated with respondents' self-reports alone. An example of such is women reporting "difficulty in arousal that is not consistent with changes in vaginal blood flow as measured by vaginal

plethysmograph,” an instrument used to detect changes in vaginal blood flow, thereby measuring physiological arousal (Masheb et al., 2004, p.323). Second, despite demonstrating clear correlational associations between and among variables related to sexual distress, the research has yet to demonstrate causality as a result of more highly controlled, rigorous research designs and methods.

With respect to more differentiated study limitations, Dennerstein et al. (2008) reported various limitations with important implications for reader interpretations. In their study, Dennerstein et al. only administered the FSDS in the last year of the study, with participants completing the SPEQ over the course of the previous decade. Therefore, it may be difficult to determine the temporal nature of the association between low sexual functioning and high sexual distress. Another significant limitation of this study was the age range of participants: 56-67 years old. It is possible that, by studying an older population of women, the rates of sexual distress were not adequately represented due to the fact that older women tend to perceive sexual problems as more normative at this age and thus, less distressing than it might be for younger women (Bond et al., 2012; Moreira, Brock, Glasser, Nicolosi, Laumann, Paik, et al., 2005).

Lastly, as part of their study, Van Lankveld et al. (1996) also explored sexually related distress within the context of solitary masturbation. The authors found that heterosexual women with vulvodynia reported lower ratings of distress and improved sexual functioning during the course of self-stimulation. Therefore, it seems worthwhile to explore experiences of sexually related distress in women who are not currently in relationships.

Relationship Distress

Within the literature, there is a strong overlap between measuring and studying distress related to sexual functioning and that of relational concerns. As described in the previous section

on sexual distress, it is clear that sexual functioning for heterosexual women with vulvodynia within relationships is a source of distress. Clearly, the research reflects distressing implications for heterosexual women in relationships who are, as a result of their chronic pain condition, unable or unwilling to engage in sexual intercourse with their male partners. However, only a handful of researchers have attempted to study sexual distress and relationship distress as separate psychological entities (Bond et al., 2012).

For example, Bancroft, Loftus, and Long (2003) examined sexual distress in heterosexual women through a U.S. national survey. Bancroft et al. attempted to differentiate and distinguish specific forms of sexually related distress resulting from sexual dysfunction by asking women to report distress about their sexuality as well as distress related to their sexual relationship. The authors found that 19.8% of women reported marked sexual distress related to their sexual relationship, while 14.7% reported marked sexual distress related to their sexuality. Additionally, Bancroft et al. discovered “that lack of emotional well-being and negative emotional feelings during sexual intercourse with the partner” (p. 202) served as significant predictive factors of sexual distress for American, heterosexual women. Essentially, this study suggests that more women experience marked levels of distress related to their heterosexual relationship than their own sexuality or sexual functioning.

In their qualitative study of heterosexual women with vulvodynia and their experiences in relationships, Ayling and Ussher (2008) found that six of the seven women interviewed considered themselves to be inadequate sexual partners. Through a “Foucauldian post-structuralist framework” (Ayling & Ussher, 2008, p. 297), the authors hypothesized that participants’ perceptions of inadequacy as a sexual partner were a direct result of their inability or unwillingness to satisfy their male partners’ sexual desires and needs. In other words, these

women considered themselves to be violating a clear social norm associated with heterosexuality and their heterosexual relationships, and thus, evaluated themselves as abnormal and inadequate, compared to other heterosexual women (Ayling & Ussher, 2008). The authors found that the participants experienced increased relationship stress due to feeling sexually inadequate and expressed marked concern about the future and integrity of their relationships. The women feared that their male partners, whom they reported as supportive and loving, might still seek sexual satisfaction outside the relationship or simply terminate the relationship altogether, therein, resulting in significant relational distress.

Another study that examined distress related to sexual dysfunction, found that relationship factors, specifically levels of relationship satisfaction, were more highly correlated with distress than the actual sexual dysfunction itself (Öberg & Fugl-Meyer, 2005). Öberg and Fugl-Meyer (2005) conducted their study with 926 Swedish women in heterosexual relationships. Each participant completed an author-generated questionnaire about sexual dysfunction, as well as the LiSat-11 checklist (Fugl-Meyer, Melin, & Fugl-Meyer, 2002), a measure of life satisfaction that focuses “on the individual's perception of the difference between the subjective reality and needs or wants regarding several important domains of functioning and activity/participation” (p. 239). Although Öberg and Fugl-Meyer found a positive correlation between distress and relationship dissatisfaction, many of the women who participated in this study also reported their male sexual partners as experiencing sexual dysfunction as well, such as difficulty achieving and/or maintaining erection or early or delayed ejaculation. This phenomenon occurred more often in relationships for women with dyspareunia. The authors purported that partner erectile dysfunction may have developed in response to their fear of hurting their female partners during intercourse. Therefore, it is possible that decreased

satisfaction within sexual relationships, and subsequent experiences of distress, may be, in part, attributed to negative feelings about the overall relationship, not just the sexual component.

In their study on couples counseling for heterosexual women with vulvodynia and their male partners, Sheppard, Hallam-Jones, and Wylie (2008) interviewed eight heterosexual women about their experiences of emotional distress, damage to the sexual relationship, emotional isolation and insufficient social support, issues related to loss, dissatisfying encounters with medical staff, sexual intercourse, previous treatments, value and benefits of couples counseling, and vaginal pain. The authors found that six of the eight interviewees experienced increased distress around fear of losing their partners (Sheppard et al., 2008). Furthermore, they found that each participant expressed feelings of loss and mourning surrounding their diminished ability to intimately engage with partners, with some characterizing the experience as resulting in losing a piece of self or failing in their relationships. However, Sheppard et al. were surprised to find that, despite previous research on relationship distress, most respondents described minimal damage to current relationships as a result of strong emotional connectedness and support. This was an important finding because the authors found that participants' feelings of isolation and alienation were a result of feeling abnormal or different compared to other women, but reported feeling emotionally connected to their partners. In fact, some women admitted that their partners were the only individuals they could relate to on matters related to sexual functioning.

Limitations and critiques. The research clearly indicates that heterosexual women with vulvodynia or other sexual dysfunction experience increased relationship distress. What the research has yet to elucidate is the nature of the relationship between decreased sexual functioning and increased relationship distress. It is still to be determined if relationship distress is an outcome of sexual dysfunction and resultant diminished sexual intercourse and emotional

intimacy, or if relationship distress serves as a predictive factor for the onset of vulvodynia or other sexual dysfunction. It may be that these two seemingly disparate, albeit related, distress constructs reflect a singular, complex, subjective phenomenon.

Despite this lack of understanding, there are certainly other limitations concerning the research on relationship distress within the context of vulvodynia and sexual dysfunction. For instance, the participant populations continue to represent heterosexual women, primarily of Caucasian ethnicity. Although Bancroft et al. (2003) did recruit African American women their participant distribution was 2:1, Caucasian to African American, perpetuating the overrepresentation of White, heterosexual women. Given this is the only known study that actively sought more diversity in participant sampling, it is evident that there is still very limited generalizability to women of color with vulvodynia and their experiences of relationship distress.

Furthermore, Bancroft et al. (2003) acknowledged that it was difficult to determine whether women self-reporting distress (either due to their own impaired sexual functioning or sexual relationship) had a sexual problem or dysfunction that could be confirmed by a physician; thus, there may be implications for interpretation given the phenomenon of interest may not have been accurately or adequately captured through this population-based study. However, Bancroft et al. suggested that, with more research, it might be possible to make distinctions between sexual dysfunction and more circumstantial distress related to having vulvodynia, although they doubt the feasibility or applicability of such a method when conducting large-scale population-based studies.

Öberg and Fugl-Meyer's (2005) study, although illustrative of Swedish, heterosexual women's experiences with sexual and relationship distress, suffered from methodological issues. Their use of non-validated measures of sexual dysfunction presents concern for interpretation,

calling for readers to exercise extreme caution when considering their findings. However, an advantage of both Bancroft et al. (2003) and Öberg and Fugl-Meyer was their large, population-based sample sizes.

In contrast, despite gathering immensely rich and descriptive data, Ayling and Ussher's (2008) findings must be considered carefully given they interviewed seven heterosexual, Caucasian women from Australia. In this case, generalizability is extremely limited, notwithstanding the insightful and illustrative information they collected. It is also notable that their interview questions could provide physicians, mental health providers, and friends and family members a starting point to initiate a dialogue about thoughts and feelings these women experience in light of their chronic pain condition.

Accordingly, the findings from Sheppard et al. (2008) are not applicable to those beyond their specific study. However, a major limitation of the study was the lack of demographic data provided about each participant. Other than their heterosexual orientation and their geographical region (United Kingdom), no information regarding age, ethnicity, length of relationship, age of male partner, etc. were discussed. Therefore, it is difficult to interpret the utility of findings even on a much smaller scale, since the authors neglected to adequately describe their participants.

Summary

According to the current body of literature examining correlations between heterosexual women's experiences of vulvodynia and depression, sexually related distress, and relationship distress, it is evident that many women with vulvodynia struggle with one or more these three psychosocial stressors. Unfortunately, due to methodological limitations and the difficulty in measuring these constructs, very little is yet known regarding directionality and the more nuanced details of the ways in which these constructs perpetuate each other in creating and

exacerbating experiences of distress. The next section will review literature on the prevailing theories of gender identity as well as the limited existing body of research on the relationship between vulvodinia, gender identity, and experiences of distress related to gender identity, specifically negative appraisals of gender identity.

Gender Identity and Vulvodinia

Given the very intimate nature of vulvodinia, it is important to consider its impact upon gender identity and the ways in which women with this condition might be at risk for negative gender evaluation. However, it is important to first define gender identity and describe the predominant theories of gender identity development, so as to better contextualize the ways in which vulvodinia may prove damaging to heterosexual women's meaning making processes around this construct.

Theories of Gender Identity Development

According to the American Psychological Association's (APA) Guidelines for Psychological Practice with Lesbian, Gay, and Bisexual Clients (2011) gender "refers to the attitudes, feelings, and behaviors that a given culture associates with a person's biological sex" (<http://www.apa.org/pi/lgbt/resources/guidelines.aspx>); while gender identity is defined as "one's sense of oneself as male, female, or transgender" (<http://www.apa.org/pi/lgbt/resources/guidelines.aspx>). Much research has been conducted on the development of gender identity with theories being generated from numerous perspectives, including biological, cognitive-developmental, social cognitive theory, and gender schema theory (Bem, 1981; Bussey & Bandura, 1999; Martin, Ruble, & Szkrybalo, 2002).

Biological Theories

Biological theories of gender identity development emphasize the influence of hormones and genes upon adoption of sex related attitudes, beliefs, and behaviors (Bussey & Bandura, 1999). Evolutionary psychology posits that gender identity is “ancestrally programmed” (Bussey & Bandura, 1999, p. 679) in that differentiation of behavior between males and females necessarily contributes to the perpetuation of the species. As such, evolutionary psychologists believe that gender differentiation is a result of long standing differences in behaviors that serve to generate offspring and thus, the future of their species. Research in this area tends to investigate behaviors and beliefs related to mating behaviors and preferences, parental roles, and genetic disposition of men towards aggression and women towards nurturing (Archer, 1996; Buss, 1995). For example, there is significant support for the finding that men tend to prefer young, healthy, and physically attractive women, while women tend to prefer men who are financially stable since they are most likely well resourced to provide for offspring (Buss & Schmitt, 1993).

Beyond genetic explanations of gender differentiation and adoption of sex specific behaviors, some researchers have purported hormones may also play a significant role in gender identity. For example, hormones affect the organization of neural substrates in the brain, including lateralization of certain brain functions (Bussey & Bandura, 1999). Upon investigation of differences in brain lateralization between males and females, some research has demonstrated that females exhibit less lateral brain specialization compared to males, which may account for gender differences in cognitive processing (Bryden, 1988). In other words, hormones and subsequent brain lateralization may contribute to females’ purported tendencies to perform better

on verbal tasks and males' purported tendencies to perform better on mathematical tasks (Hyde, Fennema, & Lamon, 1990).

However, biological theories are limited in that they offer a very narrow scope of gender identity, such that attitudes and behaviors related to sex are genetically predisposed and ancestrally preprogrammed solely for the proliferation of the species (Bussey & Bandura, 1999). Thus, at the core, biological theories maintain that males' and females' actions serve to perpetuate the species via reproduction and protection of offspring. Furthermore, they do not take into account changing roles of both men and women in contemporary society now that proliferation of the species is much less threatened.

Cognitive-Developmental Theory

Cognitive-developmental theory of gender identity emphasizes stages of cognitive development around gender differentiation. Lawrence Kohlberg (1966) developed this theory by applying "a Piagetian analysis of age-related changes in cognitive structures to the social domain" (Martin et al., 2002, p. 909). As such, Kohlberg generated gendered stages, similar to those of Piaget, in which children must pass before moving onto the next stage of gender development. The basic tenet of Kohlberg's model is gender constancy, or the belief that one's gender is fixed, invariant, and irreversible (Bussey & Bandura, 1999). Upon achievement of gender constancy, children realize that their sex is a permanent attribute of underlying biological properties (e.g., genitalia) and is not contingent upon such superficial characteristics like hair length, clothing, or play activities (Bussey & Bandura, 1999; Kohlberg, 1966).

However, achieving gender constancy requires passing through three discrete levels, or stages, of gender understanding: gender identity, gender stability, and gender consistency. According to Kohlberg (1966), gender identity is achieved when a child is able to label him or

herself as a boy or girl and others as boys, girls, men, and women. Gender stability occurs when a child understands that gender remains constant, or stable, over time. And gender consistency, supposedly achieved around age six or seven, refers to a child's ability to understand that one's gender stays the same regardless of activities or clothing choices (Bussey & Bandura, 1999; Kohlberg, 1966).

Unfortunately, research has failed to support the major principles of Kohlberg's theory time and time again (Bussey & Bandura, 1999; Martin & Little, 1990). For example, Martin and Little (1990) found that children preferred to play with toys traditionally associated with their gender, prior to achieving gender constancy. Furthermore, Bussey and Bandura (1984) found that children tend to model their behavior after same sex models, especially same sex parents. Overall, research has demonstrated that there is no relationship between children's understanding, or achievement of gender constancy and preferences for same gender peers or gender linked activities (Bussey & Bandura, 1984; Carter & Levy, 1988; Huston, 1983; Martin & Little, 1990).

Social Cognitive Theory (SCT)

Bussey and Bandura (1999) were called to work towards developing a more integrative theory in which cognitive constructs, biological underpinnings, and sociocultural structures were accounted for as integral and interrelated factors in the development of gender identity (Martin et al., 2002). As such, Bussey and Bandura expanded upon social learning theory, a theory that suggests children are more likely to attend to and imitate behaviors of those perceived to be like them (i.e., same sex models; Bandura, 1977). Additionally, social learning theory posits that children's behaviors are highly influenced by positive and negative reinforcement and punishment. In other words, if a child's imitation of a model's behavior is reinforced, it is likely

that the child will repeat this behavior; if a child's imitation of a model's behavior is punished, it is likely that the behavior will be extinguished (Bandura, 1977).

In their extension of social learning theory, Bussey and Bandura (1999) moved beyond attention to purely external factors influencing gender identity development, towards a more integrated recognition of the ways in which social environments, individual differences, and behavioral patterns impact attitudes and beliefs about gender. Additionally, the inclusion and recognition of cognitive factor or "internal variables improved the capability of SCT to explain the consistencies and inconsistencies of children's gender-typed behaviors across time and settings over earlier versions of social learning theory" (Martin et al., 2002, p. 904). Bussey and Bandura stressed that children's behavior is more than just imitation of models; rather behavior is a complex amalgamation of cognitive processes and role-modeling allowing for enhanced adaptability to new situations. For instance, parents or other significant models may encourage children to engage in more gender-egalitarian behaviors, while they are actually modeling more highly gender-typed behaviors. Thus, within SCT, incongruence between what is instructed and what is modeled "could be used by children to discern whether and under what conditions modeled behaviors and attitudes should be adopted, again providing for greater adaptation and complexity than simple imitation" (Martin et al., 2002, p. 905).

Another important distinction of SCT and an extension beyond social learning theory is the notion of self-efficacy, or a child's belief in his or her abilities to effect desired outcomes through gender-typed or gender-neutral behaviors (Bussey & Bandura, 1999; Martin et al., 2002). Bussey and Bandura (1999) assert that beliefs around self-efficacy develop and progress as a result of a combination of two critical factors: 1) observations of models successfully engaging in gender-linked activities and behaviors; and 2) gradual mastery of gender-linked

behaviors. Additionally, the authors believe that self-efficacy plays an important role in cognitive development. They purport that children's behaviors eventually shift from being wholly influenced and regulated by external factors towards more internal influences and regulation. More specifically, SCT claims that, once children have internalized societal and cultural proscriptions of gender roles (purported to occur in early childhood), they develop a set of internalized standards regarding gender-linked activities and behaviors. Thus, based on those internal standards, children begin to judge their own behaviors, engaging in subsequent self-praise or self-criticism when behaviors are judged as meeting those internal gendered standards and expectations or not (Bussey & Bandura, 1999). Beliefs about self-efficacy appear to be "important in determining whether children emit and persevere in gender-typed behaviors once they have established an internal basis for evaluating themselves" (Martin et al., 2002, p. 905). Moreover, generation of internal standards of gender roles and gendered behavior appear to offer explanations as to why some children continually engage in gender-typed activities or adhere to gender-typed attitudes despite efforts by parents or other significant models to alter these attitudes and behaviors (Bussey & Bandura, 1999; Martin et al., 2002).

However, critics of SCT point out several limitations and gaps in the theory. To begin with, Bussey and Bandura (1999) failed to offer an explanation or description as to how external standards of gender roles or gender-typed behaviors in children become internalized into personal standards of gendered conduct (Martin et al., 2002). Furthermore, there is no elucidation as to children's motivation for the acquisition of information related to gender roles and standards of gender conduct. Martin et al. (2002) highlight the fact that in their explanations of self-efficacy, Bussey and Bandura do not address "fundamental questions about the motivational underpinnings of children's selective attention to same-sex models and their search

for information about which gender domains are appropriate for them, both of which are needed to create self-evaluative standards and provide direction to self-efficacy” (p. 906). Finally, critics of SCT argue that Bussey and Bandura do not sufficiently describe how children selectively attend to same-sex models and associate each sex with gender-typing behaviors prior the development of and ability to correctly apply gender labels to others and themselves (Martin et al., 2002). In other words, the authors neglected to address how children come to differentiate the sexes before first developing a basic understanding of gender. This oversight is problematic because Bussey and Bandura purported that it is not essential for children to recognize similarities in same-sex models before imitating gender-typed behaviors. However, “[i]t would seem that children must be able to differentiate the sexes along some dimension(s) and know which of the two sexes is more ‘like them’ if they are to attend to and imitate the behavior of same-sex models” (Martin et al., 2002, p. 906). As such, SCT appears to offer an incomplete depiction of gender identity development, lacking important elaboration on how gender standards are internalized, the ways in which self-efficacy directs motivation for and attention towards same-sex models of gender-typed behaviors, and how children learn to differentiate the sexes before reaching that cognitive milestone. Fortunately, gender schema theory seems to more adequately address the gaps of SCT, as well as providing detailed accounts as to how children develop gender schemas and the ways in which these cognitive processes “facilitate understanding of how and when gender concepts are applied in children’s behavior and thinking” (Martin et al., 2002, p. 913).

Gender Schema Theory

Gender schema theory combines principles of cognitive developmental theory with social learning theory to explain gender identity development and differentiation. Sandra Bem

developed gender schema theory based on her belief that individuals' gender identity emerges from their cognitive development and social influences (Bem, 1983). First of all, it is important to understand what is meant by the term 'schema.' A schema is a cognitive structure that serves to organize and guide one's perceptions based on a network of associations and categories (Bem, 1981, 1983; Bussey & Bandura, 1999). And, schematic information processing refers to the ways in which individuals organize and structure meaning when presented with data and stimuli, indicating a readiness to sort information into categories based on some particular feature (Bem, 1983).

Thus, a gender schema is an "organized network of mental associations representing information about themselves and the sexes" (Martin et al., 2002, p. 911); and gender schematic processing involves spontaneously organizing behaviors and attributes into feminine and masculine categories irrespective of their differences on a variety of dimensions unrelated to gender (Bem, 1981, 1983). Bem (1981, 1983) proposed that sex-typing, or the categorization of people based on their appearance or behavior according to socially constructed perceptions of what is typical or appropriate for each sex, is to some extent, a result of children's abilities to assimilate their own self-concept into the gender schema. As children learn the content matter of their society or culture's gender schema, they acquire knowledge about which features are to be linked with their own sex and subsequently, with themselves. However, this requires more than simply learning the defined relationship between each sex and associated dimensions or features, for example that boys are to be strong and that girls are weak, but rather, involves a deeper understanding that dimensions are differentially applicable to both sexes (Bem, 1983). Therefore, the strong-weak dimension itself is absent from the schema that is to be applied to girls in the same way that the nurturance dimension is absent from the schema that is to be applied to boys.

Rather, it is more the fact that the adults in children's lives seldom remark upon the strength of young girls or how nurturing young boys can be, despite children's readiness and capacity to recognize these attributes in the 'appropriate' sex (Bem, 1981, 1983).

Furthermore, while children are learning how to differentiate the sexes along dimensions, they are also learning how to apply the "same schematic selectivity to the self" (Bem, 1981, p. 355) and choose from among the many possible dimensions of human personality traits the particular subset that is applicable to or appropriate for their own sex. In this way, children's sense of self becomes sex-typed and the two sexes become differentiated not only in degree but in kind as well (Bem, 1983). Additionally, children begin to evaluate their own adequacy as a male or female in accordance with the gender schema, matching their own attitudes, behaviors preferences, and personal attributes against those of their gender schema. As such, the gender schema evolves into the indoctrinated and prescriptive standards of appropriate gender role conduct that then serves as an important "motivational factor that prompts an individual to regulate his or her behaviors so that it conforms to cultural definitions of femaleness and maleness" (Bem, 1983, p. 605).

Thus, predicated on the core concept of the gender schema, Bem (1981) outlined specific defining features and tenets of her theory. Firstly, Bem suggests that gender schemas develop through an individuals' observation of social and cultural classification and categorization of femininity and masculinity rooted in biological differences, social roles and expectations, and socially prescribed traits and characteristic. Secondly, gender schema theory posits that individuals cognitively process, sort, and categorize new information in their environments based on degrees of femaleness and maleness. Thirdly, gender identity is an amalgamation of individuals' categorization of and conformity to social and cultural standards of appropriate

gender role conduct. Finally, gender schema theory emphasizes process rather than content. Since sex-typed individuals are viewed as processing information and regulating their behavior according to those culturally and socially determined definitions of femininity and masculinity, “the process of dividing the world into feminine and masculine categories – and not the contents of the categories – is central to the theory” (Bem, 1983, p. 605). Hence, gender schema underscores the importance of understanding how children use these schemas to organize memory and more clearly depict how schemas influence children’s attention, motivation, impressions of others, and behavior (Martin et al., 2002).

However, gender schema theory is not without limitations. Critics of the theory argue that gender schemas are abstract constructs, proving difficult to measure and define. Additionally, it has been argued that gender schema theory is more directly applicable to predicting thinking, memory, inferences about others, and attention with much less applicability in predicting behaviors (Bussey & Bandura, 1999; Martin et al., 2002)

Summary

In summary, there are numerous theories of gender identity representing various mechanisms of identity development including biological, cognitive-development, social cognitive, and gender schema models. There are also limitations and criticisms of each theory, therein representing the fact that gender identity development is a complex, multifaceted, somewhat nebulous set of processes that researchers are still attempting to further clarify and better understand.

The following section reviews existing literature on gender identity distress experiences and vulvodinia. When I refer to gender identity distress, I am referring to the phenomenon more highly gender schematic heterosexual men and women may experience in light of not feeling as

though they are meeting gender role expectations and standards (Bem, 1983), which is different from gender identity distress characteristic of gender dysphoria disorder and those individuals who identify more strongly with the opposite sex.

Gender Identity Distress and Vulvodynia

Current research shows that heterosexual women with vulvodynia may experience distress related to their gender identity, or sense of self as a woman (Ayling & Ussher, 2008; Kaler, 2006). For these women, they may be left to reconstruct or renegotiate what being a woman means to them, a task that may have important implications for their sense of self-worth and purpose (Ayling & Ussher, 2008; Kaler, 2006).

In her two-year study on vulvar pain, heterosexuality, and gender, Kaler (2006) interviewed 20 women as to how “gender and heterosexuality are immanent in the lived experiences of women with vulvodynia” (p. 52). Kaler’s wide spread recruitment efforts resulted in many more responses from interested individuals than anticipated. Therefore, in addition to the 20 one-on-one interviews, Kaler also collected data via an interactive website for individuals who wanted to participate but could not be interviewed. Through this website, the interview protocol was made available in such a way that participants could respond to the questions through written rather than spoken word. Therefore, Kaler’s findings are based on data gathered from a total of 70 heterosexual women with vulvodynia (20 individual interviews and 50 internet-based responses).

Overall, Kaler (2006) found two overarching themes she labeled as ‘real sex and ‘real women.’ The theme of ‘real sex’ emerged from women’s accounts of feeling as though, since they were often not engaging in “penetrative penile-vaginal intercourse” (Kaler, 2006, p. 58) with their male partners, then they were not having real sex. Other forms of sexual intimacy,

such as oral sex or digital stimulation, were not considered real sex due to lack of penile penetration. In her feminist analysis of the phenomenon, Kaler interpreted the theme of real sex as emerging from women's feelings of violating an important and well-established social norm of heterosexual relationships. She used the term "coital imperative" (first coined by Jackson in 1984) to reflect those "sociocultural pressures and symbolic logic which define penis-in-vagina intercourse as the most natural, normal, and healthy form of sexual behavior" (Kaler, 2006, 58). Therefore, any deviation from this imperative was perceived as unusual, abnormal, or a potential threat to the heterosexual status quo.

Kaler's (2006) second emergent theme of 'real women' reflected the expressed notion that, if heterosexual women cannot or choose not to engage in sexual intercourse, then they are somehow less than whole, or incomplete human females. From a feminist, sociological perspective, Kaler viewed this belief as resulting from the inability to fulfill expected heterosexual demands, thus resulting in heterosexual women's impaired ability to develop a feminine identity equally affected (i.e., I'm less than a woman or an incomplete woman). In her interpretations of this finding, Kaler stated that, "This sense of being 'de-gendered' was explicitly linked to the inability to perform sexual acts. Women's inability to 'perform' the paradigmatic heterosexual act of intercourse damaged their ability to claim womanhood as an identity" (2006, p. 61). Furthermore, some of the respondents discussed feeling that having vulvodynia had robbed them of certain life experiences, such as the consummation of a marriage or natural conception of a child. Kaler found that, rather than identifying ways in which participants felt womanly, such as caring for others or being a loving partner, women were much more verbose in their descriptions of those areas in which they perceived a lack of femininity (i.e., heterosexual partner).

Similarly, Ayling and Ussher (2008) found that participants who took part in their qualitative study discussed their feelings of being inadequate heterosexual women. Most of their responses reflected ideas and beliefs that men's sexual enjoyment and satisfaction should supersede that of women, regardless of their experience of pain and pleasure. However, in contrast to Kaler's (2006) findings, Ayling and Ussher found that their seven interviewees more easily identified "accounts of resistance" (2008, p. 300). For instance, several respondents spoke positively about their ability to care well for others by providing support and nurturance to those around them. In this case, the authors interpreted these findings as evidence of heterosexual women's abilities to renegotiate their definitions of womanhood to be more inclusive of all kinds of gendered experiences rather than simply those associated with heterosexuality.

Other studies investigating the impact sexual difficulty, dysfunction, or impairment have had upon gender identity have resulted in similar findings, such that heterosexual women felt somehow less than their unaffected counterparts. For example, in 2009, Hinchliff, Gott, and Wylie investigated the impact loss of sexual desire had upon their female participants' gender identity. The authors conducted in-depth, semi-structured interviews with 17 heterosexual women who sought treatment from a psychosexual clinic in northern England. Hinchliff et al. found that nearly all of the participants considered themselves different or abnormal, even using the word freak, when comparing themselves to other women. It was suggested that this sense of abnormality might have been a result of messages about normal sexuality in popular media, as well as interpersonal interactions or discussions with other heterosexual women about their sexuality (Hinchliff et al., 2009). It seemed that these feelings of being different and defective resulted in or perpetuated existing feelings of alienation, often leading some of the respondents to socially withdraw from family and friends (Hinchliff et al., 2009).

Study participants also discussed their attempts at renegotiation of self as woman, but responses were much more negative than those of the respondents from Ayling and Ussher's (2008) qualitative study (Hinchliff et al., 2009). For example, Hinchliff et al. (2009) reported that their participants described the experience of loss of sexual desire as being "sexually dead" (p. 459); therein, reflecting a type of acceptance or resignation that, for some of the 17 women, loss of sexual desire equated to loss of identity as a woman. However, Hinchliff et al. did find that a small subset of participants did not report any negative effects of loss of sexual desire upon gender identity. Although the authors did not speculate as to why this might be the case for these women, they did note that, despite "cultural expectations of womanhood and medical discourses, both of which have shaped and defined what is considered sexually and behaviorally 'normal' for heterosexual women" (Hinchliff et al., 2009, p. 460), not all women with loss of sexual desire experienced ill effects on perception of self as a woman.

Limitations and Critiques

Though much of the data collected within this body of literature is qualitative in nature, the descriptions of each participant's experiences with sexual functioning, vulvar pain, and gender identity were immensely rich and in-depth, providing readers with greater understanding as to the potentially deleterious effects women's identities may incur. However, qualitative data is greatly limited in its applicability to anyone else outside the participants of the specific study. Furthermore, when demographic data is withheld or not adequately addressed, the relevance of findings for study participants may be equally limited in terms of reader interpretation.

For example, Kaler (2006) provides very limited information about her study participants; rather she states that the "profile of the women I interviewed and who participated on the website fits the profile of the 'typical vulvodynia patient' in the medical literature, but is

probably not typical of the true population of women with vulvar pain” (p. 56). She reported on education levels but made no statement on socioeconomic status, other than it was wide ranging. She did include sexual orientation for the four respondents who self-identified as bi-sexual and one respondent who identified as lesbian, but noted that not every respondent indicated sexual orientation. Therefore, it cannot be known whether Kaler’s findings over-, adequately, or under-represent women with vulvodynia of different sexual orientations, information that could be greatly informative in understanding women’s experiences of vulvodynia within and across sexual orientations.

In addressing limitations, Kaler (2006) stated, “In retrospect, I wish I had collected more demographic information, which might have allowed me to think about how the experience of heterogender is stratified along dimensions such as age, race, sexuality, and religion” (p.56). Another important consideration is the utility of Kaler’s findings on the three strategies respondents implemented to restructure or readjust perceptions of heterosexuality and womanhood. Kaler identified the first strategy as heterosexual women’s attempts to find a good man who would demonstrate love and support despite ability to provide sexual pleasure and satisfaction, thus accepting her womanly deficits. Secondly, Kaler posited that her participants worked to make a paradigmatic shift in making meaning around what it means to be a woman. By using this strategy, women with vulvodynia attempt to extricate sexuality from their definitions of womanhood by placing other aspects of “essential womanhood” (Kaler, 2006, p. 68), such as motherhood and interpersonal sensitivity, above sexual functioning. Lastly, Kaler found that some women engaged in questioning the widely accepted notion that gender and sexuality are manifested through the act of sexual intercourse. However, Kaler noted feeling disappointed that this rejection of a bodily expression of gender was not more often targeted at

society. She had hoped that heterosexual women with vulvodynia would be more “ideologically motivated in their expressions of discontent” (2006, p. 69), taking more of a social advocacy stance, as opposed to harboring ill feelings towards uncaring medical professionals, previous partners, or inconsiderate friends and family members. Perhaps if Kaler (2006) had collected and analyzed more demographic information, her findings and recommendations might serve to be more utilitarian, not only for her 20 interviewees and her 50 web respondents, but could also stand as a basis by which to further investigate this phenomenon in women of similar and differing backgrounds.

In contrast, Ayling and Ussher (2008) gathered much more comprehensive background information on their seven heterosexual participants, thereby providing more valuable understanding as to how these women experienced life with vulvodynia. Here again, since this study used qualitative methodologies to collect, analyze, and interpret data, generalizability is limited, but by providing demographic data, interpretations can be made about participants with more confidence given the inclusion of contextual variables. Despite the value and richness of the data collected, this study is not without limitations. For example, Ayling and Ussher found that most of the respondents reported maintaining supportive and strong relationships with their male sexual partner, but they could not account for this finding since it was not a phenomenon they had intended to investigate. The authors suggested that the male partners of women who perceived themselves as inadequate likely did not experience that phenomenon. Regardless of hypothesized explanations, the authors cannot be sure about the nature of this finding since they did not include interview questions related to potential “sustaining features of heterosexual relationships” (Ayling & Ussher, 2008, p. 301). In recognizing the limitations of their study, Ayling and Ussher (2008) suggested that future research include interviewing women with

vulvodynia who represented variations in symptom duration, sexual orientations, varied relational contexts (i.e., unpartnered women), and if possible, gathering the subjective experiences of women with vulvodynia who have not yet sought treatment from professionals.

Accordingly, in their study on the effects of sexual desire loss upon gender identity, Hinchliff et al. (2009) identified areas of further exploration related to findings that could not be accounted for within their research endeavor. For instance, the authors noted that this study did not address potential factors that, separate from the loss of sexual desire, may have also impacted participants' sense of womanhood, including such variables as "the responsibilities and pressures of parenthood, a history of sexual abuse, prior depression, and poor relationship quality, all of which featured in participants' accounts and some of which were given as reasons for their desire loss" (Hinchliff, et al., 2009, p.462). Furthermore, even though Hinchliff et al. gathered relevant demographic data from their heterosexual interviewees, their use of a qualitative study design reduces applicability beyond the women of this study. Additionally, all 17 subjects were currently partnered (either married or cohabitating with their partners). Thus, another limitation of this study is the lack of perspective from unpartnered women with sexual desire loss. Moreover, 16 of the 17 participants identified as Caucasian, with only one woman identifying as African American, clearly indicating the need for future research to examine women's experiences from all ethnic backgrounds, as loss of sexual desire is not limited to Caucasian women.

It is important to note that Hinchliff et al. (2009), as well as Ayling and Ussher (2008), interviewed women from the United Kingdom and Australia, respectively. Thus, interpretations should be made with caution when considering using such data to inform understanding or work with heterosexual women with vulvodynia and/or sexual dysfunction from different geographical

locations, with different cultural/societal norms, and different levels of and access to healthcare. And, despite gathering data from women in North America, Kaler's (2006) lack of other relevant participant information allows for very minimal interpretative usefulness for women within that geographical region.

Lastly, despite describing their interpretative lenses with regards to their findings, none of the studies mentioned above offered an explicit framework or theory by which to contextualize the concept of gender identity. As such, it is difficult to fully comprehend how gender identity distress may manifest in light of vulvodynia without first offering a theory of gender identity within which to ground the reader.

Summary

The literature clearly reflects that many heterosexual women with vulvodynia or other vulvar pain experience increased psychological, relational, and sexual functioning distress. Additionally, research suggests that some women with vulvodynia negatively appraise their gender identity as a result of perceived deviation from traditional gender norms and expectations. Furthermore, given the highly sensitive and idiosyncratic nature of the experience of vulvodynia, most of the literature is qualitative in nature, allowing women opportunities to describe and share their experiences of the chronic pain condition and the ways in which it has impacted not only their worldview but also their perception of gender and their own gender identity.

However, qualitative research, although immensely fruitful in providing detailed descriptions and enhanced understanding of a particular lived experience, lack generalizability and more wide spread applicability. One way to work towards building greater applicability is to continue to conduct well-constructed qualitative studies with participants who are similar and dissimilar from those of previous studies. Thus, the purpose of this qualitative study was to

explore further how vulvodynia impacts women's gender identity and the factors that may negatively or positively influence appraisal of gender identity.

Research Aim and Questions

The aim of this study was to develop a greater understanding as to the ways in which vulvodynia affects women's gender identity. Additionally, I was interested in learning more about factors that might serve to put women at risk or protect against negative evaluations of womanhood. Therefore, the research questions guiding this study are:

1. What impact does vulvodynia have upon women's gender identity?
2. How do women with vulvodynia define "womanhood?"
3. What factors negatively impact gender identity?
4. What factors preserve and/or enhance gender identity?

This research will contribute to the existing body of literature by exploring the lived experience of vulvodynia in women from around the U.S. Furthermore, scrupulous examination and exploration as to the ways in which vulvodynia affects gender identity in women with vulvodynia was the primary focus of the study, as opposed to examining gender identity within the context of relationships, as has been the case in previous research on gender identity with this population. I explored womanhood across multiple contexts and life domains so as to create a holistic and all-encompassing depiction of what womanhood looked like for these four women with vulvodynia. Finally, for the purposes of this dissertation and the resultant findings from data collection, I used gender schema theory as my primary lens for data analysis and interpretation.

Chapter 3: Methods

Rationale for Qualitative Research Design

This study lends itself best to a qualitative inquiry. Given that the purpose of this study was to build greater understanding and insight about the impact of vulvodynia on women's gender identity, any attempt to categorize or quantify participant responses would be antithetical to the research aim. Unfortunately, within the social sciences, it seems that quantitative approaches to research are more highly valued, as evidenced by higher rates of publication, with the randomized controlled trial considered the gold standard for design and methodology (Yin, 2011). Despite the potential for determining causality and allowing for greater generalizability, quantitative designs do not afford the same opportunities for richness and depth when describing social phenomena (Yin, 2011).

Qualitative studies, though, often give voice to marginalized individuals who might not otherwise have an opportunity to express their perceptions of some lived experience. Furthermore, despite very real limitations in the application of findings beyond the unique parameters of the study, qualitative studies and subsequent findings still hold relevant significance: they provide a context for initiating important discourses about a particular social phenomenon or lived experience, as well as providing a framework for professionals and researchers to explore meaning making processes of said phenomenon with those they work or study (Yin, 2011).

Validity in Qualitative Research

Within qualitative research, validity tends to be more of the focus than reliability in order to ensure that accounts from both the participant and researcher are credible, accurate, and trustworthy (Creswell & Plano Clark, 2011). According to Maxwell (1992), there are five

categories with which to measure the validity of qualitative research: descriptive validity, interpretative validity, theoretical validity, generalizability, and evaluative validity. Descriptive validity, also termed credibility by Glaser and Strauss (1967), refers to the accuracy of the data (Maxwell, 1992), or the accuracy in reporting descriptive information, such as events, behaviors, time, and place (Johnson & Christensen, 2013). Thus, the integrity of descriptive validity lies within verbatim transcription of participants' accounts. Any omission of data, no matter how insignificant it may appear to the researcher, "serves to threaten descriptive validity, the very base on which all the other forms of validity are built" (Maxwell, 1992, p. 287).

Interpretative validity refers to the degree to which participants' meanings, viewpoints, and reflections are accurately understood and reported by the researcher (Maxwell, 1992). With interpretative validity, it is imperative that the interpretations are based on the participants' perspectives and not those of the researcher (Maxwell, 1992). In order to ensure the highest level of interpretative validity, researchers must look to the transcripts for clues that offer evidence or justifiability of a particular inference or interpretation. In doing so, the reader can see how the researcher came to such an interpretation based on both participant excerpt and researcher transparency in addressing biases (Maxwell, 1992). Thus, another critical factor in ensuring interpretative validity is researcher reflexivity, in which the researcher explicitly outlines her assumptions, dispositions, and biases regarding the phenomenon of interest and how such constructs may impact or influence her inferences and subsequent interpretations of the data (Merriam, 2009). By taking a clear, detailed stance of transparency, readers are afforded a context within which to better understand the researcher's interpretative processes (Merriam, 2009). Maxwell (2005) put it best when he explained that the reason for making researcher assumptions, biases, and perspectives clear to the reader is not to eliminate "variance between

researchers in values and expectations they bring to the study, but with understanding how a particular researcher's values and expectations influence the conduct and conclusions of the study" (p. 108).

Theoretical validity "explicitly addresses the theoretical constructions that the researcher brings to, or develops during the study" (Maxwell, 1992, p. 291). This type of validity serves to evaluate the validity of the researcher's concepts and the theorized relationships among the concepts in context with the phenomenon being studied (Maxwell, 1992). In other words, theoretical validity refers to the degree to which theoretical explanations that are guiding or developed from the study actually fit the theory (Maxwell, 1992). Auerbach and Silverman (2003) refer to theoretical validity as "coherence" (p. 85) meaning that the "patterns, concepts, categories, properties, and dimensions" (p. 85) must fit together to create the constructs, which must result in an accurate re-telling of the participants' stories and the phenomenon in question.

Generalizability refers to the degree to which a study's resulting theory applies universally (Maxwell, 1992). This type of validity, also known as transferability (Lincoln & Guba, 1985; Merriam, 2009), evaluates the extent to which the study-generated theory transfers beyond the sample population to the population at large. Within qualitative research, generalizability is concerned with the extent to which the findings of a particular study can be applied to other situations (Merriam, 2009). Maxwell (1992) outlines two types of generalizability, internal and external. Internal generalizability refers to whether generalizability exists within the community that has been studied, while external generalizability refers to whether the findings generalize to settings or situations that were not investigated (Maxwell, 1992). However, generalizability within qualitative research tends to prove problematic as findings or theories may only apply to the specific study participants or small groups of similar

individuals (Maxwell, 1992). Merriam (2009) suggested that the concept of generalizability might be best understood from the reader's perspective. She proposed "leaving the extent to which a study's findings apply to other situations up to the people in those situations. The person who reads the study decides whether the findings can apply to his or her particular situation" (Merriam, 2009, p. 226). Therefore, in order to foster strong generalizability, especially reader generalizability, the researcher must strive for rich, thick descriptions of the phenomenon in question; by doing so, the researcher provides enough description to contextualize the study such that the reader can determine the extent to which her situation matches the research context and whether the findings can be transferred (Merriam, 2009).

Finally, evaluative validity refers to the extent to which the researcher was able to describe and understand the data without being evaluative or judgmental (Maxwell, 1992). This type of validity seeks to measure the degree to which the findings of a study have been determined by the researcher's own understanding of the phenomenon rather than the collected data (i.e., participants' stories). In this way, evaluative validity moves away from the data itself and tries to assess the evaluations drawn by the researchers (Maxwell, 1992). This type of validity is unique "in that it involves the application of an evaluative framework to the objects of the study, rather than a descriptive, interpretive, or explanatory one" (Maxwell, 1992, p. 295). However, the matter of how the researcher evaluates the data she collects may be questionable as to how well grounded in the data the evaluation was made, which is why the researcher is best served by taking a transparent stance in explicitly acknowledging biases and assumptions and their potential impact upon evaluative validity.

Although the qualitative researcher must work to ensure that the rigors of scientific inquiry are intact as much as reasonably possible, the worldview, or fundamental set of beliefs or

assumptions the researcher uses to guide the study (Creswell & Plano Clark, 2011), tends to place emphasis upon certain forms of validity above others. Thus, it is critical that the researcher understand those guiding sets of assumptions and biases within her worldview, in order to assure the reader that the rigors of scientific inquiry were met.

Constructivist Worldview

The philosophical framework, or worldview, through which I analyzed and interpreted data, was the constructivist worldview. According to Creswell and Plano Clark (2011), this worldview is most often “associated with qualitative approaches” (p. 40) in which understanding or meaning of a chosen phenomenon is “formed through participants and their subjective views” (p. 40). I found this worldview particularly congruent with my research agenda since constructivism holds a fundamental principle that research participants construct meaning of some phenomena “shaped by social interactions with others and from their own personal histories” (Creswell & Plano Clark, 2011, p. 40). From this perspective, “research is shaped from the bottom up – from individual perspectives to broad patterns and, ultimately, to broad understandings” (Creswell & Plano Clark, 2011, p. 40).

Philosophical underpinnings. With respect to ontology, or the ways in which individuals construct meaning around the nature of reality and existence, a constructivist worldview “assumes that reality is socially constructed, that is, there is no single, observable reality” (Merriam, 2009, p. 8). In other words, constructivism holds that there are multiple realities and interpretations of a single event or lived experience. Thus, constructivist researchers seek out multiple perspectives from participants, most often developed through multiple interviews and illustrated via direct quotes (Creswell & Plano Clark, 2011). Epistemological foundations of constructivism, or the ways in which individuals construct beliefs about the nature

of knowledge, are closely tied to the nature of the relationship between the researcher and the research participant (Creswell & Plano Clark, 2011). Within this framework, the researcher attains knowledge or understanding of an individual's perspective through careful examination and interpretation of that individual's description and meaning-making processes of some lived experience or phenomenon. In terms of methodology, or the process of collecting data through research endeavors, constructivism takes an inductive approach, therein working from a bottom up framework to build theories or generalizations based on multiple, individual accounts of some lived experience (Creswell & Plano Clark, 2011). Lastly, regarding axiology, or the role of values, constructivist researchers recognize and acknowledge their biases, actively discussing them and the ways in which they impact interpretations (Creswell & Plano Clark, 2011).

Interpretative Phenomenological Analysis (IPA)

Why IPA. Interpretative Phenomenological Analysis (IPA) is a form of qualitative research with an idiographic approach to inquiry, in that the aim is to develop in-depth understanding as to how an individual, within a particular context, makes sense of or constructs meaning around personal and social experiences and events (Smith & Osborn, 2008). By definition, phenomenology is a philosophical approach to the study of experience (Smith, Flowers, & Larkin, 2009). It provides a framework within which to understand and examine a particular lived experience. Furthermore, IPA researchers strive to conduct studies in such a way that, as far as possible, enables the lived experience to be expressed in its own terms, rather than predetermined classification systems (Smith, Flowers, & Larkin, 2009). Based on the phenomenological philosophy and the fact that it was originally developed for qualitative health psychology, IPA was chosen as the qualitative methodology for this study (Smith, 1996).

Jonathan A. Smith (1996) developed IPA upon recognition of the importance of understanding patients' perceptions of and interpretation of their bodily experiences, the meanings with which they assign to them, and the value this data holds for health psychologists and their work. IPA offers opportunities to explore these subjective experiences, and helps researchers to describe and understand the respondents' account of the processes by which they make sense of their experiences. Furthermore, the vast majority of published work using IPA has been in the field of health psychology (Brocki & Weardon, 2006).

IPA continues to garner compelling support that it is particularly suitable in health psychology research and most notably at illuminating processes operating within models as opposed to the traditional focus on outcome measures (Brocki & Weardon, 2006). For example, Flowers et al. (1997) used their analysis of sexual decision-making in gay men to highlight the inadequacies in psychological theories relating to sexual health and sexual health promotion. Thus, the inductive nature of IPA allows authors to discuss their analysis in the light of varied existing psychological theories, models, or approaches. Additionally, IPA is congruent with the increase in patient-centered research and is in line with increased efforts within the National Health Service to make greater efforts to acknowledge the voices of service-users (Brocki & Weardon, 2006).

Description of IPA. As is made evident by its name, IPA is theoretically rooted in phenomenology and as such, involves thorough examination of an individual's lived experience (Smith & Osborn, 2008). Edmund Husserl (1859-1938), the founder of phenomenology, held the belief that intellectual disciplines lacked scientific methods of inquiry that could elucidate the nature of their fundamental concepts and constructs (Ashworth, 2008). At the core of Husserl's phenomenology was a commitment to rejecting the widely recognized presumption that there

must be something “behind or underlying or more fundamental than experience” (Ashworth, 2008, p. 11). Thus, upon initiating research endeavors, Husserl called for researchers to begin investigations by ‘bracketing’ or discontinuing the question of a separate, objective reality from subjective experience (Ashworth, 2008). Additionally, Husserl coined the term ‘lifeworld’ to represent the summation of subjective experience as consisting of a system of interrelated meanings (Ashworth, 2008). Therefore, phenomenological researchers work to build careful understanding of an individual’s lived experience, or lifeworld, by placing greater value upon “an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself” (Smith & Osborn, 2008, p. 53).

Within IPA, equal emphasis is placed upon the interpretive role of the researcher in his or her pursuit of gaining an insider’s perspective into one’s subjective world; thus, IPA is a synthesis of phenomenology and hermeneutics, or theory of interpretation. Martin Heidegger (1889-1976) understood hermeneutics to be ontological in nature, in that it served as a framework by which individuals constructed meaning or understanding about the nature of reality (Ashworth, 2008). Heidegger believed that “we live in an interpreted world and are ourselves hermeneutic; we are interpreters, understanders” (Ashworth, 2008, p. 19). In this way, researchers using IPA must be keenly aware of personal biases and the ways in which such biases might affect interpretative processes and analyses (Creswell & Plano Clark, 2011). Smith and Osborn (2008) call this dynamic process a “two-stage interpretation process, or a double hermeneutic” (p. 53). Similarly, Larkin, Watts, and Clifton (2006) refer to the two aims of IPA: first, to provide an opportunity for an individual to describe his or her lifeworld, and second, to embark upon an interpretative analysis of said lifeworld and the sociocultural context within

which it exists. However, the ultimate task of the IPA researcher is to try to make sense of an individual trying to make sense of his or her lived experience.

Sampling

Participants were sampled via a purposive sampling method. More specifically, a convenience, criterion sampling approach was utilized to gather data for qualitative interviews. In other words, I intentionally recruited participants who had been diagnosed with vulvodynia given vulvodynia was the criterion or construct of interest. With respect to the number of participants, Creswell and Plano Clark (2011) suggest that “rather than select a large number of people or sites, the qualitative researcher identifies and recruits a small number that will provide in-depth information about the central phenomenon or concept being explored in the study” (p. 174). By studying individuals who were willing to offer maximum disclosure regarding their lived experience of vulvodynia and its impact upon their gender identity, I was able to maximize the development of rich and in-depth understanding of this phenomenon. It is this value of enhanced understanding that distinguishes IPA and other qualitative methods from quantitative methods: “The qualitative idea is not to generalize from the sample (as in quantitative research) but to develop an in-depth understanding of a few people – the larger the number of people, the less detail that typically can emerge from any one individual” (Creswell & Plano Clark, 2011, p. 174). As such, Creswell and Plano Clark (2011) suggested that when studying cases with the intention of developing rich and in-depth understanding, a small number of participants, say “4 to 10” (p. 174), is ideal. Thus, in line with IPA and the central value of examining and understanding a particular human experience (Smith, Flowers, & Larkin, 2009), I studied four women with vulvodynia.

Participants

Eligibility. Participants were considered eligible for this study based on the following criteria: 1) had received a diagnosis of vulvodynia from a medical practitioner within the last two years; 2) were between the ages of 25 and 30 years old; 3) identified as heterosexual; 4) had no previous substance abuse/dependence history; 5) had no previous severe mental health history, including, schizophrenia, bipolar disorder, or a personality disorder; and 6) had no concomitant chronic health conditions, including diabetes, MS, ALS, or fibromyalgia. Eligibility criteria were determined in order to study otherwise physically and mentally healthy women with vulvodynia. It was hoped that such criteria would allow for a rich context in which maximum, honest, and candid disclosure would follow. Furthermore, decisions such as age range and receipt of diagnosis within the last two years were based on the fact that such individuals have not been well represented in previous research (Ayling & Ussher, 2008; Khandker et al., 2011; Lamont, Randazzo, Farad, Wilkins, & Farad, 2001; Masheb et al., 2009; Masheb et al., 2005), as well as the hypothesis that women in this age group may at be greater risk for negative appraisals of gender identity since research has demonstrated that women in their late twenties exhibit higher hormone levels, are often involved in stable romantic relationships, and are of peak child bearing age (Brassard, Dupuy, Bergeron, & Shaver, 2015; Chandra, Martinez, Mosher, Abma, & Jones, 2005; Davison, Bell, LaChina, Holden, & Davis, 2008, 2009; Haavio-Mannila & Kontula, 1997). For a more comprehensive description of eligibility criteria, refer to Appendix B for the Telephone Eligibility Screen for Interested Participants.

Recruitment. Recruitment took place on both a local and national level. Locally, fliers and brochures were posted in the Pelvic Pain Clinic, the Department of Obstetrics and Gynecology, and the Department of Rehabilitation Therapies in a large, Midwestern university

hospital. See Appendix A for a sample flier. This hospital and clinics system was chosen as it serves a varied and diverse patient population due to the frequency of out of area patient visits, thereby further reducing potential bias due to convenience sampling. Additionally, local health care providers who treat women with vulvodynia agreed to advertise this study to their patients. Nationally, the National Vulvodynia Association (NVA) posted notices of this study within the NVA newsletter and website. After speaking with the NVA's President, Phyllis Mate, I was informed that women with vulvodynia who belong to the association are very motivated to participate in research and historically have high rates of study participation and completion.

Despite a relatively robust expectation for participant response rates, incentives for participation were offered. Participants were mailed 20 dollars following each interview, and were informed at the outset that they were entitled to compensation even if they discontinued interviews early or did not complete them. However, each woman completed all three interviews, thus each woman was paid in total 60 dollars for their participation.

Interview recruitment timeline. Participant recruitment for individual interviews commenced May of 2014, at which point, fliers and brochures were placed in the three clinics. Clinic directors were contacted four weeks following the first distribution of publicity materials to inquire about the utility and effectiveness of such items, given only one participant had contacted me about participating in the study. This first participant served as the sole participant for the pilot study and thus was not enrolled in the subsequent research study. After another eight weeks, only one other woman contacted me about participation, met all eligibility criteria, and was the first study participant to be enrolled. Thus, due to low participant enrollment rate (n=1) at that time, a notice was placed upon the NVA website and newsletter to invite individuals with vulvodynia to take place in an individual interview via the telephone. Within two weeks of that

notice, three participants were successfully screened and enrolled in the study. Thus, participant recruitment was terminated. In summary, five total women, including the pilot study participant, were screened for eligibility with only four subsequently enrolled into the study as they met all eligibility requirements. The pilot study participant, although meeting all eligibility criteria as well, was not enrolled into the study since her participation was limited to the pilot study only.

Study participants. Following successful eligibility screens, four Caucasian, heterosexual women, between the ages of 25 and 30 years (mean age = 28) were enrolled in this study. Three participants were married (Anna, Alesha, and Melissa) and one participant (Kellie) was involved in a long-term relationship at the time the study was conducted. During the interview process, Anna was six months pregnant with her first child. Melissa was also a mother of two children, but neither Anna nor Alesha had children. Kellie and Anna reported their highest level of education as a Bachelor's degree, while Melissa and Alesha had both obtained Master's degrees. Anna was not currently working due to her decision to quit her marketing job in light of her pregnancy. The other three participants were employed full time: Melissa was an athletic trainer, Kellie worked as a hospital administrator, and Alesha was a teacher. Anna, Alesha, and Melissa all identified as Christian, while Kellie identified as unaffiliated.

Three participants (Melissa, Alesha, and Kellie) reported age at onset of symptoms around their first menses, approximately 12 or 13 years. They all described the experience of using tampons extremely painful and ultimately impossible, looking to other means for menstrual protection during times of menstruation. Anna reported age at symptom onset around 22 years, during her first experience of sexual intercourse. Both Alesha and Melissa were abstinent prior to marriage but only Alesha sought treatment immediately thereafter. Melissa sought treatment later into her twenties following her first pregnancy in which her symptoms

were greatly exacerbated and aggravated. Anna sought treatment approximately six months after marriage, upon her realization that her symptoms were worsening. And Kellie sought treatment approximately three months after her first experience of sexual intercourse. At the time of diagnosis, Alesha and Melissa were both 28, Kellie was 24, and Anna was 23. Table 1 presents a demographic summary description of each participant, while Table 2 presents a summary of vulvodynia specific information.

Table 1. Participant Demographic Information

Pseudonym	Age	Race/Ethnicity	Relationship Status	Children	Highest Level of Education	Current Employment	Religious Affiliation
Anna	25	Caucasian	Married	Pregnant with 1 st child	Bachelor's Degree	Stay at home wife/mom	Christian
Alesha	30	Caucasian	Married	None	Master's Degree	Teacher	Christian
Kellie	26	Caucasian	In a relationship	None	Bachelor's Degree	Hospital Administrator	Unaffiliated
Melissa	30	Caucasian	Married	Two	Master's Degree	Athletic Trainer	Christian

Table 2. History of Vulvodynia

Pseudonym	Age at Onset of Symptoms	Sexual Experience	Age at Diagnosis	Treatment Experiences
Anna	Onset upon first sexual intercourse, age 22	2 sexual partners	23	Lidocaine, physical therapy, dilatory therapy, topical hormone cream chiropractor, yoga, trigger point injections
Alesha	Onset at first menses, age 12-13	Abstinent prior to marriage, 1 sexual partner	28	Lidocaine, topical steroid cream, Gabapentin, physical therapy, dilator therapy, vestibular anesthesia, topical hormone cream, acupuncture
Kellie	Onset at first menses, age 12-13	1 sexual partner	24	Lidocaine, topical steroid cream, Gabapentin, physical therapy, support group
Melissa	Onset at first menses, age 12-13	Abstinent prior to marriage, 1 sexual partner	28	Physical therapy, dilatory therapy, topical hormone cream, relaxation exercises

Materials and Procedure

All participants consented to the conditions of the study, including audiotaping each interview. Each of the three interviews was conducted over the phone in order to accommodate geographical distance. The first interview focused on individuals' "vulvodynia story," in which they were asked to discuss how vulvodynia impacted their lives, their process of diagnosis, their interactions with medical providers, and the impact of vulvodynia upon their body image. The second interview focused on gender identity, the construct of "womanhood," and the impact of vulvodynia upon both. The third interview served as a member check. Prior to the third interview, participants' were sent transcripts of their interviews as well as my analysis (e.g., the super- and subordinate themes) and then asked to discuss whether they felt I accurately captured their lived experience of vulvodynia. Specifically, I asked participants whether they felt I had accurately captured the essence and meaning of their experiences, and if not, to please clarify where I went wrong and help me to correct and better understand what they had originally tried to express. None of the four participants felt misrepresented or inaccurately depicted, thus, the third interview served to enhance validity in that participants endorsed my interpretations of their lived experiences.

Pilot study. In order to determine validity and appropriate fitness with the research aims, the protocol presented in Appendix C was first piloted on one individual who met all eligibility criteria. This woman was the first individual to contact me regarding participation in the study following disbursement of study materials to the aforementioned hospital clinics. However, she was not enrolled into the actual research study following the completion of the pilot study. The objective of the pilot study was to enhance data collection and analyses process in order to streamline and enhance efficiency throughout the actual study. Following the pilot study, I

consulted with the participant regarding her experience of the series of interviews and whether she felt as though the interview questions were well suited to my intended line of inquiry. The pilot participant reported finding some of the questions very broad, suggesting I incorporate follow-up probes in case other participants felt similarly overwhelmed or uncertain as to how to answer such wide-ranging questions.

Although I appreciated the feedback and understood the utility of incorporating follow-up probes, I found myself very resistant to adding further structure or limitations upon my interview questions. My goal in conducting this research study was to provide an open forum within which women with vulvodynia have the freedom to express themselves and their experiences of vulvodynia in a way that is unrestricted and limitless, and that also allows others, especially healthcare providers to develop a rich, contextualized understanding as to how this condition greatly impacts women's lives. Being that I am mental health provider and have worked with women with vulvodynia within the context of psychotherapy, I found myself not wanting to perpetuate any wrongdoing or further offense onto the participants. In my work with my patients with vulvodynia, I have heard stories about how dismissive and invalidating their healthcare providers were. I fully acknowledge that I did not want to be perceived as another dismissive provider, and I see how this desire impacted my willingness to alter my interview protocol and impose any more of an agenda upon the participants than is absolutely necessary.

Thus, upon significant self-reflection and acknowledgement of my bias, I did not make any changes to my interview questions. However, at the outset of each interview, I explicitly explained to the participants that the questions were intentionally broad and vague as I wanted them to feel free to respond in ways that felt congruent to and salient with their lived experience of vulvodynia. I told each participant that I was not looking for them to answer in any particular

way and simply wanted to offer them space to answer these questions openly and honestly. As such, I was met with much less uncertainty about how to answer questions, as well as increased verbosity and candidness compared to my pilot participant.

Overall, as a result of the pilot study, the interview protocol was clarified in that I acknowledged the expansive nature of the questions followed my intention to allow the participants liberty and autonomy to reply to the questions in ways that felt most significant and relevant to their stories. Furthermore, in conducting the pilot study data analysis and interpretation processes were carefully performed and examined which served to improve those processes throughout the actual research study.

Data preparation. Using the audio recordings, all interviews were transcribed verbatim by me. I used a digital audio recorder and uploaded the digital audio file onto a secure, password protected computer. Prior to commencing the first interview, I asked each participant for a pseudonym as a way of further protecting personal information. Furthermore, no information regarding place of residence was collected, again, as a way of ensuring confidentiality and privacy.

Each of the three interviews was transcribed and all interview transcripts were uploaded into the qualitative research software, Dedoose (2014). Dedoose is a secure, internet-based program designed to aid in analyses of qualitative data. This software program incorporates multiple levels of security in order to maintain the integrity of sensitive and confidential information. For example, access to the database can only be gained by the correct username and password, both of which were self-generated and consisted of alphanumeric characters. Dedoose offers data encryption and protection and provides safeguards against computer theft, disk or drive failure, memory loss, file corruption, and other comparable issues related to storing data on

a particular computer or device. As such, Dedoose was a useful tool in organizing notes, descriptive comments, and emergent themes throughout the analysis and interpretative procedures.

Data Analysis and Interpretation

Smith, Flowers, and Larkin (2009) characterize IPA as “a set of common processes (e.g., moving from the particular to the shared, and from the descriptive to the interpretative) and principles (e.g., a commitment to an understanding of the participant’s point of view, and a psychological focus on personal meaning-making in particular contexts) which are applied flexibly, according to the analytic task” (p. 79). As such, Smith and Osborn (2008) suggest following an idiographic approach to analysis, with careful examination of one interview prior to moving on to subsequent interviews. In this way, analysis takes on an iterative and inductive process, paralleling that of a series of case studies, such that detailed attention is paid to one transcript at a time, beginning with particular examples of a shared lived experience and slowly working towards building a more generalized snapshot of the lived experience across participants. Thus, the first step of analysis in the current study was to read the first transcript thoroughly, followed by subsequent re-readings of the interview. Smith, Flowers, and Larkin (2009) suggest starting analysis with “the interview that you found to be most detailed, complex, and engaging” (p. 82), which in this case, was Alesha’s set of interviews. After reading the interview transcript multiple times, I became deeply familiar with the material, building greater awareness and insight into the Alesha’s lived experience of vulvodinia. While reading and re-reading the interview, I took initial notes on her responses, paying close attention to material that was especially thought provoking or evocative. Thus, I made both descriptive and conceptual comments that focused on describing the content (e.g., Alesha discussed negative interactions

with medical providers) and developing early hypothesis (e.g., time seems to play a role in mitigating negative impact upon gender identity). As I continued to read through the interview, I also took notes on and paid close attention to “similarities and differences, echoes, amplifications and contradictions in what a person is saying” (Smith & Osborn, 2008, p. 67). Simultaneously, I was also attending to my own thoughts and curiosities about Alesha’s use of language, her use of certain words, phrases, and sentences, and my own resultant thoughts, biases, or assumptions.

Once I felt confident that I had carefully and thoroughly gone through the interview transcript, I then went through my initial notes and took a second round of notes related to emergent themes. In this stage, the objective is to turn those initial notes, the descriptive, linguistic, and conceptual comments, into themes (Smith, Flowers, & Larkin, 2009). I was tasked with developing themes that “reflect not only the participant’s original words and thoughts but also the analyst’s interpretation” (Smith, Flowers, & Larkin, 2009, p. 92). In other words, the emergent themes bring together a range of understandings and interpretations related both to Alesha and myself and our sets of interpretative processes. Thus, ideally, emergent themes will accurately capture and reflect my understanding of Alesha’s understanding of her experience.

Next, the list of emergent themes was reorganized so as to illustrate connections among themes, including areas of convergence and divergence. Smith, Flowers, and Larkin (2009) refer to this process as abstraction, in that like is matched with like, ultimately resulting in the creation of superordinate themes. Thus, my task was to make sense of those connections, organizing associated clusters of themes into superordinate themes (Smith & Osborn, 2008). However, before moving on in the analysis, I returned to the interview and confirmed that those clusters of themes and overarching concepts were congruent with what the participant reported. In other words, I drew “on one’s interpretative resources to make sense of what the person is saying, but

at the same time, one is constantly checking one's own sense-making against what the person actually said" (Smith & Osborn, 2008, p. 72). One way to maintain that my interpretation of the material was in line with the participant's responses was to use excerpts from Alesha's transcript to represent themes.

The fourth and final step in IPA data analysis was to compile a table of themes in which each cluster of themes was given a label to represent the central theme at work. Furthermore, the table of themes included corresponding excerpts pulled from the interview in order to assist me in determining which theme or themes was more predominant and richly embedded in the interview, and which theme or themes did not fit well within the emerging structure or were not as richly present within the interview transcript (Smith & Osborn, 2008). This pattern of iterative analysis (e.g., the four steps of analysis) was then implemented in all subsequent interview transcripts.

However, given "the existing literature on analysis in IPA has not prescribed a single 'method' for working with data" (Smith, Flowers, and Larkin, 2009, p. 79), it would have also been appropriate to consider each individual interview transcript as a case study in its own right. However, it is most common for IPA researchers to use the first transcript and resultant themes as a means of orientation for subsequent transcripts (Smith & Osborn, 2008). In this way, by being mindful of what was found in the first transcript, I was able to identify what was "new and different in the subsequent transcripts and at the same time find responses which further articulate the extant themes" (Smith & Osborn, 2008, p. 73). Thus, I used Alesha's transcripts to serve as a means of orientation for subsequent data analysis. Specifically, upon completion of analyzing Alesha's Interview 1 transcript, I went on to analyze the remaining three participants' Interview 1 transcripts.

Following completion of thorough examinations of each Interview 1 transcript, a final list of principal, superordinate themes was constructed. It was at this time that I determined which themes to focus on basing priority and inclusion upon, not only the prevalence of themes within the transcripts, but also “the richness of the particular passages that highlight the themes and how the theme helps illuminate other aspects of the account” (Smith & Osborn, 2008, p. 75). Thus, I developed a list of superordinate and subordinate themes based on my analysis of Interview 1. I performed these exact steps in my analysis of Interview 2 and 3 transcripts. I generated a list of super- and subordinate themes from my Interview 2 analysis, but found that Interview 3, the member check, did not result in any pertinent or additive themes. Thus, my last step was to compare both lists of themes from Interview 1 and 2 and determine which of those themes appeared to most accurately capture the essence of vulvodynia’s impact upon gender identity. Although numerous super- and subordinate themes were discarded at this point of analysis, the themes that best served the research aims of this study were retained.

In sum, it was hoped that by taking an interpretative phenomenological approach, the reader would be able to develop an understanding for the “essential, invariant structure or essence” of the phenomenon (Creswell, 2007, p. 62); in this case, how the lived experience of vulvodynia impacts these specific participants’ personal sense of womanhood. In other words, this essential, invariant element provided a rich description of the nature of the lived experience of vulvodynia for the reader so as to foster an understanding that might not otherwise be garnered. Creswell (2007) put it best when he said: “The reader should come away from the phenomenology with the feeling ‘I understand better what it is like for someone to experience that’” (p. 62).

Validity

Within IPA, descriptive validity, internal generalizability, and interpretative validity are of utmost importance in ensuring that the information obtained during data collection and analysis is accurate, trustworthy, and credible (Creswell & Plano Clark, 2011). Thus, descriptive validity was achieved through a slow and attentive transcription process, requiring significant time listening to the audio recordings again and again, followed by numerous reading and re-reading of transcripts. By doing so, I was able to confirm an accurate reporting of participants' accounts, as well as ensure that I had not inadvertently distorted or omitted any information.

Internal generalizability was confirmed through the third interview in which participants were able to respond to the interview transcripts and my study findings, namely the sub- and superordinate themes. Had there been discrepancies, distortions, or omissions of data, participants could have used that final interview to voice their concerns or offer clarifications, at which time data would have been re-analyzed to account for oversights and mistakes. In this case, however, each participant reported feeling as though their stories had been accurately reported and that the themes accurately and honestly reflected the essence of her lived experiences with vulvodynia.

Interpretative validity was achieved through the use of participant quotations to illustrate results, as well as reflexivity. Yardley (2008) defines reflexivity as a “term used for explicit consideration of specific ways in which it is likely that the study was influenced by the researcher” (p. 250). IPA researchers engage in a practice of reflexivity, so as to maintain awareness as to the impact personal biases may have upon analytic and interpretative processes (Merriam, 2009).

Reflexivity. An important consideration for me to keep in mind over the course of data collection, preparation, analysis, and interpretation was how my beliefs, assumptions, and worldview influenced each stage of the research process. Given the researcher is the primary tool of interpretation, it is important that readers have a basic understanding of who I am and the biases I bring to this research endeavor. I am a 30 year-old, heterosexual, married, Caucasian woman. I have never experienced vulvar pain and have never been diagnosed with vulvodynia. However, I have clinical experience in providing psychotherapy to women with vulvodynia and as a result of that background, entered into this study with the following biases: 1) vulvodynia is a widely misunderstood chronic pain condition, and is often misdiagnosed as a psychological disorder; 2) vulvodynia serves to negatively impact women's gender identity as a result of inability or marked difficulty in assimilating this information into well established gender schemas; and 3) some healthcare providers' tendency to discard and distrust women with vulvodynia contribute to strengthening of gender typing, therein resulting in further negative appraisal of gender identity.

In order to maintain the quality and integrity of the scientific endeavor, I engaged in constant self-reflection as to the ways in which my biases, attitudes, and dispositions may have impacted the data analysis and interpretation. I was thoughtful and committed to reflexivity throughout the each stage of data collection, analysis, and interpretation, especially with regards to the development of emergent themes and how such themes were then prioritized and interpreted. Over the course of the entire study, I kept a journal within which to make personal records and notes related to my thoughts and reactions to participant responses, and then used those materials to aid in the interpretative process, all of which will be discussed explicitly in the discussion section of the manuscript.

Chapter 4: Results

The process of analysis of the eight interviews (Interviews 1 and 2) produced a number of emergent themes regarding the impact of vulvodynia on gender identity. Specifically, four overlapping superordinate themes and seven subordinate themes emerged as most salient: 1) *critical time periods* which included the subordinate themes of hopelessness for the future following onset of symptoms, diagnosis was a turning point, and acceptance of vulvodynia and the development of healthy coping strategies; 2) *alienation and isolation*: which included the subordinate themes of feeling inherently different from other women often manifested through downward comparisons and feeling misunderstood and not believed by others, including medical professionals; *critical time periods* which included the subordinate themes of initial adjustment to vulvodynia after first sexual intercourse was the most difficult time period, diagnosis was a turning point, and acceptance of vulvodynia and development of healthy coping strategies; 3) *positive impacts upon life* with the subordinate themes of finding my voice and reclaiming and renewed appreciation for my body and my physical self; 4) *personalized definitions of womanhood based on individuals' lived experiences and social contexts*.. See Table 3 for a summary of all emergent themes.

Table 3. Thematic Summary

Subordinate Themes	<i>Superordinate Themes</i>		
Critical Time Periods	<i>Initial adjustment to vulvodynia after first sexual intercourse was the most difficult time period</i>	<i>Diagnosis was a turning point</i>	<i>Acceptance of vulvodynia and development of healthy coping strategies</i>
Alienation and Isolation	<i>Feeling inherently different from other woman</i>	<i>Feeling misunderstood, dismissed, and not believed by others, especially by medical professionals</i>	
Positive Impacts Upon Life	<i>Finding my voice</i>	<i>Reclaiming and renewed appreciation for my body and my physical self</i>	
Personalized Definitions of Womanhood Based on Individuals' Lived Experiences and Social Contexts			

Critical Time Periods

Each participant spoke about her lived experiences of vulvodynia within the context of time. They all referred to the past, most often when describing what life looked like up to and before receiving the diagnosis. There appeared to be a consensus among the four participants that this stage in their vulvodynia story proved to be the most difficult, not just due to untreated chronic pain, but also due to lack of education, understanding, and validation from self and others. This next section will elucidate how the participants' lived experience with vulvodynia changed over the course of time and how receiving a diagnosis became a turning point to which they were able to come to a place of acceptance through more positive coping strategies.

Initial adjustment to vulvodynia after first sexual intercourse was the most difficult time period. It is not surprising that each woman described their initial adjustment to the symptoms of vulvodynia as the most difficult time in their lives in light of their experience of vulvar pain and uncertainty around etiology, symptomatology, and duration. This time period represented hopelessness for the future and loss of possible self or selves in their fear that their

experience of vulvar pain and painful intercourse may never abate. Each participant all spoke to losing hope for the future, especially around enjoying sex. For example, Anna described feeling “despondent” in the beginning:

I felt like there’s a really good chance I’m going to have this for the rest of my life. It was hard to imagine not having it because every time I tried something new to make it better and it didn’t work, it was just so disappointing, that I like didn’t ever really let myself get to that place where I’m like ‘I could be free” because, you know, there are those people, like my husband’s sister who had it, not as bad as me, but she had a kid and is completely cured, but I wouldn’t let my mind even go there because I felt like it would be so disappointing. I was much less hopeful about the whole thing and kind of more resigned to it, like sex with my husband is just never going to feel good, like it’s just not going to happen for me.

It was clear that at this point in her life, Anna felt hopeless about a life without chronic vulvar pain, or even reduced pain, due to numerous discouraging encounters with providers and ineffective treatment trials. However, at this point, Anna had not yet been diagnosed with vulvodynia, thus recommendations from friends and providers, like use more lubrication or have a few drinks before sex, were bound to be ineffective given they were not appropriate treatment options for vulvodynia. These failed recommendations further compounded her sense of resignation in that she was actively seeking answers and support from others, only to be met with no change in symptoms. At this time, Anna was also experiencing discouragement around the loss of a future self that enjoys sex with her husband. Additionally, Anna was experiencing loss around her identity as wife given that her beliefs and schemas about marriage included mutual sexual gratification.

Melissa also described how she had "...gone through stages with it. At different points I felt different. When we were really upset and looking for a cure for intercourse it was completely overwhelming and took over my entire life. We just kept trying things, trying to figure things out. At that point it was all consuming and all-consuming in a bad way." Thus, as a result of failed treatment attempts and exacerbated pain following pregnancy, Melissa, in her desperation to fix her pain and improve her sexual functioning, began to feel discouraged and dejected that her disposition would never improve. Ultimately, during this critical period, Melissa's experience of feeling all consumed by her desire to find a cure, served to negatively impact not only her symptoms and experience of pain, but also her ability to relate sexually to her husband, whom she reported feeling "rejected" by at times. Additionally, it was during this critical period that Melissa experienced "something sort of like a faith crisis. I just felt really disillusioned with God, and like, maybe, like I did something wrong to deserve this." In this way, Melissa expressed her experience of added injury in that her experience of vulvar pain and despondency called her faith in God into question. Here again, Melissa echoed a sense of hopelessness for the future, underscored by her doubts in God and uncertainty and skepticism about His plan for her. In this way, Melissa's sex-incongruent gender identity proved to be more valuable and a stronger influence over self-perception than her faith schema and identity as Christian. Rather than turning to her faith to aid in meaning making processes or even ways in which to easily incorporate this information into her gender schema (i.e., God is testing my faith vs. I am less of a woman), Melissa created meaning around her lived experience of vulvodynia from the framework of not meeting her standards of womanhood (i.e., identifying as sexually undesirable).

Alesha, also a devout Christian, did not experience onset of symptoms until after marriage since she practiced abstinence until that time. As a result of lack of education and understanding around her symptoms, as well as feelings of embarrassment, Alesha avoided seeking treatment and attempted to manage symptoms on her own following onset. She described her first year of marriage as “miserable” and that:

It was really painful when I first started. It was really emotionally taxing. It made it really difficult to bond emotionally with my husband because it felt like this thing that we had, like, been waiting for forever, turned out to be kind of awful. It was really pretty devastating in the beginning because I didn't know if this would, like, prevent me from having kids and becoming a mother, which is, like, a really important thing for me.

So for Alesha, hopelessness was characterized by two experiences: 1) feelings of resignation and discouragement that sex, a thing she had waited for and expected to be beautiful and pleasurable, might never be enjoyable or emotionally intimate, as well as 2) fear and grief around potentially losing the opportunity to have biological children of her own. Similarly to both Anna and Melissa, Alesha felt despair around the loss of hope for a pleasurable and affectionate sexual relationship with her husband. However, she was the only participant to more explicitly describe her fear that her emotional intimacy with her husband might be stunted due to a lack of physical and sexual intimacy. Moreover, she was also feeling sadness and grief around potentially losing the opportunity to identify as mother. Thus, Alesha's lived experience of vulvodynia proved highly threatening to not only her identity as woman, but as wife and future mother.

Kellie's experience of hopelessness very much echoed that of the other three participants. She stated:

It was hard to stay positive about other things because everything was associated with pain. I was really upset about it, probably depressed for a little while because I was scared it could be something that I dealt with my entire life, because I knew that for some women it clears up and for others they deal with it for the rest of their lives. I was just like, 'will I ever be pain free?'

Although Kellie was involved in a committed relationship, it was interesting that her identity as sexual partner appeared less distressing than the fear of never being pain free. It is possible that her identity as sexual partner was less salient for her than Anna, Melissa, and Alesha, seemingly protecting her against negative appraisals of that identity. However, her experience of hopelessness around enjoying sex and simply living a pain free existence appears quite in line with that of the other women.

Thus, this initial period of adjustment to symptom onset reflected a sense of loss around the possibility of sexual pleasure and a pain-free existence. Especially in light of feelings of rejection and undesirability, as well as failed attempts at treatment, participants were experiencing bereavement around the loss of their future selves, including but not limited to wife and mother, and as such, were mourning the loss of the future they had imagined up to that point in life. Furthermore, participants were left to manage their experiences of pain on their own and with limited resources, which resulted in significantly diminished quality of life.

In understanding this first critical period from gender schema theory, I interpreted this time period as the time at which participants attempted and failed to assimilate their lived experiences of vulvodynia into their existing gender schemas. In trying to understand and create meaning around their impaired sexual functioning and lost selves, they all came to the conclusion that such an experience is atypical for the average, heterosexual woman. As will be

made clear within the second superordinate theme of alienation and isolation, participants routinely compared their experiences to other women (friends, family, and women portrayed in the media), serving to only confirm their new perspective that they are gender-incongruent women (i.e., since they cannot or do not enjoy heterosexual intercourse, they are atypical women, thus gender incongruent). Thus due to an inability to integrate this information into their beliefs about womanhood, feelings of hopelessness, grief around lost selves, and despair for the future became hallmarks of this particular critical period.

Diagnosis was a turning point. Fortunately, upon receiving the diagnosis of vulvodynia, each participant described a sense of relief that her experience of chronic pain was not simply “*all in my head*” but rather a chronic medical condition with specific routes of treatment and medical specialists. Compounding the relief of naming their condition, was the fact that diagnoses were given by attentive providers who validated and normalized participants’ experiences, thus offering a corrective emotional experience for women used to feeling discarded and rebuffed. Melissa spoke to her renewed sense of hope for the future when she stated, “I was pretty excited, like now maybe we can solve it, since before it wasn’t really considered a problem apparently by anyone else or defined or anything, now I have a chance at doing something about it.” Reflecting back on her experience of diagnosis, Anna stated:

I finally got to my doctor and started seeing her, and within two seconds she looked at what I was saying and did a vaginal exam, and she knew within two seconds that I had vulvodynia, based on my skin, my experience. I almost cried. It was like the best moment of my life. That was amazing even though I didn’t get cured right away, just, like having someone who understood, I just didn’t feel weird going into her office because I felt like she believed me when no one else believed me. Once you get a name to it, it’s still scary

because there's no obvious cure, there's no silver bullet, but it's still like I have a diagnosable issue, I'm not crazy, I'm not just weak.

Similarly, Alesha felt a great sense of relief stating, "So I was actually diagnosed a year ago with vulvodynia, so that was a really big relief to have a doctor say 'oh, you're right, this is what you have.'" For Kellie, the diagnosis was "the biggest thing that helped me, so like just defining the problem and not, like, letting it take over my whole life, I would say that that, like, really helped me kind of regain my sense of womanhood."

As was evident from each participant's descriptions of the diagnosis process, receiving a diagnosis from a doctor was a very transformative experience. Not only were they treated with respect and had their pain validated as 'real' rather than 'psychological,' but naming their condition offered a rejuvenated sense of hope for the future that the life they had envisioned for themselves prior to the onset of vulvodynia might not be completely out of their reach. Thus, as a result of being given the diagnosis, the participants were able to assimilate this information (i.e., I have a medical condition that can be treated and managed) into their existing gender schemas, which in turn served to restore their gender congruent identity. In other words, this new information (e.g., the diagnosis) no longer conflicted with their view of womanhood because their vulvar pain and corresponding experiences of hopelessness and grief were now judged to be temporary and livable conditions. Thus, they all experienced hope that once the vulvodynia was more effectively managed and treated, they had faith in their ability to adapt and reclaim once considered lost selves. It was during this critical time period that participants began to feel empowered to face vulvodynia head on and began to research and initiate courses of treatment in a way that they were able to reclaim their bodies and extend grace and positivity towards themselves and their sexuality.

Acceptance of vulvodynia and the development of healthy coping strategies. With the support of an understanding provider, the diagnosis pointing to more appropriate routes of treatment, and restored sex-congruent gender identity, each woman was able to engage in treatment and began to see life with vulvodynia as something other than a life sentence. Throughout the interviews, they were able to reflect back on those difficult times and recognize that their lived experience with vulvodynia had become much less negative and much more positive and optimistic. For example, Kellie stated:

Since then, vulvodynia doesn't seem as big a part now, it's mostly me just looking back to two years ago because I am mostly pain free now, and I mostly just take medication and do a little physical therapy, but, I don't know, I think I'm stronger being a woman and being okay with being a mix of the parts that are feminine.

Kellie's ability to accept vulvodynia as one aspect of her life came about in large part due to significant reduction in pain. She lives mostly pain free now, and as such, is not constantly trying to assimilate information that is incongruent with her gender schema. As a result, she sees herself as a stronger woman and more readily accepts her femininity. This strengthening of gender identity is likely a result of a more broadened and expansive sex-typing and gender schema. In successfully assimilating the diagnosis into her schema, and it not threatening her ability to sex-type herself as sex-congruent, she appeared to create a gender schema of womanhood that is more inclusive and representative of more diverse traits, thus reinforcing her identity as a woman. It seems that this was a pattern for the remaining three participants as well. This alteration of gender schemas will be discussed in further detail later in this chapter.

Alesha's path toward acceptance was very much the result of successful physical therapy treatments. In this next excerpt, she reflected on the impact physical therapy had upon her pain and subsequent ability to learn to live with vulvodynia:

I think physical therapy has been one of the most, like, helpful things in helping my pain down there. My doctor referred me to this amazing woman and she has really helped me, like learning how to do the exercises on my own has really made me feel like there's a light at the end of the tunnel and that my whole life, like, won't totally be dictated by the fact that my vulva feels like sitting on a cactus all the time. For the first time in like forever, it feels like, yeah, it just feels like there's a light, like there's hope again.

The physical therapy not only served to reduce Alesha's vulvar pain, but also fostered and strengthened hope for the future of a pain free, or at least a less painful future. Additionally, her physical therapist teaching Alesha how to engage in exercises at home contributed to feelings of empowerment, optimism, and faith in her capability and capacity to effectively manage her symptoms on her own. She is more able and willing to engage sexually (though not always through penile-vaginal intercourse) with her husband, feels more desirable to her husband, and is able to envision those selves that at one time seemed lost to her.

For Melissa, acceptance came about through the development of a more positive framework within which to view vulvodynia as simply one part of her life rather than her entire life:

I think it's more successful to just find ways to live my life in a happy way, safer to operate. I'm still not okay with not having intimacy, but I'm at the point where I'm okay with maybe not having, like, vaginal intercourse at this stage of my life...I still have this

great relationship and so many positive things have been brought about even through the suffering I had to go through.

Here again is an example as to the ways in which the participants created space and diversity in their gender schemas and their ability to re-identify as a woman. Melissa was able to reframe her perspective on finding ways to live a happy and successful life, which included finding ways to foster intimacy, sexual or otherwise. In doing so, she is creating a meaning making system that represents womanhood in a manner that is more than just ability to engage in intercourse and feel sexually desired by her husband, like valuing relationships and self-acceptance.

Similarly, Anna was also able to come to a place of acceptance due to a restructuring of perspective based on widening her gender schema parameters:

I was just able to kind of, like, come to terms with the fact it's not like I can't do anything else, I just can't do this one thing. Once I was able to see that, now I feel like I have a different outlook on my whole life from like a relational and sexual perspective. It's like, you're still a woman, you have those things but part of it doesn't work very well, like I still have periods and everything else, and it's better than before, like when I was just lumping everything together, so I was able to compartmentalize and face that this is medical, this is not emotional, this is not like, I mean, it's not like something is wrong with me, well obviously there is something wrong with me, but I don't like let it affect my worth anymore, so like once I started engaging successfully in other things and taking the pressure off, like 'hey, I don't need to have intercourse this year, I don't need to have intercourse next year,' you know what I mean, I can still have like, a very normal sexual life without that.

In sum, it appeared that, for these four women, treatments that reduced pain, development of attitudes that reflected hope and optimism, and acknowledging strengths beyond sexual abilities resulted in more effective pain management and lower distress related to sex and vulvodynia. And in light of those results, a renewed sense of hope and ability to imagine future selves, such as sexually satisfied self, self as wife, and self as mother, served to alter once highly restricted gender schemas and sex-typing processes.

Alienation and Isolation

This superordinate theme is representative of the first critical time period in which participants had not yet been diagnosed with vulvodynia and were struggling to manage both physical symptoms and emotional repercussions related to their lived experiences. As such, my analyses showed that the single most difficult piece of information to assimilate into existing gender schemas was making sense of feeling different compared to other women. In comparing their sexual experiences to those of their female friends, family members, and even woman portrayed in print, film, and television, the four participants ultimately came to the conclusion that their experiences of painful sexual intercourse was atypical, thus leading them to identify as sex-incongruent.

Inherently different from other women. For each participant, a resounding theme that became apparent over the course of their interviews was the feeling of being different from other women. The participants discussed this difference as a perceived defect or flaw that set them apart from their non-vulvodynia counterparts. For example, Anna stated:

It was just so important to me to be a wife, and you know, be a woman in that way because, like, you know even 16 year olds can do it, you know, like everyone can do it except like I can't. I'm older, a professional, I'm married, I like have all these things but I

can't do these things that I think are like one of the most basic functions of the human body for women, it's just like not possible for me...I couldn't do something that's a very normal human thing that people like in third world countries, uneducated people can do every day and I just couldn't.

Anna's account of feeling so very different from women of all ages and backgrounds greatly reflected her definition of womanhood, which included sexually satisfying her husband. As such, her inability to engage with her husband in a way that felt she was fulfilling her roles as both woman and wife, proved incompatible to her gender schema. Thus, rather than adjusting her schema to be more encompassing of differences, Anna chose to accept the fact that she did not meet criteria for womanhood, as determined by her gender schema.

In this next excerpt, Alesha explicitly stated how vulvodynia affected her ability to identify as a woman as she felt so inherently different from women around her:

I think it really affects how I see myself as a woman when I'm with other women because I feel like I have a dirty secret, so I feel like I have this thing that separates me from other women because it makes me different in a bad way...it's a secret but a secret that means that I'm not really okay and I can't participate in this really basic part of marriage that everyone does.

In seeing vulvodynia as a dirty secret to be kept hidden from others, especially other women, Alesha appeared to arrive at the same conclusion as Anna (i.e., sex-incongruent), since there was no room in her existing gender schema to account for vulvar pain and impaired sexual functioning. From her perspective, typical women do not experience this phenomenon; ergo, she is not a typical woman, or even a woman at all.

What quickly became apparent to me in my analyses were the ways in which participants engaged in downward comparisons to other women, again, indicative of their perception of vulvodynia as a signifier of defect rather than individual difference, like body shape or size. Thus, these downward comparisons represent how they made sense of differences between themselves and other seemingly typical or sex-congruent women. In other words, downward comparisons served to explain or provide evidence as to reasons why they could not identify as a woman and more aptly fit a sex-incongruent category within their schemas. For example, Melissa referred to herself as “defective” and “damaged goods,” noting that, “I feel very different and that can be really distressing, like, well, maybe I’m just like not really a woman or like maybe something is just wrong with me...I think it’s made me feel like a failure as a wife and, um, as a woman more generally;” implying that vulvodynia has somehow stripped her of her femininity or deservingness to be considered a woman, thus confirming her sex-incongruent status. Similarly, Kellie stated, “...and when I’m with other women, I’m really physically aware of the difference, which kind of makes it hard for me to be around others who don’t know what vulvodynia is like.”

Anna also engaged in denigrating herself when she referred to herself as “a 10 year-old boy” in the following excerpt:

I think the other way it affected me was like, I mean I had literally never heard of anyone having this problem before, just feeling different from other people, like just feeling, you know, that camaraderie, I didn’t really feel like I fit in because I couldn’t, because I was just different, you know, like talking about bachelorette parties or, I was part of this women’s bible study and I literally felt like a 10 year-old boy, like it was that weird, I just felt like I had nothing in common with these people, and it was hard for me to think of

myself and think like how could we both be the prototype of a woman if like, I can't even engage in like sex.

Anna's comparison to a young boy greatly underscores just how pervasive and fortified her sex-incongruent identity became for her. She explicitly spoke to feeling as though she had more in common or could more similarly identify with the opposite gender as a result of failing to assimilate her lived experience of vulvodynia into her existing gender schema.

Thus, the implications reflected in the participants' lived experience of vulvodynia is that, due to their condition and their difficulty to engage in traditional sexual intercourse, an act that, to the participants, is perceived to be basic, normal and natural, they no longer meet the standards of womanhood (as set forth by their gender schemas) and can no longer identify as a woman in the same way they see womanhood reflected in their non-vulvodynia counterparts (e.g., typical women). Additionally, based on participants' accounts and my understanding of how they made sense of their lived experiences in comparison to other women, participants seemed significantly more impacted or activated when around other women, thus, many of them consciously distanced themselves from women in their lives, as the constant reminder of their lost identity as a woman was simply too painful to withstand. Therefore, their new identities as sex-incongruent women served to considerably intensify feelings of differences, resulting in devastating experiences of isolation and alienation from other, typical, sex-congruent women.

Misunderstood, not heard, and not believed by others. Further exacerbating this sense of inherent difference and identity as a sex-incongruent woman were the inconsiderate and dismissive reactions and responses from friends, family, and worst of all, their healthcare providers. These negative experiences of feeling misunderstood and disbelieved by others who resulted in confirmation from others, including individuals deemed as experts, that their

experiences were unlike those of sex-congruent women. Thus, rather than continue to put themselves in situations where they were around other women discussing their lived experiences of sex, participants isolated themselves, often choosing to avoid conversations about sex, or interpersonal interactions altogether in light of feeling so disconnected from those women around them. For example, Melissa stated:

Most people just don't understand. It feels like literally no one understands, or that you're faking it. I went to OB/GYN's that were like, 'you're totally normal, you have no medical problems, you just need to relax and have a glass of wine' and here I am in excruciating pain and I know that it's not just because I'm not relaxed. I didn't talk to anyone about it for probably like 6 months; the couple people I tried to, it was just so alien to them, they can't help, they have the stupidest suggestions possible like 'you should just use lube' and obviously I've thought of that. Obviously it shows that people just don't understand it...I have one friend who knows about my experience and she's like 'that sucks but I can't imagine;' not really coffee talk material. I don't think I even know anyone else personally with it, ever, like if anyone had they obviously didn't publicize it which I understand, but you know, it's hard because the only people telling you what to do are doctors and sometimes they're like 'wow' that sucks, well try this; not a whole lot of sympathy...they just don't connect with it.

From this account, Melissa made it very clear that discussing her lived experience of vulvodynia with her female friends was highly unsatisfying and damaging to her gender identity since she felt so misunderstood and greatly disconnected from other typical women. Thus, for her, sharing her atypical experiences with other women, as well as her unsympathetic and dismissive doctors only offered more evidence to support her burgeoning identity as sex-incongruent woman.

Similarly, Alesha's struggled to share with other women. It seemed that Alesha very much wanted to talk about her experiences as a means of seeking support from others but felt uncertain about when and with whom to share:

For me, it means that I have a pain condition that's really embarrassing to talk about. It means that I feel kind of isolated in that part of my life, it means my marriage is constantly figuring out how to survive it, and living with it, vulvodynia, means that I'm always trying to figure out how much to share when I need support from a friend and when to be just really vague.

However, Anna appeared much less uncertain and more resolved in her decision to remain cautious in sharing with her female friends:

In my interpersonal relationship with females, I feel a little bit more reserved in the ways I interact with other girls because I have this huge difference that I can't share with all my friends. The couple times I've tried, like with one of my best friends, she just can't understand it and says just such ignorant things, I just have to protect myself, so I'm much more careful with the way I interact with people because I feel more vulnerable in that place.

Interestingly enough, Anna recognized that her restrained and more conservative manner of sharing her experiences with female friends was a means of protecting herself against not only negative judgment and disappointment, but also revealing her sex-congruent identity to others. Here again, as a result of feeling so disconnected and so dissimilar to these her female friends, Anna is further distancing herself from them (i.e., protecting herself) as evidenced from her unwillingness to share openly and honestly within these interpersonal interactions.

Regrettably, perhaps worse than reactions from friends and family, were the unexpected and discouraging reactions from medical providers. For example, Kellie stated, “I would say that when I first started this process, I wasn’t heard as much by my doctors.” Anna had a similar experience with some of her doctors, feeling not only discarded, but also very misunderstood by individuals who are supposed to be experts in women’s health. This next excerpt is an example of a particularly negative experience in which Anna did not feel heard by her gynecologist:

She was just absolutely horrible. She had literally never (pause) I don’t think it was in her Rolodex that, like, people can have sexual pain. She looked at me, did a physical exam, and she was like ‘you look great, everything was healthy’ and I had just gotten finished telling her that this was the worst pain I’ve ever experienced in my life. I’ve tried all these different things, I’ve tried to relax, I’ve tried to drink alcohol, like all of these things, breathing exercises, and she was just like ‘you look fine, you just need to learn how to relax and take some more pressure off yourself,’ and I’m just like bawling in her office, like I’ve tried all those things, you need to give me an answer or refer me to someone who might understand.

Melissa had a similar negative experience with a provider who inappropriately blamed her vulvar pain on her “religious upbringing” and “thought it was because I was abstinent before marriage, that I hadn’t explored myself sexually, that I was just afraid of sex.” Alesha, also abstinent prior to marriage, received similar disparaging feedback from her gynecologist:

So she did my exam and it was really, really funny that she was like ‘you just need to use gel.’ My speculum insertion was almost impossible and it was so extremely painful, and she was like ‘you need to wait at least a month to adjust because for me it took six months and besides you’re very old to start,’ and I’m 26 and she’s telling me that if I’d

started at 16 this wouldn't happen. So that was my first OB/GYN experience, being told that I was too old to start having sex, and I didn't know whether to believe her because I didn't know what to compare it to, but I knew something was wrong because it was so extreme, but she definitely didn't know enough to diagnose, and I don't know if she even wrote it in my chart, but it was kind of like 'no big deal, you just started and you're old so try some more.'

Sadly, Alesha had several more devastating medical encounters, including this one described in the following excerpt:

So I found another OB/GYN that summer right before going overseas again, and that was a man, my first male gynecological exam, and he told me that it was my husband's fault because he wasn't giving me oral sex. (long pause) He also told me I might have chlamydia and needed to be tested for STD's, so I went through scrapings and biopsies, which was really painful and completely unnecessary. I don't have other partners, but yeah, that was his diagnosis, that 'you're not sufficiently aroused,' and I didn't know whether to believe him because...I was so angry about it, I went back and saw another OB/GYN who owned the clinic and complained and had another exam with him because I noticed tissue changes and open bleeding spots, like tears; (pause) there's no way in heck this is normal, don't tell me this is normal. And he said 'well you have vaginismus, that means there's not a provoked cause except for fear and it's a spasm of the vagina due to fear of penetration. He thought that I just need to practice relaxing, he thought the open sores were nothing, but just in case, he prescribed the steroid for me while overseas, and he was like 'oh, you'll be fine.'

In sum, all of the participants were told by providers at some point in their treatment seeking process that there was nothing medically wrong, to try to relax more, drink a glass of wine, and keep having sex until it feels good. These messages were very damaging for each participant and often resulted in them discontinuing treatment seeking for a period of time. These messages, especially those from gynecologists, further reinforced their rigid gender schemas and how they no longer could identify as sex-congruent women in light of their atypical experiences of vulvar pain and painful sexual intercourse. Fortunately, participants did eventually have very positive interactions with providers, generally the providers that accurately diagnosed them with vulvodynia, which became a turning point for hope, acceptance, and personal growth.

Positive Impacts Upon Life

Following the critical time period of acceptance and coping, as well as successful assimilation of their lived experiences of vulvodynia into newly organized gender schemas, all four women began to see the ways in which their experiences of vulvodynia and accompanying suffering fostered a framework within which to acknowledge and recognize personal growth and positivity. Thus, throughout the interviews, each participant spoke to ways in which life was positively impacted by their lived experience of vulvodynia. One of the most powerful impacts was the ability to find their voice and no longer remain silent about their chronic pain condition.

Finding my voice. Given each participant spoke about her reluctance or sheer avoidance of talking about vulvodynia with others, finding the courage and strength to speak up and stand up for oneself was a very positive, transformative experience. Melissa spoke to that when she said, “I feel more confident standing up for myself. It’s like, if I hadn’t learned how to stand up for myself and say something, like all those times with my doctors, maybe I wouldn’t be where I am now.” Similar to Melissa, Kellie’s ability to voice her thoughts, feelings, and needs to her

doctor was the first step in re-engaging in life again and participating in activities she once felt were no longer possible:

I also had to, like, learn to do a few more things for myself, like seek out my own treatment and find doctors who can help. I had to fight more for healthcare, and it means being disappointed, but also helps me appreciate other things and see things in a different way...it got to the point where I was a lot better, in a way too, it kind of made me stronger, being able to speak up and do things for myself, in a way it makes you feel like you don't have control over certain parts of your life but then like doing all the things that help make you get better, I guess helps give you more a feeling of control, I spent last year traveling abroad for most of the year and I was able to get my medications, enough of them to last while I was abroad and so, I think, it was like once I could talk about it, I felt like, okay, I know how to help myself and how to deal with it, so that like, I could do the things I still wanted to do.

For Anna, being able to communicate with other women with vulvodynia was the most significant factor in finding her voice. It was in those connections that she was able to find empowerment in supporting and validating women who were similarly struggling:

On the positive side of it, since I've become more vocal about it I've had awesome encounters with people who have struggled with it too; (pause) it has made me way more open, I've encountered a lot of people, and it's cool to send people to my doctor who has been such a, she's really been like a saving grace for me. Now, I just feel like a lot less alone and help people feel less alone during a time I felt really alone, like after intercourse for the first time or after getting married.

Finding other women with vulvodynia with whom Anna felt she could relate, was an incredibly significant factor in her ability to create space in her gender schema for differences and diversity. Subsequent to her diagnosis, experiencing validation from women's health experts, and feeling connected to other women again, Anna was able to use this information to successfully assimilate her own experiences and those of other women with vulvodynia into her schema such that she and others were no longer excluded from womanhood. She was able to recognize that womanhood consists of more than sexual activity and as such, redefined traits of womanhood to represent such values as interpersonal relationships and emotional expression and communication. Thus, she and other women with vulvodynia with whom she felt connected to and genuinely understood by, could now identify as a woman based on renegotiated schemas.

Alesha also spoke about the positive impact meeting and speaking with other women with vulvodynia had upon her ability to find her voice:

I just think that meeting in a group with women who had it too, I was in a support group for a long time, just like really, it really did help me get to a place where I could talk about it more with my boyfriend without feeling as embarrassed or ashamed... there is a difference when you meet with others for something supportive or something spiritual or, um, in that kind of realm where you're surrounded by all woman, there's just a difference in that kind of environment with how the free you feel to talk about yourself and the connection with other women who really get what it's like: it just feels more protective, being in that environment definitely helped me, like, find my voice again.

Thus, predicated on broadened schemas and feeling more connected to other women again, each participant felt more comfortable, even empowered, sharing their experiences, such that they not

only supported other women in their struggles with vulvodynia, but also themselves in using their voice to foster and nurture important and growthful interpersonal relationships.

Reclaiming and renewed appreciation for my body and my physical self. Participants also spoke about developing a positive perception of their bodies and reclaiming them as something to be celebrated rather than something to be hidden and ashamed of. Women found that being so well educated and informed about their bodies as a result of better understanding vulvodynia, their appreciation for the complexity and beauty of not only their vulva and vagina, but their bodies as a whole, actually became a point of pride and improved self-esteem. For example, Alesha stated:

I feel that I'm much more educated about my anatomy than most woman. I know a lot more about my parts and how they work than most people and I see that as a really positive thing, the more that I learn, the more empowered I feel...yeah I feel more in touch with my physical femininity, sort of my physical womanness...um, I think just the education piece is big, that I feel more educated about my femaleness and, um, I see that as really positive, and I think it's really positive to be able to help other people learn about themselves too... really I think all girls need to be educated more than I was about their bodies and that its okay to talk about it.

For Kellie, taking care of her body and making health and wellness a priority also resulted in improved self-esteem and self-worth:

I think it's had positive effects on my self-esteem, like just because I've had to really work, not work but think about it and commit to the physical therapy and the counseling. I kind of threw myself into taking care of my body, and I think that's definitely helped my self-esteem, to know that I could treat my body well and take care of it...I actually

think it got me more in touch with my body, definitely made me appreciate it more, like when I wasn't in pain and learning to be healthier, exercising a lot more, aware of things like sugar intake and caffeine intake. Being in touch with my body more helped me be more present throughout the day and think about myself and realize that my body is a part of that...I think it's actually helped me like embrace myself as a woman even more.

In much the same way, Melissa's ability to see her body as something to be appreciated rather than concealed and secreted allowed her to embrace her sexuality for the first time:

It helped me understand my body more, like I didn't even know my anatomy that well before I had vulvodynia, so yeah, it's definitely made me a lot more comfortable with my physical body and having to do like physical therapy, it's help me be a more sexual person, like, connected sexuality to being a woman...but like getting diagnosed and going to the treatment and getting in touch with my body, and like, having a partner that was willing to work with me and look into what I needed and try different things out, um, definitely opened up sexuality and being a sexual woman and being able to express that, express yourself and to like own your body.

Similarly, Anna developed an appreciation for her sexuality, and in viewing her body from a more positive perspective, actively sought sexual pleasure for the first time:

I would say that another thing that really helped me was like kind of expanding my definition of what sex was, in the sense of like, like we finally got this expensive vibrator and we started to just say like okay we're going to figure out how to make sex fun and not stressful given the fact that we can't have intercourse, and I think that, for me, I had never really allowed myself to include all of those more kinky or weird things, but because we didn't have a lot to work with, it was like okay I've never been into

masturbation at all, and I'm still not, but I'm a lot more comfortable with like vibrators and that kind of stuff now and I think that that's because I don't see my body as this, like ruined thing, it's more like, okay, this is what I'm working with and that's okay.

Therefore, it was apparent that the development of a more positive attitude towards one's body, coupled with newfound education about their bodies and genitalia, allowed the participants to reclaim their bodies and their sexuality as something to embrace and honor rather than something aversive and associated with pain and indignity. Again, their decisions to alter their perspectives of their bodies reflects newly designed schemas that allow for differences between women. In other words, their newly expanded schema of womanhood reflected physical differences, allowing them to successfully categorize their own and other women's bodies as meeting standards of womanhood, rather than serving to exclude them.

Personalized Definitions of Womanhood Based on Individuals' Lived Experiences and Social Contexts

The last theme that was prevalent and persistent throughout each woman's account was just how personalized and contextualized definitions and perceptions of womanhood were. Initially, when first posed the question 'How do you define what it means to be a woman, or the concept of womanhood?' all four participants struggled, demonstrating reluctance to offer definitions, as they were fearful that any such characterization or classification would serve to exclude others, no matter how broad and universal the parameters may be. Given their experience of gender exclusion and sex-incongruent identities in the beginning, their reticence to create categories that inevitably are not universal to all women makes very clear sense. For example, Alesha stated:

So much of that concept is culturally constructed rather than examined. It's so, uh, it's just part of the air we breathe, and we don't talk about it very much, and it's just really interesting how in different cultures you can still see key differences and what that looks like and how that plays out. I definitely don't have a corner on the word, I don't have it figured out, and I don't have an answer to your question really other than to say it's an interesting concept...because as soon as you have a definition someone like doesn't really fit it and then you have an exception, um, but I think part of what we mean when we say womanhood is the, I think it's partly referring to an experience of women in general, experiencing life as themselves, so kind of that experience of being essential to who you really are, and when I think of the word womanhood I think of someone who, I think of it is a positive word which is interesting because I don't really feel very positive about being a woman sometimes, but I think of that as a really positive word, and I think that's because it means that you are yourself and, um, you're part of this community, yeah, being part of who you are in a larger sense.

Much the same, Kellie viewed womanhood as a construct highly influenced by society and discussed her struggle in what she believes makes a woman a woman versus the pervasive impact society has had upon that working definition:

I still don't have like a straight answer for that because I think there are so many different kinds of women and I think that like the typical answer to that, like what it means to be feminine and what it means to be a woman, um, if you are a woman then it's like whatever you are doing. I mean that's being a woman, right? And, um, and yeah, I don't have like, I don't think that women have certain roles or that there's many characteristics that are like typical of all women, but really what women are is taught like what we

should be. I haven't necessarily figured out yet like how to separate like the idea, I don't know, like how to figure out if there's like characteristics that women just have naturally or if most of them have just been taught that we should have them and whether or not that even makes a difference.

However, Kellie was able to shed light on how she identifies as a woman and her working definition of womanhood, specifically as it pertains to her and her individualized social context:

...but if we're talking like specific to me, definitely the sexuality part, like being able to see that sexuality is a key part of womanhood...One other thing too, like, I think that being a woman is also about being able to connect with other women, um, sort of that, like that, yeah, being able to like, yeah, to connect with other women is a key part and kind of changed my idea that having vulvodynia and having meaningful connections with other women, that kind of thing, I think women being able to meet on their own is a really powerful part of womanhood.

Anna, as well struggled at first to offer a definition, generally describing a broader understanding of the concept of womanhood, yet she describes the ways in which she identifies as a woman, describing how much more valuable interpersonal relationships and taking care of others is compared to ability to engage sexually with her husband:

I'm not sure I believe that there are intrinsic differences between male and female, but I um, I think it's hard to pin down, because I don't think it's fair in society when you start defining it. I feel like it boxes people in but, it's kind of a hard question...I guess, I mean there are definitely traits that I think are, like, that women have more likely than men, but I don't think they're like specific to men and women, and I don't think it's always a good

thing, so I don't really think they define womanhood. For me, I have like, just this desire to help and be a support to others, and I think that's a huge thing for me as a woman, and also, just like a strong nurturing hospitality impulse, like, it's more about, like, being with others in, like, a supportive way, and knowing that I am expressing something that's like core to my identity as a woman in being supportive and nurturing to other people, but that's for me and maybe not something for, like, every woman on the planet.

For Anna, given that she was pregnant at the time of the interview, it is possible that her association of womanhood with nurturing and support were a result of her burgeoning identity as a mother. It is possible that more than just renegotiating her gender schema to allow for individual differences between women, her pregnancy and new identity as mother, contributed to her new working definition of womanhood.

Melissa's account is very similar in how she was able to recognize that there are too many similarities and differences between women to even attempt to characterize womanhood. However, she does speak to a perceived universality in the ways women may manage or respond to relational and sexual distress, which appears to foster a kind of inclusive perception of womanhood for herself and others:

I just feel like I define it more broadly and like what it can look like, and like things that I never thought could happen to a woman would be a part of it, and probably a million other things that I've never heard of that women can go through that, like, I just can't, I don't think I would define womanhood the same as I would before this whole thing. I think that like, I still think that, like with other women that don't have vulvodynia, I feel a lot of similarities come out in the way, like in the way people deal with problems and like a lot of similarity in the issues that deal with sex, like being infertile or having

relationship problems, like in the way that they internalize it or they way they feel like, 'okay, this is not about who I am as a person this is just one part of my life.' It's just interesting because I feel like some of it has made me think about how women are really different, I just think it's really interesting in what defines a woman, like it's not just an outward thing, so I do think that there's an outlook on life that's like different, and I think it's really interesting how women can respond to things similarly, like vulvodynia, even if they're very different.

Melissa's account nicely demonstrates how her gender schema has evolved in light of her lived experience with vulvodynia. She explicitly discussed thinking about the ways in which women are different from each other, such that differences do not mutually exclude them from owning a sex-congruent identity.

This process of thinking about women differently and allowing space for in-group differences seems to be representative of the other three participants gender schema evolution. It seemed that, prior to being diagnosed with vulvodynia, each participant held a prototype of womanhood as the set of standards by which to categorize themselves. Upon onset of vulvodynia symptoms and subsequent negative impact upon their sex lives, the participants, no longer meeting their standards of womanhood, had no choice but to identify as sex-incongruent women. This new status was further perpetuated again and again by messages from women in their lives and medical providers, therein confirming their belief that they were atypical women. Yet, once a trusted and caring gynecologist diagnosed them with vulvodynia, a shift occurred in their gender schemas that allowed them to successfully assimilate their lived experience of vulvodynia into a newly formed schema. Furthermore, meeting other women with vulvodynia and feeling as though they were not alone in their experiences, translated into broadening schemas to account

for individual differences. In other words, participants' gender schemas seemed to reflect their new ways of thinking about what makes them women, thus expanding definitions beyond one, prototypical women. Thus, their standards and criteria of womanhood allowed for individual differences, especially in relation to successful and satisfying engagement in sexual intercourse with male partners.

Results Summary

Overall the results of this study show that, for these four women, vulvodynia had a very real impact upon their experience of gender identity. The findings demonstrated that vulvodynia both negatively and positively impacted gender identity over time and across critical periods. More specifically, the findings illustrated that in the first critical time period, their symptoms of vulvodynia proved highly threatening to their existing gender schemas, such that they no longer met their standards of the typical woman, resulting in a new identity as sex-incongruent women. However, within the second and third critical time periods, participants began to renegotiate their standards of womanhood, resulting in evolved gender schemas, coming to a place where they were able to acknowledge their suffering, both physically and emotionally, and began to craft an appreciation for their bodies, their voices, and individual differences between women. My findings also reveal how powerful relationships with other women with vulvodynia were for the participants, as that was a significant factor in creating space within schemas for those differences. In other words, they were able to renegotiate their standards of womanhood based on how they saw other women with vulvodynia living well as well as seeing how their lived experiences were not unique to them but something many women experience. Thus, each participant was able to accept vulvodynia as a fact of living and re-establish positive connections

and perspectives on their bodies (no longer viewed as defective or deficient) and gender identity (being a woman is about much more than having sex).

Chapter 5: Discussion

Vulvodynia is on the rise for women in the United States, and as a result, those women are at great risk of experiencing negative impact upon gender identity. Furthermore, given the lack of information and understanding around the biological and neurological etiologies and correlates of this chronic pain condition, it is often regarded by medical providers and laypersons as a psychosomatic complaint or manifestation of some distress around sexual intercourse. Based on this real threat to gender identity, the present study aimed to gain a greater understanding of women's lived experience of vulvodynia as well as its impact upon gender identity, and offer implications and recommendations for providers on how to work with women with vulvodynia with understanding and validation. This final chapter provides a discussion of my findings in which answers to the four overarching research questions are explored. To review, the four guiding research questions for this study were: 1) what impact does vulvodynia have upon women's gender identity?; 2) how do women with vulvodynia define womanhood?; 3) what factors negatively impact gender identity?; and 4) what factors preserve and/or enhance gender identity? After these findings are discussed, researcher reflexivity, implications for providers, limitations to the present study, and future directions of research in light of current findings, will be addressed.

Vulvodynia's Impact Upon Women's Gender Identity

Based on the results of this study, it appears that, for these four women, vulvodynia clearly impacted their gender identity, both negatively and positively. However, the negative impact appeared to be significantly mitigated by the passage of time and the critical time periods through which women passed. Prior to onset of symptoms, participants' gender identity was rooted in their gender schemas, such that their standards and criteria for womanhood reflected

their own beliefs, attitudes, and perspectives. It is likely that their gender schemas were organized and developed based on personal female role models and ways in which media portrayed women; however, that line of inquiry was not explicitly studied, thus that is simply my working hypothesis as to the initial gender schema creation and structuring.

Based on my analyses though, it was clear that painful sexual intercourse with male partners and pervasive vulvar pain were not experiences already accounted for in their existing schemas, thus, onset of symptomatology resulted in a significant threat to their ability to claim status as a sex-congruent woman. In working to make sense of their experiences, within the context of their gender schemas and what they believed to be typical of sex-congruent women, participants came to the conclusion that they must not be sex-congruent women in light of their inability to successfully assimilate their lived experiences of vulvodynia into their schemas. Furthermore, it seemed that the participants regularly engaged in comparisons to other women, often resulting in feeling abnormal, atypical, and dissimilar. These downward comparisons only served to further perpetuate their identity as sex-incongruent women. Thus, this first critical time period is characterized by failed attempts to assimilate vulvodynia in their schemas.

Fortunately, it seemed that receiving the diagnosis of vulvodynia from a gynecologist that listened to the participants' stories and trusted in their lived experiences of pain, served as the impetus into the next critical time period. This time period appeared to be characterized by re-organizing schemas such that their experiences of vulvodynia no longer contradicted their once rigid standards of womanhood. Although it is difficult to know exactly what the shift in cognition looked like, it is clear that some shift in their schemas occurred such that they were able to successfully incorporate their experiences. In their critique of gender schema theory, Bussey and Bandura refer to the unknown and abstract nature by which individuals process and

assimilate this information into existing schemas. However, as mentioned previously, this study did not examine those cognitive processes, thus only hypotheses can be made at this time in terms of the suspected underlying processes at play.

Lastly, with newly formed schemas allowing for greater diversity and individual differences between women, participants began to engage in healthy coping behaviors, to not only more effectively manage vulvar pain but extend grace and acceptance towards themselves as women. Additionally, an important hallmark of this critical time period is reconnecting with women, primarily women with vulvodynia. By establishing relationships with other women with vulvodynia and noting ways in which they are similar in their lived experiences of vulvodynia, their renegotiated gender schemas, characterized by individual differences, are further reinforced in that womanhood represents significantly more than successful engagement in heterosexual intercourse. Thus, with the support of their gynecologists and other women with vulvodynia, the four participants in the this study were able to redefine womanhood for themselves, based on the values and standards they deemed fitting, therein broadening their once restricted and narrowed definitions of womanhood.

In summary, this study found that indeed, vulvodynia does impact gender identity. However, for the four women who participated in this study, the impact was two-fold, with both negative and positive factors represented over the course of the critical time periods. Although previous and existing research appear to echo the findings of negative and positive impacts of vulvodynia upon gender identity, no known research to date has positioned such phenomenon within the context of time, or critical time periods.

Definitions of Womanhood

As evident from my analysis, definitions of womanhood for the participants were highly individualized and contextualized. I also found that definitions of and standards for womanhood appeared something of a moving target as they reflected their gender schema evolution throughout the critical time periods. Although not explicitly addressed, I was able to develop an understanding as to how these four women perceived womanhood prior to symptom onset. In hearing how that experience left them feeling different and atypical, I was able to piece together their initial definitions of womanhood; namely that women, especially married women, were expected to engage successfully in heterosexual intercourse. The experience of vulvar pain and painful sexual intercourse was considered an atypical trait, causing them to begin to question their status as sex-congruent women. Furthermore, as they compared themselves to other, typical women, women they viewed as enjoying sex, experiencing pleasure, and giving pleasure to their male partners, their sex-incongruent status was further solidified, as their experiences were very dissimilar in comparison. They also described fear of and grief around lost selves, especially wife and mother, therein speaking to the inherent value those identities held for the typical married or seriously committed woman. As such, I was able to glean the importance of those roles and potentially lost selves and what they represent within their gender schemas. In general, it seemed that, although not wholly alike, the four participants shared common factors in how they defined womanhood prior and up to receiving their diagnoses.

However, upon renegotiations of gender schemas and broadening their views of womanhood to account for individual differences, the participants came to more individualized and person ways of defining womanhood for themselves, rather than a universal definition for all women. As such, participants were able to incorporate core values, such as nurturing others,

connecting with other women with vulvodynia, and open self-expression about their vulvodynia, into their newly organized schemas. This phenomenon of renegotiating definitions of womanhood to more accurately reflect personal values has been documented in previous research as well. Respectively, Ayling and Ussher (2008), Hinchliff et al. (2009), and Kaler (2006) all described similar processes by which some of their participants chose to view womanhood in light of their lived experience of vulvodynia differently as it was causing them significant distress related to not only their gender identity but to their identity as sexual partner as well. Upon renegotiation of what it means to be a sexual woman, Ayling and Ussher found that one participant rejected the notion of being an inadequate woman, describing herself in contrast to the other three participants as an adequate woman. She realized that she could still engage sexually with her partner and that engaging in traditional sexual intercourse did not have to be the defining trait of womanhood (Ayling and Ussher, 2008). More similar to the findings of the current study, Kaler (2006) found that women who broadened their definitions of womanhood negatively appraised gender identity much less than the participants in the study who accepted “the idea that intercourse made one a woman” (p. 68).

Unfortunately, the cognitive processes by which these renegotiations of definitions occurred was not explicitly investigated or addressed in these studies, but it seems reasonable to hypothesize that these women also reorganized their gender schemas allowing for more values-based standards and acceptance of diversity among women.

Factors That Negatively Impacted Gender Identity

Based on each woman’s accounts and the findings of this study, one of the most significant negative factors was the feeling of alienation and isolation from others; each participant discussed her experience of feeling inherently different from other women.

Furthermore, this feeling of difference was within the very negative context of feeling defective, flawed, or damaged in such a way that resulted in withdrawal from friends and family, thus further perpetuating perceived differences. As such, it was in the downward comparisons to other women, feeling disconnected with other women, and ultimately identifying as sex-incongruent women that their gender identity was most significantly, negatively impacted.

This finding has been well documented within the existing body literature. For example, with regards to negative impact upon gender identity, Marriott and Thompson (2008) found that women living with vulvar pain experienced a sense of loss of femininity as a result of diminished sexual confidence in light of not meeting standards around “how sex should be” (p. 248). Similarly, Ayling and Ussher (2008) found that six of their seven participants, all of whom had vulvodynia, described themselves as an “inadequate woman” (p. 299) because of their inability to meet standards around being a “good woman” (p.299) and ability to “attract and keep a man” (p. 299). Likewise, the participants in Kaler’s (2006) study reported feeling disconnected from their sense of self as a woman, describing themselves as “degendered and defeminized by vulvodynia, specifically by the fact that their vulvodynia foreclosed the performance of intercourse” (p. 60). Kaler interpreted this act of “de-gendering” (p. 61) as a loss of womanhood in light of impaired or inability to perform sexual intercourse.

Additionally, within their study, Marriott and Thompson revealed the same sense of inherent difference or “feeling weird” when participants compared themselves to “other ‘healthy’ heterosexual women from whom they felt different” (Marriott & Thompson, 2008, p. 248) as those reported by the participants in this study. Those participants reported feeling “excluded from ‘normal’ life,” in that their beliefs around normal sexual and relational functioning were incongruent with their ability to actually engage sexually and relationally with their partners

(Marriott & Thompson, 2008, p. 253). In other words, when they compared themselves to other women without vulvodynia, they felt abnormal and different in a fiercely negative way (Marriott & Thompson, 2008). Therefore, it is clear that one of the major themes of this study, namely isolation and alienation, has been well represented in the research on vulvodynia, thus offering further support that this phenomenon is likely a common experience for heterosexual women with vulvodynia, albeit unfortunate and damaging to their gender identity and overall sense of self.

Furthermore, this phenomenon of identifying as sex-incongruent in light of such circumstances, including but not limited to loss of sexual desire, infertility, and decision not to have children though otherwise healthy, has also proven damaging to women's gender identity. Thus, it seems that there is a body of evidence indicating that for some women, sex-incongruence within gender schema negatively impacts gender identity. For example, in 2009, Hinchliff, Gott, and Wylie investigated the impact loss of sexual desire had upon their participants' sense of womanhood. The authors conducted in-depth, semi-structured interviews with 17 heterosexual women who had sought treatment from a psychosexual clinic in northern England. Hinchliff et al. found that nearly all of the participants considered themselves different or abnormal, even using the word freak, when comparing self to other women. It was suggested that this sense of abnormality might have been a result of messages about normal sexuality in popular media, as well as interpersonal interactions or discussions with other women about their sexuality (Hinchliff et al., 2009). It seemed that these feelings of being different and defective resulted in or perpetuated existing feelings of alienation, often leading some of the respondents to socially withdraw from family and friends (Hinchliff et al., 2009).

Clearly, study participants within Hinchliff et al.'s study experienced very similar feelings of alienation and isolation from other women due to feeling different, and thus, atypical. Although Hinchliff et al. did not analyze their data through the lens of gender schema theory, it makes sense that in recognizing clear differences from women portrayed in the media and their female friends, some of the 17 participants appeared unsuccessful in their attempts to assimilate their lived experiences of loss of sexual desire into their schemas, ultimately concluding that their experiences were incongruent with that of a prototypical woman.

Interestingly enough, those study participants also discussed their attempts at renegotiation of definitions of womanhood. For example, Hinchliff et al. (2009) described the experience of loss of sexual desire as being "sexually dead" (p. 459); therein, reflecting a type of acceptance or resignation that, for some of the 17 women who participated in the study, loss of sexual desire equated to loss of identity as a woman. However, Hinchliff et al. did find that a small subset of participants did not report any negative effects of loss of sexual desire upon sense of womanhood. Although the authors did not speculate as to why this might be the case for these women, they did note that, despite "cultural expectations of womanhood and medical discourses, both of which have shaped and defined what is considered sexually and behaviorally 'normal' for heterosexual women," not all women with loss of sexual desire experience ill effects on perception of self.

However, again it makes sense that those women whose gender identity was not as significantly negatively impacted by loss of sexual desire were more successful in either assimilating information into an already broad and expansive gender schema or that they were more readily able and willing to broaden and expand gender schemas in order to successfully

assimilate the information. Thus, this finding from Hinchliff et al.'s (2009) study is further evidence to the impact gender schema can have upon gender identity.

Likewise, women who do not bear children, either due to infertility or by choice not to do so despite ability to do so, can sometimes suffer similar ill effects upon gender identity. For example, Daniluk (1999) found that women without children often negatively evaluate themselves as odd or unusual when compared to women who have borne children. She also found that it was “not uncommon for voluntarily childfree women to find themselves doubting their normalcy in the face of their lack of maternal instinct or desire” (1999, p. 86). Additionally, Daniluck brought attention to the ways in which some women experience prejudice or marginalization as a result of deviating from the expected social norm of motherhood. For instance, childless women spoke about interpersonal interactions with other men and women, including family members, who challenged their womanhood, suggesting that they were immature, lacking morality, uncaring, or cold-hearted (Daniluck, 1999). In this way, women who do not bear children and women with vulvodynia may be faced with the difficult task of reconstructing an authentic female identity in a society that denigrates those who deviate from traditional, heterosexual gendered roles and expectations.

Lastly, the participants of this study discussed their experiences of feeling misunderstood, not believed, and unfairly blamed for the experience of vulvar pain by others, primarily healthcare providers, and how such harmful encounters served highly damaging to their global sense of self. Participants received very clear messages from providers that if they could only relax more while engaging in intercourse, if they had simply chosen to have sex earlier in life, if they could just push through the pain, then their vulvar pain would likely cease. These kinds of victim-shaming and blaming messages from “experts” resulted in increased anguish and

unnecessary psychic pain, therein negatively contributing to both emotional and physical functioning. However, this phenomenon of dismissing women's narratives or presuming a mindset of "it's all in your head" is a longstanding trait of the patriarchy that continues to drive such things as wage inequality and sexism.

Unfortunately, research illustrates that dismissiveness of vulvar pain and chronic pain in general is a phenomenon that appears all too common an occurrence. In their qualitative study, Marriott and Thompson (2008) reported a theme of "importance of being believed (legitimacy of problem)" (p. 252). Specifically, participants were told, "that they needed to relax during sex, and sometimes this was interpreted as though they were being told it was all in their heads" (Marriott & Thompson, 2008. p. 252). Additionally, Nguyen, Ecklund, MacLehose, Veasley, and Harlow (2012) found that women with vulvodynia with co-morbid pain conditions (irritable bowel syndrome, interstitial cystitis, fibromyalgia, endometriosis, and chronic fatigue syndrome) "were significantly more likely to experience feelings that no one believes that they are in pain (invalidation)" (p. 596). These feelings of invalidation were most often attributed to interactions with medical providers, thus Nguyen et al. suggest that "[i]f physicians play an important role in manifesting feelings of validation for a woman's chronic pain condition, perhaps validation by physicians may improve women's feelings" (p. 596).

Factors That Positively Impacted Gender Identity

Each of the four participants discussed ways in which they felt vulvodynia had positively impacted, even enhanced their gender identity. Based on the findings of this study, it appears that engaging in interpersonal interactions and developing relationships with other women with vulvodynia most positively impacted women's gender identity. In developing fellowship with other women with vulvodynia, the participants were able to combat feelings of alienation and

isolation by engaging in narratives with other women in a context much devoid of judgment, skepticism, blaming, and shaming.

Moreover, through the establishment of community and inclusion, the participants began to share their own stories and lived experiences, recognizing that their narratives were similar to those of other women with vulvodynia. In this way, the participants felt validated and supported in their experiences, thus discontinuing their silence and allowing their voices to be heard. As such, within their established vulvodynia communities, they gained strength and empowerment to engage less often in downward comparisons and recognize the beauty in differences between women and the understanding that women are better served through environments of inclusion rather than exclusion.

To date, there is no known existing body of literature related to this finding. However, given the previous body of literature supporting the phenomenon of chronic pain sufferers' experiences of isolation and alienation, it is reasonable to believe that further inquiry into the impact of connectedness and community with others suffering from vulvodynia, or chronic pain in general, would likely support this finding; that such individuals might feel less isolated and more connected upon developing connections with others who similarly struggle with pain, and as such, that women with vulvodynia may experience less negative impact upon gender identity.

Another significant factor that positively impacted gender identity was validation from medical providers and the recognition that their lived experience of vulvodynia was real and not in fact 'all in their heads.' Here again, validation of their pain and assigning a diagnosis proved to be another important combatant against feeling isolated and alienated from others. It also served as the foundation upon which the participants could develop a common language to engage in discourse with others, providers and non-providers, as well as begin to find others with

whom they could relate (e.g., other women with vulvodynia). Upon naming and knowing that they were suffering from the chronic pain condition vulvodynia, the participants began researching it, thus finding support groups and sympathetic providers to aid in their treatment process. As previously mentioned, Marriott and Thompson (2008) found that many women with vulvodynia experienced feelings of invalidation from their physicians. They found that “it was important to feel understood by health professionals” (Marriott & Thompson, 2008, p. 254) in order to begin to make sense of their pain. However, most research around chronic pain attends to the negative impact of invalidating experiences rather than attending to the positive impacts, both emotionally and behaviorally (e.g., treatment seeking and compliance behaviors), that validation from medical providers can have upon individuals with chronic pain. Within this study, once the participants felt heard, understood, and believed, they reported readiness and commitment to begin seeing vulvodynia as a part of life rather than viewing it as a barrier to living a full life. More research investigating the impact of validating women’s experiences of vulvar pain is warranted given the potential mental and physical health benefits for women and potential financial benefits for women and the healthcare industry at large (i.e., insurance providers).

Additionally, each woman in the current study spoke to feeling empowered in educating themselves not only about vulvodynia but about their bodies as well, therein leading to a sense of appreciation for and reclaiming of their bodies as valued aspects of themselves to be honored, rather than denigrated or degraded. In knowing more about themselves, vulvodynia, and their treatment options, the participants felt significantly more in control of their lives and their potential to actualize those once considered lost selves. Thus, rather than feeling as though they

were victim to this unknown vulvar pain and painful intercourse, they were able to determine the direction of their treatment and the extent to which they allowed vulvodynia to impact their lives.

Ultimately, each woman spoke to the positive impacts that finding strength and courage through relationships with other women, validation from providers, and empowerment through education had upon their global self-esteem and gender identity. It was in those experiences that acceptance and coping were fostered and a new gender schema was established. Finally, each woman reported a renewed ability to find growth and strength in her suffering, a phenomenon that allowed for appreciation of their bodies and their gender, and a platform upon which to advocate for those that yet still suffer.

Reflexivity

Throughout the data collection and analysis process, I kept a journal within which to reflect upon my own biases and reactions to the participants and their stories. I found myself often angry with those individuals who negatively impacted participants, especially the medical providers. Each participant sought out support, treatment, and understanding from healthcare providers and were routinely met with disregard, disbelief, and indifference. I felt outraged that many of these “experts,” these pillars of hope and aid ended up perpetuating egregious offenses against the participants. Thus, I found myself quickly aligned with participants, often feeling protective and outraged at their protracted suffering and invalidation from so many.

To that end, I found myself asking the interview questions with caution, often not engaging in as much follow-up questioning as I might have had I not been so concerned about ensuring that participants had the space they needed to fully express themselves. Thus, the interview protocol may have been weak in being too broad and open-ended. However, given my awareness around my hesitance and reluctance to impart too much of my own research agenda upon the

participants, I acknowledge this as a limitation of the study. I also realize that I gave these four women an opportunity to share their stories without restriction or restraint, an issue of immense value to me.

Another point of reflection for me was around my role as researcher. I am primarily a clinician and spend nearly all of my professional time conducting psychotherapy with individuals. I found it difficult to remove my therapist hat and replace it with my researcher hat. Throughout the interviews, I often utilized basic microcounseling skills, such as reflection of content and feeling, paraphrasing, and summarizing. These skills were used, not to facilitate a therapeutic relationship, but to foster trust and relay my understanding that they have struggled and suffered in a very real way. I also see the use of these skills as a strength, because they allowed me opportunities to check in with the participants and ensure that I had accurately heard both the content and the underlying emotion; but if I was mistaken, there was then an opportunity for clarification or correction that only served to enhance validity.

I believe that in asking these brave women to speak candidly about an especially private and historically shameful experience, it was important to establish a mutually trusting relationship. In doing so, I believe that the participants felt freer to discuss painful experiences with me, knowing that I genuinely cared about them and was invested in sharing their stories, their perspectives with others.

Implications for Providers

The purpose of this study was not only to elucidate the lived experience of vulvodynia and the ways in which it impacts gender identity, but also to offer recommendations for healthcare providers on how they might engage with more compassion and awareness when working with women with vulvodynia. To begin with, as was very evident from the participants'

numerous accounts with medical providers, a theme of not feeling heard, believed, or understood proved damaging to both their global sense of self and gender identity. In fact, it speaks to the participants' strength, courage and resolve that they continued interacting with medical providers at all in light of the damage and mistreatment they so routinely encountered. For other women with vulvodynia, the notion that they could likely encounter similarly injurious providers might serve as a barrier to treatment or result in avoidance of treatment seeking. More than just dealing with a chronic pain condition, the participants were dealing with the deleterious effects upon self-worth and gender identity as a result of negligent and harmful providers who once swore to do no harm to their patients.

Given the shame and stigma around vulvar discomfort and pain associated with sexual intercourse, medical providers might more effectively serve women with vulvodynia by simply listening and attending to their stories with a sense of curiosity rather than dismissiveness so as to avoid feelings of denigration and discouragement. In light of this study's findings and the participants' experiences with medical providers, simple acknowledgement of both physical and emotional pain is also an important recommendation. This action can serve to not only to validate their lived experience of chronic vulvar pain, but also aid in destigmatizing their condition, contributing to an environment in which women feel more comfortable discussing and describing their symptoms, thus hopefully expediting the diagnosis process.

It may also be prudent to better inform women about the ambiguous nature of vulvar pain, the diagnosis process, and how diagnoses like vulvodynia tend to be one of rule out, sometimes taking up to months or even years to accurately diagnosis. By more thoroughly informing women of possible outcomes, procedures, and timelines, women may feel more active in the diagnosis process, thus feeling as though they have more agency and active participation in their

subsequent treatments. In the same way that healthcare providers discuss informed consent prior to initiation of treatment, healthcare providers might work to ensure that women with vulvodynia are as informed as possible throughout each step of the ruling out process.

Another important factor for healthcare providers to bear in mind when interacting with women with vulvodynia is to consider all possible etiological correlates without blaming the woman. For example, multiple physicians referred to a lack of sexual experience as a likely source of vulvar pain. Thus, instructing participants to “keep at it” and continue to engage in painful sexual intercourse served to only further alienate women from medical providers, as well as perpetuate shame and guilt, as if they were to blame for their chronic pain condition. It may have seemed helpful in that moment for the provider to suggest that there is nothing medically wrong, but it was significantly damaging to the participants to feel so invalidated and blamed for their experience of pain.

Lastly, healthcare providers working with women with vulvodynia are in a unique position to offer referrals and resources to help women connect with, not only medical and psychological specialists, but other women with vulvodynia. Firstly, the most effective treatment of chronic pain includes a psychological component given the ways in which the mind and the body interact to both reduce and exacerbate experiences of pain. Thus, medical providers working with individuals with any chronic pain would serve their patients well by providing appropriate referrals to mental health providers. However, given the more sensitive nature of vulvodynia, having specific referrals to mental health providers that specialize in sexual health, sexual pain, or women’s health, offers more comprehensive healthcare and increase likelihood of reduced pain and/or improved quality of help. Secondly, gaining awareness around social support resources, such as the National Vulvodynia Association and local support groups, will aid

women with vulvodynia in making those important connections with other women, not only instilling hope for the future, but combatting feelings of alienation and isolation. One of the clearest findings of this study was how important connecting with other women with vulvodynia was in learning to accept and cope with their chronic pain condition and move towards a more positive appraisal of gender identity. Healthcare providers that can offer these kinds of social support resources again, serve to validate women's real experiences of pain while imparting upon them the real truth that they are not alone in their struggle.

Study Limitations

As with any research endeavor, this study was not without its limitations. To begin with, there is a lack of diversity with regards to race, ethnicity, sexual orientation diversity, and socioeconomic status. Thus, women with vulvodynia who identify differently than the four participants of this study, may feel that this study is not an accurate portrayal of or close approximation to their lived experience of vulvodynia. This is especially significant given that, according to the Agency for Healthcare Research and Quality (AHRQ; 2014), the quality of healthcare and access to healthcare resources are inadequate and insufficient for minority and low-income women. Additionally, AHRQ (2014) researchers found that between 2002 and 2007, women were more likely than men to be delayed medical services or simply unable to access or receive necessary and needed medical care, including prescription medication and dental care. Lastly, current research shows that approximately one-third to one-half of U.S. women with chronic vulvar pain do not seek treatment or consult medical providers about their symptoms (Bachmann et al, 2006; Harlow & Stewart, 2003; Nguyen et al., 2012), therefore, it is possible that the experiences reported by the participants in this study may lack applicability to non-treatment seeking women with vulvodynia.

As such, all four participants had access and means to resources, namely those related to healthcare. The participants were all insured and able to pay out of pocket expenses when their insurance carriers would not approve certain medical encounters and tests. Being denied claims was not an uncommon occurrence given the lack of etiology and suspicion that their vulvar pain was psychosomatic rather than biologically based. Thus, despite repeated negative experiences with medical providers, they not only had the determination, but financial ability to continue to seek out second and third opinions, run laboratory tests, and pay for various treatment methods (medications, ointments, and physical therapy). Therefore, it is possible that women who lack the financial means and access to quality healthcare may be at greater risk for vulvodynia to more negatively impact their gender identity, not to mention increased risk for poorer overall health and prognosis.

Another limitation of this study was the lack of investigator triangulation, intercoder agreement, and independent audit. According to Merriam (2009), investigator triangulation refers to the use of multiple investigators in the data collection, analysis, and interpretation processes. Using multiple investigators throughout the research process allows for opportunities to confirm or disconfirm emerging findings, thus strengthening all three types of validity integral to IPA: descriptive, interpretative, and internal generalizability (Merriam, 2009). Similarly, intercoder agreement, a process in which multiple researchers code transcripts and then compare findings with other researchers to determine whether they arrived at the same, similar or different codes and themes (Creswell & Plano Clark, 2011), also serves to enhance overall validity, especially credibility. Lastly, an independent audit is when an independent researcher, an individual who played no role in the research project, is tasked with checking “that the final report is a plausible or credible one in terms of the data which have been collected and that there

is a logical step-by-step path through the chain of evidence (Smith, Flowers, & Larkin, 2009, p. 182). Again, such an act greatly promotes trustworthiness and credibility, enhancing the reader's ability to generalize these findings to her own situation or lived experience. However, I believe that, despite the aforementioned limitations, scientific rigor and integrity was met as a result of detailed attention to the recordings and transcripts, the use of reflexivity, and member checks in which the participants were able to respond to the data and emergent themes. I also recognize and acknowledge that overall validity might have been further strengthened through the use of multiple investigators/coders or a third party audit.

Future Directions of Research

Future studies about vulvodynia and its impact upon women's lives is an important area of research that demands further attention. The current body of literature especially lacks diversity in terms of study participants and populations of interest. For instance, nearly every study to date has either investigated solely heterosexual women with vulvodynia or failed to report sexual orientation. Either way, the voices of women who identify as anything other than heterosexual have not yet been heard. Future research investigating the impact of vulvodynia in women who identify as non-heterosexual would likely shed more light on the ways in which their lived experiences are similar or different to those of their heterosexual counterparts.

Additionally, there is a dearth of research investigating the experiences of women of color with vulvodynia. This scarcity is significant and likely parallels the disparity of quality healthcare to women of minority or low socioeconomic status. It is for this very reason that this line of inquiry is of great importance. It is possible that, by conducting such a study, much could be learned about barriers to access and how to best serve a historically underserved population.

More research is also warranted around treatment seeking and developing a sense of when women are more and less likely to seek treatment for their symptoms. Additionally, research around the type of treatment being sought out might prove to be helpful in educating those individuals most likely to have the first point of contact with women with vulvodynia. The implication of such a study would be to ensure that medical or mental health providers who meet with women seeking treatment for the first time could offer a positive and supportive experience in which to encourage continued treatment and healthcare, advocacy in getting healthcare needs met, and assurance that their voices have been heard.

Finally, as previously mentioned, the interview protocol was greatly limited in light of my decision to allow for space for participants to respond in such a way that was of greatest salience and importance to them. However, I realize that my analysis and subsequent results may have greatly benefited from specific inquiry about influences of participants' female role models, especially their mothers or female caregivers. In doing so, I may have come to a greater understanding as to the ways in which their gender schemas were originally shaped. More specifically, I might have collected more information around how significant female role models contributed to organization of information that served to establish their prototype of sex-congruent women.

Summary

It is hoped though, that this study might serve as an entrée into establishing dialogues with healthcare providers, women with vulvodynia, and friends and family of women with vulvodynia in such a way that the stigma, misinformation, misdiagnoses, and invalidation might begin to chip away. Individuals can ask women with vulvodynia about their stories and wonder how they might compare to those represented in this study. It can allow for an opportunity of

greater understanding, compassion, and empathy in helping women with vulvodynia reclaim their voices and their bodies and re-engage in the world through a lens of inclusion and acceptance.

Appendix A

Sample Recruitment Flier

Research Opportunity for Women with Vulvodynia

Are you a woman between the ages of 25 and 30 years old?

Have you been diagnosed with vulvodynia or vulvar vestibulitis within the last 2 years?

If you answered yes to both, you may qualify for participation in our study. We are interested in learning more about your experiences with vulvodynia, as we hope to learn about how to best support other women with this condition and combat the negative impact upon self worth.

Nearly 16% of American women suffer from this chronic pain condition at some point in their lives. Given the sensitive nature of this condition, many women with vulvodynia do not openly discuss their experience often resulting in social isolation, embarrassment, and negative self-esteem.

Please email us at vulvodynia.study@gmail.com to learn more.

Compensation is available.

Appendix B

Telephone Eligibility Screen for Interested Participants

Hello, and thank you for your interest in this study. My name is Emily McCann, and I am inviting women with vulvodynia, or vulvar vestibulitis, to participate in a series of interviews to learn more about the ways in which this chronic pain condition impacts gender identity. If you decided to participate, you will be asked to participate in three interviews. Interview questions will focus on your experience of vulvodynia, including onset of symptoms and path to diagnosis, as well as how vulvodynia may have impacted your gender identity, or how you view yourself as a woman. Interviews will last no longer than one hour and compensation will be provided. Should you decide to participate: 1) you are free to discontinue your participation at any time; and 2) all personal information will be de-identified and kept confidential at all times.

Does this sound like a study you are interested in participating?

If no: Thank you for your time. Good-bye.

If yes: Is this a good time to complete the 2-3 minute phone interview to determine if you are eligible for the study?

If no, schedule another time to conduct the eligibility screening.

If yes: Great, let's get started.

1. Have you been diagnosed by a physician with vulvar vestibulitis, or vulvodynia, in the last 2 years?
2. Do you identify as heterosexual?
3. Are you between the ages of 25 and 30 years old?
4. Have you ever abused alcohol, illicit drugs, or prescription drugs?
4. Have you ever been diagnosed with schizophrenia, bipolar disorder, or a personality disorder?

5. Have you ever been diagnosed with a chronic health condition, such as diabetes, MS, ALS, fibromyalgia, etc.?

If ineligible: It looks like you are not eligible to participate in this study. Thank you so much for your time.

If eligible: It looks like you are eligible to participate in this study which would involve completing the first of three interviews. Are you interested in participating?

If no: Thank you so much for your time.

If yes: Would you like to schedule a time for that interview?

Appendix C

Individual Interview Protocols

Interview Protocol #1

1. How old are you?
2. What is your identified race or ethnicity?
3. What is your current relationship status?
4. Do you have any children? If so, how many?
5. What is your highest level of education?
6. What is your current employment?
7. What is your identified religious affiliation?
8. What was your age at onset of symptoms?
9. At what age were you diagnosed with vulvodynia?
10. Have you ever sought treatment for vulvodynia?
 - 10a. If yes, please describe the treatment.
 - 10b. If no, please describe why.
11. Are you currently undergoing treatment for vulvodynia?
 - 11a. If yes, please describe the treatment.
12. What does living with vulvodynia mean to you?
13. Describe what life looks for you as a woman with vulvodynia.
14. What did the diagnosis process look like? What were your interactions with medical providers like?
15. How did you feel once you were diagnosed?

16. How has vulvodynia impacted your life, including but not limited to your relationships with others and your self-esteem?

17. How, if at all, has vulvodynia impacted your body image or your experience of your body?

Interview Protocol #2

1. How do you define what it means to be a woman, or the concept of womanhood?
2. What cultural/societal factors influence your definition of womanhood, including but not limited to gender role expectations, media influences, family of origin influences?
3. How has living with vulvodynia affected how you see yourself as a woman?
4. Living with vulvodynia, in what ways do you feel more and/or less like a woman?
5. How, if at all, has your perception of womanhood changed?

Interview Protocol #3

1. After reading transcripts from both Interview 1 and 2 do you feel that the researcher accurately captured the meaning of your experiences?
2. If not, please clarify and correct the areas that were inaccurately represented.

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