

**STORYING THE IMPACT OF PARTICIPATING IN A PSYCHOLOGICAL
TREATMENT INTERVENTION FOR PROVOKED VESTIBULODYNIA, 5 YEARS
LATER: A NARRATIVE INQUIRY**

by

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Abstract

Provoked vestibulodynia (PVD) is the most common cause of coital pain in reproductive aged women who continue to experience significant barriers to accurate diagnosis and effective treatment. Psychological interventions have been accumulating research support as effective for improving pain symptoms and the well-documented negative psychological and sexual sequelae of PVD. Quantitative results from a recent RCT comparing eight-week group MBCT with group CBT ('COMFORT study') with 130 PVD-diagnosed women, showed both interventions significantly improved pain symptoms, sexual functioning, psychological and sexual distress, (Brotto et al. 2019). Research suggests individual women may benefit differently from change oriented therapeutic modalities like CBT or acceptance-based therapeutic modalities like MBCT, and that non-modality specific elements of program delivery may account for some of the documented positive impacts. There are few qualitative inquiries exploring how women with PVD experience their participation in psychological interventions or which aspects of programming they attribute to personal change. The current study used a narrative inquiry to provide insight into how 8 women experienced the COMFORT program and may be unique in providing their perspective more than 5 years after participation. Women storied their experiences via semi-structured interviews, with responses audio recorded, transcribed verbatim and constructed into eight narratives in collaboration with interviewees who provided feedback, edits and approval of the final versions presented here in full. Thematic analyses across cases revealed common themes related to the difficult journey to diagnosis and treatment, the painful disruption of symptoms to their identity, psychological and sexual functioning and intimate relationships, perceived benefits of participating, and suggestions for improving treatment for women with PVD. Women reveal how personal histories, beliefs, and individual, relational and

cultural contexts impacted their treatment experiences, the benefits they attributed to participating, challenges they experienced before, during and after their participation and their ideas about what constituted treatment ‘success’. These narratives contextualize quantitative findings, may help to inform future empirical inquiries, provide information that may be useful in clinical contexts and lend further support to the importance of including qualitative research into treatment program evaluation and sexual health research more generally.

Lay Summary

Provoked vestibulodynia (PVD) is a common cause of painful sex for women and negatively impacts an affected woman's mental, emotional, relational and sexual health. Many women struggle to find accurate information about the condition and will commonly see many healthcare providers who are unknowledgeable about the diagnosis or treatment. Psychological therapies have been shown effective for reducing pain and distress. A recent study showed that eight weekly group sessions of either Mindfulness-Based Cognitive Therapy (MBCT) or Cognitive Behavioural Therapy (CBT) significantly improved women's symptoms ('COMFORT study') (Brotto et al. 2019). Some women may benefit more from some psychological approaches than others, but few studies have asked women about their experiences with these treatments directly. The present study shares the stories of eight women who participated in COMFORT and they provide insight into how these groups helped, what they thought could be improved and how they are doing five years later.

Preface

This thesis is an original, unpublished, independent work of the author, Adrienne Diane Marsh.

This research was approved by the University of British Columbia's Behavioural Research Ethics Board as a qualitative follow-up study to a quantitative research protocol for an RCT comparing the effectiveness of group Mindfulness-Based Cognitive Therapy with Cognitive Behavioural Therapy for Provoked Vestibulodynia ('COMFORT study') conducted by Dr. Lori Brotto and colleagues. The UBC Ethics Certificate Number obtained to conduct the present research was H18-01146.

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List of Abbreviations

CBT- Cognitive Behavioural Therapy

COMFORT (study)- Cognitive Behavioural or Mindfulness-based Cognitive Therapy for

Provoked Vestibulodynia

GPPPD-Genito-Pelvic Pain/Penetration Disorder

HCP- Health Care Provider

MBCT- Mindfulness-Based Cognitive Therapy

MVP- Multidisciplinary Vulvodynia Program

PVD- Provoked Vestibulodynia

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Chapter 1: Introduction

The purpose of the present study was to use a narrative inquiry to develop a deeper understanding of how women with diagnosed provoked vestibulodynia (PVD) experienced their participation in the COMFORT study—a trial comparing the effectiveness of an 8-week group Mindfulness-Based Cognitive Therapy (MBCT) with group Cognitive Behavioural Therapy (CBT) for improving pain, distress and sexual functioning (Brotto et al., 2019). It was hoped that eliciting stories of that lived experience might expand on the knowledge derived from quantitative analysis and provide valuable insight into how participants experienced the intervention as helpful or not, what they found most and least helpful and how their individual contexts may have influenced the effectiveness of the study intervention. The overall goal was to determine whether a qualitative study might provide information useful for improving the COMFORT program, for healthcare providers (HCP) providing treatment recommendations and support for women in their care, and informing future intervention research for women with PVD. Interviewing women five years after their participation also provided insight into their perception of the long-term impacts of psychological treatment for PVD symptoms by providing a snapshot of how a subsample of participants were currently managing their diagnosis.

The goals of the present inquiry were to elicit, co-construct, present and analyze the stories told in response to the research question: “Please tell me a story about your participation in COMFORT, and your journey with PVD since”. This inquiry also provided an important opportunity for women to include their voiced perspectives and collaboration in research they have been the subjects of.

1.1 Literature Review

Vulvodynia is an idiopathic chronic pain syndrome characterized by symptoms of burning, cutting, rawness and irritation of the vulva. Provoked vestibulodynia (PVD) is the most common subtype of vulvodynia and is specific to the experience of pain provoked by touch or pressure to the vulvar vestibule, representing approximately 80% of vulvodynia cases (Moyal-Barracco & Lynch, 2004; Wesselmann et al., 2014). PVD is the leading cause of dyspareunia (painful intercourse) in reproductive-aged women, with point prevalence in the general population estimated at 8% and with as many as 28% of women affected across their lifetimes (Arnold, Bachmann, Rosen & Rhoads, 2007; Harlow et al., 2014; Reed et al., 2012).

PVD may be further divided into subtypes depending on onset: symptoms may have been present with their first attempts at vaginal penetration with a tampon, during a medical exam or intercourse ('primary' or PVD1) or symptoms may have appeared after a period of months or years of pain-free vaginal penetration ('secondary' or PVD2) (Goldstein et. al, 2016). Women with vulvodynia often present with vaginismus (involuntary spasming of the muscles of the vaginal wall in anticipation of or in response to vaginal penetration), other comorbid pain conditions and sexual, psychological and social challenges (Lester, Brotto & Sadownik, 2015). PVD overlaps with the current Diagnostic and Statistical Manual of Mental Disorders classification of genito-pelvic pain/penetration disorder (GPPPD), where diagnostic criteria are met when persistent or recurrent difficulties with one or more of the following have been experienced for at least 6 months, involve clinically significant distress, and other potential psychiatric or physiological pain sources have been excluded: (1) difficulties with vaginal penetration during intercourse; (2) pain associated with vaginal penetration; (3) marked fear and/or anxiety about pain in anticipation of, during, or as a result of penetration; and (4)

involuntary tightening of the pelvic floor muscles during attempted penetration (5th ed.; DSM–5; American Psychiatric Association, 2013). Clinically, women may receive a diagnosis of PVD when a knowledgeable medical practitioner, having ruled out secondary vulvar pain sources (infection, disease, injury) elicits an intense pain response by gently palpating the vulvar vestibule during a physical exam, and patients report the provoked pain has been present for at least 3 months (Bornstein et al., 2016).

As vulvodynia and PVD are nomenclature used more commonly than GPPPD in the scientific literature reviewed for this inquiry, I will use terms vulvodynia and PVD to refer to these conditions in this text. As the majority of published scientific literature has focused on cis-gendered heterosexual women in relationships with cis-gendered men, references to ‘women,’ ‘men,’ and ‘partners’ reflects a cis-gender, heterosexual identity and relationship context unless specified otherwise.

1.1.1 Impact

1.1.1.1 Barriers to diagnosis and treatment

Despite the high prevalence of PVD, and considerable advances in the field, women experience significant barriers to diagnosis and treatment (Sadownik, 2000). Receiving an accurate diagnosis and effective treatment of vulvodynia is a well-documented challenge for women, with only 60% of those women experiencing symptoms likely to seek treatment, and less than half of those receiving an accurate diagnosis (Reed et al., 2003; Harlow et al., 2014). A 2013 population-based American healthcare study found 35% of women in their sample had attended more than 15 medical appointments and waited over 36 months between symptom onset and receiving a diagnosis of vulvodynia (Connor, Brix, & Trudeau-Hern, 2013). Knowledge

regarding the diagnosis and treatment of vulvodynia amongst healthcare providers remains low despite the high prevalence of PVD (Toeima et al., 2011).

The feelings of shame, low-self-esteem and beliefs of essential defectiveness, often reported by women with vulvodynia, may prevent women from seeking help (Ayling & Ussher, 2008). Unfortunately, those that do are more likely to find those feelings and beliefs exacerbated by feeling stigmatized and dismissed by physicians (Nguyen, Turner, Rydell, Maclehose, & Harlow, 2013). In a 2018 systematic review of 9 peer-reviewed qualitative studies exploring the subjective experiences of 185 women living with vulvodynia, the majority of women interviewed described paternalistic and dismissive interactions with unknowledgeable healthcare providers (HCP) which they reported increased their emotional distress and had negative psychological consequences over and above the impacts of living with unexplained vulvar pain (Shallcross et al., 2018). A 2016 qualitative assessment of the unaddressed needs of PVD patients in a clinical sample, mirrored results of quantitative inquiries regarding the difficulty acquiring a diagnosis and challenges accessing treatment while also relating perceptions of unknowledgeable and dismissive HCP (LePage & Selk, 2016). Women have reported this lack of knowledgeable, HCP remains a significant barrier to receiving an accurate diagnosis and accessing treatment (Shallcross et al., 2019). Further, women consistently describe receiving the message from HCP that they are imagining or exaggerating symptoms that are ‘all in their head’ (Brotto et al., 2013; Marriott & Thompson, 2008; Sadownik et al., 2012) leaving women feeling “belittled, dismissed, and violated” following these visits (Shallcross et al., 2019). Women often find advice they do receive unhelpful, with some having tried at least 3 different treatments before noticing any positive impact on their pain experience (Sadownik, 2000).

The presence of multi-site idiopathic pain may increase caregivers' perception of patient malingering (Tuck & Bean, 2019). As research suggests that approximately half of all women with vulvodynia have comorbid pain conditions (Nguyen, Ecklund, Maclehose, Veasley, & Harlow, 2012), feelings of isolation and hopelessness may be further exacerbated by their interactions with HCP (Nguyen et al., 2012). Women with comorbid pain conditions experience more pain intensity and greater interference of pain with sleep and day-to-day activities, show poorer overall health and more severe dysfunction related to depression, anxiety and posttraumatic stress disorder (PTSD) symptoms than women with vulvodynia alone (Iglesias-Rios, Harlow, & Reed, 2015; Reed et al., 2016). These women will likely have tried many more unhelpful treatment interventions, made more visits to specialists and have higher levels of anxiety and depression than those women presenting with vulvodynia alone (Lester, Brotto & Sadownik, 2015).

The cost to the Canadian Healthcare system of multiple medical visits in addition to the individual financial burden of treatment is significant. In the U.S., the annual economic burden of vulvodynia is estimated to be between \$31-72 billion (Xie, Shi Xiong, Wu & Veasley, 2012). Although pharmaceutical interventions prescribed by doctors may seem to offer a low-barrier and affordable treatment option, these have been shown to have limited effectiveness, iatrogenic impacts on sexual functioning and strong evidence for a placebo effect (Brown, Bachman & Wan, 2018; Foster et al, 2010; Miranda, Soriano, Silveira & Vale, 2018). A knowledgeable clinician may recommend scientifically supported interventions like pelvic floor physiotherapy, individual, couple or group psychological support (Sadownik, 2014); however, these therapies are not covered under the Canadian health system, and for those with extended medical benefits, coverage may be limited when available.

1.1.1.2 Psychosocial Impacts

The costs to women extend beyond the time and money wasted on unhelpful advice or the inaccessibility of effective interventions. PVD symptoms can impact non-sexual, day-to-day activities with discomfort or pain associated with tampon use, gynaecologic exams, tight clothing, sports activities or sitting and contribute to sleep disruptions (Dargie, Gilron, & Pukall, 2017; Ponte, Klemperer, Sahay, & Chren, 2009; Reed, 2006). Chronic dyspareunia frequently leads to significant negative impacts to a woman's psychological and sexual health and disrupts her intimate relationships (Dunkley & Brotto, 2016; Payne et al., 2005; Sadownik, Seal & Brotto, 2012). The psychological sequelae of vulvodynia are well-documented and most women with vulvodynia show clinically significant distress across several psychological domains (Brotto, Basson, & Gehring, 2003; Dargie, Gilron, & Pukall, 2017).

Trait anxiety correlates with the intensity of pain and the severity of disability experienced by chronic pain patients (McCracken LM, Gross RT, Aikens J, Carnrike, 1996). Compared with the general population, women with PVD show state and trait anxiety characteristics ten times more than would be expected as the norm and are more than three times as likely to be clinically depressed, additionally showing reduced ability to cope with distress and increased sensitivity to day to day stressors (Basson, 2012; Payne et al., 2005). A diagnosis of vulvodynia increases risks for new and recurrent onset of depression or anxiety disorders (Khandker et al., 2011) with some having reported historical or current suicidal ideation or intent (Jantos & White, 1997). A 2020 retrospective chart-review of 352 women with diagnosed PVD from a specialty pelvic pain clinic, found 22% met criteria for pain-related anxiety alone, 4% for depression alone, and 27% for both pain-related anxiety and depression (Govind et al., 2020). The study authors noted that rates of depression were lower than reported in community samples

but speculate rates of depression may be higher for women experiencing chronic vulvar pain without a diagnosis and highlighted their findings showed a statistically significant association between attempts at prior treatment and greater pain-related anxiety and depression (Govind et al., 2020).

Although other chronic pain and mood disorders can commonly disrupt sexual functioning (Basson & Shcultz, 2007), as PVD pain most often occurs in the context of sexual contact, it can lead to significantly negative impacts on a woman's experience of her sexuality and identity and disrupt her intimate relationships (Dunkley & Brotto, 2016; Payne et al., 2005; Sadownik, Seal & Brotto, 2012;). Unexplained dyspareunia often leads to avoidance not just of intercourse, but all sexual activities and often non-sexual forms of physical intimacy for many affected women (Sadownik, 2000). As women learn to associate intercourse with pain and anticipate sexual contact will lead to the experience of pain, those affected typically exhibit clinically significant levels of decreased sexual desire, arousal and orgasm frequency, more frequently report negative associations with sexual cues and intercourse, report lower sexual self-esteem and deficient sexual communication skills, when compared with controls who do not experience dyspareunia, in addition to increases in pain hypervigilance and catastrophizing, and increases in anxiety and depressive symptoms commonly found across the experience of chronic pain syndromes (Bergeron, Corsini-Munt, Aerts, Rancourt, & Rosen, 2015; Gates & Galask, 2001; Hallam-Jones, Wylie, Osborne-Cribb, Harrington, & Walters, 2001; Nylanderlundqvist & Bergdahl, 2003; Payne, Binik, Amsel, & Khalife', 2005; Wylie, Hallam-Jones, & Harrington, 2004).

As with other chronic pain syndromes, the most distressing effects of PVD are often not the experience of the physical pain itself, but the way it disrupts their overall quality of life. As

PVD prevents engagement in or enjoyment of sexual activity often associated with individual and cultural perceptions indicative of their value as women and romantic partners, many may begin to question their individual worth and experience increasing feelings of shame related to beliefs of their essential defectiveness and a withdrawal from valued expressions of social and romantic connection (Ayling & Ussher, 2008; Bergeron, Rosen & Corsini-Munt, 2018; Shallcross et al., 2018). The modest body of qualitative literature provides further insight into the difficulties women experience that are not easily quantified. Themes of shame, isolation, hopelessness/despair and unfairness/injustice figure prominently in women's qualitative accounts of the impact of living with PVD and women often connect these feelings to beliefs of their essential otherness as the source of their suffering (LePage & Selk, 2016; Shallcross et al., 2018; Shallcross et al., 2019; Webber et al., 2020). A recent systematic review summarizing the qualitative research exploring the lived experiences of women with PVD, examined nine publications meeting their quality criteria (Shallcross, 2018). They summarized themes found across qualitative accounts where feelings of otherness were reinforced by cultural discourses about sex and gender shared by partners, friends, HCP, education and the media that promoted a 'normal' they felt excluded from, 'invisibilizing' their pain and, by their own accounts, mediated the psychological and emotional distress quantified in empirical literature:

Women [in these studies] experienced negative consequences of social narratives around womanhood, sexuality, and femininity, including the prioritization of penetrative sex, the belief that women's role is to provide sex for men, and the portrayal of sex by the media as easy and natural. These discourses affected women's relationships, both intimate heterosexual relationships and relationships with other women, from whom the women with vulvodynia felt excluded.

Moreover, women experienced the healthcare system as dismissive, sometimes being prescribed treatments that exacerbated their pain. These experiences left women feeling silenced and isolated, and experiencing shame and guilt because of the social taboo, especially around female sexuality, which in turn led to the experience of psychological distress, low mood, anxiety, and low self-esteem (Shallcross, 2018).

There is a growing body of literature suggesting partners also suffer negative psychological, sexual and relational consequences, with 73% of male partners in one sample reporting their partners PVD negatively impacted their relationship (Smith & Pukall, 2014). Partners of affected women have reported lower rates of intercourse frequency and sexual satisfaction and poorer dyadic adjustment relative to controls (Desrosiers et al., 2008; Jodoin et al., 2008) with some describing negative impacts to their personal psychological and emotional functioning comparable to their affected partners (Sadownik, Smith, Hui & Brotto, 2017). Empirical inquiries have found male partners of women with vulvodynia experience increased symptoms of depression relative to controls, (Nylanderlundqvist & Bergdahl, 2003), and increases in erectile dysfunction and decreased sexual satisfaction (Pazmany, Bergeron, Verhaeghe, Van Oudenhove, & Enzlin, 2014). A 2017 qualitative inquiry, interviewing male partners, found their descriptions of experiencing psychosexual distress and mental health challenges were generally similar to women with PVD, including “feelings of stress, frustration, anxiety, and depression”, and of sexual inadequacy, isolation, guilt and abnormality (Sadownik, Smith, Hui & Brotto, 2017).

The frustration and isolation women experience as a result of their interactions with unknowledgeable and unsupportive HCP unable to provide an accurate diagnosis or helpful

treatment recommendations, may also be shared by their partners, where couples affected report feeling increasingly socially isolated and different from ‘normally’ functioning couples, with negative impacts on their shared sense of sexual competency and relationship satisfaction (Connor, Robinson, & Wieling, 2008). Couples report these negative consequences ameliorated when (and if) they receive an accurate diagnosis, information about the condition and effective treatment options (Connor, Robinson, & Wieling, 2008).

Research has suggested that male partners tend to underestimate the level of pain experienced by their partners during intercourse which can affect how he responds to her expression of pain (Rosen, Sadikaj, & Bergeron, 2015). How partners of women understand and respond to her pain, including their willingness to be involved in the treatment process, has been shown to impact prognosis for affected women (Desrosiers et al., 2008; Rosen et al., 2010). Specifically, responses to her PVD symptoms that emphasize her fragility, described as ‘solicitous’ (including communicating exaggerated sympathy, frequently asking about the intensity of the pain and encouraging avoidance of intimacy) or overtly negative responses (those characterized as hostile, critical or rejecting including expressing frustration, disappointment or anger) may increase her experience of vulvar pain and reduce her sexual satisfaction and the sexual functioning and relationship satisfaction of both partners (Rosen, Bergeron, Leclerc, Lambert, & Steben, 2010; Rosen, Bergeron, Sadikaj, & Delisle, 2015; Rosen et al., 2010; Rosen et al., 2014). Solicitous and negative partner responses may reinforce the emotionally and cognitively perceived threat of pain and the avoidance of sex, where ‘facilitative’ responses (those that encourage adaptive coping and expressed happiness and enjoyment for non-painful sexual activities) have been shown to reduce her vulvar pain, increase her sexual satisfaction and lead to more satisfying sexual encounters for both partners, possibly by maintaining non-

threatening sexual connection and communication, increasing intimacy and encouraging adaptive behavioural and emotional coping and shared sexual self-efficacy (Rosen, Bergeron, Glowacka, Delisle, & Baxter, 2012; N. Rosen, Bergeron, Sadikaj, & Delisle, 2015; Rosen et al., 2014; Rosen et al., 2012; Rosen, Muise, Bergeron, Delisle, & Baxter, 2015).

Interestingly, many affected couples participating in research express a high degree of satisfaction in the quality of their romantic relationships while still reporting pain negatively impacts their feelings of closeness and intimacy (Blair, Pukall, Smith, & Cappell, 2015; Smith & Pukall, 2011, 2014). This may be a result of selection-bias as study authors have reported challenges recruiting male partners and couples for their protocols and have speculated their samples may represent an otherwise well-functioning, highly motivated and collaborative subsample of a larger population of partners and couples impacted by PVD symptoms (Corsini-Munt, Bergeron, Rosen, Mayrand, & Delisle, 2014; Sadownik, Smith, Hui & Brotto, 2017). Researchers have advocated for more study designs that include partners (Corsini-Munt, Bergeron, Rosen, Mayrand, & Delisle, 2014; Sadownik, Smith, Hui & Brotto, 2017) to better understand how interpersonal variables may effect women's pain and how vulvodynia impacts couples' shared sexual experiences (McCabe et al., 2010).

1.1.2 Etiology

Although currently there is no consensus on a definitive cause for vulvodynia, there is general agreement that it is not a unitary condition and multiple etiologic pathways may exist for individual women and across vulvodynia presentations that contribute to the initiation and maintenance of chronic vulvar pain (Bornstein et al., 2016). The 2015 consensus terminology and classification of vulvar pain highlighted several potential factors associated with vulvodynia

involving neurologic mechanisms, neuro proliferation, genetic predisposition, local tissue inflammation, musculoskeletal patterns, hormonal and psychosocial factors (Bornstein et al., 2016).

Central sensitization is believed to underlie the development of PVD and chronic pain syndromes generally, whereby chronically experienced stressors dysregulate the nervous system responses to stimuli and lower thresholds of tolerance for physical, psychological and environmental stressors (Latremoliere & Woolf, 2009; Woolf, 2011). This likely accounts for the multifactorial etiology of PVD, its common comorbidity with other chronic pain conditions, and for the role of emotional and psychological factors in the onset and maintenance of chronic pain and associated distress and for the effectiveness of psychological interventions for improving both (Zoulnoun et al., 2006).

1.1.2.1 Central Nervous System Sensitization

The experience of pain has been understood to be an adaptive response, alerting the organism to impending or actual tissue damage to encourage behavioural avoidance of further injury. However, decades of research have shown that pain is not always a reliable indicator of damage or threat of damage and its persistence when tissue damage has healed or an initial ‘triggering event’ (injury, infection, disease) has not occurred, is a hallmark of chronic pain syndrome presentations. Melzack and Wall’s conceptualization of the Gate Control Theory of Pain, was the first to account for how brain processes, influenced by psychological, emotional and contextual factors, can modulate the subjective experience of pain by amplifying or inhibiting pain signals from peripheral nerves based on the relative assessment of threat or when attentional resources are directed to other salient internal or external stimuli, may explain the wide variability in the perception of pain (1965). Lumley and colleagues’ 2011 review of a

decade's worth of research into the relationship between emotion and pain perception, highlighted the principal role of the brain and spinal cord in persistent pain expression where pain and pathology are unreliably correlated. They noted the overlapping of brain systems that process physical and emotional pain, particularly the "social-attachment neural system", serving "the role of minimizing dangers associated with social separation as well as avoiding physically painful stimuli", arguing this may offer some explanation for the powerful moderating effect of emotions and interpersonal connection on the experience of physical pain (2011). They specify that emotional valence (positive or negative) interacts with emotional arousal (intensity) such that highly arousing positive affect can have analgesic properties and intensely experienced negative emotions can amplify pain perception. For example, they reference the analgesic properties of orgasm (Bianchi Demicheli & Ortigue, 2007), the distress associated with social rejection increasing pain sensitivity (Eisenberger, Jarcho, Lieberman, & Naliboff, 2006), and how histories of psychosocial trauma have been shown to predict hyperalgesia and persistent idiopathic pain (Lumley et al., 2011). In-laboratory research has found that the salience of positive or negative emotional experience associated with a painful stimulus is correlated with the degree to which the experience of pain is diminished or increased, respectively (Rhudy, Williams, McCabe, Russell, & Maynard, 2008; Rhudy, Bartley, & Williams, 2010).

Central nervous system sensitization is thought to be the outcome of repeated stressful stimuli that changes the communication pathways between the central and peripheral nervous system such that neuronal response to stimuli is amplified, resulting in the perception of physical pain that may be spontaneous (no physiological trigger detected), out of proportion to the stimulus (hyperalgesia), or in response to non-noxious stimuli (allodynia). Increased allostatic load, or the accumulation of acute and chronic stressors overtime, which may be external

(environmental/interpersonal stressors) and/or internal (physiological, personality-related, beliefs, cognitions and emotional stressors), can lead to chronic over- or under-responding of the body's stress response system, (Basson, Driscoll & Correia, 2016). Nervous system sensitization is a multifactorial process whereby environmental factors (e.g., experiences of traumatic or chronic stress, physical injury or illness, disruptions to social connections) dysregulate sensitivity to pain (Chapman, Tuckett, & Song, 2008) and increase individual vulnerability to developing a pain syndrome (Slade et al., 2007). These factors combine with individual susceptibilities (e.g., genetic vulnerability, comorbid chronic health conditions, mood disorders, habitual cognitive attribution patterns) to further increase likelihood of CNS sensitization (Basson, 2012; Diatchenko, Nackley, Slade, Fillingim, & Maixner, 2006; Payne et al., 2005). The resultant amplification of neural signalling responsible for pain perception, may further contribute to stress (e.g., negative affect, disability) which may then reinforce this cycle of amplification (Basson, 2012; Sutton, et al., 2015).

Research support for the role of nervous system sensitization in the initiation and maintenance of chronic vulvar pain has been steadily accumulating, with nervous system changes detected in women with vulvodynia consistent with peripheral and central sensitization (Bohm-Starke, 2010; Tympanidis, Terenghi & Dowd, 2003). These mechanisms implicated in the initiation and maintenance of chronic idiopathic vulvar pain likely operate in a bidirectional relationship (Bornstein et al., 2016). Evidence for the shared role of nervous system sensitization in vulvodynia and other chronic pain syndromes can be inferred from the high comorbidity between these conditions, (Arnold, Bachmann, Rosen, & Rhoads, 2007; Basson, 2012; Peters, Girdler, Carrico, Ibrahim, & Diokno, 2008; Reed et al., 2016; Sutton, et al., 2015). In a clinical sample of 50 women with vulvodynia participating in an RCT comparing psychological

interventions, 78% reported other non-genital chronic pain conditions, (Masheb et al; 2009). Of 1847 women with diagnosed vulvodynia, 45% reported via survey data having diagnoses of other chronic pain conditions thought to involve sensitization such as chronic fatigue syndrome, fibromyalgia, interstitial cystitis, or irritable bowel syndrome (Nguyen, Ecklund, Maclehose, Veasley, & Harlow, 2012).

Pukall, and colleagues found that measuring brain activation of women with PVD using fMRI while a researcher elicited vestibular pain showed a “typical pain signature” that has been observed with other chronic pain syndromes (e.g., fibromyalgia, IBS, idiopathic back pain). (Pukall, Strigo, Binik, Khalife, & Bushnell, 2005). Women with symptoms of PVD have been shown to have lower touch and pain thresholds over all, such that when compared with matched controls, women with PVD perceived touch to non-genital body parts sooner, and registered touch as pain more often (Giesecke et al., 2004; Pukall, Binik, Khalifé, Amsel, & Abbott, 2002). Evidence derived from brain imaging has shown, via patterns of neural activation, that acute and chronic pain are processed differently, with acute pain activating the brain’s sensory areas and the experience of chronic pain activating areas associated with motivation, reward and emotion (Apkarian, Bushnell, Treede, & Zubieta, 2005). It has been shown that the expectation of pain produces a neural pattern of activation similar to experiencing pain, adding further evidence to the role of cognitive and emotional processes in modulating pain (Ogino et al., 2007).

1.1.2.2 Biomedical contributors

Findings from the vulvodynia literature show diagnosed women differ significantly from healthy women without dyspareunia with respect to reported histories of repeated gynaecologic infections (yeast, bacterial vaginosis), dysmenorrhea and hypoestrogenization of vulvar tissue associated with prolonged use of hormonal birth control (Bergeron, Rosen, & Morin, 2011),

which may contribute to the initiation of persistent pain for some women. However, a local ‘triggering’ event is often not found in the medical histories or recollections of many women. Some may have congenital susceptibilities as evidenced by reports of pain with first tampon use, and a greater likelihood of proliferation of local nociceptors and polymorphisms in genes regulating inflammatory response, when compared with pain-free women (Harlow, Wise, & Stewart, 2001; Bergeron, Rosen, & Morin, 2011).

Genetic susceptibility to the development of chronic pain syndromes has been evidenced in twin studies, where heritability estimates range from 25-60%, although investigators have noted the difficulty of adequately controlling for shared environmental factors (Denk, F., & McMahon, 2017; Nielsen, Knudsen & Steingrimsdottir, 2012). A 2012 study examining heritability of chronic pain in an available health cohort study of 7644 individuals in 2195 extended families, controlling for shared environmental and individual factors, estimated heritability of chronic pain at 16% for ‘any chronic pain’ and 30% for ‘severe chronic pain’, although they also acknowledged that they could not adequately account for confounding psychosocial factors or for the role of epigenetic (genes x environment) factors (Hocking et al., 2012). Although an early study examining vestibulectomy outcomes reported one third of their sample reported a relative with dyspareunia or vulvodynia (Goetsch, 1996), and a more recent RCT comparing psychological interventions found 14% of their sample reported a family history of vulvar pain (Masheb et al., 2009), there have not been any controlled studies examining the heritability of chronic vulvar pain specifically (Pukall et al., 2016).

Most women with vulvodynia also have overactive pelvic floor muscles resulting in protracted and excessive tightening of vaginal muscles (Bergeron, Brown, Lord, Oala, Binik, & Khalifé, 2002). Although the development of hypertonicity of the pelvic floor muscles can be

secondary to a variety of factors (biomedical- surgery, injury, childbirth complications, global musculoskeletal dysfunction, or psychosocial- fear-based bracing due to negative sexual beliefs or histories of traumatic abuse), chronic hypertonicity has been shown to contribute to hyperalgesia and allodynia, and may be a precipitating factor for chronic vulvar pain for some women and likely a maintaining factor for most (Pukall et al., 2016).

1.1.2.3 Environmental Factors

Adolescent women reporting dyspareunia were more likely than similarly aged women without pain to report histories of sexual abuse (Landry & Bergeron, 2011). Significantly higher incidences of histories of childhood physical and sexual abuse and neglect have been found in women with a diagnoses of vulvodynia (Harlow & Stewart, 2005; Khandker, Brady, Stewart, & Harlow, 2014). These early experiences of victimization have been shown to be a risk-factor for the development of vulvodynia and to also modify the degree to which the syndrome disrupts psychological and sexual functioning and the intensity of the resultant distress experienced (Leclerc, Bergeron, Binik, & Khalifé, 2010; Corsini-Munt et al., 2017). Women who have been the victims of emotional and sexual abuse in adulthood are also much more likely to have sexual difficulties generally and dyspareunia in particular (Luftey et al., 2008).

Daily non-traumatic stress has a negative impact on sexual functioning generally (Hamilton & Julian, 2014; Hamilton & Meston, 2013). Women with PVD have reported experiencing more day-to-day stressors than women without vulvar pain and a reduced ability to manage general stress (Basson, 2012), an experience compounded for those with other comorbid pain conditions who report a greater depletion in coping resources and lower-tolerance to stress than those women with PVD alone (Lester et.al, 2015). For women with vulvodynia, experiencing other comorbid pain is significantly associated with greater psychosocial distress

with those affected endorsing increasing feelings of isolation and invalidation relative to the reported number of chronic pain conditions (Nguyen, Ecklund, Maclehose, Veasley, & Harlow, 2012). A clinical sample of 33 PVD-diagnosed women (compared with 28 healthy matched controls) showed symptomatology associated with burnout, reported elevated emotional and physiological stress symptoms and tested morning levels of cortisol indicative on chronic stress (Ehrström et al., 2009). The stress experienced by women with PVD is detailed in the qualitative literature where women have consistently reported across inquiries the additional stress experienced by being disbelieved by HCP, partners and friends (Shallcross, 2018) and it is accepted that the experience of living with chronic unexplained pain is itself a nervous system stressor (McEwen and Kalia, 2010).

1.1.2.4 Emotional and Psychological factors

Maladaptive psychological and emotional factors have been shown to be important contributors to the pathophysiology of vulvodynia in addition to an outcome of living with chronic unexplained vulvar pain (Harlow & Stewart, 2003; Sadownik, 2014; Bergeron, Rosen & Corsini-Munt, 2018). These factors operate as internal stressors, mediating the distress, pain intensity and disability of chronic pain syndromes by contributing to nervous system dysregulation and sensitization and can include personality characteristics (Diatchenko, Nackley, Slade, Fillingim, & Maixner, 2006) and comorbid psychiatric diagnoses (Khandker, Brady, Vitonis, MacLehose, Stewart, & Harlow, 2011). An American community-based population study comparing 256 women self-reporting symptoms consistent with vulvodynia with 194 pain-free matched controls, found 26.7% of women with vulvodynia had a diagnosed mood or anxiety disorder before the first onset of vulvar pain symptoms, compared to 11.3% of controls during a similar time frame, with the authors concluding that the pre-existence of a mood or anxiety

disorder had a four-fold increase in the likelihood women in their sample would go on to develop vulvodynia (Khandker et al., 2011). A 2015 American population-based study involving 1,795 women showed a positive screening for PTSD correlated with a twofold increase in the likelihood of also having vulvodynia, with a 53% higher prevalence of vulvodynia in those who screened positively for depression (Iglesias-Rios, Harlow, & Reed, 2015). A clinical sample of 50 women participating in an RCT comparing an individually delivered CBT intervention with supportive psychotherapy, found 66% of participants had been diagnosed with a DSM-IV Axis I disorder (most commonly depression and anxiety), and 36% reported a history of sexual abuse (Masheb, Kerns, Lozano, Minkin, and Richman 2009).

Several psychological factors have been implicated as variables of particular interest in their contribution to the onset, intensification and maintenance of the pain experienced and the common sequelae of sexual dysfunction, including pain self-efficacy, catastrophizing and hypervigilance (Pukall et al., 2016). Pain catastrophizing refers to a negative affective-cognitive response to actual or anticipated pain, characterized by a tendency to ruminate upon pain sensations, to overestimate the threat of pain and to feel helpless about pain. It has been linked to abnormal brain processing of painful stimuli (Seminowicz & Davis, 2006) and has been associated with greater pain and disability in persistent pain conditions such as temporomandibular disorder, headache, rheumatic diseases, chronic prostatitis, and pelvic pain (Drahovzal, Stewart, & Sullivan, 2006; Edwards, Bingham, Bathon, & Haythornthwaite, 2006; Tripp et al., 2006). Pain-hypervigilance is characterized by over-attending to somatic sensations and excessively monitoring bodily sensations for threat of pain and chronic pain sufferers show attentional biases towards pain-related materials, (He et al., 2014; Schoth & Liossi, 2010) with greater pain-vigilance associated with increased pain sensitivity and catastrophizing in clinical

and experimental settings (Herbert et al., 2014). Pain self-efficacy refers to one's confidence in their ability to handle or manage pain and associated symptoms while participating in activities that may induce pain, with low pain self-efficacy associated with reports of greater pain intensity and increased disability (Foster, Thomas, Bishop, Dunn & Main, 2010; Karasawa et al., 2019).

For women with vulvodynia, pain hypervigilance and pain catastrophizing have been found to have a significant relationship with the intensity of pain experienced during intercourse (Desrochers, et al., 2009) and may predict the continued presence and intensity of pain after psychological interventions (Brotto et al., 2020; Desrochers, et al. 2010). Pain catastrophizing, on its own, was found to be significantly associated with greater pain severity during intercourse (Desrochers et al., 2009; Smith et al., 2019). Lower pain self-efficacy has been associated with increased pain intensity and lower sexual satisfaction (Davis et al., 2015) and with increased sexual impairment (Desrochers, et al., 2009).

Women with PVD commonly report internal psychological stressors similar to people with other chronic pain conditions like reduced self-esteem (Gates & Galask, 2001), negative self-image (Brotto, Basson, & Gehring, 2003) lower self-efficacy and a tendency to ruminate and catastrophize (Desrochers, et al., 2009), perfectionism and fears of negative-evaluation (Jantos & Whyte, 1997; Sutton et al., 2009) and hyper-vigilance to physical sensations and increased harm-avoidance behaviours (Granot & Lavee, 2005).

Psychosocial factors likely maintain and exacerbate pain symptoms and disrupt adaptive coping after onset. The presence of depressive symptoms in women with vulvodynia have been shown to be positively correlated with pain severity and negatively with social and/or occupational functioning (Masheb et al., 2005) and anxiety symptoms correlated with fear-based hyper vigilance and avoidance behaviours contribute to increased perception of physical pain and

increases in sexual dysfunction (Pukall et al., 2016; Bergeron et al., 2011; Vlaeyen & Linton, 2000). For women with PVD it has been found that negatively anticipating that genital contact will be experienced as painful and distressing, intensifies physical pain reported (Brotto, Basson, et al., 2015; Sadownik, 2014).

What isn't clear is why some people develop specific chronic pain conditions rather than others, although it is suspected that attending to 'normal' pain sensations with heightened anxiety and/or during chronic stress may initiate this cycle for some (Basson, 2012; Desrochers, et al. 2010; Sutton, et al., 2015). Given that a number of biomedical, environmental, and psychosocial characteristics have been identified as risk factors for developing chronic pain syndromes (Diatchenko, Nackley, Slade, Fillingim, & Maixner, 2006), and the complex relationships and interactions between these factors, determining the specific etiologic pathways of any individual presentation of vulvodynia may not be currently possible for most women.

However, a recent metanalysis found specific etiology (physical infection, disease, trauma, emotional or psychological stress) of any dyspareunia presentation did not predict the helpfulness of medical or psychological interventions with the authors concluding that presumed etiology (after the exclusion of acute pathology) is not more useful for guiding the selection of treatment than the subjective report of pain and distress, where psychological interventions show comparable effectiveness for improving sexual, emotional and psychological functioning across conditions that may lead to chronic sexual pain (Flanagan et. al, 2015).

1.1.3 Treatment

Until recently, treatment for chronic vulvar pain, when it was offered and available, was biomedically focused (topical and oral medications or surgery) and often based on expert or clinical opinion with few RCTs evaluating treatment effectiveness (Foster et al., 2010; Ayling &

Ussher, 2008). Vestibulectomy, the surgical removal of the vulvar vestibule, has shown superior pain relief when compared with medications, for a subset of women with PVD (Haefner et al., 2005; Landry et al., 2008). However surgery has not shown to reliably lead to the resumption of intercourse and, given its variable efficacy and significant exclusion criteria, it is usually considered a last resort after less invasive options have been trialled (Tommola, Unkila-Kallio, & Paavonen, 2010). Topical and systemic medications that have been researched show low long-term efficacy and generally do not perform better than placebo (Foster et al, 2010; Miranda Varella Pereira, et al., 2018). Pelvic-floor physiotherapy for 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), although uptake and effectiveness is further improved when used in combination with psychotherapy (Morin , Carroll & Bergeron, 2017). Current treatment recommendations endorse a multidisciplinary approach including medical interventions (when appropriate), combined with pelvic floor physiotherapy, education and psychological support as most likely to provide long-term improvements in pain and sexual functioning and psychosocial and sexual distress (Brotto et al., 2015; Sadownik, 2012; Smith et al, 2019; Spoelstra et al., 2011). Additionally, as few multidisciplinary treatment programs exist, most women would be required to pursue community options for intervention recommendations separately.

1.1.3.1 Psychological Interventions

As the body of treatment-evaluation research has grown, and biomedical approaches, on their own, have proven largely ineffective at reducing the physical experience of vulvodynia pain (while not addressing the deleterious emotional, relational and psychological impacts), and as the connection between nervous system sensitization, stress and chronic pain has become better

understood, psychological interventions for a variety of chronic pain conditions, including vulvodynia, has gained acceptance (Andrews, 2011; Masheb et al., 2009).

1.1.3.1.1 Cognitive Behavioural Therapy (CBT)

CBT has been tested in a variety of trials for the treatment of chronic pain conditions and has consistently shown beneficial effects for reducing distress, disability and pain (Ehde, Dillworth, & Turner, 2014; Williams, Fisher, Hearn, & Eccleston, 2020). The body of evidence for the use of CBT for the treatment of PVD is similarly robust, outperforming the minimal benefits documented for pharmaceutical interventions (Bergeron, Khalife, & Dupuis, 2008; Brown et al, 2018; Foster et al, 2010; Lester et al; 2015), and at least as effective as, or superior to surgery and pelvic floor physiotherapy (Bergeron et al, 2001; Bergeron et al., 2016; Goldfinger et al., 2016; Masheb et al., 2009). CBT targets psychological and sexual distress commonly associated with chronic vulvar pain (Bergeron, Rosen, & Corsini-Munt, 2018) by focusing on recognizing and challenging maladaptive cognitions related to pain and associated negative affect and teaching skills to address avoidant behaviours that maintain anxiety and pain. Those participating in CBT-based treatment interventions report high rates of treatment satisfaction, and improvements in pain and sexual functioning that are maintained long-term (Bergeron, Khalife, Glazer, & Binik, 2008; Brotto et al., 2019; Desrochers, et al. 2010; Goldfinger, et al. 2016; Masheb et al., 2009; Ter Kuile & Weijnenborg, 2006).

Bergeron and colleagues' 10-session CBT group for women with diagnosed PVD, reported an overall 30% reduction of pain-intensity at 6 month follow-up, mediated by clinically significant improvements in sexual and psychological functioning, with positive impacts maintained 2.5 years later (Bergeron et al., 2008; Ter Kuile & Weijnenborg, 2006). Participants in CBT group interventions for vulvodynia have shown improvements in pain catastrophizing,

hypervigilance and self-efficacy, with statistically and clinically significant improvements observed for both pain severity and sexual functioning (Bergeron et al., 2001; Bergeron, Khalife, & Dupuis, 2008; Bergeron et al., 2016). An RCT comparing 10-sessions of individually delivered CBT to non-directive supportive psychotherapy (SPT), with 50 vulvodynia-diagnosed women, found 42% of participants showed clinical improvement in pain of at least 33%, and significant self-reported improvements in pain-severity, sexual dysfunction and in anxiety and depressive symptoms, across treatment arms at 12-month follow-up (Masheb, Kerns, Lozano, Minkin, & Richman 2009). Women in the CBT condition additionally reported greater satisfaction and confidence in the credibility of CBT relative to SPT participants, and showed more improvements in pain severity on physical exam and in reported sexual functioning with authors hypothesizing that the inclusion of specific behavioural skills included in the CBT arm possibly accounted for this difference (Masheb et al., 2009).

CBT has shown to be an effective intervention for improving pain and psychosexual distress whether delivered in a group format or individually and is a recommended intervention in current international guidelines for the assessment and treatment of vulvodynia. (Goldstein et al., 2016). However, it has been suggested that the change-based and goal-oriented approach of CBT may not equally meet the needs and preferences of all women seeking treatment, and that more research is required to compare other psychological interventions, to facilitate the isolation of modality-specific benefits and provide information useful to clinicians for predicting which women in their care may most benefit from specific therapeutic approaches (Bergeron et al., 2011; Brotto, Basson, Driscoll, Smith, & Sadownik, 2015; Chivers & Brotto, 2017; Smith et al., 2019).

1.1.3.1.2 Mindfulness

In contrast with CBT, mindfulness-based approaches emphasize acceptance of unpleasant sensory information by promoting the practice of directing attention to the present-moment with non-judgmental awareness of thoughts, emotions and physical sensations as they arise, without identifying with, or attempting to change them. Cultivating acceptance of unpleasant physical sensations without cognitive elaboration has been found to promote engagement with valued activities and reduce associated distress despite the continued presence of pain (McCracken et al., 2004). Mindfulness-based approaches have been accumulating research support for improving pain, associated disability and distress for chronic pain sufferers (Grant & Rainville, 2009). Early research based on the 8-week Mindfulness Based Stress Reduction (MBSR) program developed by Dr. Jon Kabat-Zinn, focused on training in mindfulness meditation practices, reported improvements in pain, disability, mood and anxiety symptoms for chronic pain patients with effects maintained after 4 years (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985).

One way mindfulness is thought to modulate the subjective experience of pain is by disrupting the anticipatory negative appraisal of painful stimulus—an ‘uncoupling’ of sensory experience from its evaluation that has been supported by brain-image research of experienced meditators (Grant, Courtemanche, & Rainville, 2011). The active, present-focused acceptance of internal and external sensory information associated with mindfulness practices has been shown to significantly reduce reported intensity and rated unpleasantness of painful stimulus in inexperienced meditators after even brief training interventions (Zeidan et al., 2010). In-lab studies reported the brain scans of long-term meditation practitioners showed 40-50% reductions in brain-activity associated with pain processing, and reported greater tolerance to experimental

pain when compared with matched controls (Orme-Johnson, Schneider, Son, Nidich, & Cho, 2006) and mindfulness training in inexperienced meditators showed increased pain-tolerance when compared with those who spent the same amount of time learning guided imagery (Kingston, Chadwick, Meron, & Skinner, 2007).

Several systematic reviews of the evidence-base for improving chronic pain and associated distress and disability using mindfulness-based interventions have demonstrated reported improvements in pain, depressive symptoms, coping, disability and quality of life, although authors across reviews reported several methodological issues (e.g., lack of uniformity of interventions, outcome measures, follow-up and controls), limiting the conclusiveness of the findings (Bawa et al., 2015; Chiesa & Serretti, 2011; Lee, Crawford, & Hickey, 2014). A 2017 systematic review and meta-analysis of 38 RCTs evaluating the effectiveness of mindfulness for improving chronic pain and associated distress and disability, found similar methodological weaknesses across publications, but nevertheless found mindfulness meditation was associated with statistically significant improvements in psychosocial functioning, with high-quality evidence for improvements in depressive symptoms and a significant, but small effect-size for pain improvement when compared to treatment as usual, education-only, or peer-support groups (Hilton et al., 2017). Acceptance-based approaches may be particularly effective for chronic pain sufferers who have not responded to CBT-interventions. A 2011 meta-analysis comparing both found similar impacts on pain intensity, anxiety and overall quality of life and found acceptance-based interventions may be especially beneficial for those with chronic pain and recurrent depression (Veehof, Oskam, Schreurs, & Bohlmeijer, 2011).

Mindfulness-based interventions have also been shown effective for improving sexual functioning and distress in women experiencing difficulties with desire and arousal (Brotto et al.,

2012; Stephenson & Kerth, 2017). Individuals reporting greater present-focused mindful attendance to sexual cues, physical sensations and emotional experiences in sexual contexts also report greater overall sexual satisfaction (Leavitt, Lefkowitz & Waterman, 2019). For women with PVD, greater pain acceptance has been associated with less pain with intercourse, lower anxiety and depression and greater sexual functioning and satisfaction (Boerner & Rosen, 2015), although mindfulness-based interventions have only recently begun to be investigated for their potential to improve PVD symptomatology.

An exploratory study evaluating the effectiveness of a four-session mindfulness- based intervention in a clinical sample of 62 PVD-diagnosed women, found significant improvements in mood and sex-related distress, in allodynia, pain-catastrophizing, hypervigilance and self-efficacy when compared with PVD-diagnosed women in a waitlist condition, with improvements maintained at 6-month follow-up (Brotto et al., 2015). The authors note that as the intervention also included some elements of CBT (using the model to illustrate the impact of thoughts on experience, thought records to promote identification/awareness of problematic thoughts), but with an emphasis on observing thoughts as transient “mental events” (rather than the goal oriented approach of challenging/restructuring their content), and included education about the pathophysiology of chronic-pain, the related etiology and impact of PVD and information about sexual functioning, women may have shown benefit from components of the intervention not specific to the cultivation of mindfulness skills (Brotto et al., 2015). They additionally highlight that improvements in sexual distress and self-efficacy were found for waitlisted women (although both groups benefited to the same degree after treatment), and improvements in dyspareunia could not be detected as few women engaged in intercourse during the measurement period despite improvements in clinician-measured vulvar-pain (Brotto, et al. 2015).

1.1.3.1.3 Mindfulness versus CBT

Based on the promising results from a 4-session mindfulness intervention for improving the pain and distress in women with PVD, Brotto and colleagues initiated the first empirical trial comparing a group Mindfulness-Based Cognitive Therapy (MBCT) or group CBT intervention for women with PVD (Brotto et al., 2019). A non-inferiority comparison involving a clinical sample of 130 PVD diagnosed women, randomized (or assigned without participant choice to avoid treatment delay) to 8 weekly MBCT or CBT sessions were assessed at pre-treatment, 2-4 weeks post treatment, and again at 6 and 12 months for clinician measured vulvar pain, self-reported dyspareunia, treatment confidence and satisfaction and completed measures assessing overall sexual functioning, distress, pain catastrophizing, hypervigilance and acceptance at all timepoints (Brotto et al., 2019). Participants consistently reported high levels of satisfaction with treatment across time-points and both interventions showed comparable benefit to women for improving overall sexual functioning and reducing sexual distress, although women in the MBCT arm showed significantly more benefit for improving dyspareunia, and all effects were maintained at 6-month follow-up (Brotto et al., 2019). Authors additionally found equally “dramatic” reductions in pain-catastrophizing, and comparably similar, although smaller, decreases in pain hypervigilance, and similar increases in pain acceptance, for both treatment arms and these benefits continued in the same direction by the 6-month mark (2019). Data collected at 12-months and analyzed separately, found reported reductions in pain with intercourse held and clinically assessed allodynia and sexual distress continued to decline (Brotto, Bergeron, Zdaniuk & Basson, 2020). Interestingly, study authors found mediators of change they had hypothesized would be unique to treatment modality were found to be shared across interventions. Specifically, they predicted measured changes in pain catastrophizing, a

variable derived from the Fear-Avoidance Model of pain, would uniquely mediate improvement in vaginal pain intensity in the CBT arm, but in fact improvement effects were twice the size in the MBCT group (Brotto, Bergeron, Zdaniuk & Basson, 2020). Mindfulness-related constructs of pain-acceptance and decentering (or metacognitive awareness) were also unexpectedly found to mediate improvements in clinically assessed vulvar pain (although not pain with intercourse) and sexual distress in both MBCT and CBT interventions, suggesting shared pathways to improvements for pain and distress in both psychological approaches (Brotto, Bergeron, Zdaniuk, & Basson, 2020). Of all of the mediating variables examined (acceptance, self-compassion/criticism, mindfulness, decentering and pain catastrophizing), none were found to uniquely mediate improvements in pain or sexual distress in the CBT treatment arm, although authors note other variables derived from the Fear-Avoidance model of pain, such as self-efficacy, fear of pain, anxiety and avoidance, which have been found to predict pain and sexual distress in other studies, may have resulted in contributions that were not measured in their analysis (Brotto, Bergeron, Zdaniuk & Basson, 2020). Unique to the MBCT treatment arm, the study team found that the acceptance variable ‘willingness to accept pain’ mediated improvements in vaginal pain intensity, and self-compassion mediated improvements in sexual distress, with the additional novel finding that changes in ‘self-criticism’ mediated improvements in clinically assessed vulvar pain and self-reported dyspareunia and sexual distress (Brotto, Bergeron, Zdaniuk, & Basson, 2020).

Given that placebo effects have been found to account for some degree of improvement in both medical and psychological interventions, Brotto and colleagues, assessing the degree to which expectation of benefit moderated improvement, found higher treatment credibility measured in participants at baseline predicted greater improvements in pain intensity for MBCT

participants only. (Brotto, Zdaniuk , Rietchel, Basson, & Bergeron, 2020). Further, it was found that those reporting most satisfaction with treatment were the most likely to re-engage with intercourse post-treatment, and that 43% of their sample had resumed intercourse post-treatment independent of condition, with the likelihood that an individual woman was engaging in intercourse increasing by 31% at each follow-up (Brown, Zdaniuk & Brotto, 2021).

The study authors emphasize that using resumption of intercourse as a primary outcome for assessing the effectiveness of any treatment intervention for women with PVD provides an incomplete picture of potential benefit, noting that 29% of their sample of 130 women had either not engaged in intercourse at any time point or had discontinued intercourse at follow-up despite overall high ratings of treatment satisfaction and improvements in other domains (Brown, Zdaniuk & Brotto, 2021). They found that those women who avoided intercourse across time-points showed lower pain acceptance and openness to experience and higher pain intensity and catastrophizing at baseline, although these variables could not predict who was most likely to discontinue intercourse. Although reported perceptions of treatment-related sexual improvements predicted those who continued or resumed intercourse when compared with those women who did not engage in intercourse, it did not predict discontinuation (Brown, Zdaniuk & Brotto, 2021). These authors suggest that for some women, personal goals for treatment may not include the resumption of intercourse and that treatment-related improvements in sexual satisfaction and overall functioning may be related to reengaging in non-penetrative forms of sexual activity and other improvements in overall distress and psychological functioning (Brown, Zdaniuk & Brotto, 2021).

Qualitative follow-up interviews of 14 PVD-diagnosed women participating in a 4-session group mindfulness intervention, found women felt connecting with other women who

shared similar PVD symptoms and the related negative social and psychological impacts felt more 'normal' and less isolated, experienced less fear and anxiety about their symptoms, more hope for their prognosis and increased efficacy managing maladaptive thinking patterns and improved social and sexual confidence (Brotto et al., 2013). Women who credited participation with positively impacting their relationship, cited the education about PVD included as part of the mindfulness intervention facilitated more understanding from their partners, better overall communication and increased solidarity in the face of relationship challenges related to PVD (Brotto et al., 2013). Women described a reduction in their pain and anxiety symptoms in addition to improved overall psychological well-being they attributed to developing acceptance via learning the mindfulness-based psychological skills but also expressed appreciation for having access to the program, some after many unsuccessful attempts to find treatment (Brotto et al., 2013).

Overall, quantitative research supports effectiveness of MBCT and CBT for reducing both the experience of pain and ameliorating psychosexual distress (Brotto, et al., 2018). There are additionally tentative conclusions that can be drawn that suggest some women may benefit more from goal and change oriented approaches like CBT and others more from mindfulness - based approaches that emphasize acceptance and that their individual treatment goals, relationship status, psychological and medical profiles and confidence in the perceived effectiveness of any suggested intervention will likely impact how effectively it meets the needs of any individual woman. For example, in the above analysis, those with higher levels of baseline pain acceptance were more likely to have resumed intercourse if they had participated in MBCT, and interestingly (although only reaching moderate significance) those with lower baseline pain acceptance were more likely to have resumed intercourse if they had participated in

the CBT arm (Brown, Zdaniuk, & Brotto, 2021). Women in relationships of shorter duration and with fewer years of symptoms showed more improvements on overall sexual functioning with MBCT and those in relationships of longer duration and/or more years of symptoms improved more in the CBT treatment arm, and younger age and greater pain intensity predicted larger improvements in pain reduction across treatment arms (Brotto, Zdaniuk, Rietchel, Basson, & Bergeron, 2020).

There are suggestions that women participating in psychologically based interventions in clinical contexts may be experiencing benefit from a variety of factors not unique to the particular modality assessed. Therapeutic elements of general support (not specific to modality) have shown similar, although less-robust improvements in pain and psychosexual functioning when compared with CBT (Masheb et al., 2009), and research has shown vulvodynia specific education on its own (including information about the role of central nervous system sensitization and models of sexual response), resulted in significant long-term improvements in psychological symptoms of depression, anxiety, sexual functioning and distress and self-reported pain intensity (Brotto, Sadownik, & Thomson, 2010). Additionally, women participating in psychological interventions in a clinical context may also be simultaneously engaging in pelvic floor physiotherapy, which when engaged with on its own compared similarly on self-reported improvements of pain, pain catastrophizing and self-efficacy similarly with CBT only (Goldfinger et al., 2016). It has previously been shown that the relationship between levels of self-catastrophizing and pain have been found to be moderated by levels of pelvic-floor dysfunction and perceived partner support (Benoit-Piau, et al., 2018), with research suggesting a relationship between partner support impacting prognosis for women more generally (Rosen et al., 2014). In qualitative interviews, women who reported positive partner support before

participating in a mindfulness intervention also described greater improvements to their own psychological well-being than women whose partners were less supportive (Brotto et al., 2013). Qualitative interviews of participants in psychoeducation groups have also reported significant benefit from “being with” other women with vulvodynia in a group context, describing feelings of normalization and validation, increased confidence in their ability to manage their condition and less shame and isolation, while also reporting improvements to their sexual functioning and distress they associated specifically to vulvodynia educational components (Brotto et al 2013; Sadownik et al., 2012).

It has been noted by several researchers investigating effectiveness for psychologically-based treatment for PVD, consistently measured overall benefit to participants aside, that results generally show wide variability in rates of improvement and domains of change, complicated by the individual and relationship contexts, psychosexual and pain profiles of participants and the shared therapeutic benefits derived from educational components, therapeutic relationships with knowledgeable clinical team members, and group contexts which likely present underdocumented therapeutic elements and predictors of change (Bergeron et al., 2011; Masheb, et al., 2009; Smith et al., 2019). Researchers suggest future inquiries should seek to understand the experiences of women who may have chosen not to engage in intercourse and are not experiencing personal or relationship distress as a result (Brown, Zdaniuk, & Brotto, 2021), to evaluate women’s subjective needs and goals for PVD treatment directly, to include measures that assess the functioning of intimate relationships and partners, and to isolate therapeutic elements not specific to modality (e.g., education, clinical context, group effects), (Brotto, et al., 2013; Brotto, et al., 2015; Goldfinger, et al. 2016; Ter Kuile & Weijenborg, 2006).

Chapter 2: Methodology

2.1 Purpose

As the reviewed literature attests, more research is needed to understand how individual women may benefit more or less from particular interventions for vulvodynia, particularly how their beliefs about what constitutes effective treatment, their confidence regarding interventions offered and how their individual characteristics and interpersonal contexts may impact the effectiveness of any particular intervention (Bergeron, et al., 2011; Sadownik, Seal & Brotto, 2012). Recommendations for the inclusion of qualitative assessment of the impacts of participating in psychological interventions for vulvodynia can supplement and expand on quantitative inquiries by providing insight into the treatment preferences of women, their own perceptions of what they found most (or least) helpful about participating, assess unaddressed needs and direct attention to contextual variables of interest that may inform future empirical inquiries (Flanagan, 2014; LePage & Selk, 2016; Shallcross et al., 2018).

Although qualitative research is becoming increasingly common in many fields it remains less so in the field of healthcare research, despite its potential for illuminating possible reasons for observed data patterns, particularly where the complexity of patient behaviour, present context and life experiences can impact the uptake and effectiveness of health interventions (Busetto, Wick, & Gumbinger, 2020). Some have argued for the routine and ongoing inclusion of qualitative inquiries into healthcare setting program evaluation research, which they suggest would assist practitioners to assess and better predict variability in treatment outcomes and intervention uptake and help to refine quantitative data collection (Drabble & O’Cathain, 2015; Chambers, Glasgow & Stange, 2013; Lamont et al, 2016). Using qualitative methods to evaluate complex multi-component interventions could be particularly effective for

“addressing questions beyond ‘what works’, towards ‘what works for whom, when, how and why’” (Busetto, Wick, & Gumbinger, 2020). It has been argued that supplementing quantitative methods in sexuality research, provides necessary context and a broader perspective on experience (Tolman & Szalacha, 1999). Context is especially relevant when studying human behaviour and important when considering the relational and social contributions to sexual health—a complex relationship not easily quantified (Frost & de Vries, 2007). Bellamy and Hinchliff (2013) argue that qualitative methods may be best positioned to capture these influences and should be viewed as an essential component of sexuality research. The Canadian Sex Research Forum (CSRF) recently recommended the elicitation and support for more qualitative method research designs for sexuality research to enrich what has been a primarily empirical conversation in presentation and publication (Lachowsky et al, 2017).

Objective measures and standardized questionnaires used in empirical research are limited in their ability to capture the complex relational, cultural and psychosocial aspects that influence the experience of vulvodynia or the effectiveness of any treatment (Donaldson & Meana, 2007). There is a small but growing body of qualitative inquiries documenting women’s subjective experiences of living with chronic vulvar pain but fewer eliciting women’s experience of treatment interventions available or inquiring what treatments and supports women themselves would like to have access to (Shallcross et al, 2018). Shallcross and colleagues identified themes shared across eight published qualitative studies exploring women’s subjective experiences of living with vulvodynia for their 2018 systematic review that are un(der)represented in empirical publications but have important implications when considering what kinds of supports women need and what quantitative variables to include in future inquiries. For example, they found that while the difficulties women experience seeking care are

documented in the empirical literature, the direct impact of delays to treatment, visits with dismissive and unknowledgeable care providers, and the increasing self-doubt and isolation women describe in interviews as contributing to their distress beyond their experience of physical pain, is suggested but not measured in empirical publications (Shallcross et al, 2018). Additionally, how cultural discourses influence women's personal beliefs about the meaning of their pain experience, such as the role of women as sexual care-providers in the form of intercourse for male partners, what 'normal' sexual behaviour is in the context of a heterosexual relationship and the perception of female sexuality and pleasure as being unimportant in comparison to the experience of their male partners, is described consistently as a major source of their distress across the qualitative literature, although relatively unaccounted for in empirical publications (Shallcross et al, 2018). Shallcross and colleagues argue more qualitative research looking into long-term outcomes for treatment interventions, including examinations of how these interventions were experienced and conceived of as helpful or not, and more conversations with women regarding the larger social and cultural implications of this experience may provide an opportunity to fine-tune future intervention research and may contribute to the identification and intentional deconstruction of cultural narratives that may be precipitating and perpetuating factors in the experience of chronic genital pain and which might extend therapeutic possibilities beyond what quantitative measures can foresee or conceptualize (2018/2019).

The inclusion of qualitative research also has immediately practical benefits for the purpose of treatment program evaluation, and the few qualitative studies looking into the experiences of women who have undergone treatment for vulvodynia have confirmed unquantified clinical experiences, identified needs unaddressed by the interventions evaluated and/or revealed information that led to the modification of the interventions under investigation.

Brotto and colleagues (2013) used data from qualitative interviews following women's participation in a 4-session mindfulness intervention to expand elements in the 8-session intervention that is the subject of the present inquiry. Specifically, results from these interviews led to increased focus on single women participating, more facilitation of discussion between women about their shared experiences, strategies for identifying and overcoming barriers to long-term practice and more information about the importance of continued practice to continue or maintain benefits (Brotto et al. 2013). Sadownik and colleagues (2012) also identified the continued frustration and negative mental health impacts of diagnosis delays and dismissive HCP visits while conducting qualitative interviews with women completing a multidisciplinary program for PVD that included visits with specialist gynaecologists, psychoeducation and psychological skills training and support and pelvic-floor physiotherapy (Sadownik, Seal, & Brotto, 2012). This provided support for her team of researcher-clinicians to secure additional funding for specialized training of medical residents in their urban hospital vulvar clinic and led to more direct outreach to general practice physicians, and modifications to programming at the same clinic that increased assessment capacities to further address barriers to diagnosis (Sadownik, in conversation September, 2019).

As previously stated, the purpose of the present study was to use a narrative inquiry to expand on the knowledge derived from quantitative analysis to develop a deeper understanding of how women experienced their participation in an 8-week intervention study comparing the effectiveness of group MBCT with group CBT for improving pain and distress for women with diagnosed PVD. It was hoped that eliciting stories of that lived experience would provide valuable insight into how participants experienced the intervention as helpful or not, what they

found most and least helpful and how individual context influenced the effectiveness of the study intervention previously described.

The goals of the present inquiry were to elicit, co-construct, present and analyze the stories told in response to the research question: “Please tell me your story about your participation in COMFORT, and your journey with PVD since.” This inquiry provided an important opportunity for women to collaborate in research in which they participated and to include their voiced perspectives.

2.2 Method: Narrative Inquiry

A narrative inquiry allows participants to freely story their experiences without the restrictions of a question-and-answer format and may reveal information predetermined questions cannot anticipate and provide an opportunity for women to contribute to the construction of the narratives of PVD to “restore agency in research and theory” (Riessman, 2008). Complex experiences of shame, identity-threat and inadequacy are difficult to capture in questionnaire format but important to investigate where “material symptoms are mediated by relational and discursive factors” (Ayling, & Ussher, 2008). The open-ended interview inherent in narrative methods may “provide special insights into the complexity of community intervention implementation over and above more familiar research methods” (Riley & Hawe, 2005).

Narrative inquiry is a qualitative methodology rooted in a social constructionist epistemology, which uses narrative, or stories, as its data. In this perspective, story is not a primarily descriptive exercise—one that reveals an aspect of reality, but one that is creating a personal reality in the telling. Narrative inquiry is based on the assumption that human lives are storied lives and storytelling a universally human impulse, and that all meaning is co-constructed

in relationship with an audience and situated in a specific time, place and cultural milieu (Riessman, 2008). Narrative researchers make the case that as storytelling is the central way that we create and exchange meaning and construct and co-construct our identity, a “primary mode of knowing” (Lieblich, Tuval-Mashiach and Zilber, 1998), so narrative inquiry can make claims to knowledge that more closely reflect our own ways of ‘knowing’ (Riessman, 2008). Research into human experience, in social policy creation and scientific inquiry, often privileges the data produced from quantitative research, rooted in notions of the value of objectivity, where context is a confound; ‘noise’ in the data to be controlled (Frost & de Vries, 2011; Polkinghorne, 2007). Qualitative inquiry, in contrast, and narrative in particular, privileges context as integral to subjective meaning and assumes that objectivity, even under the most rigorous controls is impossible, when the controls, measurement, analysis and interpretation are set, and thus limited by, the subjectivity of individuals. It assumes it’s content, or the ‘what’ of any given story, provides incomplete, limited and potentially misleading interpretations when it is isolated from it’s context, or the ‘why’, ‘how’ and ‘where’ of a story’s telling (Riessman, 2008).

Clandinin (2007) describes how expanding context in social science research to include contact with the meta-stories, the discourses, that inform our culture can better meet its goals of improving human lives because stories reflect “cultural conventions and language usage ... [and] reveal the prevailing theories about ‘possible lives’ that are part of one’s culture” (Clandinin, 2007). Language is a central actor in a narrative inquiry, in contrast with empirical inquiries where the possibility of language to reveal ‘possibilities’ is limited to pre-selected constructs (Lieblich, Tuval-Mashiach & Zilber, 1998) and cannot accurately describe an objectively, knowable reality (Polkinghorne, 2005).

While a story can only ever provide a snapshot into a reality that is ever-changing, unlike the snapshot provided by quantitative data, it provides a fuller picture of all available factors, particularly those important to the storyteller. Using stories as data can make essential contributions to social science where “real-life problems” may best be understood through the “real-life measures” and contexts of narrative methods (Lieblich, Tuval-Mashiach & Zilber, 1998). Frost and de Vries (2011) argue that “given sexuality-related phenomena and the policies that shape the experience of one’s sexuality are inherently and simultaneously personal and social, evidence from both quantitative and narrative research paradigms are necessary” to evaluate the effectiveness of any policy or intervention related to human sexuality.

2.3 Recruitment

2.3.1 ‘COMFORT’ Study Participants

As CBT has been established as an effective treatment option for PVD symptoms and the associated negative impacts to psychological, sexual and relationship functioning, and with preliminary support for the use of MBCT for women with PVD (Brotto, Basson, Smith, Driscoll, & Sadownik, 2015), the first study to compare the two treatments was initiated in Dr. Lori Brotto’s University of British Columbia Sexual Health Lab in 2012. Nicknamed the ‘COMFORT’ study (Cognitive Behavioural Therapy versus Mindfulness-Based Cognitive Therapy for the treatment of PVD), the study team developed two manualized treatment modules, delivered over 8 weekly 2.25 hour group sessions each facilitated by two clinicians with expertise in the diagnosis and treatment of PVD and training and experience in MBCT and/or CBT group therapy. A sample of 130 treatment-seeking women from 2 tertiary care academic health centers specializing in sexual medicine, who had a confirmed diagnosis of PVD, expressed interest and consented to participating after their eligibility was confirmed, were

enrolled and randomized or assigned to either the MBCT or the CBT treatment arm from 2012-2016, (for further details regarding study development, eligibility criteria and enrollment procedures see Brotto et al., 2018, 2019, & 2020).

Research participation involved agreeing to attend all 8 sessions, not initiating any new treatment over the course of their participation and completing assessment of vulvar pain via cotton swab and a questionnaire package before, and 1month, 6months and 12 months after participating in the group intervention. Questionnaire packages included demographic and clinical background treatment credibility ratings (at baseline only), self-reports of intercourse pain intensity, and validated measures assessing general sexual functioning and sex-related distress, catastrophizing, pain vigilance, pain acceptance, and self-reported global change ratings for dyspareunia and overall improvement of their sexual life. Their satisfaction with treatment and amount of homework completed between weekly sessions was also measured. Demographic characteristics of the final sample of 130 women is provided below.

Table 1. Baseline demographic and clinical characteristics of women assigned/randomized to CBT (n = 63) and those assigned/randomized to MBCT (n = 67)

Measure	CBT	MBCT	Total
Age in years, mean (SD)	31.24 (8.99)	33.72 (7.48)	32.35 (8.21)
Relationship status, N (%)			
Married/common-law	41 (66.1)	45 (67.2)	86 (66.7)
Dating	13 (21)	11 (16.4)	24 (18.6)
Single	8 (12.9)	11 (16.4)	19 (14.7)
Length of relationship in years, mean (SD)	7.56 (6.79)	7.77 (6.16)	7.67 (6.5)
Satisfaction with relationship closeness (/10), mean (SD)	7.79 (1.99)	7.26 (2.29)	7.52 (2.15)
Ethnicity, N (%)			
Euro-Canadian	38 (62.3)	46 (70.8)	84 (66.7)
South/East Asian	11 (18)	10 (15.4)	21 (16.7)
Other	12 (19.7)	9 (13.8)	21 (16.7)
Education, N (%)			
High school	2 (3.6)	1 (1.7)	3 (2.6)
Some college	17 (30.4)	10 (16.9)	27 (23.5)
University degree	24 (42.9)	31 (52.5)	55 (47.8)
Post-graduate	13 (23.2)	17 (28.8)	30 (26.1)
Level of typical pain (/10), mean (SD)	5.96 (2.11)	6.04 (1.82)	6.00 (1.96)
Level of worst pain (/10), mean, (SD)	8.23 (1.32)	8.23 (1.10)	8.23 (1.21)
Years since diagnosis,* mean (SD)	6.02 (4.72)	9.85 (7.72)	7.95 (6.67)
PVD history, N (%)			
Lifelong	37 (58.7)	43 (64.2)	80 (61.5)
Acquired	26 (41.3)	24 (35.8)	50 (38.5)
Received past treatments for PVD, N (%)	29 (46.0)	36 (53.7)	65 (50.0)
Receiving medication to treat PVD at baseline, N (%)	11 (17.5)	8 (11.9)	19 (14.6)

CBT = cognitive behavioral therapy; MBCT = mindfulness-based cognitive therapy; PVD = provoked vestibulodynia.

*Significant difference between the groups ($P < .01$). Years since diagnosis was controlled for in all analyses involving between-group comparisons.

Table 2.1: Baseline demographic characteristics of original COMFORT sample (Brotto et al., 2019).

A number of women were recruited from the Multidisciplinary Vulvodynia Program, (MVP) for participation in COMFORT, including 2 of the 8 women whose stories are included below. Given that these women describe how participating in this program, before they enrolled in the COMFORT study, was a significant part of their journey to wellness, a brief description of the program follows. The MVP is a healthcare program for women with vulvodynia operating out of the BC Centre for Vulvar Health in Vancouver General Hospital. As its name suggests, the MVP provides research-supported Multidisciplinary care, including diagnosis and follow-up with a gynecologist, psychologist and pelvic floor physiotherapist. The program consists of a

combination of individual appointments with clinicians as well as psychological-skills training and educational seminars. The program additionally offers an educational seminar for partners and encourages women to involve their partners in their appointments and home practice of learned skills where appropriate. Quantitative and qualitative results from program evaluation research suggests the MVP effectively addresses the physical pain experience and psychosexual distress associated with having PVD (see Brotto, Yong, Smith, & Sadownik, 2015). However, this program is considered to be an ‘introduction’ to the kinds of interventions that may help support women in meeting their treatment goals, and the treatment plan developed over the course of their program participation is intended to be continued in the community with their family doctor following their care.

Eight women were recruited from the 78/130 women who completed the 8-week intervention and agreed to be contacted for future research. Eight is considered an appropriate sample size for a narrative inquiry where the analysis of themes across cases is secondary to the primary goal of a close and thorough analysis of themes within individual cases (Fugard & Potts, 2015). A larger sample size risks missing important themes and diluting individually voiced experience (Braun & Clark, 2006).

2.3.2 Procedures

2.3.3 Invitation

Email invitations with a description of the current study were sent to selected women (appendix B). Sampling was purposive with the goal being to capture the greatest variety and description of experiences (Marriott & Thompson, 2008) rather than for the purposes of representation or generalizability. Polkinghorne referred to purposive sampling in narrative inquiry as looking for “notable exemplars” where a variety of influences on the experience being

explored are considered before initial invitation to participate to enlist maximum variation in a small sample of accounts (2005). I considered information I collected in participants' initial screening and from my own recollection of my interactions with women in order to attempt to capture these 'notable exemplars'. This was an inherently subjective process as those experiences that I considered 'notable' were limited by my outsider experience (as a woman who does not have PVD), the demographic data already collected, my own familiarity with previous vulvodynia research and with participants stories through my interactions with them. I attempted to enlist a diverse pool of women who had expressed either to me directly or via survey data that they had not found their participation helpful, who had experienced barriers to participating, those who did not identify as heterosexual or Caucasian, those who were now 'pain-free', who were not in sexual relationships during their participation, who did not have confidence that psychological interventions would be helpful for PVD before participating and one participant I was aware of who had participated in more than one treatment arm. Although these specific selection criteria cannot possibly reflect the diversity of experiences of individual participants, explicitly documenting demographic factors considered in recruiting each participant helps to ensure transparency regarding selection (Polkinghorne, 2005). It cannot assume to be an exhaustive list of specific contextual factors which I am also aware may include duration of symptoms, previous relationship experiences and relationship satisfaction, previous experiences with healthcare providers or other comorbid mental health or physical challenges, for example.

I invited selected women by email, four at a time, to volunteer for an audio recorded, 60-90 minute in-person, face-to-face discussion about their experiences participating in the group sessions and study follow-up. I provided the question statement in and emailed letter of

invitation : “I am interested in hearing your story about participating in the COMFORT study and your journey with PVD since” (Appendix B, ‘Introduction to interview’).

Selected participants that expressed interest were emailed the consent form (Appendix A) and upon its return were invited to meet with me at their home or in a private interview space at Vancouver General Hospital if they preferred. However, some women agreed to participate if these interviews could be done via secure videoconferencing and one interview was done by telephone due to a participant’s challenges logging on via the videoconferencing link. Four women contacted by email declined, six contacted did not respond and two participants who had initially agreed to participate withdrew before an interview was scheduled. In total, 20 women received the invitation of which 8 agreed to participate, consented and scheduled an interview. A snapshot of relevant demographic and study participation information introduces their narratives below. Women were not remunerated for participating and UBC’s research ethics board approved this study.

2.4 Data Collection

2.4.1 Interview

Once an interview time and location was agreed upon and informed consent obtained, I confirmed they were comfortable with audio-recording our conversation and reconfirmed once the recording was initiated and then asked each participant: “Can you tell me a story about your participation in the COMFORT study and your journey with PVD since then?” Interview probes were minimal and limited to signifiers of active listening and occasionally verbal encouragement to continue (e.g. ‘can you tell me more about/what you mean by, that?’), to explore the meaning participants intended to convey in their narrative account (examples of follow-up questions, Appendix C). Before closing our interview, I additionally asked women what advice they might

give to healthcare practitioners providing care for women with chronic vulvar pain and to those women who may be seeking care for the same. Their answers to these closing questions are incorporated into the conclusion of their narratives.

Through this open interview I followed Lieblich, Tuval Mashiax & Zilber dialogical listening guide, which emphasizes the “shared space of conversation” and “intentional co-composition” with my narrators (1998). I hoped this would help to rebalance the power differential often inherent in a research relationship between ‘subject’ and ‘expert’ towards a co-learning relationship where participants are free to engage in an equal partnership in the co-construction of the meaning interpreted from the narration of their experiences guided by the initial research question. I relied on my counselling training during the interview process which Polkinghorne describes as naturally conducive to a deeper exploration of meaning in qualitative inquiry where the “ability to form an accepting relationship, skill in active listening, and focus on the other's experiential world” create ideal conditions for an investigation of experience that goes beneath the level of content description towards “producing a full account of the experience under investigation” (2005).

2.5 Data Analysis

2.5.1 Field notes

At the conclusion of the initial conversation I completed field notes documenting any observations that came to mind regarding the specific physical context of our discussion (time, place), the relational context (rapport), notes about ‘how’ the story was told (body language and physical gestures, affect, facial expressions) and included personal observations alongside of those (assumptions I held that were challenged or confirmed, my own comfort or discomfort in the conversation, questions I wished I had asked or information revealed that was unexpected).

2.5.2 Transcription

Clandinin argues that data analysis begins with transcription as choices made during this process impact the final data set, and transparent documentation of the process is an essential component of evaluating the trustworthiness of the data presented and the analysis that follows (2007). I transcribed the audio recordings verbatim with attention paid to lengths of pauses, affect and emphasis, and false starts. I then created another ‘condensed’ copy eliminating interjections, non-verbal utterances, repeated words or phrases and tightened the transcript into complete sentences. With the resulting ‘clean’ transcript, I created a new copy and continued to condense the transcription into a cohesive story using track changes to account for what I eliminated and colour-coded words that I added for coherence and clarity and re-ordered text where necessary to maintain a chronological account. I added notes where input or clarification from the participant about intended meanings of some words and phrases would be helpful so that I could document or perhaps limit my own interpretations. With each pass through the condensed narrative I saved a new copy so that I was able to track my editing decisions. I followed Lapadat and Lindsey’s, (1999) ‘steps’ and ‘considerations’ for transcribing interviews and writing narrative accounts:

Transcription-“Inherently theoretical process” (adapted from Lapadat & Lindsey, 1999):

Steps	Considerations
1) Include documentation of contextual factors	<ul style="list-style-type: none">• the ‘how’ and ‘why’• reflexivity/ positioning
2) First draft of transcription soon after interview	<ul style="list-style-type: none">• verbatim• order of exchange• coding for affect,• emphasis• length of pauses,/false starts
3) Develop a transcription key	<ul style="list-style-type: none">• make interpretation process explicit- audit trail

4) Revisit recording at least 3 times	<ul style="list-style-type: none"> • re-visit audit trail
5) Write Narrative account	<ul style="list-style-type: none"> • Editing for coherence, • working with a single interview at a time, isolating and ordering relevant episodes into a chronological account, using narrator's words • Submit stories to participants to confirm intended meaning and for clarification, when necessary

2.5.3 Narrative Co-construction

I then sent my first draft of these narratives, including the colour-coding of words I had added for clarity and questions I had about intended meaning to participants for their approval and feedback. I invited participants to a brief follow-up interview for this purpose or asked them to respond in writing with answers to my clarification questions, or with clarifications of their own and with tracked editing changes. I have provided member-checking questions, including samples of the kinds of clarification questions asked in Appendix D.

Participants' own language use was prioritized when condensing the transcripts into cohesive and readable stories. Eliciting participant feedback and approval was a more challenging process than I had anticipated. In my attempt to adhere to a collaborative process that honoured the language and story-telling style of each woman, the first drafts that I sent participants with additions or changes in language colour-coded, notes in the margins with questions about intended meaning and follow-up questions resulted in a copy many women found deciphering 'overwhelming'. Two women also found reviewing their stories emotionally painful with one rescheduling our follow-up interview twice and another choosing to give her approval to my editing choices without finishing her review of the document. I followed-up with a draft which limited highlighted changes and follow-up questions and was able to complete the

review process. Three women chose to provide editing and feedback by interview, three by writing, one gave her approval to the draft as sent and another without reviewing in detail.

2.5.4 Thematic Analysis

Analysis of the individual narratives followed the Thematic Content Analysis model outlined by Braun and Clarke (2006). An analysis model they describe as ‘theoretically flexible’, where evaluative differences would be expressed through units of analysis and level of thematic description, where themes “represents some level of patterned response or meaning within the data set (2006, p.82)”. In the present case, my findings were represented in two parts- the stories that have been co-constructed from the narration of each woman’s experience included in their entirety and a separate analysis of common themes contained across narratives of women’s experiences participating in the COMFORT study. My ‘reading’ of these narratives were subjective interpretations and the meanings I derived from these interpretations were a few of the many possible interpretations of these texts. By presenting participant’s narratives in full, I leave open the possibility of other interpretations by other readers.

2.6 Assessing Trustworthiness-Evaluating Rigor

I followed Riessman’s guidelines for evaluating narrative research for rigour and safeguarding trustworthiness by utilizing the following criteria of: ‘Coherence’, ‘Comprehensiveness’, ‘Resonance’, and ‘Pragmatic Value’ (2008):

Criteria	Action Steps
Coherence	<ul style="list-style-type: none">• Member checking• Peer debriefing• Comparison of analysis with previously published research

Do the narrative analyses/ co-constructed stories create an evocative account? Are the conclusions drawn well supported by the stories elicited?	
<p style="text-align: center;">Comprehensiveness</p> <p>Are the elicited narratives richly described and does the analysis explore a multiplicity of possible meaning? Is the reflexivity of the researcher transparent in the research process and analysis?</p>	<ul style="list-style-type: none"> • Member checking • Audit trail, field notes • Data immersion • Checking for negative cases • Dialogic listening • Transparency regarding my positioning
<p style="text-align: center;">Resonance</p> <p>Do the co-constructed stories resonate with each participant's experience of their participation in the COMFORT study and with the meaning they intended to convey? Do the cross-narrative analyses resonate with previous research and theory and with experience of clinicians?</p>	<ul style="list-style-type: none"> • Checking for negative cases • Using participant words and sentences throughout each narrative • Supervision • Member checks of narrative account
<p style="text-align: center;">Pragmatic value</p> <p>Was participating in this study meaningful to participants and can this research be useful to clinicians, researchers and women with PVD?</p>	<ul style="list-style-type: none"> • Audit trail/field notes • Supervision • member checking and peer consultation • informed consent

Table 2.2 Criteria and action steps for assessing rigour and trustworthiness in narrative research adapted from Riessman, 2008.

Documenting my reflexivity was an integral part of ensuring confidence in the credibility of this inquiry. As mentioned previously I have attempted to carefully consider issues of transcription and editing for clarity and cohesion, with regular member checking an important part of representing narrative accounts as accurately as possible (Oliver, Serovich & Mason,

2005). The above guideline was followed when asking participants for approval of the final version of the narratives presented here as well as of two experts in the field of vulvodynia treatment and research whose comments are provided separately.

2.6.1 Situating myself, the Researcher

My initiation into vulvodynia research and sexual health research more generally began with my role as a study coordinator in Dr. Lori Brotto's UBC Sexual Health Lab in 2012, and later taking over this role for the COMFORT study in 2014. I was responsible for initial screening of potential participants for eligibility after a confirmed PVD diagnosis and to randomizing or assigning them to participation in one of either the CBT or MBCT groups taking place at the BC Centre for Sexual Medicine at UBC. I scheduled their initial visit with a clinician at the centre and their follow-up visits 1 month, 6 months and 12 months after their group was finished. I was in regular contact with these women during their participation for these purposes although our interactions were not limited to coordinating appointments. While I coordinated the follow-up appointments and collection of their questionnaire data, I was often privy to threads of stories of frustration with the state of medical care for their diagnosis, the lack of awareness of PVD by most of the doctors they had gone to and the often unhelpful advice received ('have a glass of wine and relax', 'sometimes sex hurts'), of relief that their experience of pain had an accepted diagnosis and was not simply 'in their heads' and sometimes of a related mistrust of a psychological treatment for a condition they experienced physically that seemed to some to confirm judgements of others that they were imagining, 'making-up' or exaggerating their pain experience. I heard stories of hope and hopelessness related to their prognosis, of women trying to get pregnant or improve intimacy in their relationships and of practical barriers to accessing the study treatment intervention such as taking time off work or driving out to UBC. As the

majority of these women were recruited from a clinical setting, their primary motivation for participation was to receive treatment they hoped would ameliorate or resolve their symptoms and not everyone was keen to be a part of the extra work involved in participating in a research study (the questionnaires, the follow-up visits) although some expressed interest and curiosity in the process and some were enthusiastic about being a part of research they hoped would lead to better treatment options more readily available to women with PVD. Many women expressed gratitude that their experience was ‘finally’ being treated seriously by the research community and to the healthcare providers involved, and for an opportunity to access a potentially promising intervention, and sometimes frustration that a similar intervention was not widely available in the community. Psychological support for individuals or couples was out of reach for many who could not afford the cost of services not covered by MSP or by the limited options available through extended benefits, if they had them. Some women expressed that they found the focus on a group psychological intervention inadequate and were disappointed that despite the fact they felt their symptoms remained unchanged, they had reached ‘the end of the line’ for treatment options. It was within these conversations that my initial interest was sparked to conduct a qualitative follow-up interview with women who had participated in this research to document how they experienced participating as helpful (or not) and to determine what women felt they needed.

After finalizing the narratives presented here and as I was beginning my analysis, I began a new job as the Clinic Care Coordinator with the MVProgram (previously described) in 2020. My role involved interviewing women after their initial physical assessment to explain the multi-component process, to assess barriers to participating which often included logistical challenges (attending multiple appointments during work-hours, travel, childcare), their confidence in the

recommended interventions, and their coping and support resources, to connect women with community support and educational resources as needed, and to follow-up with women throughout the process and after they completed introductory programming to document progress and assess unmet needs. My experiences in this position likely additionally informed my thematic analysis.

I expect my own feminist position that sex and gender are socially constructed in ways that materially privilege male bodies, sexuality and subjectivity at the expense of female bodies and experiences influenced my reading of the stories presented here, particularly the pervasive but often uninterrogated belief that in many heterosexual relationships, sexual pleasure for women is secondary to her role providing pleasure to their male partners via intercourse. I am also aware that as someone who has not experienced any challenges to my own sexual functioning that I am an ‘outsider’ to the experience of vulvodynia. I suspect other factors would influence these conversations, such as the potential perception of me as an ‘authority’ given my relationship with PVD research, my previous role as the study coordinator and current role as ‘researcher’ in the context of this project, the individual motivations and circumstances of the women who agreed to volunteer to tell their stories almost 5 years after their initial participation, and the development of my ideas and skills as a student in a counselling MA program.

2.6.2 Ethical Considerations

Important ethical considerations beyond the basic requirements of consent, clarifying confidentiality limits, ensuring data protection, and acquiring REB approval include my own presence in the collection and presentation of the ‘data’ of the narratives. I attempted to address this by actively documenting my presence in data collection and analysis, privileging the perspectives of the narrators and striving to address power imbalances between researcher and

participant by being transparent regarding my own positioning and collaborating in the co-creation of the narrative accounts elicited for the purpose of this study. As previously mentioned, this also meant responding flexibly to participants' present contexts and my own evolving understanding of the relative priority of transparency and collaboration balanced with the emotional, cognitive and time burden a participant assumes telling their story and their potential active involvement in the construction process. Nevertheless, I have attempted to clarify areas of ambiguous meaning directly with participants, and where I have been unable to incorporate their clarifications, I have left ambiguous expressions as spoken.

Chapter 3: Results

3.1 Biographies

I have introduced each narrative with a brief biography of the storyteller to provide a demographic snapshot to situate the reader into the personal context of the text. The experiences each woman stories in response to the research question also reveals important information about how women identify themselves and their histories in relation to that. Narratives are presented in the order interviews were conducted.

3.1.1 ‘Christine’

Christine was 27 years old when she participated in the CBT arm of the COMFORT group in 2015 and had been married to her male partner for 2 years after dating for 5 years. She was given a tentative diagnosis of vulvodynia by her family doctor who referred her directly to the program in 2014 where she received a diagnosis of primary provoked vestibulodynia. She was a student in a mental health and addictions worker program during her participation. Our interview took place in her home 5 years later in late 2019. She is currently employed as an addictions support worker and lives with her husband. Christine provided feedback on the narrative drafts via telephone interview and approved of the version presented here in 2020. She describes her enrollment in COMFORT as the first time she had participated in treatment intended to specifically address vulvodynia. Although she still finds penetrative intercourse painful, and the lack of intercourse in her relationship is still occasionally a source of conflict, she says she feels much less distressed by the pain and now enjoys exploring non-penetrative sexual intimacy. She describes communication around physical intimacy in her relationship has improved and both have seen positive changes in their sexual relationship that continue. Since COMFORT she has continued practicing CBT skills, sees a trauma focused counsellor regularly,

has enrolled in and completed MVP and continues with pelvic floor physiotherapy. She and her partner are hoping to conceive soon and are considering alternatives to intercourse for conception. Christine is of mixed Asian decent and describes her family background as religious-conservative.

3.1.2 ‘Sophie’

Sophie was a 26-year-old student in a local university arts program who had been in an open and later monogamous relationship with her male partner for 5 years when she enrolled in the CBT arm of COMFORT in 2013. She had initially been referred to the MVP by a GP at a walk-in clinic in 2012. She was first diagnosed with secondary PVD through MVP and started the COMFORT group a few months after completing that program. Although she had previously visited community GPs about the pain when she first began experiencing it at 20, it would be another 5 years before she received a diagnosis and was first introduced to treatment options via MVP in 2012. Our interview was conducted in-person in a private space at Vancouver General Hospital in 2019. Sophie provided feedback on the narrative draft via telephone interview after rescheduling twice because she found revisiting her story “emotionally painful”. She approved of the version presented here in 2020. She currently works as a writer and has now been with her male partner for over 10 years. Sophie began regularly attending mindfulness groups in the community and seeing a counsellor individually which she attributes in part to her ongoing progress. She describes her PVD pain symptoms as ‘resolved’ although she finds she requires extra planning around sexual encounters with her partner to ensure she has plenty of time to practice the skills she has found helpful. Sophie describes her background as ‘typical Canadian’ and is of mixed Asian decent.

3.1.3 ‘Celine’

Celine described herself as a “48-year-old, cis-gendered, single, heterosexual female working as a numbers person in the public sector” at the time of our interview in 2019. Celine was referred to the program by one of the MDs involved in the COMFORT study program who diagnosed her with PVD in 2009. She had previously sought advice from several medical professionals over a period of 15 years before receiving her diagnosis and had tried numerous topical and oral medications after her diagnosis but before she enrolled in COMFORT. Celine was enrolled in MBCT treatment arm in 2014 and although not in a relationship at the time, attended the COMFORT partner-session. Our interview was conducted in-person in a private space at Vancouver General Hospital. Celine provided detailed feedback and edits by email and by editing a shared draft directly. She approved of the version presented here in 2020. After COMFORT, she continued the daily mindfulness practice she began as a participant and initiated individual CBT-focused counselling with a psychologist with expertise in vulvodynia. She began dating again with the support of her therapist and although she experiences occasional discomfort, she no longer experiences pain with sexual penetration. Celine is a second-generation Asian-Canadian who describes her family background as ‘traditional-conservative’.

3.1.4 ‘Jaime’

Jaime was a 30-year-old yoga teacher who had been with her male partner for 8 years when she enrolled in the CBT arm of the COMFORT study in 2013. In 2011 she was referred to the MVP after reading an article about the program in a local newspaper. She was first diagnosed with secondary PVD through MVP in 2012 and enrolled in COMFORT after completing that

program. Although she had found her mindfulness and yoga practice helpful for dealing with general physical pain before she was diagnosed with PVD, she describes MVP as the first time she has been introduced to vulvodynia-specific treatment options. She currently works as a health-care provider in a multidisciplinary chronic pain program and gave birth to her first child in 2016. She describes regularly using the skills she learned in the programs to manage pain and distress as it arises and uses her experiences with pain and post-graduate training to teach others skills for self-management. She describes her PVD pain symptoms as significantly reduced and any occasional physical discomfort she experiences as manageable. Our interview was done via zoom in 2019 and Jaime provided written feedback on her narrative drafts by email in 2020 before approving of the version presented here. Jaime is Caucasian Canadian.

3.1.5 ‘Sherry’

Sherry was 46, working in marketing, and had been living with her male partner for 5 years when she was referred to the COMFORT study by a gynaecologist in 2012. Before seeing that gynaecologist she had undergone multiple medical tests to explain vulvar discomfort that began in her early 40s and quickly escalated over a period of a few months to intense pain that prevented her from engaging in sexual penetration she had previously enjoyed. Sherry was diagnosed with secondary vulvodynia and enrolled in the CBT arm in 2012. After she had completed her final research follow-up, she joined an MBCT arm in 2014. The groups were her first introduction to vulvodynia treatment. During her participation in the groups she and her partner attended the COMFORT partner-session and couples counselling. Sherry describes her physical pain as even worse today than when she first sought treatment although she describes the groups as helpful. Since participating she has continued to seek the help of MDs, hormone-

therapy, pelvic-floor physiotherapy, meditation, dilator practice and acupuncture but discontinued without any reduction in her pain or distress. She described little confidence any treatment options will help and ongoing frustration with conflicting messages she continues to receive from health care practitioners. She describes significant and ongoing relationship conflict related to a lack of penetrative intercourse. We conducted our interview via zoom in 2019. Sherry answered follow-up questions by email and approved of the first draft after reading but without edits in 2020. Sherry is Caucasian-Canadian.

3.1.6 ‘Ashley’

Ashley was a 26-year-old student and exclusively dating her male partner for several months when she enrolled in the COMFORT CBT-arm in 2015. She had previously attempted to address the pain through her GP and a gynaecologist but did not find their suggestions helpful. She was connected with COMFORT by a university professor who had discussed vulvodynia in a sexual health module as part of a clinical psychology class she was enrolled in. COMFORT provided her first diagnosis of PVD and was her first introduction to treatment. After finding the group helpful she sought out other therapeutic groups (mindfulness and DBT) that she credits with her continued progress. Although her relationship ended during her group participation, she found using the skills she learned with her current partner helpful. She finds there is occasionally pain with initial penetration, but she no longer finds it distressing and describes intercourse as pleasurable. We conducted our initial interview via zoom in 2019 with initial draft revisions via email and follow-up telephone interview with final draft approval completed in 2020. Ashley is Caucasian-Canadian.

3.1.7 ‘Anya’

Anya was a 26-year-old working in print editing and living with her male partner for 3 years when she enrolled in the MBCT-arm of the COMFORT study in 2015. She described PVD symptoms present with her first sexual experiences and gynaecological exams. She says her GP did not seem concerned about the pain she was in and with an abnormal pap test and follow-up procedures 2 years later at 23, developed the belief the pain was a sign of physical damage. She later discussed her pain with an MD at a walk-in clinic who was familiar with the COMFORT study and made the referral. COMFORT was where she first received her diagnosis of PVD and her first introduction to treatment. She credits the group with introducing her to the value of using psychological interventions for PVD and for reducing her pain with physical exams, but did not find the mindfulness practices and homework activities helpful and continued to experience physical pain and distress during intercourse with her partner. Two years after participating, and still in significant pain and distress, she began couples and individual counselling and, for the first time, pelvic floor-physiotherapy. She says the combination of these have started to make a difference for her although she still experiences pain with intercourse. We conducted our initial interview via zoom in 2019 with draft revisions completed via email and final draft approval completed in 2020. Anya is Caucasian-Canadian.

3.1.8 ‘Jenny’

Jenny was 36 years old, working as an emergency-room nurse and married to her male partner for 12 years when she enrolled in the MBCT-arm of the COMFORT study in 2015. She describes a supportive relationship with a family doctor she had been seeing since she was 15 and who had sourced pediatric specula for pap exams that Jenny had always found painful. She

did not experience pain early on in her sexual relationship with her husband, although they had other physical challenges with sexual intimacy related to his spinal cord injuries. She discussed the pain with her doctor who was not able to provide an explanation or treatment recommendations. Several years after this initial discussion, her GP came across information about the COMFORT study and referred her. She first received her first diagnosis of PVD and introduction to treatment options through her participation. Although she did not find the mindfulness exercises and practice helped reduce her pain symptoms, she described the education about the diagnosis as significantly reducing her distress. Jenny and her husband no longer attempt intercourse but regularly engage in other forms of sexual intimacy they both find pleasurable and rewarding. She has not pursued any other treatments for her vulvodynia symptoms. We conducted our interview via zoom in 2020 with edits via email. Jenny did not respond to several requests for a final approval of the narrative, incorporating those edits, presented here. Jenny immigrated to Canada in her teens from a Spanish-speaking country and describes her background as traditional, although not conservative, Christian.

	Christine	Sophie	Celine	Sherry	Ashley	Anya	Jaime	Jenny
Tx Arm	CBT	CBT	MBCT	CBT/MBCT	CBT	MBCT	CBT	MBCT
Enrolled	2015	2012	2015	2012/2013	2015	2015	2013	2015
Age @ enrollment	27	26	43	46	26	26	30	36
Pre-COMFORT Dx?	Y-GP	Y-MVP	Y-Gyne	N	N	N	Y-MVP	N
Partnered @ Enrollment?	7 yrs	5 yrs	No	5 yrs	<1 yrs	3 yrs	8 yrs	12 yrs
Lifelong (LL)/ Acquired (AQ)	LL	AQ	LL	AQ	LL	LL	LL	LL
Intercourse?	No	No	No	Yes	Yes	Yes	No	Yes
Pre-COMFORT Tx attempt?	MD/Psych	MD (Mx) /MVP	Psych/ MD (Mx)/Rx	MD (Mx) /Rx	MD	MD(Mx)	MD (Mx) /MVP	MD
Tx during participation	lidocaine	No	No	Cpls psych	No	No	mindfulness	No
Tx Post-participation	Lidocaine/ dilators/ Ind. psych	Ind. psych/ grp mindfulness	Ind. psych	MDs-Rx / Physio/ Acupuncture	DBT group	Ind. psych/ Cpls psych/ physio	No	No
Continued skills practice?	Yes	Yes	Yes	No	Yes	No	Yes	No

	Christine	Sophie	Celine	Sherry	Ashley	Anya	Jaime	Jenny
Interview/F up	2019/2020	2019/2020	2019/2020	2019/2020	2019/2020	2019/2020	2019/2020	2019/2020
Interview context	IP	IP	IP	Video	Video	IP	Video	Tele
Review/edits	interview	interview	written	interview	interview	written	written	declined
Approved copy	Reviewed- yes	Reviewed- yes	Reviewed- yes	No review- Yes	Reviewed- yes	Reviewed- yes	Reviewed- yes	No response
Post COMFORT Improvement:								
Pain?	No	Yes	Yes	No	Yes	No	Yes	No
Distress?	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Relationship?	Somewhat	Yes	Yes (dating)	No	Yes (dating)	No	Yes	Yes
Post COMFORT Intercourse?	No	Yes	Yes	Yes	Yes	Yes	Yes	No

Table 3.1 Summary of narrative-related demographics of eight participants of COMFORT study participating in narrative follow-up

3.2 Co-Constructed Narratives

3.2.1 'Christine'

I was raised in an ultra-conservative, Roman Catholic family where I internalized the message of fear and shame about nudity, sex and masturbation. I wasn't *always* the most obedient of Christian children, but I did decide to wait until marriage before I had sex. When I was 20, I was in a sexually coercive relationship which I didn't recognize as abusive until it culminated in an assault. Some of the emotional baggage associated with that trauma led to me losing trust with myself, like I should have done something differently. Maybe if I had been firmer with him the first time he pushed my boundaries it would never have gotten to the point that it did. I would never hold other women in similar situations up to that same standard of responsibility, but it took me awhile before I could see myself that way. Although I had always experienced sensitivity and tenderness with tampons, it was after that assault when I can pinpoint the over-sensitivity, burning and real tenderness getting exacerbated, where tampon brands I had used before felt too big and abrasive and I had to switch to youth ones. I went for a bunch of tests to see if there was anything, like an STI, causing the pain, but they all came back negative, so I just assumed the pain was a normal response to penetration.

Six months later I met my future husband who was super respectful and patient with my boundaries and he never pushed them. I thought having sex with him would get rid of that emotional baggage by replacing that abusive experience, but none of our attempts worked out because I was always too tender, and I would involuntarily tense up whenever we tried. We decided to put sex back on hold until we got married. It wasn't until an attempt on our honeymoon 5 years later, which led to me hysterically crying, that he became adamant I see my doctor about it.

My doctor took me seriously and took his time talking to me and my partner and about what he knew and what he didn't know about PVD. He had heard about COMFORT and expressed confidence and optimism that it would bring mental health and the physical together in a way that could help me. It felt validating getting a PVD diagnosis but also really scary to hear there wasn't a physical cure. I was also kind of shocked to realize I was so cut off from this part of my body. I've lived the majority of my life since puberty in some kind of physical discomfort either from migraines or dance injuries, so this was just another thing. I had already been seeing a psychologist a couple of times a week to deal with the assault trauma and some of the negative messaging I had received about sex growing up, and I had gotten to a place where I didn't have the shame and guilt about sex my mom had enforced. To suddenly realize there was a whole other chapter, this physical part that I had been so disconnected from, meant I still had so much work to do. I had this feeling like I had failed despite all of the work I was doing.

Before my first COMFORT assessment, the study coordinator talked me through the appointment beforehand, which was very reassuring, but I was still scared and shaking like a Chihuahua on my first exam appointment. The doctor was incredibly gentle and respectful and talked me through exactly what she was doing with the Q-tip test while I watched in a mirror. It was the first time I had really looked down there since I was five and was grounded for getting caught exploring. She showed me in the mirror how even though my pelvic floor was really tight, I would tense further in response to the Q-tip. She told me how my defensively pulling in was a completely normal way to try to protect yourself when you've experienced trauma. I couldn't do a Kegel when she asked me to attempt one, but I felt the extra tension in response to the Q-tip once she pointed it out. I didn't know before what it felt like to be relaxed, but I was beginning to sense differences in muscular response at a specific physical site which gave me

something I could aim for on my own and use that new awareness of sensation to develop more consciousness of it later. Being able to pinpoint those sensations made them less overwhelming and began to put me back in control of my body where before it just felt like *everything* hurt. It was the first step for me towards reconnecting to my body and reclaiming myself. She demonstrated how my skin flushing with pressure was something she looked for in a healthy vulva and meant I had healthy tissue and proper circulation. She explained any burning and tenderness after the exam was common for women with PVD and not a sign that any damage had been done. It was just insanely relieving to hear her say: “You are healthy”. I had been angry and blamed myself for what was wrong with me and that I couldn't be a physical partner to my husband. But in that moment, I realized I wasn't *doing* this. I had a physical condition making penetration painful, but it wasn't going to interfere with me having children by leading to miscarriage or anything like that. It also meant the person who assaulted me hadn't won or permanently taken sex away from me. There was nothing diminishing my biological functioning or my capacity to feel pleasure.

Both the coordinator and the doctor made that first appointment a therapeutic experience in every sense. The coordinator helped make the ‘exam appointment’ humanizing by just taking the time to chat with me about how it went and how I was feeling about it. She always seemed genuinely interested when asking how school and life things were going when I dropped by her office after groups too. I was so impressed they always remembered details of my life even though they had so many people coming through and so much information to deal with. It was incredibly valuable to me to feel like I wasn't just a test subject; I was being noticed as more than just a vagina to study. I did not like the sharp pain from that swab or the cold room, but that first appointment was still such a validating, normalizing experience.

I was anxious during the first group session because I had no idea what to expect from the other women. I was the youngest in the room which made me feel lucky timeline wise, but also worried I wouldn't be able to relate to anyone else there. The only woman close to my age seemed really resistant to the idea of being there and actually dropped out after the first session. I remember her saying something like, 'I need this fixed! My husband wants this dealt with! You need to fix me! Make me normal!'. She was verbalizing so many things that I had thought even though I knew there was no such thing as 'normal'. Although I understood where her anger, desperation and frustration came from, hearing it from someone else was so jarring. I know it can be frustrating trying therapy for the first time when you think your thoughts and feelings aren't the problem. I felt very uncomfortable not knowing how that dynamic would progress as the group went on.

The facilitators introduced the tools they were going to be teaching by drawing parallels between PVD and other chronic nervous system conditions in a way that normalized PVD and made using CBT for coping with it seem plausible and doable. Learning about the connection between chronic pain and mental health along with my previous experience using CBT for anxiety helped affirm my hope that the group would be helpful. So, despite some skepticism in the room, I felt empowered by the possibility I could manage this on my own because I knew how effective CBT could be if you work at it. I also knew it wasn't going to provide an immediate solution and that we'd be looking at thought processes and at pain *management*, but I left that first day feeling tentatively hopeful.

I don't have any spotlight memories about session material or what order things went in but there were moments that stand out. Studying my vulva for the drawing exercise tricked my brain into looking at myself in an appreciatively clinical fashion. It helped remove some of the

instinctive resentment and anger that I felt towards my body when pain feels debilitating and prevents me from doing things that seem easy for other people. I could recognize those negative emotions as they came up and accept them as human and part of a process instead of them being all-consuming. I had cut myself off from that part of my body and the drawing helped me in the process of renewing that connection. Learning about physical focal points helped you realize how much you can do that won't hurt, like manipulation outside of the inner lips or oral. It made the pain seem more manageable or not as scary because it wasn't *everything*. We also learned what helps women become naturally aroused and what gets in the way. Before COMFORT, I didn't know what my libido was actually like, but I can now recognize when I'm aroused because I can feel those different sensations. By acknowledging how much I had been hiding from myself by bringing shame out into the open, I was able to see myself in a more whole way again. Being back in touch was putting me back in control.

There were some things that weren't in the material that we learned from just talking to each other. I had challenges using meditative breathing for penetration but talking to other women led to me trying it for non-sexual situations. Even though it wasn't helping when I seized up during sex, it really helped when some asshole cut me off driving! That encouragement to practice breathing in other contexts helped make it more automatic and not just a formal practice 'for insertion'. I realized in the group how telling someone you connected with their experience might help them to open up more because of how it helped me to be less shy sharing.

Showing mutual respect for each other's experiences helped these barriers between us came down despite very different personalities in the group. We started talking more about our personal lives, about school, work or partners. We were genuinely concerned when someone's partner had gotten sick. A group member emailed me to make sure I was coming back when

migraines made it impossible for me to come to a couple of sessions. When a group member burst into tears announcing she was pregnant, I'd never been so happy and so hopeful for someone outside of my family or close friends before. Everyone in the group was so excited. After the announcement, another woman admitted that she was happy but also angry because she wanted that for herself. The reaction in the group was everyone coming together to say her feelings were fair and valid. It displays a lot of bravery taking a risk of saying that and shows trust knowing the group could handle her being vulnerable. The pregnant woman shared she appreciated hearing what she'd herself felt but hadn't been able to say in the past when her friends had conceived. There was that shared relief of: "you all get what I am saying. Even if your experience is incredibly different, you're not doubting what I say and I don't have to justify anything". For a lot of us that was really different from what we experienced outside of group when we felt we were alone in this. It also meant a lot to me to be able to just talk about pregnancy and giving birth. I view childbirth with major terror because it's painful enough but what happens when you add PVD in? She brought her twins to our one-year check in and told us the burning she experienced seemed identical to what other women who had given birth described. She felt her body knew what to do and it didn't turn into a big extra thing. It was reassuring and I was able to look at my own feelings about childbirth with curiosity and less fear. Feeling so optimistic for her also meant I could feel optimistic for me.

Recognizing I would never hold any of them up to the standards for progress I sometimes force on myself, because of my anxiety and depression, means I am less likely to fall down that self-directed spiral. We didn't hold each other up to specific scales, it was all progress period. We could see the different incarnations of progress in a way that redefined what progress meant. Being open in this community of women of different life stages, cultures and ages who were

genuinely interested in each other's lives outside PVD validated your experiences and helped with some of the shame. We were all there for a shared goal and we were celebrating each other. It wasn't about 'fixing' it anymore but knowing we all believed we could work through it and we weren't alone. It was more validation that I wasn't just a fellow test subject but was seen as a whole human being, not 'a PVD'. Even as contact after the group tapered off, I never had the sense I was being forgotten. It was more that everyone was managing to some extent and our new coping skills were working and we didn't necessarily need each other anymore.

I hope they are still doing the program, but I think it should be longer than 8 weeks. You deal with all of the nitty-gritty in the first couple of months and then you transition into your normal life and then the questions you have are different. Most women aren't going to have these big changes in that time period because you just start building relationships and you need that community for it to work. I felt a little adrift afterward when questions started coming up as I progressed but there weren't any check-in appointments after the follow-up. I think having some kind of formal ongoing follow-up, like having check-ins every two or three months for the first year, would be huge for long-term progress. On-going follow-up is something I see happen in other group programs for things like trauma, addiction recovery, for after cancer or even for dealing with chronic hormone issues. I would like to see the skills that Comfort teaches be more accessible because they apply to so much more than just sexual health. Sometimes when I feel the despair coming back, I've been able to use some of the tools to pull me out of it.

COMFORT was normalizing, validating, and with tools that made sense that I was able to internalize for dealing with the physical pain and my resentment to my body. It gave me language to talk about what I was experiencing. The fact that the group was put together by medical professionals who had gotten research funding for this, validated that my experience was

legitimate. I'm the hardest on myself and sometimes I accept a lot of shit if it's only on me, but the moment it starts affecting other people I come out fighting. And so when you see all of these other women, from all different backgrounds, struggling and suffering and you don't blame them- you don't see it as their fault, you don't see them as wrong, then you couldn't say to yourself that you're a freak or it was your fault anymore. I wasn't alone in this suffering and if I'm not alone, then I don't deserve this struggle because no one else deserves it.

I even began to face resentment I had towards my family for teaching me that sex was scary and dangerous, and that pain is a given for women and something you're helpless in the face of. There was this conundrum that I had always been so good at isolating body sensations and muscles through ballet and swimming, but I had avoided this other entire part of me. It was huge to acknowledge for the first time how that avoidance was at least partly because of the shame I was taught in my family. I built on previously learned CBT skills and applied them to the dynamics between me and my mom around my sexual life. The anger began to release as the skills became more natural and I began to relax around my mom enough to talk about it.

My husband and I still struggle. We have successfully had sex three times since the program, but it was still painful. Someone had suggested trying lidocaine in group, but I was worried I'd become dependent on it. The study doctor reassured me that if it helped give me time to remember to breathe, I could wean myself off of it when I got to where I wasn't panicking and tensing. It does work for the initial pain but trying to figure out the logistics of it means it's not always convenient. I require a lot of foreplay so when do I apply it? How fast does it wear off? I don't want to apply too much, but I want it to last. But then I can't really enjoy foreplay. So, do we stop in the middle to reapply it? Then there is the logic around the "Yay! We're going to get it on! Just let me get my cream and now wait 7 minutes while I sit like a cat

roasting his chestnuts in front of the fire”. I keep the lidocaine as an option because there’s still uncertainty, but I don’t grasp it as a life preserver.

When my husband is under a lot of stress and hits that bursting point he has said things would be different if we could just have sex. He can’t always tell that I’ve been working on it or see anything helping. He was angry and felt he was being spoken down to after a meeting with the doctor where she suggested he be present when I tried inserting dilators at home. So, he wasn’t exactly cooperative with that. He was trying so hard to be supportive but was physically frustrated and resentful of the whole process. Who wants to wait 5 years to get married and then still not be able to do this? He was resentful of my ex for the assault and of my mom and a little bit towards me, which of course bothers me but I also understand. But we talk about it more now and he can acknowledge there have been times I have tried to be intimate, but his stress has made his libido disappear. He does see things are getting better. We both believe I will get there. So, there’s hope now and I don’t question that.

I get frustrated sometimes when my friends talk about a romantic weekend and something new they tried and I wish I could do that too! There’s annoyance, frustration, and maybe anxiety from uncertainty but there is no all-consuming desperation anymore. Internalizing the breathing and CBT skills means it is less of a process and I know now I can get to the point where I can enjoy sex even if I’m never completely pain free. I can see progress. I still have trouble doing the Kegels without moving external muscles, but I know which are which now and I can relax my pelvis. I found a toy recently that I can actually use and it vibrates! Sometimes I can even insert it and move it around without burning. I still get flare ups on my period which I might bitch and moan about but I’m not dwelling on it the way I did before. Even days when I’m more sensitive, 9/10 times I can switch to external stimulation and focus on what will bring me

more pleasure in the moment instead of just stopping everything like I would before. I also don't beat myself up for wanting to stop and I don't try to push through just for the sake of pushing through. Maybe I really am just too tired or it's too aggravated right now. I don't criticize or blame myself anymore when I can't. COMFORT helped reinforce CBT as an ingrained part of my lifestyle and my thought process now. When thoughts of self-blame come up now, I acknowledge them and then basically blow raspberries at them until they go away. I have accepted PVD might be a part of my life sometimes, but it isn't everything all the time. That's a positive difference and we call that progress.

3.2.2 'Sophie'

In an attempt to be a rational human being, I would like to think that not everything in life is about sex. It wasn't until the pain started that I realized how much stock I put into the fact that I could or couldn't be a sexual human. Sex had been a form of freedom for me as I was coming into adulthood and just discovering who I was. There were all of these choices and possibilities about who I could be, who I might want to be with and for exploring what is pleasurable to me, and then, all of a sudden, I was no longer in charge. Looking around and seeing other people enjoying these freedoms, I thought: "F**! *This* is who you're going to be!?" I took for granted that I could have sex without pain before PVD. Before it was: "You're attractive. You're attractive, and you're attractive- let's go!" and then it became: "sex sucks and now I hate everything". It was like something in me had broken. It was really unsettling how losing sex really knocked me over because I thought it shouldn't matter so much, like "why is this your entire identity? You travel and write and take photos and you're a great friend. Why aren't any of those things enough?" Not only was sex now not even an option but it had turned into this thing that was actively making my life miserable. It was really destructive and

completely derailed my identity and my relationship and knocked me on my ass. To suddenly be completely chopped off from this part of myself was so disturbing because it was so connected to what it meant to me to be an adult or in an intimate relationship.

I remember trying to figure out how it started. I traced it back to when I was 20, had just started birth control, and was in a relationship that was my first introduction to some alternative ways of being sexual which were rougher than what I had previously been used to. The pain didn't happen very often in the beginning even though there was lots of sex. I could drink through it or we would laugh that the reason it was hurting was because we were doing it so good! "Look she's sitting on an ice bag. That's hilarious. Hi-Five." I just thought it was normal then but wondered later if that's when it got provoked.

My current relationship was open in the beginning which took a lot of the pressure off me, but my partner is hard-wired to be monogamous. However, things had gotten to a point in our relationship where there couldn't even be a hint of the kind of physical intimacy that he needed to be vulnerable and feel connected. I felt like I was depriving him by staying in the relationship; that I was being selfish and self-centered and taking advantage of him. He was doing all the supportive things and getting none of the boyfriend stuff in return. If he sat too close to me, I'd completely freeze up thinking if I didn't move away, he'd hope, and I'd have to say no again. I wouldn't even change in front of him in case I mistakenly misled him into thinking sex was a possibility. I felt like a bitch! I had internalized that idea that penetration was sex and everything else was a lead-up to that and I was avoiding all of it. When you're taught about sex in school it's about the scary consequences of penetrative intercourse, like STIs and pregnancy- they didn't teach us about other things. So, engaging in any of the other stuff felt like it was foreplay, which felt like I was being misleading about where this was going. It was terrible

rejecting the most supportive person in my life. All we could do together was eat and watch TV and I ended up putting on a bunch of weight because we were so miserable.

As a girl I had been told that I have overreacted or was being ‘hysterical’ about all manner of things. You’re primed to believe that maybe you *are* being unreasonable or a hypochondriac. Then when you go to a doctor and they’re like “have a glass of wine, relax, use more lube”, the message is that it's all in your head, you're just imagining things. I was trying to tell people that I was in pain while they were trying to tell me that I wasn’t, or I was blowing it out of proportion. I had sort of curled up into a ball at that point and only got a PVD diagnoses because a friend of mine with similar symptoms was proactive about figuring out what it was. She decided that there *was* going to be a diagnosis and went out there kicking down doors and met with a bunch of different doctors before she got a PVD diagnosis. Then she took me and the Qtip tests to a clinic and stood there and made the doctor do it which was how I got my diagnosis. It was such a relief seeing a doctor who was open to exploring the possibility, even though he admitted to not knowing much about PVD. Naming that monster meant I wasn’t crazy or overreacting to something no one thought was a big deal but me. It was a real medical thing that was currently happening in my body and not hysteria. It was acknowledgement that what had knocked me over was a truck, not a f**ing leaf and it was validating that other people could see that. The invisibility part was awful.

My friend and I both enrolled in MVP and then I went into COMFORT shortly after. I was very much in crisis when I first joined MVP but being there gave me a chance to pull myself out of the hole and get back on solid ground. What I remember most about MVP was the very unique experience of having electrodes around my vagina to measure my pelvic floor tension. I had no idea what it felt like to relax or tense my pelvic floor; that was a part of my body I'd never

really given much thought to. Through biofeedback I learned what my base tone looked like compared with what tensed or relaxed looked like and I could then differentiate between those physical feelings. To be able to be in my body and know what I am feeling and where I am feeling it, was like the first time you learn to stand up straight and hadn't realize you'd been slouching the whole time. There was also a brief introduction to CBT in MVP where I began to feel change happening on the surface. I felt a little adrift when it was over so I was relieved to get an email about the COMFORT program because it meant I could keep that momentum going. A lot of my unhelpful thought patterns and reactions had settled into habit and I needed that extra structured time to go deeper with the CBT skills and to really internalize them, so they became the habit.

I went to my first COMFORT appointment feeling like I had two crises going on. I told the doctor there about feeling overwhelmed and isolated transferring to UBC from a small studio program and she spent time normalizing what I was going through and basically counselling me. She put the school crisis in perspective as an experience that is normally stressful but usually okay in the end for most people. It validated my life outside of PVD and allowed me to focus on what *wasn't* normal in the group. It was important that she listened to me, took me seriously *and* was knowledgeable about PVD, when most healthcare providers aren't even aware it exists. I know most doctors have tons of patients in a day and it's probably normal for them to be jaded when someone comes in with something that they've never heard of. Getting this information to doctors and increasing awareness would help to legitimize this. But women should be listened to and taken seriously, anyway.

I believed COMFORT was going to be a helpful experience, but I would often feel so exhausted during group that I wasn't an ideal participant who always had something to say or

something to share. Eight o'clock in the morning was a terrible time for me as a working student, but I always came because, for an hour or so a week, I was sitting in a room with other women who knew how I felt. Women had come from all over the place to be there. Most didn't have somebody in their lives who understood their experience with PVD. Every girl I know has had painful intercourse at some point but it's harder for them to really grasp what it could be like for it to hurt every time or for it to hurt without you even doing it. You hear the same unhelpful advice from friends about how you just need to relax or use more lube. But here I could explain to the group how if my partner looks at me out of the corner of his eye, I think 'ow'! and other women in the group would say: "Yes! I completely understand!" We could talk about these totally irrational but rational ways we all developed these systems of defense. How is it not rational to avoid pain in the moment? We all have that fear response, so you survive. Completely avoiding my partner meant I could 'survive' a physically painful situation but was obviously not going to be something that would actually serve me for much longer than that and it was actively hurting my relationship. In the group there was this great blanket acceptance of all of those things about PVD that were really hard to explain to anyone who hadn't felt it. We shared the same language, knew the same symptoms, had been through the same stuff and felt broken in the same way. Seeing someone crying meant you could cry too, but not expressing emotion didn't mean anybody there thought you weren't in pain. We had a similar, shared experience of PVD, and by sharing our different stories and perspectives you can begin to piece together a fuller picture and understanding of your own situation. We're social animals and we are built to survive in communities and herds and groups. You might be able to survive being outcast from a group or not having any group to belong to, but it makes it really difficult to thrive. I could have *survived* PVD on my own and I would have probably been some version of okay, but now I feel

great and a lot of that had to do with the fact that I've had so much support. I think that community made it a lot easier for me to get there faster because I wasn't doing all of the work on my own in isolation. Just having and sharing those stories was therapeutic.

I remember going to the building at UBC Sexual Medicine for COMFORT for eight weeks, but I don't remember what we specifically did in any of the individual sessions. One experience that stands out was doing the John Kabat Zinn body scan meditation. I couldn't do it initially because I really didn't like the voice and I objected to the number of times that he said 'relax'; it started to feel sort of prescriptive and nagging. I was fulltime at UBC then and doing the whole 'there are 19 usable hours in a day thing', so the daily hour commitment was a struggle. The same friend who had got me into the MVP program, she's kind of a star, has this very dreamy voice and re-recorded the bodyscan for me at around 20 minutes which made it a lot easier to do on a daily basis. In the end it was one of the more helpful things in the program because it was a tool that actually felt restful. There was just the constant cognitive load of trying to talk myself down from fear and calm myself down from panic and express thoughts that had been knocking around in my head for a long time and it was a lot of work and I was already exhausted. I found that the more I practiced the bodyscans the more I could do little mini versions without the recording when I needed to. Sometimes just the thought of the potential for sexual intercourse could provoke this stabbing pain, without him even touching me, but doing these little scans, going from head to toe, seemed to help a lot. I have since found other versions that I still do regularly.

Having the time in COMFORT to make new habits with the tools I had started learning through MVP helped to make them part of the way that I talk to myself now. I'm not always going to have access to electrodes, but I can always talk *myself* down from the edge of a cliff. I

had developed all these really awful habits of catastrophizing rocketing into negative self-talk and negative assumptions about what this all meant about me as a person. The ‘Snowball exercise’ from COMFORT is something that I still find useful for catastrophizing. Now, when I look at what's *actually* happening in the moment, I’m aware that its meaning is whatever I assign to it, good or bad. I usually see that it's not really as bad as it seemed in the past. Being able to name and identify thoughts and feelings as they were happening and tracking my assumptions helped me to unpack things and deflect them one at a time so that they weren't all coming at me at once. If I was feeling stabbing pain triggered by a sexual cue, I could track myself extrapolating to: “This is it. My life is over. My relationship is over. I’m a shitty partner. He’s going to stick around because he's a great guy but he's going to be *miserable*”. Then I could pare it down to the middle of the snowball and talk back to those thoughts: “Really it's just a pain in your gut and a racing heart. These physiological sensations don't need to mean ‘my life is over’. It doesn't mean that I can't *just* hold his hand”. I could counter “what if it *starts* hurting in the middle of sex though?” with “this resistance is just an old habit -let's see if there’s evidence from the last year or two of any actual painful experiences.” Before I would just shut sex down, or it would snowball into other stuff, like a panic attack. Reviewing the evidence that sex *didn't* make me cry %100 of the time, or even half the time, opened up possibilities. As a recovering perfectionist, there is always a lot to unpack whenever I don't do or feel what I think I should be doing or feeling. I'm better at being more empathetic with myself but it’s a work in progress. It was helpful to be more aware of context and to widen my perspective so that I could recognize these changing patterns and see that what I was trying was working. I would never have been able to do any of that before and I don't know that I would have come to that naturally on my own.

Sex sucked for a really long time and avoiding sex became a habit. I still sometimes feel resistance even though the pain isn't really there anymore, and I know sex is going to be good once I get there. I don't always know if that habitual avoidance is because I'm worried it might be uncomfortable or if it's that I just don't have the energy today or there's just other life stuff that I need to be doing. I wonder how much of the resistance is just normal for people who have been together for 10 years and if it would be the same now even if it had never been painful? I imagine other women have different issues with sex so I'm sure that it's not 'whoohoo' for everyone all the time. I make a point now of going into my calendar to see how long it's been since we've had sex, because I know if I let it go for too long then the anxiety builds up, so it's more likely to go poorly, which then makes it harder in the future. Now I will set aside a whole day where I'm not doing anything else, so I have space to use the tools, de-catastrophize and talk myself down without any time pressure or distraction. I like to schedule my spontaneity! Rules make the game fun!

I assume not every person researching PVD has it, yet people were willing to spend their time, education and jobs trying to figure it out. That people were studying it, had developed a test for it, and treatment groups for it, meant it was real and it *mattered*. At the risk of sounding super dramatic, those programs saved my life to some degree. It was like someone came along with a bucket of water and said "Hey-you're on fire! You aren't imagining it!" The programs were a starting point where professionals hold your hand a little bit of the way and then give you a roadmap of where to go. Without that, good luck finding your way out of the darkness alone when everything is on fire. Just knowing those kinds of programs are out there helps. It means there are tools that I can access if I need them without having to go through a hospital or a doctor. When I found CBT and mindfulness useful in MVP and Comfort, I started doing more of

both. Going to other meditation groups and counselling on my own ended up being a huge part of getting me through.

Of course, it would have been nice if I could have gone to a doctor in the beginning who said they had a cure, and I wouldn't turn them down now if they did, but I'm not holding my breath for that. I had hoped that someone would say if you do this program and practice these things you'll be done. It took some time to wrap my head around the fact that it was going to be a process and not really a promise of any kind of truly complete resolution at the end of it. I was disappointed, but I wasn't surprised. I know that's not how bodies work and it's something that I've had to get used to for a lot of other things in life. No matter how well you heal from something, you'll never heal to the point where it never happened. It becomes a part of you- a scar or a memory-like trauma you've worked through but doesn't just disappear. As horrible as it was at the time, I can look back and see I was growing. How do I develop empathy if I don't know what absolute shittiness feels like?

I was extremely lucky my friend took our shared symptoms seriously enough to get us into treatment. But PVD was still devastating for her and her relationship fell apart. Her partner was not willing to put in any kind of work and bailed when she was part way through the program. It undermined her ability to trust anybody's willingness to actually stick it out and have those conversations. She has a casual partner now who has no idea about her vulvodynia and she probably just powers through pain when it comes up with him. Painful sexual intercourse involves a partner being present so having loving support from a partner is a huge part of what might make this program successful for someone. I know you can't find someone a supportive partner or make their partner more supportive, but I think it would be really useful for partners to hear from a doctor or a counselor, that PVD is real: "No, she's *not* blowing it out of proportion.

A lot of partners feel the way that you're feeling. Here's what the research says we should do" and so on. MVP's partner education session helped us because my partner wasn't getting his information delivered by me in an extremely emotional way. Having that as a regular part of treatment would mean less doubt that a partner is making it up or exaggerating. My partner never doubted my word for it, he was supportive from the beginning, but he wished that there had been a group for the guys. He said a few times that it didn't seem fair when it was something that affected both of us but I was the only one who had to find the time and energy to go to group, do all of the work and then also bring back all the information and then teach him about it. He would have appreciated having a space where he could ask questions about PVD and where he could also talk to other guys who may have shared that experience where every offer of intimacy was being rejected. What a terrible space to be in just getting rejected by your partner on a regular basis and not knowing what, if anything, you could do about it. Of course, the guy would have to be willing to go.

My relationship is even better now because we survived a very difficult period in the beginning when most relationships are about sex and enjoyment of each other. My partner and I don't talk about 'cures' anymore and I've gotten used to thinking of it as an ongoing process. The quality of my life improved a lot because PVD got resolved. Now the headwaters are happy and all else is manageable. Of course, other things in life changed along the way, but that basic building block of home being good and me being good at home made it easier to build other stuff. If that stuff gets knocked over, I can come back to this stable baseline of a solid, happy relationship and start over. Having that back means that now everything is better.

I have no idea how things would have gone for me if I hadn't done the programs, but it was going to a *not* good place very quickly. Before treatment, I felt very much broken. PVD

really contaminated everything for me: my mental health around identity, ability, competence, and adulthood was all tied up in that. When you're really struggling, you're not able to take care of yourself or other things in your life. I was always *in it*, sometimes trapped in it, and I didn't have the skills or the awareness or the support to actually be in charge of anything that was happening with my body. It was all running away from me. Something I got out of the program was getting back the ability to actually do something about my experience instead of just helplessly riding along. It was about being back in control and feeling like a capable human being again.

I think it would have been neat to do a follow-up like this closer to the program and then have routine check-ins every year so you can get more information about how it actually changes over the long term. I don't want to bum anybody out and say it's going to take a good eight years before things settle, but it could take a bit of time. Progress is slower than you might ideally hope, but it continues going in the right direction for me. If you stick it out and use the tools that trend should continue. I am not in absolute mastery of it, but with more agency I feel more capable. It doesn't permeate everything anymore. Now it's less of a big scary, catastrophic thing and more of just an annoying thing. We've had to adjust the way that we do things. We keep all foreplay external and we don't go as long as we used to. There isn't any pressure around it anymore, it just takes a little bit of work and planning. I honestly don't know if I saw a doctor now if I would even still 'have' PVD. I'm now aware that it's now mostly within my control and on the minor occasion it hurts it's only as big a deal as I make it and I can usually breathe through it until it passes. We don't have sex on a regular basis, but it's great when we do and nobody is crying after. We just had a 10th anniversary getaway weekend which was *very successful* in a way that I wouldn't have imagined before my first group. It was fantastic.

3.2.3 'Jaime'

I have a long history with persistent pain issues which started when I was 11 years old. In our culture there's a dependency on clinicians to identify the structural pathology causing our pain so that they can fix it. I developed PVD symptoms in my twenties and saw countless physios, GPs, chiropractors and massage therapists without getting a diagnosis. That common experience of visiting multiple practitioners, as often happens with persistent pain, can get you stuck in a hope and despair cycle. That feeling of despair reminds you of your other experiences of despair, which amplifies it until you are really in a pit of despair and you start to identify yourself with that. With every new practitioner I saw there was renewed hope that they might have the answer that the others didn't; some explanation for what was wrong with me that the others couldn't find. I had been carrying around a subconscious belief that I was rotting inside, because if pain can only be explained by some structural pathology, but mine couldn't be identified, there must be something *fundamentally* wrong with me to explain it.

I got connected to MVP in 2013 after I read about it in the Georgia Straight and then I did the COMFORT program a year later. Prior to the programs I had found that yoga and meditation were really helpful with my widespread body pain, but it was through the programs that I got an understanding of *why*. It was my first foray into pain education and learning about the idea of a sensitized system and how the body gets better and better at pain really changed my belief about *needing* to find a specific structural pathology. It was a life changing answer that finally made sense of so much of what I'd been through. It was eye opening and empowering to be given education and tools I could use to make a difference for myself and it was so powerful for reducing the fear of pain. Pain became something that was less alarming, less concerning and more understandable that it had been for most of my life. It takes time for deep conceptual

change to happen but getting that education is when it started for me and a new story began unfolding from there.

Although I remember pelvic floor physiotherapy was specific to MVP, the content of the two programs are blurred together a bit for me. The multidisciplinary approach with MVP was a really valuable introduction to CBT and mindfulness skills and the pelvic floor physiotherapy helped me observe pain more objectively so I could approach it and come to the realization it didn't actually hurt *everywhere*. There is freedom in that, but you could get really hijacked by focusing on pelvic floor exercises and lose track of the influences of your thoughts and the way you're responding to things in the full picture of life. So, it was perfect having that introduction to psychological factors topped up and reinforced in COMFORT.

When I enrolled in the CBT group, I had already been developing a mindfulness practice. I started my yoga teacher training in 2009 but initially struggled committing to practice for an hour every day because my life at that point was all over the map. I learned the Sanskrit word, 'tapas' which is commonly translated as discipline, but I now understand to mean 'consistency builds commitment'. The idea is that when you're trying to make a new habit, less is more, so I started practicing five minutes a day every day, no matter what. It was really useful for me to bring that practiced skill of consistency to making habits of the tools that I learned in COMFORT which made them that much more effective. It was the foundation for incorporating those skills into my life and for then bringing them into my work. It's difficult for me to say which skills had the most impact because I have benefited from using them all in my own life and in my work with others.

There's a certain degree of skill overlap with CBT and Mindfulness in that they both foster an awareness of yourself, your thoughts and how you're responding. I think people will

find similar benefits with either mindfulness *or* CBT- maybe one person connects more with the meditative components and someone else with the focus on changing habits in thinking. I think a good percentage of humans go through life without really questioning what's running through their head or why they're responding the way that they are. As you become more aware of your thoughts, you can reflect on where they come from and how and why you are responding to them in a particular way. It's not that mindfulness or CBT bring you to this sudden place of, 'whoohoo!', but more this soft place of meeting the truth of this moment with curiosity instead of judgement. Self-compassion is a huge part of taking those exercises and practices in the direction of making them new habits. Beating yourself up about not doing it right or doing it enough when learning and practicing those skills just pulls a lot of your life energy. Now I can acknowledge a feeling I'm having as a really crappy moment and have compassion for that rather than getting pulled into it because I know I'm going to keep stepping forward. Despair hasn't been a part of my life for a long while because learning those tools gave me space to choose to respond to it differently rather than fall into that pit.

Our culture emphasizes productivity and so it can really hit your sense of self-worth when persistent pain puts you in a place where they are doing less. There is real isolation and loneliness that can come with chronic pain in general, but even more so with sexual pain which can be so entrenched in shame. Although PVD didn't physically impact me outside of intercourse, I felt so much shame and less-worthy because I felt fundamentally broken. I was really struggling with this uncomfortable reconciliation of how I could feel my self-worth was locked up in pleasuring a man when those feelings didn't align with my values. There's a long history in patriarchal culture of the objectification of women and of women bodies. I was a competitive synchronized swimmer growing up and there was a hyper focus on your body shape

and size where, even at 11 years old, swimmers were getting put on strict diets to lose weight and our bodies were regularly forced into unnatural alignments that cause pain and injury. I had done a lot of work learning to relate to my body outside of it being an object, but it was an experience in the group led me to reflect on how deeply embedded those cultural messages can be. I remember a woman in the group who shared she had lifelong PVD and had recently gotten engaged. I was shocked to notice I was thinking “you’ve never had sex and *you never can* have sex, and someone is going to marry you?!” I had this realization then that we weren’t, as a culture, beyond that, although I wanted to believe we were. I had to look at how deeply that internalized objectification runs. If our self-worth is wrapped up in being an object of pleasure is that really self-worth? It was a really challenging and awesome experience to dive into those types of questions and challenge some of the ideas we carry somewhat subconsciously. Having the opportunity to be in a room full of women that share the experiences of shame and invisibility that come with PVD, but who are intelligent and insightful and *normal*, was so helpful in normalizing that whole experience. When you can look at somebody else and not see them as less worthy that challenges your own sense of yourself.

I had gotten to a certain point with recovery after the program where I was doing a lot better, but something would happen, and it would knock me down and set me back. A year after I did COMFORT, I was rear ended on the highway. In came all of these thoughts and beliefs about how life and the universe were knocking me down. I had enough awareness at that point to see it was not helpful thinking and I used the thought record tool from COMFORT to work through it. I laughed out loud when I got to my alternative thought “life is knocking everybody down” because I realized that I was taking hardship so personally. There was the awareness that subconsciously I didn’t believe I was worthy enough to reach a certain point of wellness which

prompted me to reflect on my life and my history. I had a rougher upbringing than my social circle, but I always had shelter, food, and clothing. I've had incredible access to education, and I live in a relatively safe part of the world. So, if I am going to consciously subscribe to the idea that the universe knocks people down, I'm really not the person that life is taking hard hits at, but I lived my life carrying around that story. Without the mindset and the tools to be actively reflecting and actively engaging in these things you just carry around beliefs that life is knocking you down. I kept getting better at using the tools and got more out of them the more I practiced.

As I've since learned more about pain, I have a new understanding that it is about a perceived need for protection, which comes out of Lorimer Mosely's work. He has a tool called the Protectometer which is like a thermometer where things that increase your perceived need for protection move you up on the Protectometer and a sense of safety, or 'un-guarding' decreases that. This gives power back to the person with pain because there is so much that an individual can do to influence that perceived need. One of the examples I use when I'm teaching is that if I have a knife in my leg, all these danger signals are coming from that part of my body and taking the knife out is going to influence my brain's perception of safety. But if a person put a knife in my leg then put a gun to my head, I probably would not have pain in my leg, because pain is about protection. I think you can map that understanding onto the wholeness of a human. You begin to see that there's so much possibility for someone to have a positive influence on their pain whether it's getting a pet or getting outside more or being more socially connected, or whatever it might be.

If I rewind to the past, having sex when I knew it would be a bit more sensitive, like around my period, would have been a lot worse, but now I recognize it's just hormones doing their thing. I can look at whether the degree of discomfort I'm in is consuming and I need to check out

or if I can shift focus and engage elsewhere. By the time I did my final Q-tip exam for COMFORT my highest pain score might've been a 3 and I even had some zeros, where it was previously all nines and tens. It really made a phenomenal difference. I've been with my husband since we met in 2005 and our sex life was largely non-existent before the programs changed how I approached my sexual life by paving the roads. Although getting pregnant wasn't a primary concern or an immediate goal when I enrolled, it was reassuring to learn in COMFORT that PVD wasn't really going to be much of an issue with a vaginal delivery. I don't think the difficulties I experienced during labour and delivery were because of PVD or were that different from what other women experience. Things with my partner are a lot better, and if there is discomfort during sex, I don't fret about it and I don't feel powerless in the face of it. In the moment there is awareness I can change my thoughts or change my breathing and have an influence over things.

I remember answering the COMFORT survey questions was a bit of a laborious process because there are a lot of questions asked in so many different ways and I would get lost in my head and forget if I answered one already and said something different another time. I also often found with some of the questions that none of the options really reflected where I was at, but I would pick the best answer and move on. It wasn't anything that I was begrudging because I was really grateful for everything helpful that I had received through the program and I felt a kind of responsibility to do my part in exchange for that.

I've read, reviewed and critiqued pain studies during a post-grad program in pain management and I continue to in my work. Something that I have noticed was that all of the benefit I have gotten from participating is not being accounted for in the research, especially beyond that year or so from treatment. The kinds of tools that you teach in COMFORT have

more exponential benefit. The more that you become mindful of your thoughts and whether they're serving you or not, the better you continue to get at doing that. When I first started learning about mindfulness, a good while before the programs, it seemed kind of airy-fairy, but I'm at the point now where I think if there's a secret to life, mindfulness is in the running. I have a daughter now who's three and I can't imagine parenting without mindfulness. I would be so much more impatient and have so much less presence in my relationship with her. A lot of that came from MVP and COMFORT planting stronger seeds of that in my life that just keep growing. They are the kinds of skills that you get better at the more you practice. But research doesn't account for how that generally unfolds in your life, which is why it's quite interesting what you're doing this so many years later.

I don't have a recollection of a big change moment; it has been more that gradual unfolding. I will have a reflective moment that I'm doing better, and things are easier and that it's been that way for a while. It used to be that if I woke up with a new pain in some place in my body I would be thinking "my goodness, how many practitioners are we going to have to see about this? How much of my life energy is this going to take and how is this going to hinder my activity levels? How much is this gonna cost me?" Something I learned to do because of the programs was to think "meh, there is a new pain. It'll likely pass" which has been really positive in that it allowed me to respond to pain so much differently. Right now, I've got a flare up of pain in my hip that has been challenging for a couple of weeks. I've been more aware of it while I've been talking to you, but I've also had lots of times since it started where I haven't been aware of it at all. I'm riding it out knowing it will pass and that I've got tools and resources I can use. I know now that hyper vigilance doesn't make it better.

I used to get the question ‘Are you healed?’, or ‘Are you fixed?’ a lot and I never knew exactly how to answer because I’m way better now in so many different ways. I really grasped onto John Kabat Zinn’s differentiation between how a cure is fixing something and healing is finding a sense of wholeness in the midst of whatever’s going on. It’s hard to say if the benefit I’ve experienced since the programs would be the same if this hadn’t become my life’s work. Because so much of what I’ve done and learned since the programs has continued to be so helpful that my instinct is to say probably not. I also think my background in yoga really helped. Exactly what seeds might’ve been planted in the program that would just grow in life in and of themselves? My life now is very structured around attending to wellness. I do a lot of yoga, a lot of meditation, I’m careful about what I eat, and I prioritize sleep. I often joke that I’m going to be rocking as an 80-year-old because of those self-care things. When I don’t do those things, I can quite quickly start to experience a lot more pain in my body. I still struggle with pain in different capacities, but I don’t feel broken anymore and I think it’s that idea of wholeness that is the key. After participating in MVP and COMFORT I started working specifically with people with chronic pain as a yoga teacher and then did a postgraduate certificate in chronic pain management. I now work at a multidisciplinary pain clinic where I run an eight-week program that has pain education, mindfulness, relaxation training, stress management and CBT skills and looks at loss and grief, exercise and diet and overall wellness and resilience. My own history with pain opened doors for me to be in the service of other people who suffer so much, and I feel profoundly grateful to have the opportunity to bring more ease, more optimism and empowerment to people’s lives. That would not be there if I had not lived that story and I wouldn’t be doing work I am so passionate about if it wasn’t for the MVP and COMFORT programs. It would be an asset having somebody, particularly with PVD, who’s had lived

experience with the breathing and mindfulness tools and come out the other side using them. It could be really inspiring and really enriching because those are tools of lived experience more than they are tools of knowledge. The people I work with value that I personally understand what it's like to live with persistent pain.

It's hard to think about specific advice I would give other women because I'm so biased by the work that I do and I'm not sure how to separate it. We treat pain as a biopsychosocial condition most effectively treated with a biopsychosocial intervention. I would never discredit anything that helps move you down that protectometer and has a positive impact on your experience of pain, whether it's during a pap or playing the piano or whatever it might be. But I think I would say your *overall* well-being matters and to focus on that. I would definitely say to do the program! I am really, super grateful for MVP and COMFORT and I hope that they've helped other people as much as they've helped me.

3.2.4 'Celine'

When I was in my early 20s (in the 1990s), I first went to see an older, male psychiatrist recommended by my family doctor, about genital pain and PTSD from a sexual trauma. The genital pain existed prior to, and continued after, this traumatic incident. He was very condescending and said the pain was all in my head and I just needed to relax. I had many sessions with him, and he never seemed to believe that my genital pain was real. My most memorable advice from him was to go drink some warm milk. That was the last time I saw him. I was so frustrated. It was pre-Internet and there wasn't information about female genital pain available anywhere. Later, with the Internet, it was either worst-case scenarios, like lopping off genitals to get rid of the pain, or discussions, which mirrored my own experience, about how frustrating it was that there was *nothing* out there that helped. My family doctor had not been

very supportive about finding solutions and resources, but when he retired my new doctor got me a referral to UBC Sexual Medicine where I finally got a PVD diagnosis in 2009. At that time, I'd had this issue for close to 15 years. I felt some relief learning PVD was a real medical condition with a name, and not something I was just imagining, but it was also incredibly frightening to find out there wasn't a cure; nothing that would make the pain go away for good after I completed the treatment or dosage, like how antibiotics treat an infection. I was very skeptical when they suggested the COMFORT study because mindfulness didn't seem like a real solution. But I wasn't hopeful anymore that there *was* a solution. I had already spent a couple of years trying creams and ointments and pregabalin and other drugs prescribed that didn't help. So initially I just went to hear other people's stories and maybe learn some coping tools. I didn't go into the program very positively or hopefully.

I participated in the COMFORT mindfulness program almost five years ago, in the fall of 2014. I appreciated the group was connected with knowledgeable medical moderators who could correct misinformation, because you don't get that with internet communities. They provided us with up-to-date information and taught us about how important the mind/body connection was with PVD and how the emotional, mental, and physical were all connected in the nervous system. I didn't know about that connection before, but it was really helpful to understand because the emotional and mental are probably the biggest factors in living with and being able to manage pain. The group was a mix of ages, professions, life stages, and viewpoints. Some women had been recently diagnosed, while others had been on this journey for a long time like me. Besides sharing common experiences related to PVD, we were all so different. There was no "typical" profile of what a woman with PVD is like. It could be any woman and every woman. I

was initially nervous sharing my emotions and feelings in the group, it was a new experience for me, but the support from the moderators and the other participants made it much easier.

Group discussions started with us sharing our experience doing the homework activities. Some of them, like drawing the ‘snowball’ and filling it with all of our emotions and feelings about PVD, naturally brought out our personal stories. Someone shared how sex always ended in either pain or tears. That was exactly my experience: pain or tears or pain *and* tears. That one phrase encompassed our shared experience of a two decades journey. It was so reassuring to say something in the group and hear someone respond they’d felt that too. No one thought I was crazy. We were helping each other put into words what we didn’t have words for before. We shared the frustration of not knowing where PVD comes from or *why* it started. We told each other it wasn't our fault. It was powerful, that sharing. *Finally*, after 15 years of isolation, it was the first time I didn’t feel so alone or like a freakish failure. I wish we’d had more moderated group talks, discussions on the exercises we did and more time to share stories. But I realize that there's a short time frame to do the group and that it takes a lot of resources. I think it could be helpful for women with PVD to be able to access an ongoing support group, online webinars, or moderated online websites to help us find a community, encouragement and support from others who understand what it is like living with and managing this condition

After the first day of the group I wrote my new goal for the program, ‘to develop a daily mindfulness practice’, on the first page of my binder and called the last date of the group ‘day one’ of this goal. I had to try to do something to change my situation and the moderators seemed so sure that mindfulness had helped other women. I also did not have any other options left after all this time. It was really hard at the beginning of the program doing 30 and 40-minute meditations when you’ve never done it before, and you're not used to your mind going all over

the place. The way I got myself to practice was to just start with two-minute practices I found online and slowly build it up to three, five, and then 10 minutes. I wish they'd emphasized more that your mind wandering is just part of the experience and to just be aware it's happening instead of trying to stop it. I know now there's no right or wrong way of doing it and that learning takes time to practice, but when I started, I would get discouraged thinking I was messing it up. I still get discouraged sometimes. There are days when meditation and mindfulness come easier and days when it is more difficult. When I first began developing my practice, I did a lot more of the Loving Kindness-type meditations, repeating mantras to be kinder, especially to myself, which has always been very difficult for me. I used to be much more critical and harder on myself. Without being kinder to myself, I don't think I could have kept up the mindfulness meditations, as I would have given up earlier thinking I was failing. I've learned and accepted that perfection is not the goal, and I don't beat myself up over it anymore. Since November 2014, I've done a meditation every single day and I have never missed a day. If I'm sick, or I'm late for work, I will just do a two-minute meditation that day because I know if I skip it and try to make it up tomorrow, I might not do it at all. I usually do between 10 and 15 minutes every morning and maybe 20 or 30 minutes on the weekend. I have meditations on my phone and on my iPad, so even when I travel I have them with me. When I spend time at my parents, I bring a "do not disturb" hotel sign that I put on the door when I'm meditating. They kind of laugh about it, but they accept it. Meditation is a part of my life now.

My mindfulness practice is a big thing I took away from COMFORT. I may have found mindfulness some other way, but I don't think I could have connected it to managing PVD pain, on my own. Whenever I'm dealing with pain, I can acknowledge the pain in the moment, and also how it makes me feel, and then let it go. It was really helpful to me when I had 2 eye

surgeries over the last 5 years that were both painful as hell! It also helps during work stress where now I can take a breath and at lunch just focus on eating instead of the 20 things I still have to do. When I feel really stressed, it benefits me to be able to take a quick inventory of my body and how I feel physically, emotionally and mentally and then take a two-minute breather. It was a new experience for me to be able to relieve stress just through really noticing where my mind and my body are at in the present moment. Before, all I could feel was overwhelmed. PVD pain always felt overwhelming and impossible to manage, which led to feelings of failure. Now I can notice the pain is in *this* moment and that doesn't feel insurmountable. For me, it was more like finally "owning" the pain rather than fighting the pain and being ashamed of it. By accepting the emotions that I felt, it made them (especially the negative ones) feel less personal. Mindfulness has taught me not to *control* my emotions but to be with them. I now try to be in the moment, to feel whatever it is, good or bad.

Something we talked a lot about amongst ourselves, but wasn't addressed in group, was approaching relationships with PVD. What do you say to a new potential partner and when? If you say something too early you are frightening them off, but wait too late and they feel that they were taken in by you. Women in relationships had a different set of issues related to thinking they were letting their partners down. It would have been really beneficial to have a discussion about how to deal with partners, whether you had one or not. Although I didn't, I attended the partners' session hoping for some of these answers. At the Q and A I asked how to tell a potential partner about PVD. When I got a general answer I realized it was a question that couldn't be answered specifically. But I really wanted an answer! That's when I decided to get individual therapy, although my therapist never really answered that question for me either. I learned *effective* therapy helps you to find answers for yourself, because all of our life journeys

are different. If I could learn to manage the pain of PVD, perhaps I could also learn to manage the shame of having PVD and there might be a possibility of being in a relationship again. Therapy wasn't easy, especially at the beginning, because I had to trust a stranger and open up about the most vulnerable and broken parts of myself. But we did get there.

I requested and was given a referral list of psychologists knowledgeable about sexual pain from UBC Sexual Medicine. I chose a male psychologist who was familiar with the COMFORT program because I wanted to see someone who knew about PVD and also *might know* what male partners are thinking. It felt so intimidating to talk to a guy about this, but I thought if I could talk to him about this, then I could talk to anybody. Besides he was a stranger, and I promised myself that if I did not feel comfortable with him after 2 sessions, I wouldn't go back. It was a little like doing my first CBT exposure which I didn't know anything about before I started working with him. His CBT approach really complemented what I had learned in the mindfulness group because he knew about PVD and how both CBT and mindfulness could be helpful. Working with him also helped to counteract the negative experiences I'd had with male doctors in the past. I'd learned that male medical professionals did not believe women's genital pain was real and that they thought we were hysterical and exaggerating when describing its devastation to us physically, emotionally and mentally. The 'warm milk' psychiatrist had told me that one day it would be like a light switching off and the pain would just go away (since he said it was all in my head anyway). I'd thought I must be overreacting, and I questioned whether the pain I felt from PVD was real or not, which therefore meant the shame and distress I felt about it were not warranted. I felt so diminished and dismissed for such a long time. It was the complete opposite with this psychologist. He believed me. I did not have to explain what PVD was. He did not dismiss it as something I made up. He not only acknowledged the reality of PVD but helped

me focus on what I could *do* about it instead of waiting around for a cure or for it to go away on its own. It was incredibly powerful because he didn't think I was crazy; he didn't even feel sorry for me. That was important to me because I didn't want pity or to feel like a victim.

We focused on how to meet my goal of being able to have a sexual relationship where I could be open about my condition and be able to manage the pain. My biggest fears were being rejected by a potential partner after I told them about PVD so I had avoided meeting anyone. With support from my therapist I started dating again. I didn't know what to expect physically if I started a sexual relationship, but I knew if I experienced pain, I was more capable of handling the emotional and mental aspects of it. As it turned out I wasn't rejected by any guy that I told, and I even had a couple of brief relationships. No one was shocked or grossed out or scared away and all expressed kindness. I was able to say: "This is what PVD is. I need to approach sex cautiously. You really need to listen to me when I say stop". Being able to say that and not be rejected for it was more liberating than the actual sex which, while unremarkable, and somewhat uncomfortable, was *not* painful. There were feelings of hope and empowerment I had never had before.

It would be so useful to include a conversation about appropriate individual counselling resources when the group sessions end. I felt the COMFORT group was a great beginning, but I had issues with PVD that the group didn't address. In the group we touched on the idea that shame is self-aversion, but we didn't really get into how to let go of shame even though it's acknowledged as a big part of the problem with PVD. Since the mental and physical are so linked, the shame (and self-aversion) of having PVD and carrying that emotional burden probably maintains or exacerbates the PVD pain. Individual counseling helped me work through the self-aversion and negative thoughts and repetitive patterns, like forecasting negative

outcomes (e.g. I will be rejected by a potential partner if I tell them about PVD). Through the group I had learned to manage the physical part of PVD and watched my Q-tip tests go from eights and nines to fours and fives. But the whole emotional and mental part hadn't caught up with the physical progress and that needed more individual attention to keep that momentum going. Carrying the shame and blame of PVD made me feel broken and it was very difficult to change that thinking and much harder to overcome than the physical part. I used to think that if the pain of PVD was cured, then that would be the solution to "fix" everything. I could use topical anesthetic if I had to and not feel the pain temporarily, however getting to where I could *be* in a sexual relationship was more challenging mentally and emotionally.

Something I noticed in the group, and later in the partner information session, was there were no other middle-age Asians there except for me. I don't think that the 1 in 10 statistic discriminates by age or ethnicity. Looking around the rooms you would almost think PVD is a first world problem. Why aren't we represented? I guess it's about who feels more comfortable talking about this openly because in my culture, sex, women's health and emotional or mental issues are still mostly not talked about. I never discussed sex with my mom. The psychiatrist I was referred to was also part of the Asian community and after he dismissed me, I gave up seeking professional medical treatment and advice completely for a while. I had trusted this expert who said it was all in my head and I believed that if my pain experience wasn't real then something must be *really* wrong with me mentally and emotionally. I was isolating myself because of this shameful secret of PVD. I felt completely alone in this pain and couldn't talk to anyone about it. There was cultural shame and wondering if the pain was a punishment for having sex before I was married and personal shame from this idea that sex was supposed to come as naturally as breathing, sleeping or eating, but I kept failing at it. I remember learning

about Maslow's Hierarchy of Needs in school where sex is considered a physiological need, so I felt like a total loser that I couldn't fulfill a basic human function. Working through the shame started with learning to talk about sex. It's horrifying how shameful and secretive it has to be for women. Sex is always portrayed in media, movies, and TV from a male perspective, where women's pleasure and non-penetrative sex have been relatively taboo topics. Women's bodies and health issues are often dismissed or considered secondary to male issues. What does it say about women's bodies that at least 1 in 10 women are going through this but nobody's talking about it? If 10% of women are experiencing PVD, there must be a lot of women just suffering in silence. I wonder if female pain has always been ignored.

I had thought before the group that I would never be able to talk to anybody about this. I had been alone on this journey for so long and believed it was never going to change. But I met other women who felt they could never be in a relationship, who had felt dismissed and diminished, who hated or felt let down by their bodies and it was everything I had felt. The group gave me the confidence to go to counselling. It helped me see *I* could do something about how I thought or felt; that I could change that. I'm not ashamed to have these conversations anymore. Participating in the program was a first step towards completely changing who I was. It was a lot of hard work to get to this place where I can say now that I'll be okay. I'll still have doubts or frustrations or negative thoughts, but I don't feel an overwhelming burden or fear or hopelessness. I will always wish I never had PVD, but for the first time in my life sex doesn't end in tears and pain. I think all of these factors over the last five years- learning PVD was real and that I wasn't alone, mindfulness, CBT skills, self-compassion and forgiving myself, added together, have helped me get to this point. Now, I don't see PVD as a permanent pain condition but as a manageable, chronic discomfort. I think of it similarly to how someone with diabetes

takes insulin, but I'll do the mindfulness meditation. I hope you can tell future participants that even if their PVD doesn't go away completely they *will* be able to manage it.

I know you can't change the past, but sometimes I wonder what would be different if I had been diagnosed properly earlier and if COMFORT had been available when I was in my early twenties. I've never been married and didn't have children because I was so ashamed and closed off. Maybe I would have treated myself better if I hadn't been so angry at myself for having this 'defective' body. That lesson at the beginning of COMFORT that shame is self-aversion was a powerful one. I spent 20 years just focused on work and doing anything to avoid interpersonal relationships. But with self-compassion I've learned to be kind to myself and my body, with meditation, exercise, eating healthier, and seeking better balance in my life. I never asked for PVD but it's here now and if it's never going away, at least I'm not alone and I can learn to cope with it. I can always look back at the steps I've taken since I first started, and I have my daily mindfulness practice.

There's still so much unknown about PVD. With something like cancer, you know it's rapidly dividing cells and you can put it under a microscope and see it. PVD is more nebulous. There's something wrong with a response in your nervous system, but why do some women have it but not others? Why do some have it their whole lives and others get it later? What triggers it in the first place? I've learned to focus less on the unknown whys and more on what I can do about it now. I can't be sure that knowing 'why' would even help me change my experience, so I don't give it the same power. There is much better research now and information is getting to doctors in a way that it didn't before. I heard every UBC medical student learns about PVD in their gyne rotation, now. So, going forward, there's hope that doctors will be aware of it and can properly diagnose it earlier. Things are getting better.

3.2.5 'Sherry'

I have always found Tampons and gynecological exams physically uncomfortable, but it was never intolerable. I never experienced serious discomfort with sex and had a very happy and joyous sex life up until PVD symptoms began in my 40's. Over 4 months the pain went from a 2, moved to a 3 then a 4, and reached a 5 before I believed there was something seriously wrong and went to my doctor. By the time I saw her it was like a hot curling iron burning, it was so painful. I went to the STD clinic after my doctor couldn't find anything wrong and those tests didn't find anything either, but the pain level kept going up and up from there. I finally saw a gynecologist who knew about COMFORT and referred me there. By that time, it was full blown, and I often wonder if I had known right away if I could have nipped it in the bud or done something differently before it progressed. I would (and will) try anything that might alleviate the symptoms because nothing I've tried has helped my PVD pain so everything keeps burning down around me.

I found great value in COMFORT. There were great suggestions for books, dilators, pelvic floor therapy, and other options which gave me hope. Learning about how there were more pain receptors in the brain with PVD and about the white blood and mass cells was brilliant. Discovering there is a real physical response in the body legitimized my experience of pain and made it real because when there are no visible signs you wonder if you are crazy or just imagining it. Going through the workbook with my partner also helped with his doubts it was legitimate. Being able to show him that diagram with the pain nerve endings led to him being more tolerant and understanding that it wasn't just in my head or me rejecting him. The arousal cycle model was also fantastic and was really different from the understanding I had about desire before. It helped me realize we could get there even if I didn't feel it right away. All the women

in the group could relate to the business about losing your sexual desire when you know the end result's going to be pain and frustration and maybe your partner rolling their eyes and leaving the room. I didn't feel so alone or like I belonged on a leper colony. Being in the group took away some of the shame and the judgment. There really isn't a lot of awareness about PVD and most people don't know what it is. I can't imagine how some women went through this for years, maybe their whole sexual lives, thinking that this was normal and not being able to get any help. PVD didn't hit me until I was in my forties but some other women in the room were in their twenties or always had it. There was one girl who wanted to get pregnant with her husband and I thought, how do you have a baby come down your birth canal when you've got PVD?! I came home counting blessings that I'd had a beautiful sex life. I didn't consider myself such a victim anymore.

I did both the Mindfulness and the CBT group. I know some studies say that mindfulness actually helps more than CBT but I think it depends on the kind of person you are. I think that doing the CBT group first was really good for me because I'm more analytical and learning concrete skills felt more important than the meditative stuff. I didn't want to be told to just meditate it away. Learning to work through the emotion, situation, and automatic, biased thoughts in the work sheets felt really concrete. There were just more tools to use in the CBT group and those exercises allowed you to target the mental junk and the judgment and shame. I got more out of that than the 'put this raisin in your mouth and feel it' exercise. Don't get me wrong, I think everyone should develop a mindfulness practice, but I don't know if that's necessarily the one thing that would help women with PVD the most. Besides you can get mindfulness anywhere now.

I remember some of the meditation recordings in the mindfulness group were really bad because the voice sounded so creepy. Some of the pauses between dialogue were so long I'd be stressed-out wondering if it had ended which often brought me out of meditation. I do believe in the overall concept and I have continued to practice meditation on and off since even though it hasn't seemed to have helped with PVD. There were two times in the last seven years where the pain level went down to a three and that lasted for about a month around the same time I was meditating a lot. I can't pinpoint it and I'm not even sure if the change could be attributed to the meditation or if it just happened to be at the same time. Regardless, even if it helped part of the way it didn't continue. I know on paper meditation is supposed to help and that's why I keep doing it. It's kind of like brushing your teeth where even though you don't see the results, you know that it's probably helping. But when results aren't immediate, doing things like meditating, eating properly, drinking less, or going to the gym, don't feel urgent or important enough in the moment and they fall to the wayside when you're busy. You know rationally that they *are* important, but it's harder to make them a priority or feel motivated to do it when you don't get *something* out of it immediately. It feels like using a glass of water for a forest fire.

It is hard to tease the two groups apart completely because I know there was also a lot of overlap between the two and I think you need to have a bit from both. I joined the mindfulness group after the CBT group even though things didn't get better because I still had hope. I was willing to do whatever it took. I didn't see any physical improvement, but I had such a better understanding and thought maybe the second group *would* help. I really fought for it though because they had said I was too old at 46 when it was time for the second group even though I wasn't menopausal. I was eventually accepted into the program but in the end there was still no difference. It might even be worse now. I think I'm so tight now that you couldn't get a toothpick

in there. I also tried several things after the group like pelvic floor physio, wax dilators, acupuncture, estrogen cream and none of it helped. I spent so much time and money on it but because nothing I tried worked, I haven't really bothered in the last couple of years. I heard recently from a doctor that I could actually have been making my situation worse with the pelvic floor physio by tightening my pelvic floor rather than relaxing it. Someone else said that I should have been give progesterone rather than estrogen. It's difficult to know whose advice to trust. It's really frustrating.

It would be great to be able to find out about what other studies say about treatments tried for PVD like pelvic floor therapy, or acupuncture or anything else they have looked into. I probably spent, \$1,500 on pelvic floor therapy and at least that much on acupuncture in the faint hope that it might work. If someone said to me that 0.2% of people find relief by doing acupuncture, then I can decide it's more a placebo effect or just snake oil. I ran into a woman from our CBT group at the couple's session who had said that after 14 days of meditation at a Buddhist retreat her PVD symptoms had gone away. So if someone can say that they *know* from their studies with mindfulness that 30% of the participants who did, 30 to 40 hours, or 40 minutes a day for seven days a week for six months, found that their pain was alleviated then someone's more likely to stick with meditation. Hearing 'we think it helps' or 'it might help' is very vague and nebulous and some of us want to see the facts and the numbers. I understand correlation does not equal causation, I know there are other factors involved in why something may work or not but let me see the research so I can decide for myself. I need to know what the chances are before I deplete my bank account and add to my and my partner's frustration. It just dashes my hope that there is any chance of getting this into remission, so you're stuck with the

pain and you're stuck with no sex. You're stuck with having this hole in your life and you're stuck with feeling broken. If you have hope, then you will try things and you'll keep pushing.

We recently attempted intercourse again and I had some bleeding just from him trying to penetrate my vagina. We spent a lot of time, pre-penetration, getting my body ready but it didn't help. We have tried non-penetrative ways of being intimate like oral sex or manually stimulating each other to orgasm but he says it's not the same or enough. He wants to try anal sex and I'm nervous because it's an area of pain for me. Anal sex is supposed to be really uncomfortable as it is, but with PVD on top of that, I don't really want to try and my partner resents me for that. He's been on the verge of just walking away and breaking up with me multiple times because of this. His resentment has been going on for a while. When I was still part of COMFORT, we saw a couple of therapists that told him he was being emotionally abusive to me. He agreed and said he was fed up because of PVD: "how would you feel if you were with a partner that couldn't have sex?" It's still always hanging over us. Just two months ago he said that if something doesn't change, he's either leaving me or will cheat on me and he was getting into a new exercise regime and losing weight in the effort to attract somebody else. That made me feel really rotten. He told me it was too horrible to accept the prospect that at 53 he was never having sex again for the rest of his life. He attributes most of the problems in our relationship to this lack of penetrable sex. He says I should understand why he feels the way he does and its importance to him should be enough for me to try more. He doesn't think I do anything to try to change the situation. I did give up in a sense. Why put all the effort into something that's not going to change? It feels hopeless.

When I was in the study group other women described how supportive their partners were and I broke down crying and had to leave the room because mine wasn't. Mine was not just

unsupportive but verbally aggressive, yet I was more afraid of being on my own than of tolerating his abuse. My options now are either to choose to be by myself or take it. I'm at the end of my rope and tired of him making me feel like the bad guy. I'd rather be alone for the rest of my life than deal with being treated like his roommate or his enemy in my own house. Home is supposed to be your soft place to land but very often it's where I feel the most strife and anxiety. When he's not there I don't feel his judgment or feel inadequate because of the pain. I'm on medication for really hardcore anxiety because I feel everything so deeply. My anxiety goes through the roof when my partner is being either indifferent to me or overreacting to small things which he attributes to his frustration with no sex life. But whether I stay with my partner or not, I'd still like to fix this for myself because I really used to love having sex. The loss I feel now that it's not part of my life isn't just because of the problems it has caused with my current partner but because sex was a great and important part of my life before PVD.

When the pain first started happening, I wondered if PVD was brought on by the fact that I wasn't that physically attracted to him, I was more attracted to his intelligence and his humor. It's never been one of those things where I wanted to jump his bones. I can still look at somebody in the supermarket, or at the gym and have that little pitter patter- that part has not gone away. But as far as having a libido, or wanting sex, I don't at all. I'm just not interested. I know I'm not a viable partner to someone in the marketplace going forward anyway. I have to accept that I'll never be with someone again because no one wants to be with a woman who's sexually broken, they want someone intelligent, warm, loving, *and* a sexual being and attractive partner. I'm no longer marketable and can't go out and meet somebody and have a happy ever after when no one will want to be with me because I'm missing that key piece. Being a girlfriend or a lover or a wife, even with my boyfriend right now, are no longer on my dance card. My choices in new

partners would be much more limited because this big part of me isn't functioning. It's like a disability. There was an exercise we did in the group about whether our whole persona is defined by being a sexual being or if we are more than just a sex object. I can recognize that I'm a good person, a really good friend, funny, smart and kind. I am a good fur baby Mama and I'm a good cook and I'm a really good daughter to my dad. I feel like I'm also a really good partner to my boyfriend besides the sex part of it. I have a lot of other roles in my life and I know I shouldn't be completely defined by the fact that I'm broken in the sex department. Feeling you're letting your partner down in that way affects your self-worth even if that's not what self-worth should be defined by. But I feel like *I am* defined by this when it comes to finding a new partner because I *still* feel like a new partner will not want to be with me because of that. A new partner doesn't want to be my friend or my doggy baby or my Dad or my brother. A partner isn't looking for a good aunty. A partner wants somebody who can have an active, healthy sex life.

I think it's innate that a man wouldn't want to be with a woman who can't have sex. I think all men think sex doesn't count without penetration although saying it out loud makes me wonder if that's really true. I've been so indoctrinated by my boyfriend saying to me for so long that it's what all guys want and that it's just how it is. I don't think he could know 100% of what 100% of men want and need. He doesn't even have a lot of male friends, so he doesn't know how any male brain is other than his own. He doesn't talk to other guys about sex or anything else. This is why I think CBT is one of the best things on the planet, it's so smart, because it really always brings me back to: how do I know this is true? Where's the proof, and what is the percentage likelihood it could be true? What are the alternate possibilities? Maybe there are people out there that are not focused on sexual intercourse as 'it' in a relationship.

It still feels really shameful to talk about it. I recently got back from a trip to Mexico and my friends were joking about how I wouldn't be getting any sleep that night when I got home to see my boyfriend. I laughed it off but I was thinking: "well that ain't going to happen". I wouldn't say that aloud because of the shame. It feels like something you can't talk about because you're afraid of being judged or looking like a weirdo or like less of a person or not whole and I already have those feelings about myself. To have other people feel the same way about me is even more tragic. I don't need any more judgment. But why is women's sexuality still a taboo subject where people can't even discuss it except when it's used on TV commercials for things for men? How often do you hear about erectile dysfunction and Viagra? If there were men having this issue, they would have been looking at it a lot sooner than now and would have spent millions of dollars finding a cure. I know I would have a lot of more options on how to fix it. But we won't even talk about sex for women. My three closest friends know I have this now because I *eventually* told them, but they can't really relate because they've never had it. It's a silent disease, an invisible disability. It's something that no one wants to admit to because there's such shame around it because it involves sex and because it makes you feel like you're a broken person. Isolation and shame go together. Being a part of those groups helped knowing I wasn't an island; other women had gone through this. It was a relief knowing I'm not a weirdo, that I didn't bring this on myself, I didn't wish for this to happen and it wasn't me deliberately rejecting my partner. Having other women in the room who shared this specific experience but came from all different backgrounds helped me not feel so sorry for myself anymore because it wasn't just me and sometimes it was worse for other women. It might be good to have some kind of ongoing support group.

I know the UBC clinic has a really good reputation and is on the leading edge in this kind of research. It would be great if you had a website that had an updated list of new resources or research that you recommend. If the whole idea is to help women with this as opposed to just study women with this then maybe in the future you could break down the COMFORT program into online modules or just have the parts that deal with physical aspects like the pain receptor diagrams. It could explain the CBT diamond and the relationship between thoughts and behaviors and PVD. Maybe one of the study doctors could do 10-minute videos walking you through some aspects of the course. If I had access to something like that, I could watch them and remind myself of what I've forgotten and get back on that track of trying to help myself. It might remind me to forgive myself for having this affliction. The website could also have a place for partners to get information. At some point I had got a pamphlet for partners through the pelvic physio clinic and there was a two-hour couple's group during the study and both helped my partner with understanding although it was so long ago it's fallen out of his head. You could have a page for them that shows how PVD works and explains that it's not in the woman's head or just an excuse to not have sex. It could point out things not to say or do, like offering sympathy or pity and how that makes the situation worse and what they can actually do to be supportive. I would love to see any kind of an online resource tool, even if it's just a rudimentary couple of pages of updated recommendations and a FAQ section answering questions about antidepressants or physiotherapy. A website like this could be helpful to medical practitioners too. I think PVD needs to be taught in medical school or doctors need a refresher on this. I remember showing the COMFORT binder to my doctor and her saying how she wished she had something like it for some of her patients. When I look online it seems like everything is in the US or England and it'd be nice to have resources here in Vancouver that were regularly updated.

They have online modules for people who have sexual difficulties because of cancer or for people dealing with social anxiety. If there are elements of the program that aren't proprietary, then have them available for the public. If it's true that 2 out of 10 women suffer from this at some point in their lives, then help a sister out.

If I could give other women with PVD any advice I would tell them the opposite of all the negative things that I think of or tell myself. I would say even if you don't have this part of your life working right now, you're not broken, you're still a valuable, worthy, wonderful, whole human being. It's easier to say those kinds of things to someone else than to myself. I'd probably also say to tackle it right now-don't wait, don't let it become a habit. Don't let your body develop those neuropathways where they become that superhighway. Deal with it now, while it's still a goat path. Keep at it until you find something that works and don't give up hope.

3.2.6 'Ashley'

When I first brought the pain up with my doctor, I had been experiencing it for a couple of years. She didn't know anything about it or really what to do about it, so she sent me to a gynecologist. The gynecologist told me it might be vaginismus, recommended dilators and then sent me to a LGBTQ friendly bookstore for information about that. I was really disappointed when they also didn't know or have anything and after that I just didn't bother too much with it. Nobody I saw knew about PVD or were aware of any real treatment for the pain I was experiencing. I remember thinking that this must just be how I am, and I was just going to suffer. It was especially hard because I was already dealing with a good amount of anxiety and self-esteem issues and those doctor's cluelessness really didn't help with that. Being told to have a glass of wine to make it right was never ever, ever going to work for me. I just felt broken at that point. Here is this thing that I should be able to do easily, and I should be able to enjoy like the

rest of the population, but I can't. I started wondering what was wrong with me- why I was so messed up? I had talked to a co-worker when she mentioned having some sort of pain issue during sex and I remember thinking, "thank God, it's not just me". But that was really the only person this had ever come up with; I had never heard of anybody else having issues. I wasn't really sure where else to go and didn't think there was anything that could help. I heard later this experience is a little bit too common for women with PVD but I hope it's more commonly known now.

I was connected to the COMFORT study through a visiting professor at my university who had given a talk about sexual health in my clinical psychology class. After spending so much time avoiding pain because I thought nothing could be done about it, I approached her after class in her office hours and she was super helpful getting me information and putting me in touch with the study team. Through my assessment appointment with the study doctor I finally got a PVD diagnosis and enrolled in an upcoming group. For the first time there was a light at the end of tunnel and the possibility there was something out there for what I was dealing with.

The group itself was fantastic. I really appreciated the CBT focus and learning how CBT works as a therapy. It really spoke to me in a way that I found very useful for changing my headspace and learning ways to deal with my generalized anxiety which I see now as a big part of the reason why I had an issue with PVD in the first place. I think CBT is a little bit more up my alley and probably worked better for me in the end than mindfulness would have. I have studied some meditation-based therapies since the group, but I like how CBT really digs into the reframing of thoughts which I need more. It was helpful for me to be able to challenge my thoughts and realize that just because you think something doesn't mean that it's true.

During the study we learned how many women experience pain during sex and it was really a relief to hear that I wasn't alone. It was really refreshing how even though everybody in the group was so different we could all talk about PVD and understand those experiences. Knowing that what was wrong with me was fixable opened the door for me to talk about it with my friends and partners. It wasn't an overnight fix learning about it, but it was a massive relief to hear that it wasn't something that I was necessarily going to suffer with for the rest of my life.

I don't recall anything specific about any group sessions. There were moments where some of the things the women said resonated with me, but it was more how it all came together as a whole. There was the getting to know your body exercises and the relaxation stuff and the thought exercises which all helped together. I'm curious what they did in the mindfulness group because I remember thinking it was a lot of mindfulness stuff. I remember doing the Body Scan which really helped me be more aware of what was going on with my body in the moment and noticing different sensations I wouldn't notice before. I had no idea how much I was tensing up down there or that I was actually tense down there most of the time. The breathing exercises helped me realize I could breathe into it. I was just telling my boyfriend last night about the exercise where you touched your vulva step-by-step, in different areas, to see where it actually hurts and doesn't hurt. I learned to kind of assess what the pain actually feels like and where it was instead of just freaking out about any contact because I thought it was all going to hurt. I remember the progression of first using my finger and then having a partner use a finger and then working your way up to intercourse. When I progressed through those steps with my current boyfriend, I was definitely more aware of what hurt and exactly how much and where. I could notice that it didn't hurt as much as I thought it was going to and realize it wasn't as bad as I had catastrophized it to be! I could see there were spots I knew weren't going to be super painful and

so it wasn't as painful overall as I had expected. I also remember doing the drawing exercise where you took a mirror and you drew your ladybits. I don't think I'd ever actually really looked down there before, especially not like that. I don't know if the drawing on its own was super helpful, but I wasn't very aware of myself in that way and along with the other activities it was really helpful in my becoming more comfortable with my sexuality.

I went through an absolutely brutal breakup partway through COMFORT which put a bit of a hiccup in my progress. I had avoided being intimate with him because of the pain and he got pretty frustrated. I dealt with a lot of pressure in that relationship through *a lot* of guilt tripping and it spiralled out of control to the point I did not want to have sex at all. He was controlling in a lot of ways and I found out he was also looking for sex elsewhere before we broke up. I didn't blame myself for his issues, but I fell off the bandwagon as far as homework and practice goes. But I found the group of women really supportive and later I was able to get back to the things that I learned. Even after that hiccup during group I kept going because I believed it would likely help me in the future even though I didn't feel it at the time. I knew I wasn't going to be alone for the rest of my life, that somebody else would eventually come along, and I wanted to learn this to be ready for that. There is also a part of me that doesn't like quitting things and because I was involved in psychology in university, I understood how much use you can be to a study, especially being part of such a small group, and I still wanted help from the study too.

After that big, bad break up I kind of just gave up for a while. I tried dating someone else after the group and he was super sweet and really patient and understanding but there wasn't a lot of chemistry for me and without that I just didn't have the motivation. I haven't dated a lot of people, but so far, I've had more good experiences telling them about PVD since the group than I expected to. Now being a little bit older and caring less about some things and meeting someone

where there just isn't that pressure, I've been able to let go a little bit. I met my current boyfriend almost four months ago now and because it's long-distance there was about three weeks in between when we first met and when we got to really hang out again. So, I had time to revisit the workbook and the practices that we'd done in the class. Because of that, I was able to talk to him about PVD right from the start. I wasn't sure what we were going to be able to do and he was very understanding and patient with that. At first, we didn't really try much, but I found that when I applied what I learned and went slowly that there wasn't much of an issue, which I was really excited about. I don't remember relationships being something that was directly addressed in COMFORT, but it always seemed to come up in conversation, and became a part of the group that way. The relationship part is pretty integral for me. Going through all of that stuff and having a supportive partner versus not having a supportive partner was night and day for progress in this. I feel like progress for PVD is generally going to be fairly slow and you have to have somebody who's patient and understanding and willing to work with you through it.

Because of how being a part of that group really helped me reframe things and look at them differently, I followed it up with a DBT group close to home so I could continue to practice those skills. I later found dialogical thinking exercises beneficial because I learned to name my emotions and identify when I was feeling them. I saw some similarities between the groups but it more just cemented things and helped to solidify those skills with more practice. CBT and DBT, together really helped me look at things objectively. I sometimes still have a hard time with that but I can catch myself now.

It might be helpful to have a follow-up group to refresh those skills, but I think actually doing it out in the real world is what helped for me. For a while I really didn't practice because I had other stuff going on, but I could always go back to the workbook and look at what I'd done

and what we discussed and that helped. I don't know if I would have been able to keep up with more meetings because it was a long drive to get to COMFORT, especially during the work week but it also wouldn't be the same just having the workbook the first time you're learning. Having somebody walk you through while being in a group of people who have the same sort of thing going on and was so beneficial. It could be useful to have something online, so you don't have to take time off work or class. It would also help if the group was more widespread and there were meetings outside of Vancouver. I hope that other women with PVD know that these groups are available to them for help when they are ready because it was so helpful to me. I would want them to know they are not alone and there are people who know what they are going through and how bad it sucks. COMFORT was just really helpful: the information that I was given in the groups, the exercises we worked through, gaining that better understanding of your body, and of course being surrounded by a group of women that had the same sort of issue too. I'd probably also recommend including DBT because it did help me with a lot of underlying issues that were affecting my sex life.

It would definitely help if doctors knew what PVD was. I understand that GPs have a million things that they have to know, and that they can't know it all. Maybe I need to be a little bit more involved in the world of doctors to understand exactly how best to communicate with them. The group really helped me be less shy talking about stuff like this, but I never really saw PVD as a thing to be ashamed of and I didn't have any problem going to my doctor about it initially. I think there's still a lot of stigma out there about women's sexual health in general, so I can definitely see that impacting how information gets out. Society still doesn't think it's important for women to be enjoying sex which causes harm in a lot of other areas too. I never got the message from my parents that sex was shameful or that you shouldn't talk about it. I've never

really had a lot of issues with shame around sex when talking with my friends about it either. It wasn't until somebody framed it that certain way that I was able to identify shame and stigma around sex or see it happening. Maybe shame is more this underlying thing and you don't think about what you don't do because of it. I don't see it as something I deal with directly. No one told me exactly how I should be, except maybe with shitty partners. It's more indirect. Like how sex is portrayed in the movies and on TV and stuff like that.

I have definitely noticed a change after participating in COMFORT. There's usually still a little bit of a pain with penetration initially and a little bit of difficulty when we get going, but it's gone very, very quickly. If we go for round two, it's like there wasn't any pain in the first place. It's so complicated to know what it was that changed exactly, because it has just been so many things that have all kind of accumulated together. I needed all of those pieces -supportive relationship, skills, and practice – working together. I don't think there's a formula; I think that's different for everybody. It does take a lot of patience, keeping your expectations reasonable and giving yourself time to work through things. I think time is very, very important. I don't think it will be a problem for me again because I won't let it get to that point. I'm still working through some hurdles but it's nothing like it used to be and it's constantly getting better. I had never orgasmed through intercourse before my current relationship. I couldn't have imagined that being a possibility before so that's been fantastic. Before, I would have been a lot more afraid to expand on the sexual activities I engaged in but I'm a lot more open now to trying new things. I'm definitely a lot more open now and less afraid, in general.

3.2.7 'Any'

I first started having pap tests when I was 18 — when I was in my first sexual relationship. They always made me cry because they were so painful, but being young and really

not knowing any better, I thought perhaps they made everyone cry. It was always horrible: My doctor would just tell me to relax and never tried to dig deeper or question why I was in so much pain during those exams. She would just tell me my pap tests were “normal” and leave it at that.

During my late teens and early twenties, in any relationship I was in, I noticed that sex wasn’t much of an issue. But I think it was probably because the relationships were much shorter in length. Whoever I was with just had to go slow in the beginning, and it would then be fine once we got going. That being said, I still wouldn’t be able to have sex for a week afterwards because I’d be so sore.

With my current partner, sex was great in the beginning. But six months in, it started getting more and more painful until there was always pain with sex. I also started to notice that I would spot after sex. Concerned with this new symptom, I scheduled an appointment with my doctor. I ended up having an abnormal pap test, which was followed by a colposcopy a month later, and then a LEEP (Loop Electrosurgical Excision Procedure) a month after that.

This was a really stressful time in our relationship. I had already spent almost 15 years of my life thinking painful sex was something that every woman dealt with, but now I had it in my mind that any time I had sex, I was damaging myself internally somehow — even after every test was clear.

About a year after the LEEP (and all the follow ups), I went to a walk-in clinic for something entirely unrelated but happened to mention my issues with sex. That doctor was the one who told me about the COMFORT groups. I had never done anything like group therapy before, but it was a huge relief to learn not only that the pain I was experiencing was abnormal, but that there was actually something I could do about it.

Before COMFORT, I had thought PVD (Provoked Vestibulodynia) was strictly physical. Learning that PVD was mostly mental and that I had to attack this from a different perspective was a pretty big hurdle for me to get over. I have a bachelor's degree in psychology, and I highly praise seeing counsellors, psychologists, and psychiatrists, but I had never been to one myself.

Unfortunately, the group aspect wasn't helpful for me in the sense that I felt shy speaking up about certain things in front of people. We had one-on-ones with a doctor, but those appointments dealt with the physical symptoms (rather than the mental ones). I think it would have been more helpful to have individual appointments with the actual psychiatrists or psychologists who were teaching us the skills. Although my shyness kept me from speaking up, I still valued the environment of the group — everyone was really supportive and I appreciated the fact that there was a huge range of ages and backgrounds. It was also reassuring to actually see and be with other women who are dealing with the exact same thing (or in some cases, much worse), and to know that I wasn't alone.

Outside the group, I struggled quite a bit with mindfulness practice. I'm a yoga instructor and understand the benefits of mindfulness, but I don't always practice what I preach. I see the value of being in the moment, slowing down, and not fretting about anything, and I know it's something I should work on, but it was a challenge, nonetheless. In other contexts, I was much better at calming myself and shutting my mind off, but as soon as I was in a sexual situation, it just didn't work, I couldn't do it. I just kept thinking: "This pain is terrible," "My boyfriend isn't enjoying this because he can't do anything," and "Why can't I just be normal?!" I struggled to flush those thoughts out, but I just couldn't shut them off. I knew I shouldn't be focusing on health stuff and that I should just be breathing, but I couldn't activate it or action it.

Maybe I was just bad at practicing something over and over again when it was something I didn't like to do (obviously, because of the pain in this situation). Friends used to tell me that I'd learn to like red wine, but why would I want to keep drinking something that tastes awful?! I didn't want to practice mindfulness during sex because sex hurt, and my partner and I would both just get frustrated. I'd be frustrated with the pain, and he'd be frustrated because he had to go really slow and he was always worried about hurting me. Any attempts at penetration would hurt, and even though I would try hard to focus in on other sensations, it never worked. So, mindfulness practice was difficult to say the least.

We also had pain journaling homework through COMFORT; this focused on getting our emotions out as opposed to trying to make them better. But the pain journal didn't make sense to me. I understood the point of the homework was to focus on a different pain from the day — to recognize it, to feel it, and notice it pass — and then make that same association with PVD pain, but it just didn't connect with me. If my knee is bothering me, I don't start thinking ridiculous things like, "Oh, that's new. I should go see a doctor because I've probably broken my kneecap." Likewise, if I start to get a headache (a frequent type of pain I am constantly living with), I don't think I'm dying. I take some drugs and forget about it. But I can't do that with PVD pain. For me, even though I was in the clear after the LEEP and all of the follow ups, I still had it in my mind that spotting (after sex) must mean "I'm hurting myself." I recognized the pain, but then I didn't have the ability to feel it and let it pass, it seemed to make it worse.

Although I didn't initially connect with COMFORT, I was hoping that I would eventually. I finished the program (even though it didn't seem to be helping) because I don't like leaving things unfinished (and I also know from my psychology background how hard it is to keep participants). I did appreciate the information in the education piece and the way everything

was visually presented, but the overall sense I got was that some things were glossed over and, in the end, it felt like we were left to our own devices. During one of our group sessions, I had asked if we were going to get support afterwards and the answer was that the research group was over, but I could speak to the clinic doctor if I wanted. Unfortunately, I associated that doctor with the physical aspects and I had more issues with the mental aspects, so I didn't reach out to her. In the end it left me thinking: "Well, what can I do from here?"

I sought more psychological help after the COMFORT study ended, once I realized I needed that. My Q-Tip test had improved significantly by the end of the group, but it hadn't improved with my partner — that is, I still experienced pain. Even though I kind of got better physically, that mental stuff was still there. My partner and I had been struggling throughout that entire time, but it took me a couple more years to get to a place where I could admit I needed more help. I realized that I couldn't do things by myself because I kept trying what we learned in COMFORT, but it just wasn't helping.

My partner and I saw a sex therapist who said we were relatively okay as a couple, and that I should probably look after this issue on my own. Then my partner told me he couldn't do it anymore, and that he was giving it until the end of the year to see if things changed. I know he was just trying to be honest with me, but that was one of the hardest things I've ever been through. Was he saying we had to have pain-free sex or he's gone? I was also changing birth control pills at the time, so my hormones were a little crazy and I was so much more sensitive; it was horrible. And things just kept getting worse and worse. I decided I just had to deal with this shit and get it over and done with by actually working through this stuff and figuring it out. I saw a health consultant and ended up seeing a bunch of counsellors, trying to get someone who fit, until I found the counsellor I'm working with now, whom I love!

I remember a discussion we had during the COMFORT study about how sex (intercourse) was not the be all, end all. I really struggled with this because sex is the best way I personally share my love in an intimate way, and I still can't get my head around sharing it any other way. All the other things are lovely and nice, yes, but sex is really important to me. When my partner and I had conversations about this idea (that is, sex is not the be all, end all), he agreed with me. Sensate focus (which is an exercise that is supposed to help with enjoying all other aspects of sex — so everything *before* intercourse) was also totally lost on us; we just gave up on it. No one else in the group seemed to be having issues understanding it so I didn't say anything.

My partner and I revisited this with my counsellor and it had clicked in a way that was much more helpful — it was like a light went on. She suggested taking sex totally off the table while we worked through sensate focus and that made a big difference. We also decided to drop the end-of-year ultimatum because of how much it was stressing us both out, and as soon as we made these decisions together, a weight lifted off of me. It was a huge relief.

We took a step back and started at the beginning, just going on dates. We took turns focusing on one person at a time: One date, we'd do something I wanted to do; the next date, we'd do something my partner wanted to do. I think that piece was really important because the focus is on having that person enjoy themselves completely. In COMFORT, I had wondered what you could do besides massages, and I didn't see the point in just petting my partner. But the touching stages made so much more sense when my counsellor explained it to us both. She also offered suggestions like drawing each other a bath or giving each other facials. Learning that sensate focus was just about sensations and listening to what your partner wanted made “sexy

touch” dates so much easier to do. Obviously, my partner wasn't super pleased shelving sex, but we worked on it regardless. It went well, even though it felt it wasn't working fast enough for us.

My counsellor also recommended a physiotherapist who just focuses on pelvic floor issues. With the physiotherapist, we worked with biofeedback — you can literally see what's going on down there! I could see myself relaxing while I was actually relaxing, which was super, super helpful. We also did some exercises with me touching the vulvar vestibule, and I practiced clenching and releasing, which helped more than when it was suggested in COMFORT. The physiotherapist also taught me how to use dilators properly — turns out I had been using them wrong the whole time I had them! I'm still working on all of it and, when I keep up with my physio exercises, I do notice a difference. It hasn't improved drastically, and it still hasn't helped 100% in the penetration department. I should be doing them more, but life sometimes gets in the way.

I know the group was about learning mindfulness, but it would have been helpful to talk about how PVD might impact our relationships. I understand that the focus was on us because we are the ones with the pain, but it takes two to tango! I think that the relationship part and that key piece of how to talk about PVD was missing. The cards that have been dealt to me unfortunately affect my partner in so many ways; it's still affecting him. I think it was really hard on him once the pain got in the way because he thought that, suddenly, I didn't love him anymore.

We've been together almost seven years now, and we've been dealing with this for six and a half of those years. I could go on and on about how good he's been throughout this entire process; he's been a champion. But I know this has been a huge struggle for him too. It would have been so helpful to have had some discussion about how to communicate through that

relationship stress. I don't know that a full couple group would be necessary, but I think incorporating couples' issues or having a separate couples' appointment with a professional who knows about PVD would be helpful.

It made so much sense when the COMFORT doctor explained why the pain seemed to be so much more of an issue with my present partner than with previous partners — because those relationships had all been short-term. When our relationship extended beyond six months, all of that adrenalin and all that happy, new relationship stuff started to die down, and the pain started to take over. It was so helpful to understand that. But when I went home and tried explaining it to my partner, I don't know that I was explaining it correctly. I joined COMFORT to benefit my relationship — it wasn't strictly for me, nor was it strictly for my partner. Having couples counselling sessions where someone is there for the relationship would have been a great option during the group sessions. At the very least, it would have been super helpful to have a couple's education session with the same knowledge that we got with the facilitators (drawing on the boards and answering questions).

It's huge that 15% of women have sexual pain at some point in their lives, and yet it's *never* talked about. I think society is somewhat to blame because that's where these ideas and stereotypes (that sex is the most important thing, that sex should be wonderful, that sex should be easy, and so on and so forth) come from. So then when it's not (important/wonderful/easy), or when it's the exact opposite of all of those things, you feel like something is really wrong with you. Of course, I can't speak for other women, but I know I felt a lot of shame because of that. I don't really want to admit this “brokenness,” and I still struggle quite a bit with that. I've been told over and over again that nothing is broken or wrong. Maybe it's not, but *I* do not feel normal. It isn't fair that my partner and I (especially my partner) have to deal with this, when

most people don't have to. The shame piece is definitely directed towards not being able to give my partner what he could easily get in other relationships. It's just another thing that needs to be worked on. But I wish it wasn't there; it would just be so nice to have sex without pain, like the majority of other women.

I hate to bring sexism into it, but I swear, if men were having painful sex, the situation would absolutely be different, and there would be so much more research and awareness on the topic. Though, I don't want to hate on men too much, because they have their own stereotypes to deal with (they should be able to go on forever, they should be able to get it up right away, etc.). It's not even really talked about in psychology. I took a human sexuality class my last semester in university and pain was never mentioned. Sex education classes should include all of this information (along with the good stuff). It really should start from the beginning and start early. Hopefully, these ideas and stereotypes will change once word gets out there that this shit exists.

I get really emotional talking about this stuff, though I truly am an emotional person. I often joke that I'm like Kristin Bell, where if I'm between a 3 and a 7 (out of 10), then I'm fine. But anything below or above that, I'm crying. But, really, it also just sucks having PVD because I've been dealing with this for 15 years; it's really frustrating. Even just talking about it now and going through it all over again in depth and getting into the specifics still feels raw.

The fact that I actually went out and got individual help for this was a big step for me. It's helped things get better, and now my partner and I both have confidence that we can do this. Though it's still stressful because penetration is still a challenge (and painful). I have to remind him that I will probably always be dealing with this. But at least now we have strategies, and I know where I can ask for help. I want to get married, but he's still concerned about the sex stuff.

So, I still feel that pressure but so much less so than before. I'm optimistic that it's all going to work this time...it feels good to believe that.

I've thought about writing a book about my experiences to reach other women with PVD, so that women know this happens (and how hard it is to deal with). I would title it, "I Shoulda Been a Nun"; and it would be an autobiography explaining PVD and the shit I've been through because of it. I would want to tell women with PVD what to do, what to read, and where to go for help. Until then, what I would tell women diagnosed with PVD is that they should try everything. I'd let them know that even if it feels like it's not getting better, it probably *is* improving (just very slowly). I'd tell them to keep on pushing through it, one baby step at a time.

For me, one-on-one counselling and physiotherapy really helped. I'm back in yoga, and I'm taking dance workshops that specifically focus on slowing down, which I think is a really big piece. My partner and I eventually made it through sensate focus, and things did get a little bit better. But I know, if things get worse, I can return to my counsellor and my physiotherapist, and just keep on going — one baby step at a time. I'm still hopeful things will get better.

3.2.8 'Jenny'

When you look around sex is everywhere, and it seems like it's always so easy for everyone else. My husband is a quadriplegic, so with his mobility challenges and *my* problem with pain on top of that, all the stars must line up *exactly* for us to be able to have sex. Sex didn't hurt early in our marriage, but it slowly grew overtime to the point that I would be crying anytime we tried. I wasn't crying necessarily because of the physical pain, but because it was so emotionally painful that we couldn't engage in healthy sexual relations like everyone else. Sometimes I would feel like, "Why us?! Why do we have to deal with this on top of my husband's disability?". It was an embarrassing secret I kept because everyone assumes *that* part

of your body should just work and I knew I'd be judged because mine didn't. I didn't feel proud as a woman in the sexual component of my life, but a lot of anger, grief, and *shame* about it. When I finally went to see my doctor about the pain, I had this sense of being a failure as a woman, of really feeling less-than, because it seemed like I was the only one who had this problem.

I have been blessed to have had a good relationship with the same doctor since I was 15 years old. It would have been extremely hard disclosing to a doctor what I was going through, if I disclosed at all, if they hadn't been as supportive. She already knew that I struggled with painful pap exams when I approached her about my difficulties with intercourse. But when she diagnosed me with dyspareunia, I was really discouraged to hear from her there was nothing we could do to fix it. My husband was always *very* supportive and comforting when we attempted intercourse, saying we didn't have to do it at all but I always wanted to give it a try. So, I spent a lot of time after that diagnosis investigating how to fix dyspareunia on Google. I found dilators on the internet that gradually increase in size so you could learn to relax enough to eventually take a penis comfortably. I even considered trying things that made me extremely uncomfortable like intravaginal massage or seeing a female therapist who advertised how she could arouse your sexuality with intimate touch using feathers or other materials. As a Christian, sex is something so sacred to me. It is designed by God to bond two people together in an act of love. I went through more turmoil and anguish just considering engaging in these 'therapies', anticipating the additional shame I would feel doing something that seemed like having sex with someone besides my husband. I was so desperate to find any help to fix myself, but the idea of trying these things didn't sit well with me spiritually, so in the end I decided against it. I was feeling completely hopeless until my doctor received information about COMFORT and referred me to

the study. The first time I heard of Provoked Vestibulodynia and my first introduction to any kind of legitimate treatment was when I was diagnosed through COMFORT. I felt nervous going into the group, but also hopeful that it could help me.

My experience with the program was good from the beginning. The gentleness, kindness and discretion that everybody showed, from the receptionist to the study coordinator and doctors, really promoted safety. The study coordinator communicated with participants in a way that I never felt different or odd for having PVD. Although I was very nervous and tense during the q-tip examinations, the doctor was so gentle and reassuring and took her time communicating everything that she was doing step by step. Having the mirror during exams was a sometimes good, sometimes bad experience depending on how I was feeling, but it did help me to learn a lot about how sensitive my nerve endings were and where it was most sensitive. I also appreciated how the doctors promoted trust and safety on the first day of the group by facilitating our shared agreement to be respectful of each other's emotions, reactions and stories and by emphasizing confidentiality. They were so good at explaining how PVD worked in a way that was easy to understand which made me feel really confident in their expertise. Having that knowledge and the science behind it was revolutionary for me. It was such a relief learning there's a known physical component to the pain- that it wasn't all just in my head. Understanding why I perceived sensation more intensely normalized that experience. It was validation that I'm not incompetent in the bedroom, I just have this condition.

Participating in the group had an impact beyond what I would have gotten from just reading about how PVD worked. For one, just being part of a research study was validating because it meant experts had identified PVD as a legitimate problem. The fact they were researching how to help all these women said our experience was important. Another benefit of

participating in the group was having the opportunity to have our questions answered by these experts. Learning there were other women like me, physically seeing them and hearing their stories, and getting support and understanding from women in the same boat, was also important. Before I had kept this thing that was ‘wrong’ with me a secret because I was afraid of being judged by others. I was dealing with this terrible shame, frustration and guilt for not being able to perform as a woman and a wife, all alone. But, here we were in community, sharing this problem together. We could talk honestly about how PVD affected us, the shame we felt, how our partners were responding to it and things we had tried to make it better that have or haven’t worked. More than learning practical tips though, it was *being* with women like me and feeling safe openly sharing experiences we hadn’t felt we could reveal before, maybe even to ourselves, and being vulnerable in that way, that was so powerful for acceptance and understanding. By accepting each other, we learned how to accept ourselves, so that even that belief that you’re broken begins to change.

I experienced a lot of mixed feelings as the group progressed. Seeing all these other women with the same problem I had did make me feel less odd, but it also made me sad to know so many other women were suffering like I was. I felt even more grateful for how understanding my husband had been, but it was extremely painful to hear stories about spouses not being supportive, understanding or encouraging of women in the group. I purposely held back details about how wonderful my husband was through this because I didn’t feel it would benefit the women whose partners were not supportive at all. Some talked about how their partners made them feel diminished because of their inability to engage in intercourse or were seeking sex elsewhere. It made me think about whether I would even consider trying to find somebody else if my husband were to pass away while I’m still young. I think PVD would be a huge factor with a

more able-bodied male and I don't want anybody to make me experience all those feelings of being less-than that I felt before. I used to feel so ashamed and ugly before my husband because he had gotten a broken wife. My husband never felt that way about me and thankfully I don't feel that way anymore.

I might have it easier in my relationship because my husband's disability means he understands what it's like to live with physical limitations. I think it could be helpful to involve men in at least an education session, because otherwise we might be the only knowledge connection between them and our condition. Partners learning about PVD and its impact on relationships from an expert could lead to more understanding and choice about what *they* can do. We can only act on or react to situations in life based on our previous experience and knowledge and these men wouldn't know anything about the illness, just as we didn't. Having a supportive and understanding partner who doesn't shame you or put you down for not being able to have intercourse but adapts intimacy in a way that works for *both* partners contributes to the betterment of the person with PVD and their relationship. It might be a source of embarrassment to acknowledge in front of other men that something so intimate in their marriage is *not working*, so I don't know how many would show up. Maybe they feel the problem reflects negatively on *them*, or they think it's just about rejection or maybe it's just her problem to fix. But if they could just lower that pride a little bit and get involved, learning about this together could be about growing together while trying to make the best out of a situation that impacts their partnership so much.

Learning new skills takes a lot self-discipline and because I personally find change hard, I wasn't sure if developing a mindfulness practice was something I could really *do*, but I was willing to try. I found some of the practices easier than others. During COMFORT, my husband

and I worked together to apply the mindfulness techniques I was learning, but we've only seldomly attempted sexual intercourse since the study. I thought using a mindfulness approach made sense because I believe in the power of our minds to impact our physical experience in helpful or harmful ways and so much of sex is in your mind. I found I could be intentional and observe my sensations while doing a neutral or familiar activity like eating or exercising and I did learn to just pause and be present in my daily activities. I found it far more challenging trying to stay present during intercourse so I could learn to let the pain pass. I was always hesitant at the point of penetration, anticipating how much it was going to hurt. Mindfully attending to physical sensations, already heightened because of sensitized nerve endings, just intensified them for me. It was like how images on a newer TV seem so much more vivid than on older ones- like experiencing the pain in HD. I appreciate that the course taught me the basics of mindfulness, and if I choose to do it for a particular purpose, then I can do it. I still have the study binder so I can revisit it one day, but I haven't made a conscious effort to continue *practice*. I use the principles of mindfulness when I practice deep breathing or progressive muscle relaxation to control arthritis pain, so it has been a helpful foundation for other things.

I believe it's possible the pain could eventually improve if we continued practicing mindfulness during intercourse, but my husband doesn't want to cause me pain and I don't want to have pain either, so we are intimate in other ways. We enjoy non-penetrative sex, more like foreplay, which is physically satisfying and where we both feel connected, loved, and cared for. Everywhere else in our life together we live by the principle that we do what we can do, and we don't do what we cannot do. Learning sexual intimacy isn't solely intercourse and incorporating that principle into our bedroom means we are free to adapt our sexual activity to our conditions, and both enjoy what we can do. We always have touch- hugging, kissing, holding hands or lying

in each other's arms when we're watching TV. We've all been programmed to think that sex without penetration doesn't count or won't be satisfying to people. Maybe that focus on intercourse comes from the natural connection between penetration and how kids are made where humans follow the same patterns we see in the animal kingdom. If you fall out of that pattern you are different and difference in our society has a negative connotation. We all watch the same movies where sex is portrayed as easy and nobody worries about protection or getting pregnant and they all have the best orgasms ever and then life just carries on. The reality is more complicated for a lot of people and the truth is sex isn't always stars and fireworks for everyone, able-bodied or not, all the time. This idea that all humans want to and can engage in sexual activity just isn't true for everyone. Defining sex by penetration can be harmful for people that desire intimacy but are limited in the kinds of sexual activities they can engage in by making them feel like a personal failure. Having more discussion about how experiencing pleasurable sexual sensations or emotional closeness doesn't depend on intercourse could be revolutionary for some like it was for me. We are grateful that all other areas of our marriage are really good, and we are happy. So, if we are happy the way we are then it's working; nothing is broken.

I think it's hard in general for people that are healthy to understand the challenges of people with physical limitations. This is especially true with when it's something you can't see and nobody talks about, like sex. Because my husband's disability is visible, people are sometimes openly curious about how we have sex. With his permission, I answer their questions because I think it's important to understand that people with disabilities don't just forget about sex. PVD is not a disability that you can *see*, it's a difficulty experienced in private. I don't have a visible injury or adapted device or obvious behaviour that shows something is wrong. Someone who doesn't have it won't be able to understand how it impacts me. I avoid sex not just because

of the physical pain it provokes, but also because of the mental anguish and emotional distress that comes with it. If somebody knows that I physically can't enjoy intercourse, they'll just think it's weird. If you were to suddenly lose your ability to use your arm, people won't question it in the same way. Another part of the problem is that women in our society are sexualized more than men and *are still seen as sexual objects*. I think it's an especially male perception that there cannot *really* be anything wrong with a vagina that prevents penetration- that every woman should be able to perform this 'natural' body function of sexual intercourse because it is supposed to be *the* basic and normal function of a vagina. When it isn't working you fear being judged 'faulty' and carry around a shameful secret about being a failure as a woman. That invisibility can lead to a woman not being believed, or even worse, laughed at or thought of as crazy.

As a nurse in an emergency ward I often chaperone gynecological exams. I used to sweat profusely and felt so sick just anticipating women's discomfort that I was sometimes asked by the attending doctor if *I* was ok. I just don't want any woman to suffer like I have, and I would like to see more education in healthcare settings about conditions like PVD so my colleagues would be better trained to take care of women in that situation. I remember once trying to explain to a doctor I was working with why a woman waiting for a pelvic exam might be nervous about it. I told him what provoked vestibulodynia was and that it was being studied at UBC. He seemed surprised and even laughed in disbelief. He just brushed me off saying 'Oh, tell her the exam's a piece of cake'. He completely dismissed me. If healthcare providers don't know PVD even exists, they aren't thinking about how much more painful or traumatic a pelvic exam could be for that person. In nursing school when we go through the reproductive system, you learn about infectious disease, endometriosis or fibroids, pregnancy and miscarriage, but nothing really

related to sexual disorders. It's still taboo to talk about when sex isn't working for women.

Although I have been able to talk about sex in relation to my husband's disability, I am guilty of not sharing my own experience with PVD, even now. I don't want somebody joking if I'm in a bad mood one day that it's because I can't 'get laid'. I can imagine organizing an in-service, but I don't want to have to share my own experience and I would have to think of things to say when people wondered why I was doing it. It's so important and yet on a personal level it is so difficult because I really don't want to be the example. I guess that is me still struggling with some of the shame.

Overall, the COMFORT program helped change my self-perception as a sexual failure, a faulty woman or a broken wife because I can't have intercourse without pain. I believe now that my womanhood isn't defined by my sexual ability and PVD is not all of who I am. The information and explanation the program provided about the nervous system and hyper nerve endings just *made sense*. It gave me a new understanding that allowed me to accept my vagina as it is, today. Now I just see PVD as another one of my diagnoses, like my migraines or my rheumatoid arthritis. I don't think about getting fixed anymore because my husband and I are happy the way we are, so there is nothing to fix. We both feel satisfied with the amount of sexual contact that we have and our relationship is about a lot more than intercourse. Sex is not a higher priority than emotional connection, loving actions and serving one another for us. Those are the things that keep us connected. Able-bodied or not, we all end up old and wrinkly and the thing that keeps a marriage alive are friendship, love, laughter, respect, grace and forgiveness. I appreciate having this follow-up now to reflect on how much the program helped me find peace and acceptance and I hope it helps other women as much as it helped me. I am so glad that I am able to contribute to these stories that you're gathering, because it gave me an opportunity to

express how grateful I am that I was a participant and how it really changed my perception of myself in terms of my sexuality.

3.3 Thematic Analysis

Each narrative account followed roughly similar patterns, beginning with what led the women interviewed to the COMFORT program, then what they recalled about their experience participating (including what they found helpful, challenges they had participating and program critiques) and closing with a description of how they are functioning now and recommendations for future programs. Throughout their narratives they often also refer to how shared cultural discourses in relation to sex and women's bodies have contributed to their difficulties and these comments are included in a final theme. This loose temporal organization provides the scaffolding for the emergence of 4 umbrella themes across 8 narratives: Theme 1) 'What Led Me to COMFORT' which includes subthemes: 'Looking for answers' and the 'Pain of PVD in my life'; Theme 2) 'How COMFORT Helped Me' which includes: 'Skills I learned', 'Reconnecting' and 'Redefining the Cure'; Theme 3) Program Critique and Recommendations, with subthemes: 'Explicitly address practice/participation challenges', 'Involve partners and discuss relationships', 'Provide ongoing follow-up/support' and 'Democratize access to knowledge, education and treatment resources, and finally Theme 4) 'Role of Social Discourse in Defining and Prescribing Women's Bodies and Sexuality', including subthemes: 'Shame: Signifier for Violation of Gender norms', 'Resists: Dominant Discourses of Female Sexuality- Feminine Objects/Masculine Subjects' and 'Persists: Dominant Discourses of Male Sexuality-The Coital Imperative.'

3.3.1 ‘What Led Me to COMFORT’

No participant began storying her journey in response to the research question (“Tell me a story about your participation in the COMFORT study and your journey with PVD since”), with her first memory of contact with the program. All begin by describing a painful journey looking for answers and their attempts to find a ‘solution’ for their pain, which often led to many, usually unhelpful, encounters with healthcare providers. After looking for answers and finding none, women describe how PVD pain disrupted their intimate relationships and then began to permeate their lives. They describe beginning to believe their inability to have pain-free intercourse meant something more ominous about their physical or mental health or, even, reflected a fundamental defectiveness in their womanhood and/or a sign of their singular otherness.

3.3.1.1 Looking for answers (“go drink some warm milk”)

All participants describe previous experiences with healthcare practitioners while looking for a medical explanation and solution for their pain. Most women recount frustrating previous encounters with MDs whom they felt had been dismissive of their pain and distress and had little to offer in the way of meaningful help. Christine and Jenny suggest their own positive experiences with their family doctors were not common when they make a point of highlighting how supported they felt despite their doctors’ lack of knowledge about vulvodynia and its treatment. Though the women’s accounts of their interactions with clinicians varied in participants’ descriptions of their helpfulness and supportiveness, most women report how initially not finding a medical diagnosis that included a medical solution for their pain experience, led to them reinterpreting the meaning of the pain in an attempt to explain it. For many women, the negative impact of not finding an explanation from medical experts for their

pain was compounded by their negative experiences with practitioners during these medical appointments.

Christine describes how for faith and personal reasons she had committed to waiting for marriage before she had intercourse. Although she recalls tampons were always uncomfortable, it was after she was sexually assaulted by her then boyfriend at 20 when she remembers “the burning and real tenderness becoming exacerbated.” Without any experiences of pain-free penetration and after medical tests ruled out infections, she “just assumed the pain was a normal response to penetration.” Anya relates coming to the same conclusion that ‘all women experience vaginal penetration as painful’ after enduring repeated pap tests that “always made me cry because they were so painful” yet were consistently reported back to her by her doctor as ‘normal’. She became tearful describing her “frustration” with these visits: “My doctor would just tell me to relax and never tried to dig deeper or question why I was in so much pain during those exams. She would just tell me my pap tests were ‘normal’ and leave it at that.” Both interpreted the continued presence of pain in later attempts at penetration as sign of psychological or physical damage (respectively) that was *abnormal*. Christine began to interpret the pain’s persistence and intensification as a psychological response to the sexual trauma she had experienced combined with the negative messaging she had received about sex growing up. She references a significant element of self-blame for not being able to resolve the pain with individual psychological interventions to address those issues. For Anya the pain was evidence that “I was damaging myself internally somehow” as it seemed cumulative; new relationships began with pain-free intercourse, but the pain would inevitably return and intensify with repeated intercourse. She felt this belief confirmed when the pain showed up in her current relationship around the same time she received abnormal results on a pap-test. She describes how this belief

persisted even after multiple tests following a Leep returned ‘normal’ results: “I had already spent almost 15 years of my life thinking painful sex was something that every woman dealt with, but now I had it in my mind that any time I had sex, I was damaging myself internally somehow — even after every test was clear.” She acknowledged that this concern persists to some degree today.

Sophie reflected on how she had initially enjoyed “Sex [as] a form of freedom . . . as I was coming into adulthood and just discovering who I was.” When the pain began during a period of intense sexual exploration, she also tried to normalize the pain with intercourse as a sign “we were doing it so good!,” “Look she’s sitting on an ice bag. That’s hilarious. Hi-Five.” She said she began to reinterpret what her experience of pain signified was ‘wrong’ *with her*, when the pain persisted and she was not able to find a doctor who would take her complaints seriously. She started avoiding all forms of physical intimacy and felt overwhelmed by the “negative assumptions about what this all meant about me as a person.” She discussed throughout her story how she began to worry her distress was an “irrational” response, a sign of “hysteria” or that she must be “crazy”:

When you go to a doctor and they’re like ‘have a glass of wine, relax, use more lube’, the message is that it’s all in your head, you’re just imagining things. I was trying to tell people that I was in pain while they were trying to tell me that I wasn’t, or I was blowing it out of proportion. I had sort of curled up into a ball at that point and only got a PVD diagnoses because a friend of mine with similar symptoms was proactive about figuring out what it was.

Ashley described similarly wondering if the lack of medical knowledge or concern about the pain she had already been experiencing “for a couple of years” when she went to her doctor,

meant there was something “*wrong with me.*” She introduced her story with her first attempt to get medical help for her PVD symptoms:

When I first brought the pain up with my doctor . . . she didn’t know anything about it or really what to do about it, so she sent me to a gynecologist. The gynecologist told me it might be vaginismus, recommended dilators and then sent me to a LGBTQ friendly bookstore for information about that. I was really disappointed when they also didn’t know about it or have anything to help and after that I just didn’t bother too much with it. Nobody I saw knew about PVD or were aware of any real treatment for the pain I was experiencing.

She concluded that “nothing could be done about it” and added, “I started wondering . . . why I was so messed up?” She also explained how her “doctor’s cluelessness” exacerbated her parallel struggles with “anxiety and self-esteem issues.” She said: “I remember thinking that this must just be how I am, and I was just going to suffer.”

Sherry’s story is unique among the women interviewed for this inquiry in that her experience of pain was characterized by a rapid onset after many years of pain-free sex: “I never experienced serious discomfort with sex and had a very happy and joyous sex life up until PVD symptoms began in my 40’s. Over 4 months the pain ... reached a 5 before I believed there was something seriously wrong and went to my doctor.” She underwent several medical tests looking for a source of infection that would explain the intense burning pain she was experiencing. A medical explanation was never identified and her PVD symptoms continued to escalate and had (and continues to have) a significantly negative impact on her relationship. She refers to struggling with ‘what the pain meant’: “when there are no visible signs you wonder if you are crazy because you’re just imagining it.” As her struggle to find a ‘solution’ to the problem of

painful penetration continued: “nothing I’ve tried has helped”; her story, particularly her primary use of the present tense throughout her narrative, reflects a meaning-making process that is ongoing.

Celine, like Sherry, was also in her mid-forties, and like Anya, had also been experiencing the pain for 15 years before getting a diagnosis. She described beginning her quest for answers:

When I was in my early 20s (in the 1990s), I first went to see an older, male psychiatrist recommended by my family doctor, about genital pain and PTSD from a sexual trauma. The genital pain existed prior to, and continued after, this traumatic incident. He was very condescending and said the pain was all in my head and I just needed to relax. I had many sessions with him, and he never seemed to believe that my genital pain was real. My most memorable advice from him was to go drink some warm milk.

She remembers the impact of feeling “diminished and dismissed [by healthcare practitioners] for so long”:

I’d learned that male medical professionals did not believe women’s genital pain was real and that they thought we were hysterical and exaggerating when describing its devastation to us physically, emotionally and mentally. The ‘warm milk’ psychiatrist had told me that one day it would be like a light switching off and the pain would just go away (since he said it was all in my head anyway). I’d thought I must be overreacting, and I questioned whether the pain I felt from PVD was real or not, which therefore meant the shame and distress I felt about it were not warranted.

Jenny had always “struggled with painful pap exams” which her “supportive” doctor had accommodated by sourcing pediatric speculae to use for these visits, but like Anya and Sophie, she did not initially experience pain in her sexual relationship with her husband. She explains how the pain “slowly grew until I would be crying anytime we tried.” She described pre-existing challenges in her sexual relationship because her husband is a quadriplegic: “all the stars must line up exactly for us to be able to have sex.” Initially only her husband knew about the pain and she avoided telling anyone else because she did not see her experiences reflected anywhere around her:

It was an embarrassing secret I kept because everyone assumes that part of your body should just work and I knew I’d be judged because mine didn’t. I didn’t feel proud as a woman in the sexual component of my life, but a lot of anger, grief, and shame about it. When I *finally* went to see my doctor about the pain, I had this sense of being a failure as a woman, of really feeling less-than, because it seemed like I was the only one who had this problem.

Hopeful her doctor would have a solution for her pain she became “discouraged” when told “there was nothing we could do to fix it.” Like Celine, she turned to the internet and was also disappointed with what she found there: “I spent a lot of time after that diagnosis investigating how to fix dyspareunia on Google” and found things like “like intravaginal massage or seeing a female therapist who advertised how she could arouse your sexuality with intimate touch using feathers or other materials.” She says the idea of trying “these ‘therapies’” made her “extremely uncomfortable,” and she ultimately decided against them because they “didn’t sit well with her spiritually.” She recounts feeling so “desperate to find any help to fix myself,” that she seriously considered trying them despite “anticipating the additional shame I

would feel doing something that seemed like having sex with someone besides my husband.”

She explains “as a Christian, sex is something so sacred to me. It is designed by God to bond two people together in an act of love. I went through more turmoil and anguish just considering engaging in these ‘therapies’.” She recalls feeling “hopeless” and “broken” and began to struggle with what the pain might mean about her: “I had kept this thing that was ‘wrong’ with me a secret because I was afraid of being judged by others. I was dealing with this terrible shame, frustration and guilt for not being able to perform as a woman and a wife, all alone.”

Jaime reflected on how the “common experience of visiting multiple clinicians” without finding solutions can lead people with chronic pain to ‘identify themselves with despair’:

It can get you stuck in a hope and despair cycle. That feeling of despair reminds you of your other experiences of despair, which amplifies it until you are really in a pit of despair and you start to identify yourself with that. With every new practitioner I saw there was renewed hope that they might have the answer that the others didn’t; some explanation for what was wrong with me that the others couldn’t find. I had been carrying around a subconscious belief that I was rotting inside, because if pain can only be explained by some structural pathology, but mine couldn’t be identified, there must be something fundamentally wrong with me to explain it.

Celine’s dismissal by healthcare practitioners affirmed a growing belief the pain was a sign of more serious mental health issues and led to her subsequent social withdrawal:

after [the psychiatrist] dismissed me, I gave up seeking professional medical treatment and advice for a while. I had trusted this expert who said it was all in my head and I believed that if my pain experience wasn't real then something must be

really wrong with me mentally and emotionally. I was isolating myself because of this shameful secret of PVD. I felt completely alone in this pain and couldn't talk to anyone about it.

After looking but not finding an explanation for or resolution to their vulvar pain, women interviewed describe how PVD symptoms began to, as Sophie explains, “infect my life”. She said:

PVD really contaminated everything for me: my mental health around identity, ability, competence, and adulthood was all tied up in that. When you're really struggling, you're not able to take care of yourself or other things in your life. I was always *in it*, sometimes trapped in it, and I didn't have the skills or the awareness or the support to actually be in charge of anything that was happening with my body. It was all running away from me

3.3.1.2 Pain of PVD in my life (“it’s not *just* about the physical pain”)

Not seeing their painful experiences with intercourse reflected in personal conversations with friends, information online or in their educational experiences, in representations of sex and relationships in TV or film media, and then finding healthcare providers dismissive when seeking help, they found a growing sense of otherness and irreparable brokenness affirmed. They described the loneliness of being invisible to others and a mystery to themselves and the shame and fear of feeling broken or failed as a woman. While the women interviewed referenced the experience of physical pain in response to vulvar contact when storying their experiences, what they narrated most often and most vividly was how the physical pain of PVD led to profound disconnections from their bodies and sexuality, their most-loved ones and their over all sense of belonging.

When Jenny reported repeated attempts at intercourse with her husband ending in tears she explained how, “I wasn’t crying necessarily because of the physical pain, but because it was so *emotionally* painful that we couldn’t engage in healthy sexual relations like everyone else”. She said she “avoided sex not just because of the physical pain it provoked, but also because of the mental anguish and emotional distress that came with it” and had felt “so ashamed and ugly before my husband because he had gotten a broken wife”. Celine also blamed herself, felt “angry ... for having this ‘defective’ body” and avoided dating and intimacy. She said:

Carrying the shame and blame of PVD made me feel broken and it was very difficult to change that thinking and much harder to overcome than the physical part. I used to think that if the pain of PVD was cured, then that would be the solution to “fix” everything.

Anya, Sherry and Ashley also connected the unexplained physical pain of PVD with the isolating emotional pain of feeling uniquely broken and the shame of otherness. For Anya these beliefs persists to some degree today:

you feel like something is *really* wrong with you... I felt a lot of shame because of that. I don't really want to admit this brokenness and I still struggle quite a bit with that. I've been told over and over again nothing is broken or wrong. Maybe it's not, but I do feel *not normal*....

Sherry detailed the emotional pain of isolation and otherness she continues to experience:

It feels like something you can't talk about because you're afraid of being judged or looking like a weirdo or like less of a person or not whole and I already have those feelings about myself. To have other people feel the same way about me is

even more tragic...it makes you feel like you're a broken person. Isolation and shame go together.

Sherry's story is also remarkable for being the only participant interviewed who described her experiences with PVD symptoms as "worse now" than before she participated, despite recounting what a positive and helpful experience attending two groups was.

Ashley seemed to agree that not seeing her experience reflected around her or recognized by anyone that she went to for help, led her to feel alone in her experience and resigned to 'suffer': "I just felt broken at that point. Here is this thing that I should be able to do easily, and I should be able to enjoy like the rest of the population, but I can't."

Christina recounted the "shock" she felt that the pain remained despite all of the psychological work she was doing to address the trauma and sexual shame she felt had caused it. She said the realization she was "so cut off from this part of my body", resurfaced "the instinctive resentment and anger that I felt towards my body when pain feels debilitating and prevents me from doing things that seem easy for other people". She felt angry and blamed herself "for what was wrong with me that I couldn't be a physical partner to my husband".

Jaime too said her distress was less about the physical experience of pain and more about what she began to believe it meant about who she was: "Although PVD didn't physically impact me outside of intercourse, I felt so much shame and less-worthy because I felt fundamentally broken." Sophie agreed the disconnection she felt went beyond the physical pain she was experiencing with intercourse: "it was like something in me had broken. It was really unsettling how losing sex really knocked me over because I thought it shouldn't matter so much, like 'why is this your entire identity?'" For Sophie, PVD

was really destructive and completely derailed my identity and my relationship and knocked me on my ass. To suddenly be completely chopped off from this part of myself was so disturbing because it was so connected to what it meant to me to be an adult or in an intimate relationship...She said “looking around and seeing other people enjoying these freedoms, I thought: “F**! *This* is who you’re going to be!?”

Interestingly, some of the most common descriptors of the pain of vulvodynia, cutting and burning, are also used when describing the life-impact of PVD. Many women described feeling ‘cut-off’ from their sexual bodies, partners and others and both Sophie and Sherry used metaphors of fire to explain how PVD burned “everything” in their lives. The physical pain is an important part of the story, but it is the emotional, psychological and even existential pain they experienced because of it that caused their suffering. As Anya explained while tearfully recounting her story: “It’s just really emotional because it’s not *just* about the physical pain.”

3.3.2 How COMFORT helped me

Women chronicled how the validation of the diagnosis, the expertise and empathy of the professionals involved in COMFORT, and the community of the group were important for normalizing their experience and giving them new hope that ‘something could be done about’ their pain and distress. They highlighted the education about how PVD ‘worked’ in the nervous system and how it impacted their sexual desire and functioning, and PVD-focused CBT and mindfulness skills, as components of the program they found helpful in addressing the painful impact of PVD on their lives. Their previous accounting of how their physical experience led to profound disconnections from others, their bodies, sexuality and sense of identity also

foreshadow their descriptions of how they have been most helped (or how their quest for help continues).

3.3.2.1 I learned...

Despite many women offering the caveat that they doubted they would be able to remember details about the program after 5 years; all were able to identify specific psychoeducational aspects of the program that still stand out as being helpful to them. Women discussed information presented about the diagnosis and central nervous system sensitization, sexual response cycle, psychological skills and associated homework exercises as educational components of the program that stood out to them as ‘normalizing’, ‘validating’ and ‘empowering’.

3.3.2.1.1 I learned that PVD is real (“Naming the Monster”)

Many women expressed some ambivalence about first receiving their PVD diagnosis, particularly those who were diagnosed before entry into the COMFORT program. There was a sense of relief that their experience was ‘real’, mixed with ‘fear’ or ‘disappointment’ that getting a diagnosis, without medical treatment options, meant nothing could be done for them outside validating their pain experience as a legitimate source of distress.

Celine explained: “I felt some relief learning PVD was a real medical condition with a name, and not something I was just imagining, but it was also incredibly frightening to find out there wasn’t a cure; nothing that would make the pain go away for good after I completed the treatment or dosage, like how antibiotics treat an infection.” Christine agreed “It felt validating getting a PVD diagnosis but also really scary to hear there wasn’t a physical cure.”

For Sophie first learning about PVD as a diagnosis meant ‘naming the invisible monster’ that had wreaked havoc on her life:

Naming that monster meant I wasn't crazy or overreacting to something no one thought was a big deal but me. It was a real medical thing that was currently happening in my body and not hysteria. It was acknowledgement that what had knocked me over was a truck, not a f**ing leaf and it was validating that other people could see that. The invisibility part was awful.

When Ashley received a diagnosis as part of her enrollment in COMFORT she felt “massive relief to hear [PVD] wasn't something that I was necessarily going to suffer with for the rest of my life”, because “what was wrong with me had a name” and “there was something out there for what I was dealing with”. Jenny felt hope learning PVD was a “real medical condition” after her doctor found out about COMFORT and referred her to the program: “The first time I heard of provoked vestibulodynia and my first introduction to any kind of legitimate treatment was when I was diagnosed through COMFORT.”

3.3.2.1.2 I learned about PVD and nervous-system sensitization: The mind/body connection (“it wasn’t just all in my head”)

Women accounted how being given a detailed and evidenced-based explanation for why they were experiencing provoked vestibular pain was to varying degrees, as Jenny said “revolutionary”. Most women referenced how a shift in their understanding of what PVD ‘meant’ about them and new hope that they could have an influence over their experience, began with the education they received about peripheral and central nervous system sensitization.

For Jenny, “the information and explanation the program provided about the nervous system and hyper-nerve endings just made *sense*”. She explained:

having that knowledge and the science behind it was revolutionary for me. It was such a relief learning there's a known physical component to the pain- that it

wasn't all just in my head. Understanding why I perceived sensation more intensely normalized that experience. It was validation that I'm not incompetent in the bedroom, I just have this condition.

Jaime described this education as 'life-changing':

It was my first foray into pain education and learning about the idea of a sensitized system and how the body gets better and better at pain that really changed my belief about needing to *find* a specific structural pathology. It was a life changing answer that finally made sense of so much of what I'd been through.

Celine had her diagnosis for 6 years and had exhausted all the available medical options for treatment without any changes in her pain experience when she enrolled in the COMFORT group. She "wasn't hopeful anymore that there was a solution" and was "skeptical" that mindfulness might help where medicine had failed: "I just went to hear other people's stories and maybe learn some coping tools". However, after the "knowledgeable medical moderators" had "provided up-to-date information and taught us about how important the mind/body connection was with PVD and how the emotional, mental and physical were all connected in the nervous system", she was convinced enough to make a commitment to herself, that morning, to develop a daily mindfulness practice that she continues to this day.

Christine, who felt she'd "failed" when counselling alone did not resolve her physical pain, related throughout her narrative how COMFORT gave her a new understanding of "the mind/body connection" that was instrumental in changing her relationship to her physical experience. She described the renewed hope she felt after her first day in the group:

The facilitators introduced the tools they were going to be teaching by drawing parallels between PVD and other chronic nervous system conditions in a way that

normalized PVD and made using CBT for coping with it seem plausible and doable. Learning about the connection between chronic pain and mental health ... helped affirm my hope that the group would be helpful...I felt empowered by the possibility I could manage this on my own.

Sherry, whose PVD symptoms continue to be a profound source of distress, nevertheless “found great value in COMFORT”:

Learning about how there were more pain receptors in the brain with PVD and about the white blood and mast cells was brilliant. Discovering there was a real physical response in the body, legitimized my experience of pain and made it real, because when there are no visible signs you wonder if you are crazy or just imagining it....[but] it wasn't just all in my head.

Anya did not find the group context or mindfulness exercises particularly helpful during participating and she and her partner also continued to struggle. Her pain ‘scores’ on follow-up exams had “improved significantly by the end of the group”, but these positive changes did not translate to less pain with intercourse: “even though I kind of got better physically, the mental stuff was still there”. She said, “before COMFORT, I had thought PVD was strictly physical”, and found “learning through the program it was mostly mental and that I had to attack this from a different perspective was a pretty big hurdle for me to get over”. However, it was her understanding of the connection between her physical experience and mental health, which she had learned through her participation, that eventually led her to seek individualized psychological support for the first time. She has since revisited many of the practices she first learned about in COMFORT with the support of a therapist and found them much more helpful.

For Jenny, the pain education, on its own, was enough to “change my self-perception as a sexual failure, a faulty woman or a broken wife because I can’t have intercourse without pain”. For others, that education was an important entry point to connecting their mental, emotional and physical experiences, but just the beginning of translating that understanding into practice. Jaime recounted how the education about nervous system sensitization helped her embrace the suggested practices and tools as part of her changing relationship to pain:

Prior to the programs I had found that yoga and meditation were really helpful with my widespread body pain, but it was through the programs that I got an understanding of *why*.... It was eye opening and empowering to be given education and tools I could use to make a difference for myself and it was so powerful for reducing the fear of pain. Pain became something that was less alarming, less concerning and more understandable that it had been for most of my life. It takes time for deep conceptual change to happen but getting that education is when it started for me and a new story began unfolding from there.

3.3.2.1.3 I learned to challenge my sexual beliefs

Women receive similar education regarding Basson’s Sexual Response Cycle, the importance of temporarily taking sexual penetration ‘off the menu’, engaging in non-penetrative sexually pleasurable activities and strategies for communicating with sexual partners in both treatment arms. All women discussed how their beliefs about how they ‘should’ be performing sexually were challenged, and many told how incorporating what they had learned led to reappraisal of their sexual beliefs and practices and to more satisfying sexual encounters. As this information was presented in their groups within the context of either a mindfulness-based or

CBT-based treatment modality, the language they used to describe how things have changed for them reflected this.

3.3.2.1.4 CBT skills and ‘Sex Education’ (“just because you think something doesn’t mean that it’s true”)

Women who had been part of the CBT arm discussed how restructuring cognitive distortions related to their sexual experiences allowed them to redress unhelpful beliefs about their defectiveness and more confidently approach previously avoided intimate activities with less judgement and fear. They related how the practice of recognizing negative emotional responses, identifying associated thought distortions, and generating more realistic alternatives to these, disrupted habitual patterns of feeling overwhelmed by negative emotions and self-judgement. They talk about the space it gave them to respond flexibly rather than automatically, how a renewed sense of agency replaced feelings of helplessness and how they began to approach and to reevaluate discomfort instead of avoiding it. As a result, many found their experiences of physical pain seemed less ‘scary’ and ‘overwhelming’ and its salience reduced as a result.

Christine had already found CBT helpful for symptoms of anxiety and depression and had been seeing a counsellor for several years before joining COMFORT. She had found counselling helpful for addressing the “fear, shame and guilt” about sex she’d learned in childhood and felt was reinforced after a sexual assault in her first intimate relationship. For Christine, COMFORT helped her to connect the practice of CBT skills to her ability to influence her *physical* experience. She described how drawing her vulva as a homework exercise in group provided an opportunity for her to challenge negative thoughts and feelings she had about her body:

I could recognize those negative emotions [I felt towards my body] as they came up and accept them as human and part of a process instead of them being all-consuming....Learning about physical focal points of pain helped you realize how much you can do that won't hurt, like manipulation outside of the inner lips or oral. It made the pain seem more manageable or not as scary because it wasn't *everything*.

She concluded her story by explaining how practice using CBT skills in sexual contexts to counter unexamined avoidance helped:

Even days when I'm more sensitive, 9/10 times I can switch to external stimulation and focus on what will bring me more pleasure in the moment instead of just stopping everything like I would before. I also don't beat myself up for wanting to stop and I don't try to push through just for the sake of pushing through. Maybe I really am just too tired or it's too aggravated right now. I don't criticize or blame myself anymore when I can't. COMFORT helped reinforce CBT as an ingrained part of my lifestyle and my thought process now. When thoughts of self-blame come up now, I acknowledge them and then basically blow raspberries at them until they go away. I have accepted PVD might be a part of my life sometimes, but it isn't everything all the time.

She also found learning about responsive desire and the importance of context useful: we also learned what helps women become naturally aroused and what gets in the way. Before COMFORT, I didn't know what my libido was actually like, but I can now recognize when I'm aroused because I can feel those different

sensations...and I know now I can get to the point where I can enjoy sex even if I'm never completely pain free.

Sophie found the introduction to CBT skills in MVP a helpful foundation to the extended practice opportunity COMFORT provided:

Having the time in COMFORT to make new habits with the tools I had started learning through MVP helped to make them part of the way that I talk to myself now... I had developed all these really awful habits of catastrophizing rocketing into negative self-talk and negative assumptions about what this all meant about me as a person.

She described how she continues to use the 'Snowball' exercise with cognitive restructuring practices to recognize and challenge unhelpful thoughts and avoidant behaviours related to negative emotional responses to sexual contexts and to re-evaluate catastrophic predictions:

Now, when I look at what's actually happening in the moment, I'm aware that its meaning is whatever I assign to it, good or bad. I usually see that it's not really as bad as it seemed in the past. Being able to name and identify thoughts and feelings as they were happening and tracking my assumptions helped me to unpack things and deflect them one at a time so that they weren't all coming at me at once. If I was feeling stabbing pain triggered by a sexual cue, I could track myself extrapolating to: 'This is it. My life is over. My relationship is over. I'm a shitty partner. He's going to stick around because he's a great guy but he's going to be miserable'. Then I could pare it down to the middle of the snowball and talk back to those thoughts: 'Really it's just a pain in your gut and a racing heart. These

physiological sensations don't need to mean 'my life is over'. It doesn't mean that I can't just hold his hand'. I could counter 'what if it starts hurting in the middle of sex though?' with 'this resistance is just an old habit -let's see if there's evidence from the last year or two of any actual painful experiences.' Before I would just shut sex down, or it would snowball into other stuff, like a panic attack. Reviewing the evidence that sex didn't make me cry %100 of the time, or even half the time, opened up possibilities.... It was helpful to be more aware of context and to widen my perspective so that I could recognize these changing patterns and see that what I was trying was working.

Jamie had a mindfulness and yoga practice before enrolling in COMFORT that had been helpful for managing body pain, and like Sophie found her participation in MVP to be a helpful introduction to the potential helpfulness of CBT skills. Of using CBT exercises she said:

I think a good percentage of humans go through life without really questioning what's running through their head or why they're responding the way that they are. As you become more aware of your thoughts, you can reflect on where they come from and how and why you are responding to them in a particular way.

She described how ongoing practice of CBT skills she learned in MVP and COMFORT continue to be helpful:

A year after I did COMFORT, I was rear ended on the highway. In came all of these thoughts and beliefs about how life and the universe were knocking me down. I had enough awareness at that point to see it was not helpful thinking and I used the thought record tool from COMFORT to work through it. I laughed out loud when I got to my alternative thought 'life is knocking everybody down'

because I realized that I was taking hardship so personally... if I am going to consciously subscribe to the idea that the universe knocks people down, I'm really not the person that life is taking hard hits at, but I lived my life carrying around that story. Without the mindset and the tools to be actively reflecting and actively engaging in these things you just carry around beliefs that life is knocking you down. I kept getting better at using the tools and got more out of them the more I practiced.

She explained how these skills improved sexual intimacy by “paving the roads” to avoid “pits of despair”:

Things with my partner are a lot better, and if there is discomfort during sex, I don't fret about it and I don't feel powerless in the face of it. In the moment there is awareness I can change my thoughts or change my breathing and have an influence over things.

Ashley also had found that actively challenging the thoughts and beliefs she had related to her sexual functioning were helpful beyond the improvements she experienced in her sex life:

I really appreciated the CBT focus and learning how CBT works as a therapy. It really spoke to me in a way that I found very useful for changing my headspace and learning ways to deal with my generalized anxiety which I see now as a big part of the reason why I had an issue with PVD in the first place. . . . It was helpful for me to be able to challenge my thoughts and realize that just because you think something doesn't mean that it's true.

She described how using these skills combined with physical exercises she learned in COMFORT continue to be useful:

I was just telling my boyfriend last night about the exercise where you touched your vulva step-by-step, in different areas, to see where it actually hurts and doesn't hurt. I learned to kind of assess what the pain actually feels like and where it was, instead of just freaking out about any contact because I thought it was all going to hurt. I remember the progression of first using my finger and then having a partner use a finger and then working your way up to intercourse. When I progressed through those steps with my current boyfriend, I was definitely more aware of what hurt and exactly how much and where. I could notice that it didn't hurt as much as I thought it was going to and realize it wasn't as bad as I had catastrophized it to be! . . . I found that when I applied what I learned and went slowly that there wasn't much of an issue, which I was really excited about.

Sherry first attended the CBT group and found the information and group context validating and normalizing, although she did not experience any reduction in pain during intercourse which continues to be the central source of conflict in her relationship. She was hopeful that lobbying the study team to also participate in the mindfulness group would help ameliorate the pain she continued to experience but was disappointed it remained after completing both groups. She nevertheless felt the CBT group was more immediately useful “because I’m more analytical and learning concrete skills felt more important than the meditative stuff” and “learning to work through the emotion, situation, and automatic, biased thoughts in the work sheets felt really concrete. There were just more tools to use in the CBT group and those exercises allowed you to target the mental junk and the judgment and shame.” She demonstrated

using cognitive restructuring while struggling with the belief that PVD symptoms mean she is “not a viable partner to someone in the marketplace going forward”:

I have to accept that I’ll never be with someone again because no one wants to be with a woman who’s sexually broken. . . . There was an exercise we did in the group about whether our whole persona is defined by being a sexual being or if we are more than just a sex object. . . . I have a lot of other roles in my life and I know I shouldn’t be completely defined by the fact that I’m broken in the sex department. . . . But I feel like I am defined by this when it comes to finding a new partner because I still feel like a new partner will not want to be with me because of that . . . I think it’s innate that a man wouldn’t want to be with a woman who can’t have sex. I think all men think sex doesn’t count without penetration although saying it out loud makes me wonder if that’s really true. I’ve been so indoctrinated by my boyfriend saying to me for so long that it’s what all guys want and that it’s just how it is. I don’t think he could know 100% of what 100% of men want and need. . . . This is why I think CBT is one of the best things on the planet, it’s so smart, because it really always brings me back to: how do I know this is true? Where’s the proof, and what is the percentage likelihood it could be true? What are the alternate possibilities? Maybe there are people out there that are not focused on sexual intercourse as ‘it’ in a relationship.”

Sophie like, Christine, Ashley and Sherry, referenced Rosemary Basson’s circular sexual response cycle with its emphasis on context and responsive (versus spontaneous) desire as information that was new to her at the time but still stands out to her today. She said she now understands “sex is going to be good when I get there,” and even now makes a point of

scheduling a day for sex in her calendar so she can use her relaxation and cognitive restructuring skills “without any time pressure or distraction.” Today she actively nurtures contexts conducive to responsive desire: “We’ve had to adjust the way that we do things. We keep all foreplay external and we don’t go as long as we used to. There isn’t any pressure around it anymore, it just takes a little bit of work and planning.” She laughed when adding: “I like to schedule my spontaneity! Rules make the game fun!”

Sherry recalled: “The arousal cycle model was also fantastic and was really different from the understanding of desire I had before. It helped me realize that I could get there even if I didn’t feel it right away.” However, attempts to spend more time on sexual activities that did not elicit pain to increase her arousal, within the context of a conflicted relationship where painless penetration remains an urgent and primary goal, haven’t helped:

We spent a lot of time, pre-penetration, getting my body ready but it didn’t help.

We have tried non-penetrative ways of being intimate like oral sex or manually stimulating each other to orgasm but he says it's not the same or enough.

3.3.2.1.5 Mindfulness Skills and ‘Sex Education’ (“be in the moment, feel whatever it is, good or bad”)

There were fewer direct references to the helpfulness of learning mindfulness skills in the context of sexual pain and far more critiques of the usefulness of the practices which will be discussed separately. Sophie and Jamie participated in the CBT arm but spoke highly of mindfulness practices learned through COMFORT, MVP and community groups. Sophie found adapting the ‘body scan’ meditation introduced in MVP and then in the CBT arm of COMFORT, helpful in combination with cognitive restructuring exercises. She later pursued mindfulness practices in community groups. Jamie, who had developed a mindfulness practice before joining

MVP and then the CBT arm of COMFORT said: “I’m at the point now where I think if there’s a secret to life, mindfulness is in the running.” However, of those who attended the MBCT arms (Anya, Jenny, Celine and Sherry in a second group), only Celine committed to a regular, daily practice which empowered her to “see I could do something about how I thought or felt; that I could change that” while also noticeably changing her pain scores on follow-up q-tip tests “from eights and nines to fours and fives.” Sherry did associate some temporary improvements in her pain during a brief period of regular mindfulness practice but was not confident enough in a causal relationship to continue where the ‘cost’ burden of a regular practice outweighed the lack of immediate benefit.

Jenny expressed an appreciation for being introduced to mindfulness skills and committed to the practices during her participation but did not find them helpful during intercourse and did not revisit them after the group ended. Although she explained the pain education component of the program helped most with her distress, she regularly referenced developing ‘acceptance’ and ‘self-compassion’ and ‘presence,’ hallmarks of the benefits of mindfulness practices, as instrumental in changing her ‘negative self-perceptions’ of being a ‘sexual failure’ and embracing program suggestions for non-penetrative intimacy without judgement:

I thought using a mindfulness approach made sense because I believe in the power of our minds to impact our physical experience in helpful or harmful ways and so much of sex is in your mind. . . . I appreciate that the course taught me the basics of mindfulness, and if I choose to do it for a particular purpose, then I can do it . . . but I haven’t made a conscious effort to continue practice. I use the principles of

mindfulness when I practice deep breathing or muscle tension and releasing to control arthritis pain, so it has been a helpful foundation for other things.

I believe it's possible the pain could eventually improve if we continued practicing mindfulness during intercourse, but my husband doesn't want to cause me pain and I don't want to have pain either, so we are intimate in other ways.

Jenny closed her narrative by summarizing this shift in perspective: "Sex is not a higher priority than emotional connection, loving actions and serving one another for us. Those are the things that keep us connected . . . the program helped me find peace and acceptance. . . . [and] really changed my perception of myself in terms of my sexuality".

Celine initially "didn't go into the program very positively or hopefully," saying "mindfulness didn't seem like a real solution", but

after the first day of the group I wrote my new goal for the program, 'to develop a daily mindfulness practice' . . . I had to try to do something to change my situation and the moderators seemed so sure that mindfulness had helped other women. I also did not have any other options left after all this time.

She adapted the assigned practices, finding shorter meditations and those that emphasized self-compassion to meet her daily goal:

When I first began developing my practice, I did a lot more of the Loving Kindness-type meditations, repeating mantras to be kinder, especially to myself, which has always been very difficult for me. I used to be much more critical and harder on myself. Without being kinder to myself, I don't think I could have kept up the mindfulness meditations, as I would have given up earlier thinking I was failing. I've learned and accepted that perfection is not the goal, and I don't beat

myself up over it anymore. Since November 2014, I've done a meditation every single day and I have never missed a day.

Although Celine was not in a sexual relationship where she could practice mindfulness exercises in a sexual context during her participation, she found embracing the practices changed her relationship to her PVD symptoms to where she no longer felt defined or overwhelmed by them: “By accepting the emotions that I felt, it made them (especially the negative ones) feel less personal. Mindfulness has taught me not to control my emotions but to be with them. I now try to be in the moment, to feel whatever it is, good or bad.” She credits her participation with COMFORT as “a first step towards completely changing who I was”. Like Jenny, she found coming to a place of acceptance, practicing self-compassion and focusing on the present-moment, a positive impact of participating. She recalled how making the connection between the educational components and mindfulness practices, while in a structured group focused on PVD, was foundational to her commitment: “I may have found mindfulness some other way, but I don’t think I could have connected it to managing PVD pain on my own”.

Finding self-compassion was fundamental for both Jenny and Celine over-coming beliefs that they were ‘sexually defective’, ‘broken’ or ‘failed’ women. For Jenny this meant accepting intimacy without intercourse and gratitude for other positive, non-sexual aspects of her relationship, but for Celine this was a ‘first step’ in the direction of exploring her sexuality, in many ways, for the first time. She described how participating in group discussions, connecting the education with her developing mindfulness practice, and noticing the positive influence these new experiences were having on her pain symptoms, empowered her to approach, rather than avoid sexual contexts in conversations with family and friends, with individual counselling and eventually in sexual relationships.

3.3.2.2 ‘(Re)connecting’ (“by accepting each other, we learned how to accept ourselves”)

While all women cite the pain education as integral to the study program’s positive impact, and many found the MBCT or CBT practices supported redressing negative beliefs and avoidance of intimacy, it was the context of the delivery of that information that helped to embed new beliefs and practices into their daily lives. All cite being part of a group of women who shared their suffering and the learning process, while guided by knowledgeable and compassionate professionals, a powerful antidote to the shame and isolation they had experienced. Themes of disconnection are prominent in women’s stories when narrating the painful impact PVD had on their lives. They described feeling ‘broken’ physically and psychologically, ‘cut-off’ from their physical bodies, sexuality and sense of agency, and ‘isolated’ from others who did not understand or believe their distress and from whom they had anticipated or received judgement for disclosing their suffering. The pain had become central to their experience of themselves, their lives and relationships and without hope this would change, withdrawal became their primary protection. They narrate how encounters they had participating in COMFORT led to them confronting beliefs they were singularly and irreparably broken or defective and to feeling safe exploring feared and avoided internal and external experiences.

Some found the very existence of the research and the delivery of the group by knowledgeable professionals important for affirming that their experiences of distress were legitimate and new hopefulness that participating would be helpful. Sophie said: “I assume not every person researching PVD has it, yet people were willing to spend their time, education and jobs trying to figure it out. That people were studying it, had developed a test for it, and treatment groups for it, meant it was real and it *mattered*.” Christine agreed: “The fact that the group was put together by medical professionals who had gotten research funding for this,

validated that my experience was legitimate”. Jenny explained how “just being part of a research study was validating because it meant experts had identified PVD as a legitimate problem . . . [which] said our experience was important.” Ashley also found the expert moderators and group context essential to overcoming feelings of isolation and important for embracing new information and skills: “It wouldn’t be the same just having the workbook the first time you’re learning. Having somebody walk you through while being in a group of people who have the same sort of thing going on was so beneficial.”

Sophie, Jenny and Christine additionally referenced how their interactions with other study team members who had treated them with empathy and showed interest in their lives and experiences outside of their roles as study participants or patients were as Christine says, “humanizing.” She said, “it was incredibly valuable to me to feel like I wasn’t just a test subject; I was being noticed as more than just a vagina to study.”

All women acknowledged how the community of the group immediately relieved their felt isolation and provided the means for them to accept and reconnect with themselves with more openness and compassion. For Jenny it was:

More than learning practical tips though, it was being with women like me and feeling safe openly sharing experiences we hadn’t felt we could reveal before, maybe even to ourselves, and being vulnerable in that way, that was so powerful for acceptance and understanding. By accepting each other, we learned how to accept ourselves, so that even that belief that you’re broken begins to change.

Christine agreed that connecting compassion for others helped her to direct compassion towards herself: “when you see all of these other women, from all different backgrounds, struggling and suffering and you don’t blame them- you don’t see it as their fault, you don’t see

them as wrong, then you couldn't say to yourself that you're a freak or it was your fault anymore."

Jaime said similarly that:

having the opportunity to be in a room full of women that share the experiences of shame and invisibility that come with PVD, but who are intelligent and insightful and *normal*, was so helpful in normalizing that whole experience. When you can look at somebody else and not see them as less worthy that challenges your own sense of yourself.

Celine also described how the "mix of ages, professions, life stages, and viewpoints," normalized her experience and created a safe place for her to begin to overcome her "self-aversion." She explained why: "Besides sharing common experiences related to PVD, we were all so different. There was no 'typical' profile of what a woman with PVD is like. It could be any woman and every woman." Although she was "nervous" about disclosing personal experiences she had not shared before, she found:

It was so reassuring to say something in the group and hear someone respond they'd felt that too. No one thought I was crazy. We were helping each other put into words what we didn't have words for before. We shared the frustration of not knowing where PVD comes from or why it started. We told each other it wasn't our fault. It was powerful, that sharing. Finally, after 15 years of isolation, it was the first time I didn't feel so alone or like a freakish failure.

Although Sherry still struggles, the group context helped relieve some of her shame, self-blame and isolation:

I didn't feel so alone or like I belonged on a leper colony. Being in the group took away some of the shame and the judgment. . . . it helped knowing I wasn't an island; other women had gone through this. It was a relief knowing I'm not a weirdo, that I didn't bring this on myself, I didn't wish for this to happen and it wasn't me deliberately rejecting my partner. Having other women in the room who shared this specific experience but came from all different backgrounds helped me not feel so sorry for myself anymore because it wasn't just me and sometimes it was worse for other women.

For Ashley connecting with others who shared her experiences led to her opening up to others outside the group: "During the study we learned how many women experience pain during sex and it was really a relief to hear that I wasn't alone. It was really refreshing how even though everybody in the group was so different we could all talk about PVD and understand those experiences," which "opened the door for me to talk about it with my friends and partners."

Although Anya did not find the group a useful context for learning and applying the information and skills presented, she appreciated the community aspect of the groups:

Although my shyness kept me from speaking up, I still valued the environment of the group — everyone was really supportive, and I appreciated the fact that there was a huge range of ages and backgrounds. It was also reassuring to actually see and be with other women who are dealing with the exact same thing (or in some cases, much worse), and to know that I wasn't alone.

Sophie explained why, despite the practical burden of weekly attendance while she was a full-time student, she committed to participating in the group:

In the group there was this great blanket acceptance of all of those things about PVD that were really hard to explain to anyone who hadn't felt it. We shared the same language, knew the same symptoms, had been through the same stuff and felt broken in the same way. Seeing someone crying meant you could cry too, but not expressing emotion didn't mean anybody there thought you weren't in pain. We had a similar, shared experience of PVD, and by sharing our different stories and perspectives you can begin to piece together a fuller picture and understanding of your own situation. We're social animals and we are built to survive in communities and herds and groups. You might be able to survive being outcast from a group or not having any group to belong to, but it makes it really difficult to thrive. I could have *survived* PVD on my own and I would have probably been some version of okay, but now I feel great and a lot of that had to do with the fact that I've had so much support. I think that community made it a lot easier for me to get there faster because I wasn't doing all of the work on my own in isolation. Just having and sharing those stories was therapeutic.

Many women discussed how the program provided safe avenues for intentionally exploring feared physical experiences of painful vulvar contact, were important on their path to healing an estranged relationship with their sexual bodies and to reintegrating rejected body parts into their felt experience.

Christine explained how the educational physical exam that confirmed her diagnosis began the process of reconnecting with genitals she had avoided because of learned shame and fear of pain:

I didn't know before what it felt like to be relaxed, but I was beginning to sense differences in muscular response at a specific physical site which gave me something I could aim for on my own and use that new awareness of sensation to develop more consciousness of it later. Being able to pinpoint those sensations made them less overwhelming and began to put me back in control of my body where before it just felt like *everything* hurt. It was the first step for me towards reconnecting to my body and reclaiming myself.

She later described how a homework exercise of observing and drawing her vulva “tricked my brain into looking at myself in an appreciatively clinical fashion. . . . I had cut myself off from that part of my body and the drawing helped me in the process of renewing that connection.” Ashley also found the drawing exercise expanded her awareness of her sexual body beyond her pain experience: “I don't think I'd ever actually really looked down there before, especially not like that. I don't know if the drawing on its own was super helpful, but I wasn't very aware of myself in that way, and along with the other activities, it was really helpful in my becoming more comfortable with my sexuality.” She recalled “there was the getting to know your body exercises and the relaxation stuff and the thought exercises which all helped together . . . I remember doing the Body Scan which really helped me be more aware of what was going on with my body in the moment and noticing different sensations I wouldn't notice before. I had no idea how much I was tensing up down there or that I was actually tense down there most of the time”. She found “the exercise where you touched your vulva step-by-step, in different areas, to see where it actually hurts and doesn't hurt” helped her learn to “assess what the pain actually feels like and where it was instead of just freaking out about any contact because I thought it was all going to hurt”.

For Sophie and Jaime, the therapeutic benefit of reconnecting with their physical experience began with the pelvic floor physio component of their participation in MVP before they enrolled in COMFORT. Sophie said:

What I remember most about MVP was the very unique experience of having electrodes around my vagina to measure my pelvic floor tension. I had no idea what it felt like to relax or tense my pelvic floor; that was a part of my body I'd never really given much thought to. Through biofeedback I learned what my base tone looked like compared with what tensed or relaxed looked like and I could then differentiate between those physical feelings. To be able to be in my body and know what I am feeling and where I am feeling it, was like the first time you learn to stand up straight and hadn't realize you'd been slouching the whole time.

She explained that a new relationship to her physical experience continued with the practice of the body scan meditation and the cognitive restructuring exercises that allowed her tease apart her physical, mental and emotional experiences and learn more about how they influenced each other and how she could intentionally influence her felt responses to those experiences: "I'm not always going to have access to electrodes, but I can always talk *myself* down from the edge of a cliff."

Jaime agreed that combining the physical exercises in pelvic floor physio with psychological practices are more helpful together, than physical practices would be on their own:

the pelvic floor physiotherapy helped me observe pain more objectively so I could approach it and come to the realization it didn't actually hurt *everywhere*. There is freedom in that, but you could get really hijacked by focusing on pelvic floor

exercises and lose track of the influences of your thoughts and the way you're responding to things in the full picture of life. So, it was perfect having that introduction to psychological factors topped up and reinforced in COMFORT.

She explained how supporting physical awareness with the practice of psychological skills helped her "respond to pain so much differently." She said: "Something I learned to do because of the programs was to think "meh, there is a new pain. It'll likely pass." She recalled how learning to connect with rather than avoid her physical experience means:

Now I can acknowledge a feeling I'm having as a really crappy moment and have compassion for that rather than getting pulled into it because I know I'm going to keep stepping forward. Despair hasn't been a part of my life for a long while because learning those tools gave me space to choose to respond to it differently rather than fall into that pit.

For Celine it was the meditation practices that allowed her to reconnect with and befriend her physical experiences, recognize their temporality, and disentangle herself from the self-judgement that had been automatic when feeling pain:

Whenever I'm dealing with pain, I can acknowledge the pain in the moment, and also how it makes me feel, and then let it go . . . when I feel really stressed, it benefits me to be able to take a quick inventory of my body and how I feel physically, emotionally and mentally and then take a two-minute breather. It was a new experience for me to be able to relieve stress just through really noticing where my mind and my body are at in the present moment. Before, all I could feel was overwhelmed. PVD pain always felt overwhelming and impossible to manage, which led to feelings of failure. Now I can notice the pain is in this moment and

that doesn't feel insurmountable. For me, it was more like finally "owning" the pain rather than fighting the pain and being ashamed of it.

She described how the fear of pain, and the judgement she felt and expected because of it, had led to her avoiding intimate relationships. Developing a new relationship with her physical experience meant she was able to approach sexual relationships and discuss PVD with potential partners and found "if I experienced pain [during intercourse], I was more capable of handling the emotional and mental aspects of it."

Anya discussed how she initially found it difficult to 'wrap her head around' how addressing the "mental and emotional" distress she felt as a direct response to pain could be ameliorated by practicing mindfulness in the context of pain: "I recognized the pain, but then I didn't have the ability to feel it and let it pass, it seemed to make it worse." She said:

Maybe I'm just bad at practicing something over and over and over again, when it's something I don't like to do. People keep telling me I'll learn to like red wine, but I don't want to keep drinking it because it tastes awful! I don't want to practice during sex because it hurts and we both just get frustrated. . . . Any attempts at penetration would hurt and I would try hard to focus in on other sensations, but it never worked. So, practice was difficult.

Anya also did not 'buy-in' to the idea of temporarily taking penetration off the table while practicing other partnered physical exercises like Sensate Focus and felt shy joining group discussions or asking questions about any of the homework or practices: "it was also totally lost on [me and my partner]; we just gave up on it. No one else in the group seemed to be having issues understanding it so I didn't say anything." However, she said seeking individualized support was a "game-changer" for getting an understanding of how practices recommended in

COMFORT that focused on her physical experience could help. She began by re-visiting Sensate Focus while she and her partner agreed to put intercourse, and a deadline for fixing the pain or ending their relationship, on hold. On the recommendation of this counsellor, she also began seeing a pelvic-floor physiotherapist which she found especially helpful for re-connecting with her physical experience:

With the physiotherapist, we worked with biofeedback — you can literally see what's going on down there! I could see myself relaxing while I was actually relaxing, which was super, super helpful. We also did some exercises with me touching the vulvar vestibule, and I practiced clenching and releasing, which helped more than when it was suggested in COMFORT. The physiotherapist also taught me how to use dilators properly — turns out I had been using them wrong the whole time I had them! I'm still working on all of it and, when I keep up with my physio exercises, I do notice a difference.

Anya now feels more hope that she can influence her physical experience by intentionally connecting with it.

For the women who storied their experiences of participating in COMFORT, connecting with other women in the group with compassion and without judgement initiated a compassionate and non-judgmental re-connection with themselves. For many, this led to them connecting with more support outside of COMFORT, by talking more openly about their experiences with friends, family, current or potential partners, or by seeking individual or couples' therapists or joining other therapy groups. For some, experiences during their participation that encouraged exploration of their relationship to their sexual body, their vulvas and vaginas, with safe and intentional contact with their physical pain, reinforced a new

openness to experience that provided the evidence they needed to rewrite limiting storylines that the pain defined them. Rather than feeling ‘helpless’ and ‘overwhelmed’ when anchored into physical experience, they find new space to separate their emotional and psychological distress from pain sensations and describe feeling ‘empowered’ to influence how they respond. As Christina said: “Being back in touch was putting me back in control.”

3.3.2.3 Redefining ‘the cure’ and challenging binary notions of wellness (“I’m a whole human being, not ‘a PVD’”)

All women continue to experience pain symptoms to varying degrees, and cite the COMFORT program as an important, but not exclusive, part of an ongoing and open-ended process of recovery. For those women who described the program as most helpful, it did not eliminate or ‘cure’ their physical pain symptoms, but rather supported them in decentralizing the physical pain from defining their experiences and provided information and tools they felt empowered them to practice responding to pain in the present without feeling overwhelmed by suffering that had previously felt all-encompassing. As some considered their pain symptoms in the context of the connections between their psychological, physical and social health and practiced leveraging those connections to disentangle suffering from physical pain, their goals for wellness changed and the language and expressions they use to describe their progress reflected that. They move from totalizing, binary and static descriptions of wellness as something you ‘have’ or ‘are’: (broken/fixed, abnormal/normal, or painful/pain-free), to a dynamic, holistic and fluid sense of wellness. For these women, wellness is not a singular achievement but a gradual process towards a ‘wholeness’ of experience, requiring intentional contact with discomfort and the regular practice of self-compassion in response. Wholeness as a direction

rather than a destination required regularly attending to the balance of the overall health of her body, mind and relationships.

Jaime explained how the salience of her physical pain is reduced when she actively attends to her overall health:

My life now is very structured around attending to wellness. I do a lot of yoga, a lot of meditation, I'm careful about what I eat, and I prioritize sleep . . . When I don't do those things, I can quite quickly start to experience a lot more pain in my body. I still struggle with pain in different capacities, but I don't feel broken anymore and I think it's that idea of wholeness that is the key.

Jaime felt the tools she learned in COMFORT began a process of separating pain from suffering that is ongoing. She described how feeling safe in the physical body, rather than hijacked by signals of threat and danger in the context of persistent pain without a known “structural pathology,” begins with an understanding of what pain is and how it works and continues with practicing openness to internal and external experiences which creates space to objectively reappraise the sensed threat of danger, and respond appropriately:

As I've since learned more about pain, I have a new understanding that it is about a perceived need for protection, which comes out of Lorimer Mosely's work. He has a tool called the Protectometer which is like a thermometer where things that increase your perceived need for protection move you up on the Protectometer and a sense of safety, or 'un-guarding' decreases that. This gives power back to the person with pain because there is so much that an individual can do to influence that perceived need. One of the examples I use when I'm teaching is that if I have a knife in my leg, all these danger signals are coming from that part of my body

and taking the knife out is going to influence my brain's perception of safety. But if a person put a knife in my leg then put a gun to my head, I probably would not have pain in my leg, because pain is about protection. I think you can map that understanding onto the wholeness of a human. You begin to see that there's so much possibility for someone to have a positive influence on their pain whether it's getting a pet or getting outside more or being more socially connected, or whatever it might be.

While thinking about when she knew things were better for her she said: "I don't have a recollection of a big change moment; it has been more that gradual unfolding. I will have a reflective moment that I'm doing better, and things are easier and that it's been that way for a while." Jaime recalled,

I used to get the question 'Are you healed?', or 'Are you fixed?' a lot and I never knew exactly how to answer because I'm way better now in so many different ways. I really grasped onto John Kabat Zinn's differentiation between how a cure is fixing something and healing is finding a sense of wholeness in the midst of whatever's going on.

Women previously described their fear about 'what the pain meant' about them, and how the pain's persistence was experienced as a threat to their sense of self, and a signal of danger from an unfixable core defect. For Ashley, getting a diagnosis and enrolling in COMFORT meant "a light at the end of tunnel and the possibility there was something out there for what I was dealing with." She said: "It wasn't an overnight fix learning about it, but it was a massive relief to hear that I wasn't necessarily going to suffer for the rest of my life." What 'fixable' meant was not 'fixed' but learning that she was not actually "doomed to suffer" which opened

space for hope, possibility and curiosity to displace doom, powerlessness and fear. She related how she learned to progressively feel safer thinking about, exploring and talking about her sexual body in new ways and with new confidence in her ability to manage physical discomfort and without fear or self-judgement. She has found that committing and recommitting to developing an openness to experience, regular maintenance of her overall mental health, and prioritizing a healthy intimate relationship, has meant pain with intercourse is occasional but not distressing. Like Jaime, Ashley recalled a gradual and open-ended process:

It's so complicated to know what it was that changed exactly, because it has just been so many things that have all kind of accumulated together. I needed all of those pieces—supportive relationship, skills, and practice – working together. I don't think there's a formula; I think that's different for everybody. It does take a lot of patience, keeping your expectations reasonable and giving yourself time to work through things. I think time is very, very important. I don't think it will be a problem for me again because I won't let it get to that point. I'm still working through some hurdles but it's nothing like it used to be and it's constantly getting better. I had never orgasmed during intercourse before my current relationship. I couldn't have imagined that being a possibility before so that's been fantastic.

Before, I would have been a lot more afraid to expand on the sexual activities I engaged in but I'm a lot more open now to trying new things. I'm definitely a lot more open now and less afraid, in general.

For Sophie, separating her physical pain from the suffering caused by automatic, catastrophic predictions about what the pain meant about her, was also gradual, required regular practice of learned psychological skills and learning to contextualize setbacks as part of an over-

all growing process. She said she continues to intermittently experience pain with intercourse, but no longer feels defined or overwhelmed by it:

I honestly don't know if I saw a doctor now if I would even still 'have' PVD. I'm now aware that it's now mostly within my control and on the minor occasion it hurts it's only as big a deal as I make it and I can usually breathe through it until it passes. We don't have sex on a regular basis, but it's great when we do and nobody is crying after . . . my relationship is even better now because we survived a very difficult period. . . . My partner and I don't talk about 'cures' anymore and I've gotten used to thinking of it as an ongoing process. The quality of my life improved a lot because PVD got resolved."

Although the pain may not have been 'cured,' the suffering associated with identifying herself with it has been "resolved." Sophie described how her initial desire for a 'cure' for PVD evolved from hoping the elimination of physical pain would resolve her distress into a gradual re-storying of her pain experience as one of growth, resilience and expanded empathy:

Of course, it would have been nice if I could have gone to a doctor in the beginning who said they had a cure, and I wouldn't turn them down now if they did, but I'm not holding my breath for that. I had hoped that someone would say if you do this program and practice these things you'll be done. It took some time to wrap my head around the fact that it was going to be a process and not really a promise of any kind of truly complete resolution at the end of it. I was disappointed, but I wasn't surprised. I know that's not how bodies work and it's something that I've had to get used to for a lot of other things in life. No matter how well you heal from something, you'll never heal to the point where it never

happened. It becomes a part of you—a scar or a memory-like trauma you’ve worked through but doesn’t just disappear. As horrible as it was at the time, I can look back and see I was growing. How do I develop empathy if I don’t know what absolute shitiness feels like?

She also described progress resolving PVD pain as gradual and open-ended:

progress is slower than you might ideally hope, but it continues going in the right direction for me. If you stick it out and use the tools that trend should continue. I am not in absolute mastery of it, but with more agency I feel more capable. It doesn’t permeate everything anymore. Now it’s less of a big scary, catastrophic thing and more of just an annoying thing.

Rather than curing her PVD symptoms, Sophie found participating resolved her feelings of helplessness and empowered her to take her life back despite the continued presence of provoked vestibular pain: “Something I got out of the program was getting back the ability to actually do something about my experience instead of just helplessly riding along. It was about being back in control and feeling like a capable human being again.”

Before Celine enrolled in COMFORT she too had hoped for a ‘cure.’ She described the reality that learning to de-identify herself from her pain experience was a gradual and ongoing process that required directly facing negative self-beliefs she had developed about what the pain meant about her. She related how participating in COMFORT initiated that process for her:

Participating in the program was a first step towards completely changing who I was. It was a lot of hard work to get to this place where I can say now that I’ll be okay. I’ll still have doubts or frustrations or negative thoughts, but I don’t feel an overwhelming burden or fear or hopelessness. I will always wish I never had PVD,

but for the first time in my life sex doesn't end in tears and pain. I think all of these factors over the last five years- learning PVD was real and that I wasn't alone, mindfulness, CBT skills, self-compassion and forgiving myself, added together, have helped me get to this point. Now, I don't see PVD as a permanent pain condition but as a manageable, chronic discomfort. I think of it similarly to how someone with diabetes takes insulin, but I'll do the mindfulness meditation. I hope you can tell future participants that even if their PVD doesn't go away completely they *will* be able to manage it.

She recalled how once she identified “self-aversion” as the root of her suffering, overcoming that became more important than ‘fixing’ her physical pain:

In the group we touched on the idea that shame is self-aversion, but we didn't really get into how to let go of shame even though it's acknowledged as a big part of the problem with PVD. Since the mental and physical are so linked, the shame (and self-aversion) of having PVD and carrying that emotional burden probably maintains or exacerbates the PVD pain.

She said her daily mindfulness practice and getting individualized counselling helped her to change her aversive relationship to herself and attend to her overall health: “with self-compassion I've learned to be kind to myself and my body, with meditation, exercise, eating healthier, and seeking better balance in my life.” She no longer ‘avoids interpersonal relationships’ and has found being able to have conversations about sex with friends and family, including discussing PVD symptoms with potential sexual partners “empowering.” Like Jaime and Sophie, for Celine freedom from suffering did not necessarily mean identifying a source or cure for physical pain symptoms but changing her relationship to what the pain meant about her

and taking back her power to define her experiences. This involved gradually developing the ability to respond to physical pain symptoms behaviourally, psychologically and emotionally and accepting pain may be a recurring presence in her life. Focusing on having compassion for her current experience rather than ruminating on why her symptoms developed, has helped her to move past the power her symptoms previously held over her: “I’ve learned to focus less on the unknown whys and more on what I can do about it now. I can’t be sure that knowing ‘why’ would even help me change my experience, so I don’t give it the same power.”

Christine continues to experience some frustration, self-blame and relationship tension for not being able to have pain-free sex with her husband, but nevertheless sees progress in her ability to connect to painful experiences with less distress and avoidance and negative self-evaluation.

I get frustrated sometimes when my friends talk about a romantic weekend and something new they tried and I wish I could do that too! There's annoyance, frustration, and maybe anxiety from uncertainty but there is no all-consuming desperation anymore. Internalizing the breathing and CBT skills means it is less of a process and I know now I can get to the point where I can enjoy sex even if I'm never completely pain free. I can see progress. I still have trouble doing the Kegels without moving external muscles, but I know which are which now and I can relax my pelvis. I found a toy recently that I can actually use and it vibrates! Sometimes I can even insert it and move it around without burning. I still get flare ups on my period which I might bitch and moan about but I'm not dwelling on it the way I did before. Even days when I'm more sensitive, 9/10 times I can switch to external stimulation and focus on what will bring me more pleasure in the moment instead

of just stopping everything like I would before. I also don't beat myself up for wanting to stop and I don't try to push through just for the sake of pushing through. Maybe I really am just too tired or it's too aggravated right now. I don't criticize or blame myself anymore when I can't.

For Christine, progress is a non-linear process requiring regularly practice making contact with avoided physical experiences and developing an awareness of the painful emotional and psychological responses sometimes evoked. She explained, "by acknowledging how much I had been hiding from myself by bringing shame out into the open, I was able to see myself in a more whole way again." As she connected with other women in her group and began directing the compassion she felt for them and received from them in return, towards herself, her goals for change became reconnecting with a sense of "wholeness," rather than "fixing" the physical pain:

Recognizing I would never hold [women in the group] up to the standards for progress I sometimes force on myself, because of my anxiety and depression, means I am less likely to fall down that self-directed spiral. We didn't hold each other up to specific scales, it was all progress period. We could see the different incarnations of progress in a way that redefined what progress meant. . . . It wasn't about 'fixing' it anymore but knowing we all believed we could work through it and we weren't alone. It was more validation that I wasn't just a fellow test subject but was seen as a whole human being, not 'a PVD.'

Christine explained she no longer sees progress with PVD symptoms as the elimination of physical pain but instead finding a sense of wholeness, where pain is still a presence but no longer "in charge" of her life:

When thoughts of self-blame come up now, I acknowledge them and then basically blow raspberries at them until they go away. I have accepted PVD might be a part of my life sometimes, but it isn't everything all the time. That's a positive difference and we call that progress.

For Jenny, her freedom from suffering was directly related to learning that her PVD symptoms were just unpleasant physical sensations associated with a sensitized nervous system and not indicative of a personal failing, a realization she described as “revolutionary”. With the support of her husband, who had already suggested they take intercourse off the table, she felt relieved of the guilt and shame for being a “sexual failure” and “broken wife” for not being able to perform “this basic function.” She said:

I believe now that my womanhood isn't defined by my sexual ability and PVD is not all of who I am. The information and explanation the program provided about the nervous system and hyper nerve endings just made sense. It gave me a new understanding that allowed me to accept my vagina as it is, today. Now I just see PVD as another one of my diagnoses, like my migraines or my rheumatoid arthritis. I don't think about getting fixed anymore because my husband and I are happy the way we are, so there is nothing to fix.

Where women are on this described continuum of wellness in relation to PVD, is implied by the language they use when discussing their current experience with symptoms: those feeling most free of distress tended to take a more expansive and holistic view of health where they accept pain symptoms may recur but feel confident that they can disrupt their social, emotional and psychological responses in a way that limits suffering. To the degree that some still find

symptoms intrusive, language tended towards the judgmental, binary, and present tense when describing themselves.

Anya and Sherry both say they don't think a woman with PVD symptoms should feel ashamed or think of themselves as abnormal or broken but describe themselves that way. What they learned about pain during their participation did not help them change how they felt about it while they experienced explicit threat their intimate relationships would end if they were not able to 'fix' the pain that was preventing intercourse.

Anya began to make progress towards less pain and distress when she and her partner, with the support of a therapist, decided to "drop the end-of-year ultimatum [to fix pain with intercourse or end the relationship] because of how much it was stressing us both out, and as soon as we made these decisions together, a weight lifted off of me. It was a huge relief." This has initiated the process of deprioritizing pain-free intercourse as an urgent treatment goal, towards thinking of progress as a gradual process requiring regular maintenance of the connection between physical, psychological and relationship health:

The fact that I actually went out and got individual help for this was a big step for me. It's helped things get better, and now my partner and I both have confidence that we can do this. Though it's still stressful because penetration is still a challenge (and painful). I have to remind him that I will probably always be dealing with this. But at least now we have strategies, and I know where I can ask for help. I want to get married, but he's still concerned about the sex stuff. So, I still feel that pressure but so much less so than before. I'm optimistic that it's all going to work this time. . . . it feels good to believe that.

For Sherry, accepting a gradual process towards wellness doesn't feel possible while her partner emphasizes she is responsible for resolving PVD symptoms preventing intercourse and regularly threatens to "find sex elsewhere" unless she does. She described how PVD is "still always hanging over us." In this context, she finds it difficult to commit to recommendations that don't provide an immediate and noticeable difference:

when results aren't immediate, doing things like meditating, eating properly, drinking less, or going to the gym, don't feel urgent or important enough in the moment and they fall to the wayside when you're busy. You know rationally that they *are* important, but it's harder to make them a priority or feel motivated to do it when you don't get *something* out of it immediately. Like using a glass of water for a forest fire, why bother?

Sherry explained how her partner:

attributes most of the problems in our relationship to this lack of penetrable sex. He says I should understand why he feels the way he does and its importance to him should be enough for me to try more. He doesn't think I do anything to try to change the situation. I did give up in a sense. Why put all the effort into something that's not going to change? It feels hopeless.

That Sherry experiences the continued presence of pain with intercourse as a sign of her own personal failing and defectiveness is expressed throughout her narrative, but summarized when she tearfully adds to the end of her story:

If I could give other women with PVD any advice I would tell them the opposite of all the negative things that I think of or tell myself. I would say even if you don't have this part of your life working right now, you're not broken, you're still a

valuable, worthy, wonderful, whole human being. It's easier to say those kinds of things to someone else than to myself.

The suffering of PVD was diminished to the extent that women were able to de-identify themselves from their symptoms while accepting them as a part of their broader experience. Those most free of suffering in the continued presence of pain see wellness as existing on a spectrum and as a process, where they recognize social, mental, physical and emotional health are interconnected in a larger whole. Women suggest that resolving the distress associated with PVD does not begin with the elimination of physical pain and would be difficult in the context of unaddressed disruption in any other single area, like a conflicted intimate relationship, persistent catastrophic thinking, or shame, for example. For some women, as the all-encompassing 'life pain' of PVD is addressed, the experience of PVD symptoms are gradually limited to temporal vulvar sensations and their salience is diminished.

3.3.3 Recommendations for clinicians—what we need

All women interviewed credited the program with being an important part of their journey to wellness but varied in how much of their individual progress they ascribed to it. Many saw COMFORT as an introduction to the kinds of practices and support they would need to continue and some credited pre or post- COMFORT experiences with the same as being instrumental to their progress. As women consider how the program was helpful, or not, they also discussed how the group intervention might be improved and other interventions and follow-ups they would like to see included in the future to help other women struggling with undiagnosed or untreated PVD symptoms.

There was general feedback shared by most of the women, given how common they learned it was for women's lives to be disrupted at some point by vulvodynia, that medical

practitioners should be more knowledgeable about the diagnosis and familiar with appropriate intervention and support resources. They also wanted to see a group like COMFORT more accessible by having it offered in several communities, outside of regular business hours or as an interactive online program. Specific suggestions to expand programming included access to pelvic floor physiotherapy in tandem with the group education and psychological skills training and practice, and embedding individual and couples psychological support, in addition to group education specifically for partners, more strategies for coping with challenges in current or potential intimate relationships, and more discussion about overcoming barriers to practicing skills. As previously discussed, women came to see freedom from the centrality of PVD in their lives as an ongoing process rather than the result of a single intervention. So, many wanted to see programming that had flexibility for them to return to ‘top-up’ their skills, follow-up and check-ins with team doctors and re-connect with other women, as their informational and support needs differed when first enrolling and changed over time with their life and relationship contexts.

3.3.3.1 We need: knowledge (research, resources, treatment, education) democratized (“people need to know this shit exists”)

General recommendations that all women shared were ensuring healthcare practitioners have at least some general knowledge about vulvodynia or at least take women’s complaints seriously, as a rule. Sophie discussed how she had figuratively “curled up into a ball” in response to the distress she was experiencing because of PVD symptoms and feared being judged as “hysterical” by doctors. She described how a friend who had similar symptoms found a copy of the q-tip test online and “dragged” Sophie to a walk-in clinic and “made him” conduct the test. She said “It was such a relief seeing a doctor who was open to exploring the possibility, even though he admitted to not knowing much about PVD”:

I know most doctors have tons of patients in a day and it's probably normal for them to be jaded when someone comes in with something that they've never heard of. Getting this information to doctors and increasing awareness would help to legitimize this. But women should be listened to and taken seriously, anyway.

Jenny would like to see in-services provided to both emergency room doctors and nurses with information about vulvodynia. When storying her experiences, she contrasts her supportive experience with her family doctor and those with the COMFORT study team with one she worked alongside in the emergency department of a local hospital:

As a nurse in an emergency ward I often chaperone gynecological exams... I would like to see more education in healthcare settings about conditions like PVD so my colleagues would be better trained to take care of women in that situation. I remember once trying to explain to a doctor I was working with why a woman waiting for a pelvic exam might be nervous about it. I told him what provoked vestibulodynia was and that it was being studied at UBC. He seemed surprised and even laughed in disbelief. He just brushed me off saying 'Oh, tell her the exam's a piece of cake.' He completely dismissed me. If healthcare providers don't know PVD even exists, they aren't thinking about how much more painful or traumatic a pelvic exam could be for that person.

Sherry continued to seek medical help after participating in both COMFORT groups without a positive impact on her symptoms and found the lack of knowledge about PVD and contradictory advice she received from doctors, before and after, so frustrating and unhelpful she "gave up":

I heard recently from a doctor that I could actually have been making my situation worse with the pelvic floor physio by tightening my pelvic floor rather than relaxing it. Someone else said that I should have been give progesterone rather than estrogen. It's difficult to know whose advice to trust. It's really frustrating.

She added: "I think PVD needs to be taught in medical school or doctors need a refresher on this. I remember showing the COMFORT binder to my doctor and her saying how she wished she had something like it for some of her patients."

Ashley described how receiving advice from HCP 'to have a glass of wine and relax,' "was never going to work for me." Not finding the advice of a gynaecologist to visit an LGBT bookstore to learn about using dilators for vaginismus helpful, she "gave up" seeking help until she came across information about vulvodynia in a clinical psychology class. She said, "It would definitely help if doctors knew what PVD was." Celine had hope that doctors were now receiving this information and that more women will receive a diagnosis and be connected to treatment options sooner than she was:

There is much better research now and information is getting to doctors in a way that it didn't before. I heard every UBC medical student learns about PVD in their gyne rotation, now. So, going forward, there's hope that doctors will be aware of it and can properly diagnose it earlier. Things are getting better."

Women also wanted to see information reach people beyond the medical community so women experiencing symptoms are not dependent on individual doctors for access to information and treatment options. Sherry, Celine and Anya, after visiting multiple doctors, were eventually connected with a doctor already knowledgeable about PVD. Jenny and Christine's doctors first learned about PVD by seeking out information about the COMFORT study in

response to their patients' unexplained pain symptoms. Jaime read about the MVP in a local newspaper, which eventually led her to COMFORT after years visiting healthcare practitioners without information or help. Ashley received information about vulvodynia in a psychology class, but Anya was disappointed when she "took a human sexuality class my last semester in university and pain was never mentioned". They imply that having more information about vulvodynia in community contexts will increase the likelihood women will not need to rely on the knowledge of any particular health provider. Anya had even considered writing a book so "people know this shit exists":

I've thought about writing a book about my experiences to reach other women with PVD, so that women know this happens (and how hard it is to deal with) . . . I would want to tell women with PVD what to do, what to read, and where to go for help.

Women would like to see the specific education and skills they acquired as a part of their participation accessible in locations outside Vancouver, outside of regular business hours or as modules on an online platform with the option of real-time virtual facilitation of the group.

Ashley found driving for two hours every week to attend the COMFORT group challenging and would prefer to practice the skills on her own using the material in the COMFORT workbook that she still has. However, she thinks having the structured support offered through the group while learning was essential and would like to see similar options available in communities outside of Vancouver:

It might be helpful to have a follow-up group to refresh those skills, but I think actually doing it out in the real world is what helped for me. For a while I really didn't practice because I had other stuff going on, but I could always go back to the workbook and look at what I'd done and what we discussed and that helped. I

don't know if I would have been able to keep up with more meetings because it was a long drive to get to COMFORT, especially during the work week but it also wouldn't be the same just having the workbook the first time you're learning. Having somebody walk you through while being in a group of people who have the same sort of thing going on and was so beneficial. It could be useful to have something online, so you don't have to take time off work or class. It would also help if the group was more widespread and there were meetings outside of Vancouver.

Sherry suggests having concrete information about research supported interventions readily accessible in an online format can help to maintain hope that continued skills practice will help:

Hearing 'we think it helps' or 'it might help' is very vague and nebulous and some of us want to see the facts and the numbers. I understand correlation does not equal causation, I know there are other factors involved in why something may work or not but let me see the research so I can decide for myself. I need to know what the chances are before I deplete my bank account and add to my and my partner's frustration. It just dashes my hope that there is any chance of getting this into remission, so you're stuck with the pain and you're stuck with no sex. You're stuck with having this hole in your life and you're stuck with feeling broken. If you have hope, then you will try things and you'll keep pushing.

She describes a virtual resource that included the group modules and informational resources like recently published research and recommended interventions and community practitioners:

I know the UBC clinic has a really good reputation and is on the leading edge in this kind of research. It would be great if you had a website that had an updated list of new resources or research that you recommend. If the whole idea is to help women with this as opposed to just study women with this then maybe in the future you could break down the COMFORT program into online modules or just have the parts that deal with physical aspects like the pain receptor diagrams. It could explain the CBT diamond and the relationship between thoughts and behaviors and PVD.

I would love to see any kind of an online resource tool, even if it's just a rudimentary couple of pages of updated recommendations and a FAQ section answering questions about antidepressants or physiotherapy. A website like this could be helpful to medical practitioners too. They have online modules for people who have sexual difficulties because of cancer or for people dealing with social anxiety. If there are elements of the program that aren't proprietary, then have them available for the public. If it's true that 2 out of 10 women suffer from this at some point in their lives, then help a sister out!

Jaime thought it would be helpful to involve participants in group facilitation to leverage the knowledge of their 'lived experience':

My own history with pain opened doors for me to be in the service of other people who suffer so much, and I feel profoundly grateful to have the opportunity to bring more ease, more optimism and empowerment to people's lives. That would not be there if I had not lived that story and I wouldn't be doing work I am so passionate about if it wasn't for the MVP and COMFORT programs. It would

be an asset having somebody, particularly with PVD, who's had lived experience with the breathing and mindfulness tools and come out the other side using them. It could be really inspiring and really enriching because those are tools of lived experience more than they are tools of knowledge.

3.3.3.2 We need: More time to explicitly address practice challenges (“consistency builds commitment”)

Both Celine and Jaime's account stands out for how they embraced practice as a regular part of their daily lives after their participation, and both suggested that future programs emphasize and explicitly address challenges related to practice, particularly for mindfulness skills. The delivery of the skills in COMFORT as part of a research protocol required treatment elements, including the meditations assigned for homework, to be the same for everyone for the duration of the study. The most consistent critiques of COMFORT involved this mindfulness homework: the sound and length of the recordings, a misunderstanding of the goals of mindfulness (present moment, non-judgmental awareness versus 'shutting off' thoughts), and a related sense of frustration or self-judgement for not 'doing it right'. Some quit practicing or concluded that mindfulness was not helpful for PVD symptoms. Others adapted practices, finding differently voiced recordings, reducing the length of daily practice from 40 minutes to 5-20 minutes, and/or those emphasizing self-compassion, to overcome barriers to daily practice. There were fewer critiques of learning the CBT skills which some implied were easier to use and practice as presented and experienced with more immediate benefit. Women suggest having more time and flexibility to explicitly address practice challenges for both MBCT and CBT skills during the group would foster confidence in their ability to positively influence their experience and self-compassion when their practice is not 'perfect' and progress not immediate. They

discuss how freedom from pain and distress expanded to the extent they were able to ‘internalize’ the skills, so they became ‘habitual.’

Jaime and Celine argue that explicitly nurturing self-compassion as part of the intervention would be integral to participants integrating new psychological skills into their daily lives, rather than giving up before they begin to notice the positive impacts for fear they aren’t “doing it right.” Jaime says:

It’s not that mindfulness or CBT bring you to this sudden place of, ‘whoohoo!’, but more this soft place of meeting the truth of this moment with curiosity instead of judgement. Self-compassion is a huge part of taking those exercises and practices in the direction of making them new habits. Beating yourself up about not doing it right or doing it enough when learning and practicing those skills just pulls a lot of your life energy.

Celine, who did not have any experience with mindfulness before her participation, found she had to adapt the assigned homework to shorter meditations focused on self-compassion, to meet her goal of developing her daily practice. She says:

It was really hard at the beginning of the program doing 30 and 40-minute meditations when you’ve never done it before, and you’re not used to your mind going all over the place. The way I got myself to practice was to just start with two-minute practices I found online and slowly build it up to three, five, and then 10 minutes. I wish they’d emphasized more that your mind wandering is just part of the experience and to just be aware it’s happening instead of trying to stop it. I know now there’s no right or wrong way of doing it and that learning takes time to practice, but when I started, I would get discouraged thinking I was messing it up.

I still get discouraged sometimes. There are days when meditation and mindfulness come easier and days when it is more difficult. When I first began developing my practice, I did a lot more of the Loving Kindness-type meditations, repeating mantras to be kinder, especially to myself, which has always been very difficult for me. I used to be much more critical and harder on myself. Without being kinder to myself, I don't think I could have kept up the mindfulness meditations, as I would have given up earlier thinking I was failing. I've learned and accepted that perfection is not the goal, and I don't beat myself up over it anymore.

Sophie, who was part of the CBT group, found the same challenges with the length of the body scan meditation, and also (like Sherry), found the sound of the voice and some of the content of the recording off-putting. Her friend, who had facilitated her diagnosis and entrance into the MVP before she enrolled in COMFORT, re-recorded the meditation to run at a shorter time that, along with the sound of her "dreamy voice," made a regular practice she continues today more manageable. She also felt the extended immersion in skills offered in COMFORT, after being introduced in MVP, was an important part of making them a "habit":

There was also a brief introduction to CBT in MVP where I began to feel change happening on the surface. I felt a little adrift when it was over so I was relieved to get an email about the COMFORT program because it meant I could keep that momentum going. A lot of my unhelpful thought patterns and reactions had settled into habit and I needed that extra structured time to go deeper with the CBT skills and to really internalize them, so they became the habit.

She implies that the extended, and structured time was also helpful for developing self-compassion rather than focusing on, as Celine said, 'perfection as the goal':

As a recovering perfectionist, there is always a lot to unpack whenever I don't do or feel what I think I should be doing or feeling. I'm better at being more empathetic with myself but it's a work in progress. It was helpful to be more aware of context and to widen my perspective so that I could recognize these changing patterns and see that what I was trying was working. I would never have been able to do any of that before and I don't know that I would have come to that naturally on my own . . . having the time in COMFORT to make new habits with the tools I had started learning through MVP helped to make them part of the way that I talk to myself now.

Jaime emphasizes how having flexibility to adapt mindfulness practices to manageable time increments can encourage the development of a daily practice:

When I enrolled in the CBT group, I had already been developing a mindfulness practice. I started my yoga teacher training in 2009 but initially struggled committing to practice for an hour every day because my life at that point was all over the map. I learned the Sanskrit word, 'tapas' which is commonly translated as discipline, but I now understand to mean 'consistency builds commitment.' The idea is that when you're trying to make a new habit, less is more, so I started practicing five minutes a day every day, no matter what. It was really useful for me to bring that practiced skill of consistency to making habits of the tools that I learned in COMFORT which made them that much more effective. It was the foundation for incorporating those skills into my life and for then bringing them into my work.

For Jenny and Anya, the mindfulness practices did little to address the pain they experienced with intercourse and in fact seemed to make the pain worse, and both discontinued using mindfulness in a sexual context. Jenny says:

Learning new skills takes a lot self-discipline and because I personally find change hard, I wasn't sure if developing a mindfulness practice was something I could really *do*, but I was willing to try. I found some of the practices easier than other. . . . I found I could be intentional and observe my sensations while doing a neutral or familiar activity like eating or exercising [but] found it far more challenging trying to stay present during intercourse so I could learn to let the pain pass. I was always hesitant at the point of penetration, anticipating how much it was going to hurt. Mindfully attending to physical sensations, already heightened because of sensitized nerve endings, just intensified them for me. It was like how images on a newer TV seem so much more vivid than on older ones—like experiencing the pain in HD.

Anya also describes how trying the mindfulness practices while attempting intercourse that continued to be painful and distressing also seemed to intensify her physical pain experience. She describes self-judgement for 'not doing it right':

I see the value of being in the moment, slowing down, and not fretting about anything, and I know it's something I should work on, but it was a challenge nonetheless. In other contexts, I was much better at calming myself and shutting my mind off, but as soon as I was in a sexual situation, it just didn't work, I couldn't do it. I just kept thinking: "This pain is terrible," "My boyfriend isn't enjoying this because he can't do anything," and "Why can't I just be normal?!" I

struggled to flush those thoughts out, but I just couldn't shut them off. I knew I shouldn't be focusing on health stuff and that I should just be breathing, but I couldn't activate it or action it.

... I didn't want to practice mindfulness during sex because sex hurt, and my partner and I would both just get frustrated. I'd be frustrated with the pain, and he'd be frustrated because he had to go really slow and he was always worried about hurting me. Any attempts at penetration would hurt, and even though I would try hard to focus in on other sensations, it never worked. So, mindfulness practice was difficult to say the least.

As previously discussed, she found not feeling comfortable discussing the challenges she was having in the group context led her to give up practicing what didn't seem to be working.

Christine did not have previous experience using mindfulness and found related practices much more difficult to incorporate until she received advice from more experienced group members:

There were some things that weren't in the material that we learned from just talking to each other. I had challenges using meditative breathing for penetration but talking to other women led to me trying it for non-sexual situations. Even though it wasn't helping when I seized up during sex, it really helped when some asshole cut me off driving! That encouragement to practice breathing in other contexts helped make it more automatic and not just a formal practice 'for insertion'.

Some women implied that the goals of CBT practice, an 'active' challenging of maladaptive thoughts, seemed to have more immediate benefit than practicing non-judgemental

acceptance of their response to the anticipation or experience of provoked vulvar pain. Sherry, says:

I did both the Mindfulness and the CBT group. I know some studies say that mindfulness actually helps more than CBT but I think it depends on the kind of person you are. I think that doing the CBT group first was really good for me because I'm more analytical and learning concrete skills felt more important than the meditative stuff. I didn't want to be told to just meditate it away. Learning to work through the emotion, situation, and automatic, biased thoughts in the work sheets felt really concrete. There were just more tools to use in the CBT group and those exercises allowed you to target the mental junk and the judgment and shame. I got more out of that than the 'put this raisin in your mouth and feel it' exercise. Don't get me wrong, I think everyone should develop a mindfulness practice, but I don't know if that's necessarily the one thing that would help women with PVD the most. Besides you can get mindfulness anywhere now. . . . I do believe in the overall concept and I have continued to practice meditation on and off since even though it hasn't seemed to have helped with PVD.

Ashley would seem to agree:

I think CBT is a little bit more up my alley and probably worked better for me in the end than mindfulness would have. I have studied some meditation-based therapies since the group, but I like how CBT really digs into the reframing of thoughts which I need more. It was helpful for me to be able to challenge my thoughts and realize that just because you think something doesn't mean that it's true.

Christine had recalled another group member quitting the CBT group after the first day where she had angrily expressed she was looking for something that would ‘fix’ her and make her ‘normal’. She says: “she was verbalizing so many things that I had thought even though I knew there was no such thing as ‘normal’ . . . I know it can be frustrating trying therapy for the first time when you think your thoughts and feelings aren’t the problem.” She had found her previous experience learning CBT skills in individual counselling prepared her to connect this practice with PVD symptoms:

I felt empowered by the possibility I could manage this on my own because I knew how effective CBT could be if you work at it. I also knew it wasn’t going to provide an immediate solution and that we’d be looking at thought processes and at pain *management*, but I left that first day feeling tentatively hopeful.

Many women found having previous experience with the skills or finding a context (individual or couples therapy or other group interventions) where they could continue these skills were an important part of their progress. They imply having flexibility within the group intervention to adapt mindfulness practices to shorter lengths, with different voice options, emphasizing self-compassion and more explanation and clarification on the goals of mindfulness and how it might help with PVD pain would make participants more likely to adopt regular practice. Women in both treatment arms also emphasized the importance of understanding that regular practice was important, and that positive change would be gradual, and suggest that some women, depending on their contexts (busy or stressful lives, conflicted relationships, inexperience or misunderstanding of the goals of the intervention) would need more time and support to ‘internalize’ the practices. Jaime suggests providing women with the opportunity to learn both skill sets so that they are able to connect with a practice that works best for them:

There's a certain degree of skill overlap with CBT and Mindfulness in that they both foster an awareness of yourself, your thoughts and how you're responding. I think people will find similar benefits with either mindfulness *or* CBT- maybe one person connects more with the meditative components and someone else with the focus on changing habits in thinking.

Much of the advice participants suggest for other women with PVD is patience with change that may be so incremental as to not be immediately perceptible. As Ashley states: "It does take a lot of patience, keeping your expectations reasonable and giving yourself time to work through things. I think time is very, very important." Sophie also emphasizes the importance of thinking of progress as a long-term process:

I think it would have been neat to do a follow-up like this closer to the program and then have routine check-ins every year so you can get more information about how it actually changes over the long term. I don't want to bum anybody out and say it's going to take a good eight years before things settle, but it could take a bit of time.

Jaime agrees following up with women beyond 12 months may help to identify how women may overcome barriers to practice and how the benefits of regular practice continue to "unfold" across someone's life:

I've read, reviewed and critiqued pain studies during a post-grad program in pain management and I continue to in my work. Something that I have noticed was that all of the benefit I have gotten from participating is not being accounted for in the research, especially beyond that year or so from treatment. The kinds of tools that you teach in COMFORT have more exponential benefit. The more that you become mindful of your thoughts and whether they're serving you or not, the

better you continue to get at doing that. . . . A lot of that came from MVP and COMFORT planting stronger seeds of that in my life that just keep growing. They are the kinds of skills that you get better at the more you practice. But research doesn't account for how that generally unfolds in your life.

3.3.3.3 We need: the option of ongoing follow-up and support (“what can I do from here?”)

The women emphasized they thought most would need more time and flexible support options for practicing and using psychological interventions to ameliorate the pain and distress of PVD symptoms. Many had suggestions for providing women with ongoing structured support and lowering barriers to accessing these services with online or community options connected with a program like COMFORT. Many women suggested including individual appointments as part of the group intervention and available in follow-up would help address practice challenges, clarify information and support skills maintenance.

Ashley credits her participation with changing her understanding of how her mental and emotional life was impacting her sexual life and sought continued support: “because of how being a part of that group really helped me reframe things and look at them differently, I followed it up with a DBT group close to home so I could continue to practice those skills. She explained: “I'd probably also recommend including DBT because it did help me with a lot of underlying issues that were affecting my sex life.” Sophie also found she was able to continue her progress with more support: “When I found CBT and mindfulness useful in MVP and Comfort, I started doing more of both. Going to other meditation groups and counselling on my own ended up being a huge part of getting me through.”

Celine would also like to see the groups expanded to include an option to follow-up. She stated,

I think it could be helpful for women with PVD to be able to access an ongoing support group, online webinars, or moderated online websites to help us find a community, encouragement and support from others who understand what it is like living with and managing this condition.

She credits her participation with beginning her journey to wellness and inspiring confidence to pursue individual support. She would like to see women encouraged to seek individual support to continue their progress. “It would be so useful to include a conversation about appropriate individual counselling resources when the group sessions end. I felt the COMFORT group was a great beginning, but I had issues with PVD that the group didn’t address.” She further explains:

Individual counseling helped me work through the self-aversion and negative thoughts and repetitive patterns, like forecasting negative outcomes (e.g., I will be rejected by a potential partner if I tell them about PVD). Through the group I had learned to manage the physical part of PVD and watched my Q-tip tests go from eights and nines to fours and fives. But the whole emotional and mental part hadn't caught up with the physical progress and that needed more individual attention to keep that momentum going. . . . His CBT approach really complemented what I had learned in the mindfulness group because he knew about PVD and how both CBT and mindfulness could be helpful. Working with him also helped to counteract the negative experiences I’d had with male doctors in the past.

As previously described, Sophie (similarly to Christine and Jenny) had found her individual visits with the study doctor who ‘counselled’ her about the stress she was experiencing in the rest of her life facilitated her trust in the process. Anya is explicit in her recommendations to include individual appointments alongside the group. She’d had a difficult time asking questions about her challenges with the material and practice during the group and said

she and her partner had been struggling throughout that entire time, but it took me a couple more years to get to a place where I could admit I needed more help. I realized that I couldn't do things by myself because I kept trying what we learned in COMFORT, but it just wasn't helping.

She sought individual and couple support and found that when “My partner and I revisited [the material presented in COMFORT] with my counsellor and it had clicked in a way that was much more helpful — it was like a light went on”. She said that during her participation

We had one-on-ones with a doctor, but those appointments dealt with the physical symptoms (rather than the mental ones). I think it would have been more helpful to have individual appointments with the actual psychiatrists or psychologists who were teaching us the skills. . . . I did appreciate the information in the education piece and the way everything was visually presented, but the overall sense I got was that some things were glossed over and, in the end, it felt like we were left to our own devices. During one of our group sessions, I had asked if we were going to get support afterwards and the answer was that the research group was over, but I could speak to the clinic doctor if I wanted. Unfortunately, I associated that doctor with the physical aspects and I had more issues with the mental aspects, so

I didn't reach out to her. In the end it left me thinking: “Well, what can I do from here?”

Anya felt that what ended up ‘really helping’ was “one-on-one counselling and physiotherapy”:

My counsellor also recommended a physiotherapist who just focuses on pelvic floor issues. With the physiotherapist, we worked with biofeedback — you can literally see what’s going on down there! I could see myself relaxing while I was actually relaxing, which was super, super helpful.”

Although not all women expressed interest in personally attending follow-up groups or individual check-ins, many would like to see that as an option for women who are continuing to struggle or who may be learning the information and skills presented in COMFORT for the first time. They would like to see something available online that provides the same information both for new learners and as a resource to refer back to and that included recommended community supports (individual and couple therapy, physiotherapy) and updated research. Some would like to see an online version of the group with moderators and attendance in real time and in-person groups like COMFORT available in communities outside Vancouver and regular business hours.

3.3.3.4 We Need: Treatment that involves partners and includes relationships (“It takes two to tango”)

When discussing barriers to treatment and what they thought was missing in the COMFORT group intervention most women discussed the importance of considering the context of their intimate relationships. They would like to see more explicit discussion in groups about the impact of PVD on relationships and strategies for addressing these impacts, education about PVD delivered directly to partners, and partners included in the therapeutic process either with

couples groups, partners groups or individual couples therapy, in tandem with COMFORT.

Women highlight the role of the quality of support from their intimate partners as pivotal to their progress and recommend intimate relationships be specifically addressed as part of future treatment interventions.

Sophie emphasizes throughout her story how important her partner's support was to her progress and would like to see all partner's receive educational material similar to what was delivered in the MVP, in addition to a specific support group for them:

Painful sexual intercourse involves a partner being present so having loving support from a partner is a huge part of what might make this program successful for someone. I know you can't find someone a supportive partner or make their partner more supportive, but I think it would be really useful for partners to hear from a doctor or a counselor, that PVD is real: "No, she's *not* blowing it out of proportion. A lot of partners feel the way that you're feeling. Here's what the research says we should do" and so on. MVP's partner education session helped us because my partner wasn't getting his information delivered by me in an extremely emotional way. Having that as a regular part of treatment would mean less doubt that a partner is making it up or exaggerating. My partner never doubted my word for it, he was supportive from the beginning, but he wished that there had been a group for the guys. He said a few times that it didn't seem fair when it was something that affected both of us but I was the only one who had to find the time and energy to go to group, do all of the work and then also bring back all the information and then teach him about it. He would have appreciated having a space where he could ask questions about PVD and where he could also talk to

other guys who may have shared that experience where every offer of intimacy was being rejected. What a terrible space to be in just getting rejected by your partner on a regular basis and not knowing what, if anything, you could do about it. Of course, the guy would have to be willing to go.

The friend who had helped her access treatment through the MVP and COMFORT did not have a partner “willing” to participate. Sophie says:

PVD was still devastating for her and her relationship fell apart. Her partner was not willing to put in any kind of work and bailed when she was part way through the program. It undermined her ability to trust anybody's willingness to actually stick it out and have those conversations. She has a casual partner now who has no idea about her vulvodynia and she probably just powers through pain when it comes up with him.

Sherry's relationship stands out in stark contrast to Sophie's for providing security, understanding, support and a 'willingness to participate'. Sherry's partner attended the couples' education session offered in COMFORT, received partner-directed information about PVD from a physio-clinic, and attended couples counselling while she was participating in COMFORT, and where she says he recognized he had been being “emotionally abusive”. However, at the time of our interview, unlike Sophie's partner who felt it was ‘unfair’ she had to do “all of the work” to resolve the relationship impact of PVD, Sherry's partner felt it ‘unfair’ (and “horrible”) that he had “a partner that couldn't have sex”. She says,

he's been on the verge of just walking away and breaking up with me multiple times because of this. His resentment has been going on for a while...Just two months ago he said that if something doesn't change, he's either leaving me or will

cheat on me and he was getting into a new exercise regime and losing weight in the effort to attract somebody else. That made me feel really rotten.

Sherry explains that “he attributes most of the problems in our relationship to this lack of penetrable sex. He says I should understand why he feels the way he does and its importance to him should be enough for me to try more. He doesn’t think I do anything to try to change the situation”. Where Sophie’s partner saw the problem as shared, Sherry’s partner saw it as hers to solve, on her own. Providing education to partners about PVD may not be enough on its own if partners are unwilling to participate in a therapeutic process that may require an, at least, temporary change in their expectation that there is no ‘sex’ without intercourse.

Jenny also thinks many male partners may be unwilling to attend education or couples’ sessions and like Sophie believes this may be due to a belief that her avoidance of intercourse is about rejection or signals their personal failing. However, like Anya, Sophie, Celine and Sherry, she thinks that this may be helped by getting them information about PVD as a legitimate diagnosis, its impact on relationships and practical advice about how their participation could help, might encourage more collaboration:

I think it could be helpful to involve men in at least an education session, because otherwise we might be the only knowledge connection between them and our condition. Partners learning about PVD and its impact on relationships from an expert could lead to more understanding and choice about what *they* can do...

Having a supportive and understanding partner who doesn’t shame you or put you down for not being able to have intercourse but adapts intimacy in a way that works for *both* partners contributes to the betterment of the person with PVD *and* their relationship. It might be a source of embarrassment to acknowledge in front

of other men that something so intimate in their marriage is *not working*, so I don't know how many would show up. Maybe they feel the problem reflects negatively on *them*, that it's just about rejection or just her problem to fix. But if they could just lower that pride a little bit and get involved, learning about this together could be about growing together while trying to make the best out of a situation that impacts their partnership so much.

Anya found once she involved her partner in couples counselling where he received information similar to what she had learned in COMFORT, he became involved in the therapeutic process and they began to work together with "less pressure" about a particular "timeline" to reach a specific goal, she began to see progress. She also thinks that couples support, and partner education should be included as part of COMFORT:

I know the group was about learning mindfulness, but it would have been helpful to talk about how PVD might impact our relationships. I understand that the focus was on us because we are the ones with the pain, but it takes two to tango! I think that the relationship part and that key piece of how to talk about PVD was missing. The cards that have been dealt to me unfortunately affect my partner in so many ways; it's still affecting him. I think it was really hard on him once the pain got in the way because he thought that, suddenly, I didn't love him anymore...I know this has been a huge struggle for him too. It would have been so helpful to have had some discussion about how to communicate through that relationship stress. I don't know that a full couple group would be necessary, but I think incorporating couples' issues or having a separate couples' appointment with a professional who knows about PVD would be helpful...I joined COMFORT to benefit my

relationship – it wasn't strictly for me, nor was it strictly for my partner. Having couples counselling sessions where someone is there for the relationship would have been a great option during the group sessions. At the very least, it would have been super helpful to have a couple's education session with the same knowledge that we got with the facilitators (drawing on the boards and answering questions).

Ashley described “falling off the bandwagon” with skills practice during her participation because of a “brutal break-up” where she had felt pressured to continue painful intercourse and had found out he was having sex with other women. With new confidence discussing sex and PVD after participating, and with the material from COMFORT to refer back to, she found she and her current “understanding and patient” partner were able to anticipate and work through any sexual difficulties, slowly, together. She says:

The relationship part is pretty integral for me. Going through all of that stuff and having a supportive partner versus not having a supportive partner was night and day for progress in this. I feel like progress for PVD is generally going to be fairly slow and you have to have somebody who's patient and understanding and willing to work with you through it. They never directly addressed that stuff in COMFORT, but it always seemed to come up in conversation.

Celine, who was not in an intimate relationship during her participation, agreed that “something we talked a lot about amongst ourselves, but wasn't addressed in group, was approaching relationships with PVD”. Her PVD symptoms had led her to avoid intimacy and she attended the COMFORT couples' session hoping there would be more information and advice for navigating intimacy in relationships. Not finding what she was looking for she was able to eventually address and overcome some of the fears she had about potential partners' response to

her PVD symptoms with individual counselling. She wanted to know: “What do you say to a new potential partner and when? If you say something too early you are frightening them off but wait too late and they feel that they were taken in by you. Women in relationships had a different set of issues related to thinking they were letting their partners down.” She suggests, “It would have been really beneficial to have a discussion about how to deal with partners, whether you had one or not.”

Jenny recalls “it was extremely painful to hear stories about spouses not being supportive, understanding or encouraging of women in the group” and how “she purposefully did not share stories about how supportive her husband was because she did not think it would benefit” those women who described male partners that “made them feel diminished because of their inability to engage in intercourse or were seeking sex elsewhere”. Sherry remembers at one point during one of the group sessions she attended how

other women described how supportive their partners were and I broke down crying and had to leave the room because mine wasn't. Mine was not just unsupportive but verbally aggressive, yet I was more afraid of being on my own then of tolerating his abuse. My options now are either to choose to be by myself or take it.

Women describe how what they learned in COMFORT helped them to address their own sense of shame for ‘failing’ as partners or women because they could not engage in pain-free intercourse. However, beliefs about the centrality of intercourse to the value of their contribution in an intimate relationship persisted to the extent that male partners insisted on its importance and viewed a lack of penetrative sex as her responsibility to, urgently, resolve. They discuss how an intimate partner’s support and understanding could be better facilitated, and collaboration

encouraged, by delivering education about PVD to partners directly, including them in the therapeutic process, and explicitly addressing and expanding discussion about relationship impacts and tools for communication as part of the group intervention. They imply that where male partners are not willing to adjust their expectations for 'sex', work that women may do on their own will be much less effective.

3.3.4 Role of Social Discourse in defining and prescribing women's bodies and sexuality-

What is 'normal'? ("Maybe women's pain has always been ignored")

Dominant discourses of gender are reconstructed across narratives, revealed where heteronormative ideologies of womanhood (and manhood) are reproduced and resisted in the story telling process. Throughout their stories, women discussed how they had believed their inability to have pain-free intercourse signaled personal failure and essential defectiveness. As previously described, the diagnosis, group context, and psychoeducation began the process for many of the women of externalizing or de-essentializing the source of their pain, creating new possibilities for how they saw themselves and responded to distress. While many women have gotten to a place where they no longer see themselves as 'abnormal' they often reference less confidence that others (doctors, partners, friends) will see them this way. They imply there are limits to change where the objectification and second-class status of women's bodies and sexuality is culturally pervasive.

3.3.4.1 Shame: Signifier for violation of gender norms ("sex was supposed to come as naturally as breathing, sleeping or eating, but I kept failing at it")

The frequent use of 'shame' as a signifier on their journey to wellness, reveals a self-policing of properly performing or embodying social norms related to heterosex as a cornerstone

of womanhood, and thus personhood, and an internalization of expectations of judgement for violating these norms.

Christina discusses shame about sex as learned, then internalized and embodied: “I was raised in an ultra-conservative, Roman Catholic family where I internalized the message of fear and shame about nudity, sex and masturbation”. She explains how this messaging combined with punishment at 5 years old for getting caught masturbating, and a sexual assault by her first boyfriend led to her ‘cutting herself off’ from “that part of my body” and ‘losing touch’ with her sexuality. She describes feeling responsible for not preventing the assault and struggling with self-blame for PVD symptoms that prevented her consummating her marriage on her honeymoon after waiting for 5 years: “I had been angry and blamed myself for what was wrong with me and that I couldn't be a physical partner to my husband”. While she had found counselling helpful for relieving some of the “shame and guilt about sex my mom had enforced”, it was experiences she had throughout the group that led her to re-embodying her sexuality and directly confronting what she had been taught about women’s bodies and sexuality: “I even began to face resentment I had towards my family for teaching me that sex was scary and dangerous and that pain is a given for women and something you’re helpless in the face of. There was this conundrum that I had always been so good at isolating body sensations and muscles through ballet and swimming but I had avoided this other entire part of me. It was huge to acknowledge for the first time how that avoidance was at least partly because of the shame I was taught in my family”.

Celine also frequently references shame when describing PVD’s painful impacts and like Christine recalls these were taboo topics in her family’s culture: “in my culture, sex, women’s health and emotional or mental issues are still mostly not talked about. I never discussed sex with my mom”. Complicating the message she received from her family and later a psychiatrist that

sex and pain were not worthy of addressing for women, was also learning that sex should be 'easy'. The judgement she expected from others became internalized as "self-aversion":

I was isolating myself because of this shameful secret of PVD. I felt completely alone in this pain and couldn't talk to anyone about it. There was cultural shame and wondering if the pain was a punishment for having sex before I was married and personal shame from this idea that sex was supposed to come as naturally as breathing, sleeping or eating, but I kept failing at it. I remember learning about Maslow's Hierarchy of Needs in school where sex is considered a physiological need, so I felt like a total loser that I couldn't fulfill a basic human function. Working through the shame started with learning to talk about sex. It's horrifying how shameful and secretive it has to be for women.

She said: "I spent 20 years just focused on work and doing anything to avoid interpersonal relationships" and "I've never been married and didn't have children because I was so ashamed and closed off." She had felt sure future partners would reject her and be "shocked or grossed out or scared away" if she told them about PVD, but also worried that waiting "too long" to tell them would result in them thinking "that they were taken in by you".

Jenny described the shame and guilt she had that her husband had "gotten a broken wife" and how the COMFORT group was also the first time she had discussed her PVD symptoms with anyone besides her husband and doctor:

It was an embarrassing secret I kept because everyone assumes that part of your body should just work and I knew I'd be judged because mine didn't. I didn't feel proud as a woman in the sexual component of my life, but a lot of anger, grief,

and shame about it...Before I had kept this thing that was 'wrong' with me a secret because I was afraid of being judged by others. I was dealing with this terrible shame, frustration and guilt for not being able to perform as a woman and a wife, all alone.

She says later:

Although I have been able to talk about sex in relation to my husband's disability, I am guilty of not sharing my own experience with PVD, even now. I don't want somebody joking if I'm in a bad mood one day that it's because I can't 'get laid'... I guess that is me still struggling with some of the shame.

Sherry has also avoided discussing PVD symptoms that had disrupted a previously "joyous and happy sex life" and made her feel "disabled" as a woman and like she "belonged in a leper colony":

It still feels really shameful to talk about it. I recently got back from a trip to Mexico and my friends were joking about how I wouldn't be getting any sleep that night when I got home to see my boyfriend. I laughed it off but I was thinking: "well that ain't going to happen". I wouldn't say that aloud because of the shame. It feels like something you can't talk about because you're afraid of being judged or looking like a weirdo or like less of a person or not whole and I already have those feelings about myself. To have other people feel the same way about me is even more tragic. I don't need any more judgment.

It's something that no one wants to admit to because there's such shame around it because it involves sex and because it makes you feel like you're a broken person. Isolation and shame go together.

Sherry's story stands out for the explicit reinforcement from her live-in partner that her shame was justified, and that if she didn't 'fix what was broken' he was entitled to seek intercourse elsewhere.

Anya, like all of the women interviewed, discussed how learning how many other women have PVD helped with some of her shame. However she said she continues to feel she isn't 'normal' compared to "the majority of other women": "It isn't fair that my partner and I (especially my partner) have to deal with this, when most people don't have to. The shame piece is definitely directed towards not being able to give my partner what he could easily get in other relationships."

Jaime agrees that the shame of having PVD symptoms is connected to cultural beliefs that women's role in heterosexual relationships is to provide pleasure for her partner through intercourse:

Our culture emphasizes productivity and so it can really hit your sense of self-worth when persistent pain puts people in a place where they are doing less. There is real isolation and loneliness that can come with chronic pain in general, but even more so with sexual pain which can be so entrenched in shame. Although PVD didn't physically impact me outside of intercourse, I felt so much shame and less-worthy because I felt *fundamentally* broken. I was really struggling with this uncomfortable reconciliation of how I could feel my self-worth was locked up in pleasuring a man when those feelings didn't align with my values.

Sophie equated painful intercourse with no longer being "a sexual human" and says "It was really unsettling how losing sex really knocked me over because I thought it shouldn't matter so much, like 'why is this your entire identity?'". While Sophie never uses the word

shame, she describes similar feelings of guilt and inadequacy about “depriving” her partner of intercourse “that he needed to be vulnerable and feel connected” and withdrew all physical contact to avoid disappointing him:

I felt like I was depriving him by staying in the relationship; that I was being selfish and self-centered and taking advantage of him. He was doing all the supportive things and getting none of the boyfriend stuff in return. If he sat too close to me, I’d completely freeze up thinking if I didn’t move away, he’d hope, and I’d have to say no again. I wouldn’t even change in front of him in case I mistakenly misled him into thinking sex was a possibility. I felt like a bitch!

Ashley says, “I never really saw PVD as a thing to be ashamed of” , but agrees with the other women interviewed that she also felt “broken” because “I should be able to do [this] easily, and I should be able to enjoy [sex] like the rest of the population, but I can’t”.

I never got the message from my parents that sex was shameful or that you shouldn’t talk about it. I’ve never really had a lot of issues with shame around sex when talking with my friends about it either. It wasn’t until somebody framed it that certain way that I was able to identify shame and stigma around sex or see it happening

She says, “maybe shame is more this underlying thing and you don’t think about what you don’t do because of it.”

3.3.4.2 Resists: Dominant Discourses of Female Sexuality- Feminine Objects/Masculine Subjects (“Sex is always portrayed...from a male perspective”)

Women invariably describe shame as a secretive, internal process with few understanding outside witnesses, and the beginning of shame’s undoing arriving with the sharing of stories.

They connect compassion for themselves with the compassion they feel towards other group members. They express a sense of injustice “that so many women” are “invisible” and “have been suffering in silence” for so long. As women discussed the importance of partner support, understanding and collaboration for resolving the distress associated with expectations about how they ‘should’ be sexually performing, many also resist these prescriptions by openly interrogating the source of these beliefs about women’s roles in heterosexual relationships. They also discuss how it may be difficult to change collective and individual minds where ‘sex’ is socially constructed from the perspective of masculine subjectivity.

Celine sees the devaluing of women’s sexual bodies relative to men’s as culturally pervasive:

Sex is always portrayed in media, movies, and TV from a male perspective, where women’s pleasure and non-penetrative sex have been relatively taboo topics.

Women's bodies and health issues are often dismissed or considered secondary to male issues. What does it say about women's bodies that at least 1 in 10 women are going through this but nobody’s talking about it? If 10% of women will experience PVD there must be a lot of women just suffering in silence. I wonder if female pain has always been ignored?

Ashley also suggests how insidious cultural messages emphasize male pleasure and ignore female experiences: “I think there's still a lot of stigma out there about women's sexual health in general, so I can definitely see that impacting how information gets out. Society still doesn’t think it’s important for women to be enjoying sex which causes harm in a lot of other areas too.” She says: “No one told me exactly how I should be, except maybe with shitty

partners. It's more indirect. Like how sex is portrayed in the movies and on TV and stuff like that".

Sherry might argue that while expressed indirectly, the silence around female sexuality relative to males' has direct impacts:

Why is women's sexuality still a taboo subject where people can't even discuss it except when it's used on TV commercials for things for men? How often do you hear about erectile dysfunction and Viagra? If there were men having this issue, they would have been looking at it a lot sooner than now and would have spent millions of dollars finding a cure. I know I would have a lot of more options on how to fix it. But we won't even talk about sex for women.

While Anya hedges with "I don't want to hate on men too much, because they have their own stereotypes to deal with (they should be able to go on forever, they should be able to get it up right away, etc.)", and "I hate to bring sexism into it," she says, "but I swear, if men were having painful sex, the situation would absolutely be different, and there would be so much more research and awareness on the topic."

Jenny says, "when you look around sex is everywhere" and like other women interviewed, she saw sex portrayed as "always so easy for everyone else". She also suggests, part of the problem is that women in our society are sexualized more than men and are still seen as sexual objects. I think it's an especially male perception that there cannot really be anything wrong with a vagina that prevents penetration- that every woman should be able to perform this 'natural' body function of sexual intercourse because it is supposed to be the basic and normal function of a vagina. When it isn't working you fear being judged 'faulty' and carry around a shameful secret

about being a failure as a woman. That invisibility can lead to a woman not being believed, or even worse, laughed at or thought of as crazy.

Anya also refers to how pervasive cultural representations about how sex ‘should’ be, assumes ‘normal’ women have few challenges engaging in intercourse. She describes how the silence around sexual experiences, particularly for women whose do not fit these narrow scripts, makes it difficult to disentangle oneself from them, even when they are personally acknowledged as problematic:

It’s huge that 15% of women have sexual pain at some point in their lives, and yet it’s *never* talked about. I think society is somewhat to blame because that’s where these ideas and stereotypes (that sex is the most important thing, that sex should be wonderful, that sex should be easy, and so on and so forth) come from. So then when it’s not (important/wonderful/easy), or when it’s the exact opposite of all of those things, you feel like something is *really* wrong with you. Of course, I can’t speak for other women, but I know I felt a lot of shame because of that. I don’t really want to admit this “brokenness,” and I still struggle quite a bit with that. I’ve been told over and over again that nothing is broken or wrong. Maybe it’s not, but I do not feel *normal*... I wish it wasn’t there; it would just be so nice to have sex without pain, like the majority of other women.

Jenny agrees with other women that the way sex is portrayed and discussed assumes intercourse as the prototypical sex act and primary source of physical pleasure and connection for heterosexual couples, can be isolating for those that may not experience intercourse as pleasurable or easy. She says:

We all watch the same movies where sex is portrayed as easy and nobody worries about protection or getting pregnant and they all have the best orgasms ever and then life just carries on. The reality is more complicated for a lot of people and the truth is sex isn't always stars and fireworks for everyone, able-bodied or not, all the time. This idea that all humans want to and can engage in sexual activity just isn't true for everyone. Defining sex by penetration can be harmful for people that desire intimacy but are limited in the kinds of sexual activities they can engage in by making them feel like a personal failure.

Women suggest that intercourse, as the cornerstone of heterosexual intimacy; something men 'need' and that women's bodies are designed to provide, is largely unchallenged at a cultural level. They describe how these assumptions can be read through the silence surrounding female sexual difficulties which render them invisible and personal relative to sexual difficulties men may have which are communicated as emergent problems worthy of society's collective investment to resolve. This cultural message is further reinforced in healthcare settings when women seek help for intense and distressing pain experienced during intercourse and hear from doctors to 'have a glass of wine and relax' (or in Celine's case, 'drink some warm milk'); a message resonant of the Victorian directive to 'lie back and think of England'. The implication is that their experience of pleasure and pain is unimportant relative to the provision of sexual pleasure via intercourse for male partners and that if women want to participate in heterosexuality and secure the commitment of their male partners, submitting to sexual penetration is a requirement, whether or not they enjoy it. If they find it painful it is their 'fault' and their 'problem', their distress about it 'hysterical' and their avoidance of painful penetration 'abnormal' and 'unfair' to male partners who are immersed in the same cultural messaging that

centralizes masculine subjectivity and women's bodies as objects for male sexual pleasure. Women interviewed express a sense of injustice that these assumptions about how 'normal' women 'should' be functioning sexually are rarely challenged in their day-to-day lives.

3.3.4.3 Persists: Dominant Discourses of Male Sexuality- The Coital Imperative (“all men think sex doesn't count without penetration”)

Women explicitly challenge gender essentialism in societal standards of heterosexual womanhood and yet see it unlikely that patriarchal cultural norms that reify these standards, and individual men who benefit from them, will change. In the end, women are still responsible for their own pain and pleasure, but also responsible for his pleasure- even if his pleasure causes her pain.

Understanding, supportive men are viewed as an exception to how 'most' men would respond to violations of culturally sanctioned gender performances. While women problematize universal, essentialist notions of heterosexual womanhood, and imply you can resist taking an object-position in heterosexual relations, they suggest the coital imperative remains a culturally pervasive standard for defining normative sexuality.

Jaime discusses how insidious the objective positioning of women within heterosexual intimate relationships is:

I had done a lot of work learning to relate to my body outside of it being an object, but it was an experience in the group led me to reflect on how deeply embedded those cultural messages can be. I remember a woman in the group who shared she had lifelong PVD and had recently gotten engaged. I was shocked to notice I was thinking “you've never had sex and you never can have sex, and someone is going to marry you?!” I had this realization then that we

weren't, as a culture, beyond that, although I wanted to believe we were. I had to look at how deeply that internalized objectification runs. If our self-worth is wrapped up in being an object of pleasure is that really self-worth? It was a really challenging and awesome experience to dive into those types of questions and challenge some of the ideas we carry somewhat subconsciously.

Sophie recalls thinking "I'm a shitty partner. He's going to stick around because he's a great guy but he's going to be miserable" because she felt she was "depriving him" of sex that "he needed". She describes taking the 'coital imperative' for granted partly because of early educational messages that equated sex with the dangerous outcomes of intercourse and was silent regarding other sexual activities. When she began experiencing pain during intercourse and when anticipating it as the expected outcome of any physical intimacy she withdrew all physical contact with her partner so as not to "mislead" him into thinking she was initiating 'sex'. She says:

I had internalized that idea that penetration was sex and everything else was a lead-up to that and I was avoiding all of it. When you're taught about sex in school it's about the scary consequences of penetrative intercourse, like STIs and pregnancy- they didn't teach us about other things. So, engaging in any of the other stuff felt like it was foreplay.

Anya agrees that beyond the portrayal of sex in the media as 'easy', discussions about sexual challenges and pleasure should be included in sex education. She says

It's not even really talked about in psychology. I took a human sexuality class my last semester in university and pain was never mentioned. Sex education classes should include all of this information (along with the good stuff). It really should

start from the beginning and start early. Hopefully, these ideas and stereotypes will change once word gets out there that this shit exists”.

Although Jenny and her partner “enjoy non-penetrative sex, more like foreplay, which is physically satisfying and where we both feel connected, loved, and cared for” she continues to see how “we’ve all been programmed to think that sex without penetration doesn’t count or won’t be satisfying to people.” Jenny thinks that “having more discussion about how experiencing pleasurable sexual sensations or emotional closeness doesn’t depend on intercourse could be revolutionary for some like it was for me”. However, she suggests that “because of my husband’s disability” she “may have it easier than other women” when it comes to “incorporating that principle [of non-penetrative sexual pleasure] into the bedroom” because they have already had to adapt their sex life to his abilities and isn’t confident an “able-bodied man” would be as supportive and understanding.

She describes how sex-education for healthcare workers centres around issues related to reproduction and implies that because women’s pleasure is not necessary for reproductive intercourse, female pain and pleasure is rarely a focus. She says she sees this silence and dismissiveness in healthcare settings continue, and despite finding “peace and acceptance” within her own sexual relationship, she does not want to be the ‘voice’ for PVD because of the judgement she anticipates from others:

In nursing school when we go through the reproductive system, you learn about endometriosis or fibroids, pregnancy and miscarriage, but nothing really related to sexual disorders. It’s still taboo to talk about when sex isn’t working for women. Although I have been able to talk about sex in relation to my husband’s disability, I am guilty of not sharing my own experience with PVD, even now. I can imagine

organizing an in-service, but I don't want to have to share my own experience and I would have to think of things to say when people wondered why I was doing it. It's so important and yet on a personal level it is so difficult because I really don't want to be the example.

Jenny thinks without more open conversations about diversity of sexual ability and desire people will not be able to understand what they can't see:

I think it's hard in general for people that are healthy to understand the challenges of people with physical limitations. This is especially true with when it's something you can't see and nobody talks about, like sex. Because my husband's disability is visible, people are sometimes openly curious about how we have sex. With his permission, I answer their questions because I think it's important to understand that people with disabilities don't just forget about sex. PVD is not a disability that you can see, it's a difficulty experienced in private. I don't have a visible injury or adapted device or obvious behaviour that shows something is wrong. Someone who doesn't have it won't be able to understand how it impacts me... If somebody knows that I physically can't enjoy intercourse, they'll just think it's weird. If you were to suddenly lose your ability to use your arm, people won't question it in the same way.

Jenny implies centralizing the coital imperative in sex discourse without open acknowledgement of the variability of experiences people, particularly women, may have with intercourse, inevitably leads to the kind of judgement she heard other women in her group were receiving from their male partners: "It made me think about whether I would even consider trying to find somebody else if my husband were to pass away while I'm still young. I think PVD

would be a huge factor with a more able-bodied male and I don't want anybody to make me experience all those feelings of being less-than that I felt before."

Sherry's partner blames his mistreatment of her on the lack of penetrable sex in their relationship, and actively reinforces the notion intercourse is requisite for sexual intimacy in relationships. The idea that because she is "broken in the sex department" her choices are to either to "be alone for the rest of my life" or "tolerate his [emotional] abuse" is one she returns to often in her narrative. She says:

I'm no longer marketable and can't go out and meet somebody and have a happy ever after when no one will want to be with me because I'm missing that key piece. Being a girlfriend or a lover or a wife, even with my boyfriend right now, are no longer on my dance card. My choices in new partners would be much more limited because this big part of me isn't functioning. It's like a disability. There was an exercise we did in the group about whether our whole persona is defined by being a sexual being or if we are more than just a sex object... But I feel like *I am* defined by this when it comes to finding a new partner because I *still* feel like a new partner will not want to be with me because of that.... I think all men think sex doesn't count without penetration although saying it out loud makes me wonder if that's really true. I've been so indoctrinated by my boyfriend saying to me for so long that it's what all guys want and that it's just how it is.

Anya, also emphasized the importance of intercourse for both her and her partner, and difficulties she had accepting advice to temporarily remove penetration from their sexual repertoire:

I remember a discussion we had during the COMFORT study about how sex (intercourse) was not the be all, end all. I really struggled with this because sex is the best way I personally share my love in an intimate way, and I still can't get my head around sharing it any other way. All the other things are lovely and nice, yes, but sex is really important to me. When my partner and I had conversations about this idea (that is, sex is not the be all, end all), he agreed with me.

Although some women problematize the 'coital imperative', all women, with the exception of Jenny, reference 'successful' sexual encounters as those times they were able to engage in intercourse with reduced pain or increased pleasure. They find the primacy of intercourse expressed in media depictions of sexuality that privileges male sexual desire, in personal conversations where female sexual difficulties may be absent, in healthcare and educational contexts that equate sex with intercourse, and cultural assumptions that a woman's sexual role is that of responsible gatekeeper of male desire and vessel of reproduction and male pleasure. Women would like to see more representation of diverse sexual experiences in education, healthcare and media, where women's subjectivity is emphasized when considering 'successful' sexual outcomes with or without intercourse.

Chapter 4: Discussion

The present narratives of eight PVD-diagnosed women who participated in an 8-week group MBCT or CBT intervention were co-constructed 5-8 years after their attendance and provide valuable insight into the long-term impact of their participation. The following discussion will highlight where women's accounts of the impacts of living with chronic vulvar pain and their recollection of the helpfulness of participating in a psychological-based treatment intervention are consistent with research literature, where they diverge and suggest directions for future research and implications for clinicians who may find these women in their care.

The findings from the themes identified in this narrative inquiry contextualize and lend support to quantitative inquiries and are consistent with the body of qualitative research regarding the negative psychological, emotional and relational impacts of living with chronic vulvar pain and the continued barriers to receiving an accurate diagnosis and treatment. Women are clear that addressing barriers to effective treatment should not be limited to educating HCP although most suggested general knowledge of the possibility of PVD as a diagnosis would itself help to disrupt the cycle of shame, self-blame and isolation by normalizing their pain experience and validating their distress. The narratives also suggest how each woman's individual context (her history, beliefs, treatment goals and relationship, mental and physical health challenges) and the shared influences of the limited possibilities available in cultural discourses regarding women's sexuality, interacted in ways that limited or facilitated opportunities for program elements to positively impact their experience. Most would like to see the availability of an expanded COMFORT embedded in vulvodynia-specific programs that are widespread, individualized and multidisciplinary with flexible access options that emphasize partner involvement and include relationship support for partnered and unpartnered women.

4.1 Contextualizing Quantitative Outcomes

Although the qualitative data presented here through the stories of eight COMFORT participants cannot be directly compared with quantitative outcome data collected from the original sample of 130 participants, their accounts lend general support to many of the conclusions drawn in quantitative analysis, insight into possible sources of variance within the data set and suggest directions to explore unanswered questions. Constructs of pain catastrophizing and pain hypervigilance (derived from the fear avoidance model of pain), pain acceptance (the degree to which one attempts to control or avoid pain and engages or avoids valued activities despite the presence of pain), and mindfulness related constructs of self-compassion and self-criticism, were measured across participants and timepoints via validated questionnaires. Several women directly used words ‘catastrophizing’, ‘acceptance’ ‘compassion’ and ‘self-criticism’ when storying their experiences and others used descriptions of their internal experiences that overlap with the operationalization of those constructs and generally map onto the pattern of results found by Brotto and colleagues in their quantitative analyses. For example, developing *acceptance* that pain will likely be a continued presence in some capacity, references to feeling more freedom from *catastrophic thinking* or negatively forecasting that the pain will overwhelm their coping resources, *metacognitive awareness/ decentering*, or space to separate oneself from thoughts and automatic emotional responses and practicing responding with patience, kindness and *compassion* towards themselves instead of self-judgement and *self-criticism*, were identified as significant changes that resulted from participating by six (Christine, Sophie, Jaime, Celine, Ashley, and Jenny) of the eight participants. This is in line with quantitative results that showed changes in pain-catastrophizing, pain acceptance, and

decentering were found to mediate pain intensity and sexual distress across treatment arms (Brotto, Bergeron, Zdaniuk & Basson, 2020). Interestingly, quantitative results showed increases in self-compassion and reductions in self-criticism mediated improvements in sexual distress in the MBCT arm only, but women in the present analysis cited changes in self-compassion and self-judgment as foundational to their progress regardless of intervention arm, lending further support to these constructs as important treatment targets and measures of progress for vulvodynia (Brotto et al., 2015; Davis et al., 2015; Bergeron et al, 2016; Brotto, Bergeron, Zdaniuk & Basson, 2020). Although study authors found none of their measured variables uniquely mediated improvements in the CBT arm, they suggested other unmeasured variables associated with the fear-avoidance model of pain including self-efficacy, fear of pain and pain avoidance may have contributed to changes in pain and distress that were undetected (Brotto, Bergeron, Zdaniuk & Basson, 2020), and the above six women described these as important in line with previously published research (Bergeron et al., 2001; Bergeron, Khalife, & Dupuis, 2008; Boerner & Rosen, 2015). Women who felt the most hopeful about their prognosis emphasized constructions of self-efficacy, in support of research connecting changes in these constructs with changes in pain distress and sexual functioning (Desrochers et al., 2009/2010; Davis et al., 2015). Authors hypothesized that therapeutic elements shared across treatment arms may have contributed to some of these unexpected, shared results (Brotto, Bergeron, Zdaniuk & Basson, 2020). Indeed, the above six women identified their pre-enrollment experiences, sometimes the enrollment procedures themselves, the group context, and the credibility they afforded a group psychological approach because of the involvement of the experts, and their delivery of vulvodynia-specific education, as therapeutic elements that began to change their beliefs that they were defective, helpless and blame-worthy in the direction of de-essentializing

their pain experience, developing a sense of ‘agency’, ‘empowerment’ and belief in their ability to influence their experience, and developing patience, compassion and kindness for themselves. The authors also hypothesized that shared elements of exposure-like experiences in both treatment arms may have been responsible for some of the shared changes by exposing participants to their feared stimuli- vulvar pain (Brotto, Bergeron, Zdaniuk & Basson, 2020). Participants in the present inquiry identified experiences that put them ‘in touch’ with avoided vulvar contact through the educational physical exam, homework exercises involving intentional drawing or touching their vulvas, and practicing the body-scan, mindfulness and restructuring skills in the context of sexual contact, that allowed them to safely explore and thus re-assess the threat value of their pain experience and which they described as having reduced their fear, anxiety and helplessness. Three women also directly referenced how pelvic floor physiotherapy before or after participating also put them in safe contact with pain in a way that reduced their fear and adjusted their predictions that they would be emotionally and physically overwhelmed by the experience of pain. Altogether this lends further support to the efficacy of safe exposure-like exercises whether via an educational gynaecologic exam, home practice encouraging genital self-exploration, or pelvic floor physiotherapy (which additionally improves pelvic tone and control and thus pain intensity) when used in combination with therapeutic techniques, to support women to recognize fear-responses, improve self-efficacy and reduce fear, anxiety and pain (Bachman et al., 2006; Goldfinger, et al., 2016; Bergeron, Rosen & Corsini-munt, 2018; Ter Kuile, et al., 2013).

Body-focused mindfulness practices intended to increase present awareness of physical sensations without judgement or cognitive appraisal have been found effective for increasing arousal and reducing fear and anxiety related to sexual contact, although research has been

inconsistent concluding its effectiveness for reducing dyspareunia (Jaderek & Lew-Starowicz, 2019). Although several participants described the body-scan as a helpful way to ‘get in touch’ with their physical experience and an opportunity to practice responding to physical sensations with acceptance and compassion, two participants (Anya, Jenny) described how using mindfulness in the context of sexual pain seemed to increase their fear, pain and anxiety. It has been suggested that while mindfulness increases interoceptive awareness it does not reliably correlate with interoceptive accuracy and for those with higher emotional susceptibility and with limited capacity to self-regulate, body-focused mindful practices may actually increase fear and anxiety associated with physical sensations (Gibson, 2019). It may be that some women, particularly those who are highly distressed and do not have experience with mindfulness, may find the active approach of identifying, challenging and restructuring pain-related cognitions more immediately helpful or they may require more education about the goals of mindful practice, how it may help their pain experience and more support using skills of mindfulness in contexts with high threat-value (like painful sexual contact) to separate themselves from maladaptive interpretations of those sensations.

Women described mixed experiences in regard to pain-reduction at clinical exam and improvements of pain with intercourse. Although six women described significant improvements in sexual distress and sexual satisfaction only four have found a significant reduction in dyspareunia despite effusive praise of the program’s overall helpfulness, in line with authors suggestions that reductions of either clinically measured or self-reported pain may not adequately capture participation benefits, as reportedly high ratings for satisfaction with treatment did not reliably correlate with pain reduction or a return to intercourse (Brotto et al., 2019). Authors note that non-penetrative sexual activities were not assessed (Brown, Zdaniuk & Brotto, 2021), and

both Jenny and Christina discuss a positive benefit of participating was a return to non-penetrative sexual activities despite not being able to engage in intercourse because of pain, in line with calls in the research to expand assessment of sexual outcomes beyond measuring engagement in intercourse (Bergeron, Rosen & Corsini-munt, 2018; Dunkley & Brotto, 2016).

Authors also cite previous research that suggests that levels of relationship intimacy may impact engagement in intercourse beyond the severity of pain symptoms (Boise, Bergeron, Rosen, McDuff & Gregoire, 2013, cited in Brown, Zdaniuk & Brotto, 2021) and intimate relationship factors were identified by most women in the present narratives as a significant element that influenced their treatment trajectory. For Jenny the strength of the support and commitment in her relationship, combined with the education that PVD was a legitimate diagnosis and not a sign of a personal failing, was enough to reduce her distress, and with her partner's encouragement, to permanently disengage from intercourse while connecting sexually in other ways. Christina has begun to explore non-penetrative sex with her partner and despite only engaging in intercourse 'successfully' three times since completing the group, she is happy with her progress, although incorporating regular intercourse into her partnered sexual activities remains a goal for her partner, who she acknowledges is less satisfied with the pace of change. Anya and Sherry reported a return to regular intercourse remained a primary and time sensitive goal and they continued to attempt intercourse, despite pain, before during and after participation. Taken together, this supports suggestions in the literature that the reasons women may decide to continue, discontinue or reengage in intercourse are worthy of further exploration and measures that rely on participation in intercourse to assess sexual outcomes and treatment success may be limited in capturing the full impact of PVD symptoms on women's lives, relationships and treatment experiences (Brown, Zdaniuk & Brotto, 2021).

Anya and Sherry's stories suggest they continued to attempt painful intercourse throughout group participation, continued to make catastrophic attributions about the pain (it's causing physical damage, I can't handle it, my partner will leave me), critical and judgmental self-evaluations (I'm abnormal, I'm broken, I'm an inadequate partner), impatience with the pace of change and frustration with the homework and skills practice (I can't do this, this isn't working). Anya discusses how neither she nor her partner were convinced that mindfulness practices would help during her participation and how instead they experienced increased frustration and decreased confidence in the practices and in her ability to effectively use them. Analyses reported by the study team showed treatment credibility moderated improvements in pain intensity in the MBCT arm, that women in shorter relationships showed greater improvements in sexual functioning in the MBCT arm (with the opposite pattern reported for CBT), and women with primary PVD improved more on pain-catastrophizing in the CBT arm (and the opposite pattern in the MBCT arm) (Brotto et al., 2020). Anya who had primary PVD, was not convinced in the effectiveness of mindfulness and gave up practicing mindfulness early on, may have benefited more had she participated in the CBT-arm.

Sherry described her pain as 'worse' now despite participating in both treatment arms and although she thought CBT was more credible in the context of PVD treatment, said she found her participation in both groups valuable. Sherry's description of significant relationship conflict related to a lack of pain-free intercourse along with Anya and Christine's accounts of continuing to experience dyspareunia with partners who place high value on returning to intercourse, lend further support to previous research suggesting partner's beliefs about and responses to pain, and the overall functioning of the intimate relationship (e.g. partner response to pain, quality of intimacy/communication) are important treatment targets and factor in the prognosis of PVD

(Bancroft, Loftus, & Long, 2003; Rosen et al, 2010, Rosen et al. 2012, Bois et al., 2013; Rosen et al, 2014). Women in highly conflicted relationships are much less-likely to experience the benefits of any individually focused intervention (Bergeron, Rosen & Corsini-Munt, 2018), and Sherry may have been better helped with focused relationship support and education which encouraged her partner's collaboration before treatment targeted at reducing the symptoms and negative impacts of vulvodynia.

Researchers have reported that most women seeking treatment have not had adequate vulvodynia specific education, despite research showing comprehensive education about the diagnosis, its impact on women and their partners, and how recommended interventions can help, has been shown to improve anxiety, depression, pain and sexual distress independently of psychological support, with women additionally describing receiving this education as 'normalizing' and 'validating' (Brotto, Sadownik, & Thomson, 2010; Sadownik, Seal, & Brotto, 2012; Guillet, Cirino, Hart, & Leclair, 2019). All women in the present inquiry discuss the positive impacts of the educational components, particularly the pain education relating central nervous system sensitization to the development of chronic vulvar pain, as significant therapeutic elements that began the process of changing previously held beliefs about what the pain 'meant' and researchers have suggested learning about sensitization can be an antidote for beliefs and external messages that their pain 'all in their heads' by providing a material location for their pain that legitimizes their experience as 'real' (Bergeron, Rosen & Corsini-Munt, 2018). For most of the women, this education initiated a re-storying of their identity in relationship to PVD symptoms by decentralizing the outsized influence PVD had on their identity stories and beliefs about their abilities.

Although many women in the present narratives identified learning psychological skills as important for their healing journey, for many it was how the stage was set for them (their interactions with the study team, the credibility afforded the experts involved and the education), before the introduction and practice of these skills, that helped them to embrace continued practice.

4.2 Comparison with Qualitative Outcomes

An exploratory study designed by Brotto's research team to evaluate a four session, group-MBCT intervention for the treatment of vulvodynia, conducted a qualitative follow-up of 14 of the original 22 participants, 12-18 months after their participation to explore how their pain symptoms, emotional, psychological and sexual functioning had progressed (Brotto, Basson, Carlson & Zhu, 2013). The themes derived from a content analyses of the transcripts of these interviews show considerable overlap with those generated from the current analyses: "(1) feelings of normality and community, (2) positive psychological outcomes, (3) impact of relationship, (4) an appreciation for treatment, (5) barriers and (6) self-efficacy" (Brotto, Basson, Carlson & Zhu, 2013). Similar to the experiences storied here, women participating in the four-session group-MBCT intervention appreciated being in a group context with other women from a variety of backgrounds who shared their difficulties, and described exchanging experiences with similarly affected women as normalizing, validating and an antidote to the isolation and shame they had endured prior and credited the group context with initiating a change in self-perceptions of their essentially defectiveness (Brotto, Basson, Carlson & Zhu, 2013). Study authors found, and women in the present inquiry also expressed, that the positive impacts to their psychological and emotional functioning, particularly the use of the skills to decenter maladaptive thinking

patterns, contributed to their perceptions of treatment success independently of any improvement to their pain symptoms (Brotto, Basson, Carlson & Zhu, 2013).

Women in both inquiries emphasized the impact of relationship factors with many expressing a desire for more relationship focused material. Brotto and colleague's qualitative analysis found those women in supportive relationships seemed to derive more benefit from participating, those in conflicted or less supportive relationships experienced continued difficulties with sexual and relationship intimacy and ongoing pain symptoms, and single women felt somewhat isolated from discussions of relationship impacts (Brotto, Basson, Carlson & Zhu, 2013). Brotto's team thus included more information for unpartnered women and expanded relationship-focused material in COMFORT modules in response (Brotto, Basson, Carlson & Zhu, 2013; Brotto et al, 2019). As this issue remained a significant theme in the present inquiry, despite participating in an intervention that included more relationship-focused material, their narratives further emphasize the importance of partner related impacts on treatment effectiveness and support for prioritizing this in future treatment and intervention outcome studies.

Described barriers to efficacy were also similar in both interventions. Women here and in Brotto's qualitative inquiry expressed challenges continuing the regular practice of skills, particularly when benefits were not immediate, with similar descriptions of guilt or feelings of inadequacy about imperfect practices, sometimes suggestive of a misunderstanding of the goals of mindfulness, and likely related to the request in both samples for ongoing explanation and support for skills practice (Brotto, Basson, Carlson & Zhu, 2013). Also, in line with the present inquiry, women in Brotto's study described increased self-efficacy as a significantly positive impact of participating, where women expressed feeling newly empowered to manage any ongoing difficulties with symptoms, and goals for progress that shifted from looking to 'fix'

symptoms towards more openness exploring their sexuality regardless of the continued presence of pain (Brotto, Basson, Carlson & Zhu, 2013). Brotto and colleagues suggested future interventions more explicitly discuss practice barriers, including potential guilt about the perception of inadequate practice, and clarify the purpose of mindfulness as a practice of non-judgemental acceptance of ‘what is’, in line with participant suggestions in the present narratives (Brotto, Basson, Carlson & Zhu, 2013).

4.3 Continued Barriers to Care

Women identified many barriers to care which included the well-documented difficulty getting an accurate diagnosis and effective treatment when seeking help from uniformed and/or dismissive healthcare providers, which they attributed to exacerbating the deleterious impact vulvodynia was already having on their mental health, identity, and relationships. They discuss how elements of their individual context also created unique barriers to accessing and committing to recommended treatments, particularly the quality of intimacy and support in their sexual relationships, and many also made reference to how limiting social discourses regarding female sexuality (e.g., media portrayals of sex as easy, the pervasiveness of the coital imperative) informed partner expectations, HCP responses and their own initial treatment goals.

4.3.1 Dismissive and Unknowledgeable Healthcare Providers

It is significant that all women responded to the research question “Tell me a story about your participation in the COMFORT program and your journey with PVD since” with detailed descriptions of a sometimes years-long painful journey looking for, but not finding, explanations for their chronic vulvar pain which they related to their increasing distress before contact with the study intervention team. Quantitative data has consistently shown that despite the high prevalence of PVD, and a significant output of research over 20 years into accurate diagnosis and

treatment interventions for addressing the well-known negative impacts of living with chronic vulvar pain, up to 40% of women remain undiagnosed and without treatment options after repeated visits to healthcare providers at significant cost to individual women, their partners and healthcare systems (Xie et al., 2012; Reed et al., 2012; Harlow & Stewart, 2016). Doctors have reported a lack of knowledge, training, resources and comfort assessing and treating sexual issues generally and vulvar pain in particular (Goldstein, Lines, Pyke, & Scheld, 2009; Toeima & Neito, 2011; Leusink et al., 2018; Edwards et. Al, 2018), a perception commonly shared by their female patients (LePage & Selk, 2016). The difficulty finding healthcare providers aware of vulvodynia and treatment recommendations was identified as a significant barrier to recovery beyond simply frustrating their timely referral to knowledgeable practitioners. These visits were frequently described as further contributing to their feelings of hopelessness, despair, self-doubt, erosion of their confidence in the healthcare system and trust in their own ability to accurately assess the legitimacy of their distress, themes consistently mirrored in the qualitative literature (Webber, et. al, 2020; LePage & Self, 2016; Sadownik, Seal & Brotto, 2012; Kaler, 2006; Shallcross et, al, 2018; Buchan et. al, 2007; Munday et. al, 2007).

The stories here lend further support to recommendations made by vulvodynia researchers and women seeking care, that successful treatment of vulvodynia begin with a care provider who acknowledges her pain as real, validates her distress as legitimate and facilitates an accurate diagnosis via prompt referrals to specialists when they lack specific knowledge diagnosing and treating chronic vulvar pain (Sadownik, Seal & Brotto, 2012; Bergeron, Rosen & Corsini-Munt, 2018; Webber et. al, 2020). However, many women may experience the same difficulties with MDs with specialized training in gynaecologic issues. A recent survey of 58 directors of gynaecologic training programming in the U.S. and Canada, found 93% reported

residents received adequate training to manage vulvar pain disorders in the community, although variability in the amount of adequate clinical exposure was cited as a barrier to appropriately recognizing and treating specific vulvar conditions, in practice. (Edwards et al., 2018). An additional barrier cited by 60% of respondents was a “lack of interest” in vulvar disorders, an especially troubling percentage given conservative population prevalence estimates of 8%, would mean approximately 590, 000 Canadian women aged 15-44 may have met criteria for a diagnosis in 2020 (Edwards et al., 2018; Reed et. al, 2012; Statistics Canada, 2020). In Vancouver, British Columbia, home to several internationally recognized clinician-researchers with expertise in vulvodynia, two clinical centres dedicated to accurate diagnosis and empirically-supported treatment interventions, and the inclusion of current vulvodynia research into “undergraduate, postgraduate, and continuing medical education programs”, these research-clinicians continue to find “women are still misdiagnosed, dismissed, prescribed ineffective remedies, or told that their condition is untreatable” (Basson, Driscoll & Correia, 2016). For women living outside of the urban centres where these treatment and training programs exist, the barriers to accessing care providers with knowledge of even the existence of vulvar pain syndromes is even more pronounced (Webber, et. al, 2020).

The consistent reports women feel dismissed, belittled, judged, stigmatized and disbelieved by HCP while seeking care for chronic vulvar pain (LePage & Self, 2016; Sadownik, Seal & Brotto, 2012; Kaler, 2006; Shallcross et, al, 2018; Nguyen et. al, 2013; Webber et. al, 2020; Marriott & Thompson, 2008) may also be making their physical pain worse. There is research support that this common experience may additionally contribute to the further entrenchment of maladaptive behavioural, emotional and psychological responses and to a worsening of symptoms (Donaldson & Meana, 2011). Research supporting early intervention for

other chronic pain syndromes suggests that delays in accessing appropriate treatment and support may contribute to entrenching avoidant behaviours and further nervous system sensitization and intensification of the pain experience (Sanders, Harden & Vincent, 2005). Receiving accurate information about chronic vulvar pain from knowledgeable health care providers when first seeking help may disrupt the cycle of reinforcement, improve uptake of suggested interventions and overall prognosis (Donaldson & Meana, 2011). Women in the present inquiry reported also struggling with other chronic mental health and pain conditions, comorbidities that are commonly reported in the literature that have been shown to increase the severity of symptoms and also the likelihood they will have negative and unhelpful experiences with healthcare providers, (Tuck & Bean, 2019; Lester et.al, 2015; Nguyen et al., 2012; Khandker et al., 2011; Masheb et al; 2009). This may lead to a viscous cycle of increased alienation, helplessness and pain amplification as it has also been shown that social rejection, low self-efficacy, chronic stress, and negative mood increase pain symptoms (Lumley et al, 2011; Eisenberger, Lieberman, & Williams, 2003; Wiech et al., 2006).

Canadian bioethicist Diane O'Leary whose work focuses on the integration of holism (versus mind/body dualism) into medical practice, argues that despite biopsychosocial models of care being the endorsed philosophy behind the healthcare recommendations of the World Health Organization, American Psychiatric Association and the Canadian Public Health Association, (WHO, 2019; Benning, 2015; CPHA, 2011; Rease, 2014) they remain aspirational in practice and mind/body dualism persists in medical contexts (O'Leary, 2020). She suggests this is a problem that has material impacts for people with chronic mental and physical health conditions, particularly women, the majority of whom will remain undiagnosed when presenting with physical symptoms without obvious biomedical origin (O'Leary, 2020). Women in the present

narratives perceiving MDs viewing their symptoms as suggestive of ‘hysteria’ rather than a valid medical concern, mirror reports that women’s physical symptoms may be attributed to psychological causes more than ten times as often as men’s (O’Leary, 2020).

Although women interviewed for this inquiry were not directly asked about their experiences with PVD before participating in the COMFORT program, why many described experiencing profound relief for having their concerns validated and legitimized and their hope renewed upon enrolling, as some of the most helpful elements of participating, can only be adequately understood in the context of these histories where multiple encounters with dismissive and unknowledgeable healthcare practitioners figured prominently. Medical gatekeepers did not just prolong their distress by delaying accurate diagnosis and treatment, but actively reinforced and intensified their distress and remained a painful memory for many, more than five years after participating in COMFORT. Lumley and colleagues’ 2011 review of a decade’s worth of research into the relationship between emotion and pain perception cites research supporting the inhibition of anger, particularly when one wants to express anger but fears the consequences of doing so, increases the perception of pain intensity in chronic pain sufferers (van Middendorp , et al., 2010). He writes: “it is interesting to consider how much the inhibition of emotions actually stems from negative reactions patients have received when expressing their emotions to health care providers who would rather focus on biomedical issues” (Lumley et al., 2011).

4.3.2 Limiting Social Constructions of Female Sexuality

The sexism women suggested was common in their experiences with HCPs dismissive of their concerns, was further compounded by advice they receive from doctors, presumably intending to be helpful, to ‘have a glass of wine and relax’, implying the solution was to tolerate

penetration by their partners despite the pain and distress it caused, and affirmed cultural messages that their right to sexual pleasure was not equal to their male partners. Women identified the media as a primary vehicle for disseminating unrealistic sexual standards that they attributed to informing their beliefs that they were ‘abnormal’ women, ‘defective’ partners and sexually ‘broken’. The role the media plays in contributing to beliefs women with dyspareunia were ‘failing’ at sex which was ‘easy for everyone else’ is a prominent theme across qualitative inquiries regarding women’s experiences with chronic vulvar pain, with many connecting the unequal and unrealistic sexual standards portrayed with negative consequences to their perceived self-worth and psychological, emotional, social and sexual functioning (Ayling & Usher, 2008; Buchan et al., 2007; Kaler, 2006; Marriot & Thompson, 2008; Shallcross et al., 2018).

It has been an assumption often taken up in research that men have a stronger motivation for engaging in sex than women (Baumeister, Catanese, & Vohs, 2001), although study authors rarely take into account the very different ways that men and women have been socialized or the uninterrogated assumption that sex is defined as intercourse (Chivers & Brotto, 2017; Sadownik et al., 2008). Traditionally, men and women are differently socialized to embody gender-specific roles, beliefs and expectations about sexual behaviour which informs individual sexual scripts for performing these gendered roles, resulting in a pervasive sexual-double standard and unequal responsibilities for adherence or consequences for deviation from these roles (Jonason & Fisher, 2009). ‘Appropriate’ feminine sexuality is viewed as more motivated by emotional and romantic connection, as naturally passive or receptive but with an embedded responsibility for ‘sexual-gatekeeping’, where women limit their own sexual expression and male sexual access as leverage for attaining romantic commitment from their male partners in exchange for exclusively meeting men’s sexual needs (Seabrook et al., 2016). In contrast, men are viewed as less ‘in

control' of their sex drive, inherently driven to pursue intercourse with multiple feminine objects and the pursuit of sexual pleasure and conquest over emotional connection (Seabrook et al., 2016). These social norms are often reinforced through sex-education where the "hydraulic male sex drive" (a biological need/reflex that individual men are not in control of) (Vitellone, 2001), is framed as a potential danger to women who are responsible for protecting themselves against urges their male counterparts are unable to control, and women's desires, beyond securing the commitment of their male partners (and avoiding negative social consequences for unsuccessful gatekeeping), and their sexual anatomy beyond their reproductive capacities, is very rarely discussed (Decarie, 2005).

The ready availability of free online pornography may be filling the gap in the limited sex-education most adolescents receive and where many turn to learn about 'real' sex (Rothman, et al., 2015; Rothman, et al., 2021). Rothman and colleagues surveyed a nationally representative sample of 1266 American youth and found a quarter of those aged 18-24 considered pornography to be the most helpful source of information about how to have sex (Rothman, et al, 2021). Many have argued that although consuming sexually explicit material is not inherently harmful, the free material most readily available to youth reinforced a distorted view of human sexuality, gendered double-standards and misinformation about sexual pleasure, including misogynistic tropes that most women enjoy physical pain and domination and that female pleasure was predominantly derived from penetration, with many youth reporting imitating the practices they viewed with their partners (Rothman, et al, 2015). Johnson and colleagues surveyed 706 American heterosexual women aged 18-29 to measure the relationship between consumption of pornography and sexual preferences, experiences, and concerns, and found 83% of their sample had viewed pornography, with consumption rates positively correlated with the

degree to which it informed women's sexual scripts (Johnson, Ezzell, Bridges, & Sun, 2019). They reported more time spent viewing was associated with an increased likelihood of emulating the behaviour and responses of female actors, imaginably engaging with pornographic images during partnered sex, decreased sexual enjoyment, increased rates of body dissatisfaction and decreased engagement with non-penetrative sexual practices (Johnson, Ezzell, Bridges, & Sun, 2019) a pattern they had found similarly mirrored in their earlier survey study of 487 American men (Sun et al., 2014). Many have argued for a need for comprehensive sex education (which includes discussion about gender, pleasure, porn literacy and consent) that is responsive to the realities of adolescence and youth, to counteract culturally constructed sexual scripts that reinforce gendered double-standards, the coital imperative and increase possibilities for the mutual exchange of pleasure, while additionally proving more effective at reducing sexual violence, unplanned pregnancies and STIs than traditional 'abstinence-only' sex education (Johnson, Ezzell, Bridges, & Sun, 2019; Peter & Valkenburg, 2009; Rothman, et al, 2015; Rothman, et al., 2021; Sun et al., 2014). Researchers studying the sexual behaviors and beliefs of youth argue additionally that "how sexual norms/ideals are constituted among women and men needs to be highlighted by educational professionals, parents, and youth workers" (Elmerstig, Wilma & Bertero, 2008).

Mainstream print, film and television media are another influential way women are socialized to prioritize romance and commitment over their own sexual pleasure in intimate relationships (Warr, 2001). Analyses of men's and women's magazines has found both generally adhere to a single version of female sexuality where an idealized woman is one who successfully attracts and then 'keeps' her male partner by prioritizing his sexual satisfaction (Krassas, et al, 2001). Research has additionally shown that television consumption is positively associated

with endorsing heteronormative sexual scripts, like the sexual double-standard, and the centralization of intercourse as the definitional sex-act (Seabrook et al., 2016). It was found that the gendered assumptions of the sexual-double standard most informed the individual sexual scripts, practices and performances of heterosexuality amongst those who reported the most consumption of television, even when these same individuals recognized unequal standards as problematic (Seabrook et al., 2016).

The impact of gender socialization on the sexual experiences of heterosexual men and women can also be inferred from a recent cross-sectional empirical inquiry exploring the prevalence of sexual dysfunction among youth just beginning to participate in partnered sexual activity. A sample of 114 male and 144 female youth recruited from Canadian urban high schools completing validated measures for assessing sexual dysfunction and related distress found roughly 50% of both male and female adolescents sampled reported sexual problems, a percentage substantially different when compared with adult populations where significantly fewer men than women report the same (O'Sullivan, Brotto, Byers, Majerovich, & Wuest, 2014). Their study also showed rates of sexual problems declined for the young men in proportion to the extent of their sexual experience and particularly when in the context of a relationship, a pattern that was not found for the young women (O'Sullivan et al., 2014). The authors suggest that this may be partially attributed to differences in gender-role socialization (O'Sullivan et al., 2014). Perhaps it is that as adolescents are newly exploring the sexual aspects of their diverging gender roles, they may be similarly distressed at this stage that they 'aren't doing it right'. As these gendered roles promote the kinds of sexual experiences that allow men to achieve a sense of 'mastery', (where women are encouraged to be 'mastered'), it shouldn't be surprising that men's rates of sexual problems may decline over a lifetime of accumulated 'mastery' experiences.

There is evidence that these limited sexual scripts centralizing intercourse and male pleasure are negatively impacting the sexual experiences of heterosexual women during partnered sex. College students discussed the impact of sexual double-standards while participating in semi-structured focus groups about sex and consent, where participants regularly described sex (as intercourse) as something men needed, and women provided to achieve or maintain committed relationships (Baldwin-White, 2019). Consent in these contexts was sometimes assumed if men perceived their female partners were enjoying sexual contact, or something to be ‘achieved’ with persistence, and women described feigning pleasure or ‘giving in’ to the persistence of their partners to protect them from feeling hurt or rejected, whether or not they were experiencing sexual enjoyment themselves (Baldwin-White, 2019). A sample of 52,588 American adults who had completed an online questionnaire about orgasm frequency and sexual behaviours found that when compared to heterosexual men, gay men, lesbians and bisexuals of either gender, heterosexual women were the least likely to have experienced orgasm in the previous month of sexual encounters (Frederick, John & Garcia, 2018). They found a relationship between variety of sexual practices, openness to sexual communication and experimentation and orgasm frequency, such that women who rarely or never experienced orgasm during sexual encounters had the least variety of sexual practices, usually centred around intercourse (Frederick, John & Garcia, 2018). A 2018 survey study involving a U.S. probability sample of 1,055 women ages 18 to 94 who were asked about their experiences of sexual pleasure found only 18.4% of women orgasmed from intercourse alone and the majority required or preferred direct clitoral stimulation (Herbenick et al., 2018). Herbenick and colleagues found similar results in an earlier survey with 3990 adults (ages 18-59), reporting on their most recent partnered sexual event, where men were more likely to orgasm when sex included vaginal

intercourse and women were more likely to orgasm when they engaged in a variety of sex acts which included clitoral stimulation such as oral sex (Herbenick et al., 2010). Interestingly, the authors interpreted results of 85% of heterosexual men reporting their partner had an orgasm at the most recent sexual event, as compared with only 64% of heterosexual women reporting having had an orgasm at their most recent sexual event, as heterosexual men likely generally overestimating their partners experience of pleasure (Herbenick et al., 2010).

Individual sexual scripts informed by these cultural narratives may be creating ideal circumstances for the experience of vulvar pain, where fulfilling perceived obligations of women's role in providing for the sexual 'care' of their partners and prioritizing his pleasure over her own, may mean little time is spent on non-penetrative sexual activities that might increase her arousal and enjoyment. A Swedish qualitative study conducted at an urban health centre for youth, interviewed 16 heterosexual women aged 14-20 who described persisting with intercourse despite coital pain (Elmerstig, Wilma & Bertero, 2008). The authors reported few women had discussed the pain with their partners and all described prioritizing their partners pleasure and sexual satisfaction to affirm their sense of their desirability, partner value and social expectations of ideal womanhood (Elmerstig, Wilma & Bertero, 2008). The subsequent lack of arousal and desire for sex that they anticipated would be painful, but felt guilty for avoiding, negatively impacted their self-image. Women described resigning themselves to experience pain to maintain intimacy and keep their partners affection and feigned pleasure to protect male partners who might feel inadequate or rejected and who they believed would think women were faking pain as a strategy to avoid intercourse (Elmerstig, Wilma & Bertero, 2008). It is interesting that these women expected their partners would disbelieve they were in pain but not suspect they were faking pleasure.

A more recent qualitative study about experiences of sexual pleasure in a sample of 14 female Canadian University students, aged 19-28, who had sex with men, found all described faking orgasm to end consensual but unwanted intercourse (Thomas, Stelzl, & Lafrance, 2017). Women described female pleasure as dependent on the sexual skills of their partners, and faking pleasure was depicted as a way to satisfy their partners needs and end experiences that were unsatisfying, uncomfortable and/or painful, and where male orgasm was the primary goal of the encounters and defined their completion (Thomas, Stelzl, & Lafrance, 2017). Braksmajer and colleagues interviewed 53 women with dyspareunia (half meeting criteria for a diagnosis of vulvodynia) about their reasons for continuing to engage in intercourse that was experienced as painful, found women described voluntarily engaging in unwanted intercourse to fulfil perceived obligations of their role within a romantic relationship to provide sexual care for their partners as a means of maintaining intimacy (Braksmajer, 2017). Coining the term “sexual care work” as another aspect of heteronormative scripts that limit avenues for heterosexual women to engage in an equal exchange of sexual pleasure with male partners, the authors suggest that being unable to meet their perceived ‘obligations’ within their intimate relationships by either avoiding partnered sex or ‘submitting’ to intercourse they experienced as painful and distressing, was likely the primary cause of the commonly reported belief by women with vulvodynia that they were ‘failed’ partners and ‘abnormal’ women (Braksmajer, 2017).

Dominant discourses of gender were reconstructed across the present narratives, revealed where heteronormative ideologies of womanhood (and manhood) were reproduced and resisted in the story telling process. Throughout their stories women discussed how they had believed their inability to have pain-free intercourse signaled personal failure and essential defectiveness, with descriptions of shame signalling how they believed they had failed to live up to cultural

gender prescriptions for heterosexual womanhood. This adds further support to a growing body of qualitative literature which has consistently found women with chronic dyspareunia (with and without a diagnosis of vulvodynia) report feeling they are ‘neutered’, ‘failed’, ‘broken’, or ‘unreal’ women based on the notion that sex, defined by intercourse, is something men ‘need’ and that women partnered with heterosexual men are expected to provide. (Ayling & Usher, 2008; Buchan et al, 2007; Munday et al., 2007; Kaler, 2006; Marriott & Thompson, 2008; Johnson et al., 2015; Elmerstig et al., 2008; Shallcross et al., 2019; Braksmajer, 2013; Webber et al., 2020).

4.3.3 Partner-related Factors

The consequences of heteronormative sexual scripts which lead to sexual double-standards and centralize the coital imperative cast a long shadow within the sexual relationships of heterosexual men and woman, limiting possibilities for sexual exploration and communication more conducive to an equal sharing of sexual pleasure. These beliefs have material impacts on the sexual experiences of women who have sex with men, where non-penetrative sexual activities are regulated to the periphery, as foreplay, an accessory or lead-up to the defining act, rather than being understood as central to the mutual exchange of sexual pleasure. As it has been shown that women are more reluctant to communicate pain than feign pleasure, where men may underestimate her pain experience and overestimate her pleasure, and sexual double-standards inform heterosexual scripts that women meet male partners sexual needs at the expense of their own, treatment for PVD that doesn’t involve male partners, challenges their limited sexual scripts, including beliefs about ‘real’ sex, may be less effective for women, particularly those in relationships with poor communication, low levels of intimacy and shared limited sexual beliefs and practices.

While many women in the present narratives problematized cultural constructions of female sexuality that centralized male pleasure via intercourse they imply, or are explicit, that their own individual progress would be limited to the degree their partners are willing to collaborate. Those women who described their partners as understanding and supportive emphasized they thought them exceptional, or at least not typical of how ‘most’ men could be expected to respond to a woman unable to engage in intercourse and doubted many would participate in a therapeutic process for a problem most would see as hers to solve. They suggest that ‘most’ men would reject a woman with vulvodynia for not being able to perform their role as sexual care giver unless alternatives to sexual double standards were normalized in media, healthcare and educational contexts. As previously cited research suggests, and present narratives support, women with vulvodynia may persist with painful penetration to attend to the sexual needs of their male partner while neglecting their own, a practice which leads to more pain and anxiety for her, but also decreases in sexual satisfaction and psychological functioning for him and deterioration of the shared intimate relationship (Muisse et al, 2017). The women in the present narratives emphasized an unmet need for the inclusion of male partners in education and treatment that might encourage collaboration and an expansion of limited sexual scripts.

Unfortunately, treatment for PVD remains primarily individually focused (Bergeron, Rosen, Corsini-Munt, 2018; Rosen, Rancourt, Corsini-Munt, & Bergeron, 2014), despite consistent recommendations from researchers and clinicians that partners of affected women be routinely involved in educational and psychological interventions for PVD (Barksy-Reese, 2009; Dunkley & Brotto, 2016; McCabe et al., 2010). It has also been recommended that therapy additionally be expanded to directly interrogate unexamined cultural narratives that inform individual and shared beliefs about gendered roles of sexual expression and the centralization of

the coital imperative within heterosexual relationships as a way to further externalize the source of the problem and create more space for individuals and couples to choose sexual practices from an expanded sexual menu that promote the mutual exchange of pleasure and intimate connection (Anders et al., 2021; Ayling & Usher, 2008; Elmerstig et al., 2008; Shallcross et al., 2018).

Given the inherently intimate interpersonal context within which PVD pain is most often experienced, changing the beliefs, emotional responses and behaviours of the woman in pain is likely to have a limited capacity to improve her sexual experiences and distress if her sexual partner's beliefs, responses and behaviours are informed, unchallenged, by limiting social constructions of heteronormative sexual expression. There are calls in the literature to expand the fear and avoidance model of sexual dysfunction beyond treatment focused on reducing anxiety (and thus avoidance) of sexual contact at an individual level, when sexual contact is experienced with legitimate negative outcomes (e.g. pain, lack of pleasure, relationship conflict), and the assessment of the threat-value of pain is adaptive (versus irrational/maladaptive), in which case the interpersonal context (versus the individual) would be a more appropriate and effective target for therapeutic intervention (Stephenson, & Meston, 2015).

Three women in the present analysis discussed ongoing challenges with partners who viewed PVD as a problem she was responsible for resolving to return their sexual relationship to 'normal' and ensure their continued commitment. Christine describes making personal progress reconnecting with and exploring her sexual body, although a lack of intercourse, which she continues to anticipate will be painful, remains a point of conflict in her relationship. Anya's partner was initially adamant the problem be resolved for their relationship to continue, and despite reduced pain at clinical exam she did not experience any improvements with dyspareunia until her partner got involved in couples therapy and they collaborated on adaptations to their

sexual and romantic relationship. For Sherry, who describes her pain as ‘worse now’ despite engaging in multiple individual interventions before and after participating in two groups, described intense conflict in her relationship related to a lack of intercourse, including responses to her increasing distress by her partner that she describes as emotionally abusive.

The quality of the relational context has been shown to be an important predictor of distress regarding any sexual impairment (Bancroft, Loftus, & Long, 2003), the attendance of both partners in therapy is a significant predictor of improvement for the member of the couple experiencing sexual improvement, correlating with improvements in sexual satisfaction for both (Günzler & Berner, 2012), and improving sexual communication through education or therapy is consistently correlated with increasing sexual satisfaction of the couple (Awada, Bergeron, Steben, Hainault & McDuff, 2014). There is a growing body of research that suggests improving relationship satisfaction by promoting positive communication between partners about PVD can ameliorate women’s experience of pain (Rosen, Bergeron, Glowacka, Delisle, & Baxter, 2012; Rosen et al., 2010; Rosen et al., 2013; Rosen et al., 2014; Rosen, Bergeron, Lambert, & Steben, 2013). Research has demonstrated that how a partner responds to women's coital pain impacts her subjective pain experience and both partners' psychological functioning (Rosen et al, 2010, Rosen et al. 2012, Rosen et al, 2014) and women with vulvodynia whose partners provide more adaptive support experienced reduced pain and distress. (Rosen et al, 2015). Improving intimacy by promoting empathic response and disclosure through couple interventions has been shown to improve sexual distress and dissatisfaction of couples coping with vulvodynia (Bois, Bergeron, Rosen, Mayrand, Brassard, & Sadikaj, 2016) and psychological interventions designed for couples whose relationship has been negatively impacted from vulvodynia significantly improved dyspareunia (Corsini-Munt, Bergeron, Rosen, Mayrand, & Delisle, 2014). As the

quality of the relationship has been consistently reported as mediating women's progress with vulvodynia treatment including pain relief, initial relationship counselling for women in relationships prior to beginning therapy for pain, is particularly important for those in relationships with poor communication, a lack of intimacy and conflict (Bois et al., 2016; Brotto et al., 2013; Corsini-Munt et al., 2014; Sadownik et al., 2013; Bergeron et al., 2018).

Cognitive Behavioural Couples therapy intervention with 9 couples confirmed that a psychological intervention targeting both members that included PVD specific education, information about the relationship between psychological well-being and sexual functioning, the impacts of PVD on both members and strategies for communication and behavioural exercise to target intimacy avoidance, improved psychological and sexual functioning, sexual satisfaction, and efficacy of both members and 75% reported "moderate" or complete resolution of her pain experience (Corsini-Munt et al., 2014) a much larger improvement in pain symptoms than that reported in individually focused psychological interventions.

Many women expressed their doubts that 'most' male partners would be willing to attend psychoeducation, intervention or support groups for PVD and research attempting to evaluate the impact of psychoeducational interventions on both have noted challenges recruiting couples or male partners for participation (Corsini-munt et al., 2014; Sadownik et al., 2017). Although the negative emotional, psychosexual and relational impacts of vulvodynia on male partners has been reported from their perspective in other publications (Smooth & Pukall, 2014; Connor, Robinson & Wieling, 2008; Nylanderlundqvist & Bergdahl, 2003), the majority of research available has explored the impacts on the couple from her perspective. However, when couples and male partners have been involved in research, they have also expressed how receiving vulvodynia-specific education and therapeutic support improved their own feelings of

inadequacy, isolation and abnormality and led to a re-storying of their relationship, and changes in their sexual beliefs that facilitated an expansion of sexual practices not reliant on intercourse and increased intimacy and overall improvements to their perception of their relationship functioning (Connor et al., 2008, Sadownik et al., 2017). Qualitative interviews of male partners of women who participated in the MVP found men reported positive impacts to their own feelings of hope, efficacy and normalization, appreciated receiving vulvodynia-specific education and described improvements in communication as well as sexual benefits related to an increase in intercourse (Sadownik, Smith, Hui & Brotto, 2017).

Although it may seem intuitive that when the context of the intimate relationship is conflicted or dysfunctional and/or a woman has experienced a history of unrewarding sexual experiences that her desire for sexual activity and response to sexual cues will be muted, this is not commonly considered when assessing female sexual dysfunction (Chivers & Brotto, 2017). It has been suggested that assessment and education of women's sexual partners is especially relevant for female sexual impairments, where a male partners knowledge of female arousal generally, and where the setting, the techniques employed and time dedicated to non-penetrative stimulation may be insufficient for adequate sexual arousal and pleasure which also facilitates comfortable intercourse (Basson, 2008; Carvalheira, Brotto & Leal, 2006;) and orgasm which also has well established analgesic effects (Leknes & Tracey, 2008; Whipple & Komisaruk, 1988).

Therapy for couples with vulvodynia often focuses on shifting focus away from goal oriented sexual activities (like orgasm and intercourse) towards approaching sexual expression as a mutual exchange of pleasure, and mindful attendance to the present sexual context, in line with McCarthy and Wald's "good enough" sex model (2013). In this model, sex is defined as a couple

process of sharing pleasure, with or without intercourse, and encourages realistic goals and expectations to counter unrealistic individual performance goals of ‘erotic perfectionism’, described as a binary “pass-fail test” that leaves many individuals and couples developing beliefs that they don’t measure up sexually, and decreased desire for sexual contact that becomes negatively anticipated (Connor et al., 2008; Corsini-Munt et al., 2014; McCarthy & Wald, 2013). Taken together research suggests the involvement of male partners in therapy and education could provide both partners with material benefits, rather than just an avenue for altruistic support of affected women and create a context within which pain symptoms can be more effectively addressed.

4.3.4 Lack of Access to Educational and Support Resources

Recommendations for improving treatment for women with vulvodynia in the present narratives included flexible access to psychoeducational and support options including interactive online options and ongoing follow-up. As these interviews were conducted before the global Covid-19 pandemic which forced the conversion of many in-person medical and psychological consults into online appointments, there will likely be considerably more data regarding the comparative effectiveness of these options available in the near future. However, there is preliminary data available that virtual support and education may be similarly beneficial and provide an accessible and cost-effective alternative to in-person delivery of supports for a variety of difficulties.

Internet- based peer support groups combined with education can improve depressive symptoms (Houston, Cooper & Ford, 2002; Griffiths, et al. 2012), guided online individual therapeutic support can improve depression and anxiety (Andrews et. al, 2010), and virtual CBT-based group therapy for PTSD demonstrated improvements in trauma, anxiety and depression

symptoms maintained at 18 months (Knaevelsrud & Maercker, 2010). There is similar support for online interventions for chronic pain and sexual dysfunction: an online group delivery of CBT for chronic pain patients showed similar improvements in effective coping between groups, with patients participating equally satisfied with in-person or virtual delivery (Mariano et al, 2021), a 6-session online MBCT module, with real-time chat support for women with mixed sexual problems demonstrated improvements in sexual response and distress in participants and their partners at 3 months, (Hucker & McCabe, 2015), internet-based sex therapy improved the sexual functioning of men experiencing erectile dysfunction (Blanken et al, 2014), and online delivery of CBT-based psychoeducation for women with low sexual desire improved sexual function, distress, self-efficacy and feelings of normalization (Zippan, Stephenson & Brotto, 2020).

A 2016 systematic review of the evidence available for the effectiveness of internet-delivered CBT for anxiety, depression and emotional distress related to physical illness found most to be cost-effective supports that reduced the severity of symptoms, with similar improvements for those professionally-guided and moderated or automated, although therapist-involvement seemed to improve adherence, with low participation and high-drop-out rates a common weakness across studies reviewed (Gratzer & Khalid-Khan, 2016). The authors note that many of the 1104 articles reviewed were found to be of low-quality, and there were few published replications of positive results reported by well-designed RCTs included (Gratzer & Khalid-Khan, 2016). A more recent review of the literature regarding online therapeutic groups published in response to the global pandemic that forced many in-person groups online, concluded most of the available evidence supported that a well-designed online environment could deliver many of the same therapeutic impacts associated face-to-face groups, with some

caveats (Weinberg, 2020). The author highlighted there were few available studies, many were of low-quality or with difficult to compare protocols and that many noted obstacles to creating and maintaining therapeutic presence and connections between group members and called for future RCTs to compare the quality of therapeutic elements between in-person and virtual therapeutic groups (Weinberg, 2020). Other research has demonstrated that online interventions may be especially prone to drop out, may be limited in providing the benefits of ‘togetherness’ associated with group participation or presence of the therapists, may be perceived as less effective and private, and that couples in particular may be more reluctant to pursue virtual therapy despite research support it may also deliver many of the same benefits as in-person support (Renn et al, 2019; Kysely, Bishop, Kane, Cheng, De Palma, & Rooney, 2020).

Women suggested the development of online psychotherapeutic and comprehensive educational modules, along with regularly updated community resources for complimentary therapy interventions and easily accessible research support for treatment recommendations. Adapting effective psychological interventions to online interventions was recommended by the study team associated with the COMFORT intervention (Brotto et al., 2019). Brotto and colleagues have demonstrated that online platforms may be especially promising for the purposes of education and knowledge translation, providing affordable and accessible options that can be coordinated with social media awareness campaigns and real-time webinars and have the potential to reach large numbers of viewers when they are easy to find and well designed to optimize navigation (Brotto, et al., 2016; Brotto, Nelson, Barry & Maher, 2021).

As it has been shown that many women with vulvodynia may have reduced trust in the recommendations of medical providers and are less likely to commit to psychological and physical interventions that require a considerable investment of time and money, and clinical

researchers have suggested that many women seeking medical care for vulvodynia have limited education about sexual health generally and vulvodynia in particular, providing easy to access educational options may increase the likelihood that women and their partners will engage in therapeutic supports (Sadownik et al., 2017; Webber et al., 2020). Some women also suggested that centralized services that included flexibility to revisit therapeutic interventions would increase the likelihood they could continue progress as their needs and circumstances changed and help them to more effectively address set-backs, mirror research recommendations for centralized clinical services to coordinate multidisciplinary care for women and their partners as the most effective approach for addressing the deleterious impacts of vulvodynia on women and their partners (Bornstein, 2016; Sadownik et al., 2017; Webber et al., 2020)

4.4 Future Directions

Women discussed how their individual and interpersonal contexts, including dynamics within their intimate relationships, comorbid medical or psychological difficulties, feelings of disconnection from their sexual bodies and challenges understanding, accepting or practicing recommended psychological skills presented additional barriers to progress that were difficult to overcome without additional support and suggested future interventions assess and address these factors. Many women also referenced how pervasive cultural and social narratives regarding ‘normal’ sexuality created additional challenges for embodying and expressing a more inclusive and expansive sexuality when partners, doctors, friends, family, media and education settings continue to subscribe to and perpetuate limiting sexual discourses which prioritize male bodies and experiences, centralize male pleasure and define sex as intercourse. Women emphasized the importance of how revising their story about what PVD ‘meant’ about them changed their

relationship with their pain symptoms and significantly reduced their distress, whether or not they continued to experience provoked vulvar pain.

Although the research question asked women to story their experiences participating in the COMFORT study and their “journey with PVD since” all women began by describing a painful journey “looking for answers”, some referencing dismissive and unhelpful care providers, an absence of stories around them that reflected their experiences, disruptions to their intimate relationships and an internal process of essentializing their experience as reflective of a fundamental core defect. Many women returned to these themes when describing how the program helped them, needs that remained unmet and when suggesting what was still needed for other women who may also be looking for answers. They suggested doctors should be taking their complaints seriously regardless of their individual knowledge about vulvodynia, that more information be available to doctors and in community contexts, more realistic depictions of sex, including female pleasure and sexual challenges portrayed in the media. Women questioned whether treatment for vulvodynia could be successful without active participation or ‘buy-in’ from male partners and some implied it unfair that they were solely responsible for returning partnered intimacy to the ‘normalcy’ of easy intercourse. Women directly and indirectly challenged the coital imperative in sociocultural definitions of sex, where sex education was focused on the dangers of intercourse, female sexual pleasure is absent and doctors are still telling women to ‘have a glass of wine and relax’. Although the lack of knowledge about sexual issues and discomfort discussing them amongst general health practitioners is well documented, future research quantifying pain and distress in women with vulvodynia and the impacts of treatment interventions might explore the degree to which these experiences might further reinforce and amplify the pain experience and the deleterious psychosexual impacts.

Many women commented that ‘being with’ other women who shared their difficult journey, despite being from ‘different backgrounds and life-stages’ was one of the most powerful antidotes to their feelings of shame, self judgement and isolation. Most spoke of how feeling empathy and compassion for other women in their group sharing stories of feeling ‘hopelessly broken’ initiated their own cultivation of self-compassion. Including the stories of other affected women in online psychoeducational interventions when real-time groups are not possible, either through the voiced perspectives of women available in published qualitative studies, via video or voice recordings of volunteers telling their stories of how PVD impacted them, testimonials from women describing how treatment has helped them and including platforms for the sharing of the same, may help to address the feelings of loneliness, isolation, shame and self-judgement described here and elsewhere. Actively incorporating the lived experiences of these women into online educational and therapeutic interventions may also help to increase women’s confidence that suggested interventions offer an effective ‘real-life’ solution to their pain and distress while also tempering unrealistic expectations about treatment success. Also including and deconstructing limiting cultural narratives about what ‘real’ sex is, connected with research that supports an expanded definition of sex that is beneficial to the sexual enjoyment of both partners may help to inoculate heterosexual women (and their partners) from relentless messaging in most other media contexts that affirms a narrow definition of sexual expression and functioning, and a ‘normal’ many will be excluded from at some point in their lifetimes. In line with this, additionally including the voiced perspectives of men with affected partners and couples who have struggled, sought treatment and re-navigated their sexual relationship may help to reach men who are struggling with their own feelings of shame and inadequacy and those that are resistant to collaborating with their partners or change their own behaviours. Although women

with PVD have additional therapeutic needs given the commonly experienced impacts to sexual functioning, additionally including basic information about vulvodynia on the platforms of chronic pain researchers and treatment centres, especially given vulvodynia's high rates of comorbidity with other chronic pain conditions, might also help to reduce the stigma associated with chronic vulvar pain, increase awareness of PVD as a legitimate diagnoses and perhaps encourage women to seek treatment.

4.4.1 Clinical Implications

Comprehensive education about vulvodynia and information about effective interventions is an important stand-alone intervention and may also better prepare women to participate in psychological interventions to continue benefits. Research has consistently shown that confidence in any intervention improves its effectiveness, and that women and their partners may be reluctant to seek psychotherapeutic support without a clear understanding of how it may help them in the context of vulvar pain (Webber et al., 2019, Bergeron, Rosen & Corsini-Munt, 2018; Connor et al, 2008). Comprehensive education that connects pain education with research supporting the effectiveness of psychotherapeutic interventions may help, as it did for Anya, to “plant the seeds” that may lead to separately committing time and resources to focused support. This may be especially important in the context of the likelihood many women may have reduced confidence in the recommendations of HCP who they have experienced as dismissive and invalidating and for whom without detailed explanation may perceive referrals to psychotherapists as affirming vulvodynia is just ‘in their heads’. Although quantitative analyses of COMFORT data did not reveal any impact of previous treatment, including MVP participation, on the outcomes measured (Brotto et, al 2019), many women in the present narrative inquiry credited their previous experiences with MVP, mindfulness practices and

psychological support (including previously learning CBT skills) as important to the improvement they experienced. As women with Provoked Vestibulodynia tend to have higher levels of perfectionism, self-criticism, anxious rumination and fear of negative evaluation (Brotto, Basson, & Gehring, 2003; Ehrstrom, Kornfeld, Rvlander & Bohm-Stark, 2009; Payne, Binik, Amsel, & Khalife, 2005) they may more quickly lose patience with the rate of change and self-perceptions they ‘aren’t doing it right’ and it may be particularly important to assess women’s history with psychological interventions and their understanding of how they may be helpful for PVD, to allow for more time for explanation and supported practice for women exploring the use of these skills for the first time. Some have suggested integrating CBT and mindfulness modalities in future group interventions to foster the development of mindfulness skills in-tandem with identifying and restructuring automatic thinking patterns to nurture the development of self-efficacy, pain-acceptance and self-compassion, (Dunkley & Brotto, 2016).

Although CBT has robust research support for improving psychological and sexual functioning for women, it centers on a “goal-oriented rather than pleasure-based approach, focusing on objective, behavioral, and physiological endpoints without attending to subjective meaning, embodiment, and connection” (Dunkley & Brotto, 2016). Moreover, it is well known that change-oriented strategies, considered hallmark to CBT, may not be appealing to or effective for all clients (Brotto, Basson, Driscoll, Smith, & Sadownik, 2015; Dunkley & Brotto, 2016) From this perspective, individual behavior change without consideration of the context within which the targeted behaviours are performed can be viewed as “changing a woman’s behavior to comply with society’s expectations about how she perform sexually” (Dunkley & Brotto, 2016). Clinicians and researchers have argued that what is required is a clinical shift toward improving the quality of sex over sexual frequency, and sexual experience over

performance and away from viewing any particular challenge to sexual functioning as an individual problem (Connor et al., 2008; Corsini-Munt et al., 2014; McCarthy & Wald, 2013; Sadownik et al., 2017; Webber et al., 2020).

As those women who are currently experiencing the most freedom from the negative impacts of PVD suggest, setting realistic goals for therapy that explore motivations for pain resolution, so interventions are responsive to her individual context. As each woman's story suggests, their assessment of what they perceived their vulvar pain 'meant' about them, foreshadowed their description of program elements they found most helpful, or where their needs remained unmet. For example, a woman wanting an increase in intercourse frequency may be seeking increased intimacy or sexual pleasure, or may feel pressured to perform perceived relationship obligations, in which case, specific goals of increasing non-sexual physical contact or expanding sexual her sexual menu, developing more pleasure-focused sexual practices, deconstructing cultural narratives regarding sexual double-standards and the coital imperative and addressing partner expectations would all be appropriate therapeutic goals. Women in the present narratives emphasized improvements that are gradual and incremental, and often involved participation in physical therapies, group, individual and couples support and holistic self-care and clinicians should be cautioned against endorsing the complete resolution of pain as a goal and instead focus on specific short-term goals like improving intimacy, acceptance, self-compassion and/or redressing maladaptive cognitive responses (for example), with the understanding that pain may be a continued presence. As previously cited research has shown that not all women will experience a reduction in pain, yet many report a decrease in its negative consequences following therapy, clinicians should avoid general, nonspecific sexual goals that may place further pressure on the patient with pain, such as an increase in sexual frequency or

sexual desire (Bergeron, Rosen, & Corsini-Munt, 2018. Inviting the woman *and her partner* to deepen their understanding of their goals and to examine their individual and shared beliefs about the pain encourages, collaboration and sexual approach goals versus sexual avoidance goals that can improve her pain experience and their overall sexual relationship (N. Rosen, Muise, Bergeron, Impett, et al., 2015).

With the general acceptance of a multifactorial etiology for vulvodynia, each individual woman is likely to present to therapy with complex and interdependent issues impacting her pain experience including, for example, her sexual and pain beliefs, her understanding of and confidence in the diagnosis, relationship factors, cultural influences, comorbid psychological and/or medical diagnosis, chronic and/or traumatic stress, histories with dismissive healthcare providers, mistrust of the diagnosis and/or a misunderstanding of how psychological interventions may be helpful. So long as the application of a biopsychosocial model for care remains aspirational in practice, where clinical practice of psychotherapy continues to centralize cognitions, emotions and behaviour change for improving experience, medicine focuses on pathophysiology, and both continue to focus on individual change with sociocultural factors unevenly accounted for across psychological and medical disciplines, effectively addressing sexual challenges will remain less effective (Benning, 2015).

Women confirmed clinical impressions and research results that women preferred having multiple treatment options that included comprehensive education, group formats and individual and couples psychotherapeutic approaches available via centralized services that also provide complementary interventions like pelvic-floor physiotherapy consistent with a multidisciplinary approach that is currently recommended as best practice for effectively treating vulvodynia (Borstein, 2016, LePage and Selk, 2016; Sadownik et al, 2014; Webber, 2020). Unfortunately,

centralized services are out of reach for most women, and many may be reluctant to seek these options when they are available or continue the therapeutic recommendations in their community due to a lack of understanding of their benefit, the significant financial and time burden, lack of partner support and unavailability of knowledgeable clinicians. Education about sexual health, including vulvodynia needs to be readily available not just for those experiencing sexual challenges but for the clinicians supporting these women and collaboration between medical and mental health professionals will be essential for improving care. Having an understanding of central sensitization syndromes and how the physical body, emotions and cognitions interact, might improve counselling therapists ability to support clients, as CNS sensitization has been implicated in the development of PTSD, ‘unexplainable’ physical symptoms and chronic pain syndromes and substance misuse and associated with chronic fatigue, depression and anxiety. Although not a panacea, educating clients about CNS sensitization provides an explanation for their symptoms, materially delineates the territories for intervention and empowers clients with new understanding of the possibility they can influence their emotional, psychological and physical response (Brotto et al., 2013; Brotto, Sadownik, & Thomson, 2010; Nijs et al., 2011; Sadownik et al., 2012). As with the women here, it may be helpful for others to learn their symptoms are not the sign of essential defectiveness but a dysregulated nervous system response that ‘makes sense’ given an accumulation of internal and external stressors, a response that is amenable to therapeutic intervention.

4.4.2 Suggestions for Future Research

More research is needed to understand how individual women may benefit more or less from particular interventions for women with vulvodynia, particularly how their beliefs about what constitutes effective treatment, their confidence regarding interventions offered and how

their individual characteristics and contexts may impact the effectiveness of any particular intervention (Sadownik, Seal & Brotto, 2012). Treatment outcome research is often focused on measuring individual factors preventing intercourse with less focus on other aspects of sexual experience like pleasure and satisfaction which may remain impaired, regardless of individual changes in intercourse frequency and research needs to include multiple sexual outcomes (Brotto et al., 2019;). There is a lack of significant correlation between pain intensity during intercourse and overall sexual function, as well as pain and sexual satisfaction, suggesting they may be distinct or only partially dependent phenomena (Rosen, Bergeron, Leclerc, Lambert, & Steben, 2010). More research on how interpersonal and contextual variables may influence these outcomes is needed to better understand variability in outcome data (Bergeron, Cosini-munt & Rosen, 2018). Research-clinicians with expertise in female sexual difficulties have argued that even the most reliable validated measures provide an incomplete picture of the sexual functioning and relative distress or satisfaction of individual women seeking treatment or participating in research when their desire for sexual activity has been shaped by their present relational contexts, their previous experiences with and beliefs about sex, and sociocultural expectations of women's sexual expression (Chivers & Brotto, 2017; Brotto, Bitzer, Laan, Leiblum, & Luria, 2010). The present inquiry suggests the importance of considering individual goals and beliefs and their evolution, depending on where a woman is on her journey towards wellness, that with further inquiry may suggest a map for individualizing treatment.

Male partner beliefs about pain and goals for treatment have also been identified as understudied education, treatment and research targets and it has been additionally suggested that interrogating limiting social discourses of heterosexuality in future research from the perspective of male partners may provide further insight into how partner beliefs interact with the treatment

outcomes for women with PVD (Jodoin et al., 2011; Sadownik, et al., 2017). A related goal may be to explore whether the documented negative psychological impacts of vulvodynia on male partners is connected specifically to its disruption of intercourse, secondary to feelings of helplessness or distress witnessing the suffering of their partners, of guilt (for hurting their partners, for ‘not doing it right’), rejection (she doesn’t ‘want’ me/ isn’t attracted to me), and/or the loss of sexual connection and intimacy because their partners have withdraw from all sexual or physical contact. Additionally, eliciting the underexplored experiences of queer persons with vulvodynia and their partners would address a significant gap in the literature to help clinicians better support them and may illuminate heteronormative assumptions inherent in treatment outcome literature that might improve care for all persons and their partners.

Increasing access to education and knowledge translation may involve expanded outreach to community stakeholders beyond academics, HCP and affected women to reach unaffected women and men and might include educational systems, chronic pain initiatives, ‘sex shops’, social and mainstream media outlets and more research directed at improving dissemination to contribute to a restorying of limiting cultural narratives of sexuality (Elmerstig, Wilma & Bertero, 2008; Thomas, Lafrance & Stelzl, 2018). More research directed at the effectiveness of online platforms for psychoeducation and support and whether it provides a low-cost, low-barrier alternative to in-person services with comparable benefits.

The findings presented here additionally support recommendations to routinely incorporate qualitative research into program evaluation and treatment outcome studies to improve understanding of how interventions are experienced as helpful (or not) by those who participate in them and would be useful for generating new hypotheses for empirical inquiries regarding effective assessment and treatment of affected women and their partners.

4.5 Strengths and limitations

This narrative inquiry may be unique in eliciting the storied experiences of women more than five years after participating in a group psychoeducational intervention for PVD and notable for participants' recollections of components of the COMFORT program that still stand out as helpful to them. Their insights may prove valuable for future inquiries into many unanswered questions about what helps which individual women, how and when, and for clinicians encountering women in their community practices where a full assessment of their individual contexts may help tailor recommendations that take each woman's journey, beliefs, treatment goals and relationships into account.

There are limitations related to such a significant passage of time, and many participants expressed concern that they would be unable to remember details of their participation. By framing the research question when asking about their participation by also including "your journey with PVD since" it was hoped that women would be able to relate specific program elements that still stood out to them as helpful, while also capturing their overall functioning in relation to PVD, including any continued difficulties they experienced along the way and how they have managed them. As these narratives rely on retrospective recall for considering their participation from the perspective of how they are doing now it is likely the content of their recollections is influenced by the current degree of presence of PVD in their lives and may have been recalled differently at times they were experiencing more or fewer difficulties with their symptoms. However, the accounts presented here are significant for the many program details they still recalled and their perceived relation to their overall journey towards wellness.

The present inquiry shares limitations common to qualitative research generally and narrative in particular, including a small unrepresentative sample size (Riessman, 2008).

However, the goals of this research method are not intended to collect data for the purposes of generalization but to capture ‘notable exemplars’ and facilitate a rich, ‘experience-near’ exploration of individual perspectives to contextualize quantitative data and provide insight into explanatory possibilities not captured in variables measured (Polkinghorne, 2005). A sample of eight is considered an appropriate size for a close reading of individual cases and cross case analysis (Fugard & Potts, 2015; Braun & Clark, 2006).

There are also strengths and limitations inherent in the demographics of the sample of women who responded. There are strengths related to demographic elements that fall well outside the range of the average characteristics of the original sample that meet the goals of a narrative inquiry to capture ‘notable exemplars’: half of the women interviewed did not identify as Caucasian, and two grew up speaking non-English languages at home, two women were several years older than the average of the original sample, one was single, another had participated in both interventions and their pain status, time to diagnosis and relationship quality varied considerably. However, much like the original sample, and a commonly reported demographic limitation in vulvodynia research, all were at least college-educated (many with psychology or health-care related degrees) and heterosexual. It is possible that their educational background influenced their interest in participating in the present inquiry, their engagement with the original intervention and educational material and their available means for pursuing follow-up support. How chronic vulvar pain may impact and be influenced by the sexual beliefs and intimate relationship contexts of those women not interested in pursuing sexual relationships with men are also missing.

As previously mentioned, women’s participation in the construction process also varied and it is possible that the two women who did not review their final narrative draft in detail may

not have endorsed my final construction. Although all expressed some degree of appreciation and gratitude for their experience with the original program not all women appear to have benefited to the same degree and many report therapeutic benefits not specific to the modality of the intervention. Some reported program elements they found unhelpful, and many had suggestions for what they felt was lacking, suggesting the interviews meet the original goals of this inquiry to shed light on questions regarding the variability in quantitative outcomes, how particular women may respond differently to each modality and therapeutic elements shared across treatment arms or experienced outside the group intervention during their participation. Additionally, the themes developed across the narratives presented here are reflected similarly in the available qualitative literature supporting the likelihood experiences storied here are shared by many heterosexual women with PVD symptoms and strengthen support for recommendations for treatment that includes comprehensive education, coordinated clinical care and emphasizes partner involvement and relationship support for partnered and unpartnered women.

4.6 Conclusion

The present inquiry reaffirms difficulties experienced by women with PVD reported consistently across the research literature regarding the negative emotional, psychological and relational impacts of living with unexplained chronic vulvar pain, difficulties further compounded by interactions with healthcare providers that are experienced as invalidating and judgmental and remembered as a significantly painful experience many years later. Outreach, support and education for community medical practitioners regarding the wide-ranging negative health impacts of living with chronic conditions and an understanding of available support resources may help them to better address patients with complex and seemingly unexplained physical symptoms. Resources and support to increase MD comfort, confidence and basic

knowledge discussing sexual issues and awareness of tertiary specialty clinics that may help to address these and will be important to avoid delays in treatment that may worsen symptoms and entrench maladaptive beliefs and behaviours that may make these conditions more challenging to treat. Multidisciplinary approaches for treating vulvodynia including medical, psychotherapy, comprehensive education and pelvic-floor physiotherapy services have been suggested in the research as likely offering the most reliable benefit for their complex needs although there remains a lack of easily accessible centralized services. Community follow-up with recommended interventions like psychotherapy, sex-therapy and pelvic floor physiotherapy may be too costly for many women, and some may be unlikely to pursue them without a better understanding of how they may help. A thorough assessment of women with chronic vulvar pain should include collecting information about her treatment goals, her history pursuing treatment and her perception of its helpfulness, her beliefs about her symptoms and her understanding of the diagnosis and additionally involve her intimate partner when appropriate so treatment can be individualized to her personal context and additional education provided to both partners about the diagnosis, prognosis and therapeutic elements of recommendations when necessary to support them in making realistic goals and improve uptake and adherence to recommendations. This may require additional follow-up appointments and opportunities to revisit psychotherapeutic and educational supports as women's individual contexts change. The creation and implementation of virtual educational and psychotherapeutic supports for women and their partners may help to address the limited resources of some women and of healthcare service providers. Finally, researchers and clinicians should regularly collaborate with patients and research subjects for the purposes of treatment evaluation and knowledge-translation.

It is hoped that this inquiry will contribute to current research by providing information useful to program evaluation, future treatment research, and needs-evaluation. By illuminating the individual experiences of participants in a psychological intervention study, by adding important contextual information to compliment interpretation of quantitative analyses and by providing the opportunity for women to contribute to the narrative of PVD treatment, this inquiry may enrich existing research literature regarding the experience of PVD and its treatment.

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Appendices

Appendix A Informed Consent

 <p>THE UNIVERSITY OF BRITISH COLUMBIA Faculty of Education Department of Educational & Counselling Psychology, and Special Education</p>	<p>Vancouver Campus 2125 Main Mall Vancouver, BC Canada V6T 1Z4 Phone: 604 822 0242 Fax: 604 822 3852</p>	
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Consent Form

**Storying the Experiences of Women Participating in the Cognitive behaviour therapy Or
Mindfulness for Treating PVD (COMFORT) Study: A Narrative Inquiry**

I. STUDY TEAM: Who is conducting the study?

Principal Investigator:

Dr. Marla Buchanan
Professor, UBC Education and Counselling Psychology
[REDACTED]

Co-Investigator(s):

Adrienne Marsh
MA Candidate, UBC Counselling Psychology
[REDACTED]

Dr. Norm Amundson
Professor, UBC Education and Counselling Psychology
[REDACTED]

Dr. Lori Brotto
Professor, UBC Faculty of Medicine, Department of Obstetrics and Gynaecology
[REDACTED]

II. INVITATION AND STUDY PURPOSE: Why are we doing this study?

You are being invited to take part in this research study because we are interested in your stories about your participation in the COMFORT study. This research is being conducted to fulfil the thesis requirements of a UBC Graduate Degree in Counselling Psychology.

III. STUDY PROCEDURES: How is the study done?

If you agree to take part in this study, you will be asked to tell the researcher a story about your participation in the COMFORT study that will be audio recorded. This storytelling can take place in your home or in a private office at Vancouver General Hospital or by videoconferencing. If you decide to participate in the interview via video link, this will not be video recorded, but audio recorded just as the in-person interviews. The session will be expected to last for approximately 60-90 minutes. This experience may be different from other kinds of research you have participated in which may have involved questionnaires or a question-and-answer interview

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format. The researcher will begin the recording by asking: "Tell me a story about your participation in the COMFORT study" and will reserve any questions about your narrative until after you have finished. You are also welcome to ask the researcher any questions you may have at this time.

IV. STUDY RESULTS

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books. If you are interested in receiving the results of this study there is an option below to indicate your interest and the best way to get the study results to you (email, mail).

V. POTENTIAL RISKS OF THE STUDY

We do not believe that participating in this study will be harmful to you. However we acknowledge that your telling of your story is very personal. Your confidentiality and privacy are important. As such interviews can take place in your home or in a private office space at Vancouver General Hospital if you feel more comfortable. The audio recordings will be downloaded into UBC's Workspace 2.0, which has been approved for research purposes and can only be accessed by the investigators listed above. The written story that is created from your recorded narrative will be de-identified and submitted to you before it is analyzed for your approval or for further clarification.

VI. POTENTIAL BENEFITS OF THE STUDY

Participating in this story may not provide any direct benefits to you. However, we think it is important to include the voices of research participants alongside the information gathered through questionnaire data. This may benefit others by providing information that may be useful to the development of future group interventions, like COMFORT, and to provide deeper insights to researchers into the lived experience of study participants.

VII. CONFIDENTIALITY: Measures to maintain confidentiality

Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law. Audio recordings and transcriptions will be stored on UBC's online platform Workspace 2.0, which has been approved for research purposes, and will only be accessible by the above investigators. Principal investigator, Dr. Marla Buchanan, will retain responsibility for all data and hard-copy documents secured in a locked filing cabinet in her UBC research office. All data will be retained by the principal investigator for a minimum of 5 years after the date of publication, as per UBC policy. After this time paper documents will be securely shredded, and audio recordings and de-identified transcriptions deleted from Workspace 2.0. You will be identified only by your chosen alias and will not be identified by name in any reports of the completed study.

VIII. PAYMENT

Participation is voluntary and there is no payment for the time taken to participate in this study.



IX. CONTACT FOR INFORMATION ABOUT THE STUDY: *Who can you contact if you have questions about the study?*

If you have any questions or concerns about what we are asking of you, please contact the study leader, Adrienne Marsh or the Principal Investigator, Dr. Marla Buchanan whose contact information is listed at the top of the first page of this form.

X. CONTACT FOR COMPLAINTS: *Who can you contact if you have complaints or concerns about the study?*

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

XI. PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on you.

- *Your signature indicates that you consent to participate in this study.*

Participant Signature

Date

Printed Name of the Participant signing above

☐

I would like to receive the results of this study:

Please indicate the email or mailing address you would like these results sent to:

Appendix B : Introduction to Interview



THE UNIVERSITY OF BRITISH COLUMBIA
Faculty of Education
Department of Educational & Counselling
Psychology, and Special Education

Vancouver Campus
2125 Main Mall
Vancouver, BC Canada V6T 1Z4
Phone 604 822 0242
Fax 604 822 3302

Dear (Comfort Participant's name),

You are being invited to participate in a follow-up study for former COMFORT participants. You previously indicated that you would like to be contacted for future studies and this present study is looking to collect stories from women about their participation in the COMFORT study.

Adrienne Marsh, who was the study coordinator for COMFORT, is conducting a Narrative Inquiry seeking to add the personal accounts of women like you to the body of research on Provoked Vestibulodynia. A Narrative Inquiry uses stories rather than questionnaires or structured interviews as its data. This provides an opportunity for participants to add their voices to research while also providing important information that isn't easily captured in survey data. The hope is that this will contribute to the development of programs like COMFORT while also providing insights into the lived experiences of women with PVD and of women who have participated in a treatment intervention study.

If you choose to participate in the study, you will be asked to take part in a 60-90 minute audio-recorded meeting with Adrienne either at your home or in a private office at the Diamond Centre at VGH depending on your preference. The option of conducting the interview remotely through video meeting via Zoom, which has previously been approved for research purposes, will also be provided if meeting in person is not possible. Adrienne will begin by asking you to "tell a story about your experience with the COMFORT program, and your journey with PVD since". When you have finished telling your story you will be asked some open-ended follow-up questions based on what you have narrated. You will also be invited to ask any questions of Adrienne or share any additional information you feel is important. Once the interview is transcribed it will be edited for cohesiveness and you will be sent a copy to ensure that it represents the meaning you intended to convey.

This research project will be supervised by Dr. Marla Buchanan a professor at UBC in the Counselling department and will also involve the input of Dr. Lori Brotto, the principal investigator of the COMFORT study, and Dr. Norm Amundson a professor at UBC in the Counselling department.



THE UNIVERSITY OF BRITISH COLUMBIA
Faculty of Education
Department of Educational & Counselling
Psychology, and Special Education

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There are no risks to you participating in the study. The story you tell will remain anonymous and confidential, and all information reported will not identify you. The data collected in the interview will be audio recorded, and following the interview, the recording will be transcribed and deleted. Interview transcripts will be kept in a password protected document on a secure password protected computer. You will be invited to provide an alias to be used to identify your narrative.

If you are interested in participating in the interview, please contact Adrienne Marsh at [REDACTED]

Sincerely,

Adrienne Marsh

MA Candidate, University of British Columbia

Appendix C : Interview Probes and Follow-Up Questions

Open-ended Probing Questions

At the end of the participant's narration I may ask questions or use statements or probes to further enrich the account:

1. Could you please tell me more about how that (information, exercise, moment, awareness, realization, insight, etc.) was for you?
2. Can you tell me more about what that experience meant to you?
3. How was that (information, exercise, realization) significant for you?
4. What were your thoughts and feelings during that (experience, module, exercise, conversation with your partner)?
5. What did you mean by...?
6. How do you think going through the Comfort changed your sexual self-perceptions?
What about your sexual well-being?
7. How has the program influenced your relationship with your partner?
8. What were the challenges you experienced in completing the COMFORT program? How did you navigate them?
9. What were the benefits you experienced in completing the program?
10. What motivated you to complete the program?
11. Is there anything else you would like to add about that?
12. What would have been helpful for you in improving your experience with the COMFORT program?
13. If you were speaking to someone who is experiencing sexual or relationship difficulties because of PVD what advice would you give them?
14. What advice would you like to give to health care providers treating women with PVD?
15. What specific feedback would you like to give to the developers of the COMFORT study, about the content or delivery of the program, or the support available to participants as they work through the program?

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Appendix D : Member Checking Evaluation Guide

VALIDATION INTERVIEW GUIDE QUESTIONS

The purpose of this interview is to review your personal narrative that I have written based on the material from our earlier tape-recorded interview. I have provided you with a draft of this document which also includes clarifying questions regarding wording or phrasing you used in your interview to ensure the meaning you intended is accurately conveyed. Please also consider the following questions while reviewing the narrative constructed from transcriptions of our original interview:

1. Coherence - Is your story coherent? Are the findings understandable? Is there anything missing from your story – anything that you would like to add or change?
2. Comprehensiveness – Overall, is your story comprehensive? Are there enough details and content?
3. Resonance – Is the narrative an accurate reflection of your experience of completing the COMFORT program? Does it adequately capture the meaning you intended in response to the research question: “Please tell me a story about your experiences participating in the COMFORT program and your journey with PVD since?”.
4. Pragmatic – Did you find participating in this inquiry provided any new insights for you into your COMFORT participation and overall journey with PVD? What, if any contributions do you feel your story will make to understanding the experiences of women with PVD and with psychological treatment interventions?