

WHEN SEX HURTS:  
COUPLES' EXPERIENCES OF FEMALE SEXUAL PAIN

by

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## ABSTRACT

The experience of pain during or after sex is a common and serious phenomenon among women (Laumann, Paik, & Rosen, 1999). Although there is a growing field of literature on this phenomenon, very little of it has shed light on what female sexual pain means for a couple. To meet this need in the literature, the present study was undertaken. The following research question was posed: What are couples' experiences of recurrent physical pain on the part of the female partner during or immediately following sexual contact?

In order to best answer the research question, a narrative method was employed. Eight Canadian, heterosexual participants (four men and four women) shared their stories of female sexual pain in individual narrative interviews. The participants chose pseudonyms to be referred by in the narratives. Holistic and thematic analyses (Lieblich, Tuval-Mashiach, & Silber, 1998) revealed contextually different narratives, and across-narrative themes representing common experiences. These experiences were: Adapting to a different sexual relationship, shifts in sexual self-view, challenges to creating a family, difficulties with dealing with medical professionals, and coping. The findings have implications for professionals who work with women and couples experiencing female sexual pain, as well as for future research in this area.

## TABLE OF CONTENTS

Abstract .....	ii
List of Tables .....	vii
Acknowledgements .....	viii
CHAPTER 1: INTRODUCTION .....	1
CHAPTER 2: LITERATURE REVIEW .....	7
Sexual Self-View .....	7
Pain Theory and Research .....	10
Women and Chronic Pain .....	12
Sexual Pain: Prevalence, Descriptions, Causes, and Treatments.....	16
Prevalence and Descriptions .....	16
Causes .....	18
Physical causes.....	19
Psychosocial causes. ....	20
Treatments.....	25
Summary .....	30
The Couple Relationship and Sex.....	31
Summary of Literature Review and Rationale for the Present Study .....	33
CHAPTER 3: METHOD .....	35
Rationale for Narrative Inquiry Method .....	35
Researcher's Subjectivity.....	37
Procedures.....	37

The Pilot Interview .....	37
Recruitment.....	39
Participants.....	40
Data Collection .....	42
Telephone screening interviews.....	42
The narrative interviews. ....	43
Data Recording, Transcription, and, Data Management.....	45
Data recording.....	45
Transcription. ....	45
Data management.....	47
Data Analysis .....	47
Writing the Narratives.....	48
Sending Back the Narratives.....	49
Ethical Considerations .....	50
CHAPTER 4: RESULTS.....	53
The Narratives.....	53
Nicole's Narrative: My Little Nightmare .....	54
T.J.'s Narrative: A Test of Strength.....	59
Jane's Narrative: The "Girl with the Sexual Problems" .....	65
Aiden's Narrative: Twisted with Guilt .....	73
Yasmin's Narrative: The Crease in my Bed Sheet .....	78
Alex's Narrative: The Niggling in the Back of my Head .....	82
Michael's Narrative: The Destructive Power of Sexual Problems .....	85

Sara's Narrative: No One Would Listen.....	93
Across-Narrative Thematic Analysis.....	98
Adapting to a Different Sexual Relationship.....	99
Shifts in Sexual Self-View.....	103
Difficulties in Dealing with the Medical System.....	110
Coping.....	113
Summary.....	119
CHAPTER 5: DISCUSSION.....	120
Findings in Relation to Psychological Theory.....	120
Findings in Relation to Research.....	121
Adapting to a Different Sexual Relationship.....	121
Shifts in Sexual Self-View.....	125
Challenges in Creating a Family.....	128
Difficulties in Dealing with the Medical System.....	129
Coping.....	129
Implications for Counselling Psychology.....	130
Couple and Sex Therapy.....	131
Transition and Grief Counselling.....	134
Teaching Communication Skills.....	136
Support, Validation, and Advocacy.....	136
Implications for Medical Professionals.....	138
Implications for Research.....	139
Criteria for Evaluating the Worth of the Study.....	140

Fidelity .....	141
Resonance .....	141
Pragmatic Usefulness.....	142
Strength and Limitations.....	143
Concluding Comments.....	145
References.....	147
APPENDICES .....	159
Appendix A: UBC Research Ethics Board's Certificates of Approval .....	159
Appendix B: Recruitment Poster .....	162
Appendix C: Invitation Letter to Potential Participants.....	163
Appendix D: Telephone Screening Script .....	165
Appendix E: Consent Form .....	167
Appendix F: Interview Question.....	169

**LIST OF TABLES**

Table 1: Physical Conditions Associated with Chronic Dyspareunia.....	170
Table 2: Transcription Key.....	172
Table 3: Helpful Coping Strategies for Couples Experiencing Female Sexual Pain.....	173

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## CHAPTER 1: INTRODUCTION

The experience of pain during or after sex is a common phenomenon among women. In an American, national epidemiological study on sexual health, 21% of women in their twenties, 15% in their thirties, 13% in their forties, and 8% in their fifties reported experiencing recurrent genital or pelvic pain during sexual activity (Laumann, Paik, & Rosen, 1999). Women describe the pain as knifelike or burning, and it is often experienced upon genital stimulation, penetration, during intercourse, and/or following intercourse (Bergeron, Meana, Binik, & Khalife, 2003). Recurrent, painful sex can lead to an interruption of sexual activity or the inability to engage in sex altogether (Bergeron et al., 2003).

Given the prevalence of sexual pain in women, and its potentially devastating consequences, a better understanding of this phenomenon is warranted. To date, however, little is understood about the etiology of sexual pain. Further, empirically validated treatments are lacking. Women and health professionals alike have expressed frustration with some treatments (Bergeron, Meana, Binik, & Khalife, 2003). As Sophie Bergeron (1997) noted in her review of treatment outcome studies for female sexual pain, pain relief does not necessarily mean an improved sexual relationship for these couples. Some couples continue to have dissatisfactory and infrequent sexual exchanges after a “successful” surgery. In addition, although common, sexual pain is still misunderstood by many people. Women may face challenges in having their sexual pain understood, believed, diagnosed and treated (Binik, Bergeron, & Khalife, 2000). The current limitation of treatments for female sexual pain underscores the importance of learning

from the women themselves what struggles they are experiencing and how they are coping with those struggles.

Historically, women's pain has been unbelievably and under-researched. However, in recent years, research has shed light on women's experiences of pain. Charmaz (1983, 1991) found that women with chronic pain undergo identity changes. The inability to complete daily tasks, such as maintaining a home or maintaining employment, for women with chronic pain can undermine their sense of competency and success. Women's experiences of becoming unable to care for a spouse and children, and of becoming dependent on others, were linked to shifts in identity. Some of these women came to view their chronic pain as defining who they were.

Sexual pain is also likely to impact women's identity. Given its emanation from a valued act (Meana & Binik, 1994), sexual pain is likely to carry meaning for women. Some studies have revealed that for women, sex is a way to connect to their intimate partner (Ogden, 2007). Relational theories of women's psychological development (Gilligan, 1982; Jordan, 1986; Miller, 1984; Surrey, 1984) underscore the importance of the maintenance of connections to others in women's healthy psychological development. When women chronically experience pain during intimate relations with their partner, the ability to feel connected may be compromised. Given these aspects of sexual pain, research needs to address how this phenomenon impacts women's identity.

Not only does sexual pain emanate from a valued act, it also involves another person (Meana & Binik, 1994). For women in couple relationships, the other person is a loved and significant person. When women experience recurrent pain with sex, that significant person is also very likely to be impacted. What would it mean to a male

partner if his wife or girlfriend experienced pain during most of their sexual acts? What would it mean to a woman to know that her partner was also being impacted by her sexual pain?

Surprisingly, very few sexual pain studies have involved the partner. Apart from a quantitative study conducted by Gibbons (2005) and a phenomenology study conducted by Connor (2005), no studies have looked at the partner experiences of sexual pain. Connor (2005) made a call for more research in this area.

Given gaps found in the literature, the present study was undertaken. The purpose of the present study was to shed light on couple experiences in which the female partner experiences recurrent pain with sex. The following research question was posed: What are couples' experiences of recurrent physical pain on the part of the female partner during or immediately following sexual contact?

A qualitative method was chosen in order to best answer the research question. Qualitative research is appropriate for exploring topics about which little is known. Qualitative research enables researchers to explore, in-depth, the meaning of experiences (Creswell, 1998). Within the qualitative research paradigm, I chose to utilize a narrative inquiry approach.

Narrative studies of pain and illness experiences have become increasingly popular in the research literature. For years, research has been limited to the physician's perspective of an illness. As well, multiple studies reveal that doctor-patient interactions do not typically leave the patient feeling like they were able to tell their story (e.g., Johansson, Hamberg, Lindgren, & Westman, 1996; Werner & Malterud, 2003). These experiences fueled researchers to begin to look at the lived experiences of pain and illness

from the “insiders’ perspectives.” Narrative research lends itself well to this type of inquiry. In telling their stories it is assumed that people are making sense of their experiences and constructing themselves (Mahoney, 2003, Murray, 2003, Polkinghorne, 1988, Reissman, 1993).

Very few studies have investigated narratives of both members of a couple. Recently, narratives of couples were used to illuminate the experiences when the female partner has cancer (Mccarthy, 2005; Skerrett, 1998). No studies to date have employed narrative methods to investigate sexual pain or sexual problems. The present study will fill this gap in the research literature.

Through the use of narrative interviews, the present study illuminated the experiences of couples in which the female partner has recurrent sexual pain. To analyze the data, I used the holistic-content analysis procedure outlined by Lieblich, Tuval-Mashiach, and Zilber (1998). This analysis allowed me to capture and represent the data as holistic narratives, as well as across-narrative themes.

This study has important implications for the field of counselling. Counsellors may play many roles in the treatment of couples with sexual pain. A couple experiencing female sexual pain may present to a couples counsellor and/or sex therapist before seeking any other help. In many cases, women are referred to counsellors by gynecologists who cannot find any physical reasons for the sexual pain. In specialized clinics, counsellors may work as part of a multidisciplinary team that is treating the couple. In some cases, counsellors may need to work with secondary effects of female sexual pain, such as the traumatic experience of the client having her sexual pain repeatedly unbelievably or minimized by doctors. Whatever the capacity in which they help

clients, counsellors need up-to-date, relevant information. The present study revealed useful information to better able counsellors to be effective in their work with these clients. Implications for health professionals who work with women and couples with sexual pain were discussed.

Sexual pain is uniquely located at the intersection of several fields of research: sex, pain, and the couple relationship. Thus, theory and research from all of these fields are helpful in informing sexual pain research. Theory of the development of sexual self (Daniluk, 2003), biopsychosocial perspectives on pain (Engel, 1977), and cognitive-behavioral theory of couple relationships (Epstein, Schlesinger, & Dryden, 1988) were drawn on to situate and inform the present study.

Theories on sexual self-view (sometimes called sense of sexual self or sexual self-concept), posit that individuals hold a fluid view of the sexual aspects of themselves (Andersen & Cyranowski, 1994; Daniluk, 2003). Sexual self-view has been empirically shown to influence, and be influenced by, sexual experiences (Andersen & Cyranowski, 1994). It is assumed from this theory that women's experiences with pain during sex will influence their sense of sexual selves.

This research is also framed by a biopsychosocial perspective of pain and illness (Engel, 1977) which posits that biological, psychological, and social elements of human nature interact in the development and maintenance of pain and illness. The specific aspect of this model that applies to the present study is the idea that pain in one partner will impact on, and be impacted by, others. Others who may be particularly influential in women's pain experiences include intimate partners and health professionals. Based on

this model, I assume that intimate partners and health professionals will influence, and be influenced by, women's experiences of sexual pain.

The cognitive mediation model of couple relationships (Epstein, Schlesinger, & Dryden, 1988) is a cognitive-behavioral theory of couple relationships that informs the present study. It is based on the premise that members of a couple actively interpret and evaluate each other's behaviors, and that their emotional and behavioral responses to one another are influenced by these interpretations and evaluations (Epstein, Schlesinger, & Dryden, 1988). The present study will shed light on ways in which couple members interpret and respond to behaviors resulting from the women's sexual pain.

In sum, sexual pain experiences are common among women in their twenties and thirties and can have devastating consequences for the relationship and for each partner's sexual self-view. I attempted to fill a gap in the literature by investigating, through the use of narrative inquiry, the experiences of couples in which the female partner experiences recurrent sexual pain. This study provides important information for other couples with sexual pain as well as for the mental and medical health professionals who serve them.

## CHAPTER 2: LITERATURE REVIEW

In this chapter the literature that informs the present study is reviewed. First, the literature on sexual self-view is reviewed. Next, the literature on women's experiences of chronic pain is reviewed. Then, the literature on prevalence, causes, and treatments of recurrent sexual pain in women is reviewed. Next, the literature on couple relationships and sex is discussed. Last, a summary of how the literature informs the present study is provided.

### Sexual Self-View

Sexual pain occurs in the context of an individual and a relationship. Masters and Johnson (1966), Kaplan (1981), and Kinsey and colleagues (Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, Martin, & Gebhard, 1953) contributed important work to the field of sex research. Their research produced scores of data on human sexual behavior, which led to the sexual response cycle. In recent decades, sex researchers and practitioners have pointed out that these early studies reduced sex to mechanics, without taking context into consideration (e.g., Hall, 1994; Tiefer, 2004). One aspect of context is one's sexual self-view. Sexual self models and research have informed the present study in important ways. This study is based on an assumption that context, including how one thinks of oneself, is important and impacted by experiences such as recurrent painful sex. Thus, I include a description of the sexual self literature in this review.

Daniluk (2003) defines the sexual self-view as a "fluid, complex entity consisting of various forms of self-relevant knowledge . . . these are the beliefs and perceptions that a woman holds about the sexual aspects of herself" (p. 15). Daniluk also theorized how sexual selves develop in women. She stated:

As women experience various events or situations that they define as sexual, they come to view themselves as a particular kind of “sexual” person, or “nonsexual” person, as the case may be. . . as they repeatedly encounter particular sexual situations over time, they build up particular ways of responding that reflect their characteristic sense of themselves as sexual people (pp. 15-16).

Daniluk’s (2003) model of the development of sexual self-view in women will inform the present study. Specifically, this model suggests that women’s experiences of recurrent sexual pain may impact how they view themselves as sexual people. Women who experience recurrent pain with sex may come to view themselves as less sexual or more sexual people, depending on how they appraise their sexual pain.

Andersen and Cyranowski (1994), based on six studies, stated that women with a positive sexual self-view view themselves as “emotionally romantic and passionate and as women who are behaviorally open to romantic and sexual relationships and experiences” (p. 1094). Conversely, women with a negative sexual self-view describe themselves as “relatively emotionally cold or unromantic, and by their own admission, they are behaviorally inhibited in their sexual and romantic relationships” (p. 1094). The latter are less sure of themselves in sexual matters, and their self-views are more vulnerable to being moderated or defined by others, compared women with positive sexual self-views.

Sexual self-view has been found to play a role in the development of sexual difficulties, and has been found to result from sexual difficulties. Cyranowski, Aarestad, and Andersen (1999) put forward a model in which individual differences in sexual self-view predict sexual difficulties. The authors suggested that “stressful events or assaults to



the sexual system—such as certain medical or psychological stressors—may interact with negative (or, for males, weak) sexual self-schema to create deficits in sexual functioning” (p. 226). The researchers tested their model in a sample of sixty-one, predominantly White, female cancer survivors. Hierarchical multiple-regression analyses were performed on the following variables: sexual functioning before diagnosis, extent of treatment, menopausal symptoms, and sexual self-schema scores. Sexual self-schema accounted for twenty-eight percent of the variance in the prediction of current sexual responsiveness, over and above the other variables. The authors concluded that positive sexual self-views may facilitate sexual functioning, and that negative or weak sexual self-schemas may represent vulnerability to the development of a sexual problem.

Lavie and Willig (2005) found that sexual self-view was affected by women’s experiences of not being able to orgasm. They studied women’s experiences of inorgasmia and the meanings they gave to their experience. Six women were interviewed, and transcripts were analyzed using interpretative phenomenological analysis. The meanings women made of their experiences of inorgasmia revolved around three themes: its impact on sense of self, its impact on their partner’s enjoyment, and personal sexual enjoyment. Generally, the women indicated that inorgasmia shifted their sense of sexual selves by causing them to feel sexually “defective” and “inferior.” The authors also noted that the women were more distressed by the relational meaning of the experience, rather than the absence of physical pleasure.

The theories and research described underscore the importance of taking into consideration the sexual self-view when conducting research on sexual behavior. Sexual experiences impact sexual self-view, particularly in females (Andersen & Cyranowski,

1994). Sexual self-view also appears to influence post-treatment sexual responsiveness in female cancer patients (Cyranowski, Aarestad, & Andersen, 1999). No research to date has explored ways in which the experience of recurrent female sexual pain impacts sexual self-views of both members of the couple.

### **Pain Theory and Research**

Pain theory and research has informed the present study. Recurrent pain with sex has been conceptualized by some researchers as a pain syndrome (e.g., Binik, 2005). Biopsychosocial models have been very influential in the chronic pain research field. Engel (1977) called for a biopsychosocial alternative to the traditional biomedical philosophy in health care. This call has produced multiple biopsychosocial models, all of which rely on the assumption that humans are inherently biopsychosocial organisms in which the biological, psychological, and social factors are intertwined (Melchert, 2007). Each part interacts with and is affected by the other parts. The cyclical interaction of the parts also means that impacting one part of the cycle can affect the other parts. This philosophy is the basis for most cognitive-behavioral pain management programs (Hanson & Gerber, 1990).

In a review on the biopsychosocial approaches to pain research, Gatchel, Peng, Peters, Fuchs, and Turk (2007) explained the biopsychosocial perspective as it relates to pain: "in order to fully understand a person's perception and response to pain and illness, the interrelationships among biological changes, psychological status, and sociocultural context need to be considered." The biological and psychological parts of the model refer to genetic predispositions, central biological, somatic, cognitive, and affective processes, and peripheral autonomic, endocrine, and immune processes of the individual

experiencing pain. The social part of the model refers to people who affect and are affected by one's pain. These people may include family, friends, and medical professionals, among others.

Recently, Yitzchak Binik (2004) called for a conceptualization of sexual pain as a pain problem, rather than a sexual problem. Binik (2004) argued that "pain in the genitalia can be described and classified in the same way as pain in head or back and systems proposed by the International Association for the Study of Pain are useful starting points" (p. 8). Binik also calls for a biopsychosocial approach to sexual pain:

The preponderance of the currently available evidence suggests that what is currently called "genital/sexual pain" is best understood as a pain syndrome not as a sexual dysfunction and not as the direct result of a pathological process. If this assertion is correct, then our research and clinical efforts must be directed at understanding the biopsychosocial mechanisms underlying chronic and recurrent pain. (p.8)

A biopsychosocial approach towards sexual pain management has also been recommended by other sexual pain researchers and practitioners (e.g., Bergeron, Meana, Binik, & Khalife, 2003).

In applying the biopsychosocial approach to the present study, I am most focused on the psychological and social aspects of the model. I am interested in ways in which sexual pain in a woman impacts her emotions, thoughts, and behaviors; the ways in which the sexual pain influences her interactions with her intimate partner; and the ways in which these interactions influence herself, her partner, and their relationship. I am also interested in ways that her interactions with medical professionals impacts the

psychological aspects of herself. Studies that look at the impact of female sexual pain on the partner are lacking and it is hoped that the present study will begin to fill this need.

### **Women and Chronic Pain**

Theory and research on chronic pain specifically in women informs the present study. Researchers have found that the experience of pain or illness impacts women in many ways, including her sense of self. Illness/pain specific to the genital area can also impact women's sexual self-view. Following is a summary of recent theory and research on women's chronic pain experiences.

Based on her research, Charmaz (1983, 1991) theorized that the experience of illness influences self. She suggested that chronic illness is experienced not only as physical discomfort but also as a loss of self. Her research revealed that individuals with chronic pain or illness suffered from social isolation, restricted lives, being discredited, and the feeling of burdening others. These experiences resulted in a "crumbling" of pre-illness selves.

Charmaz' (1983, 1991) research has been supported with multiple studies on women's experiences of chronic pain. Qualitative studies on the experiences of women with chronic pain reveal that when the chronic pain sufferer is a woman, the likelihood of their pain being invalidated by others, including medical professionals, is very likely (Johansson, Hamberg, & Lindgren, 1996; Werner & Malterud, 2003). Women must "work hard" to have their symptoms believed by medical professionals (Werner & Malterud). There are many speculated reasons for this finding. Women are more likely than men to be diagnosed with pain "syndromes" that are medically unexplained (Walterud, 2000). These syndromes provide challenges for medical professionals because

effective methods of diagnosis, treatment and prevention are unknown (Natvig, Nessioy, Bruusgaard, & Rutle, 1995). The challenges are experienced as frustrating by medical professionals (e.g., Self, Matthews, & Stones, 1998). Many medically unexplained pain problems such as chronic pelvic pain and fibromyalgia are considered low on the medical hierarchy of "disease prestige" (Album, 1991) and thus may be given less attention and care. Given the general view that many women are not being validated in their experiences with medical professionals, Warwick, Joseph, Cordle, and Ashworth (2004) suggested medical professionals improve their way of communicating with women.

Some researchers have investigated how women's experiences of chronic pain can impact on their intimate relationships and sex life. Schlesinger (1994) employed a generic qualitative research design to explore women's experiences with chronic pain. Twenty-eight women, self-described as living in pain, were recruited from the community. The sample consisted of mainly White, middle-class women. Semi-structured interviews were conducted. The interviews were transcribed and then analyzed using grounded theory coding techniques. Themes that emerged included invisibility, legitimacy, pain talk, learning to live with pain, caring, and negotiation.

Schlesinger (1996) analyzed excerpts from her 1994 study for ways in which the women managed the impact of pain on intimate relationships and sexual experiences. Strategies used by the women to deal with the impact of pain on their intimate relationships included: ending relationships in which their partner did not understand or believe their condition, finding support from family members outside the marital relationship, using verbal or non-verbal cues and "rules" to communicate and negotiate, using laughter and humor about pain, and using anger or guilt to distance themselves

from their partner. Strategies used to deal with the impact of pain on sexual activities included avoiding sexual relationships, learning alternative activities to share with intimate partners (e.g., a romantic dinner), adjusting sexual activities and positions to avoid pain during or after sex, and choosing a “good day” of pain for sexual activity.

Schlesinger (1996) also observed that, “in defining pain, some women equated pain with their ‘selves’” (p. 253). For example, some women based their decision whether to become a mother on their perception of themselves as healthy or ill. For others, pain became part but not the whole of their identity. Others denied any influence of pain on their identity. The author concluded that the women knew of and could employ several kinds of coping mechanisms to manage the effects of their pain on their relationship and sex. The author also made a call for more research that is focused on sex/sexuality and chronic pain as experienced by people in the community. She noted that previous research overemphasizes pathology and that it would be beneficial to learn from women with pain about how they cope, sexually, with pain and disability.

Focusing on the specific experience of genital and pelvic pain, Theve-Gibbons (2000) explored problems encountered by women with vulvodynia and/or vulvar vestibulitis. Vulvar vestibulitis is a subset of vulvodynia, a skin condition that consists of chronic discomfort of the vulva. Her research followed a generic qualitative design, and her research questions focused on the following three areas: women’s perceptions of problems and issues related to genital pain, the impact of the pain on sexual/intimate relationships, and the impact of pain on women’s sexuality and identity. The author interviewed thirteen women, six in person, and 7 by email. All of the participants had a

diagnosis of vulvodynia or vulvar vestibulitis, were White, lived in the United States, and were in long-term relationships.

Four themes were developed inductively from the interview data. These will be listed with examples of quotes from the article: (1) A perception of stigma and shame for having chronic vulvar/vaginal pain: "You could tell the woman behind you in the grocery line that your back really hurts and you need to go home. But you can't very well say- oh, I gotta go home, my vulva hurts!" (p. 8). (2) Feeling invisible and unbelieved: "Any time I would see any emergency room doctor, they would be like, 'I've never heard of that [vulvodynia], I don't know what you're talking about'" (p. 10). (3) Changes in relationships and sexuality with intimate partners: "He's been depressed about it...I feel more for him, than I do for me, you know....[during sex] he'll say 'well how does it feel?'" and...I try to disguise as much as I can, but how can you disguise it, I mean my face tells everything" (pp. 11-12). (4) Loss of femininity and womanhood: "sometimes I feel like, well, I shouldn't make myself look nice, because...that might make him want to do something...it's changed the way I am. Because I don't want him to think I look sexy at home" (p. 12).

Theve-Gibbons (2000) concluded that health professionals working with this population need to remember to ask their clients about the impact of pain on relationships and daily life. She explained that pain impacts individuals in complicated ways, and knowing whether they are ashamed or isolated, for example, will assist health providers in conducting assessments and choosing interventions.

A summary of the literature of women's experiences with chronic pain revealed a pattern of struggles for these women. These struggles shifted women's sense of selves in

significant ways. The serious impact of chronic pain on women underscores the importance of taking a closer look at women's experiences of sexual pain. Sexual pain is similar to chronic pain in some ways. It is recurrent, lasting longer than 3 months. In other ways, sexual pain is unique. It occurs only in association to the act of sex, and thus implicates one's sex life, as well as one's sexual partner. In addition, because it occurs only during a particular situation, sexual pain may not necessarily interfere with daily functioning as chronic pain does. As a result, experiences of couples dealing with female sexual pain may differ from those of people dealing with chronic pain. Further research is thus warranted to explore what the experiences are for women who experience sexual pain, and for their partners.

### **Sexual Pain: Prevalence, Descriptions, Causes, and Treatments**

The literature on sexual pain has grown in the fields of sexology, gynecology, and psychiatry. It is beyond the scope of this project to review all of these fields. However, a brief review of the prevalence, causes, and treatments of female sexual pain is necessary to understand the current situation for women and couples dealing with this problem.

#### **Prevalence and Descriptions**

The prevalence reports of sexual pain vary, depending on the type of population sampled and the diagnostic criteria used. In an epidemiological study of sexual health in a community sample, 21% of women in their twenties, 15% in their thirties, 13% in their forties, and 8% in their fifties reported experiencing recurrent, genital pain during sexual activity for a period of 3 months or more (Laumann, Paik, & Rosen, 1999). In a clinical sample of women receiving primary care services, 46% of sexually active women



reported pain during or after intercourse (Jamieson & Steege, 1996). Although the experience of painful sex is common, it is widely speculated that only a small percentage of women in pain seek help (Bergeron, Meana, Binik, & Khalife, 2003; Jamieson & Steege, 1996).

Bergeron et al. (2003) provided a description of the most commonly experienced sexual pain. During penetration and intercourse, and sometimes from touch to the genitals, women experience pain near the opening to the vagina (superficial) or within their pelvic region (deep). Some women experience more than one type of pain. The pain is described as knifelike, burning, or like rubbing sandpaper on skin.

The theoretical conceptualization of female painful sex is far from straightforward. In the 1800s it was conceptualized as a physical problem with unknown causes and no name (Meana & Binik, 1994). Interest in sexual problems began to emerge in psychology in the early 1900s; however, the emphasis was on male problems. Female painful sex, like most other women's health problems, was left uninvestigated.

In the 1960s and 1970s sex therapy research exploded due mainly to the work of Masters and Johnson (1966), Kinsey and colleagues (Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, Martin, & Gebhard, 1953), and Kaplan (1981). The culmination of this work was the entry of several sexual dysfunctions into the DSM-III (American Psychiatric Association, 1980). The experience of recurrent, painful sexual intercourse entered the DSM-III as "dyspareunia" and officially became a psychiatric disorder. The term "dyspareunia" means "difficulty mating" in Ancient Greek (Meana & Binik, 1994). The current revised DSM-IV-TR (American Psychiatric Association, 2000) continues to include dyspareunia, and has it under the umbrella category of sexual dysfunctions.

According to this latest revision, the diagnosis of dyspareunia requires the experience of (a) recurrent or persistent genital pain associated with sexual intercourse in either a male or a female that (b) causes marked distress or interpersonal difficulty, and (c) is not caused by vaginismus, lack of lubrication, an Axis I disorder, direct effects of a substance, or a general medical condition (American Psychiatric Association, 2000).

Although “dyspareunia” is a commonly used term in sex research, I have chosen not to use it in the present study, for a number of reasons. First, the term excludes sexual pain which stems from a medical condition. The present study illuminates experiences of couples in which the women experiences recurrent, painful sex regardless of the cause of the pain. Second, the term “dyspareunia” describes pain which only occurs during sexual intercourse. To capture a broad range of sexual pain experiences, I included women in the study whose pain also occurs during sexual activities other than sexual intercourse, such as clitoral stimulation and oral sex. Given these limitations of the term dyspareunia, I have made a deliberate choice to refrain from using it to describe the sexual pain experiences of women. In its place I will use the terms “sexual pain” or “painful sex.” These phrases connote a lived experience, broad enough to include many women’s experiences with pain associated with sex.

### **Causes**

Physical and psychosocial causes of initial pain have been identified. Physical causes of sexual pain will be reviewed first. Next psychosocial causes will be reviewed.

### **Physical causes.**

Female sexual pain sufferers frequently present with medical conditions that act as causal, precipitating, or maintaining factors (Heiman, 2002; Leiblum & Segraves, 2000; Schover, 2000; Wiegel, Wincze, & Barlow, 2002). The possible physical factors associated with female sexual pain are numerous. In their review of sexual dysfunctions, Wiegel, Wincze, and Barlow (2002) identified the most common physical contributing factors of sexual pain. These are: vulvar vestibulitis, atrophy of the vaginal canal, cervical cancer, local infection, hymenal tags, endometriosis, pelvic tumors, prolapsed uterus, or an allergic or irritative reaction to self-administered feminine-hygiene products, and pelvic inflammatory disease (p. 503). More recently, a team of experts on genital, sexual pain met and established a comprehensive list of physical conditions associated with sexual pain (Weijmar Schultz, Basson, Binik, Eschenbach, Wesselmann, & Van Lankveld, 2005). A reproduction of this list is presented (see Table 1).

The most common diagnosis thought to underlie superficial sexual pain is vulvar vestibulitis (Brotto, Basson, & Gehring, 2003). Vulvar vestibulitis is a subset of vulvodynia, a skin condition that consists of chronic discomfort of the vulva. Friedrich (1987) is credited as identifying the diagnostic criteria for vulvar vestibulitis. These are: severe pain and tenderness with touch and pressure to the vestibule (entry to the vagina), and redness of the vestibule. Because it is impossible to penetrate the vagina without the vestibule being pressured, vulvar vestibulitis almost always leads to pain with intercourse. Recent research on etiology of sexual pain has focused almost exclusively on vulvar vestibulitis. In a recent review of the literature on vulvar vestibulitis, Green and Hetherington (2005) concluded that the etiology of vulvar vestibulitis remains unclear.

A common cause of deep pelvic pain with sex is endometriosis (Bergeron, Meana, Binik, & Khalife, 2003). In her dissertation, Segal (1999) explained the role of endometriosis in sexual pain. Endometriosis involves the growth of endometrial cell clumps in abnormal areas, such as the pelvis. When these cells are pressured during deep intercourse, pain is produced.

A final common physical condition linked to sexual pain is excessive tension in the pelvic floor muscle. This hypertension prevents the opening and relaxing of the vaginal area during penetration (Reissing, Brown, Lord, Binik, & Khalife, 2005). Excessive muscle tension can be detected in a physical exam. Although no studies have provided support for this theory, several studies have purported the usefulness of incorporating the work of physical therapists in teaching women with dyspareunia to relax their pelvic floor muscle through the use of education, exercises, and biofeedback (Mattsson, Wikman, Dahlgren, & Mattsson, 2000; Reissing et al.).

### **Psychosocial causes.**

Although many women with dyspareunia present with medical conditions, many other women present with no physical symptoms. In one study, Meana, Binik, Khalife, and Cohen (1997) found that one quarter of the women presenting with sexual pain had no abnormal physical attributes. Psychosocial factors are thus thought to contribute to the development of female sexual pain. Even in cases where the initial cause of the pain is physical, psychosocial factors can contribute to the maintenance and exacerbation of sexual pain (Bergeron, Meana, Binik, & Khalife, 2003). Wiegel, Wincze, and Barlow (2002) summarized the most common psychosocial factors of sexual pain. These are: negative attitudes toward sexuality, anxiety, depression, relationship adjustment, and a

history of child abuse or sexual trauma (p. 503). The authors warned that “clear empirical evidence for these psychosocial factors is still largely lacking” (p. 503).

Empirical studies investigating causes of sexual pain are lacking. A few researchers have attempted to identify psychosocial causal factors of sexual pain by comparing women with sexual pain to women without sexual pain on the results of physical exams, and responses in interviews and self-report questionnaires. These studies will be reviewed.

Meana, Binik, Khalife, and Cohen (1997) compared 105 women with dyspareunia to 105 women with no sexual pain on various biological, psychological, and social measures. The women underwent a gynecologic examination, colposcopy, and endovaginal ultrasound. In addition, they completed the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), the Sexual Opinion Survey (Fisher, Byrne, White, & Kelley, 1988), the Locke-Wallace Marital Adjustment Scale (Locke & Wallace, 1959), and a structured interview about pain, sexual functioning, and abuse history. Compared to the control group, women in the dyspareunia sample had more physical pathology, higher levels of sexual difficulties and more negative attitudes about sexuality. In terms of mental health, the women with dyspareunia reported more psychological symptoms including depression, interpersonal difficulty, obsessive compulsive tendencies, and phobic anxiety. Women with dyspareunia also reported lower levels of relationship adjustment. The two samples did not differ significantly on histories of abuse.

The dyspareunia sample was then subdivided into two types, those showing vulvar vestibulitis symptoms and those with no physical findings. Twenty-four percent of the women with dyspareunia showed no physical abnormalities. This subgroup indicated

higher psychological problems and relationship difficulties than the healthy controls. However, their sexual functioning (desire, arousal, orgasmic ability, and intercourse frequency) did not differ from the controls. By contrast, the vulvar vestibulitis subgroup did not differ from healthy controls on psychological scales or relationship adjustment, but reported sexual problems in all areas of the sexual response scale as well as negative attitudes about sexuality.

Based on their results, the authors concluded that pain with sex may be related in part to psychological and/or relational difficulties. Further, women whose pain stems from vulvar vestibulitis should not have psychosocial causes attributed to their pain. The findings of this study need to be taken with caution, however, given the relatively small numbers of people in each sample and subsample.

Gates and Galask (2001) compared the psychological and sexual functioning of women with vulvar vestibulitis to that of healthy women. A battery of standardized questionnaires including The Center for Epidemiologic Studies Depression Scale (Radloff, 1977), the Brief Symptom Inventory (Derogatis & Melisarators, 1983), the Derogatis Sexual Functioning Inventory (Derogatis & Melisarators, 1979), the Sexual Depression Subscale (Snell & Papini, 1989), and the Sexual Self-Schema Scale (Andersen & Cyranowski, 1994) were administered to fifty-two women with vulvar vestibulitis and forty-six healthy controls. The samples contained largely white, middle-aged, married women. Group differences were examined using multivariate analyses of variance and covariance.

Compared to the control group, women with vulvar vestibulitis reported significantly higher scores on the measures of depression, anxiety, psychoticism,

paranoid ideation, obsessive compulsive disorder, hostility, interpersonal sensitivity, and phobic anxiety. Overall, fifty percent of women with vulvar vestibulitis, compared to eleven percent of women with no pain, had scores that were suggestive of clinical depression. In terms of sexuality, women with vulvar vestibulitis reported lower levels of sexual satisfaction, less frequent sexual activity, higher levels of sexual depression, and more negative sexual self-concepts, compared to the controls. The sexual activity scores revealed that many women in the vulvar vestibulitis sample avoided sexual activities such as massage, kissing, manual stimulation, and oral sex. Many of the women reported dissatisfaction with their lack of sexual intimacy. Fifteen percent of the women with vulvar vestibulitis rated their sexual relationship as highly inadequate and eight percent reported that their sexual relationship was the worst it could be, whereas none of the women in the control group chose those categories. The authors suggested that health care providers for women with vulvar vestibulitis be trained in recognizing depression, and be prepared to refer patients to mental health, couple, or sex therapists for depression, marital problems, or sexual problems, respectively.

Psychological profiles of women with vulvar vestibulitis were obtained in Brotto, Basson, and Gehring's (2003) study through the use of a retrospective chart review. The researchers reviewed fifty cases of women treated at the BC Center for Sexual Medicine, a tertiary care facility focused on assessment and treatment of sexual dysfunctions. Brief psychological questionnaires were administered to the women during the assessment phase. The questionnaires included the Personality Assessment Screener (Morey, 1991), which screens for at-risk behaviors such as suicidal thinking, the Golombok Rust Inventory of Sexual Satisfaction (Rust & Golombok, 1985), the Phobia Rating Scale

developed for use in the authors' clinic, and The Fear of Negative Evaluation scale (Watson & Friend, 1969). Results were compared to 25 women who did not have a sexual dysfunction.

Women with vulvar vestibulitis scored significantly higher than the healthy women on phobic anxiety and fear of negative evaluation. The inclusion of the fear of negative evaluation scale was based on clinical observations indicating that it was hard for women to fully comply with the home-based treatments due to the high standards they keep for themselves at work, school and home. The results supported this assumption and the authors suggest that future treatment for sexual pain address anxiety.

The psychological screener showed that fourteen percent of the women with vulvar vestibulitis were markedly distressed, twenty-seven percent were moderately distressed, twenty-seven percent were mildly distressed, and thirty-three percent were in the normal range. Social withdrawal and negative affect were the most frequently endorsed variables of the scale. In addition, twenty-two percent of the sample of women with vulvar vestibulitis reported suicidal thoughts.

The authors also found psychological distress to play a role in treatment outcome. In terms of sexuality, women with vulvar vestibulitis scored higher on areas of sexual dissatisfaction including non-sensuality, sexuality infrequency, avoidance, vaginismus, and general dissatisfaction. The authors concluded that the use of psychological inventories in assessment and treatment is supported.

Generally, these three studies indicate that painful sex is associated with a multitude of psychological problems. However, these studies need to be interpreted carefully, in light of several methodological and theoretical limitations. First of all, in all



three of these studies, the majority of women sampled had sexual pain due to vulvar vestibulitis. Women with sexual pain not associated with this condition may present very differently, psychologically. Secondly, although many researchers have used these studies as evidence for psychological causes of painful sex, the cross-sectional and correlational nature of these studies prevents any attributions of cause from being made. It is unknown whether the psychological problems in the women contributed to their development of sexual pain, or whether the psychological distress is a result of the experience of sexual pain, or whether other factors were contributing to the pain. Moreover, none of the described studies included the perspectives of the women's partners. Exploring the partner's perspective may shed light on psychosocial aspects of sexual pain.

### **Treatments**

Research on treatment for painful sex is in its infancy (Bergeron, Meana, Binik & Khalife, 2003). Based on clinical observation, however, several treatment suggestions for painful sex have been made. Bergeron et al. (2003) recommend that treatment be multidimensional and based on a biopsychosocial model of pain. They recommend components of psychoeducation, sex therapy, psychotherapy, pain management, physical therapy, medication and/or surgery in treatment. The inclusion of the woman's partner in treatment, including couple and/or sex therapy, appears to improve the likelihood of success and is therefore recommended (Weijmar Schultz et al., 2005). Detailed assessment and treatment plans have been described by various multidisciplinary teams such as Bergeron et al., Graziottin and Brotto (2004), and Weijmar Schultz et al. (2005). Although these plans are comprehensive, they have not been empirically validated.

Few outcomes studies exist on dyspareunia treatments. In a 1997 review of the studies, Bergeron et al. (2003) found most studies to be focused on surgery and reported that almost all of the studies were plagued with methodological problems. In this section, I review the treatment outcome studies that have been published after Bergeron et al.'s review.

In a 2001 study, Nyirjesy, Sobel, Weitz, Leaman, Small, and Gelone explored the effectiveness of cromolyn cream as a treatment for female painful sex. One hypothesis underlying painful sex, particularly vulvar vestibulitis, is that at one time the woman had an infection. After the infection is resolved there is a persistence of mast cells that lead to inflammation and pain. Cromolyn is an anti-histamine designed to inhibit the growth of inflammatory mast cells, and is routinely prescribed as a first line of treatment for painful sex (Weijmar Schultz et al., 2005). Twenty-six women with vulvar vestibulitis, who had not been using another treatment for at least one month, participated in the study. Women were instructed to apply a cream to their vestibule three times a day for three months. In a double blind random assignment, women were either applying cromolyn or a placebo cream. Once a month the women returned to the clinic to have their pain monitored. At each visit, the women graded their pain symptoms on a scale from 0-3. As well, investigators assigned a score from 0-3 based on physical signs of tenderness. Results found five women in the cromolyn group and six women in the placebo group to report a fifty percent reduction in pain symptoms. The authors concluded that cromolyn cream did not provide a significant benefit in their sample of women with vulvar vestibulitis and suggested larger controlled studies to better understand the large placebo effect in this study.

The placebo effect is a common phenomenon in pain treatment and research (Koshi & Short, 2007). As Koshi and Short explained, pain theorists regard the placebo as representative of the nonspecific aspects of treatment. Several nonspecific aspects such as medical setting, practitioner and treatment credibility, the nature of patient-practitioner relationship, and practitioner's attitude toward the patient, and enthusiasm with which the treatment is recommended have been shown to influence a placebo effect. Koshi and Short summarized the placebo as an important part of the psychosocial aspect of a biopsychosocial approach towards pain. Binik (2004) argued that outcome studies showing large placebo effects on creams/medications for sexual pain are evidence for using a biopsychosocial pain treatment approach with female sexual pain.

The most commonly studied treatment for painful sex is surgery. In a recent study, Schneider, Yaron, Bukovsky, Soffer, and Halperin (2001) investigated the outcome of surgical treatment for superficial dyspareunia resulting from vulvar vestibulitis. A vestibulectomy was performed on 69 women with vulvar vestibulitis. This surgery involves incisions in and around the vestibule. The researchers sent a questionnaire to the women six months after the surgery. Seventy-eight percent of the women replied. Women were divided into three levels based on the pain severity, abstinence from sex, and on whether the pain had always been there or was acquired.

The results were positive for a majority of the women. Before the surgery, eighty percent of the women had been engaged in other forms of treatment such as creams and sex therapy. After surgery, only thirty-four percent of the women were utilizing these treatments. A repeat surgery was deemed necessary in 9 women because of persistent pain, and 7 of those women agreed to a second surgery. Ninety-six percent of the women

in level 3, the most severe pain category, reported that their improvement was moderate to excellent. Seventy percent of women with less severe cases reported the same improvement. Overall 83% of the women said they would recommend the surgery to other women. The remaining seventeen percent of women experienced severe postoperative pain, and thus would not recommend the treatment. The authors concluded that surgery is recommended for women with dyspareunia but should be reserved for women who do not respond to other medical treatments.

Studies on psychosocial treatments for painful sex are lacking. Bergeron et al. (2001) conducted the first study to compare cognitive-behavioral therapy, vestibulectomy, and surface electromyographic biofeedback treatments for vulvar vestibulitis-based dyspareunia. Seventy-eight women with dyspareunia were randomly assigned to one of the three conditions and were assessed pre-, post- and 6 months after treatment, through a gynecological exam, structured interviews, and standardized questionnaires about pain, sexual function and psychological adjustment. Participants in the biofeedback group received eight 45-minute sessions of education, exercises, biofeedback, electrical stimulation, and manual techniques over 12 weeks. Women in the CBT group received eight group sessions over 12 weeks based on a treatment manual designed specifically by the authors for the study. The treatment included education about dyspareunia, vulvar vestibulitis, sexual anatomy, and pain; progressive muscle relaxation, Kegel exercises; communication skills training; cognitive restructuring; vaginal dilation; distraction techniques; and rehearsal of coping statements.

The drop out rate was low for each of biofeedback and cognitive-behavioral treatment groups (one woman each) and higher for the surgery group (seven women). On

average, women reported a reduction of pain by 19 to 70% depending on the measure of pain. The women in the vestibulectomy group reported a significantly higher percentage of pain reduction than the other groups. However, this finding should be interpreted with caution given the smaller number of women in this group as well as the fact that several women refused to go ahead with the surgery. At the six month follow up, 34.6% of women in the biofeedback group, 39.3% of those in the cognitive-behavioral group, and 68.2% of those in the vestibulectomy group were deemed a success based on their scores of 4 or 5 on a 5-point scale of pain relief. However 9.1% of women in the vestibulectomy group reported their pain as worse than before the surgery. None of the women in the other treatment groups reported worsening symptoms.

The authors concluded that dyspareunia stemming from vulvar vestibulitis can be improved with medical, behavioral and cognitive-behavioral interventions. The authors suggested that surgery may be more effective than the other treatments, but that these findings are muddled by the differential rates of drop outs in the three treatment conditions. Women who decided to go ahead with the surgery may have held biases in favor of the procedure and thus may not represent those in the general population of women with dyspareunia. Further studies comparing treatment outcomes for sexual pain may strengthen the findings of these authors.

A review of recent treatment outcome studies led to a number of conclusions. First of all, very few recent studies exist, and studies from a few decades ago are plagued with methodological problems. Although cromolyn cream is commonly prescribed to women with painful sex it appears that its effect is largely due to a placebo effect and further studies are needed to clarify the role of cream in women's pain relief. Surgical

intervention appears to be an effective treatment for many women with severe cases of painful sex for whom other interventions have failed. However, the occurrence of severe or worsened pain for a minority of the women following the surgery is a serious concern of this treatment. Cognitive-behavioral and biofeedback outcome studies are severely lacking in the literature. The one comparative study that was reviewed indicated that about one-third of the women who tried these treatments had benefited. Thus, these treatments are helpful for a minority of women with painful sex, and more follow-up needs to be conducted into the women who are not helped by these interventions. A problem across all the studies is the failure to include follow-up studies past six months. Clinical accounts indicate that benefit from surgery is short-lived, with symptoms flaring up again at about 18-36 months (Weijmar Schultz et al., 2005). As well, it may be the case that women who engage in less invasive treatments such as cognitive-behavioral therapy may not show immediate improvement but may reap the benefits of the therapy further down the road.

### **Summary**

In this section, I reviewed the literature on what is known about the theoretical constructions, prevalence, etiology and treatments of female painful sex. Although long regarded as a mental problem, painful sex is now discussed in mainly biomedical terms. In fact, the social and relational perspectives on painful sex have largely been ignored in recent research. Although painful sex is one of the most common sexual complaints among women, it is largely underreported and understudied. Although several causal mechanisms are being explored, the etiology of painful sex remains unclear. Expert practitioners promote the use of a multi-modal treatment approach. However in practice

and in research, a unidimensional approach is commonly employed. Although successful surgical treatments have been reported, these findings need to be interpreted cautiously. Other outcome studies have reported an improvement in a minority of women with painful sex. Future research needs to be conducted on multi-modal approaches, and needs to include long-term follow up studies. In sum, it appears that women experiencing painful sex are faced with the decision between trying generally ineffective treatments or undergoing an invasive and potentially harmful surgery. Given these current limited options, it is important to learn from the couples how they are making these choices and what they are finding helpful in their journey to manage female painful sex experiences.

### **The Couple Relationship and Sex**

Female sexual pain invariably leads to a reduction in sexual desire and/or arousal. As Barbach (2001) stated,

While a minimal amount of pain can enhance the arousal of some women—creating a bittersweet sort of feeling—a greater level of pain can totally interfere with sexual pleasure. Whether the pain is experienced at the opening to the vagina, deep inside the vagina, or as a result of an illness or an injury in some other part of the body, the presence of pain almost universally signals the end to pleasure. (p. 231)

The end of pleasure with sex is certain to impact the woman's behavior during and towards sex. Several studies have reported on the sexual difficulties of women with sexual pain. Compared to healthy controls, researchers contend that women who experience recurrent, sexual pain are more likely to have other sexual dysfunctions and a negative sexual self-concept. They are less likely to instigate sex, have sex, or engage in

other sensual activities such as cuddling or kissing (Brotto, Basson, & Gehring, 2003; Gates & Galask, 2001; Meana, Binik, Khalife, & Cohen, 1997).

Sex is a relational process and any difficulties experienced by the woman are likely to also be experienced by her partner. For example, if women's pain reduces the frequency with which they initiate sex, this may affect their partner. Although researchers have not directly studied the influence of painful sex on intimate relationships, clinical accounts suggest that sexual difficulties impact both members of the couple, and the couple relationship (Aubin & Heiman, 2001).

The cognitive mediation model of couple relationships (Epstein, Schlesinger, & Dryden, 1988) is a cognitive-behavioral theory of couple relationships that informs the present study. This model posits that cognitive processes influence the following aspects of a couple: partners' views of each other generally, the specific interpretations each makes of the other's behaviors, and their emotional and behavioral responses toward each other. The model can be depicted as a cycle:

Interpersonally, each spouse's emotional and behavioral responses simultaneously result from his or her own cognitive appraisals of the partner's responses and, in turn, serve as stimuli that will be appraised by the partner. Intrapersonally, each partner's emotions, behaviors, and cognitions interact. A person appraises his or her own emotions and behaviors as well as those of a partner (Schlesinger & Epstein, as cited in Epstein, Schlesinger, & Dryden, 1988.)

Based on this model of couple relationships, it is assumed that sexual pain influences the woman's behaviors towards sex, as well as her cognitions and emotions. Her partner's appraisals about her change in behavior and emotions will influence his



own cognitions about what is happening. His thoughts will lead to certain behaviors and emotions, which in turn, are appraised by his partner.

In applying this model to the present study, the cognitive mediation model of couple relationships illustrates how a shift in behavior in one member of a couple can influence the other member, in a cyclical manner. The introduction of sexual pain is likely to shift behavior in one member, and this model predicts that these behavior changes will impact both members of the couple. With the exception of Connor (2003), no research to date has illuminated the experiences of both members of a couple when the female member experiences recurrent sexual pain.

When both members of a couple are negatively impacted by sexual difficulties, the quality and stability of the relationship may be impacted as well. McCarthy (2002) maintained that sexual activity serves a number of functions in an intimate relationship. He argued that, when going well, sex plays about 15-20% of the role in the relationship. It can help foster intimacy, reduce tension, create shared pleasure, and re-energize the couple bond (McCarthy, 2002). On the other hand, when sex is not going well, it can seem like that problem is taking over the relationship. In fact, two of the most commonly cited reasons for separation in the first two years of marriage are sexual conflict and/or the development of a sexual problem (McCarthy, 2002; Oggins et al., 1993). Research is needed to address how the experience of female sexual pain impacts both members of the couple, and how this impacts their experience of the intimate and sexual relationship.

### **Summary of Literature Review and Rationale for the Present Study**

A review of the literature highlighted a number of concerns about sexual pain. First of all, although sexual pain has been a concern for women for centuries, treatments

for them are only in their infancy. Health practitioners and women alike are often frustrated at the lack of effectiveness of available treatments (Bergeron, Meana, Binik, & Khalife, 2003). Improvement in pain and sexual enjoyment can be a slow, intense process (Hall, 1994). Chronic pain research on women has revealed the ways in which pain experiences impact on women's sense of self.

Sexual pain is necessarily a relational experience and it comes during an activity that is meaningful and valued by many couples. The combination makes sexual pain quite a unique experience. Thus, couple narratives on their experiences of sexual pain can contribute to the literature in many fields: sex, pain, and the couple relationship. A literature search found only one qualitative study investigating couples' experiences of sexual pain (Connor, 2005). To date, no narrative studies have focused on couples' experiences of sexual pain.

Given this research need, the purpose of the present study was to shed light on couples' experiences with this phenomenon. Thus, the research question that framed this project was: What are couples' experiences of recurrent physical pain on the part of the female partner during or immediately following sexual contact?

### CHAPTER 3: METHOD

The purpose of this study is to shed light on couples' experiences of female sexual pain. The research question that frames this project is: What are couples' experiences of recurrent physical pain on the part of the female partner during or immediately following sexual contact?

#### **Rationale for Narrative Inquiry Method**

In this study I am exploring an area in which relatively little is known. Given this fact, it was appropriate to choose a qualitative research method (Creswell, 1998). Within the qualitative research paradigm, narrative inquiry was chosen because it facilitated my answering of the research question. Many social-constructionist researchers maintain that the primary way humans make sense of their experiences, and construct their selves, is through the telling of stories (Crossley, 2000; Mahoney, 2003; Murray, 2003; Polkinghorne, 1988; Reissmann, 1993). Thus, narrative inquiry was appropriate for a study aimed at understanding human experiences of sexual pain.

In addition to choosing a method that facilitated answering the research question, I also wanted an approach that fit with my social-constructionist epistemological philosophy. I believe that in many ways our experiences are socially constructed. Narrative inquiry fits with my epistemological ideas.

Within the narrative analysis methods, I chose to use the holistic-content narrative approach outlined by Lieblich, Tuval-Mashiach, and Zilber (1998). This approach allowed me to represent the narratives as contextual, holistic accounts. This was important because I believe there are contextual differences in everyone's experiences with a phenomenon. However, using this approach also allowed me to look for patterns

that emerged across the narratives. Being able to represent the findings as both holistic narratives and across-narrative themes meant the findings would be accessible to a wide range of readers. This was important to me because I wanted the study to be pragmatically useful to both couples with sexual pain and the professionals who serve them.

Researchers' focus on illness narratives began out of the concern that patients were not able to share their stories with their doctors. Researchers such as Elliot Mishler (1984), Kathy Charmaz (1983), and Arthur Frank (1993) found that the structure of clinical and research interviews hindered the interviewee's story telling. Mishler (1984) described this problem as the conflict between the "voice of medicine" and the "voice of the lifeworld." The difference with a narrative interview is that the narrator is encouraged to share his or her illness story in a detailed, contextualized, personal way that gives the interviewer an in-depth look into his or her life with the illness.

In the past two decades, illness narratives have become increasingly popular in the literature. Illness narratives are stories given by patients on their lived experiences of an illness or pain condition. Illness narratives have been used in research to learn about the lived experiences of a variety of conditions such as HIV/AIDS (Ezzy, 2000; Mosack, Abbott, Singer, Weeks, & Rohena, 2005), cancer (Woodgate, 2006), pain (e.g., fibromyalgia; Navon, 2003) and mental illness (e.g., depression; Dyer, 2005).

Although pain and illness narratives of individuals have increased dramatically in the literature, there are only a handful of published accounts of couples' illness narratives (Esmail, 2006; McCarthy, 2005; Skerrett, 1998), and these studies are focused on life threatening illnesses such as cancer. There is a dearth of narrative studies on couples'

experiences of non-malignant pain or on sexual difficulties. A narrative study exploring couples experiences of female sexual pain was necessary and timely.

### **Researcher's Subjectivity**

As a woman, researcher, and counsellor, I come into this research with knowledge and biases. These roles have led me to form personal assumptions about female sexual pain and its treatment. I believe that treatment for sexual pain should be biopsychosocial in nature and client-centered. I also believe that people are experts on their own bodies.

During the course of this project, I bracketed my biases to ensure I was not leading the data. I practiced reflexivity about my assumptions by keeping a journal and consulting with my supervisor frequently. I also practiced neutrality in the research interviews.

### **Procedures**

#### **The Pilot Interview**

A pilot interview was conducted for two reasons. First, I wanted to practice the interview to learn what to bring and how to be. Second, the proposal committee recommended I conducted a pilot study. The committee suggested I videotape a research interview and obtain feedback on it as a way of increasing my competency in research interviewing. The committee also wondered whether couples could produce substantial stories on such an intimate topic in a joint couple interview format, and suggested a pilot study to answer this question.

I asked an acquaintance who had told me of her sexual pain whether she and her boyfriend would be willing to act as my pilot interview participants. I asked that they

participate in a joint interview and that they not disclose whether the details of the story were real or fictional. They both agreed to participate.

I arrived at their home on a weekend morning and we arranged the furniture so that we could all be on video-camera. I read the consent form aloud and emphasized that they could stop the interview at any time. They each signed the consent forms and a copy was given to each of them. I then read the interview question aloud, and placed it on the table in front of them. The interview lasted 1 hour. After the interview I turned off the camera, and asked them for feedback on the interview process and my style. I also made notes to myself about my sense of how I did as an interviewer, some field notes about the context of the interview, and some reminders about what to bring for the actual interviews.

The participants had helpful comments. They confirmed that I listened well, and liked how I clarified things they said because it helped them to remember to elaborate. They suggested that I incorporate more questions into the interview. The reason I had avoided asking questions was because I wanted to remain neutral.

Afterwards, I watched the pilot interview by myself and made notes on my body language and interviewing behavior, and made suggestions for rewording the interview question. Next, I watched the tape with my supervisor and again took notes while she and I discussed what we saw. Through consultation with my supervisor, I learned that I could incorporate questions throughout the interview and still remain neutral. In this way, questions could invite the participant to delve more deeply into their story telling.

Another important observation made by my supervisor was that the participants were not really telling stories; rather, they were having a conversation with each other.

They interrupted themselves many times to check in with the other about what they were saying. For example, while the woman spoke, she checked in with her partner through eye contact and a questioning tone in her voice. She also often stopped talking to ask him his thoughts and did not return to the narrative she had been telling. The man's body language and verbal responses indicated he was there to support her. He often held her hand and looked in her eyes and nodded along with her. However, even when prompted, he did not really go into a story of his own and did not seem to have the space to express whether he saw any parts of the story differently from his partner. At the end of the interview the couple indicated that they had really enjoyed the process because it had brought them closer to hear each other speak about this issue again. Thus, although the pilot interview produced closeness for the couple, it did not produce the in-depth stories I was seeking. Based on the pilot interview, I decided to alter my procedures and interview the members of the couple separately in order to allow each member the privacy necessary to tell his or her story.

### **Recruitment**

Snowball sampling was employed to obtain a sample of couples who were willing to speak of their sexual pain experiences. Participants were recruited by networking with a local support group for women with vulvar vestibulitis syndrome, via advertisements on boards of local campuses and medical clinics, and through word of mouth. Interested individuals were asked to contact me by email or by leaving a message on a confidential voicemail.

## **Participants**

I was interested in stories from couples with varying backgrounds of sexual pain at various stages of treatment. Initially, I aimed to collect stories from both members of a current couple. However, early on in the recruitment stage, it became clear that individuals who had ended relationships due to sexual pain in the female partner also had rich stories and were willing to share them. For this reason, I changed the inclusion criteria to the following:

1. (a) Individuals in a current relationship in which a female partner has experienced unintentional pain during or within 24 hours following sexual activity, repeatedly, for a period of three months or longer, or (b) individuals who, in the past, have been in a relationship in which a female partner experienced unintentional pain during or within 24 hours following sexual activity, repeatedly, for a period of three months or longer.

2. Are over the age of 19.

3. Speak, read, and write English.

Exclusion criteria included the following:

1. Individuals under 19 or who did not speak, read, and write English.

2. Individuals whose genital/pelvic pain was not associated exclusively with sex (e.g., individuals who experienced pain all the time).

For individuals in a current relationship, I let them know that I was interested in interviewing both members. However, in one case, only one member was interested in participating, and I allowed her to participate.



I interviewed a total of eight people. This sample size is the norm in narrative research (Arvey, 2003; Mcleod, 2001; Murray, 2003). Of the eight participants, seven told a story of their sexual pain experiences within a current relationship, and one spoke of a past relationship.

A description of the age, marital status, employment status, education level, ethnic background, and pain experience will be provided for each couple or individual, depending on the case. All of the participants were heterosexual. The reader may want to refer to this section when reading the narratives. The names used in this paper are pseudonyms chosen by the participants.

Nicole, 36, and T.J., 37, had been married for four years. They had one 13-year old child each from a previous relationship. T.J. worked full-time and Nicole did not work. Both had some high school education. Nicole began experiencing sexual pain three and a half years ago. She had been diagnosed with endometriosis at age 16, and attributed her sexual pain to a surgery that had been conducted to alleviate endometriotic symptoms. The couple had separated six months ago. However, they stated that they spent much of their time together, were in couples counselling, and were hoping to move back together soon.

Jane, 24, and Aiden, 24, had been together for six years, and became engaged a few months previously. Aiden worked in child care and office work, and Jane worked in the social service field. Both had undergraduate degrees. Jane had experienced pain since her first sexual encounter with Aiden, six years ago. Two years ago she had been diagnosed with clitoral phimosis and vulvar vestibulitis.

Yasmin, 23, and Alex, 27, had been dating for one year and were in a monogamous couple relationship. Alex was Black Canadian, and Yasmin was Arabic Canadian. Both had undergraduate degrees. Alex worked in non-profit administration and Yasmin was job searching. Yasmin had experienced occasional, recurrent abdominal pain during or immediately after sex for five years. She had not sought help or received a diagnosis.

Michael was interviewed about his experience of sexual pain in a previous relationship. Michael, 31, and Beth, 28, had been together for six years and ended their relationship one year ago. Michael was Spanish/White Canadian and Beth was White Canadian. He had Master's level education and worked part-time. Beth had experienced recurrent painful bladder infections that were associated with sex since she was 22. Although Michael's partner appeared to experience discomfort rather than intense pain, Michael's narrative was included because it was an articulate and illuminating narrative of the experience of the partner.

Sara, 26, and Rob, 27, had been dating for 3 years. Sara had a college diploma and worked in service. Sara's only sexual experiences had been with Rob, and after six months together those experiences became very painful. She was recently diagnosed with endometriosis. Although Rob initially expressed interest in participating in the study, he ultimately chose not to participate.

### **Data Collection**

#### **Telephone screening interviews.**

When an interested individual contacted me I first set up a time to do the telephone screening interviews. Fifteen-minute screening interviews were conducted with

each potential participant. The screenings were conducted to establish whether the potential participant met the inclusion and exclusion criteria, to inform the potential participant of the objectives of the study, what their participation would involve, the potential benefits and risks of the study, and to obtain verbal informed consent. If the individual was a member of a couple I asked if his or her partner would like to be involved, and if so, I also went through a screening interview with the partner. I let each participant know that the interviews would be largely unstructured, and that the participant would have the opportunity to share his or her story of sexual pain over 1 to 2 hours. I read the interview question aloud to get a sense of whether they were willing and able to talk on the subject. At the end of the conversation, I asked them to prepare for the interview by thinking about the research question, reading old journals, and writing down some things that they wanted to be sure to say in the interview. We then set a time and place to do the interviews. Nine individuals were screened, all of whom met the inclusion/exclusion criteria. All agreed to participate in the study. One participant who had agreed to participate cancelled the narrative interview, and did not reschedule due to time constraints.

### **The narrative interviews.**

A total of eight participants were interviewed. The interviews were conducted in the participants' homes and each interview took between 50 minutes and 2 hours. Members of a couple were interviewed back to back. While I interviewed one member of the couple, the other member went for a walk or watched t.v. in a separate room. They would then switch places so I could interview the second member.

The narrative interview is meant to be an in-depth, unstructured interview designed to elicit narrations (Jovchelovitch & Bauer, 2000). I began by offering a snack or drink for us to enjoy. Then I obtained the participant's written informed consent and gave each participant a copy of the informed consent form. After obtaining consent, the digital audio recorder was turned on. Then, I read the interview question aloud and set it out in front of both of us. The interview question was: "Please tell me your story of sexual pain. This may include the story of your relationship and the emergence of the pain, your struggles with the pain, the impact of the pain on your intimate relationship, how the pain shaped your sense of self, and how you managed with the pain. The easiest place to start may be at the beginning, before the pain began." I told the participants that I would let them tell their story and that I would not interrupt very much until they seemed like they were finished.

All of the participants had a story to tell. Even when they appeared shy, it was clear that they had something that they wanted to get across. While the participants talked, my role was to actively listen and to ask for elaboration on areas that needed clarifying. When the participant appeared to be finishing, I asked if there was anything else that was missing in their story. The participant would then talk for a little longer. When they were finished, I then asked again if anything else was missing from their story and if there was not, I asked some specific questions about certain events requiring more information. At the end of the interviews I also asked the participants for recommendations for health professionals who serve women and couples with female sexual pain, and for other people experiencing female sexual pain. After my questions were answered, I asked the participant if they could think of a title for the story. Half of

the participants came up with their own title, and half asked me to choose a title based on their transcript. I then thanked the participant for sharing his or her story and turned off the audio-recorder. The participants were then asked to provide pseudonyms that would be used in their stories and write up. I ended the interview by explaining that I would write up a 5-7 page version of their story and send it to them for their feedback.

After each interview I made notes on the length and context of the interview. I also took notes on my interaction with the participant. For example, I noted our body language, eye contact, sense of rapport, and whether I sensed a power differential between myself and the participant. I later used this information in helping me understand and analyze the transcripts.

### **Data Recording, Transcription, and, Data Management**

#### **Data recording.**

The interviews were audio-taped with a digital audio recorder. All of the participants gave written consent to be audio-taped before the recorder was turned on. The recordings were then uploaded to a computer and protected by password.

#### **Transcription.**

I transcribed each interview myself. Transcribing helped me become very familiar with the transcript. I created and followed a transcription key (see appendix F) that was modified from Jefferson's (1985) transcription key. Transcription is a theory-laden process (Lapadat & Lindsay, 1999). From a post-modern perspective, words tell only a part of the information a person conveys in an interview. In addition to the actual words used, the participant also conveys a lot of information in the way he or she uses those

words and in his or her non-verbal behavior. In order for the transcripts to capture as much of the richness in the interview as possible, I transcribed all recorded sounds in the transcript, including silences, tones of voice, laughing, crying, sighs, sniffing, coughing, word emphasis, intonation, and where we cut each other off or overlapped in our talking.

Following is an excerpt from Aiden's transcript. I share this example to illustrate how the interviews were transcribed.

A: I felt like, (talking speed: rushed) I mean obviously I wanted to have sex and um I mean I knew and she told me that it was okay like it wasn't that bad but I didn't really buy it and I felt like. I dunno it felt like I wanted to have sex but that was the same thing as wanting to hurt her? And that just (sigh) fucked with my head. I mean I didn't want to hurt her but I wanted to have sex. And then occasionally when I would (.) I guess I would get a bit guilt-trippy. And then I would feel REALLY guilty about that (talking speed: resumes to normal). And just generally, just made me, like sometimes I wouldn't think about it and I'd get horny and we'd have sex and then it'd be great and then afterwards yeah she'd tell me I'd be like, "did it hurt that time?" And she'd be like, "not that much." And I was like, "Not that much?" I felt like she was never getting anything out of it and that she was doing it just for me? And I always felt a bit bad just because I didn't want it to be something just for me, I wanted her to just enjoy it but she just seemed like she was incapable of it. I mean when she I uh ah when she first told me about the pain I thought it was just me being (.) terrible in bed, again having nothing to compare it to. Must be doing something wrong. It seems like a simple task (tone: berating). But I'm clearly doing it so poorly that it hurts. And then when I found out that there was some sort of rare bizarre thing, at least that's what the doctor said, it did make me feel a bit better. But it was still

like ( . . ) (sigh) but then I make me feel like she's got this whole, still I don't think she's been to a gyno here and she's on a waitlist for like 2 years. So still I (.) we we haven't had well vaginal intercourse in I don't know how long? Did she go into this? Well I guess you can't answer that (yeah) but we had it recently sort of. It's just that's how it happened, and she said it didn't hurt but she never really gets anything out of it. And that's the that's always bothered me. It's like whenever we have sex, you know it's like when someone gives someone else a massage. It's like getting a massage, the person getting a massage is like yeah this is great, and the person giving the massage is just working hard and giving the massage. And I always feel that that's the way it is when we have sex. ( . . ) because it's either neutral or it hurts you know?

### **Data management.**

The transcripts were saved as Microsoft Word documents. All hard copies of transcripts, audio-tapes, and field journals were kept in a locked storage unit in the researcher's home and all computer files were kept under password protection. As an additional effort to ensure confidentiality, I used pseudonyms to identify the participants in all documents.

### **Data Analysis**

The analyses were completed using a traditional paper-and-pen approach. The transcripts were analyzed in two ways. First, they were analyzed holistically. I began the analysis by transcribing the interviews to become familiar with the material (Lieblich, Tuval-Mashiach, & Zilber, 1998). For the analysis I followed the first two steps of Lieblich et al.'s holistic-content data analysis procedure, summarized here:

1. Read the transcript several times until a focus or pattern emerges. While reading, keep an open, empathic mind. The meaning of the text "will speak to you" (p. 62).
2. Note your initial and general sense or impression of the piece. Take note of exceptions to this general sense, and unfinished statements, or contradictions.

Next, I analyzed each transcript for themes. I followed the last three steps of Lieblich, et al.'s (1998) analysis procedure to complete the thematic analysis. These procedures were:

1. Decide on the "special foci" (p. 63) of themes or content that I have followed from beginning to end of the story. A special focus may be apparent by the space, detail or repetitions given to it, or alternatively, by the omission of it.
2. Read the entire story repeatedly for each theme, separately, and mark the various themes using different colored markers.
3. Note your thoughts on each theme as it appears throughout the story using the following guidelines: Be aware of when it emerges and disappears, how themes transition, and their context and salience. Note content that contradicts the themes in mood, content or in how the speaker evaluates it. (p. 62-63).

### **Writing the Narratives**

After I analyzed the transcripts I wrote the stories. The holistic analysis helped me become very familiar with each transcript. For example, while repeatedly reading the transcript I tried to understand what point the participant was trying to get across, what tones they spoke in and what topics were salient to their story.



I then wrote up my interpretation of their story, staying between 4 to 7 pages. At times, this meant reducing the transcript considerably. The analysis process helped me decide which parts of the story to include.

In writing the stories I used the actual language and phrases of the participants as much as possible. I wrote in the first person to help bring the stories back to life (Arvay, 2003). I moved sections of the story around so they were chronologically in order. I combined all the verbatim on a certain event or theme into one paragraph to increase readability and decrease length. I changed details that could have allowed others to identify them, and I limited the inclusion of third parties in the stories. Many of the stories appear to be left unfinished or unresolved. These are postmodern tales, reflective of the fact that in reality, the plot of their lives is in process (Arvay, 2003).

### **Sending Back the Narratives**

After writing each narrative, I sent it back to the participant (Arvay, 2003). Along with the narrative, I sent a page of instructions. In it, I asked the participant to provide a response to whether the story reflected their intended meaning, or how the story could be changed to better reflect their intended meaning. I also asked the participants to respond to whether any details in the story needed to be changed or deleted in order to further protect themselves or third parties from being identified. The participants could respond through email, mail, or request to meet me in person. I enclosed a stamped, addressed envelope in each package.

The feedback from the participants is provided here. Jane, Aiden, Sara, and Michael replied in writing. Jane stated, "Read the story - who knew I talked so much?! It looks great. Aiden and I haven't had a chance to share ours yet, but I'd very much like to

do that soon. Everything in mine looks good - just a few typos to review, but that's about it. Do you think it will get published? Let me know if it does! Keep in touch!" Aiden stated, "Sorry for the delay in getting back to you. The story looks fine to me. I sometimes sound like an idiot, but that is the way I talk, so I'll have to just accept that when I open my mouth, I ramble like an idiot. There's no changes I would make." Sara stated, "Thank you so much for the story. There is nothing I would like to change. I think you got all the important points." Yasmin stated, "The summary seems fine to me, although I can't believe you actually used my word 'squisheled' as a real word :) Feel free to use 'squished' if you want to give your spell checker a break!" Alex stated, "I think the narrative you built does represent my story. In a much more coherent way than when it came out of my mouth too, so congratulations." Alex also suggested some changes to ensure his anonymity and these were incorporated. In Michael's response to me, he suggested that some words be changed to reflect his intended meaning: "Hey, read the story, it's great. I just made a few alterations." I incorporated his suggestions into his narrative. I did not hear back from T.J. and Nicole and called them to follow-up. Both stated over the phone that their stories were "fine as is."

### **Ethical Considerations**

Before beginning recruitment, ethics approval was obtained from The University of British Columbia Behavioral Research Ethics Board. Given the qualitative and in-depth nature of the study, two ethical issues pertinent to study were confidentiality and informed consent (Haverkamp, 2005). Because the participants disclosed detailed life stories, I went to extra lengths to make sure their identities were protected. I changed identifying details in the narratives, taking care not to alter the meaning of the accounts

(Haverkamp, 2005) and omitted detailed verbatim about third parties. In addition, I stored all documents and tapes properly as described in a previous section.

Process informed consent (Haverkamp, 2005) was used in this study. During the pre-interview screening on the phone, I informed the participants of the purpose of the study, the number and nature of the interviews, how their identities would remain confidential, how the results would be reported, any benefits and potential risks they might receive from participating, and the fact that they could withdraw from the study at any time. Potential benefits included a chance to tell their story and an opportunity to participate in helping others learn about sexual pain. Potential risks that participants were advised of were the impact of accessing and recounting emotionally loaded stories, and feeling uncomfortable while disclosing personal accounts to me on the sensitive topic of sexual pain. Process consent and referrals to counselling agencies ensured that these potential risks were minimized.

At the beginning of the interview, a written informed consent form outlining the above information was signed by each individual. During the interview I watched the participants for behavior indicating that they were becoming distressed. If these behaviors were noticed, I gently interrupted the participant, shared my observations, and let him or her know that they were in control, and may therefore end a particular story or the entire interview at any time, without penalty. I also brought a list of three counsellors in the participant's geographical area with openings or drop-in availability during the research period. Only one participant appeared upset during the interview, and she had warned me beforehand that she "cried at everything" and that her crying was a common way of expressing herself. I checked in with her throughout the interview about whether she

wanted to continue, and she always wanted to continue. I also asked her to monitor herself because she knew more than I did about what was normal behavior for her. The list of counsellors was offered to all participants at the end of the interviews, and all declined.

## CHAPTER 4: RESULTS

This study sought to illuminate the experiences of couples in which the female partner has recurrent physical pain during or following sexual contact. In this section, the findings of the study are presented. First, eight narratives are presented. These narratives represent the meaningful experiences of women with sexual pain and their partners. Secondly, the themes that emerged across the narratives during the analysis are presented. Five themes are presented and illustrated with excerpts from the narratives.

### The Narratives

In this study, I asked women and men to narrate their experiences with sexual pain within the context of their intimate relationship. I heard stories of love, sexual desire, pain, failed surgeries, changed selves, broken dreams, and strengths through adversity. These narratives were written by me, based on a careful, holistic analysis of the interview transcripts and field notes. The narratives were written in the first person to bring the stories back to life (Arvey, 2003). The names used in the narratives are pseudonyms chosen by the participants.

Nicole's narrative is presented first, followed by her husband, T.J.'s. Next Jane's narrative is presented, followed by her fiancé, Aiden's. Then, Yasmin's narrative is presented, followed by her boyfriend, Alex's. Next, Michael's narrative is presented. Because his relationship has ended, his partner did not participate. Last, Sara's narrative is presented. Her partner did not participate in the study. A description of the age, marital status, employment status, education level, and pain experience was provided in Chapter 2. The reader may want to refer to these descriptions before reading the narratives.

### **Nicole's Narrative: My Little Nightmare**

I have been dealing with endometriosis for most of my life. In 2003, I had a routine laparoscopy to help with my endometriosis. I'd had two of these same surgeries before which were okay. But this third surgery changed my life. I went in hoping it would help me and came out with a whole new problem: Sexual pain.

I have entry pain and what they figure is cervical pain. So I experience pain during intercourse. Actually, I feel the pain the whole time, from entry to withdrawal. To put it bluntly the more excited he gets, the harder he gets, and the more pain I'm in. It feels like I'm making love to a knife. I have to be completely heightened to the point where I'm just about to have an orgasm to be open enough for me to be able to have intercourse with a manageable amount of pain. I don't even think T.J. enjoys it. I'm laying there gritting my teeth, holding my breath, with a pained expression on my face the whole time he's going at it. It's just not enjoyable for either one of us.

When I first met my husband we had a very satisfying sex life. I used to be the flirt in our relationship. We would make love almost daily, and I was much more into sex. But now it's like I have no sexual desire. I think it's because I know the pain will come. I don't want to have oral sex or engage in other sexual activities because they all come down to the same thing. They all come down to intercourse.

Basically, the only reason that T.J. gets sex is because it's my wifely duty. So I do concede. I give in and have sex, about once a week or once every two weeks. Otherwise I would rather do without the pain. I mean how would you feel if every time you had sex someone tried to cut your leg off? You'd never want to have sex again. So it's the same thing with me. It's unfortunate but that's kind of the way it is now.

I would never have had the surgery if I'd known this would come. It's like this was done to me and I had no control or say in it. I trusted the surgeon who did the surgery. Dr. W. He was a trusted gynecological surgeon who I had been seeing for 13 years. He was the doctor who delivered my daughter. He also did the first two surgeries. But I know that whatever happened in that third surgery is the cause of my pain. I have no doubt in my mind. I don't know if he nicked something or cut off something but something definitely happened. I'd had two of these same laparoscopies before and never had any pain after. I was allowed to have sex pretty much right away. But the first time we had sex after that third surgery I was in pain.

Of course I went back to the surgeon and told him what was going on. Both of us went. I showed him where I was having the pain and told him it was excruciating. He told me the pain was in my head. He even did a physical exam including a pap, and during it I was sliding up the table in pain from his fingers. And still, he insisted it was in my head. I knew it wasn't in my head but to fight with him was beyond me. I'm not going to fight with anybody about it. Him telling me it was in my head, and refusing to do tests made me believe that he had done something wrong. His only suggestion was getting toys. He thought it was an expansion problem, although I have a child, and had never had problems with T.J. for two years prior. So obviously that was ridiculous. I went to my family doctor and asked if there was another doctor I could go and see. To me Dr. W. created that pain and now I have to live with it.

I did try and go back to find Dr. W. a little while ago. And he's taken off. Nobody knows where he is, the hospitals, they don't know anything. I phoned the College of Physicians and Surgeons and they couldn't tell me if he was in practice or not. So he's

got all my files and my whole medical history is gone. 13 years. Gone. All the history right from when my daughter was born. He never really sent any information to my family doctor, so I have nothing. I have to go by memory now each time I meet a new doctor. And my memory isn't the greatest anymore.

When I left that surgeon I was referred to a female doctor. She wasn't a specialist in this but she saw women that had pain issues, like abdominal pain. I went to see her and the first day she recommended I go and see Dr. C who is a specialist in pelvic pain. We were excited to get Dr. C. We said to others, "We've got the granddaddy of doctors!" We thought she would be our miracle doctor.

I met with Dr. C. She had me do eight different blood tests for everything from rubella to estrogen production. I went through all these tests and she did an internal ultrasound. She found some areas that were clouded, I guess, on the ultrasound machine. So she said she wanted to book me for an appointment for an endoscopy. If you imagine the laparoscopy as a facial, the endoscopy is like face reconstruction. It is much more an invasive and thorough process.

She did the surgery and found quite a bit of endometriosis which she cut out. She also found a 1 cm tumor. I actually have pictures. When I woke up, she said to me, "I found the source of your pain." Even though I had been through so much it was such a relief to hear those words. She handed me a list of all the procedures that had been done and what she had found. I was still so drowsy from the anesthesia that I didn't understand what she was saying. I just went home and then had to look up all the words in my medical dictionary to understand what had just happened.



The recovery was hard. You can't even imagine how much I was bleeding and how much pain I was in. I couldn't move. My sister and husband helped me. I couldn't even get up to get a drink or go to the bathroom. I was in bed for at least ten days and even after that it was still hard to do things. I had to use a cane to get around. It impacted all of us since I'm the one who usually cooks and cleans.

We were told to wait three to four weeks to have sex. So we waited. Even though I was recovering there was still that anticipation of finally being able to be pain-free during sex. I think we were really looking forward to it. Finally, after 4 weeks, T.J. and I finally made love. And. PAIN. I couldn't believe it; she had said she had fixed it! We were so disappointed. They've still never found what's wrong.

To me, this problem was created by someone else. And yet I'm the one living it. I wonder, where the sense is in that? I can't deal with the pain; I have no way to manage it. I'd rather just become celibate and not have to worry. But avoiding sex is hard for me, given my role as wife. The only way to deal with it seems to be having another surgery. That would be my fourth surgery. But the thing is, the more surgeries you have the more scar tissue you get. And that can create more pain because the scar tissue creates a glue inside so every time you move you're stretching it and it hurts. It's like you're just constantly ripping open the scar tissue you had in the first place. So there's no great answer.

The pain is also impacting mine and T.J.'s dream of children. We each have a child from a previous relationship and we want to create one together. We'd planned that from the first day we got married. And here we are four years later, and no children.

The endometriosis is creating problems with conceiving. When I ovulate my pain gets worse, so I try to avoid sex at that time. But it really screws up trying to have children because if you're not having sex at the right moment it doesn't work.

I was told that to get rid of the pain I would have to undergo a partial hysterectomy. I was told not to have kids, just go for the partial hysterectomy and that would cure the pain. That's what the doctors have said.

And yet a pregnancy could also cure the pain, they told me. So we are going with that route. The surgeries were supposed to help me become more fertile. I even tried fertility drugs to make my period regular. I took those for so many days and then I had to take hormone pills. But I will never take fertility pills again. I was like a wild bear out of its cage in the middle of the city. It was scary. See the thing is I produce too much estrogen. And of course fertility drugs are just filled with estrogen so it created too much in my system and that's how my body reacted. I was quite the bitchy person. So I said I would never go on them again and since then I've been looking for alternatives. But alternatives are really expensive.

Sometimes it's almost like I'm waiting for menopause to come along. Sometimes I can't wait for it to come because maybe that will help me with the pain in some way. At least then I could then go out and get a full hysterectomy and then possibly the pain could be over. They say more women become more sexual once they hit menopause, because there's nothing to worry about.

This is not like how I imagined my marriage would be. We got married after not even four months. We were so in love and happy. And now it feels like I am a 90 year old woman who has been married for 70 years. It's like everything has become old. I've

become old. We've become old. And our relationship, because of sexual pain, has become old. We're like this very old couple who doesn't have sex often anymore and who almost have to have separate bedrooms or something like that. We don't even hold hands as much as we used to.

This is my silent struggle. I can't be too vocal about it or make it too big. That's why it's a "little" nightmare. There are way too many other things going on in this world. I've got a 13 year old to worry about. I've got animals to care for. I've got so many other things to worry about that I can't make this issue a priority. If I could put this first I would, but I can't. Perhaps if I had pain all the time it would come first. But sex can be shut away. It's not in my face all the time so I don't have to deal with it.

We were recently separated and we're working hard to be together. The sexual pain played a big part in the separation because we weren't having sex. In the big picture it meant less intimacy. And that affected our everyday life and our emotions. So it had a big effect on our separation. It was hard. We lost a really beautiful home that we shared. We are still living apart but are seeing a couple counsellor now. Things seem like they are going well and we hope that we can make it work this time.

I think if you have this problem you should do as much research as you can. Learn about the doctor. Don't just believe anything he or she says. You're the only one who can read your body. So it's important for you to be informed.

### **T.J.'s Narrative: A Test of Strength**

In the beginning everything was great. Nicole had mentioned that she had endometriosis and that she had experienced some difficulties. But our sexual relationship was strong. Very strong. We could talk all night and make love all day and night. If she

wasn't content, I'd say, "Let's go again," until she was satisfied. Sex was a foundational part of our relationship. I had found a partner who was sexually compatible with me, when all the rest had tried to be.

But just 6 months later that was ripped away from me. At first I didn't understand what was going on. It wasn't being fully explained to me, by her or the doctors. All I knew was that we had had a very strong sexual relationship and then suddenly we started to struggle. It was really hard. I had all these thoughts going on in my head. I was trying to understand. The doctors were saying, "Everything seems okay," but your partner's suddenly going, "No, no, no," in the bedroom. She wasn't able to have orgasms anymore and she was disinterested in sex due to the pain. By then we were already married and committed but I feared that there was someone else in the relationship.

It's hard when you've had partners who tell you that sex with you was one of the best things about you, that anybody would be happy with you, and then all of a sudden you're running into a struggle. I was brought up making sure that my partners were always satisfied. Getting to know who the women were and what they liked. You always heard them say about past partners, "Oh, he sucked, he sucked, and he sucked." Sex was the one thing I always made sure we talked about but in this relationship things just seemed to become less open. I started feeling inadequate.

It's a traumatic thing. To get something, something that is one of your favorite things, and then to have it taken away from you. It's like a slap in the face. I'm a really sexual person and it's so hard to be turned away. The feeling was like being pushed aside. I didn't have that emotional contact with her anymore.

I felt our relationship wasn't as open as it used to be. It felt like we were growing further apart. I don't know, she said the love was still there but I was pretty confused. It made me feel less committed.

It seemed that the pain started when she went to her gynecologist to get, "cleaned out," as the doctors put it, to get the endometriotic patches removed. That's when she started suffering some complications. Later, the research would show that the more this procedure is done, the more scarring tissue there is. But when Nicole went back to the gynecologist to tell him about the pain, he said to my wife, "It's all in your head. There isn't a problem and everything is clear and looks great." Lo and behold, two years after the fact, they found a tumor. So they figured that it was part of the problem, that it was inflicting the bulk of the pain. But removing it didn't change the sensations my partner was feeling. So Nicole went in for the third surgery to remove more patches. I prayed. I gave healing a chance. I gave it time. But when the time came to try again, it appeared that the surgery hadn't helped much at all. The pain was still there. It was like a slap in the face. Again. I thought the medical staff was more advanced than that. I was told that this should have taken care of the problem and that we would have our lives back. But no.

Our sex life is different now. We don't go for hours on end, and we're not spontaneous. If I want to have sex I ask Nicole how she is feeling first and then we decide whether to do it. It kind of feels like we're in "appointment mode" which isn't very loving but it is better than being turned down once we're started. Then once I'm in there I'm always trying to be gentle and delicate, as if I'm handling a piece of thin glass

and the wind's blowing hard and I don't want it to break. A certain depth is all it takes to cause a tear or whatever and set off the pain. One wrong move and game over.

I can only imagine what a woman goes through with pain in that location. I, myself, have chronic back pain. If I even just twist in the wrong way or bend over and I get pain down my sciatica. It feels like someone has stabbed me with a nail. Nicole says that for her it's like Freddy Krueger coming at her with razor blades. I can only imagine how that would feel in that area.

I also sympathize with Nicole's struggles with the doctors, them telling her it was in her head. When your partner hits the headboard due to pain, you know it's real. You know the look of pain when you see it on somebody's face. There was never a doubt to me that she was in a real pain. Again, it's like my back problem. I can still walk and talk and make love and everything else so people look at me and are like, "Yeah right you've got back problems." But I've got them and they're there and they're real. Just because you can't see it, just because it's internal doesn't mean it's not there. So I can sympathize with her.

But as much as it is her problem it affects both of our lives. It's not just sexual intercourse. It affects how you feel about your partner. It affects everything.

It was a struggle for a long time. But once I started learning about it I could kind of make it one of my lesser deals and try to work with it. I think you have to get to a place of accepting the problem for what it is and decide to learn about it. I can see that a lot of people would get separated or divorced if they don't get over that initial struggle. I could have walked away. But Nicole's the person I intended to be with and wanted to be with. You don't just walk out on someone because she's got a personal problem.

We stay together because there's a lot of love, a lot of love and not wanting to give up. I have a hard time giving up on almost anything I do. To throw your hands up in the air and walk away is just downgrading yourself to failure. I'm not one of those people who likes failing so I just push ahead. If you have strong feelings like we did then you're able to get around it and work with it. There are some people out there who don't understand and would sooner move on. And in the old days that would have been me. But when I came to this marriage that was one vow I kept with myself. I just made a thing with God and said, "Hey, if there's a god out there, this is one thing I want to do true." It's a test of strength or will power. It's definitely a test. And I'm 5 years strong already.

I try and do everything I can to help her. I've spent weeks on end reading up on it and learning about it. I've been with her to the doctors and helped her through recovery. After her last surgery she was just keeled over in pain for three days. So I picked up the extra slack and tried to nurture her. I involve myself because I'm married to Nicole, and marriage is a two way thing.

I've researched this quite a bit. You need to learn about it to know whether you can be in it together. Because if you know nothing about it, the emotional aspect will eat you inside and out. It's a heavy weight to carry on your emotions. And you'll have to go through that loss. And it's even harder if the woman hasn't learned much about it yet.

But unfortunately, there's only research about the woman's perspective. For men who are trying to cope with their partner's pain, there's nothing. I think there should be more research. Because like I said there must be high rates of infidelities, divorce, everything, for men to be able to cope with that. Men are men. We like to be the kings of

our castles. We like to be sexual Adonises and all that. And one thing for sure, we like to mate. Plain and simple. Even gay men. It's in our genes.

Personally, I have so much pent up frustration and no release for it. I just have to take matters into my own hands. It's a one man show these days. And if she walks in then I let her know I'm thinking about her. I've restructured my life to be able to live with this. Aside from masturbating, I've taken up hobbies. Put my energy into something. But other than that, there's not much else to do.

So if there's one thing I want to say to the medical professionals it is to research, research, research! Get it right! There's got to be something out there, even if it's a vaginal lubricant to put in 24 hours before to help moisten up the scar tissue. It's like impotence and Viagra. The pill finally came out and now there are a lot of happy men, and also happy women! So with endometriosis, they have to do the research too. It's affecting the well-being of a lot of people. It alters lives.

I know that our lives have changed dramatically. Everything used to be more free, not a care in the world. We were trying for kids. Within the first month of our meeting I said I wanted kids. And she said she wasn't having kids without the committed relationship. And we built our life on that.

But the complications have meant fertility problems. And the pain means we don't get too much of an opportunity to have sex. Ironically, we learned that the cure for the pain is getting pregnant or getting a hysterectomy. A positive or a negative. We're going to try for the pregnancy and so hopefully it'll be a positive.

This is definitely not a beat around the bush subject, and I don't get too much opportunity to talk about this. It's not talked about openly. But the problem is real. It's



now. It does exist. It's a sickness, and it's not something affecting only us. My sister has endometriosis, my former partner has it and I know others as well. It's popping up. But unfortunately, it is still more common than it is talked about.

Looking over the years, I know this has been a problem for us. But I'm optimistic. I have to be. But I am hoping that one day there will be things available that will help us. Or that we'll get a pregnancy and that will free her body for a while. Or some other kind of miracle cure. You have to keep that hope alive.

### **Jane's Narrative: The "Girl with the Sexual Problems"**

Ever since I was a kid I was interested in sex. My parents had been very open about puberty and sex so I was the one telling my friends about it. I considered myself quite sexually curious. I remember in a dance competition once when I was like 13 or 14 the adjudicator said, "You're very sensual." I was excited to learn what sex was like and I wanted to wait until I was in a good relationship to try it.

Aiden and I started going out in our last year of high school. In the beginning of our relationship the desire was high. All I wanted to do was make out and fool around. We both lost our virginity to each other. That night, I remember I was like, "Holy shit, it really hurts!" But I thought that the first time always hurts so maybe later it wouldn't be so bad. So we kept doing it. It was new and exciting and I thought this was just the beginning and that it would get better. But it kind of stabilized for a long time. And it never really felt good. I was like, "What's everyone talking about?"

After high school I went east for college and Aiden stayed in our home town. We saw each other during holidays. Sometimes I would go home; sometimes he would visit me at school. When we saw each other and had sex, it was always painful. I often had a

burning sensation after vaginal intercourse. And I would feel really uncomfortable for half an hour to an hour after. And the clitoris was a definite no-go zone. Any touching around that area was extremely painful.

It was in college that I started talking about the sexual pain and learned that it made me different. Before I just thought that the pain was normal, that everyone experiences pain like that during sex. But in college I had a few girlfriends who were very sexual and they would tell me about their experiences. And first I wondered if they were lying, if they were just saying sex was great when it really wasn't. But they just really and honestly enjoyed sex and had sex with a lot of people.

I told them about my painful sex experiences. I'm an open kind of person and I share things with friends. And somehow I became known as the "girl with the sexual problems." Everyone knew about the pain. It got to be hard because people were always making suggestions, offering sexual tips. And I began to get a little resentful. "Why should giving a perfect blow job be my responsibility anyway?" I said. "I'm not getting anything out of sex, no fault of Aiden, so why should I give give give give? How about we just not receive anything mutually? And then it's just kind of a moot point."

My friends had stories about how great their sexual relationships were and what they were trying and what their feelings were. The way they talked about it kind of made me feel left out. I don't think it was malicious or anything. I think they were just sharing their experiences. But I couldn't relate. It separated us a bit.

Even now I think some old friends still remember how I was when I was more sexual and I think that's what they still expect from me. Or maybe that's how I still think of me. But I guess to most of my current friends I'm the girl with the sexual problems.

And I've kind of taken that on as my sense of self too. To a certain extent. I'm still very aware of bodies and things like that but it's like I've become this almost asexual person.

In my last year at university things started to become more interesting with the pain. A friend of mine noticed an ad asking for research participants in a painful sex study on campus. It was a study on vulvar vestibulitis. She just forwarded it to me, kind of as a joke. Because, like I said, everyone knew about the pain. It was always like, "Hey Jane! How's the pain?"

I wrote the researcher and said that I would be interested in participating in the study. First I had to go through a 2-hour screening process where the research assistant poked things at me while asking me to rate my pain. Then, the gynecologist came in and saw me. He took a look at me all splayed on the table and said, "Have you seen anybody about this?" And I said, "What are you talking about?" And he said, "You can't be in this study because although you do have a form of vulvar vestibulitis, you also have another problem called clitoral phimosis." So I don't know if you're familiar with that, but it's basically like skin has fused over the clitoris. So that's why that part is really painful. In fact, I remember I was yelling and screaming in the office from the pain when he poked me there. So I was experiencing two types of pain. And still am. Actual direct intercourse pain, which would be the vulvar vestibulitis. But also it has always been a definite no-go zone around the clitoris. And I thought that was normal. Not so normal!

The gynecologist said he wanted to follow up with me on the clitoral phimosis. So he gave me some estrogen cream and told me to pull and stretch it. I did that for a while and went back to see him and he said it looked a little bit better. But because Aiden and I were living in separate provinces at the time, I didn't really have the opportunity to test it

out. And to be honest I was a little scared. I didn't want to dive back into full-on contact there because it was just so painful.

Getting that diagnosis of what was clinically wrong helped in some ways. It took some of the pressure off me. I didn't feel like we had to have sex as often. Also, it was a relief to learn that there was actually a medical problem that existed with me. That it wasn't all just in my head. And also that it wasn't Aiden's fault.

Aiden had always blamed himself for my pain. He thought he was just a really bad lover, having had no other experience to compare it to. And of course I would always say it wasn't him but it must have been very hard for him because I was simply not interested in sex anymore. I know he got frustrated with me. And I think he thought that I didn't find him attractive. Or that I'm not attracted to him. So it was good that the diagnosis alleviated some of the blame Aiden was putting on himself.

When I graduated from university, I finished with that gynecologist. I moved back home and my family doctor referred me to a female gynecologist. I had to wait seven months for the appointment. And then when I saw her, she told me she had never seen the clitoral phimosis situation before. Even the doctor couldn't understand! She said she would talk with her colleague and then get back to me because she didn't know how to treat it. At that time she just gave me some recommendations like wear cotton underwear. And she said not to do anything that will cause pain down there. And that I shouldn't have vaginal sex.

The reason for avoiding sex and pain was because she said I have to break the psychological circuit that links thinking about sex to thinking I will experience pain. I automatically tense up when I think about the pain I will experience during sex so I know

I need to reprogram myself to think that maybe I won't experience pain. I have to break that psychological barrier.

That gynecologist also told me that all a man needs is a warm place to put his penis. And so we thought we'd give anal sex a go. And in the beginning it was actually fine. It wasn't painful at all, I was surprised. Taking it on also showed Aiden that I was willing to try something new to help our situation. I know most of my friends have never and would never even consider it. I'm an open person so I was telling some of my friends about it and they were like, "Oh my God! What did it feel like?!" And I was like, "It actually wasn't that bad." I think people have this notion that anal sex is like dirty and bad and all that stuff, but it's just another way of being intimate with your partner. So I'm really happy that I tried it. But now, again, I just don't have any sexual interest. And anal sex has become painful at times, depending on various factors, like lubrication. It's not nearly as painful as vaginal sex, but it's not as unpainful as it was in the beginning.

However, we do do it. Last night I thought I'd initiate it. It had been a long while since we'd had sex and I thought I owed it to Aiden. He had been really patient; he hadn't been pressuring me, except in passing, so I decided I would do it. I psyched myself up for it. But I didn't end up initiating. I don't know what happened, maybe we were tired. It's this whole game that we play. Sometimes I decide to initiate. I just want to give it to Aiden because he's a young guy and he loves me. But Aiden knows that if I initiate I'm just doing it to please him. And that isn't what he wants. So sometimes I manipulate it so that he feels like he's the one initiating it. And sometimes I do feel pressured by him to have sex. Like if he gets caught up in the moment. You know he is a male and whatever. And then he feels guilty after. There are all kinds of psychological things going on.

It doesn't sound very intimate does it? For me, it feels like we're not being very intimate when we're having sex. Like there are always apologies in our sexual relations. I'm apologizing that I'm not "normal," that I experience so much pain when other people are experiencing pleasure. He's sorry that he's hurting me. Sometimes when I'm wincing in pain he's like, "Am I hurting you? Are you ok? AM I HURTING YOU?" And that just kills whatever moment we might have been having. Meanwhile, all I'm thinking about is what I have to buy for groceries tomorrow and when this is going to be over. And I hate looking at it like that.

It gets me thinking, because, yeah, we are getting married next year. And you know, I think it's going to be in five years that we would like kids. And then I think, "Oh my god, I have to have sex to have kids!" And here I am already wondering if we can just use some kind of contraption, like ejaculate into a turkey baster and put that up? I'm already thinking that far in advance, and I'm thinking that I won't be fixed.

Apparently there is a surgery that I can do that might alleviate the pain. It would involve cutting the skin over the clitoris. But I don't know. I just don't think it would be that easy. For them to say, "Here, now we're going to fix you physically and you're going to be right as rain and you're going to have orgasms coming out your ears," I just don't think that's realistic.

Even if the pain problem went away, there are of course underlying issues. It's like this thing has cropped up and we've kind of moved around it. It's kind of like an elephant in the room analogy. It's there and although we do talk about it, we don't all the time. I don't tell him how I'm feeling about it and I don't actually know what he thinks. There are some problems that won't necessarily disappear with a surgery. I think there

would be other work that would need to be done. Perhaps a sex therapist would be able to help us.

I'm angry that we can't seem to have a normal sexual relationship. I mean we're getting married and I don't want to have sex. Like EVER. There are a million other things I'd rather do than have sex. I feel like we're sixty and we've been married thirty years, and people just don't have sex anymore. And you know we're in our early twenties, so this shouldn't be happening!

It makes me sad sometimes, the whole situation. It makes me sad that Aiden has never been with anyone else and that he's missing out on something. I think he's sacrificing a lot for himself because if he's going to be with me, he's not going to have very frequent sexual relations. It's just the way it is. In some ways it makes me love him even more because I know that he's giving up something that he really enjoys. Sometimes I think that if I were with another guy he would have up and left a long time ago. I think that we're told that we need to give the guy sexual favors, that that's part of a relationship. You give and are meant to receive in return. I don't really want to believe it, but I think I've been socialized that way.

I think people view me as someone who is deviant, who doesn't really follow along. I have a friend who also has painful sex. But she just goes along with it and never makes a fuss. She had a boyfriend and never really spoke to him about it. It's like women can go along with it, like my friend, and not make a fuss, or they don't, and are accused of somehow putting up a barrier to their own enjoyment.

My family and friends are concerned and always asking me if anything's changed. It didn't bother me at first but now it does because nothing is changing. "I have

to wait a year to see someone so quit asking me!" I mean I am glad that I don't have to hide it from them, but they always ask in such a sympathetic concerned way that makes me feel like they are feeling sorry for me. And I don't want them to feel sorry for me. It's not something that I'm constantly aware of. It's just something that I've had to learn to live with. There are larger problems in the world.

Despite the sex pain, Aiden and I have been going strong. I think this experience has strengthened our relationship. Our relationship is definitely not based on sex. We've found other things that give us pleasure out of each other. Like we talk a lot in bed and we cuddle A LOT. We are very physically affectionate. But it's just not in the traditional sense that couples, or at least the way that everyone else perceives couples, to be intimate. We've found other activities that we both really like. I mean even just living together, we just love it. We communicate more. We definitely joke about it. I think that's one way that we've managed it. I made a joke last night that we're kind of born again celibate people! I think if we were dwelling on it too much it would be too serious and too depressing all the time.

And it seems like good things have been happening this past year. I mean, we're getting married, so I guess we're doing something right! So I don't know if the sexual pain has taken a back seat, or that I'm kind of more comfortable with it now. Maybe it's that we both know there's nothing we can do right now, until we see the specialist. I've heard that women in their late thirties, early forties kind of come into a sexual renaissance. I hope something like that will happen. But, I also hoped that when I first became sexually active that it would be this great thing and then that didn't happen. So



while I do hold out some hope, I'm reserved about it. I've seen what's happened these past few years. I'm not about to set myself up again with false hope.

### **Aiden's Narrative: Twisted with Guilt**

Jane and I have been together for a long time, six years. I don't really remember when she started telling me about the pain, but the first time I noticed something was weird was when we first had sex. We were both virgins and it was all very awkward. I was going down on her and I went towards her clit and she seized up and said, "No you can't touch that, it's very sensitive." I thought, well this shouldn't be happening; this is where I'm supposed to be working towards. So I checked with her. And she was firm, "No you can't touch there at all." I might have thought it was odd but I mean I didn't have anything to compare it to. I just thought everything I'd heard before was wrong. I was like, "Oh, I guess this is the way it is."

As time went on though it became more than the fact that I couldn't go near her clit, it would be the fact that we'd have sex and she'd never really seem to be that interested. She wasn't like, "meh" but she never seemed to really be enjoying it.

Then, after sex, she starting telling me it had hurt. The first time she told me we hadn't had sex for a long time and I just sort of assumed that it was painful because we hadn't had sex for a long time. We'd spent quite a bit of time doing a long distance relationship. She was at York for 4 years. And three years of that was long distance. So there would be long extended periods of time between our sexual encounters and I thought that was the reason for the pain.

And then when it started happening every time we had sex I felt really bad. I thought it was me being terrible in bed. I had nothing to compare it to and I just thought I

must be doing something wrong. "It seems like a simple task! But I'm clearly doing it so poorly that it hurts," I thought.

There was so much guilt. It felt like obviously I wanted to have sex and she told me it was okay, like it wasn't that bad, but I didn't really buy it. I felt awful because I was inflicting pain on the person that I love more than anyone else.

It felt like wanting sex was the same thing as wanting to hurt her. Asking her to have sex was like saying, "Hey, Honey, can I punch you in the face?" It's just like, "No, of course she doesn't want to have sex with you, you fucking idiot, you hurt her." And that just fucked with my head.

And then occasionally I would get a bit guilt-trippy with her to have sex. And then I would feel really guilty about that. I would get mad at myself for wanting to have sex in the first place. It really twisted me up.

Sometimes I'd be horny and not thinking and we'd have sex. Afterwards I'd be like, "Did it hurt that time?" and she'd be like, "Not that much." And I'd be like, "Not that much?!" I felt like she was never getting anything out of it and she was just doing it for me. I felt bad because I didn't want it to be something just for me. I wanted her to enjoy it but she just seemed like she was incapable of it.

I'm sure there were times when she felt bad about not being able to have sex as frequently as I would have liked. And I'm sure she sometimes had sex with me because she felt guilty about not having a regular libido. And I think sometimes she'd tell me it didn't hurt just to protect my feelings. But I would think these things and then feel bad for wanting to have sex in the first place. I feel like I've repeated myself a dozen times here.

It was so complicated. Sex is supposed to be something that a couple should be able to do that's the complete opposite of pain and hurt, but for us that's what it is. It's pain. And I hate that.

So what happened was Jane went to a health centre at her school and they identified it as clitoral whatever and vulvar something, I can never remember the names. According to the doctors, there was some sort of rare thing going on with her. And when I heard that I started to feel less guilty. I mean I felt bad for her that she had to deal with this medical thing. But I didn't feel as bad as before.

After we finished school and traveled, we came back here. Jane saw a new gynecologist here several months ago. That doctor told her to stop having sex. And, actually, that made it easier. When the doctor said, "You shouldn't be having sex," it was like that's all there was to it. That was the bottom line. She didn't have to feel guilty for not having sex with me. I didn't have sex with her and therefore didn't feel guilty about hurting her. It was sort of a way to have it off both our hands.

After that came the bum sex. It wasn't something I'd pushed on her before, not until the vaginal avenue had sort of hit a roadblock. Then I asked her and I was very happy that she was willing to try because most people I know say they hate it. It's the fact that she could at least try and on a semi-regular basis. And now that we've switched to anal intercourse I don't feel so guilty. It's a different area obviously, so it doesn't hurt, apparently.

Even if it doesn't hurt, though, she just doesn't get much out of it. And that still bothers me. It's like getting a massage from your partner. The person getting the massage is like, "Yeah this is great!" But the one giving the massage is just working hard. And I

always feel that's the way it is when we have sex. Because it's either neutral or it hurts. And if it's neutral for us, that's good because at least there's not pain. But I don't want it to be neutral and I definitely don't want it to be painful for her but there's nothing I can really do.

So we don't have much sex. I've stopped initiating entirely. It became too hard because she never really wanted to do it. I think she just generally does not want to have sex because of all the problems that she has had. I know that if she didn't have the problems it would be completely different, but it's not.

I have a group of friends who meet and talk about everything including sex. And they don't know what's going on with me and Jane. So I kind of just go along with things and let them assume that we have sex. It's not a big deal. It's not like I would be filling them in on our sex life anyway. But occasionally I feel uncomfortable when that kind of situation comes up.

I don't talk about this much; I'm pretty much left on my own. Well, I have Jane and one friend who know. But I don't really need to talk to people about it. A couple years ago it was much bigger. Now, it doesn't bother me so much.

It's just become less of an issue. I guess I've gotten older. And fatter! I'm more mature and my relationship is more mature. It just doesn't bug me as much. I just don't think about it as much anymore.

I do hope that one day she'll be able to see a specialist. Jane is on a waiting list. It's taking two years, a long time, but that's the system. It's unfortunate, but nothing can really be done about it. Maybe the new gynecologist who will have some kind of wonder drug and maybe everything will be well and good. Maybe her sex drive will pick up and

then we can have a more active sex life. But you know, if it doesn't happen, it wouldn't really matter. I've adapted, I guess.

I jerk off a lot. I don't know if I'd be doing it as much if we were having regular sex. But actually now that I think about it I don't do it that much compared to some people I know. Actually, I had a scare a few months ago; I found a lump in one of my testicles. It freaked me out so I went to the doctor. And she said it was just an inflammation and a couple weeks later I went back and it was gone. It's funny because the doctor had a lot of trouble telling me I should masturbate. She said, "A lot of people think it's good to um keep the pipes clean." And I was like, "You're using a metaphor?" Of all people, shouldn't a doctor be able to straight up tell me to masturbate? Anyway, I liked having a doctor prescribe masturbation.

But it's not like we don't have physical intimacy. We cuddle a lot. And I love cuddling. And we're also having sex, although it's bum sex. So that and masturbation fit the bill.

Up until now I haven't really thought about whether this is our problem or Jane's problem. We do go through it together. But to call it "our problem" would be a bit of a presumption. Obviously she's the one with the pain and I just have to help her. I guess I don't want to be like "oh I have so much pain and angst over it" when she's the one that really feels the pain. So it would be selfish to say it's a 50-50 shared problem. But on the other hand it's cold to say it's Jane's problem. So I don't really know how to get it across.

Jane is the only person I've had a real relationship with, the only person I want to have a relationship with. So it's not like being with Jane suddenly means being without sex. Or shutting a door. I never really pictured myself as someone who'd have a lot of

partners. When it comes right down to it I love Jane and I love being with her so the sex really isn't that big a part of it. I mean I would like it if we were able to have sex, but that is secondary, tertiary to everything else.

We are getting married. And before I met Jane I always thought marriage would be sharing your life with someone you love. Sex wasn't the main part. It's not, "Oh I really like having sex with this person so I'll marry them." The way I've always thought it would go is, "Oh, I really love this person so I'll marry them." And that's what happened. It hasn't changed my philosophies about marriage. She's the one I want to spend my life with and that's not affected by the fact that she has sexual pain.

### **Yasmin's Narrative: The Crease in my Bed Sheet**

I have snippets of when the pain was bad, but I can't say that there was really one point when the pain began. It's just something that has always been there, in my memory of my last two partners. The pain occurred with my last partner for four years, and has happened with my current partner, Alex, for the last year.

I have no idea what the pain is. I can usually feel it coming on. It only happens during penile-vaginal intercourse. And I think it is associated with rougher sex, but I can't say for sure, because there have been times when we've had rough sex and I've had no pain. I've never been diligent enough to record the duration and type of pain, and our various sexual scenarios. Sometimes when the pain comes on, if we stop having sex, it will go away. But other times it will crescendo and then I'll need a 5-minute time-out. I usually go and sit in the bathroom alone or I curl up with a hot water bottle and just wait for it to stop. And it always does. So that's why it's never been a huge concern.

There's a word to describe the pain in my language but not in the English language. It's kind of like cramping. I imagine dough being kneaded in but really being squished out. It really is like menstrual cramps but higher up. It's deeper in than you would expect the pain from intercourse to be, so it might be referred pain, like from something hitting the cervix. I feel like there's this "on" switch, like in pin ball, like you suddenly hit the on switch and that's how it starts. On a scale from 1 to 10 of pain it is a 6 or 7 and then either crescendos or stops.

About 4 or 5 months ago I had a bout where the pain came pretty frequently. I'm not really sure what it was, whether it was a certain position we were using at that time or what. I was considering going and seeing someone but then it just stopped again. And I was like okay, it's gone again. That was the only time where it was an issue, where my partner said, "Okay if it happens one more time I'd really like you to go see someone. I'm worried about you." But then it stopped for a while. So I've never gone to see someone.

I'm aware that it's not so common, that I'm a bit of an anomaly. But I've really only been concerned enough that one time to almost get it checked out. I just don't know what I would say to a doctor. And I don't know if there's any sort of diagnosis for that. I don't have faith that doctors would be able to pinpoint something. I guess if there were like 3 or 4 things I needed to see someone about I might say something about it. Or if someone were to explicitly ask me about it I might. Or if I read anything that said pain with sex may lead to cervical cancer, I would get checked out. But that hasn't happened. It seems like there's nothing really out there about sexual pain.

I don't know that I struggle with the pain. It's just sort of an inconvenience or a hassle. Because certain parts of sex are about you and certain others are more about your partner. So depending on where we are in that sometimes I don't want to take that moment away from my partner just because I have pain. So sometimes I struggle with where to draw the line. Am I more important right now, or are you more important right now? I struggle with trying to strike that balance.

The other thing I struggle with is my partner trying to console me and being like, "Are you okay? Did I do something?" I don't want the guilt from him because I know it has nothing to do with him. Also, I don't like people smothering me when I know I don't need that. For these reasons, I usually remove myself from the situation when the pain starts. I leave the room and usually end up sitting on the bathroom floor.

But Alex and I have become a lot more comfortable with it. So now I might not even leave the room. I might just grab a pillow and put it against my stomach because that pressure distracts me from the pain.

I feel like I can manage the pain because it is always contained, and because I have some control over it. I know it's contained, that it'll be 10 minutes and I know what the pain will be like. It's like if I rip off this band-aid I know what that will feel like so I have a sense of control over it. It's also controllable. I know that it is only sex that brings it on, and that if sex stops it will eventually stop. It's malleable to me. Also, my pain tolerance tends to be higher than others. For example, I am totally happy to get waxed, whereas others are not. So that probably helps me manage.

What we will often do when the pain starts is move into oral or manual stimulation. So the pain might reduce the frequency of penile-vaginal intercourse but



we'll just move onto something else. At times I'll say, "I need to stop now because it just started and I think it's going to hurt. "No sex right now," basically. And I get the guillotine down on that. Sometimes the pain will come on when I know he's just about to orgasm, and I let him do it. After that the pain will get bigger, and that's when he feels the worst, the most guilty. Because the pain has happened right after his pleasure. And I feel bad too, but you know, it was my decision to do it, it's not like he forced me to put up with the pain.

I don't find I need to blame anyone for this pain. But sometimes my partner might take some of that blame. I have to explain that he isn't responsible for the pain. I don't even know how I bring it up. I think they can see the pain on my face and ask if I'm okay. Then, I have to explain, "It's not you, it's something that happens." I don't want him to feel guilty or like it's something he is doing to me. Like obviously there are some sexual positions that may contribute to the pain, because of the depth of penetration. I think it's never happened when it's woman on top. It's always man on top in some way. I think it's just something to do with the pressure, with the way it would hit. But I have to separate that for them, like "It's not like you were doing anything. I realize that you're not trying to hurt me." I have to tease it out so he knows he's not the one creating it.

I don't know if this pain has had any impact on my intimate relationship. At least not in the number of times we have sex. It just means that we end up abruptly stopping sex some of the time. We are able to talk about it, and that helps. I think of it as something that's just there some of the time and that we work around.

### **Alex's Narrative: The Niggling in the Back of my Head**

The time I thought most about Yasmin's pain was when it first happened. I think it was fairly early on in the relationship. We had just finished having sex and she seemed really uncomfortable and went to the bathroom. She didn't seem too distressed, but at the time we were still getting used to each other, and I wasn't really sure what my reaction should be. I was worried and uncomfortable and upset all at the same time. But afterwards she told me that it was something that had happened to her before and that after a few minutes it would generally pass.

In the beginning there was this idea in my head like maybe I was doing something to hurt her. So I had feelings about it. It wasn't exactly guilt, because I think I believed her when she said it had happened before and wasn't a big deal. But in the back of my head, I had some sense of feeling responsible.

I also felt concerned. It wasn't something that I knew about or had encountered before with other partners. Also, as I got to know Yasmin, I learned that she was the type of person to think that she was tough enough to get through anything. So if she wasn't feeling well and needed to call a doctor she wasn't the type of person to do it without some prodding. In the back of my head I thought maybe there was something seriously wrong and she was just too tough to say something about it.

I also remember that, in the beginning, it kind of got in the way of our intimacy. She experienced the pain right after we had sex, which was a time when I would normally feel close and intimate with her. But the times she had pain, she would leave right then. So it sort of took away some of those intimate moments from us.

I think in a weird way I was more uncomfortable with it because I was more unfamiliar with it and because the intimate connection between us wasn't as strong. And just the fact that she would be in pain and would need to leave, especially in the beginning, made me feel uncomfortable. And I think as time went on she got more comfortable with me and more comfortable letting on and showing she was in pain with me. So that solved some of it for me.

It's one of those things that you think about when it happens. So when it does happen I still wonder whether it is something she should get checked out. And then it doesn't happen for a while and it just sort of slips away. But there is always a little part of me that thinks about it and worries about it. I think once or twice we looked it up. There was a period where it happened more often. We googled it and didn't find very much--a couple possible things--but she didn't really feel like they described her experience. So after that we didn't look it up again.

In terms of my sense of self, especially in the beginning, it impacted who I thought I was. I didn't think I was the type of person who was so callous as to derive pleasure while my partner was in pain. In the beginning there was that niggling in the back of my head worrying that this meant I'm the kind of person who is oblivious that way. And there was a sense of not wanting to be that kind of person, of believing I'm the kind of person who is sensitive in both an emotional and physical way. So my sense of self was a little threatened in the beginning.

One thing that helped me through that was time. Another thing that made a difference for me was the timing of the pain. It generally happened after we had sex, or at least that's when she would acknowledge it. I'm still not completely sure when it starts

for her. But because it was an after-effect of sex it didn't feel as bad in some way. If it had come on during sex, my sense of self might have been impacted a little more.

It hasn't impacted our sex life and relationship so much. I still want to have sex, and Yasmin still wants to have sex. I think the major factor why it has not had a huge impact on our relationship is that it doesn't happen every time we have sex. So there's not this sense that all of our intimacy is tainted by the pain. Also, it doesn't seem to happen during a particular sexual position or type of sex, so that helps take away the idea that we are doing something wrong, or that I am doing something wrong. It's more like this random thing that happens sometimes with sex, and that neither one of us is responsible for.

The only way it might have invaded us a bit, is the way I have these thoughts in the back of my mind during sex. When it happened more frequently I would think about it more, and ask more often if she was okay. Last time she had pain, I was thinking that the next time we have sex maybe we should be careful. It didn't ruin our sex life in any way, it just sort of temporarily changed my head space while we were having sex.

The main way that I've helped manage with this experience is just taking it less personally. Both the pain and the being cut off. Instead of something that would stop us from being close after sex it just became part of the routine. Yasmin would just go to the bathroom or sit on the bed with a pillow for ten minutes and then we'd come back together and start as if it hadn't happened. And I think that was me being able to take it less personally and also us getting more comfortable with each other. So we both could take it less personally and it could just be something that happened instead of something that would have to interfere.

It's there but it seems like one of those things that in the times that it isn't happening it just sort of fades into the background. I won't pretend that it doesn't bother me when it happens because it's someone I care about and something I'm involved with. It doesn't disappear completely. What I hope is that at some point we will both stop procrastinating and find out if there is something going on. But in terms of how we deal with her pain in the moment, we have done well. I think we've found a pretty stable pattern that is working for us.

### **Michael's Narrative: The Destructive Power of Sexual Problems**

When I met Beth I had come out of a very traumatic breakup and wasn't looking for a serious relationship. I wanted to be casual. Even though I made this clear to Beth, she still wanted to try a casual relationship. I hesitated when I found out she was a virgin because I wanted her to be sure. But she wanted to be with me so we got together. We weren't a couple, more like friends with benefits. Beth was 21 and I was 25.

Beth fell in love with me. Looking back I should have known she would. She was just not the type to be casual with someone. But I was not ready to open myself up to love someone yet. It created friction and we decided to break off our sexual relationship. We tried many times. But the chemistry was so strong; we would always end up together again.

Finally, after four years of this, we broke up. For real. Even though I instigated the break up I took it really hard. The way it affected me kind of woke me up and made me realize how much I did care for her.

Then she told me that right after the break up she had slept with another guy. I was angry and devastated. To make her understand how she had hurt me I told her that I

had slept with someone as well. Even though it wasn't true it was enough to see her real feelings for me. She wanted to be with me again and asked to get back together. And we did. And this time I let myself fall deeply in love with her.

From that moment on we were an official couple. It was different, but it was great. We weren't the type of couple that saw each other once in a while. We spent a lot of time together. We liked hanging out together, just watching t.v. or going for walks. We enjoyed each other. And we had a great sex life. Even after knowing each other five years, we weren't a couple that had sex once a week. I mean, if it was up to me it would be daily. The whole culture of sex was just very enjoyable for us. The cuddling and the going for food afterwards and the listening to music. It was a wonderful ritual for us. Our sexual connection was hands-down our most powerful connection. Anytime we had a problem or fight we would always be able to re-connect sexually.

The bladder infections had been intermittent before we became a couple. She had told me about them but they weren't a great concern to me. I just thought they were just something that most women get after sex occasionally.

So it wasn't very clear that it was going to be a serious problem. It was just more of a nuisance. But for her it was quite painful. And I didn't get this at first, because I hadn't ever had a bladder infection. Part of me would almost think, what's the big deal? Maybe it's not as bad as she's making it out to be. I didn't think it was a good thing, but I certainly didn't think it was anything that was threatening to us. Man was I wrong.

I think part of my reaction was feeling helpless. I mean she would be in obvious discomfort. And I was just feeling helpless around someone in pain. You can't do anything so one of your strategies is to say, "What's the big deal? Don't worry about it.

We'll just get something for it." It was like not really being able to get the gravity of the situation.

We were still having sex frequently. The more rigorous the sex was the more problematic it would be because it could agitate the bladder area. When it got worse, an infection would happen sometimes within even an hour of us having sex. And it had secondary implications. Like it led to yeast infections, vaginosis, and antibiotics. And those conditions led to vaginal tenderness. All of these things were disagreeable to her and would drop her whole system. With her overall health down, her desire was down too.

It was difficult for me to witness pain become a part of our sex life. It was interfering with the natural process that we had established. I loved giving her pleasure and she was so good at receiving it, and it was hard when pain got mixed in.

It snowballed. I still try to remember when the turning point was. It just started to come in much shorter successions. Like one would happen and another would happen not too long after that. Often, the bladder infection would come on suddenly. She started to have a panic-type reaction to it. She would worry a lot that one was coming on and that would make her scared. When a bladder infection would start she would go to the clinic. And then she would feel shitty for a week, her health would get worse and then finally a little better. Most of the bladder infections went like that. But some were so bad I took her to emergency. And she would have to take something immediately for the pain.

It seeped into the emotional and psychological levels of the sexual intimacy that we had. First it showed up physiologically. She had more apprehension or physical tension around the act of sex. Because what did sex mean? Sex started to mean potential

bladder infection. Potential pain. Potential illness. Potential drugs that she would have to take for a week. Potential problems at work. Then it became apparent psychologically. Her fear would accompany even the possibility of sex. And then it finally became an emotional thing where I just felt like her emotional connection to me started to atrophy. That's what really put the last nail in the coffin.

I was starting to get more seriously interested and involved in the matter. I finally realized that it was important. So I started learning.

We learned new ways of preventing bladder infections. The doctor advised her to go pee right after sex to flush out any unwanted bacteria. So after sex she would be off to the bathroom as quickly as possible. Also, she stopped using birth control because she thought that might be causing it. So then I started using condoms, which I hadn't used before. The condoms were also another way to protect each other from bacteria.

These techniques were necessary to prevent the infections. But when sex began to revolve around them, it really changed the feel of our sex life. It was no longer about taking it easy and enjoying the aftermath. It was about prevention.

Though we were making changes, she kept getting the infections. And the doctors just kept giving her antibiotics. In retrospect, I'm really upset with the doctors. Because they didn't address the issue as much as they just said, "Okay, give her antibiotics, tell her to take antibiotics." So short-term, yeah, it killed everything and got rid of the infection. But long-term, the infection was more likely to come back because her body was weaker and more prone to it. In the last year, it had gotten so bad that she had been on antibiotics 12 or 15 times in a row.



When those weren't working, she went in for operations like urethra openings or something. It was quite frightening and a horribly painful ordeal. Turns out they didn't do any good at all. And it wasn't even clear from the research if some of these operations they were suggesting were useful. So that really made me angry.

It infiltrated in to us. Beth began to push me away. As she pushed, I pulled on her. There were times when I was just bingeing or trying to have sex with her all the time. I wanted to spend more time with her, I think out of fear and insecurity. I thought I was going to lose her or something. It was like she was slipping away and my response was, "I have to grab onto this." I had finally opened myself up to love and connection with her, the connection that I had at first been so afraid of. And then I saw that person moving away from me. It was frightening.

At the same time there was a part of me that was like, "You have to let her go. There's nothing you can do to stop this from happening." Some part of me understood that the turning point had already occurred and that I could not go back and change it.

Beth was simply exhausted. She had gone through a lot of pain and sickness and hurt. So she physically removed herself and went home. She left Calgary and went back to Vancouver Island to recover. We didn't break up at that point but it was the beginning of the end.

I threw myself into researching what I could do to help. Right away it became apparent how poor the advice had been of all these doctors. It was almost as if the things they told her to do were last resorts. There were so many simple things we could have tried prior to doing an invasive operation. For example, I learned that during foreplay I had to be careful not to accidentally spread bacteria from the anus to the vagina. Reading

the information helped me feel more optimistic. I was not going to call it quits. But at the same time I was angry at the doctors. I felt like if we had gotten a good doctor, someone that knew what was going on, that he could have prevented the infections from destroying our relationship.

I read a lot of accounts of women with bladder infections. They said that it had affected their sexual relationships so badly they ended up broken up or divorced. Their stories validated how I felt about our situation. The bladder infections had infiltrated our relationship in many negative ways and led to Beth leaving.

Once Beth went away she started to recover. Because, of course, we weren't having sex. So that was good. But she would come east to visit me and we would sleep together. And at least a couple more times she got this infection again. And it was just like, "fuck." That just confirmed for her that being with me means being sick. And she didn't want to be sick anymore.

The last time I saw her we didn't have sex. I said, "I'm not going to have sex with you until you get better." It was a huge commitment for me to make, being such a sexual being, but in retrospect I wish I'd made it a year earlier. It was too late.

So I think I got connected with the illness. Like physiologically, psychologically, and emotionally. They all started to set in. And I think the break up was almost a survival thing for her, for her to feel safe.

I kind of noticed it happening. But I noticed it too late. And part of me was angry at myself for not noticing the beginning of the end. For not having seen that seemingly small problem as a very dangerous thing. If I could do it over I would have addressed the issue immediately, as if she had gotten diagnosed with cancer.

When she broke up with me she said some things. In my mind, all I was heard was, "You're not sexually safe. I can't have good sex with you. I'm not sexually attracted to you. I want to have sex with guys who can satisfy me." I was absolutely crushed. It was like the ultimate blow. My whole sense of self was like basically pulverized. I've always felt that my strongest competency is in the realm of intimacy and sexuality. So it's like someone saying to you, "You know that thing that you feel most comfortable doing and that you have a love for? Yeah, by the way, it doesn't really do it for me anymore." It pummeled me to hear those words coming from the woman with whom I'd had, for years, my most profound sexual connection with. I felt powerless. I felt impotent.

It really shook me up. I found myself looking to validate my sense of attractiveness. I wanted to feel sexually attractive to women again. I did meet women who were interested in me. And though I wasn't ready to be with them, with anyone, it was reassuring and nurturing to know that they wanted to be with me.

I experienced my own sexual pain after the relationship ended. Psychological pain. Whenever I went to masturbate or fantasize it would be excruciatingly painful for me. Because my sexuality was so tied into Beth and I would be reminded that we weren't together, and that she was probably with another guy by now. The pain and jealousy were so powerful. So it was like sex was no longer safe for me. The pain I felt from Beth leaving me and my sexuality being connected with her caused me to make a drastic decision not to return to my sexuality until I felt healed.

For this reason and spiritual reasons, I decided to practice total celibacy. I've been celibate for a year and three months. Which for anyone who knows me is unheard of because I've always been such a sexual person. Celibacy has been great, but tough. I've

realized how much of my health, integrity, stability, and vitality is tied up in my sexual energy. I needed to heal and create a new sexual relationship with myself.

I've also been doing a lot of research and reading on evolutionary psychology, neurochemistry and biology. I don't care about the nice fairytales of relationship and sex. I want to know the nitty gritty of why our bodies work the way they do, and how we're conditioned. Because I want to understand what happened. For me, healing is understanding the meaning behind my pain and difficulty. It helps me feel like this life is worth living.

I am finding meaning in what was otherwise a terrible tragedy. That's the beautiful thing that came out of this extremely painful experience. And the funny thing is that now I feel like I'm ready to get into another sexual relationship. I honored Beth. I honored myself. And that was important to me. And now I can give myself permission to be sexually intimate with someone else.

So, yes, there were a lot of repercussions to that recurring bladder infection. I feel like I've gone through a few different versions of this story that have had meaning for me. Right now it's the physiological, psychological, emotional one. I don't know. I think this story is unfinished. I think this is part one. Because down the road, who knows what might happen between Beth and me. We had everything that two people need to have an enduring relationship but the sexual pain proved to be too much of a problem. If I could leave you with some words of advice, they would be: Do not underestimate the destructive power of sexual problems in an intimate relationship. But also never give up no matter how bleak things look because there are always possibilities waiting to be discovered.

### **Sara's Narrative: No One Would Listen**

I wasn't sexually active until I was 23. It was not by choice, really, I had just not yet found someone I felt comfortable enough to be with. When I met Rob, my boyfriend of three years, I told him I was a virgin. He was surprised. Before we became sexual, he wanted to make sure that I understood that sex was a big deal. The night it happened, he set up candles and made a really beautiful scene. He walked me through everything. It wasn't spectacular but I felt powerful that I had finally had sex. There was pain but I figured that was natural.

I hoped sex would improve, and we continued to have a fairly active sex life for about a year. During sex I tended to not be connected to my body or emotions. I was always desensitized. I blocked out my body. I couldn't connect what we were doing with the act of loving each other.

Gradually, it started to hurt. I was really conscious of the pain, so I started to come more into my body during sex. The pain started getting worse. I think it was his penis bumping up against something inside me, and the more aroused he got, the more painful it became. It felt like a knife stabbing me deep inside my pelvis. Afterwards, I would also sometimes feel a burning pain and tenderness as if I had gotten punched. My back often also hurt afterwards.

I didn't tell anyone. I felt very ashamed that I wasn't capable of having fantastic sex like everyone else in the world. Whenever I was with my girlfriends, they would say sex was the greatest thing ever and I would sit there and silently disagree and feel left out.

I didn't even tell Rob. As the pain got worse my sex drive went down to zero, but his desire was still strong. I didn't want to let him down, disappoint him, or hurt him. Also - and this is the biggest surprise to me out of this whole pain experience - I was too scared to tell him because I thought I would lose him if I didn't provide sex. That I thought that way blows my mind because I was raised by a feminist mother, and I

consider myself a strong woman and a feminist. The last thing I expected of myself was a belief that I had to have sex with a guy to hold onto him. But, at the time the pain was happening, I just honestly believed that as a girlfriend, I needed to provide sex.

So I continued on, silently struggling with the pain. It started to get horrific, to the point where I was grinding my teeth just to get through sex. Then, I started picking positions so he couldn't see my face. This went on for about a year. Finally, one time, I screamed out loud because it was hurting so badly. It scared him to death because, after all, he'd had no idea that this was going on. I said, "It's hurting me." And he said, "Well, how long?" And I said, "I can't remember when it was good."

We figured something was wrong so I went to my family doctor. I wondered if something in my body, like my ovaries, had changed. My family doctor is good but all she said was, "You just need to relax, because if you're not relaxed then your uterus doesn't move out of place during sex." So we practiced a lot of relaxing. But the pain was still so bad. I couldn't admit it to Rob. I felt like I wasn't a woman and I wasn't a good partner. I didn't want to talk about it. I started holding my stomach when I felt pain because that helped to alleviate it somewhat. But Rob eventually connected my holding my stomach to the fact that I was still experiencing pain, and insisted we deal with it.

I went back to the doctor, and this time I took Rob with me. I said, "I'm serious, it's not feeling good." She told me to give it a week and then try again. She suggested having some wine to relax. Honestly, no one would listen! When it's a broken ankle, people listen. But because it was sexual, it was just brushed off, like it was not important. But given how much this pain has affected me, my relationship, and the potential of our future together, it's a big deal. The frustration I felt when no one would listen was one of the hardest experiences I've had with this pain.

I got referred to a gynecologist. We booked a laparoscopy. She said something to the effect of, "There's a possibility it is endometriosis. But I don't know if the pain is real, it may be in your head. Maybe you should examine yourself mentally before we

examine you physically.” I knew where she was coming from. Sure, I had developed psychological problems with sex from the pain. But sometimes I couldn’t walk after sex, it had been so bad. The pain was killing me. So how could this pain be in my head? But her words had an effect on me. I doubted myself. I wondered if I was just making this up. So I cancelled the surgery and decided that maybe I needed to think about sex in a different way.

The insecurity I developed about myself from the sexual pain experience is a huge struggle. It seemed like everyone was making this big thing about something being wrong with my head. Their disbelief in my pain caused me to doubt myself. I also silenced myself. I kept quiet all the time and didn’t say, “Stop hurting me.” I did not stand up for myself. I continued to carry a belief that went against who I thought I was. My behavior, and other’s behaviors, conveyed a lack of respect for me. The result of all this is really low self-esteem.

Perhaps things would have been easier if the doctors had just showed that they believed me. If that gynecologist had just phrased her words differently and said, “It sounds like you’re really hurting, so let’s see what it looks like,” I would have felt okay about myself. Or, if she really doubted the physical nature of the pain she could have said, “If this is really happening to you let’s get you support so you can deal with it.” At least, then I would have begun to get some help.

I did really try to think differently about sex for a few months, but nothing changed. Finally, I called back my gynecologist. I asked some more questions about the surgery. She was really patient, and walked me through the process. I decided to do the surgery and when they went in, they found endometriosis. They rate it on a scale of 1 to 5 and said it was a 2.5 Part of me felt validated that something had been found, it was some sort of proof that it wasn’t all in my head.

The gynecologist told me that after the surgery I should be better. So I imagined that within a week I would be having this fantastic sex life and the pain would be gone.

And then it wasn't. The pain was the same, but actually worse, more intense. We had to wait two months before we could even have proper sex because I would just sob from the pain. Rob supported me through my recovery. But I still felt ashamed and yucky. It was a failure. I went back and told the gynecologist about the worsened pain, and she said that bodies need time to heal from surgeries.

The diagnosis of endometriosis also meant that my ability to have babies might be lessened. That news affected me deeply. I had always thought I would have children. I felt like less of a woman because I might not be able to provide Rob a child. It just made this whole sexual pain experience even worse.

The gynecologist then suggested I talk to someone to make sure that I hadn't built up a mental block to sex. That's when Rob and I went to see the psychologist. She has hospital experience with clients with sexual pain, and understands the physical side. She said to me, "You're not stupid. It's not your imagination. Yes, sex has become so painful that you have made a wall there and we will work on that, but there is definitely something physical doing on." That was huge for me. Up until that point I hadn't been able to trust myself. Her words helped me believe myself.

We're in the beginning stages of our work with her and it's been good but very hard. Facing this pain means that it's real and I can't just pretend it will go away any longer. Rob and I deal with it differently, too, which means I am sometimes alone in this challenge.

Something that's really been helpful in therapy is learning about the reality of sex, rather than the myths, and especially learning about male sexuality. I'd never been taught about male sexuality, because I grew up amongst women. It helped me to hear that just because a man has an erection; it doesn't mean he needs to have sex at that moment. We've been told not to have sex. We're working on helping me open the door to sex again by connecting it to love and fun. We're doing fun and loving non-sexual activities



like giving each other massages. The next step will be going back to my gynecologist, and asking what we can do next on the medical side.

I've gotten up the courage to tell two of my girlfriends about my sexual pain. They were so supportive and said that sex wasn't always so great for them either. That opened up a whole new world for me. I started realizing that I'm not completely alone in this. However, it still feels like if anyone else is experiencing this that they are too far away. I haven't spoken to anyone yet who feels my kind of pain. If there is a support group for women with sexual pain, I would be interested. Admitting that sex is horrible for me, in this society where sex is so valued, is shaming and isolating. A support group may help. Other problems, like depression, are more talked about. But the discussion on sexual pain is just so quiet.

The experience of sexual pain has damaged our intimate relationship, for sure. We had such an honest, open relationship so it was really hard for Rob to find out I hadn't been honest with him about my pain. But the learning we are doing is helping. I've learned that having to speak up and say no to sex sort of reversed our roles, since he had been the one to teach me about sex. The guilt I felt when he seemed to need sex has also lessened as I've learned about male sexuality. Truthfully, though, I don't know if our relationship can withstand this problem if it ends up being long-term. It's a thought that saddens me.

I'm not sure how we have managed to make it this far. We fight about it, but even when we fight, Rob's still there. It's like there's all this chaos flying and whipping around us but somehow we still are able to look through it and see the other person on the other side, unmoving.

It's been a month and a half since we've last had sex, and I'm feeling like I'm actually able to be a successful person. It's weird. I'm feeling like I can still be a good woman, girlfriend, and person now, without providing sex to my partner. I'm still working on it though, still playing with that idea of how to be a good partner if I'm not

having sex. I think it's a healthier perspective. Rob's noticed. He says I'm more confident now.

I think I'm feeling stronger because I'm finally dealing with the pain. Before it felt like it was happening to me, and now I'm saying I'm going to be in control. Seeing the doctors and therapist were good steps. Even doing the surgery was empowering, because it meant taking control and not being a victim to the pain. Reading research on sexual pain has helped me understand what is happening in my body and what future treatment might entail. One of the main things that I did to help myself was to take the leap to trust myself, to believe that what I'm experiencing is real. I am now working on trusting that we can survive this process. Holding off on sex and going through treatment will help me in this relationship or in a future relationship. Rob has to wait at least two months to have sex while I am getting better. I'm finally in a position where I'm starting to believe that I am worth the wait.

### **Across-Narrative Thematic Analysis**

In this study, I asked women and men to narrate their experiences with sexual pain within the context of their intimate relationship. The social constructionist framework for this study allows me to interpret these narrations as ways the participants make sense of their experiences, and construct themselves. The stories were different from one another not only in context, but also in the ways in which events were interpreted by the participants. These differences underscore the uniqueness of each participant's meaning-making experience and each participant's self-construction.

From the thematic analysis, however, patterns emerged in the experiences that the participants went through. These patterns will be presented here. The five patterns that emerged are: Adapting to a different sexual relationship, shifts in sexual self-view, challenges in creating a family, difficulties in dealing with the medical system, and

coping. It is not my intent for these themes to override the learnings that come out of reading each story as a whole. Rather, it is my hope that in presenting themes across the narratives I am opening up a discussion about female sexual pain and its implications for both members of an intimate relationship.

### **Adapting to a Different Sexual Relationship**

All of the participants discussed changes in the sexual domain of their intimate relationship and their experience of adapting or struggling to adapt. I will refer to the sexual domain of their intimate relationship as the “sexual relationship.” Aspects of the sexual relationship had to be adapted in order to accommodate the sexual pain. Participants spoke of the resulting relationship as different from their perception of a “normal” sexual relationship.

Participants discussed struggles with the changes in sexual relations, in general and specific ways. Generally, the sexual relationship was described by most, but not all, as unsatisfactory. Participants compared their sex lives to others and expressed regret and unfairness at not being able to have a “normal” sexual relationship with their loved one. Jane discussed her feelings about her sexual relationship in this excerpt:

I'm angry that we can't seem to have a normal sexual relationship. I mean we're getting married and I don't want to have sex. Like EVER. There are a million other things I'd rather do than have sex. I feel like we're sixty and we've been married thirty years and people just don't have sex anymore. And you know we're in our early twenties so this shouldn't be happening!

Nicole, who is 37 years old and in a 4-year marriage, echoed Jane's sentiments that she is living the married life of a much older couple. She stated

“...it feels like I am a 90-year old woman who has been married for 70 years...We’re like this very old couple who doesn’t have sex often anymore and who almost has to have separate bedrooms.” Whereas these couples described an overall struggle with their sexual relationship, not everyone did. Alex and Yasmin emphasized their satisfaction with their sexual relationship in their narratives, and Michael generally spoke in positive terms about his sexual relationship.

In addition to general descriptions of the sexual relationship, the participants spoke of specific ways that sexual pain had impacted their sexual relationship. The participants often experienced struggles in adapting to these changes.

The women described the physical pain they experienced during sex. The pain was felt as a burning, cutting, cramping, or like they had been punched. It was experienced differently by different participants. Pain was experienced during intercourse, after intercourse, and with clitoral stimulation. The pain was very challenging for the women, and was described as the reason that they had no sexual desire. Nicole explained, “How would you feel if every time you had sex someone tried to cut your leg off? You’d never want to have sex again. So it’s the same thing with me.”

Given the women’s lack of sexual desire due to the pain, and the men’s continued interest in sex, another commonly identified struggle was the awkward script they followed in communicating when sex would take place. Jane used the analogy of a “game” to describe the interaction that usually takes place for her and Aiden:

It's this whole game that we play. Sometimes I decide to initiate...but Aiden knows that if I initiate I'm just doing it to please him...so sometimes I manipulate it so that he feels like he's the one initiating it...there are all kinds of psychological things going on.

The difficulties in beginning a sexual exchange meant that oftentimes sex did not take place, even if one person desired it. Most of the men talked about not having enough sex with their partner, while the women said they had sex more often than they desired.

Common among the women was the experience of feeling guilty for not being able to provide regular sex to their intimate partner. The women expressed more worry about their partner's lack of sexual fulfillment than about their own.

Others talked about the nature of sex as a two-part process. Yasmin stated,

Because certain parts of sex are about you and certain others are more about your partner. So depending on where we are in that sometimes I don't want to take that moment away from my partner just because I have pain. So sometimes I struggle with where to draw the line. Am I more important right now, or are you more important right now?

Although the women discussed believing that they should not have to have painful sex, the women also disclosed continuing to engage in painful sex.

Reasons for continuing included believing that their partner "deserved it for being good," they felt it was their "wifely duty," or because "girlfriends provide sex."

The women described tension between their beliefs in women's right not to have

to undergo painful sex and their continued engagement in painful sex. Sara, in particular, emphasized this tension:

I thought I would lose him if I didn't provide sex. That I thought this way blows my mind because I was raised by a feminist mother, and I consider myself a feminist. The last thing I expected of myself was a belief that I had to have sex with a guy to hold onto him.

Also common among the narratives was the idea for both men and women that sexual pain had changed the "culture" of sex from a spontaneous, carefree, relaxing experience to a more measured, careful, formal exchange. Michael discussed the implications of taking precautionary measures against bladder infections, such as wearing a condom and making sure Beth urinated immediately after sex: "It really changed the feel of our sex life. It was no longer about taking it easy and enjoying the aftermath. It was about infection prevention." Alex also discussed the impact of the sexual pain on his ability to connect intimately with Yasmin, in the beginning: "She experienced the pain right after we had sex, which was a time when I would normally feel close and intimate with her. But the times she had pain, she would leave right then. So it sort of took away some of those intimate moments from us."

The men described being cautious and gentle in touching and engaging in intercourse so as not to set off pain in the women. T.J. illustrated this process with an analogy: "I'm always trying to be gentle and delicate, as if I'm handling a piece of thin glass and the wind's blowing and I don't want it to break." For Jane, the constant emphasis on preventing pain hindered her ability to feel intimate with

Aiden. She stated, "It feels like we're not being very intimate when we're having sex... there are always apologies in our sexual relations... he's like, 'Am I hurting you? Are you ok? AM I HURTING YOU?' And that just kills whatever moment we might have been having."

Sex within the intimate relationship changed for all of the participants with the development of sexual pain. Whereas these changes were necessary to prevent or decrease pain, they nonetheless were described by the participants as disruptive to the flow of the sexual relationship. Participants generally had difficulties adapting to the various changes. Furthermore, the changes contributed to some of the participants' perceptions of their sexual relationship with their partner as not "normal."

### **Shifts in Sexual Self-View**

The participants' narratives illustrated many ways in which sexual pain impacted their sexual self-view. Many of the participants, particularly the males, spoke of ways that sexual pain changed their sense of themselves as sexually competent. The women also spoke of how it made them feel less as a woman, and more deviant.

For some of the men and women, their sexual competence was closely connected to their ability to have pain-free sex. All of the men expressed feeling sexually inadequate because their partners had ongoing sexual pain. For Michael and T.J., the sexual incompetence was a significant change in their sexual identities. They had always had a strong interest in sex and had been told by previous lovers that they were exceptionally skillful lovers. Their interest in sex

was not having an orgasm, but in creating pleasure for their partner. Michael and T.J. shared that when their partners began to experience pain with sex, and associated loss in sexual desire, the men experienced confusion about their sexual competence and self-esteem. For T.J., the change in Nicole's sexual interest was so dramatic that at first he wondered if "there was someone else in the relationship." When Nicole denied this, and the doctors insisted nothing was wrong with Nicole, T.J. began feeling sexually "inadequate." In Michael's case, when Beth decided to end their relationship, she spoke about desiring a fresh start and a possibility for pain-free sex. In his narrative, Michael expressed the impact Beth's words had on him:

I've always felt that my strongest competency is in the realms of intimacy and sex...so when Beth said 'I can't have good sex with you'...I was absolutely crushed. It was the ultimate blow. My whole sexual self and self-esteem were like basically pulverized.

These two men experienced the loss of sexual competency and self-esteem as a result of their partner's sexual pain and subsequent lack of sexual desire.

Aiden's experience differed from the other two male participants. He had never had a sexual partner before Jane, and had never believed himself to be sexually competent. He described thinking that he was such a bad lover from the start that he accepted Jane's pain as a result of his incompetence: "I thought it was me being terrible in bed. It seems like a simple task! But clearly I'm doing it so poorly it hurts." The experience was not a loss in competence, but a confirmation of a belief in his sexual incompetence.



The men's narratives also shed light on how the sexual pain impacted their experience of their perception of bodily desires. Aiden described putting such guilt on himself for his part in Jane's pain that he eventually could not even experience sexual desire without also feeling intense guilt.

There was so much guilt. I felt like obviously I wanted to have sex and she told me it was okay, like it wasn't that bad, but I didn't really buy it. I felt awful because I was inflicting pain on the person that I love more than anyone else...asking her to have sex was like saying, "Hey, Honey, can I punch you in the face?" It's just like, "No, of course she doesn't want to have sex with you, you fucking idiot, you hurt her".

Alex also talked about negative feelings, ones close to guilt, in the beginning of this relationship:

In the beginning there was this idea in my head like maybe I was doing something to hurt her. So I had feelings about it. It wasn't exactly guilt, because I think I believed her when she said it had happened before and wasn't a big deal. But in the back of my head, I had some sense of feeling responsible.

Michael also expressed an impact of the sexual pain on his experiences of sexual desire and behavior. Michael said that after the break up, whenever he engaged in sexual behavior, he would immediately remember the loss of Beth and the sexual incompetence he felt, and would imagine that she was with another man. The feelings of loss, incompetence, and jealousy were strong enough to convince Michael to become celibate for over a year.

The women also described ways in which their sexual competency and self-esteem were impacted by their sexual pain. For Jane, the sexual pain brought about a major shift in her sense of sexual competency. She had been brought up to understand sex and puberty, and had expected to become a sexually competent adult. When her pain developed her sexual identity shifted and she no longer felt sexually competent.

Sara had grown up with good self-esteem. When she began experiencing recurring pain with sex, however, she began to feel shame and decreased self-esteem. She said, "I felt very ashamed that I wasn't capable of having fantastic sex like everyone else in the world." For over a year she felt like she "wasn't a woman or a good partner" because she wasn't "capable" of having good sex. Now in treatment, Sara's view of herself has shifted to a more positive perspective: "I'm feeling like I'm actually able to be a successful person. It's weird. I'm feeling like I can still be a good woman, girlfriend, and person now, without providing sex to my partner. I'm still working on it though."

Sara stated that the sexual pain made her feel like she "wasn't a woman" and the other women echoed her sentiment. Nicole stated that she had lost her "flirty" side because of her sexual pain. She no longer felt free to flirt with T.J. for fear that it would lead to intercourse. Jane stated that the pain made her less and less interested in sex and that she had become "almost asexual." However, she did not feel like all of her sensuality was gone. She held onto her sense of being a sensual woman through activities like getting dressed up and going to dance class. Infertility issues also had implications for one participant's sense of womanliness. On learning that her condition might mean

difficulties with conceiving, Sara said, "I felt like less of a woman because I might not be able to provide Rob with a child."

Both men and women also discussed the impact of the sexual pain on their sense of self as sexually different or deviant from others. Some of the participants described feeling isolated or different because of their situation with sexual pain. Sara described not being able to disclose her experience to anyone, including her partner and close friends, because of the intense shame she felt. Even though she is now able to discuss it with some of her friends, she is not finding that others can really understand or relate: "I'm starting to realize that I'm not completely alone in this. However, it still feels like if anyone else is experiencing this that they are too far away. I haven't spoken to anyone yet who feels my kind of pain." Jane also discussed feeling very alone and unique, especially when her gynecologist had never even seen her condition before.

Sara and Jane also discussed feeling "deviant" from their friends and North American society. Sara stated, "Admitting that sex is horrible for me, in this society where sex is so valued, is shaming and isolating." When Jane's friends would offer sex tips, she felt angry and upset because it implied a belief that Jane was responsible for her poor sex life. In describing why her friends made those suggestions, Jane stated, "People view me as someone who is deviant, who doesn't really follow along... accused of somehow putting up a barrier to their own enjoyment."

For the men, being able to discuss sexual pain with their friends was a challenge. Aiden described how he would just go along with conversations on sex with his friends,

not letting on that he was experiencing difficulty. T.J. also stated that this is not something he is able to discuss with his male friends. He said, “This is definitely not a beat around the bush subject, and I don’t get too much opportunity to talk about this. It’s not talked about openly.”

In many ways, sexual pain altered the participants’ sense of their sexual selves. Most of the participants were impacted by feelings of sexual incompetence, low self-esteem, and feelings of guilt, of being different, and of feeling isolated. These shifts in sexual identity had implications for the sexual relationship, as described in the first theme.

### **Challenges in Creating a Family**

Many of the participants discussed aspirations to create a family. They had always assumed they would be able to have children. The severity of pain during intercourse, however, limited their ability to conceive. Jane described visualizing an attempt to conceive with Aiden in the future:

It gets me thinking because we are getting married next year. And you know, I think it’s going to be in five years that we would like kids. And then I think, ‘Oh my god, I have to have sex to have kids!’ And here I am already wondering if we can just use some kind of contraption, like ejaculate into a turkey baster and put that up?”

Nicole explained the difficulty in trying to conceive when sex is painful: “When I ovulate my pain gets worse. So I try to avoid sex at that time. But it really screws up trying to have children because if you’re not having sex at the right moment it doesn’t work.”

For Sara and Nicole, the challenges in conceiving with sexual pain were further complicated due to their diagnosis of endometriosis, which has implications for fertility. Sara stated:

The diagnosis of endometriosis also meant that my ability to have babies might be lessened. That news affected me deeply. I had always thought I would have children. I felt like less of a woman because I might not be able to provide Rob a child. It just made this whole sexual pain experience even worse.

Nicole talked about the disappointment in not being able to live out her dreams with T.J.: "The pain is also impacting mine and T.J.'s dream of children...we'd planned that from the first day we got married. And here we are four years later and no children." T.J. echoed her disappointment: "Within the first month of our meeting I said I wanted kids. And she said she wasn't having kids without the committed relationship. And we built our life on that. . . But the complications have meant fertility problems."

The struggle with having painful sex and trying to conceive was even further exacerbated for Nicole and T.J. when doctors stated that that two treatment choices for endometriosis include becoming pregnant or undergoing a partial hysterectomy. Both could potentially alleviate Nicole's endometriosis symptoms, including sexual pain. T.J.'s hope that a pregnancy could both relieve Nicole's pain and allow them to become parents was clear in his narrative. Nicole's narrative, however, revealed more ambivalence and confusion. In the beginning of her narrative, she emphasized her desire to begin the parenting stage with T.J., but by the end of the story she sounded more hopeful about reaching menopause so she could abandon hopes of conceiving, and undergo a hysterectomy to relieve

the pain: "It's almost like I'm waiting for menopause to come along. Sometimes I can't wait for it to come because maybe that will bring me some relief."

As evidenced in these excerpts, creating a family was an important dream for many of the participants, and sexual pain and its underlying conditions complicated the achievement of that dream. Participants managed this challenge by visualizing alternate methods of conceiving or undergoing fertility treatments. In some cases the participants had to choose between a treatment for sexual pain and keeping open the possibility of having children.

### **Difficulties in Dealing with the Medical System**

All of the participants spoke of their interactions with medical professionals, treatments, and the health care system in their narratives. A commonly expressed feeling was frustration with treatments that had no effect or a worsening effect on the women's sexual pain. Nicole and Sara both described how their sexual pain worsened after receiving a surgery that was supposed to help. Jane spoke about receiving suggestions such as wearing white cotton underwear and stretching the area, which did not alleviate the pain. Michael spoke of the frustration he felt when doctors prescribed antibiotics and performed invasive surgeries and did not teach him how to prevent the infections. He stated, "...I felt like if we had gotten a good doctor, someone that knew what was going on, that he could have prevented the infections from destroying our relationship."

Nicole based a large part of her story on the doctor she blames for her pain. She described in detail her trust in him, the surgery he conducted that caused her pain, and his ultimate disappearance. Her faith in doctors was temporarily

restored when she was referred to a specialist. However, once again, Nicole became disappointed when that “miracle doctor’s” procedure did not work. Her lack of trust in the ability of doctors is evident in this excerpt: “I think if you have this problem you should do as much research as you can. Learn about the doctor. Don’t just believe anything he or she says.”

T.J. described a similar shattering of his belief in the ability of doctors. When the surgery conducted by the specialist did not change Nicole’s pain during sex, T.J. said, “It was like a slap in the face...I thought the medical staff was more advanced than that.” T.J. and Nicole have spent many years as patients in the care of medical professionals as a result of sexual pain, endometriosis, and infertility. This experience has tainted their belief in doctors and the medical system.

For Aiden and Jane, although help had been sought for the sexual pain two years ago, they had yet to receive any treatment because of long wait times. However, both had resigned themselves to the fact that the medical system was slow. Aiden stated, “It’s taking two years, a long time, but that’s the system. It’s unfortunate, but nothing can really be done about it.” Still at the beginning of the process of receiving treatment, Aiden expressed a belief that a medical procedure would cure Jane’s pain: “Maybe the gynecologist will have some kind of wonder drug and maybe everything will be well and good.”

For her part, Jane expressed doubt that a medical intervention could solve everything for her and Aiden:

Apparently there is a surgery that I can do that might alleviate the pain...but I don’t know. I just don’t think it would be that easy. For them

to say, "Here, now we're going to fix you physically and you're going to be right as rain and you're going to have orgasms coming out your ears," I just don't think that's realistic.

Jane went on to explain that the problem had penetrated their relationship to the point that a medical intervention would need to be combined with sex therapy or couples counselling.

All of the women who had sought medical help disclosed being told or having it implied by health professionals that their pain was "in their head." Nicole opted to ask for a new doctor when her doctor would not medically assess or treat her pain. Sara's narrative primarily focused on the impact of multiple doctors' invalidation of her pain. She doubted herself, experienced a loss in self-esteem, and chose to delay treatment. She stated, "It seemed like everyone was making this big thing about something being wrong with my head. Their disbelief in my pain caused me to doubt myself. I also silenced myself." Sara and Jane both spoke of the need for doctors to be more sensitive about their choice of words, as they could have an impact on their patients' self-esteem. Sara said, "If that gynecologist had just phrased her words differently and said, 'It sounds like you're really hurting, so let's see what it looks like,' I would have felt okay about myself."

The participants' narratives highlighted the difficulties in interacting with professionals in the health care system. Attempts to communicate their pain often resulted in feelings of self-doubt, invalidation, aloneness, or frustration. Participants also struggled with treatments and wait times for specialized services.



## **Coping**

The last theme that was salient in all of the participant's stories was the experience of coping. All of the participants spoke of sexual pain as a stressor on themselves and their relationships. Jane was the only participant who described the pain as "strengthening" her relationship; however, she also spoke of the damage it had caused. The participants described ways they attempted to manage the pain and the various impacts of the pain.

All of the participants but one expressed an ability to cope. Nicole was the exception. She stated: "To me, this problem was created by someone else. And yet I'm the one living it. I wonder where the sense is in that? I can't deal with the pain; I have no way to manage it." A crucial difference between her narrative and others' narratives was her emphasis on the pain being "done to her." For Nicole, the pain was uncontrollable. Sara's statements support this analysis. She stated, "I think I'm feeling stronger because I'm finally dealing with the pain. Before it felt like it was happening to me, and now I'm saying I'm going to be in control." Sara appears to have moved past the stage of feeling no control and now has a more active role in her well-being. Yasmin, who expressed coping very well with the pain stated, "I feel like I can manage the pain because it is always contained, and because I have some control over it."

Apart from Nicole, the participants discussed ways that they had tried to cope with sexual pain. Some of these methods were sometimes regretted and described as unhelpful. Others were stated to be helpful, and were recommended to other couples experiencing a similar phenomenon.

Strategies that were deemed unhelpful often involved silently coping on one's own. For example, blaming self for desiring sex or for not being able to provide sex was named as an unhelpful coping strategy. This resulted in further feelings of shame, guilt and isolation, and no positive feelings. However, this reaction was common in the beginning, before help had been sought, and a medical explanation found.

Decreasing communication and "openness" between the partners was also identified as unhelpful. Sara's decision to not disclose her pain to her partner ultimately put a strain on her relationship. Similarly, T.J. felt confused when Nicole did not fully explain her pain, and began to wonder if "someone else was in the relationship."

Although it was sometimes helpful for the participants to re-frame their pain problem as small, it was not helpful to ignore it altogether. This usually resulted in continued and exacerbated pain with sex. Jane and Sara disclosed feeling that if they had addressed their pain earlier, they could have more quickly found relief. Michael stated repeatedly that if he had addressed his partner's sexual pain problem earlier and more seriously, they might still be together.

The last coping strategy that was unhelpful was blindly relying on doctors, without learning about their conditions and treatments. Michael regretted allowing the doctors to continually prescribe his former girlfriend antibiotics, and for not researching the surgery before it was done. Nicole also expressed regret at not understanding the surgeries before they were conducted. Going into doctors' appointments and treatments unprepared left participants feeling disappointed and

sometimes in worse pain than when they began. These experiences often led the participants to become more active in their treatment process.

Many helpful ways of coping were identified by the participants (see Table 3). One of the most common effective strategies was conducting research about sexual pain, sexual behavior, treatments, and medical professionals. Participants named information gathering as a very important way of coping. They appreciated when medical professionals directed them to good websites and expressed the desire for more of that. The internet helped them prepare for doctors' appointments and treatments, and was also integral in helping them through their feelings of isolation and inadequacy. Michael stated, "I read a lot of accounts of women with bladder infections...their stories validated how I felt about our situation." A couple of the participants also identified sex conventions, books, and sexuality shops as helpful resources.

Another strategy that helped all the couples was incorporating more acts of intimacy into their lives. T.J. stated that they always went to bed cuddling. Jane and Aiden both emphasized in their stories that they did a lot of cuddling and were physically affectionate with each other, if not in the way that "couples are supposed to be."

Another important strategy that was voiced by many of the participants was reframing the problem so it was not so ominous or negative. One way that Jane and Aiden accomplished this was by incorporating humor into their discussions about sex. Jane exclaimed, "I made a joke last night that we're kind of born again celibate people! I think if we were dwelling on it too much it would be

too serious and too depressing all the time.” Alex used reframing to take the pain less personally: “The main way that I’ve helped manage with this experience is just taking it less personally. Both the pain and the being cut off. Instead of something that would stop us from being close after sex it just became part of the routine.” T.J. and Nicole used externalizing as a way to reframe the problem as something outside of them. This served to remove blame from self and partner. Further, it helped them remember that other people were dealing with the problem too. T.J. stated, “The problem is real. It’s now. It does exist. It’s a sickness. And it’s not something affecting only us.”

Seeking professional help in the form of counselling was a strategy utilized by many of the participants. Nicole and T.J. both disclosed that they had been separated recently for a few months and that the sexual pain played a large role in that decision. At the time of the interview they had been to a couples’ counsellor several times to try to stay together. Sara and her partner had started couples sex therapy to help them work through the sexual implications of her sexual pain. Jane spoke of her interest in trying sex therapy or couples counselling. Her inaction to seek professional help lay in her feelings of uncertainty towards what counselling would look like.

The main reason the participants found couples counselling to be helpful was that it enabled the partners to be more open with each other. As a result, they could share thoughts and feelings that they had about the sexual pain. Sara also identified the learning she gained from counselling. Her therapist had helped her and her partner challenge beliefs about sex based on myth and had provided

education about the reality of male sexuality. Sara also identified the counsellor's validation of the reality of her pain as important in her healing process: "That was huge for me. Up until that point I hadn't been able to trust myself. Her words helped me believe myself."

Finding social support also helped the participants to cope effectively. For example, having at least one person other than their partner to confide in about their challenges with sexual pain was seen as helpful. For the men, this was a difficult task. It was not common for them to find others who spoke of sexual pain. When they could not connect to someone, they found that a counsellor or the internet could help fill that need. For Jane, it was the opposite problem. At one point, everyone seemed to know about her sexual pain and it was not helpful for her. She learned that it was not always helpful to disclose, and now shares her pain experiences only with those very close to her.

By using the strategies discussed above, both members of the couple were better able to cope with the women's sexual pain and its impact on them and their relationship. There were some strategies, however, that were only described by the female participants as helpful. Others were only described by the male participants as helpful.

The women discussed many ways that they were able to feel more empowered and in control of their pain. The women felt empowered at learning about their conditions and at how these conditions interacted with their bodies. Women also spoke of being able to allow themselves to become fully aroused, almost to the point of climax, before allowing their partners to penetrate them, as

a way to reduce the pain. For two of the women, putting pressure on their stomachs also helped to relieve the pain once it had begun. Some women also found it helpful to monitor times when their pain worsened (e.g., during times of stress and during ovulation) and to avoid sex at those times. In addition, some women tried to cope by being open-minded to their partner's suggestions for alternate sexual behaviors (e.g., anal sex). All of the women named patience and understanding with themselves as important. In addition, all of the women discussed the importance of validating themselves, of believing that their pain was real.

The men also voiced some strategies that were helpful for them. Two men named strategies that helped them remain committed and faithful in relationships in which sex had decreased. One man used will power, a reliance on his wedding vows, and prayer to stay faithful and committed. Another man had viewed marriage as based on love, not sex, and that helped him stay content. These men also disclosed using masturbation and hobbies to relieve their sexual tension.

The men also spoke of ways that they could help their partners cope with sexual pain. The men initiated sex less often, or not at all. It was particularly helpful if they avoided initiating sex when the partner was already experiencing pain or illness from a previous bladder infection, surgery, or sexual experience. The men altered sex so it was gentler and/or tried less painful sexual options to vaginal intercourse such as anal sex. T.J. spoke of trying to include Nicole in his masturbation, by letting her know he was thinking of her. The men found it helpful to their partners and to themselves if they accompanied their partners to

medical appointments. Sometimes they would also take part in the medical treatments, such as gynecologist appointments, fertility appointments, and couples counselling. Two of the men also discussed helping by contributing to household tasks when a partner was in recovery from sex, illness, or treatments.

The majority of the participants were able to find ways of coping with sexual pain. Their ability may have been based on their ability to feel “in control” of the pain. Some unhelpful strategies were identified. Many more helpful ones were also identified. Women and men used many of the same strategies, but also used strategies that differed from their partner.

### **Summary**

In my analysis of the participants’ narratives of their experiences with sexual pain, I found five themes that were salient across the narratives. My interpretation of these five themes—adapting to a different sexual relationship, shifts in sexual self-view, challenges to creating a family, difficulties with the medical system, and coping with sexual pain—were described in this section. Most of the themes highlighted the struggles, challenges, and difficulties in living with sexual pain in an intimate relationship. However, the final theme shed light on the resilience, creativity, and strength of the participants to seek solutions. Strategies were described by men and women that served to lessen the negative impact of sexual pain on themselves and their relationships. These results reflect hopeful outcomes for some couples experiencing female sexual pain in their intimate relationship

## CHAPTER 5: DISCUSSION

In this section I describe the findings in terms of the literature. First, I discuss how the findings of this study fit with psychological theory and research literature. Second, I discuss implications of the findings for counselling psychologists and other health professionals. Third, I discuss the implications of the findings for future research. Last, I describe strengths and limitations of the study.

### **Findings in Relation to Psychological Theory**

This study was informed by three theories: Daniluk's (1993) model on the development of a sexual self-view, biopsychosocial perspectives on pain (Engel, 1977), and cognitive mediation theory of the couple relationship (Epstein, Schlesinger, & Dryden, 1988). The findings of the study provided support for each of these theories. Sexual pain experiences impacted the participants' sexual self-views, in negative ways, lending support to Daniluk's theory.

Biopsychosocial models of pain (Engel, 1977) were also supported. Women's experiences with sexual pain were influenced by others. Specifically, health professionals and intimate partners had a significant impact on women's sexual pain experiences. For example, women's sense of self-esteem depended in part on whether health professionals expressed the belief that the women's pain was real. Women's sexual pain experiences also impacted others, specifically their intimate partners. For example, the partners were deeply affected when sex was pleasurable for them, but painful for their partner.

Finally, the women's behaviors towards their partners, particularly their declining pursuance of sex, were appraised by the partners in ways that impacted the partners' thoughts (e.g., whether someone else was in the relationship), emotions (e.g., guilt), and



behaviors (e.g., initiating less or clinging more). These partner reactions were appraised by women in ways that produced thoughts (e.g., I'm not a good partner), emotions (e.g., guilt), and behaviors (providing sex even though it was painful). These findings provide support for cognitive-behavioral theory of couple relationships (Epstein, Schlesinger, & Dryden, 1988). In the next section, I will describe in more detail how the findings fit with research.

### **Findings in Relation to Research**

Five across-narrative themes of couples' experiences of female sexual pain in the context of an intimate relationship were interpreted in this study. Following is a discussion of how each theme fits with the current research literature on female sexual pain. As will be discussed, the themes are generally consistent with current literature. However, in some cases there is no relevant sexual pain research. In these cases, the findings are compared to research in related fields. Finally, in some cases the findings of this study differ from past research. Speculation on reasons for these differences is provided.

### **Adapting to a Different Sexual Relationship**

The women and men in the present study spoke of the experience of adapting to changes in their sexual relationship. Many of the female participants in this study expressed struggles in their sexual relationship. This finding is consistent with existing quantitative research investigating sexual pain in which women with dyspareunia or vulvar vestibulitis reported higher levels of sexual difficulties (Meana, Binik, Khalife, &

Cohen, 1997), and lower levels of sexual desire and sexual satisfaction (Brotto, Basson, & Gehring, 2003; Gates & Galask, 2001).

The women in this study also spoke about a lack of sexual desire. Given their descriptions of sexual pain, their disinterest in sex was understandable. On the one hand, the women generally accepted their lack of sexual desire as reasonable, given their pain. At the same time, however, the women expressed feeling “abnormal” due to their low sexual desire, and wished for a procedure that could help “fix” their desire. Their partners also expressed hope that a pharmaceutical intervention could increase their partner’s sexual desire.

The finding that some of the participants found their low sexual desire abnormal may reflect the post-Viagra trend in sex research (Leiblum, 2007) to conceptualize low sexual desire in pre-menopausal women as medically “dysfunctional” and “fixable” through pharmaceutical means. Women may expect that high sexual desire in women is the norm. Counsellors could normalize their experience by educating them on prevalence of low sexual desire in coupled women and suggesting that findings ways to have comfortable and pleasurable sexual experiences with their partner could help improve their desire (McCarthy, 2004).

The medicalized view of female sexuality also suggests that if all the working parts are in order, then enjoyable sex should be achievable. Feminist sex researchers (e.g., Tiefer, 2002) have criticized this assumption and highlighted the fact that many relational, social and political factors hinder the experience of enjoyable sex (Tiefer). One participant in the study commented on this point. After experiencing pain with her

partner for six years she believed that the pain had produced problems in her relationship. She stated,

Apparently there is a surgery that I can do that might alleviate the pain. It would involve cutting the skin over the clitoris. But I don't know. I just don't think it would be that easy. For them to say, "Here, now we're gonna fix you physically and you're gonna be right as rain and you're gonna have orgasms coming out your ears," I just don't think that's realistic. . . there are some problems that won't necessarily disappear with a surgery. I think there would be other work that would need to be done. Perhaps a sex therapist would be able to help us.

One empirical study on sexual pain found improved treatment outcomes for surgical intervention when it was combined with sex therapy (Bergeron et al., as cited in Davis & Reissing, 2007).

The women in this study held quite firm views that women with sexual pain should not continue engaging in painful sex behaviors. Jane illustrated this belief by contrasting herself with a friend who does not tell her boyfriend about her sexual pain and continues to engage in painful sex. However, despite their general attitude that women with sexual pain should not engage in painful sex, the women in this study disclosed occasionally "giving in" to painful sex with their partner. In Sara's case, she shared that she often had painful sex with her partner. The women suggested several beliefs they held that could explain this behavior. The beliefs were: providing sex is a "wifely duty," "giving sexual favors is part of being a good girlfriend," and "I will lose him if I don't provide sex regularly." Generally, these beliefs speak to the women's interest in fulfilling their role as intimate partner and in maintaining their relationship.

In a theoretical paper on the painful sexual experiences of women with interstitial cystitis, McCormick (1999) stated that "traditional sex-role socialization teaches heterosexual women to be more concerned with male pleasure than their own pleasure" (p. 12). McCormick suggested that women continue to engage in painful sex regularly out of guilt, duty, or fear of rejection. The findings of this study support her claims. Feminist researchers in women's psychological development (e.g., Gilligan, 1993; Jordan, 1991) have stated that women's main psychological task, historically, has been to maintain connection with others through caring and interdependency. Women today may continue to hold the belief that it is their duty to engage in sex as a means of staying connected to their partner. Future research could investigate the disparity between women's attitudes about painful sex, and women's continued engagement in painful sex in more depth.

Some of the men in this study struggled with the reduction in frequency of sex in their intimate relationship. This finding is supported by research that indicates that, on average, men in intimate relationships desire sex frequently (Klusmann, 2002). In a meta-analysis on gender differences in sexuality, Vohs, Catanese, and Baumeister (2004) concluded that men have a stronger sex drive than women, with men desiring and having more frequent and varied sex relative to women. The findings indicate that sexual pain may be one reason why women's sex drives may be lower than their male counterparts.

The male participants and one female participant described their struggle in the sexual relationship as involving adaptation to how it was initiated, frequency of sex, the length and spontaneity of sex, sexual behaviors that were sanctioned or allowed, and changes in the aftermath of sex. These changes in sexual behaviors led to participants'

perception of their sex lives as not “normal.” These findings support Conner’s (2005) findings in her phenomenological study with couples in which the female partner has vulvar vestibulitis. The participants in her study expressed struggles with adjusting to the women initiating sex, women directing sex, and a lack of spontaneity of sex. Her participants also described their new behaviors as not the “normal or natural way to have sex” (p. 17). Similar findings in the present study underscore the importance of helping couples accept unchangeable parts of their sexual relationship and at the same time improve their sex lives in meaningful ways.

### **Shifts in Sexual Self-View**

The women in this study discussed a loss of the sensual, womanly side of them, as a result of sexual pain. Whereas Jane felt that she could still express her sensuality in ways other than sexual (e.g., through dance), Nicole felt reluctant about expressing her sensual side for fear that her husband would take it as a signal that she desired sex. Women’s loss of “womanliness” is consistent with Theve-Gibbons’s (2000) study in which women with vulvodynia (chronic vaginal pain) expressed a loss of their “womanhood” and “femininity.” This finding underscores the importance of working with women to explore their ideas of femininity, womanliness and sensuality and to challenge ideas that prohibit a healthy sexual self-view. This finding provides support for Daniluk’s (2003) theory that one’s sexual self-view as sexual or womanly is impacted by sexual experiences.

In past studies investigating women with sexual pain, a loss in self-esteem has been reported (e.g., Conner, 2005; Theve-Gibbons, 2000). Interestingly, none of the women in the sample, except for Sara, described a loss in self-esteem as a result of their

pain. This finding may be explained by the ability of most of the women in the present study to seek and receive a medical diagnosis for their sexual pain, and also to have their pain believed and attended to by their partners. Research has found women with a medical basis for their sexual pain to report fewer psychological difficulties than women with no physical abnormality found for their pain (Meana, Binik, Khalife, & Cohen, 1999).

In Sara's case, she was told by two medical professionals that her pain may not be real. As well, because Sara did not share her pain experiences with anyone including her partner until over a year and a half after the pain began, she did not experience validation of her pain by non-professional others. In her narrative, she described the serious impact of her inability to experience validation of her pain on her self-esteem. This finding provides support for a biopsychosocial model of pain which posits that interactions with others, such as medical professionals, can impact an individual's experience of pain. Howell (1994) developed a theory in which she states that women with chronic pain require validation by others in order to validate themselves, and eventually proceed along the pathway of recovery. The findings of this study provide support for Howell's theory.

In the present study, it was the men who emphasized a loss of sexual competency in their narratives. The men in this study told tales of feeling sexually inadequate and incompetent as a result of their partner's sexual pain and subsequent loss of interest in sex. For some of the men, their sexual competency was a large part of their sexual self-view, and the subsequent loss had a damaging effect on their sense of physical attractiveness and self-esteem. The only other study that has investigated the partners'

experiences of female painful sex is Conner's (2005) study, and the men in her study did not disclose experiences of loss of sexual competency and self-esteem.

The difference in findings may be explained by the differing data collection methods. In this study, separate interviews for both members of the couple were conducted to give each partner the privacy necessary to tell their story. I chose this method based on my pilot interview in which I observed individuals having difficulty telling their story in front of a partner. Connor interviewed the couple together, and then, individually, asked individual participants if anything needed to be added to their joint interview. It is possible that in my study, men were more inclined to disclose the impact of their partner's sexual pain on their own sexual self-view because they were interviewed individually. Alternatively, difference in results may also be a result of the small sample size of the present study.

Although no other studies have illuminated men's sense of inadequacy in studies on sexual pain, Aubin and Heiman (2004) made observations from clinical experience of the impact of women's low sexual desire on their partner. They stated, "Cognitively, the men will look for inadequacies in their sexual abilities and conclude that if their partner does not desire them sexually, it must be because they have not succeeded in fulfilling them sexually" (p. 503). The authors go on to say that although this may be true at times, the majority of women with low sexual desire do not identify their partner's skills as a causal factor.

The finding of men's experiences of sexual incompetency in the face of their partner's sexual pain and subsequent loss of sexual desire supports biopsychosocial models of pain which propose that an individual's experience of pain will impact others

such as significant others. The findings also support cognitive-behavioral theories on couple relationships which posit that behavior in one member will influence cognitions, emotions, and behavior in the other member, in a cyclical manner (Epstein, Schlesinger, & Dryden, 1988). Finally, the finding provides support for Daniluk's (2003) theory that one's sexual self-view is impacted by sexual experiences. Persistent feelings of sexual incompetency may produce sexual problems such as erectile difficulties (Barry, 2002). Future studies on sexual pain need to take the partner's experience to help confirm and clarify this finding in the present study.

### **Challenges in Creating a Family**

Some of the couples in the study discussed a desire to create a family. Women and men both discussed challenges in their ability to conceive a child through intercourse because of the woman's sexual pain, and also because of underlying conditions of the pain such as endometriosis. Confusion arose when plans to conceive conflicted with procedures that could reduce sexual pain (e.g., a hysterectomy to alleviate sexual pain due to endometriosis) but render complications for conceiving. No research to date has uncovered challenges with conceiving a child as a major implication for couples experiencing female sexual pain. However, challenges with conceiving abound in studies on couples in which one member of the couple has an injury or disability that has implications for conceiving through intercourse (e.g., Ducharme, 2006). Further research needs to address this issue in couples in which the female experiences sexual pain in order to understand and address the couples' needs.



### **Difficulties in Dealing with the Medical System**

An important finding in this study was the experience of having difficulties in dealing with the medical system. Women in this study discussed having their pain unbelieved by doctors, requiring multiple doctors and referrals, experiencing negative side effects of surgeries, and being given long wait-times for specialized services. These findings are supported by a vast amount of qualitative research that has pointed to women's difficulties with having chronic pain conditions diagnosed and treated in a satisfactory manner (e.g., Connor, 2005; Theve-Gibbons, 2000; Werner & Malterud, 2003). Research needs to continue to address this issue by shedding light on patient experiences, but also needs to go further by giving suggestions on how to reduce women's negative medical experiences. The implications section of this study contains some tentative suggestions for counsellors and medical professionals to better meet the needs of women with sexual pain.

### **Coping**

The participants in this study spoke of the many ways they coped with sexual pain and its implications for their sexual relationship. Both men and women spoke of implementing information gathering, pain reframing, inclusion of more non-sexual intimacy acts, and the accessing of professional counselling. The women also found it helpful to learn about their bodies and to adjust timing and method of sex accordingly, to be open-minded to their partner's suggestions of alternate sexual behaviors, and to validate their own pain. The men engaged in prayer and will power to remain committed, and relied on masturbation and hobbies to release sexual tension. As well, the men tried to help their partners by initiating sex less, altering their intercourse behavior so it was

gentler, trying alternate forms of sex, accompanying their partners to medical appointments, and helping out with housework when their partners were in pain.

The participants also mentioned ways of coping that proved unhelpful. These included blaming self, ignoring the problem, decreasing communication and openness with their partner, and passively relying on doctors' ability to help them.

Given the current lack of effective treatments for sexual pain (Bergeron, Meana, Binik, & Khalife, 2003; Green & Hetherton, 2005), it makes sense that couples perceived their situation as stressful and sought cognitive and behavioral ways of coping (Lazarus & Folkman, 1984). Heiman and Aubin (2004) stated that some coping strategies serve to maintain or exacerbate sexual problems. Some of the participants' unhelpful coping strategies such as ignoring the problem or reducing communication could be seen as serving to maintain sexual pain. The abundance of helpful coping styles may reflect resiliency of the participants in their struggles with sexual pain difficulties.

### **Implications for Counselling Psychology**

It was revealed that the couples in this study who were dealing with recurrent female sexual pain experienced a lot of struggle. They had struggles adapting to changes in the sexual relationship, with shifts in their sexual self-view, with challenges in creating a family, and with difficulties in dealing with the medical system. The findings underscore the importance of these individuals to be able to cope and manage through long-term pain and transition, to re-define several aspects of self and relationship, to be able to communicate effectively with others including their partner and doctors, and to be informed about appropriate resources and medical services available to them. Counsellors

can play a valuable role in helping individuals and their partners to successfully carry out these tasks.

The following is a description of some of the roles that counsellors may fill in providing service to couples presenting with female sexual pain, and tentative suggestions for these roles, based on the findings of this study. Where appropriate, I also include throughout this section various coping strategies that were identified as useful by the participants in this study. It is hoped that the inclusion of participants' strategies will help other couples and professionals brainstorm creative ways to work through their struggles of sexual pain.

### **Couple and Sex Therapy**

Through couple and/or sex therapy, counsellors can support clients dealing with female sexual pain struggles by assisting them in their intimate and sexual relations. Pain with intercourse was difficult because intercourse was the main part of their sexual repertoire. For many couples, orgasm through vaginal intercourse is seen as the ultimate goal of sex. Feminist scholars and sex therapists have criticized this view of sex as patriarchal and pleasure-limiting (e.g., Barbach, 2001; Daniluk, 2003; McCarthy, 2002; Tiefer, 2002). Barbach (2001) suggests that intercourse as the ultimate goal of sex is one of many sexual scripts that individuals learn. The counsellor could educate clients about how sexual scripts are learned and on sexual difficulties that arise when conflicts between various sexual scripts occur (Barbach, 2001). The counsellors could then help clients explore what sexual scripts they follow and challenge those that are unhelpful or not pleasurable for the couple. The couple could be encouraged to de-emphasize their focus on intercourse, and expand their sexual repertoire to increase pleasure.

One of the participants spoke about trying to change the goal of sex for him and his partner from orgasm through intercourse, to just having an enjoyable experience. Another participant spoke about using anal sex as a major part of their sexual repertoire since both vaginal intercourse and clitoral stimulation were painful for his partner. Counsellors could share these coping strategies with their clients as examples of deconstructing the “ultimate goal of sex” and incorporating more creative and broader sexual experiences into their repertoire.

For some couples, vaginal intercourse is an important part of their sexual relationship and cannot be replaced or downplayed. For these clients, counsellors could, in consultation with medical professionals, help clients manage the pain by utilizing a pain-management approach or referring the clients to a pain-management group. Pain management for sexual pain often combines cognitive-behavioral techniques such as reframing, visualization, breathing, and relaxation training (Bergeron, Meana, Binik, & Khalife, 2003).

The participants discussed their struggles with sex becoming more scheduled and formal. Counsellors could explore the couples’ beliefs about spontaneity of couple sex and challenge beliefs based on myth. Counsellors could also explore with the couple the benefits of having scheduled sex exchanges. For example, one participant said that an advantage of scheduling sex is that she can mentally prepare for it. Scheduled sex can also lead to more frequent sex, especially for busy couples (Barbach, 2001).

Participants also struggled with role reversals (e.g., in who initiates or takes the lead in sex). These changes gave participants the sense of having a sex life that was not “normal” compared to other couples. Counsellors could help normalize feelings of

awkwardness and deviancy that may accompany the introduction of new behaviors to traditional sexual scripts (Barbach, 2001). Counsellors could also help redirect couples away from others' sex lives, and towards identifying what makes sex meaningful for them. In building meaningful sex back into their lives, counsellors could help clients create and reach achievable goals. McCarthy (2002) advises sex and couple therapists to introduce the concept of relapse prevention into their work with clients, to prevent clients from getting discouraged when they experience setbacks in achieving their goals.

The disparity in sexual desire between couple members was apparent in this study. Women with sexual pain understandably lost their interest in sex. Meanwhile, their partners maintained strong sexual desires. Counsellors could work with the couple to creatively come up with ways to have the partners' sexual desires met in the context of a relationship in which the woman experiences low desire due to pain.

All of the male participants in the sample used masturbation and hobbies as ways to reduce sexual tension. Past research revealed that when men engage in masturbation in the context of an intimate relationship, female partners may experience feelings of inadequacy or confusion (Vohs, Catanese, & Baumeister, 2004). Counsellors prevent this outcome by normalizing the inclusion of masturbation in an intimate relationship. For example, counsellors could provide education to couples citing current research such as Klusman's (2002) study in which 84% of men in an intimate relationship reported masturbating at least once a month and nearly half of the men masturbated over once a week (Klusman, 2002).

Couples can be asked to come up with their own ways of allowing the partner to have his/her sexual needs met in a way that is respectful of the other partner. One male

participant said that during masturbation he tried to be sensitive to, and inclusive of, his partner by letting her know he was thinking about her. Counsellors have an important role to play in educating, and in facilitating discussions about sex in couples whose sexual relationship is impacted by sexual pain.

### **Transition and Grief Counselling**

The findings illuminated multiple shifts and losses in the participants' lives due to sexual pain. Shifts in sexual self view were common experiences among the participants. Women experienced a loss of womanliness, men felt sexually inadequate, and both experienced a loss in competency. Counsellors can help clients through these shifts in their sexual identities by helping them explore their beliefs about themselves and challenge unhelpful beliefs.

Counsellors can explore with women their beliefs in what it means to be sensual and womanly and help them expand their definitions. Judith Daniluk suggests that women redefine sexual selves by broadening their beliefs in what constitutes sexual experiences, and by engaging in those experiences (Daniluk, 2003). Her suggestions for types of experiences that could be helpful include guided imagery exercise, movement and body work, artwork, psychodrama, and non-genital sensual sensory experiences with clothing, music, or bubble baths. Indeed, one of the participants said that she feels her sensuality returning when she gets dressed up to go out or when she is dancing.

Counsellors could help reduce feelings of inadequacy in men by normalizing the women's experiences of desiring less sex, as a result of the pain. Educating a male client about the nature of his partner's medical conditions may also help to take away their self-blame. One of the participants said that his guilt lessened when he learned there was a

medical basis for his partner's sexual pain. It is important to quickly help men through their feelings of inadequacy because persistent irrational beliefs about sexual self-esteem can result in further sexual problems (e.g., lack of sexual desire, erectile problems; McCarthy, 2004). Cognitive-behavioral treatment can help men resolve issues of sexual inadequacy that are persistent or have resulted in further sexual problems. (McCarthy, 2004).

Some men and women experienced a loss in their sense of competency. Difficulties with sex affected those who had formerly believed that sex was the "thing that they were good at," and/or tainted their image of self as a "successful person." They took the events of sexual pain as "devastating" for their sense of self. Counsellors can work with clients to challenge unhelpful beliefs such as these. It is also suggested that counsellors help clients become active participants in treatment. Many of the clients said that learning about the pain and getting treatment helped them feel active in their lives again, and helped them feel like they could be successful again.

Participants also experienced loss in their perceived ability to have biological children, and a loss in plans to become parents in the near future. Counsellors could help clients re-define their future plans. One participant spoke of her probable inability to conceive through intercourse, and had already begun visualizing alternate ways to conceive. In addition, counsellors could connect clients to specialized fertility services. Today, there are many options for couples having difficulty conceiving. Counsellors could be a valuable resource to couples exploring these options.

### **Teaching Communication Skills**

Given the sensitive and personal nature of many of the topics that couples need to discuss when dealing with sexual pain, effective communication between the couple is essential to their success. Counsellors can implement communication skills training (e.g., Gottman, 1999) to help couples remain open with and supportive of one another through their journey with sexual pain. One participant described the sexual pain as the “elephant in the room,” in her relationship. She expressed an interest in meeting with a couples counsellor to help her and her partner express themselves more openly with each other about their experiences with sexual pain.

Participants also experienced difficulties in communicating with friends and family about sexual pain. Counsellors could normalize the difficulties in speaking to close ones about topics that are considered “taboo.” Counsellors could help clients identify safe people to speak to about their pain, and could role play scenarios that could come up in their interactions with others.

In addition, participants spoke of difficulties in communicating with medical professionals. Counsellors need to help clients increase their ability to communicate effectively with medical professionals. Counsellors could provide assertiveness training, including role-playing, to help prepare clients for interactions with medical professionals.

### **Support, Validation, and Advocacy**

A common experience among participants was difficulty in navigating the medical system. Participants discussed many difficulties including having doctors imply that their pain was not real, dealing with unexpected negative surgery outcomes, doctors not responding quickly or seemingly disappearing, doctors not being familiar with their



particular condition (e.g., clitoral phimosis), and long wait times for specialized services. Some of the participants described a tainting of their belief in the efficacy of medical professionals as a result of their experiences in the medical system for their sexual pain.

It is advised that counsellors work from a client-centered model, in which the clients' needs are assessed and the clients' concerns are validated. This study points to the importance of counsellors' role in validating the clients' pain, and expressing a belief that the pain is real. Having pain validated by others such as professionals and partners has been found to be a crucial step towards getting better for women with chronic pain (Howell, 1994).

Counsellors can also advocate for clients to receive specialized medical services, consult with the client's medical professionals when the client is struggling with those professionals, and follow up with clients after referring them to medical services to ensure they have received timely and appropriate services. One participant said that a support group for women with sexual pain would help her feel less alone. Counsellors could help connect women to support groups, many of which are online. Counsellors should also keep up-to-date on the changes in the ever-changing field of sexual health, in order to understand their clients' needs and provide effective resources.

I have outlined some of the roles that counselling professionals may take in working with clients facing female sexual pain, and suggestions for working in these roles. This is not an exhaustive list. Counsellors may work in many different capacities with women and couples with sexual pain. These are simply a few of the ways counsellors can serve women and couples, based on the narratives provided by the participants.

### **Implications for Medical Professionals**

As an individual trained in counselling psychology, providing advice to medical professionals on how to best conduct their practices is outside the scope of my competency. One of the questions I posed to the participants, however, was what advice they had for medical professionals who serve women and couples dealing with female sexual pain. The inclusion of this question in the interview was based on the large amount of research indicating women were not satisfied with their experiences in the medical system (e.g., Connor, 2005; Theve-Gibbons, 2000; Werner & Malterud, 2003). In this section, I present the participants' suggestions on improving service by health care professionals. I present their ideas in order to help create sensitivity around the needs of clients with sexual pain, among all kinds of professionals and helpers in the health field.

Participants commonly expressed hope and desire that medical professionals and researchers continue to conduct research into the causes and treatments of sexual pain and that they disseminate new findings to patients. Some participants also discussed how useful it was when health professionals helped them become active participants in their recovery by directing them to well-regarded and up-to-date websites containing information on sexual pain. One participant spoke of his disappointment in western medical treatments, such as antibiotics and surgery, and suggested that professionals combine their learnings and teachings with eastern and holistic health care approaches.

Finally, three participants spoke of the need for improved competency in communication of health professionals. One of these participants spoke of the difficulties in understanding the medical terminology and suggested that professionals explain the risks and expected outcomes of procedures such as surgeries in plain, jargon-free

language. Two participants found certain choices of words or phrases, and the manner in which these were delivered, dismissive of the existence or seriousness of their pain. These participants suggested increased training to improve ways of communicating.

### **Implications for Research**

The present study illuminated an area of couple and sexual life in which research was very much in need. However, in shedding light on the experiences of couples facing sexual pain in the female partner, this study also revealed more gaps in research literature. The study provided support for cognitive-behavioral theory of couple relationships. Given that the present study was a narrative inquiry, a theory was not drawn from the research. However, a future study employing a grounded theory approach may be able to develop a theory of the process couples go through when the female has sexual pain. Given the finding that men developed unhelpful beliefs (e.g., that they were sexually incompetent) as a result of their partner's sexual pain, cognitive-behavioral couple and/or sex therapy may be appropriate interventions. Future research could measure the effectiveness of these interventions for couples experiencing female sexual pain.

More research is needed on the disparity between women's attitudes and behaviors towards painful sex. Cross-cultural research could explore how attitudes and behavior towards painful sex differ among women from different cultures.

Future research exploring men's reaction to their partner's painful sex experiences is needed. Future research could replicate and expand on the present study, with a larger sample.

The couples in this study engaged in many coping strategies. It has been suggested elsewhere (Aubin & Heiman, 2004) that disparity between styles of coping between couple members can serve to maintain or further exacerbate sexual problems. Further research could explore how different coping styles between the couple members affect their ability to successfully manage their struggles with sexual pain.

The participants in this study were all heterosexual. Future research could explore how the experiences of lesbian couples are different from the experiences of heterosexual couples.

Research into couples' experiences with sexual pain is timely and needed. There are many questions yet to be answered. Based on the findings of the present study, many ideas for the expansion of research on sexual pain were provided.

### **Criteria for Evaluating the Worth of the Study**

Narrative analysis falls within the constructivist and post-modern paradigms. Thus, certain assumptions from a positivist epistemology, such as the existence of an objective truth, are not applicable to this research project. As Riessman (1993) stated, "A personal narrative is not meant to be read as an exact record of what happened nor is it a mirror of a world 'out there'" (p. 64), and there is no reason to believe that an individual's narrative will be consistent with each telling. Narrative research can still be evaluated; however, the object of the evaluation is verisimilitude, which is a similarity or likeness to a truthful claim but not "the objective truth" (Bruner, 1986; Polkinghorne, 1988). The criteria with which I have chosen to evaluate my research are fidelity, compellingness, and pragmatic usefulness.

### **Fidelity**

Fidelity refers to the degree to which the results of the study are a faithful reflection of the participants' reports (Blumenfeld-Jones, 1995; Grumet, 1988). To achieve this criterion, I first audio-recorded the interviews, and transcribed them carefully and thoroughly to maintain as much of the interview data as possible. I also kept field notes to help me remember the context of the interviews. Consultation with my supervisor during the analysis process also helped me stay faithful to the data. Finally, member checks were conducted to ensure the stories were faithful to the participants' interviews. As described previously, I sent each participant a copy of their story and asked whether it was faithful to their intended meaning. Seven out of eight of the participants said the story reflected their meanings, and the eighth said the story would reflect his intended meaning if certain word changes were made. These changes were incorporated into his narrative.

### **Resonance**

The second criterion was resonance (Reissmann, 1993). Resonance refers to the degree to which the final paper resonates, not only with the study participants, but also with others who have experienced sexual pain. I included as much context in the narratives as possible, given constraints such as confidentiality, in order to help the reader relate to the narrative. Member checks helped me ensure the narratives resonated with the participants. In addition, a woman with sexual pain who had not participated in the study was asked to read the stories and themes and describe whether they resonated with her experiences. This was her response:

Even though some of the specific experiences shared in the narratives are

different from what I have experienced with sexual pain in my relationship, the underlying essence of each theme resonates with my experience living with sexual pain and dealing with the impact it has had on my relationship and my own identity. Not only do the messages of the stories resonate with my experience, but also give me comfort that I am not alone in what I am experiencing.

### **Pragmatic Usefulness**

Insider, narrative research is meant to be shared and to be useful (Reissman, 1993). It is important that my study produces information that is useful to couples experiencing sexual pain and the professionals who serve them. In order to meet this criterion, I included in the results a table of the various helpful coping skills utilized by the participants. In addition, I included sections on implications for counsellors and medical professionals in the discussion chapter. Finally, I conducted an expert review with Bianca Rucker, PhD, who has worked with women and couples as a sex therapist for over 20 years. Dr. Rucker read the across-narrative themes and stated that they were “relevant and useful” and that they “resonated with what the couples have said to [her].” She recommended I move the paragraphs describing participants’ experiences of feeling different from others from the “difficulties with the medical system” theme to the “shifts in sexual self-view” theme, and suggested wording changes in two of the theme names. These suggestions were taken under advisement and changes were incorporated.

In order to ensure this study is shared, the results of the study will be disseminated in several ways. I plan to present the study at international and national conferences in the fields of counselling psychology, narrative studies, and couple/sex therapy. I also plan to

present the study to classrooms in the counselling psychology, medicine and nursing fields. The narrative format allows me to reach a larger number of audiences. In some contexts it will be more useful to read aloud some of the narratives; in other contexts, a description of the themes will be more appropriate. The use of both formats has the potential to allow more people access to the study results.

### **Strength and Limitations**

The present study had several strengths and limitations. In terms of strengths, this study shed light on an area of couples' experiences in which very little had been studied. Second, the findings were represented as both stories and themes. In this way, the findings can be disseminated more widely and understood and appreciated by a wider range of readers. Finally, an emphasis on making the findings pragmatically useful was taken in this study. Several specific coping strategies named by the participants were presented in an easily accessible table format, and implications for counsellors and health professionals were suggested.

This study also had limitations, and the findings should be understood in light of these. As a qualitative study, the focus of this study was on in-depth exploration rather than on producing generalizable findings. Thus, the findings cannot be taken as representative of other couples experiencing sexual pain. Rather, it is hoped that in presenting in-depth stories of eight participants, the reader is instilled with a greater sense of awareness, understanding, empathy, and compassion for what the experience of sexual pain has meant for these couples.

Although these findings will not generalize to others, they should resonate with couples experiencing sexual pain in the female partner. However, the degree to which

these findings resonate with other couples may be related to the characteristics of the participants. The stories and themes reflect the experiences of the eight participants who volunteered for the study. The participants were diverse in age, socioeconomic status, marital status, educational background, pain experiences, and involvement with treatment. In terms of nationality and ethnicity, all of the participants were Canadian, five were White, one was Black, one was Arabic, and one was Spanish/White. All the participants were motivated to tell their story of sexual pain, and able to clearly articulate their experiences. Some non-White or non-Canadian individuals may have decided not to contact me based on the inclusion criterion of fluency in English in this study.

Because I sought participants who self-described as experiencing recurrent, sexual pain, the participants described a wide variety of pain diagnoses, types, causes, treatments, and experiences. The inclusion of women with diversity in sexual pain experiences has its advantages; light is shed not only on many sexual pain experiences, but readers may also be made aware of the existence of sexual pain types. Indeed, I first became aware of the condition called clitoral phimosis during an interview with a participant. The risk of including participants who solely experience a particular sexual pain type/diagnosis within a sample, however, is that they may be viewed as representatives for that particular pain phenomenon. It is important that the findings not be read as representative of other women but as experiences of the particular, unique participants in this study. Perhaps the reader will find his or her experience reflected in these stories, and perhaps not. The participants' stories, however, do provide significant insights into their struggles with this phenomenon.



Additionally, although the sample size of the present study was consistent with other narrative research (e.g., Arvay, 2003), the inclusion of more participants may have increased the pool of experiences narrated in this study and strengthened the validity of the themes. With greater resources and time for recruitment and interviewing, more participants could have been included, and a follow-up interview could have been conducted to more adequately confirm the findings. However, time constraints hindered further data collection.

Last, a longitudinal study could have produced experiences of several couples going through the years-long process of initially seeking help for sexual pain, going through treatment, and managing post-treatment. This would be a useful future research study.

### **Concluding Comments**

This study illuminated the experiences of couples in which the female partner has recurrent sexual pain. Highlighted in this study was the strong impact of women's sexual pain not only for herself, but also for her partner. Both partners struggled with the impact of sexual pain on their sexual relationship, sexual self-view, dreams of creating a family, and undertakings with the medical system. Just as important in this study were the many cognitive and behavioral strategies that the participants used to help them and their partners cope with these various struggles. The findings of this study underscore the importance of taking a relational stance in researching women's experiences of sexual pain, when it is occurring within the context of an intimate relationship.

The findings of this study are meant to invite a closer look and understanding at the experiences of a few couples going through this phenomenon. The participants

constructed very personal narratives of pain, struggle, and strength. It is hoped that in presenting these narratives I have sensitized you to the experiences of, and compelled you to learn more about, the lives of couples facing sexual pain in the female partner.

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The University of British Columbia  
Office of Research Services  
**Behavioural Research Ethics Board**  
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## CERTIFICATE OF APPROVAL - MINIMAL RISK AMENDMENT

<b>PRINCIPAL INVESTIGATOR:</b> Marla Buchanan	<b>DEPARTMENT:</b> UBC/Education/Counselling Psychology	<b>UBC BREB NUMBER:</b> H06-80623
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
Institution	Site	
UBC Point Grey Site Other locations where the research will be conducted: Interviews will be conducted in the participants' homes if they prefer to do them there.		
<b>CO-INVESTIGATOR(S):</b> Natalie Hansen		
<b>SPONSORING AGENCIES:</b> Unfunded Research		
<b>PROJECT TITLE:</b> Couples' experiences of female sexual pain: A narrative inquiry (B06-0623)		

**Expiry Date - Approval of an amendment does not change the expiry date on the current UBC BREB approval of this study. An application for renewal is required on or before: August 30, 2007**

<b>AMENDMENT(S):</b>	<b>AMENDMENT APPROVAL DATE:</b> May 1, 2007	
Document Name	Version	Date
<b><u>Consent Forms:</u></b>		
Consent Form	N/A	April 25, 2007
<b><u>Advertisements:</u></b>		
Recruitment poster	N/A	April 20, 2007
<b><u>Questionnaire, Questionnaire Cover Letter, Tests:</u></b>		
Screening script	N/A	April 25, 2007
<b><u>Letter of Initial Contact:</u></b>		
Invitation Letter	N/A	April 25, 2007
The amendment(s) and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<i>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</i>		

Dr. Peter Suedfeld, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Arminee Kazanjian, Associate Chair  
Dr. M. Judith Lynam, Associate Chair  
Dr. Laurie Ford, Associate Chair



## **Appendix C: Invitation Letter to Potential Participants**

THE UNIVERSITY OF BRITISH COLUMBIA



Department of Educational and Counselling  
Psychology, and Special Education  
2125 Main Mall, Vancouver BC, V6T 1Z4

### Invitation Letter

Dear Madam or Sir:

You are invited to participate in a Master's thesis project entitled **"Couples' experiences of sexual pain in the female partner: A narrative inquiry."** The purpose of the study is to learn more about how couples experience female sexual pain. I plan to interview participants over the next month. The principal investigator is Dr. Marla Buchanan, UBC Associate Professor. The co-investigator is Natalie Hansen, a Master's student in the UBC Counselling Program. The research is being conducted for Natalie Hansen's Master's thesis.

#### **You are eligible to participate if you:**

- Are a woman who has experienced pain during or immediately following sexual activity for a period of at least three months with your current or past intimate partner, or
- You are a man or woman whose current or past female intimate partner experienced pain during or immediately following sexual activity for a period of at least three months
- And you speak fluent English and are at least 19 years of age

If you are currently in a relationship I am interested in interviewing both members in individual interviews.

#### **Participation will involve the following:**

- A 10 minute phone screening interview per person
- A 1 to 2 hour individual interview in person
- An invitation to providing feedback on the initial results by mail
- Total commitment time per person is approximately 2.5 hours

### **Appendix D: Telephone Screening Script**

When individuals interested in participating call, I will state the following:

Thank you for your interest in the study. This study focuses on couples in which the female partner experiences painful sex. I am particularly interested in learning about the experiences of couples in which the female partner has experienced pain during or after sexual activity, on an on-going basis, for at least 3 months. There is currently very little research in this area and I hope to fill this gap. If this sounds like a study you would be interested in, I would like to ask you some questions to determine if this study is a good fit for you. The questions will take about 10 minutes to go through per person. Is this a good time for you? (If no) When would be a good time?

Either at that time or at a later time specified by the interested individual, I will go through the following screening interview with one member and then the other member of the couple:

1. Have you experienced unintentional pain during or within 24 hours after sexual activity (e.g., intercourse, oral sex, genital touching) on an ongoing basis for a period of at least 3 months?
2. Are you over the age of 19?
3. Do you speak and understand English at an intermediate level?

If the individual answers no to any of the questions, I will say:

Thank you for your interest in this study, however, your experiences do not match the study criteria.

If the caller matches the initial criteria I will ask:

1. Are you currently in a relationship?

If the caller answers no, I will say I am interested in your experiences of sexual pain in past intimate relationships.

If the caller answers yes, I will say I am interested in your experiences and also the experiences of your intimate partner. After I explain more about the study to you, if your partner is also interested in participating, I would like to do this same screening with him or her on the phone. If he or she is not interested, I would still like to interview you about your experiences.

If the caller would like to continue, I will say:

Your experiences appear to match the study criteria. I will explain a little more about the study now. The study will involve meeting with each of you to interview you separately

about your experiences of sexual pain. Each interview will take between 1 and 2 hours. The interviews will be audio-taped and transcribed, but to ensure confidentiality you will each choose a pseudonym that I will refer to you by. As well, we can decide together what details you would like to be changed for the paper. If you choose to participate the information you share will be kept confidential and will not be shared with anyone outside of the research team, including your partner. I will then write up a briefer version of your stories and send them to you for you to let me know if it reflects the intended meaning of your story. I will only send you the story of your interview but you may want to share your story with your partner as the final write up will be available to public.

I also want to let you know about potential benefits and risks of participating. This study does not involve therapy or treatment of any kind. A potential benefit is helping to raise understanding of sexual pain. Potential risks of this study include feeling uncomfortable or embarrassed while speaking to an interviewer about a very personal topic, and revealing new information about yourself to your partner if you decide to share your story with him or her. However, you may end the interview or withdraw your participation in the study at any time.

That is all I want to let you know. Thank you for your interest in the study. You do not have to make a decision now. I will hold a space for you in the study for one week but after that the number of participants required may be satisfied. If you have any questions in the meantime you can call or email me. Have you decided if you would like to participate?

If the participant decides to join the study, I will say:

Great, thank you for your offer to participate. I want to make sure you have a chance to say what you really want to at the interview so there are some things you can do to prepare. Think about the interview question. I will repeat it at the end of this phone call. Look through journals or photos you have to jog your memory of your experiences. Write down some key parts of your story that you want to remember to say.

The interview question is: Please tell me the story of your experience with sexual pain. This may include how it has impacted on areas of your life such as sex, your sexual self-view, your sense of being a partner, your various roles in life, and so on. The easiest place to start may be at the beginning, before you first experienced the pain.

I will now need to go through this screening interview with your intimate partner if he or she is interested and available.

**Potential Risks:**

Telling your story of your experiences with sexual pain may bring up uncomfortable feelings. You may experience embarrassment at speaking about a sensitive topic. If you feel uncomfortable and wish to skip a question or end the interview you can do so. You may withdraw your participation from the study at any time. Please note that this is a research interview, and not a therapy interview. Should you wish to discuss any issues with a counsellor, the co-investigator will provide you with a list of available and affordable counseling services at the interview.

**Confidentiality:**

All efforts will be made to ensure your identity remains completely confidential. If you choose to participate the information you share will be kept confidential and will not be shared with anyone outside of the research team, including your partner. Your name will not be included in the final report. You will choose a pseudonym to go by and that is the name that will be used in the final report. Direct quotes from the interview may be used in the final report but these quotes will be chosen so as not to reveal identifying information. All transcripts, tapes and other study documents will be kept in a locked filing cabinet and the reports will be password protected on the computer.

**Remuneration/Compensation:**

No remuneration or compensation will be provided for your participation.

**Information about Rights as a Research Participant:**

If you have concerns about your rights and treatment as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

**Consent:**

Your participation in the study is entirely voluntary and you may refuse to participate or withdraw your participation from the study at any time.

Your signature below indicates that you consent to participate in this study. Your signature also indicates that you have received a copy of this consent form for your own records.

---

Participant Signature

---

Date

---

Participant Name (printed)

### **Appendix F: Interview Question**

Orienting interview question:

#### **Please tell me your story of sexual pain**

This may include:

The story of your relationship and the emergence of the pain

Your struggles with the pain

The impact on your intimate relationship

How the pain shaped your sense of self

How you managed with the pain

The easiest place to start may be at the beginning, before the pain began.

Table 1

**Physical conditions associated with chronic dyspareunia**

Superficial	Deep
Vulvitis, vulvovaginitis	Estrogen deficiency
Bartholinitis	Vaginitis
Condylomata	Mechanical or chemical irritation
Atrophia	Changed vaginal profile
Dermatologic diseases	Scarification
Noninfectious inflammations	Endometriosis exterior/internal
Epithelial defects	Vaginal septum
Large labia minora	Urethritis, cystitis
Vulvar intraepithelial neoplasia	Uterus in retroversion
Vulvar vestibulitis	Fibroid uterus
Scarification	Ovarian tumor
Size of the penis	Ovarian remnant syndrome
Urethritis, cystitis	Chronic abdominal pain
Anatomic variations	Abdominal wall pain
Hymenal remnants	Irritable bowel syndrome

Superficial

Deep

---

Radiation

Hemorrhoids

Episiotomy/rupture/neurinoom

Note. From "Women's Sexual Pain and its Management," by W. Weijmar Schultz, R.

Basson, Y. Binik, D. Eschenbach, U. Wesselman, & J. Van Lankveld, 2005, *Journal of Sexual Medicine*, 2, p. 309. Copyrighted 2005 by Blackwell Publishing. Reprinted with permission.

Table 2

**Transcription Key**

SYMBOL	MEANING	EXAMPLE
<b>A. Gaps &amp; Overlap</b>		
//	Overlapping talk	I : //You thought// P: //it was never// ending I mean (...) I don't know
(.)	Pause. One period per second.	
/	Being cut off	P: I felt/ I: /It was like you felt
<b>B. Characteristics of Speech</b>		
?	Rising intonation	You know what I mean?
.	Falling intonation	And that's how we lived.
,	Quick pause before continuation of same intonation speech	You know, they liked him too
!	Emphatic, animated tone	And he was there!
<u>underlining</u>	Word emphasis	It's not like <i>I</i> would do that.
CAPITALS	Loud speaking	I don't know WHY THEY JUST CAN'T GET IT!
< >	Soft speaking	He said <you know it's hard to talk about>
(laughs)	Laughter	I (...) (laughs) It's funny to even think about it now
(cries)	Crying	It's (cries) (.....) <i>my</i> body
<b>Bold</b>	Emotion-laden speech	It was like <b>it was like he didn't even (cries) (...) he didn't believe me</b>
(different font in brackets)	Tone	Yah, cause ( <i>sarcastic tone</i> ) I'm the beauty queen in the family ( <i>resume normal</i> ). But anyway, what I meant Crazy, you know? (Mm-hmm).
(mm-hmm)	Interviewer says "mm-hmm)	
<b>C. Transcriber's Notes</b>		
( )	Transcription doubts	"Holy smokes," Dr. (Macintosh) said to me
(Inaudible...)	Inaudible speaking with periods marking seconds	He's so (...) (inaudible speaking ...) sometimes

Note: Adapted from Jeffersonian Transcription (Jefferson, 2004)



Table 3

**Helpful Coping Strategies by Couples Experiencing Female Sexual Pain**

<b>Men</b>	<b>Men and Women</b>	<b>Women</b>
Accompanying partner to appointments	Acceptance	Learning about body
Gentler sex	Expanding sexual repertoire	Monitoring pain
Hobbies	Increased non-sexual intimacy	Open-mindedness
Hope	Information gathering	Pressuring stomach
Housework	Professional counselling	Self-validation
Initiating sex less often	Reframing	
Masturbation	Social support	
Prayer		
Willpower		