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Living with dyspareunia: A qualitative study

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LIVING WITH DYSPAREUNIA: A QUALITATIVE STUDY

by

Robyn L. Donaldson

Bachelor of Science
College of Charleston
2002

A thesis submitted in partial fulfillment
of the requirements for the

Master of Arts Degree in Psychology
Department of Psychology
College of Liberal Arts

Graduate College
University of Nevada, Las Vegas
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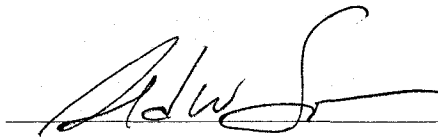
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Living with Dyspareunia: A Qualitative Study

is approved in partial fulfillment of the requirements for the degree of


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ABSTRACT

Living with Dyspareunia: A Qualitative Study

by

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Attempts to fill the gap in knowledge of the psychosocial implications in the lives of women with dyspareunia have 1) been limited to less than a handful of studies, and 2) lack an accurate account from the women themselves as to how they have been impacted. Using a semi-structured interview, women were asked in an open-ended fashion about how having dyspareunia has affected their lives. Grounded theory methodology was utilized to identify emergent themes, their interrelations, and build a meaningful theory of experience of early dyspareunia. Cognitive and behavioral representation in women with dyspareunia from onset of pain to the decision point of seeking treatment was identified as the core process of the theory. Those encountering pain struggle to understand what they are experiencing and why, suffer from compounded consequences personally and in their relationships and must then assess whether the pros of seeking treatment outweigh the cons. Unique to this sample of women was the absence of incentives to seek treatment, resulting in a resignation to suffer in silence. The emergent theory proposes that the extent to which women perceive and understand their experience of dyspareunia may be a determinant in whether they seek medical treatment.

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CHAPTER 1

INTRODUCTION

Dyspareunia is one of two sexual pain disorders in the latest revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-R, 2000). It refers to the experience of recurrent pain with sexual intercourse that causes distress or interpersonal difficulty. A substantial proportion of women suffer from dyspareunia which has an estimated prevalence rate of approximately 14% (Laumann, Paik, & Rosen, 1999). The impact that the disorder has on this subset of the population is considerable. Experiencing such pain reduces a woman's pleasure and, subsequently, her desire for sex and her arousal during sex. This interference can rise to the level of sexual aversion, but more commonly it can result in anorgasmia. Pain with intercourse can consequently have deleterious effects on a woman's sense of sexual self, as well as her self esteem (Meana & Binik, 1994). A woman's marital or romantic relationship is also likely to be negatively affected, even potentially triggering depression in the partner (Nylanderlundqvist & Bergdahl, 2003). It is not difficult to see how this disorder might influence many important parts of a woman's life and how she lives it.

It was not until the end of the 19th century that the perception of dyspareunia changed from being a physical symptom of unknown origin to a sexual dysfunction with possible psychological causes. Once psychological factors started to be considered, the emphasis was on psychoanalytic notions of conscious versus unconscious motives for the

pain and very little research addressed the actual experience of pain. Women who presented with dyspareunia were often considered to be suffering from hysteria or sexual frigidity, which was a recurring theme in the health care of women until the 1960's and 1970's (Meana & Binik, 1994). The dramatic increase in sex research and therapy at that time helped start to finally chip away at the pernicious labeling of all women's problems as a symptom of hysteria. Finally, in the 1980's, dyspareunia was upgraded from a psychosomatic disorder in the DSM II to a sexual pain disorder in the DSM III, thus legitimizing the experience, pain and distress of millions of women.

The shift from predominantly physical conceptualizations of dyspareunia to a more psychologically oriented approach was not, however, without difficulty. Studies have found that women with dyspareunia suffer from higher levels of depression and anxiety (Brotto, Basson, & Gehring, 2003; Gates & Galasky, 2001; Jantos & White, 1997; Marin, King, Dennerstein, & Sfamini, 1998; Meana, Binik, Khalife, & Cohen, 1999), however, it is difficult to assess whether these psychological symptoms preceded the experience of dyspareunia or were a consequence of it. In addition to the complexity of establishing the order of symptom presentation over time, it is also a challenge to tease apart the physical from the psychological. Even with some of the physical treatments (i.e., biofeedback, physical therapy, and vaginal dilation), we do not know whether improvement is due to the physical manipulation of muscle groups or to the psychologically desensitizing components of these treatments. More research is needed to help address some of these conundrums.

Most recently, there has been yet one more shift in the study of dyspareunia. In the last decade research has moved away from the psychosexual correlates of dyspareunia

to the experience of pain. Previously, dyspareunia had not been taken seriously enough as a disorder for researchers to examine the pain exclusively. Despite the fact that pain is the presenting problem, research and clinical practice seemed intent on finding psychosexual causes of the pain (e.g. sexual abuse) rather than on understanding the characteristics of the pain experience. This new focus on pain started on a theoretical basis with Meana and Binik's (1994) review of the literature in which they questioned dualistic approaches to the study of dyspareunia. Meana, Binik, Khalife, and Cohen (1997a) followed this up with an investigation of the types of descriptions for dyspareunic pain and found that a pain classification system (such as that of the International Association for the Study of Pain) outperformed the psychiatric one (DSM-IV) in the description and diagnosis of different sub-types of dyspareunia. As a result, many began to consider dyspareunia to be better categorized as a pain disorder than as a sexual dysfunction. Studies then began narrowing their focus on the specific pain characteristics of dyspareunia. Pukall, Binik, and Khalife (2004) found that women with VVS have lower pain thresholds in both vestibular sites and other body parts, like the deltoid and labium minus. Research focusing on pain threshold and nociceptor sensitization found that women with dyspareunia have sensory dysfunction in the posterior and anterior portion of the vestibule (Bohm-Starke, Hilligies, Brodda-Jansen, Rylander, & Torebjork, 2001). These are just two examples of the new direction taken by dyspareunia researchers consequent to the shift in focus from sex to pain.

This concentration on the pain experience of women with dyspareunia has helped to create an almost exclusively pain-oriented zeitgeist in the field of sex research. The result has been somewhat extreme in its stripping dyspareunia of its sexual context and

focusing exclusively on the pain. In addition, pain-oriented researchers have begun lobbying to change the categorization of dyspareunia from a sexual dysfunction to a pain disorder in the upcoming edition of the DSM. Binik (2005) now proposes creating a new category of “urogenital pain disorder” in the DSM and relocating dyspareunia there. In this way, dyspareunia would be a pain disorder that interferes with sex, rather than a sexual disorder characterized by pain. The argument is that dyspareunia fulfills all the requirements of a pain disorder in the DSM whereas it does not fit as well into the sexual dysfunction category.

Whether one espouses the pain approach to dyspareunia or not, there is no doubt that sexual activity is the main stimulus for dyspareunic pain. Even if the fact that the pain is located in an area that gets stimulated primarily through sexual intercourse is incidental, the reality is that this pain is unique in its involvement of an activity that is socio-culturally and interpersonally loaded with meaning and strong emotions. It would be impossible for there not to be a significant psychological involvement in the experience of this pain. Yet, there is still much about the psychological impact of having dyspareunia that is unknown. If dyspareunia is reassigned to the pain disorders, it is possible that the current focus will become fixated, more so than it is now, on the physical aspects of the pain experience to the exclusion of the psychosexual aspects of this disorder. Treatment outcome studies are already demonstrating that eradication of pain does not necessarily result in the resumption of sexual activity (Basson & Riley, 1994; Bergeron, Binik, Khalife, Pagidas, Glazer, Meana, & Amsel, 2001). It would be hard to argue that a treatment that has rid the woman of her pain but not made any gains in sexual activity or satisfaction has achieved a fully positive outcome.

There is currently a dearth of empirical research about how this pain affects the people involved. Sexual pain is different from other chronic pains. It requires the involvement of another person. Sex, being a highly emotionally charged activity, is bound to engender negative consequences when tainted with pleasure-preventing pain. Without diminishing the importance of understanding the pain properties of dyspareunia, this study adds balance and depth to the current research by focusing on the psychological experience of women who suffer from this disorder. Using a qualitative methodology, we investigated the phenomenology of how this disorder affects women. However, a comprehensive review of the literature on dyspareunia has to be the starting point.

CHAPTER 2

LITERATURE REVIEW

The Diagnostic and Statistical Manual of Mental Disorders classifies dyspareunia as a sexual disorder, characterized by recurrent or persistent genital pain which occurs during sexual intercourse (DSM-IV, 1994). Symptoms must cause distress or interpersonal difficulty to meet the criteria. According to this definition, dyspareunia is not considered to be produced by the physiological effects of a substance or a medical condition. The DSM also distinguishes the genital pain of dyspareunia as not being caused solely by Vaginismus, lack of lubrication or another Axis I disorder. Symptoms of dyspareunia are classified as being lifelong or acquired (the course tends to be chronic), generalized or situational, and due to psychological or combined factors. Based upon this current definition, studies have looked at the prevalence of dyspareunia, the term itself, as well as similar and associated terms such as “pain during sexual activity” and even “vulvar pain.” Regardless of phraseology, prevalence rates have been substantial.

Prevalence

In one of the largest sexual surveys conducted in the United States, Laumann, et al. (1999) interviewed 1410 men and 1749 women aged 18 to 59. They found approximately 14% of women suffered from dyspareunia. Younger women, ages 18 to

29, had the highest prevalence rate at 21%. The older the woman was, the lower the prevalence: 30 to 39, 15%; 40 to 49, 13% and 50 to 59, 8%. Out of the specified ethnic groups, Caucasians had the highest rate (16%) followed by Hispanics (14%) and then African Americans (13%). The selection of "Other" yielded 19%.

One study inquiring about the sexual concerns of women seeking gynecological care at Obstetrics and Gynecology at Madigan Army Medical Center in Washington found that 71.7% of the 683 women who responded in the affirmative to having sexual concerns suffered from dyspareunia, 61.8% experienced high frequency symptoms while 10% experienced low frequency of symptoms (Nusbaum, Gamble, Skinner & Heiman, 2000). An epidemiologically sound telephone survey conducted by Bancroft, Loftus, and Long (2003) on individuals aged 20-65 in heterosexual relationships found that approximately 3% of the 853 surveyed reported pain or discomfort during sexual activity 50% or more of the time. The percentages increased with age: 20 to 35, 2.2%; 36 to 50, 3.7% and 51 to 65, 4.3%. No statistical difference was found between Caucasians and African Americans.

Harlow and Stewart (2003) surveyed women from five ethnically diverse communities in the Boston area. Of those 3358 who responded, 15.6% suffered from unexplained chronic vulvar pain and 16% had had a history of chronic burning, knifelike pain or pain on contact that lasted three months or longer. Hispanic women were 80% more likely to experience chronic vulvar pain than were Caucasian and African American women. Percentages decreased with age: 18 to 25, 6.8%; 25 to 34, 5%; 35 to 44, 3.4%; 45 to 54, 3.6% and 55 to 64, 3.9%.

A sex survey and interviews conducted with 2810 men and women, using the Swedish Central Population Register, found the prevalence of dyspareunia to be higher for women over 50: 50 to 65, 8% and 66 to 74, 12%. Both age groups of 18 to 24 and 25-34 had a prevalence rate of 6% and the 35 to 49 age range was the lowest at 4% (Fugl-Meyer & Fugl-Meyer, 1999). In another Swedish study, 3017 women being screened for cervical cancer yielded prevalence rates for prolonged (6 months or more) and severe (no definition given) dyspareunia that varied from 13% in the youngest group to 6.5% in the oldest (Danielsson, Sjoberg, Stenlund & Wikman, 2003).

Najman, Dunne, Boyle, Cook, and Purdie (2003) looked at sexual dysfunction in the Australian population. They conducted a telephone survey of 908 women and 876 men aged 18 to 59 years. Subjects were asked whether during the prior 12 months there had been a period of several months or more when physical pain during sexual intercourse was experienced. The prevalence rate was highest for women in the youngest category (18 to 29, 23%) as compared to the rest of the age groups: 30 to 39, 17%; 40 to 49, 10% and 50 to 59, 14%.

The overall prevalence rates for dyspareunia found in the aforementioned studies varied from as low as 3% and as high as 23%, although most figures stayed close to 15%. This disorder is clearly not limited to the United States, as other countries have found similar prevalence rates through their own investigations. Regarding age, most of the studies found higher prevalence rates with younger women. More research is needed on ethno-racial groups as it is currently unclear whether there are between-group differences. Some studies have found rates for Caucasians to be higher (Laumann, et al., 1999) while others find Hispanics more prone to having dyspareunia (Harlow & Stewart, 2003). What

is evident from the literature is that dyspareunia is a disorder which affects a considerable number of women across race, age and geographical location and is receiving increased awareness from researchers.

Classification

Dyspareunia has been described and classified both in terms of its properties as a sexual dysfunction and its properties as a pain disorder. Systems that have focused on dyspareunia as a sexual dysfunction use variables such as interference with sexual behavior, situational determinants of the pain and lifetime onset in order to describe and typify the type of dyspareunia experienced. Those that categorize dyspareunia as a pain disorder concentrate on the specific properties of the pain, such as location, intensity and potential etiologic pathways. A trend is emerging in the literature to integrate both approaches, so as to create a more comprehensive picture of the different types of dyspareunia.

The DSM-IV categorizes dyspareunia as a sexual dysfunction primarily, emphasizing the psychological correlates of the disorder. The pain is described in terms of three dimensions: lifetime onset, situational determinants and factors that contribute to the experience of pain. Onset is classified as either lifelong, such that pain has been present since the start of sexual activity, or acquired, such that pain is described as having developed after a period of pain-free penetration. The pain is also classified as either situational or generalized. The classification of dyspareunia as situational indicates that the pain is confined to specific situations such as particular contexts or partners. In generalized dyspareunia, pain is experienced in all penetration attempts or no pattern can

be discerned in regards to its occurrence. The DSM-IV also attempts to account for the presence of both psychological and physiological factors impinging on the disorder. Although its emphasis is on psychological factors contributing to the onset, severity, exacerbation and/or maintenance of the disorder, the DSM-IV does allow for the presence of a medical condition and/or substance use. It thus classifies dyspareunia as having a psychological etiology or a combined one (psychological and medical).

Kaneko (2001) has proposed another sexually centered classification system for pain with intercourse, using a strictly behavioral approach that differentiates vaginal pain according to how sexual functioning is affected. Based upon his study of women with suspected vaginismus, Kaneko (2001) suggests there being at least three types of difficulties with intercourse: penetrative disorder, dyspareunia, and sexual avoidance disorder. Penetrative disorder is considered to be present if no coitus or vaginal penetration is possible due to the degree of pain and/or spasms. When penetration is possible but pain persists, then the condition is dyspareunia. In sexual avoidance disorder, coitus is possible, yet avoided for any number of reasons including, one would presume, fear of pain.

A growing number of researchers are using common descriptors of pain, such as location, onset during an intercourse episode, and duration of the pain in an attempt to better classify dyspareunia. Location is one of the best predictors of differential diagnoses of dyspareunia (Meana, et al., 1997a). Women with dyspareunia experience pain in specific regions of their genitalia. Some report pain only in the vagina, in the introitus exclusively, or deeper in the pelvic region. Others experience some combination of all of the above (Meana & Binik, 1994). The use of a "pain map" has become a vital tool for

patients and physicians in pinpointing this pain. The creation of this “pain map” involves palpation during a physical examination and recording the specific locations of hyperalgesic areas that mimic the pain experienced with intercourse (Graziottin, 2001).

Another reason location of pain is so vital for classification purposes is that it can aid in determining potential etiology. For example, women who experience pain at the entrance of the vagina are more likely to suffer from vulvovaginitis (inflammation of the vulva and vagina), vaginismus (prolonged and painful contraction or spasms of the vagina), or vulvar vestibulitis (inflammation of the vestibule, the opening to the vagina and the tissues around the vaginal opening). Those with vaginal dyspareunia may suffer from pelvic floor spasms or urethral diverticulum (a pouch-like enlargement in the urethra) and deep thrust dyspareunia may signify such medical conditions as endometriosis, uterine prolapse or pelvic inflammatory disease (Steege & Ling, 1993).

Lifetime onset of dyspareunia, onset of the pain within an intercourse episode, and duration of the pain are pain characteristics which have also been found to be good predictors of factors associated with dyspareunia. Meana, et al., (1997a) found that the lifetime onset of dyspareunia was most often described as being acquired. In terms of onset of the pain within an intercourse episode, as well as its duration (whether it starts before, during, or after intercourse and how long it lasts), Meana, et al. found that 60% of dyspareunic women had pain throughout penetration and that the pain also continued for some time after withdrawal of the penis. Pain limited only to thrusting was experienced by 38% of the sample and only 2% reported pain prior to penetration.

The taxonomical system of the International Association for the Study of Pain (IASP) has been used by Pukall, Payne, Binik and Khalife (2003) to describe the pain of

those with vulvodynia (chronic discomfort of the vulva characterized by burning, stinging, or irritation), dyspareunia, generalized vulvar dysesthesia (pain located anywhere on the vulva), dysesthetic vulvodynia (constant noncyclic vulvar or perineal discomfort or sharp pain), vestibulodynia (hypersensitivity and pain experienced with light touch on the vestibule), vulvar vestibulitis syndrome (VVS), and vaginismus. The IASP organizes pain symptoms along five axes: region affected (vulva, vagina, uterus), system involved (nervous, musculoskeletal), temporal characteristics (continuous, intermittent, recurring regularly, linked to sensory stimulations or not), patient's statement of intensity (mild, moderate, severe), duration (time since onset) and etiology (trauma, inflammatory).

In an attempt to find better ways to describe and classify dyspareunia, some researchers have created classification systems that integrate the sexual dysfunction and the pain disorder perspectives. One such method of defining dyspareunic pain recommends using the timing of the pain during sexual intercourse: with external contact, partial entry of the penis, an attempt at full entry of the penile head, deep thrusting, penile movement, the man's ejaculation, the woman's postcoital urination, or pain for some time after intercourse has ended. This integrative approach incorporates physical findings as well as the presence or absence of arousal before and during intercourse to describe the type of dyspareunia experienced (Basson, 2002).

Meana and Binik (1994) proposed a classification system that uses most of the variables from the systems mentioned above, as well as a couple of other pertinent variables. Both the Meana-Binik system and the DSM-IV use lifetime onset (lifelong or acquired) and situational variables (specific versus global). Meana and Binik, however,

continue where the DSM-IV leaves off by including properties of the pain, such as location and duration (before, during, or after intercourse). They also include the functional interference variable which assesses the impact on sexual function.

Interference is considered mild if there is a small or no effect, significant if penetration is difficult and severe if penetration is impossible. This system has shown promising results in accurately diagnosing different types of dyspareunia. Meana, et al. (1997b) compared the diagnostic capabilities of the DSM-IV criteria, the IASP system, and the Meana-Binik system. The DSM-IV system correctly identified 42% of women with no pain-related findings, vulvar vestibulitis, and atrophy, the IASP system was more accurate with a 60% correct classification rate, but the Meana-Binik system outperformed both, correctly classifying 72% of the women in their sample.

Subtypes of dyspareunia have also been classified according to hypothesized etiology. Meana, et al. (1997a) found four groups among their sample of 105 women: no physical findings, vaginal atrophy, VVS, and mixed findings. The first group had no physical findings on any of their gynecological exams (pelvic exam, colposcopy and endovaginal ultrasound) or cultures that could reasonably be linked to the experience of pain during intercourse. The VVS group had severe pain on vestibular touch or attempted entry, tenderness to pressure localized within the vulvar vestibule, and physical findings of vulvar erythema (redness). The atrophy group had visible lack of skin elasticity, turgor and labial fullness, and thinning of the vaginal mucosa. The mixed group had a variety of physical findings that could be directly linked to their pain (e.g., ovarian cysts, uterine fibroids, episiotomy scarring) excluding atrophy or vulvar vestibulitis.

Precise methods of classification are crucial in the identification of etiology and in providing information necessary for appropriate treatment. Traditional classification and diagnostic systems focus on either sexual or pain-oriented aspects of dyspareunia. Emerging evidence is showing that combining variables from both sexual function and pain provides for a more accurate diagnosis and earlier and more effective treatment. Hopefully, this will become the trend for physicians and clinicians alike in working with women with dyspareunia, as we start to move away from misguided dualisms regarding exclusive differentiations between physical and psychological factors. All the data available seems to be pointing to the fact that in most cases of dyspareunia both physical and psychological variables appear to be at play.

Etiology

Part of the difficulty in classifying, diagnosing and treating dyspareunia lies in our lack of knowledge about its causes. With the many different manifestations of dyspareunia documented, identifying the factors that contribute to this disorder has proven problematic. For some women, the pain may simply be a byproduct of a physical problem, like an episiotomy scar. For others, there may be no physical findings that would indicate pain but plenty of psychological complaints, like depression or anxiety or even relationship maladjustment. One of the difficulties in teasing these apart is that the factors that caused the disorder may not be the same ones that maintain it. For example, the woman with the scarring problem may end up developing psychological issues around the idea of penetration, even if the originating cause was physical. If she has experienced pain for a long time, she may have become classically conditioned to

experience pain at the suggestion of intercourse, even after the originating cause has been resolved. In the case of the woman with psychological distress and no physical findings, it could be that the originating problem was resolved but it has left a world of distress and relationship problems in its wake. The majority of women with dyspareunia are thus likely to have overlapping etiologies, making it a daunting task to differentiate this disorder's cause from its effect. In many cases of dyspareunia, the pain may simply have multiple causal pathways.

Physiological findings

Neurological

When considering the physiological correlates of dyspareunia, as with any type of pain, it is important to assess the basic neurological component: the nerves themselves. Some cases of dyspareunia may constitute a nerve inflammatory reaction to a type of antigen in the body. Bohm-Starke, Hilliges, Falconer, and Rylander (1999) took biopsies of the Bartholin gland (which secretes fluid to maintain the moisture of vaginal mucosa's vestibular surface) of sixteen women with VVS. All biopsies contained immunoreactive nerve fibers. The increased numbers of nerve endings found in the vulvar epithelium were nociceptors: sensory receptors which respond to pain. Although results indicated some type of immune response, the study did not look at what might have been causing the inflammation.

It is also possible that other cases of dyspareunia may involve a type of neurological dysfunction in which the nerves perceive an antigen when no antigen is actually present. Or, the inflammation may be due to some type of allergic reaction, like contact dermatitis. However, in a study by Bazin, Bouchard, Brisson, Morin, Meisels,

and Fortier (1994), little or no correlation between eczema, contact redness to specific agents like perfume, soaps or metals and VVS was found. The potential of there being other allergies, however, has not been tested.

Sensory nerve dysfunction has been found in many studies of women with VVS. One study found sensory nerve dysfunction in women with vulvar vestibulitis at the posterior and anterior parts of the vestibule. Different sensations were applied including vibration, warmth, cold, heat, cold pain, and von Frey filaments to elicit pain. They found increased pain sensitivity (allodynia) in these patients when compared to controls (Bohm-Starke, et al., 2001). Other researchers have also found lower pain and tactile thresholds in VVS patients (Lowenstein, Vardi, Deutsch, Friedman, Gruenwald, Granot, Sprecher, & Yarnitsky, 2004; Pukall, Binik, Khalife', Amsel, & Abbott, 2002). In an effort to standardize the measurement of thresholds around the vestibule, the vulvagesiometer was developed. The vulvagesiometer is a mechanical device which is cylindrical, hand-held and pen-like with springs of different compression rates and a cotton swab at the end. Even with the use of this more sophisticated device, findings have remained consistent with previous research: lower pain thresholds and higher unpleasantness ratings in women with VVS compared to controls (Pukall, et al., 2004).

It is possible that these women's nerve dysfunction or hypersensitivity, causing enhanced pain perception, may be generalized to non-genital areas. When pain and unpleasantness thresholds have been tested on nongenital parts of their bodies, VVS subjects' responses for thresholds were constantly lower than controls (Granot, Friedman, Yarnitsky, & Zimmer, 2002). Pukall, et al., (2002) tested thresholds on the labium minus, on the arm over the deltoid muscle, and on the tibia with similar results. Other evidence

that pain nerve fibers may be generally hypersensitive is that women with dyspareunia have more somatic complaints (Danielsson, Sjoberg, & Wikman, 2000). Brotto, et al., (2003) found that 24% of those with dyspareunia suffered from either tension headaches, temporomandibular joint syndrome (a disorder of the jaw joint characterized by facial pain, headache, ringing ears, dizziness, and stiffness of the neck) or irritable bowel syndrome (a disorder characterized by abnormally increased motility of the small and large intestines, producing abdominal pain, constipation, or diarrhea).

Endocrine

It has also been hypothesized that dyspareunia may be caused by some endocrine or hormonal imbalance. White and Jantos (1998) found that 69% of women with dyspareunia suffered from three or more symptoms of premenstrual syndrome and dysmenorrhea. Dyspareunia is also common in peri- and post- menopausal women, possibly linked to lower levels of estrogen associated with vaginal dryness and atrophy, making for more painful intercourse. These endocrine findings have led some researchers to investigate the effect of oral contraceptives. The results, however, are conflicting. One study found that VVS was associated with early oral contraceptive use (Bouchard, Brisson, Fortier, Morin, & Blanchette, 2002); while others have found that some patients with dyspareunia have never used oral contraceptives (Bohm-Starke, et al., 2001). Yet other researchers have found no difference in the use of oral contraceptives between women with dyspareunia and controls (Danielsson, et al., 2003).

Vascular

Inflammation associated with dyspareunia may be caused by a vascular condition resulting in excessive vasodilation. The most painful areas in VVS patients, the posterior

fourchette [a fold of mucous membrane just inside the point of posterior conversion of the vulva (labia majora)] and the posterior vestibule [area located at the dorsal portion of the vaginal opening] have shown an increase in blood flow. Erythema (redness) has long been associated with genital hyperalgesia and constitutes one of Friedrich's (1987) three criteria for a diagnosis of VVS. This may be a result of increased capillary growth or the presence of an inflammation at deeper levels. Another possibility could be that there was some type of initial inflammation which received continuous irritation, thus maintaining sensitization of nociceptors and vasodilation (Bohm-Starke, et al., 2001).

Muscular

Dyspareunia may also be caused by a muscular condition involving hypertonicity of the pelvic floor. Such intense tightening can reduce introital space, causing significant pain with penetration. Clinicians have found co-existent perivaginal muscle hypertonicity through self-report of women with dyspareunia, as well as via physical exams (Brotto, et al., 2003). Hypertonicity of the pelvic floor has also been recorded via surface electromyography (sEMG), indicating an elevated baseline (White & Jantos, 1998). These researchers suggest that a muscular etiology for dyspareunia be based upon the presence of at least of three of the following conditions: instability of muscle, slow muscle recovery after contraction, elevated resting baseline level, either reduced frequency of signals on the sEMG or reduced muscle contraction strength. Glazer, Rodke, Swencionis, Hertz, and Young (1995) have also utilized sEMG for baseline purposes in their treatment study on electromyographic biofeedback. The success of this treatment study is another indicator of muscular hypertonicity as a potential factor in dyspareunia which, in some instances, can be reduced through biofeedback. The use of

sEMG for strictly diagnostic purposes, however, requires additional research to establish reliability. Engman, Lindehammar and Wijma (2004) found sEMG could not differentiate between women with VVS and asymptomatic women.

Infectious

Certain infections have been theorized to be associated with dyspareunia. The most common one of these is candidiasis (yeast infection). Multiple studies have indicated that women with VVS report histories of recurrent candidiasis (Bohm-Starke, et al., 2001; Denbow & Byrne, 1998; White & Jantos, 1998; Witkin, Gerber & Ledger, 2002). Dyspareunia has also been linked to viral infections such as sexually transmitted diseases (STDs) and the human papilloma virus (HPV). White and Jantos (1998) found that of women with vulvar pain, 44% reported a history of STD's. The presence of a gene linked to HPV was found in 25.9% of subjects. In cultures taken of women with vulvar pain and VVS, HPV was found in the majority of them (Danielsson, et al., 2000; Umpierre, Kaufman, Adam, Woods, & Adler-Storthz, 1991). This virus may trigger a proinflammatory immune reaction causing dyspareunia (Witkin, et al., 2002). Genital herpes has also been confirmed in 20% of subjects with vulvar pain (Denbow & Byrne, 1998). A study investigating different correlates of dyspareunia found no prevalence of gonorrhea, chlamydia, trichomonas, or mycoplasma in subjects. However, the viruses, bacteria and fungi that were present included gardnerella (14%), candida (8.8%), ureaplasma (17.5%), and HVP (5.3%) (Bazin, et al., 1994).

Women with urinary tract infections (UTI) often experience dyspareunia. Of women with lower urinary tract symptoms and urinary incontinence, 44% report having a sexual pain disorder (Salonia, Zanni, Nappi, Briganti, Deho, Fabbri, et al., 2004).

Recurrent urinary tract infections may be more frequently associated with inflammation of the genitalia and a reduction in lubrication during intercourse. The combination of the two conditions often results in a significantly higher number of sex pain disorders. Treatment of UTI's has led to improvement of arousal and sexual pain disorders in this population (Salonia, et al., 2004).

Assorted gynecological conditions

There are other medical conditions that can play a role in the etiology of dyspareunia, although none of them account for a significant number of women with dyspareunia. Some of the contributing urologic disorders include cystitis [inflammation of the urinary bladder], interstitial cystitis [chronic inflammation of the mucosa and muscular tissue of the bladder, resulting in reduced bladder capacity], lichen sclerosis [a skin condition of the vulvar region characterized by thinned, white areas, thickened white skin and irritated red skin], urethral diverticulum [a pouch or sac branching out of the urethra], and urethritis [inflammation of the urethra]. Uterine and ovarian disorders that may cause dyspareunia are adenomyosis [a form of endometriosis characterized by invasive, usually benign growth of tissue in the uterus], leiomyoma [a benign tumor] of the uterus, an ovarian mass or prolapsed ovary, and polycystic ovarian syndrome [disease of the ovary characterized by amenorrhea, infertility, irregular menstruation, and enlarged ovaries]. Dyspareunic women may suffer from endometriosis or have a fixed retroverted uterus (Canavan, Timothy, Heckman, & Celeste, 2000). Dyspareunia may be due to certain vaginal disorders like atrophic vaginitis [thinning of the vaginal epithelium], pudendal neuralgia [pain extending along the nerve fibers of external genitalia], vaginismus, vaginitis, vulvar dermatoses [skin disease of the vulvar region], or vulvar

vestibulitis. There may be anatomical complications with sexual activity such as the swelling of a Bartholin's gland [small gland located on each side of the vaginal orifice that secretes a lubricating mucus] cyst during intercourse or a formation of hymenal ring adhesive bands during arousal. Other genitourinary complications involved may be coccygodynia [pain in the region of the coccyx], fissures in the perineum, and pelvic inflammatory disease (Graziottin, 2003). Again these are all conditions that can result in pain with penetration however the vast majority of women with dyspareunia do not have any of these conditions.

Iatrogenic

Sometimes dyspareunia is caused by a medical procedure intended to address an unrelated problem. These iatrogenic causes include episiotomies, radiotherapy for cervical cancer (which may cause loss of vaginal structures such as the labia, clitoris and introital stenosis), radical hysterectomy (which removes most uterosacral and cardinal ligaments and upper one third of vagina, causing severe vaginal shortening), medication side effects, and pelvic surgery scarring (Canavan, et al., 2000). These procedures can result in vulvar pain but again they do not account for a significant number of dyspareunia cases.

Psychosocial findings

In addition to the myriad of physiological theories on etiology, researchers have long ascribed psychosocial correlates (often implying causality) to dyspareunia. Lazarus (1980) organizes these psychosocial correlates into three main areas: developmental, trauma-related, and relational. Another area for which there is some support is that of individual psychological factors not directly related to Lazarus' three areas.

Developmental

Developmental aspects which could lead to dyspareunia later on in life include early sexual attitudes, upbringing, sexual schema, parental messages about sex, and any other formative experience related to sexuality. As with many aspects of dyspareunia, conflicting findings exist. Some researchers have found no difference between women with vulvar pain and those without in regard to body image disturbances during adolescence (Edwards, Mason, Phillips, Norton, & Boyle, 1997). On the other hand, women with vulvar pain have been reported to have more negative feelings toward sex and sexuality and less positive sexual views (Meana, et al., 1997a; Reissing, Binik, Khalife, Cohen, & Amsel, 2003; White & Jantos, 1998). These women also have been found to have a less positive sexual self-schema but not a more negative self-schema (Gates & Galask, 2001). It is not clear if these views on sexuality are due to the environment in which these women were raised and how/what they were taught regarding sex, or whether this is a result of pain now paired with intercourse. Only longitudinal studies could address these questions and none exist.

Trauma-related

Evidence of sexual trauma in the histories of dyspareunic women is also mixed. Women with vulvar pain appear to experience more sexual abuse/assault in their adult lives (Brotto, et al., 2003) than any abuse during childhood (Edwards, et al., 1997). Other researchers have found that sexual abuse has little connection with dyspareunia, especially during childhood (Danielsson, et al., 2000; Van Lankveld, Weigenborg, & Ter Kuile, 1996). Meana, et al., (1997a) found no difference between women with dyspareunia and controls on reports of physical or sexual abuse during childhood or

adulthood. Of those women who had been sexually and/or physically abused during childhood, Schloretd and Heiman (2003) found that they did not differ from others in relation to sexual pain, difficulties in arousal and achieving orgasm and sexual desire. These women, however, did have more negative perceptions about their sexuality and higher frequency of negative moods during sexual arousal. It is not clear if such views on sexuality are due to the abuse or to dyspareunia. Future research is needed on this subject.

Individual psychological factors

Individual psychological factors without direct links to trauma or identifiable early childhood experiences have also been associated with dyspareunia. Depression, anxiety and pain hypervigilance may be important in the eventual development of pain with intercourse. Again, in the absence of longitudinal studies, it is currently difficult to ascertain if these were present before the symptoms of dyspareunia or whether they developed consequent to the onset of the pain. Women with VVS have been found to have elevated levels of depression, psychological distress (anxiety, psychoticism, paranoid ideation, OCD, hostility, interpersonal sensitivity, phobic anxiety), and sexual depression (feelings of depression regarding one's sex life) than controls (Gates & Galask, 2001; Meana, et al., 1997a, 1998). Nylanderlundqvist and Bergdahl (2003) found similar results on depression and anxiety between women with dyspareunia and controls using the Beck Depression Inventory (BDI) and the State-Trait Anxiety Inventory (STAI-S). Over half (58.6%) of the women with dyspareunia rated a 10 or above on the BDI, indicating a potential diagnosis of mild to severe depression. In addition, Jantos and White (1997) found that those with dyspareunia scored high on suicidal ideation (57%) and depression (60%).

Some women have been found to experience more anxiety (Jantos & White, 1997) or even experience a sexual phobia (Marin, et al., 1998). Nunns and Mandal (1997) found that women with dyspareunia had higher state and trait anxiety scores than controls. Subjects with VVS reported experiencing phobic anxiety to vaginal touch or entry (Brotto, et al., 2003). They also scored higher in the dimension of harm avoidance (a tendency to react with pessimistic worry and increased anxiety to future problems), to be passively avoidant, fearful, shy with strangers and to have rapid fatigability (Danielsson, Eisemann, Sjoberg, & Wikman, 2001). Anxiety and stress may play the role of magnifying the symptoms of dyspareunia (Marin, et al., 1998).

Pain hypervigilance is another individual psychological factor that has been investigated. Women with dyspareunia suffer from more somatic complaints and experience phobia, possibly as a function of pain hypervigilance. It could be that some of these women have a higher tendency to over-attend to pain and somatic symptoms when exposed to different stressors, either physical or psychological (Danielsson, et al., 2001). During sexual situations, this hypervigilance to pain could be manifesting itself as an attentional bias for pain stimuli. This attentional bias may distract them from sexual stimuli during sexual activity. The anticipation of pain may cause the woman to focus on pain and related concerns about not being able to perform. With attention diverted from erotic cues, sexual arousal may be impaired, which can exacerbate the pain (Payne, Binik, Amsel & Khalife, 2005).

Relational

The quality and characteristics of a woman's relationship with her partner may also contribute to the experience of dyspareunia. Women with dyspareunia have reported

more marital dissatisfaction (Masheb, Brondolo, & Kerns, 2002; Meana, et al., 1997a). Interestingly, the more adjusted the couple, the lower the pain rating (Meana, Binik, Khalife, & Cohen, 1998). How the partner reacts to the situation, how much empathy is present and the ways in which they solve problems together may be important facilitators of healthy adjustment to the problem of dyspareunia. It is also possible that the more adjusted couples have sexually satisfying and less pain producing methods of sexual stimulation.

Changes in sexual behavior and desire/arousal may also be associated with dyspareunia. Decreases in desire and arousal may result in insufficient lubrication. Subsequently, greater potential of injury, inflammation and recurrent irritation is possible. Women with dyspareunia have a higher incidence of engaging in sexual intercourse with reportedly low levels of lubrication, arousal, and desire, all of which can produce and or exacerbate the experience of pain during intercourse (Marin, et al., 1998; Nunns, & Mandal, 1997; van de Wiel, & Schultz, 1998; Wonda, Hartman, Bakker, & Bakker, 1998). It is possible that the arousal and desire problems of many women with dyspareunia are linked exclusively to fear of penetration rather than to a more generalized sexual aversion. Marin, et al. (1998), measured the arousal of women with dyspareunia and controls when exposed to erotic scenes. Overall, women with dyspareunia experienced as much physical and subjective arousal to the visual stimuli as did control women. However, when viewing coitus scenes specifically, women with dyspareunia experienced a decrease in vaginal vasocongestion, although they subjectively found the coitus scenes arousing.

Although women with dyspareunia are capable of engaging in many forms of painless sexual expression and foreplay, many are avoiding all types of sexual activity. It could be that they are generalizing the pain to all forms of sexual activity (Gates, & Galask, 2001). Solitary masturbation may be the exception, as women with dyspareunia have reported less frequent problems and distress with masturbation than with sexual interaction (Van Lankveld, et al., 1996). Perhaps they fear that if they engage in any type of sexual activity with their partner, it will invariably lead to a request for intercourse. It is not clear whether negative thoughts regarding sex are related to this lack of sexual interaction, since some women with dyspareunia report more negative thoughts about or aversions to sex (Nunns & Mandal, 1997) and others do not (Van Lankveld, et al., 1996).

Summary

The number of possible causes for dyspareunia seems as varied and unique as the women who experience them. In reviewing the physiological and psychosocial correlates of dyspareunia, it is easy to see how they can overlap and even contribute to one another, so that a woman whose symptoms started out as predominantly physical can quickly develop psychological symptoms as well, or vice versa. Thorough investigation of different subtypes and etiologies of dyspareunia would be helpful in customizing treatment options.

Treatment

Different forms of treatment for dyspareunia have been guided by existent etiological theories and hypotheses. Some treatments have focused on physical causes, emphasizing pain and inflammation reduction, whereas others have attempted to

counteract the psychological impact or correlates of the pain through cognitive behavioral therapy (CBT). However, it has often proven just as difficult to identify whether a treatment falls under the psychological or physical rubric as it is to pinpoint whether etiology is physical or psychological. When successful treatment outcomes are obtained, it can be difficult, if not impossible, to ascertain whether the active ingredient in the treatment was physical or psychological. For example, does progressive vaginal dilatation work by gradually desensitizing the vaginal area and mechanically reducing hypertonicity or is it simply a case of systematic desensitization whereby the woman psychologically habituates in a hierarchical manner to a feared stimulus? Current research has been unable to answer such questions. However, the success of multimodal treatments indicates that addressing both the potential physical and psychological causes and correlates results in the greatest improvement.

Physical approaches

Topical administrations

The least invasive interventions to alleviate pain during intercourse include a variety of lubricants and topical creams. Lubricants may help some women, but, clearly, they are not the solution for most or dyspareunia would have been easily addressed decades ago. Anesthetic gels are suggested to help numb hypersensitive areas; however they cause initial burning in some women with VVS and they may also interfere with the pleasurable sensations of intercourse for both the woman and her partner. They also clearly preclude spontaneity, as the gel has to be applied some time before intercourse takes place. Corticosteroid creams have also been prescribed in an attempt to target the non-specific inflammation evident or hypothesized to exist. Hydrocortisone has also been

administered systemically. Estrogen creams are intended for the possibility that vaginal atrophy is responsible for the pain. Antifungal creams and systemic antifungal agents such as Fluconazole are prescribed when yeast infections are present or suspected. Although there is some anecdotal evidence that some of these treatments have some limited success with certain women, no controlled studies have been conducted with any of these interventions and no clinical reports boast of great success with any of them (Bergeron, et al., 1997).

Hypoallergenic treatments

Based upon the etiological theory that dyspareunia may be caused by an allergic reaction, hypoallergenic/hypocontactant therapy has been attempted. Patients are recommended not to use lotions with perfumes or coloring. Lubricants are avoided, since they may contain irritants. These women are instructed to wear loose, white cotton underwear and to avoid all contact with scented products. They are also advised not to wear panty-liners, as these are potentially irritating. To help ease the pain, sitz baths using crushed ice are also suggested. In a study conducted by Fowler (2000), subjects had four months of this hypocontactant therapy. Between 7 and 20% of subjects had complete response, 57% had partial response and 23% no response. Of those who responded to the therapy, 60% had one or more level of improvement, going from having class 1 dyspareunia (prohibits intercourse) to a class 2 (frequently prevents intercourse) or from a class 2 to a class 3 (causes discomfort but does not prevent intercourse). One of the difficulties with this treatment approach has been adherence.

Anti-depressants

Different types of mood-altering medications have been prescribed to women with dyspareunia. Tricyclic antidepressants, like amitriptyline, desipramine, and nortriptyline have been used to treat dyspareunia. These older generation anti-depressants have long been used to treat other types of chronic pain (e.g., back pain) with some success. The rationale for their use has been two-fold: 1) chronic pain and depression, which happen to be highly co-morbid, may share common neurological pathways and can be concurrently targeted by these medications, and 2) even if the depression is a consequence of the pain, relieving the depression may also help alleviate pain or, at the very least, attitudes towards the pain experience (Meana, 1998). There are many side effects, however, like dry mouth and eyes, palpitation, sun sensitivity and weight gain, making this treatment approach less than optimal. Serotonin-reuptake inhibitors (SSRI's), which have fewer side effects, have also been used. These antidepressants are thought to reduce anxiety and depression by blocking the reuptake of serotonin and epinephrine and helping to reduce the pain by inhibiting the pain fibers (Bergeron, et al., 1997). However, SSRI's also have the common side effect of dampening sexual desire, clearly of particular concern in the case of women with dyspareunia. Again there are no controlled clinical trials testing the efficacy of these mood-altering drugs in the treatment of dyspareunia.

Assorted medical approaches

There have been sundry other medical treatments with only occasional reports of success. Anticonvulsants have been prescribed in attempts to help relax the muscles of the pelvic floor. However, results have been unpredictable. Another medical treatment

which has shown to be successful with VVS patients is interferon injections. Interferon is thought to modulate local cytokines (cells that aid in generating an immune response) or increase levels of natural killer cell activity. Success rates for the use of these injections range from 38% to 88%, with the majority being around 50% (Bergeron, et al., 1997). Some women with dyspareunia have also been found to have high levels of oxalate in their urine. For these women, physicians have prescribed diets low in oxalate, with an augmentation of calcium citrate to bind with the oxalate. To be effective, patients must purportedly adhere to this regimen for at least six months (Stewart, 2003), however, this mode of treatment is still lacking in controlled study support (Bergeron et al., 1997).

Surgery

Surgery has been the most effective form of treatment, especially for those with VVS. The two most commonly performed surgeries are vestibulectomies and perineoplasties. A vestibulectomy consists of the removal of the vestibule (entry of the vagina) by making a superficial excision of a few millimeters of epithelium in a U-shape around the entry, then advancing vaginal tissue towards the opening of the vagina. A perineoplasty involves excision of the vestibule with epithelium advancement over the excised perineum (below the vaginal opening). Abramov, Wolman and David (1994) reviewed the cases of seven patients with VVS who had vestibulectomies. They found that five resumed normal sexual activity within three months after surgery. Pagano (1999), who followed VVS patients for five years after they had received treatment, found significant improvement in 20 of 22 patients who had surgery. Bergeron, et al. (2001) found similar results in treating dyspareunia in women with VVS. Subjects who underwent surgery experienced a 70% pain reduction as indicated by the vestibular pain

index, 52.5% with regards to pain intensity during intercourse, 46.8% as measured by the McGill Pain Questionnaire-Pain Rating Index (MPQ-PRI) scale and 47.1% on the MPQ-Sensory scale. In a review of publications on surgical treatments of vulvar vestibulitis, Bornstein, Zarfati, Goldik, and Abramovici (1999) found that 89% of 646 women who had perineoplasty had a significant decrease in symptoms. Thus, at the moment, these genital surgeries appear to be the most successful with women who have a specific type of dyspareunia, vulvar vestibulitis syndrome.

Physical therapy

Physical therapy has recently become an increasingly popular form of treatment boasting some success. Physical therapy conceptualizes dyspareunia as the body's attempt at protecting itself from pain through a tensing up the muscles involved. This increased tension, however, intensifies the pain, thus producing a negative feedback cycle (Magnuson & Collins, 2002). The goal of physical therapy is to arrest the negative feedback cycle through various exercises such as Kegel exercises, biofeedback, electrical stimulation and vaginal dilatation. Physical therapy has been shown to significantly reduce symptoms from pre to posttreatment as well as to increase sexual desire, arousal and intercourse frequency (Bergeron, Brown, Lord, Oala, Binik, & Khalife, 2002).

Biofeedback is a method common to physical therapy. It involves the relaxation of pelvic floor muscles and the performing of rehabilitating exercises with the use of a portable electromyographic device. Glazer et al. (1995) conducted a study of 33 women with VVS who underwent biofeedback training for a period of 16 weeks. Of the 28 who were abstaining from intercourse at the beginning of the study, 22 resumed sexual activity by the end of the training period. Seventeen reported pain-free intercourse.

Electrical stimulation has also had promising results. After an average of 16 weeks, pelvic floor muscle contractions increased 95.4%, resting tension levels decreased 68%, and instability of the muscle at rest decreased by 62%. Subjective reports of pain decreased an average of 83%. Seventeen of the 33 patients reported pain-free intercourse at 6 month follow-up. At each evaluation, pain decreased from the previous evaluation and muscle stability increased (Glazer, et al., 1995).

Finally, alternative treatments are starting to make their debut into the dyspareunia treatment literature. Danielsson, Sjoberg and Ostman (2001) conducted a pilot study to assess the success of using acupuncture to treat 14 VVS patients. Subjects described three major factors in their lives most affected by VVS, completed a visual analogue scale (VAS) of pain intensity and evaluated two quality of life (QOL) factors from 0 to 10 (ten being the highest quality of life). Thirteen women completed these measures right before treatment, one week after ten treatments and three months after treatment. At the end of treatment, 12 reported their problems as less pronounced than before treatment according to the ratings on negative QOL factors. On positive QOL factors, nine women scored higher right after the ten sessions of treatment. Scores were unchanged for three women and one had lower scores. Although this study indicates potential benefits from acupuncture, further research involving larger sample sizes are needed.

Psychological approaches

Psychoeducation and psychotherapy have long been used in the treatment of dyspareunia, although there are very few studies examining the efficacy for these interventions. Women with dyspareunia have often been told that the pain is “all in their

head” and many have suffered from feelings of dependency, loss and abandonment (Binik, et al., 2000). Learning that their disorder is real and that treatment is available can be very empowering. Basic forms of psychological treatments focus on education about the disorder and pain management strategies: how dyspareunia affects desire, arousal and orgasm; multifactorial views of pain; education about sexual anatomy; the current state of knowledge and options for physical treatments including relaxation techniques, Kegel exercises, vaginal dilation exercises, and cognitive restructuring exercises (Binik, Bergeron, & Khalife, 2000).

The most common style of psychotherapy recommended for dyspareunia is cognitive-behavioral therapy (CBT) (Bergeron, et al., 2003). This type of therapy can help correct counterproductive mental images such as the vagina stretching, tearing and ripping with pain while engaging in intercourse and replace them with relaxing and/or erotic images. With the practice of repeating positive, coping self-statements (i.e., “I am feeling some pain now, but I know how to deal with it”; “I can reduce my pain by imagining pleasant scenes”), the client can replace irrational thoughts which may be causing emotional distress with more measured cognitive responses (Binik, et al., 2000). CBT not only addresses the cognitive arena of mental images, self-talk and psychoeducation but also combines other therapeutic forms of treatment, i.e., pain management, sex therapy, etc.

Pain management techniques are also helpful in teaching women with dyspareunia how to cope with their disorder. They may be asked to monitor the occurrence of their pain over the course of a couple of weeks to ascertain precipitating thoughts and actions which may have a negative impact. Pain management may include

practicing the stages of sensate focus with or without a partner, where the woman is instructed to pay close attention to the sensations of touch, slowly progressing to sexual arousal and penetration. Different types of relaxation may also be recommended such as meditation, visualization, and progressive muscle relaxation. By relaxing both mentally and physically, the conditioned response of tension which exacerbates the pain experienced may be reversed. Hypnotherapy is a type of pain management technique which has also been used to alleviate dyspareunia. A 26-year-old woman, with a history of three years of sexual pain following five years of pain-free intercourse, underwent 12 weekly sessions of psychotherapy, eight of which were hypnosis. No pain was reported following treatment and for up to 12 months afterwards (Kandyba & Binik, 2003).

With the devastating effects dyspareunia can have on relationships, couple and/or sex, therapy needs to be considered to help the partners learn to reconnect and regain intimacy. Sex therapy can assist in resolving many of the issues pertaining to sexual intercourse, as well as other types of couple issues. Couples may have developed negative attitudes regarding sex which need to be addressed. The partner may be experiencing frustration and anger at perceived rejection as well as fear of causing pain. Sex therapy can improve communication by offering ways in which the couple can clearly and frequently discuss ways in which to reduce the pain and what each partner needs sexually. Couples can learn to focus on pleasure rather than performance, expand their repertoire so that the penetration ceases to be considered the “main event,” encourage a less catastrophizing reaction to pain or discomfort and place less pressure on themselves to “succeed” at intercourse while affirming the importance of intimacy, closeness and connectedness over and above any specific sexual act. In addition to

processing emotions and learning new communication skills, couples may also be assigned homework, such as sensate focus and/or vaginal dilation that promote some of the aforementioned goals.

Considering that some of these treatments are more invasive, expensive and time consuming than others, it would be beneficial to have a clear understanding of which treatment is most effective. This answer, however, has not yet been found. Bergeron, et al. (2001) compared surgery, CBT, and physical therapy. At the 6-month follow-up, subjective improvement measures indicated that 68% of vestibulectomy (surgery) participants, 35% of biofeedback participants and 39% of CBT participants had achieved a successful outcome. Those who had surgery reported lower levels of pain during intercourse and lower pain scores during a gynecological examination designed to measure vulvar pain. Interestingly, however, women who underwent the surgery were not engaging in higher frequency of intercourse than women in the other treatment groups. It is also important to consider that there were significantly more women who refused the surgery than women who refused the other two forms of treatment offered in this study. Compared to psychotherapy, surgery is actually less expensive and time consuming. Bergeron, et al. (2002) further suggest that, although the effects of CBT may be slower to appear and that vestibulectomy may be better at reducing vestibular pain, CBT may be as efficient in managing pain and fear of pain during intercourse. Studies have yet to definitively reveal the optimal treatment.

Most clinicians and researchers are recommending the use multimodal approaches to treatment (Binik, 1997; Bergeron, Binik, & Khalife, 2003; Lazarus, 1980). A woman may receive a type of treatment, such as medication or surgery, which relieves the

inflammation and/or vulvar pain. However, she still may be conditioned to the fear of coital pain, resulting in a lack of desire and arousal. The addition of psychotherapy would be beneficial in such a case. Binik, et al. (2000) include gynecologists, clinical psychologist/sex therapists and physical therapists on their multidisciplinary treatment team. Using these various resources, they strive to reduce or control the pain in their patients, help them deal with the negative consequences of having experienced the pain and assist in re-establishing a pleasurable sex life.

In the few treatment outcome studies available, there remains a dis-connection between pain reduction and sex frequency. Treatments that result in pain reduction do not necessarily result in a resumption or enjoyment of sexual activity. This raises important questions about appropriate outcome measures. If dyspareunia is a disorder of sexual functioning, then the main outcome variable should be the resumption of sexual intercourse, not to mention pleasure. If we focus on dyspareunia as a pain disorder, then pain reduction would appear to be an adequate measure of success. There is little question that treatment success would be considered by most to be a combination of both pain reduction and an active, satisfying sex life. Yet, we have yet to find a treatment that improves both pain and sex in the majority of women.

Controversies

Back in the 19th century when dyspareunia was included in treatises on the diseases of women, it was considered a physical ailment with no reference to mental or emotional causes in descriptions of the disorder (Meana & Binik, 1994). With the advent of psychology and psychoanalytic theory, dyspareunia started to be conceptualized as the

somatic manifestation of an intrapsychic conflict or relational problem. For years, women with dyspareunia were dismissed as having emotional problems and treatments consisted either of psychoanalytic explorations or commands to “relax.” The last decade has seen a resurgence of interest in dyspareunia and a general acknowledgement that more sophisticated conceptualizations of this disorder are called for. The work of Meana and colleagues in the 1990’s brought dyspareunia back into the research spotlight and the seriousness of the disorder was highlighted by these researchers’ emphasis on the properties of the pain experienced in dyspareunia. Since then most of the work on the topic has focused on dyspareunia as a pain disorder with little mention of psychological factors contributing to the pain. Some believe that the pendulum has swung too far from the extremes of dyspareunia as intrapsychic conflict to dyspareunia as uncomplicated pain disorder. The current literature is alive with this controversy and the race is on to settle on a conceptualization of dyspareunia, with some favoring its consideration as a sexual dysfunction and others favoring the pain disorder approach.

The arguments for classifying dyspareunia as a pain disorder, spear-headed by Yitzchak Binik, concentrate on the lack of definitional accuracy in the DSM-IV-TR (1994) as well as on the advantages of using pain criteria. Critics of the sexual dysfunction approach argue that dyspareunia would be more accurately categorized as a pain disorder in the DSM namely because it meets all of the criteria for a pain disorder. Dyspareunia appears to have similar pain characteristics as other types of pain (Meana, et al., 1997a). Gynecological exams show different locations of pain from vulvar to pelvic areas. Timing and qualities of pain vary with the different sites as well. The pain qualities listed above would be overlooked if one used the sexual dysfunction criteria to assess

dyspareunia. In addition, the pain classification of anatomical region, organ system, temporal characteristics of pain and pattern of occurrence, patient's statement of intensity and time since onset of pain and etiology (from the International Association for the Study of Pain) does a better job of categorizing those with dyspareunia than the DSM (Meana, et al., 1997b).

By continuing to classify dyspareunia as a sexual dysfunction, it perpetuates the misconception that symptoms pertain to sexual activity only. However, sex is not the only activity that triggers the pain. Women with dyspareunia experience pain with numerous nonsexual activities such as tampon insertion, urination, sports, pelvic exams, etc. Dyspareunia has even been reported by some women as preceding their history of sexual intercourse (Binik, 2005). This disorder, defined by the DSM-IV-TR, as "...genital pain associated with sexual intercourse," does not appear to fit its own description.

A difference in treatment approaches is another argument Binik uses for conceptualizing dyspareunia as a urogenital pain disorder. The mode of addressing chronic pain has included multidisciplinary approaches and methods, focusing on pain control and reduction. This enables treatment to include a combination of treatments ranging from pelvic floor exercises to hypnosis. With dyspareunia conceived of as a sexual dysfunction, women go from medical doctor to psychotherapist to surgeon in the quest to find the right cure without necessarily combining resources and treatments.

Matching the compelling arguments for a pain-centered focus of dyspareunia are equally compelling arguments for retaining some of the psychosocial focus. One of the main reasons why critics disagree with Binik's suggestion is that his findings were based

on VVS subjects predominantly, 46% of cases in Meana, et al. (1997a) and 100% in Pukall et al. (2002). Women with VVS would indeed meet the criteria for having a Pain Disorder, and not Dyspareunia, in the DSM-IV-TR. However, those with VVS account for a small number of dyspareunia cases (Carpenter & Anderson, 2005; First, 2005). Also, it is not clear if the findings of VVS can apply to other types of dyspareunia (Spitzer, 2005). For example, dyspareunia and VVS may have very different causes, making it ill-advised to use the two terms interchangeably, as Binik has done (Grazziotin, 2005; Meana, 2005; Wakefield, 2005). More research needs to be conducted on identifying additional subgroups of dyspareunia and analyzing the existing ones, as found by Meana et al. (1997a), before considering such a drastic change in nomenclature.

If dyspareunia is reclassified as a pain syndrome, then pain specialists will guide the treatment teams. If not currently involved, it is not likely that they will take more interest in dyspareunia cases than the gynecologists and mental health professionals have, as criticized by Binik (2005). It is possible that these specialists may miss the diagnosis, given they have no gynecological training (Grazziotin, 2005). Plus, those in pain management teams rarely encounter conditions which are sexual in nature. Consequently, it is suspect whether they would have the comfort and skill necessary to assist these women (Levine, 2005).

Even if dyspareunia was classified as a pain disorder, the pain disorder category does not list any specific pains, so no one would recognize it as the new diagnostic location for dyspareunia (First, 2005; Meana, 2005). Dyspareunia would be considered a “Pain Disorder Associated with Psychological Factors” or a “Pain Disorder Associated with Both Psychological Factors and a General Medical Condition,” and placed on Axis I

or both Axis I and III. If no psychological component was present, then dyspareunia would be coded on Axis III and given the general diagnosis of Pain Disorder. The previous method of record keeping, specific diagnostic coding and reporting would lose its uniqueness, and it would be difficult to differentiate between dyspareunia and other pain disorders with psychological factors. Failing to identify co-morbid sexual dysfunction would also be an issue, as dyspareunia would be strictly considered a pain disorder (First, 2005; Masheb & Richman, 2005).

Taking dyspareunia out of the Sexual Disorder category does not erase the sexual impact of the disorder (Grazziotin, 2005; Levine, 2005) as most women seek treatment due to the interference with intercourse and not the pain (Payne, 2005). Dyspareunia affects all stages of the sexual response cycle: desire, arousal, pleasure, lubrication, orgasm, etc. (Gates & Galask, 2001; Jantos & White, 1997; Meana et al., 1997a; Nunns & Mandal, 1997; Payne, 2005; Reissing, et al., 2003; van Lankveld, et al., 1997). The high percentage of comorbidity with other sexual disorders reinforces this: 58.1% have reported acquired desire disorders, 50% acquired arousal disorders, and 40.3% acquired coital orgasmic difficulties (Graziottin, Nicolosi, & Caliri, 2001).

The ultimate impact of how dyspareunia is categorized will affect those who suffer from the disorder. For some women, pain during intercourse is the most significant limitation on their daily functioning. For others, it impacts much more than that. Women draw their understandings of their own dyspareunia from the way that others, particularly others considered knowledgeable and in positions of authority (e.g., doctors), react to their reports of pain during intercourse. How dyspareunia is perceived, either through the lenses of a psychological/sexual disorder or a pain disorder will determine who will

primarily treat them, the direction of future research, etc. Many of these women had been told that their problem was all in their head or that they were frigid, dysfunctional, repressed, or sexually abnormal. They had been told this by doctors and therapists alike. The result has been devastating. Meana et al., (1999) found that once women with dyspareunia were finally given a diagnosis, they experienced a huge relief that there really was something physically wrong with them, that they “weren’t crazy.”

Aims of the Study

There is a definite gap in our knowledge of the psychosocial impact of dyspareunia. Before we can consider such a drastic change in classification, we need to collect more information. We know that women with chronic vulvar pain report worse psychosocial functioning than women without (Masheb, et al., 2002), but we do not know to what extent. We know very little about the experience of women who have dyspareunia. How do they conceptualize the disorder? Do they experience it as a pain problem, a sexual problem, a combination or something completely different? Only one study we found attempted to gather this type of information. Gibbons (2000) performed a pilot qualitative study involving in-depth interviews. The four major themes which arose were: (a) perception of stigma and shame associated with having chronic pelvic pain (b) invisibility of such pain syndromes (c) changes in sexuality and relationships with intimate partners and (d) overall feeling of loss of “womanhood” that includes lack of perceived femininity, dignity, and self-esteem.

In an attempt to fill the gap in our knowledge of the psychological/ psychosocial aspects of dyspareunia and of the phenomenological experience of pain with sex, we

conducted a qualitative study with women living with dyspareunia. Through in-depth interviews we elicited women's causal attributions for the disorder, their conceptualizations of the disorder, their view of maintaining factors, their views on their prognosis, their ideas about treatment, the ways in which they cope, as well as the ways in which the disorder affects their self-concept, their sex lives, their relationships and other key aspects of their lives.

Using grounded theory methodology, we built a theory of the experience of dyspareunia that can be subjected to quantitative inquiry in future research. It is curious that with all the controversy surrounding both the cause and treatment of this pain disorder, only a couple of researchers have bothered to ask women themselves what their views are on their own condition. Using this qualitative methodology, we hope to add women's voices to the crowded chorus on the topic of dyspareunia.

CHAPTER 3

METHODOLOGY

Participants

Interviews were conducted with 14 participants, at which point saturation was estimated to have been achieved. The average age of our participants was 19.07 (SD=1.44). Of these women, nine were European-American, three were African-American, one was Hispanic/Latina, and one was Asian-American. Eight participants indicated they had a steady boyfriend, four were single and currently dating, one was cohabitating with her partner, and one was single and not dating. Participants had been sexually active for an average of 34 months (SD=17.73) and had been experiencing pain for an average of 14.23 months (SD=15.20). All were nulliparous. Only five participants had reported their symptoms to a doctor and one had undergone surgery for endometriosis.

Research Approach

Grounded theory methodology consists of strategies aimed at streamlining qualitative data collection and interpretation (Charmaz, 2002). It is often applied at the explorative stage of research when the goal is to gain a specific population's perspective and/or to develop theory (Stern, 1980). The theory is developed through the identification and examination of major thematic categories that emanate from the qualitative data and their relationships so as to best represent the construct being studied (Becker, 1993).

Grounded theory was developed by two sociologists, Glaser and Strauss, in 1967 in an attempt to improve quantitative and qualitative methods by essentially combining them. This new methodology represented a blending of both of their backgrounds, Glaser in positivism and Strauss in constructivism and symbolic interaction. The positivist influence is evident in the methods of grounded theory, such as structured interviews, detailed coding and categorization based on observation. The constructivist ideas in grounded theory are based on the assumption that individuals' realities are shaped by social interaction, which then influence communication and understanding (Fassinger, 2005). The key component of grounded theory methodology is that the theory emerges not from preconceived ideas or a hypothesis but from data itself; hence the theory is *grounded* in the data.

Data is collected via qualitative analysis methods such as in-depth interviews with open-ended questions, open-ended focus group discussions, examination of documents, and direct observations (Krahn & Eisert, 2000). This data is collected and analyzed in a continuous manner such that, in the example of interviews, each interview was analyzed before the next interview was conducted so that emerging themes can be integrated into subsequent interviews (Charmaz, 2002). The identification of themes in the data is conducted through a three-tiered coding strategy: open coding, axial coding and selective coding (Strauss & Corbin, 1990). Open coding consists of transcribing each interview and then breaking it down line-by-line into discrete parts so that themes were identified and labeled. Axial coding involves refining, developing and relating categories to one another, and selective coding puts the categories and ideas together to find the core category.

While coding, the researcher is guided by the following questions: What is going on here? What is this person saying? What are people doing? What do these actions assume? Coding continues with themes being compared, conceptualized and categorized. These themes are examined for dimensions, properties, and relationships to other categories. This continuous examination of the emerging theory is known as the *constant comparative method* of grounded theory (Glaser & Strauss, 1967). As the themes emanate from the data, the researcher is guided by such questions as: What process is at issue here? Under what conditions did this process develop? How does the interviewee feel, think and act while involved in this process? When, why, and how does this process change? What are the consequences? (Charmaz, 1995). Coding continues until *saturation* is achieved, a term used to denote that point at which no new themes are being discovered from additional data (Glaser & Strauss, 1967). Throughout the entire coding process, the researcher engages in memo-writing. This involves documenting thought processes, observations, assumptions and decision-making as they occur. These notes are intended to reflect the researcher's ideas in such a way that another researcher could understand the logic behind the sequences of events and how theory emerged (Charmaz, 1995).

Considering that controversy surrounds how accurately researchers can measure constructs of qualitative research (also true of quantitative research), it is important to address the standards placed on data collection. Some researchers have developed criteria to categorize the data (Lincoln & Guba, 1985) and assess it (Henwood & Pidgeon, 1992), whereas others have outlined principles of good theory construction (Strauss & Corbin, 1990).

In lieu of the traditionally quantitative concepts of reliability and validity, Lincoln and Gruba (1985) adopted the terms credibility, transferability, dependability, and confirmability to describe the “trustworthiness” of a qualitative study. *Credibility* refers to correctly identifying and describing the data by considering different points of view from several different people (researchers, interviewees, people who interact with interviewees). *Transferability* is similar to generalizability of the findings to different settings and different groups of people. *Dependability* refers to another researcher arriving at the same categorization or coding of data, similar to inter-rater reliability. And, lastly, *confirmability* is the extent to which the procedures can be replicated by another researcher.

Henwood and Pidgeon (1992) created seven criteria for assuring rigor in data collection: (1) keeping close to the data refers to the requirement that all categories and information that emerge must source directly from the data, (2) integrating theory at diverse levels of abstraction posits that the theory that emerges must be discernable at all levels of abstraction or coding, (3) reflexivity necessitates awareness on the part of the researcher of the potential bias of his/her personal views and procedures and its effect on the subject and/or themes and theory, (4) documentation requires that the research process track the thoughts, decisions, and observations of the researcher throughout the study, (5) theoretical sampling and negative case analysis refers to the scrutiny of the theory for exceptions, (6) sensitivity to negotiated realities requires that the themes and theory be reviewed by the study participants to check for agreement on interpretations of the data, and (7) transferability of findings refers to the generalizability of the study to other situations. All of these criteria help to hold qualitative research to the standards of

quantitative research, while at the same time acknowledging the difficulty specific to the data and methods employed. As it pertains to theory development, Strauss and Corbin (1990) recommend that a good theory should fit the phenomenon being studied, provide understanding, and be comprehensible to those being studied and others knowledgeable in the area. Grounded theory incorporates rigorous and systematic methods for collecting qualitative data and developing theory. Considering that the aim of this study was to better understand the experiences of women with dyspareunia, this method was ideal due to its rigorous and systematic procedures for collecting qualitative data and developing a theory. In this way, it is hoped that the theory or theories that evolve may be of considerable benefit to the participants as is stipulated in the principles of grounded theory (Turner, 1981).

Measures

Female Sexual Functioning Inventory (FSFI: Rosen, Brown, Heiman, Leiblum, Meston, et. al, 2000)

The FSFI was used for screening purposes. This instrument is composed of 19 questions pertaining to six domains: desire (items 1 and 2), arousal (items 3 through 6), lubrication (items 7 through 10), orgasm (items 11 through 13), satisfaction (items 14 through 16) and pain (items 17 through 19). Each item represents a separate component of the domain (i.e., frequency, difficulty, and satisfaction). The items addressing sexual pain query the frequency of discomfort or pain during vaginal penetration, frequency of discomfort or pain following vaginal penetration, and the level during or following vaginal penetration. Possible responses to the items on frequency of pain include: Did not

attempt intercourse, Very high, High, Moderate, Low, Very low or none at all. For the item regarding level of pain, options for responding are: Did not attempt intercourse, Very high, High, Moderate, Low, Very low or none at all (SEE APPENDIX I).

Participants will be selected if they respond with “Sometimes (about half the time)” or above to items 17 and 18 and “Moderate” to item 19. The FSFI has been found to have high test-retest reliability ($r = .79 - .86$), high internal consistency (Cronbach’s alpha values of 0.82 and higher) and acceptable discriminate validity as demonstrated by significant difference between scores of women with female sexual arousal disorder, female orgasmic disorder, hypoactive sexual desire disorder and control groups (Meston, 2003; Rosen, et. al, 2000). Divergent validity has been found by using the Locke-Wallace Marital Adjustment Test (Meston, 2003).

Background questionnaire

A background questionnaire collected information regarding age, ethnicity, relationship status, number of children, onset of dyspareunia, whether or not a diagnosis has been attained, and the types of treatment administered (SEE APPENDIX II).

Semi-structured interview

A semi-structured interview was conducted (SEE APPENDIX III). Participants were asked questions regarding the impact of dyspareunia on their lives. The questions and prompts in the interview were constructed to encourage participants to elaborate the following dimensions of their personal experience with dyspareunia: description, perceived etiology, functional expectations of future impact, interference, social and medical support, and perceived prognosis.

Procedure

Participants were recruited from Psychology 101 classes via two different routes. In the first, an announcement was made asking female students to participate in a study on female sexuality. Those who were willing then were asked to complete the FSFI. On the last page of the questionnaire, the participants were invited to leave a phone number for us to contact them if they would be interested in participating in a study for research credit. The completed FSFI's with phone numbers were then scored and those that endorsed dyspareunia were selected. Those individuals were contacted and if they were still willing to be interviewed, arrangements were made for a mutually convenient place and time. The second method of recruitment involved placing an announcement in the subject pool website announcing that we were looking for women who had pain with intercourse. Those who called the phone number provided were then administered the FSFI over the phone and if they qualified, arrangements were made for the interview meeting.

Participants received a brief description of the study, were informed of their confidentiality, and reassured that they could withdraw from the study at any time. These participants were reminded that the open-ended interviews would be audio-taped and any concerns they had were discussed at that time.

Data Analysis

All audio-taped interviews were transcribed by the researcher and then reviewed via the three steps of coding. First, each line was analyzed according to what theme might

be present (open coding). After identifying all possible themes, each theme was then compared to each other and organized into categories (axial coding). This process of coding was completed before conducting the next interview, so that emerging themes could be incorporated into subsequent interviews. Selective coding was conducted once all interviews had been conducted.

In an attempt to maximize reliability and validity, this procedure for data collection and analysis adhered to the following procedures, based on Henwood and Pidgeon's (1992) recommendations:

Reflexivity

In light of the difficulty of removing subjectivity from the process of analyzing and interpreting data, it is important that the researcher document his/her own biases both a) as a way to raising awareness of biases in the hopes that this awareness and disclosure makes it less likely that the bias will interfere with the coding of data, and b) as a public disclosure so that evaluators of the ultimate theory can be fully informed of the possible effects of these biases on the research process. This disclosure is called *bracketing* in the qualitative research and is conducted prior to data collection. The primary investigator's biases about the experience of dyspareunia are provided in Appendix IV.

Detailed documentation of the research process

Another way of remaining as transparent as possible about the process that led to the evaluation of the theory is to give as much detail as possible in regards to the research process. To that end, the primary investigator provided a list of all open-coding themes, detailing which of these were subsumed under which axial codes, and finally which axial codes were further subsumed into selective codes. Then a narrative explanation of how

the selective codes were further elaborated into a theory is provided. In this fashion, the process of theory building will be open to evaluation.

Keeping close to the data

It is essential to ensure that the data and the theory are a good fit. This criterion thus centers on verifying that the categories that form the theory are reflective of the data gathered. We accomplished this by having a second researcher (the research supervisor) engage in the coding of data at the open and axial stages, independently of the primary investigator. When both had completed their open and axial stage coding, the two researchers met to evaluate agreement on codes and emerging themes. Disagreements were discussed until a code/theme that both researchers felt was accurate to the data was arrived at.

Negative case analysis

This criterion refers to the sampling and examination of cases that may be inconsistent with the developing theory, in an effort to test the accuracy of initially formulated categories, guide modifications of the theory, and ultimately build a rich, complex theory.

Theory evaluation

Further testing of the theory's validity and usefulness was conducted by evaluating the theory as to its clinical significance in contributing to knowledge about the phenomenological experience of dyspareunia and the extent to which this knowledge can inform current treatment approaches. This evaluation was of a qualitative nature and is presented in the discussion of the final thesis document.

CHAPTER 4

RESULTS

In total there were 369 women screened for dyspareunia from Psychology 101 classes and from the Subject Pool. Of those participants, 325 (88.08%) indicated they were interested in participating in later stages of the study by leaving their contact information. Twenty-three of these 325 (7.08%) had responded to the FSFI in a non-random fashion and met criteria for dyspareunia on the FSFI. Fourteen of these 23 women (61.87%) were successfully reached and agreed to be interviewed. These 14 women constituted our final sample.

Pain Characteristics

Pain with intercourse varied in terms of lifetime onset (primary or secondary), location, duration, description, and severity. Four participants reported the pain to be primary (present from first intercourse attempt) while the rest of participants reported that the pain had started after an initial period of pain-free intercourse. The location of the pain ranged from the introitus (entry of the vagina), to within the vaginal canal to deep in the pelvic region and combinations thereof. Seven of the participants reported pain introitally, seven reported pain within the vaginal canal and seven reported pelvic pain. Ten of the 14 participants experienced pain in more than one area. All participants reported the pain to occur during intercourse. Three also reported the pain to persist some

time after intercourse. The most common descriptors of the pain were consistent, burning, throbbing, stabbing, pressure, tearing, sharp, cramping, stretching, ripping, irritating, stinging and tight. Severity of the pain ranged from uncomfortable to very severe.

Reliability Analysis

Each transcribed interview was coded by two independent raters. The percent agreement between raters on themes present in the interviews was .84, indicating good interrater reliability. When differences arose or when only one researcher noted a theme, the two researchers discussed whether or not to include the theme in question. Themes were only included in the final analyses when both researchers agreed that the data supported the theme, even if one rater had originally missed it. Thus all themes listed and discussed had unanimous agreement by both researchers, either from their initial coding or after discussion and reference to data support.

The Emergent Theory:

A Cognitive-Behavioral Model of Early Dyspareunia Experience

The construction of the emergent theory involved collapsing first order themes, originated from line-by-line analysis of the transcripts, into broader second order themes. These second order themes were then further collapsed into categories from which a sequential model was then derived. Table 1 outlines the process of theory building from right to left, starting with first order themes, then collapsed into second order themes and then further collapse into major model categories.

Table 1 Construction of the emergent theory

Categories	Second Order Themes	First Order Themes
Problems Identifying Disorder	No outside information available	<ul style="list-style-type: none"> • Not covered in health class • Never informed by doctors • Parents, family did not educate about this
	Not disclosing because of embarrassment (no confirmation of experience)	<ul style="list-style-type: none"> • Lack of disclosure to boyfriend, mother, sister, friends • Considers the topic to be private • Embarrassed to have a sexual problem
Cognitive Search for Causal Attributes	Does not know what is causing the pain	<ul style="list-style-type: none"> • “I don’t know” response to what could be causing the pain
	Anatomy	<ul style="list-style-type: none"> • Penis too big • Vagina too small
	Infection	<ul style="list-style-type: none"> • Recurrent yeast infections • Urinary tract infections • Sexually transmitted diseases
	Unknown medical	<ul style="list-style-type: none"> • Arthritis in hips? • Endometriosis?
Personal Cognitive and Behavioral Attempts to Control Pain	Distract thoughts	<ul style="list-style-type: none"> • Focus on partner’s pleasure • Mentally shut down • Think of anything except for sex
	More Foreplay	<ul style="list-style-type: none"> • Spending more time doing anything but penetration • Focusing on getting and giving pleasure via alternate means
	Changing Sexual Activities/Position	<ul style="list-style-type: none"> • Certain positions are impossible; others are enjoyable • Inclusion of clitoral stimulation • Less focus on penetration
	Lubricants	<ul style="list-style-type: none"> • Using lubrication especially when not as turned on
Accumulating Impact/Consequences on Relationships	<u>Decrease in Sexual Function:</u> <ul style="list-style-type: none"> • Desire • Arousal 	<p>Anxiety about sex; less desire than before</p> <ul style="list-style-type: none"> • Decrease in physiological and subjective arousal

	<ul style="list-style-type: none"> • Orgasm • Avoidance • No initiating 	<ul style="list-style-type: none"> • Fewer orgasm, less frequent • Attempts to avoid intercourse • Hesitant to initiate due to anxiety
	<u>Problems in Relationship:</u> <ul style="list-style-type: none"> • Lack of emotional connection • More fights • Partner upset • Fears partner will cheat • Fears partner will leave 	<ul style="list-style-type: none"> • Feel something is missing from relationship • Fighting over not wanting to have sex and little issues • Partner is angry, frustrated, does not understand • Worried partner will find someone who can satisfy him sexually • Worried stress is too much and partner will leave relationship
Accumulating Impact/Consequences on Self	<u>Emotional instability</u>	<ul style="list-style-type: none"> • Increased moodiness • Anything makes her go off
	<u>More negative emotions:</u> <ul style="list-style-type: none"> • Anger • Depressed • Frustrated • Embarrassed 	<ul style="list-style-type: none"> • Angry at self, situation • Sad, cries a lot, disappointed, worried, loses sleep over it • Frustrated at self, situation, partner • Compares self to others and is embarrassed to have this problem
	<u>Negative effect on self-esteem:</u> <ul style="list-style-type: none"> • Not normal • Decrease in self-confidence 	<ul style="list-style-type: none"> • Something is wrong, not normal, weird; feels incomplete • Does not feel “good enough;” increased insecurity
Barriers to treatment seeking	<ul style="list-style-type: none"> • Belief in its disappearance • Doubt medical assistance • No belief in a cure • Fear of severity • Do not want to admit to having had sex • Fear stigma 	<ul style="list-style-type: none"> • Thinking it will just go away one day • Does not think doctors can do anything better than what has been tried already • Fear it will not go away, will just have to deal with it, disbelief in a cure • Fear the doctor will say it is cancer or worse, that it will not go away • Concerned parents will find out no longer a virgin • Worry that others will judge them as

	<ul style="list-style-type: none"> • Not a medical problem 	<ul style="list-style-type: none"> • being promiscuous, having an STD, etc. • The pain is a sexual problem and should be dealt with within the relationship, not by a doctor.
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The core process that emerged from participants' descriptions of their early experience of dyspareunia was one that started at the first experience of pain and proceeded through a set of cognitive and behavioral processes that led to the decision-point of whether or not to seek treatment by the time they had enrolled in our study. Pain at first intercourse was generally not experienced as particularly alarming, as women tended to think that it was transitory and most probably a function of it being their first experience. However, as it became evident that the pain was recurrent, women sought to understand what was happening to them and why. They experimented with a variety of options in order to control the pain, the majority of which failed to bring significant relief. The pain also began to impact the women personally, especially in terms of their relationships. With the pain worsening or failing to abate and with the accumulation of both personal and relational consequences, the women arrived at a point at which they deliberated on whether or not to seek treatment. In our sample, it seemed as if women sought treatment predominantly when the benefits of doing so appeared to outweigh the costs or barriers. Our sample identified a number of barriers and no clear incentives for treatment-seeking.

Grounded in participants' accounts, this emergent theory proposes that many young women with dyspareunia may undergo a similar process in their early experience of pain. This process has both cognitive and behavioral components that unfold from the

first experience of pain to the point at which they decide whether or not to seek treatment. In light of the scarce public health information available about dyspareunia, their cognitive, lay interpretations of their intercourse pain may be an important factor in treatment-seeking. Behaviorally, the results of personal attempts to resolve or ameliorate the pain also contribute to the formation of their cognitive representations of the pain and whether or not there is likely to be a resolution to it. For a schematic representation of the proposed cognitive-behavioral theory of early dyspareunia experience, see Figure 1.

In addition to the development of this general model of how early dyspareunia experience may unfold, we have provided the details of how that experience was more specifically lived by the women in our sample. A detailed elaboration of the grounded theory is presented below in the words of the participants themselves. For a schematic representation of the theory as presented by our sample, see Figure 2. The following sections of this results section flesh out each of the model's components as per the specific experience of the women in our sample.

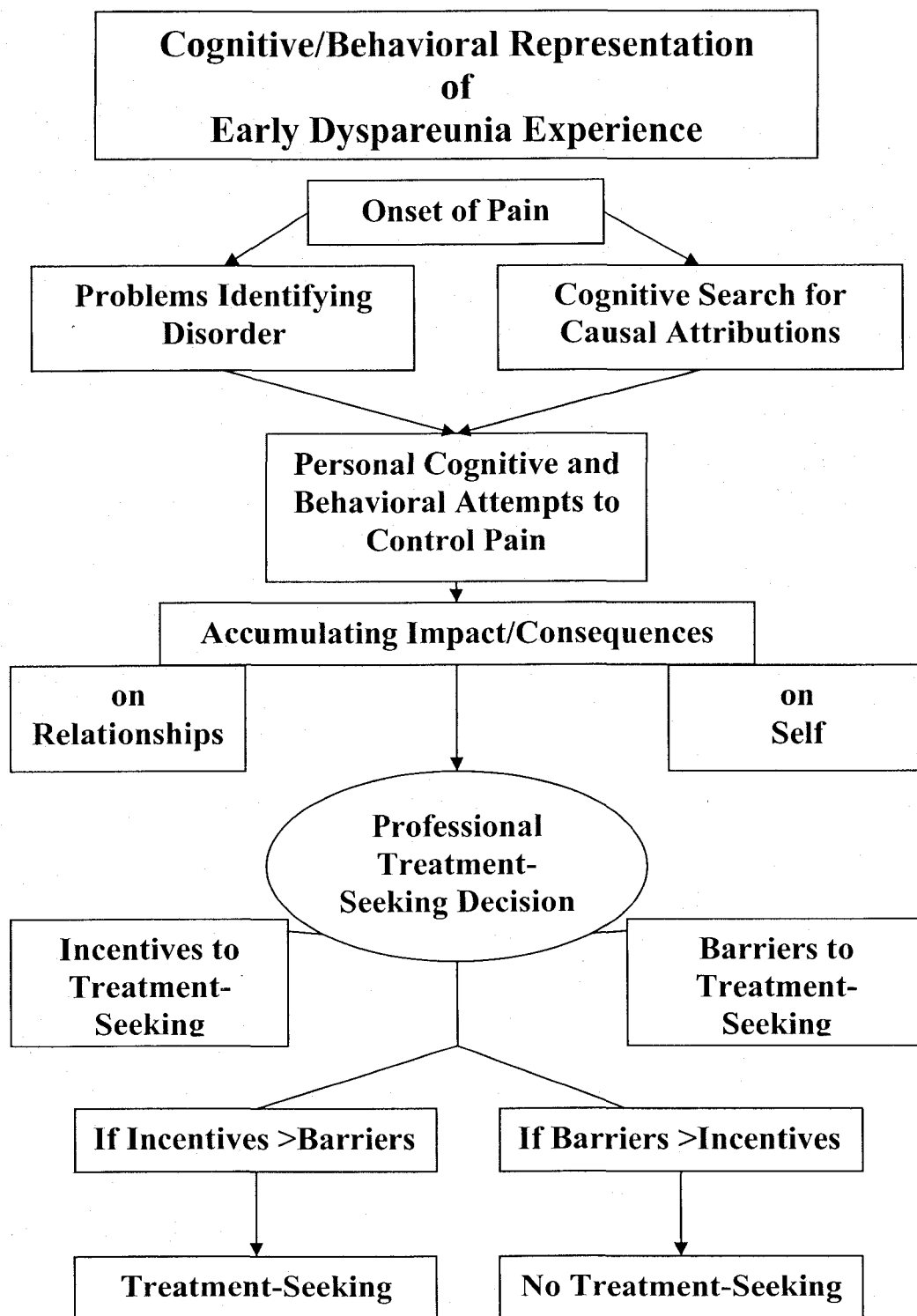


Figure 1

**Cognitive/Behavioral Representation
of
Early Dyspareunia Experience: Current Study**

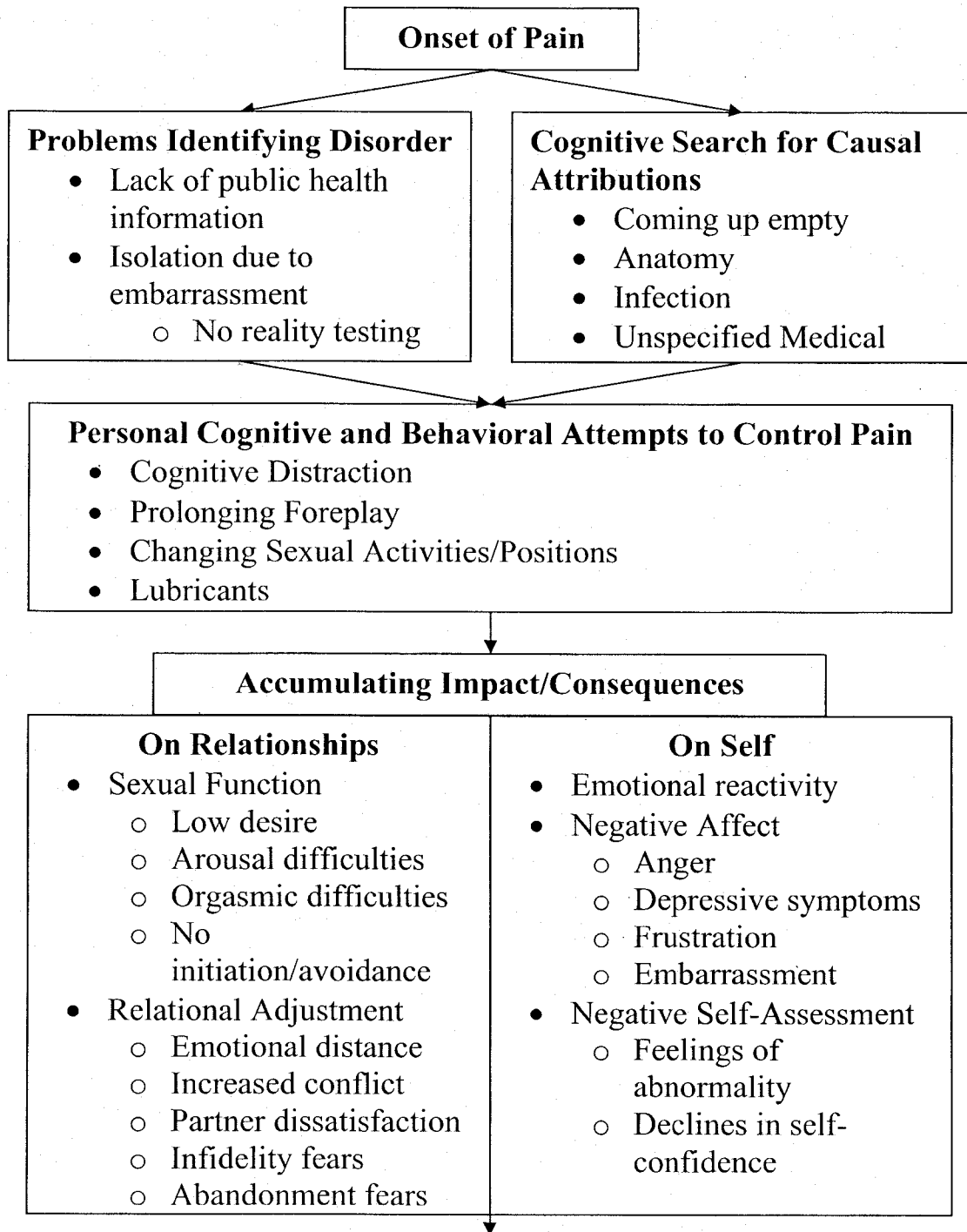


Figure 2 (cont'd on next page)

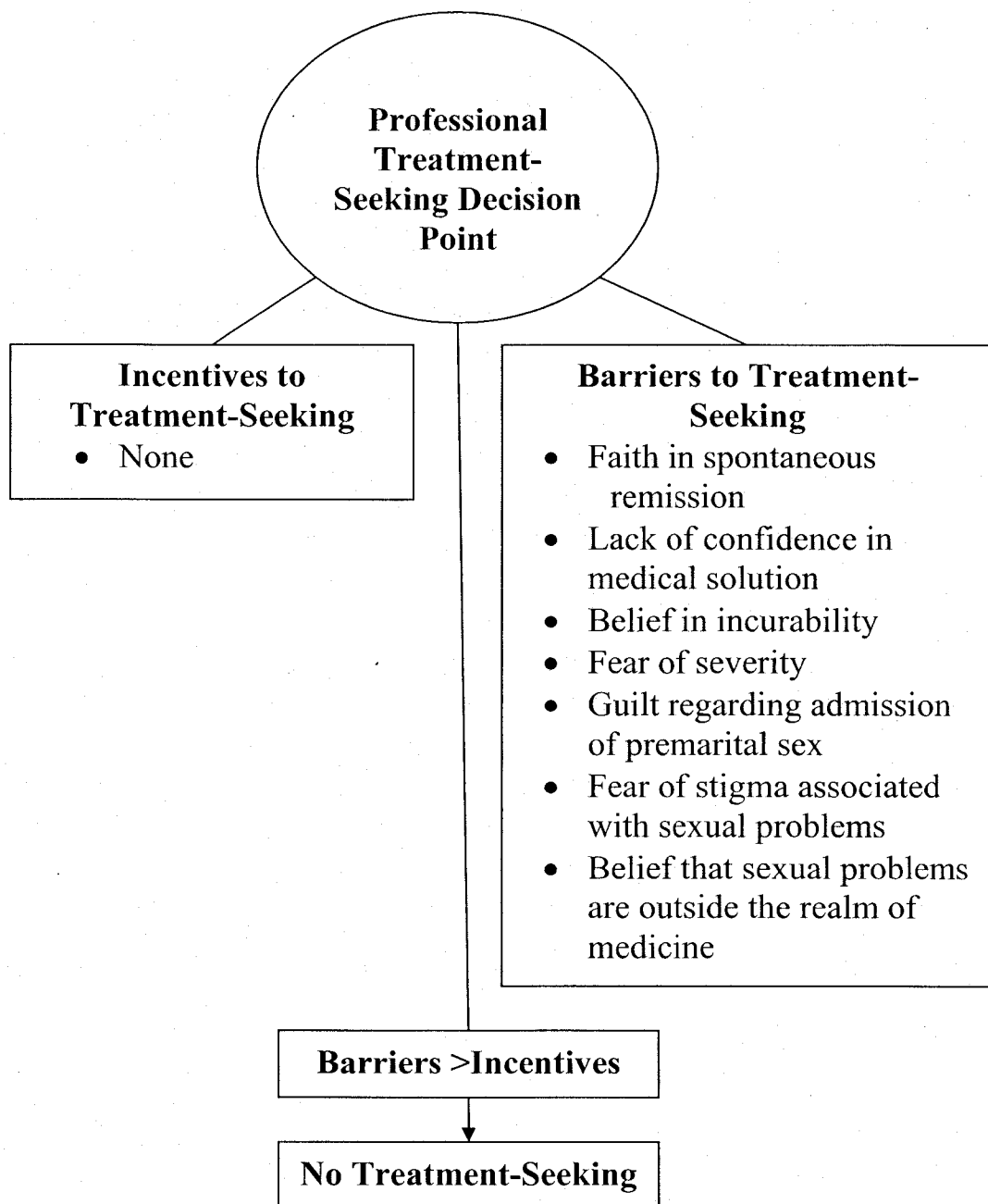


Figure 2 (Continued)

Problems identifying the disorder

Participants consistently reported not being able to identify they were experiencing a symptom of a recognized disorder. First, it is not unusual for the first intercourse experience to be anywhere from uncomfortable to painful for a significant number of women. Thus, pain with first intercourse did not immediately indicate a problem. However, even when they started to realize that the pain was not going to go away, the women still had difficulty conceiving of it as a disorder.

Well, I didn't even think it was a disease or a disorder or anything. I never thought about a cure. A cure is usually associated with a disease. I never really thought of it as a disease.

Most, however, acknowledged that something was amiss and that they were fairly certain that most other women were not having the same experience. Importantly, few of the participants reality tested with friends or family members. They had difficulty disclosing their problem primarily out of a sense of embarrassment about having a “sexual problem” and fear that others might judge them. Many also doubted other people’s ability to relate to them and so did not seek advice.

If there were people who could relate to me, it would make a difference... but (telling) people how I feel...who don't really know how I feel? I don't think that would help me at all.

The difficulty in the participants’ ability to acknowledge their pain as part of a disorder is likely to be the consequence of a lack of public health information about prevalent problems that can impact sexual function. Most of these women had learned about sex from their mothers, sisters or close female relatives, none of whom knew any more about dyspareunia than they did. Sexual dysfunction is not commonly addressed either in sexual education or health classes or by most gynecologists. Thus, considering

the isolation of having a sexual problem that is not easily shared with others and the lack of easily accessible public health information about pain with intercourse, it is not surprising that these women did not know what exactly was wrong with them or how to address it.

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

Search for causal attributions

The attempt to understand causation, generally speaking, is a central cognitive activity. Although women clearly had difficulty identifying and labeling the disorder from which they suffered, this did not stop them from trying to figure out what was causing it. The following themes were common in their attempts.

Coming up empty

The large number of participants responding, "I don't know," when asked why they thought they had pain with intercourse underlines the confusion they felt in regard to their problem. Almost every participant expressed ignorance about possible causes. Some were able to generate some hypotheses when prompted by the interviewer to say whatever had crossed their minds, but these speculations lacked conviction. The women expressed little confidence in their lay causal theories for dyspareunia. The most common sentiment is illustrated with this quote from one participant, "*I have no idea, I'm not even sure why the pain is there to begin with.*"

Anatomy

Several participants considered the pain to possibly be caused by an anatomical discrepancy between partners; her partner's penis was too big and/or her vagina was too small. Women who started experiencing the pain with their current partner would often ascribe the problem to his penis size, whereas those who had had pain with multiple partners questioned their own genital proportions as a possible culprit. The following woman considered all possibilities:

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

Infection

The pain was sometimes attributed to various infections, yeast and urinary tract infections being the most predominant. This is not surprising, as women sought to identify other problems that had affected their genitalia and wondered about the connections between intercourse pain and these other problems.

I think it's a lot of factors. I've had problems in the past with yeast infections and stuff like that, so basically the whole sexual experience I've had, hasn't been, overall, the best.

A couple of women also wondered if their pain could possibly be a side-effect of a sexually transmitted disease.

Unspecified medical reason

Some participants reported that they thought the cause of their pain was probably medical in nature, but they did not specify what type of medical problem could be responsible for pain limited to sexual intercourse. This non-specific guess seemed to be offered up as an assertion that there were no significant psychological or relational problems that could reasonably account for the dyspareunia.

Previous sexual experience

Some women thought the pain could be explained by sexual experiences they had had in the past. Some invoked having had too much sex, others mentioned bad relationships, and one thought the pain might be linked to a rape.

I'm healthy overall. I just have had bad experiences with sex. And I think the bad experiences lessen the amount of time I want to focus on the sex, engaging in sexual activity, or anything. I just don't want to do it as much.

Cognitive and behavioral attempts to control pain

All participants, whether or not they had any idea what might be causing their pain, engaged in different types of ameliorative efforts. These attempts to self-treat or simply manage the pain consisted of both cognitive strategies and behavioral modifications. None were particularly successful in making the pain go away. The following are the most commonly reported measures taken.

Cognitive distraction

Many participants reported using some form of cognitive distraction to take their attention off the pain they felt during sex. The types of cognitive distraction varied. Some indicated they used mantras, repeating to themselves that the pain would be over soon or that it did not hurt that much. Others focused on the positive aspects of sex, including the pleasure of their partner, and yet tried to occupy their thoughts with anything other than sex.

I wouldn't think about it. I would think about going to the mall or what I was watching on TV- anything to get me out of the situation and thinking about something else.

Prolonging foreplay

Attempting to increase and prolong foreplay appeared to be a common strategy in assisting women to endure their sexual encounters. The longer they could spend on sexual activities other than penetration, the better. The purpose of prolonging foreplay was two-fold. On the one hand, it delayed the painful moment of penetration, while on the other it increased their subjective (feeling turned on) and physiological arousal (lubrication), which made penetration easier and less painful.

Changing sexual activities/positions

Others tried to expand their sexual repertoire so as to de-emphasize intercourse as the only route to orgasm. Most women had experimented with different intercourse positions and had found that some were definitely less painful than others. No one particular position worked best for all participants, possibly suggesting different locations in which the pain was felt. For some, assuming the superior position (woman on top) resulted in the most pain reduction, whereas for others that position proved to be the most painful. The following participant, in particular, had the most success with “spooning” (lying side-by-side):

There are certain positions like when he is on top that help out, but if I am on top it does not feel good at all for me. If we are, I don't know what you'd call that, spooning each other? That kinda feels a little better. The worst one is when I am on top.

Lubricants

The use of lubricants brought a limited amount of relief for some of these women, especially those who described their pain as a “tearing” sensation. However, one woman had an allergic reaction to lubricating products and others found that it had no impact on their ability to continue having sex because the pain remained unacceptably high.

Accumulating impact/consequences on relationships and self

While these women were struggling to understand why they were experiencing the pain and engaging in thoughts and behaviors to relieve it, they were beginning to experience detrimental side effects in their romantic relationships and in their feelings of self-worth.

Relational impact

Sexual function

Given that dyspareunia is a sexual pain disorder, it was not surprising that the impact on sexual functioning for these participants was severe. The experience of pain affected all areas of their sex lives from desire to arousal to orgasm.

Lower desire

Soon after experiencing the pain, most participants reported experiencing a decrease in sexual desire. The activity of sex, which was supposed to give them pleasure, now had a negative association and was simply not enjoyable.

I just can't, I don't want to do it. I never come home and just want to have sex anymore. Or I'll never, when I get home from the club, I'll never want to go have sex. I'd be fine just going to sleep. But it used to be, when it didn't hurt, that I'd just want to do it or things like that.

Arousal difficulties

Most participants indicated that the pain made it difficult to become subjectively, as well as physically, aroused. For many, it was even difficult to get aroused with non-penetrative foreplay activities, as they could not help anticipating the pain they were surely to experience when penetration happened. This anticipatory anxiety interfered with mental and emotional feelings of arousal, as well as with physiological arousal processes

such as lubrication. This interference made the pain even worse than it would have been had the arousal process been instated.

Honestly, since I've been having this severe pain over the last year I haven't wanted to (have sex) because I think the few times I've attempted it was very painful and I couldn't get aroused and it's just not worth it.

Orgasmic difficulties

Nearly all women who indicated having had orgasms before the onset of dyspareunia, reported that the pain had interfered with their ability to experience orgasms. In some instances, the women were not able to achieve orgasm at all because they were no longer engaging in the types of sexual behavior that had previously facilitated orgasms. One woman would try to endure penetration as long as she could so as to reach orgasm, but it felt like a race between the pain and the arousal.

I am focused on the pain. It hurts and so your focus is more on, like ok I just want this to end because it hurts - then I want it to keep going so I can reach orgasm.

No initiation/avoidance

Considering how unpleasant sex had become for them, it is not surprising that most of the women we interviewed found it difficult to initiate sex and some actively avoided it as much as possible.

I never want to have sex now. There is never a time when I initiate it. Never. It's always him coming to me, and half of the time when he comes to me, I have to turn him down, because I'm not in the mood, and nothing he does can turn me on.

Relational adjustment

The impact on romantic relationships ranged from changes in how they felt about their partners to how they perceived their partners to be affected. The frequency of sexual activity, which generally promotes intimacy in a relationship, in all cases greatly decreased and this caused ripples of disturbance in their interactions. The following are

the most common ways in which the women we interviewed described the impact of pain with intercourse on their relationships.

Emotional distance

Women reported that not being able to connect with their partners on a physical level resulted in emotional distance. In their avoidance of this intimate activity, there was a loosening of the bond between them and their boyfriends.

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

Some women put distance between them and their partners so as to not have to engage in sex with them.

It makes me distant with my partner. At times I don't want to have sex because it's not as enjoyable for me as it is for him. So, I guess sometimes I feel guilt in that. So yeah I guess I do get mad and pissed off at the situation sometimes.

I kind of would try to push myself away from him, try to distance myself from the whole situation rather than make him feel better for something that I am having to deal with personally.

Increased conflict

The tension created by difficult sexual relations often led to an increase in arguments. For some, the fights directly related to the woman's problems having sex. However, most often the pain was an underlying cause for the increase in emotions which then resulted in arguments over insignificant differences of opinion. The following two women described how the increase in conflict in their relationships was a combination of the pain and their feelings toward their partners:

I'm just usually angry and then we usually get into fights and he's not sure why because I won't tell him. I really don't think it (the problems with intercourse) matters to him. It just frustrates me.

I mean, we don't really fight, but sometimes we do get into heated discussions and small fights about almost anything and it's just frustrating sometimes.

Partner dissatisfaction

At some point, participants were no longer able to pretend it did not hurt or that there was no problem with sex. Some couples were not able to continue having sex the way they used to and sometimes this would upset the men. Some partners became angry and frustrated when the participant would not want to have sex or would have to stop. Others seemed to resent the fact that sex was not as frequent as it had been. One woman noticed the connection between not having sex and her partner's behavior:

I notice if we were to have sex one day, the day would go good. We'd have a good day and sometimes I feel like he's just angry or has built up inside that I've been telling him "no" for two days so now he wants to have an attitude problem or something like that. And of course he won't admit, "I'm mad that we haven't had sex," but I know that. I'm not stupid. So I know that that's one of the reasons. Maybe he just has an attitude cause of something I said, but I know that on top of what I said, he has that on his mind as well.

Infidelity fears

As problems developed in the relationship and sexual intimacy declined, insecurity set in and couples questioned whether their partners were remaining sexually faithful. Participants were concerned that the lack of sex in the relationship would cause their partner to fulfill their sexual needs outside of the relationship.

He's in the military, he went home on leave for a couple of weeks and it was like in the back of my head like oh, he is probably out with all of his friends and he is going to find somebody and he is going to realize that he can find somebody who is going to do that for him and satisfy that need.

As reported by our participants, some of their partners also perceived the participants' lack of interest in sex as a possible sign that they were seeing someone else.

He thinks I am cheating because I don't want to have sex anymore. He thinks that I am attracted to someone else. He'll blame my close guy friends because he thinks that it is them that I'm cheating with.

Abandonment fears

Apart from specific fears about infidelity, women in this study also feared that their partners would decide that they could no longer handle the relationship and the problematic sex life and essentially break up with them – even if there was no one waiting on the sidelines. This was especially true for couples for whom sex was practically non-existent.

In the beginning when we weren't having sex at all, I was extremely concerned, but that was when I had very low self-esteem and I think that played a major part in feeling like that he would just leave because I wasn't going to have sex with him.

Impact on self

Emotional reactivity

The stress of experiencing pain and its impact on their relationships made many women more “moody” and undergo a wide range of strong emotions in short periods of time. Some reported being much more likely to “fly off the handle” and over-react to what were essentially insignificant occurrences. The affect was almost always negative.

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

When you have something hanging over you like that you know, you are more bitchy. Not as caring about certain things.

Anger

Women reported feeling angry at times. The target of their anger was sometimes themselves and their bodies, while at other times they felt angry with insensitive partners.

They even felt angry that they could not enjoy sex the way they had previously or the way they had thought they would.

Well after I stop (the sex), he gets mad, so that makes me mad. And it's always me that's stopping it, so I feel bad for myself and because I'm doing it to him.

Depressive symptoms

Some women cried more often, others felt a significant sadness related to their pain with sex. Most reported some type of depressed affect.

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

Frustration

The main response most participants had to experiencing the effects of pain with intercourse was frustration. They reported feeling frustrated about having to stop, not being able to fix the problem, and about not feeling normal.

The noncure at the moment. That type of situation is very frustrating.

It's frustrating too because I like sex but to feel like that (pain) definitely changes your mind. You shouldn't have to feel that way about something like that.

I wanted to please him but it was so frustrating, all of that stuff was happening at once. You just have to take baby steps, you have to deal with this stuff. It is like everything is pushing on you all at once, like your relationship not being able to be satisfied and not being able to satisfy that person.

It is frustrating because most people don't have to deal with it so why do I? And it gets better and then it gets worse and it's kind of confusing because you never know. Is it going to hurt this time or is it not? So, frustrating and confusing.

It frustrates me because I always wonder if the guy that I'm with feels like it's his fault or feels like I don't want to be with him, like I'm making up excuses or feels like he wants to be with a girl that can do whatever position any time he would like. Because I don't have that ability. So those three things frustrate me and I enjoy sex. I consider myself a very sexual person so it really bothers me when I feel sexually aroused, but it hurts so much I can't do it. It's really annoying.

Embarrassment

For certain participants, having pain with intercourse was embarrassing and that embarrassment prevented them from seeking support from family members or friends.

Sex was generally considered a private topic for these women and having sexual pain was considered by many to be somewhat humiliating.

Well, I don't talk to other girls like this - I know a lot of girls that go out and drink coffee and talk about their sex life and all that but no-I'm too embarrassed to talk about it. I don't talk about it.

He's like my best friend too, so I don't always think about it, but when it starts to come up or if we're with friends and they start to talk about their sex lives, then I kind of want to walk away, I don't even want to be around cause I just kind of feel embarrassed and I'm just like oh please... cause I know what he's thinking. He's probably thinking oh she's in pain all the time. Our sex life isn't that great. So I just kind of feel embarrassed, and so I just kind of want to walk away when someone talks about it.

Negative self-assessment

Having dyspareunia appeared to have negative consequences on how participants viewed themselves. These women felt separate from the rest of the female population because they could not perform sexually and have normal relationships and they suffered from insecurity, low self-confidence and self-doubt.

Feelings of abnormality

On some essential level, the women in our study did not feel normal. Surrounded by friends who talked about sex gleefully, they felt damaged in their inability to share in that pleasure. The experience was described as isolating and internally stigmatizing.

I went into this thinking like, I am abnormal. I am different. Like, something's wrong.

I'm just not normal like everyone else.

Declines in self-confidence

Our participants reported decreases in self-confidence. They did not feel sexually desirable and they felt they were bad sexual partners. Some compared themselves to “normal” women who did not have dyspareunia and focused on their shortcomings.

I have noticed since I've been experiencing the pain, I don't dress as sexy as I used to.

I got very insecure with myself Insecure with the fact that there are other girls out there that can do more than I can.

Professional treatment-seeking decision point

After attempting to discern the source and cause of their pain and making efforts to alleviate the symptom, the women would reach a point at which they judged the effects of the pain on themselves and on their relationships to exceed their ability to handle this situation on their own. At this point they considered whether or not to seek treatment. Our sample of women with dyspareunia reported no incentives for seeking treatment, although the obvious incentive would be to possibly resolve the problem. The major problem was that they did not believe a resolution probable. On the other hand, the barriers they could summon for not seeking treatment were numerous.

Barriers to treatment-seeking

Faith in spontaneous remission

Some participants had not sought treatment because they thought the pain would improve on its own. They manifested a belief that the pain would fade away without any major intervention.

I'm pretty hopeful that it will just go away. That this is just something that is going on with my body right now and is changing or whatever is going on and that it will just one day be gone.

Lack of confidence in medical solution

A significant barrier to women seeking treatment was their belief that the medical profession would have no effective intervention. It is difficult to ascertain why these women doubted the ability of doctors to address their problem, except for the fact that some had seen a gynecologist for other reasons and the gynecologist had not spontaneously volunteered that he noticed anything amiss. This is curious, considering that they had not told the doctor about the dyspareunia. One woman felt that if she had not been able to figure out what to do, a doctor would not know much more.

The doctor may know something about it but he'd probably say something like he didn't know what caused it. That he didn't know why women felt pain.

Belief in incurability

Without the anchor of knowing what a probable cause for the pain could be, many women doubted the existence or possibility of a cure for dyspareunia. Some thought that there might be a way to alleviate the pain, but they could not envision an intervention that could take away the pain completely.

It's not like a regular thing that there could be a cure for.

Fear of severity

Another barrier to seeking treatment was the fear that the pain was a symptom of a severe health condition, like cancer. Additionally, others believed that the pain would never go away and they hesitated going to the doctor as they did not want that fear confirmed definitively.

I am just scared about finding out the worst. Because everybody, all the girls I have talked to have not really experienced this. So I am the only one. Their advice of what they think it is when they aren't experiencing it - they don't really know

what to tell me so going to a doctor would tell me exactly what is wrong and I am kind of scared about that because I really don't know what is wrong with me.

Guilt regarding admission of premarital sex

Our sample consisted of young women still heavily influenced by their family and the religious values they had grown up with. Going away to college may have given them the opportunity to engage in sexual activity for the first time, but many had not told their parents, siblings and/or friends that they had had premarital sex. One major concern was that if they sought treatment, their parents might discover that they were sexually active.

I just never went and got it fixed. I just let it happen because my mom didn't know that I lost my virginity. I don't know if that would be the reason and then she would find out. So I just didn't say anything.

Fear of stigma associated with sexual problems

Many of these women reported worrying about how other people would judge them if they told them they experienced pain with intercourse. This concern translated into a barrier to treatment. If they were diagnosed with a sexual disorder, other people might judge them as being promiscuous or as having contracted a sexually transmitted disease.

I don't think that people understand, especially if they don't experience it then it might be assumed that there's something wrong, like you have an STD or something negative.

Belief that sexual problems are outside the realm of medicine

Some participants lumped sexual and relational problems together and defined these outside of the realm of medicine. They did not believe the medical profession would be able to assist them because they did not appear to have a strictly medical problem. Interestingly, the reluctance to seek medical help by one woman was borne of her belief that pain somehow stood outside of the concept of disease or tissue damage.

I don't want to talk to the doctor about it, and I don't think it's been much of an issue. I think it's just pain. Pain is pain.

CHAPTER 5

DISCUSSION

The women in our study described a commonality of experience in their encounter with dyspareunia at an early age. At the time of the initial onset of pain, they lacked the necessary information to label their pain and its potential etiologies. The attempts they made to ameliorate the pain, such as altering sexual activities and using cognitive distraction, constituted their own personally generated guesses about what might be causing or influencing the pain. Ultimately, these efforts elicited limited to no relief. The experience of dyspareunia thus started to have a cumulative negative effect on their lives. Finally, despite the deleterious impact of the disorder on their relationships, sexual functioning, and psychological well-being, these women failed to seek treatment because they were unable to find sufficient incentives to outweigh the barriers to such action.

These women's inability to identify their disorder can be explained in two ways; a lack of available public health information about dyspareunia and social isolation specifically in regards to this experience, consequent to embarrassment about having a "sexual problem." The lack of information available regarding dyspareunia creates a type of "invisible" disorder for the women experiencing it (Gibbons, 2000). When Meana and Binik (1994) reviewed the available literature on dyspareunia, they found a paucity of

research. This lack of research appeared to have been accompanied by little clinical attention of the question of pain with intercourse. Although their work spurred more than a decade of intense research activity (e.g., Bergeron, et al., 2001; Canavan, & Heckman, 2000; Masheb, et al., 2002; Meana, et al., 1997a; Meana, et al., 1997b; Meana, 1998; Meana, et al., 1998; Meana, et al., 1999; Wonda, et al., 1998), a clear understanding of dyspareunia remains elusive. Currently, controversy surrounds the very definition and classification of dyspareunia (Binik, 2005). Questions of etiology are also still confounding researchers, with no single causal pathway appearing to explain most cases (Bergeron, et al., 2001; Binik, et al., 2000; Canavan & Heckman, 2000; Graziottin, 2003; Meana, Binik, & Thaler, in press). Without the benefit of clear answers from the research enterprise, clinicians struggle to treat the problem, with little success. If the task of clearly defining dyspareunia and its causes is daunting for researchers and clinicians, it is no wonder that the women experiencing the pain are confused about what they are experiencing as well.

An additional complication in understanding their experience of pain with intercourse emanates from these women's own reluctance to share this experience with others, including clinicians. Society tends to shy away from sexual issues, relegating them to the personal and private realms that preclude general discussion. Having a sexual disorder, then, would naturally result in many women isolating themselves out of embarrassment. Medical doctors also play a role in the disorder's mutism. In general, doctors do not inquire about sexual function and thus sexual problems are not identified as medical concerns, despite the fact that sexual dysfunction negatively impacts quality of life and emotional states (Sadovsky & Nusbam, 2006). Given that sexual health is

considered by the World Health Organization to be an integral part of overall health, the lack of questioning about sexual problems on the part of many medical professionals is concerning (as cited by Coleman, 2002). Essentially, women experience this problem in isolation due to the lack of public health information and lack of medical attention to it. Further compounding the problem, this pain happens in the context of sexuality which is generally considered private and in the context of the stigmatizing nature of sexual problems (Gibbons, 2000).

The impact of dyspareunia on the psychosocial world of the women in our study confirms previous findings in the literature. Although the pain appears to have significant effects on the way these women feel about themselves, our findings supported the already existing literature that women with dyspareunia have unremarkable psychosexual profiles to begin with (Meana, et al., 1997). We did not subject our participants to psychological testing but it was fairly evident that they were high-functioning college women whose primary problem was the pain with intercourse and not some predisposing condition. We did however find them to experience emotional lability, including an increase in anger, depression, frustration and embarrassment related to the dyspareunia. There was also a tendency to think negatively of oneself, feeling abnormal in comparison to other women and having an overall decrease in self confidence. Meana, et al., (1997a) found women with dyspareunia to have more negative attitudes about sex as compared to controls. In his qualitative study, Gibbons (2000) also found that this disorder had a negative impact on self esteem. Other researchers have found that women with VVS, a specific form of dyspareunia, score high on markers for depression and psychological distress, such as

anxiety (Gates & Galask, 2001; Jantos & White, 1997; Nylanderlundqvist & Bergdahl, 2003) which can exacerbate the experience of pain (Payne, et al., 2005).

Our sample also experienced negative consequences across the sexual response cycle: lower desire, less arousal, and difficulties with orgasm. This comorbidity of dyspareunia with other sexual problems is another consistent finding in the quantitative literature, namely desire, arousal disorders, and orgasmic disorders (Graziottin, Caliri, & Nicolosi, 2001). Van de Wiel, et al. (1998) found low physiological arousal and Marin, et al. (1998) found a lack of subjective arousal in women with dyspareunia. Payne et al., (in press) considered the pain to act as a distraction from sexual cues, thus explaining the decrease in arousal for women with dyspareunia. Graziottin (2003) posited that dyspareunia has a direct inhibitory effect on arousal and indirect inhibitory effect on orgasm, satisfaction, and libido, thus explaining the co-morbidity of sexual symptoms reported in clinical practice. In addition to decreased functioning, the women in our study experienced cognitions and feelings of sexual inferiority and lower sexual confidence which have also been found to occur in women with dyspareunia in other studies. Gates and Galask (2001) and Meana, et al., (1997a, 1998) found that women with dyspareunia in their studies had negative sexual schemas and feelings. Women in our study also reported a lack of initiation and even an aversion to sex altogether. One study of women suffering from vulvar vestibulitis found similar aversive behavior in women experiencing pain with intercourse (Nunns & Mandal, 1997).

The majority of our sample also experienced significant relational adjustment difficulties, such as significant emotional distance from partner, increased conflict, partner dissatisfaction and fears of isolation and abandonment by their partners, similar to

the findings of Masheb, et al. (2002), Meana, et al., (1997a, 1998) and Gibbons (2000). Gibbons' (2000) pilot study involved conducting interviews of women with dyspareunia, all of whom indicated that the pain had a significant impact on their relationships. Masheb, et al. (2002) found that women with dyspareunia experienced global marital dissatisfaction. In examining subtypes of women with dyspareunia, Meana, et al. (1997a) found elevated psychological symptomatology and marital maladjustment. Meana, et al., (1998) examined relational adjustment and pain intensity and found that better marital adjustment predicted lower pain ratings, suggesting a cushioning effect of positive relational interactions on the experience of pain.

As afore-mentioned, most of the women in our study failed to seek professional help for their problem despite the fact that the disorder was already wreaking havoc on their personal and relational lives. This seems counterintuitive. Why would these women not seek help in light of a painful health problem with significant negative effects? We think this can be partly explained using the Common Sense Representations of Illness Model (CMS) (Leventhal, 1980). The CMS is comprised of five dimensions of a person's experience of their illness and what prompts them to seek treatment: identity, consequences, timeline, attribution about causes, and cure or control. The identity dimension reflects the individual's ability to recognize the symptoms they are experiencing as part of a disease or disorder. Our sample was unable to accurately recognize that their symptom was a part of a disorder called dyspareunia. This resulted in a negative impact on their understanding of what they were experiencing, why, and what to do about it. They lacked a point of reference and were thus at a loss to identify their pain as a legitimate health problem requiring attention.

The consequences dimension of the CMS refers to the perceived severity and impact of the illness. If the potential illness is perceived to be too severe, people may avoid seeking treatment due to fear and potential stigmatization (Martin, Rothrock, & Leventhal, 2003). A number of women in our study openly expressed the fear that the pain might signal a serious illness. They were afraid to consult with a doctor who might have very bad news for them about what in fact was wrong. They were also afraid that they might be told it was a sexually transmitted disease. They feared the stigmatizing potential of such a diagnosis. Finally they did not want to have it confirmed that they had a sexual problem, another stigma tainted diagnosis. Their fears about the severity of a potential diagnosis may have been partially responsible for the lack of treatment-seeking.

The timeline component of the CMS refers to the beliefs about the duration of the supposed illness and its treatment, specifically symptom development, course, whether the illness is acute or chronic and potential for relapses (Lau & Hartman, 1983). Our sample seemed surprisingly convinced that their pain would not have a cure. They seemed to have pretty much determined it to be a chronic condition. If the pain was going to go away, it would have already disappeared. This also contributed to their lack of treatment-seeking.

The fourth dimension of CMS involves the attributions about the causes of the symptom. The perception of possible causes of an illness can affect treatment-related variables such as predicted recovery, treatment engagement, and experience of psychological symptoms (Meana, et al., 1999). Disorders that have an unknown etiology create a distrust of medical knowledge for a cure. Our sample expressed an uncertainty as to the causes of their pain, although some offered suggestions related to anatomical

discrepancies, infections, etc. Lacking a clear understanding of etiology or causal attributions, combined with uncertainty regarding a cure and/or recovery, these women internalized the disorder in the form of negative affect and negative self-evaluation and chose not to seek treatment.

The last component of the CMS consists of possible actions or level of control, to help the symptoms or to be a cure (Lau, 1997). How people perceive their control over their illness and their theories of a cure impact health-related behaviors (Lau & Hartman, 1983). Our sample made various attempts to control their pain, from use of lubricants and cognitive distraction to prolonged foreplay and different intercourse positions. However, after these attempts failed to remedy the situation, they did not believe that there was any other type of treatment available beyond what they had already attempted. This resulted in them not seeking medical or other assistance. Thus, considering the women in our sample had difficulty identifying the disorder, could not imagine potential causes, feared that the pain indicated a severe condition, and lacked belief in a cure, it is not that surprising that they did not seek help.

Although it remains perplexing that women doubted the possibility of a cure considering their lack of knowledge, they happen to have been fairly accurate. There is currently a lack of standard care and low treatment success for what is generally prescribed (Meana, in press; Binik, Bergeron, & Khalife, 2000). For example, for patients who undergo hypocontactant treatment, where patients avoid all contact with lotions, lubricants, and clothing with irritants such as perfumes and dyes, only 20% experience a complete response (Fowler, 2000). Antidepressants, either prescribed for the physical or the psychological impact of this disorder, have the common side effect of lowering sexual

desire. Interferon injections have only 50% success rate, which is the same as chance (Bergeron, et al., 1997). Even the most effective method of treatment, surgery, is only ameliorative (46.8-89% decrease in symptoms) for patients with VVS, a very specific type of dyspareunia (Bergeron, et al., 1997). And of the women who choose this invasive form of treatment, few resume their normal sexual activity after surgery. Research has found that biofeedback shows only 35% improvement and only 39% of those receiving Cognitive Behavioral Therapy showed a successful outcome (Bergeron, et al., 2001). Although these outcome figures could be more encouraging, they do indicate that for a significant number of women, medical, surgical or psychological help does provide relief and sometimes the eradication of symptoms.

Even though the women in our study were relatively accurate in their assessment of their being a sure cure for their pain, they were unaware of the medical approaches that have provided many women with significant relief. For women with VVS, pain reduction has been evidenced in 70% of women who had a vestibulectomy in one study (Bergeron, et al., 2001) and in 89% of those who had a perinioplasty in another study (Goldik & Abramovici, 1999). Physical therapy has been shown to significantly reduce symptoms from pre to posttreatment as well as to increase sexual desire, arousal and intercourse frequency (Bergeron, Brown, Lord, Oala, Binik, & Khalife, 2002; Rosenbaum, 2006). Other, more alternative forms of therapy such as electrical stimulation have also shown some promising results (Glazer et al, 1995). It is indeed a shame that these young women are not availing themselves of these possible treatments, as there is a good chance that some of them may effectively reduce their symptoms or even resolve the problem.

This study was not without limitations. The most obvious one was that participants were self-selected. The women who participated in this study were Psychology 101 students who volunteered for the study to receive research credit. It is unclear what type of selection bias this introduced. Clearly, these young women were willing to disclose this information to a researcher and they may be different in unknown ways from women with dyspareunia who chose not to participate. It is possible the women who did not volunteer for the study had sought treatment and so did not feel they needed additional information on the disorder or that they did not fit criteria because they were already being treated. Another limitation to the study was that there was no gynecological exam performed on the women in this sample to confirm a diagnosis or to identify potential dyspareunia sub-types. On the other hand, the diagnosis of dyspareunia is always made on the basis of self-report, so we have little reason to believe that the participants in our study were misrepresenting their pain with intercourse.

The goal of this study was to add to the psychosocial knowledge about the experience of early dyspareunia. The model created in this study illustrated how women respond to their experience of dyspareunia in a cognitive and behavioral fashion. Despite methodological limitations, this grounded theory of the experience of early dyspareunia has brought us closer to understanding the psychosocial impact this disorder has on young women. The negative consequences on these women contaminate how these women view themselves as well as how they relate to their partners, friends, and the medical profession. Although not life threatening, dyspareunia has an exponentially-increasing negative effect on the lives of these women. In order to prevent this inevitable cascading of consequences, the pain needs to be identified and treated early, before the

damage pervades all aspects of the woman's life. The age range of our sample would be ideal for initiating treatment.

The current tendency for the medical profession to remain silent regarding issues and symptoms related to sex needs to change. Doctors, especially OBGYN's, must take the initiative in asking about their patients' sex lives and inquire as to the symptoms they are experiencing. In this way, they can open the lines of communication and possibly increase treatment seeking behavior in these young women. The medical professionals also have ample opportunity to educate women as to the existence of dyspareunia by means of pamphlets and signage in their waiting rooms, as well as through discussions with their patients. This would aid in increasing public awareness and women's ability to identify dyspareunia when it occurs. Considering the importance of early intervention for this disorder, future studies aimed at investigating predictors of treatment-seeking, such as perceived support, incentives for seeking treatment, and previous experience with the medical profession, would be beneficial. Comparing women who do seek treatment versus those who, like those in our study, remain silent about their pain could provide essential information to aid in increasing treatment seeking behavior in young women with this psychosocially devastating disorder.

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APPENDIX I

Female Sexual Function Index (FSFI)

Participation Number: _____ Date: _____

INSTRUCTIONS: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential. In answering these questions the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.

Sexual intercourse is defined as penile penetration (entry) of the vagina.

Sexual stimulation includes situations like foreplay with a partner, self-stimulation (masturbation), or sexual fantasy.

CHECK ONLY ONE BOX PER QUESTION.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how **often** did you feel sexual desire or interest?

- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

2. Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?

- Very high
- High
- Moderate
- Low

Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how **often** did you feel sexually aroused ("turned on") during sexual activity or intercourse?

No sexual activity
Almost always or always
Most times (more than half the time)
Sometimes (about half the time)
A few times (less than half the time)
Almost never or never

4. Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turn on") during sexual activity or intercourse?

No sexual activity
Very high
High
Moderate
Low
Very low or none at all

5. Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?

No sexual activity
Very high confidence
High confidence
Moderate confidence
Low confidence
Very low or no confidence

6. Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

No sexual activity
Almost always or always
Most times (more than half the time)
Sometimes (about half the time)
A few times (less than half the time)
Almost never or never

7. Over the past 4 weeks, how **often** did you become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

8. Over the past 4 weeks, how **difficult** was it to become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

9. Over the past 4 weeks, how often did you **maintain** your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

10. Over the past 4 weeks, how **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?

- No sexual activity
- Almost always or always

Most times (more than half the time)
Sometimes (about half the time)
A few times (less than half the time)
Almost never or never

12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?

No sexual activity
Extremely difficult or impossible
Very difficult
Difficult
Slightly difficult
Not difficult

13. Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

No sexual activity
Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied

14. Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?

No sexual activity
Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied

15. Over the past 4 weeks, how **satisfied** have you been with your sexual relationship with your partner?

Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied

16. Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?

Very satisfied
Moderately satisfied
About equally satisfied and dissatisfied
Moderately dissatisfied
Very dissatisfied

17. Over the past 4 weeks, how **often** did you experience discomfort or pain during vaginal penetration?

Did not attempt intercourse
Almost always or always
Most times (more than half the time)
Sometimes (about half the time)
A few times (less than half the time)
Almost never or never

18. Over the past 4 weeks, how **often** did you experience discomfort or pain following vaginal penetration?

Did not attempt intercourse
Almost always or always
Most times (more than half the time)
Sometimes (about half the time)
A few times (less than half the time)
Almost never or never

19. Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?

Did not attempt intercourse
Very high
High
Moderate
Low
Very low or none at all

Thank you for completing this questionnaire. If you would be interested in participating in future research for credit, please leave us your phone number so that we may contact you.

Phone number: _____

APPENDIX II

BACKGROUND QUESTIONNAIRE

Participant Number: _____

- 1) How old are you? _____
- 2) With which of the following groups do you most identify? (Please circle one)
Caucasian or European-American African-American
Hispanic-American/Latina/Chicana American Indian/Native-American
Asian-American Pacific Islander-American
Other (please specify) _____
- 3) Which of the following relationship situations best describes you:
 - a. Single, not currently dating
 - b. Single and currently dating
 - c. Steady boyfriend
 - d. Cohabiting or Married
- 4) How many children do you have? __None__ __1__ __2__ __3__ or more
- 5) How long ago did you have sexual intercourse for the first time?
____YRS____ MONTHS
- 6) Have you consistently had pain with intercourse since the first time? YES NO
- 7) How long have you had this problem? ____YRS ____ MONTH

8) Have you reported the problem to a doctor? YES NO

9) If yes, what types of treatment have you received, if any?

APPENDIX III

INTERVIEW SCRIPT AND QUESTIONS

I am going to ask you some questions about your experience of pain with intercourse and the ways in which it has affected you. Take your time and give me as much detail as you are comfortable with. There are no right or wrong answers to these questions. The intent is to get you thinking. Everyone's experience is different and I would really like to understand yours.

Do you have any questions?

OK. I will now turn the tape on.

1. Please describe what the pain feels like, where you feel the pain and during which activities it happens (sexual and otherwise, like tampon insertion, gynecological exams etc.)
2. Are there circumstances that make the pain better or worse and what are they?
3. Why do you think you have pain with intercourse? What are your personal theories about how or why it developed?
4. Before you ever had intercourse, what were your expectations about the experience?
5. How do you feel about the fact that you have pain with intercourse? How much does it bother you or cause you distress?
6. How does it affect the way you feel about yourself?
7. How do you think it affects the way that others view you?
8. In what ways does the pain interfere with your sex life?
9. How does it affect your level of sexual desire, arousal and capacity for orgasm?
10. In what ways does this problem interfere with the non-sexual aspects of your relationships?
11. To what extent are you concerned about how this problem will affect your ability to have a long-term relationship, or to have children? What worries you in this regard?
12. Does the problem interfere with or affect other aspects of your life? How?
13. What are your concerns about the ways in which this problem may impact your future?
14. What have been your strategies to cope with this problem?

15. How have you sought emotional support for this problem (discussing it with friends, family, partners)?
16. Have you sought treatment for the pain?
 - a. What prompted you to seek treatment?
 - b. How was that experience for you?
 - c. From how your doctor interacted with you, how do you think he/she felt about it?
 - d. Did they offer any treatment?
 - e. What was it?
17. Do you believe there is a cure for this and what do you think that cure would look like?
18. How hopeful are you that this problem will be resolved?

APPENDIX IV

BRACKETING

The following is a summary of the primary researcher's biases and assumptions about the experiences of dyspareunia in college-aged women.

Women with dyspareunia probably have not told many others about their suffering. When they disclose, they are often met with the attitude that the symptoms are simply psychological, that there is something wrong with them and that the symptoms will go away on their own. These women have learned not to share this information too liberally for fear of similar reactions, similar personal beliefs and low self-esteem.

In addition to not having told many about their symptoms, women with dyspareunia are reluctant to seek medical advice. Some are too embarrassed to talk about it and/or share the beliefs listed in the previous paragraph. Others have had negative experiences with their first visit to the OBGYN and do not want to repeat the experience. It is unlikely that those who do seek medical help will have a positive impression of the field's knowledge of the disorder and its attempts at treatment. Many wind up feeling like guinea pigs or are invalidated. Some choose to live with the pain rather than undergo a surgery which has no guarantee of symptom abatement. A larger number seek out the help of psychological professionals, either as a recommendation from a physician or a family member or friend. Through therapy, these women emotionally feel better about having dyspareunia, but still the pain persists. Whether or not they have received outside

help, most develop ways in which to avoid pain such as using pads instead of tampons, avoiding sexual relationships or even wearing unrestrictive clothing.

Having dyspareunia affects how a woman feels about sex. Some feel responsible for being afflicted, that they are being punished for sexual misconduct i.e., thinking self-proclaimed inappropriate sexual thoughts, having sex before marriage, engaging in casual sex, etc. For many, this echoes their preexisting negative thoughts and guilt about sex. For some of these women, this guilt results in avoiding sexual interactions and behaviors altogether. If they do remain sexually active, they may do and try all other types of sexual activities except penile-vaginal intercourse with the hopes of avoiding the act itself. A few will overcompensate and give the impression of being promiscuous. They may also resort to taking alcohol and other drugs prior to sexual situations so as to numb the pain in hopes of achieving penetration.

Relationships are greatly impacted by dyspareunia. These women will have a series of short relationships that will end ultimately due to a sexual problem. The superficial cause may be another issue (feeling suffocated, financial concerns, etc.) but with probing, dyspareunia will be at the center. Their partners do not feel connected or intimate with them and/or feel that their sexual needs are not met. When brought up, fights ensue and the woman will bring to surface many other issues so as not to focus on what she feels is her own "inadequacy." She will also start an argument in lieu of a sexual involvement with her partner so as to avoid potential pain. She will feel insecure in her relationship, constantly fearing that her partner will leave her for someone who is able to have sex sans pain. On the other hand, she may also be a devoted partner; always

reassuring her significant other so that he knows that problem with penetration is not his fault, but hers.

At this point in their lives, these women will be most concerned about how the pain interferes with their relationships. Some may hope that they will find a compassionate partner who will be sensitive to their problem. Some may hope that the pain will go away with time or through coping techniques. If planning to have children, these women will be very concerned about whether conception is a possibility. All will be interested in finding a cure, whether from someone who knows about the disorder or by doing something themselves. They are still young enough and have not had as much of a psychological impact from the disorder to have completely given up hope on improving their situation.

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