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THE EXPERIENCE OF CHRONIC VULVAR PAIN: PSYCHOSOCIAL DIMENSIONS AND THE SENSE OF SELF

A dissertation submitted

by

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to

THE FIELDING INSTITUTE

in partial fulfillment of
the requirements for the
degree of

DOCTOR OF PHILOSOPHY IN PSYCHOLOGY

with an emphasis in
Clinical Psychology

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ABSTRACT

The Experience of Chronic Vulvar Pain: Psychosocial Dimensions and the Sense of Self

Unexplainable chronic vulvar pain affects a significant number of women, although the problem is not widely recognized. For many, the condition does not resolve spontaneously or respond to current treatment. Vulvar pain is a substantive and meaningful event in the lives of those who suffer from it. Recent literature suggests the significance of psychosocial factors in the course of illness and chronic pain. The prevalence of the condition and the mixed treatment outcomes indicated a need for exploratory studies of psychosocial dimensions of the condition. Prior to this study there had been no research on the lived experience in women with the condition.

Research in pain and chronic illness suggests that mastery in the treatment and management of unpredictable physical symptoms may involve interconnections between one or more of the following factors: symptom perception, cognitive and emotional responses, social situation, and identity issues. The current study utilized these four psychological reference points in a textual analytic exploration of the ways women make sense of their chronic vulvar pain.

The 16 participants in this study represent a diverse sample of women who have had ongoing or recurrent vulvar pain symptoms for 1 year minimum (average 5.4 yrs). The research design was based upon pilot interviews, a background questionnaire, a narrative interview and a semi-structured follow-up interview. The transcribed texts were analyzed by means of constant comparative methods.

The results of this investigation suggest an interactive model of the experience of chronic vulvar pain. This model offers a preliminary conceptual basis from which to understand the lived experience of chronic vulvar pain. When a wearing, pervasive, and unexplainable pain occurs in the vulva, a woman's sense of her self is diminished in significant ways. The relationship she establishes with the pain is shaped by the meanings she makes of her situation. These meanings emerge within the context of physical, emotional, and relational elements in her life. Reciprocal interactions occur between ongoing core identity and somatic perception, self state responses, and relational interchanges with significant others, including health care providers. These experiences occur in a dynamic, interactive manner that is simultaneous and continuous. The woman with chronic vulvar pain makes sense of its presence in her life by engaging in this ongoing process.

The findings of this study suggest that the quality of these interactions may help or hinder the mobilization of resources to deal with chronic vulvar pain. Relationships which enhance a woman's sense of self worth help her manage the physical and emotional experience of the condition. The study substantiates the need for sensitivity to psychosocial experience in the treatment of chronic vulvar pain.

DEDICATION

He has seen but half the universe who has not been shown the house of pain. Ralph Waldo Emerson

For those who experience chronic vulvar pain, and for those who endeavor to help them find ease. May they discover the resources to achieve their purpose.

ACKNOWLEDGMENTS

This dissertation emerges out of the living fabric of my life, a cloth that becomes more ample, supple, many-hued, and resilient by virtue of its interconnections with the lives of others. Many people assisted my efforts in this project.

I am fortunate to have been able to work with a dissertation committee composed of scholar-practitioners of the highest caliber. Each contributed something essential to my being able to carry out this study. Joan Zilbach chaired the committee with a sure hand; her wisdom and her commitment to female identity development nurtured mine in this work. My Associate Dean, Kjell Rudestam, provided steady encouragement throughout my career as a doctoral student at Fielding, offering collegial support and a grounding in rigorous scholarship. Joan Read generously helped open doors and she brightened the way with keen attention, energetic access to resources, and good humor. Natan HarPaz read and discussed the dissertation with me at each step along the way; his clinical acumen and his appreciation of the aims of this research helped to sustain my own commitment. Marilynne McKay's participation as External Examiner contributed the credibility of medical expertise, as well as her impeccable writing skills. The research consultants who each imparted both a love of the craft and substantive instruction and guidance at different time points along the way were Rae Newton, John Landsverk, Michelle Harway, Gary Schulman, and Marsha Liss. As the dean of the Health Psychology training track, Joe Bush was another source of encouragement in this project. I thank each of these valued colleagues for their guidance and for having confidence in my ability to learn what I needed to know in order to accomplish my goal.

I offer my heartfelt thanks to Jennifer Futernick who knew how satisfying I would find this work when she introduced me to the topic, and who offered invaluable finishing touches on the manuscript. To her and to my other chosen sisters--Sherry Sherman, Paula Holtz, Jane Zones, Nana Meyer, and most especially to Annette Hess--I am eternally grateful for clear thinking, boundless enthusiasm, and the unfailing sustenance of heart connections. Katie MacKaye began with me as a competent transcriber and became a trusted research assistant on the project. A good season in a study circle with Fielding friends Vicki Jacuzzi, Judy Ross, and Elizabeth Krainer taught me valued lessons about research, assessment, linguistics, group process, and narrative methodologies. I am indebted to Katie Braznell for contributing her assistance with the graphics.

Other health care providers have helped me along this journey. Many practitioners offered information and critical interest which informed my understanding. Diana Taylor, Jeffrey Stern, Charles Bookoff, and Elliot Crames helped me get my bearings in the early years, when chronic vulvar pain was even more of a mystery than it is now. More recently, the dedicated efforts of Joanne Yount and Clive Solomons have been a source of inspiration and support for me. Bruce Johnston's steadfast attention to nuance and meaning has deepened my own.

I owe much to the family members who have lived with my longtime preoccupation, each helping in their own way. Alice and Karl Ruppenthal in many respects made the dream of achieving the doctorate possible. Michael Katz set the example of patient perseverance toward a valued goal; I appreciate the attention and support that he was able to provide. I was refreshed along the way by Heather Katz' music and her delight in the details of nature. Julian Katz was a steady and creative presence in my life even when away for his own schooling. The liveliness and intelligence of Molly Katz brightened my every day. Jennie Katz offered unflagging encouragement.

Finally, acknowledgment goes to the women with vulvar pain whose lives have touched mine, in the early focus groups and throughout the intervening years. I especially want to honor the women who participated in this study. They were willing to tell their stories that others might find courage and help to alleviate their suffering.

These are only some of the people who have been my teachers in this endeavor. I am enormously grateful to all who have contributed to my efforts, and I look forward to what we may continue to learn.

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Chapter I - Introduction

> Symptomatic vulvar burning (vulvodynia) in the absence of abnormal physical findings was long thought to be an unusual psychosomatic gynecologic problem. Within the past decade, however, a number of investigators began to study patients with this frustrating problem. Initial physician insistence on a major role for psychological factors has gradually given way to sophisticated searches for evidence of persistent infectious agents.(McKay, 1989a)

It has been estimated that 150,000-200,000 women in the United States suffer from conditions of chronic pain in the external genitalia (Brody, 1993). Of the women who seek medical relief for the condition, although some are helped, many go from one practitioner to another, and from one treatment to another, with little or no resolution of the condition, or in some cases with a progression of the pain (Friedrich, 1988; McKay, 1989b; Reid, et al., 1988; Turner & Marinoff, 1992a). Although the condition is not well known, a number of physicians take it seriously, work hard to find amelioration or cure, and "can be seriously mystified" (Andrist & Maillet, 1992, p. 181) when their best efforts are not always successful (Kaufman & Friedrich, 1985). Women whose vulvar pain resists intervention, or which returns following the use of available treatments, are left with the pain and what it means in their lives. Although several authors in medicine and nursing have called for recognition and interdisciplinary study of the psychosocial aspects of chronic vulvar pain (Crenshaw, Kessler & Hildebrandt, 1985; Lynch, 1986; McKay, 1985, 1988; Peckham, Maki, Patterson & Hafez, 1986; Secor & Fertitta, 1992; Stewart, Reicher & Baydell, 1994; Turner & Marinoff, 1992b; Woodward, 1981; Young, Azoury, McKay, Pincus, and Zerner, 1983), to date there has been little research in psychology on the topic (Heitler, 1993; Marin, Dennerstein & King, 1995; Schover, Youngs &

Cannata, 1992; Stewart, Whelan, Fong & Tessler, 1990; Stewart, Reicher & Baydell, 1994).

Vulvar pain is classified medically as a syndrome, a collection of symptoms experienced as different from normal in terms of function, appearance, or sensation. Symptomatically, women describe the condition as burning or stabbing discomfort, itching, throbbing, aching, severe pain, "swelling," hypersensitivity or tenderness of the vulva, in the labia or around the opening of the vagina (Goetch, 1991; Lynch, 1986; Marinoff & Turner, 1991, 1992; McKay, 1992, 1989a, 1989b). It may be experienced as diffuse irritation or as specific focused painful spots, on the surface or deep. It can come and go or relentlessly persist. For some women there is a cyclic quality to the pain; for others the onset of a painful episode may seem random, or it may be related to stressful events (McKay et al., 1991).

This condition was first described in gynecological textbooks more than 100 years ago as hyperesthesia of the vulva: "The sensitiveness is occasionally so exaggerated as to keep the patient from consulting her physician until it becomes absolutely intolerable" (Skene, 1888, p. 93). The problem is not widely recognized to this day, and its course is often as mysterious and frustrating to health care providers (Pyka, Wilkinson, Friedrich, & Croker, 1988; Ridley, 1990) as it is to the women who experience it (Brashear & Munsick, 1991; McKay, 1989b). Depending upon patterns of discomfort, areas affected, functional impairment, and presumed cause, vulvar pain has been described and classified variously in medical terms such as burning vulva syndrome, focal vulvitis, vestibular adenitis, vulvovaginitis, vestibular papillomatosis, tampon intolerance, periorificial dermatitis, hymenal dyspareunia, secondary dyspareunia, superficial dyspareunia, vulvar vestibulitis, pudendal neuralgia, dysesthetic vulvodynia, idiopathic vulvodynia, or vulvodynia (Marinoff & Turner, 1986; McKay et al., 1991; Reid, undated).

While medical terms provide useful categorization of diverse symptoms, at this point in the history of chronic intractable vulvar pain conditions, problems of terminology, definition, and diagnosis may also confuse understanding of the condition. Individual practitioners have used various terms and criteria for the same phenomena. Some of these terms describe symptoms, while others may imply, or seem to imply, assumptions regarding etiology. Levels of categorization are not always clear. Controversy regarding diagnosis may result in quite different prognoses, confining treatment choice and outcome. As underlying assumptions regarding pathogenesis and treatment change, so too do assignments for responsibility for cure (Aakster, 1989).

Discontinuities between professional and lay perspectives and expectations (Aakster, 1989; Bury, 1982; McKay, 1992) can lead to conflict between caregiver and sufferer. Confusion may also result from defining the condition in biomedical terms alone, which may "medicalize" it prematurely and restrict a more comprehensive appreciation and treatment of the disorder. Medical labeling, while necessary to the disease model of treatment, does not address critical phenomena--the unique, subtle, and pervasive psychological meanings of vulvar pain in a woman's life, its psychosocial aspects--and can thereby limit the patient's options in responding to the condition. Health care providers may not be familiar with the condition or sensitive to its pervasive influence on a woman's life. Many physicians who have encountered the phenomenon clinically may assume that it is purely psychogenic, particularly when physical findings are absent or the discomfort does not respond to treatment (Crook, 1982).

Little is known about causal mechanisms (Friedrich, 1988; Marinoff & Turner, 1991, 1992; McKay, 1989b; Ridley, 1990) for "chronic, intractable, idiopathic vulvar pain" (Lynch, 1986, p. 773). A woman with chronic vestibulitis or vulvar pain may attribute the onset of the condition to inflammation due to irritants, or with infection or other trauma to the tissue; however, the symptoms have been known to appear without apparent cause, and they have also been associated with several events or a sequence of contributing factors. Whatever the initial trigger, it seems that in some women, pain pathways are activated that for some reason do not deactivate when the apparent source of the irritation, infection, or trauma has been ameliorated or is no longer present.

Current medical and surgical treatments have met with mixed outcomes (Friedrich, 1988; Marinoff & Turner, 1992; Ridley, 1990). "Diseases of the vulva are at least as important as [other diseases of the accessible mucous membranes, such as] the mouth, yet chance and tradition determine whether their victims seek the advice of a gynaecologist or dermatologist . . . and each specialist tends to see only a biased sample of the vulvar disease in his area" (Rook, 1975, p. V). Different specialties may promote different treatment approaches as well. Gynecologists familiar with the condition tend to test invasive procedures such as interferon injections, laser therapy, and excisional surgery. Dermatologists and urologists may prescribe pharmacologic treatments--antibiotics, antifungal agents, topical steroids and/or low-dose antidepressants for chronic pain. The latter are also advocated by psychiatrists, who along with psychologists may also explore psychosocial factors. These issues are addressed by sex therapists as well, who may also utilize sensate focus, relaxation and desensitization, and the use of graduated dilators. Anesthesiologists and neurologists have employed anti-depressants and nerve blocks in various forms. Physical therapists use biofeedback, muscle reeducation, and deep-tissue massage of adhesions or trigger-points. In recent years, some of these practitioners have learned of each other's approaches and begun to apply in individual cases those that hold the most promise and do the least harm.

Therapies which destroy tissue carry the risk of creating further pain, exacerbating the condition they were meant to improve (Marinoff & Turner, 1986, 1991, 1992; McKay, 1992; Pyka et al., 1988; Ridley, 1990). "Too often patients with vulvar symptoms are shunted from one gynecologist to another and finally told they should seek psychiatric help" (Marinoff & Turner, 1991, p. 1232). However, as McKay (1989b) pointed out, although "in the absence of abnormal physical findings [this symptomatic pain] was long thought to be an unusual psychosomatic gynecologic problem" (p. 256), now "justification for the diagnosis of psychosomatic illness is becoming less common" (McKay, 1992, p. 432).

To date, only very few, limited long-term outcome studies of biophysical treatments have been undertaken, and minimal inquiry has been made into the natural history of the condition. Practitioners may assume if a woman does not return for follow-up that the treatment was successful, when many women give up or go on to try something else because it was not.

The review of relevant literature begins with a description of the condition and its history. This is necessarily a review of medical and nursing literature for the most part, because these are the fields in which the condition has been recognized to date. Such review is complete enough to give the reader a sense of how chronic vulvar pain has been identified and dealt with medically--to establish that it is recognized and is taken seriously, and that it is a source of puzzlement, frustration, and some controversy for specialists who attempt to treat it.

Following this review of the background of the condition from the standpoint of the practitioner, the perspective of the person who has chronic vulvar pain is considered, in a review of literature relevant to meaning in chronic pain, in chronic illness, and in female development. This exploration of the knowledge bases leads into the statement of the problem of the current study, and the research questions which inform it. The methodology of this study is introduced. The results of the study are presented, followed by a discussion of these findings in light of its congruence to other approaches to understanding chronic vulvar pain, chronic pain, illness experience, and female development. This discussion includes implications of the current findings for further research and for treatment.

Chapter II - Review of the Literature

Medical History of Vulvar Pain

> Hyperaesthesia of the vulva. -- The disease which I proceed to describe under this name, although to all appearances one of trivial character, really constitutes, on account of its excessive obstinacy and the great influence which it obtains over the mind of the patient, a malady of a great deal of importance. (Thomas, 1880)

The malady of chronic intractable vulvar pain has gone remarkably unnoticed, given that its existence and prevalence have been documented, off and on, for more than 100 years. Cases of "hyperaesthesia of the vulva" (Thomas, 1880, p. 145; Skene, 1888, p. 93) were reported to be fairly common before the turn of the century, although even then the author of a gynecology textbook of the time expressed "surprise that it has not been more generally and fully described" (Thomas, 1880, p. 145). Subsequently, this vulvar "supersensitiveness" (Skene, 1888, p. 93) went unmentioned in the medical literature for many years.

In the late 1920s a reference to "tender red spots on the vulvar vestibule that made intercourse intolerable" (Marinoff & Turner, 1986, P. 797, citing Kelly, 1928) was included in the diagnosis of dyspareunia, but after that the "problem virtually disappeared from society" (Reid, et al., 1988, p. 523). Whether it was attention and reference to the problem that ceased--for some unknown reason--or whether the problem itself no longer occurred often enough to claim medical attention, is unclear, but "for the next five decades, textbooks of gynecology unaccountably became silent on the subject, and no mention can be found even in monographs devoted exclusively to vulvar disease" (Friedrich, 1987, p. 110).

The reasons for this disappearance and subsequent later reappearance are mysterious and inexplicable. One explanation is that it may have been reported in the literature as dyspareunia (Glatt, Zinner & McCormack, 1990) before fairly recent recognition as a distinct condition. Several authors cite women's reluctance to report or disclose sexual symptoms, as well as providers' failure to inquire, as factors in the prevalence data (Glatt et al., 1990; Sarazin & Seymour, 1991), and it has been suggested that "changes in sexual behavior, an increase in sexually transmitted diseases or an increase in willingness to discuss sexual behavior" (Sarazin & Seymour, 1991, p. 30) may also have led to the recent increase in reports.

The minor vestibular glands were identified in 1942 (Hunt, 1948) but were not associated at that time with any clinical syndrome (Marinoff & Turner, 1992). In 1983 Friedrich noted that Dickenson's Human Sex Anatomy (1949) associated "a red fourchette with dyspareunia" (Friedrich, 1983, pp. 773-774). A description of pudendal neuralgia, which occurs in both women and men, reported in 1954, bears strong similarity to descriptions of vulvar pain--"often very severe and at times paroxysmal; the parts concerned become extremely sensitive to touch, while light pressure may be frankly intolerable" (Wilson, 1954, p. 304). According to Wilson, a neurologist, the condition occurred more frequently in men than in women. Manifestations of this kind of pain received little attention in neurology textbooks (Turner & Marinoff, 1991).

By the 1970s, cases of vulvar pain either became much more prevalent or the condition began to attract attention again. At the 1975 Congress of the International Society for the Study of Vulvar Disease

"Esther Weisfogel urged members to adopt an open-minded, investigative approach to patients who complain of an enigmatic problem that she termed 'the burning vulva'" (Young et al., 1984). Pain with intercourse associated with spots of inflammation was described by Pelisse and Hewett in 1976 (Pelisse & Hewett, 1976). An autopsy study (Robboy, Ross, Prat, Keh & Welsh, 1978) documented that in normal development, minor vestibular gland structures develop in some but not all women, and that they develop in widely varying numbers in different women.

The term vulvodynia (*odynia* from the Greek word for pain) came into use around this time, by Blank (McKay, 1989b) and later by Tovell and Young (1978). Diagnostic guidelines were established by Dodson and Friedrich (Dodson & Friedrich, 1978), although a decade later it was reported that "no subsequent studies have investigated the accuracy and scope of the authors' observations" (Lynch, 1986, p. 773-774). At a conference on diseases of the vulva and vagina, McKay later reported having been told that there were no answers for recalcitrant vulvar burning (McKay, 1989b), and that this challenged her to specialize in vulvar dermatology. She went on to join the task force for the International Society for the Study of Vulvar Disease on "Burning Vulva Syndrome" in 1982, which surveyed ISSVD members about the syndrome. At the ISSVD Congress the next year the task force discussed new terminology (Young et al., 1984) and proposed adoption of the term vulvodynia for "chronic vulvar discomfort, especially characterized by the patient's complaint of *burning* (and sometimes stinging, irritation, or 'rawness')" (McKay, 1989b, p. 256), while persistent, recalcitrant cases of vulvodynia with no demonstrable physical cause were designated as burning vulva syndrome. The group stated "In summary, the patient with vulvar burning appears to present a recognizable but difficult management problem," and planned further work of definition and clarification with McKay as chairman (Young et al., 1984, p. 457).

Further refinement of investigations led Marinoff and Turner to propose that the term *minor vestibular gland syndrome* be used for cases of burning vulva syndrome in which those glands appeared inflamed (Marinoff & Turner, 1986). The same year Peckham and associates failed to confirm this association, and suggested the name *focal vulvitis* for the problem (Peckham et al., 1986). One of the founders of the ISSVD, Friedrich, then proposed that the more specific term *vulvar vestibulitis syndrome* replace both this and the term *vestibular adenitis* which had been used earlier, setting forth diagnostic criteria that are currently standard (Friedrich, 1988; Mann et al., 1992; Marinoff & Turner, 1992). The knowledgeable reader, especially a woman whose vulvar pain has been carefully diagnosed or a specialist who deals with the condition, will recognize that the current brief review does not make the fine diagnostic distinctions essential to careful treatment of vulvar pain conditions. This study focuses on the experience of chronic vulvar pain and may refer to subsets (e.g., vulvitis, vestibulitis, vulvodynia) as interchangeable for present purposes, even though each has its own particular diagnostic criteria and current standard of care.

Although the nomenclature remains confusing, the syndrome in its many names has been accepted in the general dermatology and gynecology literature. Articles continue to appear, primarily in journals of these two specialties, describing the condition or reporting testing of hypotheses about biophysical etiologies and attempts to understand the pathogenesis of vulvar pain conditions through empirical investigation of various treatments. A lively debate continues on these topics, as practitioners seek ways to alleviate the problem.

Mention of vulvar vestibulitis in the popular press was sparse until 1993 (Bowles & McClear, 1991; Kaufman, 1992; Tyler, 1991). During that year, information about vulvar pain began to become more available to the public (e.g., Brody, 1993; Chaffin & Raymond, 1993; Gottleib, 1993; Heitler, 1993, 1994; Hiller, 1993; Katz, 1993; Laurence, 1993). The topic was discussed on a daytime talk show that year ("Why can't", 1993). Attention in the public media has increased since then ("Alive," 1994; Allman, 1994; Betzold, 1995; Carpenter, 1995; Cooper, 1994; Health Notes, 1994; "Help for a painful problem," 1994; Herman, 1994; Krasjean, 1995; "Medical mail box," 1994; Palmer, 1994).

Although practitioners who are familiar with vulvar pain consider it "a current problem" (Pyka, et al., 1988, p. 249), the syndrome remains unknown to many health care providers, adding to the confusion and frustration of women with vulvar pain who seek help. Even for health care providers who are acquainted with chronic vulvar pain, the disorder continues to present a challenge to understand and effectively treat (Stewart et al., 1990).

Epidemiology

> This disorder, although fortunately not very frequent, is by no means very rare. So commonly is it met with at least, that it becomes a matter of surprise that it has not been more generally and fully described. (Thomas, 1880)

How prevalent is this "common disorder?" Although authors may claim a dramatic and surprising increase in the number of women presenting with these symptoms (Dodson & Friedrich, 1978; Friedrich, 1987; Reid, et al., 1988; Stewart et al., 1990; Woodruff & Friedrich, 1985), prevalence data have not been available until recently (Lynch, 1986). According to a recent New York Times "Personal Health" column devoted to the topic, Brody (Oct. 27, 1993) reported that vulvar pain "is a disorder afflicting 150,000-200,000 American women that can literally drive them crazy" (p. B7).

Prevalence

The prevalence of vulvar pain remains difficult to estimate. A gynecology text from the late 1940s reports that, in a study population of 4,100 married women, 1.1% had dyspareunia without primary physical cause (Brashear & Munsick, 1991, citing Dickenson, 1949). Until 1991, disparate studies of clinical populations were the only source of information regarding the incidence of chronic, idiopathic vulvar pain. A review of prevalence studies for dyspareunia (Glatt et al., 1990) cited some mention of vulvar, vestibular, or introital pain related to reports of painful or difficult intercourse.

Over the course of the 1970s a handful of physicians who encountered vulvodynia clinically reported their findings in the medical literature. Less than 100 cases of vulvar discomfort and pain were reported for the entire decade (Dodson & Friedrich, 1978; McKay, 1989b; Peckham, et al., 1986; Pelisse & Hewitt, 1976; Woodruff, Geandry & Poliakoff, 1981). Practitioners in different places encountered the same phenomenon and gradually began to learn of each other's efforts to evaluate, classify, and treat the problem.

In 1971, a physician treated two patients presenting with symptoms of vulvar burning at the University of Wisconsin Hospital Clinics; this author, along with associates, later reviewed 67 cases treated over a

15-year period after 1980 (Peckham et al., 1986). A report of 30 cases appeared, under the diagnosis of *erythematous vulvitis en plaques*, in 1976 (Pelisse & Hewitt, 1976). Two years later Woodruff and Parmley described an additional 15 patients with infections, "dyspareunia and physical findings limited to the vestibule" or vestibular gland (Marinoff & Turner, 1991, pp. 1228-1229), while Friedrich reported on 13 similar cases of "vestibular adenitis" (Friedrich, 1987, p. 113). From 1974-1978 42 women presented at the gynecologic clinics at the Johns Hopkins Hospital with "dyspareunia, pruritus , and/or local discomfort" (Woodruff, et al., 1981, p. 750).

In the 1980s, both the number of journal articles about idiopathic vulvar pain and the number of cases reported in North America increased. Thirty members of the International Society for the Study of Vulvar Disease, responding to the 1982 ISSVD survey on burning vulva syndrome, reported familiarity with its symptoms (Young et al., 1984). Fifteen patients with vulvar pain symptoms of unidentifiable cause were referred to Johns Hopkins over a 4-year period (Woodruff & Parmley, 1983), 44 between 1982 and 1987 at Tufts. George Washington University gynecology clinics saw 19 vulvar pain patients in 18 months in the mid-80s (Marinoff & Turner, 1986).

By 1989, two physicians at Baylor College of Medicine had treated 103 patients for vestibulitis over a 4-year period (Mann et al., 1992), and McKay reported in early 1988 having seen "more than 300 patients with vulvar symptomatology at the Emory Clinic" (McKay, 1989b, p. 257). Four years later McKay reported having seen "more than 1,000 patients in an academic referral practice" (McKay, 1992, p. 424). Vulvar colposcopy clinics were opened in Great Britain, as well, to evaluate and treat the rapid increase of vulvar symptomatology (Byrne, Walker, Leonard, Pryce and Robinson, 1989). Reports from multiregional referral centers in Houston and Haifa (Bornstein & Kaufman, 1989), from Gainesville (Friedrich, 1983), and Detroit (Reid, 1984), established vulvodynia and the subset vulvar vestibulitis as significant clinical entities deserving investigation (Kaufman & Friedrich, 1985; McKay, 1989a).

Whereas reports from such specialty clinics may reflect referral bias and raise questions regarding representativeness, a 1989 survey of all patients seen in a private gynecology practice in Portland over a 6-month period established prevalence data for symptoms and reports of vestibular sensitivity in a general clinical population (Goetch, 1991). The study utilized both questionnaire and swab testing. Out of 210 patients, 43 reported symptoms of pain "fulfilling the definition of either borderline vestibulitis (4%) or clinical vestibulitis (15% of the whole group)" (Goetch, 1991, p. 1611). Goetch was careful to point out that this surprisingly high proportion of subjects experiencing vulvar sensitivity ranges along a continuum from minor and tolerable to severely dysfunctional.

In a discussion of this study, another gynecologist remarked that

> a prevalence of 15% seems high for my practice, but perhaps if I asked more pointed questions or used the Q-tip more frequently I would discover that I have been dealing only with the tip of the iceberg all these years (Broberg, 1991, 1614)

Chronic vulvar pain appears to be one of the conditions for which "appearance in medical statistics may be as much a result of patterns of illness behavior and situational events as it is of the symptoms experienced" (Mechanic, 1961, p. 194). McKay hypothesized that the apparent rise in prevalence is "due to women's willingness to report pain and not settling for minimization of symptoms" (personal communication, 1994). A survey of the prevalence of dyspareunia in a population that had been studied 15 years earlier, as college students, for sexually transmitted disease, found that most of the women (191 out of 313 respondents) had experienced, or were experiencing, either primary or secondary dyspareunia (Glatt et al., 1990).

With the encouragement of McKay and other specialists familiar with chronic vulvar pain, Yount founded the Vulvar Pain Foundation in 1992 (Vulvar Pain Foundation, 1992). The prevalence figure mentioned in the New York Times article (Brody, 1993) was based upon Yount's estimates that the approximately 32,000 gynecologists and 7,000 dermatologists in the United States see an average of two new patients a year who have unexplainable, intractable, inadequately diagnosed vulvar pain, and perhaps as many as 100 specialists in vulvar pain disorders see an average of 200 new patients a year each. Taking into account women who have not sought treatment or have withdrawn from the treatment-seeking process for various reasons, the resultant total was doubled. "The 100,000 is just new patients in one year" (J. Yount, personal communication, May 12, 1994). While this method of estimation cannot account for the numbers of women who see more than one physician, it does provide some sense that chronic vulvar pain is a problem for significant numbers of women. During the 5-month period between October 1993 and March 1994, the Vulvar Pain Foundation received a total of 7,092 initial inquiries for information about the condition, including referrals from some of the people who had written to the International Society for the Study of Vulvar Disease in response to an article in Good Housekeeping (Tyler, 1991).

Demographics

Who gets vulvar pain? The characteristics most often noted include age, race, history of sexual activity, and parity. Although the 19th century texts attribute many cases to menopause (Thomas, 1880; Skene, 1888), most of the studies in recent decades report that the age of patients ranges from around 20 to around 40 (Pyka et al., 1988, citing Friedrich; Michlewitz et al., 1989; Marinoff & Turner, 1986; Woodruff & Parmley, 1983). Other studies found a larger age distribution--from 30 to 60 (Secor & Fertitta, 1992), from 21 to 78 (Woodruff et al., 1981), from 14 to 67 (Peckham et al., 1986), from 11 to 80 (Goetch, 1991). Some of these studies report age of onset, while others list age at time of presentation.

Lighter-colored skin possibly may be a factor in the development of vulvar pain syndromes. Most investigators report that the overwhelming majority of patients with vulvar pain symptoms are of European descent (Peckham et al., 1986; Friedrich, 1987; Reid et al., 1988). Of the 43 subjects with vulvar pain in the Portland general practice study, "all were white except for four who were black, and one each who was Native American, Hispanic, Chinese, and Japanese. Of those with vestibulitis, all were white except one patient, who was Japanese and one Chinese patient who had borderline vestibulitis" (Goetch, 1991, p. 1610). Friedrich's study consisted of 84 white women and two Puerto Ricans (Friedrich, 1987). In this 1987 Florida study, the author found "the absence of black patients . . . remarkable and unexpected in this practice population" (Friedrich, 1987, p. 14). All patients reported in Peckham et al., were Caucasian (Peckham et al., 1986). "For unclear reasons, VVS rarely affects black women" (Secor & Fertitta, 1992, p.

161), although one study included "two black patients (who) had light brown skin and green eyes" (Reid et al., 1988, p. 524). Friedrich speculated that the condition occurring mostly with relatively fair-skinned women might "prove to be characteristic of the syndrome" (Friedrich, 1987, p. 114). It must be borne in mind, however, that this finding could reflect referral bias, and social rather than anatomic factors (Marinoff & Turner 1991), leaving room for further investigation into this possibility in the future.

In terms of history of sexual activity, most of the women in most of the studies had been sexually active without pain prior to the onset of symptoms. Generally, about half had been pregnant before (Peckham et al., 1986; Woodruff & Parmley, 1983). Some women report postpartum onset of symptoms, which would lend weight to a physical trauma hypothesis until it is noted that the method of delivery does not seem to be implicated: a significant number of these women have in fact given birth by cesarean section (Secor & Fertitta, 1992). Parity ranged from 0 to 9 in one report, with most of the nulliparas under the age of 30 (Woodruff et al., 1981). Goetch (1991) found that a disproportionate number of vulvar vestibulitis cases seemed to have developed following childbirth, regardless of whether the delivery was vaginal or by cesarean section. Some studies indicated previous spontaneous or induced abortion in some patients (Peckham, et al., 1986). Sexual abuse appears very little in the histories obtained (Goetch, 1991); this information may reflect the level of the history that was taken for this study.

The typical profile associated with vulvar vestibulitis, then, is a woman between the ages of 11 and 80, who is likely to have been sexually active before onset of symptoms, who may or may not have been pregnant, and may or may not tend to have relatively light skin. In other words--except for the question of skin color--"there is no typical profile or set of predictors that suggests which women are at risk of developing this condition" (Secor & Fertitta, 1992, p. 161).

Etiology

> Before clinicians can expect to successfully diagnose and manage a disease, they should understand the disease process. However, we acknowledge our lack of understanding of the condition...we really have no clue as to the etiology of the vulvodynia syndrome (Noller, 1993a, p. 46)

The external skin of the female genitals is a very sensitive region of a woman's body that participates in cycles of activity and reactivity on numerous levels in complex ways. Evaluation of the cause of any symptoms may be relatively more or less complex and challenging. Woodruff and Friedrich (1985) referred to the vulvar vestibule as "a 'collision zone' formed at the junction of different germ layers" (p. 141). Factors which have been associated with acute and chronic vulvar vestibulitis syndrome include the following: infections, irritants, destructive treatment modalities, mechanical factors such as over-cleaning, insufficient lubrication or excessively vigorous coitus; medications (antihistamines, steroids, antidepressants, anticholinergics, lubricants, spermicides, etc.), and miscellaneous factors including altered vaginal pH, interstitial cystitis, desquamative inflammatory vaginitis, lichen sclerosus, systemic chemotherapy, allergies, and parity regardless of delivery type (Secor & Fertitta, 1992).

Vaginal and vulvar discomforts are common symptoms (Stewart et al, 1990) that are ordinarily time-limited or responsive to treatment. Alterations in the vaginal environment "due to treatment with antibiotics, by local irritation of the vaginal mucosa, and by hormonal changes" can lead to nonspecific "symptoms such as burning, itching, and dyspareunia" (Swedberg & Petravage, 1991, p. 17) of this zone. Bacterial, fungal, and viral infections may begin in response to such environmental changes. A number of chronic vulvar pain symptom patterns have been identified (McKay, 1992) which may be challenging to diagnose. Vulvar pain may occur in the absence of physical findings (Stewart et al., 1990) or with "only a nonspecific, chronic inflammation" (Friedrich, 1988, p. 514).

In decades past, physicians assumed "if we could see nothing, nothing was wrong" (McKay, 1988, p. 697). More recently, the clinical interest of specialists and new investigative techniques have brought sophisticated diagnoses. Now a number of causes or conditions of vulvovaginal syndromes are known. Today's practitioner faces "literally dozens of well-documented vulvovaginal syndromes . . . some with very serious sequelae" (Mead, 1989, p. 553; see also Crum & Burkett, 1989). Some vulvar pain is accounted for by vulvar dermatoses, recurrent yeast infections, human papillomavirus (HPV) or other sexually transmitted diseases, allergies or sensitivities, and so forth.

Most people who have acute infections do not develop chronic pain as a result. Herpes lies dormant and can flare up from time to time in discrete episodes; *candida* may burn and itch but usually resolves with treatment; HPV is endemic in the population (Rando, 1988; Stewart et al., 1987) and is not necessarily associated with pain, although a theoretical connection has been proposed (Sonnendecker, Sonnendecker, Wright & Simon, 1993; Turner & Marinoff, 1988). Furthermore, some vulvae have a papillomatous texture, an apparently normal variant which does not indicate HPV infection (McKay et al., 1991); even "multiple papillae that may cover the entire mucosal surface of the labia minora" (McKay et al., 1991, p. 414) have not been consistently associated with either HPV infection or with clinical symptoms such as pain (Bergeron, Moyal-Barracco, Pelisse & Lewin, 1994; Cox, 1995).

One source of infection that has received little attention in the literature on chronic vulvar pain is the sexual partner. Male sexual partners may carry a variety of bacteria, viruses, or yeast organisms without symptoms. "When vaginal infection is chronic, recurrent, and untreatable, it is therefore extremely valuable to culture the man's ejaculate" to avoid "the 'ping pong' effect" (Crenshaw, 1985, p. 36).

Even when infections have been treated or ruled out, symptom patterns may remain or recur, which could be due, at least in part, to overcleaning, hormonal changes, recurrent or subclinical yeast or bacterial infections, vaginismus, and/or the use of "feminine" hygiene products or other environmental irritants. In addition, some symptoms may occur or worsen as a result of treatment. Such complications are especially seen with the use of antibiotics, topical steroids, chemotherapy, laser surgery, or the now lesser-used alcohol injections (Carcio, 1992; Fackelmann, 1991; McKay, 1992; Woodruff & Friedrich, 1985).

Symptoms may also occur and persevere in the absence of apparent trauma or irritation, and they sometimes spontaneously disappear. When known conditions have been tested for, or treatments for them tried, a substantial number of women remain in pain, some for a decade or more (Kaufman, 1992). For this significant population, the cause of the pain is not known. "We really have no clue as to the etiology of the vulvodynia syndrome. Indeed, it is a diagnosis of exclusion" (Noller, 1993a, p. 46). That many cases have no obvious physical cause challenges the traditional medical conceptual model connecting specific biological processes with specific disease entities (Andrist & Maillet, 1992).

> The etiology of the disease is uncertain; only a non-specific, chronic inflammation has been found. Infectious agents and autoimmune processes could not be identified on surgical specimens. Most patients present with a long history of unsuccessful attempts at therapy, and there is a notorious lack of response to antibiotics, antifungals, corticosteroids and sex hormones. Topical anesthetics and surgical excision have remained the only effective approaches, and they are less than ideal. (Friedrich, 1988, p. 514)

A study comparing 57 women with dyspareunia due to vulvar vestibulitis with 173 women who had dyspareunia from other causes found little support for infectious cause of vestibulitis, suggesting instead that hormonal factors such as early use of contraceptives may be involved (Bazin, Bouchard, Brisson, Morin, Meisels & Fortier, 1994). "Allergy, menstrual cycle, spinal disorders, candida . . . hygiene products, sexual abuse, (and) depilatories" (Pyka, et al., 1988, p, 249) need to be ruled out through careful investigation.

> Chemical therapeutic agents that have been linked to vulvar vestibulitis include antiseptics, suppositories or creams...5-flurouracil . . . trauma . . . the use of destructive therapeutic modalities such as cryotherapy or laser therapy . . . [as well as] drug reactions, changes in vaginal pH, and estrogen deficient states" (ISSVD, 1991)

One current theory under study is the possibility of metabolic excess of oxalic acid which may become concentrated in the vulvar tissue (Cooper, 1994; Solomons, Melmed, & Heitler, 1991; Solomons, 1994a, 1994b; Yount, 1994). Oxalate is a metabolic product that can also be produced by intestinal flora or be introduced into the body through foods high in the substance. One of the forms it takes in the body is as a calcium salt which can cause pain either in solution or as crystals when it comes in contact with nerve fibers. Oxalosis may be an acquired disorder where the nerves have been sensitized by infection or mechanical trauma, or it may represent one aspect of a heritable disorder (Stedman's Medical Dictionary, 1995). In addition, "abnormal skin and peaks in oxalate concentration all contribute to pain" (Solomons, 1994a).

Another set of studies is investigating the hypothesis of genetic susceptibility--a cross-reactivity with self-antigens in response to candidal infection (Ashman & Ott, 1989; Scrimin, Volpe, Tracanzan, Toffoletti & Barciulli, 1991; Sobel, 1989), "a vaginal allergic response [that] can predispose to recurrent *candida* infection by inducing prostaglandin E2 synthesis that suppresses cell-mediated immune responses" (Witkin, Jeremias, & Ledger, 1988, p. 412), and "the inoculation of IgE-containing semen during coitus" (Sobel, 1989, p. 577). Hypersensitivity to seminal fluid was reported in an "unusual case" in which a women with a history of atopic dermatitis developed not only pruritus but episodes of anaphylaxis when exposed to her husband's semen (Mathias et al., 1980).

Physicians may overlook the possibility of nerve damage secondary to trauma, whether that trauma was due to infection or mechanical damage to the tissue (Turner & Marinoff, 1991). "When the patient experiences discomfort without visible cutaneous changes, neurologic causes should be considered" (McKay, 1992, p. 423). Neuralgia and causalgia "can be triggered by minor stimulation...(and) are believed by some to be caused by infection (viral or bacterial) that results in nonobvious neural damage" (DiMateo, 1985, p. 152). Varieties of pain are known to exist without demonstrable tissue damage.

Some women with long-standing intractable symptoms experience resolution of the pain over time, while in others it progresses (Reid et al., 1988). These differences may or may not be due to different disease entities or other factors. McKay (1989b) detailed an association of separate factors--cyclic vulvitis, papillomatosis, and vestibulitis--that may coexist or develop in a cyclical, sequential fashion. The ISSVD task force report on Burning Vulva Syndrome (Young et al., 1984) urged thorough diagnostic evaluation of vulvar pain, and went on to describe that subset which seems to be "an 'end-stage' condition, recalcitrant to a variety of treatments," suggesting that "psychogenic factors have been strongly implicated but not well defined" (p. 457).

The issue of psychogenicity in all the various diagnostic patterns of chronic vulvar pain is complex, and has followed an historical course of its own concurrent with the progression of biomedical recognition and treatment of the condition. Early writers (e.g., Richards, 1928) demonstrated a tendency to implicate the woman patient's character in the face of what Bury (1982)--in another context--refered to as "the limits of medical knowledge and treatment regimes" (p. 173), when the current level of biomedical knowledge was not able to alleviate her suffering (Todd, 1989).

More than a century ago, Thomas (1880) speculated about hyperesthesia of the vulva being caused by perimenopausal "hysterical diathesis, or a morbid mental state" (p. 146). Skene followed suit with an observation that "the affliction" seems more likely to occur at the menopause and that "women of weak mental and physical powers are more often its subjects than those who are strong both in mind and body" (Skene, 1888, p. 93). These interpretations were consistent with 19th century sociocultural assumptions about women's bodily and mental frailty which have persevered through current times in often unexamined health profession attitudes about female problems and especially chronic pain (Crook, 1982).

Later in this century, general gynecology practitioners may have tended to approach vulvar irritations with the attitude described in the following quotation:

> Vulvovaginitis was once an uncomplicated subject. There were only three recognized syndromes--moniliasis, trichomoniasis and nonspecific vaginitis--each of which was considered to be a minor female annoyance without serious sequelae. The treatment options were limited and assumed to be uniformly effective. Lectures to students on vulvovaginitis were given by the least knowledgeable member of the faculty and usually consisted of three Frank Netter slides and a testimonial to the speaker's favorite medication. (Mead, 1989, p. 553)

Given that the diagnosis and treatment of vulvar and vaginal symptoms have proved to be more complicated, however, psychogenic assumptions about chronic vulvar pain persist. Dodson and Friedrich (1978) outlined what they claimed to be "hallmarks of psychosomatic vulvovaginitis," (p. 24):

1) Persistent symptoms of long-standing duration
2) Lack of demonstrable pathology
3) Sexual inactivity as a direct result of symptoms
4) Unsuccessful consultations with multiple physicians
5) "Allergy" to many common vaginal preparations
6) Reluctance to accept the suggestion of a psychophysiologic cause
7) Emotional lability and dependency

The assumption of psychogenicity fails to take into account the possibility that the examiner does not know what to look for, that chronic inflammation (e.g., from yeast infection) makes the tissue burn when topicals are applied, that vulvar vestibulitis often leads to dyspareunia, or that iatrogenicity or the condition of chronic pain itself might contribute significantly to the occurrence of some of these signs.

To date there have been very few studies published addressing psychosocial variables and chronic vulvar pain. In early research on "psychosomatic vulvovaginitis" conducted between 1978 and 1980, Woodward (1981) organized a study of 92 patients who presented with symptoms of vulvovaginitis and no organic findings, "to determine whether the condition could be understood in psychosomatic terms and that this aetiology and resultant treatment were acceptable to staff as well as to patients" (p. 1673). Another aim of the study was to determine if one counseling session could lessen patients' persistent demands for bio-physical treatment ("chemotherapy") even when such treatment proved ineffective.

Three-quarters of the patients in the study had experienced symptoms for between 2 and 8 years; 81% had sought treatment before presenting at the infection testing clinic; of the 70 who had been given chemotherapy earlier for the condition, 50 reported not having been examined prior to treatment, and only 6 of those examined had been cultured. "The 70 patients were given some 260 prescriptions; one patient reported 30 visits to a hospital clinic" (p. 1674). Most of the subjects (91%) reported an idiosyncratic pattern of variability which the author categorizes as characteristic of psychosomatic conditions.

The report identified underlying patient issues of psychopathology in four major categories: "strong feelings of conflict created by parental attitudes which were experienced as diminishing [the patients] as people;" "anger or resentment towards their male partner;" "marked feelings of nervousness, sexual inadequacy and depression;" and "reaction to a current situation" (pp. 1674-1675). It is not clear whether these categories emerged from the counseling sessions and accounted for all underlying patient issues of psychopathology or whether data from the sessions was sorted into preconceived concepts. The report does not indicate any efforts to determine whether these issues pre-existed the condition of chronic vulvar pain. The assumption of psychogenicity in the absence of organic findings is explicit and unexplored in this report, and apparently in the treatment conditions of the study itself.

In another study, Stewart et al. (1990) compared 83 consecutive referrals of women with persistent or recurrent symptoms of vulvovaginitis with a control group of 32 women to determine whether symptomatic women with consistently negative clinical examinations and cultures ("unconfirmed" vulvovaginitis) differed from women with positive clinical examinations ("confirmed" vaginitis) or from the asymptomatic healthy controls. The control group was recruited by an advertisement and from women visiting a gynecology clinic for reasons unrelated to vaginitis.

This study addressed the problem that women with intractable vulvovaginitis may be diagnosed as psychosomatic by exclusion or without clear guidelines. The purpose of the study was to measure possible differences between symptomatic women with positive and negative clinical examinations and cultures.

All participants completed the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) the Center for Epidemiologic Studies--Depression Scale (Radloff, 1977), the Dyadic Adjustment Scale (Spanier, 1976), the sexual behavior and response questionnaire (Campion, Brown, McCance et al., 1988) and an additional study questionnaire seeking demographic information and information regarding sexual attitudes and behavior, which presum-ably was designed by the researchers but was not described in the report. Pelvic examinations and cultures were performed by physicians on all participants, and wet smears and gram stains were also taken from the symptomatic women. Participants who made subsequent visits were administered a wet smear, gram stain, and an amine test on every visit. Examinations were performed by a gynecologist and a specialist in infectious diseases.

Results indicated that 57 women had confirmed vaginitis on at least four occasions in 6 months, and 26 women had unconfirmed vaginitis every visit for 6 months. Data analysis utilized a Chi square with a Yates correction to compare differences among the groups, and an analysis of variance to compare the groups' scores on the instruments. No significant differences were found between groups in terms of age, marital status, number of sexual partners, use of oral contraceptives, frequency of intercourse, parity, or reports of allergies. No significant difference in use of antibiotics for nongenital infections was found between the confirmed and unconfirmed vaginitis groups, although both symptomatic groups reported higher use of antibiotics than did the control group.

Depression, as measured by the Center of Epidemiologic Studies--Depression Scale, was highest in women with unconfirmed vaginitis, followed by the group with confirmed vaginitis; both groups rated significantly higher than the controls who were similar to reported population norms (unconfirmed vaginitis group p = .006, confirmed vaginitis group p = .02). The women with unconfirmed vaginitis scored significantly higher than the controls on both the Global Severity Index (p = .02) and the Positive Symptom Distress Index (p = .005), and significantly higher than the confirmed vaginitis group on the Positive Symptom Distress Index (p = .04).

Ten women with unconfirmed vulvovaginitis accepted psychiatric referrals following the study; subsequently six of these women were found to meet DSM-III-R (APA, 1987) criteria for a diagnosis of major depression or dysthymia. The researchers reported being unable to determine whether the emotional distress and depression women with vulvovaginitis experience resulted from the condition or predisposed them to it, possibly through immune mechanisms or somatization.

Although no difference was found among groups in the frequency of intercourse and orgasm or in the Dyadic Adjustment Scale, the unconfirmed vaginitis group reported significantly more discomfort with intercourse (p = .01) than the confirmed vaginitis group, who in turn reported significantly more discomfort than the control group (p = .02).

The authors recognized referral bias, given that all symptomatic participants were referred to a subspecialty clinic for the intractability of their symptoms. The authors acknowledged that this limited the generalizability of the study. That the symptomatic women had experienced previous unsuccessful diagnosis and treatment may also contribute to the elevated depression and distress scores. The authors also speculated that increased use of antibiotics in the symptomatic groups could contribute to symptoms. Another limitation of the study was that the diagnoses considered for assignment to symptom groups may have excluded other biophysical sources of irritation. The report included no description of the symptoms themselves, except to indicate that the "unconfirmed" group reported significantly more burning than the "confirmed" group, while the two symptomatic groups reported the same amount of itching and discharge.

Since part of the control group was selected by a means different from the symptomatic participants, selection bias could further threaten the internal validity of the study. Another limitation to this study concerns the reliability and validity of the data collection instruments used. Most of the instruments are previously published and appropriately cited, and their reliability and validity is assumed, although the authors do not address these issues specifically. Of concern is the study questionnaire presumably designed by the researchers. Since it inquires into attitudes and behaviors as well as demographic data, mention of efforts to establish its validity and reliability would have been helpful, as would a description of the instrument.

Perhaps the most notable and positive result of this study lies not in its findings, but rather in the subsequent outcomes of the 10 women with unconfirmed vulvovaginitis who accepted referral for psychiatric care. Although the study questionnaires were unable to demonstrate "sexual anxiety or a sociosexual or marital setting involving high levels of stress" (p. 855), the authors reported that of the 10 who later accepted psychiatric referral "all subsequently reported early traumatic sexual experiences and/or continuing sexual or marital difficulties" (Stewart et al., 1990, p. 855). Six who were diagnosed as clinically depressed showed improvement with psychotherapy or antidepressant medication, with five of these six reportedly experiencing relief or disappearance of the vulvovaginal symptoms.

Although the authors drew no conclusions from this small sample, they did emphasize the importance of providers obtaining an in-depth interview regarding psychosocial issues which may confirm or refute clinical impressions. While raising the important question of the role of psychosexual trauma in the development of vulvar pain, this report does so in an ambiguous way, in conflating past sexual trauma and current sexual or marital difficulties which could in fact result from, as well as contribute to, the painful condition. The authors recommended further studies to substantiate the role of psychotherapy or anti-depressants in the treatment of women with vulvovaginitis.

Since vulvovaginitis has been a source of frustration for both patients who experience it and for providers, and since treatment has ranged from the application of topical preparations to surgical vulvectomies, solid research providing new insight into potentially related psychosocial issues is welcome. Although the generalizability of this study is limited, it offers directions for further study that might prove helpful for those suffering from vulvovaginitis.

In a follow-up study published while the current research was in progress, Stewart et al. (1994) explored differences between women with vulvodynia and other vulvar pathology, and between those with essential vulvodynia and those in whom a cause had been identified.

From a vulvar clinic population, 50 women diagnosed with vulvodynia were compared with 32 with other vulvar pathologies, and a group of asymptomatic women attending the same hospital for well-woman gynecology visits. The study package given to each woman included a questionnaire about demographics, general health, and physical and sexual abuse. All subjects completed the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), the Center for Epidemiological Studies-Depression Scale (Radloff, 1977), the Barsky Somatosensory Amplification Scale (Barsky & Wyshak, 1990), and the Whitely Index for hypochondriasis (Pilowsky, 1967). The vulvar clinic patients' examination by a gynecologist and a dermatologist utilized a detailed clinical history and a thorough gynecological exam including careful vulvar colposcopy with acetic acid, the swab test, biopsy of suspicious or symptomatic areas, and cultures for yeast and bacteria.

Exam results indicated that 32 of these women had essential vulvodynia with no abnormal findings. The vulvodynia in the remaining 18 women was thought to be accounted for by HPV, vestibulitis, vaginitis, irritant vulvitis, pudendal neuralgia, plasma cell vulvitis, and folliculitis. The third group (n=32) had vulvar pathologies but no vulvodynia. The comparison group (n=31) was asymptomatic. Data were analyzed with multivariate analysis of variance of age and all psychometric measures across the found groups, with multiple comparisons. Groups were compared for continuous variables with the Student *t* test, and Chi-square analyses were used to test for group differences on discrete variables.

Women attending the vulvar clinic scored significantly higher on all measures. Women with vulvodynia scored significantly higher on the general health questions, the Whitely Index, and the somatization and anxiety subscales of the Brief Symptom Inventory. Women diagnosed with essential vulvodynia scored significantly higher than those with identifiably caused vulvodynia on the anxiety subscale of the Brief Symptom Inventory and on general questions for suggestibility. Although 10% of all the patients in this study reported previous physical or sexual abuse, 20% of the vulvar clinic patients and 6% of the comparison groups did not answer the questions on these topics. Chi square analysis found no significant differences between the groups on these variables.

In discussing these findings, the authors underscored that they "do not establish a psychosomatic 'cause' for symptoms, as they may result from the stress of having chronic symptoms for which an etiology cannot be found" (Stewart et al., 1994, p. 589). The relatively low prevalence of reported physical and sexual abuse is discussed in light of findings to the contrary in other populations of women with pelvic pain, the fact that 20% of the vulvar clinic patients did not answer relevant items on the questionnaire, and the need for sensitive history taking and repeated openness to this information within the context of "a better relationship" (p. 589). The higher incidence of anxiety, somatizing, and interference in sexual functioning in the essential vulvodynia group suggests heightened concerns that need to be addressed with stress-reduction techniques, counseling, psychotherapy, and normalizing information. Antidepressants may also be of help in these cases. The tendency of vulodynia patients to consult multiple providers is noted, with the suggestion that this should be discouraged, since management is likely to improve with coordinated care. I would add that sensitive attention to a woman's motivations in "doctor-shopping," and education about the time and work of healing, might lessen this tendency, as would the availability of one caregiver to coordinate multidisciplinary treatment as these authors recommend.

A study of psychosexual aspects of vulvar vestibulitis (Schover et al., 1992) also concluded that a comprehensive treatment approach is indicated. This research evaluated the first 45 consecutive women diagnosed with vulvar vestibulitis in an interdisciplinary gynecology and clinical psychology/sex therapy program. All women were subject to thorough examination with swab test mapping of tender sites and colposcopy using dilute acetic acid. Of these, 31 were willing to undergo psychologic examination in 60-90-minute interview including a history of physical abuse or sexual trauma, current depression, anxiety, or somatization, life stresses at onset of pain, sexual functioning, and quality of current social and sexual relationships. Twenty-seven women also filled out a sexual history questionnaire, the Dyadic Adjustment Inventory (Spanier, 1976), and the Brief Symptom Inventory (Derogatis & Melisaratos, 1983). Partners of women in relationships were invited to participate in this interview.

Of the 27 women who completed the questionnaire instruments, only two scored in the marital distress range. Brief Symptom Inventory scores and mean patient scores on individual subscales of depression, anxiety, and somatization were within the normal range. Factors of marital conflict, onset of pain in a new relationship, somatization disorder, and depressive symptoms emerged more clearly in the interview, however. Sexual dysfunction, as measured by frequency of intercourse and non-coital sexual activity, was found to be high in the interview sample. Childhood sexual trauma and spousal abuse were reported, although it is not possible to evaluate the findings clearly because of the way they are presented. Three reports of incest, three of molest, and one rape are listed, without specifying whether the reports were from different or the same women.

By report, onset of pain was associated with apparent repeated vaginal or urinary tract infections, multiple trials of antibiotic or antifungal treatment, elective abortions, late luteal menstrual phase, childbirth, treatment with fluorouracil or laser surgery, and life stress such as beginning a new sexual relationship, marital conflict or dissolution, work difficulties, or financial problems.

In interpreting these associations, the authors concluded that some of these factors could be viewed as organic or psychogenic. Vulvar vestibulitis may be caused by an infective or irritative agent that also causes vaginal or urinary tract symptoms; irritability in these areas could also be en expression of such psychogenic factors as depression, or sexual trauma or dysfunction. Pain following abortions could be related to enduring guilt and intrapsychic conflict, or to changes in the hormonal environment or exposure to a pathogen. Postpartum vulvar pain might be associated with episiotomy pain, hypoestrogenic state, or sexual dysfunction secondary to fatigue, depression, or fear of dyspareunia.

Regarding the difference between questionnaire results and interview data, the authors speculated that this group is reluctant to relate their vulvar pain to psychological distress. Since the instruments do not measure response bias, psychosocial problems which could be minimized on the questionnaires could have been more evident in the interview. Although the presence of the partner in 7 out of these 31 interviews may also have influenced the results, no significant differences were found between information from these interviews compared to those where the partner was not present, in terms of reporting spouse abuse, sexual trauma, marital conflict, chemical dependency, affairs, or depressive symptoms. The report did not specify how many of the 31 women interviewed were in committed relationship. It is also not clear in the report whether each of the women who completed the questionnaires participated in the psychosexual interview.

On the basis of the findings the authors suggested that vulvar vestibulitis may develop through a complex interaction between factors such as physiological vulnerability due to unknown local or genetic conditions, pathogens, or a hypoestrogenic state, combined with psychological risks in women who react to stress with symptoms, and concomitant reduced sexual desire and arousal.

These response patterns may be associated with dyspareunia from endometriosis, childbirth, gynecologic surgery, or repeated urogenital infections. Trauma to the tissue due to coitus in an unaroused state, with vaginismus, may be associated with emotional stress and a conflicted relationship, which sets up a pattern that may cause vulvar inflammation and lesions in women with overall vulvar vulnerability. The study raises many issues regarding the complex and multidetermined etiology of vestibulitis. It must be noted that in a population of women with vestibular pain, sexual frequency may not be an accurate indicator of psychosexual dysfunction so much as a behavioral change necessitated by the condition.

Issues of sexual functioning were also investigated as part of a treatment and research project in Melbourne, Australia, that was aimed at identifying sexual function and behaviors and other stressors which contribute to the etiology or maintenance of "vulvar disease" (Marin et al., 1995). This classification apparently included a variety of conditions that affect the skin of the vulva and vagina, such as precancerous skin changes, lichen sclerosus, yeast infections, and contact dermatitis. One hundred-twenty-eight patients at a dermo-gynecology clinic participated in a semi-structured interview and the administration of the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and The Spielberger State Trait Anxiety Inventory (Spielberger, 1984), along with medical examination and treatment.

Only a preliminary report of this study is available at this time. The number of women participating in each aspect of the study is not specified. The methodology is not entirely clear, and this report does not include the results of the psychological tests. It does identify several factors which may be relevant in individual cases of chronic vulvar pain. Areas investigated and reported in the results include sexual activities, practices of self treatment and personal hygiene, and stress factors.

Of the vulvar disease patients in their sample who were sexually active, a relatively high percentage engaged in unaroused, "undesired" coital activity, in the absence of vaginal lubrication. A relatively high proportion of women were found to engage in hygiene and self-treatment practices judged "likely to aggravate any existing skin problems" (Marin et al., 1995, p.5). Many of the participants reported psychosocial stressors which may be associated with onset of vulvar symptoms. These included stresses in family, work, relationship, finances, and other health problems. A large percentage of these women evaluated themselves as unable to cope with these stresses. The overzealous use of personal hygiene products is noted and discussed in terms of negative female self-image regarding genital odor, as well as resultant further irritation to the tissue of the vulva.

The authors concluded that unaroused sexual activity and damaging self-treatment can lead to symptoms of vulvar disease. They discussed these problems from the viewpoint of the woman's experience, noting that women may feel obliged to continue attempts at coitus even when in pain, and that "the temptation to apply something to an itchy, sore vulva [which] seems insurmountable in many cases" (Marin et al., 1995, p. 6) may cause further tissue damage to the vulva. The authors expressed the belief that some of the patients in the study are somatisers who express emotional pain physically and have poor coping skills and psychological insight. They concluded that "behavioural and stress factors significantly contribute to and, in some cases, cause vulvar disease" (Marin et al., 1995, p. 9).

While it is not possible to evaluate the methodology or the data from this preliminary report, the conclusion that vulvar disease (i.e., non-malignant chronic vulvar pain) results from a "complex interaction between organic pathology, stress, sexual behavior, hygiene, and self treatment behavior" (Marin et al., 1995, p. 9) warrants consideration and further research.

Another report (Crenshaw et al., 1985) raises issues which may also contribute to understanding multiple etiological factors in particular cases of chronic vulvar pain. This study presented a case of dyspareunia due to chronic cystitis, urethritis, and sympathetic dystrophy. These conditions have been associated with chronic vulvar pain. Sympathetic dystrophy is defined as "an illness consisting of superficial and deep pain of a spreading and burning character, vasomotor disturbances, trophic [interruption of nerve supply] changes, and limitation of movement, occurring in an extremity after some physical disturbance in that extremity" (Stedman's Medical Dictionary, 1972).

In this case, a menopausal 55-year old multipara who had developed intermittent cystitis at age 18 began to experience severe pain and burning around the urethra following intercourse, masturbation, and cunnilingus. Careful investigation revealed two important factors: untreated prostatitis in the sexual partner which caused repeated reinfection through intercourse, and a cystocele with marked anterior hooding and lateral bands, with fusion of the hymenal meatal area. This anatomic configuration exposed the meatus to constant friction during sexual activity. Cystoscopy revealed severe urethritis with a narrow urethra and multiple urethral fronds. That the woman's five sisters had the same bladder symptoms could indicate a hereditary component to the problem; one sister had required surgical placement of a synthetic urethra.

The authors concluded that the patient became depressed as a result of the chronicity of the problem, the suggestion by several physicians that "the urinary tract problem was a psychological maneuver on her part to avoid sex" (Crenshaw et al., 1985, p. 18), and the resulting strained relationship and emotional distance with her husband. The final diagnosis was inclusive: dyspareunia, uterine tetany, sympathetic dystrophy; chronic cystitis, trigonitis, urethritis; chronic pyelo-nephritis with hematuria, chronic inflammation of periurethral glands, and exogenous depression.

In another case study (Heitler, 1993), a woman was referred to a clinical psychologist for psychosomatic evaluation because of severe and apparently intractable vulvar pain. As with the previous case, this woman had been accused by physicians of manufacturing the pain to avoid having sexual relations with her husband; she had also been blamed for a disappointing treatment outcome on the assumption of failure to comply with medication regimens. Careful psychological exploration revealed no underlying reasons for the pain; it also brought to light the psychological devastation of the experience of this particular kind of chronic pain, which had pervaded "her thoughts, feelings, and in fact every area of her life" (p. 1).

Several psychosocial dimensions of vulvar pain emerged from the psychological evaluation: the demoralizing and exhausting effects of chronic pain; the burden of bearing private pain that affects one's self-image as a woman; the anxiety of the unknown; the stress of having practitioners respond to treatment failure by blaming the person and invalidating her experience; potentially severe relational strains with one's partner; isolation from relationships with family, friends, and normal life and the extraordinary need for emotional support; and depression, sometimes to the point of suicidal ideation (Bowles & McClear, 1991), when hope vanished. These studies underscore the clinical relevance of careful exploration of psychosocial factors.

Personality variables and psychosexual trauma may indeed play a role in attitudes and behavior of women with chronic vulvar pain, e.g., in failure to obtain timely medical care, obsessive overcleaning of the vulva, primary dyspareunia, or sexual arousal disorders. However, in the vulvar pain literature most women who developed chronic symptoms including dyspareunia had been sexually active before onset of the condition.

The point here is that the vulva is a sensitive area--sensitive both biophysically, and symbolically in terms of the meaning it has for both practitioner and the person suffering pain (e.g., Bury, 1982; Carcio, 1992) in that particular location of the female anatomy, and that the existence of psychosocial issues in a given case does not rule out the presence of biophysical factors as well. An either/or mentality (e.g., "The doctor said it's all in my head") may more represent a "clash of perspectives" (Friedson, 1961, in Scambler, 1984, p. 224), or "discontinuities between professional and lay thought" (Bury, 1982, p. 167) or models (Aakster, 1989; Andrist & Maillet, 1992; Heitler, 1993; Julian, 1994) than it does a sensitive recognition of the subtleties of differential diagnosis or a consideration of the fact that "anxieties are heightened when problems affect the genitalia" (McKay, 1992, p. 432).

The question of psychogenesis is extraordinarily complex and ultimately, except perhaps in the case of frank psychopathology, not particularly useful. As McKay (1992) wrote, "the patient with vulvodynia is no more psychologically unbalanced than one with atopic dermatitis or acne. Patients with psychiatric disease . . . present with a variety of somatic complaints, only one of which might be vulvodynia" (p. 432). The condition of chronic intractable vulvar pain is one of many human ills which prompts examining the utility of the distinction between body and mind.

In summary, it is clear from the preceding discussion that "no one factor can be identified as the specific cause of vulvodynia" (McKay et al., 1991). The vulva and vulvar vestibule are sensitive and highly reactive regions, and like any other area of the body respond constantly and in characteristic ways to inner and outer environmental changes in order to maintain and re-establish homeostasis. Incorporating both mucous membrane and cutaneous epithelium, the vulvar area is particularly complex and sensitive to change. This region responds to hormonal changes which alter the pH level of vaginal discharge, to materials and substances that contact the vulva from the outside, and to physical and emotional trauma as well as to normal physiological activities.

The genesis of chronic idiopathic pain is mysterious. The adjective "idiopathic" is defined medically as denoting a disease of unknown cause (Stedman's Medical Dictionary, 1995). In general usage the word "idiopathic" means both "peculiar to the individual" and "arising spontaneously or from and obscure or unknown cause" (Webster's Seventh New Collegiate Dictionary, 1967). Although the medical definition presents the possibility that each case may stem from the same--although unknown--cause, the more general usage lends weight to an assumption that may have more practical utility, i.e., that each occurrence of chronic unexplainable vulvar pain is multidetermined and complex in terms of multiple factors, biopsychosocial levels of activity and interactions among them (Engel,1980; McKay, 1989b; McKay et al., 1991; Secor & Fertitta, 1992).

The question about pathogenesis of chronic vulvar pain is really the question: Why is it that at some times, for some women, discomforts which normally would subside become refractory, even when the original condition that seemed to cause them ought to have abated on its own or has been treated with the standard of care? The chronicity of the condition develops insidiously; symptoms that are relatively trivial (Bury, 1982)--in the sense that temporary vulvar discomforts are not unusual--progress to cause for concern when their intensity, duration, and/or frequency increases rather than following an expected pattern of resolution.

In a description of another chronic illness, Robinson (1990) described "initial symptoms [that] may appear gradually, and only over long periods of time reach the threshold of visibility as potential illness. . . . The medical diagnosis of disease itself is contingent on entry into the medical system which is likely to be delayed" (p. 1175). Not all women who develop chronic vulvar pain may choose to seek the help of a practitioner. This can be a problem because early treatment is often essential to the successful management of vulvar diseases, some of which can be life-threatening (Reid et al., 1987; Wilkinson, 1992). Yet with a condition whose etiology is as uncertain as that of chronic vulvar pain, entry into medical care is likely to bring complications of its own (Crook, 1982).

> Commonsense assumptions lose their grip and yet alternative explanations do not readily present themselves. The individual is unsure about whether and how to disclose the illness, both to significant others and to outsiders, such as the GP. But for those who decide to consult a logic is set in motion, although the course of referral is rarely a smooth one. (Bury, 1982, p. 171)

The above quote from a study about the experience of quite a different chronic illness (multiple sclerosis) continues, to describe difficulties in obtaining accurate diagnosis. The description it offers of sufferers beginning the search for causation may be apt for women who experience chronic vulvar pain as well.

The meaning I propose to make of the potential impasse regarding etiology is that chronic pain challenges the biomedical assumption that pain is "no more than sensation, a symptom, a problem in biochemistry" (Morris, 1993, p. 5). Chronic vulvar pain presents an opportunity to examine critically the notion that the body and the mind are separate and independent of each other, and to engage in dialogue between medical and nonmedical experiences that may enlarge the scope and depth of understanding, which in turn may lead to sufferers and caregivers working together more effectively on the problem (Aakster, 1989).

Before beginning to address the meaning of the experience for those who have the condition called chronic vulvar pain, a review of current treatments is necessary, to review where various assumptions about etiology have led and may lead in the future.

Treatment Modalities

> The treatment of this condition is most unsatisfactory. I have met with a number of cases of marked character, and in not one was complete relief given by treatment. Whether they subsequently recovered I cannot say, but they certainly were not cured while under my observation. (Thomas, 1880)

Efforts to treat the syndrome of chronic vulvar pain have been frustrating for women seeking relief as well as for the caregivers who attempt to help them (Katz, 1993; McKay, 1984, 1988, 1989b, 1992; Stewart et al., 1990). Two concepts are salient in the effective care of vulvar pain: first, that early treatment for any pain condition enhances success; second--and creating the tension of paradox when juxtaposed with the first--that early resolution is not always possible. The 'tincture of time' is an important aspect of treatment: overaggressive or inappropriate application of therapies in pursuit of a rapid 'cure' can actually exacerbate symptoms and contribute to chronicity.

"The main goal is to reduce trauma to the affected tissue in order to decrease the stimulation of the nerve endings and thus decrease pruritus and enhance healing" (Carcio, 1992, p. 158). This calls for a conservative, common-sense approach.

> The least invasive treatments should be instituted first. Next-in-line therapy should only be introduced after a reasonable trial of at least 6 weeks. This time frame should include at least one menstrual cycle. Joint assessment by both the patient and clinician should determine the decision to institute next-line-therapy. This consensus process supports a therapeutic relationship and minimizes iatrogenic sequellae. (Secor & Fertitta, 1992, p. 165)

This conservative approach is not always what a woman receives when seeking biomedical care for the condition. Possible lack of knowledge or diligence on the part of the practitioner, heightened anxieties in both caregiver and patient due to the genital nature of the pain, and the pressure to do something dramatic to alleviate her very evident suffering can combine to lead to aggressive treatments rather than careful attention to all factors that may contribute to the individual's condition (Aakster, 1989; Crook, 1982).

Once primary infection has been ruled out or treated, the first line of response should be home-based self-care. As will be seen later in this section, the preceding sentence contains a contradiction inherent in the uncertainty of the condition of chronic vulvar pain: it is possible that the very therapies used to treat vulvar infections (and sometimes to diagnose them, by exclusion) can contribute to increased symptoms or the development of new ones. Within a complementary patient-caregiver relationship that is based on trust, thoughtful monitoring of experience, and communication, such risks may be undertaken carefully, as mutual decisions (Aakster, 1989).

The commonsense first line of care is gentle and noninvasive, eliminating possible environmental irritants and soothing the inflamed and/or sensitive tissue. Emotional support--including encouragement of an active attitude and confidence that, with time, the condition will subside--is an essential ingredient to the effectiveness of treatment from the start (Aakster, 1989).

> If a patient has a relatively mild case of vulvodynia but has received multiple treatments (e.g., drugs, salves, creams, and steroids), I usually begin by asking them to take two weeks out of their schedule for a course of "vulvar care." Unfortunately, it is usually necessary to stop working during this time because of the rigors of the treatment program. About one-third of women with relatively minor symptoms will respond completely to this care plan and go back to relatively normal activities. (Noller, 1993b, p. 53)

Noller recommended a regimen of four 20-minute sitz baths a day in a bathtub with colloidal oatmeal extract, followed by gentle drying and the use of a hair dryer on the "cool" setting; and the wearing of long, loose clothing and no underwear. In terms of sexual activity, Noller suggested the avoidance of oral sex during the 2-week course, because saliva contains amylase which seems to irritate hypersensitive perineal tissue for some women. Following this course, Noller recommended sitzbaths twice a day until "relatively" normal activities can be resumed--expanding the definition of "normal" to include permanent behavioral changes such as cotton underwear and avoiding jeans, pantyhose, pants, and menstrual pads, and any activity that involves prolonged moisture in the perineum.

Other aspects of vulvar management that seem to have helped some women include using only white (or preferably unbleached) cotton underwear that is changed frequently and washed separately, mild soaps (not detergents) for laundry (with a second cycle of plain water to rinse completely) and for hygiene, frequent rinsing with plain water especially during or after urination, very mild sea salt sitz baths, careful experimentation with sexual activities to determine what works without exacerbating symptoms, the use of vegetable oils if additional lubrication is needed in sexual penetration; the cessation of the use of any creams or salves (the so-called "inert" media of many topical preparations--even medications intended to quiet inflammation--have been found to irritate in some cases); dietary changes including the low oxalate-high calcium citrate diet, anti-yeast diets, and elimination of caffeine and sugar; vitamin E oil; spirulina; hydrangea and dandelion (the herbs prescribed by naturopaths for kidney stones); use of 100% cotton menstrual pads or tucking tampon string into the vagina if pads irritate and tampons are tolerated, the topical application of purified aloe vera gel and spray; and eliminating synthetic fibers and all constricting clothing or the prolonged wear of wet bathing suits, and the use of deodorant products, scented soaps or detergents, fabric softeners, bubble bath, perineal powders, and commercial sanitary pads or tampons if they irritate (Carcio, 1992; Noller, 1993b; The Vulvar Pain Newsletter, Spring 1993; "Natural Therapies," 1995).

Representing a different viewpoint on the subject of "elaborate washing and drying procedures" (Jainchill & Pincus, 1986, p. 980), a brief psychiatric report suggested that encouraging such behaviors might reinforce the patient's "sense of helplessness . . . reinforced by the physician's inability to identify a specific problem . . . (which) frequently led to a suicidal preoccupation" (p. 980). These authors emphasized the importance of optimistic reassurance combined with insight-oriented psychotherapy to help women cope with the disease rather than let it run one's life.

Self-assessment through the use of symptom diaries can assist thoughtful and appropriate decision-making about treatments. Journal-writing and other expressive modalities, meditation, self-hypnosis, and stress management techniques have also proved helpful for some women. Understanding support from partners and friends is a significant adjunct to any management strategy, essential to a woman's well-being. Healing the skin and nerves of the vulva may take weeks, months, or even a year to accomplish (Carcio, 1992; The Vulvar Pain Newsletter, Spring 1993).

Before continuing the discussion about other therapies, a digression is in order to acknowledge that an unknown but significant portion of women experience the symptoms of chronic vulvar pain without becoming (or remaining) "patients" because of it. It has been suggested that the few specialists who are thoroughly familiar with chronic vulvar pain are only accessible to woman who have the inner and material resources to find and utilize them (Yount, 1992). While these qualities will assist a woman in her search for competent care, it is also true that women of lower socioeconomic levels receive care at vulvar specialty clinics. The frustration of not being able to find competent care is common to many women regardless of their background. In general, however, economic disadvantage greatly increases health risks and reduces access to such care, including access to the practitioners who know something about the condition of vulvar pain. Economics may well play a part in women not seeking or continuing to seek treatment.

Whether informational and emotional support is available or not, some women utilize whatever self-care strategies that they have discovered empirically and "tough it out." In some cases this self-care may be effective; in others it may be deleterious, for instance when a woman tries an over-the-counter anti-itch preparation containing menthol, camphor, propylene glycol, polyethylene glycol, or other substances that irritate the tissue and exacerbate symptoms.

Avoidance of medical assistance for vulvar pain may be a conscious decision, borne out of previous unsatisfying encounters with the medical establishment, religious belief, or a commitment to natural remedies. It may be the result of economic factors or other social factors such as availability of information or of a trusted and diligent practitioner. It may occur in situations when a woman might go to a doctor for another condition but is unable or unwilling to seek care for vulvar symptoms for emotional or psychological reasons--such as shame, not considering one's symptoms (in particular or in general) worthy of medical attention, certainty that nothing can be done for it, or accepting the condition as a given in one's life rather than considering it a problem (Crook, 1982; Sarazin & Seymour, 1991). Several of these factors may operate in an individual's life, possibly adding in significant ways to the psychosocial stressors of the condition itself.

Returning to the discussion of natural treatments, it becomes clearer now that such therapies are likely to be followed within a particular social context. Women need access to enough social and material resources--time, information, education, money, medical insurance, supportive relationships, experience--to engage in such pursuit. They also need the personal history and inner resources that lead one to expect that such a problem can and should be fixed. Although not all patients are well-educated, the treatment of vulvar pain is, among other things, a function of social status and unexamined assumptions (Schover et al., 1992). The present discussion reflects the bias, for instance, that the woman with chronic vulvar pain lives in a home and has other basic resources which enable her to provide the self-care strategies described above.

Outside the home, other measures have helped some women: homeopathy, naturopathy, acupuncture, Chinese herbs, hypnosis, authentic movement or other expressive therapies, and emotional support groups (Bornstein, 1994). Noninvasive clinical treatment includes topical anesthetics, Prophyllin compresses, transepidermal nerve stimulation, physical therapy for vaginismus, biofeedback training for vaginismus and/or breakdown of adhesions, stress management, sex therapy, and individual, couples and/or group psychotherapy (Abramov, Wolman & David, 1994; Rooney & Yount, 1995; Schover et al., 1992; Turner & Marinoff, 1991).

> Ongoing support and education must be provided throughout the treatment process. Therapy selection must be consistent and negotiated with the patient. In addition, the patient's condition must be routinely monitored and reevaluated by both the patient and clinician. The range of medical therapies should be systematically initiated from the simple, safe, and inexpensive. Generally, surgery should be considered only after all nonsurgical therapies have failed to provide relief. Rare exception may be made when the patient chooses perineoplasty over further nonsurgical trials. (Secor & Fertitta, 1992, p. 168)

When noninvasive symptomatic treatment does not ameliorate the symptoms, some women and their practitioners have found the use of analgesics, topical capsaicin, oral acyclovir, a brief course of corticosteroids, sex hormones, or topical or long-term systemic anticandidal therapy to be of some help, depending upon the results of careful diagnosis as well as idiopathic response. Antidepression medication--low doses of a tricyclic (given for its analgesic effects, sometimes with an antispasmodic or anticonvulsant)--have had some success in vulvar pain associated with pudendal neuralgia (Turner & Marinoff, 1991) and dyesthetic vulvodynia (McKay, 1993), although many women find the side effects difficult to handle. When the pain has established as chronic, relief also takes time. "Neither the patient nor the physician should expect rapid resolution of symptomatic vulvodynia, even with appropriate therapy" (McKay, 1989b, p. 258). McKay reported that "recalcitrant symptoms may represent new problems," some of which can result from the treatments themselves, e.g., topical corticosteroids causing an inflammatory rebound (McKay, 1992) or (along with anti-biotics) predisposing one to a yeast infection, or sensitivities developing to other medications.

"Non-intended and non-desirable changes in the patient's health state caused by the treatment" (Aakster, 1989, p. 297) are generally considered acceptable in Western medicine, when they are relatively less serious or long-lasting than the condition being treated. The dangers and burdens of both diagnostic and treatment procedures are only incidentally mentioned in the medical literature on chronic vulvar pain, if at all.

The paradox of the risks of treatment emphasizes the element of uncertainty that accompanies chronic vulvar pain. Since a number of treatments--including even overcleaning or the "inactive" base in ointments (Secor & Fertitta, 1992)--have proved irritating in some cases, an approach including sensitive and thoughtful diagnosis, treatment trial, monitoring of responses, and patience is essential.

Along with a gynecologist, a biochemist who had been studying oxalates and burning skin initiated a vulvodynia research project to study the cause of this burning pain in the genital tissues (Melmed, 1994; Solomons, 1994b). Several findings emerged, including the indication that the sensitivity and pain also occurred in many women in the lips and tongue, bladder, intestine, and possibly in tissues involved in fibromyalgia. A familial pattern of vulvodynia was found in a subgroup of the women studied. This, in addition to the prevalence of light-complexioned women with vulvar pain, prompted Solomons to initiate a laboratory component of analytical connective tissue research within the project.

The low oxalate-high calcium citrate diet used in the vulvodynia project apparently made a significant impact on the lives of some 250 women who participated in the project, completely alleviating or significantly reducing pain. Controls were not used, and neither the total sample nor the outcome criteria are specified. Subjects who have not responded to the approach are being studied further. Melmed (1994) reported a significant effect in 46 out of 60 patients followed long-term. Solomons stressed the importance of relying upon patient self-assessment about levels of pain and functioning, which he pointed out "was a new experience for some patients" (Solomons, 1994b, p. 7). Although the low-oxalate approach met with initial skepticism in the medical community, according to the Vulvar Pain Foundation, 602 women have reported "significant recovery" over the past 2 years on the regimen, and "several hundred physicians are now associated with the project," ("Update," 1995, p. 11). In Israel, Bornstein and colleagues (Bornstein, Zarfati, Goldik & Abramovici, 1994) have begun to treat intractable vulvar vestibulitis with 6 months (minimum) of low oxalate diet and calcium citrate supplementation. Although demanding, the diet has gained numerous proponents among sufferers as information about it has become available in the popular press (e.g., Cooper, 1994).

When less invasive measures do not prove sufficient, several specialists have experimented with interferon cream (Biraghi, de Vergilis, Sasso,Zannoni & Sideri, 1986) or interferon injections to the painful sites, to enhance immune system response to the inflammation which is presumably due to HPV (Bornstein, Pascal & Abramovici, 1991; Bornstein, Zarfati, Goldik & Abramovici, 1994; Kirby, 1988; Sawchuck, 1992; Sonnendecker et al., 1993) or to herpes (Glezerman et al., 1989). This seems to have brought relief to some, although the improvement may be temporary. Because there is no accepted experimental model (Kirby, 1988) studies of these trials have not been well-controlled and "the response rate has often been in the placebo range" (Noller, 1993b, p. 55).

More aggressive medical and surgical treatments include tissue destruction: chemical destruction with trichloroacetic acid (a caustic) or topical fluorouracil (a cytotoxic), or surgical destruction with laser ablation or plastic surgery to remove the source of pain, depending upon the diagnosis. In the many cases where the cause is not known, "specific therapy is not available" (Noller, 1993b, p. 54), yet these therapies may be used experimentally, in spite of poor success rates (Fackelmann, 1991; Friedrich, 1987; McKay, 1992; Michlewitz, Kennison, Turksoy, & Fertitta, 1989; Reid et al., 1988), out of desperate hope for a cure.

Cytotoxics such as fluorouracil act by causing necrosis and sloughing of growing tissue, and can cause severe inflammatory reactions, burns, and scarring. Treatment with laser has proved controversial and potentially harmful (McKay, 1989a; 1992; Woodruff & Friedrich, 1985), although some women report relief of symptoms following this modality. Surgery to remove the painful area is a last resort for the desperate. Although the goals differ, the procedure of perineoplasty resembles what a facelift does. A crescent of affected skin is removed and skin from the vagina is undermined and advanced to cover the excised area. Some women experience gradual relief from pain after the recovery period, particularly if the procedure was properly performed (Bornstein et al., 1994) and they have been able to heal thoroughly before resuming active life. Others have been disappointed to find that post-operative pain becomes chronic or the original pain returns. "I am constantly amazed that some gynecologists always begin with surgery (vestibulectomy) as their first line of treatment when only about half of patients respond to this modality" (Noller, 1993b, p.55).

> The clinician must avoid contributing to the chronicity of the patient's condition. Examples of iatrogenic practices include performing multiple vulvar biopsies, treatment of normal variant vestibular papilloma, failure to accurately diagnose and treat concurrent infections especially those associated with acute VVS (leading to chronic VVS), and failure to offer ongoing support and education. Failure to offer nonmedical treatment options before surgery may also be interpreted as iatrogenic practice because surgery is associated with greater risks and possible sequelae when compared with nonsurgical approaches. (Secor & Fertitta, 1992, pp. 165-166)

Treatment outcome is related to numerous factors. Comprehensive approaches to treatment take this into account. The Schover et al. (1992) study examined outcomes of a treatment program that combined psychological evaluation, surgical treatment, and postoperative psychosexual counseling. Some of the factors involved in treatment outcome were investigated. Women who had painful vestibular lesions were offered localized excision of the involved areas. This is an outpatient procedure less invasive than perineoplasty.

Those who underwent the procedure were asked to return for counseling of pelvic floor exercise, the use of vaginal dilators, and other techniques of sex therapy. Women whose pain persisted were offered a psychiatric referral for management. In a detailed follow-up telephone interview at least 3 months post-surgery, subjects were asked about their pain and sexual functioning. Outcome was rated on a 5-point scale from very much improved to very much worse. Data were analyzed statistically.

Thirty-eight of the original 45 women evaluated had the surgery. Of these 20 reported improvement or resolution of symptoms, 15 some improvement, and 8 no change. None of the surgical candidates reported worsening of symptoms. Demographic variables of higher socioeconomic status, positive parity, and higher age were found to predict overall ratings of improvement. Psychologic factors at onset of pain, psychologic test scores, frequency of sexual activity, and partner's participation in evaluation or counseling were not associated with outcome ratings. Women who were willing to be evaluated by the psychologist preoperatively had significantly better outcomes than those who refused the consultation, and women who had at least one session of postoperative sex therapy also improved. All of the eight women who reported no postoperative improvement in their pain refused postoperative counseling. Of the 16 who had psychologic evaluation, surgery, and postoperative sex therapy, 56% reported much improvement, 44% some improvement, and none reported having not improved.

In a stepwise regression analysis, only three factors exceeded tolerance levels: compliance with psychologic evaluation, number of children, and socioeconomic status accounted for 24% of the variance outcome, and "may be helpful clinically in predicting prognosis with our treatment program" (Schover et al., 1992, p. 634). This study also found that treatment outcome was related to the location of pain--to the extent that the surgeon is cautioned not to consider this surgical procedure for women who report vague, diffuse genital pain or deep dyspareunia, or those who refuse psychologic evaluation.

Although statistical analysis did not suggest that higher socioeconomic status and localized pain accounted for the positive response to the combined treatment, the authors found that participating in the psychological evaluation contributed to successful treatment outcome. The authors suggested that the interview helped women to accept the role of psychological stress in dyspareunia and vulvar pain. Women who appreciated the multifactorial cause of pain were "more willing to take an active role in rehabilitative efforts after surgery" (Schover et al., 1992, p. 634), and, presumably, to endorse a multidisciplinary teamwork approach to intervention.

The writers also speculated that "a woman who perceives her pain as diffuse and overwhelming, and expects the physician to magically solve it with surgery, is unlikely to take an active role in her own rehabilitation" (p. 634), and is likely to have a poorer outcome. They assumed that such attitudes may be related to the relatively lower sophistication associated with socioeconomic status.

The outcome measures and the range of the outcome report from time of the procedure (1 to 24 months) suggest the possibility that the outcome measure is not stable. It would be helpful to have specific functions assessed as a fuller measure of treatment outcome. The report suggested further avenues of exploration that may contribute to improved treatment. The assertion that sex therapy without removal of lesions has poor success, and the suggestion that participating in the evaluation interview contributed to successful outcome, together indicate the need for further detailed inquiry into the role of psychotherapy interventions with chronic vulvar pain.

Relevant issues include therapist and patient attitudes towards psychological treatment, and the quality of the therapeutic relationship. Of particular interest is the association between poor surgical outcome and refusal of psychologic intervention, which bears further investigation, including evaluation of the meanings that both surgery and the particular treatment program hold for individual women, in addition to the more obvious interpretation that women who refuse psychological intervention are unwilling to consider that stress factors contribute to their pain. Other factors may be active this dynamic, such as the context in which the intervention was presented conceptually. This study highlights the need for controlled trials of treatment with a combination of interventions, as well as sensitivity to the issues of the particular patient in assessing treatment options.

Several of the other reports discussed in the previous section on etiology reflect therapeutic sensitivity to the many dimensions of vulvar pain in a woman's lived experience. Treatment in the case study of the woman with dyspareunia due to chronic cystitis, urethritis, and sympathetic dystrophy (Crenshaw et al., 1985) followed an eclectic, individualized approach in response to the severity, chronicity, and diversity of the problem. This included amitriptyline for both its antispasmodic and antidepressant properties, cognitive behavioral techniques and insight psychotherapy, relational and sex therapy, cystitis counseling, ampicillin for recurrent severe cystitis, vaginal dilations, and finally (after referral to a pain management center where the diagnosis of sympathetic dystrophy was made), a series of spinal nerve blocks.

The authors reported that after 2 years of attentive multimodal treatment the patient had improved communications with her partner, resumed sexual functioning without pain, and tapered off the antidepressant. Based upon the outcome of this treatment plan the authors offered guidelines in treating chronic urinary tract problems related to sexual activity which may also pertain in cases of chronic vulvar pain:

> Obtaining detailed histories and physical examination of both sexual partners;
> Treatment for physical, emotional, and interpersonal factors of both partners;
> Outlining from the beginning a variety of alternative treatment options to explore--to avoid unrealistically high patient expectations and disappointment and to sustain motivation;
> Coordination of care with referrals to other specialists and to maintain continuity of care with regular follow-up appointments to monitor current status of all levels of treatment and response;
> Reinforcement of improved functioning;
> Preventive measures;
> Never assuming that the problem is psychological even when physical cause is difficult to detect;
> Ongoing awareness that chronic pain produces depression;
> Reassurance that the practitioner will not give up even if no easy solutions are apparent. (Crenshaw, 1985, p.25)

A comprehensive, individualized teamwork approach such as this includes understanding and moral support (Julian, 1994) for women who may be "angry and discouraged after numerous frustrating medical experiences" (Crenshaw et al., 1985, p. 23).

The Woodward (1981) study took the opposite approach to psychogenicity but also emphasized the importance of taking the person's experience seriously and providing time to explore psychological issues. Woodward identified underlying patient issues of psychopathology in four major categories: "strong feelings of conflict created by parental attitudes which were experienced as diminishing [the patients] as people;" "anger or resentment towards their male partner;" " marked feelings of nervousness, sexual inadequacy and depression;" and "reaction to a current situation" (p. 1674-1675).

The report did not specify whether these categories emerged from the counseling sessions and accounted for all underlying patient issues of psychopathology or whether data from the sessions was sorted into preconceived concepts. Although no figures are given on prevalence of themes, spousal conflict is mentioned as the most frequent, and some women apparently experienced more than one of these factors. The author reported that when patients began to make the link between strong emotions and symptoms, they experienced a sense of having a choice to continue as before or to let the symptoms go.

The treatment condition in the study utilized a form of sex therapy which integrates a psychodynamic and behavioral approach (Kaplan, 1974). Counseling sessions involved taking the patient's experience seriously and giving her time for discussion and exploration of emotional issues. Rather than being told that "nothing is wrong," each patient was told that she had a condition that was fairly common but was not an infection, which involved utilizing symptoms to protect herself from unacknowledged feelings. Each patient was gently encouraged to seek what these might be for her and to explore how her body has responded to emotions. Part of the process included keeping a symptom diary to raise awareness of emotional and physical reactions (Woodward 1981).

It appears that the 92 patients were divided into two groups, although no information is furnished regarding assignment or comparisons of variables between the two groups. One group received limited counseling (presumably one session), while women in the other group were allowed to determine the number of sessions, with the average being four. The author reported that of these "most consider themselves able to respond to short-term psychotherapy" (p. 1677), while 10 patients in the limited group requested, and on humanitarian grounds were granted, further sessions. No control group was utilized.

Assessment 6 months following treatment included physical examination by a different clinic doctor from the treatment provider, and self-report from the patients on level of satisfaction based upon a 4-point rating scale (free of symptoms, improved, no change, or worse). The author reported in the conclusion section that the two treatment groups reported similar success rate: 87% were assessed by both exam and self-report as free of symptoms or improved. The report does not break down these numbers more specifically, nor does the it offer explanations for the unexpected success rate of the limited treatment group.

The author stated that given the absence of organic findings and the patients' "own high evaluation of psychotherapy," (p. 1677), even though the study produces no hard evidence of the existence of a psychosomatic form of vaginitis, it does provide "evidence which cannot be lightly dismissed" (p. 1677). The report ends with a recommendation "on commonsense grounds that all vaginitis patients with two 'normal' swabs should be offered a short time to discuss the possibility of emotional causes and be encouraged to ventilate their feelings" (p. 1677), as well as recommending further counseling referral for patients whose symptoms persist.

This study appears to have been basically a quasi-experimental outcome study with two groups, pre-test and post-test measures (self-reported symptoms and a physical exam free from organic findings) and two treatment conditions. Although the design of the study is not clear, it appears that a number of competing variables may have threatened internal validity. These might include other influential events occurring between the first and second tests, changes in instrumentation, expectancy effects, placebo effects, mortality in the sense of changes in group composition, attributes of the experimenter, and demand characteristics. Although the variability of symptoms is noted as a characteristic of psychogenic vulvovaginitis, this variability is not taken into account as a factor in the outcome measures. Threats to validity do not necessarily invalidate a study, but they can confound results. Threats to this study were not taken into account critically, and they qualify the kind of generalizations to which the results may be applied.

The stated design was to determine (1) whether the condition of non-organic vulvovaginitis could be understood in psychosomatic terms, (2) whether it could be accepted by (a) clinic staff and (b) patients as psychogenic, and (3) whether one counseling session would alleviate patient requests for medications which did not seem effective. The first question does not specify whose understanding is being addressed, nor does it operationally define the concept of psychosomatic. Since the explicit premise of the treatment is that the condition is psychogenic, this concept is not being tested as a hypothesis so much as inculcated in the subjects. No mention is made of staff understanding and acceptance of psychosomatic terms; the study does not appear to address these issues after stating this as one of its purposes.

Although the design of the study, the methodology and the analysis of data may be flawed in terms of quantitative methodology, this report draws attention to important issues. Primarily, the very lack of clarity between stated purpose and the actual research project is useful in posing the clash between the epistemologies of "objective" science and "being with." The work of the study addresses the potential effectiveness of the practitioner taking the woman's experience seriously, listening to her nonjudgementally, and encouraging an exploration of psychosocial meanings, as well as the use of symptom diaries to enhance self-awareness and self-monitoring. These may be seen as phenomena of connection--between practitioner and sufferer, between the woman and the meanings her history and social situation have for her, between her observing self and her physiologic and emotional cues, and in her awareness of the connections between these cues. These conceptual connections could be operationalized in a variety of ways for a quantitative study of more rigor than the one reported here, or they could have been addressed qualitatively to explore the meanings inherent in the situation.

Treatment in the case study reported by Heitler (1993) also focused on thoughtful attention to each of the issues that had emerged in the psychological evaluation, which led in this case to socio-behavioral changes and ultimately to a "fully normal life" (p. 2). The woman reorganized her priorities and activities to accommodate the dramatic decrease in energy caused by the pain; this enabled her to be less irritable and overwhelmed with her family and associates. Talking openly with the therapist and trusted friends about her frustrating medical experiences helped her see that the hurtful words of some physicians had come from their own sense of helplessness and that there was nothing wrong with her personally for having the pain.

Finding ways to remind herself experientially of her identity as a whole person also helped alleviate the sense of personal and physical defectiveness. Sensitive discussions with her (fortunately understanding) spouse enabled them to deepen their relationship in these times of trouble. The woman dealt with her anxiety by informing herself as much as possible about vulvar pain and communicating with other women who had the condition, to share information about research and treatment and to feel less alone. Working with a team of dedicated practitioners, she explored treatment options in an atmosphere of mutual respect, which led to remoralization as well as relief of symptoms. Her depression, which became most serious at times when a promising treatment proved unsuccessful, diminished significantly, as together they found a biochemical treatment that eventually alleviated the physical pain. This case study exemplifies a thoughtful, comprehensive approach to the experience of chronic vulvar pain as it affects a woman's entire life, and may serve as a guide to significant psychosocial dimensions of the condition (Aakster, 1989).

As these reports indicate, through trial-and-error, self care and self assessment--especially if carried out in the context of social support and/or with a sensitive health care provider--some women have been able to marshal the particular combination of resources that work for them, either to incorporate the symptoms manageably into the rest of their lives or to free themselves from pain. The process of self-discovery, and filling in gaps in one's own knowledge base, appears to have real therapeutic value for some women.

Practitioners who thoughtfully attend to their patients' experiences and the meaning they make of them are upholding an appropriate standard of care in the definition and treatment of chronic vulvar pain. The forgoing reports attest to the stress women experience in seeking the help of practitioners who are not sensitive to their experience. Some authors go so far as to suggest that "failure to offer ongoing support and education" (Secor & Fertitta, 1992, p. 165) in itself is actually an iatrogenic practice or a source of psychological trauma (Gottlieb, in press). "Listening to our patients has once again proved to be an effective means of defining a clinical problem, and listening remains an important part of vulvodynia therapy" (McKay, 1989b, pp. 261-262).

Chronic Pain

The multidisciplinary field dedicated to the study of pain offers several concepts which may illuminate and further sensitize us to salient issues in the research of chronic vulvar pain experience. Chronic pain is not simply the persistence of acute pain, with the same neurological mechanisms and physiological effects continuing over time. The changes from acute to chronic pain constitute a significant transition involving many levels of the human organism. The sympathetic nervous system fight or flight responses to acute pain habituate, and neurovegetative signs--such as sleep disturbance, fatigue and anergia, irritation, seclusion, lowered pain tolerance, and decrease of motor activity--emerge, possibly due to a depletion of central serotonin activity (Sternbach, 1984).

> The usual drugs and surgery known to be successful for the acute problem are applied and only transiently help the patient who now becomes worse. Both the patient and physician become desperate seeking stronger medications and more mutilating surgery until each regards the other as being incompetent or psychologically disturbed. Referral is made on to other specialists who have a try until the patient becomes firmly labeled with the regrettable terms of "CROCK" or "CRAZY." (Black, 1980, p. 209, author's emphasis)

How pain becomes chronic is explained in different ways. Conflicting explanations reflect the social history of medicine as well as the experience of a woman who suffers with exquisite burning in the skin of her vulva being told that it is all in her head (Crook, 1982). The conflict is inherent in the unidimensional model that opposes the organic or sensory-physiological (peripheral) and the functional or psychogenic (central).

> The sensory-physiological view espoused by Descartes gained ascendance in the late 1800s with advances in sensory physiology and psychophysics. Psychological factors, when considered at all, were relegated to positions of secondary interest. However, despite major advances in our understanding of the nervous system, in the development of potent analgesic preparations, and in increasingly sophisticated surgical procedures, permanent amelioration of pain was not achieved. The inadequacy of surgical and pharmacological treatment regimens produced frustration as many patients continued to report pain despite the interruption or blocking of putative pain pathways. Moreover, clinicians observed that patients responded quite differently to the same pain syndrome and reported widely varying benefits from identical treatments. Perplexed by these anomalies, physicians who adhered to the unidimensional sensory-physio-

> logical model began to suggest that the differences, if unrelated to pain neuropathways, must be the result of psychological (*psychogenic*) factors. That is, if the putative pain pathways are severed and the patients continue to report pain, then the pain must ipso facto be caused by psychological mechanisms. (Turk & Rudy, 1986, pp. 760-761)

The idea receives general, if unexamined, cultural acceptance--that pain is either in the body or in the mind. According to this traditional (peripheralist) position (Caillet, 1988), peripheral nociceptive stimuli continue to bombard the dorsal columns, maintaining pain-producing pathways. Many physicians seeking to help alleviate chronic pain operate implicitly from this position. Certain that an unknown agent such as a virus must be causing the pain, they respond as they would to an acute pain problem, giving more credence to objective signs than to subjective symptoms, and assuming that it is possible to measure pain and positively to identify the pathological sources that cause it. Patients also tend towards a somatic preoccupation, needing affirmation that their painful condition is "real," and fearing the implication that they are making it up (Kerns & Jacob, 1992; Pilowsky & Spence, 1975).

In response to the limitations of this perspective, growing clinical and research interest in the psychological components of the experience of pain led to the development in the mid-1960s of the Gate Control Model of pain (Melzack & Wall, 1965). Although some of the neurological mechanisms proposed by this model have been challenged (Wall, 1978), it is still considered very valuable conceptually and clinically in its emphasis on "the importance of both the central and the peripheral nervous systems in reports of pain" (Turk & Rudy, 1986, p. 761). The model differentiates between the sensory phenomenon of nociception and the subjective perception of pain, leading to the centralist position that the initial sensory bombardment initiates a pattern which becomes self-perpetuating whether the peripheral nociceptive stimuli that originally caused the acute pain have diminished, disappeared completely, or are still in operation; pain mechanisms now persist regardless of sensory input (Caillet, 1988).

One centralist description of chronic pain acquisition revolves around the idea that the acute pain of injury has both a sensory component involving inflammation and other neurochemical changes, and a reactive component in which anxiety, attention, and memory are activated. Peripheral physiological mobilization is encoded during trauma or crisis, and becomes associated with chronic pain and/or anxiety and vigilance, and centrally sustained by unconscious motor memory circuits in the brain. Ordinarily the two components, the sensory and the reactive, are balanced; but when pain becomes chronic the sensory component diminishes while the reactive component expands (Wickramasekera, 1988). Although this description contributes conceptually to thinking about chronic pain, in reframing the central/peripheral dichotomy with a synthesis, it does not address the process by which the imbalance of the two components occurs.

Another approach to pain theory utilizes an operant model which focuses on behavioral manifestations (Fordyce, 1976) rather than sensory phenomena. In contrast to this model, what is most useful for the current study on chronic vulvar pain is Melzack and Wall's (1965) emphasis that pain perception includes cognitive, affective, and sensory factors. Bridging these two approaches and building on them, Turk, Kerns, Rudy, and their associates (Kerns & Jacob, 1992; Kerns, Turk & Rudy, 1985; Turk & Rudy,1986) developed a model sensitive to the transactional nature between emotional factors, sensory phenomena, and behavioral responses from the standpoint of the perspective of the individual.

> The cognitive-behavioral transaction model describes pain as a complex, multidimensional, perceptual phenomenon. Pain perception is not the end result of the passive transmission and registration of impulses from physically defined stimuli. Instead, it is a dynamic, interpretive process. To better understand and treat pain, consideration must be given to the role of cognitions, emotions, and behavior as well as to sensory contributions in the formation of pain perceptions. Attempts to determine when pain sensations end and pain perceptions begin are often arbitrary, and attempts to make such distinctions seem unfruitful, if not impossible. (Turk & Rudy, 1986, p. 762)

Returning to the phenomenon of chronic pain in particular, descriptively, after a period of time (traditionally 6 months, although depending upon normal healing mechanisms chronicity can become apparent within 3-6 weeks) the "concept" of pain becomes deep-seated and resistant to any peripheral intervention. All acceptable therapeutic approaches fail to relieve the symptoms, and the patient becomes or remains disabled far in excess of the apparent diagnosed impairment. The cause of the pain now becomes obscure. Symptoms become relatively unexplainable, and pain itself changes from being a symptom of disease process to being considered a "disease entity" in its own right (Sternbach, 1974).

Emotional response and psychological effects of pain undergo alterations as well in "the transition to chronicity" (Nerenz & Leventhal, 1983, p. 26). While acute pain involves characteristics of anxiety, almost all psychological studies of chronic pain patients report mild but significant depression as one of its features (Blumer, Zorick, Heilbronn & Roth, 1982; Nerenz & Leventhal, 1983; Sternbach, 1984). This depression may be acknowledged or it may be masked by preoccupation with symptoms. People with chronic pain have been observed to adopt chronic invalid behaviors, such as occupational disability, social limitations, sick role, health anxiety, and resistance to reassurance, all of which can lead to "abnormal illness behavior" (Sternbach, 1974) which resists treatment and rehabilitation.

Other socio-behavioral effects of pain include inactivity, polysurgery, polypharmacy, loss of status, family strain, and tyranny or manipulation. "Once pain associated with tissue damage has occurred and becomes chronic, it serves as a 'sink' for all intra- and interpersonal problems" (Sternbach, 1974). Under the burden of constant pain, a person may become oblivious to familial and occupational sources of tension. In addition, a tendency may develop to satisfy dependency needs through invalidism or narcotics.

Much work has been done on cognitive factors influencing the experience of pain and suffering. For instance, cognitive distortion--such as catastrophizing, overgeneralization, personalization, and selective abstraction--has been found to have important emotional and behavioral effects related to excessive impairment (Keefe & Williams, 1989). Another cognitive factor that influences experience is "patients' beliefs about the cause of pain, its likely future trajectory, and what treatment will benefit them, (which) appear(s) to have an important influence on emotional adjustment and compliance with therapeutic interventions" (Keefe & Williams, 1989, p. 557). Clearly, "patient's beliefs, attitudes, and expectations about their pain and its treatment are an important and underevaluated aspect of the assessment process" (Schwartz, DeGood & Shutty, 1985, p. 806). Research into illness beliefs, control, and coping seems to uncover useful pieces of the puzzle, but to do so at considerable remove from the actual experience of chronic pain in a person's life.

The role of psychological and social factors in pain is generally assessed through interviews and self-report measures. Standardized assessment instruments help identify potential areas of psychosocial difficulty that are common to chronic pain in general. In addition to indicating issues for clinical focus, the use of such instruments in the initial clinical session may facilitate engagement of "the patient and others in a collaborative effort that will maximize treatment participation and outcomes" (Kerns & Jacob, 1992, p. 237).

It is helpful to understand that chronic pain is a complex subjective experience which changes and may progress through a series of stages, and that there may be critical periods of ambivalence whose meaning is significant to the person suffering the pain. Mapping behavior patterns, pain beliefs, and sensory decision pathways may add useful information, although these approaches do not address the insider's experience directly and at close range (Conrad, 1990).

Since "pain represents private data" (Merskey, 1975, p. 301), the intense sensory, affective, evaluative, and social components that chronic pain holds for the individual (Caillet, 1988; Crook, 1982; Gracely, 1980; Kerns & Jacob, 1992; Turk & Rudy, 1986) are critical to an understanding of chronic vulvar pain and its treatment. Chronic pain has been observed to "dominate the sensorium" (Sternbach, 1984, p. 173, quoting both Livingston, 1942 and Bonica, 1953), disturbing emotional as well as physical equilibrium to the extent that it can create psychoneurosis:

> Patients usually complain of delayed sleep onset and frequent awakening because of pain. They arise in the morning feeling unrested and tired. They feel quite exhausted, drained of energy not merely from lack of sleep but because the continuous pain wears them down . . . . These patients also find themselves irritated by minor actions and trivial comments of those around them. They complain that they find themselves snapping at family members for insufficient reasons, repeatedly, despite resolving not to do so. They frequently seclude themselves to avoid further verbal attacks on the objects of their aggression . . . . This suggests a pattern similar to the need-state for rest suggested by Wall. (Sternbach, 1984, p. 174)

Effects as intensive and pervasive as these can happen to anybody stricken with a massive chronic experience of pain, yet clearly there must be an interplay, as well, between the quality, intensity, and duration of the pain and the character of the individual who experiences it. Coping styles may be seen as defenses which can help or hinder. The strong effects of pain interact with personality variables and the emotional vulnerability or ego strength of the individual, as well as with significant social and environmental factors. The notion of reciprocal and dynamic interaction is the operable concept here (Kerns & Jacob, 1992). While "personality traits and mood states . . . might underlie, exacerbate, or hamper the progress of the chronic pain patient" (Schwartz et al., 1985, p. 806), it is also relevant that "because psychological and social dysfunction are highly probably consequences of persistent pain, it would be a mistake to use global evidence of emotional and behavioral problems to diagnose so-called 'psychogenic pain'" (Craig, 1984, p. 156).

Chronic pain has been the topic of much research and writing over the past 30 years, some directly relevant to the present study of chronic vulvar pain.

> The total pain experience which includes nociception, pain sensation, suffering, and behavioral response is the net effect of incredibly complex interactions of ascending and descending neural systems, biochemical, physiologic and psychologic mechanisms and neocortical processes that involve dynamic, constantly changing activity that takes place simultaneously in most parts of the nervous system concerned with sensory, motivational, cognitive, and judgemental processes and affective reactions. (Bonica, 1980, p. 9)

In light of this description, the question, "Is it all in my head?" does not seem to be particularly useful: it can be argued that all pain involves central nervous system mechanisms (Boivie, 1989). In distinction to the pervasive unidimensional assumptions of the body/mind split implicitly held by many practitioners and laypeople alike (Crook, 1982), the chronic pain experience has been more meaningfully characterized by decades of pain research as complex, dynamic, and multidimensional (Kerns & Jacob, 1992). Furthermore, "many experts agree that pain is ultimately a private, subjective experience or perception" (Turk & Rudy, 1986, p. 764). This perspective suggests the importance of investigating the individual psychosocial context in which chronic pain develops and gives rise to consequences. It is this essentially personal quality of chronic pain which brings us now to observations from the field of medical sociology in the experience of illness.

The Experience of Chronic Illness

Psychosocial aspects of chronic illness have received increasing attention over the past four decades, primarily in the field of medical sociology. "Although the experience-of-illness framework has not been fully developed conceptually, in the past few years there have been a number of studies that could easily be termed experience of illness studies" (Conrad, 1990, p. 1260). Historically, thinking about chronic illness has followed two traditions in this field, the first one stemming from Parsons' (1951) formulation of the sick role and the second taking a more interactionist, "insider's" perspective (Shontz, 1983).

The sick role model, as described by Parsons (1951), "established the frame for social research on sickness behavior . . . [conceptualizing] illness as deviance and the physician as social control agent" (Conrad, 1990, p. 1258). The model delineates the processes of identification of symptoms, the decision to seek treatment, the assumption of the sick role with temporary acceptance of dependence while undergoing treatment--and finally, recovery.

The sick role model accounts for neither "the patient's interminable journey through the medical mill" (Violon,1982, p.32) when the help one seeks proves to be ineffective or deleterious, nor for the fact that "the conditions which underpin most forms of disablement involve fluctuating symptoms and uncertain outcome" (Bury, 1982, p. 168). The particular assumptions of the model do not contribute to understanding chronic illness experience (Bury, 1982; Lubkin, 1990). In fact, Conrad (1990) asserted that the sick role model is "the classic outsider framework . . . inadequate for understanding the social psychological aspects of illness" (p. 1258) in general, because it does not address the perceptions and expectations of the person who is sick. Parson's model generated a great deal of research and thinking, however, leading to such concepts as deviance and adaptation (Bury, 1982), which connect to subsequent interactionist work on illness meaning.

In the 1960s, just as researchers in the field of pain were beginning to explore the personal and psychological aspects of pain perception and experience, so too were medical sociologists beginning to consider the "insider's" perspective (Conrad, 1990, p. 1260). This second tradition and line of research in medical sociology "is that of symbolic interactionism, focusing upon issues of meaning, identity, and the management of long-term (stigmatizing) illness and disability" (Williams, 1987, p. 151). The work on illness behavior (Mechanic, 1961) established the importance of learning more about "the ways in which given symptoms may be differentially perceived, evaluated, and acted (or not acted) upon" (p. 189), and of using this understanding "constructively and effectively in medical practice" (p. 194).

Coming even closer to the perspective of the individual's experience of illness was the work of several researchers, most notably for the purposes of this study, the work of Goffman (1968) and that of Glaser & Strauss (1967). The former brought descriptive and analytic insight to issues of identity and stigma, and the latter substantively established the field of qualitative research on chronic illness (Gerhardt, 1990). The experience of illness has meaning to the person experiencing it, (Kleinman, 1988). Accordingly, study of the subjective perspective of the ill person "necessarily focuses on the meaning of illness" (Conrad, 1990, p. 1260).

The disease and the experience are not the same. When thinking about illness, it is useful to consider this distinction (Barondess, 1979; Eisenberg, 1977). Disease refers to pathogenic change, to "abnormalities in the structure and function of body organs and systems" (Eisenberg, 1977, p. 11), the "undesirable physiological process or state" (Conrad, 1990, p. 1258) that the practitioner seeks to identify and treat in a patient who presents with symptoms. Disease as a concept is a technical reconfiguration of the patient's problem that enables medical practitioners to focus on it "through the theoretical lenses of their particular form of practice" (Kleinman, 1988, p. 5).

The concept of illness, on the other hand, has to do with the lived human experience of symptoms and suffering, "disvalued changes in states of being and social function" (Eisenberg, 1977, p. 11), "the social and psychological phenomena that accompany these putative physiological problems" (Conrad, 1990, p. 1258). Illness "has more to do with perception, behavior and experience" (p.1258); it has meaning, and it involves the individual in a multitude of personal, social, and cultural processes which also have meaning.

In a further conceptual refinement, Kleinman (1988) and Robinson (1990) are among those who discriminate between the psychological and the social aspects of the meaning of health status with a third designation. Robinson suggested that sickness is the social status-of-health equivalent to the medical status of disease and the personal health status of illness. Where the source of attribution for illness is self perception, and the source of attribution for disease is biomedical perception, the designation of sickness is attributed by social perception.

> The relationship between disease, sickness and illness is clearly complex. Personal perceptions of illness, social perceptions of sickness and biomedical perceptions of disease appear to operate in different places which are profoundly discrepant in their general mode of defining, accounting for and managing health problems, yet which are so closely congruent at some temporal points that it is difficult to analytically separate accounts which interweave the personal, the social and the biomedical." (Robinson 1990, p. 1174)

Bury (1982, p. 179) addressed cultural issues by suggesting that the tendency to identify "medical thought with disease and lay thought with illness" seems "oversimplified," and proposed a consideration of the ways these two different modes of thought may be continuous or discontinuous: "I wish to suggest that medicine be treated as a cultural system, as both an important resource to people in times of distress and pain and as a constraint in their search for the deeper meaning of experience" (p. 179).

Whether the account is defined and based upon a biomedical, social, or personal conceptual framework, Robinson (1990) asserted that it is implicitly a *narrative* --building, ordering, and documenting "preceding events, findings and circumstances . . . [in] a clear trajectory which constitutes the disease, sickness or illness" (Robinson, 1990, p. 173). The focus of the disease account is medical diagnosis, prognosis, and therapy; sickness is focused on social status; and illness on personal life goals. The respective "imputed negative change(s) in health status" are: deficit (impairment), handicap (stigma), and loss (bereavement) (Robinson, 1990, p. 1174).

In the section on chronic pain the problem of onset and recognition, the "insidious onset" and the "transition from trivial symptoms to a developing and persisting disability" discussed (Bury, 1982, p. 170). Disruption in "taken-for-granted" bodily states emerges into consciousness in a stage of wondering what is happening to oneself. Bury (1982) refered to this phenomenon as a disruption of assumptions and behaviors, and "the breaching of commonsense boundaries" (p. 169). Robinson cited Locker's (1981) use of the term "problematic experiences" in describing such perceptions:

> Most peoples' lives . . . are lived with virtually constant attention to phenomena which may or may not be designated by themselves as illness, by others as sickness, or by those professionally operating with a biomedical model as disease. These ubiquitous phenomena, or 'problematic experiences' as Locker calls them, appear to continuously invade everyday life and call on an array of personal, social and professional interpretive frameworks to make sense of them. The complexity of personal perceptions and actions which turn 'problematic experiences' into self-recognized symptoms and illnesses have been widely noted, as have the multiplicity of responses thereby generated. (Robinson, 1990, p 1174)

The uncertainty surrounding the onset of problematic somatic perceptions is critical: whether the symptoms are serious, whether they will intensify, the degree of discomfort, incapacity, or disability; the duration of the episode, the reversibility of the condition--these are some of the uncertainties somatic symptoms bring.

> The person who has symptoms will be concerned primarily with whether he hurts . . . how much they interfere with his life and social relationships depends on whether they are permanent or temporary, predictable or unpredictable, publicly visible or invisible; also on their degree (as of pain), their meaning to bystanders (as of disfigurement), the nature of the regimen called for to control the symptom, and of course on the kinds of lifestyle and social relations which the sufferer has been accustomed to. (Strauss 1986, p. 95)

Concepts such as symptom perception establish that "the individual's subjective experience of pain and discomfort is an interesting and important variable in its own right" (Watson & Pennebaker, 1991, p. 21), influencing decision-making and action. Symptom perception also evokes emotional reactions.

If the initial experience of disruptive or problematic somatic perceptions centers around the uncertainty of what is going on, a closely related phenomenon is "the arousal and the minimization" (Leventhal & Diefenbach, 1991, p. 250) of emotional response and distress--how one feels about what is going on. "The meaning people attribute to their experience and how they make sense of what is happening to them and their bodies" (Conrad 1990, p. 1261) involves an emotional component which may be an important aspect of what Strauss (1990) conceptualizes as "the work of managing" the illness (p. V).

> Little use has been made to date of the role of somatic sensations as reminders of vulnerability, elicitors of worry, and potential motivators of preventive and treatment behaviors. It is likely that they have been ignored because of their double-edged character: Somatic reminders can instill motivation to control or regulate threat and they can instill loss of hope and passivity. The interpretation of somatic sensations and the responses to them are key; that is, are they interpreted as signs of disease and an uncontrollable and dire fate or are they seen as cues to necessary preventive or treatment actions where failure to act, and not the somatic signs, elicit the perception of threat and loss? (Leventhal & Diefenbach, 1991, p. 265)

Conrad (1990) agreed that how people manage their emotional responses to illness and how the emotions affect illness are issues that have not been well explored. This emotional experience of, or response to, illness may not be generally thought of as work, yet the management of emotions arguably is a significant part of the theory of illness trajectory work, everyday life work, and biographical work that emerged from the Corbin and Strauss research on the "unending work and care of managing chronic illness at home" (Corbin & Strauss, 1988).

From Viney's (1983) content analysis of open-ended interviews with hospitalized and bedridden people who had a variety of illnesses and bodily damage from accidents, themes emerged "which transcended these illness groups and were common to many ill and injured people" (Viney, 1983, p. 14). The patterns of illness found in Viney's research were described in terms of the dominant emotions of the images used. Most frequently used images were either distressing or pleasant. The six types of predominantly distressing images were uncertainty, anxiety, anger, helplessness, depression, and isolation. The more pleasant images of illness were happiness and humor, competence and control, and support and friendship.

Images of uncertainty, helplessness, and isolation were found to have a negative effect in the experience of illness. The more pleasant images were found, as one would expect, to effect the illness experience in positive ways. The distressing images of anxiety, anger, and depression had mixed effects. They were often detrimental to the self-esteem of the ill person, but they could also be marshaled on behalf of increased well-being.

The previous section on chronic pain addressed some aspects of "the difficulty of managing emotions, especially with pain and exacerbations of illness" (Conrad, 1990, p. 1261). Although the chronic pain literature has given less attention to issues of identity, it is implicit that the complex interactions between "sensory, motivational, cognitive, and judgemental processes and affective reactions" (Bonica, 1980, p. 9) in the experience of chronic pain occur within a self. Concepts of self or identity in the interactive tradition of the medical sociology of illness provide the third phenomenon that will serve as a sensitizing concept for the current study of chronic vulvar pain. The fields of psychology and sociology converge in the concept of the self (Gergen, 1971).

Goffman's (1968) work on self in social psychology is particularly relevant to this discussion of self and illness. In developing an analysis of identity norms and their "very direct effect on the psychological integrity of the individual" (p. 952), Goffman wrote: "It is a question of the individual's condition, not his will; it is a question of conformance, not compliance" (p. 953). Qualities relating to one's condition and conformance impact directly on illness experience and the self, in terms of social identity and the understanding of the issue of stigma (Goffman, 1968), and in terms of personality identity and the issue of information control (Goffman, 1969). As Bury (1982) pointed out, however, both these conceptions of self have to do with the concerns and definitions of others. Addressing this matter, Goffman "introduces a third type of identity, 'ego identity,' allowing him to consider what the individual subjectively feels about his or her stigma and its management" (Williams, 1987, p. 144).

Bury (1982) developed the concepts of disruption and uncertainty in relation to the self, noting that disruptions in peoples' normal explanatory systems require "a fundamental rethinking of the person's biography and self-concept" (p. 169), and that uncertainty in the experience of illness (especially chronic illness) involves "a re-evaluation of the relationship between the . . . disease and selfhood" (p. 172). He goes on to observe the relief many people feel when their illness has been recognized and diagnosed as a disease by a medical authority--as well as its faltering effects on their sense of self:

> To be able to hold the disease "at a distance," as it were, assists the claim that one is a victim of external forces. To do anything less is to accept fully the burden of responsibility . . . . However, the point of the argument about reification, at least in chronic illness, it that a strict separation of disease and self (for that matter disease and social relations in general) is precarious. The experience of patients in this study underlined the uneasy balance which is struck between seeing the condition as an outside force and yet feeling its invasion of all aspects of life." (Bury, 1982, p. 173)

Salient concepts from medical sociology that inform the present study of the experience of chronic vulvar pain focus on three main illness phenomena: "the *experiences* undergone by the ill with the illness itself . . . the *work* of managing the illness . . . [and] how experiences and work impact on the *identities* of the ill and their intimates" (Strauss, 1990, p. V). These concepts may be addressed in terms of the bodily experience of somatic perception, the work required in dealing (or not dealing) with one's emotional responses to these perceptions, and the impact of these phenomena upon the identity of the ill person.

Strauss (1986) pointed out that specific illness trajectories contribute to "what happens to a sense of identity . . . quite possibly in *patterned* ways" (p. 97). Charmaz (1983) studied the impact of a variety of chronic illnesses on the sense of self, concluding that the diminished control over one's life and one's future in chronic illness often leads to a loss not only of self-esteem but also of the sense of self, one's very identity. She also discovered the continued importance of motivations to people with chronic illness, hypothesizing a hierarchy of "identity goals" (Charmaz, 1990, p. 1166) that needed to be readjusted in accordance with the illness trajectory.

Finally, Gerhardt (1990) suggested that "the impact of a disease or treatment on the patient as a person, i.e. his identity, may be an aspect widely neglected in modern clinical practice," (p. 1149). Enlarging the scope of clinical understanding will redress this negligence. Such enhanced understanding on the part of practitioners may assist the "redefinition of a patient's precarious identity [which] is shown to restore his sense of living a valuable life" (Gerhardt, 1990, p. 1155).

The phenomena of identity, emotional response, and sensory perception can be seen as psychological reference points in a consideration of the experience of chronic vulvar pain. How does a woman with this condition achieve a valued life, minimizing the effects that chronic pain exerts on her daily life and her goals for herself? Mastery over the unpredictable physical course of the disease (Robinson, 1990, p. 1184, in writing about multiple sclerosis) may well involve interconnections of somatic perceptions, the work required by the emotional responses to symptoms, and the ways in which the ongoing process, vicissitudes, and uncertainties of chronic pain redefine one's identity goals and sense of self.

The disruptions vulvar pain in particular brings to a woman's sense of femininity, the significance of her physical pain and disability to her sense of herself, may influence her psychological organization in adult development (Notman, Klien, Jordan & Zilbach, 1991). As with the more expected maturational challenges of menarche, pregnancy, and menopause, chronic vulvar pain and the internal and relational losses associated with the condition can be viewed as a developmental crisis involving female body awareness, emotional organization and affective ties, and ongoing identity formation (Notman, Zilbach, Baker-Miller & Nadelson, 1986).

In terms of social role perspectives, disruptions of affective ties shape a woman's "personal self concept" (Crook, 1982) in the various roles that link her to the others in her world. Female relational roles as caretaker may be shifted by the presence of chronic pain in ways that raise complex issues for both individual and group. Treatment choices may be influenced variously by role relationships. For instance, a woman with chronic pain may continue to care and do for others rather than comply with a treatment regimen that would mean taking time for herself. She may be pressured by a spouse to seek the provision of more aggressive interventions. She may experience a loss of relationship leading to isolation and a "basic threat to . . . role identity" (Crook, 1982, p. 73. These conflicts become exacerbated when occupational roles are also stressed by the requirements of the pain, intensifying the strain on identity formation.

The foregoing discussion strongly suggests that people respond to illness in active, constructive and selective ways, making sense of disruptive physical sensations and the feelings they engender in ways that are "not just a passive response to external events and circumstances" (Robinson, 1990, p. 1184) but that originate in, and have meaning for, the person's sense of personal identity. The impact of vulvar pain as a life event for a woman's identity has particular psychological and social meanings.

Conrad (1990) identifies "seven concepts . . . [that] have emerged from the extant research on chronic illness experience: uncertainty, careers, stigma, biographical work and reconstitution of self, managing regimens, the role of information, awareness and sharing, and family relationships. Though they often have not been theoretically connected, work on each of these issues has begun to accumulate" (p. 1260).

The concepts raised in this section on illness experience emanate from research on a variety of chronic non-malignant illnesses such as epilepsy, multiple sclerosis, and rheumatoid arthritis, as well as thinking about women's unique developmental issues. These concepts may prove useful in the study of chronic vulvar pain. A focus on sensory perception, emotional responses, and impact on identity as sensitizing issues in the qualitative research of chronic vulvar pain may well touch upon aspects of all seven of the concepts identified above. "This kind of research should be of interest to practitioners if only because those matters in turn greatly affect the clinical management not only by the ill but the health practitioners themselves" (Strauss 1990, p.V).

Chapter III - Statement of the Problem
and Research Questions

Statement of the Problem

Although it is not widely recognized, the problem of unexplainable vulvar pain affects a significant number of women. In some, the condition resolves spontaneously over time; in others it is ameliorated or cured by treatment. For a significant number, however, the condition persists. Since the middle of this century women have presented the phenomenon of chronic vulvar pain to their practitioners with increasing frequency, leading to referrals to specialists who began to take the syndrome seriously as a diagnostic and treatment challenge. Although several causal and risk factors have been identified, diagnosis of the condition is a case-by-case process of rule-outs and educated guesses, which may involve treatment trials with modalities that can prove to be ineffective or harmful. Practitioners treating the condition recognize that psychosocial factors play an important role in diagnosis and treatment, and have called for further research into the psychosocial components of the condition.

Concurrently, since mid-century, clinicians and researchers who work with chronic pain have become increasingly interested in the emotional factors, sensory phenomena, evaluative processes, and social components of the pain experience from the standpoint of the individual. Although chronic pain literature does not always focus on the serious disruption that chronic pain can wreak on all levels of one's life, the private, subjective nature of the experience is generally recognized.

During this same historical period, medical sociologists began to direct similar research efforts towards understanding the lived experience of illness. Salient concepts from medical sociology focus on phenomena of experience, emotional work, and identity as they relate to the meaning illness has to the individual.

To date there has been little research into psychosocial aspects of chronic vulvar pain, and in the lived experience of the condition. Recent literature suggests that psychosocial factors play a large part in the course of illness and chronic pain. The prevalence of vulvar pain as a diagnosis and the limitations of the biomedical model in treating the condition suggest the need for exploratory research into sensory, affective, and evaluative components of chronic vulvar pain.

The phenomena of sensory perception, emotional response, and identity can be seen as psychological reference points in a consideration of the experience of chronic vulvar pain. Little use has been made to date of the role and meanings of somatic sensations in chronic illness. How people manage their emotional responses to illness and the interplay of emotions and illness are issues that have not been thoroughly explored from an "insider's" perspective. The impact of a disease or treatment on the identity of the person experiencing it has also been relatively neglected in research and clinical practice. These issues emerged as salient in the focus groups with women with chronic vulvar pain that I conducted in 1990-1991.

In terms of treatment and management of unpredictable physical symptoms, recent literature suggests that mastery may involve interconnections between somatic perceptions, the work required by the emotional responses to symptoms, and the ways in which the ongoing process, vicissitudes, and uncertainties of chronic pain redefine one's identity goals and sense of self. To date no research has been undertaken of these phenomena in chronic vulvar pain.

The current study addresses chronic vulvar pain from the perspective of how a woman makes sense of her experience of the condition as an ongoing psychosocial event. The meanings of sensory perception, emotional response, and impact on identity guided the research as sensitizing issues in the exploration of chronic vulvar pain.

When the patient is as specific and descriptive as possible about the physical aspects of the pain, this information helps the practitioner to diagnose and treat effectively. Vulvar pain often presents few or no physical findings. It is a substantive and meaningful emotional event in the lives of those who suffer from it. Psychological issues are significant in thinking about its causes, treatment course, and outcomes. Study of these issues will advance understanding about chronic vulvar pain. The purpose of this study is to enable women with vulvar pain and their practitioners to enter into a wider dialogue more inclusive to issues of meaning, which may enhance their separate and mutual inquiries into the existence and treatment of chronic vulvar pain. This study undertakes to increase useful understanding of psychological dimensions of chronic vulvar pain; to expand the knowledge base in the experience of chronic pain; and to add to the conceptual understanding of the meaning of illness.

Research Questions

1. How do women live with chronic vulvar pain?

2. In what ways do women with chronic vulvar pain construct definitions of their illness, self, and situation?

3. How do a woman's somatic perceptions of her vulvar pain develop, change, and give rise to consequences?

4. How do a woman's emotional responses to her vulvar pain develop, change, and give rise to consequences?

5. How is shaping of the self related to the meanings the woman with chronic vulvar pain makes of the somatic sensations of the condition and her emotional reactions to them?

Chapter IV - Methodology

The current study is grounded in phenomenological, narrative, interactionist, and hermeneutic perspectives which provide the theoretical basis for exploring the research questions. This chapter begins with a brief explanation of these perspectives as utilized in this study. A description of the sampling, instrumentation, data collection and recording procedures, phases of inquiry, and methods of data analysis used (Rudestam & Newton, 1992), and the criteria of soundness that were applied to the study will follow.

The goal of this study was to explore how women with chronic vulvar pain make sense of their experience as related in their own terms (Belenky, Clinchy, Goldberger & Tarule, 1986). Given this purpose of exploring psychological significance, a phenomenological approach was used. As a methodology of human inquiry, phenomenology focuses interest on the person's lived experience, with the assumption that subjective reality is multi-dimensional, and not fixed but processural (Charmaz, 1980). The major procedure in phenomenological methodologies is the qualitative interview, which allows for the possibility of both participants discovering new understandings of the described experience (Hoshmand, 1989). The relationship between inquirer and participant is collaborative. The inquirer adopts an open attitude, reflecting upon and suspending preconceptions and biases through a process known as bracketing.

One of the presuppositions of this study was that chronic pain and illness are significant life events. Another was that people tell stories to help explain and make meaning of such events. The stories people tell to themselves and others are essential "subjective portals" (Linde, 1993, p. 48) into the person's experience of these events. Individual illness narratives address how the person integrates the illness experience into "normative conceptions of the body in relation to the self and world" (Kleinman, 1988, p. 13) and the temporal organization or life trajectory of valued personal goals (Robinson, 1990).

The interview narratives were interactionist, in that they were co-created within an interpersonal context between two people. When the interpersonal function of the interview situation is acknowledged and valued, it becomes apparent that "the interviewer/listener enters actively into the respondent/narrator's production of a story by the form and intent of her questions as well as by her assessments, acknowledgments, and silences" (Mishler, 1986, p. 102).

This act of co-participants investigating meaning together is also an occasion in which the participants share, communicate, and manipulate symbolic meanings (Denzin, 1989b). Such activities imply that it is an occasion of interpretation, on the part of both participants, and on many levels. By seeking to provide congruous interpretations of a co-created narrative text, this research project is also hermeneutic. As such, the interpretation of the narrative texts is the basis for coherent, vital, and faithful construction of stabilized meanings from the transcribed narrative (Hoshmand, 1989).

Hermeneutics seeks to clarify and elucidate by considering each part of the text in relation to the context from which it derives its meaning. Closer to the original form of hermeneutics as textual exegesis, the "context" is the text as a whole. In the more contemporary application of hermeneutics in human research, the context includes the social context of the participants in interaction. Using both these levels of contextual analysis, the process of shifting focus back and forth from the particular to the whole in many cycles until "the whole itself becomes more transparent" (Tesch, 1990, p. 94) is referred to as *the hermeneutic circle* or *spiral*.

The research interests of this project include comprehending meaning and discovering regularities. In seeking to comprehend the meaning of the interview event/text, this study involved both the discernment of themes of phenomenology and hermeneutic interpretation. In seeking to discover regularities within the data, it involved the discernment of conceptual patterns, identification and categorization of elements, and exploration of their connections. The discussion of research instruments, procedures, and analysis to follow will specify how these goals were approached.

In 1990-1991 I conducted chronic vulvar pain focus groups in which the concepts of somatic perception, emotional response and identity development emerged as dominant experiential themes for the members. These concepts also appear in the literature on chronic pain and illness experience. Rather than being operationalized into definitions at this point in the research process on chronic vulvar pain, they were used as psychological reference points or "preunderstandings" (Linde, 1993), which sensitized me to learn more about the processes that represented them and the specific meanings these concepts held for the participants in the study (Denzin, 1989b).

Participants

Chronic vulvar pain was defined in this study as ongoing intractable symptoms of discomfort in the skin of the vulva and/or the vaginal vestibule, which may be diffuse or in specific loci, and either persistent or episodic. For the purposes of this research project, participants in the study had experienced ongoing or recurrent symptoms for 1 year or more. I interviewed a sample of women with vulvar pain that was as diverse and representational as possible in terms of age, socio-economic status, education, race, sexual history and orientation, parity, medical and treatment history, degree of severity of symptoms, age at onset, and overall duration of symptoms. Diversity was a criterion for inclusion and exclusion. The study excluded persons under the age of 18, mentally retarded persons or those with psychological disabilities. This exclusion was carried out through the use of trusted referral sources, the informed consent form, and clinical judgment in the initial telephone contact. The study was approved by the Research Ethics Committee of The Fielding Institute.

To obtain participants I contacted providers (physicians, psychologists, nurses, and physical therapists) in California who treat chronic vulvar pain. After an initial telephone contact, the research packet was sent to providers who were willing to inform potential participants about the study. The research packet consisted of a cover letter, participant questionnaire, and informed consent forms (see Appendixes). Patients who qualified and expressed interest in the study were given my name and telephone number. I sent the research packet to all women who called and met the criteria. Since "any sample derived from hospital or clinic sources will reflect the bias in selection of the hospital or clinic" (Scambler & Hopkins, 1990, p. 1187), I also made the project known to the director of the Vulvar Pain Foundation, who notified support group leaders in California. They made the project known to potential research participants in their groups. With the approval of the dissertation Committee, the original 2-year criterion of chronicity was revised to 1 year, to reflect definitions of chronic pain and enable the study to include participants closer to the beginning of their illness trajectory.

None of the participants in the research study was known to me before the initial contact. This decision was based upon the intention to prevent the possibility of subtle coercive effects or conflict of interest of a potential dual relationship, should any of the members of the vulvar pain focus groups I led in 1990-1991 seek a psychotherapeutic relationship with me in the future, or if any persons otherwise known to me had sought to participate in the research.

In addition to two participants with whom I investigated the interview procedure in a pilot study, 16 women participated in the research study itself. All participants chose to complete the project. Six of the participants lived in San Diego and the Los Angeles area, and the remainder in the greater San Francisco Bay Area and Sacramento. All participants had been diagnosed with chronic vulvar pain and had been symptomatic for 1 year or more. Table 1 is provided to display the demographics in a concise manner.

Table 1 Demographic Background

NAME	AGE	RACE (self-described)	SEXUAL PREFERENCE	RELATIONSHIP STATUS	EDUCATIONAL STATUS	G/P/Ab	AGE AT ONSET	DUR. OF SYMPTOM
Megan	27	"White"	heterosexual	married	M.A. student	1/0/0	26	1 year
Diane Lyn	32	"Caucasian"	heterosexual	married	A.A.	0/0/0	27	5 years
Shannon	20	"mostly Irish"	heterosexual	committed relationship	college student	0/0/0	19	1 year
Susan	30	"White"	heterosexual	single	M.A.	0/0/0	29	1 year
Gina	29	"Hispanic"	heterosexual	married	2 yrs. college	0/0/0	27	2 years
Jerry	39	"Black"	lesbian	single	H.S. Diploma	1/1/0	35	2 years
Lynn	26	"White"	heterosexual	married	M.A.	1/0/0[a]	22	4 years
Emma	37	"European mix"	bisexual	committed lesbian relationship	L.Ac.	0/0/0	30	7 years
Sarah	36	"White Anglo"	heterosexual	married	J.D.	0/0/0	26	10 years
Jane	46	"White"	heterosexual	married	some college	0/0/0	39	7 years
Isabelle	33	"White"	heterosexual	married	M.A. & M.B.A.	1/0/1	19	14 years
Lynette	25	"White"	heterosexual	married	B.A.	0/0/0	18	6 years
Mary	65	"Caucasian"	heterosexual	divorced	B.A.	2/3/0[b]	54	11 years
Rita	34	"Jewish"	heterosexual	married	B.A.	2/0/2	32	2 years
Linda	44	"Caucasian"	heterosexual	married	M.B.A.	2/0/2	33	11 years
Anne	24	"White"	heterosexual	committed relationship	Pharmacy D.	0/0/0	22	2 years
Summary Range of Values	20 - 65	Relatively light-skinned			H.S. Diploma - Pharmacy D.	G 0-2 P 0-3 AB 0-2	18 - 54	Duration 1 - 14 years

Note. G/P/A = Gravida (number of pregnancies)/Parity (number of live births)/Abortion (spontaneous and therapeutic).

[a] Pregnant at time of study. [b] One multiple pregnancy (twins).

Instruments

The instruments used to gather the data in this study were as follows:

A pilot interview

A background information questionnaire included in the
research packet

An in-depth interview with each participant

A follow-up interview with each participant

Audits of the process with four research associates

A member check

The researcher herself

Two tape recorders

A computer program for storage and analysis of the data

The Interview Guides are provided in Appendixes D & E

Procedures

Throughout this research project I endeavored to be mindful of my biases, and to explore the meanings of the vulva and chronic pain and illness in my own experience. Work with members of the dissertation committee and other colleagues, and in personal depth psychotherapy, has deepened this examination of beliefs, reactions, opinions, blind spots, and previously unquestioned assumptions.

Initial work on the interview process led to a pilot study interviewing two women who met the research criteria. The pilot study was an "interviewee-oriented" (Reinharz, 1992, p.38), open-ended exploration of the person's experience of chronic vulvar pain--and also of the experience of talking about it in an interview setting with me. The purpose of the pilot study was to sensitize me to the work of establishing an appropriate interactive context and focusing on the topic of living with chronic vulvar pain, in an intensive and sensitive way, with the participant as a co-researcher. Based upon what I learned in these preparatory nonstandardized interviews, I was better able appropriately to vary the dimensions of scheduling and topic control in the research interviews themselves.

Participants in the study were informed in advance that their confidentiality and anonymity are protected; this has been accomplished in the following ways. Only absolutely essential identifying information was used to conduct the study. Participants were given the opportunity to select a pseudonym for any presentation of text taken from their interview transcription.

Eight (50%) of the participants elected that their real name be used. When this occurred, the woman's desire to claim her own voice was respected. The idea that participants have "the 'right' to have their views represented as belonging to them, if they so wish" (Mishler, 1986, p. 124) may seem unusual when discussing assurances of confidentiality. In a "culture" that has been so invisible and silent that members have no way of knowing with whom they share it--as is often the case with women who have vulvar pain--taking this responsibility for disclosure may be a source of empowerment for some women, and I believe it was important to respect this right in the current research project. Participants also were given the opportunity to choose the amount and kind of identifying information from their transcripts for public use.

The taped interviews were transcribed by a professional linguistics transcriber sensitive and bound to the ethics and practice of confidentiality. Each tape and transcript was given a number for purposes of identification; I hold the master list linking these numbers and the participants' names in strict confidence. The informed consent forms are kept in a locked container, separate from the interview transcripts and the analysis protocols. A copy of each tape and transcript is retained in my possession for possible future validity checks (Tesch, 1990). I have undertaken to preserve both the audiotapes and the transcriptions of the interviews in locked storage.

The interview opened with an invitation to the woman to tell her story of having chronic vulvar pain, in any way she was comfortable doing. I responded as necessary to encourage the narrative flow, without interruption. I maintained a flexible conceptual focus of the psychological reference points in mind to ensure that the data from each interview would be comprehensive (Patton, 1980).

My task as researcher was to provide a context of inquiry and rapport that provided coherence and met my informational objectives, at the same time that it conveyed to each participant the sense that she controlled the flow of information (Gorden, 1980; Mishler, 1986). In each interview I sought to develop the trust and rapport with the participant, to evoke her authentic reactions in a minimally intrusive manner (Hoshmand, 1989), so that we could create an "inter-view," i.e., together to investigate private meanings and generate "thick description" (Denzin, 1989a, p. 32) of her experience of chronic vulvar pain. A copy of the interview guides for this study is included (see Appendixes D & E).

Once the shape of the narrative seemed basically complete, I returned to parts of the story for further clarification or with curiosity about the sensitizing concepts (the "preunderstandings") of the study. Where one of these areas had not been addressed I guided the conversation in an exploratory way. This made it possible to obtain information about the same basic subject areas with each woman in a way that was consistent with our interpersonal styles as we interacted with each other in the interview. Reinharz (1992) refers to a form of feminist interview research as "partially structured personal conversations" (p.34); this phrase conveys a sense of the orientation of the interviews more toward the interviewee than toward the instrument *per se*.

Each initial in-depth interview lasted approximately 1 1/2 hours. Fourteen interviews were conducted in person; two were conducted by telephone, due to the scheduling requirements and location of the participants. Implications of this difference were discussed with the dissertation committee. To insure comparability of the interview information of these two telephone interviews with the in-person interviews, a comparative content and process analysis was conducted. No notable differences were found in rapport, depth of disclosure, or emergence of issues and themes.

Following the interview as closely in time as possible, I wrote or taperecorded a "memo" about the interview experience. I made use of these impressions, feeling responses, hunches, and questions, to make the interpretive process as transparent as possible.

The initial interviews were audio-recorded on two tape recorders, to insure efficacy in case of technological failure. The taped interviews were transcribed in a notation system that included speech dynamics, overlaps and interruptions, and pauses. The transcriptions were numbered by page and line to enable careful analysis. It is significant to bear in mind that the transcription itself is a level of interpretation (DeMattos, 1994; Mishler, 1986). Because decisions go into transcription that may be unexamined this process needs to be monitored. Accordingly, the transcriber was instructed to transcribe the complete tape, omitting nothing. As the only other person in the project who worked with every word of every interview, she proved to be a valuable member of the research team, offering interpretive comments, insights, emotional reactions, and questions in response to the material, which were used as a secondary set of memos to enrich the interpretive process.

I listened to the interview tapes while reading the transcriptions, further sensitized to the situation by referring back to the memos, and making additional notes to assist in a recreation of the event that was as faithful as possible, and to continue the process of immersion-for-understanding that began in the interview. A copy of her transcription was sent to each participant, with the agreement that she would make note of anything she might like to delete, add, or otherwise change.

Analysis of the data, following Hoshmand's (1989) description of grounded theory technique and hermeneutic interpretation, utilized constant comparative methods as propounded in the technique of grounded theory data analysis. That is to say, with immersion in the data--listening to the tapes, reading and rereading the transcripts, and reflecting upon the memos--I began to index the natural meaning categories used by the participants, as incidents, analysis units, and shifts of meaning began to stand out that related to the experience of chronic vulvar pain. As these key phrases and constructs accumulated into stabilized meanings, they became the units of analysis. I organized them as issues and themes. Each datum incident was coded into as many categories as possible. As categories emerged and as data emerged that fit existing categories, I began to think in terms of the possible theoretical properties of the category, its dimensions and relations to other categories, and conditions under which it was pronounced or minimized (Hoshmand, 1989).

The analytic process involved deconstructing and reconstructing, going back and forth from text to emergent categories in a hermeneutic circle, "interrogating" the data with imaginative variations, looking for constituents, distinctions, relationships and themes. This process of data analysis proceeded simultaneously with the collection of new interviews, facilitating a cumulative theoretical sensitivity to meaning units which enabled me to follow up on emergent themes. Thematic categories were coded with brief labels which conveyed something essential about the content and topic of the units that they contain. The coding process was continually refined during the data analysis phase, as I went over the material repeatedly in different levels of analysis.

When the first of the emergent codings begin to fall into a "cookbook" of coherent categories, two auditors provided peer debriefing to help determine whether the preliminary category sets that I had formulated converged in a stable and meaningful way for them as well, and to negotiate discrepancies until agreement was found. The auditor with background in illness experience research read and coded four transcripts according to the coding system she had devised for her most recent study. Subsequent to this we discussed the two coding systems for convergence of meanings and comprehensiveness, to refine the system for the current study. The second auditor is a clinical psychiatric social worker in medical practice. In a method suggested by one of the research consultants to this project (Newton, 1995), this auditor read and coded every 5th page of each of the 16 interviews, to test the coding system for goodness-of-fit, gaps, and overlaps.

In these audits, anomalies were questioned and compared with positive categories, in order to discover patterns that best matched the text and included all instances. When coding categories became saturated and new categories no longer emerged from subsequent interviews, the initial interview gathering process came to an end.

After a discussion with the dissertation committee regarding the geographic diversity of the participants, it was agreed that the follow-up interview would include the member check originally intended to occur in a group meeting format. Accordingly, I sent a letter to participants informing them of this change in the original design. This alteration was confirmed by participants during the telephone contacts to schedule the follow-up interviews.

The follow-up interviews occurred between 2 and 4 months after the initial interviews. The follow-up interview addressed each woman's responses to reading the transcription, any changes she wished to make to the record, and an update of her story of vulvar pain in the time that had passed. I also included a brief set of questions to fill gaps in the health history data base (see Appendix F), and I took notes during the interview, as part of the process of immersion in the data. The second interview served as a method of triangulation in adding another temporal point of data collection. This interview ended with a discussion of the emergent preliminary findings and their goodness-of-fit with each participant's experiences with chronic vulvar pain. The second interviews lasted for approximately 1/2 hour. They were audio-recorded and transcribed for analysis of patterns of meaning. These data became part of the ongoing base for analysis.

At this point I conducted an audit with the student member of this dissertation committee, to confirm the audit trail from meaning unit to category, and to refine the conceptual analysis of the preliminary results and the member checks. At several time points, the analysis process received further scrutiny and conceptual discussion with a certified nurse midwife and family nurse practitioner who has extensive experience in clinical issues in the psychology of women's reproductive health.

The data were organized and classified with the help of a computerized qualitative data analysis program for the indexing, searching, and theorizing of non-numerical, unstructured data (NUD*IST, 1995). This enabled cross-referencing and data retrieval necessary to track the meaning units, codes, categories, and patterns, and to examine the relationships between them. It also documented the analysis trail from textual origin to themes and back.

The patterns of meanings that emerged from this ongoing interpretive process formed the basis for "thick" descriptive categorization into themes and issues (Denzin, 1989a), which led to the development of a preliminary conceptual model of the experience of living with chronic vulvar pain. Each descriptive theme or theoretical pattern is traceable to its exact place in the text by means of an audit trail.

All participants received a summary of the findings by mail at the conclusion of the research. This summary was also provided to the referral sources who assisted in participant recruitment and/or expressed interest in the results of the study. Following completion of the study, participants were given the opportunity to attend a group debriefing meeting to discuss the results of the study and the experience of participating in it as co-reasearchers.

In the fields of sociology, anthropology, and linguistics it is recognized that discourse as narrative text can be reanalyzed in many ways. Because this is some of the first psychological research on the experience of vulvar pain, and because it is anticipated that this study will be part of ongoing research efforts, these data may serve as the basis for other studies both as a primary and as a secondary source. The informed consent form includes notification that the data may be used in possible further research endeavors and publications, with assured continued protection of confidentiality and anonymity.

Criteria of Soundness

Efforts for assessing the value of this research project follow Marshall's (1985) ten standards for judging qualitative study reports:

1) Data collection methods are explicit.
2) Data are used to document analytic constructs.
3) Negative instances of the findings are displayed and accounted for.
4) Biases are discussed, including biases of interest (personal, professional, policy-related) and theoretical biases and assumptions.
5) Strategies for data collection and analysis are made public.

6) Field decisions altering strategies or substantive focus are documented.

7) Competing hypotheses are presented and discussed.

8) Data are preserved.

9) Participants' truthfulness is assessed.

10) Theoretical significance and generalizability are made explicit.

Potential Benefits and Harm to the Participants

No specific benefits or risks were anticipated in participating in this study. It is possible that individual participants volunteered for the project out of a sense of an altruistic desire to add to the knowledge base about chronic vulvar pain, in addition to having the opportunity to talk about their own experience with an interested listener. These satisfactions, if they occurred, were not particular benefits (Rudestam & Newton, 1992).

Although my preference is that the experience of participating in this interview process as a co-researcher was positive for each participant, this could not be guaranteed. If some benefit such as greater self-awareness occurred, this might be similar to what Schneider and Conrad (1980) encountered in their study of people "in and out of the closet" about having epilepsy--a positive strategy of stigma control:

> Particularly for those who have concealed what they see as some personal blemish or flaw . . . telling can serve a 'therapeutic' function for the self by sharing or diffusing the burden of such information . . . . Such therapeutic telling seems instrumental primarily in its impact on the actor's self-definition: at the minimum, it simply externalizes what is believed to be significant information about self that has been denied one's intimates and associates. (Schneider & Conrad, 1980, p. 34)

The sensitive, intensely personal and private nature of the experience under study makes attending to questions of potential risk and informed consent particularly important. The informed consent form (Appendix 5) enabled potential participants to assess the potential negative personal and social consequences of participating in the study (Mishler, 1986). This form makes clear the voluntary nature of participation, and the participant's freedom to withdraw from the study at any time, should she experience mental discomfort during any part of the process. It also clarifies the "procedure for contacting the investigator within a reasonable time period following participation should stress, potential harm, or related questions or concerns arise" (APA, 1990).

Chapter V - Results

Introduction

Sixteen women with chronic vulvar pain participated as co-researchers in a narrative study of their personal experience making sense of the condition in their lives. Study results are presented in this chapter. The data analysis was guided by the research questions which focus on the meaning of living with chronic vulvar pain. The research questions were organized along four reference points of chronic vulvar pain experience: somatic perception, emotional response, situation, and shaping of self. The reference points elucidate key elements of the experience of living with chronic vulvar pain.

The reference point of somatic perceptions elucidates the physical experience of chronic vulvar pain: the disease trajectory, and the descriptions, metaphors, and explanations that contribute to the meaning of the illness. The reference point of emotional response traces emotional and evaluational experiences connected with having chronic vulvar pain. The self states that emerged from these data were organized into clusters of emotional pain, anger, fear, hope, pleasure, and questioning one's sanity. The reference point of situation explores alterations in function and activities. It also addresses the inter-action between the presence of vulvar pain and one's significant relationships. Finally, the reference point called shaping of the self delineated ways in which the meaning of the vulva, issues of gender identity, changes in perspective, and ongoing identity formation interact with the experience of chronic vulvar pain.

These categories of meaning provide the basis for the development of the provisional model of the interactive experience of living with chronic vulvar pain presented in the discussion chapter. Verbatim examples from the narratives are cited to illustrate the categories of meaning that emerged. Aside from minor alterations for grammatical clarity, the participants' words are unaltered.

Analysis of Interviews

Analysis of the narratives took place on progressive levels. Early data analysis focused on the emergence of meaning units and their provisional categorization into themes and issues with regard to the four reference points of the research questions. This coding and sorting process led to a descriptive conceptual structure of themes and issues. The next level of analysis guided the development of a preliminary theoretical model of the experience of living with chronic vulvar pain integrating the themes and issues in a way that is both dynamic and explanatory. This chapter is organized around the themes and issues comprising each category. The model is presented at the end of the chapter.

The Physical Experience

The reference point of somatic perceptions highlights the story of the disease trajectory, descriptions of chronic vulvar pain, and women's explanations about their pain. This section begins with the story of vulvar pain symptoms--onset, description, location, duration, variations, precipitating factors--and the consequences to which these sensory changes gave rise. Consequences include self management and seeking the help of practitioners, and focuses on diagnostic procedures, diagnoses, treatment and management strategies, and their outcomes. Data about this level of experience provide the basis for the category termed the disease trajectory. An abbreviated version of each woman's disease trajectory is sketched in the participant profiles. The section closes with an analysis of the issues and themes that emerge in the women's descriptions and explanations of their physical experience of chronic vulvar pain.

Participant Profiles

Each interview began with an invitation to the participant to talk about the experience of chronic vulvar pain, in any way she found comfortable. Stories were told on successive levels. The first time around, each narrator talked about her perspective of the medical treatment process, as she related her efforts to make sense of her symptoms. Although the sequencing and the details varied, invariably the first story of each participant began with the onset of the pain and a description of interactions with care providers, diagnostic tests and findings, treatments and their outcomes--the "official" course of the condition. This is one level of the definition of chronic vulvar pain that each woman constructs.

This story level, the disease trajectory, is presented in abbreviated form in the patient profiles, which will also acquaint the reader with the individuals who participated in this study and provide brief contextual orientation. The profile is not a medical or psychological history; rather, it represents each woman's attempts to arrive at an explanation and to find help.

Megan

Megan is 27 years old, and working on her M.A. in psychology. She is of northern European ancestry, with fair hair and skin. She is a devout Christian, proud of having been a virgin when she married. She and her husband enjoyed sexual intimacy as "very special," until about 2 years after they got married, when she awoke one morning with severe and constant vulvar burning that prevented her from sitting, walking, or other basic activities. She consulted several gynecologists in turn, each of whom treated for yeast infection initially, then tested and treated for other conditions, and finally told her they could find nothing. Megan and her husband attempted to educate themselves about a condition for which they had no name. The severe and constant vulvar burning increased; the external genital skin was red, raw, and slightly swollen.

Megan heard about a specialist in benign diseases of the vulva in another part of the country. She moved there immediately and began a treat-ment of estrace cream to calm the inflammation and to rebuild the tissue. With the physical therapist on the team, she then began a program of biofeedback to reeducate the pelvic floor muscles that had been chronically contracted against the pain. Megan's husband relocated on his job and joined her. They were able to engage in sexual intercourse again, and with the encouragement of the physician they conceived a child. At the time of the initial interview, Megan had been free of vulvar pain symptoms since 8 weeks into the pregnancy. The follow-up interview occurred 2 weeks postpartum. She had given birth vaginally. Although complications had required a large episiotomy, she continued to be pain-free. She planned to resume use of the estrace cream on an as-needed basis and following sexual intercourse. Megan leads the local vulvar pain support group and does telephone counseling with women around the country who are in vulvar pain.

Diane Lyn

Diane Lyn is a tall, slender Caucasian woman with dark hair and pale skin. She works in marketing sales, and is 32 years old. She reports being anorgasmic and not having had much sexual experience, but that she enjoyed a "normal sex life" with her future husband for the first 2 years they knew each other. Around the time of their wedding she began experiencing a burning, stinging vulvar sensation and increased vaginal discharge. After yeast treatments the condition worsened. Initially in intercourse there would be entry dyspareunia only; later the pain did not diminish. Over a period of months she consulted numerous specialists whose treatment strategies proved unsuccessful. She entered into counseling, took a thoughtful approach to vulvar care, and continued to follow the treatment regimen for yeast in-fection. Pain began to occur with bathing or touch to the vulvar area, and she could no longer wear pantyhose. She began to have shooting, stabbing pains while standing or walking. Gradually she and her husband came to abstain from sexual activity together.

Diane Lyn learned about vestibulitis from an article in a women's magazine, and found a doctor who confirmed the diagnosis and treated with a trial of cortisone therapy which was unsuccessful. After taking "a mental break" from treatment when symptoms did not improve over time, Diane consented to laser surgery to remove the vestibular glands. The pain did not resolve. Diane Lyn found a vestibulitis specialist who treated her with estrace cream. At the time of the initial interview, her condition had improved somewhat. However, Diane Lyn's marriage was "in a fragile state." She expressed regret that she had dealt with the pain by shutting herself off from closeness with her husband. In the follow-up interview she reported that biofeedback treatment had helped so much she decided to go off the estrace cream. The pain returned so she resumed estrace treatment, which she plans to use forever. She reported that a few weeks after resuming treatment she was generally symptom free. She does not know if she would have pain upon intercourse now. She and her husband have separated.

Shannon

Shannon is 20, a small blonde woman of "mostly Irish" background, a junior in college majoring in marine biology. Since she started college she has been in a committed relationship with the young man who was her first sexual partner. Six months into this relationship, after a recurrent series of urinary tract infections and treatments, she began to have symptoms of raw, stabbing, burning vulvar pain. She consulted a number of providers and tried antibiotics, counseling, and a lengthy treatment with acid to burn off presumed HPV. After this she could no longer engage in sexual penetration. A diagnosis of vulvar vestibulitis led to treatment with antibiotics, which precipitated a yeast infection. She had a negative biopsy for HPV. Antihistamine treatment made her too groggy to work. Cortisone injections to the painful sites were unsuccessful. The pain severity and the vulvar care regimen were so demanding that she had to decline a training opportunity in her field of study. She was put on amitriptyline, and she also began acupuncture treatments. Her menstrual periods went from regular to diminished intensity, frequency, and duration. After several months of this she began heavy menstrual bleeding which continued for 2 months. Her physician put her on oral contraceptives.

Shannon learned about treating vulvar pain with a low oxalate diet, timed citrate, and oxabsorb. She had been on this regimen for 3 months at the time of the initial interview, with no noticeable improvement. She located a specialist in vulvar vestibulitis, who confirmed that diagnosis and thought she was a strong candidate for estrace and biofeedback. Shannon responded well to the muscle re-education of biofeedback. She tried analgesics and topical anesthetics to get her through final exams. She reported being unable to concentrate on schoolwork or to have a social life, and that she had almost lost her sex drive, which was taking a toll on her relationship with her boyfriend. In the follow-up interview she was discouraged because her caregiver had told her that the deposits of cortisone in her vulvar tissue had caused a thinning which counteracted the strengthening effects of the estrace cream. These deposits had finally dissolved, however, giving her some hope for the prospect of improvement within the next year. She had also begun taking a herpes medication which she said some women have found helpful with vestibular pain.

Susan

Susan is a single woman, 30 years old, who is tall, blonde, and Caucasian. She has a master's degree and works in the entertainment industry. Susan's uncomfortable vaginal sensations began after she had an abnormal Pap smear. When she consulted her gynecologist about the symptoms she cultured positive for yeast for the first time in 15 years. After yeast medication the pain improved but later returned. She began to feel a constant pain near the cervix. Her gynecologist performed a colposcopy, and cervical, vaginal, and vulvar biopsies. After this Susan said she was in so much pain she couldn't sit. Her physician again found yeast infection and gardnerella, which she treated. The biopsies were positive for flat condylomas (HPV) in the vaginal canal and on the vulva. By this time Susan said she was feeling a constant deep stabbing pain.

Susan reported having had only 2 sexually intimate relationships with men, the last of which ended more than two years before the onset of her pain. She reported having had no sexual contact since then, until just prior to the abnormal Pap smear, when she had met a man with whom she had engaged in sexual activity but not penetration. She attributed the onset of her gynecology problems to this sexual contact. With her physician's agreement, Susan tried alternative treatments. A homeopathic practitioner gave her remedies and herbal teas, and eliminated all dairy products, soft drinks, alcohol, caffeine, wheat, yeast, sugar, red meat, shellfish, and certain fruits from her diet. A chiropractor put her on high vitamin and mineral supplements. She began to lose weight; her chronic headaches ceased, and she reported that the stabbing edge was taken off her vulvovaginal pain. The pain was still constant and debilitating, however. On the advice of her gynecologist--a woman who had overcome her own chronic vulvar pain with low doses of amitriptyline--Susan began this treatment as well. She reported getting stronger gradually. Over time she passed large menstrual clots. The papillomatous tissue changed color, scabbed over, and then cleared. The pain remained constant but was less sharp and distracting. She began transepidermal nerve stimulation treatment to the sacral area to interfere with the pain signals, which ultimately seemed to have a soothing effect.

Results from her next Pap smear were abnormal. At the time of the follow-up interview the latest cervical and vulvar biopsies showed inflammation but no abnormalities. Her gynecologist told her she was free of any sign of the virus, and that there was no scarring. Susan reported feeling constant dull pain, with occasional stabbing pains on one side of the vulva. Since medication had no effect on the ongoing signs of yeast, Susan continued to treat the condition with diet, herbs, vitamins, and homeopathic remedies. She reported having begun psychotherapy.

Gina

Gina is 29, a media director, married for the second time. She has light skin and dark hair, and is of Hispanic origin. She reports that under the stress of her first marriage breaking up and during the following year she had several urinary tract infections (UTI) that she described as strong. She was symptom free when she and her current husband met. Around the time of their wedding she experienced some urinary frequency, pain on urination, and redness in the vestibular area--but tests showed no UTI. The symptoms passed after a few months. She reported that she and her husband "were having a great time" until symptoms recurred 6 months later. First there was some intermittent pain with intercourse, and then vulvar burning and a stinging itch that progressed from the vulva to vagina and rectum over time. She and her husband went from "a wonderful sex life" to none at all.

Over the next months Gina consulted many physicians and was given many tests, cultures, and trials of medication--antibiotics, antifungals, anti-viral treatments. She worked with a psychotherapist. She ultimately learned about the Vulvar Pain Foundation, and this contact inspired her to locate a urologist-gynecologist whose diligent diagnostic approach and urethroscopic investigation revealed polyps, scar tissue, and infection of the urethra. After a course of antibiotics they began a process of urethral dilatation to remove the polyps. She also traveled some distance to see a specialist in vulvar vestibulitis who found heightened irritation in the left vestibular gland, which was treated with estrace cream. Gina began to feel better. She reported not ever being pain-free, but having breaks from severe pain, and a sense of being stronger. She was put on a trial of oral contraception.

At the time of the follow-up interview she reported that the urethral infection had been eliminated, leaving only residual redness and irritation that they were giving time to heal. She was off antibiotics. Her cultures consistently showed no bacteria. The vestibular tissue was "almost completely back to normal." The tissue had improved enough for her to begin biofeedback treatment, which had strengthened the pelvic floor and enabled her to reach states of muscular relaxation normal for a woman without vestibulitis. She was feeling enough improved that she and her husband tried resuming sexual activity. Penetration was painful at first, but became "tolerable" as they continued. Because the inflammation flared up in the days that followed, her physicians suggested they wait for the tissue to heal more completely before resuming sexual intercourse.

Jerry

Jerry is a 39-year old fair-skinned African American woman with light brown hair and green eyes. She has given birth to one child. She has a high-school diploma and does inventory control in a warehouse. She identified the onset of vulvar pain with her first yeast infection, which had occurred 6 years before. While treating her for yeast, the practitioner at the health center had noticed some warts on the left side of her vulvar vestibule, which he burned off chemically. Following the second of these treatments Jerry experienced irritation to the tissue which did not resolve when the skin healed. The sensation developed into raw, burning, stinging pain, becoming more intense from ovulation to menses. She began a series of cultures, biopsies, and rule-out treatments, none of which yielded information about this burning pain. Topical hydrocortisone, yeast medications, and xylocaine further irritated the tissue. For the past 7 years she has had symptoms that feel like a yeast infection. The doctors say the discharge is normal; it irritates the tissue. Sometimes the pain feels like a mild burn, sometimes it throbs, and sometimes there is a sense of growing pressure on the left side of her vulva, as though there were a mass inside the skin.

Jerry has had a number of sexual partners over the years, most of them women. The last serious relationship broke up a few years ago, partly because Jerry's pain had progressed to the point that she couldn't tolerate being touched. She has seen the same gynecologist for many years, whom she calls when the pain becomes severe. He always makes time to see her, even if there is nothing he can do. He speculates that the wart treatment might have damaged nerves in the genital skin.

Lynn

Twenty-six year-old Lynn is a botanist, with fair skin and brown hair. When she was in college she met the man who is now her husband. After having "great sex" for a year, she began to have symptoms of a yeast infection. Following treatment a dull vestibular pain set in. She developed repeated yeast symptoms, which were treated, and then gardnerella, which took two courses of Flagyl to clear and was followed by more yeast symptoms. Terazol treatment for this irritated the vulvar tissue. She went to various physicians about the ache that remained, and underwent interventions such as baking soda douches for suspected lactic acid burn, biopsy for suspected HPV, removal of a mole on the side of the vaginal opening, and liquid nitrogen to freeze off presumably infected tissue. The dull pain in the lower part of the vestibule continued, and now itching began to occur inside the labia, developing into severe burning pain. Cortisone eased the itch but nothing took the pain away. She was painted with gentian violet for yeast. Although she was able to become sexually aroused, and she and her boyfriend still engaged in sexual intercourse, initial penetration and friction were very painful. Because the pain increased before her menstrual period at the progesterone peak, her gynecologist took her off oral contraception. There was no change in the symptoms.

Lynn joined the Vulvar Pain Foundation and helped start a support group. She began the timed calcium citrate and low oxalate diet. When rectal fissures developed she consulted a proctologist who eliminated the calcium citrate which seemed to be an irritant for her. Lynn's symptoms diminished enough for her and her husband to resume sexual intercourse and conceive. The pain became severe during the progesterone surge of the first three weeks of her pregnancy, but then improved. Her pain level stays low unless she eats something like chocolate or asparagus. At the time of the follow-up interview, Lynn reported that her libido had returned in full during the second trimester, and she was enjoying the pregnancy.

Emma

Emma is a small 37-year-old woman of mixed European background, with fine brown hair and delicate skin. She is an acupuncturist. Her vulvar pain symptoms had begun 7 years before, while in a committed relationship with another woman who had been recovering from recalcitrant vaginitis when they'd first met. Two years after they got together Emma began to develop symptoms of painful intercourse, excessive discharge, and focal vulvar burning. Over the years she tried various therapies--gentian violet, Terazol, boric acid--but the symptoms slowly worsened. While in China for medical school, Emma developed chronic hives and lost weight. The vaginal discharge and vulvar burning intensified. She felt as though her immune system was not right, and nothing seemed to help. Upon return home she had a sexual relationship with a man that brought on bladder infections which were treated with antibiotics, and which worsened the burning and discharge. When the vulvar burning was most severe, pains would shoot down her legs. This went on for years.

Emma researched the condition in the medical school library, following every clue that might help. She saw a number of practitioners and tried many treatments. A biopsy of the splotchy vulvar tissue only increased the pain. Although results were inconclusive for HPV, she had a short trial of interferon, which gave her a temporary break from the ulcerations. A gynecologist "who really knows germs" confirmed the diagnosis of glabrata yeast and treated her with Sporanox. This seemed to help with the hives. She began to regain some of the weight she'd lost, but she was concerned about the medication further stressing her immune system.

One of Emma's physicians put her on high doses of vitamin C and calcium, which exacerbated the vulvar burning. She stopped both, and the symptoms lessened somewhat. At the time of the first interview she was taking a multitreatment approach--meditation, herbs to boost her immune system, thyroid treatment, Sporanox, herbal sitz baths, an occasional plain water douche, and a trial of low-dose antidepressants. Although she still had burning that prevented vaginal penetration, with the help of acupuncture needles she was able to sleep, and she no longer had shooting pains down her legs. She was less fatigued, and had begun to gain back some weight. She had learned about the Vulvar Pain Foundation through the New York Times article, and was running a vulvar pain support group. By the time of the follow-up interview she reported that she and her long-time lover had ended a 9-year domestic relationship.

Sarah

Sarah is a 36-year-old Anglo-American attorney currently on leave from work. She is married and has never given birth. She is slim and blonde. For the past 10 years she has had vulvar pain in one very defined point, on her clitoris. It began suddenly. One day there was a very sharp pain upon touch. Her physicians tested for all possibilities. She took topical steroids and several courses of different antibiotics. On the assumption of an infection in the skin, tissue was removed through cryosurgery. She remembered this treatment being particularly ineffective. Her health care providers tried systemic treatment for yeast. Ultimately they concluded that they knew of nothing that would help her. The pain would vary, and it improved somewhat over time. Sarah reported initially having medicated with painkillers and Valium.

Over the years Sarah learned how to manage the pain with breathing exercises, meditation, and massage. She noticed that when she resisted the pain, its intensity increased. She found that it diminished at times when she was eating well and not using caffeine, and taking care to attend to her body. She says she "probably wouldn't be alive" if the pain had continued at the original intensity. She rated her current pain intensity as moderate, with occasional shooting pains that remind her of how it was before. The pain contributed to great tension in her marriage. Prior to the onset of the pain, she used to be very open and active sexually. This is no longer the case, as touch and pressure can be very painful for her.

Somewhat recently, Sarah noticed a connection between this clitoral pain and her coccyx. She began chiropractic treatment for structural imbalances found in the lower spine. At the time of the follow-up interview, she said that several months of chiropractic treatment had not led to any dramatic improvement in the clitoral pain.

Jane

Jane is 46, a blonde woman of Anglo-European background with porcelain-fine skin, who works as a dental assistant. Jane has been married for 20 years. She has had vulvar pain for 6 years, which felt at first like a yeast infection, and was treated with local medication. She began to have pain in intercourse; there was no discharge or itching as with a normal yeast infection. After a few months when the condition had not improved, she and her doctor tried courses of sulfa creams, betadine douches, and other medications that did not resolve the pain. A culture revealed nothing. By now the pain was so severe she and her husband could not have intercourse. They had both been virgins when they married, and sex had always been an important and special part of their lives together.

The doctor removed a lesion in the vulva. The pain spread from one spot to the whole vulva and became constant. Jane tried antidepressants briefly, with no change. She was referred to a gynecological oncologist who treated with interferon injections. The pain did not diminish. The specialist told her she was one of his first interferon treatment failures. He did a partial vulvectomy. She was careful to follow the post-operative protocols for thorough healing. After 6 months, vaginal penetration was possible but extremely painful--a minor improvement. Her customary menstrual cramping grew more intense and constant, and she was diagnosed with endometriosis. After a laparoscopy, removal of endometrial tissue, and the clipping of a uterine ligament, her abdominal pain disappeared. The vulvar pain remained severe. She enrolled in a pain clinic program that included transepidermal nerve stimulation. After the first TENS treatment, Jane and her husband were able to have sexual intercourse successfully for the first time in years.

As the vulvar pain began to diminish, Jane began to have bladder discomfort and loss of urinary urge. She reported having a sensation of something irritating in the tissue between the vagina and the urethra. A complete urinary workup found no infection or mechanical problem. By the time of the follow-up interview, Jane and her family had moved to another part of the country and she was beginning the process of finding health care providers. She reported that her vulvar pain had increased slightly, which she thought could be due to perimenopausal changes. The urinary discomfort had persisted. When she went for a physical, there was blood in the urine, but she had not received the results of the urinalysis. Jane reiterated her opinion that these dis-comforts are something she's just going to have to live with.

Isabelle

Isabelle is 33 years old, a tall, slender woman of European background with two advanced degrees, who works as a product manager. She grew up in Europe. After an abortion at 19 she had an affair with a man she met on vacation. Shortly after this she experienced vulvar itching and burning. Later that year she began to have severe vulvar burning which continued unabated for the next 14 years. At age 21 she and an American student met and fell in love. When she told her new boyfriend about her painful condition that precluded intercourse, he began to accompany her on her round of consultations with physicians to find a cure. She saw many gynecologists, dermatologists, psychologists, and psychiatrists over the years, and tried many treatments, which either did not help or made the pain worse.

At the time when her boyfriend had returned to the U.S. to finish his degree, Isabelle was committed to a psychiatric hospital for the "sleeping cure," a sedative treatment to break the cycle of chronic pain. She remained there, isolated and against her will, for more than 5 months. When her boyfriend located her she had lost 20 pounds and still had vulvar burning. With his help she was released. The next year they got married. They continued to search for help for the pain.

A general practitioner identified irritation at the opening of the Bartholin gland. This physical finding gave her credibility with a gynecologist who took enough interest in the problem to search a computer data bank for information about the condition. He found an article about vestibulectomy, and sent her to the U.S. for the surgery. The vestibulectomy did not remove all the painful tissue. Later one of the Bartholin glands dried up and was surgically removed. Isabelle reported that before this, vaginal penetration had been painful; after the operation she was no longer able to become sexually aroused. Since the pain continued near the urethra, her doctor decided to remove the Skene's glands, which he said were enlarged. She healed very slowly from these surgeries; considerable scar tissue formed.

When the opportunity came to do some of her studies in the U.S., they picked a large urban location so that she could pursue her search for specialists who could help. She found a urogynecologist who worked with a physical therapist. Pain assessment determined that she had developed fibromyalgia and interstitial cystitis. When the urogynecologist performed the cystoscopy, she also removed a last bit of tissue from the Bartholin gland that had been left from the earlier surgery and had been hardening painfully with sexual arousal.

Isabelle began an intense daily treatment program with her physical therapist to reduce the scar tissue with deep tissue massage. Gradually both the vulvar pain and the fibromyalgia decreased. She discovered a vulvar pain support group and began to attend and to take on responsibilities there. She learned about the low oxalate diet and had immediate relief when she began using it. Her vulva, which had been bright red for 15 years, became pink. Six weeks prior to the interview she had started using estrace cream. A week before we spoke, she and her husband had been able to make love for the first time without pain. She reported not being completely pain free, but having regained functions and being less distracted by the pain. The lumps of scar tissue were diminishing. By the follow-up interview the inflammation had calmed down to the point that she was able to drink coffee every day and to eat chocolate occasionally without a flare-up. She thought that her original problem 14 years ago was a yeast or urinary tract infection which set the pudendal nerves on a cycle of chronic pain.

Lynette

Lynette is a tall redheaded, 25-year-old Caucasian woman, who works as a desktop publisher. Her first pelvic exam at 18 was very painful. Intercourse with her future husband was very painful too. Lynette attributed this to her virginity, and she didn't tell her partner about the burning, tearing sensation at the outlet, or the sharp pain she experienced with full penetration. They got married. After each sexual experience she would contract a urinary tract infection, which was treated with antibiotics. Annual gynecology exams were painful but since her doctor never remarked on this, Lynette assumed there was no medical problem. At some point during the next 6 years, she admitted to her husband that sex was painful for her. Since neither of them knew what to do, they ignored it, until about a year prior to the interview when they began counseling with their parish priest. Lynette overcame her embarrassment and began to seek medical help.

A gynecologist familiar with vulvar conditions diagnosed vaginismus, classic signs of vestibulitis, urinary tract and yeast infections, and the possibility of endometriosis. Her bacteria count was high. To lower the pH to avoid transmitting infections to the urethra every time she had sex, she began douching with a hydrogen peroxide solution. After 2 months this brought the pH down. Then she began to use a low dose of estrogen cream to thicken the tissue. A month later she was able to tolerate insertion of the speculum with ease for the first time.

Lynette and her husband continued relational counseling and began work-ing with a sex therapist to enhance their communication skills and explore intimacy issues. She discovered the Vulvar Pain Foundation and joined a support group. At the time of the initial interview she had tried intercourse, sooner than their therapist recommended, and had found it mildly pleasurable once they got past the entrance--this was a first for her. She said it helped her recognize that she had a long way to go but was on the right track.

By the time of the follow-up interview Lynette had become disillusioned with her caregiver because he wanted to operate. She found a gynecologist in her HMO interested in the challenge of her case. They discontinued the peroxide douches, the estrogen cream, and the oral contraceptives which she had used since age 18. She tried xylocaine gel to break the pain cycle. Lynette has become a supportive resource for another woman in the vulvar pain group who is at the beginning of the process of looking for medical diagnosis and care.

Mary

Mary is 65 years old, a slender fair-skinned woman of northern European background, and the divorced mother of three grown children. She is currently self-employed at home. Twelve years ago when she was vacationing in the mountains she woke up one morning with a sudden strong sensation of vulvar irritation and discomfort. Upon return home she consulted her gynecologist, who "found nothing severe," but prescribed Flagyl for both Mary and the man she was in a relationship with at the time. When this didn't help, her physician increased her Premarin, but she was unable to tolerate the higher dose. The soreness remained, making it difficult to wear underwear or to sit. She described it as an irritated, prickly burning sensation around the introitus that was hypersensitive and tender to touch.

Over the years Mary tried different practitioners. Tests determined no sign of infection or hormonal cause. She was treated with anti-inflammatories, antifungals, antibacterials, with no response. Any topical application exacer-bated the irritation. The irritation would fluctuate unpredictably, but always worsened by the end of the day. Application of ice was her only relief.

One of the specialists Mary was sent to found some acetowhitening and did a course of three rounds of cryosurgery, which did not help. She went to the medical research library for help understanding her condition and tried all the self-care strategies she could. Finally, because of the article in the New York Times about vulvodynia, Mary found a gynecologist familiar with the condition. They discussed the oxalate theory and decided rather than spend money on the urinalysis she could try the low oxalate diet. She discontinued the calcium citrate because it bothered her digestion.

For the year prior to the interview, Mary had followed this diet. Although she found no direct, time-specific correlation between high oxalate food and the vulvar burning, over time she noticed some improvement in the symptoms. Since many foods contain oxalates, she thought it impossible to avoid them entirely. She was careful to avoid caffeine and chocolate, and cut down on eating tomatoes; other than that she reported being fairly flexible about foods. She reported that she expects the vulvar irritation is something she'll probably have, to some degree, for the rest of her life.

Rita

Rita is a small dark-haired Jewish woman, 34 years old, who works as a university fund-raiser. When she and the man she married were first getting together their attempts at intercourse were painful for her, which she attri-buted at first to their difference in size. The pain became a concern, however, as it continued. Prior to each menstrual period, she experienced one or two spots on the vulva becoming sensitive to touch and radiating a pulsating burning. Sometimes she experienced a focal feeling of pressure. When this pain began, intercourse was impossible. At its worst, the pain prevented her from sitting still.

Over time Rita consulted a variety of doctors who tested repeatedly for herpes, cysts, lesions, genital warts, and yeast, with no results. Yeast was usually blamed, initially, but Rita said she knows the itching of yeast and this burning is different. She found a woman gynecologist who had experienced chronic vulvar pain herself, who convinced Rita to try low doses of Elavil, which she did for 6 or 7 months. Rita found improvement in day-to-day pain of sitting at work, but only intermittent relief from the coital pain. Her doctor thought the hormonal changes of oral contraceptives could contribute to the problem. Rita went off the pill, and the pain diminished. She reported being aware of muscle tension and low lubrication, as well as introital pain.

Linda

Forty-four year old Linda is from the United Kingdom and of northern European background, with slender bones and fine brown hair. She has an M.B.A. and is presently unemployed and seeking work in her field. She has had chronic vulvar pain for 11 years. It began when she was training for a 10K run, and developed into red irritation on the outside of her vulva that was so severe she had to stop exercising and seek medical help. After years of consults with doctors who cultured and biopsied and prescribed creams that were ineffective, she found a dermatologist at a medical center who put her on large doses of systemic prednisone to relieve the inflammation. The inflammation persisted. Linda gained a substantial amount of weight and became depressed. She dropped out of medical care for more than 2 years. The pain spread from the outside in to the vestibule. She continued to enjoy sexual intercourse after initial penetration, which was sometimes "searingly painful" and sometimes merely uncomfortable.

When Linda was ready to try to find help again she consulted a gynecologist who told her the pain was all in her head and she needed counseling. She began psychotherapy, and also joined Weight-Watchers and lost weight. Her pain improved for a period of months and then returned. When she ran out of medical alternatives again she tried homeopathic remedies, which helped for a while. Then her appendix ruptured. After surgery and massive antibiotics she started having severe yeast infections which her doctor treated with Diflucan. This greatly exacerbated the vulvar pain. Her clitoris became hypersensitive and irritated, precluding pleasurable sexual touch and arousal. Resumption of homeopathic treatments brought no improvement. The pain was so extreme she became suicidal. Her psychiatrist helped her through this time, but the pain persisted.

Linda discovered the Vulvar Pain Foundation, joined immediately, and learned about a low-oxalate diet that had brought relief to some.

This made sense to her, because years before the Weight Watchers diet, which is incidentally low in oxalates, seemed to have brought dramatic improvement to her symptoms. Urinalysis showed a fairly high oxalate level. She started the diet, but was unable to use the calcium citrate because it exacerbated the pain. After 2 months on a low-oxalate diet, she began taking Oxabsorb and within a day the pain "more or less went away," to the point where she can have intercourse again. At first the inflammation diminished, but then it returned, with the kind of stinging, burning pain she'd had 10 years before, and in addition an unfamiliar swelling. Although she was still able to have sexual intercourse, the swelling prevented exercise, and the diet was difficult to maintain and caused her to gain weight again. She began to use estrace cream, which led to a slight improvement in the inflammation. Heavier, more frequent menstrual periods, and the beginnings of vaginal atrophy both seemed to exacerbate symptoms. She reported considering hormone therapy, but she was concerned about the long-term effects.

Anne

Anne is 24, and a pharmacy student. She is a tall, slender, fair-skinned redhead. A year and a half before, she had experienced two urinary tract infections and two yeast infections in rapid succession. She was under the stress of final exams when the vulvar pain returned; she thought it was another yeast infection, but symptoms did not respond to treatment. She consulted several doctors and tried many tests and creams, but the pain remained. After 6 months, a gynecologist diagnosed vestibulitis which he treated with two rounds of electrocautery, followed by lidocaine gel. Each time, the pain diminished temporarily and then returned. One diagnosis was hypersensitivity to yeast, but yeast tests were negative. She discontinued birth control pills a year ago.

At first the pain was intermittent but became a constant burning that changed throughout the day, from manageable to severe. The tissue was swollen. The irritation began in the vestibule and became more diffuse, and redder around the urethra. Symptoms intensified with stress and menstruation. She and her boyfriend have had no sexual activity for the past year, and they stopped living together because she was so irritable in pain.

Anne researched the condition, and found both a support group and a physician experienced with the condition. She ceased using all topical applications to the hypersensitive tissue. The physician prescribed antidepressant levels of desipramine and referred her to a therapist who works with sexual issues, with whom she is learning relaxation and meditation. Anne also reported receiving regular massages and working with a physical therapist for related muscle spasm. A neurologist administered a caudal nerve block with steroids. The first treatment had no effect, the second helped dramatically, and the third had a moderate effect. Anne also reported following the low-oxalate diet. When she suspended it briefly for the purposes of having her oxalate levels tested, she reported that the pain became worse. Resumption of the diet did not appear to diminish the pain, but she reported being afraid to stop using it.

Illness Meaning: Description, Explanation and Metaphor

The profiles are an abbreviated version of each woman's story of the disease trajectory, presented here to acquaint the reader with some of the details of her attempt to understand puzzling and disruptive bodily events. A schematic of demographic variables is presented in Table 1. After telling the story from her point of view about the disease and medical treatment process, each participant would go over the story again at other levels. Another story level is the unknown quality of vulvar pain and the search for explanation and cause. The uncertainty and unpredictability of the condition serve as powerful motivators for a woman to find a cause or explanation that makes sense of its presence in her life. Finally, in the construction of meaning of the illness, the metaphors that women used to describe the illness served as markers of its meaning in their lives. Description of the pain, illness metaphor, and explanations about the condition are addressed here.

Describing the Pain

The meaning the pain has for each woman can be seen in the ways in which she describes her experience of it. Women in this study described their vulvar pain in both sensory and evaluative terms. Sensory descriptions included qualities such as burning, sharpness or dullness, and pressure. These were often also reported in terms of time and of location. Participants also described their pain experiences in overall evaluative terms and in the metaphors referring to its presence in their lives.

For instance, Megan described her pain as "incredible, like I had third degree burns." She went on to say the vulva looked "majorly fire engine red," and felt "swollen a little bit, like sitting on a ball." Her evaluation of the pain was that it was "non-stop excruciating. There was never, never a time that it was just painful or just terrible. It was always excruciating for me. Just terrible would've been an ease up."

Burning, stabbing, sharp, raw, a dull ache, a throb, radiating, pulsating, and deep stabbing pain were the sensory descriptors most often used. "Like I'm on fire," said Gina. "A feeling of great heat," was Mary's description, "like a bad case of poison oak might approximate a little bit of the feeling of this, the hot skin feeling, like prickly heat." Jerry's pain felt to her like a diaper rash. Lynn's was "dull," at first, and later accompanied by a "mad itching." In addition, some women evoked descriptions of pressure or the sensation of something "granular" inside the skin.

The evaluative descriptive component of the illness definition is exemplified in statements like Jerry's, that "when the doctor uses the glove, his hands are dry and he just starts touching me just on the outside, it feels like he's going to rip my vagina out of my body." Jane's description echoed, "the best way that I could describe the pain, it absolutely felt like someone was ripping your flesh out." For Sarah, if "just a breeze went by, you know, it would send me into fits." Gina described trying to have sexual intercourse once the chronic pain had begun: "It's as if I were made of sandpaper, it's horrible."

Metaphor for the Illness

Some metaphors for the illness focused on the condition itself--as an "enemy" or "adversary" ("it was terrible. I just want to conquer it"), an "entity of itself," a disease, and a "thing that seems to be indiscriminate." Others addressed its role in their life--as a test, ordeal, or misfortune; a "cloud over my head," "hell on earth;" being punished or like being "in prison, where your freedom's taken from you." Some women's metaphoric descriptions were personalized: "I'm a bad case, the worst case," "my body has let me down," "I felt like shit, I felt like garbage, it hurt," and "I'm like a wounded animal."

Table 2 Metaphors for the Illness

As a Condition	Role of Pain	Personalized
It's this unknown thing.	A cloud over my head.	I felt like a wounded animal.
A mystery.	Hell on earth.	Like somebody pulled a rug out from under you.
The sickness of the planet.	I was being punished.	My body has let me down.
I just wanted to conquer it.	Like being in prison, where your freedom's taken from you.	I felt like shit, like garbage.
An entity of itself.	It's really a part of me.	I'm bad, the worst case.
Like a child you always have to be responsible for.	"Good morning, heartache."	I'm sensitive in a toxic world.
Feels like diaper rash.	It's like a bad relationship that keeps coming back.	I'm broken, who would want me?
An annoyance.		I was left holding the bag.
My enemy.		
A thing that seems to be indiscriminate.		

Explaining the Condition

Besides description, illness meaning emerges in the women's explanations of their condition. For the women in this study, the search for correct diagnosis and treatment is complemented by effort to understand the nature and cause of her vulvar pain, to construct an explanation that makes sense. While this construction is different for every person, patterns do emerge. Chronic vulvar pain is an "unknown thing," as Diane Lyn puts it, "it's a mystery. It's just, you're poking in the dark trying to figure where it came from but also what's causing the pain." This leads to a kind of "fogginess not knowing what I had," said Gina. She adds, "you don't know if this is something permanent or temporary . . . you don't know what you have." She points out the unpredictable quality of the condition that is part of its mystery. "One of the hardest parts, I think, is the lack of consistency in the physical sense where maybe you're feeling great for a week and then you have a high level of pain." Jerry expressed the wish that "they would find something wrong--at least I would know." Seven of the women in the study reported responding to the need to know by having kept symptom diaries to try to track factors and correlations. Whether she kept such a log or not, every participant sought explanatory patterns in her own experience.

These explanatory patterns contained elements of historic and predisposing factors, precipitating and complicating factors, one's hunches gleaned from experience and information, and biomedical explanations from caregivers. Questions concerning historic and predisposing factors included experience with allergies, skin sensitivities, or tender vulvar skin in childhood; anatomic factors such as a thick hymen; structural factors of spinal misalignment impinging on nerves; and a history of urinary tract infections. Participants speculated about past trauma to the tissue predisposing to later vulvar pain: one woman was raped at 16, one fell on the bar of a boy's bicycle when young, 3 reported abortions, and several reported wondering whether vulvar surgeries, postural imbalances, mechanics of frequent or vigorous ("aggressive recreational") sexual activity, and the rubbing of tight clothes or menstrual pads might have contributed to a predisposition for vulvar pain.

Genetic and familial factors were also a consideration. The most salient example of a familial predisposition is that Anne's 20-year old sister has had a history of vulvar sensitivity since childhood, with chronic irritations followed by recurrent yeast infections in her teens. Their 75-year-old maternal grandmother developed vulvar pain about 1 1/2 years ago, around the same time that Anne's vulvar pain began. In Megan's family several women have diseases associated with depressed immune systems functioning; she herself had Epstein-Barr Virus for 3 years before developing vulvar pain.

Possible emotional and psychological factors were mentioned explicitly by four of the women in the study. Emma explored the connection between emotions and symptoms, starting with the example that guilt and yeast infections are linked in Chinese medicine, and coming to the idea that "when people say, oh, you know, chronic fatigue, that's because they're depressed, it's like, if you had chronic fatigue you'd be depressed too." Sarah considered how emotional stresses from an unhappy childhood and in her current family relationships might be involved in complicated ways with physical pain as she developed this theme for herself:

> Of course there's always the possibility that it's a psychological thing that kicks in. At that time . . . there was a lot emotionally going on that could have triggered it . . . . I've certainly seen therapists long enough to know, I've seen in my own body that you can create very powerful things with your mind.

In coming to accept the psychological aspects of her pain, Lynnette pointed out that "you still have to work through the physical reaction to a psychological cause." Rita examined the "psychological ramifications" of a "weird gynecological history," which began with surgery for a thick hymen in her late teens, followed closely by pregnancy without penetration while she was still a virgin, an abortion at that time and another one a few years later for a pregnancy that occurred with diaphragm use. "Obviously, as a result of those two abortions I've always been very selective about my choice of partners, and even in the 1 or 2 years where I sort of was much more free and experimenting, I was except-ionally careful to the point where I wondered was I too frightened in some ways so as not to enjoy very much." Although Rita saw her current vulvar pain as "more of a psychological problem for me than anything else" in terms of its impact upon her life, she had no doubt of its physiological basis. Muscle tension might be a contributing factor, but with regard to the vestibulitis she was certain she "wasn't manufacturing it, causing this somehow, afraid of intimacy."

Factors which women considered as possibly having precipitated onset or flare-up of pain include behavioral (mechanical irritation, or sexual activity introducing bacteria that alter the vulvar pH), organismal (yeast, bacteria, virus), hormonal (menstrual cycle, menopausal changes, oral contraception, or hormone replacement therapy), biomedical treatments, or the emotional factors of stressful life events. All participants reported a sequence of factors further complicating the original pain. Examples are an increase or change in the quality and location of pain following interventions, or the development of interstitial cystitis or fibromyalgia secondary to the onset of vulvar pain. Psychophysical developments some of the women think might exacerbate symptoms include those of primary and secondary dyspareunia: vaginismus/ muscle spasm, and diminished sexual interest, arousal, and lubrication due to fear of pain.

Whether voiced as speculation or certainty, participants' hunches about the cause of their vulvar pain included hormone imbalance, metabolic anomalies, infection, environmental sensitivity, psychoneuroimmunology, emotional or sexual issues, and age factors. Lynn's story is one of several that implicate dietary factors. While she was doing botanical surveys in the mountains her pain disappeared. When she returned home the pain also returned. She later learned about a dietary study linking vulvar pain and oxalic acid. Looking at her pain chart she realized that in the mountains she had eaten no chocolate, beans, or green vegetables--all foods that contain large amounts of oxalates. Upon returning home she had resumed her normal vegetarian diet including quantities of bean burritos and greens--and the pain had returned. She began the timed calcium citrate and low oxalate diet, and the pain diminished. When rectal fissures developed she consulted a proctologist who eliminated the calcium citrate which seemed to be an irritant. Lynn speculated that oxalate degrades the tissue and makes it more susceptible to tearing, whether in the mouth or the rectum or the vulva.

Emma was certain that she had glabrata yeast, which she said is difficult to diagnose and treat, causes burning and acetowhitening, and can lead to ulceration of the skin because it makes microscopic fissures and goes into them. One of Emma's physicians put her on high doses of vitamin C and calcium, which exacerbated the vulvar burning. Another explained that calcium and vitamin C can metabolize together to produce calcium oxalate. When she stopped using both, the symptoms diminished somewhat. Increasingly, more foods began to give her hives. Although her oxalate level was slightly elevated and she used the diet, she did not believe that high oxalates was her main problem. Her theory was that the yeast compromises the integrity of the intestine so that progressively bigger molecules pass through this "leaky gut."

Sarah noticed a connection between her clitoral pain and her coccyx: pressure on the tailbone area intensified the pain. She began chiropractic treatment for structural imbalances found in the lower spine. At the time of the follow-up interview, she said that several months of chiropractic treatment had not led to any dramatic improvement, however. Lately she had been investigating the possibility of allergy to her husband's seminal fluid, as coital activity with him also seemed to lead to a flare-up of irritation in the tissue.

Jane thought her vestibular pain and urinary discomfort could be due to perimenopausal changes. She offered the thought that the laser surgery and vulvectomy might have caused nerve damage. Susan was certain that the source of her debilitating pain was HPV which she had contracted from sexual play without penetration in one intimate encounter. Several other women concluded that chemical or surgical treatments for warts or other growths had caused nerve damage or in some other way set up a pain cycle that was self-perpetuating.

Medical care providers' diagnostic hunches tended to the organismal, hormonal, and emotional. Medical diagnoses were a great source of comfort, especially when the related treatment response was positive. Caregivers' diagnostic speculations and certainties could also be a great source of confusion and frustration. One example of confusion centered around what caregivers know and how this knowledge guides both choice of treatment options and their attitude toward the patient. Shannon's vulvar vestibulitis specialist thought she was a strong candidate for treatment because she was young; Anne's told her that younger patients with vestibulitis seem to have a more severe intractable condition than the older ones. All the participants in this study had consulted more than one practitioner for the condition, from whom they had received information and interventions of varying usefulness.

> I was sent back and forth to these specialists. The psychologists and psychiatrists saying that it was all, you know, biological, physical. The gynecologists saying it was all in my head. And, to make a long story short, the reason I think they were saying that is because the illness is not known at all. They did not know what else to say.

Questioning the medical explanation emerged in Lynn's formulation about the diagnostic procedure for HPV, which in her case followed rather than preceded painful HPV treatment: "It is not a genetic test. They just look at your acetic acid fried cells and they say, oh, these cells look weird, and so they conclude that you have it." Anne, the pharmacy student, said she thought a lot of people get treated wrongly for yeast:

> Because the symptoms are the same, and also we don't have very good ways of really determining whether people have yeast or not. I think some of the stuff in the creams has a soothing impact on the condition and so people think they're getting better and then suddenly it comes back again and they think they have another yeast infection and so the vicious cycle starts all over. I think a couple of times I probably did have a yeast infection but I think most of the time I just had vulvar pain and didn't realize it because it looks the same. I mean, it looks red, it looks inflamed, and it itches and burns so, you know, you just automatically think you have yeast and now that you can get the little stuff over the counter then you can just treat yourself forever with it. And after a while when you go--you get so disheartened going to doctors because they never know--they can never tell you anything new and so after a while you just give up and treat yourself.

Lynn summed up some of the confusion expressed by many participants when their explanatory constructions differ with those of their caregivers: "It's hard to deal with the doctors who want to treat those organismal things--here's an antiviral cream and here's an antifungal and all these other things . . . and that's such a drag because all you know is your own condition. You still think you know more than they do but they don't want to accept that at all."

The result of this confusion is either to question the practitioner and perhaps lose faith in medical treatment altogether, or for the woman to question her own knowledge and judgment and perhaps lose trust in herself. Sarah talked about the risk of pain leading to poor judgment and harmful procedures. The feeling of "I don't care what you do, do anything, you know, cut it out, just do whatever it takes" she said, can be "really dangerous if you're in the wrong hands." Rita placed this dilemma in a larger context: "It's true with a lot of things related to women's health. Women are sort of treated as not quite aware or in tune with their own bodies. All the doctors who had never heard of this condition left me feeling somehow less than sure of myself." Jerry spoke wistfully about an explanation for her vulvar pain: "Part of me would be satisfied right now if I only even knew where it came from. How did this happen?"

Summary

One level of data analysis tracked the details of each woman's illness into the trajectory of somatic perceptions developing, changing, and giving rise to consequences in the experience of chronic vulvar pain. The units of this analysis were precursors, function, event, symptoms (onset, description, location, intensity, duration, frequency, precipitating factors, sequence, progression, variations), action, diagnosis, treatment, and outcome. This level of analysis highlights the interplay between sensory changes and management strategies--diagnostic procedures, diagnoses, treatment and outcome. Another level of analysis addressed the meanings the women in this study made of their illness in terms of description and explanation. Descriptions were both sensory and evaluative. Metaphors for the illness spoke to the condition itself, its role in one's life, and personal impact. Explanations for the mysterious and unpredictable condition of chronic vulvar pain centered around history and predisposing factors, precipitating and complicating factors, hunches from experience and information, and biomedical explanations from caregivers.

The Emotional Experience

How do emotional responses to the pain develop, change, and give rise to consequences? This reference point illuminated a wide range of affect from the narratives. Analysis of this level tracked descriptions of emotion along the lines of the disease trajectory and in response to its ups and downs. Emotional response units in the interview transcripts were clustered into categories of depression, anger, fear, hope, and pleasure. The process of coding for emotion units led to a further expansion of these clusters to include not only units of affect, but also mood, appraisal, and hedonic tone, into an over-arching category that for the purpose of coding was labeled "Self States." An additional coding category about emotional responses to vulvar pain emerged from the data and was labeled "Question Sanity." This section ends with a discussion of the issues and themes of that category.

Emotional Pain

The Emotional Pain cluster includes descriptions and reports of self states of depression, sadness, isolation, guilt, deflation/worn down, giving up/defeat, loss, hopelessness, self-pity, disappointment, discouragement, despair, and suicidality. The following self states were also reported: helplessness, low self-esteem, suffering, embarrassment, neediness, shame, grief, powerlessness, and pessimism.

At times, the psychological ramifications of the condition could be even more debilitating than the physiological symptoms of chronic vulvar pain. De-pression is reported by every participant in this study as a significant aspect of dealing with the vulvar pain, and perhaps the most difficult:

> I've found it really hard lately to, well, actually, I've been having a lot of trouble with just lack of motivation. I mean I have a hard time--I guess it's a classic depression. I have a hard time getting out of bed in the morning. I just want to stay asleep, I don't want to get up and face the day.

Depression deepened in response to symptoms that progressed despite medical interventions. Shannon said, "At the beginning I was so depressed because when is this going to get better? And now I'm kind of at the point I'm so depressed because is this going to get better?" Five of the women in the study reported having experienced emotional pain to the point that Emma expresses, "It was so devastating. It felt like my pleasure was taken away. At times I wanted to die."

The experience of isolation was a frequent theme in the narratives, and came both from the sense of being the only person with an unknown condition of vulvar pain, and from the sense that nobody could understand this experience. Every participant in the study reported having had the experience that they were the only person in the world who had this condition. "I'm in a crowd and everybody else is normal." Paradoxically the pain could also lead to wanting to isolate herself, to hide, as Sarah described: "That pain is what really wears at you, really makes you kind of deflated all the time, and after a while you just want to go 'Leave me alone,' I don't even want to leave my house." Women described the sense of being alone; "a lonely kind of thing."

Anger

The Anger cluster includes descriptions and reports of frustration, anger, and self blame. "You're always blaming yourself, and the guilt is so much more painful than the pain itself." The following self states were also reported: blaming others, hatred, aggression, impatience, envy, feeling against the world, and annoyance.

Frustration emerged from not knowing what the condition was, "the incredible amount of frustration you encounter as a woman when you have a problem that nobody knows about," as Isabelle put it. Rita expressed the frustration about the limitations it imposed on function, activities, and roles: "I get very frustrated because I never had a problem like this before and it's kind of a . . . why me, and when I'm with the most important person in my whole life, why did this happen now? Why does he get denied the benefit? It really feels very unfair."

Frustration was also expressed about medical care. This theme included categories of frustration with unsuccessful interventions and frustration in interactions with providers. Linda describes the latter: "I was extremely frustrated each time another doctor would say, 'Well, let me test for herpes. Given my sexual history, I kept saying, 'I don't think I have it.' 'Well, we'll test anyway.'" Anne adds, "Every doctor I went to just kind of tried to give me something to get me out of their way. I mean, I'd call the doctors when I was in pain and they would never call me back. They'd do cultures and stuff and I'd call to get results and they'd never call me back. That was just one of the most frustrating things, just dealing with doctors." "I wasn't angry because he couldn't help me," said Shannon, "I just wish he would have said he didn't know. Instead it feels like he didn't understand, he didn't care." Four participants reported feeling envious of other women who could take the normal things of life for granted, and Mary reported, "It's gotten so I've envied men everywhere I go. They don't have to deal with this. I look around and think, lucky guys."

Fear

The Fear cluster includes descriptions and reports of fear, confusion, panic, anxiety, pretense, and disbelief. Also reported were denial, skepticism, blocking it out, hiding, lying, defensiveness, withdrawing, panic, self-consciousness, and shyness.

Fear, confusion, panic, and anxiety addressed fear of painful intercourse, of losing libido, of never being able to enjoy sex again, of not knowing what is wrong, of having AIDS, of vulvar pain leading to cancer, of the pain becoming more severe or enduring, of painful treatments, of harmful complications and side effects of treatments, of damage to intimate relationships, of feeling hopeful and being disappointed again, of childbirth pain being increased by or increasing the chronic vulvar pain, of this condition being hereditary, of having a communicable disease, of being thought crazy, of being vulnerable to and emotionally damaged by a practitioner, and of not knowing what to do.

When chronicity of symptoms first became apparent, the common response was denial. Sarah put it like this: "I just didn't want to believe that I had this. I was just sort of like, you know, 'fix it.' It was like, 'what do you mean, I have this?'" Fourteen of the participants spoke of using denial to block out the pain or to avoid dealing with its consequences in their lives. Blocking out the pain and wanting to be fixed might even lead to wanting to rid herself of the offending body part: "When you feel like this may never go away, you're like, 'Do anything, I don't care what you do, just cut it out.'" That kind of desperation was expressed by five of the women in this study.

Hope

The Hope cluster includes reports and descriptions of hope, and also includes mention of excitement/anticipation, confidence, encouragement, patience, desire, complacence, and appraisal. These self states most frequently were reported in response to discovery of a new explanation, diagnosis, or promising treatment, or to improvement or alleviation of symptoms. Sometimes when a new possibility would come along, a woman would feel, as Mary put it, "Whopee! Maybe that's the answer!" Relational experiences with caregivers, intimate others, and support groups were social contexts which could also elicit these states. "Here were all these women talking about something that was very similar to what I was experiencing. I couldn't believe it . . . that was about the first hope I had was when I heard about this."

Pleasure

The most frequently reported self states in the Pleasure cluster were feeling better emotionally and relief. "My doctor said, 'Why don't you just try the diet?' I'm always conservative anyway . . . and it seemed to me that I really was improved. I'm overall much better than I used to be so I am encouraged." Also mentioned were feeling cared for, feeling understood, pleasure, acceptance, happiness, enjoyment, positive surprise, humor, accomplishment, satisfaction, high self-esteem, not feeling alone, emotional comfort, and pride. As with the positive self states of the Hope cluster, these states arose both in response to alleviation of symptoms and in relationships with others. Isabelle described the mixed pleasures of attending her first support group meeting:

> Can you imagine? I walked into a room where there were 30 women, all super energetic. They all looked so fabulous. It was wonderful, a wonderful day. A physical therapist was there telling them what physical therapy can do to help, and she was passing around one of those plastic models. There was a removable vulvar in the model and . . . Anita grabbed the vulva on the model and pulled it out, and they all started giggling. And she said, 'Ah, that felt good!' They made me laugh and it was just great. This has been very, very good for me.

Changing Self States

Self states tended in general to be connected both to the disease trajectory and to the relational situation. These emotional nuances were experienced in mixtures that flowed and progressed. The interplay and progression of emotional response from one self state to another is conveyed in the following quotation from Linda:

> So then I went back to homeopathy and it wasn't helping but my psychiatrist was very helpful. Around that time I was becoming very suicidal. The pain was very bad, I couldn't do anything, I couldn't have sex with my husband, it was just--I couldn't see any hope in my life. Around about that time a friend of mine called me and read me out an article about the Vulvar Pain Foundation. I grabbed the number, called them that second, and so I immediately started trying the diet. I had my urine tested for oxalate and it was at 19 so it was fairly high. And I just felt like a cloud had lifted from my shoulders. Here I was, suddenly there were other people who had this problem and I just sat and cried because I was just--it was so amazing.

The progression related here reflects the experience of every woman in the study. This emotional course from despair to hope varied in response to the ups and downs of the disease trajectory. Some of the participants tended to express a preponderance of one self state cluster or another, as exemplified in Shannon's description of being "depressed almost all the time. I cry every day. I break down so easily, and I'm really worried that this might not go away and that really terrifies me that the rest of my life will be governed by this pain."

Some women shifted over time from predominantly experiencing self states of the Emotional Pain, Anger, and Fear clusters to a greater and more frequent experience of pleasurable and hopeful self states. This progression is addressed later in the chapter, in the section on personal shifts in the experience of self.

Questioning Her Own Sanity

The reference point on emotional responses to chronic vulvar pain also elucidated the theme of women questioning their own sanity. The issue of caregivers' assumptions of psychosomatic cause pervaded many of the narratives. Twelve participants in this study reported having experiences involving such assumptions at least once, and some more than that, in the context of seeking medical care for their vulvar pain.

"So I was beginning to think, yeah, it's in the mind." "The more I kept trying to explain myself the more [the doctor] would kind of distance himself and look at me as though to say 'You're cuckoo.'" "I would be willing to get in front of any camera and tell somebody, 'No you are not crazy, you are really experiencing this pain that you have.'" "I yelled, 'I AM NOT CRAZY. I'M HAVING PAIN AND YOU DON'T KNOW WHAT I HAVE.'" "So I went to see Dr. X and at this point I was, 'Oh my God, it must be all in my head.'" "It is very maddening, but at least nobody has sent me to the psychiatrist. I know they were thinking that." "One doctor especially really led me to believe that this was really all in my head, because when you biopsied the tissue it came back as inflamed but as having no pathogen in it or anything like that." "I think a lot of us have been browbeaten by our doctors for so long that it's, you know, all in our heads. Or, 'Everybody has painful sex and it's normal.'"

Such an assumption added an additional emotional burden to the complex demands of dealing with physical pain in their lives. Women reported that this caregiver attitude lead them to question their own sanity, to feel victimized by specific providers and/or the medical system in general, or to feel traumatized or abused. A physician treated one woman in this study with Neuro-Linguistic Programming, on the assumption that "if I could picture the vulva that had no pain I would eventually get better." She "tried very hard every day to concentrate on the vulva getting better in my mind," but ended up blaming herself when this treatment did not ease the inflammation.

Summary

The emotional component of the experience of chronic vulvar pain develops in response to the perception of physical changes and relational interactions, and gives rise to behavioral consequences influencing treatment. Emotional responses were coded as Self States comprising categories of depression, anger, fear, hope, and pleasure. A further category of questioning her own sanity also emerged from the data. Emotional responses of each of the self states are listed in order of frequency reported in Table 3.

Table 3 Self States: Frequency of Report

Self-State	n	Self-State	n	Self-State	n	Self-State	n
Depression	23	Denial	6	Comfort	3	Hatred	1
Frustration	23	Deflation	6	Love	3	Enjoyment	1
Fear	22	Disappointment	5	Powerlessness	3	Humiliation	
Hope	18	Suicidality	5	Avoidance	3	Against the	1
Loss	14	Feeling cared	5	Pessimism	2	world	1
Anger	14	for		Neediness		Defensiveness	1
Isolation	13	Feeling	5	Low self-	3	Panic	1
Sadness	12	understood		esteem	3	Confidence	1
Am I crazy?	12	Despair	5	Embarrassment	3	Encouragement	1
Feeling better	9	Pleasure	4	Helplessness	2	Patience	1
Guilt	9	Acceptance	4	Suffering	2	Complacence	1
Confusion	9	Disbelief	4	Grief	2	Desire	1
Self-pity	9	Discouragement	4	Failure	2	Appraisal	1
Giving	7	Blame others	3	Shame	2	Excitement	1
up/Defeat		Skepticism	3	Withdrawal	2	Diffidence	1
Self blame	7	Blocking it out	3	Compassion	1	Surprise	1
Anxiety	7	Hiding	3	Envy	1	Pride	1
Pretense	7	Self-		Feel dead	1	Impotence	1
Relief	7	consciousness	3	Happiness	1	Paranoia	1
Upset	7	Lying	3	Impatience	1	Aggressiveness	1
Hopelessness	6	Not alone	3	Annoyance	1		

The Experience of the Situation

How do women make sense of the situation of living with chronic vulvar pain? Answers that emerged from the interviews clustered around changes in function and activity, and in their relational lives. As Gina put it, "I didn't even think about it before, but you've got this pain in this area of your body and . . . that part of you has been cut off . . . there's a lot of things you can't do, little things and big things too." What follows is a description from the narratives about ways in which, in Anne's words, "It takes up your whole life and it really does change you," and the issues and themes raised by this point of reference. Changes in function and activity are discussed first, followed by an examination of the impact of vulvar pain in relationships.

Function

The most basic functions can be affected by chronic vulvar pain. Seven women said that sitting, bending over, or picking something up was uncomfortable or sometimes impossible. Crossing the legs could be difficult. Sleep was disrupted for some:

> I didn't sleep. I would go to bed and I think out of pure exhaustion you might sleep about 30 minutes or so but I remember just waking up and rolling over and, and just touching him on his shoulder, just touching another human being to say, this has got to end.

Nine women had trouble standing or walking when the pain was severe. Urination was painfully difficult for three of the women. Seven spoke of having had times when pain rendered them unable to concentrate enough to think, to engage in conversation, study, read, or watch TV. Two women reported that the forced inactivity led to muscle deterioration. Weight gain or loss was a problem for others. The pain was described as distracting and preoccupying; people said things like, "I can't function," "I could not do anything any more," and "It stops my life."

Every woman in the study spoke about disruptions in sexual functions. Rita spoke for the group when she talked about always having taken the ability to be sexual for granted: "I never questioned, you know, will I be able to make love tonight? I never really thought about things like that." "That freedom has been taken away from you," said Jane, "not to be able to have sex." Lynette went through what she called a hard transition in admitting to her husband that she had coital pain. Diane Lyn talked about feeling as though she were living a lie, not being "a whole person," because of restricted sexual activity with her new husband. "This is real to me," said Gina. "Not having sex and having days of pain . . . I feel this all the time." For most of the women in the study, the vulvar hypersensitivity prevented pleasurable genital touch of any kind, including masturbation.

Activities

Of necessity, vulvar pain changed peoples' basic day-to-day activities. Five women reported having to miss work when in severe pain, and others remarked on the practical difficulties of going through the work day. There were times when the severity of the pain prevented five of the women in this study from cooking, cleaning, or shopping, driving a car, or even bathing or showering unassisted. Exercise, travel, going out, and riding a bicycle were frequently mentioned as favorite activities that had to be given up. Jerry, who keeps her bicycle in her apartment in the hopes of being able to use it again, articulated the frustration of many when she said, "At this moment, if it was an emergency and I had to ride my bike, I'd have to walk." Care of the vulva (such as frequent sitz baths) as a necessary daily activity organized the time of many women in this study.

Vulvar pain poses difficulties for function and activity because touch, heat, and moisture can irritate the tissue to an intolerable degree, requiring detailed changes as well in the use of contraceptive and menstrual products and many restrictions in the choice of clothing. Half of the women reported that they could not use underwear; several others spoke of searching for a fabric, style, and size of underwear that would be wearable. Finding comfortable pants was another big problem, pants that don't bind or even touch the vulva, that allow movement and look good. Pantyhose, leotards, bathing suits, and tights were out of the question for most of the women in this study. A number of them found the only solution was to wear long skirts ("granny clothes"). Changes like this can have a powerful effect on one's self esteem, as Mary explains: "It really bothered me. Not that I was ever a fancy dresser but I was told I had nice legs and, you know, I looked fairly good in pants . . . so the dressing part is, I feel sloppy. I go out and I feel like a slob." If someone called to invite her to the beach for the day, "I thought, you know, I'm not going to wear a skirt to the beach, I'm not going to take a suitcase full of clothes and say, 'I've got to take a hot shower now and change into something else.'" Limitations in clothing choices led to feeling "awkward," "covered up," and "self-conscious."

Food choices were limited for seven of the women in the study as well. Whether aware of or following the low-oxalate diet or not, some of these women found that wine, sugar, caffeine, or acids seemed to exacerbate the vulvar irritation. Although Susan's dietary changes had resulted in improved general health, she was not pleased with her weight loss or the sense of isolation that came from not being able to join her friends at restaurants and bars. Those adhering to the low-oxalate diet had mixed reviews about the regimen. Isabelle found its rigors easy compared to everything else she'd been through. Mary said she would do anything to try to get rid of the pain. To others, however, the ban on foods high in oxalates was another difficult limitation of self-care. Emma talked about her restricted diet having constrained pleasure in yet another way. Some women had heard about this diet but were unwilling to undergo its rigors or deprivations. Shannon said she finds the diet difficult to maintain and complains about it constantly. Mary and Anne noted that dietary restrictions call public attention to a problem they would like to keep private.

The social implications of these restrictions and requirements are considerable, as women withdraw from meeting new people or doing the things they used to do with others. There is a sense of "every little thing" being affected by the condition, so that with time one forgets what it is like to be comfortable in jeans or underwear, or even to sit in a chair. As Jane put it, "after a while you get to the point in your life when you're thinking with that part of your body because you are so controlled by the pain."

Relationships

Construction of meaning about one's situation raises issues regarding ways in which having chronic vulvar pain shapes and is shaped by one's relationships. This section focuses on the quality of relationships and how this theme interacts with the experience of chronic vulvar pain. Relationships with partners, health care providers, family members, friends, and support group were analyzed. The results of this study indicate that the quality of a woman's connections with others is affeckted by her chronic vulvar pain, and also that her experience of herself with the illness is significantly shaped by these relationships.

Significant Other

The primary relationship with "the significant other" can be a source of strength to a woman experiencing chronic vulvar pain, or it can be damaged by the presence of the pain. The impact of relationships with caregivers on the lives of women with chronic vulvar pain is also considerable, and is discussed in this section as well. Information about other relationships in the women's lives basically fit into the thematic categories elucidated by exploration of relationships with partner and caregiver.

Among the 16 women in this study, 9 were in committed relationships that, by the womens' reports, were strong to begin with. In the analysis of the data for definitions of situation, these relationships were coded as "we-go," because, however stressed by the presence of vulvar pain, they also provided a sense for the woman that she was not alone with her problem. Being part of a "we" was an essential source of strength and support for the woman in pain. Four of the participants in this study were in relationships that they identified as having been in trouble. These relationships were coded as "no-go," because of the sense that the relationship was further damaged by the presence of vulvar pain. The support provided by the partner in this category of relationship was variable. At the time of the interviews the partners in one of these troubled relationships were working on becoming a "we." One of the troubled relationships maintained uneasy stability, and two were ending. Three women were not in intimate relationships at the time of the study; each of these in her own way also provided insights into the situational variable of relationship in the experience of chronic vulvar pain.

The relational themes that these women's narratives highlight are about communication, understanding, protection, care, intimacy, and support. These themes were expressed along a continuum of openness or shutting down. Women described characteristics of emotional supportiveness or nonsupportiveness in partners. They explored the stresses that chronic vulvar pain places on a relationship, and the parts played by mutuality and taking responsibility, in working on a relationship stressed by this condition.

Partners who enhanced a woman's sense of being able to manage the experience of chronic vulvar pain were characterized as being supportive, nurturing, and patient. These partners believed that the pain had a physiological basis. They accompany the woman to caregiver appointments and/or help her make decisions about medical care. Partners in a "we-go" relationship found each other attractive and desirable, tried to understand each others' experience, maintained affectionate connection through "those little things," and appreciated and were willing to experiment in their sexual relationship. The women with vulvar pain who were in relationships like this also appreciated their partners' patience with the demands the pain placed upon them both.

Non-supportive partners were unable or unwilling to engage in these kinds of behaviors. Partners' sense of sexual deprivation was a theme that came up in several narratives. When Diane Lyn asked her partner for help making a decision about surgery about which she was "scared to death," his response was that if she didn't have the surgery he would have to find a prostitute. Emma's partner did go elsewhere. The role of guilt and blame was a recurrent theme in many of the narratives.

One quote will serve as an exemplar of the dynamic that vulvar pain can add to a troubled relationship:

> Well it certainly has changed my marriage because it definitely affected our sex life. I mean, my husband's very sensitive egoically in that he feels like it's his fault or something. He just takes that kind of thing on himself which is not a great characteristic, frankly, because it kind of makes the problem yours again. Because if you've got somebody who's blaming themselves for it it's kind of, you know, then you've got to deal with that. But it's a very male kind of thing to do, you know, take that as his masculinity's been challenged. And so that was damaging and that's continued to be damaging because you learn, certain responses, you

> learn to be afraid to touch because it causes so much pain. I think it's more a reflection too of how a couple can communicate and how they feel about themselves, how secure they feel, because if you can communicate about it and you can move around it and the other person doesn't feel like they're being criticized or directed because of some flaw or failing in them then, it's like anything. Even if nothing were wrong you'd still want that kind of communication.

All the women in the study explored the stresses that chronic vulvar pain places on an intimate relationship, emphasizing the idea that support or lack of support happens within a relational context of relative contact and openness. Mutuality, trust, communication, and taking responsibility emerged as key themes in working on a relationship stressed by chronic vulvar pain.

When the woman in this kind of pain is in an intimate relationship, as Jane reiterated, the sexuality of not one person but two people is affected. In Linda's words, "It is very, very difficult to have a relationship. There's a lot of emotional support and there isn't the loneliness of being alone, but it has just as many emotional problems." Both the "no-go" and the "we-go" relationships also had to deal with the pull of denial and shutting down. "I didn't want to buy a pretty nightgown because I knew it wasn't going to be hanging on the bedpost before the night was over." Jane also talked about shutting off accustomed interactions as a way to protect her partner's feelings as well as her own. Recognizing the impact of the vulvar pain situation on their partners was an important aspect of the mutuality of a "we-go" relationship. "Even though your husband loves you he might like to be with a normal woman," Linda explained. Women expressed regret about the times they had dealt with the pain by closing themselves to intimate interchange. "I shut my husband out, and that was a mistake."

Lynn talked about the sense of loss, for herself and her husband, brought about by the "death" of her libido, and her fear that it will never return. "I still don't have the raging desire that I used to, and it's never as good as it used to be." Of the chronic pain she said, "But otherwise it's really brought us together in that we talk a lot more. We've gotten to know each other better and really know each other's feelings and things." She went on, "If a relationship can handle vulvodynia it can basically handle anything."

The theme of the relationship having been strengthened by dealing with the pain comes up in a number of the narratives. Rita thinks she appreciates her partner and aspects of their marriage she might otherwise have taken for granted. "As much as I struggle with 'why can't I do things like normal people do?' there's something that feels very special unto us," she said. For Lynette, who is working with her husband on developing their "no-go" relationship into a "we-go:"

> I wouldn't say that it's saved our marriage, the fact that I've gotten treatment. It's certainly made it stronger and a relationship worth maintaining. Before it was like living in a hotel and when the two of us were here there was friction . . . all because of the sexual thing. I mean we had other issues too, but that was the underlying thing, the sore that never got healed because we just didn't know quite how to handle it. We weren't mature enough to handle it. It took a while before, you have to get slapped in the face enough to really wake up and say "I deserve better than this."

Relationships with Caregivers

For the women in this study, relationships with caregivers are central to the situation of having chronic vulvar pain, and significant along several dimensions. As several women explained, the particular meanings of pain in the vulva makes these relationships both very delicate and either a comfort or a source of increased pain. Participants in this study stressed their need for caregivers to know about chronic vulvar pain--to know that it exists as a diagnosis and is understood to have some physiological bases even if these are complex and not yet well understood. Affirmation of its reality as a biophysical problem is very important to women who have the condition, according to all who participated in this study.

Every woman in the study spoke of the need to work with physicians and other caregivers who understand that the problem is not only physical, but that it also has a profound, complex, and stressful impact on their lives. "My doctors were kind and nice but they were male and very clinical about dealing with the physical problem," Sarah said. "I don't really think they were thinking about what the other effects might be in my life other than living with a pain," she continued. "They weren't making the connection what kind of pain and how that might affect my relationship with my husband."

Almost all of the participants reported having had experiences with one or more provider making the assumption that her pain was the result of psychosexual conflict, as Isabelle said, "This is the way people treat women who have this problem, is that the first thing they look at is 'What is the couple's problem?'" One of Gina's physicians told her to have her husband sneak up on her, or to have a glass of wine before lovemaking, and then she'd feel better. "I got so angry I said, 'Then you explain to me why it hurts when I sit most of the time, when I'm not having sex, when I'm working, when I'm shopping.' I said, 'That makes no sense.'" The narratives of this study contain many similar stories. In the context of meaning for the women who experienced being treated this way, they felt that the providers were not listening to them or taking their condition seriously for what it was.

Showing emotion in consultations with caregivers could be a liability because it might confirm the related assumption that the woman is hysterical: "I told this physician that I was having problems, that there was very painful sex. I remember sitting there talking to him and I was in tears," Diane said. "This is extremely painful, it's very hard. I mean, you're a newlywed and you're not doing the normal things . . . I think he couldn't see past the tears, and the emotions got in the way." She went on to say she thought that this had "a great impact on the validity of what I was saying, he thought that it was more of an emotional problem . . . there was some hang-up." Again, this kind of experience was very common for the women in the study. According to parti-cipants, the assumption on the part of the caregiver of psychosomatic cause feels frustratingly dismissive and invalidating. Assumptions of this kind can lead to psychological damage, as described in the section on the experience of self.

The narratives also contain a number of examples of caregivers exhibit-ing qualities that these women found helpful in dealing with the disease--apart from the outcome of treatment *per se*. Knowing about vulvodynia, taking time or at least giving the illusion of having time, listening, asking for questions, considering her symptom reports seriously for diagnostic information, understanding that the pain is "real," being interested in and acknow-ledging the impact of vulvar pain in her life, taking a teamwork approach with other caregivers on the case, being willing to refer if they don't know about vulvodynia, having access to reliable information and competent referral resources, and a sense of partnership were all mentioned as characteristics of caregivers that the women in the study both appreciated and actively sought. One woman expressed this in her advice to other women with the illness who are looking for a good caregiver: "It vastly affected who I was, when I felt like no one was listening to me. Don't give up until you find a good match."

Twelve of the women in this study reported having had relationships with providers which were positive in these ways, either currently or in the past. The strengthening aspects of the "we-go" relationship can be seen in comments women made about their encounters with caregivers. "Dr. X is very, very compassionate. He says, 'Come over here, husband, and we'll look together.' So they're both looking [LAUGHTER] at what's going on and where it is and 'Now you can understand, when you're having intercourse that this spot right here is taking the brunt of all the friction.'" This quotation exemplifies both the kind of explanatory tone and the inclusive teamwork with patient and partner which were very valuable to Megan and others who had similar experiences, in increasing understanding and allaying fears that the woman and/or her partner might have. Jerry said she knew she could always count on her doctor making time for her when she felt desperate, even though they both knew he'd run out of treatment options. She talked about feeling sorry for him that he couldn't help her, but his caring meant a lot.

The sense of partnership with the caregiver--of being on the same side investigating a problem and trying to solve it--also comes through in the grammar of some of the narrative accounts. Gina, Diane, and others would sometimes use the plural pronoun when discussing medical care: "we'd start me on an antibiotic," "we might have tried some drugs," "I could get my record to see what did we do." When talking about the interventions of a provider "who took his time to really investigate what was wrong, and asked questions," for instance, Gina began to use the plural pronoun, "we're still trying to get it right. But I still felt very alone," she said, further expressing the need to feel part of a "we"--so she called the support foundation to find someone to talk to who had been through an experience like hers.

As with the primary emotional relationships in a woman's life, the sense of partnership with the caregiver is the outcome of mutual responsibility and relational skills. The women who had known satisfying caregiver relationships expressed their sense of their own responsibility to communicate their experience and their needs clearly to providers. This was something that five participants discussed having to learn how to do. After changing doctors "because I realized the first one was not seeing the problem here," Jane spoke to the next one differently: "I went in and I just told him, 'here's the deal, sex at my house is not like the way Redbook magazine says it's supposed to be and there is no afterglow.' [LAUGHTER] So he agreed that there was a problem. I think he had an indication that something was definitely going on but it was not something he could handle." He referred her to a specialist in vulvar disease.

Other Relationships

Information about other relationships in the women's lives basically fit into the thematic categories elucidated by exploration of relationships with partner and caregiver. Connections with family members and friends were noted for the relative presence or absence of communication, understanding, support, mutuality, and taking responsibility. Having someone who believes in her, whether a best friend, parent, therapist, or physician, is a theme that came up repeatedly in the narratives. As one woman with longtime vulvar pain put it clearly: "This is more than anyone can bear alone."

The three youngest women in the study had the staunch support of their mothers' help when the pain was debilitating. Jane's in-laws came to care for her and her family after her surgery. Susan's former boyfriend became her best friend when she needed a shoulder to cry on and assistance with basic activities such as shopping for food. Five of the women were currently in therapeutic relationships they count on. The emotional resource of being in a close friendship was mentioned by six participants in the study.

The personal connections of active membership in a vulvar pain support group is another source of strength in relationship for 10 of these women. As Lynette put it, "I do have people who do understand me. I have the support group and I can go and kvetch and complain and they'll all pat me on the back and say, 'yes, I know what you mean.'" Although a few of these participants reported having been reluctant initially to meet other women with vulvar pain ("I was thinking 'They're all going to be depressed,'"), most of the women in this study who have made contact with a support group find it encouraging and remoralizing to gather with others who share their experience. Information and contact with other women with vulvar pain seems to have changed the course of the illness for seven of the women in this study, and thereby changed their lives.

Summary

The limitations that chronic vulvar pain imposes upon a woman's daily life in terms of function and activity are both demanding and pervasive. Material from the narratives about women's construction of their situation is replete with illustrations of relational factors and the major part relationships played in the lives of these women with chronic vulvar pain. Whether of an intimate, professional, familial, or friendship level, relationships were found to be either a source of support to woman with chronic vulvar pain, or to be damaged or diminished by the presence of the pain in her life. In the narratives, women identified themes of communication, understanding, protection, care, intimacy, and support, expressed along a continuum of openness or shutting down. Many of the women in the study also identified the need for mutuality and for both members of a relationship to take responsibility in the situation of living with chronic vulvar pain.

The Experience of Self

According to the results of this study, having chronic vulvar pain shapes a woman's sense of who she is. Definitions of the self in relation to chronic vulvar pain emerge in examining themes of the meaning of the vulva, issues of gender identity, changes in perspective, and personal development. This section addresses each of these areas in turn.

Meaning of the Vulva

Pain in the external genitals has a unique impact on a woman's sense of her identity. In the interviews this impact emerged especially in the meaning of the vulva for the participants in this study. The category on meaning of the vulva is comprised of themes of inaccessibility in language, vision, and speech; vulnerability and exposure; stigma and disability; comparisons to pain in other body parts; and preoccupation versus learning. The category on shifts in the sense of self addresses sexuality, gender roles and gender identity, and loss.

"There's just a lot of meaning with that part of the body, I think," said Gina. Chronic genital pain is unique, phenomenologically and conceptually, in the meanings it holds for the individual and for the human group--perhaps more so for the female genitals, given their concealed, interior physical characteristics. Women in this study spoke about their vulvas in ways likely to reflect cultural as well as personal norms. Notable was the inaccessibility of the vulva to language. The vulva is referred to as 'it," "that," "there," down there," "private parts," "that part," or the vagina.

Inaccessibility to language relates both to thinking (or not thinking) about the vulva and to being able (or not able) to talk about it with others. This was a major issue in the narratives. Half the women in the study preferred to keep the matter of their vulvar pain to themselves. "Sometimes people don't tell anyone. I guess maybe they're embarrassed or something. I don't know."

For Mary it was "not the thing you could tell any of your friends about. I don't want to talk about it really." She has never talked with her sisters "in those terms." She wanted to explain to her daughter and her friend why she started wearing baggy pants that were not at all her style. She thought they must have wondered, but "I never said anything about why. I just kept it in because it didn't seem like anything you're going to lay on all these people." She thought that they wouldn't understand, that they would never have heard of vulvar pain so it wouldn't help to tell them, and that "they'd think, what's the matter with this person?" Mary went on to point out that when she had a neck injury "that was an acceptable pain . . . you can tell people, they're sympathetic. And it doesn't require your taking your clothes off to take care of. There are of course privacy problems in talking about it and coping with it. Other pains you know what they are."

"In some ways its such a sort of taboo part of the body," is how Diane Lyn explains this. Several women in the study acknowledged the difficulty in discussing "things that often people wouldn't talk about." Some women did not want to "burden" their parents with this information that would explain, for instance, why the marriage was shaky or why there were no grandchildren. Susan said she would never tell her mother about this: "It's humiliating."

Rita did confide in her mother about her vulvar pain. "It was really odd. I'd never discussed sexual issues with my mom but I wanted to know if she had ever experienced anything like this." Anne's family members knew about her pain and were supportive, but she spoke for many in the study who expressed the wish to keep the matter private in general. Diane Lyn's family doesn't discuss sexual matters, and until she found the support group she had no one to talk to about her pain. She described the experience of men finding her attractive at work, "and I kind of feel, if you only knew . . . it's a secret and I would never, ever in a million years let anyone know that." Not wanting people at work to know, not wanting people to have this information about her marriage, and wanting to protect her partner's image were other reasons given for not disclosing their condition to others who might be a source of under-standing and support.

When she tried to tell family members about her vulvar pain, Isabelle discovered that "people don't know how to deal with it because they couldn't talk about it. I don't think anybody can grasp what vulvar pain is, how painful it is, what it means and we don't, I mean, really, talk about it because it's something uncomfortable to talk about. It's a taboo subject." Women mentioned the unique difficulties of discussing such private pain with male family members, male practitioners, and other men in their lives.

Finding words for the pain and its location seems to be part of coming to terms with its meaning in the woman's life. Recently Mary has been able to mention her condition, since she found out its name and that she was not alone in having it. "Over this year, ever since all this oxalate and since it's become a word, I've found myself telling, maybe not even saying the word vulvodynia but saying, 'Well, I have this kind of prickly heat condition and it's hard for me to sit too long.'" Lynette has also found "it's become easier and easier for me as I've gotten talking about it in counseling and with the group and with people who don't have it." She's found comfort in their response, "not that they understand it but they sense that it's a big deal for me."

Women in this study experienced particularly keenly the meanings of the vulvar taboo. The vulva is a protected, interior configuration. Part of its taboo is that women are taught from an early age not to look at, feel, or touch the vulva. This prohibition prevents women from becoming familiar with this part of themselves by matching sensation with visual and tactile cues. The unaccustomed sensory focus of pain in a forbidden, unfamiliar, unseen, unnamed part of the body can be upsetting, as Rita described. "I mean, it's ridiculous because why should I be so keenly aware of a part of my body that I never felt before in everyday life and it was just very awkward." Linda was also bothered by having to put so much attention on the changed sensation of vulvar swelling. "It still doesn't help the fact that I'm so preoccupied with my--my private parts. I mean, I must look at the inflammation and examine it at least three times a day in a mirror."

Isabelle addressed the cultural prohibition when she talked about how women are advised to stop paying so much attention to the painful area: "Doctors tell you, don't concentrate on it like that!" Yet, a lack of familiarity with her own body and the names of the parts may prevent a woman from receiving the care she needs. The process of breaking the taboo by learning more about one's body seemed to be very significant for a number of the women in the study. As an exercise in sex therapy Lynette and her husband drew pictures of their genitals and named all the parts, "just to get really familiar with our bodies." She used a mirror for the first time with her doctor and nurse so she knew what redness and irritation they were talking about. "It made a big difference in how I perceived--it's not all in my head, you know?" "It's very important for women to look at their vulvas because it's not enough just to have the sensation. When people have a scratch on their hand they look at it constantly," said Isabelle. "That doesn't change the healing process. So why can't we look at our vulvas?"

Diane said she had never visually examined her vulva on her own to see what was wrong. She was humiliated on an initial office visit by a male doctor "grabbing a mirror and sticking it down there and having me look at myself. I mean, you're in a very vulnerable state when you're in these stirrups." She appreciates her current provider respecting this vulnerability. "He asks, "Would you like to?' Not, 'Look here,' as a command. You know?" Isabelle explains being "able to describe the pain because I know the area so well."

Five participants reported experiencing a process of becoming desensitized. "When you start exposing that part of your body to doctor after doctor, I know they're doctors but they're men too--men after men, mostly men I've had to deal with," Gina said. "You become desensitized to that, and verbally as well. It becomes a lot easier to talk about it. So what if this is taboo or whatever? That's not the point anymore." She had overcome the sense of stigma in an effort to help others, by being interviewed about vulvar pain for a television information news program.

> It was very important to be honest as much as I could even if it was embarrassing. I went on camera saying, 'Oh, it hurts and I can't have sex.' And I thought, gosh, everybody I've ever known or even dated is going to know this stuff. But I thought, well, so what? Because if I could've just seen something like that in the throes of trying to understand what had happened to me it would have been so helpful. So, I just let it out and I thought, okay, I'm just going to look at this like I'm talking to somebody one on one.

Chronic pain in this area of the body compelled the women in this study to make the generally elusive image of the vulva more specific. The women in this study reported mental representations of the vulva in terms of disability, damage, and removal. "Something is wrong. Something is missing," was how Jerry put it. "You're broken," said Diane Lyn; "and you feel like that part of you has been cut off," adds Gina. "I've thought a lot about this," said Linda. "I mean, that feeling that I am in some way--not deformed but just kind of malfunctioning." Megan describes her fears:

> I had lived 26 years before I had sex so why would I be defined as that part? But once I had experienced it and then once it was stripped of me I all of a sudden felt that way . . . I thought, it's going to be cut away. What happens when you have cancer? Well, you take it away. You know, you take the breast away, you take the lip away, you take the part of the tumor of the brain away so part of that's gone. So what do you do there? You take it away. So I had already imagined that that might be cut away and stripped of me forever.

The women in this study struggled with ways to maintain a positive sense of themselves while living through experiences of vulvar vulnerability, pre-occupation, stigma, in addition to the pain that for many precluded any genital sexual pleasure. "Even though sex is in many ways the way we, you know, define parts of ourselves as women, it's not the only thing. You know, you're more than the sum of your parts," Gina stated. And then she added, "Even the dysfunctional ones." When Megan's vulva began to heal, she described a new positive aspect to her relationship with this very private part of her body: "I tapered off to every other day using the cream and then I'd totally stopped and I felt like I did before I ever got this. I'm fine, I'm fine. I mean I've even looked at it to say [LAUGHTER] my old friend!"

Gender Identity

The second aspect of constructing definitions of self in relation to vulvar pain addresses shifts in the sense of self that occur along with changes in the vulva. This category contains themes of gender identity, loss, and sexuality. Gina articulated the connection between anatomy and identity, body image and body-self: "I think the part of my body that it affected, you know, I mean that part of your body you attribute to your femininity and your sexuality and having children. I almost felt like not male or female."

Themes of loss revolve around issues of sexuality and sexual function, and gender and identity. Women spoke repeatedly and movingly about the loss of sex drive and the ability to function sexually, and about having had sexual freedom of choice taken from them. Loss of penetration, of being able to receive, of being able to express oneself sexually, of being able to give or share pleasure--these themes pervade the narratives.

> This problem affects me in such a more personal way. I mean sex was really important to me. I really enjoyed sex. But I've lost almost all sex drive. I'm just not . . . a sexual being really at this point which is also really hard for me. Also, like I'm so young, everyone around us is having so much sex and I'm just totally resigned to not having sex and there's nothing I can do about it.

Loss of the ability to feel sexual and to function and communicate as one would like to sexually can be related to profound changes in a woman's sense of her genderedness, as Gina illustrated above. Others expressed this loss in such terms as, "I didn't feel very womanly," "I lost my womanhood with this," "I wasn't a complete woman," and "I felt less than a woman." Seven of the women spoke of using alternate, non-painful forms of sexual expression, either with themselves or with others. However, this in itself could be a source of emotional pain, as a reminder "that there's something you can't do." "You can do other things," said Rita, "but I always feel like either I'm pleasing him--which is really nice but then I never get anything for me." Shannon talked about the resentment of not being able to receive pleasure: "I knew it wasn't his fault but it was so hard to have a sex life . . . he was having orgasms and I was just totally like the passive supplier."

The sense of loss can go beyond gender to the sense of oneself as a sexual being. "That's such a foundation of who you are. I've always felt like a very sexual person," Shannon explained. "Some women talk about how their womanhood's taken away from them, but I don't think of it so much as femininity as just like human sexuality." These comments highlight the idea several woman struggled with about gender role, and the sense that the woman's sexual role is to please. Diane Lyn described feeling that she was "not a real wife." Shannon wanted to emphasize having lost more than the ability to "provide sex"--that she felt "robbed of my sexual life." Prevented by the pain from being able to provide her lover with sexual activity, Emma decided that the most likely way to preserve their relationship would be to encourage her to have sex with other people. Rita was disappointed by her mother's reaction on learning that Rita had vulvar pain. Her mother said she felt sorry for Rita's husband. Rita said, "What about me?"

Loss can be experienced on the level of one's identity or self. Several women struggled to articulate this phenomenon. Diane Lyn and Jerry talked about not feeling like a whole person. Diane Lyn went on, "I don't feel like I'm complete, I'm really not all that I appear to be. I can't do everything. I'm not there." Of masturbation, Jerry said,

> I feel like at times that part of my body is not functional and that has to do with the sex part because . . . I might have those feelings, I might be aroused, then I take it to the next level and I feel like I don't want to do anything. I don't like feeling like that. I don't feel like a whole person. I feel like something is wrong, something is missing.

Genital pain can lead to loss of libido, to the inability to be aroused or sexually responsive. This was "the worst thing among many worst things" for Shannon. When the loss went that deep, some women expressed feeling a kind of death of self. For instance, of the period in Linda's life when she had clitoral pain, she said, "that was really a downer because at least previously I had always been able to have pleasure in sex from that but once that pain came, my life as a woman was more or less over." Isabelle put the matter in its starkest terms: "You feel dead."

The difficult task of maintaining or resurrecting self-esteem and a sense of existing as a sexual being despite pain and disability seems aided by having a sense of humor. Isabelle told about the wild laughter in her support group when they discovered that none of them could tolerate watching sex scenes in movies any more because they hated seeing what they were missing, and how they would laugh and call themselves the "bad girls" because they loved sex and couldn't have it.

Of the women in this study, only two reported having maintained a positive sense of sexual identity despite the fact of not being sexually functional:

> It was horrible--I would want it so badly. I just love sex. He always knew that there was a big problem down there, because he sees me, he knows me and he knows how I am with him, you know, his body and how I feel and how I respond to him. He knows--he knew I was a sexual person.

The effects of this particular kind of pain and dysfunction on the sexuality of a mate was another important theme. Options of expressiveness and exchange between sexual partners are severely restricted when one of them is experiencing genital pain. Jane's statement that "the actual act of intercourse is the ultimate, that's how it really does affect two people" leads into the following section, about how women construct definitions of their situation with chronic vulvar pain.

Changing Perspectives

The limitations of function and activity elucidated in the section on the experience of the situation draw attention to the pervasiveness of the condition in the everyday details of life. The women in the study found that living with the "small things" about chronic vulvar pain necessitated changes in some of the bigger things. In fact, it changed their perspectives about their lives. Living with pain required re-negotiating expectations, both for day-to-day concerns and for long-term plans. This process of reassessment centered around a basic question about changing ability that people asked themselves in different ways: "Can I do it?" "How's it going to be?" "Will this work, will this not?"

Isabelle described the issue as, "The pain itself in the vulva is bad but what is even worse, I think, is the implications it has on your sexual life, and on your own projection of yourself in the future as a wife, as a mom, and as a human being just to be able to cope with the pain every day." People reported having to alter personal goals to take the disability into account, for example whether to stay in school or do advanced training, to involve themselves in an intimate relationship, to cancel vacations, or to find work.

A major issue for the women in this study in their 20s and 30s related to having children. Megan and her husband hadn't planned on parenthood but changed their plans when her doctor said that pregnancy and childbirth could help alleviate the vulvar pain. Lynn had managed to conceive during a time when the pain was bearable. The rest of the women in this age group, however, spoke both of having to put the decision to have children on hold until they could function sexually, and of the sense of loss that this decision wasn't something they could even think about at this time in their lives. The fear that they could pass vulvar pain on to a daughter came up in four of the interviews. One of the older women raised another concern about risk, that of possible unknown long term effects of estrace cream and other hormonal therapies, both for the younger women facing the rest of their lives on hormones, and for herself:

> I feel like this thing is giving me a death sentence because it's forcing me to engage in risky medical practices just to keep my head above water so I can function. So when I decided to start using the estrace cream I sort of felt, well, so what if I take this risk? I have no life anyway . . . and I suppose that will ultimately get me to the point where I will start using the hormone replacement therapy because it would be better to have 5 or 10 years where I can--live.

Uncertainty is another recurrent theme in living with chronic vulvar pain. Shannon and Emma discussed the tension of needing hope to keep going, and fearing the pain of having their hopes dashed again. Not knowing if, when, or how the pain might "get better" makes it very hard to live with at times. Because the condition is unpredictable, there is a sense for many of the women in the study, even if their symptoms have improved over time, of being "temporarily abled." Several women expressed fear that the pain would return, or that this might be as good as it gets. Linda spoke for many in describing her shift in perspective over time:

> I would be just delighted if I could get back to where I still had inflammation but I could pretty much do a lot of things. That's the other thing you learn. First you want to go back, you want to get something that will take you back to normal and then you get to the point where, well, gee, I guess it really wasn't so bad to be back where I was in 1988. You know? And then one day will I be, well, gee, I really wasn't that bad in 1995. So . . . everything's relative, I guess.

Personal Development

By their report, chronic vulvar pain has had a significant impact on the identity of each of the women in this study. How do these women live what one of them called "a life on hold?" This last category examines what the participants have learned about themselves in the experience of chronic vulvar pain, and their perceptions about how they have changed.

The themes that emerged from this level of analysis of the narratives were coded under the label "Personal Shift." Issues raised in this category have to do with altered expectations of self and life goals. The four meaning clusters in this category are Acceptance/Rejection, Listen to Body/Block it Out, Independence/Dependence, and Helping Others. The theme of personal development seems to be related to other aspects of a woman's life, namely whether or not she is in an intimate relationship, her satisfaction with the treatment in terms of its effectiveness and/or the relationship with the provider(s), and membership in a support group.

The first cluster of themes is called Acceptance/Rejection, and includes issues of control, preoccupation with suffering versus activity, ordering priorities, setting limits, taking things for granted. Listen to the Body/Block it Out encompasses such issues as resources, finding strength, patience, learning to take care of oneself, and trusting oneself. The third cluster of themes, Independence/Dependence, brings up issues of taking responsibility, and altered attitudes toward caregivers. The final cluster is called Helping Others. It is comprised of reports of increased compassion for others who suffer, including but not limited to those with chronic vulvar pain.

While all 16 of the women in this study report feeling changed in important ways by the experience of chronic vulvar pain, at the time of the interviews there was a qualitative difference in the direction or valence of the changes women talked about. Six of the participants spoke of being changed by the experience in more consistently negative ways: "my body has let me down," "I feel like it's a hopeless case; there is no light in the tunnel," "I just live with it, but I want to forget about it," "everything's changed, my whole life is ruined," and "I've become a complete pessimist. It's changed my personality. I'm not sure how much I'll be the same if and when it's over." These women, at this point in their lives, seemed to experience self states of emotional pain, anger, and fear more frequently, for longer periods of time, and with fewer reports of hope and pleasure states.

Every participant reported having experienced the self states of emotional pain that these statements convey. However, the other 10 women in the study described having undergone an attitudinal shift at some point, a kind of reckoning that changed the balance between rejection of the pain and acceptance. The words they used to describe this process were "personal shift," "turning point," "big transition stage," "new feeling," "big awakening," "change of perspective," "I've changed," "I started to take control back," "I'm not so afraid," "refocused my energy," "I'm a much better person," and "It's deeply changed me." The differences between the two groups are arrayed along the four clusters of themes delineated above.

Acceptance/Rejection

This cluster includes accepting the pain or rejecting it, issues of control, preoccupation with suffering versus activity, ordering priorities, setting limits, taking things for granted. In limiting function, activities, and choices, chronic vulvar pain exerts control over many aspects of the lives of the women in this study. Many of the women in the study seemed especially vulnerable to physical and emotional collapse when tired, disconnected from sources of support, overstressed, or discouraged. These were times when taking things for granted and being active in order to stay in control no longer served. Jerry called it her "breaking point" where "I just don't feel like I can deal with it any longer."

> Sometimes I get real irritable, real withdrawn, when this is going on . . . I turn off my phone, I don't want to be bothered with my friends . . . Is this something I'm going to live with or am I going to go to my grave with this pain? Where do I go from here? What do I do? This brings me WAY down. I mean . . . I want to just close up . . . there is no solution.

At this point, women either stayed preoccupied with their suffering or ultimately found ways to reorder priorities, gain some control, and become active in ways that combated emotional pain without further wearing them down.

Participants found a variety of ways to exert or re-establish a sense of control in their lives. Jane and others talked about throwing themselves into work and other areas of their lives where they did have control, to survive. Jane talked about "keeping something going all the time," and making sure she always looked "great" to combat the depression. "If I kept going real fast, I didn't think about that pain. It was there but I didn't give into it, almost like a tug of war. 'Who's going to win today, me, mentally? Or you, physically, the pain?'"

Lynn expressed the need not to dwell on the pain but to go on with other things. "Just try not to think about it. You forget about it and you're busy doing other things." This issue of being active came up for Gina as well, who pulled herself out of her depression by taking control in areas of her life where she could still be active, because she wanted to feel better about herself. This control strategy was not always successful; sometimes the pain would win, and as Jane described, she would "just collapse" and cry for a week, unable to do anything. Isabelle talked about coping by "jumping into work like crazy," and then getting depressed on the weekends when "I had to face my life."

Sarah saw the tension between acceptance and rejection of the pain in terms of her personal development. When the pain first developed she managed it "pretty much the way I dealt with my life. You know, if anything hurts, just fix it, you know, take drugs, whatever . . . and I got myself in a lot of trouble that way." Over time, she said, she learned to listen to her body, to use pain management techniques, and to become more responsible for her own health care. "It's sort of like stopping banging your head against the wall . . . you just kind of learn to work around it . . . I'm getting more accepting that, you know, like, everybody's got something."

Emma expressed a new appreciation for "knowing what it is to have a body, both the pleasure and the pain of it." Many of the women talked about finding a balance between activity to feel better about themselves and rest to replenish and heal. Jane said she had to slow down and make time for herself, and to take the pain as "one of those things in life that you just learn to deal with."

Listen to the Body/Block it Out

Issues in this cluster include listening to the body versus blocking it out, resources, finding strength, patience, learning to take care of herself, and trusting herself. A tension came up in the interviews between pain affecting everything, and not letting it take over the rest of one's life. Some framed this in terms of not dwelling on the pain but blocking it out in order to enjoy and get on with other things. As Diane Lyn put it, "It's just too much. It just consumes your life. There's so much more to life than thinking about what is going on with your vulva." She and several others responded by trying to ignore it, forget it, "just park it and leave it," throwing themselves into their work, hiding, putting on a bright face for others.

Some found a balance between staying active to avoid depression, and blocking out signals from the body. This meant learning to take care of herself, to listen to the body and slow down to take her own needs into account. Breathing, relaxation, meditation, ordering priorities, appreciating what she has taken for granted, setting limits on one's energy output, asking for help, enjoying interpersonal connections, and finding someone to talk to who understood were some of the ways women in the study came to accept the presence of the pain in their lives.

Listening to the body and learning from the body were recurring themes in the narratives that women associate with having better judgment and trusting themselves. "I've grown a lot stronger. I know my body and I know myself. In terms of my judgment and in terms of who I am

. . . in some ways it's helped me to realize what I'm made of, where my limitations are."

Independence/Dependence

This cluster of themes brings up issues of taking responsibility and altered attitudes toward caregivers. All of the women in the study spoke of having begun their disease trajectory feeling dependent upon the knowledge and expertise of caregivers to "fix" the pain. Over the course of trying treatments and seeking providers who would work with them on their particular set of biophysical circumstances, a number of the women in this study began to take on more responsibility for their own care. "I don't keep getting excited about going to a doctor." Becoming "more educated about doctors," is how one woman put it. "You know much more about your body than they do, and you can provide them with very valuable information they could get no other way, if you pay attention to your own body."

Helping Others

Half of the women in this study remarked about how the experience of living with chronic illness and pain has deepened their compassion for others who suffer, including but not limited to those with chronic vulvar pain. "Admiration for people that endure" has taken on a "different meaning" now for Gina, who finds that she has become "a lot more serious." The pharmacy student spoke of realizing now how it feels to be a patient, the irritability of being in pain, and the positive or negative effects that interactions with a caregiver can have on one's experience. "In the hospital sometimes people forget that the patient is a person." For the acupuncturist:

> I work with people who are ill and have physical issues and emotional, mental issues and I really have a lot of compassion for people who have chronic stuff and are falling between the cracks.

Compassion for others came to include understanding the difficult and frustrating experiences of caregivers dealing with something they don't know about and may not be able to help. "I think chronic illness and pain is very difficult for practitioners. It's easy to burn out and take it all in or push it away and be exhausted by it."

The women in this study spoke of putting efforts into reaching out to help others with chronic vulvar pain. This help included media outreach through writing articles or being interviewed (3 women), participating in support groups (10 women), doing information and referral by telephone (5 women), and participating in this study (16 women). "If it can help one other person avoid what I went through," or "If I had only known I was not alone it would have helped," are typical statements in the narratives.

Women who experienced a personal shift reported perceiving themselves as having become more accepting of the vulvar pain in their lives, better able to listen to their body for cues about self care and treatment decisions, taking more responsibility for their own self states, feeling less dependent upon caregivers to "fix it," and feeling increased compassion that some of the participants put into action helping others.

Of the 10 women in the study who reported this kind of personal development, all were in a significant relationship at the time of the initial interview (although one of these had ended by the follow-up interview); 7 were active in a support group, and 8 were satisfied with their current treatment plan even if they were still in pain. For each of these women the pain symptoms had either improved or remained the same as at onset. The 4 who had started with severe pain had experienced improvement. The women in this study who experienced a personal shift through having vulvar pain were in relationships with others--partners, support group, supportive caregivers and/or using treatments they trusted.

For the 6 women in this study who had not experienced a personal shift, the relational picture is mixed. Half were in relationships, two were in a support group; one of these was in a relationship that was ending, and reported being somewhat satisfied with her treatment and caregiver relationship. Of the 3 single women in this group, 2 reported satisfaction in the relationship with their provider, although none of these women were satisfied with their treatment outcome. One of the women in this group had experienced exacerbation of pain symptoms; 2 rated their pain intensity the same as at onset, and 3 had gone from severe to mild. These connections are illustrated in Table 4.

Summary

Alterations in a woman's functioning, activities, and perspectives due to chronic vulvar pain require her to reassess her abilities, expectations, and plans. This level of analysis drew forth three areas of tension from the narratives: rejecting versus accepting the reality of having the condition, listening to the body versus blocking it out, independence versus dependence, and also the category of helping others.

Table 4 Personal Shift and Related Factors

Personal Shift

AGE	SYMPTOM DURATION	PARTNER	SUPPORT GROUP	TREATMENT SATISFACTION	INITIAL SYMPTOM RATING	CURRENT SYMPTOM RATING	REFERRAL SOURCE
46	7 years	yes	no	yes	mild	mild	Practitioner
44	11 years	yes	yes	yes	mod-->severe	mild	VP Foundation
37	7 years	yes-->no	yes	yes	severe	mild/mod	Practitioner
36	10 years	yes	no	no	moderate	moderate	Practitioner
34	2 years	yes	no	no	moderate	mild	Practitioner
33	14 years	yes	yes	yes	severe	mild/mod	VP Foundation
29	1 year	yes	yes	yes	mod<-->sev	mod<-->sev	VP Foundation
26	1 year	yes	yes	yes	severe	mild	VP Foundation
26	4 years	yes	yes	yes	moderate	mild	VP Foundation
25	6 years	yes	yes	yes	severe	moderate	VP Foundation

No Personal Shift

AGE	SYMPTOM DURATION	PARTNER	SUPPORT GROUP	TREATMENT SATISFACTION	INITIAL SYMPTOM RATING	CURRENT SYMPTOM RATING	REFERRAL SOURCE
65	11 years	no	no	no	severe	moderate	VP Foundation
39	4 years	no	no	no	moderate	moderate	Practitioner
32	5 years	yes-->no	yes	yes	severe	mild	VP Foundation
30	1 year	no	no	no	severe	mild	Practitioner
24	2 years	yes	no	no	mod<-->sev	mod<-->sev	VP Foundation
20	1 year	yes	yes	no	moderate	mod<-->sev	VP Foundation

The uncertain, unpredictable quality of the condition is underlined with the recurrent theme of living a "life on hold." According to the results of this study, having chronic vulvar pain shapes a woman's sense of who she is. Definitions of the self in relation to chronic vulvar pain emerge in examining themes of the meaning of the vulva, issues of gender identity, changes in perspective, and personal development. Results suggest the experience of personal development through having the condition of chronic vulvar pain may be associated with being in a primary relationship, being satisfied with the treatment and/or caregiver relationship, and participating in a support group. This section has addressed each of these areas in turn. Matrix displays of this data are provided in Table 5.

Conclusion: Making Sense of Chronic Vulvar Pain

The reference points of the research questions facilitated analysis of the meaning units of the narrative texts, bringing the key issues and meanings of the narratives into relief. The reference points interwove the mutual interactions of somatic perception, emotions, situation, and self. These key elements served as organizers of the units of meaning in the narrative data.

The element of somatic perception was organized into a category called the physical experience, which encompassed the disease trajectory as seen in the participant profiles, and the meaning of illness as elucidated by participants' descriptions and explanations of chronic vulvar pain. The element of emotions comprised the category called the emotional experience. In this category, clusters of self-states were identified as emotional pain, anger, fear, hope, and pleasure. A further element of questioning one's sanity was also included in this category.

TABLE 5 Relationship Between Personal Shift and the Variables of Relationship, Support Group, and Treatment Satisfaction

Partner Relationship	PERSONAL SHIFT YES	PERSONAL SHIFT NO
YES	10	3
NO	0	3

$X^2 = 6.3 \quad p < .02$

Support Group	PERSONAL SHIFT YES	PERSONAL SHIFT NO
YES	7	2
NO	3	4

$X^2 = 2.05$ N.S.

Satisfaction w/ treatment	PERSONAL SHIFT YES	PERSONAL SHIFT NO
YES	8	1
NO	2	5

$X^2 = 6.11 \quad p < .02$

In the category called the experience of the situation, issues and themes were explored regarding changes in function and activities. Relationships with others were also a part of this category; qualities of these relationships were noted for their interactions with the participants' experience of pain. The final category, the experience of self, illuminated the meaning of the vulva, issues of gender identity, changing perspectives, and personal development.

For purpose of analysis, the themes and issues of a woman's experiences in each of these categories were separated artificially from the ongoing fabric of her illness narrative in order to think carefully about their role in how she makes sense of chronic vulvar pain. In reality, her experiences are integral to her life and her ongoing sense of herself, and there is mutual transaction between each of the categories of her experience as well. Careful analysis of this complex interactive process has resulted in the development of a preliminary conceptual model of the experience of chronic vulvar pain which is presented in the discussion to follow.

Chapter VI - Discussion

This research was conducted to explore how women with chronic vulvar pain make sense of this condition in their lives. One of the presuppositions of the study is that chronic vulvar pain is a significant life event. Another presupposition is that individual illness narratives reflect how people integrate the significant event of a chronic illness experience into "normative conceptions of the body in relation to the self and world" (Kleinman, 1988, p. 13).

The 16 women in this study engaged as co-researchers in the meanings of their lived experience, to provide increased understanding of the psychology of chronic vulvar pain. Through careful analysis of their experiences as related in the narrative interviews, I described and sought to make sense of the patterns of meaning that emerged. These patterns coalesced into a preliminary conceptual model of the experience of chronic vulvar pain.

The review of the findings of this study begins with a description of the interactive model of the experience of chronic vulvar pain. This work is placed within the knowledge bases and contexts of inquiry out of which it grew, which are about chronic vulvar pain, chronic pain, chronic illness, the theory of illness experience, and female development. The discussion addresses the relationship of the current study findings to each of these contexts in turn. Implications of these findings will be considered. Limitations of the study and recommendations for further research are presented following this review.

Self and Other in the Experience of Chronic Vulvar Pain: An Interactive Model

The interactive model of the experience of chronic vulvar pain offers a preliminary conceptual basis from which to understand living with the condition. This model proposes that women with chronic vulvar pain share an experience that can be conceptualized in the following way. A woman's ongoing sense of her self can be seen in a continuous process of negotiation with events that are both "external" relationships with the "other" and "internal" emotional and evaluational states of the self.

When a wearing and pervasive pain which is unexplainable and apparently intractable occurs in the vulva, a woman's sense of her self is diminished in significant ways. The relationship she establishes with the pain is shaped by the meanings she makes of her situation. These meanings emerge within the context of physical, emotional, and relational elements in her life, which are categorized as follows.

The model is conceived with Self (the woman's identity) at the center. The Self interacts with two categories of other. One other is the somatic perception of the pain which is an element of the woman's physical experience. She also interacts with other people in her interpersonal relationships. These interactions with both the perception of pain and with other people lead to changes in self states (emotional and cognitive responses). Self states serve as motivators to action (behaviors), through which Self negotiates with Other (pain or person).

The woman's relationship with the pain involves complex interactions between her feelings and evaluations (Self State), what she does about it (Action), and how she experiences her Self as a result of having this pain. The action may be self-management such as medication or meditation, to change the perception of pain or her self state in relation to it. The action may involve interacting with another person, which may also change the perception of pain or her self state in relation to it. Two examples follow.

A woman (Self) comes home from work with unbearably burning vulvar pain (Pain Other) about which she has feelings--perhaps anger, frustration, loneliness, and self-pity (Self State)--which have some sort of internal dialogue with her ongoing sense of her self (Self). These feelings motivate her to negotiate (Action) with the pain (Pain Other) by applying ice to her vulva. This cools the vulvar tissue, altering the somatic signals (Pain Other), bringing momentary relief, and altering her perception of the pain and her feelings (Self State). In this case the alteration of both is quite temporary, which reminds her of unsatisfying experiences she has had in treatments and relationships with providers (Person Other). When a friend (Person Other) calls to invite her to a movie, her internal response (Self State) may involve feelings of embarrassment, shame, secretiveness, fear of being thought crazy. She wants to hide her disability from her friend. She may also experience some frustration and angry "why me?" feelings because she would like to go to the movie and be with her friend but she knows she can not sit that long. This internal transaction between self state and self motivates her to turn down the invitation without explaining why (Action). This action is a kind of negotiation between her and her friend. She finds herself having feelings (Self State) about this interchange which enhance or further diminish her ongoing sense of herself (Self) as someone who has been dealt an unfair blow by life and just has to resign herself to it and bear it alone.

In another example, the woman has found a practitioner who takes her condition seriously and initiates a diligent investigation in which she is the essential source of information about her vulva, and participates as a responsible decision-maker. Based upon diagnostic evidence, they agree upon a team treatment program to deal with the problem on several levels. She is in an empathic relationship with a partner or friend with whom she exchanges understanding, pleasure, and other forms of emotional supplies. These ongoing interchanges with others enhance the woman's sense of self through positive self state experiences. The actions of self care that she engages in may or may not ease the pain immediately, but her interchanges with these people in her life, as well as her positive evaluation about the treatment, provide encouragement to follow its regimen. The actions feed back into self states which enhance or diminish her sense of self.

When the treatment exacerbates the pain or brings no improvement over time, particularly in situations where the woman is not in mutually supportive relationships, her sense of self may be diminished. This diminishment is associated with rejection of the pain, shutting out signals from the body, dependency upon others to fix it, depleted inner resources, and prolonged hopelessness. When the sense of self is sufficiently enhanced, the woman may undergo a personal shift of meaning and sense of self, which involves acceptance, learning more about herself and her body, having access to inner resources, taking responsibility, and having increased compassion for others.

Mutual interaction occurs between a woman's ongoing core identity and her experience of somatic perceptions, emotional response, and relational situation. Each of these levels of experience--the physical sensing, the self state responses, and the relational interchanges with people in one's life--help shape the woman's sense of who she is. In this ongoing multidirectional process of mutual negotiation, her sense of who she is also shapes her experience with the physical changes of chronic vulvar pain, her affective response, and the contribution of relationships with others. This model elucidates how a woman lives with and how she makes sense of chronic vulvar pain.

A schematic for the model is provided in Figure 1. Mutual transactions occur between each aspect in the model. Adding the temporal dimension the model might be conceived in an upward spiral over time, with Self at the center, shaping and being shaped by ongoing interactive negotiations with Other (pain and person), leading to Self States, leading to Action involving further interaction with either the pain or personal Others (see Figure 2).

The results of this study suggest that relationships which enhance a woman's sense of self worth help her manage the physical and emotional experience of chronic vulvar pain. These experiences occur in a dynamic, interactive manner that is simultaneous and continuous. The woman with chronic vulvar pain makes sense of its presence in her life by engaging in this ongoing process.

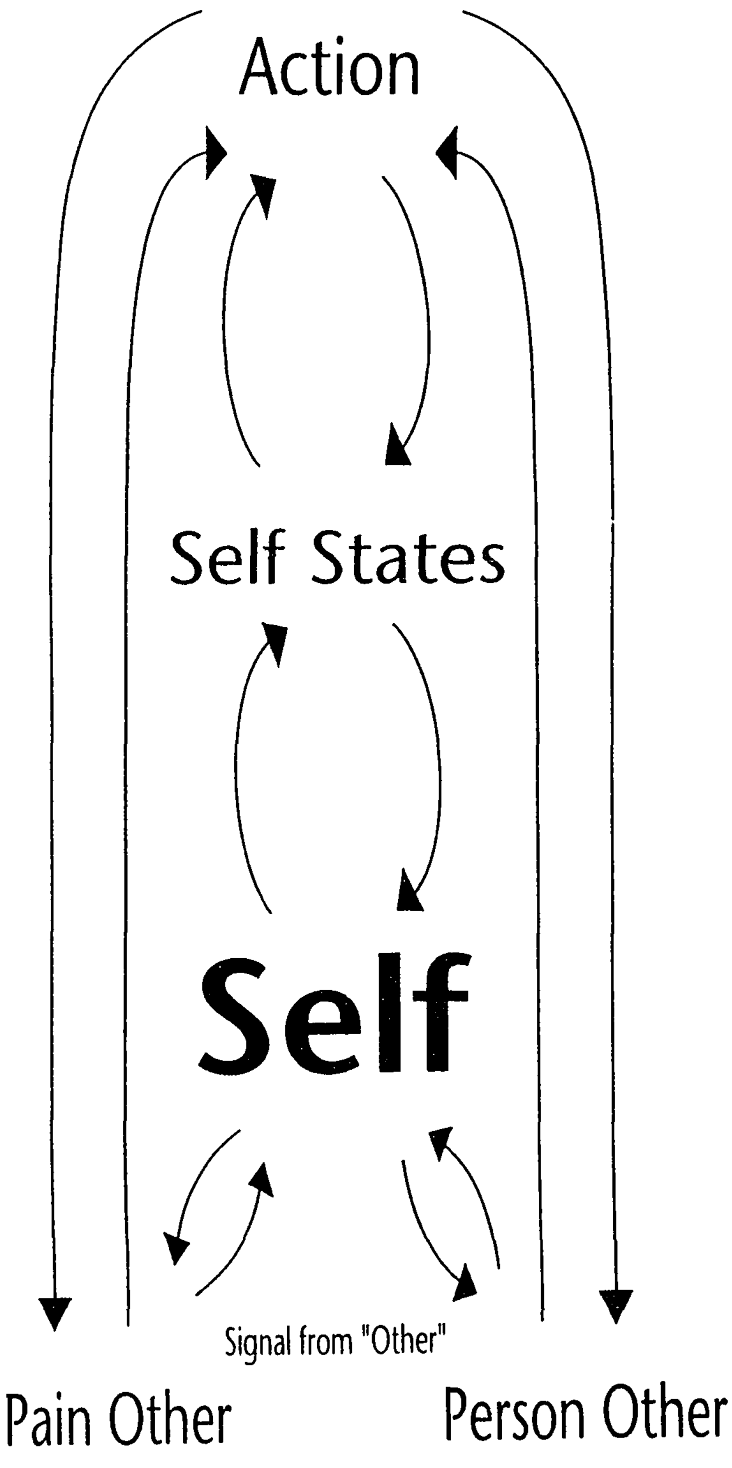

Figure 1. Self and Other in the experience of Chronic Vulvar Pain: An Interactive Model

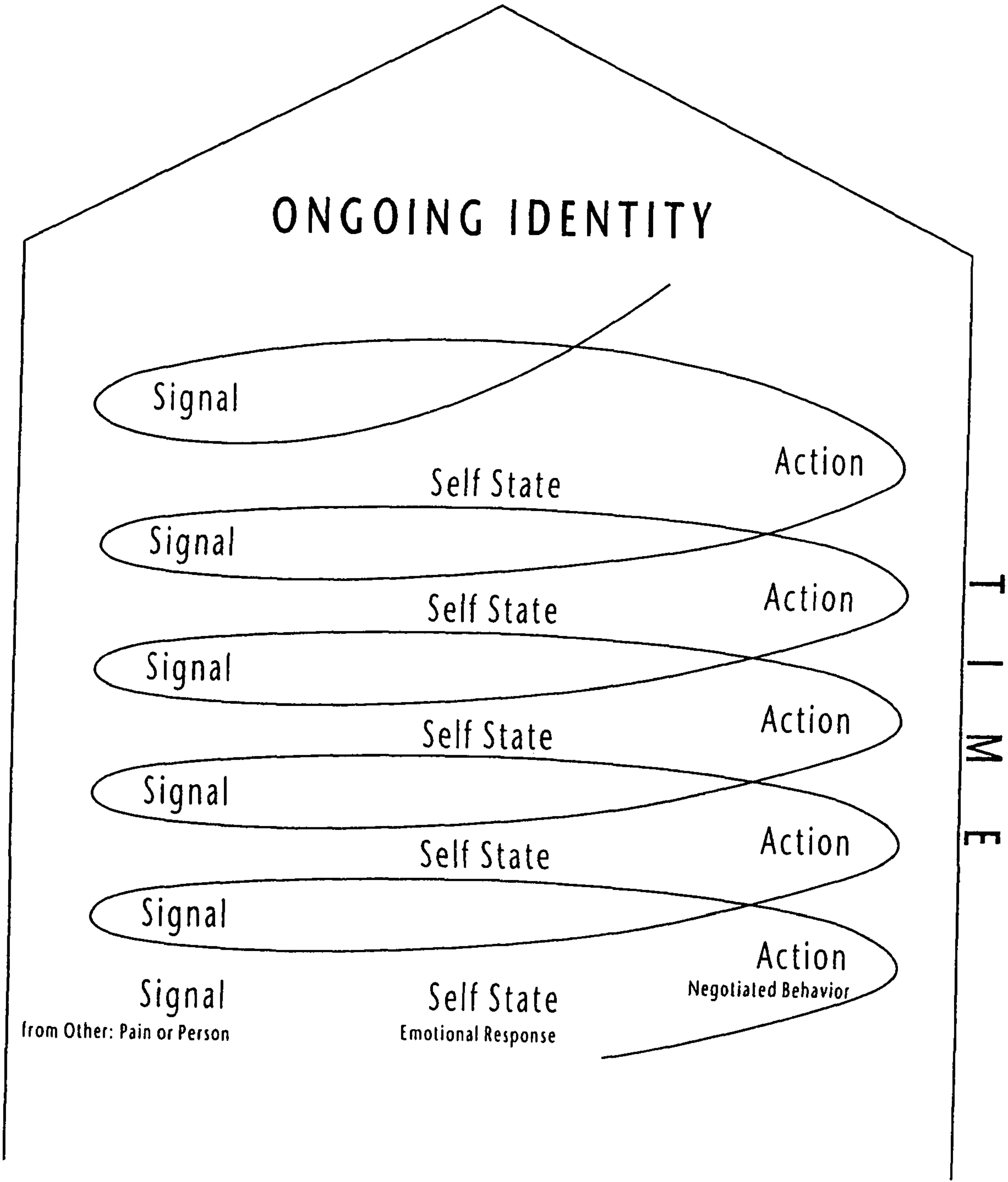

Figure 2. Interaction of self and other in time

Current Findings, Existing Research Studies, and Theoretical Formulations

This work will now be placed within the contexts of inquiry out of which it grew. These are the knowledge bases about chronic vulvar pain, chronic pain, chronic illness, the theory of illness experience and the concept of female development. The discussion addresses the relationship of the current study findings to each of these contexts in turn.

Chronic Vulvar Pain

The following is a discussion of the findings of this study relative to research and theory on vulvar pain, with particular attention to the literature on the experience of living with the condition. Participants in the study were within the range of patient characteristics reported in the literature on chronic vulvar pain with regard to age, race, history of sexual activity, and parity. With regard to etiology, self-reports of some of the participants in the study appear to confirm an association between separate etiologic factors that coexist or develop in a cyclic and/or sequential fashion (McKay, 1989). Symptoms reported reflect the considerable variation of subsets of vulvar pain. Additional factors that the participants in the current study associated with their chronic vulvar pain include urinary tract infections, interstitial cystitis, endometriosis, fibromyalgia, hemorrhoids, and anal fissures. These conditions warrant recognition as potential factors associated with chronic vulvar pain (McKay, 1993).

Findings of this study support the conclusion (Heitler, 1993, 1994; Hiller, 1993; Julian, 1994; McKay, 1992; Schover et al., 1992; Stewart et al., 1990) that the woman's experience of the pain and its impact in her life are key elements in clinical diagnosis and understanding. Any clinical examination of psychosocial issues surrounding chronic vulvar pain needs to begin with a sensitive exploration of its pervasive presence and what that means to the individual.

Current findings add weight to the conclusion that chronic pain can lead to neurotic reactions. The psychosocial dimensions of vulvar pain that emerged in Heitler's (1993) case study are confirmed in the present results: the demoralizing and exhausting effects of chronic pain; the burden of bearing private pain that affects one's self-image as a woman; the anxiety of the unknown; the stress of having practitioners respond to treatment failure by blaming the person and invalidating her experience; potentially severe relational strains with one's partner; isolation from relationships with family, friends, and normal life; the extraordinary need for emotional support; and depression sometimes to the point of suicidal ideation when hope vanished. The current study explores these dimensions within the breadth of 16 cases as presented in the narratives.

The assumption of causal underlying psychopathology (Marin et al., 1995; Woodward, 1981) appears unwarranted in most cases (McKay, 1992, Heitler, 1993; Stewart et al., 1990; Stewart at al, 1994). For example, an earlier study (Woodward, et al., 1981) identified four major factors in patients with vulvovaginitis: conflict with parents which were experienced as the patients' feeling diminished as people; anger/

resentment towards male partner; marked feelings of nervousness, sexual inadequacy, and depression; and reaction to a current situation. These findings will be reviewed in light of the current study.

Parental conflict was mentioned in two of the narratives in the current study, and another participant referred to an unhappy childhood. Aside from these descriptions, relationships with parents were presented in the context of relative support. In this respect, although it must be acknowledged that the current study did not involve clinical assessment, conflict with parents was not a strong theme in the experience of women as related in their narratives. While it is possible that feeling diminished in interchanges with caregivers may be associated with relational expectancies forged in early life experience--and this possibility warrants further examination--the issue did not emerge in the data and was not addressed in the inquiry.

The other three issues that Woodward (1981) identified do emerge in the current study. For instance, the women in fragile or previously stressed relationships were frank about intimacy or communications problems that had been exacerbated by the presence of the pain. Several women--some of them in strong relationships--expressed having experienced resentment towards their partners, often within the context of providing and receiving sexual satisfaction. Strained relationships and emotional distance, as also reported by Crenshaw et al. (1985), did appear as a relational consequence of the pain for many participants in the current study, and as one aspect of the emotional challenge presented by the pain. Feelings of sexual inadequacy were often reported, almost always as a consequence of decreased function. Of the 16 participants, two indicated premorbid sexual difficulties--one primary vaginismus, and one possible tension due to fear of risk. One woman also reported lifetime anorgasmia, which did not diminish sexual enjoyment and "may represent a normal variant of female sexuality, at least for some women" (Kaplan, 1974, p. 374; see also Kitzinger, 1983).

Vaginismus, or chronic constriction of the pelvic floor musculature as an expression of sexual or genital anxiety, exists in women along a continuum from characterological (Reich, 1961) to situational (Kaplan, 1974; Kitzinger, 1983). Some of the women in this study appear to have developed vaginismus as a conditioned response to painful touch or penetration of hypersensitive or irritated genital tissue (Abramov et al, 1994); Sarazin & Saymour, 1991. The study reported by Marin et al. (1995) found, in addition to fear and muscular contraction, that many women with vulvar pain did not understand their own sexual response processes, or ignored them within the demands of the marriage. This led to uninformed or damaging sexual practices such as permitting penile penetration without prior arousal and lubrication, which could create or contribute to vulvar pain. Marin also found pathogenically excessive hygiene practices in her sample of vestibulitis patients; this finding was not confirmed in the current study. Instances of vaginismus and poor self-knowledge about sexual function do occur in the narratives of the present study, although not with the frequency reported by Marin. These findings indicate the need for information, genital awareness, couples counseling, and muscle re-education in some women with chronic vulvar pain. Long-term depth psychotherapy is indicated for those who seek characterological change.

Depression, anxiety, and reaction to the current situation emerge from the narratives as appropriate, if troubling, patterns of response to the condition of chronic vulvar pain (Stewart, et al., 1994). Issues of parental conflict resulting in feelings of diminishment, anger and/or resentment towards partner, nervousness, sexual inadequacy, and depression may express pre-existing personality or coping styles that influence the individual's trajectories of disease, illness, and sickness in chronic vulvar pain.

The assumption of these factors as indications of pathogenesis may reflect a treatment bias that limits effective therapeutic response to a condition that has a pervasive impact on the whole life of the person (Crenshaw et al., 1985; Heitler, 1993; Jadresic, Barton, Neill, Staughton, & Marwood, 1993; McKay, 1992; Meana & Binik, 1994; Stewart et al., 1994). It is useful to consider that painful emotional issues tend to emerge when people are hurting. Their presence may be an indication of the psychological processes that the pain brings into play (Crook, 1982). Whatever the dynamics in a given case between reactive and endogenous self-states, the interactive model provides a framework for understanding that the process is multidetermined and occurs with mutuality, contingency, and reciprocity among the relevant levels. Because vulvar pain appears to represent a dynamic interaction between pathophysiologic and psychosocial factors, a comprehensive treatment approach is beneficial (Schover et al., 1992).

Chronic Pain

The current study explored experiences of somatic perception and evaluation, emotional response, identity, and situation. In part this design was based upon research trends in the chronic pain literature which highlight these factors. The data obtained support the development of a preliminary conceptual model with which to begin to understand and integrate the interaction between these factors.

In the section above on chronic vulvar pain, the assumption of "underlying psychopathology" was discussed. Much work has been devoted in the field of pain research to identifying underlying factors (Bewutler, Engle, Oro'-Beutler & Daltrup, 1986; Roy & Tunks, 1982; Smith & Duerksen, 1980; Sternbach, 1974; Timmermans & Sternbach, 1974; Violon, 1973, 1982). This traditional approach to psychological assessment of chronic pain patients identifies affects such as dependence, loss, guilt, and suffering as markers of psychogenicity. While the current findings suggest that emotional issues such as these do emerge when the participants are in pain, the etiologic assumption that such personality issues "cause" the pain is unwarranted. As explicated above, the possibility that people regress under the wearing ongoing stress of chronic pain is equally plausible.

Affect is part of the pain experience. As the participants in this study talk about their emotional responses, it is apparent that these self states arise not only in response to the pain itself but also to its presence as a pervasive "other" in their lives. The self state most frequently evoked in response to the preoccupying presence of physical pain was the cluster of feelings labeled Emotional Pain. This cluster includes reports and descriptions of depression in many forms: sadness, isolation, guilt, deflation/feeling worn down, giving up/defeat, loss, hopelessness, self-pity, disappointment, discouragement, despair, and suicidality. Chronic vulvar pain appears to be a risk factor for depression in women (McGrath, Keita, Strickland & Russo, 1990).

In considering the changes in emotional response and the psychological effects of pain when it becomes chronic, Beutler and colleagues (1986), Nerenz and Leventhal (1983) and Sternbach (1984) noted that almost all psychological studies of chronic pain identified mild but significant depression as one of its features. Crook (1982) found that the threat of relational losses to role identity produced anxiety and guilt in women with chronic pain. The findings of the current study concur. Reactive depression may be acknowledged or it may be masked by preoccupation with symptoms. These data also suggest that hyperactivity ("throwing myself into my work") may occur as a behavioral response to the pain. Whether hyperactivity is a form of "masked depression" or a defense against health anxiety awaits further investigation.

According to the cognitive-behavioral transactional model developed by Turk, Kerns, Rudy, and their associates (Kerns & Jacob, 1992; Kerns et al., 1985; Turk & Rudy, 1986) pain is a dynamic, perceptual-interpretive phenomenon that occurs on several dimensions of experience. Participants in the current study provided clear illustrations of this complex process of sensory phenomena in transaction with cognitive and emotional factors and behavioral responses.

Dimensions of pain belief within an overall biopsychosocial assessment of chronic pain are consistent with the results of the current study. When beliefs are defined as pre-existing expectations "about the nature of reality which mold our perception of ourselves and our environment and shape its meaning" (DeGood & Shutty, 1992, p. 215), the pain beliefs and attitudes literature provides useful ways of considering the data on the meaning of chronic vulvar pain. An integration of contrasting dimensions of pain beliefs can be applied usefully to the data of the narratives (DeGood & Shutty, 1992) of the current study. The dimensions of pain beliefs in this approach cover four areas: the etiology of pain, diagnostic expectations, treatment expectations, and outcome goals.

Examination of the variables of these dimensions of pain belief may shed further light on phenomena reported in the current results. On the dimension of etiology of pain, the variables are belief in somatic cause versus interaction of multiple factors; external versus internal causes; someone to blame versus unfortunate chance; and pain as symptom versus benign. Diagnostic expectations regarding history taking, clinical exams, laboratory tests, and psychosocial evaluation represent another dimension of patient beliefs regarding pain. The third dimension, treatment expectations, covers patient belief variables of being passive versus active; invasive versus noninvasive treatments; fix/ repair versus rehabilitation; and somatic/medical versus psychological/ behavioral treatment expectations. Beliefs about outcome goals comprise variables of cure versus relief; rapid versus gradual change; complete versus partial freedom from pain; and sensory change only versus quality of life change.

Several of these variables emerged in the narratives of the current study and are relevant to the finding regarding the issue of personal shift. Women in the study who experienced a positive change relative to the experience of vulvar pain in their lives developed attitudinal shifts along the dimensions of beliefs regarding the etiology of the pain, expectations of diagnosis and treatment, and their outcome goals. Women who had not experienced a personal shift with regard to having chronic vulvar pain tended to cling to somatic, external, and blaming configurations about the cause of the pain. They tended toward passive, fix/repair treatment expectations, with outcome goals of rapid, complete cure. Undergoing a personal shift involved being able to alter one's beliefs regarding the pain, to reflect the contrasting aspect of each of these variables.

This approach to contrasting dimensions of belief does not address the dynamic interaction between these belief dimensions and emotional and relational factors, issues of sexuality and gender, changes in perspective, or the shaping of self. These issues were salient in the current study. DeGood and Shutty (1992) also created an etiologic model which suggests the dynamic variables to evaluate in assessing chronic pain patients for clinical focus and intervention.

This model combines independent variables of somatic events, personality template, and environment in complex interactions with intervening variables of cognitions and affects over time. These complex interactions affect the dependent variables of the sensations and behaviors of chronic pain. This etiologic model takes the dynamic interaction of emotional and personality variables into account, insofar as they have an impact on the experience of pain.

The assumption that the environmental factor is limited to "socio/economic consequences" of pain, however, excludes consideration of relational interactions which shape and are shaped by the condition of chronic pain and its meaning to the people involved. It may be reasonable to assume that the issue of identity central to the current findings could be subsumed under the variable "personality template" and thus addressed by DeGood and Shutty's model. That the pain experience, or any of the intervening or the other independent variables, might lead to personal change or might affect identity development is not addressed. Essentially, the linear cause-effect direction of this model is not congruent with the reciprocal interactive dynamic that emerged from the current work with vulvar pain.

The dimensions of belief approach can contribute to the current study in conceptualizing the range of pain beliefs from "basic philosophical assumptions about the nature of the self and the world" (p. 216) to the generalized beliefs of personality traits, to beliefs regarding the specific pain condition and its treatment. Categorizing beliefs from the general to the specific may be a useful way for clinicians to think about the meanings women make about chronic vulvar pain, particularly when developing a treatment plan with them that takes meaning into account. The authors suggest that cognitive variables may offer "a more direct entry point to working with a patient than are the more primary psychosocial variables" (DeGood & Shutty, 1992, p. 217).

Similarly, their conceptualization implies that specific beliefs may be easier to address and alter than underlying philosophical assumptions.

Chronic Illness Experience Research

Research results have value when the work of different researchers can be found to agree on common meanings (Viney, 1983). A review of the current findings will be considered in light of relevant theory from the illness experience research which guided this study (Viney, 1983; Robinson, 1990). A study on the experience of serious illness and injury from accident explored what its author termed the images of illness (Viney, 1983). This point of focus appears to be very similar to the meanings which women with vulvar pain constructed through the interaction between self and other. Viney's findings complement the interactive model of the experience of chronic vulvar pain.

Analysis of the narratives of the present study evolved into what was termed categories, and the ensuing model was organized to acknowledge the central roles played by relationship and action in ongoing interaction with self. Viney's focus on image as the generator of feelings and source of behavior at first glance appears to differ from the interactive model which places identity at the center interacting with pain, other people, self states, and action. Viney's use of the term image has bearing on the nature of the interactions between elements in the model of the experience of chronic vulvar pain, and further illuminates the process of meaning that the self constructs through these interactions. Images also refer to self, insofar as "the images people build up to represent themselves determine how they act" (p. 63).

Where the illness image work found six types of predominantly distressing images--uncertainty, anxiety, anger, helplessness, depression, and isolation--the current work identified three clusters of predominantly negative self states as emotional pain, anger, and fear. The more pleasant images of illness were happiness and humor, competence and control, and support and friendship, in Viney's study. The current study identified positive self states of hope and pleasure. Consideration of the themes and issues of the self states and a content analysis of the images indicates that similar issues and themes, or phenomena, were reported in both studies.

Viney identified her work on the images of illness as a psychology of illness rather than as a model. Her approach to understanding the illness experience is comprehensive, based as it was on a large population (n=576) of men and women hospitalized or bedridden with a variety of illnesses and injuries. Although the construction of experience is unique to the individual, particular illnesses can lead to the construction of common images, Viney argued, because they "decrease the likelihood of certain events occurring and increase the likelihood of others" (p. 3). Her conclusion that the search for common images in specific kinds of illness is worthwhile is consistent with the goals of this study on making sense of the experience of chronic vulvar pain.

The current study provides a rich sample of the common meanings made by women who share a particular illness experience. In particular, these findings indicate ways in which women with chronic vulvar pain "reformulate the meanings of their affected body part . . . deal with changes in their body image . . . and find meaning in their new lifestyle" (Viney, 1983, p. 22). Although the illness image patterns seem generally to run true with the narrative themes of the current study, some differences do emerge.

One difference in the findings of the two studies is that none of the patients in the illness image research used an image of supportive teamwork with the provider working towards the common goal of better health. That this theme did arise in the current work is plausibly attributable to difference between the samples. Men and women hospitalized for serious illness or injury in Australia in the 1980s and U.S. 1990s female seekers of outpatient care for a different disease no doubt experience divergent critical variables in their lives, including social expectations about the illness and physical contexts.

One of the differences between the samples is that the people in the Viney study had a clearly definable diagnosis, whereas the diagnoses for vulvar pain syndrome may be ambiguous or provisional. This would lead to different expectations about the illness. Relationships with, and appreciation for, medical personnel might also be affected in different ways.

Likewise, while the theme of mutually rewarding intimacy with partners emerged in a number of the narratives in the current study, there were few images that included oneself in expression of satisfaction, appreciation, and affection in a relationship in the illness image study. Again, it would seem that both the relative severity of the medical conditions of the Australian sample, as well as particular aspects specific to the condition of chronic vulvar pain, contribute to this difference. Because of the genital locus of the pain, there may be differences in impact of this illness on women's relationships with significant others.

The discussion of current results in light of the literature on illness experience now draws upon Robinson's (1990) conceptual framework, which integrated contributions from several authors cited earlier in the review of the literature (Bury, 1982; Charmaz, 1983; Denzin, 1989a, 1989b; Glaser & Strauss, 1967; Gergen & Gergen, 1983; Goffman, 1968, 1969; Mechanic, 1981, 1986; Strauss, 1986, 1990). The model of the interactive experience of chronic vulvar pain is consistent with this integration of personal narratives, social careers, and medical courses, which elaborates "some ideas about the relationship between biomedical, social and individual aspects of disease, sickness and illness" (Robinson, 1990, p. 1185). Robinson suggested that the medical status of disease, the social status-of-health level of sickness, and the personal health status of illness are all distinct and equivalent negative health status attributions.

In speaking about changes in function and activity, the participants in the current study addressed numerous issues of deficit. This "imputed negative change in health status" (Robinson, 1990, p. 1174) occurs on the level of the physical course of the disease. On this level of somatic perception, the focus of the account is on occurrences of medical diagnosis, prognosis, and treatment. For participants in the experience of vulvar pain study, the terms of personal meaning on this level centered around issues and themes of impairment on the level of body, self state, and self.

When the imputed negative change in health status is experienced as a handicap, the corresponding designation of health status is sickness, the trajectory of which is described in terms of social career. The focus of the account on this level of the narrative is the social status of stigma conferred by the presence of chronic vulvar pain.

This social perception may be seen in the participants' expressions of the stigma of handicap. Examples of physical handicap abound, and center around the most basic life activities and functions. Participants also explored issues of feeling emotionally handicapped in terms of expressiveness and frustration, for instance with physicians upon whom they felt dependent, or in terms of sexual desire that could not be satisfied. Handicapped social identity, or stigma, emerged in the sense several participants articulated that chronic vulvar pain made them feel neutered or as though they were "less than" women. Another significant level of stigma is inherent in the socially taboo location of the handicap.

The example of feeling neutered also illustrates one of the ways in which participants expressed a sense of loss about many aspects of themselves and their expectations, relative to chronic vulvar pain in their lives. These imputed negative changes in health status occur on the level of self perception, in which the focus of the account is personal life goals. The illness work with a sense of loss is to deal with issues of bereavement. Experience on this level is considered the illness trajectory.

Robinson pointed out that the physical course of disease and the social careers of sickness have been more extensively investigated and mapped than has the structure and content of personal narratives of illness. In the current examination of the content of personal narratives of chronic vulvar pain a parallel prioritizing was observed, in the following way. Generally speaking, the woman's first account tended to be along the lines of the physical disease course. This "first round" of the story had the impersonal cast of an "outsider's" view, interlaced by different participants with varying references to a more personal story.

Once the "official" story had been told, as we sat with it, each of the participants in the study would begin to circle in closer to a more personal perspective on the social and relational issues that came up for her in having the condition. The more private, "experience-near," and sometimes emotionally charged information about self perceptions and relational intimacy tended to emerge in the last half of the interview, perhaps as the participant and I relaxed into it and she sensed my continued interest in what the experience was like for her. "To a large degree the first two trajectories can only be understood in the context of that provided by a recognition of the role of personal narratives" (Robinson, 1990, p. 1185).

As the narratives also showed, the perspectives focusing on ideas of disease, sickness, and illness are complexly interwoven and at times either, in Robinson's words, "profoundly discrepant" from one another or "so closely congruent at some temporal points that it is difficult to analytically separate accounts which interweave the personal, the social, and the biomedical" (Robinson, 1990, p. 1174). Here is an example of convergence. Megan flew to California for an emergency consultation with a vulvar specialist who diagnosed her vestibulitis and began a treatment program that made sense to her and to which her body responded positively. The diagnosis and treatment legitimized the social status of a mysterious and debilitating handicap, and helped her reconstruct her personal sense of the meaning of her life.

The narratives of this study are replete with examples of discrepancies between the three trajectories. Chronic vulvar pain has an unpredictable medical course and may present few or no signs to match the intensity of the symptoms. The outcome of interpersonal negotiations with significant others in the woman's life about the designation of sickness and its social implications may diverge considerably from her experience of her body and self states. When the trajectories of the various levels do not converge, the woman must work to develop a sense of congruence, and to create a coherent story of her personal life goals that plausibly takes these variances into account. Adding changing perceptions of illness experience and meaning, multiple social roles and designations, and medical complications from harmful or failed treatments or other biomedical conditions increases the complexity of the mixture of these levels of health experience.

The narratives of women with chronic vulvar pain can be analyzed around a framework of coherence and moving toward or away from valued personal goals (Gergen & Gergen, 1983). "The key is that all elements in the narrative relate to the valued goal state (coherence), and the time frame in moving towards or away from the goal state (directionality)" (Robinson, 1990, p. 1176). In this sense, the 10 women in the study whose stories included a personal shift have re-established a sense of progressive narrative. This shift into new congruence of self may be accomplished through improvement in the pain symptoms, but it also may be achieved through a negotiation with the pain, self-states, significant others in the relational situation, that alters or expands life goals to include the presence of chronic vulvar pain in one's life. The directional slope of the six narratives in which this sense of personal development was absent may be seen as regressing away from the valued identity goal.

The findings of this study of the experience of chronic vulvar pain concur with Robinson's integrative conceptual framework and augment it by additionally emphasizing the dynamic interactive nature of the levels. This emphasis points to potential implications for treatment and change. Because the sense one makes of one's illness is fluid and constantly being negotiated on multiple levels, it is amenable to both positive and negative input.

Female Development

Thus far we have considered the findings of this study within the contexts of research in chronic vulvar pain, chronic pain, and illness experience. While the experience of chronic vulvar pain seems to share many features with other kinds of chronic illness and pain experience, the meanings of the vulva for the woman's gender roles and identity make this a unique kind of pain in many ways as well, and of particularly sensitive significance to the woman who has it. Psychologists and other practitioners working with chronic pain must consider the "broad domain of psychosocial factors" in order to understand the individual experience and "to identify multiple targets for intervention in a comprehensive pain treatment and rehabilitation program" (Kerns & Jacob, 1992, p. 235). In the diligent treatment of chronic vulvar pain, this broad domain necessarily includes the unique and distinguishing aspects of this condition.

Women in this study spoke of having lost a sense of themselves as women, as feminine, or as gendered beings. Since gender identity is established very early in life, by 16-18 months of age, to feel neutered and no longer female, the identity loss occasioned by chronic vulvar pain can be tremendous. That such a loss constitutes a crisis in identity presents another way to understand how a woman with chronic vulvar pain makes meaning of it as part of the story of her life. The findings relate to the work of Notman et al. (1986) on female developmental crises involving body awareness, emotional organization, affective ties, and ongoing identity formation.

The interactive model of self and other in the experience of chronic vulvar pain that emerged from the narratives of this study is consistent with and illustrates this conception of psychological organization in adult female development. The crisis of chronic vulvar pain disrupts expectable identity goals of female adulthood. Relational experiences with caregivers may contribute to this crisis or help the woman work through it.

As the women in this study tell us, the complex realities of chronic vulvar pain render them unusually vulnerable to further traumatization within the context of treatment. When treatment proves harmful or ineffective, or when the provider is insensitive to the lived experience of pain and the meanings of this particular pain in her life, the woman's sense of self may be diminished in ways that contribute to the treatment outcome. Feeling discounted and misunderstood may motivate a woman to reject the pain and to shut out signals from the body. Further depleted of inner resources and disconnected from herself, she may engage in practices which maintain the symptoms, such as unlubricated intercourse, excessive cleaning, the use of irritating medications, or submitting to harmful procedures. Dismissive or infantilizing caregiver behavior and hopeless, dependent patient behavior reinforce each other.

As Apfel and Fisher (1982) said of the DES experience, it is "impossible to understand . . . without a deep appreciation of the complex nature of the patient-doctor relationship" (p. 85). The same can be said of chronic vulvar pain. Issues about women and medicine emerge from the narratives in patterns of crossed communications, divergent expect-ations, and shared "cultural uneasiness about female sexuality" (Meana & Binik, 1994, p. 271). As lived phenomena, these issues can contribute to the developmental crisis posed by chronic vulvar pain.

"Medical values help construct people's experience of their own bodies and those of others with whom they interact" (Sherwin, 1992). The role of patient in submitting to authority and having to respond gratefully for attention has the potential to increase the burden of helplessness and vulnerability posed by vulvar pain. The litany of disappointments at the hands of medical practitioners represented in the narratives of this study reflects cultural values of women as "weak, irrational, inadequate, and deceptive" (Sherwin, 1992, p. 197) and a subtextual assumption that female genital pain is either normal and expectable or the product of her personality or her fear of sex. The participants' search for respect and validation of their complaints, and the tendency of many practitioners to dismiss these complaints or to solve the problem by removing the damaged part (Apfel & Fisher, 1984) can be seen in this broader cultural context.

Shared societal assumptions about the vulva and women's sexuality (Kitzinger, 1983) also come into relief in considering the findings of this study. The unknowable, disowned, and devalued aspects of female genitalia are reflected in the images and words women use for this part of themselves, raising the question of whether the vulva itself--and not only vulvar pain--might be considered an "other" in many women's experience of themselves. Several women in the study pointed out the cultural emphasis on sexual function. However saturated the media and popular culture may be with images of romance and sexuality, overt and positive symbols for the vulva are excluded from this imagery (Friedrich, 1976).

The mystery and shame of a taboo and nameless body part, and unexamined assumptions and meanings that do not come to light about it, contribute to misinformation about one's own basic sexual functioning and genital health. The cultural-personal lack of recognition and esteem for the vulva is a reflection of women not loving themselves or trusting their own authority. This study shows that the developmental crisis of chronic vulvar pain can also offer the opportunity to reconstruct a progressive life narrative. Some of the women in the study find themselves on a journey of self-discovery and self-acceptance, impelled by chronic vulvar pain.

Positive, empathic, respectful relationships in the chronic vulvar pain narratives seem to be associated with integrating the disruption of illness in a shift into new congruence of self. The results of this study suggest that a positive caregiver relationship may contribute in significant ways to the woman's acceptance of chronic vulvar pain in her life, her ability to listen to her body for cues about self care and treatment decisions, her taking more responsibility for her own self states, and her feeling less dependent upon caregivers to "fix it."

The issue of unexamined assumptions about women's needs in the medical system emerges as a theme in the chronic vulvar pain narratives. The findings suggest that as women with this condition become more aware of their own needs within their social system, their role relationships, and their identity goals, they are better able to find ways to meet these needs.

"Women suffering from chronic pain face different personal, social, and cultural adjustments than do men with chronic pain" (Crook, 1982, p. 69). The narratives of this study suggest, among other things, that we learn who we are, and we become ourselves, through the specifics of our interrelationships with others. In this way, women's attitudes about their vulvas are shaped by their interactions with caregivers and intimate others. These interactions will be enhanced through increased understanding, and thoughtful and articulate regard for the vulva.

Limitations of the Study

Due to the underlying constructivist assumption of this study that meaning is ambiguous and emergent, it follows that the illness narratives of the participants in this study are neither definitive nor fixed. To be able to check back with them for repeated follow-up interviews over time would establish more consistency than was possible in two interviews.

Reports of high levels of physical and sexual abuse in chronic pain populations, particularly among women (Domino & Haber, 1987; Drossman et al., 1990; Haber & Roos, 1985), were not substantiated in the current study. One woman reported having been raped, one alluded to a painful childhood, and two discussed traumatic gynecological and/or sexual histories. Given the locus of the pain, that abuse did not appear more frequently in the narratives must be considered as negative evidence (Neuman, 1990). Implicit questions arise. Is a sample of women willing to discuss their stories of vulvar pain less likely to have been abused than others with the condition? Did abuse events occur in more of these women's lives? Were women not currently aware of them having occurred? Did women with abusive histories wish to conceal their occurrence? Were these events so commonplace as to have been overlooked? Did the researcher's preconceived notions prevent her from looking for this relevant data? Is the experience of sexual and physical abuse so common in this society that it fails to differentiate between patient populations? Issues of physical and sexual abuse, when present, could contribute significantly to the meaning of chronic vulvar pain in the individual's experience, and would need to be assessed within the clinical context of a comprehensive treatment program.

Qualitative research does not attempt to form generalizations. The goal of qualitative research is transferability of working concepts.

Therefore, the findings of this study are to be considered in the context of transferability, not generalizability. Transferability depends upon the sending and receiving contexts. In order to propose that the results of the current study might be applicable to another context, the similarities of the contexts would need careful consideration.

Experience of Participating in the Study

In terms of the value of participating in this research, all participants reported that being interviewed gave them the opportunity to express difficult emotions and to deal with painful issues, and that participating in the research helped them feel validated in their experience of living with this illness. This concurs with the literature that suggests that both assessing the meaning of one's illness experience (Kleinman, 1988) and telling one's story (Belenky et al., 1986; Mishler, 1986) can prove to be valuable. One participant reported that speaking with me at length about her vulvar pain was upsetting in reminding her of the hopelessness of her situation. She was able to reconstitute by the end of the interview, and reported that the experience had alerted her to the need to work with her psychotherapist again. In the follow-up interview she expressed the opinion that she had found the process of being in the study useful, in that she had not realized that vulvar pain is something she has in common with so many other women. She planned to connect with a support group, which she thought would be helpful.

Experience of the Researcher

In this attempt to expand understanding about the lived phenomenon of chronic vulvar pain, I necessarily drew upon my own personal and professional experiences. As a woman speaking with other women about very private aspects of their lives, I was often moved by their experiences and touched by their willingness to disclose intimate details about themselves for this research project. At times I very much wanted to believe in some basic difference between me and the women in this study that would guarantee my ineligibility for such a devastating life event as chronic vulvar pain. I could find no such assurance, and this was threatening. I identified both with the participants and with providers who may develop an everyday callousness to suffering, as a way to separate and protect themselves from its fearful possibilities, in order to tolerate working with it. As this study shows, the condition of chronic vulvar pain presents extraordinary and complex challenges to the provider of medical care.

Empathy is feeling with. The attempt to create an empathic context in which the participant felt safe and understood meant identifying with her experience in ways that left me with strong feelings to deal with after each interview. I took on some sense of the trauma and disruption in each woman's narrative, first in exploring her story with her, and then repeatedly, throughout the process of immersion in the data and analysis. These personal reactions became part of the data of the research process--as did those of the transcriber, who also reported feeling sometimes strongly affected by the stories in the process of transcribing them.

One of the lessons of these narratives is that people find strength to deal with their lives if they feel heard and if they know that somebody cares about their experience. Another lesson is that listening carefully to the story of a woman's actual personal experience will help caregivers respond with the sensitivity that the situation requires. I hold the participants in this study in high regard for what they have been through in their lives, and I very much appreciate their willingness to explore their experiences to add to the knowledge base about chronic vulvar pain.

Implications for Further Research

The study of the meaning of an illness experience presents a new approach to the investigation and understanding of chronic illness and the subsequent development of appropriate treatment. Such a study also provides the opportunity to conceptualize living with chronic illness as an opportunity for positive change and personal growth. This study explores the experience of those who live with a chronic illness. The findings of this study support the development of an interactive model of the experience of chronic vulvar pain. These results, although complete in and of themselves, can be further considered as a stepping-stone for continued research both in the area of chronic vulvar pain and in the field of chronic illness.

Although the relevance of examining specific diagnosis versus chronic illness as a unified category is currently debated within the fields of health psychology and medicine, recent literature repeatedly indicates that the chronically ill share many social and psychological problems (Bury, 1982; DeGood & Shutty, 1992; Kerns & Jacob, 1992). Chronic vulvar pain is a chronic illness. Application of the results of this study to research in other chronic illnesses may, therefore, be appropriate. Medical procedures, illness symptoms, and socio-cultural attitudes and assumptions may vary according to a specific illness; however, the similarities in the experience of living with a chronic illness may suggest that other chronic illnesses, or the general category, could be conceptualized in a manner similar to that suggested by this study.

On the other hand, the unique features of this particular chronic pain warrant further investigation. This study of the experience of chronic vulvar pain suggests several important areas of knowledge to explore. Further study of the prevalence, demographics, and natural history of chronic vulvar pain would provide a more complete picture of its societal influence and possible causes and preventability (Aakster, 1989). Based upon what is known about chronic vulvar pain, there is a clear need for controlled clinical trials specific to accurate diagnosis of the subsets of vulvodynia, based upon treatments that have been successful with each subset. Further outcome studies are necessary, utilizing a multimodal treatment approach which includes the provision of psychological exploration of psychosocial variables and appropriate intervention. In addition, the current findings suggest the need for further research on the relationship between caregiver and female patient, and on the role of relationships and self esteem in chronic vulvar pain.

> When ill persons receive positive reflections of self in interaction and take them as credible and real, they are more apt to regard themselves positively. But when demeaned and discredited by those to whom they attach significance--even during the briefest of interactions--then maintaining a positive self-image becomes problematic. (Charmaz, 1983, p. 181)

Gina, one of the participants in this study, explained this phenomenon in terms of the lived experience of chronic vulvar pain:

> For me it was probably one of the most difficult parts. It was extremely frustrating, and it makes me so angry because it affected my self esteem. I didn't feel, lots of times, like I was being heard. I felt that a lot of things that exacerbated my condition were because, to some extent, of poor treatment. Some doctors, in good faith, tried to do something to help, I understand that. But at other times I felt like I was just being dismissed. And I felt like I was just being told I was imagining this, that my sanity was in question. I went to at least a dozen doctors ranging from internists to gynecologists to proctology, everything, and each time you go you have hopes and they just get dashed. There was one, the first thing they started mentioning was sexual abuse and I can understand that that is something that has to be looked at. Well, I reiterated that it wasn't the case. The question was asked four or five times and I'm getting to the point where I feel like they're not believing me and I know what I have isn't that. And this one particular doctor mentioned that I was just afraid of sex. I didn't need that. I think if doctors knew this condition, women could get the treatment that they need and wouldn't develop secondary problems, because many doctors don't know what they are doing. For example, that antibiotics and cortisone bring yeast infections, which along with the yeast medications erode your tissue, and now you've got more problems. It's this vicious cycle that you don't feel you can get out of. Plus, you don't feel like anybody is recognizing the emotional part of what you're going through. It's like 'Oh you're just this crazy woman who's depressed, or, you know, paranoid about that part of your body.' When all I am was a person who was feeling pain who had this condition and of course I'm going to be upset about it.

The conceptual model presented provides a base from which to conduct further qualitative and quantitative studies. The next logical step would be a larger study of women with chronic vulvar pain operationalizing the factors that emerged from this study, and examining relationships between the variables.

Implications of the Study for Professional Practice

This study indicates the need for practitioners to be sensitive to psychosocial issues in the treatment of chronic vulvar pain. Findings also highlight that practitioners dealing with the condition understand the differences in the mechanisms of acute and chronic pain which may be relevant to effective symptom management and the mobilization of resources to advantage.

Psychosocial issues are fundamental to the sensitive diagnosis and treatment of chronic vulvar pain. Specifically, clinicians need to examine their own attitudes, biases, and values regarding gender, and the impact of these factors on the assessment and treatment of women with chronic vulvar pain. The relationships between caregivers and women with chronic vulvar pain will also work to better advantage through the exploration and appreciation of the meaning of the condition has for the individual. In the context of a recommended interdisciplinary, complementary teamwork approach, psychological treatment helps women deal with the psychosocial stressors of chronic vulvar pain. The mental health practitioner takes a careful psychosexual history as a routine part of the screening of new patients (McGrath et al., 1990), and is able to work with the levels of meaning that are involved when a woman develops chronic vulvar pain and seeks help for this disruption in her life.

The Introduction began with the words of a vulvar specialist who took on the challenge of chronic vulvar pain, curious about an area in which little was known and much is still not known. Her writings guided me to listen carefully to the stories of women who live with this condition. It is fitting to close with words from the story of the first woman I knew who had chronic vulvar pain, and the first woman I interviewed for the pilot study for this dissertation. The determination of both these women to find answers and meaning, each in her own way, have brought help to many and have inspired me to explore, in the profoundest way I could, both the mutability and the potential of female health.

> We usually have no choice in the difficulties placed in our paths. These are the burdens given to us. I hated every second of this. I got virtually no pleasure--I got a lot of flowers when I was in the hospital but I got no benefit, at the time, from the pain. In retrospect, of course, my life is forever changed. But now I can appreciate the joy of no longer being in pain. Not a day--sometimes not an hour--goes by that I don't think to myself: "I don't hurt any more when I sit down!" You may never have appreciated your absence of pain, but I'm ecstatically aware of that now. I now understand what pain is.

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APPENDIX A

COVER LETTER TO POTENTIAL PARTICIPANT

Sara Katz, M.A.
1546 Tenth Avenue
San Francisco, CA 94122

Dear Potential Participant,

I am currently a doctoral student in clinical psychology at The Fielding Institute. In partial fulfillment of my Ph.D. I am conducting a dissertation study on the experience of living with chronic vulvar pain.

I seek women over the age of 18 who have had vulvar pain for at least one year to be part of this study. Participation in this study will involve two audiotaped interviews with me. The first interview will last approximately 1 hour. I will furnish you with a typed transcription of this interview. The second interview will follow the first by 2-4 months; it will take approximately 20-30 minutes and will be conducted either in person or by telephone. During these interviews, I will ask you to speak about what it is like to live with chronic vulvar pain. Your name and any other identifying information about you will be kept strictly confidential unless you expressly state that you would prefer to have your name used. You will be provided with the opportunity to select another name for any material from your interviews that might be used in publication.

In addition to the two interviews required for participation in the study, I will offer one follow-up group meeting to discuss the preliminary results with the participants. Attendance at this group meeting is optional; participants do not need to attend to be part of this study. All participants in the study will receive a summary of the findings through the mail.

If you would like to participate in this study, please fill out the enclosed Participant Information Questionnaire and Informed Consent form and return them to me in the enclosed addressed, stamped envelope. I have included an additional copy of the Informed Consent form for your records. When I have received the completed packet, I will contact you about your participation.

If you would like to have more information about the study, please feel free to call me at (415) 566-4754, and leave a message giving several possible times when you may be reached by telephone. Thank you for your interest.

Sincerely,

Sara Katz, M.A.
1546 Tenth Avenue
San Francisco, CA 94122

APPENDIX B

INFORMED CONSENT

I agree to participate in the research study conducted by Sara Katz, a doctoral student in the Psychology Program at The Fielding Institute, 2112 Santa Barbara Street, Santa Barbara, California 93105. I understand that the research is a study of the experience of living with chronic vulvar pain that is the doctoral dissertation research of Sara Katz. I have been informed about this study by a practitioner or vulvar pain group member because I have had vulvar pain for one year or more. Sara Katz and I have no formal or informal relationship prior to participating in this research project. I am over the age of 18.

I understand that participation in the study will involve two audiotaped interviews conducted by Sara Katz. The first interview will take approximately 1 hour. Following this I will receive a typed transcription of the interview to read and respond to in a second interview of approximately 20-30 minutes, that will take place either in person or by telephone. When the preliminary results are completed, I will have the option of attending a meeting with the researcher and other participants in the study to discuss preliminary findings and the experience of being in the study; this optional meeting will last approximately 1 1/2 hours. I may choose instead to discuss these topics by telephone with the researcher, or not. All participants will receive a summary of the findings by mail when the study is complete.

I understand that participants in this study have been located through a variety of sources, including information made available in practitioners' offices and at vulvar pain support group meetings. If I have been referred to this study by another individual, I understand that this individual will not be informed whether or not I have chosen to participate in the study.

I know that the information I offer will be kept strictly confidential. A code number will be placed on the upper right hand corner of the Background Information Questionnaire and all interview material; the researcher will keep a matching list of code numbers and names only until interview participants have been selected. After that, this code list will be destroyed. I will be given the opportunity to provide a different name for any quotes that might be included in the final research report. I will also have the opportunity to remove any material when the researcher contacts me for the second interview. Interview audiotapes will be transcribed by a professional transcriptionist bound to maintain confidentiality of all material in the interviews. The information given by participants in the study will be made public in dissertation form and may be incorporated later into articles for professional publication; however, my name and any other identifying information will not be used, unless I explicitly request it. The interview data will be stored in a locked facility separate from informed consent forms. In any future use of this material for research purposes its confidentiality will continue to be protected. Rules of confidentiality also apply to the follow-up group meeting; participants will agree not to discuss anything that is said by other participants after the group meeting is concluded. No one else will be informed of my participation in this study.

I understand that due to time constraints, not all who wish to participate in this study will be able to; if I am not selected to participate I will be informed of this by letter.

I understand that my participation in this study is voluntary and that I am free to withdraw from the study at any time without prejudice or negative consequences. Should I not be selected or should I choose to withdraw, my data will be eliminated from the study. I understand that I will not receive payment for participation in the study and that there are no specific benefits to me by participating in this study. I may develop greater personal awareness of the experience of living with chronic vulvar pain as a result of participating in this research. I understand that participating in this study could involve bringing to my awareness painful emotions. Should I experience such discomfort during or after the interviews or the group meeting I may discuss my reactions immediately or contact the researcher later at the telephone number below. Should I wish to speak with a psychotherapist about this distress, the researcher will provide me with an appropriate referral. I realize that I may ask any questions about this study and my involvement in it at any time.

I have read and understand the foregoing and I agree to participate in this study. I am to sign one copy of this Informed Consent Form and return it in the enclosed addressed, stamped envelope. I will keep the second copy for my own reference.

Name of Participant________________________________(please print)

Address_______________________________________
____

Telephone (___)_____________(H)
(___)_____________(W)

Signature of Participant_____________________________

Date________________________________

Thank you very much for your participation.

Sara Katz
1546 Tenth Avenue
San Francisco, CA 94122
(415) 566-4754

APPENDIX C

(code_____)

BACKGROUND INFORMATION QUESTIONNAIRE

Age_______
Ethnic Background_____________________________
Highest Educational Degree______________________
Occupation___________________________________

Relationship Status: _______Single
_______Married
_______Other Committed Relationship
_______Divorced
_______Widowed

Number of years of vulvar pain symptoms______________________

Number and type of childbirth experiences: vaginal___C-Section___

Have you seen a doctor or other health care practitioner for your vulvar pain symptoms?____________________________________

Are you currently in treatment for the condition?_____________

How would you rate the severity of your vulvar pain at this time?
Mild__________Moderate_________Severe__________

APPENDIX D

INITIAL INTERVIEW GUIDE

1. Invitation to tell the story:

"As you know from the packet of materials and our telephone conversation, I am interested in learning about your experience of having chronic vulvar pain--when and how you first noticed it, and changes that have happened over time, what you have done about it, and how it has been for you in your daily life--generally what it's been like for you from when it began, until now."

Areas to be covered in each interview:
- Definitions of illness, self, and situation vis-a-vis chronic vulvar pain
- Physical sensations, somatic perceptions, symptoms: developments, changes, and consequences
- Emotional responses to the experience: developments, changes, and consequences
- Experiences of self in relation to somatic perceptions of and emotional responses to chronic vulvar pain

2. I encouraged clarification, relevance, depth of disclosure, elaboration, and reflection (Gorden, 1980, p. 372-374) in the following ways:

a. Easy attentive silence--the "permissive pause"

b. Encouragement--All remarks, non lexical vocalizations, and gestures, including nods of the head or open expectant facial expressions, that indicate acceptance of what has been said and encouragement to continue.

c. Immediate elaboration--to move the story onward, or to elaborate. Examples:

1. And then?
2. What happened next?
3. Tell me more about that.
4. Help me understand what you mean by that.

d. Immediate clarification--for additional information about sequence or for more detailed information on specific aspects of physiological awareness, feeling response, or effect on self image. Examples:

1. How did you manage then at work when you couldn't sit for long periods of time?
2. What did you notice that was different about the sensation?
3. How did telling your parents about your diagnosis affect you?
4. How did you see yourself then?

e. Retrospective elaboration--indicating a general interest in a topic the participant has mentioned in the narrative, without specifying what it is I want to know. Examples:

1. Going back to what you said about feeling like you'd lost 10 years of your life, tell me more about that.
2. You mentioned this being an emotinal topic with your boyfriend. Would you like to go into that a bit?

f. Mutation--bridging to a topic that was not covered in the story, to explore its potential relevance for this participant.

Examples:

1. How does this pain compare to other kinds of pain that you've experienced?
2. What do you think caused this pain?
3. So far you've given me a good sense of all the ups and downs with your doctors' appointments and treatments; how did you feel as this was going on?

3. Ending the Interview:

Toward the end of each interview I asked the following questions of each participant:

1. How do you respond when someone asks you "How are you?"
2. Knowing what you know now, what would you want to tell other women who have this condition?
3. How would you compare the person you are now with who you were before all this happened?
4. Tell me something about how the experience of being interviewed for this research project has been for you.

I then confirmed the plan to send each participant her transcript to be followed with the second, briefer telephone interview. Closure of the interview was in the form of appreciation for their participation.

APPENDIX E

FOLLOW-UP INTERVIEW GUIDE

Example:

1. I'll give you an overview of what we're going to cover in this follow-up interview. We will begin with any changes that you'd like to make in the transcript, anything that you'd like to add, or take out, or alter. The second part is anything that's happened since the interview that would be important to put into the story. Then I have a couple of health history questions to fill in. And the last part, as I wrote to you, is to talk now about what seems to be emerging from all of the interviews to see if it fits with your experience. So let's start with the first part, any changes you would like to make in the transcript.

2. The next part is to talk to me about any changes that have happened since the interview that would be important to put in.

3. Some health history information came up for everyone, but not every area in every interview. I thought it would be a good idea to fill these in for eveyone in the study. (see Appendix X: Demographic Sheet).

4. Member Check with preliminary results. Examples from a transcript:

A. It seems to me from these interviews -- whatever the conditions, the unique circumstances and particulars of how the discomfort began and the course it's taken -- that in the lives of the women I've talked with, chronic vulvar pain shapes the way she relates to herself and to the important other people in her life. So I'm looking at relationships with oneself, with one's significant others, and with the caregiver, and how we can think about those relationships in a way that might be helpful.

B. One level of analysis that has come up in the interviews is that peoples' experience is different, because of the vulvar pain, in their connections with themselves, with their body, with their functions, with their sense of sexuality and sensuality. Some people have talked about it in terms of femininity or a sense of gender, that having vulvar pain seems to affect people on these levels in different ways, and these are important levels to pay attention to. Self esteem comes up a lot. There's kind of an inner orientation to how a person experiences herself, and then an outer orientation of this experience, in expression and connections with the world. That sense of it profoundly changing how one thinks about oneself. How does that meet with your experience?

C. The other aspect of experience that comes up in every interview is connections with others, how this condition shapes who you are with other people, close relationships with partners, family and friends, and caregivers, and the qualities of those connections seem to be important for everybody in the study. How does this fit with what you've experienced?

D. Let's talk about anything else from your experience that would be important to include.

5. End of interview

I closed by confirming plans to send her a summary of the study results, and with appreciation for her contribution of time and her story to this research.

APPENDIX F

DEMOGRAPHIC LIST

code______

Psuedonym ________________
Age ________________
Relational status ________________
Ethnic background ________________
Education ________________
Occupation ________________
Sexual orientation ________________

Health history:
Anatomic factors:____
Skin sensitivity ____
Chronic conditions____
UTIs ____
Yeast infections ____
Vulvar trauma ____
Antibiotics ____
Menstrual Hx ____
Fam. health history____
Parity & type of cb____
Sxl exp prior to VP____
Current sxl status ____

Vulvar pain history:
Age at onset of sx ________________
Relational status at onset ______________________________________
Description ____
Location ____
Duration of sx ____
Progression of sx ____
Variations ____
Precipitating factors ____
Diagnoses ____

Functions affected:
____
____
____

Treatment strategies (chronological)	Effectiveness

Physician explanations

Current understanding of condition

Current severity rating

Other comments: