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Realizing Vulvas: Feminism, Physiology and Culture

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**Realizing Vulvas: Feminism, Physiology and
Culture**

by

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Dedication

This dissertation is dedicated to the women who shared parts of their lives with me that were both very private and very painful. These chapters could not have been written without their willingness to tell previously untold stories, ask new and difficult questions, and share with me a seemingly unbounded bodily vulnerability. Their honesty, courage and tenacity has been as humbling as it has been inspiring and I thank each and every one of them for their generous contributions to my project.

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Realizing Vulvas: Feminism, Physiology and Culture

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Based on thirteen months of ethnographic fieldwork in a large research hospital in the U.S., this dissertation analyzes the experiences of eighty American women seeking relief for chronic genital pain. Through extended interviews with diagnosed women, and participant-observation in a vulvar speciality clinic, I investigate the barriers—linguistic, cultural and corporeal—faced by patients who must engender greater familiarity and comfort with their sexual and genital bodies in order to successfully recover from their symptoms. Written as a cultural analysis of the vulva, the dissertation examines the ambivalent relationships between female external genitalia, U.S. dominant culture, and an autonomous female sexuality.

Attentive to the transgression, confusion and disorder evoked by the symptoms of vulvar pain, the dissertation redefines the clinical diagnostic phrase “other causes of genital discomfort” in sociolcultural terms. The concepts of “genital *dis-ease*” and “unwanted genital experience” are introduced and analyzed as corporeo-cultural phenomena that contribute to a profound sense of alienation between many diagnosed women and their genital bodies. In addition to an extended introduction and a description of both the clinical fieldsite and conditions under investigation, the dissertation uses four

progressive chapters—Accumulation, Manifestation, Integration and Generation—to theorize the lived experience of vulvar pain. Through a critical dialogue with current clinical literature, through which vulvar pain is understood in increasingly physiological terms, the dissertation argues that an acknowledgment of collective and cultural genital “discomfort” must be included in the emerging diagnostic and treatment regimens for women with chronic and unexplained genital pain.

Realizing Vulvas: Feminism, Physiology and Culture

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A NOTE ABOUT TERMS:

This dissertation is about several types of disease conditions that I will collectively refer to as “vulvar pain/disease,” “genital pain/disease,” *vulvodynia* and VVS, or simply “symptoms.” Unless otherwise noted and/or excepted, these phrases or terms are used interchangeably. I also employ the phrases “genital *dis-ease*” and “vulvar *dis-ease*” to refer to a cultural, or discursive, condition that is characterized by the disparagement, awkwardness and/or silence through which female genitalia are often apprehended in the contemporary U.S. All of these phrases and terms are more thoroughly defined in the dissertation, specifically in Chapters One and Two.

I also use the capitalized phrase “Vulvar Disease” throughout the text. Though I define this phrase towards the end of the dissertation (see Chapter Five), and am theoretically more interested in the ‘meaning’ of this phrase being experienced by the reader her/himself, I will briefly point out that this version of the phrase is meant to refer to a combination of these first two ‘syndromes.’ In an effort to mark the embodied convergence of the effects of both maladies and, in keeping with the themes of the text, I use Vulvar Disease to refer to “a complex interaction between cultural cues and physiological anomalies that accumulate and, eventually, manifest as intractable and embarrassing genital pain” (see p. 286).

Chapter One: Insinuation

PART I: OTHER CAUSES—INTRODUCTION TO GENITAL PAIN

In the spring of 2003, the *Journal of the American Medical Women's Association* published a study entitled “A Population-Based Assessment of Chronic Unexplained Vulvar Pain: Have We Underestimated the Prevalence of *Vulvodynia*?” At 7 pages, the article concisely reports the findings of a telephone survey of 5000 Boston-area women who were interviewed about symptoms that the authors defined as “chronic vulvar pain,” i.e.,

a) burning in the genital area for 3 months or longer with or without chronic itching, b) knifelike or sharp pain in the genital area for 3 months or longer with or without burning or itching, or c) excessive pain on contact when inserting tampons, during sexual intercourse, or during pelvic examinations that lasted for 3 months or longer [sic]. (Harlow and Stewart, 2003: 83)

The survey was part of a larger, 42 month-long project conducted by the Harvard School of Public Health, and was nestled between earlier pilot research that demonstrated an 18% prevalence rate for vulvar pain, and a follow-up, clinic-based study intended to correlate women's reported symptoms with objective evidence of disease.¹ The authors of the study (an epidemiologist and a researcher-physician) acknowledged that “[t]he pathophysiology of these conditions [and] ... [t]he magnitude of this problem ... [were] largely unknown” (82) but that “the true incidence of generalized and localized vulvar dyesthesia” could not be determined “without a complete medical history and physical examination to rule out other causes of genital discomfort” (83).

¹ To date, one paper has been published from this third leg of the study, and the results suggest a moderate to high correlation between reported symptoms and clinical confirmation. In a sample of 70 symptomatic women, 56 (80%) were diagnosed with *vulvodynia* on exam. See Harlow and Stewart, 2005.

For these researchers and their clinician audience, “other causes of genital discomfort” include vulvar dermatoses, malignancies, inflammatory conditions, post-operative or post-injury neurological complications, and challenging or atypical presentations of yeast or bacterial infections of the vagina and vulva. Although etiologically and pathologically varied, what links all of these “causes” of genital discomfort is the medical certainty that they are physiological, and that a resolution of the pain can and should be achieved through pharmacological and/or surgical means. As the article (and its citations) make clear, reasons for distinguishing between “chronic vulvar pain” and its possible look-alikes are related not to the nature of its source, i.e., physiological, but rather to the project currently underway in gynecological medicine—constituting and delineating a new category of genital disease. Noting that this “highly prevalent condition ... is associated with substantial disability” (87), the authors conclude with the hope that suitable prevention strategies can be gleaned from a better understanding of its “etiological pathways” (87).

This dissertation investigates the contemporary landscape of this (not so) new disease (Freidrich, 1983) in order to illuminate a distinctly faceted set of causes and prevention strategies. Chronic and unexplained vulvar pain is indeed an emerging and increasingly legitimate medical condition characterized by neuropathic inflammation, a growing number of immunological markers, and an expanding array of available treatment options (Harlow and Stewart, 2003; Haefner, 2005; Bachmann et al, 2006; Leclair et al, 2007). It is also a bodily experience mired in discourses of pollution and taboo that severely restrict women’s ability to communicate their symptoms across the necessary thresholds of medicine and genital integrity. In the words of one informant, the vulva is “off-limits” in all but the most clinical and/or sexual situations, a cultural reality that challenges women’s ability to incorporate their genitals into a body image

that is frequently invested elsewhere. Women with vulvar pain evidence the effects of these censoring discourses as they struggle with language, postpone and avoid clinical consultations, and refuse treatment options that necessitate physical encounters with their genitalia. Rooted in a “highly prevalent” social genital *dis-ease*, these behaviors index a “disability” that is no less “substantial” than the painful conditions described by Harlow and Stewart (2003: 87). I suggest that prevention strategies aimed at *these* conditions will not emerge from gynecological medicine unless it is informed by the kinds of critical cultural analysis in which (feminist) anthropology can engage.

In this landscape, the afflictions of *vulvodynia* and *vulvar vestibulitis syndrome* (VVS) are engaged in an intimate struggle with the bodies they inhabit. In the contemporary U.S., genital awareness that is unstructured by pathological or sexualized discourses is tenuous at best, and the spaces where it might be cultivated are virtually nonexistent. Women learn to disinvest from ‘normal’ vulvas, as their cultural value is compromised by an extraneous relationship to hegemonic heterosexuality. Individually felt pain, then, is both amplified *and* muffled by its relationship to collective acts, acts of vulvar disparagement and disappearance to which the female genital body is routinely—and unquestionably—subjected. Genital pain is highly personal, subjectively nuanced, and idiosyncratically encountered; on many levels it arrives—and remains—as the most private of conditions. Its presence, however, demands a dialogue. This dissertation will investigate the cultural conditions through which women, instead, keep quiet.

The lay of the land: genital dis-ease²

My body in need of treatment and the productive society surrounding me are cast from the same mold.

—Barbara Duden

The “genital discomfort” (Harlow and Stewart, 2003: 83) through which vulvar pain is lived is influenced first and foremost by a social milieu that will be elaborated in these pages—a profound sense of shame and transgression that surround linguistic, visual and/or behavioral references to female genitalia in the contemporary U.S. I use the term *dis-ease* in order to convey the awkwardness of encounters with the vulva, as well as to underscore the role that this affect plays in our apprehension of its clinical conditions. In their influential 1987 essay “The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology,” Scheper-Hughes and Lock argued that “[o]nce an organ captures the imagination of a people, there appears to be no end to the metaphorical uses to which it may be put” (17; see also White 1997). In thinking about the metaphorical uses to which the female labia and external genitalia are regularly put, we begin to outline the cultural context with which vulvar pain is in constant dialogue. It is difficult, to say the least, to physically inhabit a part of the body with which you have been otherwise taught to disassociate, e.g. through the “shaming words and dirty jokes of the schoolyard” to which Gloria Steinem refers in her introduction to Eve Ensler’s *The Vagina Monologues* (2001: xi). Freud’s notorious assertion that “the sight of female genitals give [...] rise to ‘horror, contempt, or pity’” (in Gatens, 1994: 34) is only one of the more explicit legacies through which women encounter diseased genitalia. When symptoms arise in an unmentionable place, the familiar act of uttering

² Getting the “lay of the land” was how one informant (Mary Hudson) described her first genital self-exploration with a mirror, at age eleven. The majority of subheadings throughout the dissertation are quotations from an informant, either a symptomatic woman or one of the physicians/providers with whom I worked.

the words necessary for a focused medical history (“It hurts when I breathe;” “The itching seems to be much worse at night”) requires a delicate and difficult set of negotiations between the woman, bodily ignorance, propriety, and the urgency of her painful situation.

I used my M.A. thesis (Labuski, 2002) to closely interrogate this milieu, and I questioned what kind of “sense” U.S. women could make of their genital bodies (Valentine and Wilchins, 1997) in a culture of contamination and disgust. During the months that I was writing, I tested the tenacity of this social climate (and my argument) by using the restroom graffiti blackboards in several of Austin’s local restaurants. Whenever and wherever I had the opportunity, I scribbled the phrase “Examine Your Vulva!,” upon arriving so that I could later collect any responses that I might have received. I expected that I would encounter physical evidence of the genital distaste that I hypothesized—‘dirty’ responses or prudent admonitions written by offended and nose-wrinkling customers, warnings that my straightforward advice had gone “too far.” My evidence came in another form, however, as I found that the reaction to my words was both more strident and more invisible than I had expected. Almost every time that I returned to these restrooms, my words had been singularly erased, wiped clean from public consumption. The fact that other, often lascivious, graffiti was routinely allowed to remain only served to highlight the unique, and disavowed, ‘place’ occupied by non-reproductive genitalia in the contemporary U.S.

I am drawing attention to this particular piece of earlier fieldwork not only because it materializes the erasures that I am positing, but also because of the way that it inflects the clinical-cultural relationship under consideration in this dissertation. “Examine Your Vulva,” (without the exclamation point) was a phrase with which I had another working relationship—those three words constituted the cover of a patient-

information pamphlet that I had purposefully ordered for the women's healthcare clinic where I worked for many years. The hands in which I often pressed this pamphlet were also reluctant, no more comfortable with its transgressive content than Austin's female restaurant customers. The medical venue, however, shifts the quality of this transgression: in the clinic, the *patient* does not hold the elective power over what she sees or hears through the discourses of institutionalized medicine, and the provider does not transgress by allowing these three words to remain visible. The *woman* alone in the bathroom, however, is free (and likely) to refuse the confrontation with her discursively sullied genitals. Were she to encounter the pamphlet in this space, she might throw it in the wastebasket, an act that would be far less thinkable in the hierarchical space of a medical exam room. Indeed, this power to display is based only partially on the physician's authority as expert consultant; clinical gynecology not only informs, but actively *constructs* female genitalia, shaping the vulvar body so thoroughly that it does not know itself outside of medical discourse (Foucault, 1973; Kapsalis, 1997). In the dissertation, I argue that the majority of physicians who do *not* distribute vulvar health and self-exam literature to their patients (Lawhead, 1990; Foster, 2002) participate in acts of excision. What I want to stress here is that, in the case of vulvar pain, the clinic *patient* and the restroom *woman* are one and the same, struggling to reconcile the discursive erasures of their genitals with the permission now granted—indeed, expected—to speak their material reality and suffering.

Alongside these discursive erasures, the contemporary vulva is also at risk for excisions of the material kind. Surgery is among the list of treatment options for women with *vulvar vestibulitis syndrome* (VVS) (women we will get to know in the coming chapters), as their pain is understood to be both superficial and easily circumscribed. Similarly, women with vulvar malignancies or *in situ* “pre-cancers” are typically

managed with a plan that includes cutting away enough affected and adjacent tissue to prevent a local recurrence. To fully appreciate the “genital discomfort” with which this dissertation is concerned, however, we need to briefly consider the physical and social reality of a cosmetic procedure known as labiaplasty, i.e., the aesthetic ‘reshaping’ of vulvar tissue. Indexing an intriguing convergence of feminist-informed bodily awareness, developing surgical/technical expertise, mainstreamed pornography, and market-driven healthcare, labiaplasty offers both shame-filled and sexually savvy female consumers the opportunity to have the vulvas of their—or their partners’—dreams. In an eloquent analysis of this excisional phenomenon, Simone Weil Davis (2002) asks pointedly:

What do the aesthetics of a streamlined vulva signify? The smooth groin of our favorite plastic android prototype, Barbie? A desire to approximate prepubescence? A fastidious minimization of marginal zones? ... [I]n a world where many women have never thought about judging the looks of their genitals, even if they care about their appearance more generally, we should ask what criteria make for a good-looking vagina [sic], and who is assigned as arbiter (13-4).

As a physical extension of the more symbolic excisions thus far examined, labiaplasty’s increasing prevalence (Braun, 2005; Green, 2005) offers compelling evidence for the sense of excess that informs the disparaging and contaminating discourses under consideration. Flethy (and liminally situated) labia profoundly unsettle circulating myths that construct the female body as lack (Irigaray, 1977a; Grosz, 1994; Kapsalis, 1997), troubling a landscape where women’s sexual *presence* often operates as “matter out of place” (Douglas, 1966). “To the dangers and allures of what’s hidden about the vagina,” remarks Davis (2002), “now is added the ‘too muchness’ of labial tissue ... mark[ing] the lack of tidy differentiation between inside and outside” (15).

The excessive vulva’s presence on the modern stage can be tracked across several cultural and historical registers, including: biologist George Cuvier’s fascination

with, and ultimate preservation of, ‘Hottentot Venus’ Saartje Bartman’s allegedly “over-develop[ed] ... [and] disgusting[ly] deform[ed] ... vaginal lips” (Fausto-Sterling, 1995: 37; see also Gould, 1985; Gilman, 1985; Schiebinger, 1993), and lesbian “sex-variants,” whose “larger than average vulva[s]” (Terry, 1995) rendered their bodies, sexualities and identities “deviant” from those of “normal” (143) women in WWII-era New York City. The second half of the 20th century oversaw a feminist-fueled sexual revolution that rejected Freud’s vaginal “femininity” and demanded the recognition of clitoral pleasure (Moore and Clarke, 1995; Angier, 2000), and this was soon complemented by the reclamation—by largely female providers and consumers—of ‘women’s health’ from male-dominated gynecology. Most recently, an explosive, ‘postfeminist,’ (Potts, 2002; Kinser, 2004; Gerhard, 2005) and internet-driven proliferation of pornographic and erotic images have inured many U.S. women to (at least) the *sight* of other women’s labia, at the same time that conventional medicine has gradually legitimized the existence of chronic and unexplained vulvar pain (Jensen et al, 2003; Buchan et al, 2007a, 2007b). These vulvar events, I argue, represent *amplified* female (sexual) bodies, incipient “body-blow[s] to the old male order of things” (Segal, 1994: 314) in which they would remain compliant and invisible. In a two-fisted backlash, however, discourses of disparagement work to quiet and contain the noise of their unruliness, priming female genitalia for a more pernicious betrayal. That is, since an unambiguous psychic *denial* would obviate the practice of labiaplasty, the vulva’s cultural reception is more accurately characterized as a *disavowal*, as it is made to disappear through, and because of, its excess (Sacks, 1989; Grosz, 1994; Moore and Clark, 1995; Brown, 2005).

I suggest that far greater numbers of U.S. women than those diagnosed with chronic vulvar pain sit in acute genital discomfort, discursive descendants of the female bodies whose excessive sexualities have historically—and fearfully—been held in

check. Some of these women find their way to the waiting rooms of other clinics, hoping to tend to their bodily unease by having it neatly, and professionally, sliced away. “A reminiscent bodily shame lurks behind the support for labial modifications” says Davis (2002: 26), who offered up her own genital body for inspection by a cosmetic surgeon. His suggestion that she contact some of his other patients led her to “[o]ne (heterosexual) woman [who] explained ... that although none of her boyfriends had ever remarked on her labia, ‘ever since I was fourteen, I felt like I had this abnormalcy [sic]; I felt uncomfortable changing in front of girlfriends.’” (26-7). This woman—surgical supplicant to a reinvigorated misogyny in institutional medicine—poignantly reminds us of the power that social discourses have to inscribe themselves upon—indeed *inside of*—embodied existence. Coming to terms with “abnormalcy,” whether it be pain or perceived disfigurement, requires a personal confrontation with genital *dis-ease* and its “etiological pathways,” including how a male (genital) gaze can be so thoroughly internalized. I suggest that this gaze occupies just one place on a spectrum of female bodily subordination (Hengehold, 2000) that includes sexual assault; I will use the next section to unpack this assertion.

Tell me what the man did: unwanted genital experience

I am not certain that a woman in the contemporary U.S. can escape the mediated and pernicious “blob” (de Zengotita, 2005) of discursive contamination that I am calling genital *dis-ease*; indeed, if there is a ‘clean’ cultural space in which the labia and vulva can take up residence, I remain unhappily unaware of its existence. When I interviewed women—in booths at Denny’s for example, or in bustling coffee shops—I sometimes asked them to ponder the physical space in which their words were being spoken. Not just into the tape recorder on the table between us, but into the air itself, the “open

expanse” that Irigaray has defined as “that [which] unfolds indefinitely and gathers all things together” (1993a: 40). I did this because I wanted us to imagine that our conversations—our public utterances of words and ideas too unsettling for restroom walls—were perfusing the space around us, seeping into the collective (un)conscious by way of waitresses, menus, occupied patrons and ambient noise. If the vulva needed to remain invisible in order for it to be culturally palatable, I thought, then perhaps our deliberate and unapologetic voicing—of both its existence and its precarious state—might somehow settle like so much dust onto the objects and people in its discursive and material circuits. Or, that like pheromones, our words might be naively absorbed through fluid and porous corporeal boundaries, influencing the instinctive behavior of those who were ‘exposed’ to them.³

As I sit to write these words, words that have everything to do with the public exposure of what many would prefer remain private, I am listening to a story on National Public Radio’s *All Things Considered*, in which Laura Sullivan is describing “legal hurdles” faced by many Native American women who are victims of sexual assault. Longstanding issues—jurisdictional and personal—between tribal and federal law enforcement officials limit tribal police’s scope so severely that they cannot arrest and/or prosecute any non-Indian whose criminal offense occurs on reservation land. This means that the rape of an Indian woman by a non-Indian man must be forwarded to the U.S. Attorney’s office that, more often than not, neither investigates nor tries such cases.⁴ As part of her report, Sullivan visits a healing ceremony, held on the Otoe-

³ A psychological phenomenon known as “priming the unconscious,” about which I had no knowledge until I read an article about it on the day after I wrote this paragraph. Our research often provides us with uncanny connections to the rest of the world. See Carey (2007) for a further discussion. See also Xu’s (1999) discussion of *qigong* in contemporary China, and the assertion of some masters that they can release their own *qi* into another room for the benefit of others (978).

⁴ Laura Sullivan, *All Things Considered*, July 26, 2007.
<http://www.npr.org/templates/story/story.php?storyId=12260610>

Missouria reservation and organized by a tribal member who works at the local community center (she recognized that such a ritual might be the only formal venue through which Indian survivors might process their experience.) This member tells Sullivan that the tent in which the women gather is often too full to accommodate all who seek its restorative promise. As I hear this last piece of the story, I marvel at the uncanny resonance between my own writing and thinking, and the facts that Sullivan's report reveals to NPR's audience; facts that are about the institutional disappearance and routine disavowal of the female sexual body. I think about how, though distinctly configured, my and Sullivan's stories are linked by how they index female genital bodies that are everywhere, injured, and invisible. I want the words of my informants to settle 'everywhere' in the coffee shops and restaurants where we meet because, in so many other places, they are all but 'nowhere.'

This section addresses the second factor at work in the lived "genital discomfort" under examination in this chapter—the real and disturbingly high prevalence of sexual assault in the contemporary United States. Laura Brown (1995), a self-described feminist psychotherapist in private practice, describes the context of this reality:

For girls and women, most traumas ... occur in secret. They happen in bed, where our fathers and stepfathers and uncles and older brothers molest us in the dead of night [and] behind the closed doors of marital relationships These ... are the experiences of most of the women who come into my office every day. They are the experiences that could happen in the life of any girl or woman in North America today. They are experiences to which women accommodate; potentials for which women make room in their lives and their psyches. They are private events, sometimes known only to the victim and perpetrator (101).

Many of the women that I interviewed in Portland told me about pasts that included sexual abuse or molestation; several had pursued counseling related to their experience and/or were engaged in more self-directed recovery efforts. In the recent past, it was easy for clinicians to suspect—if not smugly determine—that the inscrutability of vulvar

pain was related to a (buried) history of sexual abuse. I will recount and analyze this history in greater detail in chapter Four, *Manifestation*, but what I want to stress most in this section is how sexual abuse and assault figure into the discomfort felt and perceived by women with *and without* vulvar pain. As Brown makes eloquently clear, a psychic accommodation to the possibility of sexual assault is “not outside the range” (100) of many U.S. women’s experience. What I want to underscore is that, first, these private accommodations are also bodily—necessary corporeal adjustments made in relationship to perceived threats of violence; and that, second, these routine tweakings are also made in reaction to the discursive states of disparagement considered in these pages.

One of the arguments of this dissertation is that seeking relief for genital pain is hard work. While this assertion is an important one, I am even more invested in suggesting that the work these patients eventually do extends beyond the personal/emotional realms and well into the cultural. Indeed, I am arguing that the experiential mode through which symptomatic women first confront their symptoms is unavoidably tainted with cultural *dis-ease*, including the state(s) of genital risk engendered by what *any man* might do to her genitalia at *any time*. But I have purposefully separated sexual abuse from the discursive spheres in which it, at least partially, resides (i.e., devalued female sexuality) because I believe that they carry notably distinct amounts of cultural and gendered weight. In my various guises as friend, healthcare provider, colleague, anthropologist, instructor and feminist observer, I can report—and only partly explain—the variety of ways that U.S. women both produce and sustain the states of dirtied excess through which their bodies are interpellated. Although long-accustomed to scribbling it down in a field notebook as soon as I can, I still wince with confusion (and some despair) when it is *women* who participate; when they tell me, for example, about a friend of theirs who always “said that a vagina [sic]

looked like something that got dropped out of a ten-story window” and then wait for me to laugh.

Women’s own practices of linguistic self-degradation and surgical erasure act as co-conspirators in the disavowal of female genital bodies, fueling the “genital discomfort” in which they always-already reside. But there is no such aiding and abetting the reality of sexual abuse and its sequelae. I use the phrase *unwanted genital experience*, then, to signify a more collectively identifiable facet of female sexual subjectivity in the U.S. “Many women,” argues Brown, “have never been raped [yet] have symptoms of rape trauma ... [--being] hypervigilant to certain cues, avoid[ing] situations that [they] sense are high risk, go[ing] numb in response to overtures from men that might be friendly “ (107). Again, it is the *bodily* aspects of Brown’s assertion to which I want to attend, because I am arguing that just such behaviors occur in response to the ten-story window joke. That is, at least the first time it gets told.

Discourses of devaluation, when compared with aggressive *acts* of sexual violence, are less physically threatening, but I suggest that their differences are more a matter of degree than category. It is easy to apprehend the hypervigilant and defensive ‘tail-tucking’ of a woman that has been sexually assaulted; we can also readily grasp that a woman who has repeatedly experienced pain on genital contact might develop the same protective maneuver. But I am asking how far we need to stretch our (feminist) analysis in order to imagine that a woman whose genitals have been routinely and unquestioningly insulted might *also* come to incorporate this behavior.

I am aware that in interpreting bathroom graffiti erasures and reiterations of disparaging jokes through a frame of ‘unwanted’ experience, my argument might be perceived as politically uninformed by “pro-sex” and/or third-wave feminism (Vance,

1993; Johnson, 2002; Kinser, 2004). It is also the case that the ‘that’s not funny’⁵ analysis posited in this chapter is devoid of linguistic and/or anthropological analyses that could complicate my relatively simplistic approach to these pieces of ethnographic data. I believe that my politics, my relationship to contemporary feminism, and my ability to theorize my subject matter with adequate complexity will be made clear in the forthcoming chapters. I nevertheless want to stress that these incidents, the graffiti and the joke, are just two in what I can only describe as a regular and almost entirely uncomplicated discursive barrage of vulvar degradation and/or disavowal in the years that I have been paying concerted attention (Labuski, 2002). Whether I agree with radical feminists like Andrea Dworkin and Catherine MacKinnon (1988) that women’s sexual bodies can *only* be apprehended through patriarchal and violent legal institutions, or with scholars like Laura Kipnis (1992) and Paula Webster (1993) that women’s autonomous sexuality can (and often does) include verbal and behavioral acts that only *appear* to be misogynistically complicit, I still want to account for a large number of women—both patients and informants—who participate in and describe an unfettered (hetero)sexual identity while still approaching their genital bodies with disgust, reluctance and/or disavowal. This dissertation is only one interpretation of the vulvar erasures that I describe, but it is an interpretation informed by an analytic concept—vulvar *dis*-ease—that has not previously been adequately theorized.

In his *Outline of a Theory of Practice*, Bourdieu describes a bodily *hexis*, i.e., “imperceptible cues” (82) and “pattern[s] of postures” (87) that both structure and are structured by the (objective) conditions of one’s social world. Although I might cast a

⁵ “That’s not funny” being the index of the militant second-wave feminist who needs to “lighten up” regarding pornography, disparaging jokes and folklore, and sexual harassment, for example. I try to position myself here, but with a smile, often prefacing feminist-oriented lectures with the feminist version of the lightbulb joke: **Q:** How many radical feminists does it take to change a lightbulb? **A:** That’s not funny.

narrower frame around the conditions that I believe to be objective, I suggest nonetheless that affective awkwardness and cultural disavowals are associated with observable behaviors and outcomes, such as a measurable dysfunction in the muscles of the pelvic floor. The *hexis*, says Bourdieu “speaks directly to the motor function” of a body that is “charged with a host of social meanings and values” (87), situating unquestioned corporeal behaviors within a larger and denser social habitus. In the contemporary U.S., women experience far more shame than pride, and more fear than joy, as they live *with and in* their anatomically more vulnerable bodies. Vulvar pain and/or sexual assault will likely exacerbate or complicate this physical reality, but they will not create it; consistent and ideologically-driven devaluation of the female sexual body, however, both will and does. Bourdieu’s conceptualization allows us to think through the “three bodies” (individual, social and political) posited by Scheper-Hughes and Lock (1987: 6) through a lens that is more substantive than symbolic; the *hexis*, he argues, is “political mythology realized, *em-bodied*, turned into a permanent disposition, a durable manner of standing, speaking, and thereby of *feeling* and *thinking*” (95; emphasis in original).

In bringing sexual assault, genital pain, and disparaging discourses (and their material effects) under one analytic umbrella, I am positing that the female corporeal situation is rife with *unwanted genital experience*, and the “regulated improvisations” (11) and “generative schemes” (95) of Bourdieu’s (1977) *habitus*. U.S. women respond to the social facts of demeaning folklore and sexual violation through an enormous range of sensibilities and practices, many that directly contradict the shame and self-censorship that I propose here (Segal, 1994; Johnson, 2002; Potts, 2002). This dissertation, however, offers compelling evidence that (at least some) female bodies absorb these *unwanted* experiences and transform them into physiological and discursive

states of alienation. The three bodily modes that Brown singles out for our attention—hypervigilance, avoidance, and a state of numbness—are, in fact, prescient descriptions of the lived reality of vulvar pain (with “numbness” being the desired outcome of one treatment modality). I suggest, as does Brown, that many more women than those marked by disease or a history of assault live their genitals through any or all of these states. In adding jokes, innuendo, and disgust to the psychosocial mix, I want to widen the parameters of what constitutes *unwanted genital experience*, and to challenge our imaginations about the cultural situations to which female bodies might protectively and/or shamefully respond.

I just thought that everyone had that pain: genital alienation

Profound levels of genital *alienation* are the risk, if not the reality, of the two social conditions examined in the previous sections. I use the term *alienation* to describe a spectrum of distaste and ignorance, moored by the absences of silence and erasure at one end, and by the (hyper)presence of pain, pornographic amplification and felt excess on the other. In the dissertation, this spectrum, particularly its ‘ends,’ is a heuristic device meant to identify and thematize what I believe to be the two dominant modes through which U.S. women apprehend their (external) genitalia. In ‘reality,’ however, I understand these two states in the way that Elizabeth Grosz (1994) has asked us to conceive of the increasingly dubious ‘split’ between the mind and the body, i.e., as a flexible and dynamic Möbius strip. Grosz suggests that “[t]his model ... provides a way of problematizing and rethinking [dualistic] relations ... by showing not their fundamental identity or reducibility, but the torsion of the one into the other, the

passage, vector, [and] uncontrollable drift “ (xii) of, in this case, absence into presence, and vice versa.

Without a ‘clean’ space in which they can ‘have’ a vulva, women oscillate between and within two unacceptable alternatives: a ‘no-space’ and a contaminated one. In an invisible ‘no-space’ the vulva simply goes missing—absent from conscious awareness, untouched for its own sake, and attended to only by others (e.g. providers). Inspired by Grosz’s (1994) neuropsychosocial bodily matrix, I borrow the concept of *agnosia* from neurological psychiatry to describe this mode of vulvar *dis-ease*. In the context of an abiding ‘phantom’ pain that is felt where an amputated limb once existed, *agnosia* can be understood as its opposite, i.e., “the nonrecognition of a part of the body as one’s own” (89; see also Sacks, 1987). This state is not constituted simply by a refusal or reluctance to “Examine Your Vulva!;” rather, this is the space through which a woman remains clitorally anorgasmic, linguistically unable to describe her genitals, and perceptually unable to recognize a visible or palpable labial lesion. *Amplification*, on the other hand, is manifest through the consumption of labiaplasty and ‘Brazilian’ bikini waxes, where women confront their genitalia by removing the felt excesses of labial tissue and all of their pubic hair. The proliferation of these procedures is facilitated by another site of labial amplification, i.e., pornographic representations of genitalia against which women increasingly—often disappointingly—compare their own (Davis, 2002). But the ‘excessive’ vulvas with which this dissertation is most analytically invested are those that are in pain. Reddened, itchy, “on fire,” and recalcitrant, these labia are both amplified and simultaneously muffled by bodies that are discursively disciplined to keep them quiet. In order to ‘get better,’ these genitalia demand a quality of attention that is incompatible with either of these alienated—and embodied—extremes.

On this proposed spectrum between agnosia and amplification, if women perceive their external genitalia at all, it is as contaminated excess. Most women naturally move in and out of both spaces, and vulvar pain patients are no different. The work of Elaine Scarry (1985) and others (Jackson, 1994; Leder, 1990) has demonstrated that pain has alienating qualities all its own, often able to transcend, in this case, the awkward intimacy with which many women encounter their symptoms. But with vulvar pain, we are able to observe not only how various states of alienation inform each other in the patient's *individual* body, but also how levels of *social* alienation articulate with those that are personal. The level of genital pain is turned up high enough to be heard by the woman, her partner, her provider, and any other ears invested in her bodily well-being. Her pain, however, is absent from many clinical—and most social—registers, resulting in an ill-fit between the volume at which her symptoms manifest, and the volume of the response that she receives. Dedicated vulvar specialty clinics constitute the kind of therapeutic hyper-presence that is demanded by these conditions. Although I believe that a medicalized vulva is one from which women also can remain alienated, I suggest, nonetheless, that it can provide a balance to the innumerable absences encountered by a symptomatic woman. But as we will see, treatment strategies for *vulvodynia* and VVS are typically less-than-adequate and the majority of patients continue to have significant amounts of pain even while under an expert's professional care. This bodily reality leads to yet another level of alienation, as women whose pain exceeds their personal thresholds frequently choose to avoid the situations that threaten its recurrence. For most of the patients that I met in Portland, this meant a “shutting down” of their sexual bodies and selves, a strategic and self-directed “numbing” intended to prevent an alienating amplification (Overend, 1975).

These fluid movements across and between the various states of genital alienation are also well-characterized by Elizabeth Wilson's (2004) reworking of the Freudian concept of *obligation*. Located in Freud's writings on neurasthenic melancholia, and deployed in her own work to analyze mind-body relations, Wilson suggests that the dynamic of obligation displaces and obviates linear (or cause-and-effect) explanatory models without dispensing with the *two* that are often in tension:

[w]hile the term *obligation* is usually enlisted to designate a binding relation between people ... Freud's use of the term ... implies no such human or conscious action. ... Freud's use of obligation ... denatures the human-and-conscious-centric sense with which obligation is used elsewhere [and offers instead] ... one way of understanding a relation between psyche and soma in which there is a mutuality of influence, a mutuality that is interminable and constitutive (22).

Elizabeth Povinelli (2006) interprets Wilson and Freud's use of the term to mean that the two forces at play are "the literal material of each other, different from each other but mutually obliged rather than caused or affected, *vulnerable to* rather than *subject of*" (9). I will return to this theme of obligation repeatedly throughout the dissertation, particularly to how it has been nuanced by Povinelli. This is because of the unique way that vulvas are disavowed in U.S. culture—made present only so that they can be made to disappear. These disavowals exist in realms both material and discursive, and they are constituted through individual and collective acts and linguistic performances. In the contemporary U.S., women attend to their sexual bodies in curious ways: removing their protective pubic hair to better display their labia; surgically trimming erotic tissue in search of greater genital pleasure; and creating greater amounts of distance between their sexual anatomies and their menstrual and contraceptive habits (Muscio, 2002; Houppert, 2007). In this genital habitus, absence and presence, agnosia and amplification, "map [each other's] strange elasticity" as they find themselves socially and somatically *obliged* (Povinelli: 9).

I'm not going to abandon you as a patient: My birth in the clinic(s)

It was through my work as a gynecological clinician that I first came to speculate about these cultural conditions, and about the vulnerability of the genitalia from which my patients seemed increasingly detached. As a healthcare provider, my initial interests centered around the disease-related outcomes of this detachment, e.g., the malignant progression of an undetected vulvar “pre-cancer,” or the potentially life-threatening complications of an STD. Along with my fellow reproductive health clinicians, I routinely lamented that my patients couldn’t *talk* about the very same sexual bodies that they physically shared with their partners (Kaysen, 2001; Braun and Kitzinger, 2001). I also began to wonder about the very wide gaps that existed between what I taught patients to do and what they later (and sheepishly) told me they actually did. I am not suggesting that these gaps are unique to gynecological or reproductive medicine, for they are everywhere in institutional healthcare (Ditto et al, 1995; Smeets et al, 2007). I am saying, however, that genital health matters occupy a distinct cultural sphere, and that both clinicians and patients are challenged to invest in a bodily realm in which the rest of their worlds actively divest.

My first foray into reproductive health was in an abortion clinic and, though it was 20 years ago and on the opposite side of the country, the women, their stories, and my reactions to them are marked with uncanny resonances to those that I encountered during my fieldwork. I can effortlessly call up the feeling of angry sadness that infused my everyday collection of the contraceptive and sexual details of unplanned and/or unwanted pregnancies. I had expected, and had the professional tools to deal with, the ‘facts’ of sexual coercion, verbal inhibition, conflicted desire, lack of access, or simply

very poor planning—all colored by varying amounts of personal responsibility—that brought these women to my exam room. Indeed, a major part of my job was to help patients identify and cultivate their own sites and seeds of sexual responsibility, and to assure them that this was the way to avoid future encounters with our clinic. What I couldn't see then, however, was that I had been taught to assume far too much about the bodily integrity of my patients. A conventional program of college nursing colluded with an emerging feminist consciousness (a decidedly second-wave one), leading me to believe that my patients needed only education and information in order to make 'healthier' decisions. This dissertation is, in many ways, the handbook that that young and eager nurse needed to reconcile her politico-professional stance with a clinical reality with which it was chronically at odds. I want to tell her that she is right, that there is something *else* amiss, that her patients often can't (or won't) use contraception effectively because they are unable to confront their sexual and genital bodies. And that, despite her ability to effectively and creatively intervene in structured 'teaching' moments at the clinic (Ditto et al, 1995; Campbell, Auerbach and Kiesler, 2007), the discomfort and alienation contributing to these unwanted sexual situations (that she will continue to face in her extended career), are far more insidious and pervasive than her individual instructive efforts can address, no matter how empathetic and insightful they might be.

During fieldwork, I found that I could easily make 'gut-level' connections between these first patients and the women that I met with vulvar pain, and that my own positioning was still rooted in the politics that my work in abortion clinics helped to engender. For example, I was talking to my friend's daughter on the phone one afternoon, and she recounted having recently attended an all-day academic seminar/workshop about sexual assault and domestic violence at a local university (she

was a high school senior at the time). She told me about a “feeling” that she had never before been aware of, one that had surfaced as she listened to stories and feminist analyses of these two social realities. “It’s like in my stomach somewhere. I don’t know; it’s this *feeling*,” she reiterated, in a voice that was both clear and quiet. I could only imagine and share with her my own version of *that feeling*, and how it had emerged for me during these early and difficult years as a nurse. We spent some time commiserating about its varying and nuanced components: anger, disgust, helplessness, inspiration (to intervene), vulnerability, and a grim and abiding acceptance of what it (sometimes) means to be a female body in the contemporary U.S., about the “deep communication” (Schilder, 1950: 281) shared by body images that are similarly subordinated.

Pragmatically, I couldn’t properly attend to this feeling; in order to function effectively as a clinician, I instead channeled it into increasingly complex levels of prescriptive and supportive advice. And I continued to notice that my patients’ relative abilities to be at home in their bodies almost always ended with their genitals, particularly with the parts that were not circumscribed by heterosexual penetration or reproduction. Confronted with the full range of their alienation, I knew that their sexual decision-making would always be compromised by an absence that none of us could (yet) articulate. This dissertation, and the ethnographic research from which it was produced, constitute my scholarly attention to not only this *feeling*, but more importantly, to those that do not surface in such recognizable or tolerable ways, feelings that *dys-appear* (Leder, 1990) along with the body parts to which they are attached

Reproductive health centers and academic conferences represent some of our best feminist responses to a reality in which we feel inferior. Reconciling and investing in their discourses of choice and autonomy, however, is often both painful and confusing

in the face of competing realities, such as the one under investigation in this dissertation. Without accusing feminists of having “missed the boat” regarding the corporeal consequences of genital shame and alienation, my work nonetheless insists that much of its discourse, both scholarly and activist, remains insidiously unattuned to this reality. Indeed, the genital *dis-ease* that I posit is pernicious enough—embodied enough—to undermine the intellectually conscious efforts of my would-be colleagues and peers. Hoy (in Gatens, 1994) uses the concept of habitus to “get at [this] “‘background,’” arguing that it “capture[s] the sense in which the structures of social behaviour [...] are below the threshold of conscious decision-making” (x). Invested in the bodily utopia that slogans such as “My body, my choice,”⁶ symbolize, feminists do not properly attend to the corporeal reticence that structures many women’s perceived ability to make choices, women who are not always ready to be the strong ‘survivors’ that their feminist advocates need them to be (Hengehold, 2000).

Undaunted by—and eager to account for—this collective reticence, I have followed my impulse to dig both deeper and wider than discourses of ‘choice,’ and to try instead to locate a source of bodily independence through the *incorporation* of alienated and *dis-eased* genitalia. In this respect, my project is not particularly new or unique, as many feminist writers, artists, and scholars have ventured onto similar terrain (Corrinne, 1989; BWHBC, 1992; Muscio, 1998); indeed notable divisions exist among feminist theorists regarding the meanings we should assign to the alleged biological markers of our sexual difference(s) (Firestone, 1979; Schor, 1994a; Grosz, 1994; Fausto-Sterling, 2005). My reasons for attending to the vulva are no less academic, although they articulate with as many questions about the body *itself* as they do with the genital questions posed by contemporary gender studies (Valentine and Wilchins, 1997; Fausto-

⁶ The words that adorn my first t-shirt from an abortion rights march in Washington D.C. in 1985.

Sterling, 2000). In other words, I think that the vulva's disappearance is worthy of interrogation on two levels: 1) as a neuropsychological event; and 2) as the corporeal instantiation of female sexual inferiority. These levels are mutually obliged and the dissertation will analyze them as both separate and interactive phenomena. In widening my lens beyond the gendered and discursive to include the physical functioning of the bodies in question, I offer a more complete rendering of the unique ways in which the vulva is made both present and absent through cultural disavowal.

Although at times my analysis moves the vulva away from gender theory, my narrative remains firmly positioned in feminist politics and in the service of a critical anthropology of the (female) body. The discursive and material disavowals of female genitalia are structured and routinely sustained by the institutions of patriarchy, heterosexuality, and gynecological medicine. I went to the vulvar clinic in order to explore the bodily repercussions of this triumvirate, to get as close as I could to women whose lived genital experience not only occupied all points on the alienated spectrum that I had hypothesized, but were also well-positioned to transcend it, even if unwillingly. Medicine and sex in their mainstream guises condition women to attend only to the parts of their genitals that complement their respective penetrative goals. Vulvar pain compels symptomatic women to physically attend to the rest of their sexual bodies but their genital *dis-ease* severely constrains their ability to broaden this confrontation beyond the immediate context. Indeed, the future that many of my informants longed for was one in which they could “forget all about” their vulva(s) once again.

As we will see in the coming pages, the amplified pain of VVS and *vulvodynia* force women who have always been quietly complicit with the heteronormative state of things to both disrupt and reconfigure that part of their lives. In this respect, they

occupy a space that is almost opposite that of my typical reproductive clinic patients, i.e., women who actively minimized their genital confrontations (e.g. hormonal methods of contraception, refusal of an exam mirror), women whose vulvas disappeared in and around an easy and unquestioned (hetero)sexuality. As I will demonstrate, my broadest analysis of vulvar *dis-ease* includes both of these ‘groups,’ as they are often the very same women at different points in time, linked by the undercurrents of aversion and bodily hesitation that run through their gynecological encounters.

Health care, and nursing in particular, have often wrestled with the paternalistic nature of the word *patient*,⁷ but I have never been willing to let it go. I titled this section with a promise that Dr. Robichaud once made to a patient because it aptly describes the evolution of my own relationship to the women that I have professionally encountered over the course of my career—as nurse, clinician, and anthropologist. Despite my turn to the social sciences, and my departure from the direct-care settings where my interventions were far more concrete, I continue to think about women struggling with (their) sexuality as my latter-day patients, when *patient* is defined in the simple terms of *attending to*. More accurately, the *patient* that I have not abandoned is the female sexual body itself, the body that women with vulvar pain are speaking with and from in their search for adequate treatment.

Long disciplined and disavowed through acts of comparative disparagement (Bartky, 1990; Urla and Swedlund, 1995), I suggest that the vulva is in need of recuperation at all three levels of bodily becoming—individual, social and political (Lock and Scheper-Hughes, 1987). With this dissertation, I begin that project, offering a kind of attention to this genital flesh—in all its vulnerability, alienation and

⁷ Most recently, consumer-oriented HMO’s and web-based personal research have intensified a mode of care that is “evidence-based” and measurable. See Jaeschke et al (1994), Sackett et al (1996), and Feinstein and Horwitz (1997) for further discussions.

inconsequence—that does not exist outside of social realities through which it is either amplified or erased. In these chapters, I create a space for the vulva to exist for and as itself, i.e., as an anatomical, neurological, erotic, vascular, and functional element of a body. In this way, I contribute to the longstanding feminist project of re-imagining female sexuality on its own terms. “When the sexual self is represented by the sensual capacities of the *whole* body,” argues psychologist Jessica Benjamin (1990), “when the *totality* of space between, outside and within our bodies becomes the site of pleasure, then desire escapes the borders of the imperial phallus and resides on the shores of endless worlds” (130; my emphases).

PART II: THEORETICAL POSITIONING

Embodied history

As an anthropologist, my attention to the vulva is based in ethnographic research; as a scholar, my influences are a bit more eclectic, and this dissertation will cite sources from psychology, philosophy, cultural studies, sexuality research, history, queer theory, and performance studies, as well as literature from nursing, medicine and biology. The thread with which I stitch these potentially loose strands together is spun from feminist politics and theory, however, and it is this orientation that will most profoundly shape the arguments in the proceeding chapters. It is as a feminist that I recognize and call attention to the genital distress and vulnerability of women in the contemporary U.S., and as a feminist that I suggest that the sexual situations available to straight women in particular are, perhaps, the social reality that is most acutely indexed by vulvar pain. In staking out this terrain, I am inspired by feminist theories of the body that have been collectively referred to as “corporeal feminism” (Colebrook, 2000),

theories that “insist[...] on the positivity of morphology” and that “think the body as that which marks representation with its own force, difference, and motility” (84). Reconciling both the material variations in (differently) sexed bodies with the necessary disruption of the binaries that constrain most lived realities (Segal, 1994), corporeal feminism stresses the interpretive becoming of bodies in and through experiential worlds that are simultaneously unique and culturally configured; in short, corporeal feminism acknowledges and theorizes “the specific contextual materiality of the body” (Shildrick and Price, 1999: 5). This philosophical “solution” to many of feminism’s most vexing debates owes its apparent completeness to an important theoretical lineage, and this section will briefly outline the major trends in feminist theory’s relationship with the (female) body. Of course this work has been done elsewhere and in greater detail (Bartky, 1990; Bordo, 1993; Butler, 1993; Grosz, 1994, 1995; Young, 2005; Howson, 2005); my purpose here is to offer a background to the theoretical location of corporeal feminism, and to trace out these developments in relationship to the body specifically.

The political accomplishments of first-wave feminists in the U.S. were not based in any challenge to, or rethinking of, the bodily differences between men and women; indeed, much of the ideological work done by these women was rooted in a framework of ‘(political) equality *in spite of* bodily difference.’ The biological and ‘real’ nature of bodies deemed “troublesome” (Shildrick and Price, 1999: 4) was not questioned, but the disparate cultural “training” (Gatens, 1996: 50) that women received was identified as the source of both oppression and, in correcting such training, access to political participation. Many of these early feminists addressed the unbalanced nature of reproductive work, and some, notably Margaret Sanger, intervened at the level of education about contraception and reproductive biology (Chesler, 1993; Bailey, 1997).⁸

⁸ It is important to contextualize the work of feminists like Sanger as some scholars have associated some of their contraceptive activism with the politics of eugenics, i.e., there was a perceived need for *particular*

Women's 'natural' role, however, as mother and nurturer was not substantively questioned, nor were the bodily dimensions through which those roles were seen to derive. The evident *physical* ability of (white) women to function in both the military and the industrialized workforce during WWII lent a practical reality to the theoretical and political claims made by these first-wave activists. The eventual removal of these women from work that many found both meaningful and pleasurable stoked a feminist fire that erupted in more dramatic fashion in the middle of the twentieth century.

Second-wave feminism is more assiduously documented and recorded, allowing us to appreciate a greater diversity of positions, both theoretical and activist. During this multifaceted movement, the female body underwent a greater degree of destabilization, with some feminists actively questioning the necessity of men and/or intercourse for reproduction (Howson, 2005). In addition, increasingly available contraception allowed many women to participate in amounts and varieties of sexual activity that had borne unthinkable ramifications only a decade earlier. Sexology, a hybrid discipline that emerged from biology and experimental psychology in the 1950's, used the twin mantles of science and objective research in a quest to locate sexual response and behavior within the realm of 'natural' bodily instincts. The work of Alfred Kinsey (1953) and Masters and Johnson (1966), in particular, emphasized the sexual similarities and equalities between women and men, when it came to both sexual desire and response; this provided, in Lynne Segal's words, "a model of female sexuality which dismissed the 'harmful' view that women were more sexually passive than men" (1994: 102). It is important to think through the bodily implications of such cultural upheaval,

women to reproduce at lower rates (non-white and poorer women). The discourse of first wave feminism was also privileged in terms of work-related equality as, of course, many of these same women were and always had been working, including under the conditions of slavery. See hooks, 1981; Davis, 1983; Larson, 1995; Allen, 2000; and Ordovery, 2003 for further discussion of both of these issues.

as women moved both *into* and *out of* their former bodily realities in distinctly configured ways. Segal continues:

[o]ver and over, women were being told by one expert after another, ‘it is *your* choice’, *your* body’, *your* responsibility’: ‘Your focus must be solely on *your* sexual stimuli and whatever increases it’: [...] ‘He can give you his penis to enjoy, but the extent to which you enjoy it is *your responsibility*.’ These [...] experts were also confident that women’s sexual independence and fulfillment, seen as a type of learned competence, would ‘spread to other areas of a woman’s life’. (1994: 103; emphases in original)⁹

Aided by this discourse—along with technology and the information supplied by an emerging feminist health movement—many women underwent profound and embodied changes in their relationships with their sexual bodies, and sexual/reproductive ‘choice’ became an achieved reality that would not be easily relinquished.¹⁰

With increasing numbers of women in college as well as the halls of higher education, these on-the-ground transformations became grist for the mill that would become academic feminist theory. Although this second wave of feminism offered a more substantive challenge to essentialist notions of sexual difference, much of its practical and political energy was channeled into either ‘catching up’ or inverting relationships with male colleagues and counterparts. This meant that though “feminism ha[d] long seen its own project as intimately connected to the body[,]” a major “way forward” was to, nonetheless, “argue that the ideal standard of disembodied subjecthood was as appropriate to, and attainable by, women as it was to men” (Shidrick and Price, 1999: 1, 4). Early second-wave theory therefore borrowed heavily from the established (and masculine dominated) trends in the humanities and social sciences, appropriating what they could from available political and critical theory. Some of these feminists turned to Marxist theory, reworking ‘relations of production’ to include *reproduction*

⁹ Segal is citing two sources here: sex manuals (cited in an article from *Social Problems*, 1983) and Lonnie Barbach’s *For Yourself* (see Segal, p. 332).

¹⁰ Again, this new reality was inflected by racial and economic privilege. See Note #10.

and unpaid women's labor (Offen, 1988); some mapped out technologically sophisticated corporeal imaginaries, such as extra-uterine procreation (Firestone, 1979); and many began to theorize sexuality and sexual difference "by examining patriarchy with the tools it provide[d], of which psychoanalysis [wa]s not the only but an important one (Mulvey, 1975: 15).

'Western' post-Enlightenment culture has a long history of collapsing the categories of women, children, 'primitive' and 'raced' peoples into a conceptual realm inhabited by the figures of both animal and body (Haraway, 1989). In such a schema, the body is attended to only insofar as it inhibits or explains the intellectual functioning or social location of a person or group. Women's bodies, due to the obvious physicality of their reproductive capacity, enter this discourse as essentially—and immutably—more 'natural' and out of control (Jordanova, 1989; Russo, 1995). Freud, however, suggested that although sexual drives were linked with the types of biological instincts described by Darwinian evolutionary theory, they were equally, if not primarily, determined by developmental processes that were profoundly psychic and familial/environmental. Freud's Oedipal theory acknowledged—indeed depended upon—the reality of genital difference, but he tried to suggest that anatomy did not determine sexual behavior in and of itself; rather, it was the psychic incorporation or rejection of genitalia (one's own and/or the other's) that most profoundly shaped the sexual identity of the individual. Although it is questionable whether Freud adequately delivered on this theoretical promise, his assertion that anatomy was *not* destiny offered early second-wave feminists the opening they needed to begin to think through sexual difference in less deterministic terms. It was the eventual rejection of Freud's meager and subordinated feminine woman, however, that led to some of the richest and most vibrant writing about the female sexual body during this time.

Getting down to theory

Psychoanalytic accounts of the female body might be characterized as the *absence* from which a contemporary corporeal *presence* has arisen. Freud's ultimate rendering of women's (genital) bodies is as lack, i.e., lacking the penis (or baby) through which she is ultimately completed. The passive receptivity attached to this anatomical 'fact' was elaborated into a construction of female sexuality in which vaginal orgasmic satisfaction represented the peak of femininity, while clitorally-based pleasure was equated with an immature female sexual response (Moore and Clarke, 1995; Angier, 2000). While it was easy for many to reject these kinds of assertions (as they were routinely challenged by their own sexual bodies), it was more difficult for some to part with the theoretically rich nature of the ego, the unconscious, desire, and psychic sexual development in more general terms. When Lacan offered a symbolic *phallus* in place of the biological penis, some feminists took analytic refuge in the possibility that patriarchy's oppressive force existed only at the level of representation:

[t]he phallus is not a biological attribute, but a discursive position which constitutes women in terms of lack and men in terms of the threat of a lack. It creates a sense of difference from a power which is *illusory*—the fantasized possession, or lack, of the phallus (Segal, 1994: 131-2; emphasis in original).

Segal characterizes Lacan's ultimate rendering of female subjectivity as "depressing" (132), however, since he allows that the Symbolic order in which the phallus reigns supreme is the only order through which we exist as sexual subjects. Moira Gatens (1996) remarks simply that women are "homeless" in this social order (ix). But the most strident critiques of Lacan's psychoanalytic revisionism came from those who knew him best, i.e., French feminists, some of whom, like Luce Irigaray, were analysts themselves. Indeed, Irigaray's formal response to both Freud and Lacan, *The Speculum of the Other*

Woman, published in 1977 in France, still constitutes the single most innovative and intellectually incisive critique of masculinist psychoanalysis available today.

In some ways, Irigaray speaks for a general trend within feminism where the concept of feminine lack was stridently and unreservedly rejected. In other ways, she represents the *écriture féminine*—a style of writing epitomized by Cixous and Clement’s classic text, *The Newly Born Woman*. Writers in this vein do not so much theorize as attempt to *invent* and *write* the female body, using its (alleged) fluidity and excess(es) to “jam ... the [available] theoretical machinery [and] suspend ... its pretension to the production of a truth and of a meaning that are excessively univocal” (Irigaray, 1985b: 78). In these texts, women’s bodies are full, hysterically mimetic, and brimming with *jouissance*, i.e., the form(s) of sexual desire and pleasure that, because they are female, “cannot be articulated in the discourses and frameworks currently available” (Grosz, 1994b: 338). Based on both the explicit assertions made by some of these writers (Wittig, 1975; Cixous and Clement, 1986), and the conclusions drawn from some of its more opaque forms, many feminists have found it difficult to subscribe to what some claim are an “essentialist” set of assumptions, i.e.,

the belief that woman has an essence, that woman can be specified by one or a number of inborn attributes that define across cultures and throughout history her unchanging being and in the absence of which she ceases to be categorized as a woman. (Schor, 1994: 59)

Feminism’s “essentialism” debate is an important one for this dissertation in that genitalia are one of the most obvious markers of the kinds of sexual difference posited by some of these writers. Critics of this position argue that it is not only theoretically specious, but that it is practically and politically dangerous, to attach particular behaviors and/or predispositions to ‘the feminine’ given the ways that such associations

have historically been deployed (Haraway, 1991; Butler, 1990; Ebert, 1996).¹¹ Influenced by post-structuralist and postmodern theories of *socially* constructed differences, these critics (not unlike Lacanian feminists) locate ‘femininity’ in discourse and seek to “expose and denaturalize the mechanisms whereby females are *positioned* as women,” (Schor, 1994: 61 (my emphasis); see also Rubin, 1975) rather than inherently constituted as such. I do not have room in the dissertation to adequately address both sides of this debate, but I want to suggest that the position it occupies within feminist theorizing of the body is a developmental one, both for understanding corporeal feminism’s trajectory, as well as for grasping some of the splintering within academic feminism. In other words, while it might be relatively easy for feminists to unite around the material/sexual/genital *presence* that is denied by Freudian psychoanalysis, “[c]oming to grips” (Schor, 1994: 57) with just *how much* destiny can be explained and/or predicted by (anatomical) sexual difference is a process that is as informed by individual bodily experience as by affiliation with any group that might be labeled ‘women’ (Lorde, 1984; Mohanty, 1991; Colebrook, 2000). These “differences” need to be included in the conversation if theories are to have any politically useful explanatory power.

Irigaray has been both marked with, and “rescued” from, the label of essentialist. In interviews and conversations she dismisses those scholars—feminist or otherwise—who define her work in such terms, terms that she does not find analytically useful.¹² Irigaray remains central to the development of corporeal feminism, however (as well as to my arguments), because in addition to positing and performing a female body, she

¹¹ What is analytically challenging is that many of these ‘essentialist’ arguments lack specificity in regards to the source and/or nature of a female difference, outside of genital anatomy (which is itself not always invoked). Questions of hormonal variation, sexual dimorphism or variations in brain physiology, for example, are rarely used to assert these differences. This dissertation will do some of that work—guided by Grosz (1994), Colebrook (2000), and Wilson (2004)—but not necessarily in these terms.

¹² Personal communication, 2005; see also Irigaray 1985*b* and 1993*a*.

simultaneously displaces its location from the reproductive (and lacking) vagina to the autonomous and excessive labia. By situating her feminine here—in the “[s]ex which is not one” (1985*b*)—Irigaray offered second-wave feminists and early lesbian/queer theorists an entirely ‘new’ site of sexual difference, one that was not (yet) constrained by the phallogocentrism performed by Freud and Lacan. By drawing attention to the plenitude indexed by the vulva’s multiple folds, Irigaray insists that *these* are the female bodies that are missing from discourse, bodies that are different from, not receptacles for, those of men. “When Freud ... insist[s] that ... femininity is characterized by ‘penis-envy,’” she argues, “he is obviously defending his male point of view and his wish to perpetuate sexual homogeneity: a non-sex organ, a castrated sex/organ, or ‘penis-envy’ does not constitute a sexual heterogene but rather represents a type of negativity that sustains and confirms the homogeneity of masculine desire” (1985*a*: 63).

In recursively evoking the two sets of lips from which women speak, Irigaray effectively reframed the terms of sexual difference. In our review of feminism’s relationship to the body, we can see this move as a critical one, as it came at a time when: (1) post-Lacanian feminist psychoanalysts had turned to the role of the (desexualized) and reproductive mother in object-relations theory (Segal, 1994); (2) Derridean and postmodern feminists were beginning to read the female body as discursive text, challenging its material reality (Burke, 1994); and (3) postcolonial feminists were insisting that the worldwide differences *among* women were substantive enough to unsettle any ‘sisterhood’ engendered by second-wave feminism (Moraga and Anzaldua, 1983; Mohanty, 1991). During the years that I practiced as a clinician, I often referred to the gynecological exam as “the great leveling device” in that the bodily alienation and linguistic ignorance that I routinely witnessed easily cut across the categories of age, class background, ‘race,’ sexual orientation and education. Irigaray’s

female body, the one whose “sex/organs have [no] right to any ‘truth’ except the truth that casts her as ‘less than’” (1985a: 83), cut directly to the heart of this lived and acutely *felt* subordination. *This* corporeal ‘difference,’ in other words, could potentially be understood by a multitude of women, regardless of where else they were politically, reproductively, sexually or theoretically positioned.

Irigaray suggests that this kind of difference cannot truly exist in a masculinist economy of the One/the Same, one which is “is exhausted by (phallic) presence and (phallic) absence” (Gatens, 1996: 34). In this economy, “[t]he other is ... either ‘that Same’ (phallic) or ‘lacking’ (castrated). Positive difference is repressed, quite literally *banished from sight*” (34; emphasis in original). But in her recuperation of sexual difference, Irigaray does more than fix her eye upon the genitalia that she knows lack nothing—she literally *animates* their flesh. And, while the poetic fire of her prose corrects the “destitution in language” (143) suffered by female sexual bodies, it is her radical presencing of the vulva that, I suggest, offered many women a new incarnation of their external genitalia, the “mattering forth” (7) described by Povinelli (2006). Appropriating the excess that has historically been affixed to grotesque and overflowing bodies (Russo, 1995), Irigaray offers women a private glimpse into the transcendent power of their own morphologies:

Presupposed is an excess But this excess is no-thing: it is a vacancy of form, gap in form, the return to another edge where she re-touches herself with the help of—nothing. Lips of the same form—but of a form that is never simply defined—ripple outwards as they touch and send one another on a course that is never fixed into a single configuration. ... For to be (the/a) woman is already to feel oneself before anything else has specifically intervened. She is beyond all pairs of opposites, all distinctions between active and passive or past and future. But this surreptitious self-affection is not overt, cannot be expressed in words. It is *true* that women don’t tell all (1985a; 230; emphasis in original).

Corporeal feminism does not rest easily here, though, as Irigaray’s thinking—profound and acute though it is—cannot account for bodies that do not experience these lips in the

context of ‘the feminine,’ nor vice versa. Transsexual and transgendered bodies index a relationship to embodied and gendered genitality that unsettle the auto-affection performed by the labia that belong to Irigaray’s “women.” We must, therefore, review the work of one final group of feminists who have posited something different, feminists like Judith Butler who insist that the feminine is performed by much more of the body than genitalia, breasts or reproductive organs.

Imaginary bodies

In her now classic text *Gender Trouble: Feminism and the Subversion of Identity*, Butler argues that :

Transsexuals often claim a radical discontinuity between sexual pleasures and bodily parts. Very often what is wanted in terms of pleasure requires an imaginary participation in body parts, either appendages or orifices, that one might not actually possess, or, similarly, pleasure may require imagining an exaggerated or diminished set of parts. (1990: 70-1)

Butler’s use of ‘imagination’ stems from the work of earlier French and psychoanalytic feminists like Irigaray, but in this statement we can see that she deploys it distinctly; i.e., she allows for a feminine imaginary that can exist outside of a lifelong and embodied experience of female anatomy. By asserting that femininity is a set of physical and discursive iterations—that it is performed rather than essential—Butler allows other kinds of bodies to take up and imagine the feminine. Gender is construed as a set of arbitrary and manufactured behaviors (Kulick, 1998) that both produce and sustain a heterosexual order, an order that many feminists and queer theorists have argued is inextricably linked with the practice of capitalist expansion (Rubin, 1975; Haraway, 1991; Ebert, 1996). Linking her conceptualization with Foucault’s ideas about bodily surfaces, inscriptive processes and the disciplining power of discourse (1979), Butler

posits a ‘woman’ that is stripped of her nature, free to articulate with any number of bodies, genitalia and/or social processes or positions.

That the gendered body is performative suggests that it has no ontological status apart from the various acts which constitute its reality. This also suggests that if that reality is fabricated as an interior essence, that very interiority is an effect and function of a decidedly public and social discourse, the public regulation of fantasy through the surface politics of the body, the gender border control that differentiates inner from outer, and institutes the ‘integrity’ of the subject (136).

It hardly bears repeating that Butler’s argument has influenced an enormous body of feminist theory since its publication in 1990. Other feminists have also grappled with Foucault, arriving at conclusions similar to Butler’s, although often short of the radical separation she makes between surface and interior (Bartky, 1990; Bordo, 1993; Hekman, 1996). Attentive to the embodied experiences of transsexual and other queered bodies, feminists and other critical sexuality theorists have sought to reconcile the resonance and *sense* made by Butler and Foucault’s assertions about discourse, with the material realities of bodies that live a sexually-specific difference, i.e., the majority of bodies that inhabit either side of the gender/sex binary with significantly less ‘trouble.’ An earlier generation of transsexuals, for example, cautions us to think through the differences between bodies that “commit” to a gendered anatomy—in the form of surgical reassignment—and those that don’t (Namaste, 2000). The work of corporeal feminists is situated here, in the midst of this ongoing reconciliation. Feminists of this genre seek to positively acknowledge the kinds of differences elicited by Irigaray, to philosophically hold onto women’s physical ability to touch themselves “with the help of – nothing,” (Irigaray, 1985*a*; 230), while simultaneously allowing ‘woman’ to exist as a plastic and emergent site of becoming.

Butler’s ideas about performativity articulate with an understanding of bodies as constituted by discourse. Although she takes up the materiality of bodies in her next

book (1993), Butler maintains a focus on discourse and representation, arguing that language—rather than being mimetic of pre-discursive bodies—is, instead, productive and constitutive of them: “inasmuch as this signifying act [i.e. language] delimits and contours the body that it then claims to find prior to any and all signification” (1993: 30). Butler’s project after *Gender Trouble* is to caution feminists that the category of ‘sex’ should not be used as the basis for deconstructions of femininity and gender; a (female) sex, in other words, is no less discursive (nor less dangerous) in its ability to subordinate bodies through representation and language. Butler is concerned with the temporal assumptions through which (sexed) bodies are perceived. In questioning whether bodies can exist “prior to any and all signification,” she is suggesting that gender and sex are constituted through the same representational processes, rather than gender *following* sex. While feminists and critical theorists had successfully denaturalized and de-binarized these two categories, they had not yet removed the pre-discursive frame through which bodies continued to be understood.

Corporeal feminism begins, perhaps, with Elizabeth Grosz’s reading of Lacan in the same year that *Gender Trouble* was published. Contrasted with a Butlerian understanding of Lacan’s ‘Real’ as an effect of language, Grosz understands the Real as a pre-semantic stage. This is a crucial distinction in that a developmental stage that precedes language allows bodies the opportunity to be alternately constructed:

The Real, where the vagina, clitoris, or vulva have the same ontological status and functional utility as the penis and testicles, must be displaced and recoded if women’s bodies are to be categorized as necessarily incomplete (117).

For Grosz, the ‘sex’—or phenotype, age, disease condition etc.—of a body is always already an expression of itself. Vulvas need not be pure discourse in order for them to be separated from a natural female essence. Colebrook (2000) frames this theoretical move in terms of ‘becoming,’ suggesting that “the body marks that peculiar site of

transformation whereby the human becomes human, the body becomes sexed, and the subject emerges on its own” (85-6). In this framework, not only can differences exist materially, but they can do so collectively, so long as this set of differences (e.g., genitalia) remain fluid and individuated in their bodily expression. “We might say,” continues Colebrook, “that the human is *nothing other than* an interpretation of its own body” (86).

Insisting that “the body is a becoming meaningful” (Colebrook, 2000; 86), and allowing this meaning to come from genital difference as *one* unfixed and discursively plastic bodily attribute, corporeal feminists like Grosz, Gatens, Lloyd and Braidotti reconcile Irigaray’s “sexuate” difference with the important deconstructive work done by poststructuralist theorists like Butler. These bodies are consonant with Donna Haraway’s cyborgs (2001), denaturalized and eclectically configured by ‘nature,’ technology, discourse and social structures. They also resonate with the conditioned bodies in Iris Young’s (2005) analyses, and are disciplined to comport themselves in gendered ways. These differentiated bodies more adequately include those of my research informants, whose relationships to genitals, sexuality and bodily difference are mediated through the physicality of their symptoms, the language of institutionalized medicine and the cultural *dis-ease* theorized in this chapter—all of which are constantly in flux and which uniquely dis-articulate their experience from both mainstream and subaltern discourses. The dissertation will tell some of their stories and, through a progressive metaphor, illuminate a burdened and generative bodily landscape through which their sexual pain is lived.

PART III: CONTRIBUTIONS OF THIS DISSERTATION

When I describe my research to friends and colleagues, I am invariably asked some version of these questions about vulvar pain: “Well, what *is* it? Is it real? What causes it?” While I understand both the provenance and the urgency of this kind of curiosity, I typically find myself struggling with a reply that can convey both the information sought as well as the problematic nature of the questions themselves. Indeed, it is a primary goal of this dissertation to shift questions about vulvar pain from those based in its physiological ‘reality’ to those that can be answered through anthropological inquiry. For me, those questions center around how and why vulvar disease exists—medically and culturally—in ways that it did not twenty years ago. What are the social, political, discursive and material events through which vulvar disease now *manifests* and how do they sustain its place in the clinical world? What, in other words, are vulvar pain’s conditions of possibility, and can an analysis of these social processes deepen a symptomatic woman’s understanding of her pain?

Separating ‘medical’ from ‘cultural’ aspects of vulvar disease is, like my spectrum of alienation, a heuristic device, one that allows me to delineate the two major analytical tasks of the dissertation. My first task—the ‘medical’ one—is an elaboration of ‘embodiment’ theory. In a landmark article entitled “Somatic Modes of Attention,” Thomas Csordas (1993) defined this theoretical orientation as a “paradigm” through which the body can be understood as the “existential ground of culture” and he suggested that it “be offered as an equivalent, and complement, to the semiotic paradigm of culture as text” (135). This second element of Csordas’ assertion is important in that it historically locates this body of theory as—at least in part—a response to the interpretive work that dominated cultural anthropology in the 1970’s and 1980’s. Indeed, Csordas speaks directly to that literature by pointing out that a somatic mode of

attention asks us to encounter the body “not as an object that is ‘good to think,’ but as a subject that is ‘necessary to be.’” (135). By keeping Merleau-Ponty and phenomenology in dialogue with body-as-text analytical approaches, Csordas carved out a new space for the body in anthropological theory, one in which it could be analyzed through its mutable and *lived* experience, rather than as static cause, effect or symbolic reflection of more abstract social processes and/or categories (Douglas, 1966; Mauss, 1973; Bourdieu, 1977; 1984).¹³ “The fact of our embodiment,” he writes one year later, “can be a valuable starting point for rethinking the nature of culture and our existential situation as cultural beings.” (1994: 6).

This dissertation could not have been written, nor theorized, without the literature that resulted from Csordas’ theoretical intervention, without defining corporeality in terms of “the self, the body, and the world” (Young, 1997: 48). Indeed, I fully imagined that these perspectives would prove to be more than adequate in my ethnographic analysis of female genital pain. But I remained intrigued by the physiological aspects of these existential realities. Although phenomenological philosophers and embodiment anthropologists give far greater theoretical attention to the materiality of the body, i.e., to the ways that it *is* matter in addition to how it *matters* as representation, the work of these scholars typically lacks the flesh-and-blood specificities to which my background in healthcare has taught me to attend. As I positioned my work and my research questions in a more direct relationship with the body, I wanted to better understand *how* social processes come to be embodied; how, in other words, does culture get in there?

¹³ Bourdieu’s bodily *hexis* (1977, 1992) comes closest to this perspective, but has more of a fixed nature than does Csordas’ conceptualization. Bourdieu’s ‘structured and structuring’ (and class-based) *habitus* (1977, 1984) leaves less room for the more fluid and phenomenological *experience* that Csordas tries to capture with embodiment.

I was able to clarify this question during fieldwork as I spent an increasing amount of time with physical therapists. As my chapters will demonstrate, physical therapy has the potential to ‘undo’ the muscular tension and pain that I have suggested are (at least) a part of the experience of cultural vulvar *dis-ease*. Observing the combination of dialogue, emotional support, physical manipulation and sexual counseling employed by the most effective therapists, I began to understand genital pain in terms that were as physiological as they were indexical and/or symbolic. The elements of this equation—the “genes, hormones, cells and organs” (Fausto-Sterling, 2005: 1495) involved in a woman’s disease process—offer distinct insights about the embodiment of culture. A pelvic floor in direct relationship with discourses of devaluation bypasses—perhaps—the ‘mindful’ portion of Scheper-Hughes and Lock’s (1987) “mindful body.” Rather than analyzing the relationship between vulvar erasures and genital pain in terms of how “the mind speaks through the body[,]” we can deepen our analysis of how “society is inscribed on the expectant canvas of human flesh” (10), by thinking through the physiological nature of these inscriptive processes.

Fausto-Sterling (2005), a biologist, suggests that we consider “what it might mean to claim that our bodies imbibe culture” (1495). I draw from anthropologist Mary Weismantel (2001) and clinical psychologist Elizabeth Wilson (2004) in order to take up this challenge and to answer feminists—represented by Moira Gatens (1995)—who are “not concerned with the physiological, anatomical or biological understandings of the human body” (viii). From this perspective, the questions with which I began this section, i.e., “What is it? Is it real?” become answerable in terms that are as much about culture as they are about genetic predisposition or causative pathological agent. In the dissertation, I use my ethnographic observations about what genital physical therapy *undoes* in order to speculate about what culture *does*, about how it “gets in there.” In

this way, I take embodiment theory a step further and locate the lived experience of vulvar pain not just experientially but also physiologically, shifting extant configurations between culture, self and anatomy.

My second, or ‘cultural,’ task involves an analysis of the sexually discursive ‘work’ done by women with vulvar pain. Although perhaps a more speculative move than my first, I nonetheless want to use my ethnographic data to suggest that symptomatic women express notable ambivalences toward the routine practice(s) of heterosexuality. Unable to participate in uncomplicated penetrative intercourse, my informants demonstrated a range of problem-solving behaviors, most of which were performed in slow, cautious and/or erratic fashion. Refusing or deferring physical therapy, missing clinic appointments, improperly using prescribed medication, not talking with their partners, and/or sexually “shutting down,” patients at OHSU did not typically pursue the resolution of their symptoms in an aggressive or purposeful manner. Chapter Three, *Accumulation*, analyzes these behaviors in a context of cultural vulvar *dis-ease*, and argues that women’s ability to find relief is significantly hampered by an incorporated genital reluctance. The not infrequent revelations of my informants, however, that they “wouldn’t even be [at the clinic] if it weren’t for [their] husband[s]” suggests that women with vulvar pain bring a complicated mix of desire (including for normalcy), linguistic reticence and bodily refusal to their (hetero)sexually disrupted situations.

If the conditions of *vulvodynia* and VVS are physiological realizations of cultural vulvar distaste and disparagement, it is possible to theorize penetratively prohibitive pain as the material manifestation of a female (hetero)sexuality that is dissatisfied by the “situations” available to her. Exhorted by the media—as well as their clinicians—to move beyond penetration and explore what *else* their genital and sexual bodies might

enjoy, my informants routinely encountered male partners uninterested in such novelty. Vulvar pain patients normalized these interactions by keeping their own clinical focus on a restored tolerance for easy penetration. It is here where I locate an unstable and inchoate ambivalence, however; stated desires were frequently not followed by problem-solving behavior, and patients who were able to engage in ‘successful’ penile-vaginal intercourse sometimes described their feelings about it in angry and resentful terms (“Okay, you got what you wanted”). Faced with disrupting the penetrative narratives through which their bodies are interpellated, many of these women maintained active investments in reproducing *and* resisting them, rendering the option of sexually “shutting down” a sensible and perhaps more manageable choice.

In exam rooms and in interviews, women described expectations and disappointments around sexualities that are constructed and overdetermined by mainstream discourses. Gynecological discourse and popular rhetoric compete and conjoin to write ‘healthy’ sexual scripts that normalize a penetratively-based heterosexuality for which a compliant vulva is needed. A vulva that doesn’t ‘work’, that cannot function as an enthusiastic (or at least tolerant) receptacle, performs the ‘work’ of manifesting the female genital body in its entirety. I suggest that *this* sexuality remains inadequately theorized by feminist researchers; that its singularity is missed by theories dominated by both phallic and queer perspectives. A vulvar-based “sexual imaginary” (Gatens, 1995: xiv) opens up a space in which female genitalia can exist in all their corporeal potential, offering more women than those with painful symptoms an investment in labial, clitoral, perineal and pelvic floor sensation. Such an imaginary is not available to missing and/or alienated vulvas, locating women who recuperate their genitalia (e.g. through physical therapy) on the cutting edge of alternative female sexualities.

This sexuality is infused with possibility, with the carnal potential of a profuse, expansive and largely untapped source of pleasure and female corporeality, with a “sex” that Irigaray insists can never be just “one.” One imaginary among many (Segal, 1994; Grosz, 1995; Gatens, 1995; Potts, 2002), a vulvar-based sexuality is one that women with vulvar pain are in a unique position to inform. ‘Queered’ by their marginal relationship to penetrative coitus, but materially and discursively invested in heteronormality, the bodies of many of my informants are often sexually paralyzed by the impossibility of these contradictions. Feminist and critical theory that makes space for their experiences, however, can unseat the assumptions upon which this stagnation rests, transforming an ambivalent vestibular refusal into a recoded and generative orifice. If we read the pain and ‘burning’ of *vulvodynia* or *VVS*-afflicted genitalia as a way *in* to the conflicted desires, anger and disappointment of (some) heterosexual women in the contemporary U.S., we have established a new opening in sexuality studies through which to analyze the apparent investment that straight women make in penetrative coitus. Listening to my informants has helped me take the first steps in the process of constructing not what Lynn Segal (1994) has called a “brave new world where sexualities publicly cavort detached from either genitals or gender” (156), but a horizon where genitals matter tremendously, just not in the ways to which we have become accustomed.

hristine

In her critical examination of the journals of an 18th century German physician, Barbara Duden (1998) states that:

The first step toward understanding the complaints of the women of Eisenach was [...] to realize that my own certainties about the body are a cultural bias, one

which perhaps I could even learn to transcend. I had to create some distance to my own body, for it was clear that it cannot serve as a bridge to the past. (vii)

I take Duden's conclusions to heart and introduce the dissertation within the context of such distancing efforts. I have thought through the lived experience of vulvar pain from numerous angles, some of which will be worked through in the coming chapters and some that have been discarded along the way. Underlying most of them, however, has been an attempt to keep a social constructivist position in dynamic dialogue with the beliefs and attitudes of patients, physicians, partners and the researchers with whom I opened this chapter; i.e., the actors invested in the physiological reality of *vulvodynia* and *VVS*. I have hesitated to attach too much biological reality to symptoms that I believe to be profoundly social. I have wanted to interpret these bodies as code at the same time that I have tried to explain physiologically intractable pain by deepening the perspectives of embodiment theorists. And I have done this all without knowing—in my own body—what it feels like to genitally reject the penetration or approach of my partner, my doctor and my own hand.

As an anthropologist and critical theorist, then, I have used the tools at hand to delineate the arbitrary social conditions through which vulvar pain is experienced. In doing so, I denaturalize not only the bodies of my informants, but also my own, other women without pain and—ideally—any body that can be interpreted through the theoretical perspectives offered here. Carolyn Burke (1994) has described Irigaray's earliest project as a vulvar “fable” (43), and suggested that “the reader of such texts must be willing not to ‘believe’ in [... them but] to let go of them once they have become too useful” (44). In presenting my own vulvar fable, I offer the reader an opportunity to do just that—to locate when and if the explanatory power of my analysis threatens to become “too useful,” and to use that moment to begin to ask new questions.

Chapter Two: Examination

PART I: PARTICIPANTS, FIELDSITE AND METHODS

The women, the conditions

During my thirteen months of fieldwork, I developed relationships with the clinic's two physicians, a handful of local physical therapists, one nurse and several medical assistants, a dozen gynecology residents and a half-dozen medical students, a sex therapist, and forty-two women who allowed me to gather the details of their disrupted lives. I met, and observed the clinical consultations of, many more, but these forty-two made time to meet with me outside of the hospital and to talk at length about their struggles with symptoms, sexuality and genital well-being. I observed their surgeries, bought them dinner, accompanied them to the pharmacy and to physical therapy, brought them to yoga, had meals in their homes, brought them cake and flowers, got drunk (with one), and listened attentively to stories that, in their words, had never before been told in their entirety. To anyone. And although I socialized less with the providers that I met in Portland, my ubiquitous presence in their exam rooms, surgical suites, and treatment sessions led to hours of conversation, much of it delightfully analytical. This particular mix of methodologies allowed me to observe firsthand the developing and deepening investment(s), made by both patients and providers, in the physiological reality of otherwise unexplained vulvar pain. The difficult tales that my research enabled patients to tell, however, complicated these investments in significant ways, leaving me confused at times about how to best tell those tales to a wider audience.

But before I can begin to tell those tales, we must first delineate whose tales they

are. In other words, who gets *vulvodynia* and VVS? And why? Prior to 2003, when the Harvard School of Public Health study was published, the first of these questions would have been answered with a fairly homogenous demographic profile. Diagnosed women were almost exclusively white/Anglo-American, educated, economically stable and/or insured, partnered (usually married), and heterosexual (Furlong et al, 1991; Tympanidis et al, 2002; Masheb et al, 2002). Aside from this profile, however, published research about the *why* of vulvar pain was relatively rare in the decades before the new millennium. Confused clinicians encountered an eclectic smattering of investigative and analytical approaches in the professional literature, and were unlikely to learn about either condition from medical conferences. Whether speculating about etiological agents, constructing psychological profiles of symptomatic women, or imagining new treatment regimens, researcher-clinicians working with vulvar pain operated in relative darkness regarding what these conditions were and why affected women were so phenotypically and socioeconomically similar. The word psychosomatic was often deployed in analyses that sought to characterize the ‘kind’ of woman most likely to develop a variation of vulvar pain; such characterizations helped to rationalize the early and semi-routine use of antidepressants and other neuroleptic agents (Lynch, 1986; Schover, Youngs and Cannata, 1992; Jantos and White, 1997). And, while demographic factors such as race and income were occasionally discussed, it was more common for studies to discriminate between cases and controls by measuring pain levels, amount of sexual disruption, and comorbid conditions (e.g. depression; fibromyalgia)¹⁴ rather than by comparing racially or socioeconomically distinct groups of women (Foster, 1995; Sadownik, 1999; Reed et al, 2000; Harlow, Wise and Stewart, 2001).

¹⁴ Vulvar pain research has also consistently tried to demonstrate the “biological” nature of vulvar pain by establishing relationships between symptoms and, for example: age at first menses, family history, parity history, age of symptom onset, and previous exposure to fungal/bacterial/viral pathogens.

In 1990, a curious gynecologist named Martha Goetsch examined all of the patients in her general gynecological practice over a six-month period in order to establish some baseline prevalence data for VVS. By performing an exam specific to the condition and following it up with an interview-questionnaire, Goetsch determined that 37% of her patients had “some degree of positive testing” and that 15% of them “fulfill[ed] the definition of vulvar vestibulitis” (1991: 1609). At the time it was published, Goetsch’s data was significant for two important reasons. First, its prospective design and large sample size ($n = 210$) helped to locate vulvar pain on a clinical landscape that did not yet appreciate the number of women to which VVS’s diagnostic criteria might apply. Secondly, inclusion criteria that were based on a patient survey *and* a physical exam worked to legitimate the ‘objective’ nature of a condition for which clinicians were still tempted to make a psychological referral. Using the diagnostic technique known as the “swab,” or “q-tip,” test (see below; see also Bachmann et al, 2006), Dr. Goetsch established the parameters of “normal variation in sensitivity of vestibular skin,” (1609) and encouraged gynecological clinicians to include VVS in their diagnostic workup of dyspareunia, i.e., pain with intercourse.

Dr. Goetsch’s study is salient in my analysis as it hovers on an epistemological edge in vulvar pain research. In sketching the contextual contours of the demographics and risk factors for this ‘unexplained and chronic’ pain, I suggest that there were two ‘waves’ of institutional discourse. The first, which occurred before Goetsch’s study was published, was characterized by confusion and a lack of ‘objective’ data; the difficulty in appreciating any physical or anatomical abnormalities in these patients led to inadequate clinical workups and dismissive attitudes on the parts of many providers. Data collected during this period, as well as review articles that were written, represent the population(s) that not only presented with complaints of vulvar pain, but—more

specifically—those that were listened to. The discussion in Chapter One regarding vulvar disavowal and alienation extends—as we will see—to healthcare providers. Particularly in the late 1980’s and in the 1990’s, complaints of “pain with sex” were often dismissed as psychosomatic if a clinician could not find an obvious organic cause (Baggish and Miklos, 1995; Bodden-Heidrich et al, 1999); the vulva as a primary source or site of disease was barely imaginable. Women who found their way into research studies and/or formal descriptions were persistent enough to get clinically recognized and/or find providers attuned to the particularities of vulvar pain. This first ‘wave’ of data, then, reflects a patient with significant resources: access to a physician, emotional resilience and persistence, adequate bodily awareness and a vocabulary to express it, and the good fortune to connect with a sympathetic provider. For researchers who specialize in healthcare disparities, it is not surprising that the initial ‘profile’ of vulvar pain in the U.S. came to be that of a relatively privileged white woman (Smedley, Stith and Nelson, 2003; Smith et al, 2007).

A slow accretion of this data, coupled with a spike in clinical and political attention generated by the activism of some of these resourceful patients (see Chapter Four), led to a growing number of vulvar specialists during the late 1990’s and into the new millennium. Most operated either within a research ‘clinic’ (such as the one at OHSU), or through a more general gynecological practice; Dr. Goetsch, for example, maintained a half-time private practice after joining an emerging specialty clinic at a large research hospital. These providers, now more directly invested in articulating the clinical characteristics and criteria for these pain conditions, began asking different—along with a greater number of—questions about presenting patients (Foster and Hasday, 1997; Masheb et al, 2000; Glazer and Rodke, 2002; Edwards, 2003). Some of this research began to include the ‘racial’ and socioeconomic descriptors of symptomatic

women, an erratic and emic trend that only served to solidify providers' impressions regarding the demographic group from which their patients were drawn. Isabelle, one of my first informants, traveled out of state in early 2000 in order to consult with one of these specialists after seeing him on a PBS/Discovery channel episode of *The Body Human*. During our interview, she recalled being told by one of the physicians that there was a distinct—and Anglo—phenotype associated with VVS; this physician, who Isabelle described as “Middle Eastern,” even commented on her “pretty white skin” during the course of their consultation.

During this first wave, most researchers relied on Goetsch's prevalence data and continued to assume that approximately 15% of the population may be afflicted with vulvar pain. Indeed, the National Vulvodynia Association strategically deployed this figure in their efforts to secure greater legislative recognition of, and funding for, the effects of these conditions.¹⁵ It was not until Drs. Harlow and Stewart (2003) conducted their study for Harvard that Goetsch's figures were seriously submitted to replication efforts. The Harvard researchers wanted to first establish (new) prevalence figures by using a much larger sample size ($n = 3358$); their interests were also informed by questions and discussions that had emerged in the previous decade about the accuracy and implications of a phenotypic profile that seemed to be gaining ground. In other words, if *vulvodynia* and/or VVS were conditions specific to women with “pretty white skin,” it was imperative that research efforts at least *include* an attention to genetic predisposition and/or other biological markers. It was also important that the less

¹⁵ Evidenced by editorial updates in the NVA's quarterly publication, the *NVA News*: “NVA Forms Support Network,” (1995, 1(2)); “NIH Holds First Symposium on Vulvodynia,” (1997, 3(2)); “Congress Directs NIH to Fund Vulvodynia Research,” (1998, 4(1)); “NIH Holds Conference on Gender and Pain,” (1998, 4(2)); “NIH Allocates \$5 Million for Vulvodynia Research,” (2000, 6(1)); “NIH Awards First Vulvodynia Research Grants,” (2000, 6(2)); “NVA Meets with Congressional Leaders,” (2001, 7(1)); “NVA Awards Record Number of Research Grants,” (2006, 12(1)); “NVA Continues to Award Record Number of Grants,” (2007, 12(2)).

‘objective’ factors associated with a diagnosis (income level, education etc.) be more closely scrutinized. And finally, the association of vulvar pain with a heterosexual orientation was reason to investigate the role of particular behaviors and genital practices in the development of either of these conditions.

Conscripting a larger sample size was facilitated by Harvard’s survey-style approach, a method that also served to transform the analytical nature and implications of their study. A large-scale, and randomly generated, phone survey meant that women who had not (yet) self-identified with vulvar pain were given an opportunity to disclose symptoms that they had perhaps not previously understood in clinical or pathological terms. Harlow and Stewart had identified the need for this approach in their earlier pilot study, noting that, when asked, “women from the general population [we]re willing to provide sensitive information on lower genital tract discomfort—a first step toward bringing notice to this understudied disorder” (2001: 545). The dissertation as a whole examines some of the more theoretical implications of how disease conditions “manifest” through social processes and institutions like epidemiological research (see especially Chapter Four). For the purposes of this discussion, however, I want to take Harvard’s 2001 conclusions at face value, and suggest that their follow-up study in 2003 did indeed constitute a sea-change in the clinical data on vulvar pain. And, as we will see, this shift in analytical orientation began to produce quite different results.

Harlow and Stewart’s interest in speaking with ‘non-presenting’ women converged with an attention to the ‘racial’ profiling of patients with vulvar pain—an unprecedented 35% of their sample consisted of “non-white” women, a percentage that they claimed “allowed [them] to make one of the more accurate assessments” (87) of the racial distribution of these conditions. Whether it was the more inclusive nature of their data, or whether other as-yet-unidentified factors have contributed to an increased

overall prevalence of vulvar pain, Harlow and Stewart produced results that all but contradicted the assumptions held by the majority of clinicians invested in their data. Most startling was their assertion that “Hispanic women were at the greatest risk of unexplained chronic vulvar pain”¹⁶ (2003: 85), although this was followed closely by their finding that “there was very little difference in risk between white and African American women” (85). Although unprecedented at the time (“Nobody knows what to do with it,” was how Dr. Robichaud summed it up to me), several smaller-scale studies have emerged in its wake, each of them demonstrating that vulvar pain is not unique to Anglo-American women (Reed et al, 2004; Lavy, Hynan and Haley, 2007). It is these studies—not just those that have produced these new racial profiles, but rather those that are looking for vulvar pain *outside of* the offices in which symptomatic women present—that I am characterizing as the second ‘wave’ of vulvar pain research.

Importantly, a number of post-Harvard studies continue to suggest that vulvar pain conditions are found in a predominantly Anglotypic patient. This is not always in the form of explicit conclusions; rather the access to a “web-based” survey (Gordon et al, 2003; Kaler, 2006) or a general gynecological practice (Arnold et al, 2006) remains unquestioned in terms of the white “race” and high socioeconomic status of the women that constitute ‘cases.’ Other studies make more direct connections between the “whiteness” of vulvar pain and the presence of biological markers such as genetic and immunological alterations that contribute to a prolonged—and increased susceptibility to—physiological inflammatory responses (Bachmann et al, 2006). Indeed, one researcher (Foster, 2004)¹⁷ has reported that the interactions between specific genetic

¹⁶ They described an eight-fold risk in this study.

¹⁷ Full citation: Foster, D., Sazenski, T., and Stodgell, C. (2004). “Impact of Genetic Variation in Interleukin-1 Receptor Antagonist and Melanocortin-1 Receptor Genes on Vulvar Vestibulitis Syndrome.” *Journal of Reproductive Medicine*, 49: 503-9.

variations, including one involving melanin, lead to an “8-fold additive risk” of VVS for women with “light skin and red hair” (Bachmann et al, 2006: 454).

As intriguing as these assertions may be, what is most compelling from the perspective of a social scientist is that these two bodies of research—those that critically interrogate the ‘racial’ makeup of their samples, and those that propose a Caucasian phenotype—are not engaged in dialogue. This analytical gap is epitomized by the fact that Dr. Harlow, who co-authored the study that decisively reframed the ‘racial’ distribution of vulvar pain, is also one of the authors of Bachmann et al’s “State-of-the-Art” consensus statement on vulvodynia—a monograph that addresses race solely in terms of the biological markers of whiteness described above. It is not a primary goal of the dissertation to thoroughly engage with these very provocative data; this is a project for future research. I want to use the phenotype in question, however, to suggest that women with vulvar pain merit further feminist attention as subjects of the discourses of institutionalized and patriarchal medicine. I want to briefly examine the superficial—though uncanny—resemblances between the majority of women diagnosed thus far, and the women who ‘suffered’ both the symptoms and the ‘cures’ of neurotic hysteria at the turn of the 20th century. I want to do so in order to raise the specter of an embodied resurrection. By critically juxtaposing these two groups of ‘patients,’ I want to argue that there is at least one aspect of vulvar pain to which feminists have already attended: the elite marginalization of a group of educated and economically privileged white women in the hands of gynecological medicine.

The feminist paradox of hysteria is that its diagnosis relied on both the subordination and the almost hyper-civilization of (some) white women. Routinely conflated with children, criminals and deviants, animals, and non-white men, women at the turn of the 20th century occupied the latter half of the civilized/savage binary

(Ehrenreich and English, 1973, 1978; Haraway, 1989). Women who sought an education and/or an occupation of the 'mind' were met with resistance by dominant—and inferiorizing—patriarchal discourses and social structures. These pursuits were unavailable to non-white and laboring class women, but for distinct reasons. Discourses of racial superiority depended on clearly drawn, biologically-rationalized divisions between alleged 'races,' and sex-linked inferiority was dependent on many of the same rationale (e.g. of white male supremacy) (Briggs, 2000). In this period of increasing cultural contact, however, the salience of racial differences took social precedence, and white women were granted partial inclusion in a superior Caucasian 'race.' This meant proscriptions against educational and occupational advancement needed to be carefully couched, as the labeling of white women as too coarse, savage or deviant threatened a developing and race-based social hierarchy (Schiebinger, 1993; Horn, 2003).

The emerging science of neurology provided the tools with which women could be both included in a superior race and excluded from the full benefits associated with such membership. Delicate "nervous systems" were mobilized in order to rationalize not only the ineptitude of these otherwise privileged women for intellectual pursuits, but also to demonstrate their very real—and biological—differences from non-white women (Jackson, 1987; de Marneffe, 1996; Briggs, 2000). Preserving the purity and refined nature of this physiology was the basis for the physically confining (and socially isolating) 'rest cure' developed by neurologist S. Weir Mitchell and propagated by many of his colleagues. Justification for this cure was buttressed, of course, by the astounding variety and mutability of concomitant physical symptoms manifested by many of these women; these included choking sensations, convulsions, gastrointestinal problems, sleeping and breathing disorders, and depression (Wood, 1973; Wilson, 2004). The biopsychosocial nature of hysteria has been superbly analyzed by an array of feminist,

medical and critical historians; it is thus easy for most of us to agree with Elaine Showalter's assertion that "[h]ysteria is a mimetic disorder; it mimics culturally permissible expressions of distress" (1997: 15).¹⁸ In other words, 'hysterics' who were denied the social experiences (e.g. of education) that they sought, acted out *both* the roles through which they were interpellated (swooning and fainting) as well as their refusal to 'swallow' or comply with the limitations imposed upon them (choking and convulsions) (Merleau-Ponty, 1962; Cixous and Clement, 1986; Chisholm, 1994). Feminist author Charlotte Perkins Gilman, in a fictionalized account of her own experience, eloquently captures this overdetermined complicity: "I think sometimes that if I were only well enough to write a little it would relieve the press of ideas and rest me. But I find I get pretty tired when I try" (1989: 6).

This dissertation argues that *vulvodynia* and VVS are real physical conditions that are nonetheless circumscribed and informed by a socially structured "'symptom pool' through which distress is experienced and expressed" (Scheurich, 2000: 461).¹⁹ In the examination at hand, I want to historically contextualize contemporary medical discourses of neuropathic vulvar pain in order to deepen my investigation of culture and physiology—in this case, through the intersectionality of class, race and gender. In a thorough account of late 19th century European forensic anthropology, and its role in the discourses of 'deviance' that informed an emerging eugenics movement, David Horn (2003) describes how the science of *algometry* (pain measurement) serviced the social hierarchy through which conditions like hysteria were experienced. A heightened sensitivity to pain was equated with a more discriminating and civilized sensibility, and

¹⁸ See especially: Welter, 1966; Wood, 1973; Ehrenreich and English, 1973,1978; Showalter, 1985; Gilman, 1985; de Marneffe, 1996; Briggs, 2000; Didi-Huberman, 2003.

¹⁹ Scheurich is citing Edward Shorter in his use of the concept "symptom pool." See Shorter, E. (1992). *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era*. New York: Free Press.

algometry was practiced by prison physicians and criminologists in order to assign individuals biologically-derived—and therefore immutable—places on the social ladder.

Pain was not enlisted to extract the truth about illegal *acts*, as had been the case with torture, but rather to produce evidence of the biological nature of individuals and groups, and about the *dangers* that accompanied a “failure to evolve.” (90; emphasis in original)

Within this scientific discourse, not only was pain perception proportional to one’s level of civilization, but it was also linked with one’s moral sensibilities. Upper-class women with “pretty white skin” remained paradoxically positioned—inferior to and coarser than men, but more civilized than non-white or working-class women (Wood, 1973; Schiebinger, 1993). Elaborate narratives were constructed to support this multi-positioned social location, so that (white) women were variously defined as: less sensitive to *touch*, but more sensitive to *pain*; more likely to *fear* pain, and therefore complain of it earlier; or more likely to be “irritable” than men, irritability “being the ‘incipient, brute form’ of sensibility” (Horn, 2003: 99).²⁰ The bodies of less ‘evolved’ women—prostitutes, laborers, non-whites—were not capable of these discriminatory perceptions, and could therefore remain at the social margins.

In this historical context, it is difficult not to be struck by the repeated—and increasingly specific—descriptions of the “damaged” and hypersensitive nerve fibers of women with vulvar pain, particularly when these ‘nervous system’ anomalies are linked with a white phenotype. Clinical descriptions of “regional heightened [skin] responses” (Foster et al, 2007: 346), “exquisite [vestibular] tenderness,” (Bergeron et al, 1997: 27; Leclair et al, 2007: 53), “increased innervation” (Tympanidis et al, 2002) and “exaggerated inflammatory reaction[s]” (Bachmann et al, 2006: 454) in the bodies of affected women dictate treatment strategies that are couched—to both patients and

²⁰ Horn attributes this definition of irritability to Giuseppe Sergi, an Italian lawyer and anthropologist.

clinicians—in terms of “calming” the fired-up nerves that precipitate these conditions (Foster, Dworkin and Wood, 2005). Women with *vulvodynia*, whose pain cannot be temporally or anatomically circumscribed (see below), are particularly susceptible to these narratives. Suffering with generalized, poorly understood, and uncontrollable (read: excessive) symptoms, these patients are almost always offered some form of neuroleptic medication. Ironically, and uncannily resonant, the most effective of these drugs (in terms of pain reduction)²¹ have a sedating effect that can preclude intellectual and functional activity. Once attuned to this insight, it became difficult for me to watch the diagnostic process—where a writhing and contorted woman on the exam table is transformed into a compliant patient through the application of a topical anesthetic—and not wonder whether I was witnessing an eerie recursivity with, or an even eerier resurrection of, the symptoms of hysteria.

Drawing and elaborating the parallels between these two conditions constitutes the bulk of my analysis in the dissertation, but I want to end this discussion in the ‘racially’ framed terms with which it began. I first must assert that vulvar pain is doing the work of hysteria, particularly if we define it in Showalter’s terms (above). In other words, if “hysteria is not a discrete syndrome, but rather is the form that illness necessarily takes in a complex, social, symbolic creature such as a human being” (Scheurich, 2000: 465), then we can begin to understand vulvar pain as a set of conditions whose symbolic meaning cannot be extricated from their biological reality.

I will argue throughout the dissertation that an inability to participate in penetrative intercourse at least partially indexes a “postfeminist” (Johnson, 2002; Gerhard, 2005) ambivalence towards the forms of (hetero)sexual expression available to these relatively privileged and mainstream women (see Chapter Five for further

²¹ These are the antidepressant *amitriptylline* and *gabapentin*, a drug prescribed for bipolar disorder, seizure control and neuropathic pain conditions.

discussion of this). Genital ‘burning’ that represents pain and refusal—rather than arousal and desire—functions mimetically, allowing these women a space to more deeply explore the nature of their sexuality while they ‘sit out’ the coital activities expected of them by their husbands, friends, physicians and cultural heteronormality. But, for me, the resurrection of hysteria offers feminists and critical theorists of the body something more than another iteration of a gendered somatiform disorder. I suggest that if “hysteria, by whatever name, is alive and well” (Sheurich, 2000: 462), then we have an opportunity to more effectively analyze its relationship not only to gender, but to race and class as well. This might mean thinking through vulvar pain diagnoses as *constitutive*, rather than reflective, of a privileged whiteness. This move allows us to more critically examine claims of disparate access that, while possibly accurate, do not fully explain why *vulvodynia* and VVS either *erupt* primarily in the bodies of privileged women, or why they are only medically *attended* to when they do. In order to better accomplish this task, I will next turn to the disorders themselves in order to more fully describe some of the physical and emotional contours through which they are lived.

Vulvodynia is chronic vulvar pain in the absence of objective abnormalities such as infection or dermatoses. Dyesthetic *vulvodynia* (newly termed generalized vulvar dysesthesia) refers to episodic unprovoked stinging, burning, irritation, pain, or rawness anywhere on the vulva. *Vulvar vestibulitis* (newly termed localized vulvar dysesthesia) refers to pain consistently localized by point pressure mapping within the vulvar vestibule (Harlow and Stewart, 2003: 82; my emphases).

I begin my description with the above definitions of my subject matter for several reasons: they describe the main difference between the two experiences of vulvar pain (generalized vs. localized), but they also—in their revisions of extant nomenclature — index the ways in which these conditions are currently being *realized*. Definitions and diagnostic criteria for vulvar pain are both straightforward (pain at the vulva) and multiple (provoked vs. unprovoked? burning vs. knifelike? redness, rawness, irritation or none of the above?), clinical (neuro-inflammatory pain) and sociological (“something of a medical mystery”) (Kaler, 2006: 82). The authors of the “[s]tate-of-the-art” consensus panel convened by the NIH in 2004 defined vulvodynia as “chronic pain lasting from 3 to 6 months in the vulvar region without a definable cause” (Bachmann et al, 2006: 448), and defined VVS as a diagnostic “subset” of that condition. In this section, I will use these published criteria as background to my ethnographically-informed descriptions of vulvar pain. Neither, I suggest, is more accurate or useful. Rather, I hope to use the narratives of women that I met in the field to animate, ‘flesh out’ and complicate the medical narratives that structure the institutional experience of vulvar pain.

Patients at OHSU were diagnosed within one of three main disease classifications: *vulvar vestibulitis syndrome (VVS)*, *vulvodynia*, or one of three “lichen”—*lichen planus*, *lichen simplex chronicus* and *lichen sclerosus*. The vast majority of clinical literature does not include the latter category in their consideration of chronic vulvar pain, as they are conditions that are significantly more ‘explainable’ than the first two. As a “Program in Vulvar *Health*,” however, the clinic at OHSU manages patients with these syndromes since the symptoms and experience of living with them do not differ tremendously from diagnoses in the ‘unexplained’ category. Indeed, the phone calls that lead to initial appointments in the clinic are suffused with a genital alienation and unfamiliarity that does not discriminate between conditions that

are poorly or well-understood by clinical medicine. The skin of a woman with one of the ‘lichen’s may respond well to the treatments prescribed by an expert dermatologist, but it is unlikely that the woman inhabiting that skin will leave his or her care with a more fully integrated genital body. Since all three of these conditions are seen and managed by Drs. Robichaud and Erlich with some regularity, I will review each of them below with a combination of published, anecdotal and ethnographic data.

I. Vulvar Vestibulitis Syndrome (aka localized vulvar dyesthesia, aka vestibulodynia). VVS distinguishes itself from other categories of vulvar pain by its precise and singular location. The vulvar *vestibule* is a small (0.5-1.5 cm), horseshoe-shaped area of endodermic tissue that surrounds the opening to the vagina (the *introitus*). Looking at an introitus as the center of a clockface, the vestibule is the (typically) light pink and adjacent skin that extends outward from the 3:00 to 9:00 positions (See Figure 1). Women with a classic presentation of VVS experience skin pain *only* in this area (localized) and *only* with touch (provoked). The pain is thought to be neuropathic and/or inflammatory in nature; it is also thought to be superficial (Bergeron et al, 1997; Bachmann et al, 2006). For this reason, an application of a topical anesthetic (e.g. lidocaine—in liquid, ointment or gel form) is capable of eliminating the pain for short periods of time. Clinicians diagnose VVS first by localizing the woman’s pain to the vestibule, and then by applying light pressure with a cotton swab from 3:00 to 9:00 with a q-tip, gauging both intensity (0-3, 1-10) and quality (burning, zingy, raw) of sensations. Once these parameters have been established, the clinician covers the entire area with liquid lidocaine, waits several minutes, and then repeats the “q-tip test.” A reversal or extreme reduction of pain is diagnostic for VVS.

At OHSU, clinicians ask patients to subjectively rank their pain from 0-3, with 3 constituting the top end of the scale. They occasionally switched to a 1-10 scale, and they sometimes used words in addition to—or instead of—numbers. These would usually be a combination of the woman’s spontaneous expressions (“Yeah, that’s ‘don’t go there,’””) and words that they would provide (“Is that ‘zingy’ or just kinda ‘ouch’?”). Sometimes the clinician would provide a handheld mirror to the patient, so that she could visually identify the “zones” at which her pain began and ended. In the majority of exams that I observed, the woman had neither a working knowledge of, nor a language with which to describe, the parts of her vulva that contained her pain; these same women, however, were able to be very clear about what hurt and what didn’t. “Yeah, right *there!* That does *not* feel good!” was a phrase that I heard over and over again while clinicians mapped out a woman’s vestibule. These women were also usually able to reach down to their genitals with their fingers and orient the clinician at the beginning of the exam—“Um, it’s usually right around here...”

In order to be clinically diagnosed with VVS, then, a patient must first display a change in her response to the light touch of a q-tip as it moves from an asymptomatic area (e.g., her inner thigh) to her vulvar vestibule (Bachmann et al, 2006). Depending on the amount of pain that she manifests, a clinician may also ask a patient to supplement the exam findings with an appropriate symptom history. This would include—indeed would be *marked by*—a description of vulvar pain that is specific to touch. (This is one feature of VVS that notably distinguishes these patients from the other two groups in that many of these women narrate symptoms in terms of their husband’s desire for sexual/genital contact: “I wouldn’t even be here if it wasn’t for him,” for example.) The women from my sample who were diagnosed with VVS presented—and were diagnosed—in this manner. Although often significantly alienated

from their vulvas, and therefore unable to apprehend the localized nature of their pain, they almost always described their symptoms in relationship to genital contact, particularly penetration; this was delimited, in their narratives, to tampons, speculums and penises. Many—if not most—of these women had seen at least one other provider and been met with treatment plans ranging from confusion, to exhortations to “just relax!,” to excisional procedures. If I encountered them at OHSU, however, they were still experiencing significant pain, and were still seeking to identify not only its source, but also a route to some relief.

The women from my sample were all heterosexual (married or engaged) and insured, all had or were pursuing a college education, and all—but one—were Anglo American (Mira was South Asian). Some came to the clinic specifically to see Dr. Erlich and to request the modified vestibulectomy for which she was ‘known’ in vulvar pain circles (including online support networks). Some came hoping to find out that their condition was far less serious than they feared, and some came with the fear that their husbands would leave them if they could not participate in penetrative coitus in the near future. All but one of these women were religious, and had postponed sexual relations with their partners until they were married or, in Mira’s case, committed to each other with an engagement. All of these women were in their childbearing years and most were under 30 at the time of their diagnosis. Some had been aware of their pain from the time that they first attempted to use a tampon and others did not discover it until they attempted to have—or shortly after they began having—intercourse. All of these narrative events and demographic factors are consistent with the clinical literature, down to the details of “disastrous” wedding nights and the overconsumption of alcohol in hopes of relaxing their (unconscious) sexual inhibitions (Kaler, 2006; Buchan et al, 2007a).

At OHSU, treatment options for VVS were directed towards anesthetizing, repairing or excising the affected skin. All patients were offered a prescription for the liquid lidocaine used diagnostically by the physicians, and they were encouraged to use it liberally in their attempts to engage in penetrative intercourse. This meant that each patient was first oriented to her vestibule with both a mirror and a greater-than-scale drawing (see Appendix A), and then instructed to apply the lidocaine five to ten minutes before she anticipated and/or desired contact (including physical therapy sessions and clinical exams). Dr. Robichaud also routinely prescribed nightly application of lidocaine in the form of an ointment, based on the results of one study that had demonstrated some reduction in overall pain after seven weeks' use (Zolnoun, Hartman, and Steege, 2003). Beyond the provision of anesthesia, patients were counseled through various configurations of other available therapies: pharmacological, physical, laser and/or surgical.

Both vulvodynia and VVS are understood in neuropathic terms, but a main difference in contemporary medical narratives is that VVS's pain is thought to be local, i.e., at the peripheral nerve endings, whereas vulvodynia is thought to be generalized, or based in the central nervous system. This distinction has become clearer through the limited response that VVS patients show to the use of tricyclic and SSRI antidepressant medications, which target the regulation of neurotransmitters like serotonin, neurepinephrine and dopamine.²² In other words, regulating the circulation of neurotransmitters can affect both mood stability and—perhaps—some kinds of systemic pain perception; the localized and inflammatory nature of VVS pain, however, is not receptive to drugs that act in this way. For this reason, SSRIs may be offered to patients

²² SSRI being the acronym for selective serotonin reuptake inhibitors, a class of antidepressant that includes the drugs Prozac, Lexapro, Paxil, and Zoloft. A newer version of these drugs—SSNRIs (Cymbalta)—also regulate the reuptake of neurepinephrine. At the time I was at OHSU, these were just being introduced, and clinicians were hopeful that they could be more effective with vulvar pain patients.

who are thought to have a *vulvodynia* component to their pain, or to women whose pain has become enmeshed with depressive symptoms and/or emotional and sexual “shutting down.” It does not, however, constitute a first-line therapy for VVS.

Many clinicians—including Drs. Robichaud and Erlich—believe that the skin of patients with VVS has been locally, superficially, and situationally damaged through a combination of genetic predisposition and exposure to environmental stressors (such as repeated yeast infections) (Chadha et al, 1998; Foster et al, 2007). Leclair et al (2007) describe the histologic features of VVS as consisting of “nonspecific inflammation of the vestibular epithelium and a higher density of nervous tissue” in addition to areas of angiogenesis (i.e., construction of new blood vessels) that are “thought to be a result of vascular injury, although the nature of the insult is unclear” (54). Their paper addresses the (at times) successful efforts that have been made to attribute an infectious, hormonal and/or immune system etiology to VVS, although they conclude that because the “significance of these changes is undefined[, i]t is unclear what part [they] play ... in the overall pain syndrome” (54). Not wishing to limit their treatment efforts by an incomplete causal narrative, however, the doctors at OHSU direct their interventions toward the removal or alteration of the adversely affected skin of women with VVS. Physical therapy is also prescribed, but it is important to understand that this is an adjunctive maneuver. As I described in Chapter One, women with VVS have learned to flinch, tense up and pull away from anything resembling vulvar/vestibular contact. This almost always means that their pelvic floor muscles have become tight and contracted, and that they feel painful and “burning” sensations with penetration, *regardless* of whether their vestibular skin has been removed or repaired. Physical therapy is directed, then, towards the resolution of the concomitant problem of pelvic floor myalgia, but is

not thought—by clinicians—to directly address the problem of the “skin pain” (Bergeron et al, 2002; Goetsch, 2007)

Dr. Robichaud typically encourages her new patients to start with lidocaine, and lots of it: seven weeks of nightly ointment combined with situational, liberal and experimental use of the liquid variety for penetration and physical contact. She almost always prescribes physical therapy, and she occasionally treats a patient with an SS(N)RI for the reasons I have indicated above. Dr. Robichaud does not consider surgery to be a treatment of last resort, and she discusses it with patients at these initial consultations, but she assertively co-opts her patients into taking a ‘long view’ approach to their symptoms, suggesting that they try these first suggestions for three months before returning to see her. Dr. Erlich, on the other hand, accumulated much of her vulvar expertise around the development of her surgical technique, and patients often come to OHSU for this very reason. Her treatment plans, therefore, are often not as conservative; she is reluctant to withhold surgery from a woman who is clear that it is the intervention best-suited to her situation and bodily predilections.

Both doctors, however, offer their VVS patients a kind of in-between approach in the form of a non-invasive laser therapy. Indeed, at the time of my fieldwork, the OHSU clinicians were actively enrolling new VVS patients in a research study designed to compare the efficacy of laser therapy with (surgical) vestibulectomy. Laser therapy was thought to address the angiogenetic element of VVS—targeting and selectively disrupting the increased blood vessel formation—as well as the nerve density component, while “preserving anatomy” (Leclair et al, 2007: 54) in a way that excisional surgery could not. Of the women with VVS that I met during my fieldwork, only a small percentage opted for this procedure. The physicians recommended that patients undergo 4-7 treatment sessions before evaluating the efficacy of laser therapy,

and many women found this to be decisively unappealing; these were usually the patients who wanted a quicker and more ‘guaranteed’ approach to their pain. Additionally, since the use of pulse/dye lasers was still experimental for vulvar pain, these women felt more secure with a vestibulectomy, a procedure with a steadily increasing record of efficacy (Goetsch, 1996; Bergeron, 1997; Kehoe and Luesley, 1999). Related to this first concern was a worry that the ‘off-label’ use of dye lasers²³ would not be covered by insurance policies.

Finally, both doctors offered and performed the modified vestibulectomy developed by the same Dr. Goetsch who conducted the early prevalence study in 1991.²⁴ Surgery was typically chosen early in a patient’s treatment plan—it was rare that I saw someone move through all the other options before electing to undergo a vestibulectomy. The procedure consists of first mapping the affected skin with a “q-tip test,” and then excising an area that is large enough to remove it all without being too disruptive of the patient’s genital anatomy. Guided by the pain reversals that topical anesthetics can produce, the excision is only 2-3 mm deep; skin from hymenal “tags” is then pulled down from the introitus to cover the open area (see Appendix B). Surgery was sometimes described to patients in terms both curative and preventive. The ectodermic nature of hymenal tissue was thought to obviate the possibility of a recurrence, since only endodermic tissue, in Dr. Erlich’s words, could “get vestibulitis.” Excised tissue was always biopsied at OHSU, although the results did not consistently demonstrate an inflammatory or pathological disease process. Surgery remains

²³ These lasers are primarily used by dermatologists to remove birthmarks and other vascular-based skin lesions.

²⁴ A vestibulectomy removes the entire vulvar vestibule at a depth of just a few millimeters and a width that extends to the line of demarcation known as Hart’s line. The surgeon uses the skin at the opening/outer third of the vagina (pulled down) to replace the excised tissue. In Dr. Goetsch’s “modified” vestibulectomy, a smaller area of the vestibule is excised (mapped by the patient’s subjective reporting of pain with a q-tip test), and hymenal tissue, rather than the vagina itself, is pulled down to cover the area. See Goetsch (1996) for further details.

controversial enough (still a “last resort” for some clinicians) that risks are both amplified and mitigated in the literature, but they include infection, excessive bleeding, abnormal scarring or other anatomical complications, and—of course—continued or worsened pain. During my fieldwork, I followed five women through surgery and learned of only one postoperative complication, which was eventually resolved. All surgical patients are highly encouraged to pursue physical therapy and sexual/marital counseling, as well as to practice vulvar care measures with their skin (hypo-allergenic products, non-irritating fabrics etc).

II. Dyesthetic vulvodynia (DV). “Newly termed generalized vulvar dysesthesia,” (Harlow and Stewart, 2003: 82), *vulvodynia* is the second category of pain seen by clinicians at OHSU. Despite an ongoing evolution, the various terms used by researchers to refer to *DV* continue to translate into *maladaptive or inappropriate pain sensations at the vulva*. Like their cluster of symptoms, the characteristics of women diagnosed with this condition are slightly less circumscribed than are those of *VVS* patients, almost all of whom narrate a predictable and similar set of events leading up to their clinic consultation. In contrast, women with *DV*—though phenotypically and socioeconomically similar to each other and to women with *VVS*—are slightly more varied in their disease presentation, sexual histories, responses to treatment, and personal narratives. At OHSU, these women were typically older than *VVS* patients—the youngest in my sample were at the ends of their childbearing years—and they were not always as educated. This group contained more outliers (e.g., one woman in my sample identified as a lesbian), but generally lined right up with the prevalence data, in that all of the women that I met with *DV* were Anglotypic (Baggish and Miklos, 1995; Edwards, 2003; Arnold et al, 2006).

The two other significant differences between this group of patients and women with VVS were their relationships to penetrative intercourse and the characteristics of their pain. All of the *DV* patients whom I encountered developed their symptoms *after* a period of time (up to ten years) when sex had not been painful. Some were in sexual relationships that were now complicated by their symptoms, but some were not. These characteristics are related to a third mode of distinction: that is, because the pain of *DV* is unrelated to touch or provocation, these women were far more likely to seek relief on their own behalf rather than that of a partner. *DV* pain is more diffuse than is VVS—it cannot be precisely mapped or delimited to one or two areas of the vulva, and the quality is more fluid. It can be constant, flare-like, dull, burning, cyclic or predictably aggravated, concomitant with another condition, responsive to a wide variety of products, or all (or none) of the above. A ‘classic’ presentation of *vulvodynia* (which is more like a Weberian *ideal type*) typically includes pain that is prohibitive of *something*—this means that the removal or cessation of particular fabrics, products, and/or activities often constitutes a significant part of a *DV* patient’s life. In Oregon, this was especially notable, as roughly half of the patients I met rode horses or bicycles more than casually, and had to either give up these activities, or drastically alter the situations under which they could participate. Julia Kramer, a young Latina woman whose pain had both VVS and vulvodynia components, told Dr. Robichaud that her drawer-full of non-cotton lingerie had become “a museum”—full of panties that she continued to admire, but could no longer wear. It is important to reiterate that none of these irritating agents or activities are thought to cause *DV*; indeed, its onset is most often unrelated to any identifiable event or causative agent (Buchan et al, 2007a).

The uncontained nature of vulvodynia seems to seep over the diagnostic process itself in that *DV* is often a diagnosis of exclusion. A “q-tip test” in which the pain is not

reversed by topical anesthesia, cultures that are negative for viral, bacterial and/or fungal pathogens, and a history of unremitting pain with a “burning” quality constitute a strong case for *DV*, but it is not unusual for one or more of these factors to have a less-than-straightforward clinical presentation. Patients with these symptoms are no less anatomically alienated or linguistically reticent, making the gathering of a medical history equally challenging. And although these women are also likely to describe “shutting down” sexually, the discontinuation of sexual and genital contact does little to alleviate symptoms that are largely unprovoked. These patients can be clinically vexing, and require a level of care and expertise that is virtually unavailable outside of specialty clinics like OHSU. Physical changes are not obvious to an untrained eye, and sexual despair is often unappreciated by an inexperienced ear. Ethnographic, anecdotal and research-based evidence all indicate that these patients ‘do better’ when seen frequently and from a multidisciplinary approach (Wojnarowska et al, 1997; Jensen et al, 2003; Buchan et al, 2007b).

Since the pain of vulvodynia cannot be localized, nor reversed with topical anesthesia, these women are not candidates for surgery, laser therapy, or situational lidocaine use. Dr. Robichaud still offers these women nightly lidocaine ointment, however, counseling them that although Zolnoun’s study did not include women with *DV*, they might still benefit from its regular application. *DV* patients are also referred to physical therapy, although it does not hold the same promise as it does for women with *VVS*. This is true for several reasons. First, this group of patients has both tolerated and (more than likely) enjoyed vaginal penetration in their past, which means that their pelvic floors are not nearly as contracted and traumatized as women for whom genital approach *equals* pain. Many of these women have also had children, providing them with a slightly greater familiarity with the muscles of their pelvic floor. The third reality

is that, as I have just suggested, these women are more apt to seek relief for their symptoms sooner; their pelvic floor tension, therefore, has likely accumulated over months rather than years, making their recuperation of its flexibility easier. Physical therapy plays a role in the treatment of these patients, but it rarely makes the kind of life-altering difference that it does with VVS.

The poorly understood—and clinically challenging—nature of *DV* is eloquently captured by Buchan et al's summary of the literature:

Some success has been reported with the use of topical anesthetics and steroids, low-dose amitriptyline and other tricyclic drugs, gabapentin, antifungal medication, dietary manipulation, biofeedback, psychotherapy, acupuncture, laser therapy and surgery (2007*b*: 19).

Treatment, as we can see, is all over the place, and often only moderately successful. Specialists like Drs. Erlich and Robichaud are cognizant of the need for a “multidisciplinary” approach, but cannot usually accommodate this need in routine practice. Many of the above therapies are not covered by insurance plans, nor desired by patients themselves (e.g. psychotherapy), and some are complicated by deleterious side-effects, such as the disruptive sedation caused by both amitriptyline and gabapentin.²⁵ Switching to the SSRI neuroleptics brings the likely risk of anorgasmia, however, a side-effect that is poignantly counterproductive for the sexual recuperation of these patients. Effective doses of steroids carry long-term risks of immune system compromise, and the evidence regarding dietary modification is scant enough that OHSU physicians do not feel justified suggesting changes that are extremely difficult to maintain.²⁶ It is difficult, then, to convincingly purvey any of these therapies in ‘solution-oriented’ terms.

²⁵ Both of these drugs were used at OHSU, but usually with older (to the clinic) patients. That is, patients for whom they had been prescribed before SSRI's became available. The side-effects were real and patients described problems with them, but patients on these drugs reported the best pain relief of any of the vulvodynia patients I saw.

²⁶ A notable one of these being a “low-oxalate diet.” One theory about vulvar pain conditions is that they are related to (or at least exacerbated by) the vulva's exposure to chemical compounds known as urinary

My fieldnotes from a day that I found especially taxing make this observation: *These women are the ones whose sexuality we just don't want to deal with. And they themselves don't seem to want to deal with their symptoms. Or their treatment. It's messy. And it's difficult.* And so, although they might have turned up in the clinic sooner, I found these women to be as genitally reluctant as were their peers with VVS. And I found them to express equal—if not greater—degrees of ambivalence about returning to sex lives that had been defined in primarily penetrative terms. Ashley, for example, told me that she finally sought help when it “just felt like the whole inside of [her] vagina was raw” and like her partner was “wearing sandpaper for a condom.” In fact, what Ashley told her physician was that she had “some pain with intercourse,” for which she was told to use more lubricant. She tried talking with her partner when “it got bad enough,” but told me in our interview that “it wasn’t really any kind of a conversation. They mostly think it’s in our head—it goes along with the whole headache thing.” Believing her physician that it was solely an issue of lubrication, however, Ashley dutifully purchased a new product. Not only did this do nothing to relieve her pain, it had the unintended effect of causing her partner to believe that she was not aroused by him. When I asked Ashley if she and her partner had discussed things that he might do differently (in order to attend to their then-perception of the problem), she said “I, um ... I did try the lubrication. It’s not anything that I’m comfortable enough to ask anything at all. You grit your teeth and hope he gets the message.”

But gritting one’s teeth can only take a woman so far. In the end, these patients are primarily managed with antidepressant medications (prescribed as neuroleptic

oxalates, and that a stark reduction in their intake (and therefore output) can mitigate pain sensations. Oxalates are quite prevalent in fruits and vegetables however, making the diet quite difficult to maintain, especially for vegetarian women. See Baggish, Eddie and Johnson, 1997 and Bachmann et al, 2006 for further discussion (both pro and con).

agents), close clinical follow-up, and encouragement. They are urged to seek support with the local chapter of the NVA and/or to use online networks if they find them helpful. My experience with these patients was provocative and mixed. Ashley, for example, was a woman whom I did not look forward to interviewing after I met her in the clinic—her affect was flat and depressive and I recall telling Dr. Robichaud that I was dreading our upcoming lunch. For a time, I personified *DV* with Ashley’s affect—stubborn, kind of annoying, somewhat incomprehensible, and something/someone with which I’d rather *just not deal*. At Denny’s, however, Ashley was surprisingly animated, smart, and ribald, and our interview was an effortless two hours. Her pessimistic outlook was still hard for me to *deal with*, but, I have come to realize, so is female genital *dis-ease*. I have therefore decided to recode vulvodynia—and Ashley as its poster-girl—in the more complete, though contradictory, terms invoked by the lived experience of this disease condition: older, insistent, frustrating, a painful reality, somewhat recalcitrant, an erratic self-advocate, and a waving red flag that something is in need of attention.

III. The “Lichens”. This last category of pain conditions is more successfully managed, if not better understood, by the clinicians at OHSU. The three diagnoses that make up this group—*lichen planus*, *lichen sclerosus*, and *lichen simplex chronicus*—are inflammatory conditions that are presumed to be autoimmune in nature (Lottery and Galask, 2003; Byrd, Davis and Rogers, 2004). The first two, in particular, are commonly managed by dermatologists with either topical steroids or immune system modulators, in addition to therapeutic skin care regimens. Conventional dermatologists are not always attuned to the special needs of these patients, however, and several of my research informants disclosed histories of inadequate—even neglectful—treatment in the

hands of these physicians. What the doctors at OHSU offered to these women was an investment in the well-being of their vulva and genitalia, which necessarily included an attention to their anatomical integrity, sexual expectations and desires, and emotional reactions to being diagnosed with a chronic genital condition. Control over the symptoms of these diagnoses could be achieved relatively easily with a combination of several effective and available topical therapies. However, the reluctance and ambivalence that many of these women felt toward their genital bodies often challenged their abilities to successfully comply with prescribed treatment plans. A routine prescription for the nightly use of a vaginal suppository or cream, for example, was often made more difficult by both the bodily awkwardness of the patient and the thwarted—and penetrative—aims of a disappointed partner.

Lichen planus (LP) and *lichen sclerosus (LS)* are both chronic and autoimmune disorders of the skin and mucous membranes. Both affect the vulva but not exclusively; *LP*, for example, commonly occurs in the mouth (Edwards, 1989; Smith and Haefner, 2004), and *LS* can also affect male genitalia (Friedrich, 1983; Kunstfeld et al, 2003). On exam, *LP* is raw, moist, red and irritated; *LS* is white, dry and leathery. Both of these conditions can result in irreversible contour changes to the labia, and *LP*—if not managed correctly—can lead to drastic reductions in vaginal patency. Both are understood in chronic terms; patients are counseled about a lifetime of medical management, and that underlying cellular changes are associated with a slightly increased risk of vulvar malignancy (Renaud-Vilmer et al, 2004; Smith and Haefner, 2004).

In an autoimmune disorder, the body mounts an immune response—in the form of specific cells, chemical reactions and antigen production—in the absence of an identifiable foreign substance or pathogen. In other words, although often detrimental, it

is normal for a body to “reject” the presence of a transplanted organ, but it is maladaptive when that same physiology is deployed in the absence of a bodily threat. Autoimmune conditions, such as fibromyalgia, systemic lupus erythematosus and Crohn’s disease, are life-altering not only because of the severity of their symptoms, but because the most effective way to alter this inappropriate immune response is with the use of steroids (Ahmed et al, 1999). Since steroids work by ‘turning down’ the immune system (mitigating the ill-effects of these conditions, e.g., pain in fibromyalgia, bowel inflammation in Crohn’s disease), users are rendered immunologically vulnerable and plagued with potentially irreversible side-effects (osteoporosis, weight gain, impaired glucose tolerance/’steroid’ diabetes, growth suppression) (Stanbury and Graham, 1998; Citterio, 2001). *LP* and *LS* are challenging to clinicians without vulvar expertise, whose (legitimate) concerns about steroids override their investments in the anatomical and sexual integrity of women who might lose their genitalia without their judicious use.

In the case of *lichen planus*, the vagina acts *as if* it were responding to a bacterial or viral agent, and—in addition to producing copious amounts of inflammatory discharge—becomes red, irritated and hypersensitive. According to Smith and Haefner (2004), the “exact cause [...] is unknown [although] there may [be] a genetic link” (105). Unless halted or suppressed (e.g. with steroids; antibiotics are ineffective since there is no bacterial agent to treat) the inflammatory nature of the discharge will begin to permanently scar and compromise the patency and suppleness of the vagina. In addition, gravity’s anatomical pull on this discharge results in the vulva being exposed to its deleterious effects. The results are similar to those noted in the vagina, including a hardening and loss of suppleness to the usually soft folds of labial flesh, as well as some loss of flexibility and mobility around the clitoris and its hood.

The skin changes and pathology of *lichen sclerosus* are somewhat different. There is no discharge from the vagina, obviating the patency concerns of *LP*. Indeed, the lack of discharge and obvious inflammation are what make *LS* changes more insidious and potentially more severe. That is, a woman unaware of what her vulva “should” look like, and in the absence of generally understood markers of disease such as redness, heat, pain, and discharge, is unlikely to attend to vulvar skin that is becoming slightly drier, whiter, scallier and/or mildly itchy. By the time she is symptomatic with intolerable itching and/or vulvar pain, these changes are likely to have become irreversible. For this reason, *LS* visits were often some of the more emotionally difficult ones to observe during my fieldwork.

Loss of labial contour can be a mostly cosmetic issue, usually unaccompanied by any functional impact or change. Were she to inspect, a woman might notice labia majora that were flat and reduced in size and thickness; they might appear shiny or leathery in texture as a result of the subtle and cumulative scarring taking place. The majority of women that I have encountered—in clinical practice, personal relationships, and as informants—would neither notice nor be overly troubled by such changes, particularly if they were not associated with malignant, sensory or functional outcomes. Vaginal scarring, however, can progress to a partial or complete stenosis, and chronic vulvar flattening can cause the labia and clitoral hood to lose their flexibility and sensitivity. In clinical terms, the skin will have “[w]ell-demarcated, smooth whitish shiny plaques” and will be “thin and fragile with a cellophane paper-like texture” (Kunstfeld, et al, 2003: 850). When I met Mary Hudson, her *LS* was very well-controlled—she saw Dr. Robichaud at least every six months and she joked that she had made “an altar” to the medication that was successfully keeping her symptoms at bay. During the exam that I observed, however, she described the “muffled” nature of her

clitoral orgasms as Dr. Robichaud confirmed that the retractibility of her clitoral hood appeared to be irreversibly impaired. Indeed, Mary's clitoral tissue had severely receded several years before she found OHSU. When I interviewed Mary over breakfast a few weeks after we met, she gave me a fuller account of the ill-informed conditions under which her *LS* was detected:

MH: Um, I'm up in the stirrups [and a]ll of a sudden she goes "Oh my god," I mean, "OH MY GOD! Did you have a clitorectomy [sic]?" I'm like, 'what?' [... S]he rushes off and gets the gynecologist. 'We're going to do a little biopsy.' [...] The good news is I don't have a, I don't have a history, a story of *suffering* in the past. I ha-, .. and it was so, I was quickly diagnosed. Um, at that point in time I had *no* pain, *no* discomfort,

CL: No itching?

MH: [N]o symptoms, no *nothing*. And, Jan and I had noticed that there was kind of a whitening, and, you know, sort of what appeared to be retracting of skin and,

CL: Jan is your partner?

MH: My partner. My spouse!²⁷

CL: Congratulations!

MH: And um, .. you know you just .. because nothing, everything still w-, you know, nothing's changed in terms of *function*, um, the assumption is 'oh another sign of aging (laughs). I didn't know this happened.'

LP affects both the skin and the mucous membranes, making it more acute and visible. The skin of an *LS* patient, as Mary's story reveals, is subject to a variety of misinterpretations about the (female genital) body. Ugly, worn, aged and/or strange are characteristics routinely associated with the vulva; indeed, an *LS*—i.e., physiologically diseased—vulva might well resemble "something that fell out of a ten-story window." Raised with this narrative, both symptomatic women and inexperienced physicians often allow these changes to progress beyond the point of full recuperation. In the most extreme presentation of *LP* or *LS*, a gynecologist may need to surgically separate the

²⁷ Mary identified as a lesbian, and Portland had just legalized gay marriage when we had this conversation.

labia to make the vaginal and urethral openings accessible again. We will revisit this issue, as well as greater details about the treatment of these conditions, in Chapter Four, *Manifestation*.

And finally, there is *lichen simplex chronicus* (*LSC*) which, despite having the word *chronicus* in its name, is actually the vulvar condition that is the least so. Dr. Robichaud characterizes *LSC* as the physiological outcome of an itch-scratch-itch cycle that she believes often has a stress/central nervous system component. Indeed, some of the earliest literature on *LSC* described its changes as “neurohistologic” (Cowan, 1964: 562). *LSC* may be concomitant with other genital conditions; Dr. Robichaud first diagnosed Daphne with this and, once she had brought it under control, had a clearer picture of her underlying *VVS*. In some ways, *LSC* represents a conceptual/clinical bridge between the lichens and the other two types of vulvar pain, in that the histologic changes can be more consistently demonstrated on a biopsy (as with the other lichens), but there is clearly a side to *LSC* that is psychologically aggravated—perhaps even provoked—and well-sustained by cultural norms that marginalize its existence.

The initial itching in *LSC* is in response to some kind of stressor, which might be derived environmentally (a product) or internally (anxiety) (Virgil et al, 2001; Foster, 2002). Whatever the cause, when a woman begins to scratch, she layers skin disruption on top of the original stressor, compounding the inflammation and skin distress and leaving the underlying problem unaddressed. Dr. Robichaud suggested to me that *LSC* often has an “OCD component” and she typically used the medical history of these patients to mine for such behavior. I encountered only a few women with these symptoms during my fieldwork, but each time I did, Dr. Robichaud said something after the interview like “Did you hear that? She can’t stop scratching ...” She often followed this observation with a theory about what “function” the scratching was performing for

these women. She told me about one of her patients—a university professor—whose *LSC* “always acts up at the end of the semester when she has a lot of grading to do, or when she has horrible deadlines that she has to meet.” On more than one occasion, I heard patient’s compare their *LSC*-related scratching with the behavior of an allergic or irritated dog: “I’m like a dog. I just want to scoot myself along the floor. It’s driving me crazy!” Indeed, “driving me crazy” is a phrase frequently uttered around this disease.

Treatment of *LSC* is directed at eliminating the initial stressor, if it can be identified, and/or stopping the itch-scratch-itch cycle (Lynch, 2004). This often consists of short-term steroids and/or histamine blockers to stop the scratching that has become a compounding stressor. Dr. Robichaud also recommends the repeated—and heavy—application of an emollient (such as Vaseline or Crisco) that will protect the skin from further injury without adding any potential new ingredients to the mix. Patients are seen frequently (once or twice a week for several weeks) in order to support them in “withdrawing” from the scratching; once the skin is healed, patients might be treated with an SSRI or other psychoactive medication if the primary stressor is deemed psychological. Otherwise, the patient is counseled to avoid any other identified irritant and/or to return to the clinic promptly should her symptoms recur.

The setting, the actors

The Program in Vulvar Health (PVH) is a virtual “clinic” that operates under the auspices of the Oregon Health and Sciences University (OHSU) in Portland. The clinic was founded in 1992 by one physician (Dr. Jensen), and is currently run by three obstetrician-gynecologists, two of whom continue to see patients regularly (Drs.

Robichaud and Erlich).²⁸ The clinic is located within the Center for Women's Health (CWH), a "nationally recognized Center of Excellence for Women's Health Care", a designation that recognizes OHSU's "expertise and continued commitment to perform exemplary clinical care, research, community outreach, professional education and leadership" (OHSU, 2007a).²⁹ In global terms, this means that the PVH is squarely located—materially and discursively—within a competitive and very well-funded biomedical research institution, and enjoys the privileges and prestige consonant with such an association. On a slick and colorful homepage, for example, "Vulvar Health" is included as one of sixteen highlighted "Services and Specialties" (which also include midwifery, integrative medicine, and urogynecology). Potential healthcare consumers are promised an "unmatched" level of care for the "unique challenges" posed by (their) vulvar disease (OHSU, 2007b).

The relationship of the Program to the CWH is that of a poor stepchild, however, at least in some material ways. For example, it was primarily Dr. Robichaud's efforts that got the Program on the homepage for the CWH in the first place. She single-handedly located and contacted the website developer responsible for the Center, and then spent many of her lunch and office hours consulting with her about design (she wanted—and got—a butterfly on each page, to represent the "little butterfly lips" of the labia minora),³⁰ text, links and future administration. I was conscripted to write some new text, and the numerous "fact sheets" about vulvar health and disease that were

²⁸ Dr. Jensen, the founder of the clinic, is now focused on research (mainly contraception) and is no longer seeing new patients. He continues to see his original patients who do not wish to switch to either Dr. Erlich or Robichaud.

²⁹ OHSU is one of 20 National Centers of Excellence in Women's Health (CoEs), which serve as demonstration models of innovative, comprehensive, multidisciplinary, and integrated delivery systems of women's health care. See: <http://www.ohsuwomenshealth.com/coe/index.html>.

³⁰ I was asked to write some of the text for the website, and contributed an "Erotica Menu" for patients who wanted to explore non-genital/penetrative ways of being sexual with their partners or husbands. This is also where patients can download all of the 'fact sheets' about the vulva and disease conditions that are available at the clinic.

routinely given to new patients were given a digital format and a virtual home. Prior to these efforts, the clinic had been virtually invisible, not only on the Center's homepage, but also on OHSU's main website. Patients who had conducted their own internet searches for sources of local care repeatedly related to the clinic physicians that they rarely encountered the PVH online—they had almost always found their way through other routes, even when they were aware of the clinic's existence. By taking the solution into her own hands, Dr. Robichaud was able to increase the PVH's online visibility without costing the hospital anything but the time of an already employed web developer.

In more measurable terms, the CWH's slightly constricted support of the clinic translates into one half day per week when half of its physical facilities, and the schedules of the two expert staff physicians, are dedicated to patients with vulvar pain. This means that on Thursday mornings, the doctors are supported by medical assistants, nurses, and front desk staff who work full-time in the Center and are also specially trained to understand and respond to the particular needs of women who present with this cluster of symptoms. Nestled both physically and institutionally, the Program in Vulvar Health operates primarily as a referral clinic, meaning that patients typically come to the clinic through an outside physician or other healthcare provider. Particularly savvy and/or persistent patients occasionally secure their own appointments, but a referral model helps to ensure that "inappropriate" women (i.e., those who are symptomatic of other conditions) do not occupy the few slots that a short half-day per week allow.

To secure an appointment on a Thursday morning, then, the woman (or her provider) must report *some* version of the symptoms just described; schedulers are trained to screen out callers whose complaints do not require the vulvar expertise of Drs.

Robichaud and Erlich. Such patients might, in fact, be seen by either of these two doctors, perhaps even in the same physical space, but without a high suspicion that their symptoms are vulvar in nature, they will not be given the extended initial appointment that characterizes Thursday mornings. The fact that these visits are significantly longer than standard gynecology appointments is logistically significant—many of these women have been symptomatic (and possibly treated inadequately) for a number of years, and it takes a fair amount of time for clinic staff to sort through and collect the pieces of these histories that are immediately pertinent and amenable to intervention. Since the majority of patients reach the clinic through another provider, their medical “histories” are typically represented by numerous pages of diagnostic and treatment notes. These are routinely faxed over from at least one medical office, often incomplete, and rarely given the kind of attention that patients are led to believe they will be.

It is not unusual for an “initial vulvar” visit to last one and a half hours, not including the time spent in the waiting room (typically not more than twenty minutes). It is also not uncommon—given these temporal and logistical contours—for a new patient to wait three to six months for a consultation. Thursday appointments are also ‘special’ for a set of reasons that cannot be as easily quantified or objectively characterized. The experience of vulvar pain, as I hope to be making clear, is uniquely situated in the contemporary United States, including in our healthcare system. The shame, reluctance and aversion that many women feel towards their genital bodies compounds a set of symptoms that exist, for most clinicians, as a physiological puzzle. Genital distaste is both individual and collective—evident in the bodily and the linguistic practices of women with symptoms, some healthcare providers, partners, insurance companies and the culture ‘at large.’ Women who staff the vulvar clinic³¹ are

³¹ Dr. Jensen, who founded the clinic but no longer sees patients, is male. The remainder of the staff—physicians, nurses, medical assistants, front desk staff, medical students and residents—are virtually all

acutely aware of the enormous personal barriers that patients must overcome in order to both relate their story and ready themselves for treatment strategies that often exceed previously established corporeal boundaries. Indeed, explaining some of these treatment options (physical therapy, surgery, at-home topical anesthesia) is time-consuming in itself, made more so by the linguistic reticence and affective ill-preparedness of many patients at their initial visit. Clinic physicians and staff must therefore attend to Thursday morning (aka “vulvar”) patients in a manner that both recognizes and attempts to transcend these very personal and understandable obstacles.

Drs. Robichaud and Erlich function as a team in that they both “suit up and show up” each Thursday with the likeminded purpose of keeping vulvar pain on the clinical and institutional map. The first patients are typically scheduled at 8:00 am (Dr. Robichaud, who takes one day off per week to spend with her husband and two young children, will occasionally “squeeze someone in” as early as 7:00), and the doctors arrive somewhere before then in order to catch up on any of the myriad tasks that do not constitute direct patient care. This pre-patient time is typically pleasant and chatty, and is often the only part of the morning that offers these two colleagues a chance to talk about the other parts of their lives. While they settle in and catch up with each other, the medical assistants (Gia, Katie and Leah) and Jane, the “vulvar nurse,” busily move around setting up exam rooms, readying charts, and retrieving the first patients from the waiting room. Patients are weighed on a scale in the hallway and, once “roomed,” their vital signs (blood pressure, pulse, respiratory rate, and temperature) are taken and they are asked to provide a brief description of “why [they]’re here today.” New patients remain dressed until they meet their physician, and are allowed to sit on a built in (and

female. In the 13 months during which I observed patient visits, I encountered no more than 2 male residents/medical students. Any patient can request that she not be examined or cared for by a male provider.

padded) bench at one end of the room. “Return” patients, on the other hand, get undressed (“from the waist down”) at this point and await their doctor sitting on the exam table and covered with a crepe paper drape sheet.

The physical space of the clinic is laid out as one long hallway with four exam rooms off its left side, and two exam rooms, a bathroom and a utility room off its right. Patients are escorted from the waiting room through a set of doors that leads back to the clinical area. Once out of the waiting room, they turn left to pass one small consultation room (on their left), and then turn right to enter the main hallway. Their staff escort will typically suggest that they use the restroom as they pass it on their right, after which the patient will be deposited into her designated exam room. The front end of the hallway also houses a cramped and hyperutilized “pod,” a tiny and doorless cubby that can seat three to four at its wraparound desktop and possibly hold two to three more adult bodies at one time. The desktop holds three bulky computer monitors, and the room houses an eclectic collection of rolling office chairs, which are constantly moved in and out of exam rooms to accommodate partners, medical students, residents, and an anthropologist. The pod is where the doctors start (and end) their days, where clinical consultations and instruction are often carried out, where lunches are frequently (and incompletely) eaten, and where the majority of vulva-related paperwork (e.g., “fact sheets” and referral forms) and formal literature (e.g., the *Atlas of Vulvar Disease*) are kept. The pod is on the left side of the hallway, across from the utility room (microscope, hazardous waste receptacle, sink etc.), and is the first doorway that patients pass as they make the right towards their exam room. The clinic day officially gets going when a medical assistant turns that corner with a patient and everyone chatting in the pod notices them walking by. The vulva clinic, now occupied by patients, is “on,”

and it is highly likely that at least a dozen heart-wrenching stories will be told in its six exam rooms over the course of the next five to six hours.

Thursday mornings are, in a word, exhausting. They are also, in many words, touching, efficient, gloomy, exhilarating, devastating, puzzling, hopeful and hilarious. And they are filled with kindness, gratitude and expertise. Women who have waited up to six months to have pain of anywhere from one to ten years' duration carry with them a particular blend of optimism, inertia and despair. The fact that the pain is of a sexual nature can add a conflicted charge to their affect, but this charge is simultaneously muffled by the bodily shame that engulfs their (individual and collective) relationships to their genitalia. The doctors affiliated with the PVH have purposefully chosen to specialize in vulvar pain, yet they constantly risk becoming overwhelmed by the complicated mix of needs, desires and emotional limits expressed by these patients. The experience of vulvar pain is here again paradoxical: the genital labia are routinely eclipsed—including by gynecological medicine and 'sexuality' experts—by the vagina and its relationship to both coital sex and reproduction. In pain, however, these lips that have been pressed into silence begin to speak—sometimes scream—volumes about what female sexuality might (also) involve. Female genitalia that cannot be penetrated, yet remain amenable to caress, massage, and therapeutic attention, challenge and exceed received assumptions about (hetero)sexual bodies. These disruptions significantly inform, indeed perfuse, the lived experience of vulvar pain. Patients and physicians, therefore, must use the space of the clinic, and the alternative verbal and bodily exchanges for which it makes room, to confront and negotiate the *dis-eased* landscape upon which these patients more routinely tread.

The fact that these delicate negotiations cannot be conducted in a 'normal' fifteen-minute appointment indexes the limited resources that gynecological medicine

can contribute to novel—and vulvar-based—sexual imaginaries. One night I had dinner with Dr. Robichaud and Jill, the sex therapist affiliated with the clinic. Over sushi and several liters of delicious sake, we talked in earnest about our respective reasons for being involved with the PVH. Dr. Robichaud spoke clearly, telling us that “vulvar work” was the most gratifying part of her practice, primarily because it allowed her to more fully engage with her avocational interest in sexuality. (At that time, she and Jill actively daydreamed about establishing and running a Sexual Medicine clinic at OHSU in the not-too-distant future). I immediately began to clarify her statement by suggesting that *all* of an OB/GYN practice necessarily involved an engagement with (female) sexuality, but it was only moments before I interrupted myself realizing that this was not true.

As the three of us continued the conversation, I remained astounded that I had never before appreciated the depth of this reality, even (especially!) while I practiced. As I listed the kinds of care most frequently provided by OB/GYN practitioners—contraception, menstruation and menopause issues, pregnancy and childbirth, the prevention, diagnosis and treatment of sexually transmitted diseases (STD’s), breast health, and genital cancer prevention—we began to wince with recognition and resignation; it was unsettlingly easy to recall all of the ways that these healthcare problems are efficiently handled without any explicit attention to our shared understanding of ‘sexuality.’ Indeed, modern-day contraception epitomizes the extant and abstracted sexual body, as the most heavily prescribed methods (hormonal pills, patches and injections; IUD’s)³² absent women from their genitals in ways that an old-fashioned barrier method (diaphragm or cervical cap) never could.³³

³² The distribution and use of contraceptive methods is heavily marked by race and class, a fact that became glaringly obvious in the early 1990’s when the device known as Norplant arrived on the market. Some state Medicaid programs (including Massachusetts, where I was practicing) tried to mandate the use of Norplant by any recipient with young children, a requirement that would have been enforceable since

The tension between this traditional mode of gynecological medicine and the attention to female sexuality that is demanded by genital pain surfaces in waves in the vulvar clinic. Both symptomatic women and their doctors awkwardly (and inconsistently) generate *and* suppress the novel behaviors and language that a ‘new’ heterosexuality might require. Ignoring or marginalizing the vulva allows all of us, patients in particular, to continue to invest in the correctness, the naturalness, even the sacredness, of penile-vaginal complementarity. Conventional gynecology has long-invested in this reality and is challenged to transcend it by the dearth of materials and discourses that are rooted in alternative sexual imaginaries. A vulva that is *for itself*, however, is made available in the clinic, although perhaps only to those who can identify and actively grasp its fleeting presence. This is the vulva that disrupts a traditional association between female sexuality and interiority: treating it, talking about it, and attending to it out in the open confounds (male) gynecology’s habit of having to penetrate and reach *into* the dark depths of female bodies in order to understand them and make them better (Potts, 2002).

In a clinic featuring Drs. Erlich and Robichaud, Jill functions like a walk-on guest star. In earlier days, she had a more regular role, evaluating all new vulvar patients as a part of their treatment plan. Jill was a nurse before she obtained an M.S.W.; as a counselor, she now specializes in both sexuality and grief work

both the device could not be inserted or, more importantly *removed*, without a surgical procedure. See also Kapsalis, 1997; Ordovery, 2003.

³³ While oral contraceptives have always been marketed at least partly by their ability to lessen the length and severity of a woman’s period, contemporary—and continued-use—pills such as *Seasonale* now limit menstruation to just four times per year.

(specifically postpartum depression). OHSU no longer subsidized an automatic consult with Jill for new patients, which effectively excised the ‘mental health’ portion of the vulvar clinic. Jill maintained part-time practices both in and out of the hospital, which made her geographically available to patients who came from the greater Portland area, or for patients from longer distances who could arrange to see her on the days they came to the clinic. The issue of Jill’s ‘availability,’ however, merits deeper consideration. Though sexual counseling has been shown to play a noteworthy role in the reduction of vulvar pain (Bergeron et al, 2001), the majority of clinic patients do not pursue it, for both emotional-affective and politically-economic reasons. In my thirteen months in the clinic, fewer than five of the eighty-two patients with whom I interacted sought the help of a sex therapist.

Indeed, a far greater number of women repeatedly stressed that their relationships were “not about sex, thank *God!*,” when they detailed the disruptions in their intimate lives. The sexual relationships of symptomatic women are in various states of upheaval by the time they reach the clinic; the majority, whose pain has been present for an average of three to five years (Bachmann et al, 2006; Buchan et al, 2007a), have adopted whatever coping mechanisms and/or behavioral strategies promoted the greatest amount of marital or relationship harmony. This stagnation was one reason why some women dragged their feet about sex therapy—their emotional reactions to the prohibitive aspects of their pain were not the “burning” issue that their painful skin was. And, like any woman or couple in the U.S. struggling with relationship ‘issues,’ most of these women failed to appreciate the experiential difference that ‘talking about it’ would make in their lives. The fact that sexual counseling sessions, with Jill or any other therapist, cost upwards of \$100 and were often not covered by insurance, did not make sex therapy any more appealing. Rather, it

was the pharmaceutical, surgical and other medical management of their symptoms through which patients came to foresee their future participation in “normal” sex, the kind of sex that promised the restoration (or initiation, in the case of VVS patients) of physical and emotional compatibility with their partners.

Jill stayed current with the literature on vulvar pain and female sexuality, and she routinely lectured to, and consulted with, the medical and nursing schools at OHSU. Her approach was effective for generalists who needed an overview or introduction to the topic—she drew on clinical and physiological data about the female sexual body to shape the counseling and mental health insights that she shared with students and vulvar novices, e.g., what kinds of issues could be resolved medically/hormonally/surgically, which ones required emotional support, and which ones suggested the need for a formal mental health referral. Jill and I had wonderful conversations throughout my stay in Portland and she invited me to join the sexuality journal club with whom she met bimonthly. Given the few patients who sought her care, however, as well as the impossibility of my participating and/or observing her sessions, Jill’s work with the vulvar clinic did not significantly figure into my research. Her affiliation, however, is noteworthy in that her orientation towards vulvar pain—a physiological condition necessitating particular kinds of emotional support—does not challenge the zeitgeist of the clinic.

Jane, in contrast, had no avocational interest in sexuality, but had a solid supporting role as the “vulvar nurse,” not only on Thursday mornings, but any time that patients needed advice, support or triage. Jane was a dry-humored, middle-aged, and no-nonsense registered nurse who had come to the Center (from a dermatology practice) less than a year before I began my fieldwork. She worked full-time for the Center, and had been tapped as the vulvar nurse when the previous one had moved on to another part

of the hospital. By the time I arrived, Jane was no longer learning the ropes of the vulvar clinic; rather, she was starting to fine-tune the tricks that she could do with them. Because of the relative invisibility of vulvar disease outside of OHSU, this often meant spending a lot of time on the phone, both educating and coordinating among physicians and other healthcare providers, pharmacists, insurance companies, physical therapists, partners, and patients themselves. And, because one clinical consultation (even one that is an hour and a half) is an impossibly inadequate response to the years of suffering that have preceded it, much of Jane's "indirect" patient care involved the simple and assuring translation and reiteration of the physicians' (optimistic) plans of care.

Dr. Robichaud once described Jane as a "bulldog" to one of her patients, as she was assuring her that Jane would do what it took to secure insurance coverage for a medication that was being prescribed off-label. And though I did not personally encounter this facet of Jane's personality, I had no trouble believing it. While not exactly an antidote to the tenderness and emotional intensity that could easily dominate interactions with symptomatic and desperate women, Jane's straightforward and solution-oriented approach was nonetheless critical in meeting the practical needs of patients once they had exited the clinic's cocoon. In many ways, Jane embodies the normalizing (neutralizing?) work of the clinic—coming from an unrelated medical specialty, picking up "vulvar work" as little more than a novel set of nursing skills, and maintaining a professional detachment from the non-clinical *stories* that cling, Velcro-like, to every facet of this emerging medical disease. Symptomatic women need Jane to remind them that their pain, like any other clinical condition, can, at least partially, be confronted outside of the amplified and culturally charged discourses surrounding the source of that pain.

Hierarchically, Jane's skills and developing expertise sit below the physicians, but hover somewhere above that of the medical assistants (MAs). An entry-level job at a facility like OHSU, medical assistants operate in all of the spaces that are *in-between* the care that is dispensed by Jane and the physicians. MAs rarely run out of tasks to perform, and these range from putting charts together, retrieving and organizing faxed records, cleaning and preparing exam rooms, greeting patients and gleaned the basic elements of their history, and filling out lab and requisition paperwork associated with the diagnostic tests that are routinely performed. Two of the MAs—Katie and Leah—are in their early to mid-twenties and are using work at the hospital to inform their future career paths. Gia, who is closer to fifty, is a married grandmother who has been with the clinic for many years and most likely will stay until she retires. It is almost always an MA who first greets these patients and hears their stories, but their multi-tasking role offers them little opportunity to gather too much information. Patients that are particularly sad or desperate, however, do not fail to move these women, as theirs are the first set of ears to hear tales that are long in the making.

About half of the time, the second set of ears belongs to an OB/GYN resident. Residents are medical school graduates who have completed an internship of one to two years and are now specializing in the type of medicine they plan to practice. The vulva clinic is an elective rotation for the residents at OHSU, but one that is frequently taken advantage of; many of these doctors have worked with Drs. Robichaud and/or Erlich elsewhere in the hospital and want to learn more about this specialty. A new resident comes through the clinic each month, and the residents typically rotate between Drs. Erlich and Robichaud on alternating Thursdays. Given their imminent departure from OHSU (they are in their last year), they are more than capable of gathering the medical history and making a preliminary assessment of the problem. Therefore, once a patient

is roomed, if a resident is working, she (or he, rarely) will go in before either of the clinic physicians, take a full vulvar symptom history and then present it to the doctor with whom she is working that day. Depending on the day, the doctor, and the pace of the clinic, this presentation might turn into a pedagogical exercise in assessment and diagnostic frameworks, e.g., Dr. Robichaud might ask the resident what she thinks is going on and why. Other (busier) days involve only a brief summary, followed by the two of them going into the room together and the doctor using a quick patient interview to fill in what she believes is missing from the resident's account.

On a routine morning, then, the hallway, exam rooms and pod that constitute the vulvar clinic are peopled with somewhere between six to eight professional bodies that are, for that morning, especially invested in vulvar well-being. Each of them, as well as the front desk staff amongst whom patients sit in the waiting room, absorbs some of the hopeful or resigned energy that has crystallized for so many women in the years leading up to this day. Their professional presence, i.e., the stability and reality of their job in a vulva clinic, helps to normalize bodily experiences that have, thus far, existed far outside the range of what these patients were taught to (sexually) expect. On every other level, in every other area of their lives, vulvar pain is an extraordinary event, one that challenges the believing abilities of the husbands and doctors of symptomatic women, people who can see *nothing wrong* with these complaining bodies. The clinic, by contrast, is brimming with the conviction that these symptoms are not only real, but that they are amenable to routine medical interventions, such as surgery and medication. What I want to suggest is that this dynamic mix of hope, desperation, reassurance and simply *doing one's job*, generates some of the first particles of a biopsychosocial assemblage that is the *becoming* of vulvar disease.

PART II: THE METAPHOR

In her phenomenological study of medical practice, *Presence in the Flesh*, Kathryn Young (1997) argues that pathologists who perform autopsies locate personhood in a female corpse by draping her genitalia: “By shielding the corpse’s most ... private parts ... [t]he pathologists find personhood even [when those parts are] disincorporated, dissevered, and dispersed about the room” (126). I suggest that my cultural dissection has done the opposite. That is, by taking the drape sheets off these genitals, I have tried to locate personhood in vulvas by safely and respectfully exposing (us to) them. Attentive to—indeed animated by—the transgression, confusion and disorder evoked by the symptoms of vulvar pain, the dissertation also travels well outside of the “etiological pathways” considered by the vulvar researchers at Harvard. In the following chapters, I elaborate one potential ‘pathway’ along which a symptomatic woman might locate—or recognize—herself as she struggles to cope with a pain that is “disincorporated” from the cultural body.

With a corporeal metaphor, the dissertation establishes the material fact of female genitalia. Through progressively imagined chapters, I try to instantiate several of the embodied states through which these pain conditions are first encountered and then lived. I suggest that the symptoms arise in the body as they arise in culture; in Barbara Duden’s (1998) words, these pain conditions are an “incarnation of the world in the body” (38). My metaphor, then, is an attempt to write the female body that I have begun to theorize. I argue that this body has **accumulated** far too much “unwanted genital experience,” and that this burden makes itself **manifest** through a sense of shame and *felt excess* and/or a disavowed and contaminated absence. This body has learned to

strategically erase itself from ‘civilized’ discourse, compromising its ability to **integrate** into its social world, yet retains the potential to **generate** novel and unpredictable sexual morphologies.

With these chapters, I seek to “close the distance between the body and the world” (Duden, 1998: 38-9) and immerse the reader in the ‘experience’ of a pain that is profoundly paradoxical. Vulvar pain is acutely felt and amplified at the personal level—it is dermatologically and neurologically loud, it “shuts down” a symptomatic woman’s sexual possibilities, it is red and itchy and narrated to physicians (and husbands) as “don’t go there.” But, like Mary Hudson’s *LS*-afflicted clitoral orgasms, it is simultaneously muffled, erased and/or all-but-ignored at the broader—and collective—levels of discourse and cultural institutions. The chapters before you are meant to convey these (only seemingly) contradictory states of existence, and offer a glimpse into the paralytic torpor that they produce. But they also posit another state of existence, a potential way *out* of the condition that I refer to as Vulvar Disease. This is the pathway chosen by the patients that ‘got better’ during my time in the field, a set of steps that included an acceptance and negotiation of the extra-corporeal aspects of her pain, whether they be emotional or cultural, based in the past or drawn from the present. Vulvar pain conditions are infused with moments, histories and discourses through which the female genital body is made to disappear. By making this body appear—*again and again*—on these pages, I insist on its legitimate cultural recognition and its rightful place in the *body images* (see Chapters Five and Six) of the vulnerable and *diseased* women who are at the heart of this work.

Chapter Three: Accumulation

Shame kept a close watch on me and all my girlfriends.
—Inga Muscio

In this first of my ethnographic chapters, I propose that vulvar pain be understood as one layer—among many—of U.S. culture’s *dis-eased* relationship with the female genital body. Drawing on Mary Weismantel’s (2001) model of racial accumulation in Andean South America, I argue that genitally disparaging discourses are collected by the bodies of U.S. women, settling and shifting as embarrassing and alienated sediment. I use narratives and fieldnotes from patients’ initial consultations in order to capture the range of physical and emotional effects that are accumulated in the time leading up to their clinic visits—compounded symptoms, marital discord, inaccurate diagnoses, sexual ‘shutting down,’ depression and disappointment, and drawers full of ineffective medication. The middle section—and bulk—of the chapter analyzes the stories of several patients through the conceptual framework of accumulation.

I theorize accumulation as dynamic layering—where idiosyncratic configurations of personal resources and socially structured realities constantly shift, settle and/or erode in individual bodies that move in and out of relief-seeking behavior. A dynamic model attends to questions of agency by including layers that are passively inscribed as well as those that are purposefully sought or created. In the first section of this chapter, I use my background as a feminist clinician to further unpack this tension. Examining my own body’s relationship to the sexual bodies of my patients, I narrate a professional and personal negotiation with genital ‘baggage’ that can be discarded as well as collected.

The realities that are specific to vulvar pain should not be understood outside of the discursive burdens already carried by the female sexual body in the U.S., and I suggest that this broader-based embodiment of sexual inferiority is experienced by far more women than those with vulvar pain. In the last section of the chapter, I introduce the diagnostic (rather than therapeutic) role of physical therapy by narrating the tension and “holding” discovered in my own pelvic floor during a biofeedback session with an informant. I use this physiological ‘fact’ to describe the diffuse and “deep tissue discourses” upon and through which the more acute and eruptive sensations of vulvar pain are lived.

Since I have outlined the specifics of vulvar disease in the previous chapter, I ask the reader to temporarily hold further questions about anatomy and physiology. Women with vulvar pain and abnormalities encounter physicians and their symptoms in something of a daze, albeit an interactive one. In putting forth the transcripts and details of the patients’ visits, particularly their initial ones, I hope that the reader her/himself will experience some of the feelings associated with this fog—the lack of accurate information, the linguistic confusion, the hysterically-based thinking, a hint of skepticism (or even disbelief), and an immersion in the pernicious assumptions on which much of the clinic exchange—and the women’s narratives—are based. I want us to leave this chapter with a small yet palpable sense of the heaviness to which I bore witness over my 13 months of fieldwork, and that continues to burden the lives of the patients and the doctors with whom I formed relationships: that is, a gendered miasma of unanswered questions, impossible (hetero)sexualities, and pathologically scrutinized female bodies.

PART I: ALTERNATIVE BAGGAGE

Spend a week telling people you know and meet that you are working on a book about pelvic exams. If your experience is anything like mine, your statement will be met with a variety of reactions: nervous laughter, surprise, horror, blank stares, suggestive winks, embarrassment, anger, excitement, disgust, discomfort, absolute silence. But silence is rare, at least from women (Kapsalis, 1997: 3)

I was vaguely uncomfortable the first time that I encountered these sentences, which introduce Terri Kapsalis's important book, *Public Privates: Performing Gynecology from Both Ends of the Speculum*. My unease stemmed from the fact that, while I was overjoyed to find them printed in a scholarly text, I also wished that I had written them first. And really, I had. I had written them in numerous seminar and conference papers, and I continued to write them because I shared Kapsalis's experience. Each time that I answered my colleague's questions concerning "what my work was about," I was greeted with the same spectrum of responses, including the one most salient in this dissertation—the "stories [that] c[a]me forth" (3) from women.

I had collected many stories of my own by then, as both clinician and burgeoning feminist scholar, and I was learning how to most effectively analyze them. I believed that my genital tales offered something unique to the larger "story about power and gender" (4) that has been taking shape within feminism for over 150 years. And, like Kapsalis's, my story was also about gynecological medicine. As I became increasingly enamored of cultural anthropology, my uncertainty grew about the most suitable location from which it should be narrated. What I did know was that the topic of female genital discourse seemed to incite particular kinds of trouble—interpersonal, institutional, sometimes even intrapsychic. My research came to focus on acknowledging (and sometimes provoking) that trouble, delineating its cultural

provenance, and examining the consequences—material and discursive—associated with its praxis. With this somewhat novel line of inquiry, I was hard pressed to locate texts that offered me both theory *and* content. Scholarship about female genitalia was either reproductively oriented or, frankly, just a little old, having been largely generated by the U.S. feminist health movement of the 1970's (BWHBC, 1976; Fems, 1981). Kapsalis's book offered the analytical insights for which I hungered, and I was gratefully stunned the day I picked it up off the shelf in a feminist bookstore in Ann Arbor, Michigan. My only trouble with *Public Privates*, I have to admit, was that I was afraid that it had stolen my thunder.

As with the “inherent problem of the female pelvic exam,” my work raised eyebrows both individual and collective because it “*necessitate[d] the public exposure of the shameful female privates*” (5; emphasis in original). Further on in her introduction, Kapsalis astutely measures the socially transgressive nature of this process and, in doing so, she precisely locates at least one source of the trouble that she and I collectively provoke, and of the discomfort that we consequently share. In interrogating her own project through the lenses of mainstream discourses, specifically those that inform and construct the reactions under consideration, Kapsalis asks us to wonder “[w]hat *kind* of woman writes a book about pelvic exams?” (8). By framing her research interests in this way, Kapsalis is taking cues not only from the professional and personal interlocutors described in her opening paragraph, but from conventional and hegemonic medicine as well. She contextualizes her critical reflexivity by citing a 1978 *American Journal of Obstetrics and Gynecology* (AJOG) article that questions the use of “gynecology teaching associate[s] (GTA's)”, i.e., women who are paid by medical (and sometimes nursing) schools to give students the opportunity to learn and practice pelvic exams with real, live bodies. The author of the article relies on an efficient combination

of discursive effects to contaminate and sexualize the role of the GTA. With a commiserative wink to his (predominantly male) readers, and with no small amount of the disgust that Kapsalis and I know too well, he exhorts: “My first question, as I suspect yours may be, was ‘What *kind* of woman lets four or five novice medical students examine her?’” (8). Given that GTA’s typically labor within a politics of feminist health care, and many (like Kapsalis herself) understand their role in the pelvic exam to be both instructional and performative, we can begin to apprehend the more complicated nature of the transgressions at work. What kind of woman indeed.

Some relevant ‘facts’ surrounding the bad taste in this physician’s mouth are that: (1) in 1978, the majority of these novices would have been male (Cooper, 2003); and (2) without professional models, these students would have examined either cadavers, synthetic prostheses, anesthetized patients, or ‘non-professional’ women willing to be paid for such work (this typically translated into sex workers) (Ostrow, 1980). Live bodies were (and had always been) an option for medical schools, but historically, these bodies had not been capable of speaking—either back or for themselves—in the ways that a GTA was.³⁴ Kapsalis, a performance studies scholar, focuses her argument here, on the “gendered spectator-spectacle relationship” in traditional gynecology that is composed of “an active male physician-spectator and a passive female patient-spectacle” (23). In this configuration, there is no room for an *active female*, one that cannot be made absent, silent or disabled by the masculinist prerogatives of institutional medicine. In her analysis, we can read this physician’s

³⁴ “You’re hurting me,” being one example. The role of professional pelvic model/GTA includes orienting the student to the organs that are being examined (“Yes, that’s my ovary”) and offering feedback when any part of the exam is uncomfortable or unprofessional in her (informed) opinion. See a recent yahoo piece about “fake patients,” including pelvic models, at: http://news.yahoo.com/s/ap/20070211/ap_on_he_me/fake_patients

disdain as a conservative and misogynist reaction to the invasion of gynecological medicine by larger numbers of active female bodies. Indeed, by 1978 these bodies were not limited to the GTA's or consciousness-raised patients nurtured by the feminist health movement, but now included female bodies intent on securing positions on the "physician-spectator" end of the spectrum.

However obvious and well supported the author's medical misogyny may appear, I want to deepen our interrogation of contaminated gynecology and sexualized medicine. Because situated firmly alongside (and between) the reactionary repression of *AJOG's* article and Kapsalis's detached feminist irony, there is a voice that reminds us that female agency and genital disgust are not mutually exclusive—that of the sexually active woman who remains reluctant to confront her genitalia. Attuned to this voice for many years, I want to add another layer to Kapsalis' analysis. In approaching the "what *kind* of woman" dilemma, we need to move beyond the voice of institutionalized medicine to the disgust and repression that come from the patient on the table; to the *active female* who uses her newly acquired voice to cast suspicion on the nature of her own sexual body.

Speculum practice

I did not learn to do pelvic exams with a GTA or professional model. In the graduate nursing school that I attended, students worked with each other to develop this skill and, I will admit, it's a somewhat tricky business. Twelve of us were enrolled in a full-time program that was concentrated into one calendar year, and so we came to know each other in the strange-yet-intimate ways typical of such conditions. Long hours in lecture halls, seminar rooms, clinical placements and the library offered reasonable glimpses into our respective idiosyncrasies, family dynamics, and even regular bodily

habits. But whatever level of intimacy is cultivated by knowing that your colleague swims at the community college gym, or that she is caring for a parent with Alzheimer's disease, does not necessarily translate into using her vagina for your speculum practice. We were also distinctly invested in perfecting our techniques, as most of my classmates were not planning careers that would include pelvic exams. I, on the other hand, had been doing them for several years at the reproductive clinic where I worked before graduate school, and I happily shared the clinical 'pearls' I had collected. Under these circumstances, my classmates and I negotiated our way through a new skill—and each other's bodies—with a mix of unevenly weighted performance goals, friendly familiarity, and the professional distance that we were always expected (including by ourselves) to maintain. We each gathered what we needed from the experience, and efficiently moved on to other body parts and systems. And we did so, as I recall, without any undue sense of trespass.

I eventually became very good at pelvic exams. I say this with the certainty that comes from uncomfortably witnessing those performed by less skilled colleagues. Putting my patients at ease, both emotionally and physically, was something that I took utterly seriously. I knew that I could almost always avoid provoking pain by taking the few extra minutes that slowing down and involving the patient required.³⁵ I was fully aware that these interventions would not displace nor undo the discourses that surround *the GYN exam*—discourses of pain, martyrdom and embarrassment that are legendary among U.S. women (Domar, 1986; Angier, 2000; Kaysen, 2001). But I also knew that I could make the ten minutes over which I exercised some control, about this particular social 'fact,' into a distinct experience, one that could at least co-exist with those that

³⁵ This varied to some degree based on patient's interest and ability to participate. At a minimum, "involving" her meant keeping her aware of what I was doing "down there;" at a maximum, it might mean dispensing with the drape sheet, keeping a mirror in her hands, and/or involving her partner in the exam.

held greater cultural capital. I was rewarded for my efforts not only by grateful (and sometimes astonished) patients, but also by a growing awareness that my *personal* relationship to this profoundly cultural process was in the midst of a transformation. Speculums became extensions of my body, and the expertise with which my hands became infused reflected an emerging body schema (Schilder, 1950) that related to female genitalia with a new sensibility.

In a feminist analysis of Lacan's mirror stage, Elizabeth Grosz (1994) reads the imaginary anatomies that develop during this time to suggest that "the stability of the unified body image ... is always precarious. It cannot be simply taken for granted as an accomplished fact" (43-4). It would be an understatement to say that I was unaware of either Grosz or Lacan during the years that I practiced. As I observed and attended to the changes in my own genital predisposition, however, I couldn't help but surmise that it was possible for bodily habit(u)s to change, and that that change could occur with the conscious and sustained accumulation of experiences that challenged corporeal norms. If, as I came to suspect, the insidious and pernicious discourses of lack and disparagement could erode genital integrity, then perhaps a purposeful accretion of alternatively informed corporeal dialogues could work to fill these psychic indurations, something akin to the granulation of a deep and open wound. Indeed, Grosz contends that the "body image ... must be continually renewed ... through the subject's ... ability to conceive of itself as a subject and ... to be able to undertake willful action" (44). In allowing for the ongoing possibility that their gynecological encounter could be different, I offered my patients (and myself) a chance to renew, and possibly rehabilitate, the contaminated bodies in which we unthinkingly resided.

But my skin sometimes felt tighter before it relaxed to accommodate my shifting sensibilities. Many of the places I worked maintained a practice of subsidizing their

insurance costs by allowing staff members to receive free or reduced-cost health care at the clinic. This meant that not only could I access the services of my clinician-colleagues, but that my own gynecological patients now came to include friends and co-workers. This was no longer peers-as-pelvic-models, however, as it had been in nursing school. I was now responsible for managing the care of these individuals, which often meant learning the details of their sexual practices and genital concerns. When I walked into my exam room one afternoon and saw the clinic receptionist—who I did not know very well, whose desk I walked by countless times a day, who exercised a fair amount of power over my schedule, and with whom, frankly, I was still attempting to personally connect—I felt angry and a little victimized. It didn't seem fair to ask this of me as a staff member and, particularly, as a *brand new* clinician (fresh out of graduate school). I could see that these visits were going to require yet another level of negotiation between bodies, genitals and social decorum, a level that I wasn't necessarily eager to embody.

The happy ending is that I eventually developed a real sense of mastery in these situations, as my body, my politics and my genital sensibilities together found more stable ground than the unease still provoked by cultural and medical discourses about bodily intimacy. I worked with an instinctual ease that I would have deemed unimaginable the first time that the face on the other side of the exam drape was that of a colleague or friend. My practice, increasingly informed by an ethic that was empathetic, egalitarian and feminist, now helped me to imagine that the *practice* of my exams couldn't help but leave a distinctly informed residue in the body of the friend or woman on the table, regardless of the consciousness through which she sought me out. Hovering around these behavioral acts, and circulating amidst my practical efforts, however, was the question constructed by conventional discourse: What *kinds* of friends or colleagues choose this particular intimacy? At this writing, I can only speculate about

the impacts that these encounters had on others; it is quite possible that free health care mattered far more than any inchoate *genital integrity* we might have been mutually tending. I can say that, in my case, these bodily intimacies helped me to strike a more effective balance between friend and clinician, no matter how well I knew the woman before me.

My linguistic confidence came to match my clinical expertise, and I used every minute with my patients (often running over time) to provide them with the information and critical questions that I understood to be fundamental aspects of ‘women’s health.’ Contraceptives and sexually transmitted diseases were not just risks and benefits to be weighed, but were material gateways to the more abstract issues of sexual well-being and bodily integrity that fueled my desire to labor in this arena. I got along very well with my patients, and they typically left my exam room with levels of tension or reserve that were appreciably less. It was unusual, then, for my confidence to be shaken; it was downright exceptional for a patient’s question to render me speechless. But one evening, when an otherwise unremarkable³⁶ young woman looked right at me and asked, “God, how can you *do* this job?,” I was momentarily helpless to answer her.

At the time of her challenge, this patient was on the table in front of me, and beginning to lie backwards for her exam. We had conducted her health interview and not detected any major problems. We were going through the routine: I had stepped out and allowed her to undress in private; she had donned the white crepe paper drape sheet that the medical assistant had left on the exam table for her (Henslin and Biggs, 1971; Kaysen, 2001). After listening at the door for the rustle of paper that meant she had climbed up onto the table, I quietly knocked, asking the rhetorical “Ready?,” as I was already walking back into the room. I had helped to arrange her feet in the stirrups,

³⁶ “Unremarkable” is used clinically to indicate someone, or some body part/system, that is apparently normal. In other words, there are no “remarks” to make about it.

perhaps calling attention to the soft pads with which we made sure to cover them. I was always careful—vigilant even—not to introduce the stirrups until it was absolutely necessary, until I was ready to do the parts of the exam that dictate their use.³⁷ My fingers, therefore, were ready to work; they were gloved and lubricated, poised at the opening to her vagina. I was millimeters from her skin, and prepared to perform a task with which I had come to associate more than a little self-respect.

“How can you *do* this job?” I had not been expecting this.

Was I angry? Empathetic? Ashamed? Yes, yes, and yes—I was all of these things, most alarmingly the last. And I was silenced, if only temporarily. How to answer? What kind of woman *can* do this job? What *kind* of woman, other than a sex worker, earns her living by placing her fingers inside the genital bodies of others? As I relate this story now, more than ten years after it happened, I am struck by an eerie recursivity, by how this question, uttered somewhere around 1992, both anticipates and succeeds the two variations that have been posed by Kapsalis and the *AJOG* author, questions that want to know, more generally, “What is *wrong* with these people?” After all, argues Katherine Young (1997), “[a]part from physicians and lovers, access to the anal-genital region is specific to morticians and prostitutes, which suggests something about the body taboos that attend such access” (178). Encounters with female genitalia are so structured by proscription and contamination that all but the most heteronormative and/or the most clinically paternal are deemed suspect. In the cumulative model of female genitality that I posit in this chapter, these three questions are chronologically—and discursively—stratified across overlapping cultural zones. Although many of us can

³⁷ The first anecdote in Kapsalis’s (1997) book involves a woman whose physician left her in stirrups after he was called to attend to a more urgent issue. Neither he, nor any other staff member, told her that she could take her legs down while she waited for him to return. Afraid to pose a challenge, she stayed in this position until he returned, even when she realized that the door was open and there were people walking by. Neither she nor the doctor mentioned it upon his return.

identify more readily with Kapsalis's feminist challenge than to *AJOG's* threatened patriarchy, my patient's provocative query neatly interleaves itself between the two, and resonates with an all-too-available genital reality. We may not feel the need to stop our gynecologist in her tracks by objecting to her choice of career, but we do understand why Kapsalis feels the need—if only rhetorically—to acknowledge the transgressive nature of her project. I suggest that these three linguistic events index complex and concomitant layers of genital discourse, the figurative 'ground' upon which the lived experience of vulvar pain is unhappily situated.

Kapsalis reminds her readers that “[c]ultural attitudes about women and their bodies are not checked at the hospital door. If women are largely marketed as sexualized objects of the gaze, why should a gynecological scenario necessarily produce different meanings?” (63). This dissertation takes Kapsalis's first sentence to heart and, as departure point, argues that vulvar pain cannot be apprehended adequately—indeed, at all—without exposing and interrogating the “cultural attitudes” that surround and construct female sexuality, particularly as it is indexed by non-reproductive (external) genitalia. In making this claim, I situate myself among critical scholars of embodiment who suggest that “the specific cultural meaning of ... bodies is not distinct from but deeply embedded in the relations of domination ... that have framed” those bodies (French, 1997: 72). Of the three questions I have examined here—from feminist scholar, conservative physician, and Planned Parenthood patient—I am most interested in the last, that of the woman who approaches her own genitalia with disgust and shame. I argue that this affect is both product and producer of a female genital body that exists culturally as either polluted excess or erased invisibility. The habitual and hegemonic *disavowal* of the vulva, i.e., the “absence ...[that] is as psychically invested as its presence,” (Grosz, 1994: 41) efficiently functions as depositor of cultural residue in the

female sexual subjectivities constituted by its accompanying discourses. In *The Empire of Love*, Elizabeth Povinelli (2006) argues that discourses can “make and unmake ... bodies” through a “politics of cultural recognition” (22-3). In this dissertation, I am investigating female bodies that are (un)made via vulvar disavowal and (mis)recognition. I suggest that discursive and reiterative erasures, rather than producing a clean corporeal slate, accumulate as shameful sediment, an intractable film held in place by a deep cultural ambivalence towards the proper ‘place’ of the non-reproductive female sexual body.

Although my project is distinctly informed, Povinelli describes the first chapter of her book with words that nicely capture the work I see before me: “The purpose of this [work] is to make visible how the disciplinary operation of ... discourses is lodged in the *deep tissue*—the background conditions—of social interpretation and practice” (23; my emphasis). In telling stories of *vulvar vestibulitis* and *vulvodynia*, I will demonstrate how the experience of pain that is clinically “superficial” articulates with and indexes the “deep tissue discourses” of cultural vulvar *dis-ease*. My larger interest is in the formation of this deep tissue in all women, and in questions surrounding its disruption and/or potential for transformation. By “all women,” I mean to say that my interest in vulvar pain stems from my belief that a woman’s relationship with her genitals should not be an aversive one, whether “it hurts down there” or not. My fieldwork focused on women who are ultimately diagnosed with a pain syndrome because the material reality of vulvar pain forces them, in the most explicit of ways, to confront the discursive reality of vulvar shame.

Diseases, like racialized or gendered identities, “are not [solely] the property of bodies” at the same time that they are “identified with particular bodies” through the accumulation of specific “social histories” (Hartigan, 2005: 16). Povinelli’s use of the

term “carnality,” defined as “the socially built space between flesh and environment,” allows us to move beyond a binary that is more heuristic than practical. More importantly, it also helps us to figure women *without* pain into the cumulative effects of Vulvar Disease. In this conceptualization, vulvar pain exists as the “physical mattering forth of ... juridical and political maneuvers” (7) that underpin and give structure to the social and personal regard in which female genitalia are held. Patients in the midst of the diagnostic process cannot come to terms with their pain without acknowledging the material reality of their vulva. At the same time, they recognize and produce the circumscribed environment that informs the silence through which their pain has primarily been lived, a collective silence that transcends the singular experience of pain. Clinic patients acquire, and then cultivate, linguistic and behavioral strategies that facilitate the medical legitimation of their symptoms. Physicians prepared to offer this validation meet patients across a dynamic threshold that begins to organize their experience(s). It is here where vulvar disease is most fully realized, where these ‘new’ symptoms find meaning and repositories, and where a growing number of knowledges, services and experts proliferate (see Chapter Six, *Generation*).

It is not the presence of pain that has kept patients from developing a working knowledge of their genital anatomy; outside of their diagnosis, they share in and co-construct a dominant cultural vulvar reality that is marked by transgression. If we think in terms of cumulative layers, this shame-based self-reluctance is at the bottom, middle and top of the genital aversion voiced by my patient that evening, and by every clinic patient that told us “Well, I don’t usually look down there” In *realizing* their disease condition, however, symptomatic women have an opportunity to identify and create alternative layers. Some are present, needing only to be brought out of hiding, like the ability of many patients to accurately pinpoint an area of pain no larger than a centimeter

“Um, it’s usually right around here”); others are completely novel and require more substantial (and consistent) support, such as the purchase and regular use of vaginal dilators. The important point here is that these are behaviors that can be acquired by a wide range of bodies, not just clinicians with a feminist politics or women with vulvar pain. Whether or not you have symptoms that meet the criteria for VVS, *vulvodynia* or *lichen planus*, it helps to be able to say “The pain is vulvar and seems to be aggravated by certain fabrics,” rather than to simply answer “kind of” when (and if) your clinician routinely asks if you have pain with intercourse. The genital familiarity and integrity that *can* accompany the diagnosis and management of vulvar pain is a corporeal orientation from which a much greater population of *dis-eased* women might appreciably benefit.

The anthropological lens through which I engage with this pain is a critical factor in the development of such a collective shift. Left to their own devices, both diagnosed women and the physicians who care for them invest heavily in the physiological dimensions of these conditions. Newly acquired genital behaviors are then circumscribed by discourses of pathology and anomaly. In this framework, it is *only* women with pain that need greater vulvar awareness; cultural vulvar *dis-ease* is effectively eclipsed by physiological disease. Asymptomatic women are not the recipients of increased genital attention, nor are the patients themselves if and when their pain is resolved. This was repeatedly evidenced by the number of diagnosed women who told me they couldn’t wait until they “d[id]n’t have to deal with their vulva[s] anymore.”

In returning to the title of this section, I want to suggest that we think about the full range of (physical and cultural) genital behaviors as ‘baggage,’ and that we do so with the broadest sense of the term. Many U.S. women carry the oversize and weighty

pieces—the steamer trunks full of insults, erasures and *dys*appearances that constitute “unwanted genital experience”—living with them as the kind of baggage whose unwieldy nature limits their bodily freedom. But it needn’t be the case that *only* women with a recently recognized disease condition be given access to pieces of baggage that are lighter and more user-friendly, i.e., uncontaminated self-examination, therapeutic attention, and vulvar integrity. In my model of dynamic layering, women can *choose* to accumulate and acquire the kind of genital ‘baggage’ that facilitates alternative behaviors and bodily imaginaries, pieces that allow them to move with greater ease and flexibility. These may not—indeed, likely will not—replace the more familiar and overdetermined modes through which women carry their genital bodies; but in lightening the load of *in*consequence, they begin to displace and reconfigure the bodily belongings that *any* woman might agree to bear.

PART II: UNBEARABLE WEIGHT

What’s wrong with this body?

Louise’s presence in the waiting room³⁸ was unavoidable. She was middle-aged, white and very well put together. Very petite, almost diminutive, she wore grey yoga pants and a pink cotton t-shirt, covered with a quilted pink hooded sweatshirt that she left partially unzipped. She kept her graying and curly hair loose and chin-length, and she wore neither makeup nor jewelry to the clinic. Louise was accompanied by her husband Niko, a tall and solicitous man who appeared to be in his late 50’s or early 60’s. Niko’s appearance and demeanor were striking—handsome and olive complected, he

³⁸ The waiting room for the vulva clinic was also used by the patients of other OB/GYN physicians at OHSU.

was very well dressed in a dark suit, and he spoke with an accent that was vaguely European. It was not Louise's well-kept appearance, nor the presence of Niko, which drew uncomfortable and curious glances from the staff and patients in the waiting room, however. Indeed, Louise maintained a Northwestern style³⁹ that resembled many of the other women around her. And it was far from uncommon for male partners to occupy a seat or two in this otherwise very feminine space; when they did, their awkwardness usually led them to attract as little attention as possible. Rather, it was Louise's body that provoked some unrest in the bodies around her, including my own. What had us antsy—squirming if we were seated, and more than a little off-guard if we were just passing through—was the way that Louise inhabited her chair. That is, she wasn't sitting in it at all.

New patients in the vulvar clinic were asked to complete a substantial number of questionnaires before they were brought back for their consultation. So detailed were these forms (see Appendix A) that filling them out could take up to a half an hour, depending on the extent of a woman's history. As she described it to us later, Louise came to OHSU that day feeling as if she were "sitting in fire," a symptom that had been present for four months at that time. Because of this, she decided that it was far more reasonable to kneel on the floor in front of her chair and rest her clipboard on its seat while she wrote, rather than to subject her pelvic floor and vulva to the "stabbing pains" that were aggravated by contact with external stimuli. In the contest between immediate self-care and waiting room decorum, Louise's pain tipped the scales; she therefore

³⁹ A detail that speaks to the whiteness and class-inflected nature of vulvar pain diagnoses. See Chapter Two for the demographic profile of the clinic's patients, which are reflective of the national data. It is also important to stress the 'whiteness' of this private clinic vs. the more racially diverse patients in the (differently located) resident clinic, which is designed to serve women of lower socioeconomic means. See Chapter Five, *Integration*, for a lengthier discussion of these disparities.

worried little about the nervous energy that vectored around the room in response to her bodily adaptation.

As it turned out, Louise's story was also a bit unique, in both the intensity and acuity of her pain, as well as its relatively short duration. Rather than months, most clinic patients narrated several years' worth of symptoms that, although extreme and profoundly disruptive, they had learned to tolerate with adjustments in their behaviors and lifestyle. I mention this brief and contrastive context so that I can better emphasize the magnitude of Louise's clinical presentation. Her distress and desperation were so great, she told me on the day that I met her, that she had been looking at euthanasia sites online when her son called to tell her about the vulvar clinic. Another woman's cancellation made it possible for Louise to secure an unusually expeditious appointment; she told me that she didn't know what she would have done if she'd been forced to wait the more standard three to six months. Even the normally staid Dr. Erlich was mildly overwhelmed by Louise's narrative. When we stepped outside the room to allow Louise to undress, she said to me "These are the ones who make you think 'Oh God, I hope I know enough to help her!'"

It was this sense of urgency—performed on her knees in the waiting room (and eventually on the exam table), and then eloquently narrated throughout her two hours in the clinic—that shaped the framework through which Louise ultimately interpreted her symptoms. Already living with several (other) autoimmune conditions⁴⁰ (fibromyalgia, interstitial cystitis and irritable bowel syndrome), Louise had made major changes in her life. These included the difficult removal of as many potential irritants and toxins from

⁴⁰ Close to half of the patients that I met had been diagnosed with at least one concomitant autoimmune disorder. The prevalence of these disorders is highest among women and some scholars argue that they are gendered female (Ahmed, 1999; Whitacre et al, 1999; D'Cruz, 2007). Some authors have suggested that *vulvodynia* and VVS have an autoimmune component, but this has not yet been convincingly demonstrated (Chadha, 1998; Glazer and Rodke, 2002).

her physical environment as she had the resources to do. She linked the onset of these disease processes to a year in which she had grieved the deaths of “multiple” loved ones. Catalyzed by these stressors, Louise also cultivated habits that were both new and nourishing for her. She was planning to complete the training that would allow her to become a yoga instructor although, at the time we met, she was not able to practice yoga in the ways that she wanted (“The only time I’m comfortable is when I’m on my head”). She also complained of an inability to wear anything but loose fitting clothing, and, not surprisingly, she was incapable of tolerating sex with her husband. Within this context, Louise quickly came to apprehend her vulvar pain in terms of the losses she was sustaining, not least of which was her recent inability to occupy waiting room seats and exam tables normally. While we waited in the room together for Dr. Erlich to return with a prescription, Louise rolled on to her side to take the pressure off her genitals. She elaborated about the “state” she was in when she located the assisted suicide websites: “I had to ask ... , ‘What *else*? What *else* can you take away from me?’”

I introduce Louise into the chapter titled *Accumulation* because I want to situate her personal narrative of loss(es) within an analytical narrative of accretion. My anthropological story of accumulation is not meant to displace or discount the experiences of Louise, nor of her pain-filled counterparts (Jackson, 1994). Rather, I want to understand the losses themselves as sedimentary layers in the experience of vulvar disease. Like the gleaners in Agnes Varda’s stunning documentary (2002), women with genital pain move through their symptoms and medical consultations in a state of constant collecting: diagnoses (mostly inaccurate), prescriptions (usually inadequate), advice (often erroneous), marital discord (mostly reparable), and an increasing and inevitable sense of dread that their pain will go on forever. I am intrigued and drawn to these burdens, because I believe them to articulate with broader

social processes that inform U.S. women's personal and collective relationships with their genital and sexual bodies. I want to complicate the notion of genital pain as loss because I do not believe that most women in the U.S.—diseased or not—have ever really 'had' their vulvas to lose. The cultural absence, disparagement and *inconsequence* of female genitalia are so common-sensical that even women with debilitating pain will lack the words with which to describe it to their doctor. I suggest that this 'loss' for words is more importantly understood as a discursive deposit—a stratified layer of socially enforced silence that is an integral component of coming to terms with life-altering genital pain.

This sense of loss is yet another facet of the *genital alienation* that I described in Chapter One. Having witnessed and begun to theorize its nature as far back as my clinician days, I predicted that it would surface naturally in the vulvar clinic. Indeed, a driving analytical force behind this research project were my questions about how alienation and the 'loss' of one's genitalia were negotiated in a setting that depended upon their explicit recognition. What I found during fieldwork were physicians who were actively promoting greater genital awareness ("See this diagram? This is your vulva!"), who understood the social forces that they were up against, and who consistently disrupted these forces with their medical interventions. What I also found, particularly in the earliest verbal exchanges between doctor and patient ("Tell me why you're here,") was a profound sense of heaviness in the interactive affects of the women: tongues thick with awkward residue, shoulders stooped, eyes downwardly cast, and words that felt as if they needed to be picked up off the floor. And although I sometimes attended to this heaviness with a more furrowed brow than did the physicians, apprehending its poignancy was not my analytic terminus. Explicating and accounting

for the cultural factors that weighed so onerously on these women—individually and collectively—was.

It's twenty years of pain: collecting

In discussing racial configurations in contemporary Ecuador and Peru, Mary Weismantel uses the concept of accumulation to describe how bodies acquire a race through their daily practices, material possessions and social exchanges. The (typically) economically privileged feet of a gringo, for example, are as marked by their access to well-fitting shoes and mechanical transportation as the (often) impoverished feet of an Indian are by their lack of the same. Weismantel's metaphor is an important one in embodiment scholarship, as it effectively delineates how a discursive category, such as gender, class or race, is materially lived through the body and its environment. Potentially neutral bodies acquire peculiar and distinct shapes through their participation in, and exposure to, activities that are themselves hierarchically organized. We can say that these categories aren't *real*, then, only at the expense of ignoring the *all too real* divisions of labor, resources, power and pleasures that are disproportionately accumulated by different kinds of bodies in historically and geographically specific ways. Hands and feet, specifically, are "thrust into constant and varied interaction with the world [and] especially marked by the things we own and the lives we live," making their ill-treatment easily resonant for those willing to pay attention. "I seldom witnessed the burden of poverty so acutely," says Weismantel, "as when I watched women in Zumbagua squeezing their feet into the ill-fitting, uncomfortable plastic shoes sold in the markets" (188). The material repercussions on these feet, repercussions that are unevenly distributed along racial, classed and gendered lines, need not be genetically encoded nor inheritable for them to be biologically salient. Bodies change, sometimes

permanently, due to what they accumulate along the way. Genitalia, I hope to demonstrate, are no exception.

Bodily accumulation is dynamic, both random and ordered, and mediated through cultural norms, expectations and structures. Weismantel's use of this concept emphasizes its imbricated nature: "our social histories are not written upon our bodies like ink atop a blank page but rather woven into the very fabric of our selves" (193). In telling stories from the clinic, I want to draw attention to this process, and to how vulvar pain can be understood as a porous layer in the lives and sexual bodies of women with symptoms. I want to temporarily—and heuristically—consider this disease as a discrete and identifiable layer because doing so forces us to more carefully analyze what is 'underneath' as well as what can conceivably and comfortably fit 'on top.' Additionally, and perhaps more fundamentally, I hope to delineate both the volume and the variety of experiences that come to fill up the worlds of women like Louise. Some accumulations are obvious, even physically graspable, like medical records from old doctors that arrive at the clinic in literal *reams* through the fax machine. Others, such as the layers of genital alienation and unwanted genital experience that I argue are stubbornly lodged in corporeal sediment, have a far more nuanced nature, and precipitate even heavier burdens.

The medical history that Louise had completed on her knees contained a list of symptoms associated with vulvar diseases, such as pain with a "burning" quality and an inability to tolerate vaginal penetration. Patients were instructed to check off the symptoms that were a part of their current or past experience. Medical assistants were the first to see the questionnaires in their completed form—they would usually skim them while they walked the patients down the hall and gathered their vital signs in the exam rooms. One morning, as Gia handed off a chart to Dr. Robichaud, she gave her

the kind of look that usually meant ‘You might want to read this one a little more carefully before you go in there.’ In reviewing the chart together a few seconds later, we saw that the woman had written the word “disfigured” into the symptom section; Dr. Robichaud said simply “This is bad.”

Gia also told us that this patient had brought along a couple of diaries that documented her symptoms in great detail. My initial reaction to these diaries was almost always negative, in the sense that they made *me* feel burdened. These were feelings leftover from my days as a clinician, when I would often feel overwhelmed by the enormity of what I couldn’t do for my patients. These diaries—painstakingly kept and filled with both the vastness and the minutiae of vulvar pain—were a physical index of the gap that existed between a woman’s *lived experience* of her disease, and the much narrower lens through which it was ultimately viewed by a provider. No matter how many pages had been filled (in this case, it was two books), the clinician would base most of her treatment plan on (usually) not more than ten minutes of interview details, and—most importantly—the findings of a physical exam. Patients who coped with invisible symptoms by inscribing them on the written page brought these words with them to the clinic, but usually found that the providers’ interest in their pain seemed to stop at the physical receipt of these pages. Having scrupulously amassed the evidence of their disease, patients found that they could not give it away, could not transfer its symbolic reality into the hands of their caretaker. These documents would remain a part of the permanent collection of their genital pain.

The patient in question—Frances Hoffman—had accumulated more than diary pages in the three years that she had been symptomatic. Like Louise, she found it almost impossible to sit for long periods of time, and so she acquired an inflatable “ring pillow” that took the pressure off her vulva. Frances told me later that she had

purchased an attractive bag so that she could take her pillow with her when she anticipated needing it; she remained embarrassed to use it in certain situations (like her first week at a new job), however, because of the nature of the disability that such an item conveyed. On this particular day, the clinic fell into that category and so when we met Frances in the exam room, she was standing up and avoiding the non-cushioned contact of her vulva with the built-in bench. Unique among the women that I met at OHSU, Frances' pain was primarily the result of a surgical complication; specifically, a nerve tumor (*neuroma*) that developed after she had a vulvar cyst removed. Since *neuromas* can develop in any area rich in nerve fibers, there was nothing particularly "vulvar" about her symptoms, other than their anatomical location. But, as I argued in Chapter Two, part of why Frances was in unremitting pain three years after her surgical complication was because she had not located a physician invested enough in her vulva to take her complaints seriously. As I observed what turned out to be a lengthy and emotional consultation, I came to appreciate not only the investment that Dr. Robichaud had in Frances' vulva, but also her understanding of the complicated and pernicious layers in which her pain was lodged.

In addition to a ring cushion, a new bag, antidepressants, pain medication and antibiotics (all ineffective), sleeplessness, lidocaine patches, and several volumes of recorded data, Frances had collected an enormous amount of shame about her symptoms. This was because she felt as if she had been "railroaded" by a "cocky" surgeon into having a procedure that she might not have needed. The vulvar cyst that she had—called a Bartholin's cyst—is a benign condition that is only problematic if/when it becomes infected. This had happened several times in Frances' past, but she had always been treated with antibiotics and/or a simple procedure that drained off the infected fluid. After forty years of age, however, there is a very small increase in the

possibility that an infected Bartholin's cyst might be/come malignant, and cautious gynecologists recommend excising them rather than simply treating the inflammation (Droegenmueller, 1992; Omole, Simmons and Hacker, 2003). When Frances' cyst recurred in 2002, she was not only over forty, but she had just relocated to Oregon from California; her indecision about a surgery that she had previously refused (some women opt to have these removed the first time they get infected) was now further confused by the added fear of cancer and the fact that she had established very few relationships—medical or otherwise—in Portland.

Sufficiently unnerved, Frances complied with the recommendations of the “cancer specialist” with whom she had inadvertently secured an appointment (an acquaintance had recommended him and she got in on a cancellation). “He gave me the bum’s rush. I didn’t trust him. I shouldn’t have let him rush me into it. [But] I didn’t know anyone to ask. He said ‘cancer,’ and I was scared.” Dr. Robichaud told me later that the procedure to remove these cysts was “notoriously complicated,” and was referred to as “the bloodiest little surger[y] in gynecology.” Because of the proximity of the Bartholin’s gland (the source of the cyst) to several bundles of pelvic nerves, it was very challenging to avoid complications like the one that Frances had sustained (Leclair and Jensen, 2005). The anatomical distortion produced by an inflammation would only compound the risk; because of this, Dr. Robichaud tried to treat the infection before she performed surgery. Telling Frances “I usually try to cool them down first,” she diplomatically communicated that this might have played a role in the development of her *neuroma*.

In drawing this contrast, and in frankly asserting “You have a bad complication” at the end of the physical exam, Dr. Robichaud attended to Frances’ vulva—both past and present—in the way that I argue is unique to (these) vulvar specialists. I will return

to this point in Chapter Four, but what I want to note here is that Dr. Robichaud's interest in Frances' vulva was not circumscribed by its risk for acquiring a malignancy, infection or other pathology. Rather, Dr. Robichaud desired—and believed in promoting and preserving—vulvas that were “robust,” “juicy,” “supple,” and alive; vulvas that were vibrant in and for themselves, and with which women could develop a wide range of relationships. Her choice to let vulvar infections “cool down” before she excised anything reflected her investment in the well-being of her patients' genitalia, as did her habit of allowing women over forty to trade a risky surgery for closer clinical follow-up. With these clinical decisions, Dr. Robichaud expanded the definition of vulvar/genital *integrity* beyond the mere absence of cancer or disease to one marked by a maximum of anatomy and pleasure and a minimum of pain and shame.⁴¹

Dr. Robichaud determined that Frances had some concomitant *vulvodynia*, and they decided on a treatment plan of physical therapy for the pelvic floor tenderness that had developed thus far. She was clear with Frances that there was very little she could do for the *neuroma* pain, however, aside from systemic/oral neuromodulators, all of which had the “typical side-effects” of fatigue, wakefulness, “cloudy” feelings, headaches and gastrointestinal changes; “nothing,” in Dr. Robichaud's words, “that makes anyone say ‘Sign me up!’” Frances declined these drugs for the time being after describing how “sensitive” she was to medication, but was satisfied overall with her treatment plan, even hopeful about the difference that physical therapy might make in her eventual pain level. She and Dr. Robichaud planned for her to follow-up in three to four months, and all of us began readying ourselves to leave the room and say goodbye.

⁴¹ While Dr. Robichaud was telling me about the complication rate for these surgeries, she added that she was performing one the next morning. Having just absorbed all that she'd said to Frances and me, I couldn't help but ask her “My God, are you nervous?” She didn't miss a beat before exclaiming “Hell, yeah! Especially ‘cause I've only done like eight of ‘em!” Given the differing investments in the vulvar integrity of their patients, it is difficult to imagine any of Dr. Robichaud's patients ending up like Frances, despite the fact that she has performed fewer procedures than the “specialist” who ‘took care’ of Frances.

What happened in the next few moments, however, brought our movements to a grinding halt; it was also an unparalleled ethnographic moment, the kind that I had expected to witness when I went to the field. I knew that patients could have profoundly different experiences when and if they were seen by providers acutely attuned to the complicated mix of needs that vulvar pain engenders. I didn't always know *how* this would occur, however, and Dr. Robichaud continued to surprise me with her ability to locate traumatically infused layers of experience that even *I* (!) had not yet discerned. In this case, it was the dense network of, not nerve fibers, but sexual and bodily shame in which Frances Hoffman's *neuroma* was firmly embedded.

Dr. Robichaud referred Frances to Cathy's PT group, stressing that they provided "this extra piece" of emotional support to their work. In making this assertion, she turned to me for confirmation, and asked me if I had anything to add. I reiterated Dr. Robichaud's opinion, and told Frances that I didn't think it possible for a woman to leave Cathy's office without having learned something about her body that she hadn't previously known, "even an hour before," I stressed. As we paused to ponder this possibility, Dr. Robichaud asked Frances directly if she "blame[d] herself" for what happened to her vulva. Because her question was intuitively—and expertly—informed, she was neither surprised nor unprepared when Frances began crying ("hard," according to my notes) and said "YES! And that's the hardest part of this!" As she continued to share her sadness and regret with us, Frances began to unburden herself of the shame and self-blame that she had been carrying for three long years.

Through her tears, Frances repeatedly stressed that her surgeon "didn't listen!" when she began calling him with concerns immediately after the surgery (he apparently put her off for close to ten days). It was difficult to hear this, and to ponder the nature and the consequences of that erasure; Dr. Robichaud and I both knew that listening

supportively *now* was the minimum that we could—and would—do for this patient. But then Dr. Robichaud took it a step further. I looked over to make eye contact with her, and to ascertain that I had a role to play in this unfolding drama, and saw—to my surprise—that she was sitting back down on the exam room stool. We had been with this patient for at least an hour and a half, Dr. Robichaud undoubtedly had several patients “roomed” and waiting for her, and she had already elaborated a complete and supportive plan of care with this patient. And yet, as Frances described the scope and the impact of her surgeon’s disavowal, Dr. Robichaud, rather than taking a gracious (and understandable) leave of this woman, chose instead to add another layer to Frances’ story: her concerted and *bodily* attention to Frances’ grief. Taking advantage of the stool’s wheels, she gently approached Frances and told her: “Sometimes you don’t get over something, but you learn to live with it. You’re grieving. You’re sad and you’re mad. And you have this daily reminder [of what happened].”

Dr. Robichaud is a sensitive clinician, and her clinical style would likely be marked by exchanges of this emotional caliber regardless of the specialty that she chose. But her behavior in this story, her ability to recognize and facilitate Frances’ bodily grief, has been cultivated by her work with vulvar pain patients. Like the Vietnam grunts in Tim O’Brien’s eloquent short story “The Things They Carried” (1990), symptomatic women carried mountains of “intangibles” along with their pill bottles, ring cushions and lidocaine gel. O’Brien’s grunts are loaded down with rifles, pocket knives, Kool-Aid, cigarettes, steel helmets and sewing kits; they also:

carried all the emotional baggage of men who might die. Grief, terror, love, longing—these were intangibles, but the intangibles had their own mass and specific gravity, they had tangible weight. They carried shameful memories. They carried the common secret of cowardice barely restrained, the instinct to run or freeze or hide, and in many respects this was the heaviest burden of all, for it could never be put down, it required perfect balance and perfect posture. (15)

In the clinic, these “intangibles” exist as a dense and palpable fog, a thick miasma of alienation and despair that can either be circumnavigated or carefully waded through. Dr. Robichaud—as exemplified by this moment with Frances—is committed to guiding her patients both through and away from feelings that can too easily lead to stagnation and the “shutting down” alluded to by both patients and providers. By not only being open to, but by *initiating*, a dialogue about her grief, Dr. Robichaud attends to Frances’ intangible burden and offers her a place to put it down—at least temporarily.

An investment in vulvar well-being and an attention to its vulnerability are mutually constitutive, *obliged* in the way that I described in Chapter One. They are also, as I argued in the previous section, predispositions that can be both cultivated and acquired along with the other genital “baggage” that so many U.S. women collect. Dr. Robichaud’s ability to locate self-blame in a story with such an (apparently) obvious perpetrator has been honed by her work with vulvar pain because of the other genital/sexual ‘stories’ with which it articulates, including those of the self-blaming victim of sexual assault. As it happened, Frances’ story contained these elements as well, explicit traces of the insidious (sexual) trauma that Maria Root (1992) has argued is an underlying current of most women’s bodily habitus. Frances told us that she had two important people in her life at the time of her surgery—a boyfriend (who is now her husband), and a male best friend, who was part of the reason she had moved to Oregon. Each was available to help her that day—her friend in the morning and her boyfriend in the afternoon. Although he couldn’t stay, her boyfriend wanted to be there when she checked in and so both men were (temporarily) present when the surgeon came in to review the procedure he would perform that morning.

In this last part of our conversation, Frances reiterated how arrogant this man was, even using the stool in the exam room to demonstrate the “cocky” way that he

occupied the one in the surgical suite. What upset her the most, though, was the question that he posed to her just as she was going under the anesthesia. While dreamily—and vulnerably—counting backwards from one hundred, she heard her surgeon ask “So Frances, which one is the boyfriend and which one is the best friend?” In retelling this episode three years later, Frances could imaginatively counter her surgeon and say to us, “So I brought two men, so what?” What lingered, and what was mixed with the shame she still carried about the etiology of what would more than likely be a lifetime of (some) genital pain, was her recollection of feeling “ashamed and dirty” about her surgeon’s comments. Surrendering to the effects of the anesthesia, and still nagged by misgivings over both the procedure and the surgeon himself, Frances recounted that the “last thing [she] was aware of going into this surgery was this shame.”

When Dr. Robichaud asked Frances to describe her pain during the physical exam, she initially answered with descriptors that I heard frequently in the vulvar clinic—it woke her up, she didn’t sleep for a year, it felt bruised and it hurt to touch it. She then continued in slightly more reflective terms:

the area feels ... it doesn’t feel like my vagina. It feels like it’s trying to hide. The labia minora—I used to feel it hanging, I could feel my clitoris. It was ticklish to touch. Now, it feels like it’s pulled in, like it’s hiding.

As I analyze this story three years later, I am struck by the profound sense that Frances’ genital hiding makes. Her surgeon’s comments, the bulky ring cushion, her inconvenient complication, my (initial) impatience with the drama of her story, and even Gia’s knowing look, are the stuff of which Frances’ shame is made, the cultural habit(u)s through which we try to make her sexual body disappear. Frances’ labia and clitoris are “pulled in [and] ... hiding” in order to protect themselves from these acts of disparagement, like the muscles of the pelvic floor in their efforts to avoid penetrating interlopers. What the vulvar clinic—in the attentive hands of Dr. Robichaud in this

instance—did for Frances was to bring this sexuality out of hiding and into the light of day. Dr. Robichaud’s efforts to listen, to *sit down* in the face of a story of erasure, lighten the load of this repression and hiding, and provide an opportunity for something that is rapidly and permanently closing down to open up, and even flourish. Dr. Robichaud had very little to offer in terms of pain relief on that day—Frances had already achieved a fair amount on her own. But I insist that she gave this patient her vulva back, and that follow-up visits would continue to bring Frances’ body out of hiding. These are layers of possibility that are always there and are unfolded and multiplied—like Irigaray’s lips—by the investment of an attuned provider.

I’m not sure if it will help with the day-to-day pain

In her 1998 book *The Woman Beneath the Skin: A Doctor’s Patients in Eighteenth-Century Germany*, historian Barbara Duden uses the journals of a “woman’s doctor” in order to argue that bodily imaginaries are contextually specific. Remarking that her analysis of the text’s varied (and unfamiliar) complaints left her feeling like an “outsider,” Duden concludes:

[a]s I perceived ever more clearly [...] how different their corporeality was, I realized with growing dismay that my own sense of womanhood is conditioned by history and cannot be compared across time. (179)

Dr. Storch’s journals are vivid, and describe a body that is oriented by its “urges.” This body is animated by inner fluxes, expulsions—of hardening masses and “dirty, pustular matter” (133), for example—excrescences, and inner stagnations; it lives a *habitus* through which physical stagnation is the equivalent of moral decay. Duden makes eloquent use of these journals to substantiate her suggestion that both space and time disrupt the objective continuity of physical bodies, an argument with which I wholeheartedly agree. In elaborating our differences from Dr. Storch’s patients,

however, Duden asserts that “[w]e are far from the inner body [...] in which excess, stagnation, accumulation, and false paths are anatomically and physiologically” common (126). Although my use and understanding of bodily accumulation is distinctly informed, I do not believe that “giving a history to the female body” (vi) necessitates a complete and mutual exclusivity between ‘their’ bodies and ‘ours,’ particularly when many of the social forces that condition these bodies—e.g. patriarchy—remain both present and potent. For me, there is no doubt that Frances’ body, along with those of her symptomatic cohort, had indeed accumulated an excess of unwanted genital experiences, and that these were both specific and extraneous to her vulvodynia and iatrogenic *neuroma*.

The contextually specific bodies that Duden insists that we recognize help us to better understand what Drs. Robichaud and Erlich can create for their patients through *their* alternative imaginaries. When Dr. Robichaud says to Joan (of her *lichen sclerosis*), “You don’t have a vaginal problem, you have a vulvar problem. That’s like saying an arm instead of a leg,” she provides her with another layer in her genital reality. For women like Joan, who has lost almost all of her clitoris and the majority of her labial contour, these purposeful and clear sentences infuse a disparaged and ignored bodily habitus with neutrality and concerted attention. They create and deposit the idea that it’s both acceptable—and even worthwhile—to, in Joan’s words, “go down there and look.” Minus these interventions, collective genital proscription and defamation layer themselves under, around and on top of whatever personal resources a woman may have otherwise acquired. The genital ease of a provider and the *dis*-ease of a patient are not mutually exclusive; rather, they are most constructively understood in the imbricated and sedimentary terms theorized here. Much like the Bartholin’s *fossa* (the source of Frances’ cyst)—a functional and usually healthy drainage duct nestled deep within a

network of nerve fibers—the individual and therapeutic acts of Drs. Erlich and Robichaud can wedge themselves into the deep tissue discourses of inconsequence, and create new bodies for their patients, bodies that open up on the exam table, exclaiming “I can see!” as they are handed a mirror and examine their vulvas for the very first time. Divested of their burdens—even momentarily—the complex striations of symptomatic women’s *dis-ease* become more visible, making them, I suggest, more ‘manageable’ for clinicians and (feminist) theorists alike.

Maintaining (collective) grief

In telling Frances’ story, I made mention of Dr. Robichaud’s razor-sharp clinical instincts. This was an ethnographic observation that hit close to home, as it contrasted sharply with a growing sense that my own clinical intuition seemed to be slipping through my fingers. I had always been confident in what I thought of as a perceptual rapport with my patients, drawing from both formal and informal sources to generate the therapeutic approaches that I pursued with them. In other words, I knew that most of the time I ‘got’ what was going on with my patients, specifically how their emotional needs articulated with their physiological ones. I knew that this ability had gotten me to OHSU and that it fortified my efforts in acquiring consent and participation from the women I met there. What kept surprising me, however, was the frequency with which my evaluation of a patient’s needs, what was *going on with her*, was off. It wasn’t too often—maybe one or two times per month, but it was notable and, at least initially, a bit disarming. Newly attentive to my analytical orientation towards these patients, I reassured myself that it was the shift—from clinician to anthropologist—that was responsible; if I was becoming a less intuitive clinician, it was in the service of being a more astute social scientist.

The proud provider in me still squirms when I recall my misses, though, and my discomfort is complicated by the consistency with which Dr. Robichaud bested me in this department. It was a rare patient that eluded her insight and therapeutic grasp; Molly, to whom this story is about to turn, was no exception. I didn't miss Molly by a mile, exactly, but a brief description of our collective encounter (myself, Dr. Robichaud and Jackie, the resident) with Molly will illuminate not only the dynamic that I have thus far described, but will also sketch out what I understand to be the benefits of my perceptual shift. I understand Molly—her story, her affect, and her grief—to be part of something broader than the vulvar disease to which Dr. Robichaud so eloquently and carefully attends. My lessened ability to attend to this physiological/medical complex has been supplanted with a greater ability to delineate the social and cultural processes that articulate with her symptoms, the task that I have set for myself in this dissertation. A close look at a small piece of her visit to the clinic will (hopefully) allow us to sort and locate the important differences between Dr. Robichaud and me, differences that in my perfect world would pay me to remain there as an integral component of the clinic.

The routine that we established at the clinic was for the medical assistants to ask each patient if she would allow me to be present during her visit; they typically did this as they were “rooming” her. If the patient agreed (which she almost always did), and if there was a resident in the clinic that day (which there almost always was), then I would enter the exam room with the resident, and we would introduce ourselves at the same time. Encountering patients in this way, primed by the medical assistant's reminder to each woman that OHSU was a “teaching hospital,” framed my project, and my presence, with a medical legitimacy that undoubtedly increased the volume of patient participation in my research. I used the time after the exam—while I chatted with patients awaiting prescriptions and billing forms, or walked with them to the front desk to make follow-up

appointments—to elaborate on the ways that my project and interest in them differed from traditional clinical research. It was these conversations that laid the ground for our subsequent interviews, and our larger discussions about the meaning that vulvar pain had for them. My meetings in the exam rooms, by contrast, were amicably brief and patients experienced my research and me as entirely peripheral to their medical consultations. Indeed, my marginality was often underscored by the physical space that I occupied in the exam room. Perched on either a built in seat against the far back wall, or a somewhat durable wooden magazine rack along the side of the room, or sometimes just standing wherever I was least disruptive, I could only observe the patient’s clinical condition (i.e., her genitalia) if I asked permission and created the room to do so.⁴²

Molly was one of the very few patients that I met alone, before either the resident or the physician entered the scene. Although I always felt a bit more precarious in these situations, by the time I met Molly I had grown increasingly comfortable and confident that I had something to offer to these women, and so I didn’t preoccupy myself with worries about her refusal to participate. I also knew, by this time, that I had secured and conducted interviews that far exceeded my pre-fieldwork expectations—in both quantity and quality—and that if Molly didn’t agree to speak with me after her visit, I didn’t feel the need to push her in any way. As it turned out, my relationship with Molly was well served by this accretion of both data and scholarly confidence, as she proved to be one of the most challenging interviews to secure.

I am introducing Molly’s story because I want to argue that our struggle to communicate about her vulvar disease was significantly informed by what Molly had *accumulated* prior to her visit to OHSU. Like the majority of her counterparts, Molly arrived at the clinic laden with feelings, experiences, symptoms and questions that were

⁴² Which, to my own surprise, I eventually stopped doing. I see this as yet another marker of the shift in my positionality regarding Vulvar Disease.

both uniquely hers and meaningfully collective, i.e., shared by enough women to make her presence in the clinic relevant. It is the combination of these burdens—those that distinctly mark each and every narrative as well as those with which I came to be so familiar that I could almost finish the patients’ sentences—that are under consideration here. What I hope to demonstrate is the existence and the expressions of the genital discourse(s) that inform, influence and sometimes construct the understandings that clinic patients have of their vulvar pain. As they accrue symptoms, medications, treatment plans, counseling sessions, and painful sexual episodes, these women look for appropriate and meaningful cultural repositories—sites and processes that can attend to their experience. I argue that, instead, they often locate interpretive frameworks that are either inadequate, malignant, or absent entirely, and that these cultural erasures and disfigurings are nestled deeply in the sedimented relationships that patients have with their genital bodies.

Molly and I chatted briefly in the exam room, and I was able to adequately explain my interest in her symptoms so that she allowed me to observe and take written notes. Molly’s consent was far from gregarious, however, and she participated in our conversation with a fair amount of hesitation. Molly was twenty-seven years old, dressed in fashionable business attire and good, moderately applied makeup. When Jackie, the resident, came in and sat down to take the history, Molly faced her with an affect that was both straight-on and barely holding it together. Indeed, it wasn’t until Jackie had asked her full second question that Molly’s composure faltered, and that she began to narrate the accumulated events and details that were responsible for her being in the vulvar clinic.

Molly’s appointment at the clinic was in April, 2005. On Jackie’s prompt, she began her story by telling us that her symptoms started in November of 1999, three

months after she was married. At that time, Jackie had only been in the vulva clinic a week or two, but was learning to take the relevant history; she knew, then, that it was within reason to ask the patient about events associated with the onset of her symptoms. “Did something happen at that time?” she gently probed, and Molly immediately began to cry. She was so distraught that she could not say anything at all for a minute or so. Jackie and I sat with her quietly and waited for her to continue. When she did, she recalled that she “got a yeast infection” that was subsequently complicated by a series of bladder infections. Still crying, Molly attempted to participate in the diagnostic process by saying to Jackie “I don’t know if that’s what happened, but ” Jackie paused to touch Molly’s leg, moving a little closer to her, and switched gears to ask Molly about her current symptoms. I want to briefly point out that this quick temporal shift on the part of this resident is anything but random. Having collected the relevant data, residents would present them to the physician with whom they were working, who would evaluate their grasp of the presentation of vulvar disease. In order for a resident to present their best case, they needed to search for the right elements. As with other clinical conditions, there are key words and phrases for which a doctor listens in order to generate diagnostic possibilities. I want to point out not only this detail of the process of disease construction, but also the arbitrary nature of the knowledge exchange. For it is only *sometimes* that VVS or vulvodynia is marked by a precipitating event, and it is only rarely that VVS symptoms appear so shortly after the onset of otherwise painless sexual intercourse (Molly had been a virgin when she married). Nevertheless, Jackie had already learned to guide Molly’s story toward these details, marking her accumulating expertise in the specialty of vulvar pain.

Molly answered this second set of questions (about her current symptoms) by saying that she “get[s] what look like cuts ... around the area.” As she used her hands to

try to articulate what she meant, she added “I have one right now. It’s a burning pain. And I can tell that it’s bleeding.” In an effort to better apprehend these details, Jackie took out a page-size diagram of a vulva and asked Molly to pinpoint the location of the cuts. “If you were to look at this picture—this is your anus, this is the clitoris, this is your urethra, where you pee—does this orient you?” Molly used the diagram to point to the distinct sites where the “random cuts” and the “cuts that occur with intercourse” occurred. In response to Molly’s introduction of sexual intercourse, Jackie asked her if the pain that she had was during or after sex. “Oh we don’t have sex,” Molly replied, “the pain is through the night. And into the next day.”

For reasons that I can only attribute to the unpredictable and generative nature of ethnographic fieldwork, I found myself overwhelmed with images of Molly’s wedding while she continued to narrate her story to Jackie. It was not like me to have, let alone nourish, these kinds of speculative flights while I was observing in the exam room—I was usually far too busy trying to make sure that I got an accurate transcript of the conversations in my notebook. But the sensations with this patient were immediate and extremely poignant. I felt heavy and very sad as I imagined the excitement and promise that both she and her husband experienced at their wedding, and the loss and the betrayal with which her symptoms had forced them to co-exist. Maybe it was because Molly herself was so picture-perfect—a conventionally attractive white woman in her late twenties, well-dressed and articulate, although not overbearing in any way. She was the embodiment of the bride that millions of women in the U.S. confront each year as they peruse wedding magazines and newspaper announcements, placing themselves in her shoes, dress and veil. Maybe that’s why my fieldnotes from this visit say: *I sit here and am overwhelmed with images and thoughts re: this woman’s wedding. She is so perfectly composed, so conventionally “perfect” and I can imagine that her wedding*

was too. That it was a day she dreamed about and planned meticulously. That she and her husband looked beautiful. I can't help but think about the betrayal that a woman in her situation must feel when compared with the promise of a day like that. That all of the ideas and dreams about a marriage they had on that day have been so forcefully and painfully reconstructed and redefined It is so fresh and clear with this patient, for some reason. I can see her wedding album as I look at her sitting across the room from me.

I can see her wedding album Why did I write these notes with this patient? Because I *have* seen her wedding album. My whole life I've seen it. As I write this now, I wonder about how much I need for Molly—a symbol of a heteronormative economy—to be able to live the happiness that those images promise. Is this why I felt her betrayal so forcefully? Regardless, I relate these impressions now to contrast what Molly had expected to accumulate after her wedding with what she actually had acquired. Instead of romance, increasingly more pleasurable sex, lacy lingerie, happiness and increased sexual confidence, Molly had collected prescriptions for antifungal creams and pills, topical anesthetics in gel, cream and liquid form, antidepressants, counseling sessions, painful arguments with a man she had loved for many years, and a growing despair that her sexual life would never feel any better than this.

Jackie reassured Molly that she thought “that Dr. [Robichaud] w[ould] be able to help,” after acknowledging the “long hard road” that she'd been through. “I can see why it's hard to talk about it,” she cooed. Jackie and I relocated to the pod while Molly undressed and Jackie conveyed the highlights of what she'd gathered to Dr. Robichaud, including that Molly had “been treated with just about everything. ... I think Dr. S. sent her here for laser, basically.” But when Jackie was asked about physical therapy, she

had to reply that she hadn't "specifically ask[ed]." Dr. Robichaud checked on this upon our return to the exam room and learned that Molly had had three to four sessions through her HMO. She could not remember the therapist's name, but she did recall that "all she gave me were these exercises to do." Since most of Molly's history had been collected, and she was draped and sitting on the table, Dr. Robichaud began preparing for the physical exam, which included pouring a moderate amount of liquid lidocaine into a small paper cup. Molly had been relatively quiet up to this point, but when she caught sight of the lidocaine, she called our attention to another piece of her treatment history: "That's what I use. That exactly." This intrigued all of us, since it indicated that Molly had—at some point—been under the care of a provider who was at least partially familiar with the clinical protocols for VVS.

Dr. Robichaud deferred further investigation of this, however, and quickly moved on to examining Molly's vulva, guiding and teaching Jackie to do the same. I stayed on my magazine rack, where I could hear their conversation, but where I could watch Molly. As Jackie, who was doing most of the exam, stated "I can see where you had that cut," Molly began to noticeably tense up, in both her body and her voice. Her hands, which were clasped on top of her abdomen, were engaged in a fierce grip with one another, and she vocalized her discomfort with both numbers (2.5-3.0 on a 3 point scale) and less measured descriptors ("Yes, yes! Oh yeah!"). Dr. Robichaud and Jackie were quick to apply the liquid lidocaine, and their repeat exam was "better," according to Molly. In the few minutes that they waited for the lidocaine to take effect, the physicians tried (as they normally did) to make small talk, but Molly's emotional state was so precarious that very little was said. She managed to convey that she and her husband had probably "had sex twice th[at] year" after which she began to cry. She was attempting to contain this (*she is maintaining*, my fieldnotes say) while she re-

characterized her pain in relationship to the lidocaine. When Dr. Robichaud asked her about inserting a speculum, she answered that she “could bear it.” Dr. Robichaud replied, “How about we don’t then?”

Molly wanted a speculum exam, believing that it would contribute to a more accurate diagnosis. After Dr. Robichaud acquiesced, the three of us returned to the pod in order for Molly to dress and the physicians to discuss their treatment plan. Jackie had previously reported to Dr. Robichaud that Molly’s symptoms began three months after she got married (as a virgin). In clarifying how long ago this had occurred, Dr. Robichaud asked Jackie “So this is her first wedding anniversary [coming up]?” “No,” Jackie and I countered heavily, “it’s her sixth.” Dr. Robichaud was quiet for a moment, and then said: “There is so much grief in that room [that] *I* almost wanted to cry.” As she elaborated, Dr. Robichaud told Jackie that her observation was based on Molly’s “body language and history,” stressing that this was what had guided her towards the approach she took with this patient “from the get-go. Just the body language. She’s so tense. I mean, you can fix her vestibule, and she’s still going to be tense.”

I had easily picked up on Molly’s tension but I had not—as with Frances Hoffman—interpreted her affect in terms of grief. My initial reaction to Dr. Robichaud’s words, as I suggested at the beginning of this section, was that I had ‘missed’ this important aspect of Molly’s lived experience, but I no longer feel that way. For me, Molly’s affect, evidenced by our introductory (and stilted) conversation, her flat and purposeful self-presentation, and the way that she ‘worried’ her hands during her pelvic exam, was clearly burdened. Impressing its heavy contours onto my own body image, it resonated with the states of alienation and absence that I described in Chapter One. In making this distinction, I neither want to suggest that I (or Dr. Robichaud) had the more ‘correct’ take on Molly, nor that grief and heaviness occupy distinct affective planes,

particularly at the vulva clinic. Rather, I want to call attention to the different analytical work that our interpretations do. For Dr. Robichaud, Molly's grief was profoundly personal; her assertion that "she's still going to be tense," indexed the idiosyncratic nature of Molly's relationship to her pain. In contrast, the burdens that I saw Molly stoically bearing conveyed a more collective structure of feeling, one that I believe is a substantial part of the larger experience of symptomatic women.

Duden (1998) argues that the body that arose in the wake of Enlightenment thinking, i.e., the "modern" body:

waned as a source that imparted meaning to suffering[;] [p]ain and illness, once a form of punishment, the yoke of fate, a trial, or a burden, were turned into symptoms of disease within the body. (30)

Dr. Robichaud found meaning in Molly's pain, but continued to believe that it could be separated from her grief; they were related, but one was physiological—"you can fix [it]"—and the other was psychological. In this dissertation, I am proposing that vulvar pain may not be "fixable" outside of a collective investment in the genital well-being of (these) women. Molly's heaviest burden, I argue, is the alienation through which she lives her disease condition, much of which was accumulated before the onset of her symptoms. Drs. Robichaud and Erlich routinely disrupt the disparaged body images of their patients and, in this way, contribute to a larger transformation of the cultural vulva. But finding *only* grief, like finding *only* burdened alienation, does just part of the job.

In exposing the complex and striated layers that constitute Vulvar Disease, it becomes increasingly evident that our solutions—our 'cures'—need to be similarly layered. As invested clinicians, social scientists, and feminists, we need to interleave ourselves into these same solutions, making our insights meaningful and comprehensible to each *other* as well as to our respective disciplines and professional peers. The clinical strategies of Drs. Robichaud and Erlich complement, overlap, diverge from, and at times

contradict my own approach to these pain conditions. We needn't view this as distracting nor counterproductive, however. Indeed, a dynamic and *explicit* merging of our distinctly-informed perspectives can remind symptomatic women that the best answers to their questions may likely involve a uniquely configured 'team' of invested, and perhaps unexpected, actors.

I'm just not sympathetic. I don't feel bad for them.

Dr. Robichaud: "So, tell me what's been going on."

Deirdre: "It hurts."

Dr. Robichaud: "Where?"

Deirdre: "Down there."

Deirdre was seventeen years old, and came to her appointment with her mother, Jan. Deirdre had collected a number of difficult experiences in her young life. This included being sexually molested by her mother's ex-husband between the ages of two and six, and a belief that her vulvar symptoms began around that time. Deirdre had acquired a counselor along the way, a woman who told her that "it might be some PTSD stuff in [her] head." Prior to this visit with Dr. Robichaud, Deirdre had been diagnosed and treated for several sexually transmitted infections, including one that became complicated enough to affect her future fertility. Jan asked if the clinic could do a pregnancy test that morning because she knew that Deirdre had been having unprotected sex with her boyfriend. (*I am reeling as we take all of this in, trying to find places for the vulvar pain to fit. Dr. Robichaud is not batting an eye.*) Later in the visit, Dr. Robichaud upped the ante on this family by telling Deirdre "Your pain is classified into four different pains" which she followed by outlining the complicated details of their respective treatment plans. She soberly punctuated her clinical monologue by saying "I think you have some hard work ahead of you." Long before this extra mantle was added

to the picture, I began to feel my own body slouching with the incredible weight of this young woman's burdens, now four more. My fieldnotes from that visit say: *This mom [is] ... probably in her early 40s, but looks older, like she is tired and has had a hard life. I wonder, as she relates [Deirdre's] history so matter-of-factly, how a mother and daughter ever recover from something like this. It feels much too big for this small exam room, for us four bodies to hold and sustain. I am so sad for them both.*

Deirdre's dialogue with Dr. Robichaud (above) exemplifies the fragile and disjointed nature of the relationships that U.S. women have with their genital bodies. In providing the details of these exchanges in transcript form, I want to again suggest that there is a highly sedimented aspect to the patients' words. This is easier to grasp if we remain mindful of the social contexts through which women typically live and experience their genitals, i.e., as an inappropriate topic for almost any conversation but the one they are now being asked to have. In simplest form, my argument in this dissertation is that this seemingly small cultural fact is at the root of the rest of what these women accumulate along the way to a diagnosis and treatment of their symptoms. Not 'talking about' them—in this case the vulva and genitalia themselves, not just their pain—renders those susceptible to this cultural imperative incapable of properly attending to them.

When we met Molly, she was making do with the treatments that had been devised by her HMO physician (who had more than likely learned about vulvar pain through a conference presentation or journal article), but she continued to experience life-altering—and sexually prohibitive—pain. She was fortunate that her HMO authorized her visits to OHSU, although she told me in our interview that she was willing to pay out-of-pocket for her surgery if she had to. Obviously, Molly was fortunate in this regard as well. It is easy to see, in Molly's case, that having 'technical'

access to the services and products used in the expert management of vulvar pain do not necessarily result in the resolution of that pain. Without the attunement and dedicated investment in the long-term well-being of the vulva—*for itself*—patients often experience their “disease” as a set of prescriptions, proscriptions and procedures, rather than as a physical and sexual reality that needs to be faced squarely and consistently. Dr. Robichaud uses her first visit to communicate the investment that she expects her patients to make; her words to Molly, once she was re-dressed and ready for a plan, were “You’re going to get better. You have a lot of work to do. But you’ve already shown that you can do that.”

Many of the women that I met related stories about the advice and treatment they received from inexperienced, sometimes clueless, providers. This often led them to drag their feet about making an appointment at OHSU, even when they became aware of the expertise that resided there. Lily told me about a clinician who literally threw up her hands and said “I don’t know what’s wrong with you!” right before she referred her to Dr. Robichaud. It was also not uncommon for patients to be cajoled into finding ways to ‘ride out’ the pain—Isabelle was encouraged to “smoke a little grass,” for example. Indeed, advice to “stick it out” was rampant among the gynecologists in the Northwestern United States. Medical recommendations such as “have a glass of wine,” and “wait until you have a baby,” were generously distributed by providers whose understandings of female sexual pleasure clearly included an acceptable amount of pain.

The vulnerability that such providers refuse to acknowledge, i.e., of their inability to *do their job*, to provide a diagnosis and (most importantly) a cure, was strategically sublimated into practices that accounted for the burden of inadequate and/or unnecessary treatment regimens (and their concomitant cost). Lily, for her part, had collected “an abundance of medication,” from the doctor who ultimately threw up her

hands in frustration. Countless other patients described drawers full of both topical agents (ointments, gels, and creams) and oral medications (antifungal, antibiotic, antidepressant) that ultimately proved to be ineffective in controlling or mitigating their symptoms. JoJo, whose physician held fast to his belief that drinking wine would “loosen her up” enough to tolerate penetration by her husband, told me that she purchased more bottles of wine than she could recall, hoping to find a variety that she enjoyed. The fact that she “d[id]n’t even like wine” mattered little in the context of complying with advice that she both sought and received with sincerity. The relationship between inadequate clinical expertise and pernicious assumptions about female sexuality—how a *relaxed* pelvic floor articulates with ideas about a *loose* woman—merits our scrupulous attention, particularly when this corporeo-cultural conflation is voiced by patients and/or their partners. Upon hearing Dr. Erlich explain how physical therapy could help his wife’s pain, one husband responded by asking “So, does that mean I have to go out and get her drunk?”

The discourses through which these (clinical) behaviors can be (at least partially) understood are social realities that weigh heavily on patients with genital pain. The singular experience of constituting a clinical ‘puzzle’ for one or more inadequately educated doctors, meshes far too seamlessly with the collective experience of living in a body that has always mattered too little. A woman’s genital familiarity—in any amount—is easily threatened when the experts charged with her care demonstrate more clumsiness than proficiency. When your doctor proclaims, after a cursory examination, “Well, you’ve got lube, so you’re okay,” the matter of your sexual pain and pleasure is positioned firmly behind the matter of your sexual function. These initial encounters with medicine are based upon, permeated by, and ultimately productive of discourses through which the female sexual body is absented and deferred through its inscrutability.

A chronic condition, this absence resonates deeply and palpably, in the way that a phantom limb's absence is infused with a ghostly corporeal presence. In the contemporary U.S., women with vulvar pain index the discursive amputations of their sexual bodies, and they ache with the burdens of inconsequence and erasure. They perform important cultural work in their efforts to make their experience(s) medically known, but the weight of these cumulative encounters slows their individual progress towards adequate treatment. For some, slowness turns to stagnation for a period of months or years so that by the time they reach the clinic they are almost too heavy to walk through the door.

PART III: DEEP TISSUE DISCOURSES

Anything wrong before I touch?

Molly, in almost four years of being cared for at the local (and powerful) HMO, had participated in only “three to four” physical therapy (PT) sessions. This was not unusual among the patients I met; indeed, the majority of patients who were referred to OHSU from another provider had never had any physical therapy and, if they had, it had not made any major difference in their pain (as was the case with Molly). In stark contrast, and as I described in Chapter One, physical therapy was a clinical staple in the treatment plans of Drs. Erlich and Robichaud. Since many women were very reluctant to have surgery, at least as a first-line treatment, and since the vast majority of patients' insurance plans did not cover the cost of counseling (but did cover PT), it made practical as well as clinical sense to invest a lot of effort into linking patients with a physical therapist who understood the particular needs of vulvar pain.

Symptomatic women need physical therapy for a condition that, until recently, has been called *vaginismus*. (See Appendix D). Some physicians, like Dr. Erlich, object to the neurotic and psychosomatic connotations associated with that word (Reissing, Binik and Khalife, 1999; Leclair and Jensen, 2005) and have chosen to describe the condition in more clinically neutral terms, i.e., pelvic floor *myalgia* (muscle pain). Communication between physicians, hospitals, laboratories and insurance companies is facilitated through a glossary of nationally recognized billing codes that correspond to diagnostic categories. That is, medical diagnoses (e.g. “upper respiratory tract infection”) are assigned numerical codes, which are then used to determine a range of associated practices: number of visits needed, appropriate treatments, expected cost of recovery etc. Part of the work of the National Vulvodynia Association in the 1990’s was to establish these codes for vulvar pain in order to medically legitimate symptomatic women. During my fieldwork (2004-2005), OHSU was using two billing codes for the condition that required physical therapy services—*vaginismus* and *pelvic floor myalgia*. This was discursively relevant not just because it demonstrated the shifting nature of vulvar pain diagnoses, but also because of the feminist politics at play. *Vaginismus*, as many of us know, is a word best-loved by Freudian psychoanalysts who equate penetratively-prohibiting vaginal ‘clenching’ with neurotic hysteria and/or unresolved psychic trauma regarding heterosexual coitus. Pelvic floor *myalgia*, on the other hand, is a phrase that—at least currently—carries fewer psychological connotations and, with that, the blessing of an increasing number of progressively-minded physicians. Dr. Erlich was the only provider with whom I spoke about this explicitly, and she told me that she was making an ideological point of checking the “myalgia” box on the patient’s billing forms.

Physical therapy is intended to provide a woman with a better understanding of—and greater control over—the musculature of her pelvic floor (see Appendix E). Vestibular pain (VVS), almost always superficial, becomes confusingly deeper as the surrounding musculature becomes involved. With the approach of a potentially painful stimulant (a tampon, a penis, or a gynecological instrument)⁴³, women with VVS learn to pull in their vaginal and pelvic floor muscles, the protective ‘tail-tucking’ maneuver that I discussed in Chapter One. Although this behavior may be technically volitional the first few times it occurs, by the time a patient has developed *myalgia*, it is safe to say that she has lost control over this muscular act. Ultimately—and unsurprisingly—this strategy proves maladaptive, as the once superficial, acute, and localized pain at the vestibule becomes deep, diffuse and lingering in the large muscles of the pelvic floor. Physical therapy, done by a trained and empathetic provider, teaches a woman with pelvic floor *myalgia* to both undo, and gain greater control over, this compensatory pain.

Therapists who specialize in this area usually have a background in another variety of pelvic floor work—the muscular re-strengthening and retraining of women with urinary incontinence. PT has become standard in the management of incontinence, the techniques so effective that it is unusual for a gynecological urology practice *not* to have a physical therapist on staff (Berghmans et al, 2000; Pages et al, 2001). PT became a part of OHSU’s toolkit when Dr. Jensen, the clinic’s former director (and founder), approached a local practice that he knew was doing incontinence work and asked them if they would be willing to learn about vulvar pain (“He literally found us in the phone book,” Cathy told me as she related this story to me one afternoon). The reasoning behind his (and other vulvar pain pioneers’) efforts involved a mechanics of reversal.

⁴³ I now think of this as the penetrative triumvirate, routinely—and unquestioningly—alluded to by both providers and patients. It was noteworthy that the woman’s own hand or finger(s) was not included, another interesting bodily erasure.

Women with urinary incontinence were taught to strengthen and *direct* the muscles of their pelvic floor, i.e. to contract and release them according to their physical needs (containing or allowing a flow of urine). In this conceptual framework, it made sense to teach women whose muscles *contracted* (rather than loosened) maladaptively, to exercise and exert that same kind of corporeal direction. Physical therapists and gynecologists worked together to establish a few initial protocols and criteria, and an increasing number of both patients and PTs began to experiment with techniques.

Many women have built up enough muscular tension (during their undiagnosed and/or untreated years) to experience vaginal/pelvic floor pain in addition to penetrative resistance.⁴⁴ The pain is typically not present until penetration is attempted (or achieved), but the amount and the quality can change dramatically over the course of months or years. Women whose pain was once only—though dramatically—experienced at the point of vestibular (skin) contact, and who could tolerate coitus (or a pelvic exam) “if he could just get past that point,” eventually end up having deep and lingering pain, sometimes for “days” after vaginal penetration. An early diagnosis of VVS, and a timely prescription and routine use of topical lidocaine, can conceivably prevent the development of this deep tissue involvement, if the vestibular skin can be managed well. Women describe their muscular pain as “burning” which contributes to significant amounts of bodily confusion, in that their vestibular (skin) pain is characteristically of the same quality. It eventually becomes quite difficult—even for the most informed of women—to differentiate between the two (or more) varieties of pain, leading to an anatomical conflation and an overall sense of disorder about “what all’s going on down there.” In this scenario, diagnostic precision can be tedious and

⁴⁴ Think about the difference between muscular tension in your back that hurts only when someone begins to touch (e.g., massage) it vs. tension that hurts all the time.

difficult to achieve, and Drs. Erlich and Robichaud spend a good portion of the physical exam trying to teach their patients how to distinguish the different sources of their pain.

There are several methods employed by these specialists: bioskeletal evaluation and alignment; strengthening and/or stretching of the muscles that surround and support the pelvic floor (abdomen, hips, thighs); breathing and relaxation exercises; dilator (home)work; craniosacral therapy (See Chapter Four); vaginal and rectal myofascial, or “trigger-point” release; and biofeedback (Glazer and Rodke, 2001; Bergeron et al, 2002; Reissing et al, 2005). These techniques are used in various configurations by individual therapists, and it is probably safe to say that no two PT practices approach pelvic floor pain in exactly the same way. When I researched the providers on OHSU’s referral list, for example, I spoke with several who did not view internal/vaginal work as a necessary component of their treatment plan, and others who were not interested in what biofeedback had to offer. In the most general of terms, physical therapists tend to be split into two camps—those who understand pelvic floor pain as a musculoskeletal/alignment issue, best approached with whole body maneuvers, along with regional strengthening and complementary breathing exercises; and those who, by contrast, worked from the inside out, concentrating on the hands-on “release” of tightly contracted pelvic floor muscles surrounding the vagina (and sometimes rectum), along with similarly supportive and whole-body techniques such as diaphragmatic breathing or craniosacral massage. This second approach is nicely illustrated by this exchange between Cathy and Libby:

C: [Moves to a new spot in Libby’s vagina; a new place for pressure. She says she can feel some tightness.] As I hold, is that discomfort more, less, or staying the same?

L: Pretty much the same.

C: There’s turning, and now pressure on the right.

L: OOH!

C: Just keep breathing—finding those places. How are you doing? Can [you] do one more? [She describes and does a horseshoe shape around the vagina, from one side to the other.] Good job, you're breathing. That's it. I can feel some of those tight areas. They're just leftovers from years of pain. They're flexible, they're soft. You just work them out until they get soft. This is where the work is. There is where the work is.

L: Yes, I can feel it.

C: If you can't relax where the discomfort is, you relax around it, or as close to the discomfort as you can get.

More than a few of the women that I met through the clinic were averse to—even repulsed by—the idea of physical therapy that would take place “down there.” Clair, who I will cite below, recounted the most extreme version of this, but her sharp words differ from her reluctant peers in degree rather than category. Clair's excerpt is lengthy, but worth reading in its entirety, as she captures many of the reasons behind symptomatic women's hesitation to pursue this treatment option aggressively. Chapter Five will re-examine this issue, paying greater attention to geographic and socioeconomic factors that also contribute to a somewhat poor compliance rate with PT. But Clair's narrative—although singular in her “generational” concerns (she was fifty-two at her diagnosis)—gives us a good feel for not only the content of PT sessions, but also for some of the bodily striations with which they interleave.

C: I even tried physical therapy, and that was a horrible experience.

CL: Tell me more about that—so one of the doctors referred you to a physical therapist?

C: Hmm-hmm.

CL: And what did they tell you was wrong, what did they say the PT was for?

C: The same, they really had no um, um, ... I believe I believe that she had a name for it.

CL: Did she say vaginismus?

C: Yes, yes.

CL: Did she explain what that was to you?

C: She said if I do these exercises, I'd feel better, but that didn't work either.

CL: Tell me about, what did she want you to do, and how long did you try ...?

C: Well we tried sitting on this great big ball, we tried relaxing, and, um, a lot of exams, and she'd put a mirror down there and show me, and she, um, wanted me to, um, uh, ... satisfy myself and and .. all of those things. And ... the *whole* experience was uncomfortable to me. It, it was it was um, ... I don't know, it just it just um, I guess it was my generation. We just are not *used* to having our legs spread in a mirror and two women talking about it and looking down there and all this *exposure*. And I was never comfortable with it. *But* I was willing to go through the humiliation of it if it worked. But it didn't! So I said, you know, this is ...

CL: Yeah, and how many times did you go do you remember?

C: I think I went three times to her. (The two women being me and her) .. And she'd just act like I, we were talking about my finger! And it wasn't like that to me. So .. you know, it's, uh, maybe a generation problem I don't know, but ...

CL: You felt, um, vulnerable or exposed, or sort of?

C: I felt exposed, vulnerable, I just felt like ... um .. I don't know, it felt similar to, um, ... sexual abuse .. situations, that I'd had in my past. Um, .. it just didn't feel, um ... from a spiritual aspect, 'cause I'm a Christian, it didn't feel *right*.

CL: Mmm, hmm, mmm-hmm. So people use the word safe when they talk about that, like did it feel unsafe, or, it more didn't feel right?

C: It just didn't feel like ... it was, it was *too much*. It was just too much .. intimacy with another woman. I, I ... that's the only way I can explain it. But yet I can have a female doctor examine me and I don't have the same feeling.

I would venture to say that physical therapy is not for the faint of heart. For the virginal women with VVS in particular, establishing a connection between penetration (e.g., of the therapist's finger and/or a therapeutic dilator) and pain *relief* was challenging, and made more so for women like Clair whose symptoms were—at minimum—obliged (in the Freudian sense) to her history of sexual abuse. Clair described to me how she would “just freeze” and pretend to be asleep when the man who molested her got into bed; the bed of a couple for whom she babysat, and in which she was invited to lay down after the kids fell asleep. Physical therapists in both camps make the connection between that long-ago and little girl “freezing” and adult pelvic floor tension; those in the latter camp make emotional connections that do not necessarily run ‘deeper’ (a lifetime of muscular tension is a lifetime of muscular

tension), but that act more like curious tentacles searching for the idiosyncratic sources of a woman's "holding pattern." Given my theoretical suppositions about Vulvar Disease, I felt a greater affinity for this second group, as their therapeutic trajectories made the most room for the 'treatment' of 'cultural' causes of pelvic floor tension and pain. I will return to this in Chapter Six, *Generation*, but want to note that my own definition of "getting better," and the list of women that I came to include in that category, were both constructed out of this shared affinity between me and this latter group of therapists (personified by Cathy, Hanna and Joy's group practice).

For women who were able to commit to physical therapy, however, the results were almost always successful; this was, in part, because of the way that 'successful outcome' could be redefined in this context. Through physically intimate and supportive sessions, patients were encouraged to directly confront their genital bodies and their sexual selves, and to connect those facets of their identities to the rest of their worlds. Hanna, who routinely instructed her patients about the more sociocultural aspects of bodily habit(u)s, told Daphne during one session that the biofeedback that they were about to begin using translated into "how you do life." Because of this explicit connection, and because of an experience that I had with my own body, I want to perform a closer examination of this technique in order to conclude my analysis of the *accumulated* reality of vulvar pain. My biofeedback session epitomized my role as a participant-observer of this disease condition, both strengthening the hypotheses that I held about *their* bodies and disrupting some of the beliefs that I held about my own.

Psychologist Howard Glazer and physician Gae Rodke were some of the earliest advocates of using biofeedback for vulvar pain conditions. In their 2002 patient-centered text, *The Vulvodynia Survival Guide*, they define this technique as:

an electronically assisted measurement of physiological processes, such as heart rate, blood flow, and muscle contraction. Through the use of highly specialized computers, a specific physiological process is translated into an auditory or visual signal so that the patient can learn to control it—and return that physiological process to more normal, stable, healthy levels (63).

In more general terms, biofeedback is information about the body (and its world) provided by the body. Because of the ‘fight or flight’ responses of the sympathetic nervous system, for example, most of us experience notable physical reactions in dangerous situations—increased heartrate, palpitations, altered breathing etc. These biological events alert us to the changed nature of our physical situation, offering us the opportunity to move or change our body’s behavior (fight or flee). These ‘symptoms’ become associated with danger so that if and when they re-appear we contextualize that new situation through the same interpretive framework (a test, a speeding ticket). This, in itself, is biofeedback—my body is giving me information about how it/I interpret(s) my world. Clinical biofeedback gives this set of concepts a therapeutic spin. In a social context where a difficult test does not constitute the danger that, say, a grizzly bear on your hiking trail does, it is helpful to develop bodily skills to alter ‘inappropriate’ physiology, like a racing heart; those skills (e.g., diaphragmatic breathing) and corporeal behaviors then come to be associated with the new, relaxed bodily state. This is manipulated biofeedback. In the physical therapist’s office, and as described by Glazer and Rodke, this manipulation is carried out with the help of dedicated equipment and software, complementing a patient’s developing skillset (and bodily repertoire) with visual and auditory cues.

A good deal of the physical therapy that I was able to observe was done by one group—Cathy, Hanna and Joy. This was the group that Dr. Jensen first contacted, the group with which the physicians had the most experience, and the group in Portland that made the widest connections between physical and social bodies. They used all of the

techniques that I listed above, and used biofeedback with all of the vulvar pain patients who invited me to their sessions. I got to know them first through Libby, whose treatment lasted almost six months (averaging two treatments per month), and then Daphne, and finally Julia R.⁴⁵ These therapists had slightly different styles, but they used the biofeedback equipment in the same way. Electrodes were attached to some part of the patient's body (jaw, inner thigh, around the chest and diaphragm) and then connected to the monitor; the patient could then 'read' their body's rhythms via the color-coded lines on the screen.

With a typical patient, the therapist would start with the woman's breathing, having her use the lines on the screen to learn the difference between (less efficient) abdominal and (deeper) diaphragmatic variations. Patients were instructed to practice the diaphragmatic kind in between appointments, and to notice the bodily differences between the two. Electrodes would then be moved to the jaw and inner thigh. The therapist would gently touch the woman on different parts of her body (arm, ankle, face) and they would both watch the screen to see what kind of muscular tension their jaw (or inner thigh) was engaged in, in reaction to this bodily contact. If there was a lot—which was presumed to index a concordant amount of bodily fear or reluctance—the therapist might stay here for a session or two, before moving on to the vagina and pelvic floor. The pelvic floor was monitored with an electrode that resembled an OB tampon and, once inserted, acted just like the externally-applied ones. The therapist would, once again, touch the patient in random—and safe—places and they would watch the activity of her muscles on the monitor.

⁴⁵ I also spent time with Sandy and Lisa, who worked out of OHSU, and did not use biofeedback. Lisa—in the second camp—did craniosacral massage; Sandy, in the first, did not. Cathy's group also did craniosacral massage, but not in any of the sessions that I observed. See Chapter Four for a further discussion of Lisa's approach.

The goal was for patients to learn how to use their bodies (e.g. diaphragmatic breathing, a relaxed jaw) to *produce* lines on the screen that fell below certain numbers. The software in Cathy's office displayed a graph that went to 5.0, and patients were encouraged to work towards "2.0 and below," a level that indicated a relaxed (and theoretically pain-*less*) pelvic floor (a 1.0 was considered ideal, indicative of an uninjured, or recovered, muscular state). Once this number was achieved, the patient would take note of the bodily maneuvers that she employed to get there, in addition to the way(s) that her body *felt* at that number (e.g. "this is what a relaxed pelvic floor feels like; it can be facilitated/enhanced/achieved through diaphragmatic breathing, a relaxed jaw, and whatever thoughts or affirmations you tell yourself to achieve it"). Hanna would then encourage her patients to give this bodily state a word, one that the woman associated with calmness (Daphne's was "Europe," based on a trip she'd taken). When she needed to call it up later, i.e., for dilator work, penetrative coitus or a stressful day at work, she could shortcut the process with this word—"Body, go to 'Europe.'"⁴⁶

C: As that green line [on the monitor] starts to move in the lower direction, think 'What am I doing to make that happen?' Now squeeze, tighten, and feel that. How does that feel different? [As the line drops, Cathy say:] Can you put words on that? You've dropped a full microvolt in a matter of minutes—can you put words [to it]?

L: It feels ... really loose.

C: Loose would be a good word. Now tighten and do the opposite of 'loose.' You might feel a difference, but that's an important difference. ... My anus, my hips, my buttocks, my mind. Where do I sense that shift? Some people feel it in their feet.

⁴⁶ Although I do not have room in the dissertation, I want to refer the reader to the science studies literature for another important piece of this analysis. Epitomized by the work of Bruno Latour and Steve Woolgar, this approach focuses on the construction of medical/scientific "reality" through instruments and devices that *construct* the same "facts" that they purport to objectively "measure" and "report." In this case, where is the "truth" of Libby's relaxed (or tension-filled) pelvic floor *without* the biofeedback monitor through which she and Cathy come to know it? See Latour and Woolgar, 1986 and Latour, 1987

One evening, when Libby didn't show up for a 6:30 appointment, Cathy suggested it might be a good time for me to try out the monitor (we had discussed it before). Libby was her last patient and she was going to finish up some paperwork and close things down—it was as good a time as any to take advantage of her equipment and knowledge. I agreed with only a slight hesitation, which centered more around my vulnerability as a 'patient' and object of scrutiny than any genital embarrassment. I went ahead and purchased a sensor; Cathy and I then negotiated how much direction she would give me while I used it. Patients were usually already undressed (from the waist down) when they did their pelvic floor biofeedback. I was clothed, however, and Cathy gave me the option of undressing or of simply inserting the sensor and letting the cord come out the waistband of my pants. I chose the latter, although it soon felt strange enough that I wished I had opted for the more familiar (and half-naked) experience of a drape sheet. Indeed, it began to dawn on me that, regardless of the genital comfort I had as both a clinician and a gynecology patient, this was a role with which I was not at all familiar. I continued to chat with Cathy, however, optimistic that I would relax with practice, and that I had an interesting source of data in front of me.

Since we knew this might be our only opportunity to do this, we cut right to the chase and didn't bother with jaw or breathing electrodes. We were interested in one and only one line and that was the one that would tell us what we wanted to know about the state of my pelvic floor. I will say that there were plenty of (self-reassuring) thoughts going through my head at that time, including the ones related to my earlier stories: I had grown so comfortable with this part of my body, I made everybody (including my professors) talk about it, I had had my fingers on or in several friends in the past, all of whom trusted me enough at the time to balance just the right amounts of intimacy and

for two classic texts from this literature; see also Woolgar, 1988; Longino, 1990; Hess, 1997; and Knorr-Cetina, 1999.

professionalism when it came to their bodies. I could have done a pelvic exam on Cathy without the slightest discomfort, and I had long ago grown accustomed to talking with my own providers while they did mine. I was also expecting to see what Cathy was expecting (she told me later)—a nice even 2.0, maybe lower, reflecting the lack of genital/pelvic floor *dis-ease* in my body. Indeed, part of how I coped with my embarrassment was by imagining that I would produce an effortless 1.0, making me a pelvic floor hero whose body demonstrated what it could do with the right sensibilities, politics and emotional investments.

As you have doubtlessly begun to suspect, however, that is not what we saw. Not at all. Initially, my line was literally off the monitor. We were both a little taken aback, but we attributed my “numbers” to the newness of the situation. Cathy even generously suggested that it was due to the abruptness of plugging the electrode into the monitor. So we just laughed a little and continued to watch the screen, which didn’t change much at all. So Cathy and I started talking about it, or rather, Cathy moved into her physical therapist role and began instructing me in techniques that I could use to manipulate the line. These were things that I had heard her describe numerous times, things that I knew how to describe to my own patients, based on my knowledge of pelvic floor anatomy. But I nonetheless needed her to guide me—I felt awkward and like I was a disappointment—to her as well as to myself. Why couldn’t I do this better? My line began to drop as I paid more attention to consciously relaxing, and within a few minutes it was hovering around a 3.0. Cathy, true to form, told me that she’d step outside so that I could “play” in private, a step that I don’t think either of us anticipated she would have to do with me. Regardless, she left to begin closing up the office and I was left to “play” with my pelvic floor muscles so I could watch them relax on the screen in front of me.

But left to my own devices, things got worse. Or at least they didn't get any better. As I sat in Cathy's recliner—sensor in place, the white cord creeping out of the waistband of my pants and attaching itself to the monitor, the machine that evidenced the hard facts of my personal “holding pattern”—I was both disappointed and relieved. I sat in that *feeling* that I described in Chapter One, the one that is overdetermined, ambivalent and compassionate towards the state of the—*MY*—female sexual body. I wanted my screen to look different, to do better, in the ways that I want to get an A, i.e., I wanted to be an exceptional patient. This is individually informed not just by being an early-identified “smart” kid who wants the best grade, or by coming from a large family where competition for attention was a survival skill. I wanted to be the best at *this* because this is what I *did*, what I had been training for throughout my entire feminist career. I wanted to believe that I could beat the machine, that my purposefully collected and “healthy” genital habitus was *enough*; that it could beat not just the biofeedback monitor but what the lines on that monitor represented—the disparaging discourses of *inconsequence* and shame that appear on these pages. If I had done this, I could still attribute vulvar pain to a cultural condition, but the responsibility would lie more completely with symptomatic women who just weren't *dealing with* their environments skillfully enough. It would be just like my early days as a clinician, where I just needed to teach them what *I* had learned and done; like Dr. Robichaud's assessment of Molly, that these women were inordinately tense (or embarrassed or shut down) because of some set of personal factors that needed to be addressed in *those* terms.

I think the lowest I ever got that evening was somewhere between a 2.0 and a 3.0, but even that was a fleeting accomplishment. I was usually above a 3.0 no matter whether I was alone or with Cathy, squeezing or releasing, laughing or tranquil. And Cathy and I continued to awkwardly discuss what might be going on, such as my history

of chronic urinary tract infections that may have altered the behavior of my pelvic floor. I told Cathy that I had noticed myself doing more Kegel (strengthening) exercises during my fieldwork, as if the lack of control that patients had over their own pelvic floors was making me hyper-aware of mine. This reaction seemed to have led to my being in a constant, and almost unconscious, state of muscular contraction. I also told Cathy that I was gratified because, although it was (and is) more depressing, I probably did not ‘beat’ the monitor because my body responds to discourse(s) in the same ways that the “all women” of this dissertation do; that is, I am also a product and producer of these cultural realities. Cathy suggested that many women probably engage in some amount of regular vaginal and/or rectal tightening, and then added, “[But] for those of us who *don’t have issues down there*, we can talk about this.” When I suggested that maybe some of us might not know that we have ‘issues’ until we (try to) talk about it, Cathy said “Well, you’re definitely holding *something*” (my emphases).

And I couldn’t have agreed more. I *was* holding things, lots of them. Duden (1998) writes that our “notions of corporeality seem deeply embodied ... , like petrified deposits of the modern age to which we belong” (22). In my case, these deposits were constituted only *somewhat* differently than those of my informants. Without ‘holding’ a muscular (and/or emotional) set of reactions to the exquisite tenderness of *vulvar vestibulitis syndrome*, or to the erosion of my vulva through *lichen planus*, my pelvic floor nevertheless held the “deep tissue” discourses described by Povinelli (2006: 23) and discussed earlier in this chapter. I was—and still am—‘holding’ the genital kindling without which the totality of Vulvar Disease cannot be sufficiently interpreted, and *upon which* pain and disease may be layered. These acts of disavowal include, but are far from limited to: being asked to ‘lighten up’ in reaction to degrading humor about my sexual body; hearing that the murders of five Amish *girls* (by a man who carefully sent

home all fifteen of their male peers) was an act of *school* rather than *gendered* violence; and learning to tolerate a mass media that, by its own admission, cannot (or will not) adequately analyze or address the implications of the first serious female presidential candidate in the history of the U.S. Faced with these contaminations and erasures, I am more than capable of sending the parts of my body that are given—and simultaneously *denied*—meaning through these discursive events into the states of hiding described by some of my informants. As Cathy reminded Libby during a particularly grueling session of internal vaginal work, “it’s deep. It’s deep and it’s old.”

Chapter Four: Manifestation

It's red. It's raw. I get these little cuts. I'm late for things a lot. It itches. It's irritated. It feels like sandpaper, like someone poured acid on me, like ground glass. It's stabbing. Knifelike. It feels like you're taking a knife to me. It just feels so vulnerable. It's going to hurt. I want to pull my knees in. My skin splits and tears. It's really sensitive. It feels like a razor cut. Like a wire of pain. I just tense up. It itches so much I just want to tear my skin apart. It's like there's a wall in there. A wall of pain. I want to just drag myself along the floor, pull the crotch right out of my pants. It's that one spot. It feels like someone hit me with a sledgehammer in my crotch. It burns. Like someone put lighter fluid up there and lit a match. Like I'm sitting in fire.

* * * * *

They sit with their legs crossed under them so that there is less contact between the chair and their bodies. They stand up after they've been sitting for longer than an hour and a half. They grip the sides of the examination table with fingers familiar with the soft give of the vinyl-covered cushion. They cry, but not as much as I thought they would. They are—and they look—desperate. They are hungry for information. They apologize to the doctors—for their symptoms, their inability to correctly narrate their medical history, for being as upset as they are. They have scars, both from diagnostic biopsies and/or 'corrective' surgeries. Their skin looks white where it should be pink, leathery where it should be smooth. They are “not themselves.” They have lost the contour in the folds of their labia, the suppleness and mobility of their clitoral hood. They pull away from the touch of a hand, a speculum or a q-tip, with the speed and agility of a greyhound. Their bodies have a classic presentation of a disease.

PART I: SHOWING UP

Sexual expression must be made manifest in the physical world, somehow.

—Inga Muscio)

This chapter will unpack some of the ways that vulvar disease is realized in and through clinical spaces; specifically, the intersubjective intimacy of a physical therapy session, the clinical history of a patient, and a major medical conference about vulvar pain. I employ the concept of *manifestation* in this analysis because it allows me to demonstrate the wide and varying range of behaviors and actors that, in essence, provide the realistic contours of vulvar pain. Unconsidered, the multiple and overlapping meanings of the word ‘manifestation’—evidence, proof, appearance, demonstration—can convey a sense of superficiality, or transparency, about what “shows up” in our lives. Careful engagement with these definitions, however, provides more complex analytic ground from which to consider their (more implicit) dialogic nature. What is (culturally) manifest (apparent, clear, visible), in other words, is phenomenologically dependent upon the (often unacknowledged) processes of *perception* without which *nothing* can ever reveal itself. An exploration of how vulvar disease has commanded increasing amounts of clinical, political, and cultural attention—how it has ‘shown up,’ as it were—must necessarily consider those actors, institutions, events and structures whose immanent perception(s) co-constitute its reality.

In this analysis, my interest is in troubling and complicating the superficial, not in dispensing with it. Indeed, it would not be possible for me to describe vulvar disease without a detailed attention to how symptoms both appear and are perceived on a corporeal surface. As an anthropologist, however, my goals (in relation to these symptoms) run somewhat counter to those of the clinicians and researchers that I encountered during my fieldwork. Rather than eradicate or minimize, I wish to animate

the symptoms before me, to locate and expose the cultural and phenomenological deep tissue that manifests through surface pain. I understand the symptoms and bodily behaviors associated with vulvar disease as *eruptions*—material and witnessable realities offering clues to the profoundly sociocultural processes that are always and already occurring ‘below’ their surface. Vulvar specialists formulate treatment strategies designed to contain, manage or redirect the physiological aspects of these eruptions, including pudendal nerve blocks, pharmacological manipulation of neurotransmitters, surgical excision of tissue deemed hypersensitive, and the regular application of topical anesthesia to affected skin. By critically interrogating the medical manifestations of vulvar disease—including these commonly deployed treatments—I show how these bodily symptoms and medical behaviors operate within and reinforce accumulated discourses of silence and erasure. My attention to the amplified presence of vulvar pain challenges these received discourses, and insists on a fully contextual encounter with the socially eruptive nature of these symptoms.

You don’t have a vaginal problem, you have a vulvar problem. That’s like saying an arm instead of a leg.

In the previous chapter, I examined Vulvar Disease through the contaminated and cumulative social forces that interleave in the bodies of U.S. women, and I argued that vulvar pain must be understood in the context of these collective processes. In my heuristic depiction of these affected bodies, these overlapping layers—the *dis-eased* strata of genital experience—occupy a space that is primarily (and metaphorically) subdermal in nature. I think about these layers as corporeal bedrock, or as an embodied unconscious that functions like a reservoir of psychocultural affects, attunements, and attitudes towards female genital carnality. As an unconscious, these layers are

(technically) available for recollection and even recuperation, but only when “subject to a variety of favourable circumstances [such as] be[ing] made conscious” (Freud, 1917a: 345). In Freudian psychoanalytic theory, neurotic bodily symptoms are indications (and transformations) of earlier and suppressed psychic trauma, injury or unfulfilled desire; in short they are “a substitute for something else that did not happen” (347). The resolution of these symptoms requires that this something *else* be made consciously manifest through “an internal change in the patient, such as can only be brought about by a piece of psychical work with a particular aim” (349). My goal in this chapter is to examine the ways in which vulvar pain and disease make themselves manifest through a variety of bodily symptoms, as well as through a complex network of material and discursive transformations at both the clinical and institutional levels. Whether or not the eruption that is vulvar pain constitutes an “internal change” (of any kind) in clinic patients is a question that will be considered further in Chapters Five and Six. In order to lay the groundwork for the dialogic encounters between “deep tissue” discourses and superficial eruptions, I want to spend a bit of time thinking through unconscious reflexes as theorized by Freud and, to some extent, Darwin.

For Freud, the connection between neurotic somatization and unconscious repression is so strong that symptoms will—indeed, *must*—disappear when the historical event or injury is uncovered through psychoanalytic (or other) techniques designed to “bring about a better solution of the conflict, one [that is] compatible with health” (Freud, 1917b: 3). Juxtaposing the distinct conceptions of ‘health’ held by, respectively, Freud’s psychoanalysis, institutional (gynecological) medicine, and my own brand of critical vulvar anthropology allows us to think more carefully about the “etiological pathways” and “other causes of genital discomfort” discussed in Chapter One. Without prematurely mapping the (historical) condition of neurotic hysteria over the

contemporary diagnoses of *vulvodynia* and VVS (or vice versa), I want to take up Freud's analytic task of locating possible connections between events that are perhaps *unavailable* for recollection and manifestations of bodily distress that are all-too-obvious.

It should be increasingly clear that it is neither my intention nor desire to use this dissertation to “figure out” what causes vulvar pain. Rather, by attending to the censoring discourses and practices that uniquely structure these disease conditions, I suggest that one route to their resolution involves an analysis of the relative “availability” of the vulva to the bodily habitus of symptomatic women. In other words, the offending event, trauma, or something *else* around which neurotic patients organized their bodily topographies (which, for Freud, were both individual and psychically derived) can, in this case, be understood in collective and anthropological terms. In making these broader connections, it becomes possible to analyze vulvar pain conditions as at least partially amenable to the ‘techniques’ and interventions of critical and feminist analysis. That is, by revealing layers of *dis-eased* cultural injury—the “deep tissue discourses” described in the last chapter—might it be possible to imagine alternative and/or multiple paths toward the resolution of Vulvar Disease?

Freud suggests that neurotic conditions need not involve a total amnesia on the part of the patient, only that a “connection ha[s] been ... broken, which ought to have led to the reproduction or reemergence of the [associated] memory” (1917a: 351). My reasons for invoking Freud's unconscious, then, have everything to do with my own efforts towards restoring such connections—for symptomatic women, for feminist theorists of the body, and for invested clinicians and researchers. My experience with patients in the clinic is that this process of re-collection is far more likely to occur with the help of providers who make room for and activate connections between symptoms in

the present and feelings in either the present or the past (e.g., physical therapists, Harvard's epidemiologists).⁴⁷ A cultural analysis of these conditions effectively broadens the scope of patients' past, present and future vulvar 'symptoms' by insisting on the corporeal relevance of the disparaging discourses of *inconsequence* through which female bodies are continually experienced.

The inchoate nature of clinical vulvar disease affords patients and providers ample room for innovation and flexibility in locating points of articulation—temporal and otherwise—that are most meaningful and resonant. With Daphne, for example, this meant clearly remembering a sexually abusive past; Libby, on the other hand, needed supportive discipline in order to de-intensify her work life and permit herself to intentionally seek out and experience physical pleasure. Both of these women established these connections through intimate and painstaking work with a physical therapist, and both experienced changes in their symptoms that I would characterize as an improvement,⁴⁸ but in many ways these two women did not resemble the other patients with whom I worked. Challenged by avenues of articulation that were altogether too narrow—an aversion to sex or a history of sexual abuse and/or molestation—the slight majority of symptomatic women were far less able to locate (and subsequently reconfigure) connections between their pain and the rest of their lives. Unable or uninterested in recognizing themselves in these psychologically-inflected 'alternative' explanations for vulvar pain, many women (understandably) chose to cultivate explanations that were purely physiological.

In this latter scenario, the deeply embodied and culturally collected aversion to one's own genitals is left out of the equation. Most women opt out of the 'psychosocial'

⁴⁷ Chapter Four, *Integration*, will provide further detail about how the Harvard study accomplishes this.

⁴⁸ See Chapter Six, *Generation*, for further discussion of the concept of 'getting better.'

associations that are available, and so the ‘connections’ made by dedicated counselors, physicians and more conservative physical therapists remain vague, present-centered, and unmoored by any extra-physiological context. As both a feminist ethnographer, and an anthropologist interested in theorizing the female sexual body, I am unwilling to analyze vulvar pain in such meager terms. A critical engagement with female genitalia in their cultural context brings a world of associations, memories, discourses, events, and experiences to the table, all of which can be taken up and into a body that is always in dialogue with its social milieu. Attuned to this dialectical process, Csordas theorizes the relationship between the body and culture in intersubjective terms, and describes the “somatic modes of attention” (1993: 135) through which we relate to our respective worlds:

[t]o attend to a bodily sensation is not to attend to the body as an isolated object, but to attend to the body’s situation in the world. The sensation engages something in the world because the body is ‘always already in the world.’ Attention *to* a bodily sensation can thus become a mode of attending to the intersubjective milieu that give rise to that sensation. Thus, one is paying attention *with* one’s body (138).

The hypervigilance, ‘going numb’ and bodily avoidance discussed in Chapter One are the manifestations of a genital mode of attention that is both product and producer of particular forms of erasure and ‘repression.’ “Paying attention” *with* and *to* a body that is of little to no consequence involves complex negotiations between the visible and the invisible, the superficial and the deep.

Eruptions (you will see how easily she will well up)

My interest in making culture count does not reflect any reluctance on my part to understand the body on its own terms. To that end, and in a more strictly biological mode of analysis, the embodied layers of Vulvar Disease might be conceptualized as

what Darwin (1872) labeled “phylogenetic reflexes,” behaviors that “were at first performed consciously, [but] have [now] become through habit and association converted into reflex actions, and are ... so firmly fixed and inherited, that they are performed even when not of the least use” (in Wilson, 2004: 71). Darwin developed this concept in an effort to explain the involuntary expressions and gestures associated with human emotion and he used it to carefully discriminate between those expressions caused by the “direct action” of the nervous system (e.g., blushing), and those that “were once volitional” (70) but no longer are. Elizabeth Wilson (2004) argues that this distinction makes Darwin’s nervous system amenable to the effects of experiential and psychological events (such as traumas), as well as to physiological changes over time, both collective (evolutionary) and individual. What I am suggesting, in the case of Vulvar Disease, is that genital awareness and embodiment are similarly impressionable; that the intractable states of alienation and embarrassment in which the majority of patients are eventually situated are no more or less “volitional” than physiological reflexes that have been shaped by biocultural evolutionary forces. In the clinical setting, the shame and reticence that inhibits a comfortable and accurate description of genital pain is clearly, in Darwin’s words, “not of the least use.” But how else to adapt to a culture whose “habit[s] and association[s]” render the well-being of these same genitalia of little to no consequence? In the contemporary U.S., the individual and collective acts of erasure and censorship that constitute our *dis-eased* vulvar sensibility are “so firmly fixed and inherited” that shameful silence is easily understood as an acquired reflex, eminently adaptive and transmittable.

Freud cited Darwin frequently, and he positioned psychoanalysis alongside Darwinian evolutionary theory as two major ways that “the general narcissism of man ... [had] been three times severely wounded by the researches of science” (1917*b*: 4-

6).⁴⁹ Indeed, Darwin's influence is strikingly clear in a 1917 lecture during which Freud posits that a neurotic symptom is made up of two essential elements:

its 'whence' and its 'whither' or 'what for' ... —that is, the impressions and experiences from which it arose and the intentions which it serves. Thus the 'whence' of a symptom resolves itself into impressions which came from outside, which were necessarily once conscious and may have since become unconscious through forgetting. The 'whither' of a symptom, its purpose, is invariably, however, an endopsychic process, which may possibly have been conscious at first but may equally well never have been conscious and may have remained in the unconscious from the very start. (1917a: 352)

Freud does not, as do I, make metaphorical use of Darwin's un/volitional reflexes to illustrate his concepts, but I think that it is important to note the care that both of these men took in carving out a place for behaviors—whether psychic or biological—that cannot be explained by what is apparent; that must be rooted in something that is both deeper and less immediately sensible. I want to use these ideas to *think about* why a woman, symptomatic or not, might choose to 'forget,' or to no longer consciously respond to the barrage of social practices that render her sexual body as less than, dirtier than, and sicker than. Why, we must wonder, would she maintain the availability of these associations within what (precious) little consciousness and reason that she has historically been afforded?

Neither Freud nor Darwin extend their arguments to include cultural dynamics as they are analyzed in this dissertation. My reasons for bringing these theorists into the discussion have to do with the ways that I want us to conceptualize vulvar pain. I do not imagine that the corporeally embedded 'layers' posited by my analysis are the stuff of dreams or libidinal drives, nor do I understand them as a set of involuntary "behaviors" that are produced through a malleable or suggestible nervous system. But then again, I do. Because the issue is not which of these frameworks most adequately captures the

⁴⁹ The Copernican revolution being the third. He described the psychoanalytic "blow" as "probably the most wounding" (1917b: 6).

affective underbelly of Vulvar Disease; both psychoanalytic and bioevolutionary metaphors are equally capable of evoking the (culturally potentiated) depth and tenacity of the *experience* of genital disparagement. My point is that, whatever the metaphor, these figurative layers—experienced, I suggest, by unaffected as well as symptomatic women—both fortify and pervade what I will consider in the remaining chapters. Functioning as a kind of genital kindling, they constitute an embodied predisposition through which the experiences of pain and unfamiliar symptoms are then organized and produced.

What manifests, then—on the skin, in the clinic, during sex, on the tongue—is *obliged* to this sedimented silence and ‘forgetting’; obliged through a “mutuality of influence, a mutuality that is interminable and constitutive” (Wilson, 2004: 22). In the following pages, I will examine vulvar disease’s various manifestations, e.g., clinical, institutional, dermatological, emotional, linguistic, and relational. As I have stated, in the corporeo-cultural schema that I am sketching in this dissertation, I understand these events, discourses and symptoms as eruptions. In this model, the aspects of Vulvar Disease that are produced and maintained by the hegemonic censoring of the female genital body are underground, subdermal, suppressed. The social and physical appearance of *recognizable* problems (physical symptoms, marital discord, clinical maltreatment), however, reveals the frayed edges of threadbare cultural practices whose utility has come into question. Pain and redness erupt onto the skin of affected women, perhaps signaling an outbreak of a different order. Like canaries in the proverbial coal mine, women whose bodies refuse heteronormative penetration and the tools of medical gynecology represent a social irritant; a raw, itchy, sensitive rash that is both increasingly legitimate and stubbornly intractable. In Freud’s words, “[t]hey would not

have become symptoms if they had not *forced their way* into consciousness (1917: 345; emphasis mine).

“[W]oman[.]” according to Cixous and Clement (1975), “has always functioned ‘within’ man’s discourse ... [in an] energy [that] puts down or stifles [her] very sounds ... “ (95). From my desk in Austin, Texas—months and miles away from my encounters with the resilient women in Oregon, I want to assign their pain a great meaning. I want to suggest that its excessive and confounding nature is nothing less than the genital manifestation of a female uprising that these two French theorists demanded over three decades ago:

it is time for her to displace this ‘within,’ explode it, overturn it, grab it, make it hers, take it in, take it into her wom[a]n’s mouth, bite its tongue with her wom[a]n’s teeth, make up her own tongue to get inside of it. And you will see how easily she will well up, from this ‘within’ where she was hidden and dormant, to the lips where her foams will overflow. (95-6)

The dermatological, neurological and inflammatory eruptions that constitute clinical vulvar disease provide both a vehicle and a forum for women to incarnate their genital bodies; indeed, their disease cannot be medically confronted without new corporeal behaviors and new words to accompany them. Whether these behaviors perform the incandescent act of displacement theorized by Cixous and Clement, or the “internal change” presupposed by a (Freudian) psychoanalytic approach to the resolution of “psycho-somatic” symptoms,⁵⁰ is a question with which my ethnographic analysis remains in dialogue. Duden (1998) argues that subjectively experienced “burdens and trials”—along with the meanings attached to them—were effectively excised from scientific medicine’s modern and “objective” approach to the suffering body (30). By ascribing a “meaning” to Vulvar Pain that both accounts for and transcends *individual* psychic events or traumas, I situate patients and providers within a reconfigured medical

⁵⁰ My hyphen is purposeful—to highlight a more ‘literal’ use of the word.

milieu, one that has as much room for empirically observable markers of disease as it does for the residue and deposits of a *dis-ease* for which standard instruments of measurement have not (yet?) been developed.

PART II: BECOMING VISIBLE

Manifestation (1): a visible form in which a divine being, idea, or person is believed to be revealed or expressed

In this chapter, I offer up a range of mediums through which Vulvar Disease is expressed, some more immediately visible than others. Attuned to the suppressive forces at work, I imagine myself in the role of analyst, or forensic pathologist, using what appears to be superficial in nature in order to reveal the deeper level of discourses at work. I can think of no more appropriate guide for this work than a physical therapist; specifically the type of physical therapist who has devoted at least part of her practice to treating and attending to these patients. I devote much of the next chapter (*Integration*), to the work of physical therapy, and to the role it can play in first loosening and then reorganizing the bodily adjustments that vulvar pain patients have made to their lives. In the following section, however, I want to draw our attention to the earlier work that must be done by these providers, readying work that must be tailored to each patient's varied (and sometimes limited) abilities to attend to her genital body.

I met Lisa when I accompanied Nikki to her first physical therapy session. I had hoped that patients would invite me to these appointments, but, especially in my first few months, I was reluctant to be the one who suggested it. I was learning that these sessions would come to involve intricate manipulations of the pelvic floor (accessed through the vagina and rectum), and I did not wish to force the kind of intimacy that

such treatments would entail. I was fortunate to meet Nikki on my first day in the clinic, as she was affable and extremely receptive to having me follow her clinical trajectory. Nikki was interested in having surgery; she had previously been diagnosed with VVS and Dr. Erlich had agreed that she was a good candidate. The physicians were convinced, however, that patients “did better” with physical therapy (as either substitute or supplement for other treatments), and so Dr. Erlich referred Nikki to the in-house provider, a woman who had begun to specialize in pelvic floor disorders. When the receptionist told Nikki that she couldn’t schedule the appointment right there in the clinic, but had to make a separate phone call to secure one, I worried that this would prevent me from being invited to accompany her. It was one thing to stand next to a woman while she booked an appointment—smiling and offering support, chatting her up while I walked her to the elevator. In this scenario, I would almost always get invited to participate; we’d both write down the date and details in our calendars and happily agree to see each other there. But I wasn’t sure that I could count on a woman that I had only just met to call me with the specifics of a different kind of appointment, one with which I was not so “officially” affiliated.

Nikki did call, though, and I was immensely grateful that it was her idea for me to come with her. I readily agreed, and we met in the waiting room the day of her first appointment. Nikki and I had quickly developed an easy and comfortable friendship, one that came to include meals, coffee dates and even a couple of yoga classes. Nikki and I talked as easily about her history, her pain and her marriage as we did about novels, clothes, and what we thought of Dr. Erlich. In many ways, Nikki’s cooperation felt like a tremendous gift—when I met her (on my first day), she was coming back to the clinic after having had an initial consult more than a year before. Having processed everything that Dr. Erlich conveyed at that first visit, she was ready to comply with

whatever treatments were proposed. I am fairly certain that Nikki could see my eyes virtually light up as she and Dr. Erlich discussed a six to nine month future of surgery, follow-up, and physical therapy. I barely needed to express my interest in participating before she indicated that she was more than willing to have me tag along.

At this first physical therapy visit, neither Nikki nor I knew what to expect and so we talked about that while we waited for her to be called back to the treatment room. As it happened, our mutual ignorance worked to both of our respective benefits, since any notions of a ‘typical’ session would have been profoundly disrupted by what actually occurred. The physical therapist who normally worked out of the Center for Women’s Health—a woman named Sandy who had been doing pelvic floor work for almost as long as the Program in Vulvar Health had existed—was out on maternity leave that winter and a therapist named Lisa was filling in. Lisa did not have the expertise in genital pain that Sandy did, but she told me (in a later interview) that she was keenly interested in these patients: “This is my thing now,” she said. Because of her maternity leave, I didn’t meet Sandy until the late winter of 2004 and so I did not appreciate (until her return) the radically different approaches that she and Lisa took in their work with these patients. I will say briefly that Sandy’s technique was very rooted in the correction of musculoskeletal misalignment and maladaptation; as the reader will soon discover, Lisa worked within a distinct bodily imaginary. While I do not posit the superiority of either of their points of departure, I have often wondered how Nikki’s recovery might have been different if she had worked with either of these therapists exclusively.⁵¹

Lisa began Nikki’s sessions with some clinically focused questions, but it wasn’t long before she shifted gears. As she conducted her first assessment of Nikki’s body, she asked Nikki to describe how it felt to be touched in and around her genitals.

⁵¹ Lisa left OHSU when Sandy returned from her maternity leave, having had approximately half a dozen sessions with Nikki. Nikki had about that many with Sandy before I returned home to Austin.

When Nikki responded with “I think ...,” Lisa interrupted her by gently commanding “I don’t want you to think. I want you to **feel**. ... I want you to become aware of what’s down here.” Nikki later admitted that she “didn’t know what to do” in response to this initial challenge, but her overall reaction to Lisa’s line of questioning was refreshingly open and participatory (she was, after all, acutely interested in becoming aware of what was “down [t]here.”) Taking her cues from Nikki’s receptivity, Lisa forged ahead by directly asking if there was anything that might be holding Nikki back from getting better, anything that would cause her to “hold on” to her pain. “Are you open to finding out that there might be some emotional/feeling work to do in this getting better? [Because w]e’re going to do some mind-body work in here.”

It’s the body’s intelligence: Lisa and Nikki

I was startled, and a bit confused, to hear this question, even given Lisa’s ‘integrated’⁵² approach to bodywork. My own thinking about vulvar pain had always been oriented around a ‘mind-body’ connection, and I maintained this predisposition during fieldwork. Despite a proliferation of physiological evidence furnished by a growing number of physicians and researchers, the extraction of emotional or ‘mental’ components from the clinical apprehension and description of these conditions seemed (at least to me) like a shortsighted and, at times, anti-feminist strategy. I knew, though, that what motivated this most recent approach were the attempts of dedicated researchers to free affected women from vicious and unproductive cycles of self-blame and unmitigated pain. In this context, demarcating the existence of hyperalgesic nerve

⁵² *Integrative* medicine is one term that is commonly used to describe medical approaches that are (at least partially) informed by what are sometimes referred to as ‘alternative’ or ‘complementary’ practices, such as acupuncture, massage, yoga, chiropractic medicine, and herbal or dietary supplements or restrictions. This is of special note in the Northwestern U.S.: three of the country’s six accredited naturopathic medical schools are located in this area (Portland, British Columbia, and Seattle).

endings, for example, or locating a source of neurological pain relief in the capsaicin found in chili peppers, were clinical moves for which desperate women longed. From this more sympathetic vantage point, I could not disparage these evolving medical suppositions and yet, in addition to the medically critical perspective that I had cultivated and carried with me to the field, I was beginning to collect a number of *non-clinical* stories that were uncannily similar, and that contained a surprising number of details about sexually reluctant, violent, or painfully prohibitive pasts. The ‘mind-body’ connection that had simply made *sense*—intuitively and intellectually—before I came to the field was taking increasingly substantive shape; fleshed out, as it were, by the histories of women who were more confused than any of us about how much significance to attribute to their individual ‘emotional’ pasts.

In addition, I was not dissuaded by the providers, most of whom routinely alluded to sharing my analytic inclinations. For their part, the physicians regularly referred patients to Jill, the sex therapist whom I introduced in Chapter Two. When making one of these referrals, the doctors would typically inform patients that “we used to send all our patients to Jill,” and that it was only budgetary constraints that prevented them from continuing to do so. Dr. Robichaud, especially, impressed the salience of sexual counseling upon her patients, and she did so in a way that left vulvar pain open to extra-physiological interpretive accounts. Whether or not she made a direct referral,⁵³ Dr. Robichaud almost always told her patients about a study conducted by Sophie Bergeron, a Montreal-based psychologist who has been studying vulvar pain for almost a decade. In short, this particular study randomized women with vulvar pain to *either* physical therapy, surgery, *or* counseling (no one in the sample received more than one intervention) and the outcome was that each group demonstrated statistically significant

⁵³ See Chapter Two for a lengthier discussion about the limited access that most patients have to sex therapy.

reductions in their pain (Bergeron et al, 2001). Dr. Robichaud explained to her patients that this finding meant that each treatment strategy had a measurable role to play—in and of itself—in the ultimate resolution of vulvar pain. She would then suggest the logical conclusion to be drawn from the data, i.e., that if each approach demonstrated individual efficacy, then combining two or three of them would more than likely promise greater success. Other than the fact that there was no data to support this conclusion, Dr. Robichaud’s narrative was slippery for one other reason: for those paying attention, clinical evidence seemed to suggest that the argument for a purely physical or anatomical vulvar pain was incomplete at best, and specious at worst.

Despite the discursive aperture created by these regular (and sincere) discussions of sex therapy, however,⁵⁴ “official” medical rhetoric (purveyed by the clinic and the majority of physical therapists I knew) implied that the psychologically-based elements of female genital pain were ancillary to the “real” and physiological diagnostic categories of *vulvodynia* and *vulvar vestibulitis syndrome*. This attitude threatened to exclude significant emotionally invested events—along with the interventions that might resolve them—from the full picture of a woman’s treatment plan, a consequence that seemed inconsistent with the ‘mind-body’ awareness that circulated amongst providers. For example, during one particularly busy week, I was able to conduct extended interviews with four patients. I first encountered each of these women at their initial clinic visits, which always included an extensive—and vulvar-focused—medical history. Because I had been present and attentive at these visits, I was surprised and somewhat unprepared when three of the four disclosed sexually traumatic histories to me, episodes that had not been discussed in the clinic with their doctor. What is particularly

⁵⁴ There were notable differences between the two physicians at OHSU when discussing this with patients, with one being slightly more earnest and assertive in her referrals. This is another factor in assessing the accessibility of this treatment option.

intriguing about this is that the clinic's official paperwork contained a direct question about such events, and my interview did not. This, of course, does not mean that the physicians were less concerned than I was about these histories; the fact that the question was on the medical history form reflected their attempt to confront this reality.⁵⁵ I suggest, instead, that the asymmetrical stories that we elicited from these patients index the distinctive valences that each of us accorded such an emotionally (and, I would argue, culturally) charged past.

I left questions about sexually abusive backgrounds out of my interviews for one major and historically specific reason—I was aware of, and wished to dissociate myself from, 'mind-body' interpretative accounts of vulvar pain in which sexual trauma was the implicitly identified culprit. As we have seen, the pain experienced by affected women is typically unaccompanied by grossly visible anatomical changes. Historically, this meant that most head-scratching and brow-furrowing providers have been able to appreciate the *reality* of the pain sensations that are both described and demonstrated, but, without objectively measurable clinical *signs*, have frequently found diagnostic refuge in the hysterically-conditioned category of psychosomatic illness (Pucheu, 1998; Bodden-Heidrich et al, 1999).⁵⁶ I suggest that this medical dilemma was further informed by two culturally significant developments of the twentieth century: 1) a post-Freudian clinical climate in which physicians without even the slightest psychoanalytic predilections were (are) unavoidably aware that apparently inexplicable symptoms may have a "traumatic" foundation or component; and 2) a feminist-oriented sexual assault

⁵⁵ It is also increasingly standard for this question to be asked by mainstream gynecologists. The purpose it often serves is to alert the provider that the speculum exam may be a 'difficult' one.

⁵⁶ Although the word "psychosomatic" is rarely used in the contemporary climate, researchers have not given up on assessing the psychological profiles of vulvar pain patients. They have, instead, redirected and/or more carefully specified their analytic variables. One recent paper evaluated the relative rates of "catastrophizing" engaged in by patients with and without vulvar pain, for example (see Granot and Lavee, 2005).

movement that effectively convinced survivors, advocates and caretakers of the existence of embodied trauma (Brownmiller, 1976; Ruch, 1980; Winkler, 1994). Under these socioclinical circumstances, making a connection between inscrutable (and penetratively prohibitive) genital pain and “buried” bodily memories of sexual abuse makes eminent sense, and on multiple levels. Indeed, it is difficult for me not to cringe at the memories of my own professional encounters with these symptoms,⁵⁷ during which I attempted to use “psychosocial” assessments to illuminate this confounding clinical situation. After scrupulously determining that I could “not find anything wrong,” I—like the rest of my colleagues—almost always referred these patients to counseling.

Assigning women with vulvar pain a history of unremembered sexual suffering became a standard reflected in both practice and print (Harlow and Stewart, 2005); in this context, it was a development that did not necessarily indicate the misogynistic disinterest of institutional medicine, however. Indeed, one could argue that these psychosomatic renderings were at least partially influenced by a feminist health movement in the U.S. that had helped to legitimize the concept of embodied psychological trauma. The annual referral, deferral and clinical shelving of their symptoms, however, provoked a grassroots backlash—an eruption—among some of the most resourceful women with symptoms.⁵⁸ Tapping into a collective nerve, the work of

⁵⁷ Which probably totaled no more than a dozen. Given the available prevalence data (Goetsch, 1991; Harlow and Stewart, 2003), I am left to wonder if they constituted 15-18% of my total practice.

⁵⁸ These women and physicians are the genesis of the National Vulvodynia Association (NVA), an advocacy group who focus their efforts on lobbying, research funding (primarily hard science), and education. Members and representatives of the NVA epitomize the demographic profile of vulvar pain—educated, white, and financially stable. They publish a quarterly newsletter, assist with establishing regional/local support groups, and fund one to two small research projects per year. None of the services are free, and the lowest membership level is \$45/year is lowest level. Many of the patients I met chose not to join, although it was the only “support group” that Drs. Robichaud and Erlich specifically recommended to patients. They typically gave each new patient a brochure, telling them “This organization is patient-centered and physician-supported.” See their website, www.nva.org, for further information.

these early activists (including some physicians) focused on unsettling and disrupting a connection that, though sensible in theory, was perceived to be devastatingly ineffective in practice. Fortunately, these voices spilled into an arena that was prepared to hear them; in a matter of years, clinical research and review articles about these conditions shifted substantially in their analytic frameworks and orientations. A somewhat random, often puzzled, series of hypothetical descriptions of the psychological and “character” differences between women with and without symptoms (that were published in journals such as *Psychosomatic Medicine*) became a seemingly more systematic stream of demographic surveys. This new wave of research repeatedly—and numerically—“failed to find an association” between vulvar pain and a history of sexual trauma (Harlow and Stewart, 2005: 871; see Chapter Two for further discussion of this transition).

It was these women, and their discursive descendants, with whom I was to talk and conduct my research, and by the time I arrived in the field I knew better than to evoke and/or impose this particular variable. I saw no problem in bracketing the analytic ingredient labeled “sexual abuse” because I respected and agreed with the symbolic significance of doing so. In fact, I was willing to leave it completely out of my investigation if it did not organically emerge in some way. Not surprisingly, however, it did emerge; and it did so with a frequency and quality that neither re-imposed a purely psychosomatic rendering of vulvar pain, nor left me in a conceptual lurch regarding the broader ‘mind-body’ connections that I was reluctant to surrender. In other words, the number of women who revealed histories of a traumatic nature was consistent with the vast majority of published prevalence rates (Edwards et al, 1997; Dalton et al, 2002). Although such rates often serve varying agendas, their consistently (and depressingly) high numbers help to substantiate the claim that symptomatic women are, in fact, “no *more* likely” (Harlow, 2004; personal communication) to have survived some kind of

unwanted sexual experience. Reports of sexual abuse are high in every population, period. In my analysis, however, this does not obviate its significance and I suggest that the discrepancies between the “histories” that the physicians and I collected provide us with the opportunity that I suggested in Chapter One; i.e., to consider the term “unwanted genital experience” in a far more expansive context.

In the clinic, patients were asked to answer a question about whether they had a history of sexual abuse or assault, although their written answer to this question did not translate into an explicit discussion of *any* relationship (that might exist) between past genital “experiences” and present genital symptoms. Indeed, posing the question in this way limited such relationships to a narrow, and clinically shaped, definition of noteworthy “abuse.” During the visits that I observed, such histories were not discussed unless initiated by the patient. Conversely, my interview left the direct version of the question unasked but purposefully opened up a space through which a multiplicity of experiences—bodily, psychological *and* cultural—could be apprehended as genitally unwanted and deleterious.

Through connecting vulvar dots arranged in patterns both erratic and predictable, my informants and I asked questions about how routinized social censorship and stigmatization articulated with symptoms that went undiagnosed for five years or longer. We wondered together about why it was so hard for them to talk about their pain with even their closest friends, and why their husbands never talked about it with anyone. We often described very conflicted and contradictory attitudes towards sex, orgasms, and pleasure, and patients repeatedly stressed that their sincere desires to fiercely enjoy sex with their husbands stood in stark contrast to the (often religious) values with which they were raised. In our interviews, patients and I redefined the word ‘unwanted’ and together we considered the relationship(s) between their various life histories and their

symptoms not as causal, but neither as insignificant nor somehow ancillary. (As we will see, Nikki's "unwanted" experience did not involve her own genitals, but rather the safety and integrity of her mother and sister at the hands of a physically and sexually abusive husband/father.)

In a narrative space that was mutually constructed, and only vaguely defined, symptomatic women and I began to *diffract* extant and pervasive apprehensions and beliefs about genital pain. Donna Haraway defines diffraction as

patterns [that] record the history of interaction, interference, reinforcement, difference. Diffraction is about heterogeneous history, not about originals. Unlike reflections, diffractions do not displace the same elsewhere [D]iffraction can be a metaphor for another kind of critical consciousness ..., one committed to making a difference and not to repeating the Sacred Image of Same. (1997: 273)

Ethnographic fieldwork is what allowed me to locate and take up an inquiring residence in what I saw as a gap between medical narratives that effectively excised the psychological, and the far messier lived experience(s) of vulvar pain in which longstanding and personally held beliefs about sex and genitalia figured prominently. My analytical responsibility, as I saw it, was neither to choose a side of the gap with which to agree more heartily, nor to reconcile the two (or more) into a plausible or coherent theoretical narrative. Instead, I chose to wedge myself further and further into the space of this gap, allowing the process of diffraction to "guide [me] toward fresh ideas and understandings" and toward "working concepts [that are] ... pragmatically flexible ... [and] allow [for] multipurpose use" (Clarke and Olesen, 1999: 5).

Advancing a theory of unwanted genital trauma that is culturally insidious, discursive and collective may be a way for *me* to more comfortably think through bodies in sexual pain, bodies that literally close themselves off from the sexual act that is most available to (and expected from) them. This would be far easier, however, if the

discussions that I had with symptomatic women revealed even the slightest hint of rebellion or refusal to ‘settle for’ heteronormative penetrative sex. Indeed, I went to the field imagining that an inability to engage in penetrative intercourse might have illuminated new sexual horizons for these patients. Inspired by Oliver Sacks (1987; 1985), I thought about the generative nature of disability and I made conceptual space for transformative sexualities produced by and through “pain-full” (Jackson, 1994: 207) material realities. Patients whom I interviewed and encountered in the clinic, however, remained steadfastly attached to (re)gaining the ability to have “real” sex without pain, a set of desires that were, to my mind, dissonant with their refusing bodies. Taking a both/and approach to this disease allows Haraway’s process of diffraction to ripple through my analytic endeavors, unsettling my ability to reconcile mind and body. Indeed, sitting *in* the tension, rather than reconciling it, allows me to conceptualize these bodies in novel ways, in ways that profoundly trouble even a heuristic split between mind and body. Adele Clarke and Virginia Olesen (1999) elaborate Haraway’s initial work on diffractions, asserting that they “allow us to attempt to see from multiple standpoints ... [and that they] can allow tensions to be held simultaneously rather than ‘resolve’ them—because they may not be ‘resolvable’” (5). In apprehending vulvar pain from a feminist, critical, and anthropological perspective, I am learning to get increasingly comfortable in this ambiguity.

In a 2004 essay entitled “The Brain in the Gut,” Elizabeth Wilson interrogates the level of “distance” (39) kept by gastrointestinal (GI) physician-researchers from the emotional aspects of conditions such as irritable bowel syndrome (IBS) and Crohn’s

disease.⁵⁹ This “distance” is strikingly similar to that held and maintained by the vulvar experts with whom I came into contact during fieldwork, the vast majority of whom, like the neurogastroenterologists she critiques “consider[ed] psychological events to be peripheral to the task of isolating an [organic] etiology and treatment” (39) for *vulvodynia* and VVS. Both Wilson and I are troubled by this move—what I call an apprehensive shift—and, though our areas of anatomical interest lead us down somewhat dissimilar paths, both of us want to call attention to what is discarded, as well as what is produced, in the wake of this shift. Wilson’s argument is physiologically detailed in ways that only partially represent the current state of affairs in vulvar pain research. In order to fully appreciate the creativity—and transformative potential—of her insights, however, it is important that I use a bit of space to summarize her essay.

Wilson outlines contemporary neurological accounts of an enteric nervous system (ENS), which she defines as a “complex network of nerves that encases and innervates the digestive tract ... [and that] may act independently of the [central nervous system, i.e., the brain and the spinal cord]” (34); her goal in doing so is to “turn ... our attention to how ... distal parts of the body ... have the capacity for psychological action” *in and of themselves* (34). In other words, the ‘emotional’ components of diseases located in the gut, specifically one that is distinctly and physiologically innervated, may not *necessarily* involve the interpretive work of a central nervous system (CNS). Wilson’s argument is primarily shaped by biomedical accounts of the ENS, what at least one author refers to as a “second brain[,]” and her review of the literature suggests that:

[t]here is a tendency ... to figure the ENS as independent of CNS control. It remains an ongoing difficulty in the field to know how the disarticulation of the ENS from the CNS can be conceptualized [however]” (37)

⁵⁹ Both are autoimmune conditions that frequently co-occur with vulvar disease (or vice versa).

The difficulty she refers to is gastroenterology's reluctance to confront the "ambivalence and incoherence about psyche-soma relations" (34) that such a body necessarily lays bare. I am drawn to Wilson's argument not because I want to demonstrate (nor have the evidence for) a similarly autonomous genital (vulvar) nervous system. Rather, my interests lie in how she reconciles Freud's earlier—and more clinical—work on the nervous system with this prospective paradigm shift in gastroenterology. Wilson recuperates the work of Freud in several other essays (from a superb collection), but it is here where she most explicitly demonstrates the integrated nature of Freud's pre-psychoanalytic therapeutic regime, an approach that I see as uncannily similar to the work done by some of the more "successful" physical therapists I met in Oregon.

Frau Emmy, a patient whose hysteria manifested through a range of gastrointestinal symptoms, provides the basis for this reconciliation. In brief, Freud came to understand Frau Emmy's anorexia and digestive troubles as hysterical somaticizations of a "number of [earlier] disgusting episodes concerning food and drink," only *after* he had intervened with both clinical reason (body) and suggestive hypnosis (mind). Freud was not yet practicing psychoanalysis in its modern form, and he was using hypnotic states to facilitate symptom reduction, as well as to deepen his grasp of patients' emotional states. Freud's work with Frau Emmy involved not only "ma[king] a thorough [hypnotic] clearance of th[e] whole array of agencies of disgust" (33) that she ultimately revealed, but also in establishing connections between her gastric pain and her broader experiences of fear and anxiety, some of which began after her husband's death. In Emmy's case, after Freud administers an eclectic set of interventions, including "stroking her a few times" across the abdomen, Frau Emmy is cured, measured—in Freud's account—by her ability to "[eat] and dr[i]nk without any difficulty" (33) on the day after his final treatment; her continued ability to do so led to

her discharge from the nursing home where she had languished for weeks. Wilson's recounting of this case is not aimed at convincing us of the efficacy or innovation of Freud's techniques. She is interested in Frau Emmy because she provides a "starting point for thinking about ... how a husband's death, a patient's resistances and fears, and an analyst's authority can be gastrically internal—not just ideational or cerebral" (33).

Wilson's analysis of Emmy is meticulous and, although she remains tightly focused on the disruptive and provocative characteristics of the ENS, I believe that her conclusions are both generous and prescient regarding the reality of Vulvar Disease. How, other than *genitally internal*, should we describe a pelvic floor that has hardened into a mass of impenetrable knots, or understand skin so "hypersensitive" that the strength of this same pelvic floor helps it to lurch away from encounters with cultural and anatomical phalluses: q-tips, therapeutic fingers, and, in the words of Mira, "even a cheese doodle"? With the narratives of these symptomatic women, I suggest we have a similar "starting point" from which to consider Vulvar Disease as a cultural assemblage, an embodied fact whose existence is not necessarily dependent on processes of psychological mediation. If, as Csordas has suggested, the body is the "existential ground of culture" (1994: 135), then what is it that manifests when we critically juxtapose a sexually repressive background, the impact of being called a 'cunt,' the proliferation of cosmetic labiaplasty, and genital pain that is explained (by some) as the result of "fired up" nerves? Investigating the relationships between these discursive—and deleterious—elements is the work of this dissertation; the evidence that I have thus far gathered suggests that the *eruption* of vulvar pain is one outcome of these co-extant realities.

Freud, of course, never distanced himself from the psychological elements of his patients' hysterical symptoms; indeed, it was their non-cerebral physiologies upon

which he found it difficult to maintain his grasp. By opening her essay with Frau Emmy's story, Wilson provides a measure of historical context for the clinical narratives of contemporary (and cutting edge) gastroenterologists. These accounts reveal that what physiological researchers seem willing to surrender is a legitimate clinical sphere for the psyche. As the(ir own) evidence mounts around an increasingly complex neurological body, a "brain in the gut" that could radically transform our appreciation of a direct corporeal role for feelings, memories and experiences, these scientists continue to privilege explanatory modes that rescue GI disorders from the "metaconcerns" (39) of psychological events and experiences. Holding fast to the belief that "what happens in the gut is only secondarily or accidentally psychological[.]" (39) they reside alongside vulvar pain researchers that do precisely the same thing. Both Wilson and I are engaged in challenging this scientific state of affairs, asking questions about why researchers find it so difficult to tolerate and explore a relationship between psyche and soma that is more dialectical than epiphenomenal. What, we are asking, is gained when psychic and cultural worlds are relegated to the margins of corporeal experience? And, perhaps more importantly, what is lost?

A "maverick ENS" (36) gives Wilson a biomedical site around which to structure her argument, and this is a crucial element in answering her larger question, i.e., "What new modes of embodiment become legible when biological reductionism is tolerated and explored [by feminists]?" (3). The existence of neurons in the ENS that are "functionally and morphologically similar" (35) to those found in the brain, as well as of "every class of neurotransmitter that is found in the CNS" (36), serves up compelling evidence that a patient's (psychological) world can be *directly* experienced by her body. These biochemical 'facts' perform a discursive displacement of the conventional 'mind-body' schema in which, in Lisa's words, "the body's intelligence" is not just mediated,

but is created by the brain. Wilson wants us to appreciate the “new mode of embodiment” that is realized with this displacement. Her “hypothesis about the value of simple biological events” (3) serves as a gracious rejoinder to feminists and other critical theorists whose fear of reductionism, she believes, comes from their understanding of ‘the body’ as an inert depository or form that projects itself *through* the psyche (Grosz, 1994a: 27), rather than *as* the psyche itself. In returning to Nikki, and the “mind-body” work in which Lisa challenged her to participate, we are offered a glimpse of what *else* is perceptible when we reconfigure our apprehension of the mind, the body, the central nervous system, and experience.

In her second session with Nikki, Lisa introduced the practice of craniosacral therapy (CST). CST was developed by an osteopathic physician and is a treatment that involves subtle manipulations of the vertebral column and cranial bones in order to bring the central nervous system into greater balance. Practitioners of CST believe that bodily trauma can lead to blockages of the cerebrospinal fluid (CSF), and that by gently working with the spine and skull (primarily), the restrictions of neural passages can be eased, the movement of CSF through the spinal cord can be optimized, and misaligned bones can be restored to their proper positions.⁶⁰ Lisa requested Nikki’s cooperation in

⁶⁰ Craniosacral therapy is variously perceived across both medicine and physical therapy. It is most closely aligned with ‘alternative’-minded medicine and healthcare, embraced equally by yoga practitioners, the anti-vaccination movement, and devotees of a raw-food diet. As with many ‘alternative’ practices, however, patients are often ‘converted’ to its logic through traumatic events (such as car accidents or sexually prohibitive pain) that have been both life-changing *and* ineffectively addressed by conventional medicine. The physicians at OHSU were non-conversant about CST and, indeed, I once heard them speaking about it in the hallway in a somewhat derogatory fashion, conflating it with naturopathic and other unconventional (read: ineffective) modes of healthcare delivery. I mention this not to chastise the physicians, but to reiterate the almost *underdetermined* space occupied by PT relative to the

moving to this technique (from a more straightforward musculoskeletal one), and Nikki assented, having no prior knowledge on which to base a refusal. After deciding to proceed, Lisa added the caveat that they “wouldn’t do any dialoguing [that] day” because they were short on time. When Nikki asked “What’s that?,” Lisa said:

L: You can ask parts of your body questions.

N: Who answers?

L: You’d be surprised. ... We do a lot of [dialoguing]. Because a lot of people come in here and the doctor doesn’t know what’s wrong. And guess who knows?

N: The person?

L: The body. It’s *the body’s intelligence*. (Lisa says she’s a mediator between Nikki and her body, sort of). A lot of times, the pain is a mediator, considering how the doctors have done all the physical things they can do. So now it’s time to see if the body has some other stuff going on.

N: Fear. It’s the only thing I can identify. (my emphasis)

In this exchange, Nikki makes a connection between her VVS pain and the “fear” that her body “knows.” Conventional understandings of embodied trauma, as well as Freud’s later (and more recognizable) psychoanalytic techniques would use Nikki’s identification of fear as a way to displace her pain from her body to her mind. Clinical vulvar specialists, like Wilson’s gastroenterologists, allow room for the expression of emotions (such as fear) while actively disavowing their etiological role in the realization of vulvar pain. The clinic physicians (and most mainstream PTs) understood physical therapy’s success to be based in the physiological change(s) caused by the mechanical manipulation of tension-filled muscles period. Any “emotional” sustenance provided by the therapist was understood as just that—complementary support whose effect was additive rather than integral. Addressing Nikki’s fear, in this

PVH. That is, Cathy and her colleagues were both beloved by the OHSU physicians *and* believers in the benefits of CST. Since the physicians were relatively disinvested in the details of PT, however, this contradiction did create any cognitive dissonance regarding their PT referral preferences.

model, would be akin to the “[r]eassurance, explanation, [and] advice” that conventional clinicians suggest should accompany a full “exploration of psychological issues” and “a good doctor-patient relationship” (Talley, 2001: 2062). Such interventions—as I hope to be making increasingly clear—are based firmly in an apprehension of physical symptoms as only *indirect* effects of psychological (or ‘cultural’) events and processes. In their practices, however, therapists like Lisa, Cathy and Hanna identify somatic locations for feelings of guilt, confusion, fear and even joy in the bodies of their patients. Their interventions, epitomized by Lisa’s (relatively) unconventional style, dialogued with a body much like the ENS postulated by Wilson—a body capable of feeling, knowing and responding directly to its social environment.

The mind-body displacement enacted by an enteric nervous system and by craniosacral therapy offer a discursive template through which we can rethink pain that is intractably housed in the disparaged genitals of U.S. women. Feminist and subaltern theorists have identified the importance that ‘naming’ has in the construction of a new social reality, and vulvar pain syndromes cannot exist, indeed will never be ‘real,’ without a recognized set (and deployment) of clinically linguistic constructions. Lisa’s work with Nikki took this process a step further when she used their third session to speak directly with Nikki’s body. Before she did so, she asked Nikki to give her pain a name. “Are you up for that? Are you into that?” she asked. Nikki, who had no experience with any kind of physical therapy, and who had been “putting off” addressing her pain for almost 3 years while she finished a B.A. in architecture, readily complied and named her pain Veronica. Lisa and Veronica spoke easily and, after only a few sessions of working like this, Lisa asked Veronica if she would consider “stepping aside” so that Nikki could enjoy a sexual relationship with her husband.

L: Veronica, Nikki is in my office She's an adult now and she wants to have sexual ... relations. You have been there for her, you've been there for her in the strongest sense of the word. Can you recognize that she's an adult?

N/V: I don't know.

L: Can you trust her that she can recognize what's safe to put into her body?

Here, Lisa is attempting to uncover some of what motivates or surrounds Nikki's painful vestibule. Earlier, Lisa told Nikki (of her pain) "It's protecting you," to which Nikki replied "Yeah. From pain."

L: Veronica, when did you start protecting Nikki? When she got married? Before that?

N/V: When her parents would fight.

L: When was the first time?

N/V: In Coos Bay. (Nikki then relates a memory of her mom on the phone with her dad and crying over a conflict they were having. Nikki had never seen that before and she recounts feeling like she needed to protect her.)

What is crucial to notice in these dialogues is that Nikki contends that Veronica, i.e. her genital pain, is protecting her "from pain," seemingly of another nature. In one of our many conversations, Nikki told me that her father was emotionally, sexually and physically abusive to her mom and sister, but that she herself had only been exposed to his emotional abuse. Nikki also recounted being the one who tried to "stand up for" and "protect" the other women in her family, and that she often felt guilty for being spared and/or protected by her father. When she was a teenager, Nikki's dad violently committed suicide, an event with which, at the time that I knew her, she had made considerable peace. Nikki shared these stories with me after one of these sessions with Lisa, while we lingered in the waiting room making plans about when we would see each other again. She spoke about the guilt with which she still lived and we wondered together if her genital pain wasn't some way of managing these difficult feelings. By disallowing herself any sexual pleasure, Nikki could atone for the disparate and horrific

treatment suffered by her mother and sister, and still maintain a peaceful acceptance of her father's violent and painful life and death. This was further enabled by the fact that her mom was now remarried and living happily on the Oregon coast. Nikki enjoyed a particularly close relationship with her mother, telling me during our first meeting, "She's amazing,"

Weeks before any of her PT sessions (and the appearance of Veronica), Nikki had already been making connections between her emotionally painful past and her physically pain-filled present. This was made evident during our formal interview, which we conducted over dinner and which exceeded the first one and a half-hour tape that I'd brought with me. Just seconds after I had pressed the *record* button and indicated that we were 'on,' Nikki flatly stated, "It's important to note that, growing up, my parents were incredibly dysfunctional." She continued that her mom had "found her voice" in counseling, however, and had subsequently taught Nikki "how to say no and set boundaries with [her] dad." The "model" provided by her parents for an intimate/sexual relationship was an unfortunate one for Nikki; from as long as she could remember, she knew that her mom "detested [sex], hated it, [and] couldn't say anything nice about it."

She says that "the most negative thing for me was growing up." She then told me a story about driving in the car with her mom and sister one day. Her wedding night "appeared" to her, "the night you would consummate." She asked her mom about it and her mom's reply was negatively inflected. She says she doesn't blame her mother: "living with a husband that, um, where rape is involved? I can't blame her for that. I can't blame her for anything that she feels, you know. 'Cause I, I can't imagine what she .. went through, and I don't want to imagine, you know. So ... " (fieldnotes)

When I mentioned to Nikki that I found it interesting that she began our interview with a punctuated assertion about her “dysfunctional” family, and asked her how (and if) she thought it was connected to her pain conditions, she elaborated further:

N: Mmm. I think it’s really hard for me to feel .., um, .. I guess *positive* about it. And, it’s taken me a lot of years.. of .. continually telling myself, ‘It’s okay. You know, it’s okay to .. have sex.’

C: Mmm-hmm. And to like it.

N: Yeah! And to like it, and to .. want it more than, you know, whatever, it just ... Yeah, that was *really really hard* at the first of our marriage as well. Because I was like ‘Oh gosh! This is kinda bad, and .. and I didn’t say that! And I told Sage that. I mean, he knew, you know he knew the dynamics of my parents and stuff. And I said, you know, it ju-it really sucks because I know that it’s okay, and I’ve waited this long, and I’ve done everything that’s supposed to be right, and yet I still feel *guilty*. Yeah, that was, that was a lot of it. Guilt at the beginning.

C: [Asks if she] connect[s] the guilt with the pain? [There is a long pause.]

N: I think the guilt was something I had to work through emotionally. Um, in respect to, I guess just the touching between my husband and I? And .. I was able to .. not think of it as such a bad thing. But the pain was still there, and so to me they’re kind of like two separate issues. And at the beginning I didn’t know what it was.

I want to reiterate that making connections between vulvar pain and *any* other kind of abuse is neither my political nor analytical intention. Rather, in using Nikki’s understanding of her fear and pain which, in this case, is related to a violent dynamic in her family (and is something from which her body might have learned to protect her), I am drawing connections to the “other causes” of genital pain that are invoked in Chapter One.

I will further develop this point in my next chapter, but I want to briefly mention that it was ‘pasts’ like Nikki’s, i.e., those that were recalled as less than “safe or supported,” that women with vulvar pain were more likely to report to Harvard’s research team during their 2003 phone survey (see Chapter One). Running counter to many symptomatic women’s understandable requests that medical perceptions move

beyond this level of (psychosomatic) causation, these pasts have been increasingly relegated to the sidelines of clinical research. But what is evident in Nikki's narrative is that she can no more easily separate her "skin pain" from the pain of her parents unhappy and violent marriage than can she make ready distinctions between the "guilt" she feels about her inability to protect the women in her family and her "guilt" over enjoying sex. Indeed, this latter guilt is compounded not only by her mother's difficult sexual history, but also by the Christian theological narrative with which she was raised, and through which premarital sex was proscribed. Most intriguingly, Nikki recalls that her pain (Veronica) first arrived when she was living in Coos Bay, the only time (she told me) when both of her parents were "active in the Church."

A substantial number of providers, researchers and even patients *resist* the conclusions of providers like Lisa, and instead invest heavily in narratives that neatly compartmentalize the various sources of pain that are very likely converging in the body of a woman with *vulvodynia* or VVS. My anthropological attention to the alternative "etiological pathways" that lead to being diagnosed with vulvar pain is an attempt to establish a "safe and supported" place for understandings of these conditions that more closely resemble Lisa's. *Unwanted genital experience* arrives in packages that are deeply—sometimes horrifically—personal, as well as in collectively experienced social structures. Nikki's story is uniquely hers, but is informed by patterns of gendered violence and sexual subordination that are experienced by women whose genital bodies regularly prepare to be disparaged, harmed, or disappeared (Bartky, 1990; Brown, 1995).

In telling me that, "whether I was *hot* on sex, or whether I hated it, I would still have [this] pain," Nikki concluded an intense and intricate narrative with a neat separation between her *feelings* about sex and her ability to *have* it. But the context and

story of Nikki's pain includes both a vulvar vestibule that may or may not overproduce inflammatory chemicals (which may or may not be correlated with her melanin production), as well as a structure of feeling that is informed by the gendered vulnerability and hypervigilance under consideration in this dissertation. In my earlier discussion of Freud, I cited a lecture on the unconscious in which he contended that a neurotic symptom must be analyzed in terms of "the impressions and experiences from which it arose and the intentions which it serves" (1917a). In theorizing pain like Nikki's as an *eruptive* bodily process, I am attempting to combine Freud's psychoanalytic insights with both the radiant excess of Cixous and Clement (1986) and the phenomenological precision mapped out by corporeal feminists like Claire Colebrook, who has suggested that "the human is *nothing other than* an interpretation of its own body" (2000: 86; emphasis in original). Some bodies, I argue, are lived through the states of alienation and *inconsequence* that come with having a vulva in the contemporary U.S. Whether or not those experiences are repressed, serving as genital kindling for the eruption of vulvar pain (and its concomitant refusal of heteronormativity), is a set of questions that may remain unanswered, but they are questions for which I propose necessary and novel avenues with which to draw some interdisciplinary conclusions.

It is possible that Veronica is a liberated *manifestation* of Nikki's personally traumatic past, a restored connection now available for her recollection. Or perhaps she is a representative—a *divine being*—of the psychic pain shared between *any* women whose genitals have gone into hiding. But we need not explain why or how she 'showed up' for Nikki in order to apprehend the intimate relationship that she has with the "unwanted genital experience" examined in this dissertation. The connections between gendered and sexual violence, insidious and discursive genital trauma, and discourses of

vulvar *in*consequence may be uniquely delineated on these pages, but they are well-worn and familiar grooves in the lives of many U.S. women. Grosz has argued that “the body functions not simply as a biological entity but as a psychical, lived relation” (1994a: 27). In outlining some of the manifestations of women’s lived relationships with a disparaging world—somatic modes of attention that are particularly female as well historically specific—I am expanding Grosz’s assertion so that feminists will not limit their understandings of “unwanted genital experience” to realms (bodily and psychic) that are more individual than collective. Taking a literal page from Wilson’s gastroenterologists, I am proposing that we make room not just for a brain in the gut, vulva and/or pelvic floor, but in the agnosiac and shared *body images* that are constructed and informed by cultural discourses.

Manifestation (2): a public demonstration, usually over a political issue

If I had to conjure up a poster child for this concept of manifestation—of how vulvar pain “shows up” in the (sexual) bodies of contemporary U.S. women, simultaneously revealing the ways in which those same bodies are absent(ed) from the cultural landscape—it would be Judy. I didn’t meet Judy at her first appointment; rather, I heard about her while I sat in the pod one morning, in between patients with Dr. Erlich. Dr. Robichaud was supervising a new resident (which was partly why I wasn’t with her that day), and as I waited for Dr. Erlich to finish gathering the fact sheets and literature that she was going to give to the woman we’d just seen, Dr. Robichaud and Gina (the resident) came into the pod in a white-coated blur. They were talking very animatedly, pulling various forms from file cabinets, hastily scribbling on them, and getting on the phone to arrange an obviously urgent surgery for the patient with whom

they had just consulted. On our (primarily Dr. Erlich's) query, Dr. Robichaud told us that their patient had a case of *lichen planus* with one of the severest presentations she'd ever seen—her labia were fused together so firmly that she was urinating through a 3mm opening in her vulva. The procedure that they were trying to arrange at that moment would surgically correct the problem, as well as evaluate how much overall vaginal patency it was possible to restore. After Dr. Robichaud finished sketching out these details, Dr. Erlich, who did regular volunteer OB/GYN work in Africa (and other medically underserved areas), sighed and said “Wow, it's like she's an Ethiopian woman.” Dr. Robichaud, without missing a beat, said simply, “Yeah. It's like she's been infibulated.”

As I recounted in Chapter Two, *lichen planus* is an autoimmune condition which involves an overproduction of inflammatory discharge in the vagina, as well as generalized irritation, redness and sensitivity of the vaginal walls and tissue. If the production of this discharge is not halted or suppressed, its inflammatory nature will begin to permanently scar and compromise the patency and elasticity of the vagina. In addition, gravity's anatomical pull on the discharge allows for its deleterious effects to be realized by vulvar skin and anatomy; these include a loss of labial suppleness and an erosion of their contour, as well as some loss of flexibility and mobility around the clitoris and its hood. As I also discussed, scarring in the vagina can result in its decreased patency (or *capacity* in clinical terms); this leads to obvious difficulties with penetration, a notably ‘functional’ complement to the otherwise ‘cosmetic’ issue of vulvar contour change and/or loss.

In Judy's case, this form vs. function distinction had been rendered moot by the severity of her symptoms, the “worst case of LP” that Dr. Robichaud had ever seen. The loss of elasticity sustained by Judy's labia (they were literally fused together) did not

‘show up’ for her until she could not urinate normally. Unlike Mary Hudson (see Chapter Two), for whom “everything still w[orked]” at the time she was diagnosed with *lichen sclerosis*, Judy’s profound loss of function forced her to take notice of skin changes that go long unnoticed by many affected women. Judy’s symptom presentation served to remind her that an unobstructed vaginal opening (*introitus*) indexed a greater number of bodily possibilities than an ability to tolerate vaginal penetration. Indeed, a 3mm vulvar opening not only disallows vaginal entry, it also severely circumscribes what can exit the genital body; hence, Drs. Erlich and Robichaud’s likening of Judy to an infibulated “Ethiopian woman.”⁶¹ Judy herself could tell the doctors that it “was taking [her] ten minutes to pee,” but at that point was unaware of the role that her fused labia played in compounding her disease condition. The miniscule orifice that she presented in the clinic that morning did not allow for adequate expression of the vaginal discharge that was at the heart of her symptoms.

Judy’s story—and the irreversible skin changes and loss that her genital body had sustained—made me incredibly sad. When I came home from the clinic that day, and recounted the details to my housemate (a thirty-one year old man who learned more about female genitality that year than he could ever have hoped for), he asked me why, and more precisely, “how” such an outcome was possible in the contemporary medical U.S. I told him, “Because nobody gives a shit about the genitals of a sixty-two year old woman.” I will use the rest of this section to further this assertion, underscoring here that Judy’s age only compounds (rather than causes) the discourses of *inconsequence*

⁶¹ This kind of urinary complication is commonly cited by anti-cutting activists, as it has been well-documented by a number of researchers and healthcare providers. Other complications of ‘ritual’ female genital cutting include profuse bleeding or hemorrhage, infection, abnormal and/or painful scarring, menstrual complications, the development of fistulas between the vagina and urinary tract and/or the rectum, painful vaginal intercourse, neurological damage and death. See Lightfoot-Klein, 1989; Hosken, 1994; Dorkenoo, 1994; Rahman and Toubia, 2000; and James and Robertson, 2002 for a basic overview of the issues surrounding genital cutting, as well as further details about these complications.

through which her sexual body is interpellated. In doing so, I will demonstrate how the “3mm opening” in Judy’s vulva indexes the vastly insufficient perspectives of the providers who had been previously charged with her care. I will argue that the compromised access that Judy and the clinic physicians had to her (sexual) body resonate—both materially and discursively—with the inadequate *capacity* of these non-expert providers to properly attend to her disease condition.

I mean, would you want to look at that?

Autoimmune diseases are notoriously enigmatic. Symptom presentations often elude and exceed exact diagnostic categories and treatment regimens, making these conditions metonymic of the female (sexual) excess under consideration in this dissertation. *Lichen planus*, however, is fairly easily recognized, diagnosed and managed by knowledgeable gynecologists and dermatologists. Indeed, in just the past several years these experts have begun using immune system modulators off-label⁶² to control both LP and LS, an approach that minimizes the amount of medication a patient needs to use, as well as the number of side effects she is likely to experience. Autoimmune conditions have been routinely managed—particularly in their more acute and/or life-threatening presentations—with systemic or locally applied steroids. This approach is a kind of catch-22 however, since suppressing the hyperactive immune system exposes patients to the bodily vulnerabilities of an immunocompromised state, notably an increased susceptibility to infections and an inability to mount an appropriate immune response to pathogens that are routinely encountered (such as an influenza virus). Physicians working with various autoimmune conditions have begun to use

⁶² This means prescribing a drug or treatment for reasons other than those for which it has been approved by the Food and Drug Administration (FDA).

immune system modulators—which were developed to mitigate the physiological rejection of transplanted organs—precisely because they do not work through suppression; this generally means that they can be used with considerably less caution in patients with otherwise ‘healthy’ immune systems.⁶³

It is important to grasp some of the details of these drugs, and of their use by ‘expert’ providers, if we are to adequately analyze how Judy’s vulva had been rendered invisible prior to her consult with OHSU. Judy had a Master’s degree in nutritional science and had worked in research hospitals in the Northeast for many years before relocating to Oregon; she was what many clinicians would call a “medically savvy” patient, in other words. When she first began to notice the symptoms of her LP, she not only examined herself physically, but she quickly sought the advice of a dermatologist friend from New York. Although in some ways this friend’s ‘help’ was the beginning of a misguided series of interventions that ultimately led to Judy’s severe presentation at OHSU, Judy was happy to have solved the problem quickly (he diagnosed her correctly over the phone, based on her description) and filled the prescription for the topical steroid that he prescribed for her. Since this was several years before the somewhat routine—and, again, off-label—use of immune system modulators, her physician friend cautioned Judy to use the medication conservatively, i.e. to back off when her symptoms were under control.

Judy did so but it wasn’t long before her symptoms could not be controlled with the steroid and so her friend referred her to a dermatological colleague in Portland. In the hands of this ‘expert,’ Judy was biopsied and given a definitive diagnosis of LP; she was also switched to a higher-potency steroid, and an immune system modulator—a

⁶³ In addition to the risks of a ‘modulated’ immune system (e.g., decreased ability to fight infection), the side effects of these drugs vary from nausea, sleeplessness and skin irritation, to an increased risk for developing diabetes (in African-American and Latino/a populations) and some skin cancers.

drug called tacrolimus—was added to her treatment regimen. Again, despite the decreased risks associated with the tacrolimus, she was encouraged to use the medications only when her symptoms were present and or troublesome. The problem, as will soon become clearer, is that LP is an unpredictable and idiosyncratic condition, equally likely to ‘flare’ in stressful (physiological or emotional) or non-stressful situations. For this reason, physicians like Drs. Erlich and Robichaud encourage their patients to use the medications liberally and regularly—at *first*—in order to establish good control over the symptoms; subsequent ‘backing off’ is done under the guidance of the doctor and in order to establish whether particular stressors can be identified, predicted and/or avoided. This seemingly small material difference, i.e., the *amount* of medication prescribed by the physician, is in part a reflection of the relatively ‘conservative’ nature of a provider’s clinical orientation, and this is a dynamic encountered by patients of all stripes, notably those seeking new or off-label treatments for their symptoms. But I suggest that in Judy’s case, the amount of medication prescribed by Drs. Robichaud and Erlich simultaneously indexes a distinct orientation towards the relevance of the vulvar body, one that is invested not only in its anatomical and discursive *presence*, but also in its well-being.

Under the care of her more ‘conservative’ dermatologist, Judy’s LP (still poorly understood by her) became so severe that her labia fused together in the same way that they were when I first encountered her at OHSU (more accurately, it was the first stage of what she presented to Dr. Robichaud and Gina). Although not quite as clinically urgent, in the sense that she could urinate normally and the opening to her vagina remained patent, Judy’s labia were markedly flattened in contour and she could not accommodate any vaginal penetration. Significantly, Judy and her husband were having “difficulties” at the time; they were not sexually active and could not necessarily

imagine that they would be again. Judy shared this with her physician who subsequently recommended that Judy just “leave it closed,” then, unless and until she ‘needed’ the use of her vagina again. Unaware of any other options, and in a relationship with her genitals that was also penetratively-circumscribed, Judy agreed to the plan. It was just over a year later, when the above-described urinary difficulties began, that her dermatologist referred Judy to the Program in Vulvar Health, aware that she *now* needed corrective surgery.

The *now* of this physician’s decision adds another layer to the differences in *kind* (rather than *degree*) between the providers through which Judy came to understand her symptoms and disease condition. At OHSU, new LP patients are not only encouraged to use liberal amounts of both steroids and immune system modulators in order to gain some control over their symptoms, but they are also taught to understand the nature of their condition. Neither medication will stop the (over)production of the inflammatory vaginal discharge and, indeed, life stressors and other factors will more than likely exacerbate their symptoms from time to time, even with good pharmaceutical control. This means that each and every patient with LP is at risk not only for labial contour change and/or erosion, but vaginal scarring as well. In these more extreme cases of LP (like Judy’s) the vagina does not fuse together evenly; rather, it does so in a shape that resembles an hourglass. Clinical literature describes an “apple-core” presentation as a classic diagnostic marker, and the surgery for which Judy was referred to Dr. Robichaud would cut through this fused middle area of the vagina and restore ‘normal’ patency.

As vulvar ‘experts’ (and perhaps as surgeons), both Drs. Robichaud and Erlich take this type of advanced presentation into account when they encounter new patients. Their efforts—from the start—are actively informed by both the knowledge of this extreme outcome and an interest in preventing its unnecessary development. Although I

maintain that there is something qualitatively distinct about the OHSU physicians regarding their vulvar ‘orientation,’ this particular anticipatory behavior is no more nor less than good preventive medicine. In other words, managing your patient’s chronic (or acute) condition *as if* it could worsen at any time is standard clinical practice in any specialty area and most providers routinely do this with a wide variety of diseases (e.g. diabetes, cancer, hypertension). What I want to stress here is that managing LP *without* taking this complication into account is at least correlated with (if not guided by) a *disinvestment* in the preservation of a (symptomatic) woman’s genitalia. Since LP typically afflicts women in their later or post-reproductive years, the inflammatory obstruction of the vagina becomes conflated with the ‘unnecessary’ maintenance of robust labia, and women like Judy are allowed to progress to a point where “leaving it closed” is presented to them as a reasonable option. The physicians at OHSU, on the other hand, encourage each woman at the clinic to be pro-active in maintaining her vaginal patency, or “capacity.” This can be done either through regular vaginal intercourse with a partner or, preferably, with the regular (daily) use of a therapeutic dilator—Dr. Robicaud typically prescribes two fifteen minute sessions per day during which the patient keeps the dilator inserted.⁶⁴ While consensual and desired intercourse is certainly encouraged, the dilator is ‘preferred’ in that it can be more predictably used, and can be used with far less difficulty during the sometimes acutely uncomfortable “flares” of LP (see Appendix F).

The treatment plan at OHSU, then, in particular contrast to the one with which Judy had become accustomed, was derived from an investment in the anatomical and physiological ‘well-being’ of the vulva and vagina, *outside of* any ‘need’ for vaginal penetration or sexual activity. Liberal prescriptions and applications of medications,

⁶⁴ These sessions were the source of many jokes between patients and providers, centered around what you are supposed to *do* while you’ve got the dilator in there—watch the news? vacuum? return emails?

close follow-up to monitor for undesirable side-effects, careful instruction about the nature of LP, and treatment strategies geared towards maintaining as much vulvar and vaginal anatomy as possible were the material contours through which an OHSU patient came to experience her symptoms. These empirical strategies were obliged to a female genital imaginary in which optimal vaginal patency and vulvar contour are not options to be considered, but rather anatomical ground to be preserved.

Vulnerable vulvas

By heuristically—and temporarily—bracketing the discursively-loaded assumptions upon which a ‘normal’ vulva are based, we can productively evaluate profound and *qualitative* differences in vulvar embodiment that are generated by Judy’s two physicians. We can also see that although they wield identical tools, they deploy them with distinctly informed agendas regarding the use-value of female genitalia. These varying agendas were made manifest through a wide variety of institutional discourses that included—but were not limited to—those of the clinicians examined thus far. For example, since the treatment of LP with immune system modulators was still off-label, there did not yet exist (at the time of my fieldwork) an applicator for their vaginal use. Indeed non-intravenous delivery systems of any kind were still relatively new, and the cream formulation most readily available (i.e. sitting on the shelves of pharmacies, as opposed to having to be special-ordered) was formulated for rectal delivery in the form of a suppository. Although applied to parts of the body that are anatomically contiguous, there are sharp differences between these two modes of administration—rectal suppositories are routinely used in systemic autoimmune or post-transplant situations (they spare the gastrointestinal system from side-effects like nausea and ulcerations), whereas a vaginal preparation is primarily used for local delivery. As

long as the patient's affected skin and mucous membranes could tolerate the chemical and non-pharmaceutical base in which the drug was mixed, there was no reason that the rectal preparations couldn't be used intravaginally, however, making this a first-line treatment strategy for the OHSU physicians.⁶⁵

A dermatological tolerance for pharmaceutical base creams did not offer smooth-sailing for these patients, however. More than one patient for whom the drug itself was effectively managing her symptoms recounted tales of other types of difficulties. For Anharrad, her own discomfort with touching and manipulating her genitals—and an overdetermined reluctance to ask her husband for help—was exacerbated by the fact that she could not locate a suitable applicator for intravaginal delivery of her suppositories. She described very embarrassing conversations with a spectrum of strangers—from pharmacists to natural foods store employees—during which she attempted to describe the “equipment” she needed in order to follow her doctor's prescribed use of the drug. She eventually found something adequate at the natural foods market; her frustration, however, contributed to an ongoing conversation with Dr. Robichaud about the need for a vaginal applicator, as well as about the larger issues that informed her inability to use her fingers (or her husband's) more directly. In one of these exchanges, Anharrad told us, “This is just another thing where women have to struggle to find something that works. I told the pharmacist that if I needed Viagra, you could sell it to me by the boxload.”

⁶⁵ Because of Oregon's naturopathic-friendly environment, patients who could not tolerate standard base creams could often access a compounding pharmacist who would mix the raw form of the drug (the modulator) into a blander emollient base, such as petroleum jelly. I estimate that approximately half of the *lichen planus* patients that I met fell into this category. Since these 'compounding pharmacies' were primarily an urban phenomenon, women who came to the clinic from remoter parts of the state would have their prescriptions filled before they headed back to their homes in eastern Oregon, rural Washington, northern California, or Idaho.

Complaints from women who *were* comfortable vaginally inserting these suppositories were of an entirely different order, and revealed a hint of the misogynistic genital appropriation similar to that demonstrated by a group of Target pharmacists who refused to sell the Plan-B morning after pill to their customers beginning in the middle of this decade.⁶⁶ Several patients told me and Dr. Robichaud about how they had gotten accustomed to the clinically unnecessary and suspicious questions about the ways that their prescriptions were written. Often in front of other customers, pharmacists routinely (and sometimes hostilely) told these women that their doctor was mistaken and that this medication was intended “for rectal use, not vaginal.” Embarrassing conversations routinely ensued during which the woman explained to the pharmacist that, in fact, her vaginal condition warranted the use of *this* drug in *this* way, and that, while she appreciated his⁶⁷ concern, there was no need to alter the prescription label.

On the surface, these pharmacists are simply doing their jobs. That is, they are ensuring that the drugs they dispense will be used by their patients in the safest and most appropriate manner. This occasionally involves questioning the prescription itself—the dosage, the drug, the amount, or the delivery system—and this scenario is made more likely when a drug is prescribed off-label. Part of what is happening with these particular pharmacists, however, is that their lack of information about *lichen planus*

⁶⁶ This was a controversy that was heating up while I was in the field, and involved pharmacists at both Wal-Mart and especially Target stores refusing to dispense ‘Plan B’ emergency contraception, citing religious reasons (some believe that the ‘morning after pill,’ as it is often called, acts as an abortifacient). Spokespersons at Target defended the practice, despite a respectable public outcry, claiming that they were respecting the religious beliefs of their employees under the 1964 Civil Rights Act. What is *most* fascinating about this controversy now is that in looking online for citations to include in this note, I am unable to find any ‘mainstream’ news coverage, other than the NPR story cited below. Almost all of the coverage was in self-described feminist, progressive and/or liberal blogs. For a start, see Canedy, 1999; Coyne, 2005; and NPR’s online audio report, “Target Pharmacists Can Refuse ‘Plan B’ Prescriptions: <http://www.npr.org/templates/story/story.php?storyId=5018646>.”

⁶⁷ I recall 3 women describing this scenario—some in the somewhat distant past—and each of them described a male pharmacist. It is not my intention to suggest that this behavior is male or masculine, however.

(and its treatment) blurs the lines between questions that are inappropriate vs. questions that are ill-informed. I hold pharmacists only somewhat more accountable for this state of affairs than I do a friend or colleague who knows nothing about the subject of my dissertation. Having only a rough idea of how many drugs are prescribed off-label (thousands?), it is easy to imagine that even the most inquisitive of pharmacists would be unable to keep abreast of the myriad ways that physicians have found to use available pharmaceutical agents. Rather, I suggest that these blurred boundaries—between careful dispensation, medical misogyny, prescriptive practices, and drug delivery systems—index the pernicious breed of vulvar *inconsequence* under consideration in this dissertation. The unstable but all-too-familiar line between a lack of access to the ‘correct’ information (e.g. about intravaginal use of tacrolimus) and an active *uninvestment* in the anatomical integrity of female genitalia is not only made manifest by the experiences of these patients, but also reflects, perhaps, the deep tissue discourses to which these apparently superficial practices are obliged.

The LS-related ‘disappearance’ of Mary Hudson’s vulva (see Chapter Two) occurred under somewhat less supervision than did Judy’s; indeed it was a nurse practitioner who first noticed the apparent absence of Mary’s clitoris. I met Mary after she had been in Dr. Robichaud’s care for over a year—after she had, in her words, “built an altar” to the tacrolimus that she both tolerated well and to which she had financial access. This sequence of events made it possible for Mary to interpret the material state of her genitals through temporal—rather than misogynist—discourses, i.e., that it was all just a matter of ‘bad timing.’ But the story of Joan, who had an almost identical experience with her NP (“She says ‘How long [ha]s your skin look[ed] like this?’ She says it’s white. I said ‘I don’t know. I don’t know. ... I don’t go down there and look’”), reveals yet another facet of the structural-level *disinvestments* under

consideration here. Joan arrived at the clinic for a “vaginal screening,” telling Dr. Robichaud that “My doctor wants me checked for cancer. [That’s] all they’ll pay for.” Joan had indeed been approved for only one visit to OHSU by the state health insurance plan,⁶⁸ and the paperwork that she brought with her clearly indicated that a pap smear and/or a *vaginal* biopsy was all that would be covered. Based on both her treatment history and the description of her symptoms (“this itching is driving me crazy!”), Dr. Robichaud wanted to perform a vulvar biopsy, as she suspected *lichen sclerosis*. Unsure that the hospital would be reimbursed for it, however, she and the clinic manager agreed that it would be best for Joan to return with the correct approval, rather than for OHSU to try and obtain retroactive reimbursement.

Fortunately Joan was able to do so and two weeks later I sat in on her vulvar biopsy. Dr. Robichaud had prescribed a mid-potency steroid for Joan at her previous visit, and she reported that her itching was now only “bother[ing her] from time to time.” As Dr. Robichaud began to examine Joan’s vulva in preparation for the biopsy, they had the following exchange:

Dr. R: [Shows Joan] lots of little cuts. These are your labia majora, these thicker ones with hair. Your labia minora are gone. And your clitoris—I can’t see [it] anymore.

J: It’s probably gone too.

Dr. R: No! It’s not gone. It’s hidden, [and she explains that the scarring that has happened is because of the LS-related inflammation.]

J: Can anything be done about this?

Although this time it is Dr. Robichaud (rather than the patient) who characterizes a vulnerable vulva in terms of “hiding”(see Frances Chapter Three), we can nevertheless

⁶⁸ The Oregon Health Plan, or OHP, was inaugurated in the early part of this decade amidst a swell of hope about a state-supported single payer health plan that would cover everyone who needed it. As Dr. Erlich told it to me, the funding was very poorly managed and it was very quickly underfunded. At the time I was in the field, the OHP paid for a minimum of services, and did not cover several of the populations that it had when it started (students, part-time employees).

interpret this dialogue—as well as its broader context—as yet another layer of a vulvar *in*consequence that undermines even an invested provider’s efforts. Dr. Robichaud’s decision to forego Joan’s biopsy at her first visit was obliged to insurance and health care industry discourses that have the authority to shape what ‘counts’ as good health. In this case, it was cancer-free, but not completely contoured, genitalia that merited the financial support of the state insurance plan. Joan was left to conclude that the preservation of her labia—*in and for themselves*—was a luxury that the state could not afford. And although Dr. Robichaud exhorted Joan to maintain an investment in the material reality of her clitoris (“No! It’s not gone.”), her decision to send Joan home could have easily sent Joan’s vulva into even deeper hiding.

When I interviewed Joan several weeks later at her trailer-home in Boring, Oregon (she pleaded with me not to hold that against her!), she told me about a relationship history (she was married to her second husband and had had other lovers as well) in which sex had always figured prominently and pleasurably. Indeed, Joan had not one but several sets of nude photos of herself that had been taken by partners in the past, and she told me about them with far more of a knowing smile than any sense of embarrassment or transgression. Rather than using this fact to set up a contradiction or disingenuousness to Joan’s claim that she preferred to steer clear of her vulva, I want to suggest instead that Joan’s lifetime of bodily pleasure is perhaps what enabled her to persist in securing the coverage for her vulvar biopsy, and to return for the care that she knew could be provided by the vulva clinic. Because it was at her *second* visit, and in connection with Dr. Robichaud’s attentive counseling, that she poignantly asked whether “anything [could be] done about this”; within a context of genital investment, Joan is better able to seek solutions. Not surprisingly, however, they are quickly

compromised by the knowledge that both she and Dr. Robichaud have about the subaltern nature of such an investment:

Dr. R: [Tells Joan that what happens if you don't treat LS is that] the labia can stick together. And then we have to do surgery to separate them. If you treat it, then we don't have to do this.

J: Well, if my insurance will pay for it. If not, I'll just have to live with it.

Dr. R: Well, I would hope that your insurance will pay for some of [it].

It is easy—*so easy!*—to see and understand the insufficient ‘care’ provided to Joan by her state health insurance plan (ironically called Oregon Cares). It is more challenging, however, to locate and *hold accountable* the deep tissue discourses through which that ‘care’ is conceived and administered. Joan’s having returned to OHSU and undergone the appropriate biopsy for her symptoms did not give her back the pieces of her vulva that were already gone and it is likely that without the kind of clinical-emotional support that consistently challenges these pernicious discourses, Joan will lose more of her labia in the years to come. Finding the connections between this *absented* flesh and the all-too-present (cultural) assumptions about which genitalia women can learn to “live with” allows us to more concretely imagine how the material *presence* of non-diseased female genitalia is nonetheless fundamentally informed—and perhaps experienced—as a profound and censored *absence*.

The next time that I saw Judy in the clinic, she was bearing a mountainous basket of blueberry muffins for Dr. Robichaud and Gina and thanking them for the genitals that they “gave back to [her].” Of her (sexual) relationship with her husband, she told us “We’re in a great spot; the best in 30 years.” In the language of this dissertation, I

suggest that what the vulva clinic gave Judy was a bodily imaginary through which she could invest in the material and symbolic existence of her vulva, and with which she could generate an expanding number of genital possibilities, not least of which was a future of sexual intercourse with her husband. Judy told us that she did dilator therapy twice a day (“religiously”), adding that she “had to get up pretty flippin’ early” (4:45am) to work in a fifteen minute session before she left for work. She repeated this when she got home after work at 5:00. “I just plug in the Tivo and ... watch [that day’s episode of] *Starting Over*.” I want to end Judy’s story here because I just love this image, as much today (as I write this) as I did on the day that she said it. This is partly because *Starting Over* was a secret and guilty pleasure of mine, one that I encountered for the first time while I was in the field. Home during an unstructured weekday, I turned on the television to find a so-called reality show about a group of women living in a house with two life coaches, each of whom was trying to overcome a set of obstacles and start her life ‘over.’ It was impossible for me not to project Judy herself into that show, sharing her genital recuperation with women recovering from divorce, drug addiction or abusive relationships. Situating the resolution of a genital disease condition within this uniquely American configuration of “starting over,” I could imagine the strategies of self-discovery that a woman with Judy’s history could both offer and receive.

The vulvas that Judy, Joan and Mary Hudson struggled to eventually “live with” are bodily instantiations of overlapping and overdetermined sets of discourses regarding female sexuality, excess, reproduction, heterosexuality, ‘health,’ and genital normativity. Paternalizing pharmacists, conservative dermatologists and narrow-minded insurance administrators reveal particular slices of the vacuum-like silence through which many patients live their symptoms, and they are fragments that are readily perceived by a critical and ethnographic engagement with these disease conditions. Indeed, my

anthropological attention to these stories reveal, as I argued at the beginning of this section, how their genital bodies are rendered *invisible* by an accumulation of alienating forces. My argument in this dissertation focuses on this rendering—the disavowing and *active* nature of discourses that rob many women of a genital “capacity,” indexed here by the vaginal capacity from which Judy’s first physician encouraged her to disinvest. Delineating the social spaces through which this invisibility is realized—is made *manifest*—helps us to see that the silence in which vulvar pain is experienced is more accurately described as a censored story. Without explicitly proclaiming, “Nobody gives a shit about your genitals,” institutionally-located actors convey this sentiment nonetheless in their everyday acts of evasion, erasure and disparagement. Rather than simply being missing from the cultural landscape, the vulva is, instead, subject to structural level “displacement and deferred action[s]” (Wilson, 2004: 5), making it all the more challenging to locate and hold accountable the spaces through which this invisibility is rendered. Seeping into the discourses and practices of even those who are ‘officially’ charged with the task of bodily care—notably, physicians and women themselves—vulvar *disinvestment* hides from sight as readily as do the diseased genitals of my informants.

Manifestation (3): the state or condition of being shown or perceptible

Sometime around 7:00 a.m. on October 27, 2004, I walked up to a small table in the Hyatt Regency in Atlanta and gave my name to the expectant and amiable woman greeting me. In exchange for my name, I was given a badge to wear around my neck, and a bound notebook stuffed with an agenda, copies of scheduled presentations, supplementary articles, faculty biographies, and plenty of blank space for taking notes; I

had just officially checked in for a conference called *Vulvodynia and Sexual Pain Disorders in Women*. “A State of the Art Conference” was how this meeting was billed in the National Vulvodynia Association’s online newsletter, and my interest had been especially piqued when I read that it would be the first of its kind. This ‘cutting-edge’ promise was my rationale for spending a substantial component of my fellowship funds to come to Atlanta and, as I took a seat towards the middle of the still empty ballroom at 7:15, I silently thanked the Social Sciences Research Council. My instincts to come had been trustworthy ones—just two months into my fieldwork, I was about to spend the day with almost every physician, epidemiologist, psychologist, or other healthcare provider who had thus far been responsible for putting vulvar pain on the clinical map.

Technically, this was not the *very* first conference of its kind—some of these researchers had convened once before. Catalyzed by the dynamic energy of the National Vulvodynia Association’s members, several key medical researchers had agreed to meet with both the NVA and the National Institutes of Health (NIH) in the fall of 2003. The NVA’s goal at that time was to secure a legislative call for vulvodynia research funding, and the NIH needed the clinical expertise of vulvar specialists before they could accurately gauge their interest in sponsoring such a bill. That meeting, however, which figured significantly in the eventual passage of HB (get details from NVA newsletter), had not been ‘open to the public,’ i.e., the conversations that transpired and the conclusions ultimately reached were not available to the bulk of clinicians and providers who were treating patients with vulvar pain. (The fact that this included the two physicians with whom I worked is noteworthy, as it allows us to see the outlines of a hierarchy in which patient-centered clinicians⁶⁹ settle closer to the bottom than the top.)

⁶⁹ As opposed to research-centered. OHSU is a research *and* teaching facility, but research is, of course, only open to those who secure their own funding, something that Drs. Erlich and Robichaud (who have personal “lives”) find precious little time to do. Patients are the money-makers if you are not paying your own way with grant money.

Within the contemporary field of vulvar disease—both research and management—today’s conference marked an important beginning. An expanded group of experts were on-hand to discuss vulvar disease from innumerable angles, including: bench research; sexuality; dermatological issues; demographic and epidemiological statistics; psychotherapy, biofeedback and cognitive-behavioral therapy; neurological, immunological and pain-related physiology; concomitant urological conditions; and treatment options. And, most importantly, there was an audience full of clinicians—in various states of frustration, confusion and optimism—ready to learn from them.

I, of course, was also in the audience and from what I could tell was probably the only social scientist present that day. I quickly began using the lined pages of my conference booklet to write fieldnotes, the first of which (unsurprisingly) noted that there were “an overwhelming number of women [in the audience].” (In contrast, the dais that held the morning’s moderators and presenters was almost perfectly gender balanced). Besides this well-rehearsed initial observation, my notes from that day are fairly uncritical, and this was only partly due to the rapid pace of the presentations. Mainly it was because I was very excited to be there, and I was far more interested in absorbing the content-details of my environment than I was in critiquing it. Many, if not most, of the men and women sitting at the front of the room, as well as those listed and described in my program guide, were researchers whose names I had come to know while I learned about this disease. They were the serious heavy-hitters in the field and I was more than a little starstruck when I identified Elizabeth Stewart, author of *The V-Book*, sitting a few rows ahead of me. Among these vulvar icons was an OB-GYN physician from Rochester, New York named David Foster who, as one of the first speakers of the morning, was already seated amongst his panelists. Perched several feet over the rest of us, silver-haired and bow-tied, Dr. Foster politely listened, took notes,

and asked questions of those who presented the first papers. I know this because I paid him more attention than I did some of the others. His paper was the last before the first break, and I was mildly distracted for the first two hours of the conference as I anticipated his presentation.

Dr. Foster had become important to me because of an article (“Vulvar Disease”) that he wrote in 2002. It was published in *Obstetrics and Gynecology* (“the green journal,” as the clinic doctors referred to it) as part of their “Clinical Gynecologic Series: An Expert’s View.” I found the article during my very early dissertation research and it came to play a pivotal role in shaping the questions that I formulated for my exams and grant proposals. Dr. Foster’s goal was to provide women’s health clinicians with a comprehensive overview of vulvar diseases—their symptoms, objective signs, causes—as well as extant and gold-standard treatment protocols. Around this time, I was fashioning the argument that U.S. women were at an increased risk for vulvar cancers (and other serious disease conditions) because they were too uncomfortable with their bodies to perform a genital self-exam. Since the initial presentation of vulvar cancer (and some of the lichens) often involves dermatological changes that can best be monitored by a woman who knows what her vulvar ‘baseline’ is, any of these conditions can worsen appreciably if not detected by eyes (and hands) that are prepared to recognize a change. The gynecological clinicians who were interested in vulvar disease conditions understood women’s reluctance to examine themselves, but did not (in my mind) have an adequate grasp of the cultural habitus in which this reluctance was stubbornly lodged. Thus, their exhortations, to both patients and other clinicians, for more vulvar self-exams (Lawhead, 1990) fell on ears that were not so much deaf as they were ill-equipped to comply (See Chapter One).⁷⁰

⁷⁰ There is a similar history with the breast cancer prevention/early detection movement. Many providers and activists relate the enormous difficulties that they faced early on in making the public, patients, and

Dr. Foster was part of this cadre of vulvar specialists and he opened his survey article with the matter-of-fact observation that “the vulva most clearly defines the female phenotype and yet, the female patient commonly knows less about her vulva, in health and disease, than any other part of her external anatomy” (2002: 145). A greater (public? feminist? critical?) awareness of the bodily ignorance to which Dr. Foster was calling his readers’ attention—along with its etiologies and implications—was and remains one of the major clinical goals of my research. Around the time that I encountered this article, however, my analytical interests, though rooted in the genital body, began to shift: from the clinical and disease-related consequences of an ignorance that I knew was culturally conditioned, to a more thoughtful and in-depth analysis of the *lived experience* of this ignorance. And so, rather than use Dr. Foster’s statement to develop more sophisticated patient pamphlets, or to write an article for nurse practitioners about the dangers of undetected vulvar skin changes, I instead began to routinely cite him as part of my argument about the very state of things, as the clinical version of my anthropological departure point.

In retrospect, I can’t recall what I had expected from Dr. Foster that morning, but it was likely an expanded version of the clinical dismay that was expressed in his article. I was still learning about the medical perception(s) of these symptoms, and, at that time, I believed that any physician or researcher who had developed a specialty in vulvar pain (which would have been anyone at this conference) must have done so with the clinical urgency and chagrin expressed by Foster and other proponents of better vulvar health and medicine (Friedrich, 1983, 1987; Lawhead, 1990). Given the hyper-physiological titles of Dr. Foster’s two papers, however, I might have been better prepared for the

non-specialists feel comfortable discussing—and negotiating the ambiguously sexual aspects of—the breasts of their female patients, friends, mothers, wives and daughters.

direction that his presentation took.⁷¹ As I struggled to keep up with slides and data that were based in molecular biology and bench research, I noticed that I was battling a separate set of fieldwork-related concerns, namely that I was having trouble really *caring* about the importance of Dr. Foster's findings. What, I began to wonder, did interleukin and capsaicin have to do with the lived experience of vulvar pain? (How) would this bench research make its way into my ethnographic account of *vulvodynia* and VVS?

Again, on further reflection, these questions seem as ill-informed as the paternalizing suspicions of the pharmacists described in the last section. I am—and was—well aware of the role that clinical research plays in the 'experience' of a disease condition; most specifically in the contributions that it makes to diagnostic markers, screening tests, and/or treatment protocols. But I was nevertheless resisting Dr. Foster's paper. Indeed, I was feeling quite rebellious in the disinterested attitude that I was cultivating, and my fieldnotes contain the following excerpt: *Dr. Foster (and these other MDs) are attempting to make vulvar pain better, but they are doing so through molecular structures that have no part in the patients' narratives! These women are describing pain that literally prevents penetration by their husbands ("it's like a wall in there"). They are describing soreness after genital contact that is so severe that they need to apply bags of frozen peas or cans of frozen lemonade to their vulvas for hours afterwards. They describe what they understand to be redness around the opening to their vaginas, and particular spots that neither they nor their husband's fingers can go near without them flinching (at the very least). They talk about how things have seemed to get worse over time and about how if he "can get past that one spot," or if they are*

⁷¹ The first one was titled "Genetic Variation in Interleukin-1 Receptor and Melanocortin-1 Receptor Genes on Vulvar Vestibulitis Syndrome"; the second was "Comparative Effects of Intradermal Foot and Forearm Capsaicin Injections in Normal and VVS Afflicted Women."

on top, it can be okay. They describe how unbelievably sensitive their skin is—how “nothing” can touch it. They say that their husband “doesn’t fit” into their vaginas. Their nerve endings and immune systems are not (yet) part of these narratives.

But, of course, Dr. Foster’s research was both salient and innovative for the physicians and providers in the audience.⁷² And the ‘patients,’ on whose behalf this research was being carried out (and about whom my fieldnotes expressed such urgent concern), were represented by advocates who were equally invested in his findings. Indeed, several members of the NVA were in attendance, among them their director of research (Christen Veasley), who had been given a slot in the welcoming panel. Dr. Foster’s work with capsaicin—the heat producing chemical found in chili peppers—was somewhat of a hot topic in neuropathic pain research, evidenced by the NIH funding that he had already secured for it (Foster et al, 2005). And so not only were these providers, patients and advocates less frustrated than I, many of them were either engaged in or actively supporting similar kinds of research (CITE CITE). During the conference, I was aware of this and, as I indicated, found myself sharing more of their clinical gaze than I had anticipated I would. Yet as the presentations continued, I could not shake the sense that something was amiss. In the attention being paid to the genetic, immunological, and neurophysiological aspects of VVS, I wondered whether physicians like Dr. Foster were *losing sight* of the vulva itself? Would any of these research/treatment trajectories correct the situation that he had so straightforwardly lamented in his 2002 article, the genitally ignorant state in which most U.S. women found themselves? In thinking further, I began to wonder whether I had *imposed* the sense of dismay through which I’d always interpreted Dr. Foster’s article; that is, were his words a lamentation at all? Did he believe that the vulvar ignorance that he

⁷² He has been awarded at least one research grant each from the NIH and the NVA.

described needed to be corrected, or was pain the only problem he perceived, a ‘problem’ that was solely in need of clinical intervention?

In *The Birth of the Clinic*, Foucault contends that “[i]n order to know the truth of the pathological fact, the doctor must abstract the patient” (1973: 8), and that

the doctor’s gaze is directed initially not towards that concrete body, that visible whole, that positive plenitude that faces him—the patient—but towards intervals in nature, lacunae ...[and] distances in which there appear ... ‘the signs that differentiate one disease from another, the true from the false ... the malign from the benign.’ (8)⁷³

What became increasingly evident as I listened to the majority of papers delivered by the “heavy-hitters” that day, was that our respective perceptions of the “malign[ant]” and “true” aspects of vulvar pain conditions were distinctly informed. For me, the path towards recuperation was (and is) always through a direct engagement with the vulva itself—women with pain must confront their genital reluctance, distaste, fear and—particularly—ignorance, if they are to have any hope at all of ‘recovering’ from their symptoms. The malignant forces that *I* see operating on and in these bodies are not exclusive of molecular and physiological occurrences, but they are simultaneously and fundamentally *obliged to* the alienation and *inconsequence* that are culturally produced and sustained.

“Medical looking is not naïve,” argues Young (1997: 120) but is instead a “product of the epistemic shift described by Foucault (1973) and characterized by a change in *perception*. In the ‘modern’ body (see also Duden, 1998), “[s]igns which used to be clues to the past ... , the present , or the future ... , became symptoms, manifestations, localizations, *instances of the disease* (Young, 1997: 123; my emphases). The tension, at least for me, of the conference was exactly this: in localizing *vulvodynia* and *VVS* in the nerve endings and respective pain responses of a subset of

⁷³ Partial quotation is from Frier, *Guide pour la conservation de l’homme*, (Grenoble, 1789: 259).

U.S. women, the “clues” to the pasts, presents and futures of *any* woman with a (disparaged) vulva were being effectively excised from the broader perception of vulvar pain. The gaze of these clinician-researchers was indeed far from “naïve,” structured by both epistemological trends as well as the proliferating funding opportunities on display in the ballroom that day. The clinicians at the dais and on the schedule were hand-picked by the NVA and relevant NIH personnel, both of whom had active investments in moving vulvar pain research in particular directions (including *away* from the marginalized realm of the psychological).

As the day progressed, and I sat through lectures about the “plasticity of the nervous system,” “immunogenetic analysis,” “vulvoalgesiometry,” and “cytokines [and] steroid hormone mechanisms” in relationship to vulvar pain, I became aware of the second level of profundity that this conference held for my fieldwork. Not only was I interacting with the key players in clinical vulvar medicine, but I was also right in the middle of the apprehensive shift (regarding vulvar pain) that I had theorized in my research proposal, i.e., from an invisible and ‘psychosomatic’ embodied trauma to a hyperphysiologized pain condition. As Dr. Hope Haefner presented the first official “algorithm of care,” followed by an expert (and rather spirited) panel discussion about nomenclature and diagnostic categories, I took in the fact that I was witnessing the medical *realization* of vulvar disease. The algorithm, we were told, was about to be published (Haefner, 2005). We in the audience had been the beneficiaries of a sneak preview of what was to become the standard of care to which anyone treating vulvar pain must now compare their own efforts and strategies. It cannot be overstated that this standard of care—what clinicians call “the gold standard”—*is* medical reality. Vulvar disease was being made manifest in the ballroom of the Hyatt Regency of Atlanta, and between the hours of 7:30am and 4:30pm, to be precise. This new ‘reality,’ it was

understood, would now be maintained by the perfusion and circulation of these standards and discourses in the more general population of gynecologists, represented by many of my fellow audience members.⁷⁴

It is possible—indeed productive—to examine the kind of clinical research that Dr. Foster is doing through an alternative gaze. Anthropologists working with molecular biologists and geneticists have demonstrated that many of these scientists understand the ‘bodies’ with which they work in intriguingly plastic terms (Goodman, Heath and Lindee, 2003; Duster, 2006; Lock, 2007). The genomic mapping of bodies at the levels of individual, ‘race,’ gender, ‘cultural group,’ or nation, for example, provides contemporary scientists with models of (human) organisms that barely resemble the anatomical life forms that most of us refer to as our physical selves. “[I]n this view”, argues Haraway, [DNA] is a master molecule, the code of codes, the foundation of unity and diversity” (1997: 245). ‘Bodies’ that are redefined by their nucleotide sequences, allele frequencies or chromosomal organization are open to novel interpretive frameworks, any of which can serve to biologically reduce, reify, or exceed our received—and extant—cultural categories. In this *postmodern* bodily milieu, Haraway continues, “where the artifactual and the natural have imploded, nature itself, both ideologically and materially, has been patently reconstructed” (245).

In this broader context, I find myself less perturbed by the work of these researchers. Surrendering to—or evolving with—contemporary scientific narratives, I am cautiously enchanted with the potentially ‘liberating’ nature of molecular medicine, and with the ways that their basis in the ‘natural’ science of biology seem to cleverly cloak projects and discourses that are decidedly artificial. Or that are something *else*:

⁷⁴ This is no small thing. More than one patient recounted how one or more treatments that a previous doctor had tried with her was based on their having encountered/learned it “at a conference.”

the genome projects produce entities of a different ontological kind than flesh-and-blood organisms, ‘natural races,’ or any other sort of ‘normal’ organic being. ... [They] produce ontologically specific things called databases as objects of knowledge and practice. The human to be represented, then, has a particular kind of totality, or species being, as well as a specific kind of individuality. At whatever level of individuality or collectivity, from a single gene region extracted from one sample through the whole species genome, this human is itself an information structure (1997: 247)

Read one way, this scientific narrative has the potential to free up the essential nature of *any* kind of body—black or white, female or male, diseased or ‘well.’ That is, when bodies are manipulated and understood as genetic material, chromosomal arrangements, or alterable and interchangeable parts, they can be(come) available for a multiplicity of readings, perceptions and interpellations. In continued conversation with Haraway, we might position these scientific practices in a diffractive field, allowing them to shuffle and reconfigure the most basic elements of the bodies with which we currently live. Where, then, does a body start? What, exactly, defines its sex and sexuality? Its pleasures and its pain(s)? Its cohesion and/or disintegration?

In making myself capable of imagining that some of this more ‘basic’ research might indeed constitute ontologically distinct apprehensions of the body, and in making room for Dr. Foster’s having ‘abandoned’ the materiality of his patients’ vulvas for a material reality of a different kind (i.e., high-dollar federal funding), I have to ask myself a new set of questions. Namely, is there a connection between the abstracted ‘modern’ body postulated by Foucault and Duden, the *postmodern* bodies theorized by anthropologists of science, and the apprehensive shift that I was witnessing at the conference? Does this new line of clinical inquiry mean that nerve pathways and immunogenetic markers constitute ‘the *new* vulva? And if it is, can I make this vulva meaningful? Can I come to *care* about it?

My current answer is that I don't think so. At least not yet. Having attended to these symptoms and this body part for some time now, I am not certain that I can fully locate the gaze of these researchers within the epistemic shift that I find so productive and intriguing. My reluctance stems from an acute and experiential knowledge of how the 'bodies' in question are particularly and suggestively situated within a specific cultural context—one of routine contamination and disavowal. Although not uncomplicatedly, the apprehensive shift that I witnessed in Atlanta—the same shift evident in medical journals, funding requests, and in patient-physician dialogues—is beginning to make *absent* the site through which healing and reconciliation can occur. If, as I believe, vulvar pain does not emerge outside of the cultural experiences of *inconsequence* and alienation, then treatment strategies (and the perceptual pathways through which they are developed) that bypass the vulva entirely do not offer patients an effective path to recovery. Indeed, they actively participate in the practices of erasure that compound both the silence and the suffering of symptomatic women; a repetition that Haraway refers to as the Sacred Image of [the] Same (1997: 273).

Returning to the themes of repression and connection with which I opened this chapter, Freud argues that a “conscious presentation” (of anything) requires the coexistence of “the thing plus the ... word belonging to it” (in Grosz, 1994: 28), while “the unconscious presentation is the presentation of the thing alone.” My psychoanalytically-inflected vulvar dilemma, however, remains unaddressed by this set of propositions in that what is being *presented* at the conference is, seemingly, the *word without the thing*. In this room full of vulvar experts, there is no linguistic reticence; but this matters only slightly, given the professional responsibility through which their verbal ease is cultivated. What I fear, however, is that I am witnessing some kind of discursive trade-off, one in which the *thing* itself is being exchanged for these words that

belong to it. I am unsettled by this displacement and, as I flip through the pages of my conference notebook, this feeling is amplified. Full of powerpoint reproductions and photographs of faculty, I find only one vulva amidst a proliferation of images—graphs, text, schematics of pain pathways and neuroimmunological mechanisms, MRI scans, algorithms, symptom scales, and photographs of diagnostic instruments. Indeed, Dr. Foster’s discussion of capsaicin, which involves an injection of this chemical into the forearms and feet of symptomatic women (and unaffected “controls”), includes not one, but *three* photographs of *feet*! Has the vulva been disappeared by its own “State-of-the-Art” convocation? And if so, how will the genitals of symptomatic women be regarded by those whose “gold standard” has now been constructed through this discursive *dys*-appearance (Leder, 1990)?

My seemingly harsh conclusions about the perceptions through which these emerging standards were developed, were based on one more important factor—the complete lack of physical therapists from the conference faculty and invited speakers. Still green in the field, I might neither have noticed nor questioned their absence if the therapists in attendance hadn’t made their presence known through the numerous questions and comments that they made. Indeed, it is fair to say that almost half of the audience interaction that day was with physical therapists, most of whom had concrete, experience-based, and challenging questions for the experts. One woman in particular, who posed more than one of these queries, also shared her knowledge with other audience members when one of the panel members was stumped.

Although I had no direct experience with PT at the time, I had nonetheless begun to perceive that (at least) the OHSU physicians didn’t know (and weren’t necessarily interested in) the details of how and why PT worked, beyond its easily comprehensible efficacy in massaging out pelvic floor *myalgia*. As the epistemological gaps between

questioner and expert became more obvious and even awkward at times, I wondered about how, when and why physical therapists had been relegated to the sidelines of what was, in effect, a new realization of these disease conditions. Two years later, as I describe the perceptual and apprehensive shift that this conference made manifest for me, I have some tentative answers. The professional marginalizing of these providers may reflect distinct levels of vulvar “distance” that are maintained by different clinical orientations toward disease and the body. But what is also true is that second-class status of the physical therapists effectively reproduces a broader set of divisions between the mind and the body, and between classical and grotesque bodies (Russo, 1995). Researchers deploy masculinized and scientific minds to explain the complex molecular and neuropathic processes involved in vulvar pain and tolerate (as do Wilson’s gastroenterologists) a *complementary* role for the flesh-and-blood—and emotionally contoured bodies—that PT’s literally take into their hands. But if Drs. Erlich and Robichaud are a gauge of even the most invested clinicians, the coarse and manual details of how PT ‘works’ remain epistemologically subordinated to the abstracted scientific etiologies being ‘discovered’ by researchers like David Foster.

Some authors (Bernheim and Kahane, 1985; Masson, 2003) have argued that Freud developed the unconscious at the expense of the sexually abusive stories of his hysterical female patients. Rather than believe that such a large number of women could have been mistreated at the hands of husbands, fathers, or family friends (many of whom were colleagues or acquaintances of Freud’s), the argument goes, Freud chose to make the narratives of abuse symbolic rather than real, effectively displacing the ‘cure’ of neurotic hysteria from structural patriarchy and/or idiopathic pedophilia to the individual and psychically diseased minds of (victimized?) women. It is difficult not to marvel at the resonance that such a revisionist history has with the social and clinical history of

vulvar pain. In the second half of this century, the perception of symptomatic women has swung from that of ‘probably abused’ victim to a ‘not necessarily abused’ conundrum, to a hyperalgesic body for whom a history of sexual abuse is increasingly irrelevant. In reviewing this history, I cannot help but wonder if the clinical *realization* of vulvar pain is yet another case of an authoritative and masculinist medicine that can listen yet still not *hear* the stories that women are trying to tell.

Any response to this question is wildly complicated by the conflicting desires and refusals of symptomatic women, many of whom have insisted that there is no room for an abusive past in the etiological recounting of their pain. But, as we will see in the following chapter, a recently expanded definition of ‘abuse’ has led to a proliferation, rather than a reduction, in the number of women that are likely to report symptoms. If vulvar pain conditions are even partly the ethno-somatic eruptions that I am proposing here—i.e., culturally contoured symptoms that, long silent, have now “*forced their way into consciousness*” (Freud, 1917a: 345)—then we must follow this particular lead of Harvard’s researchers. We must continue to look for ways to infuse the definitions of *vulvodynia* and *VVS* with the embodied pasts, presents and futures of symptomatic women, many of which contain significant amounts of unwanted genital experience, vulvar alienation and bodily disintegration. Proceeding with my bodily metaphor, then, I will use the next chapter to analyze the relative ability of symptomatic women to *integrate* corporeally-contaminated pasts with clinical presents from which such histories are increasingly detached.

Chapter Five: Integration

PART I: ETHNOGRAPHY AND 'SLIPPING RIGHT IN'

Almost from the beginning of my stay in Oregon, the doctors and I noticed that my entry into the clinic had been virtually seamless and that, over the course of a year, my continued presence seemed to make imminently more sense than did my looming and impending absence. This was partly because I had inserted myself—and been received—into the Center for Vulvar Health in the manner with which we encouraged patients to work with their therapeutic dilators. That is, women whose pelvic floor *myalgia* made vaginal penetration painful or impossible were strongly persuaded to consider dilator work as a supplement to their physical therapy (PT) or other treatment regimen(s). Therapeutic dilators came in graduated sets,⁷⁵ and were meant to be used as biofeedback for patients who were learning to relax the muscles of their pelvic floor—the easy insertion and removal of a phallic object could provide corporeal confirmation that they were gaining (back) increasing amounts of flexibility around their vaginas. “You don’t want to just shove them in,” was one of the more succinct directives provided by physicians and PTs as they taught patients to increase the size of their dilator *only* when their vaginal muscles allowed that particular size to enter without any pain. Rather, proclaimed Dr. Erlich on a regular basis, “it should just slip right in.” I came to think about my presence in the clinic in these therapeutic terms—rather than forcing my way in to an inflexible and unwelcoming cavity, I had, rather, “slipped right in” to a space that had a readied capacity to tolerate, and even welcome, my presence.

⁷⁵ Typically of four to six. They could be purchased at the hospital, online, through the physical therapists and/or through the local (and woman-owned) sex shop. See Chapters Two and Four for more detailed accounts of dilator therapy. See Figure 2.

Given the cumulative nature of ethnographic fieldwork, I was not surprised that my last few months in Portland were some of the busiest and most productive. I secured interviews with new patients easily, and I was following enough of them through treatment that I often attended several appointments per day. But it was my deepening relationships with patients—achieved through months of sustained engagement with their symptoms—that provided me the greatest assurance that my research goals were relevant to them. The nature of my project led to a unique brand of intimacy with my research informants, one that facilitated ongoing dialogues about their struggles and successes—genital, sexual, marital and emotional. Their ability and willingness to involve me in these *non-clinical* aspects of their lives made the work that we were doing together cohere that much more fully.

Just weeks before I returned to Texas, Nikki invited me to dinner in the home that she shared with her husband Sage. We both sensed the need for one of these lingering conversations, as our respective work and travel schedules had made it difficult to catch up that summer. At the time, and for reasons that were not fully clear to me, Nikki was only partially committed to regular physical therapy sessions. She told me that she and Sage had “probably had sex [only] four times” that year, and that she still had pain, despite undergoing a second surgical procedure with Dr. Erlich a few months earlier. She remained undaunted however, as she and Sage went on with their lives and continued to configure their marital relationship around a sexual act that might *someday* be an uncomplicated part of it. Nikki was increasingly not averse to sharing the details of her situation with friends and family, many of whom regularly—and exasperatingly—exhorted her to “just do it!” regardless of the pain. Nikki struggled with this impatience and incomprehension and told me that, at a recent dinner party, she fought back with some exasperation of her own, telling her friends: “Look. I have an

army of women telling me that I don't have to have sex! I have a surgeon, a physical therapist, and a counselor who are fine with me being exactly where I am!" As she finished uttering this last sentence, I couldn't stop myself from interjecting "Don't forget your anthropologist!," to which all three of us laughed in commiserative agreement.

This easy and sensible 'fit' between me and the lives of symptomatic women became increasingly relevant as patients progressed in physical therapy. As I have described in Chapter Three, genital physical therapy is deeply personal and patients, particularly in Cathy's practice, are encouraged to talk openly about the emotional aspects of their pain. As symptoms improve through regular sessions and homework, therapists begin to engage each woman in frank dialogue about sexual behavior, helping to cultivate strategies that will maximize her chances for successful penetrative sex.⁷⁶ PT involves the regular penetration of a patient's vagina, either with her own or the therapist's finger(s), a biofeedback sensor, and/or a therapeutic dilator; it can also include rectal work if some of her "holding pattern" involves this related musculature. This work was intense and difficult, and each time I sat in on a session I marveled at the level of trust that these women (and their partners) placed in me and in my research. My growing respect for the courage they displayed deepened my understandings of what *else* these women faced in their confrontations with vulvar pain. This chapter will explore the content and context of this 'what *else*.' That is, I will use physical therapy as departure point to discuss the numerous facets of a woman's life that can either come together, fall apart, or remain unexamined during her attempts to alleviate her genital and sexual pain.

⁷⁶ For example, "Which position do you think you want to be in the first time you do it?" Cathy told me that almost all of her patients answered "on top."

How can I be better?: physical therapy and ‘pushing the limits’

As I describe in Chapter Two, physicians at OHSU divided the numerous ways that patients described their pain into three main categories: vulvar vestibulitis syndrome (VVS), vulvodynia, or one of the “three lichens.” The latter two conditions, as well as what Dr. Erlich calls “secondary vestibulitis”⁷⁷ typically arise later in a woman’s life, up to and including her postmenopausal years. This is important in that this group of patients—although their pain may be severe, even debilitating—has experiential knowledge of genital and sexual contact suffused with far more pleasure than pain. Women with “primary vestibulitis,” on the other hand, have no such corporeal reference point and have, at most, memories of a few fleeting weeks at the beginning of their marriage when sex was pleasurable. For the typically older women in the first group, the reality and longevity of a past without sexual pain—and the desire to have it back again—catalyzes their ability to seek attention quickly, a move that often secures an earlier and more accurate diagnosis. Without such nostalgic biofeedback, patients with primary VVS struggle—often for years—with fitting the experience of searing pain into the popular and ‘friendly’ advice that: (a) sex is “supposed to hurt,” (b) she needs to “relax,” or (c) there is no help to be had. Unfortunately, and most pertinent to the subject of physical therapy, is that by not attending to the injured skin of her vulva, each of these patients sets up the conditions through which her vagina too will begin to burn and reject penetrative contact.

⁷⁷ Dr. Erlich used this term for VVS that arose after a woman had been able to have sex without pain, for any amount of time; primary VVS was the type most commonly seen in the clinic. Dr. Robichaud did not find these terms useful, as she based her distinctions between the two diagnoses on other factors (e.g., provoked vs. unprovoked, quality of pain, diffuse vs. localized). I make this point to demonstrate that, regardless of how diagnoses are neatly classified—with research funding and publications often sustained by those criteria—things are often messier in practice. It is also worth noting that the conference in Atlanta (see Chapter Four) dedicated one-half of an afternoon to a discussion about nomenclature, a conversation that turned out to be one of the most spirited of the whole day.

I can't exactly recall when I learned that physical therapy could be part of the treatment plan for vulvar pain, but I know that I did not understand its full importance until I was well into my second stay at the clinic. Physicians considered PT to be a critical adjunctive therapy, and almost all patients with VVS were provided with a referral at their initial visit. PT was prescribed for women with other variations of vulvar pain, but only if their symptom profile indicated that it would be effective. Physical therapy is thought to work for women whose bodies have begun to compensate for, even protect them from, the painful impact(s) of genital penetration. Since—particularly with VVS—pain is only provoked through contact with a potentially invasive object (e.g., penis, speculum, tampon, finger), the muscles in the pelvic floor begin to close off when such contact is anticipated. As with a tail tucked between the legs of a cautious canine, the pelvic floor of a woman that has repeatedly—or *only*—experienced pain with direct genital contact, becomes stiff with fear, diminishing its accommodative capacity. As they begin to apprehend the long-term and predictable nature of this pain, the *pubococcygeal* and *levator ani* muscles conspire to offer some protection, tightening enough to disallow any further participation in behaviors that might be associated with insult or injury.

Physical therapists perceive a proportional relationship between the extent of pelvic floor injury and the length of time a woman's body has been in this compensatory mode; they direct their treatment efforts towards reversing the damage that has accumulated. Like any muscle grown tight from prolonged tension and contracture, the hammock-shaped pelvic floor must be loosened, stretched and retrained to open with the same vigor it has used to close itself off from injury. Depending on how long she has gone without a diagnosis, or on how vehemently her muscles have reacted to the presence of a new pain, a woman with vulvodynia or one of the lichens may need some

of this work in order to supplement a clinic-based treatment plan that more directly targets her skin. But it is primarily the women with VVS, whose genital and sexual desires have been hijacked by the ever-present possibility of contact-related pain, who most need what physical therapists have to offer. Indeed, work that is done by a combination of the ‘right’ therapist and an appropriately ‘ready’ patient can defer, and occasionally obviate, the need for skin-based regimes such as surgery, laser ablation and topical anesthesia.

I want to suggest that Cathy, Hanna and Joy—and the practice that they shared—were the ‘right’ physical therapists; I also want to complicate this assertion by further elaborating what are very complex relationships between physicians, patients, pain, insurance companies, professional turf, PTs, partners, and vulvar pain researchers. What I can say is that the three women who ‘got better’⁷⁸ during my time at OHSU (Daphne, Libby and Jessica) all worked with one of these therapists. Cathy, who owned the practice, was an Anglo woman in her mid-fifties who wore her hair long, her face unadorned, and her body clothed in sensible attire. Too easily reduced to the stereotype of an Oregon aging hippie, Cathy lived a busy but balanced life that included five children, a working husband, regular bodywork, home renovation (in the year that I knew her) and a family band that competed twice a year. She admitted to a past that was significantly more hectic—jogging during her lunch hour, working six long days a week while building her practice, actively raising her children—and she used this history to commiserate with patients who were struggling to find the time to do the homework she routinely assigned. Cathy recruited and hired like-minded therapists to work in her office, women who understood the importance of making regular and sustained

⁷⁸ I use quotation marks around this phrase in order to disrupt its definition in biomedical terms. Chapters Two and Six of the dissertation more completely describe how I view “getting better,” which includes pain reduction that is *obliged* to an embodied acceptance of its extra-physiological meanings.

connections between daily life, emotional and physical pasts, unforeseeable circumstance, and the bodies that registered the impacts of these events. In talking with her once, I commented on how remarkably effective she was, and I wondered aloud about how she both elicited and attended to the very poignant narratives that accompanied vulvar pain. Cathy told me that she could not imagine caring for these patients without addressing these facets of their symptoms. She then contextualized her approach by saying “Oh, [but] we’re definitely pushing the limits here. What we’re licensed to do, that is.”

I believe, and will demonstrate below, that Cathy’s assertion goes directly to the heart of why these therapists are so successful. In order to make the kind of difference that matters in the lives of their patients, these women must—like the vulva itself—exceed professional and culturally circumscribed boundaries. In “pushing the limits” of physical therapy—even of the genital kind—they offer their patients a view to something new, to a body that is deeply integrated and comfortable in its skin, muscles, breath and idiosyncratic rhythms. When Cathy’s interventions bring a patient to a place of greater physical tolerance (e.g. of her finger inside their vagina), or when she is simply adjusting pillows around a back or pelvis, she asks “So, how does that feel?” When the patient replies that “It’s fine,” or that she is “okay,” Cathy deftly switches the terms and uproots the terrain upon which she is asking her patients to walk. She responds with a question meant to guide her patients in areas of their lives far beyond the task at hand. “Yeah, it’s okay,” she says, “but how can it be *better*? Sure I’m comfortable, but how can I be *better*?”

How, indeed, can female sexuality be better? If the lived experience of vulvar pain indexes the fragile and disparaged state of women’s genitalia in the U.S., then (how) can ‘getting better’ provide for their meaningful incorporation? And what *else*

must be addressed in order to live in such a body? In this chapter, I will employ both of these themes in order to bring together patient narratives, clinical protocols, neurophysiology, medical research, cultural discourse and feminist theory. That is, I will carefully delineate the social and material spaces through which the vulva's *inconsequence* is routinely realized. Working with the concepts of *agnosia* and alienation that I discussed in Chapter One, I will suggest that the *body images* (Schilder, 1950; Grosz, 1994) of many women in the U.S.—epitomized by those with vulvar pain—do not contain their complete genital anatomy. “Getting better,” therefore, requires an attention to the cultural factors that inform this fragmentation, as well to its physiological sequelae. Female genitals need to matter if they are to be recuperated. The stories and analyses in this chapter will reveal that such mattering is both elusive and ephemeral, including from the work of feminist and queer theorists.

In the clinic

In making referrals to physical therapy, physicians begin a dialogue with their patients through which they hope to introduce the role that they must play in their own recovery. When they collect a patient's symptom history, physicians actively disavow the hysterical and psychosomatic discourses through which so many women have come to understand their pain. “I believe you” (*even if no one else has/does*), is Dr. Robichaud's patterned and first-line response to her new patients, women whose bodies have betrayed their sexual expectations to an extent that they themselves can barely believe. “Your pain is real,” she continues. “It is *not* in your head” (*even though no other provider has been able to delineate its source, making them feel inadequate enough to blame you*). In Chapter Two, I described the details of the gynecological exam employed in the diagnostic workup for vulvar pain. It is during this exam portion

of the consult that Drs. Robichaud and Erlich subtly shift away from the linguistic absolutism of “This is *not* your fault!” This shift undercuts and uproots a conclusion that might otherwise be drawn from this sentiment, i.e., *My knowing how and why it’s real means that I will fix it for you.* After using the q-tip test to delimit the extent and intensity of a patient’s skin pain—an act that materially fixes what is often a new reality of disease for these women—the doctors perform an internal exam to ascertain the amount of pelvic floor involvement. During this latter half of the examination, the physicians employ techniques familiar to the patient, and their sympathy and respect for her subjective experience of pain remains central to the interaction. An assessment of the musculature, however, brings a part of the body into the equation that they both know can be brought under voluntary control, at least partially. By simultaneously validating the pain felt, and by explaining how prolonged muscular contraction can lead to a “burning” pain that is uncannily and confusingly similar to the pain felt at the vestibule, Drs. Erlich and Robichaud establish a physically demonstrable connection between (part of) the pain and conscious action. Although the patients do not yet know, they are now primed for a treatment plan that re-suffuses their symptoms with personal responsibility.

As described in Chapter Three, any patient whose assessment suggests muscular involvement is given a diagnosis of pelvic floor *myalgia*⁷⁹ in addition to the diagnostic category to which her vulvar skin condition is assigned. Besides making pelvic floor pain a clinical reality, this billable code provides the patient’s insurance company with

⁷⁹ *Myalgia* means muscle pain, and *pelvic floor myalgia* was an alternate way to describe the diagnosis of *vaginismus*, a condition more commonly understood as vaginal wall constriction with a psychosomatic cause. Both terms have diagnostic (and billable) codes on the OHSU paperwork. Dr. Erlich told me that she was making a point of always checking the *pelvic floor myalgia* box as a way to reappropriate the diagnosis from Freudian notions of frigidity and fear of coitus.

an expert opinion⁸⁰ that physical therapy is medically necessary and should be covered. The doctors at OHSU consult a list of local and statewide therapists and recommend two or three to each patient. This particular medical decision is more art than science—Drs. Robichaud and Erlich both strive to offer the best ‘match’ to each patient, using quickly gleaned impressions of each woman to predict which PT approach and personality will best meet her needs.

The first criterion to be addressed is a geographic one, as many women have traveled either across or from another state for their consultation.⁸¹ Some areas of Oregon are not served by anyone on the list, but more than half of the patients that I met were given the contact information for at least one therapist within seventy-five miles of their home. Since the clinic is in the largest city in the state, patients from the greater metropolitan and suburban areas are often able to choose from several options. I offer a fairly detailed description of this process because I hope to show that what looks like a case of administrative logistics is, in fact, an indication of both the arbitrariness and messiness that inform Vulvar Disease, deriding the clinic’s best efforts to establish a uniform standard of care. With no control over the unequal access that women have to adequate clinical expertise, the physicians at OHSU nonetheless attempt to sustain their “commitment to excellence” by fashioning a treatment plan that can extend *their* expertise across the state and/or region. The difficult reality that must be faced, however, is the dearth of professionals that can sufficiently attend to these confounding

⁸⁰ Through clinical practice, research and publishing, conference presentations, and professional networking, Drs. Robichaud, Jackson and Erlich have become established vulvar pain “experts.” This is important not only for their own career trajectories, but also for patients whose insurance companies balk at paying for a visit to OHSU if the hospital or the physicians are “out of network.” A woman may appeal to her insurance company by demonstrating that her symptoms require the expertise of one of these three physicians. I cannot stress how difficult these conversations are for these women, as they must provide quite intimate details in order to convince the (usually male) adjuster that their condition can’t be treated adequately by a run-of-the-mill gynecologist.

⁸¹ Out-of-state patients are told that they must do their own research as the list is state-specific.

symptoms, including physical therapists. This fact is evident as it meddles with physicians' attempts to secure a treatment that they believe is integral to the recovery of their patients. Although none of the physicians or therapists ever explicitly acknowledged this with me, what is uncomfortably obvious during these post-exam negotiations is that these patients—and their chances for recovery—exist on an extremely slippery and stratified playing field. A sizeable number of women will not, in Cathy's words, necessarily be "*better*" for their efforts. Indeed, some may feel worse, having glimpsed how arbitrary configurations of insurance, geography and luck-of-the-draw affect the resolution of vulvar pain.

At home

Some details about thirty-two year old Mya, who had been in pain for about nine years when I met her in December of 2004, will both illustrate and seriously deepen these issues of access and disparity. By revealing the compromised genital integrity that Mya brought to the (exam) table, I want to broaden our notions of health care *access*. Because regardless of what is diagnosed, prescribed, geographically available, and/or covered by insurance plans, if a woman cannot *access* the part(s) of her body that require treatment, she is unlikely to understand or pursue the recommendations of her physician. When I interviewed Mya in February of 2005, she had not made arrangements for physical therapy, nor did she plan to. She also did not have another appointment in the clinic and told me "I don't know what I'm supposed to do next." This confusion resulted from a profound *underintegration* of Mya's clinical needs, available resources, and her affective access to her genital body. Without any one factor tipping the scales, a pattern of poorly understood—and only partially developed—treatment possibilities circulated and fragmented around Mya's pain.

I titled this section *At home* for more than rhetorical reasons. True, I do wish to juxtapose and even compare how PT figures in(to) and out (of) the clinic, an effect facilitated by literary signposts. But I also want to unpack this phrase, particularly as it relates to the questions of access under consideration. In Chapter One, I described the questions that emerged for me during my first years as a clinician, questions to which I finally turned to anthropology for answers. Those questions were about the ‘what *else*’ that has been evoked in this chapter; specifically, what *else* female bodies encounter once they have left the clinical setting, once they go ‘home.’ In those days, I understood ‘home’ as an amorphous entity that included—in some loose order—the kinds of relationships a woman was in, her family traditions and demands, and perhaps her desensitized exposure to popular media. Immersion in anthropology and critical gender studies has sharpened and formalized, but not qualitatively changed, my definition of ‘home.’ I still want to know what happens *there* when the clinic is *here*. In the *here* that is OHSU, the physicians work hard to invest in, and attend to, their patient’s bodies; they make them present and promise not to abandon them. It is easy for me to now see, however, that even the most sensitive, feminist and activist healthcare is just one discursive fragment through which a woman comes to know her body. What are her other sources of knowledge, and where does she encounter them? What happens ‘at home’ and (how) can an anthropologist intervene?

For physicians in the clinic, the phrase ‘at home’ is code for sexual intercourse. When investigating the nature and extent of a patient’s pain, for example, they instruct her to point to the areas that have been most sensitive. Patients do not always understand their pain in anatomically specific terms, however, and so they are asked, instead, to indicate “where it hurts *at home*.” Drs. Erlich and Robichaud use liquid lidocaine—applying it in healthy layers to the vulvas and vestibules of symptomatic

women—to mitigate the pain of their speculum exams. In doing so, they call attention to the “numbing agent” they are using and tell her that they will write a prescription for a supply to be used *at home* (i.e., during attempts at coital penetration). This practice in itself is not problematic. Clinicians employ a variety of euphemisms in order to avoid offending their patients and, at times, are just being verbally creative. But for Mya and her fellow patients, *at home* takes on a new set of meanings—the kind that I wondered about during my days as a clinician, and the kind that cannot be remedied with the application of a topical anesthetic. If *at home* signifies what happens *there*—outside of the clinic and its genital attention—then treatment modalities need to go both deeper and farther. They need, in Cathy’s words, to “push the limits” of what medicine is expected to do if they are to alter women’s access to recovery from genital pain.

Mya told Dr. Erlich that she had been symptomatic for two years. In reality, her vulvar condition had been evaluated (as such) for about that long, but she told me in our interview that her pain started when she was twenty-two, ten years before her appointment at OHSU. Mya did not have VVS, and she had been able to participate in, and even enjoy, sexual intercourse for a number of years before the onset of her disease. Mya’s pain was more typical of vulvodynia, as she described pain both with and outside of contact and penetration. “It can happen when I’m doing the dishes. ... Sometimes it’s as if someone is stabbing me” is what she told Dr. Erlich and me at the beginning of her visit in December of 2004, two days before Christmas. Mya also provided a history of deeper *dyspareunia* (pain with coitus), but her description of this was vague. In terms of sexual disruption, she seemed to prioritize the symptoms that she described as “outside.” Unfortunately, “because of the way [she] was brought up,” Mya had serious difficulty communicating these symptoms to her physicians—the main reason why they were not

clinically evaluated for over seven years.⁸²

In other words, *at home* for Mya also meant growing up with a mother that was “like a 50’s mom, everything had to be so perfect,” a mother who told her as an adolescent that if she used menstrual tampons she would no longer be a virgin. Mya attributed her inability to accurately describe her pain to this familial history, repeatedly telling me that it was “how I grew up.” As I hope to be making increasingly clear through this dissertation, I believe that Mya’s assessment is only partially correct. Individualistic in its focus, her narrative casts the blame solely inward, as she takes personal responsibility for the third of her life that her genitals have been in unmitigated pain. Significantly for Mya, *at home* is also the place where she lives with her partner, a man who does not believe that her symptoms are real, and that has called her a “lunatic” on more than one occasion in relationship to her complaints of pain. Although my interest here is not in culpability, I nevertheless want to locate and hold accountable the numerous cultural locations that both enable and sustain this kind of self-blame, as well as this particular brand of silence. These are the sites where vulvar *dis-ease* takes virulent hold, making *at home* far less safe than our prescriptive advice needs it to be.

Fortunately for Mya, there was a physical therapist in her area who was learning how to work with vulvar pain, ameliorating the distance of the clinic with some structural support close to home. This lone practitioner, however, proved to be no match for the cultural contexts of scarcity, erasure and denial with which Mya’s genitals were so thoroughly perfused. Dr. Erlich tried her best, ensuring that someone existed in the patient’s area before she sent her away with little more than her bottle of lidocaine. She personally located the pamphlet for the practice and, seeing the therapist’s photo inside, asked Mya “See? Doesn’t she look like she could help you?” Mya was

⁸² This is a length of time just on the outside of average. Most patients are symptomatic for 5-7 years before they obtain an accurate diagnosis.

unenthusiastic—“not terribly charmed” according to my fieldnotes—and said only “What a thing to go to physical therapy for. ... Is this the only way it’s going to get better?”

As uncomfortable as it might be to admit, well-intentioned clinicians are particularly frustrated by patients who respond in this way, reluctant or unwilling to do what we believe to be in their best interests (Ehrenreich and English, 1973; 1979), particularly when they *claim* to want to get better. But requests for relief are acutely enmeshed in so many years of shame, confusion and bodily betrayal that they must be met with a level of care that both accepts and moves through this emotionally painful terrain. Mya’s recalcitrance is, I suggest, far from anomalous and is overdetermined by the factors under consideration in this dissertation. Her ultimate refusal to participate in physical therapy, once she got *home*, was a return to her familiar frames of isolation and genital shame. Not only could she not “even imagine” sharing her bodily experience with anyone but a physician, she also voiced concerns about the nature of a small town, and the consequent fears of public exposure that such a relationship would risk.

For reasons both explored and unexplored in our meetings, the boundaries of Mya’s bodily schema were fixed at her sexual partners and her doctors; they did not incorporate the hands of a physical therapist inside of her vagina (Schilder, 1950). I will not speculate on whether, like Nikki, Mya could have benefited from physical therapy if she would have “just relaxed;” such a question—individual in focus—does not take into account the cultural factors that limit women like Mya’s access to genital well-being. Mya’s reluctance to confront her pain at its anatomical source may make her a vexing patient, but we cannot ignore the cultural work that her hesitation performs. I want to return now to the Harvard School of Public Health study with which I introduced the dissertation in order to locate Mya’s behavior within one more layer of *dis-eased*

discourse. As we will see, the bodily reticence that constrains her recovery efforts is performed within a social habitus that effectively curtails matters of female sexuality, structuring what counts as *going too far*. In their reluctance to “push the limits” of their findings, the Harvard researchers reveal a complicity with the discourses of *inconsequence* in which Mya’s choice makes cultural sense. Mya, in other words, is taking her cues from the top.

I first learned about the Harvard study at the vulvar pain conference that I attended in Atlanta (see Chapter Four); it would be an understatement to say that my assumptions about the what *else* issues—through which I was analyzing these conditions—were sufficiently challenged by what I heard that day. Some of the data produced by Drs. Harlow and Stewart (2003)⁸³ were unsurprising—they were, for example, able to replicate what had been the only other general prevalence data that existed, i.e., the 19% demonstrated by Goetsch in 1991.⁸⁴ But other findings were far more confounding. Although still vague and embryonic, a clinical common-sense was beginning to take shape in the vulvar pain community around the time of the study’s publication, and two of its *less* precarious tenets were that the vast majority of vulvar pain sufferers were white/Anglo-American and that there was no connection between vulvar pain and any prior history of sexual trauma. The Harvard data threw both of

⁸³ Specifically, Elizabeth Stewart, author of *The V Book: A Doctor’s Guide to Complete Vulvovaginal Health*, the most thorough patient-centered resource about vulvar health that is currently available. A sizeable minority of my research informants (20-25%) had purchased or encountered this book in the years before their diagnoses. Dr. Stewart is a physician; Bernard Harlow an epidemiologist.

these beliefs into disarray by suggesting that: (1) “Hispanic women were 80% more likely than white women to have experienced chronic vulvar pain” (87); and (2) women with vulvar pain were more apt to report feeling (or having felt) less safe or supported *at home*.⁸⁵ Even more striking was their finding that women with vulvodynia were three to four times more likely (than asymptomatic women) to have experienced physical or sexual abuse in their lifetimes. I have reviewed the context of these findings in Chapter Four, including the fact that it was patients and their advocates—wary of the implications of a *psychosomatic* disease—that initially challenged the link between genital pain and sexual trauma. I reintroduce this conflicted history in order to examine links between epidemiological data and many of the concepts that I have introduced thus far—unwanted genital experience, safety, alienation, integration, and the bodily *home* made vulnerable by genital *dis-ease*. Because although the Harvard researchers *asked* women about feeling ‘safe and supported,’ their response to the data suggests a degree of dissonance between their professional safety, and that of their respondents.

To reiterate, the theoretical model of Vulvar Disease that I construct in this dissertation is in sync with Harvard’s findings—that an acknowledgment of the emotionally ‘unsafe’ backgrounds of vulvar pain patients must be a part of their care. As an anthropologist, I am insisting that we expand our understandings of ‘safety and support’ to include the routine and often hostile disparagement of female genitalia that infuses women’s symptomatic experience. In doing so, I am insinuating that all is not well in the world of female sexuality. As medical researchers, Harlow and Stewart are distinctly oriented towards these concepts, but their insights about vulvar pain were keen enough to keep these themes in dialogue with their demographic research. The problem, as we will see, is that in constraining ‘safety and support’ to a set of *individually-*

⁸⁵ Personal communication, Dr. Bernard Harlow. October 27, 2004.

inflected variables previously rejected by both patients and advocates (i.e., sexual abuse), their conclusions and behavior could not help but be circumscribed by discourses of *inconsequence* and erasure that do not acknowledge the collective experience of vulvar alienation.

“The rejection ... of a female imaginary,” says Luce Irigaray (1985*b*) “puts woman in the position of experiencing herself only fragmentarily, in the little-structured margins of a dominant ideology, as waste, or excess” (30). There is a critical tension, indeed an impossibility of existence, captured in these words—the fragments through which women are discursively experienced are, simultaneously, excessive rubbish. *Your labia, your desire, your stories of improper touching or fondling at the hands of your uncle, stepfather or boss; and yes, even your pain—these pieces of you are still too much.* This reality, particularly when conveyed through stories of sexual/genital victimization, is not only difficult to bear, but it is one with which so many institutions and discourses are complicit that we all want to look away—at one point or another—from what it might mean. Analyzing this diffuse and pervasive miasma as an independent variable poses significant challenges for researchers who are variously invested in restructuring this reality at social and political levels.

In surveying women about feelings of safety and support, the Harvard researchers successfully put women’s subjective experience back on the table, muddying waters that had only recently begun to run clear. To their credit, Harlow and Stewart were unwilling to completely close off a still ambiguous line of inquiry and, instead, located flexible interstices in what only looked like a settled issue. Adding the concepts of ‘safety and support’ to the already loaded categories of “physical and sexual abuse,” was an important move in expanding the contextual milieu of vulvar pain patients. To downplay the significance of this finding—this fragment of women’s experience—or,

worse, to leave it *out* of the published study would be more consonant with Irigaray's claim, and with the acts of genital erasure that I described more fully in Chapter One. But as it turns out, that is exactly what they did.

Not long after I returned from Atlanta, I accompanied Dr. Robichaud to the School of Nursing at OHSU where she was delivering a lecture about vulvar disease to graduate midwifery students. While the students filed in and took their seats and the professor got Dr. Robichaud's presentation up on the screen, she and I sat and talked in the front row of the classroom. I told her about Dr. Harlow's talk at the conference, and about how I was both excited and confused by the data. She nodded as she listened to me wrestle with what felt like almost scandalous assertions. Unable to read what appeared to be a very knowing silence, I blurted out "Well, what's going on? What are you guys *doing* with this?" Her response was blunt and collegial: "Nobody knows what to do with it," she said. "That's why we need people like you. To figure it out."

At the time of this conversation, I had not yet read the published paper, and I assumed that it contained all of the findings that Dr. Harlow shared with us at the conference. I hadn't even imagined that the 'safety and support' data were not significant enough to be included. In this scenario then, carrying out Dr. Robichaud's request—"figuring it out"—meant trying to make sense of some disruptive data; accounting for the discrepancies between apparently contradictory pieces of a vulvar pain patient's profile. Did 'race' need to be more strictly defined? Did definitions and/or terms regarding 'sexual abuse' need to be more efficiently standardized? Would analytical interventions like these bring the data back in line, or, equally important, illuminate previously hidden pieces of the puzzle?

(In regards to the 'racial' makeup of vulvar pain patients, my research at OHSU was consistent with the otherwise dominant discourse, i.e., only 2 of the 82 women that I

met at the clinic defined themselves as Latina, and one woman defined herself as South Asian. None were African-American, and the remainder of my informants were white/Anglo/Euro-American. Questions about the whiteness of these patients almost always point to issues of access, specifically of the politically-economic variety (Dressler et al, 2005). Rather than, or in addition to, the issues of emotional readiness and/or genital ‘availability’ that complicate many women’s ability to ‘access’ dedicated vulvar care, the well-known and racially marked disparities in U.S. healthcare distribution make it reasonable to assume that non-white women—who are often poorer—do not have *access* to the type of specialty care that would diagnose and manage vulvar disease conditions with greater efficiency and expertise. I provide a more thorough analysis of the demographics of these patients in Chapter Two, but what I want to reiterate is that the relationship between race, class and genital pain is far more complex than clinicians have thus far appreciated. OHSU, like most teaching hospitals, has a GYN “resident clinic,” where low-income and publicly insured women receive subsidized or free treatment in exchange for long waits and care provided by a physician-in-training. The fact that OHSU *itself* is the site of this expertise, and that some of the care in the resident clinic—where the population is more racially diverse—is provided by *exactly* the same residents that are also rotating through the vulvar clinic, render questions of access imminently more complicated. Added to this are the physicians’ and residents’ perceptions that vulvar pain is “white” while pelvic pain—the condition far more common in the resident (read indigent) clinic—is “black,” perceptions that they maintain are anecdotally supported.⁸⁶ These intriguing

⁸⁶ These observations are of special interest in the Pacific Northwest, an overwhelmingly white part of the country. African-American women are far more visible in these waiting rooms than almost anywhere else in the city or state.

contradictions are one more reason for the continued involvement of social scientists in the analysis of vulvar pain conditions.)

But the ‘race’ data, while demographically disruptive, nonetheless found their way into the published article. Indeed, an 80% greater likelihood of being symptomatic in a group of women still missing from the clinic(s), i.e., “Hispanic women,” was a finding that demanded further investigation. Explosive findings do not necessarily index breakaway thinking, however, and I suggest that the provenance of this particular result was far less radical than the counterintuitive thinking that produced the ‘safety and support’ data. That is, regardless of what previous studies have demonstrated, delineating the racial makeup of symptom and disease-bearers is a practice that reflects no more—or less—than the common-sense habitus of contemporary clinical researchers. Changing up the terminology, orientation, and possible meaning(s) behind less quantifiable concepts, however, reflects a fresh approach to established data. So why, after finding a new way to put a non-physiological—and decidedly loaded—variable back onto the analytical agenda, was it left out when it came time to publish?

My short answer, having not interviewed either of these researchers, is that I don’t know. My longer answer, however, is one that the reader of this dissertation can hopefully begin to sketch for her/himself. In collecting these phone surveys,⁸⁷ Harlow and Stewart pushed the limits of vulvar pain research and effectively resurrected the specter of emotional pasts that may, in fact, be linked to painful presents. Dr. Harlow, in his conference presentation (but again, not in the article) even hypothesized that early experiences of “support and safety” might be powerful enough to “override” the potential impact(s) of genital trauma at a young age.⁸⁸ But venturing into these pasts, I

⁸⁷ The second phase of this study is currently underway, during which a percentage of women whose phone interviews were positive for the presence of pain are being brought in for clinical assessment and confirmation of vulvar disease. See Chapter One for these criteria.

⁸⁸ Personal communication, 2004.

suggest, is a journey that threatens to reveal risk factors for vulvodynia and VVS that are generated by systems of the cultural kind, undermining medical interventions directed at nervous, immune and/or hormonal systems.

As I try to account for their decision, I picture these researchers grimacing as they analyze their findings: they asked some five thousand women from a large metropolitan area of the U.S. if they had always felt “safe and supported” at home, and women with (hetero)sexually prohibitive genital pain answered with a resounding “No.” When I think about their conversations, i.e., about what they were going to *do* with this data, I imagine a particular combination of enthusiasm, trepidation, and inchoate self-censorship, the kind that I experienced each time I helped to develop a medical history form that attempted to be as ‘wholistic’ as possible: We *have* to ask patients about substance abuse, we would all agree in our first meeting. Of course we *need* to include questions about domestic violence and sexually abusive pasts. We *know* that these situations have major impacts on our patients’ health and well-being. But in practice, we also knew that our hands were tied and our systems impotent to address any of these problems in a meaningful manner. Refer them to recovery meetings? Sure. Give them the phone number for the domestic violence hotline? Of course. And if we are fortunate to have a rape crisis center in our city that defines sexual assault broadly enough to include all of the variations that our devised question will undoubtedly evoke, give them that number too. And cross your fingers that they call.

In other words, questions of this nature index problems that are simply *too much*, as they brazenly point to not only the hopelessly inadequate social safety net that articulates with our practice(s) of healthcare in the U.S., but also to the tenacious prevalence of female sexual situations that are chronically disappointed at best, and endangered at worst. It is just too much. Too much time will be spent gathering the

painful details and there will be no treatment plan suitable to address them. Better not to ask at all. Or, as was the case at OHSU, leave the question on the form, but only address it if the patient brings it up herself. And move on to planning and prescribing the treatment: the one that transforms *unwanted genital experience* into a physiological condition; the one that is demonstrably and continually less-than-adequate, but that makes us all feel like we are doing something about it; and the one for the symptoms that will not go away until the totality of their existence is recognized.

PART II: TOO MUCH? OR 'A LOT MORE THAN I AM'

So, I ask myself, is this what my dissertation is trying to do—confront this “totality” of vulvar pain, in its cultural and historical context? I think so. Is vulvar pain simply the embodiment of a cultural distaste for the vulva, and for the excessive sexuality that its non-reproductive nature indexes? I’m a little less certain about this. Were Harlow and Stewart reluctant to fully embrace the results of their study because they exceeded the confines of medical discourse, because they were just *too much* to take on? Of that I am even less sure. Regardless of my ability to answer these questions with any degree of certainty, I pose them because they each address the themes of *integration* that orient this chapter: the fragmented and alienated spaces through which the vulva—in both material and discursive forms—is either accessed or ignored, including by women themselves.

“If it were my job to mathematically figure out which women despise more being called a cunt or having one, I’d be hating life,” writes Inga Muscio in her 1998 *manifesta* called *Cunt*. “I’m glad that is not my job,” (27) she tersely concludes. While I am happy to have taken up this task on Muscio’s behalf, I also remain vexed by the

apparent complicity of U.S. women in the disparaging erasures of their own genital bodies. Muscio imagines, and calls for, the linguistic and bodily rehabilitation of our *cunts* through individual and collective acts (boycotting male-produced film and literature) that transgress boundaries both private and public (tasting one's own menstrual blood, retaliating against alleged sexual assailants). I understand at least one of Muscio's goals to be in line with my own, i.e., a more integrated genital 'lived experience' for women who have been shamed out of one for too long. But Muscio's *cunt* is more—or at least differently—symbolic than the one under consideration here, and our strategies for such utopic incorporations are also divergent.

Rather than making the vulva (i.e. sexual woman) manifest through confrontational and/or separatist political activism, I am drawn, instead, to delineating and analyzing the practices, habits and discourses through which genital alienation is produced and sustained. Unlike Muscio, I am reluctant to prescribe remedies until I have made a more careful diagnosis. Muscio takes the sexual desires, confidence and rebellious potential of women for granted, inviting them to simply get on board with her "cuntlovin" revolution. I have argued thus far that vulvar pain patients—who index a sizable number of U.S. women with genital *dis-ease*—are often neither interested nor able to do anything of the kind, often explicitly longing for the day when their vulva can once again recede from any purposeful attention on their part. Extended relationships and interviews with these women complicate this 'refusal,' however, and often reveal snapshots of ambivalent and confused desires. The psychic (and culturally informed) distance felt by many women towards their sexual bodies can be both mitigated and intensified with the emergence of pain; the attention demanded by their symptoms adds dimension(s)—even if painful—to their previously missing genitalia. I believe that my interviews with these women are uniquely illuminating in that they were gathered from

within this space, one that is emotionally uncomfortable, to be sure, but that is infused with an inchoate sense of possibility.

Irigaray (1993) argues that woman has been “torn apart” at the hands of masculine culture and that “she has never regained her wholeness” (114-5). Reluctant though I am to project a ‘whole’ woman into a utopian past or alternate reality, the fragments and alienation that I describe in this chapter are my ethnographic evidence of the incompleteness of the contemporary female sexual body. But an interview that I conducted with Scout gave us both a glimpse of the faraway places from which a ‘whole’ female sexuality might be accessed. As we talked in her home one rainy afternoon, she described a time when she briefly, and consciously, occupied the kind of sexual razor’s edge that I am trying to theorize:

S: I can have multiple orgasms. And I remember one time that ... that I mean, I just ... he says that ... I must have had 20. But any[way]—who was counting (laughing), I don’t know. But anyway, it was ... I never forgot this moment because it was, I think sometimes, um, ... I wonder what ... *I hold back*. Because at that, that one experience for me was Sometimes it’s almost so pleasurable it’s painful and I don’t want to know *what else I can find out*. And that day, I didn’t care. And I was just amazed. So I know there’s a lot of potential and a lot of sensations, but with stress and with *whatever else* ... I ... I ... I **believe**, or, I don’t know. I question whether *I hold back*, ... and whether I could experience *a lot more than I am* ... and Because I did.⁸⁹
C: So what would happen ... If you had to make up what it is that you might be afraid of, or what you’re holding back from, what do you think it is?
S: I don’t know. I don’t know. That’s the most frustrating part.

Two years later, I still recall this exchange with crystal clarity. We were sitting at her dining room table and it was a cold winter day in Portland. Scout had a somewhat recalcitrant case of vulvodynia that was only moderately responsive to oral and topical medications, and that posed significant problems for her work as a security guard, where

⁸⁹ Italicized emphases are mine; bold is patient’s.

she spent a lot of time driving and sitting. She had been mildly reserved when I met her at the hospital, and had agreed to an interview more out of a desire to tell her difficult story than out of any kindness or goodwill she might have sensed from, or even towards, me. By the time we got to this point in the interview, however, we had covered a good deal of intimate ground. She described an upbringing not unlike Mya's, and she spoke plainly about the toll that increasingly baggy and shapeless clothing was taking on her sexual self. When she spoke the lines that I have excerpted above, I was completely caught up in her narrative. I *felt* a space opening up on the table between us and when I posed my question, I was almost whispering, attempting to convey adequate reverence for the story she was trying so valiantly to tell.

Scout's narrative demonstrates the tension—between holding it together and falling apart—that confrontation with this most personal and frightening of pains produces. Scout intensely remembers the pleasure of this moment at the same time that she knows she cannot access *even the idea* of what she suspects she might be missing. Segal (1994) suggests that in a culture influenced by masculinist psychoanalysis, “a woman cannot exist except in the shadow of the phallus, which is what makes her sexuality so enigmatic (132). She elaborates, addressing a “place of ‘not-being’” defined by Lacan:

‘There is a *jouissance* [extreme pleasure] proper to her of which she herself may know nothing, except that she experiences it—that much she does know.’ But the unknowable truth of women's surplus of pleasure cannot, it seems, belong to the human sphere, to the symbolic world of the hegemonic phallus. It cannot, therefore, provide a woman with any way of communicating her existence as an agent of her own desire (132)⁹⁰

⁹⁰ Segal is quoting Lacan at the start of this citation. See “God and the Jouissance of the Women,” in *Feminine Sexuality: Jacques Lacan and the Ecole Freudienne*, (J. Mitchell and J. Rose, Eds.). London: Macmillan. Citation is from p. 145.

I began this chapter claiming that I would explore the “content and context of the what *else*” that vulvar pain evokes. In this interview segment, Scout invokes this concept twice, wondering what *else* she might be able to experience sexually, and “whatever *else*” (in her life) hampers her ability to do so. Her reflection and analysis of “that one experience [that she] never forgot” shows us a what *else* that hovers precariously between the fragmented and vestigial extras, the “excessive rubbish” described by Irigaray, and the necessary-yet-unintegrated pieces of a woman’s sexuality. In the contemporary U.S., this latter connotation is virtually eclipsed by the routine deployment of the former. Teleologically constituted as *lack* rather than as unpredictable and generative *desire* (Grosz, 1995), ‘sexually active’ women infrequently wonder—outside of biomedical and/or masculinist sexual discourses (think *Cosmopolitan* and *Sex in the City*)—if they are, indeed, “a lot more than” they seem to be. Culturally available sexualities address questions of feeling *better* by either trying to fix what is allegedly broken, or by assisting women to procure as much penetrative sex as they choose.⁹¹ Potts (2002) argues that in “drawing upon [such] conventional masculinist ideas of ... sexuality, desire, and pleasures, ... [women] may still be missing any alterity that might be associated with a recognition of female ... desires which are different from—and not determined in relation to—those recognized pleasures of male ... heterosexuality” (208). Women with vulvar pain, in part through integrative physical therapy, have the opportunity to bypass both of these sets of interventions, and to explore what could be *better* in novel and productive ways.

⁹¹ This discourse is epitomized by certain varieties of in-home sex toy parties designed for, and popularly attended by, women throughout the past decade. The most recent one that I attended was oriented towards not only heterosexual women, but specifically, towards partnered/married women. The vibrators and toys for sale were described to attendees in terms of their ability to arouse (and, presumably, hold onto) their male partners, guaranteeing their continued access to penetrative coitus. One product—a warming and lubricating gel—was marketed specifically to be used on the “third or fourth night that you’ve been avoiding it,” in order to better tolerate a necessary capitulation to a husband’s desires.

I can't feel female: missing body images

In her essay "The Three Genders," Irigaray (1993) analyzes women's discursive sphere in reproductive terms:

[s]he has got lost in her role as mother, or else in a sexual display that does not really match her space of meeting and embracing. ... Woman's value has been equated solely with her capacity to bear and to nurture a son, and to the language that corresponds to that function. (179)

Though I echo many of Irigaray's assertions, I am less inclined to conflate maternal and heterosexual discourses, as I believe that feminism and its sequelae have effectively widened the gap between them. I am particularly less inclined to do so given the remarkable disinterest that many of the patients that I met had towards motherhood, particularly women with VVS.⁹² The task that she sets forth in this essay, however, of "discover[ing] and inhabit[ing] ... the morphology of a [female] sexual body" (180), is one that, were I to construct it, would be near the top of my prescriptive agenda. Irigaray insists that this morphology is "different" in the way that she understands the differences between the (two) sexes to be irreducible.⁹³ The angle of difference that I am more interested in delineating, however, is the kind invoked by Haraway's (1997) diffractive field, the kind that "allow[s one] to attempt to see from multiple standpoints ... [and that] can allow tensions to be held simultaneously (Clarke and Olesen, 1999: 5). I refrain, therefore, from neatly interpreting Scout's desire to know about an alleged potential from which she might be "hold[ing] back" as reflective of an essential, knowable and even recuperable sexual identity. Rather, I locate her experience within a

⁹² Though I did not pursue this thread in this phase of my research, it is interesting to interpret it through the ambivalence and (possible) refusals that these women might be expressing towards the sexualities available to them.

⁹³ See Chapter One for a lengthier discussion of Irigaray's "irreducible" sexual difference and the feminist debate over essentialism.

cascade of bodily possibilities, within what Potts (2002) refers to as “a proliferation of intensities over the libidinal surface, an ‘opening up’ of the senses to enjoy/participate in more than the visual or tactile—to spread over a diverse array of ‘sensations’ and ‘happenings’”(239).

Although I concur with Potts on this point, I do so with some reservation. Potts’ exuberant assertion is highly influenced by a group of primarily European theorists who might collectively be referred to as post-structuralist—Lyotard, Deleuze and Guattari, Lingis, Braidotti, Massumi, Gatens, and, to a lesser degree, Grosz—and it is complicated, I suggest, by the bodies of women with vulvar pain. Conceiving of bodies as assemblages, and as desiring-machines that surge with intensities and libidinal flows, these theorists “share ... a ‘utopian’ vision for the future, according to which corporeality, thought, and/or language are radically altered” (Potts, 2002: 232). Each, Potts continues,

is concerned with disrupting hegemonic structures by challenging the dichotomous thinking inherent in western metaphysics; each posits a radical revision of bodies as erotogenic (libidinal) surfaces which are the sites of cultural inscription; each rejects the inevitability of oedipalized (phallicized) sexuality, seeking to eliminate teleology from erotic relations. They valorize difference and multiplicity, and posit desire as affirmative, rather than constituted by lack. (232)

The work of these theorists is enormously bold, intellectually and sometimes politically challenging, and typically ungrounded by the frequently messy contradictions inherent in ‘real-world’ events. Like Potts, I understand these perspectives to be critically sound, and I cannot imagine theorizing extant and future sexualities (e.g., intersexed, transgendered, and surgically enhanced bodies) without their insightful guidance. Indeed, an earlier conception of this dissertation was far more engaged with their theoretical concepts, as they promised to more adequately elucidate the unique sexual identities of vulvar pain patients than did some of the more ‘conventional’ frameworks

on which I eventually settled. But my inclinations to read these women and couples—through their non-normative sexual behaviors—as queer, and to conceive of their lived genitals as libidinal flows, were consistently muddled by the desires and pleasures that were *actually* expressed by the women that I came to know. Indeed, a majority of these patients wanted little more than to have penile-vaginal penetrative intercourse with their husbands. They wanted, in other words, to be normal.

It is difficult to move on to a space of sexual alterity when sexual conformity has, thus far, eluded your best efforts. It is, perhaps, corporeally and psychically unthinkable to actively eschew normative heterosexuality when it has either been denied to, or snatched from, the desiring-machine that you inhabit. In other words, unable to ‘wholly’ incorporate heteronormativity, women with genital pain hold fast to the pieces that remain available to them. Near the very end of my fieldwork, Colleen came in to the clinic with a diagnosis of vulvar pre-cancer (VIN I)⁹⁴ that was acting a whole lot like vulvodynia. She had already had an excisional biopsy, a procedure meant to both remove and pathologically confirm a suspected malignancy of the skin. Colleen’s vulva was still very symptomatic after her surgery, however, and, prior to her appointment with Dr. Robichaud, her “case” had been passed around between several (male) physicians who could neither explain, nor manage, her persistent pain, redness and skin fissures. “It’s almost always raw,” she reported, and “there are times it looks swollen.”

Dr. R: What happens when you have sex?

C: It hurts.

Dr. Robichaud [asks if it is the same or different than her] everyday pain.

C: Certain parts of the pain are the same; he tries to go into the pain.

Dr. R: Are you able to have penetration?

⁹⁴ Vulvar Intraepithelial Neoplasia (“pre-cancer”), at the first level of abnormality. This disease condition, because of its malignant nature and potential, would typically be managed within oncology or gynecology and outside the confines of the Program in Vulvar Health (see Chapter Two). Unfortunately for Colleen, her clinical presentation blurred a lot of lines.

C: Well, it's been hard. And then I feel pressure up in here (points to belly).
Dr. R: Like something's pushing back?
C: agrees that this is how it feels.
Dr. R: Well, I'm going to have you participate in the exam. I'm going to have you show me. [She tells Colleen that the pain she describes is her] body trying to prevent penetration. [She then reviews what patient has told her so far:] So you have everyday skin pain, pain with sex at the skin, and pain with the muscles with penetration. Anything else?
C [says she is] more sensitive around [her] ... anus?
Dr. R: How is [sic] your heart and your soul and your spirit holding up? [Nothing for a few seconds. And then Colleen starts to cry.]
Dr. R: It seems like if I just opened up, you'd fall apart. You're so fragile. [My fieldnotes say: *This patient is really crying.*]
Dr. R: Yeah, it's been really hard.
C [describes a] battle [over] who would do [her] surgery [and that she had a lot of fear about the cancer diagnosis. Her] mom had vulvar cancer ... and died of pancreatic cancer. [Her] sister died of melanoma [and Colleen was about to have a very suspicious lesion excised from her leg.] But I [still] feel like a hypochondriac! But I can't ride a bike, I can't walk. And I'm a waitress!
Dr. R: How are things with your partner?
C: He's been great! (still crying a little). [But h]ow do you *feel like a woman*? I can't *feel female*!
Dr. R: Have you asked him how he's felt?
C: Well, he's more worried.
Dr. R [explains VIN once more.] It's not cancer.
C: Then how do we make it *better*? (all my emphases)

Colleen told us that her vulvar skin often cut and bled because it was so thin, and that two physicians had “made comments about the tissue being rice paper thin.” Dr. Robichaud was attuned to the clinical relevance and implications of this fact, but in this exchange she chose to use some of her interview time to assess the thinness and fragility of another part of Colleen's genital experience. Colleen, like many of the women I interviewed, struggled with how to “feel female” (Kaler, 2006) when she could not participate in the signature gesture of her heterosexual identity. “Feeling female” can be explored from innumerable angles, but within the framework of this chapter, I want us to think about Colleen's ‘falling apart’ during her visit with Dr. Robichaud in relationship

to the bodily and sexual disintegration that her pain had both catalyzed and, perhaps, begun to reveal. “Rather than looking to ... the presence of previous pathology ... to explain severity ... of symptoms[,]” argues Laura Brown (1995), “we might begin instead to ask how many layers of trauma are being peeled off by what appears to be only one ... event or process?” (110).

Pain like Colleen’s engenders a particular brand of corporeal alienation. It threatens bodily integrity because of “the way [it] enters into our midst [...] at once something that cannot be denied and something that cannot be confirmed” (Scarry, 1985: 13). What I am arguing in this dissertation, however, is that the genital isolation produced by pain’s role as “alien, ... intruder, [and] invader” (Jackson, 1995: 209) is layered on top of a deeper and far more pernicious breed of isolation and alienation. The absence and erasure of female non-reproductive genitalia from the social landscape effectively undermines womens’ ability to ‘have’ their bodies in *any* form of entirety—painful or otherwise. These erasures are unremarkable and routine, what Brown (1995) refers to as the “continuing background noise” (103) of women’s lived sexualities. The censorship of the vulva from ‘polite’ conversation, its discursive and material contamination in pornographic media, the utter *inconsequence* that results in the sanctioned cosmetic removal of labia deemed excessive and unsightly—these everyday practices pull the rug out from a genital integrity that is always-already precarious in a culture that remains hegemonically masculinist.

In theorizing the effects on all women of what some feminists have called a rape culture, Maria Root (1992) has developed the concept of “‘insidious trauma,’” which she defines as “the traumatogenic effects of oppression that are not necessarily overtly violent or threatening to bodily well-being at the given moment but that do violence to the soul and spirit” (in Brown, 1995: 107). Like Judy (see Chapter Four), Colleen’s

clinical encounters before she reached Dr. Robichaud were riddled with an affect perhaps best described as casual. Dr. Robichaud is exceptional in her attention to the “souls and spirits” of her patients, but Colleen’s story of being tossed like a hot potato between physicians for whom her symptoms were just *too much* reflects the kind of casual disregard for her genitalia through which it is possible to understand the emergence of cosmetic labiaplasty; the kind of *inconsequence* through which Judy could find her physician’s suggestion—to let her *lichen planus*-affected vulva remain fused—as even remotely reasonable. “‘Real’ trauma,” suggests Brown,

is often only that form of trauma in which the dominant group can participate as a victim rather than as the perpetrator or etiologist of the trauma. The private, secret, insidious traumas to which a feminist analysis draws attention are more often than not those events in which the dominant culture and its forms and institutions are expressed and perpetuated. (102)

Vulvar disregard is normative and, in Brown’s terms, “outside the range” of hegemonic definitions of trauma, as it cannot be experienced by (biologically) male bodies. Brown’s goal in her essay is to widen the experiential range against which “traumatic” events are measured in order to include the “experiences to which women accommodate; potentials for which women make room in their lives and their psyches” (101). Women in the U.S., I suggest, are not traumatized by the specter of vulvar pain; at least not yet. But, I suggest, they have more than “made room” for a reality in which their genitals matter little.

“[A]gnosia” writes Elizabeth Grosz (1994) “is the nonrecognition of a body part that should occupy a position within the body image. In traditional psychological and physiological terms, ... [it] is seen as a forgetfulness, a refusal or negative judgment” (89). Grosz contrasts agnosia with the more familiar phenomenon of a phantom limb, i.e., sensations and pain that persist in the space of a surgical amputation. Her descriptions of these neuropsychological states are situated within a larger discussion of

“corporeal phenomenology,” (86) specifically the work of Merleau-Ponty, and she points out that Merleau-Ponty understood *both* phantom limb and agnosia to “demonstrate a fundamental ambivalence on the part of the subject,” as, in the case of the phantom limb, “actions which the arm, say, would or could have performed are still retained as possible actions for the subject” (89). While I have no trouble recognizing the ambivalence in both of these conditions, I would not use it to conflate the two, even symbolically, as Grosz suggests that Merleau-Ponty has done. Because it is the *potential for action*, retained by the (amputated) phantom limb that, I argue, is most seriously compromised in the case of Vulvar Disease. Constructed and beheld by discourses of disavowal, women with vulvas—pain-full or not—live out a deep and diffuse genital agnosia that stifles and paralyzes their ability to ‘have’ their genitals in meaningful ways.

The neuropsychological agnosia considered by Merleau-Ponty and Sacks (1987) is one that is typically associated with physiological anomalies, such as brain or CNS lesions, and I recognize the important distinctions between these conditions and the affective vulvar agnosia that I am proposing here. But, as Grosz also makes plain, both of these corporeal phenomena are bound up within the *body image*, a postural and proprioceptive map, or “schema,” that “registers current sensations[,] ... preserves a record of past impressions and experiences[, and] ... is formed out of the various modes of contact the subject has with its environment through its actions in the world” (66-7). In this sense, she argues, “the body schema is an anticipatory plan of (future) action in which a knowledge of the body’s current position and *capacities for action* must be registered” (67; my emphasis). The body image—overdetermined by a combination of physical, cultural and intersubjective experiences—is multiply-informed, continually produced and invested, and susceptible to the dominant cultural norms that at least

partially determine its social value (Schilder, 1950). This profoundly cultural product, therefore, can help us to make critical distinctions between the kinds of “ambivalence” expressed in the two conditions under consideration; that is, different bodies, and different *body parts* are endowed with different types and amounts of cultural capital (White, 199?).

Feminist analysis requires an attention to the gendered aspects of these differences in *body image* and *capacity for action*. For Brown (1995), it “illuminat[es] the realities of women’s lives, turn[ing] a spotlight on the subtle manifestations of [lived difference], allow[ing] us to see the hidden sharp edges and secret leghold traps, whose scars we have borne or might find ourselves bearing” (108). For Grosz, it is the physical realities of “sexuate difference” (Irigaray, 2004) that must not be neglected in our analysis of these body-maps:

it seems incontestable that the type of genitals and secondary sexual characteristics one has (or will have) must play a major role in the type of body image one has and that the type of self-conception one has is directly linked to the social meaning and value of the sexed body (1994: 58).

The words of Brown and Grosz each explicate the long-held feminist tenet that women are culturally constructed as lack, as missing, and as damaged, and that this social fact has long-influenced women’s unique way(s) of being-in-the-world. The point I want to make is both smaller and more complex. While I could not agree with either of these theorists more (nor could I argue with greater clarity), I want to extend my feminist-corporeal analysis to the specific social meanings through which the vulva is experienced. That is, the vulva—through the sustained, routine, and unquestioned deployment of censorship and shame, takes on a unique dimension of bodily absence. Missing even from a recent explosion in “vaginal” popular culture (Muscio, 1998; Ensler, 2001), still *too much* for the masses, the morphology of the vulva is constructed

by collective disavowal and absorbed by individual bodies (Turner, 1994). I suggest that Colleen's pain, and the pleasure that it proscribes, is deemed excessive by cultural institutions and actors that would prefer not to be troubled by what paying adequate attention will undoubtedly uncover.

I would have picked a different symptom: vulvar dys-appearances

Some of these bodies, confronted with inexplicable and sexually prohibitive pain, are compelled to "take action" in the service of locating relief. The title of this dissertation alludes to the linguistically compromised ability of (symptomatic) women to do so; the argument that I am developing in these pages is an attempt to flesh out those restrictions, to appropriately implicate the cultural "forms and institutions" that are impressed into and contour the female genital body image, and that inform the behavioral self-censorship that is inextricably linked with this verbal diffidence. How does one come to take individual action on behalf of a body part that is collectively and conspiratorially ignored? How, and where, does one identify and locate the bodily source of one's pain if that source did not meaningfully exist until it began to hurt? How does one attribute corporeal agency—even if only a pain-filled one—to genitals from which nothing has ever been asked or expected?

Better to clarify: asked, perhaps not; but expected? Absolutely. Vulvar agnosia is convoluted by the investment that others hold in labial stability, in the seamless and silent role they normally play in vaginal penetration. In an interview over lunch at Denny's, I asked Ashley about where vulvar discourse might most appropriately belong:

A: Sex ed. I mean, you know, if they're gonna teach about all, everything else, then they really need to teach about that. And, in a way, excluding that, makes it ... off-limits. Something *we* don't talk about. We certainly talk about penises

enough. Anything that a guy might get wrong with *them*, we all know all about. You know, I can't think of anything that we haven't ... But, if it goes wrong with a woman, that's just not acceptable.

C: How much do female genitals matter?

A: Well, as long as they're *useable*, I don't think they care much (laughs). Um, I think if they're **not**, I think you'd be hard pressed to find a date for the prom! (laughs). (*italic emphases mine*)⁹⁵.

Irigaray (1992) transforms this silent and “useable” flesh into abundant and contiguous lips that offer women the pleasures and integrity of “self-affection.”⁹⁶ In resignifying female genital lack as a proliferative body that “goes on touching itself indefinitely, from the inside” (15) Irigaray makes the vulva active, generative and multiple. The masculinist ideologies that dominate the practices of heterosexuality and medicine, however, do not have room for these dynamic lips. For (male) partners and (most) physicians, it works best if the vulva quietly recedes, much like the visceral organs and physiological systems described by Leder (1990). In *The Absent Body*, Leder phenomenologically elucidates these unquestioned recessions, suggesting that “these movements are not experienced as within the ‘I can’ of personal mastery. I do not feel a sense of guiding or controlling these processes” (46). The vulva, however, is not an internal organ and therefore need never recede from a woman’s conscious awareness of her surface anatomy. But for symptomatic women, their difficulty in delineating the specifics of “down there” index a maladaptive *dys*-appearance (Leder, 1990), an alienation simultaneously marked by a culturally sanctioned transfer of ownership. Increasingly aware of the integral role in their husband’s sexual satisfaction played by a

⁹⁵ I asked Ashley to elaborate on what would make a woman un-useable, and she told me about a friend she knew who had “lost her vagina” to cancer, presumably through pelvic/genital irradiation. This notion of Ashley’s is an important one, and one through which we can consider how the sexualities of paraplegic men and women are distinctly configured and represented, e.g. in popular media. Can a receptacle, a ‘hole,’ ever be rendered impotent, even through paralysis?

⁹⁶ Personal communication, Luce Irigaray. May 24, 2005.

well-behaved vulva, clinic patients often spoke of their appointments in terms of *his* frustrated investment, i.e. “I wouldn’t even be here if it wasn’t for him,” and “This wouldn’t bother me at all if I wasn’t married.” Similarly conscious of their doctor’s interest in compliant genitalia, they repeatedly apologized for their lack of formal knowledge, as well as for their compromised ability to tolerate routine gynecological attention.⁹⁷

Precariously owned and minimally recognized, the *underintegrated* genitals of symptomatic women make themselves manifest, rupturing the silent seamlessness through which they have thus far been lived. But the stories that I heard in Oregon also suggest that discourses of *inconsequence* and erasure are powerful enough to stanch the effects of these eruptions. Describing the pain generated by their vulvas to ears that are culturally unavailable (“Well, you’ve got lube, so you’re fine”), annually insisting that things are sexually “not right,” and being met with the examined opinion of their gynecologist(s) that there is simply “nothing wrong with [them],” and cajoled by ‘normal’ friends that they should just “move through the pain,” clinic patients are as psychically disrupted as an amputee with the first tingling sensations of a phantom limb, wondering if they are “crazy” to feel something (where) they are evidently not supposed to.

Ten-plus years of specializing in these syndromes have not been wasted on the clinic physicians and their approaches to these women are fiercely and preemptively sympathetic—“*I believe you. Your pain is real.*” But centuries of hysterically and misogynistically-informed medicine have done their cultural work, and the bodily confidence of contemporarily afflicted women is riddled with insecurities. Rosemary, who, at 82, was the oldest woman I met during my fieldwork, greeted Dr. Erlich with

⁹⁷ To be very clear, these apologies are cut short by the physicians and other staff at the clinic.

tremendous clarity, stating simply “I heard about the vulvar clinic and [I] thought you might be able to tell me what’s wrong” As Dr. Erlich gathered the specifics of her symptoms, however (which included a “fairly sexually active” 81 year-old husband), Rosemary felt the need to self-consciously—and humorously—address the assumptions that she feared were being made about her. “I feel a little embarrassed,” she said, “[because] I know you’re really busy. [But this i]s really not in my head. I’m not a hypochondriac. If I was, I would pick a different symptom.”

The cultural dynamics at play in this particular brand of ‘craziness’ are clearly gender-specific, and, thanks to critical feminist accounts of hypochondria and hysteria (Ehrenreich, 1973, 1979; Irigaray, 1985a; Chisholm, 1994; de Marneffe, 1996; Maines, 1999), easily grasped by all but the most obstinate and/or masculinist of analysts. I want to reiterate, however, that *gender* theory alone—however critical—does not attend to the totality of Vulvar Disease. In her introduction to *Psychosomatic: Feminism and the Neurological Body* (2004), Wilson argues that the analytical implications of many feminist—and otherwise splendid—accounts of hysteria are attenuated by what she refers to as a “retreat from biology.” (5) She argues, therefore, that “the particularities of the muscles, nerves, and organs in their hysterical state have remained underexamined and some of the more remarkable questions about hysteria remain unasked”:

The ... question of the body has yet to be posed as comprehensively as it could be. It seems to me that the neurology, physiology, or biochemistry of hysteri[a] ... can be disregarded only in a theoretical milieu that takes biology to be inert ... [and that] still presumes that the microstructure of the body does not contribute to the play of condensation, displacement and deferred action that is now so routinely attributed to culture, signification, or sociality. Though the body may be the locale of these intricate operations, biology itself is rarely considered to be a source of such accomplishment. (5)

In thinking about the ‘real’ bodily experience(s) of U.S. women, women who are insidiously traumatized by lifetimes of genital “condensation, displacement and deferred

action,” we must attend, therefore, not only to the discursive implications of their amplified vulvas—the “body politic” that Scheper-Hughes and Lock described twenty years ago (1987)—but also to the flesh-and-blood instantiation of genital *in*consequence. We must, as Fausto-Sterling (2005) has suggested, consider “what it might mean to claim that our bodies physically imbibe culture” (1495). In the years that I practiced, I saw and “managed” hundreds of women whose sexual bodies reflected the genital agnosia that I suggest is culturally hegemonic. From an inability to remove a forgotten tampon because of not knowing that their vagina was no longer than their middle finger (risking serious bacterial infections, such as toxic shock syndrome), to being actively averse to contraceptive methods that required genital contact or manipulation, women repeatedly revealed their preference to just not *deal with* their genital bodies. I argue that there is nothing remotely natural about this reluctance; indeed, its practice reflects no more than its place in a “universe of possible alternatives” (Bourdieu, 1984: 4) structured by the lived reality of genital alienation.

PART III: TOWARD A VULVAR-BASED SEXUALITY? ASKING NEW QUESTIONS

Following Wilson’s lead, and asking different questions than those framed by a feminism “foreclos[ing]” (8) on biology, I understand these two kinds of patients to index two levels of agnosia in concert with a dynamically physical body. The forgotten tampon, like an unrecognized sexually transmitted disease or the early symptoms of vulvar cancer, reminds us that genital alienation can, indeed, have permanent bodily consequences, that it can *turn into* the kinds of “scars” that Brown suggests are particular to women. The second patient “figure” that I invoke, whose contraceptive choice does not necessarily presage a greater risk for bodily harm, participates

nonetheless in the partial (and routine) excision of her vulva; in this case from the practice of penetrative intercourse. I suggest that even this partial excision is worth attending to, as it articulates with numerous and cumulative other sites of cultural erasure. Indeed, I hope to be making clear in these pages that in order to address these symptoms, we must understand that these cultural excisions are not purely symbolic or indexical, but that they ‘show up’ in the “muscles, nerves, and organs” of the bodies vulnerable to their effects.

Echoing Eve Ensler (2001), I’m “worried about” (3) vulvas. I’m worried about the very complicated disappearing act in which U.S. women appear to have them engaged, as it neither lends itself to any kind of female-centered genitality, nor does it benignly skim the surfaces of the bodies in question. Rather, genital alienation has a depth and tenacity that invites questions and interventions that presume a body deeply immersed in, and physically obliged to, its cultural milieu. Such a perspective allows us to think critically about what is physically *present* in a body part rendered *absent* at every turn.

This absence pervades the female sexual *body image* and severely restricts womens’ abilities to *generate* desire and sexuality on their own terms. The phrase “feel[ing] female” with which Colleen was clearly struggling, was an issue that arose repeatedly in my interviews. I asked my respondents how much of their sexuality they believed to be bound up with—or defined by—their genitalia. They often answered much like Brigitte who, over breakfast one late morning, responded:

As a woman? Oh, I’d say probably like 95%. I mean, it’s a *huuuuge* part, especially in society nowadays. I mean (long pause) yeah, I’d say it’s a large part of being a woman.

Brigitte also told me that sex with her current partner was often disrupted by her pain, but that this did not cause an inordinate amount of conflict between them. Her previous

partner, however, with whom she was involved during the onset of her symptoms, “didn’t have a clue” what she was talking about when she initially broached the subject, and so she kept the severity of her symptoms from him for the remainder of their relationship. Although Brigitte’s current partner, who joined us for the interview, was as “curious” as she was about her/the body (he was pursuing a career as a mortician after having grown up in a family business), and although they both “like[d] having sex a *lot*,” Brigitte continued to circumscribe her symptoms with the standard of penetrative intercourse. Her discomfort, she said, “didn’t really matter” outside of a (hetero)sexually active relationship. This was in spite of the fact that “you can’t study in school when you’re feeling all ... like, you know ... in pain or itchy or whatever,” and that she had had “about seven biopsies” thus far on her vulvar skin.

What I want to stress with Brigitte’s very typical situation, and with her perspective on the symbolic value of her genitals, is that what is missing from her account is the kind of (female) carnality that Povinelli (2006) alludes to, the “mattering forth” (7) of an integrated body that speaks both from and for itself. Absent genitals of one’s own, sexual identity is most sensibly defined through the terms of the Other; having penetrative intercourse (ever or once again) promises the closest thing to “fee[ing] female” that many heterosexual women have experienced. ShortRound, whose *lichen planus* was bringing up extreme dissatisfaction with the way her husband normally did things, expressed it this way:

SR: I think if I weren’t in a relationship, I think I could become very dist-, distant with this ... thing right now, and just say ‘well ...’

C: And maybe not be doing the dilator therapy?

SR: Right mm-hmm. Kind of .. distance myself from that, the sexual part of myself, and say ‘oh well’! (laughs))

As I suggested above, relinquishing the desire for normative intercourse is, perhaps, a step that bodies alienated by pain or agnosia are not quite ready to take. In a *body image* that is neurologically and psychologically absent a substantial portion of its “sexual self” (Ogden, 1999), the capacity to act in a generative manner is severely restricted. Feminists attempting to ‘queer’ female heterosexuality—including Grosz, Braidotti, Muscio and Potts—have thus far underestimated the inscriptive and infiltrative power that *dis-eased* cultural discourses wield over the process of genital integration, and have overestimated the freedom and *capacity for action* sustained by agnosiac bodies.

To be sure, women in ‘Western’ influenced cultures and locales are the undisputed beneficiaries of civil rights, feminist, and sexual revolutions that brought matters of the sexual body to the political and discursive tables, and they enjoy the sexual liberties that accompany such profound transfers of knowledge. Indeed, popular and alternative media are a proliferation of (hetero)sexually *active* female bodies that, in Lynn Segal’s words, “have everything to gain from asserting [their] non-coercive desire to fuck if, when, how, and as [they] choose” (1994: 314). While I applaud Segal’s enthusiasm, my encounters with female patients—whether as nurse practitioner or anthropologist—resonate more profoundly with Merri Lee Johnson (2002), who insists instead that “while feminism may have freed women to fuck, the fuck—and the ‘role of the fuck in controlling women’—has in many ways stayed the same” (23).⁹⁸ Ethnographic attention to the desires and proclivities of women with vulvodynia and VVS—bodies that are behaviorally queered and/or empowered (by pain) to refuse heteronormative penetration—reveals, instead, that feminists have not fully acknowledged the bodily integrity upon which an authentic, female-driven set of sexual choices ultimately needs to rest.

⁹⁸ Johnson’s citation is from Dworkin (1987: 72).

In their ongoing research on first intercourse among teens in the U.K., Holland et. al. (1998) have been led to similar conclusions, i.e., that apparent complicity with contemporarily available sexualities does not necessarily reflect an achieved sexual parity between heterosexual women and men. Even women who refuse male-centered intercourse for reasons other than prohibitive pain are, according to their analyses, “trapped in their resistance, finding it easier to disrupt male definitions of desire and natural dominance than to *produce female desire itself*.’ “ (in Potts, p. 208; my emphasis). In “The Three Genders,” Irigaray foreshadows this lament: “As for woman,” she notes, “her moves as a lover have still to be invented” (1993: 179). I will return to the production of desire in the next chapter, *Generation*, but for now I want to highlight the disjointed and unintegrated aspects of this sexual state of affairs. And I want to suggest that vulvar and genital agnosia—discursive *and* material—are at the heart of this disability.

In our extended interview, Brigitte drew parallels between the socially awkward natures of her vulvodynia and the (also transgressive) “manic-depressi[on]” with which she was diagnosed in her early teens (she was 20 when we met). Although Brigitte said that she talked openly with friends about her bipolar disorder,⁹⁹ which was well-controlled, she had a greater reluctance to discuss the genital symptoms that occupied far more of her time and attention. When I asked her to elaborate on this, she said “Why don’t I talk about it? I don’t know. It just usually doesn’t even come up in conversation.” Brigitte herself was nonchalant about this disparity; indeed, it worked in the immediate sense for her because she predicted—about her friends—that “*they’d* probably be uncomfortable” if she brought it up. The lingering and linguistic absence of Brigitte’s vulva—in pain or not—from conversations with friends indexes the reticent

⁹⁹ For an insightful analysis of bipolar disorder in the contemporary U.S., see Martin, 2007.

and contaminating habitus in which the female sexual body exists. This absence seems particularly acute given the fact that Brigitte talks openly about “just having sex or whatever” with these same friends.¹⁰⁰

On my prompt, Brigitte elaborated the differences and similarities between her experience of these two diagnoses. First stating that she understood her bipolar disorder to carry a “worse stigma” than her vulvar pain, she complicated this comparison by reflecting that they both led her to feel—at times, and differently—“out of control”:

They are very similar. It’s like, if I were to compare any two parts of my life, I wouldn’t compare, like, you know, mental health problems to like, arthritis, but I would sa--, I would compare these. They are very similar stigmas.

For Bourdieu (1984), Brigitte’s lack of concern or frustration over this routine (self)-censorship is a predictable consequence of structured and structuring relations of power and is powerful evidence of an arbitrary linguistic proscription that has been naturalized. In other words, simply because something ‘goes without saying’ does not suggest in any way that it does not register a sensible impact:

These experiences *do not have to be felt in order to be understood* with an understanding which may owe nothing to lived experience The habitus, an objective relationship between two objectivities, enables an intelligible and necessary relation to be established between practices and a situation, the meaning of which is produced by the habitus through categories of perception and appreciation that are themselves produced by an observable social condition (101; my emphasis).

Brigitte knows that the topic of her diseased vulva would, in all likelihood make her friends “uncomfortable,” without ever having to check this out conversationally. What is most critical to notice about this observation, however, is that it is *only* her pain that would have made her consider bringing her genitals up at all. Ever. Without pain to

¹⁰⁰ The absence of the vulva from discussions of sex was nicely captured in Dr. Robichaud’s observation that you “can’t do vulvar work without talking about sex,” but that you *can* do other sexual/gynecological work (contraception, obstetrics, STD diagnosis and treatment) without having to ever discuss the vulva. See Chapter Two for a more complete version of this anecdote.

animate them, female external genitalia remain lifeless, in relationship with the social conditions of repression and invisibility that this dissertation hopes to be making increasingly observable.

That kind of sex: complicating erotic imaginaries

In theorizing female sexual desire, then, we must account for the disintegrated, silent, and agnosiac bodies that index Vulvar Disease. The erotic imaginaries of the poststructural theorists described above (see p. 263-4) must reconcile the surface and extra-genital sexualities that they posit with the lived experience(s) of women who have not (yet) participated in heterosexuality's most normative event. The patients that I met through the clinic conveyed this reality clearly and convincingly; even I, who had gone to the field convinced that vulvar disease was the embodied opportunity to 'move on' from masculinist penetrative coitus, found myself, instead, rooting for the success of their surgical, pharmacological or homeopathic efforts towards having the kind of sex that mattered to them. Isabelle, who had been symptomatic for four years when she flew from Atlanta to consult with Dr. Erlich for her VVS, and who had not yet "consummated" her marriage of three years, was particularly articulate about the meaning that penetrative sex held for her:

I: I think I've always kind of associated, uh, vaginal intercourse with, um, a more spiritual connection, you know? And I think that's one thing that ... not, it's not all about [the] physical, but it's more um, you know, just

C: Can you tell me more about that?

I: Yeah, well um, I think it comes from uh, my ... my faith, um, mainly. Uh you know, just, um, I think (of course since I've never had sex I don't know), but there's just, uh, the emphasis that, uh, Scripture puts on ... sex, you know, um, uh ...

C: On *that* kind of sex.

I: Yeah, *that* kind of sex. Um, that, uh, you know, even if, really, kind of, the way I've, ... my philosophy or whatever is that even couples who are not

married, who um, who have ... intercourse, are kind of joined, you know? And so, um, that's kind of just uh, ... [the] way I think of it. More sacred. Not necessarily better or anything, just, uh ... uh ... *the most intimate*, I think, um, way that a man and a woman can be joined.

C: And something that you still very much want.

I: Yeah.

C: When you think about being able to do that with your husband, what is, I mean How, what is it like to think about finally being able to do that?

I: Yeah, it, I think just uh, just relief. And, uh, you know, I think ... a physical closeness we've ... not been able to have, uh, you know. We're very intimate, very open, and, uh, have fun. I mean, we're creative and so it's not that, uh, I mean, even if we never could, it wouldn't um ... uh ... you know, we have a ... it's not that I feel like we don't have a real marriage, but um Uh ... it would be something missing. I can't, you know I won't say that I wouldn't feel that way, but uh But, [it's] just because I think it's, that's the way we're created to be, as man and wife. Ultimately.

When I asked Isabelle if her ideas about intercourse as a sacred joining were related to beliefs about conception and reproduction, she unsettled some of my own assumptions by thoughtfully responding “To be honest, I really don’t think I want children, so I definitely don’t associate it.” For Isabelle, then, the practice of penile-vaginal intercourse indexed neither a naïve adoption of cultural norms, nor a rote submission to the masculinist-procreative prescriptions of a conservative religion. Rather, being able to have “that kind of sex” was deeply symbolic of the spiritual commitment that she and her husband had made to each other with their marriage, something from which she would, perhaps, not ever be interested in completely ‘moving on.’ As a feminist, I understand much of Christianity’s organized rhetoric to reify and perpetuate a marriage-intercourse-heterosexuality matrix that subordinates women followers; that, in Susan Harding’s words, “speak[s it]sel[f] through a submerged display of asymmetrical gender meanings” (2000: 189). Isabelle’s narrative, however, challenges my thinking about how these discourses articulate with individual desire, and reminds me that the apparently simple *practice* of normative behavior most often

reflects complex negotiations between the “three bodies” under consideration here—individual, social and political (Scheper-Hughes and Lock, 1987). Regardless, then, of my own politics about Christianity’s relationship to female sexuality, and of our disparate ideas about the definition(s) of “real sex,” women like Isabelle—doubly alienated from their genitals (through pain and erasure)—showed me that owning heteronormativity was a prerequisite to giving it away.

In the contemporary U.S., “the fuck” is the most direct route to the cultural capital promised and enjoyed by members of dominant (i.e., straight) society. Critical feminists like Segal, Grosz and Potts must acknowledge that refusing or displacing it on ideological grounds is an act that fully depends on the privileged ability to first accept it. If the “goal of change,” argues Teresa Ebert, is “the removal of all restrictions, all limits on the *play* and *pleasures* of sexual differences” (1996: 163; emphasis in original), then we must attend to the totality of these possible differences, as well as to their material bases. Ebert continues, partially citing Drucilla Cornell (1991):

Such moves may seem liberating at first until we notice that this ‘new choreography of sexual difference’ and desire posits difference and a going beyond quite ahistorically. There is no accounting here of how difference was materially instituted to begin with and how it forms the historical matrix of our lives (163-4).

For Ebert, materiality is characterized not corporeally, but rather, in terms of economy, class and labor; in her words, it is about “the struggle to emancipate women from exploitative relations of production” (164). My analysis is obviously situated elsewhere, and Ebert’s objections to the group of theorists that she labels “ludic” are harsher and more strident than are mine, but her critique is useful in its attention to what gets *left out* in radical reorganizations of sexuality. While Ebert insists that ludic feminists reinscribe their theories with the historical facts of womens’ relationship to capitalist expansion, I focus my efforts on the extant bodily differences *among* women (Mohanty, 1991). This

means cautioning poststructural sexual theorists that if calls to “enact the erotic in politically alternative ways” (Potts, 2002: 255) are framed through a feminist lens, then those “alternatives” can neither exclude my informants nor any other woman uniquely marginalized from the routine enjoyment of sexual normativity.

Indeed, symptomatic women are strangely situated with regards to the politics of dominant heterosexuality: with access to its practices proscribed by pain, the discursive privileges associated with those practices slip more and more easily through their fingers. The cultural cues that index a bodily familiarity with conventional coitus are less available, compounding their shame-based isolation with the experience of being chronically *out of the loop*. The formation of a resistant (and potentially empowered) subculture, however, is also unavailable, as the majority of these women are ideologically aligned with this same dominant sphere (Hebdige, 1979). The discursive transpositions implicit in the ‘queering’ of heterosexuality seriously belie the distinct experiential worlds in which dominant and subordinate bodies exist. Without ever having identified a need to do so, few of these women have cultivated resources that could engender radical—and potentially liberating—sexual subjectivities.

The danger of being in the majority, of your life being positioned in the mainstream, is that your ill-fit—*your non-integration*—can be easily disguised from your peers. When conversations with other women turn to (hetero)sexual matters, for example, patients find themselves profoundly alienated and sometimes “freaked ... out,” in Isabelle’s words. Clair, another religiously and sexually conservative Christian with VVS, refused to pursue physical therapy, stating that it “just didn’t feel like ... it was, it was *too much*. It was just too much ... intimacy with another woman (her emphasis).” She was, however, emotionally and spiritually intimate with women friends and

members of her church, but she found that she could not access all of the aspects of these friendships:

Um, ... I teach seminars and workshops on friendship, so I'm really very .. um, I, I know the extent of women having relationships and friendships is really important. But yet, .. when a group of women are sittin' around and one of 'em says 'oh my gosh we have the best sex,' this wall goes up and I think 'I can't relate to you.' And yet, ... it's also there's that embarrassment, there's that 'oh, if they only knew that I haven't had sex in 5 years', they'd say 'oh you poor thing,' you know. *That*, I think, that may be, um ... maybe that's a part of it. Not that I have a lot of women that do that, but .., but I *envy* that. When I hear other women talking, there's this, and I go home thinking, 'Uh, gosh I envy that.'

Isabelle and, particularly, Clair poignantly narrate a subjective reality shared not only with their fellow patients, but with any number of women whose exposure to *Cosmopolitan* magazine, *Sex and the City*, or even *nerve.com*, leaves them feeling as if they are sexually missing out on something. Women with chronic and disruptive vulvar pain, however, are estranged from both ends of the ideological spectrum in distinct and peculiar ways. Falling through a host of cultural cracks, their integration into the (hetero)sexual world(s) around them remains as fragile as their vulvar and vestibular tissue.

Critical juxtapositions

The grinding halt to which symptomatic women's lives are often forced to come can, in the best of scenarios, function as a kind of doormat, one that occupies the threshold between bodily and social alienation and a thus far unrealized corporeal *home*. Having to put their sexual desire(s) on hold allows these women the opportunity to critically examine the assumptions and hierarchies around which their desires might otherwise be organized, to question what *else* might structure or inform the sex they hope to eventually enjoy. A 'successful' transition over this threshold is dependent on a

set of factors linked with the “three bodies” we have already considered—specifically, on their ability to meaningfully cohere. These include, at a minimum: recognizing the abnormality of symptoms; locating a knowledgeable provider; having the resources to obtain services (e.g., insurance, transportation, time); trusting the provider and reporting an adequately detailed medical history; being in at least one supportive relationship; having the discipline to comply with complicated treatment regimens and the physical ability to tolerate them; balancing a combination of providers and therapies; and accepting the possibility that some pain will always remain.

In my experience at the clinic, I observed more than 70 women grapple with some combination of these facets of their disease. All are faced in many other chronic pain conditions, of course, but vulvar pain is peculiar in that the presence of its comorbid condition—pelvic floor *myalgia*—is directly related to the ways that a woman has thus far coped with her symptoms. Given the negative symbolic value of her genitals and their suffering, this coping has almost always involved hiding, repressing and/or censoring her condition from all but the most invested of actors, i.e., an attentive provider and a supportive partner, relative and/or friend. Pain in the muscles of the pelvic floor comes from guarding and contracting those muscles; *myalgia*, therefore, is at least partially an epiphenomenon of the cumulative effects of Vulvar Disease: the embarrassment, the “hypersensitivity” of nerve pathways, the transgressive nature of the symptomatic body part, and years of fear and apprehension towards sex and sexual desire—yours and your husband’s.

In my discussion of the enteric nervous system (ENS) and Elizabeth Wilson’s (2004) reworking of Freud (in Chapter Four), I asked

what happens when we critically juxtapose a sexually repressive background, the impact of being called a ‘cunt,’ the proliferation of cosmetic labiaplasty, and genital pain that is explained (by some) as the result of “fired up” nerves?

What happens, I suggest, is Vulvar Disease, specifically in the way that I am defining it in this dissertation—a complex interaction between cultural cues and physiological anomalies that accumulate and, eventually, manifest as intractable and embarrassing genital pain. I also suggested that an acknowledgement of these symptoms constitutes something like an eruption and that, in its wake, symptomatic women might either come together or fall apart. As they attempt to reconcile the reality of their now pain-filled sexual lives, these patients must face not only the accumulated baggage with which their symptoms are culturally bound, but also the possibly stolen futures of sexual satisfaction and fulfillment, futures that are as profoundly shaped by social worlds as they are by personal desire. If integration refers to “a combination of parts or objects that work together well,” then women with vulvar pain must find ways for these disparate ‘parts’ to function harmoniously.

The fact that I ‘slid into’ to the clinic like a vaginal dilator speaks directly to the cultural aspects of the diagnoses under investigation here. It was not just greater access to and rapport with patients that I was able to acquire through my combined set of skills; it was also an analytical edge that sought and identified particular sites of discord, asymmetry and/or synchronization between women, their symptoms, providers, partners, treatment options and the social malady of genital *dis-ease*. A friend that I got to know in my last six months in Portland talked with me often about the work I was doing and, when I was leaving, asked me “Well, who is going to do what you’re doing when you leave? What will the patients do?” A nice compliment, to be sure, but I mention it simply to note that my perspective and presence worked to bring elements together that might otherwise have remained too far apart. Whether validating that their disease was worth studying, attending to its details with emotional and intellectual curiosity, making room in our interviews for novel, non-clinical, or even contradictory, reflections on their

extant narratives, or talking feminism, politics, religion, childrearing, sex, shopping or any other topic that fed our unique relationships, I helped to establish a more substantial social space for their experiences, to *presence* what had been *absent* for too long. In ‘real’ terms, I am not certain that I did any more than would a critically reflective and feminist-minded friend, my own version of what Deborah Heath (1998) has called “modest interventions” (67).

In May of 2007, the *New York Times* published an article that discussed the unique genital morphologies of several breeds of ducks, which focused primarily on the spiral—almost corkscrew-shaped—male phallus. Central to the story was a description of the anatomical evolutionary changes that these phalluses sustained in reaction to changes in the oviducts of the females of their respective breeds. Neither this chapter nor this dissertation have room to conduct cross-species genital analyses, regardless of how fascinating this story was to me. The point for which I have ample room, however, and that could not have been more eloquently conveyed than it was in this article, is an attention to the role that feminists—anthropologists among them—have to play in carrying out these “modest interventions.” This is because it was a feminist-minded biologist, Dr. Patricia Brennan, “who asked herself a question that apparently no one had asked before” (Zimmer, 2007), and eventually played the pivotal role in this scientific endeavor. “Somehow,” notes Zimmer, “generations of biologists had never noticed this anatomy before.”

I conclude this discussion of “coming together or falling apart” with this news item not only because it documents yet another instance of missing female genitalia, but primarily because it underscores the integrative work of feminist researchers. One woman’s curiosity about how disproportionately large and spiral shaped phalluses ‘fit’ into the bodies of their mates was the catalyst for an entirely new set of questions and

insights about the evolution of at least one species' reproductive anatomies. And it is with my ethnographic attention to these *particular* female bodies, women whose genitalia have been attended to as inadequately as Dr. Brennan's ducks have, that I hope to place the vulva on the cultural map.

Chapter Six: Generation

Chris: What do you think this experience has **given** you?

Isabelle: I guess in having to talk about my problems so much I have been able to actually help a few women I've known, you know, with other problems. Well, like [when] my sister ... discussed some problems that she had and that she was so ... I mean could not talk to her doctor about them at all, I mean could **not even talk to her doctor**. And here I am having to tell my doctor everything, you know, right down to the most intimate detail

PART I: NOVEL MORPHOLOGIES

It recently dawned on me that I employed a metaphorical strategy in the M.A. thesis to which I referred at the beginning of this dissertation (Labuski, 2002), and in which I proposed (and analyzed) the contemporary cultural phenomenon of female genital *dis-ease*. Playing with the “human sexual response” theorized by Masters and Johnson (1966), I wrote my chapters as the set of progressive stages that they argued were universally experienced by men and women engaging in climactic sexual activity: excitement, plateau, orgasm and resolution. And while I do not want to draw attention to the derivative nature of a dissertation-as-metaphor format, I think it a useful endeavor, insofar as it helps me to draw a contrast between *Resolution* and *Generation* as orienting devices for my concluding remarks. Although I foresaw plenty of questions and analytic work ahead of me when I completed my thesis, I nonetheless viewed the project as at least somewhat “resolved,” at least enough for me to use the word in a relatively unproblematic manner. But the nature of my dissertation research, as well as of Vulvar Disease construed more broadly, leaves me with a greater sense of contingency and productivity. This sense is derived not just from the scholarly, clinical and activist work that remains to be done, but also from what Vulvar Disease *as a social reality* creates and generates—what is made *present* in the world through the efforts of courageous and

pain-filled women who are speaking up about the strangely amplified *absence* through which they have been experiencing their genitalia.

It seems that once I began imagining another bodily metaphor, I was aware that it needed to include a generative body; I knew this even before I knew that it would contain eruptions and an insinuation. I cultivated an analytical space for this chapter through the corporeally feminist and poststructuralist theory that I read while sorting through my ethnographic data, but it was a set of impressions from the field that sowed the first seeds of my thinking about generativity. While I was in Oregon, that is, I *saw* the possibilities and novel realities that were produced and sustained by the labors of patients, physicians and physical therapists, all working in their own way(s) to incorporate the reality of vulvar pain. I also observed an expanding array of discursive and material apparatuses that facilitated the circulation of *vulvodynia* and VVS beyond the Program in Vulvar Health and the bodies of women with symptoms. These included the burgeoning expertise of former OHSU residents who were establishing practices of their own or transporting their ‘knowledges’ to other institutions, as well as the growing economic success of Jill’s brother-in-law, who was the developer and main supplier of therapeutic dilators to both OHSU and It’s My Pleasure (the local and woman-owned sex boutique where some patients chose to shop for theirs). Indeed, it was the sale of these dilators at It’s My Pleasure that helped to crystallize my, until then, vague sense of how material products were (or were not) articulating with new discourses in the social realization of vulvar pain conditions. As the mainly lesbian staff of It’s My Pleasure grew increasingly savvy about the use of non-vibrating (and non-pleasure-oriented) phallic products for women who were unable to engage in heteronormative intercourse, I came to think more about the possible—and unpredictably proliferative—effects of these pain conditions.

In *The History of Sexuality: An Introduction*, Foucault constructs an eloquent argument regarding the incitements to sexual discourse that existed in the modern “West,” particularly those that were based in the social hygiene movement at the turn of the 20th century. These incitements are indexes of a *productive* power around which Foucault’s larger project is organized. He argues that this modern and more diffuse form of power is pernicious and omnipotent:

not because it has the privilege of consolidating everything under its invincible unity, but because it is produced from one moment to the next, at every point, or rather in every relation from one point to another. Power is everywhere not because it embraces everything, but because it comes from everywhere. (1990a: 93)

I do not wish to use the small amount of room I have left to engage with Foucault’s project; this has been done elsewhere and from a wide range of disciplinary and political perspectives.¹⁰¹ Rather, I want to use Foucault’s conceptualization of generative power as a departure point for the final words of this document—that is, as a way to theorize the proliferative and incitement-filled discourses and practices that surround and infuse the experience of vulvar pain. Some of these, like my own research and the funding that supported it, are easily understood within what Foucault calls a modern (and Law-displacing) “deployment of sexuality,” a regime that has its “reason for being, not in reproducing itself, but in proliferating, innovating, annexing, creating, and penetrating bodies in an increasingly detailed way” (107). This “deployment,” he continues, is linked to the economy not through a sovereign rule of law, but through the physical sensations of “the body—the body that produces and consumes” (107). Through this analytic framework, we can readily see the work of vulvar pain researchers, the lobbying efforts of the NVA, and the taxonomic strategies of clinicians striving to define a more

¹⁰¹ See, for example: Jackson, 1987; Davidson, 1987; Stoler, 1995; Halperin, 1998; and Lyons and Lyons, 2004.

precise nomenclature for these conditions as separate-yet-interlocking pieces of a “biopower” (140) that is produced and (re)produces itself with an increasingly detailed set of knowledges about the (vulvar) body.

Much of what is *generated* by vulvar pain, then, is consistent with a deployment of (bio)power that, though capable of producing the tactics by which it can be resisted, is nevertheless structured through a system of meanings and “techniques” through which the female sexual body (in particular) garners the scrupulous and disciplinary attentions of scientific medicine. I have attempted to demonstrate that the increasingly technical supervision of *dis-eased* female genitalia reflects neither a benevolent and progressive vulvar incorporation, nor an uncomplicated and patriarchal (re)appropriation of the female sexual body. Rather, actors and institutions layer themselves around and within competing and converging ideologies about the proper ‘place’ of bodies that are heterosexually and reproductively noncompliant. Within these dynamic social fields, there is room for the resistance that Foucault argues is always coterminous with (bio)power, as well for strategies and occurrences that *exceed* these circuits of power and resistance. Based in physical therapy and in the bodily imaginaries that are cultivated by (some) patients, these latter behaviors and beliefs index a something *else* to which an accepted and resolving vulvar disease condition can point: alternative (hetero)sexualities, vulvar-inclusive morphologies, and an awareness of non-hierarchical bodily difference.

Foucault contrasts the discursive apparatuses through which we develop our sexual subjectivity—the “sexuality” that he historicizes in his text—with a realm of “bodies and pleasures” that are neither circumscribed nor *incorporated* within institutional networks of power. The cultivation of these “bodies and pleasures” is more completely theorized in the succeeding two volumes of Foucault’s *History* project, and

they therefore receive little more than a vigorously comparative nod in this text (on the penultimate page, to be exact):

[i]t is the agency of sex that we must break away from, if we aim—through a tactical reversal of the various mechanisms of sexuality—to counter the grips of power with the claims of bodies, pleasures, and knowledges, in their multiplicity and their possibility of resistance. The rallying point for the counterattack against the deployment of sexuality ought not to be sex-desire, but bodies and pleasures. (1990: 157)

What is noteworthy here is that the “claims” made by Foucault’s “bodies and pleasures” are conceptualized with the same multiple, resistant and *possible* terms through which he defines power. For me, this seems to undermine the contrast that he is attempting to draw between (natural?) bodily proclivities and those that are structured by the “complex machinery” (68) of (bio)power. Although I am unable to fully develop this critique here, I want to use these elements of Foucault’s argument in order to provide a framework through which to interpret the recuperating bodies to which I will now turn. Although I understand these bodies as both generative and full of possibility, I do not see them as operating *outside of* the diffuse discourses that many of us have come to call “sexuality.” Rather, in coming to inhabit novel *body images*, Daphne and her peers may demonstrate no more—nor less—than what corporeal feminists refer to as “modalities of becoming” (Colebrook, 2000: 89)—“bodily styles, habits, [and] practices, whose logic entails that one preference, one modality excludes or makes difficult other possibilities” (Grosz, 1994: 191).

Recovery

When Daphne called me in September, 2005 to tell me that she had recently had “sex” with her boyfriend for the first time, and that *it hadn’t hurt*, we were both ecstatic. Our good feelings about this event were informed less by the fact that it was Daphne’s

first intercourse with *Brandon* (her boyfriend) than by the larger context of this having been the first time that Daphne had engaged in penetrative coitus with *anyone*. When I left Portland just a month earlier, she and Brandon had been engaging in lots of heavy petting and genital contact, and Daphne was working steadily with Hanna in physical therapy. Indeed, it was during the last PT session that I was able to attend with her that Daphne inserted her own finger into her vagina for the first time (also without pain), an experience that had helped her to establish a corporeal difference between an “inside and [an] outside” that felt significantly less alienated. I have argued elsewhere (Labuski, 2008) that Daphne’s painless intercourse was fundamentally enabled by her ability to preserve something of *herself* during sex with her boyfriend, a process that Irigaray (2004) refers to as self-affectionate virginity.¹⁰² What I want to suggest here is that Daphne’s intercourse with her boyfriend was also created by—and generative of—a novel *body image*, one that was informed by an acceptance of her pain condition as well as by a curiosity about how and whether that pain would continue to figure into her (sexual) life.

Daphne both imagined and engaged in sex with her boyfriend through a *body image* that she constructed with Hanna, and which extended beyond her vulva, genitals and sexuality. Not long before the session that I last attended with her, Daphne had arrived at one of her appointments menstruating and not particularly interested in doing what the PTs referred to as “internal work.” Hanna took this in stride and reminded Daphne that her physical therapy was always “about” far more than her pelvic floor anyway (or, rather, that any work with her pelvic floor was necessarily in dialogue with the rest of her body and her life). Hanna made it clear that working with Daphne’s ideas, thoughts and beliefs about her bodily potential was simply another kind of—and

¹⁰² Personal communication; May, 2005. See also Irigaray (2004).

equally important—“internal work.” Indeed, the first time that Hanna used the biofeedback equipment during a session, she told Daphne that it was a way for them to gauge “how you *do life*.” On this day, then, instead of lying on her back on a treatment table, or sitting in a recliner wired to the monitor, Daphne worked with Hanna from her feet, in an Aikido exercise meant to unsettle and reconfigure the elements of her (sexual) body image. Standing upright in the center of the room, Daphne closed her eyes and allowed Hanna to physically push her—from all sides—so that she could practice “holding [her] ground” in bodily situations over which she had limited control. Daphne and Hanna conducted this exercise for about fifteen minutes and Hanna never ceased to connect it with the more local/genital techniques in which they normally engaged. And I watched in fascination as the contours of Daphne’s vulva and pelvic floor became more expansive, coming to include her entire body and its ability to tolerate being pushed around.

Particularly as contrasted with the “shutting down” described by many of my informants, this ‘opening out’ of the body is noteworthy. Although in this case it is a byproduct of physical therapy, Merleau-Ponty (1962) has theorized the broader experiential dimensions of this process in phenomenological terms. For him, bodily loss and generativity cannot be understood outside of the relationships in which bodies and persons are always-already immersed—with others, with objects and with the world at large:

precisely because my body can shut itself off from the world, it is also what opens me out upon the world and places me in a situation there. ... The ... [loss] is recovered when the body once more opens itself to others or to the past, when it opens the way to co-existence and once more (in the active sense) acquires significance beyond itself. (165)

Merleau-Ponty uses a case of aphonia (vocal paralysis) in a young girl (who is angry with her parents) to illustrate that what we perceive as loss is more accurately

understood as rejection—“as one loses a memory it is lost ... in so far as it belongs to an area of my life which I reject” (161-2). I suggested in Chapter Three that I do not believe that many women in the U.S. have ‘had’ their vulvas to lose, but the tension between having-rejecting-losing in Merleau-Ponty’s conceptualization of bodily awareness is a compelling way to think through this dilemma. In relationship to a world that does not account for their genitalia, women like Daphne “shut down,” ‘lose’ and psychically reject the (sexual) bodies that they index, keeping their vulvas ‘at arm’s length’ in an act that is only partially voluntary.¹⁰³

But Daphne, with Hanna’s guidance, is able to recuperate her losses as she lays claim to a set of new corporeal connections. On the day that Daphne inserted her finger into her vagina, for example, Hanna made certain that Daphne took full account of *all of* the parts of her body that were helping her to keep her pelvic floor in a state of relaxation. And, just as Lisa asked Nikki to identify and speak with her past (Veronica; see Chapter Four), Hanna encouraged Daphne to give her future a name:

H: [Choose] a word that means relaxation to you. This is where soft is. ... Now, while you’re relaxed, I’m going to add your breath [to the monitor] When [you] need that soft quiet place, [think] ‘I know at least two ways to help me get there.’ Go inside and think ‘This is it, this is what it will feel like.’ Now close your eyes, mess your body up a little and then see if you can come back to this, [if you can] call it up.”

[Daphne does so almost immediately.]

H: That’s lovely. You get an ‘A’ for today. Can I ask what word you used?

D: Europe. [Says she went 2 yrs ago, “never felt better,” and it was, at least partially, attached to a man she knew there. She [...] felt very safe with him. Very safe. Europe evokes that feeling.]

H: Okay, you need to think sometimes, ‘My body knows how to do Europe. I need to be in Europe.’ Even when things are ugly.

¹⁰³ See Kurtz (1976) for a fascinating account of a woman who presented to a bodyworker with extremely tight shoulders. When the provider began to work out the tension, which involved asking/helping her to lower and drop her shoulders and arms, the woman began crying and resisting. Further exploration ‘revealed’ that, as a toddler, her wrists had been tied to the slats of her bed – an attempt on the part of her mother to keep her from reaching and touching her genitalia.

For Merleau-Ponty, Veronica and Europe exist as states of recovery, collected with a body that can “once more” open itself to a rejected-forgotten past. I want to complement this assertion, and suggest that we understand the work of both Nikki and Daphne in reconfigured temporal terms. That is, as *future* possibilities through which patients can *imagine* a different set of corporeal experiences (e.g. sex without pain), Europe and Veronica exist as both recovered relationships *and* as novel morphologies, both accessed through a somatic mode of attention that is unique to vulvar pain.

For Merleau-Ponty, bodily integrity is achieved through restored connections. His predilection for a body that is capable of psychically repressing experience is explicitly influenced by Freudian psychoanalysis; like Freud, he supposes the importance of an event of some kind—the “internal” conversion described in Chapter Four—as both treatment modality *and* evidence of its necessity. In the case of the hysterical young girl with aphonia, Merleau-Ponty suggests that:

[t]he girl will recover her voice, not by an intellectual effort or by an abstract decree of the will, but through a conversion in which the whole of her body makes a concentrated effort in the form of a genuine gesture. (165)

I want to draw our attention to the transformative aspects of Merleau-Ponty’s assertion, particularly to how his ‘conversion’ might resemble the “internal change” described by Freud (see p. 165). Both of these transformations involve the conscious *presencing* of a thing (typically an emotion or experience) that has long been absent/repressed. Merleau-Ponty distinguishes himself from his psychoanalytic peers by repudiating the idea that “intellectual effort” alone is capable of bringing about a desired and therapeutic change, such as recovering a voice or a relaxed pelvic floor. Instead, he underscores the physicality and the (somewhat undefined) “genuine-ness” of a gesture. But his reliance on psychoanalytic tenets is revealed not only by how he theorizes psychosomatic

manifestations, but also by the certainty through which he locates both cause and cure in an afflicted body's past.

I suggest, and indeed have repeatedly argued, that acknowledging and/or recovering 'the past' plays a crucial role in a total confrontation with vulvar pain. I have also stressed that these 'pasts' can be collective and/or 'cultural,' and that working these pasts into the "etiological pathways" that Harvard's researchers are trying to establish requires a gaze that looks both at *and* beyond individualized, biologized and/or narrowly construed criteria for "other causes of genital discomfort" (Harlow and Stewart: 93; also see p. 1 of this text). With critical and ethnographic participant-observation, however (i.e. moving within diagnostic and treatment realms and making room for multiple interpretive frameworks while collecting narratives), I was able to more fully appreciate the role of an *imagined future* in the resolution of vulvar pain. Treatment approaches that focus on 'curing' *vulvodynia* or *VVS* by excising or anesthetizing inexplicably damaged tissue, or by systemically altering a single physiological element (e.g., the overproduction of inflammatory neurochemicals) effectively "shut down" the patient's experience of her symptoms, anatomically and temporally constraining their meaning(s). Although constituted within the biomedical discourse of 'a future without pain,' treatment options such as surgery and topical anesthesia fix a symptomatic woman's experience into an imagined past, one in which sex was not painful. Rather than envisioning how they will move forward into new relationships with their (genital) bodies, patients (and physicians) construct narratives that focus on "never hav[ing] to think about [their] vulva[s] again," a reality that is construed as getting 'back' to normal.

Neuroscientists who study the *body image* contend that "[b]ehavioral, emotional and cognitive relevance must cohere" in order for "an integrated awareness" of the body to develop" (Berluchi and Aglioti, 1997: 563), and that these integrated schemas are

gradually refined through “systematic interactions between tactile, proprioceptive and vestibular inputs” (560). Physical therapists like Cathy and Hanna work from within this set of propositions and challenge their patients to locate multiple pathways through which they might make their genitals and pelvic floor *matter*—to them and to their partners. Such an approach provides patients with (sexual) ‘bodies’ that are able to accept, control, “dialogue” with, or redirect their pain sensations. With the deliberate deployment of multisensory and overlapping therapeutic techniques (e.g. biofeedback, therapeutic touching, verbal affirmations, partner participation), these therapists attempt to ensure that the overdetermined pain conditions of *vulvodynia* and VVS are understood within a resolution pathway that is equally complex. In undoing a patient’s ‘holding pattern,’ Cathy delineates the *numerous* channels through which these states of hypervigilance have been developed; this primes her patients for continued relationships with their uniquely configured ‘holding patterns,’ as well as with the emotional, physical and/or social experiences through which they have become embodied.

During one of Libby’s sessions, for example, Cathy and I stepped out for several minutes so that David and Libby could ‘play’ with the biofeedback monitor in the context of their own physical and verbal intimacy. As we gingerly stepped back into the room, Cathy whispered to me how “glad” she was that they were doing this as a couple before asking them “how it [wa]s going”:

D: She’s been at a 0.8 [on a 0.0 to 5.0 scale; 1.0 and under was the goal].

C: Can you feel when she goes there?

D: I think so.

C: Do you feel it Libby?

L: Not really.

C: That’s the tricky part for you. The win today is that you were able to get that down to below a 1.0. What does that feel like? Do I experience it in my heart, [my] head, my vagina, where?

I suggest that what Cathy is doing here is proposing a novel bodily morphology for Libby to inhabit. Using a combination of tools—partner, verbal exchange, and Libby’s emerging bodily awareness—Cathy *redistributes* Libby’s pelvic floor, allowing it to reside in her “heart, head, ... vagina, [or] where?” Without asking Libby to explicitly name anything, Cathy nonetheless offers her an opportunity to develop a dynamic and evolving relationship with her pelvic floor, one based neither in alienation nor disavowal. Although it is unclear to neuropsychologists how much of our *body images* are innate (e.g. how much of a vulva is ‘available’ at birth?), empirical evidence strongly suggests that these schemas are highly plastic and adaptive to the specifics of an individual’s experiential environment (Schilder, 1950; Fisher and Cleveland, 1968; Kurtz, 1976; Knoblich et al, 2006). The question with which I am engaging, then, and that can be more carefully analyzed when we have attended to some of the work of Merleau-Ponty, Freud, and even Darwin (in terms of the body’s ‘natural’ and/or directional schemata(s)) is whether Cathy is helping Libby to *recollect* a pelvic floor that had *once* been (unproblematically) hers; or, in (re)locating her vulva to places within her “heart, head, [and/or] vagina,” is Libby, instead, mapping out new genital and/or bodily terrain?

Whether or not the anatomical aspects of female genitalia are a perceptual component of inherited—and most likely fairly crude—postural schemas (Berluchi and Aglioti, 1997; Knoblich et al, 2006), I have argued that the ones under consideration in these pages (i.e., those in the contemporary U.S.) have accumulated the effects of vulvar *inconsequence*. Whether this ‘baggage’ is in addition to or in place of a previously established—or *prediscursive*—genital integrity is a question that I am not prepared, and perhaps not (yet) inclined, to answer. But regardless of the vulva’s relative presence on/in a woman’s inherited corporeal map, I *do* contend that there is nothing natural

about the states of alienation and phallic/reproductive orientation that she is likely to collect without incident over the course of her life. Whether Judy, Joan and Mary Hudson needed to *return* to an imagined corporeal past, or to develop *novel* and future-directed vulvar schemas, in order to notice the slow-but-steady erosion of their external genitalia is less important to me than why and how *neither* of these options were available throughout these quite poignant material erasures.

The approaches taken by therapists like Cathy, Lisa and Hanna provide patients with access to a *body image* that contains an uncontaminated and germane vulva. Cathy and I did not explicitly discuss this aspect of her work, and I cannot conclude (with any certainty) whether she seeks to establish the kinds of recovery and “internal change” that I reviewed at the start of this chapter. But if this *is* her goal, I suggest that it is effectively cloaked in a language that allows her patients to choose whichever path is most meaningful for them. Indeed, Cathy’s techniques, particularly the verbal affirmations that accompany almost all of her bodywork, do not index any clear temporal trajectory through which her patients might (re)locate their genital selves, other than the one in the immediate present of the work they are doing together.

C (while doing ‘internal work’ on Libby): I’m comfortable slowing down. I’m comfortable relaxing. I’m learning to be comfortable opening and relaxing the pelvic floor. I’m in control. I’m learning to be comfortable. (fieldnotes)

During this kind of work, patients can imagine pelvic floors and vulvas that are in less pain at another time and in another place. Libby, to whom we will turn momentarily, came to develop a *body image* that eventually included the touch of her husband, ongoing conversations and feelings about her body, her pleasure, and the sexual behaviors in which she and David were learning to engage. In a morphology that was not dependent on a past or a future where pain did not exist, the experience of possibility could remain constant.

Control (at a whole other level)

Unlike Foucault, my aim here is not to replace a misguided “repressive hypothesis” (1990: 10) with a more ‘correct’ set of ideas about productivity and proliferation. Rather, I am suggesting that women (with vulvar pain) can—and perhaps must—invest in corporeal strategies that access pasts, presents and futures that are as clean as they are contaminated—that is, in which their experience is not compartmentalized in temporal or experiential terms. For example, Daphne may well have had a greater capacity to ‘hold her ground’ as a young girl, before she had accumulated the *unwanted genital experience* that came to inform her VVS. This doesn’t mean, however, that this (hypothetically) less sullied body, or *body image*, is the one that ought to be the object of her recovery. Daphne’s body has “become-meaningful” (Colebrook, 2000) to her through an enormous and idiosyncratic range of discourses, behaviors and affects, and the plastic nature of her body schema can adapt to nostalgic as well as emergent orientations. The body with which she can have painless sexual intercourse, in other words, is an amalgam of imaginaries that she negotiates, like Foucault’s notion of modern power, “from one moment to the next” (1990a: 93).

“Hold[ing] her ground” as an adult may be situated within a bodily *hexis* considerably more contaminated than the one Daphne inhabited as a child. But, as Braidotti (2002) has suggested, “women who yearn for change cannot shed their old skin like snakes. This kind of in-depth change requires instead great care and attention” (26). The important difference between Braidotti’s “in-depth” change and the “internal” ones with which a “repressive hypothesis” is in greater sync, is the emphasis that she places on positive difference. Based in feminist and materialist philosophy, Braidotti’s assertions about bodily becoming revolve around imaginaries that are not limited to *any* spatio-

temporal reality—i.e., there is no one place and/or time through which a woman can (or should) locate her (sexual) subjectivity:

‘Becoming’ is about repetition, but also about memories of the non-dominant kind. It is about affinities and the capacity both to sustain and generate inter-connectedness. Flows of connection ... mark processes of communication and mutual contamination of states of experience. As such, the steps of ‘becoming’ are neither reproduction nor imitation, but rather empathic proximity and intensive interconnectedness. It is impossible to render these processes in the language of linearity and self-transparency (8)

In bodies that are sexed female but unable to physically access the phallogentric sexual order, Daphne and her peers live the reality of “non-dominant” memories. With “great care and attention,” however, these memories can function both as sites for production *and* as spaces of return. Women with and without vulvar pain will continue to accumulate the “[d]iscursive practices, imaginary identifications [and] ideological beliefs” (Braidotti, 2002: 26) through which their (sexual) subjectivities are constituted as alien, lack and/or *too much to deal with*. Yet through a sustained and material engagement with their pain-filled vulvas, i.e., the work of physical therapy and a reconfigured *body image*, symptomatic women have an opportunity to interact with these social phenomena in novel and unpredictably productive ways.

Such strategies are crucial for diagnosed women that are (re)encountering partners and husbands from whom they have long been physically and (sometimes) emotionally separated. The sexual intercourse that patients begin to imagine (and eventually have) requires a negotiation not only with their pasts and futures, but with a *body image* that includes newly informed—and Other—genitalia. Women who are invested (with or without clinical encouragement) in their pain being *absent* after surgery, lidocaine or laser therapy, may not develop the resources with which to confront the “intensive interconnectedness” that sexual intimacy can involve, particularly when it includes the very “common negative experiences of ...

embarrassment, disappointment and boredom” (Cameron and Kulick, 2005: iv). When Jessica, another patient who ‘got better’ during the post-surgical work that she did with Cathy, noticed that she sometimes did not want to be sexual when her husband did, she realized that she had never cultivated the skills to refuse him for any reason other than pain. In its absence, she struggled to balance a difficult mixture of desire, guilt, fear (e.g. of a recurrence), and a newly emerging sexual subjectivity—one that was as informed by the intimacy through which she and her husband had survived approximately five sexless years as it was by the corporeal autonomy that was fostered in her sessions with Cathy. Jessica had not, therefore, *returned* to a ‘normal’ marriage that included the sometimes asymmetrical sexual desires/needs of two people, although this is indeed a ‘normal’ situation across physically intimate relationships. Rather, she related to a situation through which she more closely resembled women without vulvar pain, with and through a *body image* that had yet to *produce* its/her own version of sexual refusal. I want to take an extended turn now, towards Libby and David, in order to more fully elaborate the two levels of tension—temporal and interpersonal—that patients negotiate as their pelvic floors and genitalia are fleshed out and “become-meaningful” in their lives.

During our interview, which took place about two months before her surgery and one month before she began physical therapy, Libby told me that she was excited about sex therapy because she was “looking forward to learning what to do.”¹⁰⁴ She and David were both virgins when they married and her pain had begun less than three months later; subsequently, neither of them felt terribly confident that they knew what they were doing regarding the physically intimate aspects of their relationship. This

¹⁰⁴ Libby had three sessions with Cathy prior to her vestibulectomy; she was the only patient with whom I worked that began her PT before she had her surgery, although everyone understood it to be an optimal therapeutic strategy. At the time of our interview, she imagined that she and David would work with a sex therapist, but neither she nor I knew how much “sex therapy” she would end up doing with Cathy.

facet of Libby's experience intrigued me because it was only marginally related to her pain condition. As she opened up to me about this issue, I wondered about whether she and David would have pursued sex therapy if her pain hadn't developed; or whether they, indeed, would have just figured out "what to do." This is a crucial issue for us to consider in that it indexes not only the other "U.S. women" about whom this dissertation is written (women who might feel like Libby did), but it also speaks to the 'queer' nature of vulvar pain conditions.

Given the number and variety of cultural cues that sustain its unquestioned practice in the mainstream U.S, it is indeed quite likely that Libby and David would have found their way to 'normal' penetrative sex. But vulvar pain had disrupted this heteronormative narrative, making it possible for them to acquire an *alternative* set of sexual behaviors, as well as to develop a relationship with penetrative intercourse that was decidedly unnatural. Libby resembled the majority of my informants in that she and David did not, for the most part, use the four years between her symptom onset and her diagnosis to vigorously (or even moderately) explore other ways that they could be sexual together. She was unique, however, in her frank acknowledgement of the questions and the difficulties that she anticipated in incorporating an allegedly 'natural' behavior (back) into their intimate life. What I hope to show below is that though Libby and David did 'learn' about having penetrative intercourse in their sessions with Cathy, these lessons did not constitute a simple transmission of heterosexuality in its hegemonic form. Rather, in 'learning' about vaginal-penile intercourse via Libby's vulva and pelvic floor, David and Libby acquired a mode of physical intimacy that was unsettling, not only *for* them (at times), but also *of* the masculinist, compartmentalized, and linear discourses through which they may have otherwise come to know each other's genital bodies.

Without a ‘routine’ experience of vaginal penetration (of any kind), Libby first had to make anatomical and affective room for both David *and* the therapeutic dilators that Cathy encouraged her to use. Her strategy, one that I also heard from other informants, was to make the dilators “medical” and David “sexual”:

C: Whatcha been doing [with] your program at home?

L: [Says that her period] killed everything for a week [but] we’ve used the dilator three times. And David’s finger one time.

C: [Asks a follow-up question that I missed.]

L: I’m trying very hard to make the dilator a medical/sexual. If I put David in the category of my PT, and my healing [indecipherable], then he’s still there later. Does that make sense? [The dilators are a medical] thing and David [is] a sexual thing. I’m not sure where on the spectrum to put all this stuff, so I decided that the dilator is medical and David is [she looks at David.]

C: Yeah, good discussions to have. [She talks with Libby about coming in on a Saturday so they could work jointly with a cognitive behavioral therapist who consults with Cathy’s practice.] So, given the view that you’re taking, how did you use the dilator? Yourself or with David?

L: With David, but it was as a medical/PT thing. If we did anything else, it wasn’t the result of the dilator, it was the result of spending time together.

C: Just so you have the information, some people use the dilators as sexual play.

L: Yeah, but if it’s part of PT

C: It would be very good to see Karen [the therapist] now. She could step in here, and give you some clarity.

[There is some logistical negotiation about this for a few minutes.]

L: [Moves towards David and pats him on the leg.] We can’t have sex until I’ve used all three dilators. Then it’s your turn. (*my fieldnotes say “very cute”*)

C: *Yeah!* And if while you’re fooling around, he wants to slip a finger in Allow yourself to feel aroused. *Allow* yourself to go to those places.

We can see that what Cathy seems to want in this exchange is for Libby to integrate her penetrative experiences, allowing a dilator and a husband to occupy the same discursive space in Libby’s shifting sexual *body image*. The key term here is *shifting*, however; that is, in ‘becoming’ a body that can (now) tolerate—and *imagine*—penetration, Libby is experimenting with corporeal strategies that are specific to her own experience.

What Cathy perceives as compartmental thinking, may, in fact, reflect a vaginal *body image* that is multiple, one that exceeds and/or changes the extant and hegemonic genital horizon through which Cathy interprets Libby's sexuality (Irigaray, 1993b). Oliver Sacks (1987, 1995) has written extensively about the experiential worlds of neurologically impaired individuals, making a compelling case for the generative nature of these injuries. Mixing the personal narratives of his patients with those constructed by clinical/neurological medicine, Sacks argues that "[d]efects, disorders, [and] diseases ... can play a paradoxical role, by bringing out latent powers, developments, evolutions, forms of life, that might never be seen, or even be imaginable, in their absence" (1995: xvi). He continues that:

while one may be horrified by the ravages of developmental disorder or disease, one may sometimes see them as creative too—for if they destroy particular paths, particular ways of doing things, they may force the nervous system into making other paths and ways, force on it an unexpected growth and evolution.
(xvi)

Earlier in the dissertation, I suggested that we need to "make room not just for a brain in the gut, vulva and/or pelvic floor, but in the agnosiac and shared *body images* that are constructed and informed by cultural discourses" (196-7). I want to extend that proposition once again, and reiterate that the paths that need creating are as cultural and collective as they are individually physiological. In the following exchange between Libby, David and Cathy, we can once again witness the eruptive potential of this noncompliant pain, and ask (new) questions about the heteronormative and masculinist 'nervous systems' that are perhaps ready to shed some skin and evolve:

C: Do you want David's touch again?

L: I'm okay.

C: I'm going to challenge your 'I'm okay.' One thing to think about—'cause this can help with sex and intercourse too—think about what feels good, 'I'm okay,' but 'How could I be better?'

[David has moved so that he is standing behind Libby's head and is stroking her hair (Libby is on her back on the exam table and Cathy is working 'internally' in Libby's vagina). Cathy says she "felt [an] area" loosen as David repositioned himself].

C: You'll want to think about this as you take [this work] into the bedroom; to be able to verbalize, because it's not easy for a lot of women to do that. [She coaches David, stressing that he be able to] *take it* as [Libby] learns to tell [him] what doesn't feel good [etc. She continues that] there is a difference between 'taking it' with resistance and 'taking it' openly. [She says:] He has his own work to do around that—to take what you say and truly truly accept it. [Cathy notices that Libby has been glancing towards David and says:] She keeps looking at you David, [and then turns to Libby,] What are you thinking?

L: says that she wants to know what David is thinking.

C: Would you like to ask him?

D: [says that he doesn't think he has a problem, but he'll have to] look at it.

[C is trying to help David ask Libby something directly, but they are evading it a bit. There is some stumbling around.]

C: *If you leave here and something comes up—it can be very hard to tell him, and that can be important, because he may not know.*

L: *[says that she thinks they've] always been able to talk about it. It's the strength of our relationship.*

C: *Okay, you tightened up [when you said] that.* (italics and bold emphases mine; see below)

Prior to her work with Cathy, Libby had discerned that there were things about sex that she (and David) still wanted to learn. A more conventional physical therapist may have worked effectively with Libby's pelvic floor, but made no explicit connections with the rest of her body, her relationship, or "the way that [she *did*] life." The practices of sex therapists vary even more widely and so Libby and David may have encountered anyone from a conservative Christian invested in gendered hierarchies (they were both practicing Seventh Day Adventists) to someone like Jill, who was both more liberal and more knowledgeable about vulvar pain. At any point on this spectrum, however, it is doubtful that Libby's pelvic floor would have communicated what it did to David (and to her) in the above exchange. That is, by deploying a set of "systematic interactions between [a variety of] inputs" (Berluchi and Aglioti, 1997: 560), Cathy not

only guided Libby through a morphological shift in her *body image*, she also gently established its salience in the physical intimacy that Libby and David were attempting to (re)establish.

Imagine that: corporeal feminism and anthropology

In recalling the “deep tissue discourses” discussed in Chapter Three, I want to call our attention to the last three utterances of the previous dialogue, and ask about the likelihood of them pertaining to *any* heterosexual couple in the contemporary U.S., regardless of their relationship to vulvar pain. Based on the narratives that I’ve collected in twenty-five years of talking with women about ‘sex,’ I would venture to say that it is considerable. In this imagined group of heteronormative individuals, some might find their way to sex therapists who, though unable to deliver such convincing bodily evidence, would typically make similar assertions about the importance of good communication. Conversely, clinicians that are capable of detecting pelvic floor *myalgia* would locate relief measures in the individual—and physiological—bodies of the patients under their care. In this second scenario, particularly, the burden of *dis-ease* is ascribed to, and subsequently assumed by, the women in question, making them the identified patients of a syndrome that is more accurately apprehended as culturally endemic. Approaches to (hetero)sexual distress that stop at this level of intervention, i.e., the individual or interpersonal, may be an improvement over a Freudian repudiation of the ‘real’ traumatic stories of girls and women, as well as over the psychosomatic gloss that vulvar pain received for at least a decade. But without a broader analytic stance—one that bridges a collective female structure of feeling with (some of) its individual bodily expressions—we can neither access the proliferative nature of (political) power, nor can we hope to deploy it productively.

Twenty years ago, in their seminal prolegomenon, Scheper-Hughes and Lock (1987) persuaded critical medical anthropologists to think about culture's relationship with the body at three levels: individual, social and political. This dissertation has obviously been written under the influence of that essay, in addition to the scholarly work that both inspired, and was generated by, its analytical orientation. I invoke these famous "three bodies" once again so that I can now draw explicit attention to the political nature of shifting *body images*, and of the discursive redistribution of vulvar pain. That is, if genitals are to be taken into account by a feminist project of non-hierarchical sexual *difference*, then they must be adequately differentiated *across* those bodies that position themselves as women. Rather than as indexes of phallic/reproductive capacity, sexual orientation, or dichotomized physical normativity, female genitalia can 'sex' bodies only inasmuch as they generate bodily sensations and experiences that are specific to anatomical, physiological and 'sexually' structured qualities that are shared by similarly configured bodies. Colebrook (2000) reminds us that a "[conventionally feminist] appeal to equality assumes that gender differences are imposed on otherwise equal beings, ... thereby preclud[ing] the possibility that different types of bodies might demand different forms of political recognition" (76). Through theories of corporeal *difference*, however, bodies with genitals that have been cut, eroded, mechanically altered, or simply don't 'work,'—and yet are structurally sexed as female—can be more sensibly interpreted as generative and proliferative, rather than as lacking or defective.

In her extended discussion of materialist feminism, Braidotti (2002) argues that "the subject of feminism is sexed;" and that

he or she is motivated by the political consciousness of inequalities and is committed to asserting diversity and difference as a positive and alternative

value. The feminist subject of knowledge is an intensive, multiple subject, functioning in a net of inter-connections (22).

Allowing Libby to have both a ‘medical’ *and* a ‘sexual’ pelvic floor, then, becomes as much of a political project as it is an individual or interpersonal one, as it allows for the affirmative, multiple and *bodily* difference through which many feminists hope to redistribute (political) power (Gatens, 1996). Similarly, in aligning women with *and without* vulvar pain around potentially similar struggles to communicate *from* their genital bodies, we find even more—and unpredictable—sites of articulation from which to build a feminist corporeal politics. Unsurprisingly, the key organizing device here is perspective. Adjusting the analytical focus of our questions about these symptoms, from one that is person-and defect-centered to one that is multiple and generative, makes it increasingly possible to locate the numerous nodes around which a corporeal-genital politics could emerge. For once we begin *listening* to the narratives of symptomatic women, we find that *vulvodynia* and VVS are less a (physiological) problem for women with “pretty white skin,” than a set of avenues through which women can choose to “exit from the universal mode defined by man, towards a radical version of heterosexuality, that is to say the full recognition of the specificis of each sexed subject position” (Braidotti, 2002: 27)

Such exit strategies abound once we begin to view genital pain in this way. For example, although *dyspareunia* is a quite common clinical term used to denote “pain with intercourse,” it is rarely used in the management of vulvar pain. This is because *dyspareunia* is more commonly used to describe pain that is experienced with the deep and thrusting (vs. penetrative) actions of intercourse. But this seemingly reasonable and benign distinction enacts a separation between women diagnosed with chronic vulvar pain and those diagnosed with chronic *pelvic* pain—the main symptom of which is

dyspareunia, and the majority of whom are African-American. By employing—indeed constructing—a new language with which to describe vulvar-based conditions (*allodynia*, *hyperalgesia*), clinicians not only code these women in the hysterically-inflected (and racialized) terms of “hypersensitivity” (see Chapter Two), they also make it more difficult for these two groups of women to identify and/or align themselves with each other, based in their common experience of sexually prohibitive pain. Similarly, transsexual and transgendered individuals whose ‘vulvas’ may be anatomical variations from the ‘norm,’ might, via discourses of multiplicity, experience an affective and corporeal camaraderie with *LS* or *LP* patients, whose labia are often less fleshy, “robust,” and/or quietly compliant than those of ‘normal’ women. Again, such alliances might not only *produce* new forms of political and/or social collectivity, they can also redefine the female genital imaginaries of women in the U.S., from those defined through *inconsequence* and/or *disparagement*, into novel discourses and practices that are characterized by difference and possibility.

With greater collective access to *these* imaginaries. Libby need not remain the only woman whose vulvar *body image* is redistributed to her “heart, head, ... vagina, [or] where?” Indeed, limiting the meaning of Libby’s work to her personal relationship with David would constitute an active distancing from the radical heterosexuality called for by so many feminists and potentiated by the bodily experiences of my informants. In attending to these women as an anthropologist, then, and disseminating my own interpretations of their corporeal transformations, I hope to open their experience to the legions of other U.S. women struggling with a genital and (hetero)sexual *dis-ease*, one through which they suffer their sexual dissatisfaction and disappointments in relatively silenced, resigned and/or medically pathologized terms. In relocating their genital affect to their “heart[s or] head[s],” however, away from the sites of contamination that

reinforce their silence, they may find the courage and ability to speak their experience with a greater clarity; they may feel increasingly able to “hold [their] ground” while they profoundly unsettle the territory upon which masculine-centered heterosexuality is currently lived.

Although my argument in this chapter is framed by generativity and affirmation of a relatively non-ideological kind, I am aware of the utopic realm in which these reconfigured imaginaries reside, an awareness made more acute by personal politics that are decidedly more ‘realist.’ That is, in outlining some of the possible elements of a vulvar-based female sexual imaginary, I am neither invested in, nor affirming, any *necessarily* essentialist or permanent connections between these groups or individuals. My epistemological leanings towards the materiality of the human body, however, constantly challenge this postmodern stance, leaving me vulnerable to intellectual (and perhaps political) accusations that I cannot effectively address the concerns of the players invoked here, including those of a feminist project of sexual difference. My temporary refuge is that I am still sorting it out, finding ways to reconcile physiology, philosophy, politics, genital anatomy, neuropsychology and a critical anthropology of the (human) body. But in underscoring the relationship between individual *body images* and collective bodily *imaginaries*, and locating some of their proliferative potential within the spaces that are opened up in the interpersonal work of genital physical therapy, I *am* suggesting that female genitalia cannot only be *recuperated* by attentive providers like the ones I came to know in Portland, but that they can also be *produced* by women themselves, particularly when they have access to an expansive and affirmative vulvar future. In the words of Dr. Erlich, as she counseled a patient about the emotionally difficult work involved in confronting a reconfigured sexuality: “Well,

we want you to turn a page and say ‘I want to explore the pleasure part. The orgasm part.’ It’s been a lot of years. But life is for making changes.”

PART II: GIFTS

Chris: Do you think that your symptoms have given you anything?

Clair: Um, no. I would say I feel deprived, all the time. Always deprived.

David was not the only male partner that I met whose ideas about masculine sexuality were being challenged and/or revised by vulvar pain. Jim, the budding mortician that we met in the preceding chapter (see p. 276), who also typically accompanied his partner (Brigette) to her appointments, was explicit about this during our interview.¹⁰⁵ I had asked Brigette whether she felt like her symptoms had “given” her anything, whether they had provided her with anything to which she hadn’t previously had access. After she briefly described the “better understanding of people who ... have other problems in that area,” she indicated that Jim could also answer this question, which he did:

The word humbling comes to my mind. ... Just having to be more sensitive to the situation, for myself, emotionally, to support her in that. It’s something I need to remind myself of, of why, and not just ‘we’re here,’ and not just pull the general male ‘get upset something’s wrong and not going our way’ thing.

As we continued talking, I asked them both if they thought that their sexual relationship had been challenged by her pain. Brigitte responded that Jim was “a lot more understanding than even when we started dating. He cares about me and doesn’t want to

¹⁰⁵ Jim was one of only two (male) partners who was present for an interview. I had decided that I would let the women decide about the role that they wanted their partners to play in this facet of our work together. I was not opposed to the presence of a partner, but since my primary interest was in the women’s narratives (and since I harbored a mild concern that their ‘voices’ might be muffled or diverted by the presence of a partner), I kept quiet about the subject and let my informants ask *me* if it was okay for him to be there. I agreed happily each time and, indeed, would welcome the opportunity to collect more of their stories; particularly since patients indicated that their husbands/partners weren’t talking to *anyone*.

put me in a position of pain,” to which Jim added that he had experienced “more growth emotionally” and had more (sexual) “patience.”

C: Do you two think that you have anything to teach other couples, whether they have this problem or not?

B: Just if someone’s not able to be open and talk about it, then you shouldn’t be with them.

C: Did you think that before?

B: No, I was kind of like, ‘keep it quiet.’ But now after dating Jim, everything is so much easier. I didn’t even realize it because I’d never had it, but it’s so much easier. I can’t keep it quiet with him.

I want to turn now to the voices of several of my informants who, like Brigitte and Jim, answered my questions about what the experience of vulvar pain had *given* them. As I indicated earlier, this question was in my interview because of the sense of generativity that was developing for me while I was in the field. I knew that including it was a productive act on my part, meaning that it was less likely that my informants and I would have had these exchanges had I not posed the question. But I wanted to draw them out about this topic in order to find out if their embodied experiences were reflective of, resonant with, or contradicted the (broader) social body that both structured and was structured by their individual ones (Douglas, 1966, 1973; Bourdieu, 1977, 1984; Scheper-Hughes and Lock, 1987; Martin, 1994, 2007). In other words, given the generation of both affects *and* effects from the discursive and institutional sides of vulvar pain, I was curious about its more internally *felt* striations.

And so I wondered: was Brigitte’s newfound *inability* to “keep it quiet”—a problem quite distinct from the ones under investigation in this dissertation—correlated, or even in sync, with a broader set of social processes that are, in their own ways, “inciting” her to speak? While I cannot conclude that Brigitte uncomplicatedly indexes the larger body of her symptomatic peers, as many of them are in relationships with men

who are not as “open” as Jim, I can say that my transient presence in the lives of my informants did feel well-timed; that is, I believe that I was able to capture the narratives that I did because so many of these women were *fully* recounting them for the first time. These virgin tales, once underway, were eloquent and thorough—typically untroubled by the awkwardness and/or embarrassment through which I nonetheless insist their experience is (at least partially) lived. For example, when I asked Gracie about what her experience of vulvar pain had given her, she thoughtfully replied “Well, .. this.” I was momentarily confused by her answer, but once I had conveyed this fact with a puzzled facial expression, Gracie explained that she was grateful to just sit down and tell her ‘story’ in some version of its entirety. What is most interesting for me about this answer is that, if we read it carefully, it suggests that Gracie’s pain figures into her ‘story’ as vehicle rather than content. Her pain, that is, is the event in her life that provided her with the opportunity to tell an interested anthropologist about all of it, the *what else* of not only her vulvar symptoms, but of the far more amorphous experience of contemporary—and embodied—female (hetero)sexuality in the U.S. And, although my focus on the marginal (and therefore more fundable) aspect of pain was the only reason that I was able to listen to Gracie’s story in the ways that I did, I want to reiterate that this dissertation is nevertheless in full sync with her answer. In responding to the question of what Vulvar Disease has given us (anthropologists, sexuality theorists, feminists), I can similarly say, “Well, .. this,”—an ethnographic exploration of the genital *dis-ease* with which women like Gracie’s sexuality—and sexual pain—are infused.

In a more local context (i.e., of what the symptoms of vulvar pain have generated), women were both insightful and forthcoming, voicing some overarching themes that I would like to briefly outline here. I want us to position these themes

through Sacks' discussion of disease-related generativity—that is, as manifestations of “‘a whole new world,’ which the rest of us, distracted by [normality], are insensitive to[; ...] a new state of sensibility and being” (1995: 38-9) to which symptomatic women have greater access and awareness. Although it was always intellectually heartening for an informant to start with, “Oh, that’s a good question ...,” my appreciation for these responses was rooted in my somewhat less self-centered interest in delineating the differences between me and my informants. Because although I could share in many of the affective aspects of their narratives, I was also aware that there was far more than the physical experience of pain that marked our differences. I wanted to know not just about the pain-derived experience of generativity, but more broadly, I wanted to know about generativity as *one* reverberation of vulvar pain, *one* way that women integrated their symptoms into a lifetime of broader and more insidious cultural narratives through which their genital bodies had always been structured, and from which they were eager to move on.

This is like a broken bone I didn't know about. I'm going to get a cast

A theme that surfaced both quickly and consistently is the one to which Isabelle gives such eloquent voice at the start of this chapter; that is, the bodily confidence and awareness that these patients believe that they will carry with them forever. Often spoken in words very similar to Isabelle's, women spoke of the gratification that they felt towards their newly acquired vocabulary, anatomical knowledge and the greater sense of bodily mastery that went along with them. Mya, who we met in Chapter Five, struggled to bring her body across the intimate threshold required by physical therapy, but experienced, nonetheless, a developmental shift in learning how to describe her

symptoms to a provider. In telling me about how she planned to teach her daughter the “correct” words, Mya explained that this decision was a direct result of her experience(s) with gynecological medicine:

M: I want her, when she goes to the doctor ... that was *really* hard for me to say.

C: [Can you t]ell me about that?

M: You know, people don’t realize that (laughs) Um, well, you know, because of how I grew up, noone .. *talked* about it. Even when I would go to my friend, you know, you could, you could .. get around not saying any words. And, and so that’s how I’ve always been, and so it wasn’t until really that, like, ‘the doctors aren’t getting it. I need to .. , you know, des-, describe. To say what *part* .. of my vagina it is and ...’

On my prompt, Mya admitted that she had been able to point and/or gesture towards the areas of her genitals that were most painful, but that even this had come with considerable awkwardness. When I asked Mya about the word *vulva*, after she told me that she would teach her daughter “vagina,” she responded, “Yeah, that’s a new one for me, too.” Again on my prompt, Mya indicated that *vulva* felt “a little dirtier,” but she stressed nevertheless that her new vocabulary made her feel like she was “taken more seriously,” instead of like the “little girl in their world” whose pain had been effectively shelved for close to a decade.

Although Ashley was somewhat more tentative at first, she also indicated that a closer encounter with her vulva hadn’t been *all* bad:

C: What do you think that these symptoms have given you?

A: Definitely a better understanding of my anatomy.

C: Are you grateful for that? Is that a good thing?

A: Possibly. I hope that, um, it doesn’t have to be just a way of, you know, having learned that, .. that I .. have some opportunity to use it, other than just the pain management issue. Um, so .. [it] probably would have been better to learn that earlier (laughs), would have been a little more

Ashley's response nicely captures the tinges of ambivalent regret that often co-existed with this new knowledge, the wincing with which women confronted the ignorance and/or disinterest that antedated their burgeoning vulvar expertise. Isabelle reiterated: "I deal with it better now than before. I have more information, .. no more embarrassment. And I guess ... I was before. [It just] didn't feel natural to have anybody poke around down there." And for some, like Brigitte, this emerging sense of bodily mastery played out in the sexual 'holding their ground' of which they now felt more capable.

C: Do you think you would ever have sex in pain again?

B: No, if it's really bad, no.

Lastly, Tinkerbelle,¹⁰⁶ who, at the time that I interviewed her, was still working with Dr. Robichaud to get her *lichen planus* under control, spoke about it this way:

C: What do you think that these symptoms have given you?

T: Well, it's made me a little more aware of my body, you know. *And* that these things *happen*. And that, uh, you know, not to go ten years without going to a doctor, for one. And, like everything else that's gone wrong with my body, it could, it could have possibly been prevented, you know, had I, had I had more sex.

C: Mmm. What makes you say that?

T: Well she [Dr. Robichaud] told me, you know, by using, by *doing it* more, it keeps it more elastic.

C: Yeah. Yeah, but, you couldn't have prevented the *LP*.

T: Couldn't [have] prevented it? Well, I would have jumped on it sooner.

Tinkerbelle went on to say that she hoped that her daughter would be able to avoid *her* mistakes, "that, uh, I hope, hopefully that, knowledge gained is something that

¹⁰⁶ I asked my informants to choose their own pseudonyms, which was a delightful way of learning something about them. Some, like Nikki and Stella, chose a name that conjured up an 'alter ego,' while others, like Julia Kramer, chose a name that was a part of their family history. Some chose names that symbolized strong or iconic women for them—this included Ophelia and Anharad, and some strongly preferred to be called by their given names, such as Jessica and Susan. The women that provided me with a surname have been referred to that way. Tinkerbelle—with whom I developed a particularly close relationship—was the only informant who went the route of pure silliness with her pseudonym.

I can pass on to my daughter. Anyway” Many of the women that I formally interviewed spoke about this aspect of their symptoms, particularly as they tried to think through why and how ‘genital education’ had been missing from their own lives. Indeed, enough women spoke about the hypothetical talks that they would have with their daughters that it sometimes seemed as if it it was a question I had written (it wasn’t). These thoughts would often emerge towards the end of our interviews, when I asked women if there was anything that I’d left out, if there was any part of their experience that they felt hadn’t been adequately captured by my questions. Mya, who I quoted earlier, ended our discussion by reiterating that she would be “as open as I can be” with her (special needs) daughter, “mak[ing] sure that she can be comfortable. I’ll talk to her as much as I can.” When I asked her if she was referring to vulvar pain and/or disease, Mya replied, “I *will* tell her parts of it, what’s appropriate.”

In thinking about the daughters of these patients, I am struck by one more connotation of the word *generation*, one that seems particularly apt in this discussion. The real and hypothetical daughters of these women represent something like a new generation of women, one in whom we can store and kindle our hopes that it will be better; that, in the words of Foucault, “[t]omorrow sex will be good” (7). I am leaving off the last word of Foucault’s iconic sentence (which is “again”), however, because neither I nor my informants (nor many of Foucault’s feminist critics), I would venture to say, believe that it has ever been particularly “good” for a lot of women. But in lining up these optimism-fueled daughters alongside OHSU’s residents and medical students, the National Vulvodynia Association’s and the NIH’s grant recipients, the potential audience(s) for a book like mine, and the tens of thousands of women who Harvard’s epidemiologists are poised to tap with newly configured survey research, we may indeed be facing not just one, but several generations of women who will be increasingly—and

stunningly—savvy about their vulvar anatomies. Whether this *generation* will constitute a new genital order of the kind that Irigaray (1985*a*, 1993*b*, 2004) has insisted is politically necessary in a *female imaginary* (or a paternally co-opted one through which women can not achieve greater sexual “autonomy” remains to be seen. If the “realities” of *vulvodynia* and *VVS* are eventually disseminated with little more than an ‘awareness’ campaign, marked by public service announcements, an early detection protocol, and a color-coded ribbon (my money’s on fuschia), I believe we will have an adequate sense of the feminist work that remains to be done.

He won’t like that

In this new feminist-sexual order, the exchange between Cathy, Libby and David—where Libby’s pelvic floor reminds all of them that talking about sex may not be “the strength of [*any* (hetero)sexual] relationship”—would constitute some of the “sex ed” through which many of my informants felt they “should have learned” about their (non-reproductive) genitalia. This was because the poor—or missing—sexual communication that could not be ignored in the face of searing penetrative pain was a particularly poignant issue in some of these women’s lives. This was especially true for older, sometimes post-menopausal, women who were more likely to be diagnosed with *dysethetic vulvodynia* (*DV*) or one of “the lichens.” In general, these were women who had been quietly tolerating penetrative intercourse on their husbands’ terms for twenty years or more, and whose current inability to participate was forcing them both to confront the changes that might be necessary in order for them to continue being sexual together. In one of her visits with Dr. Robichaud, Anharrad put it this way: “I feel like lately my whole life is all about my vulva. And I have to work to not be resentful of my husband, because he wants sex. And he’s only getting it once a week, the poor man.”

Unlike Jessica, who was unaccustomed to refusing her husband on *any* grounds but her VVS pain, Anharrad was struggling with how to refuse sex for any *reason*, given the dynamic of a thirty-plus year relationship in which her (sexual) needs had very rarely been prioritized.

Anharrad was the first patient whose visit I observed at OHSU; we came to know each other over many months and my lunch date with her was one of the last social outings that I had in Portland. I was initially surprised—though deeply appreciative—of the extent to which Anharrad opened up to me during our formal interview, which took place just a few months after my arrival, but I have since come to think of it in the broader terms that I am exploring here. That is, not only did Anharrad want to share her story for the sake of other women who were potentially “suffering in silence,” (which she indicated to me early on), but she was also taking advantage of the opportunity to explore the shifting and potentially generative nature of her sexually-based symptoms. During one of my last clinic visits with Anharrad, she told me that she was beginning to wonder if the trials associated with her *lichen planus* weren’t some kind of “punishment” for having “participated dishonestly” in her sexual relationship with her husband “all these years.” Anharrad was quite emotional—indeed, she was near tears—as she expressed this to me in the quiet of the exam room, while we waited for Dr. Robichaud to return with her prescriptions. The fieldnotes that I jotted down later, trying to capture this difficult moment, say: *She is fairly religious, and so there is probably so much more going on than she could really describe to me in these few moments. Although this might have been one of the first times that she had the emotional space to do so.*

In telling me and Dr. Robichaud that, though her physiological symptoms were the notable ‘cause’ of the disrupted sex in her marriage, “this [dynamic] has always been

present in our relationship,” Anharrad presaged my interview with ShortRound, who recounted the equally difficult set of marital-sexual negotiations in which her *LP* had landed her. During her first clinic visit, ShortRound told us that her symptoms began around the time of her menopause, “the year my periods changed.” She said that sex had been “uncomfortable[;] not to the point where I wouldn’t do it, but I didn’t want to.” She noted that her symptoms were penetration-based, and that she’d “gotten better now figuring out where the pain [wa]s.” After a few minutes of exchange during which she and Dr. Robichaud began discussing *LP* as a possible diagnosis (ShortRound described “thinner” and “smaller” labia, as well as areas that “were like a razor blade ha[d] cut it”), the subject of dilator therapy was raised. ShortRound had been given one by a previous provider and Dr. Robichaud began to emphasize the role that they played in maintaining the “caliber [of] the vaginal vault,” particularly for patients who had lost some.

Dr. R.: You use the dilator daily when the tissue is intact. So you can *have sex*; [so you can] continue to be intimate with your partner.

SR: That’s definitely one of my goals. (original emphasis)

On the surface, ShortRound presents an uncomplicated and self-interested desire to engage in penetrative sex with her husband (again). An attention to the beginning of her narrative, however, where she suggests that she engaged in sex that was painful—*although she did not want to*—helps us to uncover a deeper dynamic that structured ShortRound’s experience of her symptoms. Because her diagnosis was *LP*, meaning that there were effective treatment options available, Dr. Robichaud did not spend any time exploring what *else* ShortRound and her husband might have been able to do; rather, and partly due to its therapeutic purpose, she quickly directed her discussion to the restoration of regular penetration (i.e., with intercourse and dilators) when ShortRound indicated that this was one of her “goals.” In our interview, however,

ShortRound—like Anharrad—told me that her husband was “uninterested” in learning about or participating in modes of sexual activity that might not only be less painful for her, but perhaps even more pleasurable.

[She] says [their] relationship has been “deteriorating”; getting “farther and farther apart” and is “really odd right now.” “He would just like to pretend that everything is hunky-dory.” I press about new conversations [but] she is vague. On my prompt, she says that she feels like she “need[s] to get better to, to see if this relationship’s going to get back into tune again,” but that her husband won’t “even engage in a conversation about it,” even when she returns from OHSU and tries to explain it. **“The way he is is I have to fix the problem.”** He knows about dilators but he “doesn’t talk about it.” (fieldnotes; my emphasis).

ShortRound’s “hav[ing] to fix the problem” sheds new light on her “goal” of returning to uncomplicated penetrative sex, as well as onto her later question to Dr. Robichaud of “Any chance that this will just go away?” Her awareness that her husband would rather “pretend” that nothing is happening echoed Mya’s description of her boyfriend’s disappointment when her long-awaited consultation at OHSU didn’t ‘fix’ the problem:

I tell him everything so that he doesn’t think I’m full of it. [He’s just like,] ‘I don’t want to hear it!’ He was disappointed [by the outcome of the OHSU visit as well:] Yeah, ‘cause I think he really thought ‘Oh good, she’s gonna come back cured, and .. right away we’re gonna have sex (laughs). I think that’s what he thought.

Mya described some “pressure and guilt” about her symptoms, but stated that relationship counseling was “not anything we’ve ever .. brought up,” a reality that was expressed by several of the women whose stories I am exploring here. When Dr. Robichaud asked Anharrad about her husband’s reaction to the idea of seeing a therapist, she told us “He’s from a different generation. He has never believed in that. He won’t like it.” She elaborated that her work with Dr. Robichaud was just “treating the

symptoms, which is the best you can do at this point,” reminding us that she could see the underlying (and less easily ‘manageable’) problem, reiterating “If i wasn’t in a relationship, this wouldn’t be an issue.”

Having to *deal with* the unexplored, unvisualized and perhaps *unknowable* aspects of a female sexuality that may be based elsewhere—anywhere—is an overwhelming task, one to which many women understandably would rather not turn on their own. In response to the interview question that complemented the one framing this discussion, i.e., “what have these symptoms *taken away* from you?”, ShortRound eloquently captures this sense of ambivalence, disappointment and frustrated wonder:

C: Do you think that these symptoms have taken anything away from you?

SR: My sex life. My, um, *intimacy* with my husband. But, and I don’t know if this has taken that away, or if it’s, a lot of things going on and (trails off)

C: [Is this] pointing to it, maybe?

SR: It’s definitely [about] enjoy-, definitely *enjoying* my, any sexual relations, .. intercourse. You know, we still have oral sex, and ... but that’s ... seems .. what’s considered? .. seems to be more about him, so (laughs), and less about me (laughs).

C: Do you think you’ll talk about that with him?

SR: I don’t know.

C: Is is something that you want? From him?

SR: No. It’s, you know, it’s something you don’t want to have to ... I don’t know

C: [I ask if they engage in more] non-penetrative sex. [Is it] part of what you do? [Do you] do [tha]t more?

SR: We haven’t talked about it. ... This is just kind of the icing on the cake for my husband and I. It’s like a weight, you just keep adding to it. It’s like what’s next?

Ashley also struggled to articulate her very mixed feelings about what she had learned about her body, and what she might therefore be able to ask or *expect* from future (sexual) relationships (she was not in one at the time of our interview). Ashley knew—and emphasized—that men had always “got[ten] off easy—we couldn’t talk about it, and so they told us it was [us] and we believed them. But now if you’ve watched Oprah

or read a book “ But her ambivalence about what to *do* with the information that Oprah and/or sexuality literature had made available to her was also explicit: “[You] have to ask for it, [and] it’s going to be an unpleasant encounter; you have to ask for it twenty times,” something that she, like ShortRound, was relatively loathe to do.

In relocating Ashley’s vulva to the center of her attention (at least intermittently), the experience of unremitting pain had compelled her to rethink the stakes of both past and future relationships. Noting that “the sale of vibrators is not going to go down in the near future,” Ashley stressed that women (like her) are “challenging” received ideas about their inferiorized place on the sexual hierarchy. She continued:

A: and I think that, had I stayed married, I probably wouldn’t, I mean, that would have, I would have

C: [You wouldn’t] have worried about this?

A: Right, because, every time I did, in my marriage you know, I was told something like ‘Relax and enjoy it,’ or whatever .. . And I just don’t, I mean, maybe because it would have reached a point by this time that ... where that would have been hard. And until it became an inconvenience for my *husband*, I probably wouldn’t have [said anything].

Ashley hopes that a partner’s “inconvenience” will no longer be the sole arbiter of her ability to speak up about circumstances that are not to her liking. Admitting that her low (sexual) self-confidence and her belief that men would find her symptoms unacceptable allowed her to “put up with a borderline abusive partner” for a time, Ashley told me that she has “plain quit that” way of thinking and behaving. In thinking about what will be “available” to her on the dating scene, she realizes that she “might have to change things—like talk about what’s uncomfortable.”

These are the unnerving conversations around which Anharrad, ShortRound, and their respective husbands are constructing variously circuitous paths. At the time of

their diagnoses, both women were defining “intimacy” in terms that depended upon their (physical) ability to practice the kind(s) of sexual intercourse that their husbands had come to expect from them. When running smoothly, this was a pattern that allowed them to divert and displace the elements and aspects of their sex life that might have been more directly “about” them. Anharrad and ShortRound’s symptoms troubled a set of sexual—and, for their husbands, very *settled*—issues; deciding upon and sticking with a treatment plan that involved therapeutic vaginal intercourse became more volatile once each of them had been able to differently perceive their husbands’ investments in *their* (thus far under-explored) pleasure. Anharrad and ShortRound, in a sense, had to decide what kind of marital futures that they wanted their symptoms to help them to create. In this exchange between ShortRound and Dr. Robichaud that occurred at the end of one of her visits, their dialogue about her proper use of lidocaine indexes the less physiological aspects of her (and her husband’s) *dis-ease* condition:

SR: [Says she wants to try using a larger dilator with some lidocaine.]

Dr. R.: Let me tell you, the 2% gel is sticky. It will probably get on your partner’s penis.

SR: He won’t like that.

Dr. R.: No, most of them don’t. [She goes on to describe how to apply the lidocaine with a cotton ball. She compliments SR again on her correct use of the medication.] I can tell that you [are] put[ting it way] up there, up inside.

SR: *It’s kind of a hard area to reach.*

Dr. R.: *It sure is, but it’s the most important.* (my emphasis)

And finally, though typically not connected to issues specific to any *one* diagnosis or disease process, a number of women answered my questions about *generativity* in terms that were straightforwardly negative. Like Clair, cited at the top of

this section, several interviewees felt no need to look for or identify altruistic or ‘self-help-ish’ elements of their experience, elements that they simply did not believe were there. Mya, for example, although she eventually elaborated on how things would be different for her daughter, was also quite clear that her symptoms had not given her “anything but grief.”

M: You know, it’s probably made me, like if, if someone was ever gonna talk to me .. ? Then I could probably be ‘Oh yeah, I understand what you’re saying.’ So, as far as like maybe, just being someone to listen to someone else. But, for *me* ... ? No (laughs).

Similarly, Susan stretched her affect a bit in order to include the possibility of ‘helping someone else,’ but ultimately did not perceive her experience in terms of gifts or generativity:

[A] lot of uh, yeah, just a lot of trouble. I think um, you know in thinking about talking to you, ... I was thinking that *perhaps* it might, um, you know, be able to contribute toward helping other people. I also thought that perhaps it might touch some doctor or some practitioner to.. to have some compassion or some empathy

For her part, and in response to a host of symptoms that did not fall neatly into one of the categories outlined in Chapter Two, Susan had developed a fairly elaborate skin and self-care regimen over the course of several months. She and her husband had been struggling to maintain physical intimacy. Although she told me that he was very supportive and that they were both simply looking forward to things being normal again, sex was a very important part of their relationship and she was anxious to get back to enjoying the empty-nest stage that they were currently in. Thinking about the care and attention that Susan was devoting to her vulvar body each day, I asked her if she imagined that she would maintain any of her regimen, should her symptoms resolve. Her

reply was succinct and unequivocal: “No. I don’t want to have to do anything special. I guess I think that if you’re a person that takes care of yourself, you shouldn’t have to.”

And lastly, there was Clair, who on her first visit to Dr. Erlich complained of ten years of vulvar pain (“it feels like someone squirted lighter fluid up there and lit a match”) *in addition to* a lifetime of anorgasmia. Clair was reluctant to ascribe any kind of silver lining to her pain, and therefore answered my questions about generativity in the “deprived” terms that opened the second part of this chapter. I noted that Clair “did not elaborate” this sentiment in my notes from our interview, and so I followed up by asking her if she was looking forward to the sex that she and Dan were possibly going to have after she had her vestibulectomy.¹⁰⁷ Clair answered me with a burst of optimism, which was quickly punctuated with the deprivation and sexual despair that colored the broader experience of her symptoms:

Chris: What about thinking about having sex, what does [that] feel like?

Clair: Oh, it’s exciting. It’s like being a newlywed again, it’s, like falling all over, like *falling in love* again. All over again.

Chris: So you still have a lot of hope? A lot of optimism?

Chris: Yeah. I have a lot of expectations and I nee-, I don’t know what’s reality and what’s, you know, gonna be normal. ... And I would, if I go through the surgery and I come home and months goes, and I’m all healed and it’s still (trails off). I, I’m going to be very disappointed, and very delusional [sic], and very ... I’m gonna feel.. ripped off. Probably.

When I returned to the clinic on the Thursday after I drove out to Bend to meet with Clair, I told Dr. Erlich about our interview. Clair had presented us with a dilemma when we’d met her several weeks earlier: in relating her history of anorgasmia, she asked Dr. Erlich if there wasn’t something that she could give her “for the desire,”

¹⁰⁷ Clair’s surgery was planned at the time of our interview but, as of my departure date a few months later, she had not scheduled it. When I last spoke to her about it, she told me that she was waiting for her husband to “lose weight,” as she did not think it fair for her to “go through all that” if he “wasn’t going to do anything” to make himself more attractive to her.

something that would make her pain feel less prohibitive. That is, Clair believed (and expressed to us) that if she felt “enough [sexual] *desire*,” it could/would allow her to transcend her pain and enjoyably engage in the kind of ravenous sexual passion that she was convinced ‘normal’ (orgasmic) women experienced on a regular basis. Dr. Erlich and I gently explained to Clair that even if such a treatment existed, we would not offer it to her under those conditions, as no one would (clinically) advocate that she have sex in pain. Clair was disappointed, insisting that the pain would be transformed in the context of *that* kind of desire—the kind that she elaborated to me over our interview, the kind that distinguished “making love” from “having sex,” and the kind that would have banished her pain to the margins of a sexual experience that came straight out of a romance novel.

I told Dr. Erlich that Clair and I had again discussed this issue, and that I had stressed to Clair that this was how insurance companies rationalized their unwillingness to pay for VVS-related vestibulectomies (i.e., that in the absence of visible pathology, a ‘functional’ vagina was a patent vagina, regardless of subjective accounts of pain), a procedure that Clair herself was scrambling to get covered. Dr. Erlich listened to my frustrated account and then asked me, “So, do you think that I shouldn’t do the surgery then?” I want to end this discussion with this question, as I think it nicely indexes both the ambiguous space that I occupied as an anthropologist at OHSU, as well as one more proliferative effect of the growing presence of vulvar pain conditions on the cultural landscape.

Chapter Seven: Evaluation | concluding thoughts

[I]t must be said from the outset that a disease is never a mere loss or excess—that there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for and to preserve its identity, however strange the means may be (Sacks, 1987: 6).

The previously stifled and inchoate nature of my informants' narratives is what shaped the analytical structure of this dissertation. In talking with my co-chairs after I'd been back from the field for almost two years, I found myself trying to explain why I wasn't writing a more straightforward ethnography. Why wasn't I, they wanted to know, taking advantage of the pioneering data that I had gathered, of my insights as a critical medical anthropologist, and of the truly emergent quality of these conditions, and composing an ethnographic account of the spaces, bodies, institutions and discourses through which vulvar pain is being *realized*? The truth is that in that conversation, I did not have a satisfactory answer for them, aside from the one that said, "I'm writing the one I'm writing." I have since given their query a bit more thought, and will begin these concluding remarks with a more proper account of how I chose to tell the story of vulvar pain.

An ethnography of the clinic itself would have included a deeper analysis of the actors just described, and of how they work together to make the diagnoses of vulvar pain cohere (Clarke and Montini, 1993). For example, I might have described the physicians' referral practices, and how, despite not knowing much about what physical therapists actually do with their clients, Drs. Robichaud and Erlich dutifully ensure that symptomatic women pursue this line of treatment. The physical therapists (on the

receiving end of these underinformed referrals) accumulate more patients, whose bodies subsequently allow them to improve their clinical skills. The patients benefiting from these sessions report their progress to the physicians, who use that anecdotal information to rationalize continued referrals. Repeated referrals and successful outcomes help to get insurance codes on the hospital and PT billing forms, which leads to a greater likelihood that a woman's insurance company will pay for her sessions. Dr. Erlich keeps checking the box for pelvic floor *myalgia*, rather than the hysterically-coded *vaginismus*, when ordering PT for a patient (see Chapters Three and Five), which helps to redefine the discourse(s) through which vulvar pain is medically apprehended. And clinicians with the resources to do so conduct research about the efficacy of physical therapy, aware of the need to do so in an "evidence-based" medical climate (Feinstein and Horowitz, 1997). In such an analysis, each of these pieces would be analyzed regarding its place in the contemporary state of vulvar pain conditions, each role delineated so as to better apprehend the orchestration(s) of VVS and *vulvodynia*.

An ethnographic account of the clinic—and of the *realization* of vulvar pain—might also include my notes from surgery. I could describe how after each procedure that I observed, Dr. Erlich would deposit the tiny pieces of vestibular flesh that she had excised into formalin-filled cups, and then instruct the circulating nurse who was waiting with a Sharpie on how to label the specimen. "Oh, is it being sent [for biopsy]?" "Yes," Dr. Erlich would reply. "What is it?," the nurse would ask. "A posterior vestibulectomy." "A what?" "Vestibulectomy," Dr. Erlich, meeting my gaze over our surgical masks and rolling her eyes, would restate, adding the spelling when necessary. My fieldnotes from one of these mornings say: *When [Dr. Erlich] cuts off the specimen [...], she lays [it] carefully on a Telfa pad. She inspects it, sort of lovingly. I gaze at it. It's seems so insignificant, incapable of causing this much disruption in a person's life.*

I think of [Dr. Erlich] in a visit, saying “This tiny area is what’s changing your life.” [In this moment], it is not impossible for me to believe that it IS responsible. I want to believe that [she] is right.

In an instant like this, actors, medical supplies, language and bodily flesh cohere to produce the condition of VVS (Clarke and Montini, 1993; Singleton, 1998). The work of this moment is both disrupted and substantiated in later and different moments, such as when I am changing out of my scrubs in the women’s locker room, and I find myself engaged in conversation with one of the (previously) Sharpie-wielding nurses:

I say hello and then ask her what it’s like to watch those surgeries. “You’ve seen a few of them now, right?” She says “Yeah,” and seems unimpressed. I start to be disappointed that this isn’t something she is all that interested in. And then—BAM!! She tells me that one thing she notices is when they are coming out of the anesthesia, “and that’s when I think the real personality comes out,” that *they are “really whiny”* [...] I say, “Oh, ‘it hurts,’—you mean that?” (Libby had complained of a lot of pain during her surgery, from beginning to end). And Jennifer says “No, like ‘I want a blanket! I’m cold!’” (she says this in a mocking, whining tone). She says that most patients when you say “‘Okay, [the blanket i]s coming,’ they get it. Okay. But these patients, *they keep asking*, even when you tell them it’s coming.” And then she says “That’s when you start to wonder what’s going on with these patients, whether it’s all in their heads, really.” (fieldnotes).

Jennifer tells me that she had been in a relationship where “some of this was going on,” and has since wondered “if it wasn’t just my body trying to tell me that the relationship was bad. That the man was wrong for me.” This nurse’s claim that her pain was resolved when she extricated herself from a “bad” relationship contradicts Dr. Erlich’s narrative about VVS, but not necessarily Dr. Robichaud’s. Nor does it contradict the story told by the physical therapists who are seeing their patients. My purpose is not to discover or substantiate the truth of any of these accounts, but rather to demonstrate one particularly fruitful facet of an ethnographic approach; that is, how the ‘reality’ of a social fact (like a disease) is contradicted and destabilized by the same institutions,

actors and discourses—the same conditions of possibility—through which it is simultaneously realized.

In this version of the dissertation, I might have also elaborated some of the less clinical conditions of possibility through which vulvar pain diagnoses emerge. These include the ambivalent nature of postfeminism and the widespread dissemination of pornography that I have already mentioned. Both of these, I argue, sustain a socially sanctioned ‘space’ for the sexually assertive discourse that allows physicians—if not patients—to directly address the sexual consequences of vulvar pain. These frank discussions articulate with the cultural ‘moment’ of sexual medicine as easily as they do with the popular appeal of *Sex and the City*. And whether because of cosmetic labiaplasty or anti-female genital “mutilation” campaigns, the plastic and vulnerable vulva is culturally available in novel and overlapping ways. In a strange twist, the reality of vulvar pain is also informed by a post-millennial gay marriage debate in the U.S. This was made clear to me in the clinic one morning when Dr. Robichaud was recounting the hurdles over which one of her patients was being forced to jump in order to get her surgery covered by her insurance company. The woman (JoJo) had to have numerous (and embarrassing) conversations with various adjusters about her inability to have penetrative sex with her husband. It so happened that Oregon was voting on a gay marriage referendum question in that year’s election, and a few of us had been discussing it just before Dr. Robichaud entered the pod. In the ‘natural law’ discourse of penile-vaginal coitus upon which the “One Man, One Woman” campaign depended, we reasoned, was there room to refuse a woman/couple the vestibulectomy that allowed them access to that aspect of heteronormativity? Was the insurance company’s reluctance to pay for JoJo’s surgery more complicit with a misogynistic or with a pro-gay marriage agenda?

Finally, I might have used ethnographic inquiry to find out, as many of my interlocutors have asked, if vulvar pain has been there “all along;” in contrast, I might have argued away this very question. In the first analysis, the disparaging discourses that constrict a symptomatic woman’s ability to adequately attend to her pain, that—perhaps—even contribute to a worsening of her condition, would be understood as inscriptive discourses written onto a “raw” body in real physiological pain. In the second, I might argue that these unmanageable vulvas are “natural symbols” (Douglas, 1973) of the discursively ‘painful’ state of female sexuality, and that these recalcitrant symptoms perform the vital (and embodied) cultural work of alerting the social body to an unacceptable state of affairs. In this (second) case, the bodies in question would become hieroglyphs or spectacles through which cultural values and social orders can be interpreted, or discursive and transcendent texts that represent the meanings ascribed to *particular* bodies in *particular* historical and cultural domains.

My arguments in the dissertation are influenced by all of the above perspectives, but my work with vulvar pain patients and their providers took my analysis in a slightly different direction. If we posit cultural discourse as a primarily complicating—or exacerbating—force, as it is in the first approach, we run the risk of underplaying the material effects that are generated by ideological and social processes. These risks have been eloquently articulated by critical race scholars who consistently demonstrate the ‘real’ effects that racist ideologies have on ‘real (and non-white) bodies.’ Conversely, we take an equally dangerous analytical gamble if we directly translate the physical experience of symptoms into representational symbols or texts. And lastly, using a framework that keeps these two approaches in dynamic dialogue does little to question the utility of either ‘side’ in demonstrating *how* it is that culture comes to be embodied, either as intensifying co-factor or as interpretable code. In locating my analysis within

the body itself, I hope to move away from this tenacious binary. I want to use vulvar pain to keep the above perspectives alive while simultaneously transforming them with new questions, questions about culturally coded layers of flesh, discourses that bypass the brain and central nervous system, and the physical recuperation of body parts stolen by cultural narratives.

The expansive nature of fieldwork allowed me to better see “how an ‘experience’ came to be constituted in [a] modern Western societ[y], an experience that caused individuals to recognize themselves as subjects” (Foucault, 1990*b*: 4). I invoke Foucault here in an attempt to formally—and finally—situate this dissertation. In this second volume of *The History of Sexuality*, Foucault continues:

What I planned [...] was a history of the experience of sexuality, where experience is understood as the correlation between fields of knowledge, types of normativity, and forms of subjectivity in a particular culture (4).

My version of Foucault’s ‘plan’ has resulted in the chapters before you, a document perhaps best characterized as a cultural analysis of the vulva—via contemporary and emergent pain conditions. My insights about this loaded body part, as well as about female sexuality, gynecological medicine and cultural physiology are eclectically derived, but could not have been gleaned without a methodology that directly involved my own body. It was vital that I sometimes had to drive hours down the coast or over the mountains for interviews, in order to physically appreciate the distance traveled by these despairing women. I needed to be invited into Nikki and Sage’s home—and see their color-coded closet—so that I could more fully apprehend the material rigidity and order through which they lived their lives. I needed to talk to Jennifer in the locker room about her “bad” relationship, and I needed to pull up to Clare’s house and see the sign that read “Dwayne’s Hideaway” (her husband’s name) to think more carefully about the *presence* that her pain allowed her to command in that marriage.

Vulvar Disease is everywhere and articulates with the multiple and contradictory discourses indexed by these snapshots. Foucault introduces his project for *The Birth of the Clinic* (1973) by stating that

what counts in the things said by men [sic] is not so much what they may have thought or the extent to which these things represent their thoughts, as that which systematizes them from the outset [...] (xix).

In my theories about vulvar pain, I attempt to account for what “systematizes” the things that get said about female sexuality. I have been paying attention to what gets said about the vulva for a long time—formally for ten years, and informally far longer. In listening and carefully attending to one very amplified narrative—vulvar pain—I have found novel ways to theorize female sexuality, gynecological medicine and the body itself. With the expertise that my co-chairs hoped I would use to write an insightful ethnography, I have instead written a more speculative, but I hope more compelling, account.

The nature of my research project allowed me to access, listen to and record voices from whom feminist and sexuality theory have heard too little. I suggest that the dissertation, by assembling and analyzing these stories, offers something new to scholars, clinicians and other friends of female sexuality; that is, a new view to the ‘postfeminist’ sexual body in the contemporary U.S (Fems, 1981). Via their vulvas, my informants have suggested that this sexuality is vulnerable, ambivalent, erratically subject to heteroregulation, precarious, alienated, and chronically at risk of disappearing. I have used these pages to suggest that vulvar pain—and this sexuality that it indexes—cannot, therefore, be successfully “managed” without an attention to its collective and cultural dimensions. But the means through which clinicians can accomplish this task remain underexamined. I will conclude the dissertation by briefly outlining some of the

paths towards which my research gestures, beginning with a final ethnographic anecdote that can frame the discussion.

I have, and would continue to characterize my relationships with the physicians at OHSU as both productive and mutually respectful, but a comment that Dr. Robichaud made towards the end of my fieldwork reminded me that the nature of my anthropological interventions and analysis remained somewhat elusive. We were discussing what seemed like a dependence that some of her patients seemed to be developing on me, evidenced by the disappointment that one of them had expressed when I was unable to be at her appointment earlier that week, and we briefly pondered what that meant for our respective goals for these patients. Noting our contentment that my presence at the clinic was at least *enhancing* (rather than negatively complicating) their experiences, Dr. Robichaud drew attention to the role that I seemed to be playing in the lives of her patients: “Well, if you think about it Chris, how are you different than a therapist?”

In that moment, my feelings were quite mixed about her assessment, as I felt compelled to wonder about my skills as an anthropologist, or at least about my ability to translate my research questions and interests to the professionals for whom my findings would be most relevant. Without any of the requisite education or degrees to qualify me as a therapist, I could only assume that Dr. Robichaud was referring to the support and attention that I was lavishing on the patients with whom I was working closely. But had ten years of doctoral level graduate education made me no more than a good—and therapeutic—listener? While I do not not disparage this quality, as I believe that it did play a role in the warmth with which I was welcomed into many of my informants’ lives, I want to address what *else* I provided to Dr. Robichaud and Dr. Erlich’s patients, particularly since I believe that these interventions work as a possible bridge between

the disciplines of critical medical anthropology and clinical medicine. That is, in clarifying what I offer(ed) to vulvar pain patients, my interventions can be more suitably translated into treatment options, research agendas, and policy proposals.

It is, of course, true that I listened attentively to the stories of diagnosed women. But what is also true is that I was *affectively invested* in their well-being and recovery. It is important that this quality of anthropological engagement be brought to the forefront of our work, particularly when we work with other disciplines. Far from disengaged or alienated social scientists, anthropologists typically care deeply about the people with whom we work. But this does not make us therapist. Indeed, the “processing” that I did with clinic patients was rarely individualized or “psychological” in nature; rather, our conversations were always guided by my interests in the anthropological and feminist implications of their experiences, and my informants were both willing and able to speak about their lives in these terms.

Indeed, I contend that it was this affective investment that enabled me to zero in on the “safety and support” issues raised by Drs. Harlow and Stewart (see Chapter Five), and to insist that they be reconciled with the previous shelving of diagnosed women’s sexually abusive pasts *and* with the culturally-located “unwanted genital experience” that is a substantial element of these disease conditions. Regardless of the physiological, molecular, and/or immunological markers that are increasingly affiliated with *vulvodynia* and *VVH*, I argue that the sociocultural processes described in this dissertation are at least correlated concerns. Additionally, in an analysis informed by a “maverick” autonomic nervous system (see Chapter Four) and psyche-soma *obligations*, these processes can be apprehended in constitutive as well as complementary terms; in such an analysis, interventions must be theorized and carried out at the social and political levels through which vulvar pain is experienced. School health and sex

education programs that address genital health and well-being, feminist analyses of labiaplasty and of the increasing distance between contraceptive methods and female genitalia, and political alliances between symptomatic women and other genitally *diseased* women (such as transwomen; see Chapter Six) are just a few examples of these more collective modes of intervention.

Secondly, the work being funded by the National Institutes of Health (catalyzed by and in concert with the agenda of the National Vulvodynia Association; see Chapter Four) must include social scientific and humanities-based research. Again, my ethnographic data suggest that even if the conditions of *vulvodynia* and VVS are purely physiological, the similarities between the demographics and social locations of diagnosed women must be analyzed regarding the corollary, causative and/or constitutive nature of these factors. Federal and interdisciplinary funding and support can bring the concerns raised in this dissertation to the same table from which Drs. Foster, Harlow and Stewart are formulating physiological hypotheses. Such conversations can help us to converge our goals, as it should be clear that increased linguistic facility and bodily knowledge can help women to more accurately describe the nature of their symptoms. At the least, this can cut down on the number of years between symptom onset and accurate diagnosis, a span of time that now averages five to seven years. A survey the size of the one conducted by the Harvard School of Public Health (five thousand women; see Chapter One), inclusive of a wide diversity of racial backgrounds, socioeconomic situations, and sexual orientations could help us to formulate new research questions about how the social sciences can help to better understand—and *treat*—the totality of these conditions.

Third, providers must communicate with each other about their clinical impressions and hypotheses, as well as about the content of and rationale for their

treatment plans and sessions. Based on my own experience, some physical therapists are not keen on surgery as an effective therapeutic strategy, as many of them believe that successful pelvic floor work can treat almost all of the problem. Physicians, for their part, don't always understand or intellectually support the bases for some of the approaches taken by physical therapists. I spent a good deal thinking about this after I heard Drs. Erlich and Robichaud disparaging craniosacral therapy in the hall one morning, as I knew full well that Cathy and Hanna—two of their favorite PTs—sometimes employed this set of techniques. These epistemological gaps must be addressed, although further ethnographic research can first provide more convincing evidence of their existence. As this was not a set of questions that I pursued in my research, I have only anecdotal data to support my assertion.

Physical therapists must also be included in the next “state of the art” conference about vulvar pain, as do social scientists. Again, whether they are purely physiological or not, we must acknowledge and explicate the cultural milieu in which these disease conditions occur, as it has profound implications for women's relative abilities to comply with treatment regimens and recommendations. As a clinic that has already welcomed an anthropologist into their midst, OHSU can stand in the forefront of these vital and interdisciplinary collaborations. A coalitional approach can also help us to better address some of the more elusive and ‘slippery’ components of this pain, e.g. the religious dimensions and racialized aspects of vulvar pain that remain relatively undiscussed in the literature. Both of these “disease” dimensions are ripe for critical analysis; this is particularly true in the latter case, as the racial makeup of vulvar pain patients is an almost direct inverse of women who are diagnosed with chronic pelvic pain (see Chapter Six), a disease condition for which the U.S. Congress—unlike vulvar pain—has never passed an act calling for increased and federally funded research.

As I discussed in Chapter Two, the relative “privilege” of the vast majority of diagnosed women must be unpacked so that we can better analyze the amounts of weight held by structural, ideological, physiological and/or other “cultural” factors; a comparative analysis of (black) pelvic and (white) vulvar pain is one way begin this project. Harlow and Stewart (2003) reported that an unprecedented thirty-five percent of their sample consisted of “non-white” women, a figure that they claimed “allowed [them] to make one of the more accurate assessments” (87) of the racial distribution of vulvar pain conditions. This claim was, in part, a response to healthcare disparity researchers who questioned the representative nature of previously published—and clinically accepted—patient demographic tables in which women of color occupied less than 5% of the space (Sadownik, 1999; Bachman et al, 2006). In this context, Harvard’s finding that “unexplained vulvar pain was *similar* among white and African American women” and that “Hispanic women were 80% *more* likely” (87; my emphases) than either group to complain of symptoms was—and remains—logical and compelling evidence that the demographics of vulvar pain warranted further investigation. In other words, if the “non-white” women who told Harvard’s researchers about their pain were even remotely representative of the general population, then their bodies remained missing from a clinical landscape inconsonant with Harvard’s findings.

This statistical reality is further compounded by the disproportionate number of chronic *pelvic* pain diagnoses that are assigned to African American women (Jamieson and Steege, 1996; Haggerty et al, 2005). Chronic pelvic pain is a diagnosis of exclusion, assigned to women whose pain cannot be medically identified by bloodwork, radiology, symptom history, genetic profile, treatment response or surgical exploration. In practice, unexplained pelvic pain is difficult to manage and associated with malingering—clinicians often roll their eyes and rally their defenses in preparation for

consults with these patients, steeling themselves for conversations where pain medication will either be uncomfortably denied or dispensed with diagnostic apathy.

In teaching and research hospitals, chronic pelvic pain—and the black bodies who appear to bear it—is linked with the ‘resident clinic,’ i.e., the gynecology practice that is staffed by recent medical school graduates still technically under supervision. Patients seen in these clinics tolerate long waits and the (relative) inexperience of the resident doctors in exchange for low and/or subsidized fees. Chronic pelvic pain has an older medical ‘reality’ than does unexplained vulvar pain, and the racialized and class-based discourses through which it is understood precede the establishment of specialty vulvar clinics. A casual remark made by one of the residents at OHSU, that “pelvic pain is black and vulvar pain is white,” raises questions about the directionality of these associations. In these parallel discursive fields, is either factor considered as causative agent? Are pelvic pain patients racialized (Omi and Winant, 1994) as “black” regardless of their ethnic/phenotypical and/or self-selected “race”? And, given these clinical ‘truths,’ can the *vulvar* pain of an African American woman be apprehended as such if she is first encountered in the resident clinic, the space of *pelvic* pain?

OHSU is a particularly compelling site from which to ask these questions because it houses one of the very few specialty vulva clinics in the U.S.—gynecology residents are able to access the expertise of the clinic physicians by spending at least one month with them during their last year at the hospital. Since the vulvar clinic only operates one half-day per week, however, the clinic physicians work with, teach and supervise these residents in several other areas of the hospital, including the resident clinic. This means that, unlike many other hospitals and clinical practices, the services received by lower-income—often African-American and Latina—women in the resident clinic at OHSU is typically provided by the very same doctors and residents who are

caring for white patients in the vulva clinic. Such a configuration renders questions of health care *access*—the frame through which many disparity scholars (Smedley, Stith and Nelson, 2003; Smith et al, 2007) explain the demographics of vulvar pain—eminently more complicated.

While I do not disagree that these demographics are worthy of investigation, particularly in light of Harvard’s provocative data, I believe that vulvar pain can help us to pursue a line of inquiry that defines *access* in less concrete terms. Ethnographically exploring both the nature and the substance of clinical consultations in each of these sites, paying particular attention to the language used by both sets of actors, as well as the scheduling and content of follow-up care, can provide us with enormous—and new—data regarding the possible differences in the clinical apprehension of “black” and “white” female sexual bodies. In the preceding chapters, I have argued that women with vulvar pain face tremendous obstacles in their relief-seeking efforts, intangible obstacles that are shaped by a broad and pernicious cultural *dis-ease* with the female genital body. But because these patients are privileged, rather than marginalized, by the multi-faceted social structures of race and class, the struggles they face in *accessing* care are missed by analyses that stop at the ‘measurable’ variables of skin color and income (Smedley, Stith and Nelson, 2003; Brown, 2007). In the comparative analysis proposed here, this argument can be extended by attending to the possible obstacles faced by non-white women to being diagnosed with a ‘white’ pain.

The hypersensitivity discourse within vulvar pain circles merits further interrogation as an apparent byproduct of this community’s efforts to medically legitimate their ‘psychosomatic’ pain. Physicians who looked harder and further for physiological bases for female genital pain have settled—thus far—on neurological explanations. Theories of ‘fired up’ nerves now pepper the clinical literature, driving

the development of treatment options meant to calm them (Foster, Dworkin and Wood, 2005). As I indicated in Chapter Two, this apprehensive framework comes dangerously close to 19th and early 20th century racist and eugenically-inflected discourses that equated such delicacy with an elevated level of civilization, relegating ‘coarser’ women—working class, non-white, immigrant—to lower rungs on the evolutionary ladder (Horn, 2003).

For slightly different physiological reasons, women with both vulvar and pelvic pain cannot participate in uncomplicated penile-vaginal intercourse and, in this way, also trouble the patriarchal order of things. Since Alfred Kinsey began asking, U.S. women have consistently reported that conventional penetrative intercourse is not their preferred route to orgasmic satisfaction, regardless of how much pleasure they take from engaging in it. Despite several waves of feminist activism and at least one sexual revolution, however, heterosexual women struggle to find partners that will consistently explore alternatives (Potts, 2002). The dissertation argues that this aspect of vulvar pain is a potential site for feminist (hetero)sexual theory, as bodies that both desire and refuse masculinized sexual scripts may index important ambivalences and confusion in a ‘postfeminist’ era; a comparative analysis with chronic pelvic pain could both expand and complicate this argument, by adding a second group of voices to the data I have gathered thus far.

In its broadest sense, such a project can question the nature of medical categories and disease classifications, and interrogate the embodied and epistemological filters through which particular bodies are understood. Clinical medicine does not operate outside of the discursive and material lines dividing black and white female bodies in the U.S.; the particular conditions under investigation in this project index, rather than constitute, disparities that cannot necessarily be remedied with greater material ‘access’

to medical care. In Portland, African American women walk through the doors of OHSU, but they turn left (towards the resident clinic) at the place where vulvar pain patients walk straight—through a different set of doors, and into a waiting room far less crowded and uncomfortable. As I discussed earlier in Chapter Six, I suspect that the physical and emotional difficulties experienced by both groups of women in confronting their sexual pain conditions are more similar than disparate, and that their narratives can mutually inform the bodies of literature from which feminist and other disparity theorists formulate their interventions. The physical segregation of these bodies, however, challenges our abilities to make these connections. Research building on this dissertation can configure new lines of connection, and ethnographically substantiate the provocative lines of similarity drawn by Harvard’s researchers in their efforts to disrupt the settling demographic profile of women with vulvar pain. In so doing, I hope to locate new sites from which feminists, medical anthropologists and clinicians can better understand the nature of the stories that ‘raced’—as well as gendered, classed and other categorized—bodies continue to tell.

It would be an understatement to say that Elizabeth Wilson’s (2004) slim volume of essays, *Psychosomatic: Feminism and the Neurological Body*, was influential in the coming together of this dissertation. Initially inspired by Mary Weismantel’s (2001) elegant discussion of the bodily accumulation of ‘race,’ my corporeal metaphor began to cohere when I visualized the eruptive manifestations that Wilson’s ‘maverick’ enteric nervous system (ENS) helped me to imagine. I want to end by revisiting that nervous system in order to offer some tentative thoughts about the future of this work.

At present, my analysis of vulvar pain has brought me not to an autonomous and objectively observable genital nervous system, but to the cultural locations, processes and dynamics with which the symptoms of vulvar disease are always-already obliged. In this milieu, where symbolic and material erasures pile up alongside and between traumatic, contaminating and disparaging vulvar events, female genitalia are discursively—and *distinctly*—primed to ‘suffer’ their worlds in particular ways. By fully incorporating the aspects of worlds that clinical researchers would prefer to sideline—without sacrificing the meticulous attention to the body that biologically attuned feminists have placed back on the map—we can more readily conceive of something like a culturally-charged vulva. Alternately innervated and anesthetized by shame, hypervigilance and violence (symbolic and material), this vulva indexes a female sexuality that exceeds the boundaries of heteronormativity and reproductive capacity; offering female-centered exit strategies to those who can *incorporate* its unsettling potential.

Appendices

Appendix A

The Normal Vulva

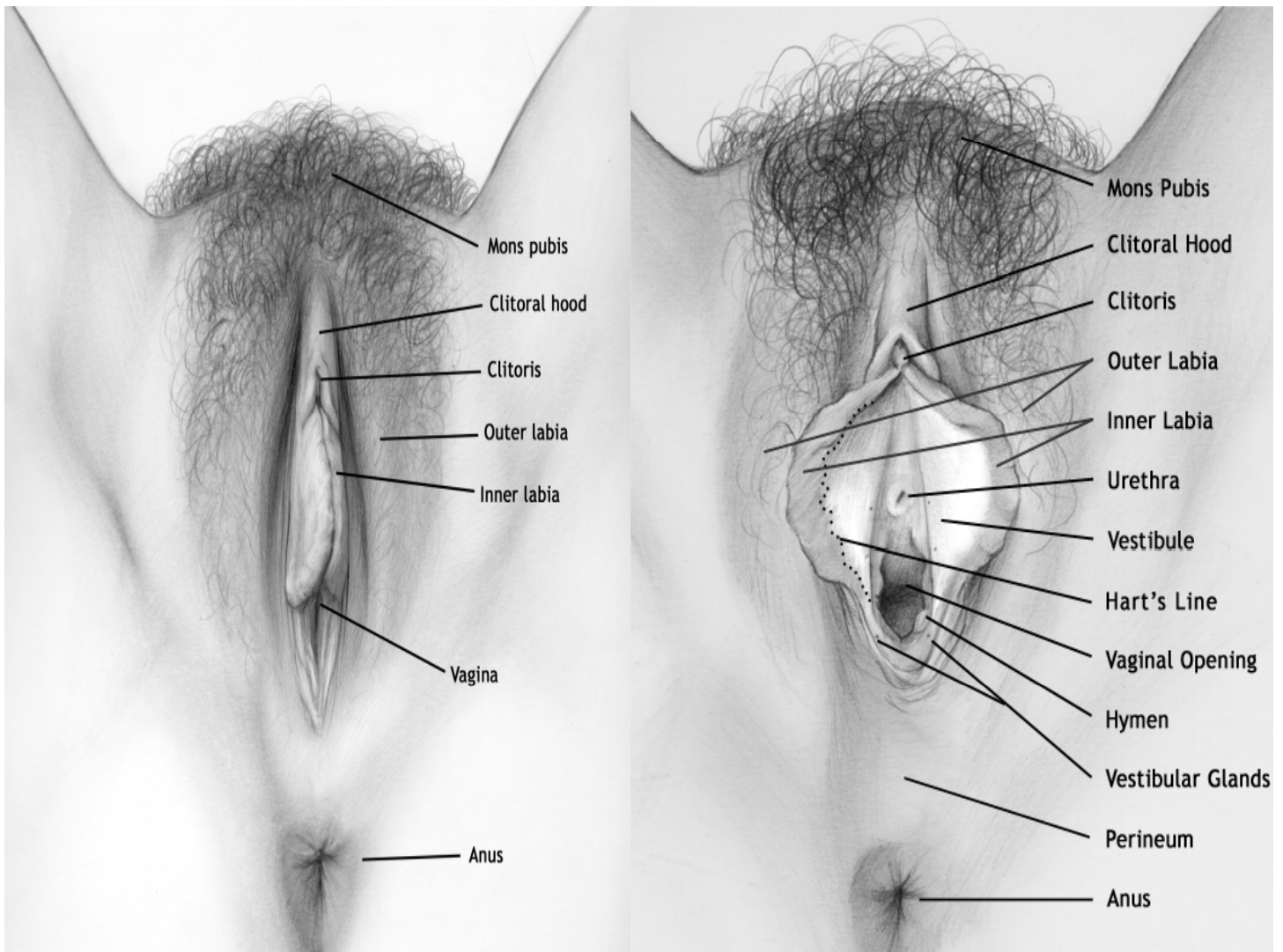
What is it?

The vulva is the female external genital organ. It is the area bounded by a fatty pad covered by hair (the mons), the groins and the back passage (anus). It has outer lips (labia) that cover the clitoris, the inner lips, and the vaginal opening. The tissue around the vaginal opening is called the vestibule.

People use many different names to describe this part of the body. Because women's genitals, unlike men's, are hidden, they can seem mysterious and confusing. It is a good idea to get to know your own body including your vulva to help to get rid of this mystery. It is also important to learn correct names for our genitalia so that we can communicate with each other and with our health care provider about our experiences, be they experiences of pleasure or pain.

How do we know what is normal?

Don't be shy! Many women get to know their bodies by taking a good look at their vulvas. This can be done by standing or squatting over a mirror and looking at the vulva. Examining the vulva allows a woman to recognize these common parts:



Appendix B



CENTER *for* WOMEN'S HEALTH

PATIENT DEMOGRAPHICS**Date:** _____

Title: _____ First Name: _____ Last Name: _____

Medical Record # _____ Social Security # _____

Address: _____

Home Phone: _____ DOB _____ Age _____

Work Phone: _____ Ethnicity _____

Cell Phone: _____ Language: _____

Can we leave a confidential message on your home phone? _____

Fax: _____

Email address: _____

Insurance Provider: _____

PROVIDER LIST

Who referred you? _____ Specialty: _____

Address: _____

Phone: _____

Fax: _____

Would you like us to send copies of your visit to any other doctors? Yes _____ No _____

Provider	Address	Phone	Specialty
_____	_____	_____	_____
_____	_____	_____	_____



SYMPTOM QUESTIONNAIRE

1. My vulvar condition began when I was _____ years old. This was _____ years ago.
2. Based on a scale of 0 (no symptoms) to 10 (worst symptoms) – what is your general level of vulvar discomfort?
Please mark the following lines to describe the level of discomfort:

VULVAR PAIN TODAY:

0 ----- 10
NONE WORST

PAIN DURING/AFTER SEXUAL TOUCH:

0----- 10
NONE WORST

3. In addition to the above, which describes your problem?

Itching

Itch without discharge

NO _____

YES _____

Itch with discharge

NO _____

YES _____

Pain, Burning, Rawness

Constantly?

NO _____

YES _____

Only with specific touch

NO _____

YES _____

Chronic abnormal vaginal discharge?

NO _____

YES _____

Skin splits:

Spontaneous splits

NO _____

YES _____

Splits just with intercourse

NO _____

YES _____

Have you noted any skin changes:

NO _____

YES: _____ Where: _____

Is the problem located in a specific area of your vulva?

NO _____

YES _____ Where: _____

Do symptoms come and go?

NO _____

YES _____

It feels better when a cream or salve is applied to my vulva

NO _____

YES _____

I wear cotton underwear

NO _____

YES _____

I use mild soaps and detergents

NO _____

YES _____

Symptoms limit the time I can sit, do activities, or do sports

NO _____

YES _____

Dietary factors affect my pain

NO _____

YES _____

I get bladder pain, urgency, frequency

NO _____

YES _____

I cannot use tampons due to pain

NO _____

YES _____

Speculums have always been painful

NO _____

YES _____

My sister, mother, or daughter have my symptoms too

NO _____

YES _____

I avoid intimate relationships due to pain

NO _____

YES _____



CENTER *for* WOMEN'S HEALTH

Symptoms continued:

Are you in a committed relationship? NO ____ YES ____

I became sexually active at age: ____

Number of lifetime sexual partners? ____ Less than 5 ____ Greater than 5

Are you having intercourse?

YES

No, due to pain

No, due to my partner's health issues

No, The reason is: _____

My vulvar symptoms started 0-6 months after a new sexual partner: NO ____ YES ____

My relationship with my partner has become strained NO ____ YES ____

I/we use artificial lubricants NO ____ SOME ____ YES ____

I experience pain at the vaginal opening during sex NO ____ SOME ____ YES ____

My sexual desire has diminished due to my symptoms NO ____ SOME ____ YES ____

My symptoms affect my ability to be orgasmic NO ____ SOME ____ YES ____

My pain started after pregnancy NO ____ SOME ____ YES ____

I have been sexually abused NO ____ SOME ____ YES ____

I have undergone a biopsy of the vulva NO ____ YES ____

When: _____

By whom: _____

Results: _____

Therapies I have tried:

It helped?

Creams or ointments

1. _____
2. _____
3. _____

NO ____ YES ____
NO ____ YES ____
NO ____ YES ____

Oral Medicines

1. _____
2. _____
3. _____

NO ____ YES ____
NO ____ YES ____
NO ____ YES ____

Other therapies I have tried:

Laser

Interferon injections

Hymen surgery

Sexual counseling

Diet Restriction

Physical Therapy

With whom? _____

Location: _____

Other counseling

Type: _____



CENTER *for* WOMEN'S HEALTH

PAST MEDICAL AND FAMILY HISTORY

For yourself, provide details and dates. For family members, please check if yes.

	Your History	MOTHER	FATHER	SIBLINGS	CHILDREN	OTHER
Stroke						
Heart disease						
Hypertension						
Asthma/emphysema						
Thyroid disease						
Diabetes						
Cancer Type:						
Alcoholism						
Drug Abuse						
Osteoporosis						
Arthritis						
Heartburn/Ulcer						
Bowel problems						
Depression/Anxiety						
Hepatitis						
Eating Disorders						

Other health issues?

List any surgeries you have had:

Description

Date



CENTER *for* WOMEN'S HEALTH

Gynecologic/Obstetric History

Age of first period _____ Date of last menstrual period ____ / ____ / ____.

History of Abnormal Paps? Yes No Treatment for HPV external warts or on cervix? _____

Bleeding after menopause? Yes No

Are periods too heavy/too painful? Yes No

Contraception? Yes No Type: _____

Current Medications (prescribed or over the counter)/supplements/herbs

Medication	Reaction
_____	_____
_____	_____
_____	_____
_____	_____

List ALLERGIES to medications including reactions

Medication	Reaction
_____	_____
_____	_____
_____	_____
_____	_____

Social History and habits:

Single	Partnered	Married	Divorced/Separated	Widowed
Do you work outside the home?		Yes	No	
What is your occupation? _____				
Do you have children?	Yes	No	Vaginal births # _____	Cesarean births # _____
Do you exercise?	Yes	No	Type/frequency _____	
Alcohol use:	Yes	No	Amount per day/week _____	
Tobacco use:	Yes	No	Past use: Yes No	
			# of cigarettes per day _____	Age began _____ Age quit _____
Drug use:	Yes	No	Type: _____	



CENTER *for* WOMEN'S HEALTH

Do you have any of the following symptoms currently?

Abdominal or pelvic pain

Constipation / diarrhea / blood in stool

Heartburn / trouble swallowing

Urine leakage

Joint / muscle pain

Breast lumps / nipple discharge

Shortness of breath

Visual/hearing problems

Weight loss, fevers, chills, sweats

Headaches – migraine or tension

Numbness / tingling / weakness of extremities

Depression, anxiety, irritability, trouble sleeping

Hot flashes / vaginal dryness

Other concerns? _____

All other body systems are negative



CENTER *for* WOMEN'S HEALTH

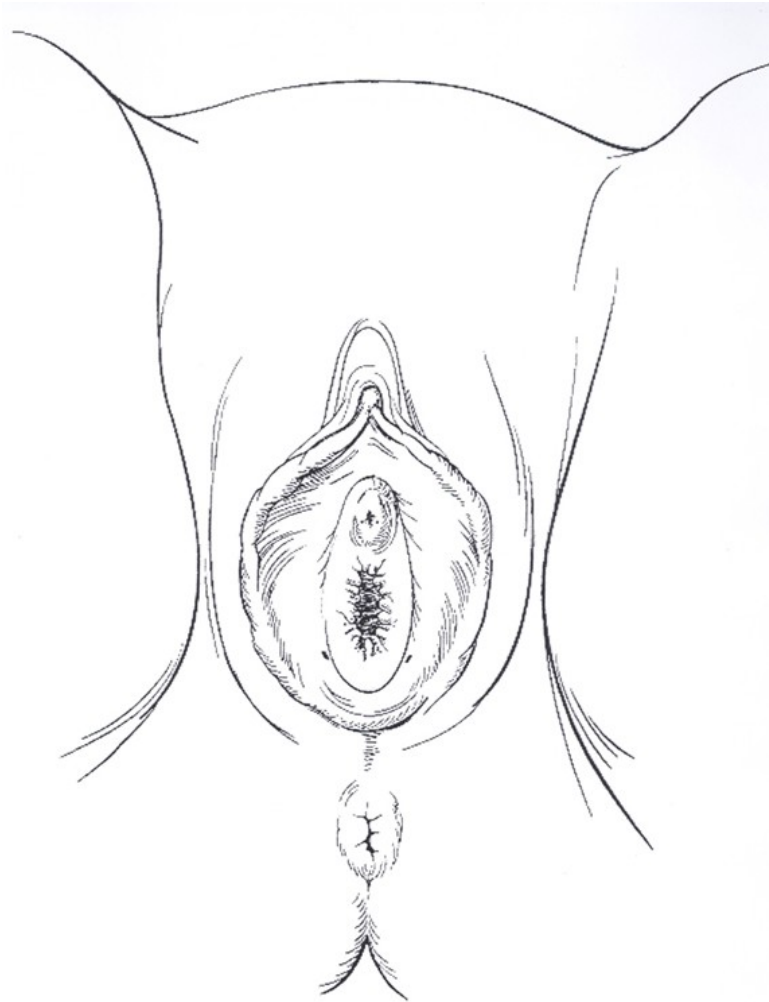
Physician's Physical Exam

- | | |
|-----------------|----------------|
| 1. Height _____ | 5. Pulse _____ |
| 2. Weight _____ | 6. Temp _____ |
| 3. BMI _____ | 8. Psych _____ |
| 4. BP _____ | |

General Physical	NE	Norm	ABN	Details
♦ Skin				
♦ Neurological				
♦ Abdomen				
♦ Masses or tenderness				
♦ Hernia				
Pelvic Exam	NE	Norm	ABN	Details
♦ External Genitalia				
♦ Clitoral Hood				
♦ Labia Majora				
♦ Labia Minora				
♦ Vestibule				AQ Lidocaine reverses allodynia
♦ Post Fourchette				
♦ Perineum				
♦ Urethral Meatus				
♦ Urethra				
♦ Bladder				
♦ Vagina				
♦ Left Muscles				
♦ Right Muscles				
♦ Cervix				
♦ Uterus (describe)				
♦ Adnexa/Parametria				
♦ Rectum (digital exam)				
♦ Anus				
♦ Other				



CENTER *for* WOMEN'S HEALTH



Aqueous lidocaine reverses tenderness

Wet Mount: PH 3.5 4.0 4.5 5.0 >5.5

_____ Inflammation
_____ Lactobacillus
_____ Spores

_____ Immature Squames
_____ Hyphae
_____ Trich

_____ Mature SQ
_____ Clue cells
_____ Other



CENTER *for* WOMEN'S HEALTH

ASSESSMENT:

1. Dermatologic
2. Infectious
3. Anatomic
4. Myofascial
5. Bartholins
6. Generalized vulvodynia

7. Vestibulodynia
8. Sexual
HSDD; Arousal; Orgasmic
9. Psychological
Depression; OCD; Anxiety

Outside records reviewed _____

PLAN: _____

Aqueous Lidocaine 4% _____

Lidocaine 2% Gel _____

5% Ointment _____

Culture bacterial _____

Culture fungal _____

Pt Referral to: _____

Pt handouts: _____

NVA brochure: _____

Counseling referral to: _____

Return for follow up: _____

Visit record faxed to referring MD: _____

Additional Dictation _____

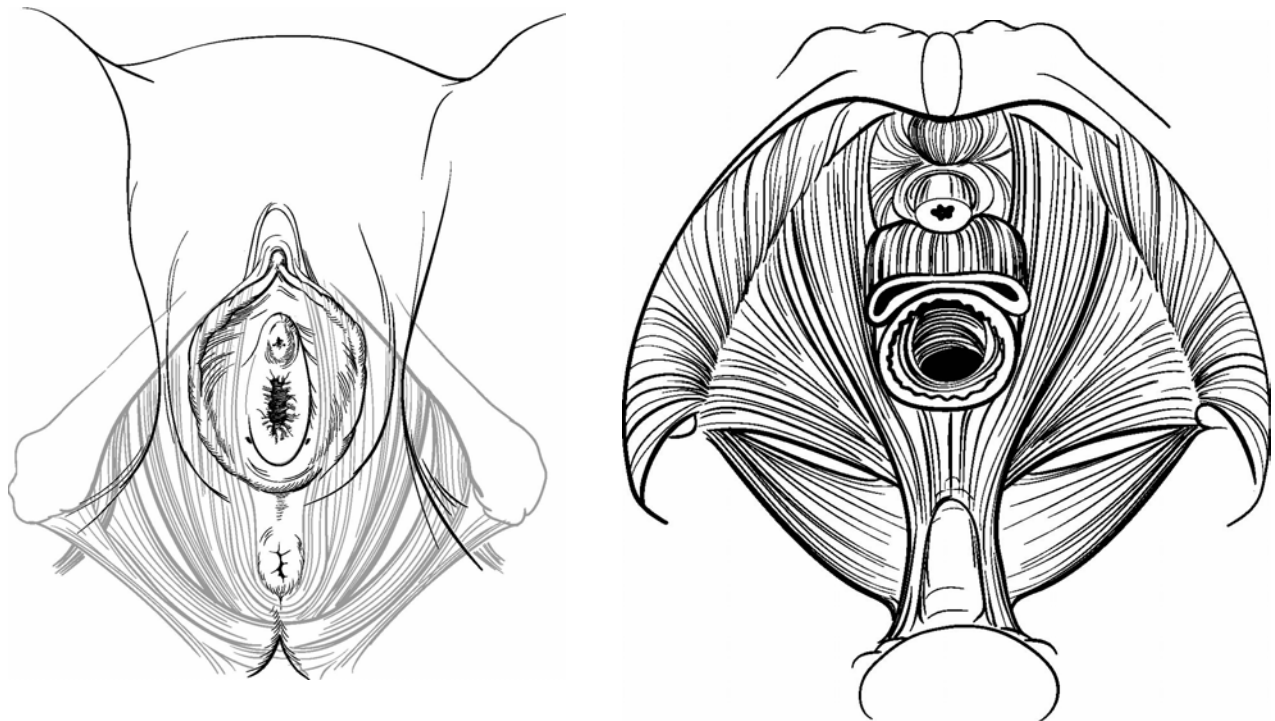
LENGTH OF VISIT _____ **MINUTES > 50% COUNSELING**

Appendix C



Vaginismus

Vaginismus is a common response to vulvar pain and it is seen in at least 50% of all women with vulvar pain conditions. Vaginismus results from pelvic floor muscles (which lie next to the vagina) tightening in anticipation or response to pain. These muscles (see illustration) contract in response to attempts to introduce something into the vagina, whether it is a penis, finger, tampon, or speculum, creating discomfort that may range from dull soreness to acute burning pain. Anticipation leads to spasm, which then leads to pain.



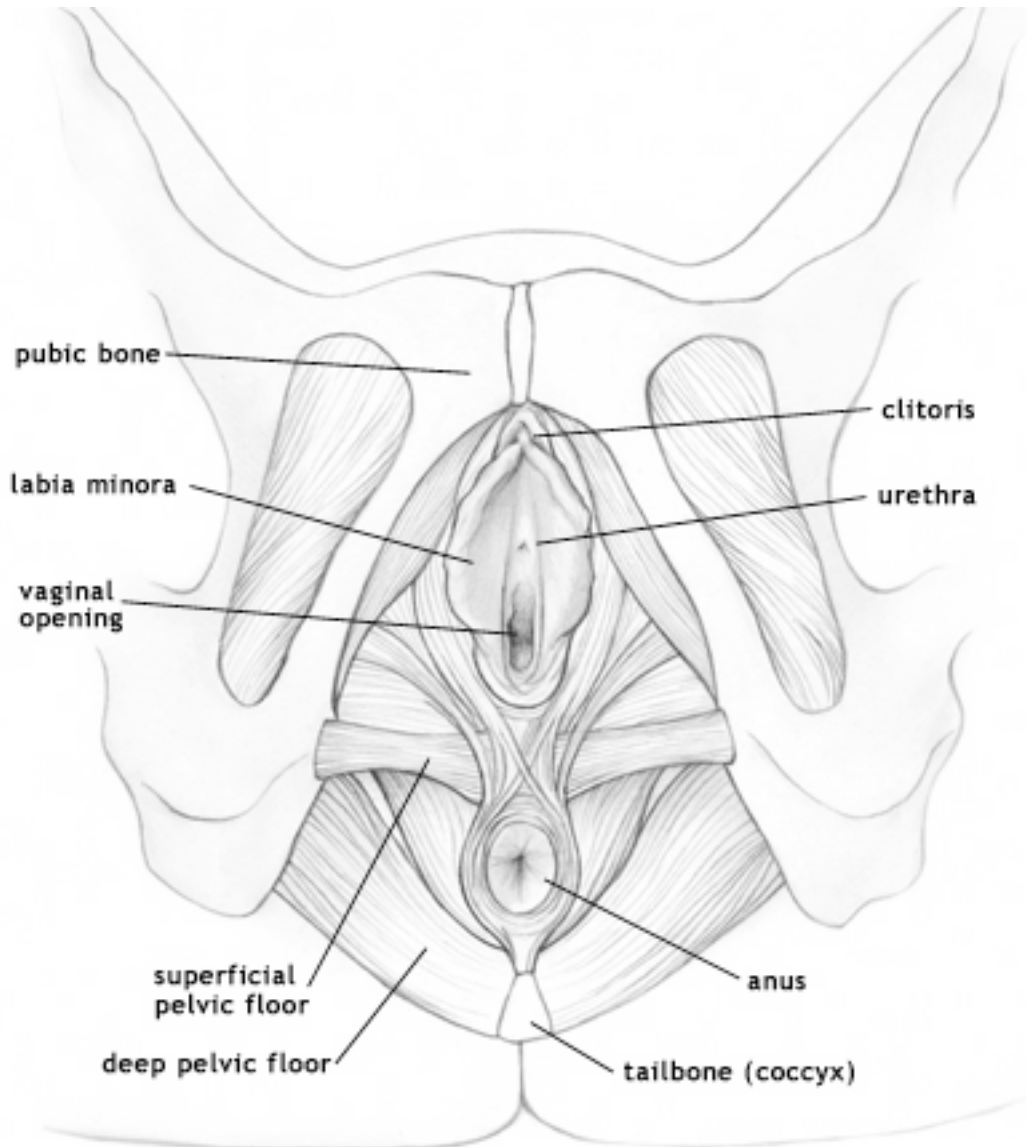
Appendix D

The Pelvis and its Structures

What is it?

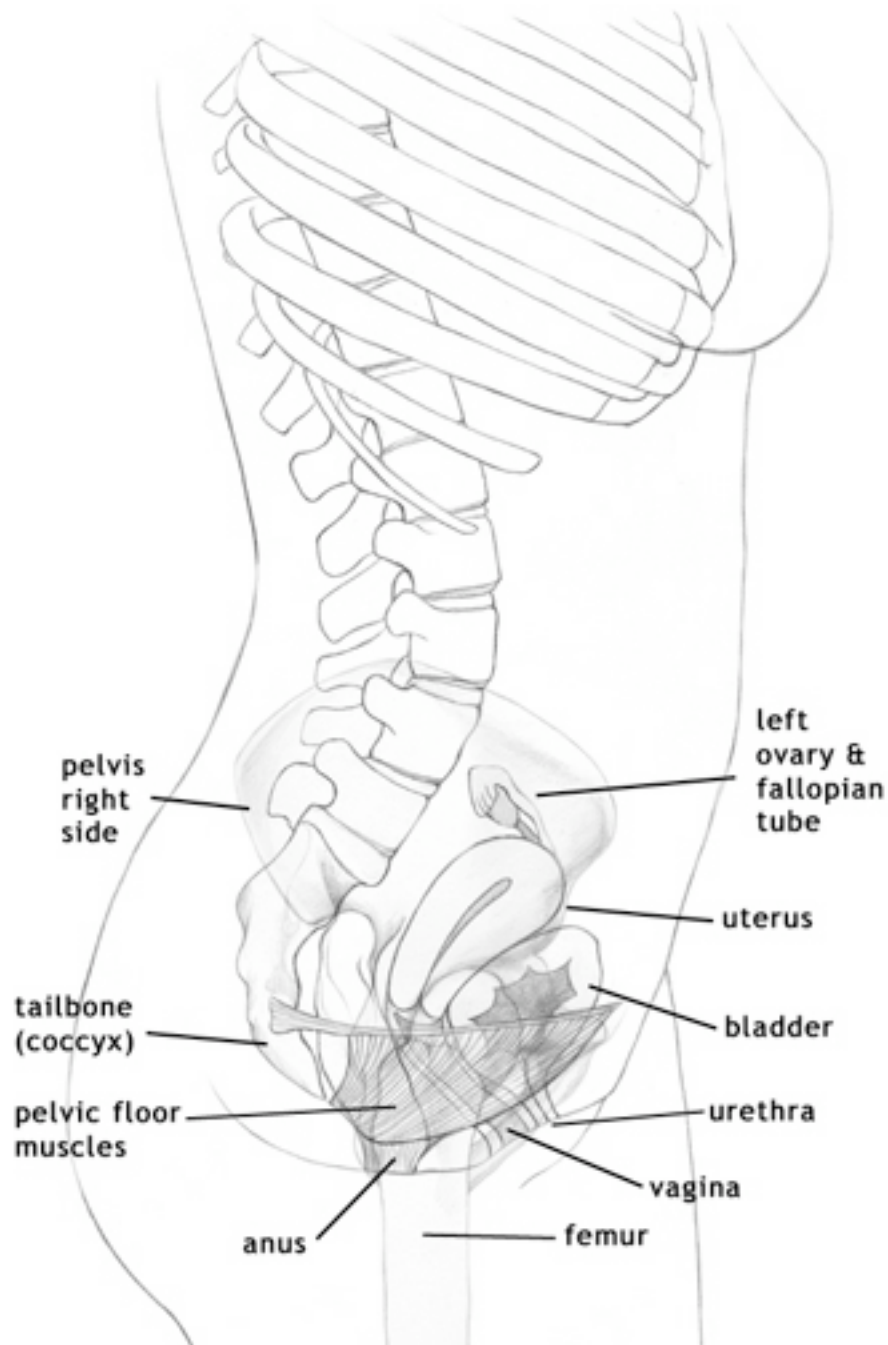
The **pelvis** is a ring of bone that stabilizes the body at its center. It is the connection between the body and the legs. There are muscles on the inside of the pelvis called the **pelvic floor muscles**, forming both **superficial** and **deep** layers. These muscles help support and position the **clitoris**, the **urethra**, the **vaginal opening**, and the **anus**. The muscles form a sling within the pelvis, attaching in the front near the **pubic bone** and in the back at the **coccyx (tailbone)**.

What does it look like?



What does it do?

The bony **pelvis** acts to protect the **bladder**, **urethra**, **uterus**, **vagina**, **ovaries**, and **rectum**, all of which are found within the ring. The **pelvic floor muscles** not only serve as support, they help to control bowel, bladder and vaginal function. The pelvis also serves as an attachment for muscles from the back, the abdomen, and the legs (both in front and in back). These muscle structures are what give us the ability to stand upright, to walk, to sit, and to lie down.



Appendix E



Vaginal Dilators

We have found that many women who have vulvar pain conditions also have "vaginismus", which results from the pelvic floor muscles (which lie next to the vagina) tightening in anticipation or response to pain. This tightening response often leads to vulvar pain and painful sexual intercourse. Lubrication is also compromised when discomfort is associated with sexual touching.

Vaginal dilators are silicone or plastic products that are available in a variety of sizes. They are to be used in the privacy of one's home to gain confidence, knowledge and awareness of the vagina and pelvic floor muscles. The goal of vaginal dilator therapy is to learn what triggers the pelvic floor muscles to contract and to develop strategies to keep the pelvic floor relaxed and soft, as you gently introduce dilators of progressively larger sizes into the vagina. With confidence, the insertion of dilators can be comfortable; that skill is then transferred to sexual activities.



At-home Dilator Therapy

Read completely before beginning your first session.

Since relaxation is essential for your success, it is important to select a time and a place when you can have privacy and warmth to practice dilator therapy. Start with the smallest dilator if you are using a set of dilators. Begin by liberally lubricating your vaginal opening (vulva) and the dilator, which will ensure that the dilator will be slippery and easy to place in the vagina.

Now lie on your back with your legs bent or lie on your side in a comfortable position. Notice your body. With your mind's eye scan your body for any areas of tension and focus on relaxing them. Pay particular attention to relaxing your abdomen, buttocks and thighs and pelvic floor muscles. When you feel that you are relaxed slip the dilator gently into your vagina. Continue to breathe and move in a relaxed manner. After a few minutes slowly remove the dilator. Follow the manufacturer's recommendation for cleaning and storage.

If you notice any discomfort burning or tightening, try one of the following strategies that have been recommended by patients and professionals:

1. Follow your out-breath, as you let go and soften the muscles of the pelvic floor. It is easier to relax the muscles during the exhalation phase of the breath cycle. Several women have suggested that counting aloud as they exhale is helpful.
2. Visualize your vagina and pelvic floor in a state of softness. A patient offered this image: "imagine my vagina is made of stretchy elastic that can expand at my will. I picture my vagina enlarging to accept the dilator."
3. Carefully attend to the messages you are receiving from your body. Keep your belly soft and open to your breathing, keep your legs comfortably relaxed and keep your breathing easy and gentle. This will allow for gentle, gradual relaxation of the pelvic floor muscles.

The complete session, including the relaxation and dilator therapy, will last about fifteen minutes. You might only have the dilator in place for less than 5 minutes. Be patient and gentle with yourself. Success is your ability to relax the pelvic floor muscles for any time period. When the dilator you are using is very comfortable and easy to place in the vagina you can progress to the next larger dilator. Some women will benefit from doing this exercise daily and others every other day. Please ask your clinician or physical therapist what is appropriate for you.

When you are using the dilator that is approximately the size of your partner's penis, you might consider adding intercourse to your sexual sharing. Initially you will feel more comfortable using positions for intercourse where you feel that you have the most control on the placing depth and intensity of penetration.

If you feel "stuck" or unable to work with the dilator comfortably, consider consulting a psychotherapist or physical therapist with expertise in this area. They should be familiar with vaginismus and vulvar pain and able to assist you in progressing through the vaginismus treatment program. Psychotherapy can help with unresolved personal or relational issues. Physical therapy can assist in specific treatments to relax muscles of the pelvis including manual therapy, exercise, and biofeedback.

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