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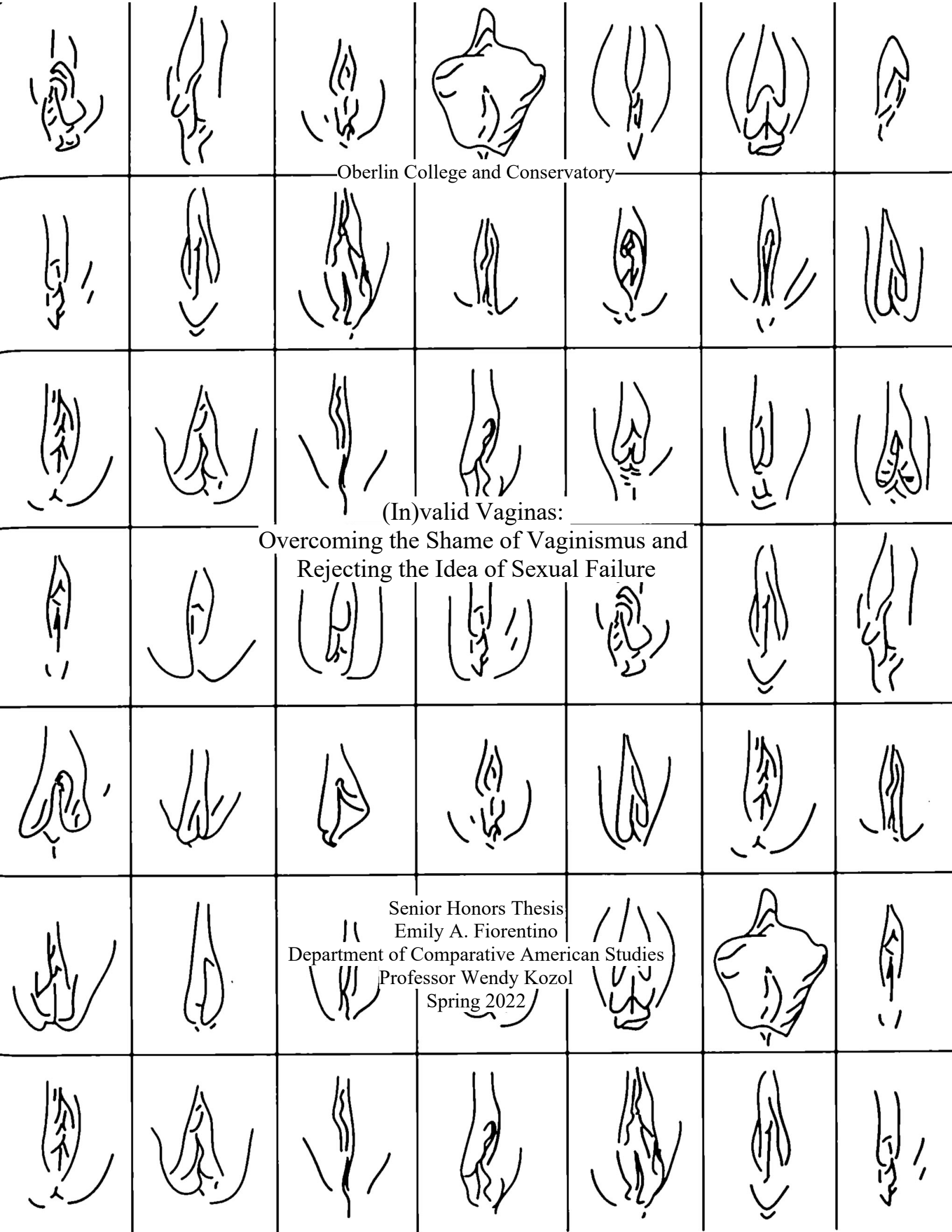
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(In)valid Vaginas:

Overcoming the Shame of Vaginismus and
Rejecting the Idea of Sexual Failure

Senior Honors Thesis
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Spring 2022

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Portland (OR): Microcosm Publishing, 2017.

Abstract

This paper seeks to understand why pelvic pain conditions cause women to feel such intense shame, and to begin to untangle the many tensions these conditions embody. Pelvic pain — particularly vaginal pain that causes pain upon attempted penetration into the vagina, including during sex — is commonly experienced, yet is only beginning to become common knowledge. Women with these conditions feel a great deal of shame, anxiety, and self-hatred, yet often suffer in silence. This paper examines how pelvic pain conditions are at once not taken seriously by the medical establishment, and have not been given the attention and research they deserve and, at the same time, how medicalization and the complex social expectations that govern pelvic pain make women reliant on treatment that will never be able to fully cure them. Women deserve to be able to understand and treat their conditions, but their suffering is also inextricably complicated by their perceived “failure” at being a woman, and the resulting disbelief in their worth as people, that is caused by their inability to have penetrative sex. I will argue that biomedical models of treatment will therefore never be adequate in fully addressing pelvic pain conditions, because they will never be capable of solving the forces of gendered norms that cause much of the suffering that these conditions induce.

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This paper was a labor of love, and I have been so humbled by all of the people who came to love it along the way, too. I would not have made it to this point without the support, validation, and gentle pushes of my dedicated advisor, Wendy Kozol. She has diligently read each new piece of my writing nearly every week since early December, and has always struck the perfect balance between indispensable feedback, and giving enough praise to keep me going. She has supported this project from the moment I proposed it to her well over a year ago, and I am forever grateful. Thank you, thank you, thank you.

My mom has also gone above and beyond in supporting this paper. She has spent untold hours laboriously editing my many drafts, on top of the time she has taken to talk through arguments with me, and listen to all of my complaining. She has been my biggest cheerleader throughout this thesis process, and in my preceding journey of struggling to make sense of my pain, doctor's appointments, and shame. Thank you endlessly for your infinite support, and for always coming through as my MVP when I need you.

Thank you also to my friends, who have endured many, many hours of me working on this project in the living room. They have listened to every enraging quote I've found, every blog post whose devastation I couldn't move past, and have made me laugh with never-ending vagina jokes along the way. I love you guys.

And to my dad, my sisters, Maddy and Katie, and all of my other family and friends who have supported me along the way, thank you knitting a web that gave me encouragement and love everywhere I went. I usually needed it, and I always had it.

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And lastly, thank you to every acquaintance who asked me about my thesis in casual conversation, probably not expecting it to be about vulvovaginal pain, but who responded with great enthusiasm for my "inappropriate" topic nonetheless. Every time this paper was treated as a valid topic of study, it gave me hope for the women who confide in others about their pain, and it made up for every time I was instead met with flustered apologies.

Introduction

When I was ten years old, I got my period for the first time. I was still just a kid, but I tried to use a tampon and when I failed, I knew there was something wrong with me. I would try to put in the tampon, something I knew I should be able to do, and immediately feel sharp and aching pain. It felt like I was hitting a wall, and that wall hurt a lot. No matter what I tried, no matter how well my mom coached me through the bathroom door, the result was always the same. Over the next decade, I went through cycles of giving up: I would accept that the effort was useless and that I would never be able to use tampons, but then I would still try again. It was always the same — I would become inexplicably filled with determination and would give myself a firm ultimatum that this time, I would try until I could do it. But always, I hit that wall, and every time, I was overcome with frustration and shame, and would end up sobbing on the bathroom floor. I can now recognize how these attempts immediately triggered my devastation at failing over and over again, for years, at something I knew I should be able to achieve.

However, in a theme that will become overwhelmingly prevalent by the end of this paper, this physical block was nothing compared to the anxiety it gave me. My mom gave me “the talk” after my first period, explaining in detail what sex is, without abstraction. This meant that, especially as I became exposed to sexualized media in early middle school, I connected the dots that I wouldn't ever be able to do it. I don't remember the moment I realized this; I don't even know if there was a single moment, because I don't remember ever not knowing. Throughout

high school, as I drifted closer and closer towards an age where I would be expected to get a boyfriend and have sex, my shame and anxiety only continued to grow. When I lay in bed at night, if I started thinking about sex, or relationships, or my future, my heart rate would noticeably accelerate. I would feel so much panic that I had to put all of my energy into pushing these thoughts back into their compartmentalized box, or else I would never get to sleep. This was my deepest, darkest secret, and I absolutely hated myself for it. I used to vow to myself that I would never, ever tell anyone that I couldn't have sex, or that I felt so afraid of ever being in a relationship. I couldn't even entertain the thought. I prayed it would just solve itself. There was no part of my coming of age that was not heavily mediated by a problem that I had no words for.

The idea that I should feel so ashamed of this pain came from so many places that I can't identify a single source, but I deeply internalized it. The assurance of social repercussion was paralyzing, and I never once questioned the validity of my fears. I don't remember ever feeling the injustice of my trauma, or ever thinking "I shouldn't have to feel this way," because I so deeply believed in the expectation that I would and should have penetrative sex. On the contrary, I wholeheartedly blamed myself. I was certain that I was the only person who struggled like this, and I don't think it ever occurred to me that that might not be true. My shame was all-consuming.

This paper is about women who experience similar pain, and why it causes us to feel such intense self-hatred. Now that I'm older, I *do* think that no one should feel the way I felt in adolescence. I didn't know it yet, and wouldn't for many years, but I was not alone in my pain — physical or emotional. In the past year and a half, as I've begun opening up to women around me about this experience, a shocking number of people I'm close to have revealed remarkably similar histories. In addition, as both of my sisters have started having children, I've frequently

listened to frustrations that are representative of the ways that women's bodies are medicalized, controlled, and stigmatized. Women are widely given less consideration and are taken less seriously by medical professionals than men, and this truth is particularly applicable in the context of pelvic pain.

“Pelvic pain” is a general term for any pain that occurs in the pelvic area.¹ This can include conditions of the urinary tract and bowels, but often refers to pain within the reproductive system, most often in the uterus, vagina, or vulva. Many of these conditions make it impossible, difficult, or very painful to insert anything into the vagina, sometimes even just a finger. But these conditions are not simply pain in need of treatment. All chronic pain has a lasting impact on one's sense of self, but pelvic pain uniquely shapes how people think of themselves as women, measure their success as social beings, and navigate their relationships to themselves and to others. Female identities are forged within the embodied experience of penetrative sex, and without that, their senses of themselves as women are put into question. Often, the greatest suffering these women experience stems not from the pain itself, but from “failing” in the social expectation to have penetrative sex. At best, pelvic pain conditions are an inconvenience that can prevent someone from using tampons or having penetrative sex, but at worst, they are something that destroys a woman's self esteem, her ability to forge intimate relationships, and her belief that she is a “real” woman.

At its core, this paper seeks to understand why these conditions cause women to feel such intense shame and self-hatred, and to begin to untangle the many tensions these conditions embody. Pelvic pain exists at a nexus of medicalization (and problems regarding structural inequality in the medical field), an endless history of stigmatizing women's bodies and denying them agency and pleasure, and the gendered roles that women are expected to fulfill. This paper

¹ “Chronic Pelvic Pain,” American College of Obstetricians and Gynecologists.

examines how pelvic pain conditions are at once not taken seriously by the medical establishment, and have not been given the attention and research they deserve and, at the same time, how medicalization and the complex social expectations that govern pelvic pain make women reliant on treatment that will never be able to fully “cure” them. Women deserve to be able to understand and treat their conditions, but their suffering is also inextricably complicated by their perceived “failure” at being a woman, and the resulting disbelief in their worth as people, which cannot be solved by medical intervention. Nor should their “failure” necessarily, even be seen as a problem that inherently *needs* to be solved. I will explore these complexities and argue that biomedical models of treatment will therefore never be adequate in fully addressing pelvic pain conditions, because they will never be capable of solving the forces of gendered norms that cause much of the suffering that these conditions induce.

Background

My research focuses on one pelvic pain condition in particular: vaginismus. This is an involuntary spasming or tensing of the vaginal muscles that causes pain upon attempted penetration into the vagina. Experiences vary greatly, but for many the pain is excruciating, and is often described as feeling like one is being split in two, or being stabbed with a knife. Women say it feels like they’re hitting a wall, and it usually does prevent vaginal penetration. Vaginismus is also often associated with fear, anxiety, past trauma, and a history of sexual assault, and thus is often viewed as purely a psychological problem. But vaginismus can also have been present since birth, without an instigating event. When we think of chronic pain, we think of people who are in pain all the time. Rightly so, we think of conditions that impact day-to-day life, and that are a constant battle to live with. Or, even if the pain comes and goes in waves, it is always

enduring, ready to be activated. However, vaginismus is unique in that it almost always only causes pain upon penetration. For most women with vaginismus, if they never tried to insert anything into their vaginas, they could go their entire lives without pain, but the potential for pain will always be with them.

The experience of having and treating vaginismus, more than any other pelvic pain condition, exposes the tensions outlined in the previous section through a unique confluence of three factors. First, it is idiopathic — having no known medical origins — meaning that upon a pelvic exam or other tests, there is no pathological evidence for why the condition is occurring. Because of this, doctors often say to vaginismus patients, “there’s nothing wrong with you,” and “it’s all in your head,” which both invalidates women’s pain and feelings, and also delegitimizes the continued study and recognition of vaginismus by not acknowledging that there is a problem in the first place. Second, as mentioned above, it primarily manifests as pain with penetrative sex, medically named “dyspareunia,”² and often prevents this kind of sex from being possible, or significantly hinders it. As we will continue to see throughout this paper, the inability to have penetrative sex is incredibly significant in women’s lives, and to their feelings of self-worth. Third, this condition is often chronic, and is difficult to treat. Although it can also be short term, many women live with vaginismus for their entire adolescence and adult life. Thus, it has often impacted years of identity formation. Other common pelvic pain conditions, such as endometriosis, interstitial cystitis, or pelvic inflammatory disease can certainly have similar stigma attached, but are significantly different in that they have clear diagnostic criteria with visible pathology, do not always impact sexual activity in the same way, and, with the exception of endometriosis, are temporary and treatable. These criteria also allude to some of the problems

² Throughout this paper, I will frequently use “dyspareunia” as a catchall term for conditions that cause pain upon penetrative sex, or simply the experience of having pain during sex.

with discussing and studying vaginismus, such as defining who are the “women” I refer to, determining how widespread this condition is, and knowing who is included in scholarly and medical discussions.

“Woman” in the context of this paper refers primarily to cis women for two reasons. My primary sources consist of blog posts from an online forum and a collection of TikTok videos, and I was unable to gather evidence from them that relates to the experience of trans and nonbinary people with pelvic pain. But more importantly, the social norms and expectations that are examined throughout this paper are rooted in the experiences of being raised and socialized as a woman in the United States, and how lived expectations of femininity intersect with pelvic pain. Alyson Spurgas, the author of *Diagnosing Desire*, a book that investigates femininity, biopolitics, and sexuality, comes to a similar conclusion in her book, saying that although “woman” is *not* a singular, binary gender, she uses it as such because it is treated this way by the literature that she critiques.³ It is because of this assumption of gender as an immutable identity that the critique becomes relevant. Terms like “femininity” and “woman” are taken for granted as monolithic categories in medical and scientific literature, and therefore that idea is being actively created and reinforced by that work.⁴ The voices of trans and nonbinary people deserve to be sought out and further considered in their own right, but their experiences did not fit into the scope of this research.

Similarly, I do not have enough demographic information about the authors of my primary sources to responsibly discuss race as a factor. Women of color, particularly black women, are given even less attention, respect, and legitimacy in medical contexts than white

³ Spurgas, *Diagnosing Desire*, 9.

⁴ Ibid

women,⁵ particularly when it comes to pain management.⁶ However, there is not enough evidence on pelvic pain specifically for me to make more than generalized arguments about how race functions in this context.

The prevalence of pelvic pain is difficult to measure because it is not always reported to physicians, and there is no way to know how many women there are who have not disclosed their pain. However, an epidemiological study published in June 2020 estimated that dyspareunia affects 10-28% of the population in a lifetime, which is consistent with other estimates.⁷ Whatever the number, all estimates are inevitably under-counting the number of people who experience pelvic pain, due to the lack of reporting, frequency of misdiagnosis, and frequency with which providers disregard reported pain and fail to make a diagnosis at all.

Like many other chronic pain conditions and autoimmune disorders, it is incredibly common for a patient with vaginismus to see multiple physicians before receiving a diagnosis or treatment. For example, in a sociological study about vulvodynia,⁸ the majority of their participants had 3-9 medical appointments before receiving a diagnosis, while 35% went to 15 or more, and 35% didn't get a diagnosis at all for 36 months or more after beginning to see a doctor.⁹ Collectively, their sample received 39 different misdiagnoses before getting an accurate

⁵ See introduction to Sacks, *Invisible Visits*.

⁶ Sacks, *Invisible Visits*, 9.

⁷ Gupta and Tayyeb, "Dyspareunia."

⁸ Defined as pain in the vulva, or the outside of the vagina. Vulvodynia can either be provoked or unprovoked, and can cause a great deal of pain and discomfort in day-to-day life, as well as upon attempted sexual activity. It shares many characteristics with vaginismus, such as its idiopathy, however, because the pain impacts daily life, not just attempted sexual activity, I decided to exclude it from the scope of this project. However, it will occasionally be referenced as it is frequently discussed, studied, and diagnosed in tandem with vaginismus.

⁹ Brix, et al., "The diagnosis of provoked vestibulodynia," 329.

For further context on estimated prevalence, this study from 2013 reported that 4-8% of women are currently experiencing vulvar pain, and 10-18% have had it at one time. These are astonishing numbers when emphasizing that this is only vulvar pain, and does not include any other chronic pelvic pain condition (Brix, et al. 324).

one.¹⁰ Yet even the researchers, who had presumably educated themselves extensively on vulvodynia prior to designing the study, significantly underestimated the lengths that these women had to go to be diagnosed. They had to recategorize their system of analysis after receiving their results because they hadn't expected anyone to have had more than 15 medical appointments, or to have gone more than 36 months before getting a diagnosis, yet in reality, over a *third* of their sample fell into those categories.¹¹ Even for women with the resources to do so, seeking treatment for pelvic pain is an arduously long process.

Finding reliable data is particularly difficult when investigating how pelvic pain affects marginalized women. In general, their pain is taken less seriously, and it is more difficult for them to receive accessible care. White women are, unsurprisingly, diagnosed at vastly higher disproportionate rates and are diagnosed differently than women of color, which is compounded by the fact that women of color are rarely included in clinical trials.¹² For example, white women are more likely to be diagnosed with vulvar pain, whereas women of color are more likely to be given the general diagnosis of "Chronic Pelvic Pain." Additionally, it is more likely that physicians will rely on "markers of difference," like race, language use, clothing, etc., over reported symptoms.¹³

In a different study measuring the correlation between level of education and level of pelvic pain reported, the group that identified as having less than a high school education reported significantly more pain in every category of measurement.¹⁴ Because low levels of education often correlate with lower socioeconomic status and race, this study suggests that marginalized women actually experience a greater amount of pain. However, it is also possible

¹⁰ Brix, et al., "The diagnosis of provoked vestibulodynia," 330.

¹¹ Brix, et al., "The diagnosis of provoked vestibulodynia," 328.

¹² Labuski "A Black and White Issue?" 163.

¹³ Labuski "A Black and White Issue?" 160-162.

¹⁴ Bachman et al., "Educational achievement and pain disability," 566.

that these results can be explained by the ways in which pain is conceptualized differently depending on race, socioeconomic status, or other identities. Either way, patients are reporting different levels of pain to their doctors. White women report experiencing less pain, yet they have a comparatively easier time accessing diagnoses and treatment. They are also vastly over-represented in clinical studies. None of this is shocking, but, as Christine Labuski, professor of Women's and Gender Studies and prolific writer on pelvic pain, puts it, "racializing framing mechanisms intersect with not only well-documented discriminatory clinical practices, but also with a gendered embarrassment unique to female genitalia, in ways that make it exceedingly difficult for Black and Latina women to report their vulvar pain."¹⁵ Women of color deserve greater respect, attention, and care in all aspects of medicine, but particularly in gynecological care.

Methodology & Methods

This thesis is an interdisciplinary project that looks at pelvic pain through the lenses of medicine, gender, and American society. It draws upon research and epistemologies from the fields of feminist and gender studies, disability studies, medical anthropology, and sociology, as well as literature from the natural sciences. As with many other projects in American Studies, my research is situated at a nexus of multiple disciplines, which has allowed me to identify connections between how the social forces that govern our society also influence our experiences in medicine.

This research was conducted by collecting material from two rich sources: a vaginismus support group forum hosted by a clinical group called Maze Women's Sexual Health, and TikTok. To collect my data from Maze, I went through the past four years of blog posts in the

¹⁵ Labuski "A Black and White Issue?" 163.

“General” tab of the forum¹⁶ and read every 10th post, for a total of 40 posts in my sample. On TikTok, I searched for “vaginismus,” but found that the search function on Tik Tok does not filter by date, nor does it tell you how many results there are. In this case, I watched every 5th video until I had the same sample size. The vaginismus blog exists on Maze’s website and is primarily a place where women share their stories about living with vaginismus. In a different format, TikToks videos about the pelvic floor and pelvic pain conditions are valuable sources that illustrate how communication and community influence one’s experience of pain. While the Maze forum is a site specific to vaginismus, TikTok is an incredibly popular and wide-reaching social media platform that makes it possible for communities to form around countless physical and mental health conditions. This yields a different kind of community, including both women with pelvic pain and women’s health professionals who create advocacy content. Neither platform provides any demographic information on the users, therefore I only know their ages or geographic locations if it is specified in the post.

Social media use is also important in communities of chronic pain because it provides support for people who are otherwise isolated by their experiences.¹⁷ For this reason, I wanted to use primary sources that could be found online. In a recently published study on social media use and pelvic pain, the “pain” group spent significantly more time on social media than the control group, and the researchers found that media and internet use was directly proportional to the amount of pain the participants recorded having. They also found an overall trust in social media, and its perceived therapeutic benefits, to be higher amongst the “pain” group.¹⁸ Therefore, this

¹⁶ There are many different threads on the forum for specific experiences with vaginismus, for example ones for discussing specific treatments, vaginismus when you have a serious partner, vaginismus when you’re single, vaginismus when you’re in menopause, etc. However, by far the most popular is the “general” thread, where women introduce themselves and share their stories.

¹⁷ Ecker et al., “Social media utilization,” 7.

¹⁸ Ecker et al., “Social media utilization,” 12-14, 18.

paper turned to the stories and testimonies that were written in a space where the authors felt safe, and were hopefully able to be open and honest in their posts.

My central methodology came from the belief that my research should be rooted in women's own voices and experiences. From this starting point, I sought to understand why women felt such shame around their conditions, and what can be done about it, which could only be answered by listening to the women themselves. This project began solely as a rhetorical study of language used by women with pelvic pain; however, it evolved to use two modes of analysis. In some cases, I use my primary sources as testimonials about women's experiences to support or refute arguments made in secondary source material. In others, I also conduct rhetorical analyses of these testimonials, finding evidence not in what they describe, but in the ways in which these women talk about themselves and their experiences.

Drawing on ideas from textual and rhetorical methods of analysis, I approached my primary sources by trying to uncover how the authors' choice of language constructs their social realities. I conducted my analysis by asking questions such as: How are these women writing about themselves, and (how) are they placing blame on themselves for their pain? What beliefs about the world, and their role in it, do I see reflected in their writing? How do they engage with their gender, and how do they relate to their partners? I read each post with the goal of understanding how these women situate their pain in relation to their identity, their self-esteem, and American society. I also read to identify themes throughout the women's posts that I had also found among secondary sources. Both as testimony and in the language they use, these women's posts provide valuable evidence to support my conclusions about how pelvic pain influences identity, and its implications for understanding medicalization.

I want to highlight that analysis of rhetorical speech is not a criticism of the women themselves, but rather it reveals that problematic, patriarchal language is often the only tool through which women can understand themselves. I am certainly not implying that they are the cause of their own suffering; however, these women often unknowingly reproduce many of the conditions that *are* causing their suffering, which is to be explicated in this paper without blame.

I approached this work with an academic mind, but it was impossible not to have strong emotional responses as I saw myself, over and over again, in my primary sources. It was often difficult to feel such outrage at the injustice of what these women feel, only to recognize that I should have felt this rage for myself, too. As I struggled with how to balance my feelings with objective writing, I found solace in the precedent of this same battle within feminist studies. I found my answer in Mary Jacobus' argument that feminist academic writing either conforms to patriarchal values of progress, logic, and objectivity, or else is seen as confirming the evaluation of women that feminists are actively trying to refute: that women are irrational, emotional, and, therefore, not academic.¹⁹ In a few cases throughout the later chapters of my paper it felt disingenuous to write unfeelingly about these women that I so deeply relate to and so, in taking issue with the assumption that displaying emotion is itself unacademic, I instead included some of my editorials in the narrative. In addition, many of the traumas these women experience come from being treated without empathy or understanding by their partners, friends, and doctors, and I didn't want to conduct myself in the same way. Therefore, I feel it is an act of resistance against the patriarchal norms that this paper addresses for me to remain, in specific cases, a subjective observer of these women.

¹⁹ Jacobus, "The Difference of View," 1979, found in Belsey, "Writing as a Feminist," 1157-1158.

Literature Review

The majority of research on pelvic pain conditions falls into the following categories: medical literature on new or existing treatments, articles on the classifications of different conditions, and psychological studies on the influence of related trauma. Two articles represent the first two categories, respectively; “‘Throwing the Baby Out with the Bathwater’: The Demise of Vaginismus in Favor of Genito-Pelvic Pain/Penetration Disorder,²⁰” and “Chronic Female Pelvic Pain—Part 1: Clinical Pathoanatomy and Examination of the Pelvic Region.”²¹ These represent broad areas of current scholarship; the first encompasses debates over definitions and classifications of conditions that cause pelvic pain, and the second gives an overall assessment of current diagnoses and treatments. It is certainly significant that the frequency of medical studies has been increasing, indicating that these conditions are being taken more seriously by physicians; nevertheless, they fail to capture the multi-dimensional ways in which the conditions affect people’s lives.

Sociologists Thea Caccioni & Janine Ferrell’s article, “The Medicalization of Women’s Sexual Pain,” revolutionized my ideas of medicalization and mind-body dualism. It also challenged my conception of pain as a “problem,” and the assumption that treatment and cure are always wanted or needed. The article provides, as the title suggests, a robust critical analysis of how pelvic pain has been pathologized by medical institutions. This article argues that heteronormative sexual practices biomedically frame chronic pelvic pain as “deviant,” because women are then unable to fulfill the expectation of performing penetrative sex.²² Therefore, medical treatment is the only outlet to turn to, and the only model of “success” is the rehabilitation of heterosexual penetrative intercourse. In addition to this being a narrow and

²⁰ Reissing et al., “‘Throwing the Baby Out with the Bathwater.’”

²¹ Apte, Gail et al., “Chronic Female Pelvic Pain.”

²² Caccioni & Ferrell, “The Medicalization of Women’s Sexual Pain,” 329.

prescriptive definition of healing, often women identify their greatest distress and discontent as coming from the failure to have sex when they are expected to, rather than from the pain itself, thus perpetuating a vicious cycle.²³

Caccioni and Ferrell provide an additional basis for my paper by articulating how they approached their research through a feminist lens. Biomedical approaches to pelvic pain reduce physiological and subjective aspects of chronic pain to their physical components, while newer biopsychosocial approaches reduce systematic social determinants (gender, sexuality, etc.) down to individual psychological or interpersonal issues.²⁴ Caccioni and Ferrell's epistemological frameworks, however, are embodied and allow for messy, non-linear research that encompasses broad social factors as well as biopsychosocial ones. Meaning, they are approaching studying pelvic pain by prioritizing what the patient feels and has experienced over diagnostic criteria. Most importantly, they also "queer" the fundamental definitions of what "real" or "successful" sex is by subverting heteronormative sexual expectations.²⁵ This framework advocates for and foregrounds women's agency over their bodies, treatments, and sexuality by validating women's definitions both of what successful treatment looks like (including choosing self-help, or no treatment at all), as well as what their own sexual goals and practices are. This model was fundamental to my ability to critique medicalization in this context, and to envision a future where women are not beholden to the expectation of medical treatment.

Focusing more specifically on treatment, Eli Clare's book, *Brilliant Imperfection*, helped me problematize the concept of "cure," and what it means to societally assume that a cure is always the goal in seeking medical treatment. Clare argues that the ideology of cure requires there to be locatable damage in the body, assumes that the body has an original state of being that

²³ Caccioni & Ferrell, "The Medicalization of Women's Sexual Pain," 334.

²⁴ Caccioni & Ferrell, "The Medicalization of Women's Sexual Pain," 330.

²⁵ Caccioni & Ferrell, "The Medicalization of Women's Sexual Pain," 3231-332.

is superior to the current one, and seeks to return the damaged body to that former state.²⁶ He unequivocally maintains this anti-cure politics, eloquently laying out the danger in assuming non-normative bodies to be broken, disposable, and in need of repair. However, he also complicates this notion with a discussion of chronic illness, particularly chronic pain, asking: can bodies be both natural and unnatural?²⁷ Can you have a body that you believe does not need to be “fixed” for its imperfections, and yet *does* need to be altered for the sake of that person’s quality of life? Can medical interventions be necessary, without implying the presence of a defect? Clare does not have answers for these questions, but says instead that “we need neither a whole-hearted acceptance nor an outright rejection of cure, but rather a broad-based grappling.”²⁸ Clare’s writing significantly helped me situate my project in an uncomfortable, but important, space between the critique of seeking a cure, and the validity of these women for still wanting one. Clare forced me to sit with discomfort and intangibility, and it was instrumental in helping me understand my project.

Christine Labuski’s monograph *It Hurts Down There: The Bodily Imaginaries of Female Genital Pain* investigates how cis-female bodies are culturally imagined and described, and how these conceptions affect the understanding and treatment of pelvic pain. In particular, she focuses on how specific language describing the anatomy of female genitalia is stigmatized, and thus pain in the vulva or labia is often inaccurately lumped in with vaginal pain. Likewise drawing on critical feminist and feminist anthropological theory, she explores how this “bioculture” — how events, ideas, and experiences thought to only be social are also coded in the physical body — and “hierarchy” of genital terms changes how pain and embodiment are understood.²⁹ This

²⁶ Clare, *Brilliant Imperfection*, 15.

²⁷ Clare, *Brilliant Imperfection*, 53.

²⁸ Clare, *Brilliant Imperfection*, 14.

²⁹ Labuski, *It Hurts Down There*, 4.

monograph provides a close analysis of how language functions and was helpful to my research both as a model of rhetorical analysis and also as a basis for understanding how language use is created and shaped by cultural contexts.

The literature I drew upon in this review provided critical epistemological and cultural frameworks, without which my research could not be a valuable addition to the field of American Studies. The belief in bodily and sexual autonomy, conceptions of medicalization as a social force, and a nuanced understanding of “cure” all provided important conceptual foundations for my research. These ideas allowed me to build a critique of medicalization and heteronormativity that is specific to pelvic pain.

Conclusion

What began as a desire to learn more about my personal experience has grown into rewarding research that has revolutionized how I think about my own pain, and how I think about Western medicine as a cultural influence. Less than two years ago, I was finally forced to begin talking about my pain by the necessity of getting my first pap smear. Facing this prospect, I burst into tears in my doctor’s office, and began a long medical journey that led to successfully using tampons for the first time and beginning to open up about my pain, which eventually led me to this project. But it also left me questioning the way I was treated by the doctors I started to see, and whether I wanted a “cure” at all.

Throughout researching and writing this paper, I have found a great deal of compassion for my younger self, for whom I used to have only anger and frustration. In coming to understand why I used to feel such intense shame and anxiety (and still sometimes do), I’ve also been surprised to be able to alleviate much of the blame that I used to put on myself for having

these feelings, and for having the pain itself. If this paper does nothing else, I hope it helps anyone with pelvic pain find similar empathy and compassion for themselves as well.

Chapter 1:

“She will have the pain as long as she pleases.”

Medicalization, gynecology, and conceptions of pelvic pain

In order to understand how pelvic pain is pathologized and treated today, we must first understand how medical treatment and conceptualizations of women’s pain have evolved throughout time. For centuries, women’s pain, psychological distress, or other physical symptoms were labeled as “hysteria.” Loosely defined as any physical, psychological, or neurological symptoms unaccompanied by physical evidence, this antiquated conception of illness originated in the belief that a woman’s uterus was “wandering” her body inflicting harm, and was intertwined with other ideas that demonic possession and witchcraft caused unexplainable symptoms.³⁰ The diagnosis of hysteria allowed real distress — both psychological and physical — to be written off as incurable or imaginary, resulting in women’s suffering being ignored and placated. The history of hysteria directly informs the trajectory of medicalization of women’s health today.

This chapter provides an overview of American gynecological history and its subsequent impact on medicalizing women’s pain, including current treatments for pelvic pain. This background illustrates the predominant medical lenses through which pelvic pain is typically seen, and, therefore, through which many women think of their pain, too. However, this chapter also grapples with the inherent tension present throughout this paper: How do we, on the one

³⁰ North, “The Classification of Hysteria and Related Disorders,” 498.

hand, critique medicalization without invalidating the reasonable desire to be free of pain? And how do we problematize the history of hysteria and of seeing women's pain as being "all in their heads," without ignoring psychological and emotional contributions to pain?

In this chapter, I aim to expose how the contexts in which knowledge is produced about women's bodies prevents them from fully understanding and treating their own, thereby structurally reinforcing conditions that create stigma and silence surrounding pelvic pain. Through analyzing the medicalization of pelvic pain, condition classifications, current treatments, pelvic exams, and other gynecological practices, I will show how biomedicine has shaped conceptions of pelvic pain and women's health in ways that reflect hegemonic ideas of what a woman's body should be or do, and which therefore see pelvic pain only as a problem that needs to be fixed.

Medicalization

Women's pain, bodies, and suffering cannot be understood without discussion of medicalization. It has shaped all aspects of women's medicine, but it also shapes how women come to see themselves as gendered and sexualized beings. Medicalization is generally defined as the process by which human problems and experiences come to fall under the jurisdiction and control of the medical profession.³¹ Though many scholars differ on the scope and inevitability of medicalization, the core principle "consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it."³² Every diagnosis, named condition, and treatment

³¹ Conrad, "Medicalization and Social Control," 210.

³² Conrad, "Medicalization and Social Control," 211.

that exists today is the result of medicalization putting bodily symptoms and experiences within the jurisdiction of physicians.³³

Medicalization is not inherently negative; this paper is not advocating for any all-encompassing divestment from Western medicine. However, it can also cause harm. Criticisms of medicalization stem from the understanding that all knowledge is socially created, and that we should therefore interrogate the ways in which biomedical knowledge is taken for granted. The distinction is not in necessarily critiquing the knowledge itself, but rather in acknowledging that it *was created* within biased social structures, as opposed to *discovered* as inherent fact.³⁴ The medical establishment wields great power by being in control of how we know and understand our bodies. According to philosopher Michel Foucault, knowledge and power are constitutive of each other, because the ideas of those in power establish and control norms and information.³⁵ The production of knowledge establishes what is “normal,” and creates power structures and discipline around these norms, because they spread and become “just the way the world works.”³⁶ Within medicalization, this manifests as the medical establishment deciding what are “normal” and abnormal bodily experiences, and what should be done about them on a societal and individual level. The tools, discourses, technologies, and practices of biomedicine collaborate to produce the “normal body,” thus creating an “other” out of any deviation from that norm.

With the authority to define and categorize behaviors and bodily experiences comes the ability to control and manipulate them, too. Pain, in particular, has become medicalized in such a way that privileges the physician’s knowledge over the patient’s. The experience of being in

³³ Ibid.

³⁴ Conrad, “Medicalization and Social Control,” 212.

³⁵ Foucault, *Discipline and Punish*, 27.

³⁶ Foucault, *Discipline and Punish*, 296.

chronic pain is isolating, and it is often extremely difficult to communicate the physical sensation of one's pain, and how it mediates their existence. Therefore, physicians often fill the role of having to listen to and interpret the "fragmentary language of pain," in order to figure out what is wrong and how to treat it.³⁷ However, this can lead to physicians trusting their own judgment over their patients' ability to understand and describe their pain, and seeing their patients as "unreliable narrators" who must be bypassed in order to get to "the physical events themselves," occurring in the body.³⁸ But, because pain often displays no physical evidence of why it is occurring, bypassing the voice of the patient means that the doctor *is*, in fact, bypassing the evidence of the "physical events," and is ignoring the important lived experience of the person in pain. Therefore, medicalization does not only explain how experiences are taken into medical jurisdiction, but also the consequences of doing so.

Lastly, sociologists Thea Caccioni and Janine Ferrell argue that the social construction of normative heterosexuality inherently drives the medicalization of sex, because those who do not fit the heterosexual normative standards must then seek a pathway to conformity: medical treatment.³⁹ This need to seek normalcy in turn reinforces itself; by using medical treatment to adhere to sexual norms, it then becomes a validating force that elevates treatment as the correct and necessary way of responding to pelvic pain. The force of medicalization is cyclical — biomedicine provides the solution that women need, however the "solution" then becomes tautological, and the fact of its existence serves to validate its own necessity. The lack of research, validation, or effective treatment is extremely frustrating to these women, however, the products of medicalization that they seek also drive their desire for treatment in the first place.

³⁷ Scarry, *The Body in Pain*, 6.

³⁸ *Ibid.*

³⁹ Caccioni and Ferrell, "The Medicalization of Women's Sexual Pain," 329.

Women's lives are particularly susceptible to medicalization because of the complex and multifaceted experiences of reproduction and childbirth.⁴⁰ The normalization of doctors' involvement in fertility and birth was one of the first instances of medicalization.⁴¹ Every element of the reproductive system — from menstrual cycles to prenatal tests, childbirth, breastfeeding, etc. — is medicalized in some way. For example, perceived “deviant” female behavior is often discounted as the result of Premenstrual Syndrome (PMS).⁴² Pathologizing normal hormonal changes during the menstrual cycle makes the commonly associated emotional experiences — mood swings, feeling intense anger or sadness, irritability, etc. — a medical problem that can be diagnosed. This results in disregarding women's perceived “irrational” emotional behavior whether they have PMS or not, because it presents as the symptoms of a known medical condition. Medicalization is also present in daily life in more measurable ways, such as through genetic screenings, workplace drug testing, doctor's notes (“medical excusing”), disability accommodations, and other ways in which medical practices surveil and moderate our daily lives.⁴³ Medicalization is present in every facet of American society, and it is crucial to understanding the way that women's experiences are constructed through embodied experiences and norms.

Gynecology today is also rooted in practices of experimentation on and exploitation of enslaved black women that allowed the female body to become more easily seen and controlled.⁴⁴ The invention of the speculum, a ubiquitous tool used in nearly every pelvic exam performed today, came from experimentation on a woman named Lucy, among countless others,

⁴⁰ Conrad, “Medicalization and Social Control,” 222.

⁴¹ Kapsalis, *Public Privates*, 49.

⁴² Conrad, “Medicalization and Social Control,” 216 and Martin, *The Woman in the Body*, 127-133

⁴³ *Ibid.*

⁴⁴ Kapsalis, *Public Privates*, 32.

who was suffering from a vesico-vaginal fistula.⁴⁵ The doctor she was sent to, Dr. J. Marion Sims, is touted, among other gratuitous titles he has been awarded through history, as “the Father of American Gynecology,” yet his successes and invaluable contributions are indebted to his exploitation of enslaved women.⁴⁶ Because fistulas are often the result of prolonged childbirth, they occurred more frequently in enslaved women who, of course, had significantly less access to medical care, and thus to intervention in their long labors.⁴⁷ Sims believed, with every case he saw, that there was no way to repair the fistula, until in 1845, when he contrived to find a way of seeing inside the vagina, and ended up with the first reported use of a speculum.⁴⁸ This invention medicalized the knowing of women’s bodies by allowing a (male) medical authority to literally see inside of the previously invisible interior of the body. Sims had, in this way, “conquered” a heretofore unknowable and uncontrollable site of the female body.⁴⁹ Sims’ surgeries and experimentation were also all unanesthetized, further defining gynecological discovery as a site of intense physical pain and degradation.⁵⁰ From the very beginning of gynecological practice, knowledge of the female body has been controlled by medical professionals, their authority allowing them to use enslaved women’s bodies however they pleased in the name of scientific discovery and capitalist profit.

The practice of gynecology is also inherently tied to how sexual difference is pathologized, and who is considered to be adhering to sexual norms. The role that race played in inventing sexual difference allowed Sims and others to use enslaved women to make their

⁴⁵ Fistulas are abnormal openings between two organs of the body. In women, the most common are between the bladder and the vagina (vesico-vaginal), or the rectum and the vagina, which are most often caused by prolonged labor in childbirth, or other traumas to the pelvic area. They can also have additional openings outside of the body.

⁴⁶ Kapsalis, *Public Privates*, 31.

⁴⁷ Kapsalis, *Public Privates*, 34.

⁴⁸ Kapsalis, *Public Privates*, 38.

⁴⁹ Kapsalis, *Public Privates*, 39.

⁵⁰ Kapsalis, *Public Privates*, 40.

medical discoveries. In summation of a vastly complex relationship between race and sexuality, Alyson Spurgas writes that “White feminine receptivity has always been produced against Black feminine hypersexuality as its counterpart. Further, white women have traditionally been framed as more sexually receptive, but women of color have traditionally been expected to actually be more receptive to sex.”⁵¹ Because enslaved women’s value lay in their ability to reproduce, and therefore provide future profit through their children, sexual norms derive from the expectation that black women will be sexually available, yet not in control of their sexuality. This allowed white women’s sexuality to be always defined in comparison to this expectation. This relationship has countless implications, but for the purposes of understanding medicalization, it has resulted in medical science and research being applied to all women, despite having been produced in racist, colonial structures that prioritize white sexuality.⁵² Studies on pelvic pain, or anything related to “women’s health” are overwhelmingly produced based on white women, yet are disseminated to all, and do not acknowledge the often very different realities of sexual expectations, experience, and pain for women of color.

Understanding the roles that medicalization and racism play in creating the institution of women’s health is a crucial step in understanding why we cannot take medical knowledge for granted. Particularly in gynecology, the lens of medicalization exposes the problematic ways in which knowledge has always been produced about women’s bodies, and therefore why we are able to question its relevance and efficacy in understanding and treating pelvic pain.

⁵¹ Spurgas, *Diagnosing Desire*, 13.

⁵² Spurgas, *Diagnosing Desire*, 12.

Idiopathy

As early as in 1851, physicians began to wonder why some women's "hysterics" had an identifiable pathology, and others seemed only to be a "functional disease," meaning an idiopathic one.⁵³ In 1889, gynecologist G.E. Herman referred to pelvic pain with no visible pathology as "hysterical mimicry," and cautioned a physician that in trying to treat it, he said, "[y]ou will damage your own reputation, for you will never cure her; she will have the pain as long as she pleases."⁵⁴ This kind of pain was labeled psychosomatic — a classification that persists today — which reinforces the idea that pain is "all in a woman's head."⁵⁵ Traditional biomedical models require an "organic genesis" (i.e. the presence of tissue damage as an identifiable origin) for the very definition of "pain." Psychological or social factors are unlikely to be the sole cause of pain, but can affect one's perception of it, and are thus only considered to the extent that they are "stressors."⁵⁶ Since the beginning of medical research, non-pathological conditions have presented a conundrum, yet the solution has been to label them as being psychological, and therefore not a "real" problem.

In recent decades, the psychosomatic model has evolved to recognize the influences that non-organic factors can have on the body. This model is a more all-encompassing approach to understanding pain, yet it still has problematic shortcomings. Biopsychosocial models now stress the inclusion and incorporation of psychological factors as equal to biological ones in order to understand pain in a new and complex way. Instead of trying to post a direct linkage between organic genesis and pain creation, biopsychosocial models better understand the complicated web of influences that contribute to a person's pain.⁵⁷ They also attempt a less reductionist

⁵³ Grace, "Pitfalls of the Medical Paradigm," 526.

⁵⁴ Herman, *Diseases of Women*, 32, found in Grace, "Pitfalls of the Medical Paradigm," 526.

⁵⁵ Caccioni and Ferrell, "The Medicalization of Women's Sexual Pain," 329.

⁵⁶ Grace, "Pitfalls of the Medical Paradigm," 527-528.

⁵⁷ Grace, "Pitfalls of the Medical Paradigm," 531.

analysis of symptoms, but often fail. Contemporary biopsychosocial frameworks “typically reduce broader social and structural forces that directly influence women’s experiences of sexual pain to individual, psychological, or interpersonal ‘abnormalities,’ rather than framing them as influenced by social determinants (e.g., shaped by constructions of gender and sexuality).”⁵⁸ Though they attempt to gain a more nuanced understanding of pain, these models also simplify pain in ways that exclude social influences.

However, this model still maintains mind-body dualism — the concept that the mind and body are inherently separate entities, an idea that is deeply rooted in medical paradigms — by considering both physical and psychological factors, but taking them to be entirely separate entities from each other.⁵⁹ Mind-body dualism in medicine implies a hierarchy of the mind over the body, thereby distancing the person from their physical ailment, and also assumes that the two are distinct, and can be defined in absolute terms with distinct and stable boundaries between the two.⁶⁰ Mind-body dualism aids the forces of medicalization by asserting that the body is not the person, and therefore the body must be “fixed” in a variety of ways *for* the person. Eli Clare chooses to use the phrase “body-mind” throughout his book, because it recognizes “both the inextricable relationships between our bodies and our minds and the ways in which the ideology of cure operates as though the two are distinct — the mind superior to the body, the mind defining personhood, the mind separating humans from nonhumans.”⁶¹ In the context of pelvic pain, mind-body dualism is a significant force that drives the feeling of blame and hatred towards the body by alienating it from the self.

⁵⁸ Caccioni and Ferrell, “The Medicalization of Women’s Sexual Pain,” 330.

⁵⁹ Grace, “Pitfalls of the Medical Paradigm,” 532.

⁶⁰ Grace, “Beyond Dualism in the Life Sciences,” 1-2.

⁶¹ Clare, *Brilliant Imperfection*, xvi.

For something as complicated and elusive as pelvic pain, maintaining mind-body dualism can prevent a full understanding of how these conditions function in the body. The sociologist Victoria M. Grace — a prolific writer on pelvic pain — argues that medical models that rely on finding the “origin” of someone’s pain are problematic, because they are “predicated on an assumption that empirical observations of the world unproblematically reflect reality; that under highly specified conditions objective observations of that reality may be made; that causal relationships are inherently linear, with the cause of necessity, [sic] preceding the effect.”⁶² The continued lack of understanding surrounding vaginismus, centuries after its initial identification, gives credence to this argument. Our current medical models are clearly failing in their attempt to understand pelvic pain, and their causal epidemiological approach continues to yield very few answers. Biomedicine is unable to fully understand these conditions, yet medicalization has meant that we still see them as medical problems, instead of trying to analyze them through a more complicated lens.

Classification & Treatment

The term “vaginismus” was also coined by J. Marion Sims in 1861, who defined it as “an involuntary spasmodic closure of the vagina... the slightest touch with a feather or with a camel-hair pencil at the reduplication of the hymeneal band produced as severe suffering as if she were cut with a knife.”⁶³ From its introduction into the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1980 until 2005, vaginismus was classified as a sexual dysfunction disorder, instead of being categorized with the pain conditions.⁶⁴ While the DSM-V was in process, psychologist Irving Binik published an argument in the *Archives of Sexual Behavior* for

⁶² Grace, “Pitfalls of the Medical Paradigm,” 533.

⁶³ Sims 361-362, found in Reissing et al. 1209.

⁶⁴ Reissing et al., “Throwing the Baby Out With the Bathwater,” 1210.

vaginismus to instead be considered a chronic pain disorder in the upcoming 5th edition.⁶⁵ He argued that the so-called “sexual pain disorders” were the only pain conditions that were classified by the activity that they interfered with, and were the only ones in a different category.⁶⁶ However, his proposal was rejected, and the new classification remains in the “sexual pain” category, clearly indicating how pelvic pain is primarily perceived as an important medical condition because of its role in preventing penetrative sex.

Instead, vaginismus, dyspareunia, and other sexual pain disorders were then combined into the catchall genito-pelvic pain/penetration disorder (GPPPD). This attempts to encompass a multi-dimensional understanding of dyspareunia, yet it is primarily defined by “difficulties” in penetration, not by the *inability* to have penetration, which fails to differentiate between and capture the importance of the experience of women who have *never* been able to experience penetration (long-term vaginismus), versus short-term pelvic pain that has occurred in women otherwise able to engage in penetrative sex.⁶⁷ Women with lifelong vaginismus have been proven to have more negativity about potential penetration, greater fear of penetration, higher likelihood of acting to avoid pain and harm (such as refusing to engage in sexual encounters, relationships, and pelvic exams) and higher rates of self-disgust and fear.⁶⁸ Regardless of the potential differences in pathology, the emotional and psychological differences between having short- versus long-term vaginismus are significant, and are not captured diagnostically within a catchall definition. Perhaps this debate indicates a larger problem of pathologization: no diagnosis will ever be able to fully encompass someone, and will, by definition, pigeonhole them into a standardized set of experiences. It also begs the question of why pain is included in the manual

⁶⁵ Caccioni and Ferrell, “The Medicalization of Women’s Sexual Pain,” 330.

⁶⁶ Reissing et al., “Throwing the Baby Out With the Bathwater,” 1209-1210.

⁶⁷ Ibid.

⁶⁸ Reissing et al., “Throwing the Baby Out With the Bathwater,” 1211.

for mental disorders at all, when this implies that pain is purely psychological. The classification of conditions such as vaginismus exposes what is important to doctors, not to the patients.

Current treatment options reflect the inconsistencies in defining pelvic pain. In 2021, the *American Family Physician* published an article titled “Dyspareunia in Women,” which thoroughly details possible causes of dyspareunia, relevant pathology, and treatments. The journal aims to educate primary care physicians,⁶⁹ and this article attempts to provide much-needed instruction for how to address pelvic pain. In the introduction, the authors stress that “treatment is focused on the cause” of pain, yet all of the research on pelvic pain clearly illustrates that, in many cases, the cause of dyspareunia is unknown.⁷⁰ How will a physician implement an origins-based approach, when the origins are unclear?

The article lists primarily non-chronic causes of dyspareunia, such as inadequate lubrication, vaginitis, interstitial cystitis, other bladder conditions, and other acute pelvic disorders, as well as pelvic floor dysfunction (PFD), vaginismus, and vulvodynia.⁷¹ PFD is defined as the inability to properly coordinate, contract, or relax the pelvic floor muscles, primarily leading to incontinence and bowel problems, but also frequently associated with dyspareunia and other pelvic pain.⁷² PFD is often diagnosed before or in tandem with vaginismus, and the two conditions are closely related. However, the possible treatments show very different perspectives. The treatments for PFD include pelvic floor physical therapy, gabapentin,⁷³ botox injections,⁷⁴ and local anesthetic.⁷⁵ Physical therapy is the most commonly prescribed treatment for

⁶⁹ “About AFP,” American Academy of Family Physicians.

⁷⁰ Hill and Taylor, “Dyspareunia in Women,” 597.

⁷¹ Hill and Taylor, “Dyspareunia in Women,” 598.

⁷² “Pelvic Floor Dysfunction,” Cleveland Clinic.

⁷³ An anticonvulsant and nerve pain medication.

⁷⁴ In these treatments, botox is injected into the vagina in order to prevent the spasming muscles from contracting and causing pain.

⁷⁵ Hill and Taylor, “Dyspareunia in Women,” 599.

vaginismus as well, yet it is only listed for PFD. For vaginismus, under a column labeled “additional testing,”⁷⁶ the physician is instructed to “identify psychosocial factors, such as sexual abuse or anxiety,” implying that vaginismus is primarily caused by psychological factors.⁷⁷ Accordingly, the recommended treatment is a “multidisciplinary approach [that] includes cognitive behavioral therapy, psychotherapy, relationship and sexual counseling, lubricants, vaginal dilators,⁷⁸ and [botox] injection.”⁷⁹ Despite indicating that vaginismus should be treated in a “multidisciplinary” way, the authors then fail to incorporate physical and emotional treatments alongside each other, instead focusing primarily on cognitive therapies and excluding the most common prescription, pelvic floor physical therapy. The anxiety and psychological distress that do often accompany vaginismus should not be invalidated or left unaddressed, but focusing primarily on those factors pigeonholes vaginismus as being only or mostly psychological.

This article highlights the lack of balance between psychological and physical factors in all of medicine, but primarily in considering pelvic pain. Anxiety and trauma should not be overstated in the consideration of vaginismus, or always seen as the primary cause, because that leads to pain being “all in your head,” and therefore not “real.” However, deemphasizing these factors in favor of physical evidence also erases work that has been done to recognize how trauma and other psychological experiences have somatic effects and *do* manifest in complex

⁷⁶ In this category, additional testing is labeled as being “usually unnecessary,” for the majority of conditions, although for some, the authors suggest performing transvaginal ultrasounds and other imaging in order to rule out more serious conditions.

⁷⁷ Hill and Taylor, “Dyspareunia in Women,” 599.

⁷⁸ Dilating is a treatment that involves inserting silicone or glass cylinders (dilators) into the vagina, increasing the size of the dilator over time in order to stretch vaginal muscles and practice accommodating an inserted object. Dilators are very frequently prescribed for vaginismus, but are also sometimes used in other situations, such as in menopause, after vaginal cancer treatments, other pelvic floor conditions, and some gender affirming surgeries.

⁷⁹ Ibid.

ways. In theory, a multidisciplinary approach should encompass these truths, but clearly that is not how doctors are currently being taught to view vaginismus.

Pelvic Exams

The pelvic exam is the primary tool of gynecology, yet it also reinforces problematic consequences of medicalization. Writer and performer Terri Kapsalis interrogates the forces at play in a pelvic exam in her book, *Public Privates: Performing Gynecology from Both Sides of the Speculum*. She argues that, though a pelvic exam is often the first step in a gynecological visit, it inherently creates an uncomfortable dissociation between the woman and her body.⁸⁰ The clinician becomes a spectator; the woman is literally cut off from knowing her body by being unable to see what is happening, whereas the clinician can see everything, and also has the interpretive powers to understand it.⁸¹ Medicalization creates circumstances where women are not allowed to know their own bodies as well as their doctors do.

Pelvic exams also implicitly enforce sexual norms, and create sites that replicate womens' expected behavior. For many women, pelvic exams are uneventful, but they structurally assume that a woman's role is to be penetrated, both in sexual activity as well as in the exam.⁸² In order to be "good" in the exam, one must accept this role without complaint. "Failure" in the pelvic exam mirrors "failure" in sexual activity, and often foreshadows for people with dyspareunia what is to come in their sexual relationships. Pelvic exams delicately balance sexual norms: A woman must remain subservient, docile, and well-behaved in the exam in order for it to stay within the realm of medicalization. However, if a woman is *too* subservient

⁸⁰ Kapsalis, *Public Privates*, 20.

⁸¹ Kapsalis, *Public Privates*, 21.

⁸² Kapsalis, *Public Privates*, 14.

and cooperative, she becomes the “seductive patient,” who over-performs femininity.⁸³ In a pelvic exam, a woman is inherently exposing herself, performing other inappropriate behavior for routine medical care in a way that male-bodied people do not.⁸⁴ Therefore, being feminine threatens to tip the scale and make the exam socially unacceptable.⁸⁵ The pelvic exam sets up the vagina as the sacred thing, not the woman herself, and therefore her job is to protect it, show it only to the right people and moderate her behavior in order to display it properly.⁸⁶ Even in the most basic of gynecological exams, women are implicitly expected to perform their femininity “properly” in order for the act of exposing one’s genitalia to remain in the medical purview.

Teaching gynecology and training practitioners to perform pelvic exams is also complicated. In medical school, having students practice pelvic exams on conscious volunteers often results in novice trainees examining the same person over and over again, creating the feeling that she is being used.⁸⁷ However, the alternative is to practice on anesthetized women, cadavers, or dolls, which all dehumanize the patient and reinforce the idea that they are supposed to be docile, numb to the exam, and completely uninvolved in the examination of their own bodies. It also teaches that the physical examination and interpretation of the body is more important than learning from and interacting with the patient.⁸⁸ Other alternatives have involved hiring prostitutes, making the case that for certain women it is acceptable to be exposed and used in that way, and which also problematizes the boundaries between the medical, and the erotic and the pornographic.⁸⁹ Doctors have to be taught these manual skills, but the process of learning

⁸³ Kapsalis, *Public Privates*, 17.

⁸⁴ Kapsalis, *Public Privates*, 14.

⁸⁵ *Ibid.*

⁸⁶ Kapsalis, *Public Privates*, 19.

⁸⁷ Kapsalis, *Public Privates*, 65-66.

⁸⁸ *Ibid.*

⁸⁹ Kapsalis, *Public Privates*, 67.

them creates the expectation for a patient's behavior that removes her from knowing and understanding her body.

As we will see in Chapter 2, visits to the gynecologist are frequently places where women with vaginismus experience painful, rough, and unsympathetic pelvic exams that are not only traumatizing, but are also discouraging when coupled with denying the validity of the patient's pain. This is not to say that all gynecologists act this way, nor to say that pelvic exams should be erased from the clinical toolkit, however the ethos of the pelvic exam, and the docile and distanced patient, leads to experiences where doctors trust their own observations and knowledge over their patients'.

Even outside of the examination room, women are denied language and knowledge about their bodies that make it extremely difficult to identify and discuss pain. Christine Labuski writes about what she calls "intra-genital dynamics," in order to discuss the way that "vagina" is used as a catchall term to refer to different genital anatomy, and that most women and young girls are not given more specific language about their bodies.⁹⁰ Specifically, the colloquial substitution of "vagina" for "vulva," and near erasure of words like "clitoris" and "labia" hinders young girls' ability to have a clear and differentiated understanding of their bodies that can then be used to address and identify symptoms and experiences.⁹¹ Therefore, Labuski refers to vulvar pain as a clinical and *also* cultural condition, because it is both a physical condition that affects women's lives, yet it also demonstrates how societally we lack sufficient vocabulary with which to discuss our bodies and our pain. Because the language is off-limits, this censorship leads to women avoiding clinical consultations and treatments, and to clinicians trying to treat something they do not fully understand.⁹² This lack of language also reinforces mind-body dualism by failing to

⁹⁰ Labuski, *It Hurts Down There*, 4.

⁹¹ Labuski, *It Hurts Down There*, 8.

⁹² Labuski, *It Hurts Down There*, 3.

give women the ability to have nuanced discussions about their bodies and therefore establishing a woman's body as something that is foreign and separate from her conscious self. In the context of pelvic pain, it also establishes a woman's body as the enemy; if a woman cannot use tampons or have sex, yet cannot identify what the problem is, her body becomes an entity that she can blame, but not know or fix. This sequence of events positions social media sites like Maze and TikTok as incredibly valuable; so many women come to these posts expressing their relief that they finally have the words to describe their conditions that they had never had before.

Our language is further stunted when it comes to pain itself. Elaine Scarry, in her foundational text *The Body in Pain*, argues that “physical pain does not simply resist language but actively destroys it,” by deconstructing the way that we usually express feelings.⁹³ She says that our language is constructed by expressing sensory experiences and feelings with an object — we have hatred *for* something, frustration *with* something, etc. — but that because pain is internal, and often unidentifiable, there is no point of reference for expressing it. She says, “it is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language.”⁹⁴ Describing pain requires putting words to something that no one else can feel or see; it is like explaining a theoretical phenomenon without an example to give it context.

On top of this, pain is incredibly isolating; it is an “absolute split between one's sense of one's own reality and the reality of other persons.” For the person in chronic pain, it is the lens through which they see and experience the world, and is “the most vibrant example of what it is to ‘have certainty,’ while for the other person it is so elusive that ‘hearing about pain’ may exist as the primary model of what it is ‘to have doubt.’ Thus pain comes unsharably into our midst as

⁹³ Scarry, *The Body in Pain*, 4.

⁹⁴ Scarry, *The Body in Pain*, 5.

at once that which cannot be denied and that which cannot be confirmed.”⁹⁵ There is no way of externalizing the feeling of pain, and it remains intangible and unknown even to someone in close proximity.⁹⁶ Therefore, pain can so rarely be expressed in a way that fully communicates the experience. With pelvic pain, we lack the language both to describe what our pain feels like, and how it is impacting our lives, and also to even describe where it is, and how it exists within our physical body.

This exploration is important because it exposes how, even without the social stigma attached to pelvic pain, women are kept silent about their conditions. It also shows how women are made dependent on their doctors, both through their ability to see women’s bodies and also through their authority to interpret pain. This further shakes the foundation of biomedicine as unequivocal fact. Again, the purpose of this section is not to call for the cessation of giving pelvic exams, or to undermine every doctor’s diagnosis and treatment of pelvic pain. Rather, it is to say that we should not take those things for granted, and that we should question the credibility of how pelvic pain is evaluated.

Conclusion

The importance of recognizing and critiquing medicalization is evidenced by how easily I found myself slipping into the same hegemonic language as I wrote this chapter. Medicine, and the rhetorical structures it creates, are taken so wholly as fact that even while in the headspace of actively rejecting them, I still ended up using these patriarchal frameworks. Even within single paragraphs I found myself bouncing back and forth between writing that a condition should be considered as either too psychological or too physical, and found it difficult to use language that

⁹⁵ Scarry, *The Body in Pain*, 4.

⁹⁶ Scarry 4.

was not so binary. Even after months of research, the rhetoric of medicalization remains deeply embedded in the way I see and make sense of the world. For this reason, beyond this chapter opening up space in which to critique the medicalization of pelvic pain, it also lends itself to fundamentally reconceptualizing the body as a physical, knowable, and bounded entity. Perhaps the “middle ground” I seek lies in deconstructing a Western view of the body that forces us to distinguish between the physical and the psychological, between the mind and the body.

Therefore, some of the problems with medical paradigms appear to be absolutism; biomedicine wants to classify, diagnose, and cleanly identify our illnesses, and leaves very little room for the reality of a more nuanced experience of pain. We should always live in the “middle ground,” of the body-mind and should always see pain holistically as a result of many different overlapping factors.

Chapter 2

“It’s not just in your head.”

Medical gaslighting, community, and how we replicate problematic norms

Maze Women’s Sexual Health is a private medical practice in New York City that “advocates diagnosis of and treatment for the physical causes of female sexual dysfunction, as well as any underlying psychological influences, by integrating education and psychological counseling with medical techniques specifically to help you achieve a full and satisfying sex life.”⁹⁷ In many ways, Maze is a revolutionary clinic whose practitioners are doing their part to change hegemonic conceptions around pelvic pain, and to voice topics that are considered taboo, despite their importance and prevalence. Their homepage proudly displays the phrase “IT’S NOT ‘JUST IN YOUR HEAD,’” proclaiming that they will listen, and take your pain seriously.

The Maze website goes beyond validating women’s pelvic pain by normalizing talking about painful sex, womens’ sex lives, and naming potential causes of pelvic pain.⁹⁸ The homepage for their “Better Sex Blog,” advertises their most recent articles, including “No, That is not a Weird Way to Orgasm,” which discusses ways and positions in which women orgasm. This post works to dispel stigma around discussing female pleasure, and is especially powerful for women with dyspareunia, who rarely or ever orgasm while having penetrative sex with a partner.⁹⁹ On the Better Sex Blog alone, there are hundreds of posts spanning 31 separate topic

⁹⁷ “Home,” Maze Women’s Sexual Health.

⁹⁸ Ibid.

⁹⁹ Marcus, “No, That is not a Weird Way to Orgasm.”

categories aimed at providing women with more information about their bodies, emotions, and sex lives.

Maze does a great deal of good, yet their model and mission also fall into the dynamic that Caccioni and Ferrell identified,¹⁰⁰ where the existence of treatment for sexual dysfunction reinforces pain only as a problem that needs to be fixed. Their rhetoric focuses solely on solving “sexual health problems,” helping women have a “full and satisfying sex life,” by rehabilitating the ability to have penetrative sex.¹⁰¹ Despite their assertion that they treat “the whole person,”¹⁰² they define pelvic pain in relation to an assumed desire to have penetrative sex, not as the women might for themselves. By rhetorically isolating their mission in this way, Maze aligns itself with the predominant biomedical approach which reinforces the binary argument that penetration is necessary in order to have satisfying sex, and that penetration is the expectation.

In addition to medical practitioners like those who work at Maze, users who post on the forum also replicate the same dynamic — doing positive work in the short-term, but also unintentionally perpetuating the heteronormative rhetoric that causes shame and anguish, and that will continue to hurt women with pelvic pain in the long-run. Maze is unique in its mission, but not in this dichotomy.

This chapter will first use testimony from the Maze forum to expose the mistreatment that women with pelvic pain experience in the doctor’s office, and then in the second section demonstrate how the act of sharing these testimonials actively rejects the shame, silence, and stigma that results from many medical appointments. Finally, I will show how these same stories that build community and solidarity for women with pelvic pain, like Maze, also uphold the conditions that cause their suffering in the first place.

¹⁰⁰ See chapter 1, page 24.

¹⁰¹ “About Us,” Maze Women’s Sexual Health.

¹⁰² Ibid

In the Exam Room

A major feature of the Maze website is their Vaginismus Forum, a support group blog designed to connect women who have vaginismus in order for them to share “questions, concerns and stories.” Sometimes these posts are positive, spreading hope and triumph, but the vast majority of them are incredibly dark, self-defeating, and anxiety ridden, as women come to share many of the traumatizing and difficult experiences they’ve had as a result of their vaginismus. Though most women come to the forum hurting, nearly everyone expresses gratitude for it showing them that they are not alone and giving them, often for the first time, people they can talk to about their condition. I felt the exact same way when I found this forum on my own, before even beginning this project, and I hope to do these women justice as I share their stories.

One user on the forum, Marie2108, describes in a post titled “Is it Really Psychological?” how doctors dismissed her physical pain, instead telling her that the “reason for [her] vaginismus is psychological [sic], since there is no evidence of any physiological problems.” She continues,

I just dont know where to go from here, since doctors wont really believe me. They just want me to learn how to relax my muscles, let go and learn that sex is completely ok. I really dont think I can improve my muscle-control skills much more and I have never felt that sex is in anyway wrong, been afraid of pregnancy or been the type of person, who is afraid to let go. I can simply not identify with the psychological characteristics that they are assigning to me. It feels like I am not really being listened to or taken seriously.¹⁰³

Her doctor’s insistence on her pain’s psychological origins makes Marie2108 doubt her own experiences, and make her question her understanding of her body and mind. She knows she is not “being listened to or taken seriously,” yet does not have enough context or knowledge to fully trust herself. Most women seeking treatment know very little about pelvic pain, and rarely

¹⁰³ Marie2108, “Is it Psychological?” 14 February 2018.

know how common their experiences are, and thus don't know enough to question their doctor's advice or expertise.

Women who seek help from their doctors for vaginismus are frequently told there is nothing wrong with them, or that it is "all in their heads." In a study measuring patients' perceived stereotyping in treatment for chronic vulvar pain,¹⁰⁴ over 30% of their sample agreed or strongly agreed to the statement that their doctors believe they are exaggerating their pain.¹⁰⁵ In another,¹⁰⁶ which examines women's experiences after receiving negative laparoscopies,¹⁰⁷ the majority of participants felt that they had to justify their pain to the interviewer, saying that they had frequently been disbelieved or misunderstood by their doctors.¹⁰⁸ Half of those same women felt that they had wasted their doctor's time, despite it being their doctor's job to try to diagnose and treat their pain. These women felt like they were perceived as people who weren't genuinely hurting.¹⁰⁹ Because medicine prioritizes illness or pain that exhibits physical evidence, women experiencing idiopathic conditions are often ignored and dismissed in doctor's offices.

This phenomenon is called medical gaslighting: where doctors and medical professionals deny a patient's symptoms, or tell them that their experiences are entirely psychological, thereby making the patient question what she knows to be true about her body. Women (and marginalized men) are much more likely to be dismissed in this way, and therefore medical gaslighting is an incredibly widespread problem amongst women with pelvic pain.¹¹⁰ Medical gaslighting creates a vicious cycle, where women are less likely to stand up to their doctors, and less likely to

¹⁰⁴ Referred to going forward as Harlow et al.'s study.

¹⁰⁵ Harlow et al., "Perceived Stereotyping," 1463.

¹⁰⁶ Referred to going forwards as Savidge et al.'s study.

¹⁰⁷ An invasive exploratory surgery done under anesthesia that examines pelvic organs, in this case, in order to try to determine the origin of their pain.

¹⁰⁸ Savidge et al., "Women's Perspectives on their Experiences of Chronic Pelvic Pain," 111.

¹⁰⁹ Savidge et al., "Women's Perspectives on their Experiences of Chronic Pelvic Pain," 109.

¹¹⁰ Moyer, "Women Are Calling Out 'Medical Gaslighting,'" 28 March 2022.

continue talking about their pain, after being invalidated by a medical authority, which means that the doctor's behavior is never challenged.

Maze user SB_815 had her first pelvic exam in an emergency room, and despite it being “so painful and traumatizing,” she was later pushed by her gynecologist to get a pap smear. In a post titled “Extreme OBGYN anxiety. Does it get better?” She recounts being offered anti-anxiety medication to mitigate the experience, but it was still “awful.” After later getting a transvaginal ultrasound, she “cried the whole way home after it,” and cries every time she thinks about the next ultrasound she has scheduled. She says, “just thinking about seeing my OBGYN giv[es] me extreme anxiety,” and then asks the forum “I’ll probably never have sex at this point so is it reasonable to skip these appointments or is it better to suffer through it even if it feels traumatizing?”¹¹¹ Instead of finding ways to effectively manage SB_815’s consistent pain in transvaginal procedures, her gynecologist pushes her to go through with other invasive procedures, causing lasting trauma and anxiety. SB_815’s doctor dismisses the boundary she established, assuming that they know better than SB_815 what that boundary should be.

User lillyd began going to her OBGYN at age 17 to manage her intense periods, saying that she was not yet sexually active, and was scared and intimidated by the prospect of an internal exam. She recounts,

as you can already guess, the whole experience turned into a nightmare... When she opened the speculum I was screaming my lungs out cause it hurt so much, and she replied to me the whole time ‘I know it hurts but it will be over soon’... Like she was talking to a 5 y/o. My mum told me afterwards she’s in pain too when she goes to her gyn so I’ve always thought it was ‘supposed’ to be like this.¹¹²

This experience explicitly normalized intense pain for lillyd by again denying what she knows to be true in her body. From both her mother and the doctor, she is told that her pain is normal, and

¹¹¹ SB_815, “Extreme OBGYN Anxiety. Does it Get Better?” 28 July 2021.

¹¹² lillyd, “Chicken or Egg?” 11 March 2021.

that she should simply accept it, push through it, and get over it. Being talked to “like she was talking to a 5 y/o,” implies the doctor’s belief that Lillyd doesn’t have the knowledge in her body, or in the exam room, in order to have a valid opinion about what happens to her. It is so difficult to advocate for yourself when you are on your back, exposed, with feet in stirrups, unable to see what is being done to you. Here she is put through trauma only to be told it is normal, and to have her loud and persistent exclamations of pain ignored and invalidated. Lillyd’s pain worsened after this visit, and she turned to the forum to ask whether her vaginismus could have been caused by her OBGYN based on the messaging that first pelvic exams are “almost always an unpleasant experience.”¹¹³ Her description of “screaming my lungs out” is far more than general discomfort or unpleasantness, yet the normalization of women’s pain in a clinical setting still causes her to doubt the injustice of her experience.

Lillyd highlights an important element of any doctor’s appointment: communication. Her gynecologist makes her feel belittled, and this contributes to her doctor’s gaslighting. In the study measuring the correlation between level of education and pelvic pain, the authors found that “nearly half of the women seeking consultation for pelvic pain in their study believed that their pain complaint was not accurately assessed. These women feared that they suffered with a serious disease as yet undiagnosed.”¹¹⁴ For many women, having unexplained pain can be frightening, and the lack of care that physicians often take with pelvic pain can exacerbate this feeling. In addition, in Savidge et al.’s study, nine women said they felt satisfied with the way they were given the results of their laparoscopy, yet their satisfaction was derived from either relief that they did not, in fact, have a serious medical condition, or from their acceptance of the limitations of medical knowledge.¹¹⁵ These women were satisfied merely by the absence of

¹¹³ Ibid.

¹¹⁴ Bachman et al. “Educational achievement and pain disability,” 566.

¹¹⁵ Savidge et al., “Women’s Perspectives on their Experiences of Chronic Pelvic Pain,” 108.

illness, and by accepting that medicine may not be able to explain their pain at all, instead of actually feeling satisfied by their progress or the information they received.

In the same study, ten women were not satisfied with the information they were given, many citing the reason as being insufficient explanations and being given little time to ask questions.¹¹⁶ For many women, learning the name of their condition, and learning how common it is, would relieve a great deal of suffering, even without treatment. Yet doctors frequently push them out the door without making sure they fully understand their diagnosis or its implications. The most galling example comes from the same study, where six of those ten women, over a quarter of the participants, were unsatisfied because they were given information while they were still sedated or still coming out of sedation, and “thus f[ound] it difficult to process the information or ask questions.”¹¹⁷ These doctors should not have conducted themselves such that the study’s authors needed to recommend in their conclusion that “time should be given for women to recover fully from the anaesthetic before results from the laparoscopy are given.”¹¹⁸ This exemplifies the ways in which women are so often completely disregarded when it comes to understanding their own health, so much so that they are not always even fully conscious when being given information.

Communication is not the only way in which physicians show disregard for their patients and their needs in the exam room. User CamJay85 was 22 when she went to the gynecologist seeking help. She had been dating her boyfriend for three years, and they had never had penetrative sex. She says that she had hoped a pelvic exam would “loosen her up” in order to be able to have sex, but also recalls a q-tip swab from a previous yeast infection hurting very badly, and therefore she went into the appointment with apprehension. She says,

¹¹⁶ Ibid.

¹¹⁷ Ibid.

¹¹⁸ Savidge et al., “Women’s Perspectives on their Experiences of Chronic Pelvic Pain,” 114.

I'm legit sobbing in her office waiting for my exam. She comes in and she is clearly irritated with me for being so irrational. I try telling her all the problems I've had with painful sex and other issues about pain with periods, etc. but she just tells me that I really should wait until I'm married to have sex and that she'll lube me up for my exam since I'm a Virgin! Then she proceeds to stick her finger in me and I'm immediately in immense pain. I Yelp out and tell her how bad it hurts and she just tells me to relax. I literally cannot relax, it felt like she was stabbing me with a knife. I tell her I don't think this sort of pain is normal, and she says no it's fine you're just really [t]ight. She leaves her finger there for awhile telling me I just need to adjust. Then she starts pressing further. I'm literally lying there crying begging for her to stop and she won't. Finally she removes her finger, informs me that she only got her finger in to one knuckle, tosses some tissues at me, and says she can't perform the exam and I could leave.¹¹⁹

CayJam85 receives multiple harmful messages through this experience, in addition to suffering intense pain. First, her doctor is irritated by her clear distress and fear going into the exam, ignoring CamJay85's real concerns in favor of her own beliefs and for clinical expediency. CamJay85's extreme pain is then belittled and ignored, too. Pain associated with vaginismus is often dismissed, and attributed to being "too tight," which sends the message that these women are overreacting. Her doctor's disregard for her pain is so high that she blatantly ignores CamJay85 "begging for her to stop" and, in what could arguably be considered malpractice, continues the exam. Finally, the doctor's flippant exit — which also fails to communicate anything of importance to CamJay85 regarding her pain — tells CamJay85 that the doctor's inability to perform the exam is her fault, while offering no explanation for why she was in so much pain. Her doctor is not only unsympathetic, but actively harms her. CamJay85's case is an example of what disregard in the exam room looks and feels like for many women. Being taken seriously is not only a prerequisite for emotional well-being and a productive doctor-patient

¹¹⁹ CayJam85, "Bad Experience," 31 March 2020.

relationship, but its absence can lead to physical harm and reinforcement of the idea that these women are not the authorities over their own bodies.

Community Formation

Each one of these testimonials works toward rejecting the stigma and shame surrounding pelvic pain by talking openly about a taboo topic. These posts bring awareness to the inexcusable treatment these women suffer at the hands of some doctors, provide a place where women see that they aren't alone, and begin to break the cycle of medical gaslighting that prevents women from seeking help. This section will show how important it is for these women as individuals to find their stories in others, and also how their testimonials are all working towards dismantling the society-wide stigma and silence that keep women from understanding themselves and their bodies.

For many users, posting to the vaginismus forum is the first time they have ever spoken about their condition to anyone. For example, user Emdeejay says,

Lastly, I should say that this problem is kept from everyone around me, my mother, family and closest friends have no idea of it, I am attending appointments in secret and I do not discuss it. I have never disclosed it to anyone. I don't know if anyone will read this long ramble but even typing my name into a forum about vaginismus is a huge, huge step of progress for me.¹²⁰

Even before getting replies on her post, Emdeejay shows that there is significant value in the forum existing, providing a space for growth, and facilitating connection with others. Many women also feel the way user Florence does, who embodies the benefits of the forum at the end of a long post that details the struggles she's had with vaginismus. She says,

I actually burst into tears when I found this forum – I'm not an emotional person generally but finding other people – REAL people who are going through the

¹²⁰ Emdeejay, "Diagnosis, Denial and Lost Years," 6 December 2018.

same thing I am that I could actually talk to about this stuff has made me feel overwhelmed with so many different emotions – empathy, relief that I’m not abnormal, sadness that anyone else has had to experience the same thing, and above all, hope that it can get better. Thank you – you guys really don’t know how much it means to me to have found you after almost of [sic] 15 years of thinking I was some kind of freak and totally alone.¹²¹

The forum is so much more than a place to share stories; for so many women, this is the first time they have ever felt seen, the first time they have ever understood what has been happening to them, the first time they have ever seen someone describe the same pain that they feel. It gives these women a place where they know they will be understood, and where they can say what they want without judgment, because everyone has been in their shoes before. Silence about these conditions prevents these women from knowing that they have a legitimate medical condition; the relief that there are women who understand them goes hand in hand with the relief that their condition is common. For many, it helps them see more of their humanity, makes them feel less “broken,” and gives them hope.

Maze is not the only place where these conversations are happening; other sites benefit women in various ways, and reach different audiences. In a visual format, TikTok is a platform that can similarly help build solidarity between people with pelvic pain. Content is easily disseminated by the speed and relevance of individuals’ “For You” pages, the creativity users have to make their own unstructured content, and the ease with which heavy topics can be packaged into digestible humor through popular trends. Videos about pelvic pain can be shared between users, sought out by individuals, or delivered by the algorithm to one’s For You page, allowing for a much broader and faster spread of information than on the Maze forum. The algorithm that generates content for each user is governed by many different factors, such as videos that your friends or people you follow are watching, meaning that someone can end up

¹²¹ Florence, “Welcome New Members,” 26 March 2017.

seeing a video about vaginismus without ever searching for it. Studies on graphic narratives, and other work in visual culture studies, also provide further insight into the work that non-textual, non-linear mediums do, showing that they can often be more effective ways of expressing trauma and the body.¹²² Therefore, it is not surprising that TikTok has become a place where people can easily find community around niche interests, such as caring about the same issues or having the same medical conditions.

Like the blog posts, many of the videos made by women with vaginismus express the difficult realities of living with pelvic pain, though on TikTok this is often done through comedic relief. For example, [a TikTok by user savsavyoungblood](#) humorously laments having to listen to her friends talk about their hookups while trying to be happy for them from afar, because her vaginismus prevents her from having the same experiences.¹²³ This 12-second video is fast paced and structured to be funny, but also shows how much her vaginismus has affected her life. The more significant aspect of this video, though, is the comment section, which is filled with people saying things like, “I feel so seen,” and saying that they thought they were broken, that they had never heard anyone else talk about vaginismus before, and that they found people who understand them. As on the forum, the relief, solidarity, and support in the comment section is replicated on countless similar videos as people see that they are not alone. Because women can find these videos without ever searching for them, the comment sections are bombarded with comments such as “THERES A WORD FOR IT???”¹²⁴ and, “so crazy how many people have it!! I really thought it was just me!!!!”¹²⁵ and, “No one I’ve talked to has ever heard of it but I’m like crying on the bus reading through the comments bc I feel there’s hope of overcoming it.”¹²⁶

¹²² Donovan, “Representations of Health, Embodiment, and Experience in Graphic Memoir,” 245.

¹²³ Savsavyoungblood, “anyone else hav #vaginismus lets talk,” 5 August 2020.

¹²⁴ legs, August 6th, 2020, comment on savsavyoungblood.

¹²⁵ Arianna Marquez, December 5th, 2020, comment on savsavyoungblood.

¹²⁶ sarah smidmore, August 24th, 2020, comment on savsavyoungblood.

TikTok is able to reach women who are scared to admit they have a problem, or are too ashamed to talk to a friend in high school about it, or don't have enough knowledge to know that this is even a condition they might have. It can open the door for these women to learn about themselves, and potentially seek treatment or take other steps towards living with their pain.

The Maze forum and TikTok both provide valuable space for women with pelvic pain. They shatter the shameful silence that so many women live with their whole lives, they shatter the wall that women like me have put up because they were convinced they were a failure, and were alone in that failure. As Labuski and Scarry prove when they write about language, having the words to describe your body and your experiences is crucial to being able to understand yourself, and these platforms give women the language they need. Little by little, sites like Maze and TikTok have begun to open the conversation around pelvic pain in ways that could radically change the tools that society gives women to help them understand their bodies and pain.

Reinscribing Norms

Despite the benefits of these testimonies, analyzing the rhetoric used in these posts exposes how even women who experience pelvic pain, and the medical professionals who want to help them, perpetuate culturally inscribed norms that continue to cause them harm. One norm that is replicated in these communities is the rhetoric of medicalization and the hegemony of medical treatment. For example, on savsavyoungblood's video, a number of comments followed the sentiment of: "Bebe I used to have it & once I dated a really nice person that I could finally trust it magically went away after the first few times we tried 🌟"¹²⁷ or "PELVIC FLOOR PHYSICAL THERAPY FIXES THIS! TALK TO UR DOCTOR ❤️🧡💚💙."¹²⁸ Certainly these

¹²⁷ Mary Kate, August 6th, 2020, comment on savsavyoungblood.

¹²⁸ Lauren, September 4th, 2020, comment on savsavyoungblood.

comments are intended to inspire hope for others, but they also reinforce a cure narrative, and an assumption that, if they could only get a good boyfriend or start physical therapy, they'll be easily cured.

In SB_815's post, while writing about her traumatic experiences, she also sets up the assumption that continuing to be in pain while seeing her gynecologist is the only way to stop her suffering. Her question — "I'll probably never have sex at this point so is it reasonable to skip these appointments or is it better to suffer through it even if it feels traumatizing?"¹²⁹ — shows both the normalization of sexual pain by asking her question so casually, and of the binary nature of pain and sex. In her rhetoric, she can either continue to be in pain, but in theory be able to eventually have sex, or avoid pain and avoid sex, too, with no in-between. In CamJay85's post, she does not say that the doctor was irritated because she *thought* CamJay85 was being irrational, but because she *was being* irrational, demonstrating CamJay85's internalization of the doctor's assessment of her behavior. Littered throughout these women's testimonials are such indications of the norms that are pressing upon them, telling them that they are broken, irrational, and in need of treatment to fix themselves.

The expectation of penetrative sex is particularly reinforced by medical professionals participating in the TikTok community. Gynecologists, pelvic floor physical therapists, and other specialists often contribute to the conversation either through informational videos, or ones that mimic the comedic format of other users. These videos are trying to be relatable, but they come from the perspective of individuals who don't necessarily experience pelvic pain themselves. Some of these videos are helpful, informative, and supportive, but they often also perpetuate patriarchal norms.

¹²⁹ SB_815, "Extreme OBGYN Anxiety. Does it Get Better?" 28 July 2021.

Returning to Maze as an institution, we see that this genre of content often sets unrealistic and problematic standards for treatment. [In one of her videos](#) on the Maze TikTok account, Dr. Bat Sheva Marcus — a sex therapist and the clinical director at Maze — sits in an examination room lip syncing to a slowed-down, dramatic version of Mika’s “Grace Kelly,” while the overlying captions tell the story of a woman with vaginismus who has been married for ten years who has never “successfully had intercourse,” with her husband. After finding Dr. Marcus through Instagram, this woman flew across the country for Maze’s botox procedure and, less than three weeks later, she was able to have “earth shattering and life changing” intercourse with her partner.¹³⁰ First, this video sets the expectation for treatment as being something that is a quick fix, as something that happens once and then produces a cure, instead of the reality of treatment being laborious and long-term. It also reflects Maze’s mission by establishing penetrative sex as the sole reason for seeking treatment, and also the indicator of successful treatment, while propping up penetrative sex as something “life changing” that women with vaginismus are missing out on. It also negates the reality that, even if the physical pain is suddenly eliminated, the psychological pain does not necessarily also vanish, and may take much longer to work through. For example, Maze user Nola218 wrote into the vaginismus forum because, although the botox procedure eliminated her physical pain, years of trauma in relationships and from attempting penetrative sex has left her unable to enjoy sex, and still trying to avoid it altogether.¹³¹ Nola218’s experience reflects the assumption that the lasting emotional trauma often accompanying dyspareunia will disappear alongside the physical pain.

Lastly, the videos produced by medical experts often also impose mind-body dualism, reinforcing the narrative that women’s vaginas are problems that make their lives more difficult.

¹³⁰ Thedrbatsheva, “If you suffer from #vaginismus and feel like there’s no hope, the Botox procedure may be life changing,” 4 October 2021.

¹³¹ Nola218, “Non-Existent Libido,” 13 September 2013.

In [one video](#) by a pelvic floor physical therapist, the creator has used a filter that superimposes their eyes and mouth over the image of a uterus and vagina. The creator is then lip syncing, as the uterus, to audio that says, in a sarcastic tone of voice, “is it me? Am I the drama? I don’t think I’m the drama... maybe I am? Am I the villain? I don’t think I’m the villain.”¹³² This video is accompanied by the caption “POV [point of view]: your 🐱¹³³ is being a real b!tch¹³⁴ when you’re... [insert problem here].”¹³⁵ This video explicitly positions the woman as in opposition to her body by calling the vagina the “villain,” a “real bitch,” and the source of whatever sex-related problem someone is having. Dualistic rhetoric reinforces the singular necessity of medical treatment, because it essentially makes an “other” out of the offending part of the body, and makes it a problem without acknowledging the ways in which our personhood is inherently tied to our bodies.

The videos produced by medical professionals are significant, because they occur within a space where women are vulnerable, and searching for common ground, validation, and comfort, and because they come from a legitimized source. These professionals have a level of cultural authority whose importance cannot be overstated. Looking again at Maze, it is clear that their practitioners are not the same as some of the other doctors we’ve seen throughout this chapter. They, as with many of the professionals on TikTok, are doing the opposite of gaslighting, and are working hard in order to validate women’s experiences. And yet, their messaging is, at its core, doing some of the same damage that these other physicians are doing,

¹³² Dr.adriortept, “POV: your 🐱 is being a real b!tch when you’re... [insert problem here],” 1 October 2021.

¹³³ Emoji representing “pussy,” slang for the vagina.

¹³⁴ TikTok censors what they deem as inappropriate language, including words related to genitalia and sex, which has led to conventions of misspelling these words or spelling them with symbols in the place of letters in order to avoid censorship.

¹³⁵ Brackets included in original caption. This is another tactic to avoid censorship, where the author has redacted the word sex altogether, assuming that the viewer will know what she’s talking about.

but in kinder packaging. Women treated at Maze are not told that their pain is in their head, but they *are* implicitly told that penetrative sex is the expectation, and that they need to rehabilitate their ability to do so, which only validates their feelings of failure and self-hatred.

Conclusion

There are so many forces that construct the experience of pelvic pain in the United States that any positive step only undoes part of the problem. A woman seeking treatment for pelvic pain is guaranteed to be taken seriously at Maze, something they can't get everywhere. Establishing a societal expectation that doctors should listen to women, take them seriously in exams, and validate their pain would make incredible progress in improving the experience that women have while seeking treatment. But this level of progress is only solving one problem, and inherently accepts the logic of medicalization by assuming that pelvic pain is a problem that should be treated in order to rehabilitate the ability to have penetrative sex. Likewise, for all of the good that these women do for each other online, the community that they build does not leave room for them to choose to reject treatment or penetrative sex. Because we are all still governed by patriarchal norms, these spaces allow women to commiserate about being trapped in the same expectations, but do not allow for a rejection of those expectations altogether.

It is undeniably a positive step for women to have increased access to discussions of pelvic pain, but there are more forces at play that are deeply embedded in our society that are being taken for granted in the positivity seen in the later sections of this chapter. The next chapter will draw out these forces that, no matter how much they are helped by the forum or TikTok, are still acting on these women, and are still causing them to feel like failures.

Chapter 3:

“How am I failing so dismally at being female on such a basic level?”

Gender, the coital imperative, and why women feel so ashamed of their pain.

On the Maze Vaginismus Forum, user Kirina opens a post by saying,

I have only recently discovered this forum while doing some research on my ‘failure’ to be a woman. Even referring to myself as a ‘woman’ makes me cringe because I feel more like a ‘thing’ and a defect at that.¹³⁶

Her post is riddled with references to past trauma, struggles to avoid sex in current and past relationships, and a desperate desire to be “normal.” But the most acutely painful sentiment is her assertion that she cannot think of herself as a woman, and barely even qualifies herself as a “defective thing.” She feels this sentiment so intensely that she says, “vaginismus is eating [her] alive” and at the end of her post reiterates that “with each passing day that sex fails or doesn’t happen just enforces my uselessness as WOMAN.”¹³⁷ It is devastating that Kirina feels like such a failure over something that isn’t her fault, a feeling that so many other women experience, too. She is not a defective woman. It is also perplexing — why does her ability or desire to have penetrative sex have any bearing on her identity as a woman at all? This sentiment is common among women with dyspareunia — where does this desperation and belief in their “failed” womanhood come from?

¹³⁶ Kirina, “8yr Story,” 21 July 2013.

¹³⁷ Ibid

Emotional pain is rarely considered in treatment plans, and physicians often discount the significant impact that these conditions have on women's lives. In this chapter, I will revisit the statements of many of the women seen in Chapter 2, this time conducting a deeper rhetorical analysis in order to show that the psychological pain associated with vaginismus is caused largely by societal conceptions of gender.

Doubting one's identity is not the only consequence of dyspareunia. Unbearable shame, embarrassment, fear, hopelessness, and a feeling of failure are present in nearly every post in my sample of forty, in addition to a fear of intimacy, doctors, and, often, their own bodies.

"Pain, shame and fear closed me down mentally... I have avoided men and relationships. I have been aware of my problem and pushed it to the back of my mind."¹³⁸

"I have never been able to even think clearly about my vaginal pain without breaking down in tears. Shame, self pity, anger, embarrassment all play a part. I cried in front of my GP, and then in the gynaecologist appointment, with the (male) gynaecologist and (lovely) nurse,"¹³⁹

"I'm also terrified of never being able to have sex like a normal person. I just don't know what to do."¹⁴⁰

"I feel completely and utterly pathetic, lost and un-hopeful. I will be 27 in a few months and I still haven't had penetrative sex and I'm scared I never will."¹⁴¹

"I am literally a brick wall... I hate to sound so negative but I am so ashamed, embarrassed, disgusted, and upset with myself. I do not know what is wrong with me nor why I am not normal! My self esteem cannot help but fall despite what my boyfriend says... I want to be able to do what I feel like every other person in the world is able to do."¹⁴²

¹³⁸ Emdeejay, "Diagnosis, Denial and Lost Years," 6 December 2018.

¹³⁹ Ibid

¹⁴⁰ CayJam85, "Bad Experience," 31 March 2020.

¹⁴¹ Justoneday, "Lost Soul Needing Some Guidance," 16 March 2019.

¹⁴² anonymous123, "New Here... Feeling Disgust In Myself," 2 November 2018.

“Everyday I have a battle with myself about why I’m not normal and it brings me to tears at the slightest thought about it.”¹⁴³

These are only a few of thousands of similar sentiments written on this blog. Counter to the website’s rosy pastel pink and purple exterior, this forum contains an immense amount of pain and suffering. These women did nothing to incur the pain they experience, yet their feelings reflect how they fundamentally see themselves as people. Questions like “why aren’t I normal?” or exclamations of “I just want to be normal!” are seen over and over again on the Maze forum. This intense conviction in their abnormality indicates how clearly the parameters of normalcy are defined for these women, and how internalized they are. These women want to achieve the norms they’ve been told to fulfill their whole lives, and their inability to do so is tearing them apart.

Gender Theory

The work of preeminent gender theorist Judith Butler shows that the ways in which gender is formed — both socially and individually — are critical to understanding why vaginismus threatens women’s identities. At its foundation, she argues that gender is not one constitutive category, and it is instead inextricably shaped by one’s other identities and culture. Gender is not a stable experience, wherein someone who is born a cis boy or girl is slotted into a preexisting mold of presentation and action, but something that is created and shaped over time by outside forces. She also argues that many structures that are thought of as existing *because of* prescribed definitions of gender actually act to create them.¹⁴⁴ For example, feminism broadly fights in defense of women’s rights, and therefore could be seen as being bounded by a

¹⁴³ Hannah, “Constant Feeling Of Being Broken,” 22 April 2018.

¹⁴⁴ Butler, *Gender Trouble*, 2-3.

preexisting definition of womanhood. However, Butler argues that its existence in fact reinforces a stable definition of gender by continuously engaging with it. Therefore, “the suggestion that feminism can seek wider representation for a subject that it itself constructs... risk[s] failure by refusing to take into account of the constitutive powers of [its] own representational claims.”¹⁴⁵ Feminism inherently reinforces the concept of womanhood, because by making the case for furthering the rights of women, it necessitates defining what, exactly, “women” are. This is just one of many examples of the ways that cultural forces create and shape gender, often doubling back on themselves to change the very definitions they are thought to be responding to. Therefore, one’s “own” gender is always made up of forces outside of one’s self, in social contexts that have many authors, or, in a sense, no author at all. One is always “doing” gender for a real or imagined other.¹⁴⁶ These forces can be visible, but more often are acting even when it feels like one is the sole director of one’s own gender performance.

Similarly, Butler describes the cyclical and self-referential nature of gender, saying “there is no identity behind the expressions of gender... identity is performatively constituted by the very ‘expressions’ that are said to be its results.”¹⁴⁷ Like with feminism, she argues that gender expressions are not reflections of identity, but the expressions *create* the identity; arguably, the way we express, act, and perform our genders simply *are* our genders. What are they if not how we express them? Without naming it, this is the conflict that these women are experiencing. If penetrative sex is an element of gendered performance, it then becomes a part of gender itself. If these women cannot perform penetrative sexual intercourse, are they even women? And if not, what are they?

¹⁴⁵ Butler, *Gender Trouble*, 4.

¹⁴⁶ Butler, *Undoing Gender*, 1.

¹⁴⁷ Butler, *Gender Trouble*, 25.

Gender and biological sex are not usually seen as separate elements of one's identity, but Butler shows us that they are. For many people, there is no difference between the biological gender that they were born with and their expression and lived experience of their gender; this distinction doesn't even cross their mind. However, if gender (identity) is entirely defined by the cultural meanings that are imposed on and assumed by the "sexed" body (biologically defined), then there isn't any reason that "gender" has to follow "sex" at all. Meaning, if gender is largely constituted through societal forces, there isn't any inherent reason that it has to go along with the chromosomes and genitalia someone is born with. Binary genders are expected to adhere to a mimetic definition of gender equaling sex, which doesn't have to be the case.¹⁴⁸

However, even "biological sex" is socially and discursively constituted in the same way that gender identity is. How do we even define sex biologically? Is it based on anatomy, chromosomes, or hormones? What constitutes gender in the physical body? Even on biological terms, gender is not so easily defined, and subjective decisions have had to be made in order to standardize the definitions that we see as inherent.¹⁴⁹ Therefore, gender is not a question of defining something concrete (sex) against something fluid and culturally defined (gender identity), but of defining a relationship between multiple facets of shaped identities that include both body and expression. Therefore, "if 'identity' is an *effect* of discursive practices, to what extent is gender identity construed as a relationship among sex, gender, sexual practice, and desire, the effect of a regulatory practice that can be identified as compulsory heterosexuality?"¹⁵⁰ Here Butler arrives at the crux of what these women are experiencing — their womanhood as defined by the regulatory practice of compulsory heterosexuality.

¹⁴⁸ Butler, *Gender Trouble*, 6.

¹⁴⁹ Butler, *Gender Trouble*, 7.

¹⁵⁰ Butler, *Gender Trouble*, 18.

Butler wonders, “what does gender want? To speak in this way may seem strange, but it becomes less so when we realize that the social norms that constitute our existence carry desires that do not originate with our individual personhood.”¹⁵¹ How do our own identities, and expressions of them, look different if we think of them as serving a purpose? The social validation of our “individual personhood” fundamentally depends on social norms, and which cultural desires we do or do not fulfill. In the case of pelvic pain, these norms are inexplicably tied to how women are expected to behave and perform sexually.

This understanding of gender sheds light on Kirina’s post, as well as on another participant’s. User Florence repeatedly describes feeling like a failure for not being able to give her boyfriend “that one simple thing” of penetrative intercourse and, after finally going to a clinic after many years, writes,

I could have cried when the doctor told me I was physically ‘normal’ – partly from embarrassment at having to show myself to a complete stranger for the first time, partly from relief that I wasn’t deformed and partly from frustration that if I was physically fine why couldn’t I perform the simplest function that any animal can do? How am I failing so dismally at being female on such a basic level?¹⁵²

Florence explicitly embodies this conflict with normativity as she struggles with being normal — according to her doctor — while not feeling “normal” at all. To Florence, having penetrative sex with a partner is the “most basic” requirement she is expected to fill in order to be a woman. Despite a long, thoughtful post where she exposes herself as an empathetic person, and also describes numerous healthy and enjoyable relationships, she still sees herself as a failure. To her, penetrative sex is the foundation of a hierarchy of expectations, where if she cannot fulfill what’s at the bottom, her positive qualities at the top are irrelevant. But, paradoxically, it is also the pinnacle of expectations, as penetrative sex is the thing she must aim for and achieve. Florence

¹⁵¹ Butler, *Undoing Gender*, 2.

¹⁵² Florence, “Welcome New Members!” 26 March 2017.

maintains a remarkably upbeat tone throughout her post; she feels lucky to have a responsive doctor, and reports being excited to embark on a treatment journey, yet returns over and over again to what she perceives as her insurmountable failure.

Another user, MiraCulix, writes a post titled “I don’t want to have my life ruined by this,” which immediately establishes how high the stakes are for her.¹⁵³ After giving background on her almost two decades of living with vaginismus, being unable to use tampons, and leaving relationships in order to avoid potential sexual activity, she says “I’ve isolated myself because of this. I thought, and probably still think, that with vaginismus I’m not a real woman, not a sexual creature at all.”¹⁵⁴ For MiraCulix, being a woman is *entirely* synonymous with being a “sexual creature,” and without sex, she cannot be a “real woman.” She may genuinely believe this, but she feels this way *because* of the external pressures and sexual norms that have shaped her understanding of her identity. Her fear that others will also not see her as a woman indicates the way that gender is formed externally and collectively. These societal forces are so powerful that MiraCulix and so many others posting on the Maze forum take it as fact that they are *not* normal, despite the overwhelming evidence to the contrary.

Intimacy

Because so much of the emotional pain experienced by women with vaginismus stems from the expectation of penetrative sex, much of it also manifests in romantic and sexual relationships. All but eight of my sample posts referenced impact on a partner or struggling with intimacy in some capacity — a far higher percentage than any other theme connecting these posts. This impact takes many forms, such as normalizing that penetrative sex is painful,

¹⁵³ MiraCulix, “I Don’t Want to Have My Life Ruined by This,” 18 June 2020.

¹⁵⁴ Ibid.

relationships straining and ending over a lack of intimacy, and women continually putting their own needs after the desires of their male partners. These posts are riddled with anxiety over whether partners will leave them, or with sentiments like user Flowerchild, who says that “what hurts the most is that I feel like such a burden to my partner especially because before me he was sexually active and I’ve now stripped it off him.”¹⁵⁵ Flowerchild discusses her paranoia, assuming the worst behavior every time her boyfriend isn’t with her, and preparing for when he finally leaves because of her “sexual issues.” For herself as well, though, she feels that penetrative sex is a critical and absent piece of their relationship. She says that, “I’ve been procrastinating about dealing with this condition because of fear but I’ve really reached a point where I genuinely want to have sex... not for my partner or my relationship but for me and the sake of my sanity.”¹⁵⁶ Her desire to have sex cannot be separated from her anxiety about her boyfriend leaving her. She is suffering so badly; she has put so much significance on being able to have penetrative sex that she believes it will restore her sanity when she finally can.

Flowerchild also uses heteronormative rhetoric in the way that she conceptualizes sex. She cites wanting to have “genuine” sex with her partner, which coincides with the concept of the “coital imperative” — the idea that vaginal-penile penetrative sex is “real” sex. Many studies have proved the reality of the coital imperative, showing that a vast majority of people consider vaginal-penile penetration as inherent to their definition of sex, and say that it is not just an important *part* of heterosex, but *is* sex itself.¹⁵⁷ One study — which tries to answer the question: how imperative really is the coital imperative? — says that,

¹⁵⁵ Flowerchild, “New Member: 3 Year Relationship, Virgin & Have Vaginismus From London,Uk” 11 January 2020.

¹⁵⁶ Ibid

¹⁵⁷ See literature review for Jozkowski et al., “Are Women’s Orgasms Hindered by Phallogentric Imperatives?” 1565-1566, as well as Braun et al., “Defining (Hetero)sex,” 230.

Intercourse [penetrative sex] is the ‘ultimate,’ ‘logical conclusion’ of sex, the ‘obvious’ progression; simply, ‘the normal thing to do at the end of it.’ In positioning themselves within a normative script of (hetero)sex, [these women] implicitly suggest that the power of such norms would make the absence of intercourse unlikely.¹⁵⁸

These participants also had a hard time defining *why* they felt that “intercourse” was so important, to which the authors theorized that articulating the importance of penetrative sex “would require them to conceptualise and think about sex as other than ‘common sense’; it would require the formulation of reasons and arguments for a problem that is almost never publicly posed.”¹⁵⁹ Interrogating why the coital imperative exists requires seeing sex as a cultural and political phenomenon more than a natural act. It is so culturally ingrained that vaginal-penile sex *is* sex that, to most people, there does not appear to be a reason why; it just is.

The coital imperative is clearly reflected in my primary sources; about a third of them referred to having “real” sex or “actual” sex, and nearly all of them simply refer to “sex,” with the assumption that it is understood to be penetrative. Sharon, an interviewee from the book *It Hurts Down There*, sees dyspareunia as a “problem” she needs to “fix” by herself, because she sees herself as the one preventing “real” sex with her husband. Because of the coital imperative, she cannot conceive of having vulvar pain *and also* a heterosexual relationship; Sharon’s body can either tolerate her pain or her husband.¹⁶⁰ According to the stories of most of the women in this chapter, couples often forgo their sex lives entirely instead of exploring non-penetrative sexual activity.¹⁶¹ The coital imperative is an extremely strong force that shapes how partners conceptualize being intimate with each other.

¹⁵⁸ Braun et al. “Defining (Hetero)sex,” 233.

¹⁵⁹ Ibid.

¹⁶⁰ Labuski, *It Hurts Down There*, 6.

¹⁶¹ Labuski, *It Hurts Down There*, 5.

Psychologists Kathryn Ayling and Jane M. Ussher, in their study on vulvodynia, heterosexuality, and womanhood, also say that “women who choose non-coital sex risk punitive consequences, such as the derogatory labels of ‘frigid’ or ‘prick tease,’ a diagnosis of sexual dysfunction,” or are simply not seen as heterosexual at all, assuming they must be secretly homosexual if they are refusing to engage in penetrative intercourse.¹⁶² If penile-vaginal sex is heterosex, and penile-vaginal sex is also “real” sex, then heterosex is the only real sex. There is, of course, overlap between diagnosable pelvic pain and choosing not to have penetrative intercourse, but simply refusing in of itself can be considered diagnosable behavior. The coital imperative is so deeply ingrained that if a woman is rejecting it, there must be something wrong with her. Ayling and Ussher also found that when “a woman perceives she cannot fulfill normative (or desired) functions of hetero-sexuality, she may judge herself as ‘inadequate’ through a process of reflexive [self-policing].”¹⁶³ This succinctly describes the pattern seen on the Maze blogs, too, where women endlessly berate themselves for being unable to fulfill the behavior expected of them. Crucially, the external expectations become self-enforced. They are so deeply internalized that most women don’t question what they feel.

What results from heteronormativity, then, is women with dyspareunia either closing themselves off sexually, or engaging in painful penetrative sex that is “more about him.”¹⁶⁴ User LonelyTears describes this experience in a post that details the progress she’s made using a vibrator in the place of dilators in an effort to be able to get pregnant. Then, she says,

I can be intimate with my husband on the most basic level i.e. I can tolerate slow penetration and that’s about it. There is no pleasure, and he has to go real slow or I wince (this is a reflex I usually can’t control). And even that has taken me a long time to achieve.¹⁶⁵

¹⁶² Ayling and Ussher, “‘If Sex Hurts, Am I Still a Woman?’” 299-301.

¹⁶³ Ayling and Ussher, “‘If Sex Hurts, Am I Still a Woman?’” 301.

¹⁶⁴ Labuski, *It Hurts Down There*, 5.

¹⁶⁵ LonelyTears, “My Mini Success Story Plus Some Questions,” 11 February 2021.

She sees penetration as the “most basic” level of intimacy, a prerequisite that should be taken for granted. She continues to engage in tedious sex, where involuntary speed or movement causes her pain, and she talks as if it is obvious that she will continue doing so.

Later in LonelyTears post, she poses a question to the forum about pleasure, saying “this is a side issue to me in the grand scheme of things. But I do wonder, will I ever feel this pleasure I hear others talk about so often?” and then continues,

It does bother me that intimacy with my husband is solely for his enjoyment. I don't say this in a selfish way, I mean because he knows I feel nothing from it which plays on his mind. I want to provide him a proper experience by feeling something in return, instead of either nothing (best case scenario) or pain/discomfort (worst case scenario).¹⁶⁶

She sees her own pleasure as so secondary to the pressures she feels to be a good wife, sexual partner, and mother that she wants to work toward experiencing sexual pleasure not for herself, but *for her husband*. A lack of libido is common amongst women with dyspareunia, and many post about wanting to feel pleasure again, or for the first time. But LonelyTears thinks that her desire to feel pleasure will be seen as selfish, and is quick to explain that she only wants it for him. She is not alone in de-valuing her own pleasure.

It has been well studied that heterosexual couples experience a phallogentric “male orgasm imperative” — where the man's orgasm is prioritized in penetrative sex, and is considered the benchmark for successful sex — and also that women often desire an orgasm not for themselves, but for the sake of their partner's feelings.¹⁶⁷ In fact,

In mixed-sex relationships, the most common concern related to a woman's lack of orgasm—identified by both women and men—is the negative impact on the male partner's ego... Thus, women were more concerned about their lack of

¹⁶⁶ Ibid

¹⁶⁷ Jozkowski et al., “Are Women's Orgasms Hindered by Phallogentric Imperatives?” 1567.

orgasm because it might make their male partners feel inadequate than they were disappointed or frustrated over not experiencing an orgasm themselves.¹⁶⁸

LonelyTears' perspective is influenced by so much more than her vaginismus. Even in relationships where women's pleasure is not hindered by pelvic pain, so many women have internalized the belief that their job is to make sex pleasurable for their male partner. It is reasonable for LonelyTears to want her husband to enjoy having sex, and to care about his feelings. However, LonelyTears *also* deserves to experience sexual pleasure, and to know it is not selfish of her to want it. Her post, in fact, only displays her selflessness, but society should be such that she knows she is allowed to care about herself, too. Phallogentrism and the coital imperative are pieces of a messy web that has long denied women pleasure and agency in their sexual relationships.

Another user, Islander, illustrates more explicitly the sole responsibility women are made to feel to fix their sexual relationships. At the time of posting, Islander had been with her boyfriend for five years, since they were eighteen, and they had never been able to have sex. After three years, they saw a doctor who diagnosed her with vaginismus. She started seeing a therapist, and, she says, "Eventually our whole relationship became about our failed sex lives. I was miserable." She continues, saying,

My boyfriend was forever blaming me for the lack of progress, saying I wasn't doing enough and he was putting in all the effort. This was really hard to hear when for me just engaging in sexual activities took every ounce of effort from me. I was constantly battling my own mind to convince myself I was enjoying our intimacy so that it would eventually lead to penetration. Which did not happen because I ended up feeling nothing but anxiety, awkwardness and eventually, pain.¹⁶⁹

¹⁶⁸ Ibid.

¹⁶⁹ Islander, "My Relationship is Crumbling Due to Vaginismus," 10 March 2019.

Later in the post, Islander describes her boyfriend as “very supportive” and says, “I love him so much and I love having him by my side,” yet he makes their sexual relationship entirely her responsibility. He doesn’t appear to be nearly as supportive as she earnestly wants to believe he is. He stonewalls her attempts at talking about and working on their intimacy, and instead she is forced to try to convince herself that she enjoys it. Her “constant battling” and blame taking has caused her intense anxiety and pain, and clearly indicates her boyfriend’s expectation that their sex life is her responsibility alone.

As these women show us, discordant sex lives often become the central focus of a relationship. Flowerchild spends her time away from her boyfriend in a state of paranoia; LonelyTears is concerned about her husband’s pleasure; Islander’s “whole relationship became about [their] failed sex lives,” and countless women have lost casual and long-term partners because of their dyspareunia. In the case of user 23years, her vaginismus led her to break off an engagement. She describes how reading or talking about her sexual issues and “the broken parts of me” incurred “bouts of anxiety,” and she considers herself “disabled” in her sexuality.¹⁷⁰ She says, when she left her fiancé, “I knew it was best. He was devastated but I was convinced it was his size and that must be the problem.”¹⁷¹ 23years’ thought process — that her fiancé’s penis is too large for her, therefore they cannot have penetrative sex, therefore they will not have a successful relationship, and should not get married — is heartbreaking. She continues her story, saying that her fiance later began counseling and,

the man he saw told him, “she wasn’t having sex with you? Wasn’t interested? Turned you away? Well please thank her next time you see her, for breaking off your engagement and giving you back a sex life!” So there it was again, the male support and complete disregard for the female suffering. And that only lead [sic]

¹⁷⁰ 23years, “Roller Coaster of Emotions,” 15 April 2014.

¹⁷¹ Ibid.

me to feel more isolated and like I had made the right choice. That no one would ever want me if I couldn't have sex. Nobody.¹⁷²

So many women go through this cycle of shame, embarrassment, and distress, only to have these feelings reinforced by professionals, as well as others. The man who was supposed to be helping 23years' fiancé through their breakup instead ridiculed her, and shamed her for not being able to provide him with the sex life that he believed men are entitled to, disregarding whatever sex life she may have wanted. It is particularly problematic when this messaging comes from medical professionals, because it means that women's sexual roles are reinforced by people endowed with cultural and social authority, and also reveals beliefs that inform how they might treat a woman in the exam room.

Treatment & Medicalization

As we saw in Chapter 1, gender and medicalization are inextricably linked. In this section, I will analyze this relationship again through the lens of gender theory, and from the perspective of the women themselves. Alyson Spurgas describes femininity as a process that is “embodied and experiential... one that in its hegemonic or dominant formulation may be experienced as coercive, and one that is most specifically connected... to the traumatizing effects of... a clinical protocol, as a technoscientific framework, and as a lived — but extremely mercurial and unstable — materialization of sexual difference.”¹⁷³ Here, Spurgas emphasizes the embodied nature of gender that is in part defined through medical paradigms. As much as social norms and other external forces shape gender, so do the physical experiences we have in our body, and so do the medical authorities and practices that govern them.

¹⁷² Ibid.

¹⁷³ Spurgas, *Diagnosing Desire*, 10.

The cyclical nature of medicalization described in chapter one — the need for medical treatment being validated and reinforced by the very existence of the treatment — is exemplified through user donnaa. She begins her post, titled “Choosing not to Treat Vaginismus,” by saying “I’m currently in a relationship with someone I adore, love and worship,” and then says that she had been diagnosed with vaginismus a year before, and had not yet sought treatment.¹⁷⁴ One reason for this is the cost of treatment;¹⁷⁵ however the second reason is that she “absolutely want[s] to give [her] partner sex.”¹⁷⁶ She thinks he would be understanding about vaginismus, but also says,

I really can’t imagine us having no sex anymore because I need treatment, because despite the pain, I feel it’s an important piece of our relationship. When we have sex he needs to “push through” to get in, but I told him I’m just a bit tight down there and that he shouldn’t pay attention to me... I wonder if I’m the only one who... wants to keep the “magic” that everything is okay alive, especially in the beginning of a new relationship?¹⁷⁷

In this binary, if donnaa were to acknowledge that she needs help, it would also acknowledge her inability to properly conform to the norm, which, she believes, would prevent her and her boyfriend from having sex at all. At the same time, treatment is her only perceived route to solving this conflict. Society’s singular notion of intimacy drives her to create a divide between her and her boyfriend by encouraging him to pay less attention to her while they have sex. The logic of medicalization tells her that this dissociative, painful act is more intimate and important than non-penetrative sex that engages them both.

¹⁷⁴ donnaa, “Choosing not to Treat Vaginismus,” 12 November 2021.

¹⁷⁵ Specialists for pelvic pain — such as sex therapists, physical therapists, and rehabilitation specialists — are often out-of-network and are widely inaccessible both geographically and financially. Maze Women’s Sexual Health, a practice composed entirely of pelvic floor specialists, does not accept medical insurance.

¹⁷⁶ donnaa.

¹⁷⁷ Ibid.

For user Polkadots, her desire to seek treatment was heavily influenced by her partner, and her feelings of failure and inadequacy were heightened by medical professionals. She describes her two-year relationship with her boyfriend, saying that they initially had “great” sex,¹⁷⁸ and then she began having “traumatizing” dreams about having sex with other men, which started causing her anxiety, guilt, and a fear of intimacy with her partner. A sex therapist, whom he encouraged her to see, initially helped, but then their intercourse began reviving her previous fear and anxiety, and began to cause pain.¹⁷⁹ She then says, “my partner told me that I needed to do something about this or he wasn’t sure that the relationship could work for him,” which forced her to see a new sex therapist, who told her that she could not help her, and to “accept that women are not meant to enjoy sex.”¹⁸⁰ Polkadots’ motivation for seeking treatment seems to come entirely from her partner’s sexual pleasure; as evidenced by the relationships in this chapter, it is too often considered the woman’s job to make sure sex is pleasurable for her male partner, which therefore makes the burden of treatment her responsibility as well..

Polkadots goes on to say that their relationship ended, and that although he “always tried to be patient,” he also “never made any effort to try and support me and empathise with how I was feeling... I was never pleased enough by him in other areas of our sex life, but I always prioritized making him feel good.”¹⁸¹ This relationship implies that sexual deviancy is an individual experience; despite being in a partnership, treating her sexual pain remained Polkadot’s sole responsibility. Yet the burden of treatment can be nearly as bad as the burden of penetrative

¹⁷⁸ She later says, in an offhand manner preceding a different thought, that “[she’s] never had an orgasm.” The goal of a satisfying sexual experience certainly does not always have to include an orgasm; however, it is notable that she has never had one, despite describing their early sex life positively. Each one of these posts contain subtle hints to how these women understand themselves and their pleasure, and, like LonelyTears, how they often value it as significantly below their male partners’.

¹⁷⁹ Polkadots, “Finding My Way,” 26 June 2019.

¹⁸⁰ Ibid.

¹⁸¹ Ibid.

sex. Ayling and Ussher's study found that "a strong biomedical focus encourages treatment regimes that 'fix the woman' for pain free coitus" and that any decrease in psychological desire or sexual activity is seen as "individual pathology rather than as an understandable reaction to chronic vulvar pain."¹⁸² They reported that, throughout treatment, "women spoke of isolation, feelings of sexual inadequacy and loss of femininity, guilt, shame, loss of self, and diminished confidence."¹⁸³ In other words, all of the suffering that women endure in their relationships is heightened, or at the very least maintained, through their experience of medical treatment. Medicalization provides no way out for these women: they are isolated and shamed for not being able to have penetrative sex, and yet, when they try to solve their problem and conform, they are given the exact same treatment. The consequence of medicalization is that if treatment does not work, which it often does not, one has then also "failed" in the only solution to "fix" one's sexual nonconformity. This is why the rhetoric that providers like Maze employ, despite good intentions, can be so destructive: it positions treatment as something that will solve all of one's problems.

Conclusion

Judith Butler sees gender through paradox; our body is both our own and also defined by others. She argues that one may have to render themselves "unrecognizable" in order to live, but this, too, is a paradox.¹⁸⁴ By becoming "unrecognizable" — a person not adhering to culturally defined categories — we are freed from the expectations imposed on us; however, we are unable to live without being perceived and shaped by others, either. In struggles for bodily freedom, autonomy, and rights, we are seen as bounded groups fighting for a unified experience. Yet, she

¹⁸² Ayling and Ussher, "If Sex Hurts, Am I Still a Woman?" 295.

¹⁸³ Ibid

¹⁸⁴ Butler, *Undoing Gender*, 4.

says, “it is through the body that gender and sexuality become exposed to others, implicated in social processes, inscribed by cultural norms, and apprehended in their social meanings. In a sense, to be a body is to be given over to others even as a body is, emphatically, ‘one’s own,’ that over which we must claim rights of autonomy.”¹⁸⁵ We are inherently dependent on others, and vulnerable to them, even to be ourselves, and to be “our” own bodies. Therefore, the question becomes not of autonomy, and the ability to conduct oneself with full independence, but of how to acknowledge and construct *each other* with freedom and dignity.

How do we live in community with one another such that we alleviate the social and sexual pressures women experience? We have the potential to make communities like Maze and that exist on TikTok spaces that fully support one another, and reject the norms that govern them. With the awareness of the expectations that burden us, we can begin to collectively move towards communities in which we are given the freedom to choose our own paths towards healing and relationship.

¹⁸⁵ Butler, *Undoing Gender*, 20.

Conclusion

At the Maze Women's Sexual Health clinic, a man named Dr. Peter Pacik pioneered a treatment for vaginismus that involves injecting Botox into the vaginal muscles in order to prevent them from spasming and tightening. They advertise a 90% success rate, defining "success" explicitly as "pain-free intercourse."¹⁸⁶ Maze appropriately emphasizes that this is only the first step in treatment, and patients then use dilators in order to ensure long-term results, but Maze promises that Botox will eliminate the pain in order to continue working through lingering physical and emotional symptoms. Yet, patient testimonials rely on familiar rhetoric claiming this to be a miracle cure: one saying that within a month her vaginismus was "cured," that she now knows what it feels like to be "normal," to have a "normal relationship, [and] normal periods." Another states that Botox treatment "changed [her] life;" she had felt she "would never be able to have intercourse," but only 15 days after treatment she was able to have pain-free penetrative sex with her husband.¹⁸⁷ Despite these testimonials of phenomenal success, it is unlikely to be everyone's experience.

A participant we saw briefly in Chapter 2 exemplifies one of the crucial findings of my study: even if the physical pain can be healed, the emotional pain remains a significant impediment both in the goal of penetrative sex, and in overall wellbeing. In contrast to posters

¹⁸⁶ Maze Women's Sexual Health, "Vaginismus Treatment Under Anesthesia."

¹⁸⁷ Ibid.

attesting to Botox's miraculous results, user Nola218 provides insights into the more complex relationship between physical and emotional trauma. She went through Dr. Pacik's treatment after 11 years of vaginismus, saying that she has never experienced pleasurable sex, and has "no understanding of what it is that [she's] trying to accomplish."¹⁸⁸ After the treatment, she says that "sex is physically possible," and therefore she feels she should be enjoying and looking forward to it. Instead, she says, "I still dread it, and I still need a glass of wine or two to even be willing to try it."¹⁸⁹ Nola218 has what so many women desperately want: a complete physical cure. And yet emotionally she doesn't seem cured at all, so what else is happening?

Nola218's post describes how, for the 11 years in between learning of her vaginismus and receiving treatment, she was in and out of relationships where sex was an extremely traumatic and painful experience. It often left her "crying and screaming" afterwards, feeling like she was "raped every time [she] had sex," and feeling like "less of a person every single time." She describes her continued dislike of having sex by saying,

I, however, feel more distant from [my boyfriend], and sometimes despise him during and immediately afterwards. Even though he respects me and will stop if it hurts, just the act of him doing to me what used to hurt me so bad makes me angry at him. I still think of sex as something that caused me years of pain and heartbreak and I can't just snap my fingers and desire it. My aversion to sex also led to an aversion to pretty much all physical touch throughout the years. My mind taught me to hate kissing or fondling because it was related to sex, and I hated sex. This has left me at age 28, with the love of my life, but unable to understand how to have a physical relationship with him, since I don't feel any physical attachment to him.¹⁹⁰

Laid out like this, it seems inevitable that rehabilitating the desire for sex of any kind would take time once the physical pain has gone away. This is the caveat of biomedical treatment: women's physical pain is not the only origin of their suffering, and therefore it follows that physical

¹⁸⁸ Nola218, "Non-Existent Libido," 13 September 2013.

¹⁸⁹ Ibid.

¹⁹⁰ Ibid.

treatment alone will not eliminate all of their pain. This is a recurring sentiment on the Maze blog, with repeated comments such as:

“I was in so much pain and worst of all my emotional pain.”¹⁹¹

“Although the physical pain is bad, it’s my emotional response that has had the most detrimental effect on me.”¹⁹²

“It’s not just the physical, it’s the broken spirit too and the emotional healing.”¹⁹³

“I can say that I am cured from vaginismus physically it has still left scars psychologically.”¹⁹⁴

These women show us that even when medical treatment works, the emotional devastation is still present; the consequences of these conditions linger. The emotional pain outlined in the previous chapter is not just an additional symptom of dyspareunia, but in fact is its most consequential harm.

Biomedical treatment, then, is incapable of ever fully “curing” dyspareunia. Biomedicine has an important role to play for some women who do see life-changing improvements, but because these women’s severe emotional pain is caused by societal expectations, social norms need to change in order to prevent this pain from occurring in the first place. These expectations — that women will have heterosexual partners, participate in penetrative sex with them, and perform the role of the ideal sexual body whose primary function is to pleasure her male partner — will not be solved on a societal level by treating one person. Talk therapy — which is often prescribed or encouraged by physicians, or sought by individuals — is not an adequate solution, either, because for every woman with vaginismus who is helped in therapy, countless more

¹⁹¹ Hannah, “Constant Feeling of Being Broken,” 22 April 2018.

¹⁹² Emdeejay, “Diagnosis, Denial and Lost Years,” 6 December 2018.

¹⁹³ 23years, “Roller Coaster of Emotions,” 15 April 2014.

¹⁹⁴ rachel, “6 Months or More Transition,” 31 July 2013.

women are experiencing the same trauma from which she is recovering. Without broadly changing our understanding of what “real” sex is, and eliminating the belief that there is a way that women “should” engage in it, these expectations will continue to cause harm.

Alternative Frameworks — Medicalization

Though medicalization is only part of the problem, shifting physicians’ approaches to treatment can help change the social conceptions of pelvic pain conditions. Caccioni and Ferrell advocate for Victoria Grace’s embodied frameworks that examine chronic pain through multifaceted lenses, looking at broad social influences as well as biological and psychological factors, which allow for “messier,” non-linear and non-causal understandings of pain.¹⁹⁵ Healthcare researcher Courtney Donovan emphasizes the importance of prioritizing patients’ personal narratives in healthcare in order to convey embodied knowledge in medical contexts.¹⁹⁶ She says that the body goes beyond objectivity and fact to incorporate different knowledge and realities. Combatting the assumption that medical lenses provide utmost authority, this framework centers the patient and their story as the primary perspective and factual center.¹⁹⁷ Particularly with conditions that medicine fails to understand with significant clarity, it would be revolutionary to ground a medical practice in the patient’s reality, instead of in the physician’s knowledge and perspective.

This framework would make it possible that someone could seek consultation with a physician and then feel supported in deciding not to pursue treatment. I hope to see a future of treating pelvic pain where doctors are more ready to admit their ignorance, not such that they send their patients away without help, but such that they acknowledge that the long and

¹⁹⁵ Caccioni and Ferrell, “The Medicalization of Women’s Sexual Pain,” 331.

¹⁹⁶ Donovan, “Representations of Health, Embodiment, and Experience in Graphic Memoir,” 240.

¹⁹⁷ Donovan, “Representations of Health, Embodiment, and Experience in Graphic Memoir,” 243.

frustrating path of treatment may not be worth it, or may not be right for their patient for another reason. An embodied understanding of complex medical conditions such as vaginismus, which would center the patient's authority, will help to build a future where treatment is not necessarily the assumed path, and both doctors and patients understand the shortcomings of many treatment options.

Rejecting the assumption of desiring a cure can help this framework. Clare says, "Cure is such a compelling response to body-mind loss precisely because it promises us our imagined time travel. But this promise can also devalue our present-day selves. It can lead us to dismiss the lessons we've learned, knowledge gained, scars acquired. It can bind us to the past and glorify the future."¹⁹⁸ The idea of a cure fundamentally relies on having an imagined, idealized past body that one is trying to return to. He argues that this mindset reduces the value of the body's current state, the lessons and knowledge it now holds. Letting go of cure as a goal — even if one may, in the end, reach what one defines for themselves as a "cured" state — will allow physicians and patients to better value the body as it is now, and better design treatment plans around ever-shifting goal posts.

Alternative Frameworks — Queering Heterosex

As the previous chapter clearly suggests, eliminating our societal expectation of penetrative sex will alleviate the intense feeling of failure that many of these women experience, and normalizing non-penetrative ways of having sex is an important step in doing so. The coital imperative assumes that in order for sex to be "real" between heterosexual partners, it has to be penetrative, classifying any other ways of having sex as queer by default. The authors of the previously mentioned study on the coital imperative say that it "is likely to be incredibly difficult

¹⁹⁸ Clare, *Brilliant Imperfection*, 57.

to challenge—sex and intercourse are conflated at the most fundamental level, and reinforced in (among others) biological, evolutionary, psychological, and religious discourse.”¹⁹⁹ However, Caccioni and Ferrell found that for the women in their study who never consulted a doctor, changing their definition of what they believe to be “real” or “successful” sex was the most commonly pursued “treatment” option.²⁰⁰ Additionally, I found that the primary sources that brought the most hope to the discussion of pelvic pain were by women who talked about finding alternative ways to have sex.

Though it will be difficult to undo the belief in the coital imperative, “queering” our perceptions of heterosex will be crucial to alleviating the burden of conforming to narrow conceptual norms. According to Caccioni and Ferrell, “in this context, queering sex does not necessarily mean engaging in same-sex sexual activity (although it may), but more widely undertakes the spirit of ‘queer’ to reflect the disruption of normative heterosexual practices and engagement in any sexual practice that provides pleasure and does not privilege, require, or culminate in penile–vaginal intercourse.”²⁰¹ For the purposes of eliminating the coital imperative, queering our understanding of sex will allow for multiple definitions of “real” and “successful” sex, which do not all rely on penetration or male orgasm, thereby reducing the risk of “failing” in a sexual experience. Already, there are positive examples of this shifting mindset among people with pelvic pain.

A [TikTok by user smurdypants](#) shows a woman with her head thrown back, with text over her that reads “being diagnosed with vaginismus and not sure if I will ever have good seggs.”²⁰² Then, the audio changes, and she comes closer to the camera, dancing confidently under text that

¹⁹⁹ Braun et al., “Defining (Hetero)Sex,” 229.

²⁰⁰ Caccioni and Ferrell, “The Medicalization of Women’s Sexual Pain,” 332.

²⁰¹ Ibid.

²⁰² A common misspelling of “sex” in order to evade censorship.

says “Me realizing that seggs is not just p3ne*r@t*o* [penetration].”²⁰³ This user is pushing a message that is rare to see: that heterosex can be non-penetrative and still be pleasurable and satisfying. Because TikTok has thriving communities of people with non-conforming gender and sexual identities where definitions of sex are already more fluid, this kind of messaging is becoming more common. The openness of TikTok allows for messaging around pelvic pain that is entirely positive and hopeful, something that isn’t usually seen on the Maze blogs. Through sites like TikTok, communities that have already been working to undo the coital imperative can influence the broader conversation around pelvic pain, and work to make heterosex a more fluidly defined experience.

Queer relationships can also directly provide a model for how to communicate about sex that will aid women in asserting what they want and deserve. One of the very few studies of queer women with dyspareunia found that they were better able to communicate their pain with female-bodied partners than with men, primarily because of their prior experiences of breaking sexual norms.²⁰⁴ Because these women had already spent years advocating for and defending their sexuality, they were better prepared to express their needs and desires in their sexual relationships. Although queer couples don’t appear to communicate *more often* than heterosexual ones, one study argues that they do communicate *better* than them.²⁰⁵ This finding makes a larger argument about the sexual education that women receive. In the ideal world we should be striving towards, there would not be rigid sexual norms that must be broken in order for women to learn to advocate for themselves in all sexual scenarios.

²⁰³ Smurdypants, “Vaginismus doesn’t mean people can’t have pleasurable and fun ... lives. #sexualhealth #vaginismus #indian,” 19 May 2021.

²⁰⁴ Ekholm, et al., “A lot to fall back on,” 7.

²⁰⁵ Cappell et al., found in Ekholm et al. “A lot to fall back on,” 3.

Nevertheless, this study shows that even in much more open and inclusive queer spaces, sexual expectations can still be problematic. One of the women in the study felt that lesbian sex should inherently be an equal and reciprocal activity in order to reject sexual hierarchies, and that her pain made her and her partner “imbalanced.” Her pain did not threaten her identity as a woman, but it *did* threaten her identity as a feminist lesbian by forcing her to engage in sex that couldn’t always be perfectly equal.²⁰⁶ Instead of feeling guilty for depriving her partner of pleasure, she felt guilty for depriving her partner of the opportunity to give *her* pleasure.²⁰⁷ In complete opposition to the guilt that many women feel in heterosexual relationships, this participant felt that reciprocity is such an integral part of queer sex that she was still failing in achieving a sexual expectation, despite escaping the coital imperative. The authors of this study argue, then, that though the norms that these queer women operate under are more liberating and less damaging than those of the coital imperative, the issue lies in the existence of sexual norms at all. No matter what they are, any expectations create distance between the ideal and the actual self.²⁰⁸ Therefore even norms that formed, with the best of intentions, to ensure sexual agency, equality, and acceptance have negative fallout when they cannot be fulfilled.

I don’t know if it is possible to achieve a society in which we have no sexual norms at all, but we certainly should aspire towards one where the only expectations are that sex is consensual and mutually satisfying, and every sexual partnership decides what that means for themselves. However we get there, we should work towards a culture in which there are not such clear expectations that they allow for the possibility of sexual failure.

²⁰⁶ Ekholm et al., “A lot to fall back on,” 4.

²⁰⁷ Ekholm et al., “A lot to fall back on,” 5.

²⁰⁸ Ekholm et al., “A lot to fall back on,” 9-10.

Conclusions

At its core, this paper advocates for validating the experiences of women with pelvic pain such that they know it does not make them any less of a person or woman, and that they feel supported in choosing one of many accepted paths to living with or treating their pain. The conclusions derived from my research are that we must both promote freedom of choice and inclusive sexual expectations and reject the imperatives of medicalization. It should be considered equally valid for one woman to choose to get the Botox procedure and to use dilators, as it would be for another to choose to only have non-penetrative sex and to change nothing about her body. The coital imperative should not dictate what one chooses to do to themselves. I cannot advocate solely for increased awareness and solidarity surrounding these conditions, however, because this does not address the problems of medicalization, which dictates that a woman's body needs to be changed to conform to societal expectations. We need to challenge the rhetoric of medicalization by promoting increased medical research, education on these conditions, and greater consideration and respect in the exam room. It should be within a woman's right to seek treatment for her pain, and she should be taken seriously, if she chooses to do so, by a doctor with up-to-date knowledge on how to best help her. In order to alleviate the social, psychological, and physical suffering of these women, we must move forward with both approaches: changing our sexual norms and *also* restructuring medical treatment.

These conclusions are not only pertinent to those with pelvic pain; this research exposes just one of the ways in which gendered expectations govern our lives, and make us feel like failures for not achieving a fabricated goal. Women without pelvic pain could be helped by the changes proposed here as they can be applied to countless other areas in which women are "failing" to meet socially inscribed expectations, and where we need to expose the possibility of

rejecting them. Similar intersectional research has and should continue to deconstruct gendered norms and also advocate for changes in medical training and practice.

This thesis aims to complicate the rhetorical binary between advancing medical progress on pelvic pain, and rejecting the logic of medicalization by changing sexual norms. In reality, there is no either-or; most of the actors in this discussion have everyone's best interests at heart, yet all of us are influenced by patriarchal norms and expectations. There must simply be space such that women choose to seek treatment for themselves, and not because it is the path to conforming to sexual expectations, or because they think they can't choose a non-penetrative path.

In an appointment this past year, my doctor and I agreed that her previous diagnosis of vaginismus had been incorrect, and that a hymenectomy might solve my pain. I was being told something that no one with vaginismus will ever be told accurately: there might be a quick fix. Yet I didn't experience the relief that I expected to feel, that I had waited my whole life to feel, and through this research I have begun to understand why. My pain has played a tangible role in how I perform and live my gender identity, and it has been doing so for thirteen years. In many ways, it feels like a part of me. I've come to see that pelvic pain is not just something I've lived with; it is something that fundamentally affected how I came of age as a woman, and how I forged my early identities. It has mediated thousands of thoughts, interactions, and decisions, and, like some of these women have seen, I realize that influence will not go away with a simple procedure. I have begun to seriously question whether I want to undergo any treatment, or whether I want to embrace the forces in which I've come of age, and to reclaim them for myself. I don't know what this future for myself will look like, but I hope it unfolds in a world in which all women are fully supported in the choices they make for their own bodies.

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