

**Visualizing Vaginismus:
A Patient Focused Approach**

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This paper is written by someone who has vaginismus.

The following offers an approach to distributing and communicating information about the female sexual dysfunction vaginismus under a patient focused model. It explores the methods of a patient over partner and patient to patient dynamic. These two approaches and their outcomes result in textual and visual information that centers the conversation around the vaginismus patient and their experiences and pain. The information in this paper is based on research and my real-life experiences as someone who has had and been treated for vaginismus both medically; physically and mentally, and through personal methods.

Vaginismus is defined as the recurrent, involuntary contractions of the perineal muscles surrounding the outer third of the vagina during attempted penetration.¹ More commonly, it is described as uncontrollable spasms of the vaginal muscles, which cause severe pain when using a tampon, having a pelvic exam, or having penetrative sex, among other types of vaginal penetration. Pain with penetrative sex, more specifically, *the inability to have sex*, is universally recognized as the most common symptom of the condition, which can also be understood as the “most important” symptom. While the frequency of this symptom, the fact that vaginismus often initially appears during the first penetrative sexual encounter is to be accounted for, the inability to have [penetrative] sex also rises to the top because of its relationship to the vaginismus patient’s partner and the inability to have sex being socialized as a personal failure.

Most current literature, medical, academic, and otherwise, very frequently uses the phrase “vaginismus sufferer” when speaking about those who have the condition. While the definition of the word is accurate and can function to acknowledge and make tangible the agony

¹ Arthur L. Burnett and Karen Elizabeth Boyle, “Sexual Function and Dysfunction in Men and Women,” in *Principles of Gender-Specific Medicine*, ed. Marianne J. Legato (Academic Press: 2010), 707.

this condition causes, I opt instead to use simply “those with vaginismus” or “vaginismus patient” to remove this descriptor that I have found to be more reductive while also evoking feelings of hopelessness.

The inability to have penetrative sex, especially when speaking about what is most commonly associated with the term (i.e., male penile penetration within a female vagina), is arguably the symptom of vaginismus that causes the most physical and mental stress. However, it is not innately more stressful than the other symptoms but has become such, especially in the lives of primarily straight, cisgender, girls, women, and assigned female at birth (AFAB) individuals due to female socialization, sexism, misogyny, and the like.

Historically, the word sex has usually denoted penis-in-vagina (PIV) sex, especially if you are growing up being socialized into a traditional female society that is dominated by the patriarchy. Breanne Fah’s article on “Compulsory Penetration,” underscores the emphasis penetrative sex and the phallus have on defining “real sex.” She notes how long standing sexual scripts and socially constructive narratives guide people in their view of what “normal” sex is; whose end is dictated by the male orgasm.²

The mainstream cultural perception of what constitutes “sex” in a heteronormative society is often thought of as the same between male and female populations. Cisgender men and people with penises are taught that sex ends with penetrative sex and their orgasm, cisgender women and people with vaginas are taught the same. In early sexual education classrooms, the group separated into young girls are taught how to put a condom on a banana, what sperm is, where the scrotum is located, and are actively pushed towards abstinence. They are not taught where the clitoris is, what it does, the difference between a vulva and vagina, anything about self

² Breanne Fahs, *Women, Sex, and Madness: Notes from the Edge* (New York: Routledge, 2020), 111.

pleasure, that sex hurts the first few times, or about sexual pain disorders or female dysfunctions. Early introductions to human sexuality, in addition to other cultural influences such as religion, familial attitudes towards sex, the demand to procreate, peer pressure, bullying, homophobia, heterosexism, and general sexism and misogyny lead young girls to believe sex only has one definition.

This belief of sex is seldom unlearned as young girls grow into young women and individuals under the same patriarchal structures. As they begin to become sexually active (primarily speaking about heterosexual couples, but also how heterosexism can influence bisexual and lesbian individuals) they not only have the ingrained belief that sex is supposed to be penetrative, but that if they cannot have penetrative sex then they are not *normal*. Citing Dr. Katz and Dr. Tabisel,

“Feeling ‘normal’ implies being in control of life’s choices such as managing menstrual flow, treating vaginal infections, having penetrative sex in a relationship or marriage, undergoing medical checkups, or becoming pregnant and giving birth. Emotionally, feeling ‘normal’ means having the body and the mind work together in harmony toward fulfillment and happiness.”³

For myself, “normal” was hinged mostly on my ability to have penetrative sex but also extended to things such as tampon use. It is incredibly alienating, especially at the middle school and early high school age, to be the only one not able to participate in a swimming activity due to a menstrual period that could not be contained internally. As I progressed to a teenager and into my twenties, that detachment grew and pushed me further away from the collective experience

³ Katz and Tabisel, *Private Pain*, 154.

of my peers discussing their successful and pleasurable sex lives. For fear of being shunned as the one to always make things negative or the nervousness of possible embarrassment from letting people know I was unable to have sex, I never engaged in those conversations. Instead, I isolated myself and lived alone with the idea that I was abnormal, that my inability to experience penetration sexually or otherwise relegated me to a category of broken and undesirable. I did not exist in the standard that would allow me to have a sound body and mind.

While this phenomenon does not exist in a vacuum, this paper's focus will now return to individuals who cannot have penetrative sex due to vaginismus. This fear of being abnormal, dysfunctional, broken, and less than does not lead to addressing the root of the problem; it leads to shame, disgust with oneself, depression, and desperate attempts to "save" relationships with male partners who are presumed to abandon a relationship without penetrative sex.

In cisgender, heterosexual relationships on the whole, women often report that when they engage in penetrative sex they fake orgasms for one or more of the following reasons: to protect their male partners' egos, to ensure their partners satisfaction for fear of losing them, to avoid conflicts, and because they feel like they "owe" sex to a partner.⁴ Those with vaginismus engage in these behaviors as well, but with the added factor of physical pain that is rarely mentioned to partners for some of the same reasons listed above. Sexual scripts that direct women's attention away from their own needs also require them to tolerate sexual pain.⁵

In a 2008 article, "Why Do Young Women Continue to Have Sexual Intercourse Despite Pain?" doctors researched motives behind this phenomenon and ultimately determined a core explanation that women were striving to be affirmed in their image of an "ideal woman."

⁴ Ibid, 22.

⁵ Ibid.

Determining factors included resignation, sacrifice, and feelings of guilt.⁶ In this study, the perceived “ideal woman” of a predominately white and European context, had several defining characteristics: willingness to have sexual intercourse, being perceptive of their partner’s sexual needs, and being able to satisfy their partners. “Prioritizing the Partners Enjoyment: A Population Based Study on Young Swedish Women with Experience of Pain During Vaginal Intercourse,” a study from the same research team four years after the 2008 article, confirmed these results and sentiments.⁷

For the women in these studies, whose results can be applied to many of those with vaginismus, engaging in penetrative sex regardless of pain, was an *affirmation* of being a normal, functioning woman. The “ideal woman” has lots of sex, always pleasures the partner, and never complains. The possibility of “failing” as a woman and feelings of shame and inadequacy not only prevent them from discussing the pain with their partners, family, friends, and medical professionals, but allows the painful sex to continue.⁸ Their own pain becomes secondary to their partner's needs and desires. Continued pain leaves those with vaginismus to feel resigned to it, where sexual pain becomes integrated into the “normal” they are striving to be. As Fahs summarizes, “Normal sex becomes that which meets men’s sexual needs even if it induces pain in the woman.”⁹

However unfortunate, even when sexual pain is addressed by means of communicating with a partner or seeking professional medical help, not much changes. Kate Manne’s work

⁶ Carina Bertero, Eva Elmerstig, and Barbro Wijma, “Why do young women continue to have sexual intercourse despite pain?” *Journal of Adolescent Health* 43, no. 4 (2008): 357-363, <https://doi:10.1016/j.jadohealth.2008.02.011>.

⁷ Eva Elmerstig, Katarina Swahnberg, and Barbro Wijma, “Prioritizing The Partner's Enjoyment: A Population-Based Study On Young Swedish Women with Experience of Pain During Vaginal Intercourse,” *Journal of Psychosomatic Obstetrics and Gynaecology* 34, no. 2 (2013): 82-9, <https://doi:10.3109/0167482X.2013.793665>

⁸ Betero, Elmerstig, and Wijma, “Why Do Young Women Continue To Have Sexual Intercourse Despite Pain?” 357-63.

⁹ Fahs, *Women, Sex, and Madness: Notes from the Edge*, 181.

“Unwanted – On the Entitlement to Consent,” draws conclusions that men’s feelings of entitlement towards sex are so severe that they will engage with coercion and violating behaviors even when explicitly told it is painful or unwanted.¹⁰ It is not unusual for a (primarily male) partner to be uncompassionate, unempathetic, and selfish when faced with a partner who has vaginismus. They cannot always be blamed individually, however, as the same patriarchal culture emboldens their behavior and the “medical advice” provided to them by doctors is that if “they were ‘more of a man’ there would be no problem.”¹¹ Resources for partners of those with vaginismus often leaves much to be desired; instead of offering practical and healthy ways to support a partner with vaginismus, literature speaks more on the negative effects and its “consequences” for relationships.

The following are quotes from *Private Pain* (2013) and *Your Vagina* (2020) that illustrate various outlooks on vaginismus. The quotes and most of the passages in each book explain how “horrible” it is for both parties (or sometimes just the partner) to “deal with” this condition. “The partner suffers as well, feeling helpless, frustrated, betrayed, and wondering about his or her own sexual competency. Being pinned between having to consider a breakup or resigned to having a limited sex life is a common dilemma.”¹² “However, when vaginismus is present, the option of “choosing” is substituted by “settling for what is available” because of the inability to have intercourse.”¹³ “Some men leave because their sexual need for penetration cannot be compromised; others leave because they wish to father children the natural, biological way and are not willing to compromise. Some men claim the lack of penetration reflects on their

¹⁰ Kate Manne, “Unwanted - On the Entitlement to Consent,” in *Entitled: How Male Privilege Hurts Women* (New York: Crown Press, 2020).

¹¹ Ditz Katz and Ross Lynn Tabisel, *Private Pain - It's about Life, Not Just Sex: Understanding Vaginismus and Dyspareunia* (Winnipeg: Kromar Printing, 2013), 55.

¹² Ibid, 4.

¹³ Ibid, 168.

masculinity, suggesting a failure, and therefore, they must go on to be with women who can accept penetration.”¹⁴ “Different kinds of sex can be introduced to satisfy the woman but will nevertheless leave the man unfulfilled.”¹⁵

There is no insight offered about how a partner can *help* someone with vaginismus or use their position of a partner to be supportive figure; it only perpetuates the idea that vaginismus is a dreadful, incurable disease that dooms all relationships. Thankfully, online blogs and articles have started to fill in the gaps left by lack of actual advice and supportive measures. A *Bustle* article titled “9 Ways To Support Your Partner Who Has Vaginismus,” directs a partner to never force sex and go at their partners pace, not to blame themselves, open their mind to a wide range of sexual activities, and realize that they are not entitled to penetration.¹⁶ However, even if that information is available, the partner has to be willing to seek it out and follow it.

Circling back to sexual pain being addressed through communicating, even when done so, the responsibility for treating vaginismus and trying to convince others of their pain still lies only with the one who has the condition. While the (primarily male) partner has somehow become the focus of vaginismus, the one who has the condition still holds the sole responsibility for “fixing” their vaginismus and managing their own mental stability while simultaneously being expected to attend to their partner's emotional and sexual needs. All the while, an unsupportive, antagonistic, and even violent partner can exacerbate these issues to an even higher degree. Cisgender women with vaginismus are expected to achieve the ability to have penetrative sex not only to please a partner sexually, but to assure a male partner's masculinity, be able to consummate a marriage, and bear children. While some may aspire to accomplish

¹⁴ Ibid, 162.

¹⁵ Odile Bagot, *Your Vagina*, (Ontario: Firefly Books, 2020), 83.

¹⁶ Sebastian Zulch, “9 Ways To Support Your Partner Who Has Vaginismus,” *Bustle*, September 22, 2016, <https://www.bustle.com/articles/181486-9-ways-to-be-more-supportive-to-a-partner-who-has-vaginismus>.

these, as they should be granted the opportunity to, the focus on healing is still overbearingly influenced by how it benefits the partner.

In her recent article “Frigid,” Jess E. Jelsma shares with her readers insight on what it’s like for her to navigate married sex with vaginismus. She describes being met with online articles about how it is the wife’s duty to “re-ignite the flame,” recommendations for gels, lubricants, and numbing creams, insertable muscle relaxants, and the threat that divorce is likely in cases of “female sexual inadequacy.”¹⁷ For the benefit of the partner and marriage, vaginismus becomes the patient's responsibility, and if you read between the lines, their fault.

Jelsma explains how her then husband’s incessant pressure to have penetrative sex despite her pain pushed her away from him entirely. She would reject any attempt to initiate intimacy, including her husband stroking her back, rubbing her thighs, or even putting lotion on her sunburned shoulders. She recounts locking herself in the bathroom on her wedding night to avoid her husband’s demand to “consummate [their] union.” He even shows her a video of them having sex in the past, remarking, “Remember the good old days?” while Jelsma can only perceive the tightness of her body and the look of pain on her face.¹⁸ Her husband never made any effort to introduce sex or intimacy in ways that were not hinged on penetrative sex, which for Jelsma, meant painful sex. For her husband, she now appeared as a frigid, sex-repulsed, ungrateful wife, but Jelsma did not necessarily dislike sex, she disliked pain.

Jelsma’s story is much a reflection of my own life and struggles with a partner who was uncaring and only focused on his sexual needs. During this relationship, sex was equal to penetration and ended with male ejaculation. It was never prepositioned to me that sex could be anything different than in a way where I experienced pain, so I slowly began to shy away from

¹⁷ Jess E. Jelsma, “Frigid,” *The Rumpus*, March 18, 2016, <https://therumpus.net/2016/03/18/frigid/>.

¹⁸ Ibid.

even the smallest forms of intimacy because I feared that it would lead to penetrative sex. During the end of our relationship, it was rare for me to even kiss my partner, cuddle, or shower together, and even sleeping in the same bed induced anxiety in me. Much like Jelsma, I appeared sex-avoidant, closed off, and devoid of warmth, but as I have begun to heal, I too realized that I did not dislike sex, I disliked pain.

The repeated act of painful, penetrative sex without intervention perpetuates a cycle of pain and will continue to exacerbate the effects and severity of vaginismus. More sex cannot be used as a way to treat sexual pain, you cannot heal the body with the action that is causing pain without addressing the root of the problem. If a star athlete broke their leg while playing their respective sport, continuing to play that sport would only cause the broken limb to become worse. The pain and broken bone need to be addressed outside of its causing factor, usually medical in nature, where it can start to be healed through different channels often specific to the athlete themselves. From there, physical therapy usually occurs to work them back up to being able to engage in their sport safely and painlessly.

Treatment for vaginismus is not as black and white as the sports injury analogy due to the emotional and mental effects of the condition, but the same underlying principles apply to addressing the root of mental and emotional distress on top of the physical. If physical pain is addressed, often the mental anguish as a result of that pain can start to be lifted as well.

Societal cultures and norms, negligent doctors, and the ignorance and cruelty of intimate partners are all factors that contribute to sex being regarded as only penetrative and the goal of treating vaginismus as being able to have penetrative sex. The current focus on partner and penetration can be detrimental to those with vaginismus, as true healing is often set back months or years due to the push to “fix” their vaginas for the sake of a partner to be able to penetrate

them instead of for their own healing and sexual pleasure. A better approach to treatment would allow one to become acquainted with their own body individually and on their own time, experiencing and experimenting with penetration they are doing to themselves before reintroducing a sexual partner to the mix.

Moving away from this into a patient focused model will require an update in literature for those with vaginismus and their partners, both in the language from research and academia, from medical professionals, as well as in our own communities and our ingrained beliefs about sex. Partners should not be removed from the equation as they are very integral to a condition that does affect sex to varying degrees amongst individuals, but they should be considered secondary; the main focus should be on those with vaginismus. Resources for partners should center on how to be helpful and supportive during this time; how to introduce non-penetrative sex and intimacy into a relationship rather than flooding their minds with divorce and their own masculine inadequacy. A partner's support (or lack thereof) can be monumentally beneficial or detrimental to a relationship and the opposite partner's physical and mental well being.

An additional benefit to moving away from a penetrative positioning is the inclusion of those who do not engage in heterosexual relationships or penile specific penetrative sex. Vaginismus, the way it is talked about now, centers heterosexual, cisgender women in the conversation. This alienates those with the condition who exist outside of those qualifiers, which can make them even *less* likely to discuss their pain as they have been led to view themselves and their symptoms as secondary in the medical realm of sexual dysfunctions.

Single individuals with vaginismus are often dismissed and untreated because there is usually no penis involved. They will be informed that they are not treating the condition "correctly" or that it doesn't even need to be addressed at all until there is a [male] partner

present. “You don’t have a partner, so what’s the problem? Wait until you’re married to address it,” are common verbal misconceptions heard by patients.¹⁹ Individuals in this category might be striving for pain free penetration with the use of their fingers or a toy, to use a tampon, or undergo a pelvic exam. Reasoning for treatment should not be contingent on any one thing or goal, especially not only for the sake of a penis. These beliefs deny adequate healthcare and can leave these individuals with hesitancy to seek out any more treatment, resigned to believe that their health is not as important.

Lesbian women are rarely, if ever, mentioned in vaginismus literature at large. They are by means of more informal articles if a search is tailored, but are rarely considered in the “mainstream.” In a 2020 article on *Medium* titled “Navigating Vaginismus as a Lesbian,” author Celeste Ziehl confirms that her online research is almost always framed within the concept of conventionally heterosexual relationships. She remarks there is very little about queer women and queer women embracing this condition and working around it.²⁰

A post in the Subreddit “r/vaginismus” by a lesbian woman shared that she read an article claiming that vaginismus doesn’t happen to lesbians, that “it is a phenomenon found essentially in heterosexual women.”²¹ A commentator in response to that post sympathized, remarking that her physical therapist asked if her eventual goal is to be able to have sex with a man.²²

The misconception that lesbian women are not affected by vaginismus is once again tied to notions of heteronormativity and “traditional” penetrative sex not being a determining factor in their relationships. Lesbian women and partnerships where both individuals have vaginas can

¹⁹ Katz and Tabisel, *Private Pain*, 201.

²⁰ Celeste Ziehl, “Navigating Vaginismus as a Lesbian,” *Medium*, May 19, 2020, <https://celesteziehl.medium.com/navigating-vaginismus-as-a-lesbian-60403c9ea79c>.

²¹ Unknown User, “Any LGBT+ women with vaginismus?” *Reddit*, 2021, https://www.reddit.com/r/vaginismus/comments/jyjhqv/any_lgbt_women_with_vaginismus/.

²² Ibid.

and do engage in penetrative sex and should have affirming care about having vaginismus. Those couples who do not engage in penetrative sex should be granted this care as well.

Furthermore, transgender individuals are severely affected by heteronormative and penetrative rhetoric, especially in cases where gender and sexuality are believed to be correlated to genitalia. Feelings of dysphoria regarding genitalia are also common among transgender individuals. These negative emotional effects can further feelings of disgust and self-hatred with oneself, which in turn can become a contributing factor toward the development of vaginismus.

There is evidence supporting that pelvic pain and by extension vaginismus can be a side effect for those who begin hormone replacement therapy with testosterone, causing vaginal atrophy which decreases the resilience of the vaginal tissues and the amount of natural lubrication.²³ Just because transgender individuals do not fit into the mold of what is considered to be the “typical vaginismus patient,” does not mean their experiences with the condition are any less valid or less deserving of treatment.

A transgender man under the previously mentioned *Reddit* thread shared:

“In my case, it's true that I'd infinitely prefer not to have a vagina, and that it gives me lots of dysphoria and discomfort, but that doesn't change the fact that it's part of my body, and I want every part of my body to be healthy and fully functional. I may end up not ever wanting to have anything up there, but it's my body and I deserve to be able to choose. Plus it's important to be able to at the very least have smear tests when necessary, which is currently pretty much impossible.”

This commenters' declarations should be circulated and understood by every person with vaginismus and the medical professionals who are treating them. Everybody and every body

²³ Emily Land, “Q&A: Gynecologic and Vaginal Care for Trans Men,” San Francisco Aids Foundation, July 23, 2019, <https://www.sfaf.org/collections/beta/qa-gynecologic-and-vaginal-care-for-trans-men/>.

deserves to be healthy and fully functional, and everyone deserves the ability to choose how and if they engage with penetration and/or sex. Every single individual with a vagina should be granted the opportunity to engage in pain free penetration whether that be with a tampon, through a pelvic exam, the use of a sex toy, a finger, or a penis. At the same time, those who do not wish to engage in penetration should also be validated in having vaginismus. This includes the opportunity to have access to physical and mental medical care, helpful online resources, and a community that is working to break down harmful, traditional ideas of what sex is.

The patient over partner model transitions into Paulina Siniatkina's "patient to patient" methodology. Siniatkina, an artist and activist from Moscow, creates work that is based around her diagnosis, treatment, and recovery from tuberculosis. In addition to her paintings and installation work that focus on confronting the stigma of TB, Siniatkina created an illustrated book titled *Tuberculosis and You*. This book, approved and distributed by the World Health Organization, was created for those who are experiencing TB and undergoing treatment. She describes the book as an easy-to-read guide containing accessible language, and uses her patient to patient methodology to relay this information.²⁴ Patient to patient means that the information being communicated about TB is coming directly from someone who had TB, who very intimately understands what other patients are going through during this often frightening and traumatic time. The first paragraph of *Tuberculosis and You* reads:

"You are reading this because you or someone you love has been affected by a disease called tuberculosis. I know how that feels and understand you need support. I have been there myself. My name is Paulina, I come from Russia and I am a TB survivor. I spent a long time in the hospital fighting for my life, and watching others struggle for survival.

²⁴ Paulina Siniatkina, *Tuberculosis and You*, (Lilly Partnership & TBPeople, 2017), https://www.paulinasiniatkina.com/files/ugd/ade267_f5cbfe0a3d2e487796ffd0158bd91c44.pdf

Many people were afraid to talk openly about the disease. My personal experience has made me want to change that. Silence is what makes TB invincible.”²⁵

Before even expanding upon the details of what TB is, Siniatkina introduces herself and her collaborators as people who have had TB and have recovered from the illness. It is at the forefront that this information is coming from someone who has been in the exact same place. The introduction continues to explain that Siniatkina and her fellow TB survivors have made the same journey the new patient is about to make and are here to provide information and dispel myths. In combining her artwork, words, and medical research, Siniatkina becomes an activist and at the same time, a shoulder to lean on. She writes that *Tuberculosis and You* is not merely a brochure with vital information, that it acts as mental support, a psychologist, and a friend.²⁶

As a visual artist inspired by this method, I began to design my own infographic about vaginismus, where the visuals and information about the condition is coming from myself, someone with vaginismus. This infographic, which has taken the form of a standard 8.5” x 11” flyer, was designed with the intended primary audience of young college students at Illinois State University. My goal in developing and distributing this flyer is to provide others with the information I wish I would have known during my time as an undergraduate student with undiagnosed vaginismus.

I developed vaginismus during puberty, and it took almost a decade for me to be introduced to the vocabulary to describe and understand what was happening in my body. During those teen years and into my early twenties, I was not taught that vaginal and sexual pain were abnormal, that “sex was supposed to hurt,” and that I was broken because of my inability to have

²⁵ Ibid, 2.

²⁶ Paulina Siniatkina, “Tuberculosis and You,” <https://www.paulinasiniatkina.com/tuberculosis-and-you>.

penetrative sex. However, even after my diagnosis, I was deeply affected by a partner and penetrative mentality from medical professionals, my own partners, and my ingrained beliefs about what it meant to be a “functional woman.”

I want to provide information to those young people like me, so they do not have to suffer for an indefinite amount of time like I did. The lack of a diagnosis, even a self-diagnosis, and invalidation of sexual pain can lead to depression, self-hatred, suicidality, and an utter feeling of being alone because you feel like no one else out there could possibly understand what you are going through. That is the root of this project, to give others with vaginismus the resources and opportunities I never had to show them that they are not alone. As Rebecca Solnit writes, “If you lack words for a phenomenon, an emotion, a situation, you can’t talk about it, which means that you can’t come together to address it, let alone change it.”²⁷

Before working on the visual component of the flyer, I developed the text that would be included, keeping in mind accessible and inclusive language, clarity, and succinctness. The goal was to not overwhelm a viewer with walls of text and dense medical jargon but to use short and clear sentences and phrases that can act as a jumping off point into learning about this condition. It was important as well to use gender inclusive language and not use woman/women as the ultimate signifier to describe those with vaginismus. While cisgender women do make up the vast majority of those with vaginismus, trans men, AFAB individuals, and intersex individuals who may not identify with the term “woman” are equally susceptible to developing vaginismus and should not be alienated when presenting information about this condition. The raw text from the flyer is presented below.

²⁷ Rebecca Solnit, “Our Words Are Our Weapons,” *Tom Dispatch*, June 1, 2014, <https://tomdispatch.com/rebecca-solnit-yesallwomen-changes-the-story/>.

Vagina Vocabulary: Vaginismus

Created by an Illinois State University student with Vaginismus

What is Vaginismus?

Vaginismus is the involuntary contraction and spasm of the vaginal muscles during penetration. These can range from mildly uncomfortable to severely painful, preventing penetration.

Symptoms

Pain with:

- Using a tampon
- Pelvic exams
- Penetrative sex

Causes

There is no one cause of Vaginismus and it often appears without a cause, some factors can include:

- Other conditions such as endometriosis
- Past sexual trauma
- Anxiety disorders

Treatments

- Pelvic floor therapy
- Vaginal dilator therapy
- Mental health support

Pain during penetration is not normal or **“all in your head”**, and it can often indicate underlying health issues. If you think you may have Vaginismus, make an appointment with your gynecologist and ask. Knowing the vocabulary to describe what is happening in your body is the first step towards advocating for yourself and becoming healthier!

The final design of the flyer combines my words with visual components pulled from my art practice (fig. 1). In my work, I use shades of pink and red to allude to the body and femininity without traversing into colors that are too “fleshy,” or bloody. I am applying the same method here, using lighter and darker pink shades that are playful and attention grabbing without being too assertive or overbearing, apparent in the faint unbound, checkered background as well. The font is a soft and “bubbly” sans serif, mixing with the rounded corners of the text boxes and border to avoid any sharp or harsh lines.

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Figure 1. Vagina Vocabulary: Vaginismus flyer created by author.

Several flyers, brochures, and infographics for vaginismus and other female centric conditions include invasive interior diagrams, stock images of “depressed women,” and harsh and overbearing colors such as bright reds (fig 2.) (fig. 3). I choose instead to not rely on imagery or diagrams that I have felt led me to think a certain way (that I am broken or reduced to my sexual organs) and focus on the overall color scheme. I want my flyer to be as striking as it is inviting, to be able to hold attention while the information is being digested, and then exist as a place of solace and understanding for those who relate to the content.

Sexual Function Disorders

Sexuality is a crucial and integral part of a woman's existence.

It's natural and adequate fulfillment is necessary to maintain a woman's quality of life and preserve her self image.

43% of American women suffer from some form of female sexual disorder that might: Decrease their sexual desire, hinder their sexual arousal, inhibit their orgasm, or cause them pain.

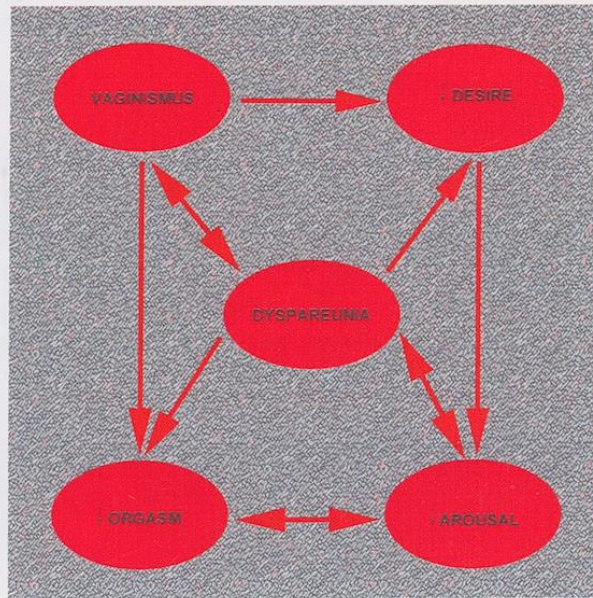


Figure 2. Author's personal copy of a sexual function disorder flyer from the PelviCure Center.

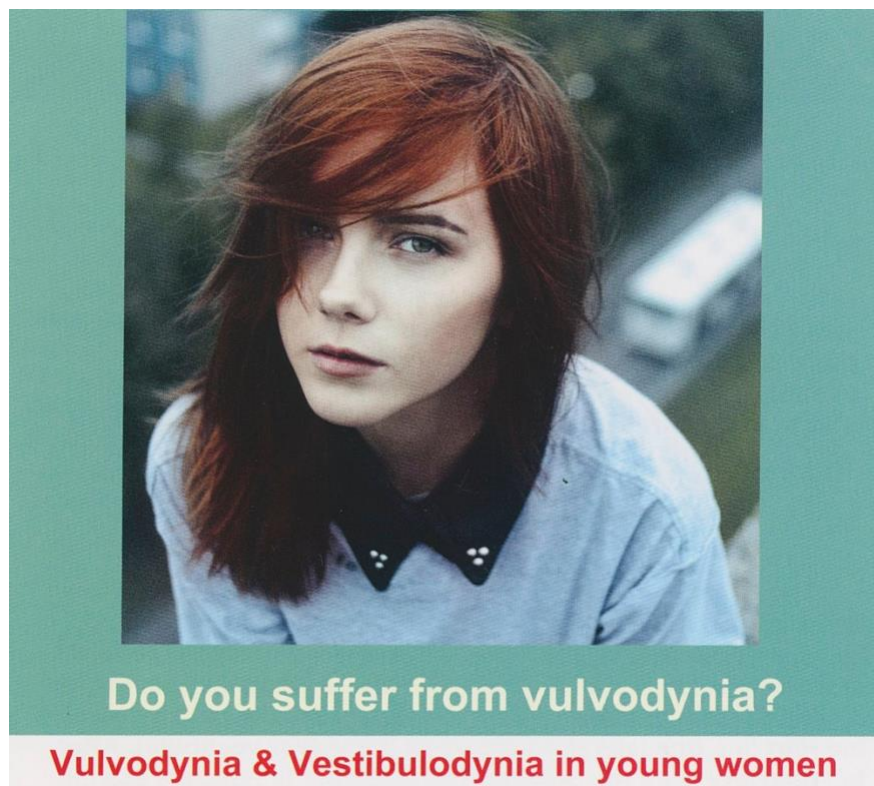


Figure 3. Author's personal copy of a sexual function disorder flyer from the PelviCure Center.

In writing the text for the flyer, there are many seemingly small yet highly intentional and effective adjustments made when compared to some of the literature mentioned in the first section. My flyer utilizes gender inclusive language, hierarchies of information, and other language choices that are influenced by a patient over partner (and penetration) mentality.

The title of the flyer, **Vagina Vocabulary: Vaginismus**, is opting to add some playfulness where others are often aggressive, “PAIN WITH SEX,” or simply add no other context than the name of the condition itself. It presents itself as educational and leaves a door open for more editions of “Vagina Vocabulary” flyers to be created.

The byline of the flyer, **created by an Illinois State University student with Vaginismus**, functions to adopt the patient to patient methodology. It is not necessarily pertinent that my specific identity or name be revealed, but it is of utmost importance that it is known this information is coming directly from someone who shares this condition. It begins to remove the shame behind experiencing vaginal and sexual pain and shows that there is someone else out there, and specifically someone else on the Illinois State University campus, who knows what that pain feels like.

What is Vaginismus? Vaginismus definitions between online and physical resources almost always begin by mentioning fear, anxiety, and the inability to have sex, which is then followed by explanation of the vaginal contractions. I have even recalled seeing a full definition describing the vaginal contractions occurring only as a result of [penetrative] sex. My definition of vaginismus reads: **Vaginismus is the involuntary contraction and spasm of the vaginal muscles during penetration. These can range from mildly uncomfortable to severely painful, preventing penetration.** My definition of vaginismus does not use the word sex or mention sex. While the use of “penetration” in this conversation will obviously lead to thoughts

about penetrative sex, it is important to offer an initial definition that is focused on what is happening inside and with the body, not what the body is “incapable” of.

Symptoms

Pain with:

- **Using a tampon**
- **Pelvic exams**
- **Penetrative sex**

As previously mentioned, the main symptom of vaginismus is recognized as pain with or the inability to have sex, primarily due to the physical and mental stress it causes from being seen as a personal failure and affects from a partner/penetrative focused society. In listing the symptoms, two important choices are made: one, listing penetrative sex at the bottom, and two, specifying it as penetrative sex. The simple act of including the adjective “penetrative” before sex and including it as the last bullet point works to describe only one facet of sex and break down the hierarchy of symptoms. Along with this, listing pain with using a tampon and having a pelvic exam first redirects the conversation back to the patient, primarily focusing on things that only affect the person, and not the two parties of the person and their partner. Thus far, I do not have any research or corroboration to support the claim that listing order provides a more comforting and individualistic response, but I have my own knowledge of being a patient for five years, and those small things would have made a difference for me in reinforcing my pain and health as the primary importance.

Causes

There is no one cause of Vaginismus and it often appears without a cause, some factors can include:

- **Other conditions such as endometriosis**
- **Past sexual trauma**
- **Anxiety disorders**

Introducing causes of vaginismus in a succinct way can be difficult due to the number of causes (or no cause at all). Within vaginismus there are two subcategories: primary and secondary. With primary vaginismus, an individual has experienced pain and muscle spasms with vaginal penetration from the first time penetration is attempted. In secondary vaginismus, individuals who previously were able to have pain free penetration develop the condition usually, but not always, from an outside factor such as menopause, childbirth, medical procedures or other conditions, anxiety, or a sexual assault.²⁸ Primary vaginismus can develop from these events or develop concurrently with another condition as well as be influenced by social factors and fears about sex, but it is important to note that sometimes vaginismus **appears without a cause.**

It is common when discussing vaginismus, especially with gynecologists and therapists, to throw every patient into the “sexual trauma” category. It is not unusual for therapists to push the patient to accept the cause of this condition was due to sexual trauma even when said patient knows this not to be the case.²⁹ Also common is shoving all patients into the “anxiety” or other mental illness box; often resulting in prescriptions that are often used as an easy way to treat a patient and make pain more tolerable without addressing the root of the problem.

For those who do not fall into those categories, especially seen with a primary diagnosis, it can be extremely alienating, frustrating, and invalidating to have a specific narrative forced upon you while also searching for an answer that will never actually come. The world is already cruel to those with vaginismus, but what is even more cruel is having to come to terms with the fact that for the unluckiest of us, vaginismus just *happens*.

²⁸ Jackie Giannelli, “Primary Versus Secondary Vaginismus,” *Maze Women’s Sexual Health*, October 18, 2022, <https://mazewomenshealth.com/blog/2022/10/18/primary-versus-secondary-vaginismus/>.

²⁹ Katz and Tabisel, *Private Pain*, 108-9.

Now that I can look back on my adolescence with the knowledge I have acquired, I am able to confirm that I first exhibited vaginismus symptoms when I was 12 years old and unsuccessful at using a tampon. I was met with discomfort, a tinge of pain, and feeling like there was a brick wall between my legs. At that time, I was not, nor had I ever been sexually active, sexually abused, or traumatized, and I did not have any reservations or overwhelming fears or anxieties about sex due to upbringing or religious beliefs. In the effort of complete transparency, my case is a little more complicated than most due to the fact I also developed interstitial cystitis, a chronic bladder disease, and vestibulodynia, chronic pain and damage of the vestibule, during puberty. While these two conditions aided in the severity of my vaginismus, the point still remains that none of those three conditions were caused by sexual trauma or a mental illness; they simply existed within my body, like I was born with them. 13 years into experiencing symptoms and 5 years into knowing what the name of the condition behind those symptoms is, I still have trouble trying to rationalize *why* I have vaginismus, *why* sex is painful for me, *why* I was so unlucky.

In sharing this anecdote, I am not trying to say that vaginismus developing as a result of sexual trauma or numerous other events is not important and should not be treated with the same care and respect as those with primary vaginismus, but to underscore how important a few added words can be in validating someone's existence and pain.

The differentiation between primary and secondary vaginismus is unfortunately too long to accurately and effectively display on this rendition of a flyer, but I chose this specific verbiage and list to be as inclusive to both categories as possible even when not spelling them out directly. The bullet points function to give an overview rather than a definitive list that one must feel like they have to fall into.

Treatments

- **Pelvic floor therapy**
- **Vaginal dilator therapy**
- **Mental health support**

Much like causes, treatments for vaginismus can vary between individuals. The list is not exhaustive, but contain three common ones that I believe are the best approaches. Ideally, vaginismus treatment should involve both medical intervention and mental health care simultaneously. It is important for patients to understand that there is a physical reaction happening in the body while also knowing that mental factors can exacerbate these issues. Pelvic floor therapy and vaginal dilation therapy usually begin in-office and then transfer to at-home/self treatment, but is also accessible to those who are not able to see doctors in person. Mental health support also exists through modes of therapy and a good community support system.

Myself and others have critiques on how treatments have been propositioned once again due to their relationship toward striving for penetrative sex. In *Women, Sex, and Madness*, Fahs lists the common treatment of vaginal dilation therapy, writing its purpose of “stretch[ing] out their vaginal opening to allow for penile penetration.” She concludes that this treatment “ensures that women’s vaginas can effectively ingest a penis, thereby constructing ‘normal’ vaginas and ‘normal’ sex as penile-vaginal intercourse.”³⁰

While I agree with Fahs that it is harmful to view only sexual penetration as the end goal of a treatment, she herself is unintentionally falling into a penetrative/penile centric view for failing to consider that vaginal dilation treatments are not only to be able to have penetrative sex, but to experience pain free tampon insertion, pelvic exams, and forms of self pleasure. This is the only

³⁰ Fahs, *Women, Sex, and Madness*, 181.

page of the book that references vaginismus specifically, and she does not offer insight into alternative treatments that she deems helpful.

Fahs, however, is correct in her conclusion and right to be critical of the medicalization of female sex and the fact that the medical community is more often concerned with complying with sculpting a “normal” woman and a “normal.”³¹ There have been recent studies advising doctors to inject botox into the vagina in order to allow women to “tolerate” penetrative intercourse;³² and it is a frequent occurrence to “prescribe tranquilizers or antidepressant medications in the hope that the [individual] will be less upset about intercourse and will be able to ‘just do it.’”³³

Dilation therapy, injections, and medication are not inherently *bad* as options for the treatment of vaginismus if they can provide one with relief and benefits (I have had good results with platelet rich plasma injections and the tricyclic antidepressant nortriptyline that treats nerve pain as well as depression), but the current problem exists in how they are asserted by medical professionals and in journals: only describing their effects and desired results as a way to have penetrative sex and not the actual comfort or ability of the patient.

A treatment option that I do not want to present as a first line of defense (or really, at all) is surgery. Some doctors will propose a hymenotomy or hymenectomy to a patient with vaginismus, respectively meaning incisions into the hymen tissue or removal of hymen tissue.³⁴ Hymen surgeries, like other treatments, are not necessarily bad but are incorrectly applied to conditions like vaginismus and often do more harm than good. While issues with hymen tissue,

³¹ Ibid.

³² Ibid.

³³ Katz and Tabisel, *Private Pain*, 216.

³⁴ “Hymen Operation For Vaginismus,” Suleyman Eserdag, <https://www.eserdag.com/en/hymen-operation-for-vaginismus>.

excess, or imperforation might cause other forms of vaginal restriction, vaginismus is not caused by hymen tissue but the contractions of the vaginal muscles.³⁵

The psychophysical nature of vaginismus will not respond to this type of surgical intervention; it is not able to address the parts of the body actually affected nor the emotional factors associated with penetration. These procedures leave vaginismus active in the body yet with the added trauma of surgery, a recovery period, failed expectations, and body alterations.³⁶

While this paper is mainly focused on vaginismus, a similar yet more invasive surgery called a vestibulectomy is available to those with vestibulodynia (like myself). A vestibulectomy surgically removes inflamed vestibular glands as well as other tissue. Recovery periods for a vestibulectomy are extremely long and painful; patients will most likely be immobilized and unable to sit for two weeks, and then face another six to eight weeks of recovery.³⁷

The day that I was diagnosed with vaginismus and vestibulodynia I was bombarded with brochures and flyers (horribly designed, I may add) about these conditions and options for treatments. The very first one I opened showcased an image of the vagina with labia being pulled apart from all sides, a clamp holding onto flesh, and scissors cutting it away (fig. 4). After an already very traumatic and painful exam that thankfully did give name to my conditions, this was the first “solution” that a terrified, 21 year old me who had only ever experienced vaginal pain was presented with. *More vaginal pain.*

³⁵ Ditzka Katz, “Vaginismus and Hymen,” *Women’s Therapy Center*, September 29, 2020, <https://www.womentc.com/blog/vaginismus-and-hymen/>

³⁶ Katz and Tabisel, *Private Pain*, 222.

³⁷ “Vestibulectomy Surgery,” Anavara Health and Wellness Facilitators,” <https://anavara.com/treatment/vestibulectomy-surgery/>

Surgical Therapy

When conservative management options have been tried and failed, **vestibulectomy** may be an effective treatment. It consists of a plastic excision of the inflamed minor vestibular glands and limited to the painful portion of the vestibule, from the hymen to the Hart line (the lateral boundary of the vulvar vestibule). After full recovery from the procedure, the patient is typically started on vaginal dilator desensitization exercises for few weeks.

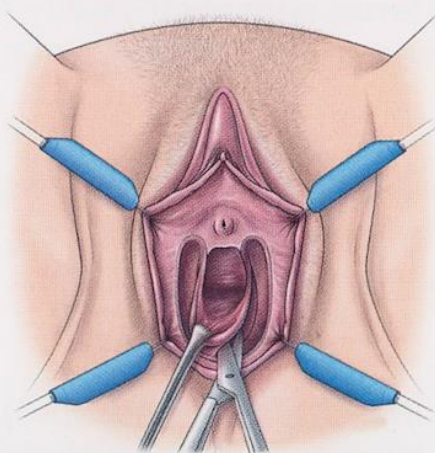


Figure 4. Author's personal copy of a vestibulodynia flyer from the PelviCure Center.

Unlike hymen surgeries for vaginismus, there are plenty of successful vestibulectomies that allow those with the condition to engage in pain free penetration after the long recovery period and continued physical therapy.³⁸ I do not wish to discredit any treatment that provides someone the ability to engage in pain free penetration as they choose to. I only want to acknowledge again, from my personal experience, how damaging and disheartening it can be to

³⁸ Jorma Paavonen, Paivi Tommola, and Leila Unkila-Kallio, "Long-Term Follow Up of Posterior Vestibulectomy for Treating Vulvar Vestibulitis," *Acta Obstetrica et Gynecologica Scandinavica* 90, no. 11 (November 2011) <https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/j.1600-0412.2011.01248.x>.

have these invasive procedures proposed to you with its only function to be able to receive penetration from a partner. I heard that rhetoric from doctors, online resources, and even from teary “pep talks” I would give myself in the bathroom mirror about having these scary procedures done so my partner would not leave me. In the end, I was always too anxious to bring it up to him (and it’s not like he ever did his own research anyway) because I was afraid he would ask me to have it done so we could “have sex” again, and I was more afraid that I would have agreed to it for him when I knew I didn’t want to have it. That partner did end up breaking up with me because of my inability to have “his” sex, but I no longer feel like I need to enact more pain and violence upon my body to keep someone around.

Pain during penetration is not normal or “*all in your head*”, and it can often indicate underlying health issues. If you think you may have Vaginismus, make an appointment with your gynecologist and ask. Knowing the vocabulary to describe what is happening in your body is the first step towards advocating for yourself and becoming healthier!

In developing the flyer, I wanted to include a section that had a “human” voice that was more conversational amidst the lists of definitions, symptoms, and treatments. Too often, those with vaginismus are dismissed or gaslit about their pain, told to “just loosen up, relax, have a glass of wine, smoke a little weed”, or the more severe “you’re just imagining it, it’s all in your head, sex is supposed to hurt.”

Not having that pain legitimized by partners or medical professionals makes us feel crazy and deters us from seeking further help. In closing, I wanted to highlight that vaginal and sexual pain is not imaginary, made up, or simply a mental illness. There are physical reactions happening in the body and due to the fact that pain is so often overlooked, how important it is to provide those with vaginismus the language to speak about their pain.

Language is knowledge, but language can also be harmful. Those who primarily write about vaginismus for medical care and research more often than not do not have the condition. While they may have years of experience working hands-on with patients, a track record of success stories, and the utmost empathy, there will always be some degree of disconnect between treating a patient or researching a condition and the patient's actual lived experiences.

I am not proposing that doctors, gynecologists, physical therapists, counselors, and the like should not continue to research and treat vaginismus (in fact, I would eagerly push for more to do so), but to be more critical and aware of the language they are using to provide information to and speak to patients. The way I am choosing to present and update this material might seem irrelevant or inconsequential to some as the base information is technically the “same” as a lot of what is circulating. However, I can with full certainty say that if I would have seen my flyer over what I was actually presented with, I would have had a much different reaction going about my treatment and healing. These adjustments may appear small, but have a huge impact.

Due to the nature of the flyer being a standard 8.5” x 11” piece of paper, it is unrealistic to be able to include everything I would like to about vaginismus. While I believe my information provides a solid general overview without being too overwhelming or wordy, I want to use this extended paper to acknowledge a few of the nuances that exist around this condition.

White women are recognized as the baseline when discussing the majority of female conditions and their subsequent medical research. They are treated as the medical canon and the degrees to which women of color experience vaginal and sexual pain conditions are often overlooked. Research on the self described symptoms of vulvodynia (chronic vulvar pain), which often appears with vaginismus, shows variation between Black and white women. While white women reported the symptom of burning pain at a much higher percentage than Black women,

Black women reported the symptom of aching pain at a much higher percentage than white women. The research hypothesizes that the difference in symptom reporting may be influenced by cultural beliefs, physiological differences, and/or neuropathic mechanisms.³⁹ What makes the impact of these differences so important is that the burning pain, which more white women reported, is one of the clinical symptoms used for diagnosis; if Black women do not report this symptom they may have a harder time being properly diagnosed with the condition.

A population based study noted that Hispanic women had an increased prevalence of vulvodynia compared to white women. The research concludes that ethnic differences alone could reflect higher frequency, or reflect again the differences in how symptoms are reported and the interpretation of “pain” or “discomfort.”⁴⁰ It calls for additional studies in Hispanic populations.

While physical body reactions might be the same from a strictly medical standpoint, there are important differences in other races, ethnicities, and cultures that should be considered to diagnose and treat cases of vaginal and sexual pain more accurately.

These flyers were designed specifically for installation in Illinois State University’s campus restrooms; women’s, men’s, and gender neutral restrooms alike. The choice of venue as the restroom was influenced by Melissa R. Ames’ article *Memoirs of a Bathroom Stall: The Women’s Lavatory as Crying Room, Confessional, and Sanctuary*. The article discusses a culture that has been born from these gendered spaces and how bathrooms and their stalls are safe havens that can eventually become a venue for feminist politics and art. It references the power

³⁹ Candace S. Brown et al., “Presenting Symptoms Among Black and White Women with Provoked Vulvodynia,” *Journal of Women’s Health* 24, no. 10 (October 2015): 831-36, <https://doi.org/10.1089/jwh.2014.5164>.

⁴⁰ Barbara D. Reed et al., “Prevalence and Demographic Characteristics of Vulvodynia in a Population Based Sample,” *American Journal of Obstetrics and Gynecology* 206, no. 2 (August 2011): 170.e1-9, <https://doi.org/10.1016/j.ajog.2011.08.012>

of graffiti in women's bathroom stalls and how the act of using words as art and a form of communication within this setting has the same outcome of facilitating conversations based in women's care.⁴¹ Ames summarizes,

“The bathroom stall is an underused spot for feminist dialogue, for politically charged artwork, for objects of thought and reflection. Advertisements for the next sorority bash find themselves plastered on the insides of bathroom stalls, but not contemplative artistic works or women's discourse.”⁴²

I am taking Ames' declaration to heart, using this venue, as well as the men's and gender neutral restrooms, to insert conversations about vaginismus, sex, and health into the population of young college students. Additionally, using the bathroom, specifically the bathroom stalls, provides a level of privacy and comfortability that should be granted when being introduced to these conditions for the first time. Due to how public discussion of female sexuality and pain is often silenced and seen as taboo, these flyers would not garner the same amount of (positive) attention if they were push-pinned to a bulletin board in the hallway. Personally speaking as well, I can see how embarrassing or awkward it could feel to stand in a crowded campus building reading or taking a picture of a flyer that talks about sex and/or sexual pain. The privacy of the bathrooms can begin to remove the shame we might feel from being vocal about these instances, and ideally encourage discussion about them with friends, family, and medical professionals.

Early into the spring semester of 2023, I met with Illinois State University's Health Promotion and Wellness with a proposal to create and install these flyers under and with university guidelines and support. They were not able to officially sign off on their circulation

⁴¹ Melissa R. Ames, “Memoirs of a Bathroom Stall: The Women's Lavatory as Crying Room, Confessional, and Sanctuary,” *The Keep: Eastern Illinois University Faculty Research & Creative Activity* (October 2006): 63-74.

⁴² *Ibid*, 72.

due to information containing medical diagnoses being outside of the purview of their “Toilet Talk” series, but unofficially granted me approval to install the flyers and were shown the flyer and notified of the time of installation.

Choices in the design were also made to help them blend as seamlessly as possible into the existing Toilet Talk flyers such as quarter inch borders, rounded edges, a patterned background, and a 150 word count. While the creation and installation of the flyer starts to tread into the category of guerrilla art because it was not fully sanctioned by the university, it was not meant to stick out. Rather, my goal was to have the flyer integrate itself into the information that had already been circulating, which often included other forms of sexual health and body wellness.

200 flyers were printed and distributed around Illinois State University’s campus by myself and a fellow graduate student for a Valentine’s Day debut in 2023. Flyers were installed in Schroeder Hall, Fell Hall, Fairchild Hall, State Farm Hall of Business, Rachel Cooper Hall, Bone Student Center, and the Center for the Visual Arts.

Due to the fact my name or any identifying information was not included on the flyers, reactions to the flyers and their effectiveness is limited to what I saw personally as well as from relayed information. The flyers were installed the night before Valentine’s Day around approximately 9 pm; by the next morning, every single flyer had been removed and thrown away from the 1st floor women’s restroom in Fell Hall. My initial inclination was to believe a member of Health Promotion and Wellness might have removed them, but upon checking to see that all the flyers in the same floor’s men’s restroom were untouched, I am led to believe that it was the action of an individual who was offended by the content.

The following information was relayed to me by a professor of mine about a conversation she had with a male teaching candidate visiting the school. During a bathroom break while the candidate was touring the school, he used the urinal inside the men's restroom which had one of the flyers directly at eye level. Upon exiting the restroom, he commented to my professor about it and she mentioned that it was created by one of her students. The candidate, being from a graphic design background, commended the design of the flyer and remarked that he was "visually assaulted" and could not look away from it. While the use of the word "assaulted" here, although not intentionally violent, is somewhat unpleasant (I think "arrested" would have been a better choice), I understand the sentiment of his comment. I am ecstatic to know the flyer is being viewed and digested by men and that between the design and logistics of placement over the urinal it becomes hard to look away from.

A male student of mine, after learning I created the flyer, corroborated the teaching candidate's experience, remarking that it was impossible not to read the flyer because of its placement at eye level. Friends of mine who use the women's bathroom stalls have also confirmed that they felt drawn to or compelled to read the flyer when it was in front of them.

While it is impossible to know all of the feedback and public reactions to the flyer, especially because my name was not attached, I am glad to have a few solid examples of how the flyer was being received. While it is reassuring to know choices I have made are effective in communicating information, I did not create this project for the sake of feedback or praise; I created it for people with vaginismus, and it is enough for me to know that people saw it.

At its heart, this flyer and paper were created with my former self in mind. I wanted to establish a new way of sharing material that would put the individual first, lessen the importance of penetrative sex, and convey the information in an accessible, digestible, and visually

appealing way. I did not have access to that before or after my diagnosis, so I created it myself. This flyer is for those whose painful and traumatic experiences mirror my own, and a gift to my former self. If it has reached the eyes of even one young college student and provided them with a word to explain what they are feeling, then my goal has been achieved.

I plan to continue using artistic intervention to raise awareness about female sexual dysfunctions not only for those who have the conditions, but for those who are ignorant and selfishly influenced by patriarchal constructs. My main focus will always be on the patient, but the larger conversation about vaginismus, sexual pain, and the systems that uphold the male and the penetrative as superior, must happen between all parties.

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