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# Full Disclosure: Herpes Stigma and Communication Practices among HSV+ Individuals

Mikayla Bobrow

Clark University, mbobrow@clarku.edu

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Full Disclosure:

Herpes Stigma and Communication Practices among HSV+ Individuals

Mikayla Bobrow

May 2016

A Master's Research Paper

Submitted to the faculty of Clark University, Worcester, Massachusetts in partial fulfillment of the requirement for the degree of Master of Arts in the department of Community Development and Planning

And accepted on the recommendation of

Ellen Foley, Chief Instructor

Laurie Ross, Second Reader

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## **Abstract**

The stigma associated with genital herpes (HSV) often leads those living with this sexually transmitted infection (STI) to conceal their status to others in order to avoid possible negative social repercussions. I interviewed eighteen individuals living with HSV and surveyed 354 more in order to understand the impact that sex and STI shaming has on an individual's life. The data from both the surveys and the interviews indicate that the shame perpetuated in both school and clinical settings augments the emotional devastation experienced following a diagnosis. In order to change the paradigm that only individuals who violate societal norms contract STIs, sexual education and medical diagnosis processes need to be revamped. Honest communication regarding sexual health and STI status is critical in order to decrease the stigma associated with one of the most common STIs.

## Introduction

Many people know the sinking feeling that accompanies a diagnosis of genital herpes. It can be a lonely experience. Feeling betrayed by your own body, you can't help but wonder if your sex life is over. Oddly, these feelings rarely result from the physical effect herpes causes on the body. Instead, they stem from the ingrained stigma associated with a sexually transmitted infection. It is precisely this stigma that makes living with a chronic STI so draining, prevents many people from discussing their status, and increases risk of contracting the virus.

This stigma reflects sex shaming that is deeply rooted in American culture. Sex and STI shaming are pervasive in health classes, perpetuated in the doctor's office, and furthered by friends and family. Sex and slut shaming are tools used to attack and control the behavior of individuals who fail to conform to societal norms about sexuality (Carr 2013). People who contract STIs are often viewed as immoral and believed to have broken the unspoken social rules that govern sexual activity. This shaming leaves those living with STIs to suffer in silence (Nack 2008).

Each year there are 20 million new STI diagnoses in the United States (STD Prevention 2013). Genital herpes (HSV 1 or HSV 2) is one of the most common STIs; roughly 50 million people nationwide live with the virus (Ebel and Wald 2007). Approximately one in five Americans over the age of 14 has genital herpes (Ebel and Wald 2007). However, few people openly discuss their status because it is so highly stigmatized. The stigma and shame that may accompany a positive diagnosis are generally far greater and last far longer than the negative physical health effects that the virus may cause. The silence and shame that accompanies a virus that has no significant

health ramifications is astounding. The limited public dialogue surrounding genital herpes may be a factor in perpetuating stigma and decreasing general communication about STIs.

The purpose of this study is to highlight the emotional components of being diagnosed with a chronic STI and to examine how the associated stigma can detrimentally impact an individual's life in multifaceted ways. STI shaming is inextricably linked to sex and slut shaming. My research asks: What effect does sex shaming have on conversations regarding STIs? This paper suggests that sex shaming in the classroom and in the doctor's office enhances discrimination against people living with HSV, heightens secrecy about one's STI status, and increases the likelihood of staying in unhealthy or abusive relationships.

This paper explores the stories of the 18 individuals (See Appendix D) I interviewed and data from the 354 individuals I surveyed, all of whom live with genital HSV. I use Link and Phelan's (2001) definition of stigma to examine the data I collected about how HSV positive people negotiate disclosure and communication practices. I use this lens to illustrate the negative impact stigma has on an individual's life. I argue that comprehensive sexual education and emotionally sensitive healthcare would greatly reduce the shame that so often accompanies an HSV diagnosis. I also employ a feminist lens that identifies how hierarchical power structures need to be broken down in order to halt the perpetuation of STI stigma and shame (Dickerson 2007; Harding 1995; Watkins and Whaley 2007; Whatley 1987). Providing culturally

and emotionally sensitive education and healthcare that encourage open dialogue have the potential to break down power structures and alleviate stigma.

While there is substantial literature on how individuals heal emotionally from STI diagnoses as well as cope with STI stigma, there is limited research on where this stigma is perpetuated. The existing research on HSV stigma focuses primarily on how individuals negotiate their status disclosure post-diagnosis. It does not explore the role that institutional settings play in disclosure conversations. Therefore, this study on the lived experience of people with genital herpes aims to explore this connection between sexual health education and medical practices with the impact that stigma has on individuals living with HSV.

### **Background on Herpes Simplex Virus (HSV)**

According to the World Health Organization (WHO), approximately 83% of the world's population under the age of 50 is infected with the herpes virus (oral and genital) (Harris 2015). There are two strands of the herpes simplex virus, HSV 1 and HSV 2. The HSV 1 strand generally prefers the oral region while HSV 2 predominantly occurs in the genital area. However, both strands can infect individuals in either location (Ebel and Wald, 2007).

Genital HSV affects infected individuals in myriad ways. While some people suffer from severe pain stemming from the genital sores caused by the virus, the majority of people living with the virus experience mild symptoms or no symptoms at all. The Center for Disease Control and Prevention (CDC) conducted a study, which found that 85% of people who test positive for genital herpes have no history of herpes symptoms



(Ebel and Wald 2007 p. 16). Furthermore, since genital herpes is not tested for in routine STI screenings, the majority of individuals living with the virus are unaware of their HSV status. Nonetheless, they are still able to transmit the virus through asymptomatic shedding.

Herpes is transmitted primarily through skin-to-skin contact such as genital-to-genital contact, oral-to-genital contact, or oral-to-oral contact. Since condom usage only lowers the infection rate by approximately 50%, many people are infected during what they consider to be “safe sex” (Ebel and Wald 2007 p.137). However, individuals who know their HSV status and are on daily suppressive medication have a reduction in both symptomatic and asymptomatic shedding by 80-94% (Ebel and Wald, 2007, p.88).

### **Stigma Theory**

The word stigma is freighted with various meanings and definitions. Erving Goffman, the sociologist who wrote the influential book *Stigma*, examined how individuals who do not conform to societal norms navigate their discredited identity. Goffman explored how individuals with invisible stigmas protect and navigate their identity by using tactics such as denying, passing, and covering (Goffman 1963). Since this publication the definition of stigma has been explored extensively and expanded upon by myriad scholars over the past 50 years. The definition of stigma that I employ here is based upon Goffman’s theory, but is expanded upon by sociologists Link and Phelan who argue that, “stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them” (Link and Phelan 2001 p.377).

Since this paper focuses on an invisible stigma, I also draw on Ragins' analysis (2008). She explores the ways in which individuals with stigmatized identities decide whether or not to disclose their identity. Individuals with invisible stigmas have the ability to conceal their identity and therefore avoid overt discrimination. However, this often comes at a psychological cost of maintaining a secret. Ragins identifies internal psychological processes, expected consequences, and environmental support as the three major variables that affect one's decision to disclose stigma (2008).

### **History of HSV Stigma**

The origins of HSV shame are tied directly to the history of sex shaming in the United States. Expressions of sexuality are not just biological expressions but rather they are largely shaped by sociocultural influences. In the United States, Judeo-Christian theology has historically divided the world into binary categories (hooks 2000). These binaries lay the foundation for oppression and prejudice, which in part led to the creation of sexual norms and the control of sexual expression (Davidson et. al 1995). According to this doctrine, sex should be reserved solely for reproductive purposes and engaging in sexual behavior for pleasure is considered sinful (Davidson et. al 1995). These beliefs were not just presented as the norm in many Christian churches, but were also incorporated into the laws governing American society (DeLamater 1981). Therefore, these religious ideals became the predominant social norm throughout the country.

Christian theology has influenced many aspects of sexuality in the United States by establishing sexual scripts that inadvertently shape sexual partner selection as well as

the types of sexual acts individuals engage in (DeLamater 1981). These scripts guide how individuals think about their own sexuality and how they think they should behave in certain arenas of their lives. These scripts are often freighted with shame and confusion about sexual behavior (Shaw and Lee 2007). While the sexual revolution of the 1960s began to change these widely held beliefs, it failed to fully change the notions about the ‘type’ of person who is at risk for contracting an STI.

Prior to the 1970s, few people had heard of genital herpes. At this time, it carried the same social stigma as cold sores or oral herpes (Cuatrecasas 2006). It wasn't until the advent of daily suppressive HSV medication that the HSV stigma soared. The pharmaceutical company, Burroughs Wellcome, launched a marketing campaign in the late 1970s to increase the company's profits, which focused on the new medication's ability to reduce the number and frequency of outbreaks as well as to drastically reduce the transmission rate (Cuatrecasas 2006). The pharmaceutical industry has notoriously used fear-mongering tactics about relatively benign diseases in order to increase profits (Moynihan et al. 2002). They disguise those efforts as awareness raising mechanisms, which in turn transforms societal understandings of those conditions (Moynihan et al. 2002). Herpes was labeled as an epidemic that resulted from the sexual revolution (Roberts 1997). The social stigma connected with genital herpes today can largely be attributed to this initial campaign and the following media attention it garnered.

In 1982, TIME Magazine featured this virus on the front cover of the magazine and labeled herpes “*The New Scarlet Letter*” (Leo 1982). The article claimed that this rising “epidemic” had the ability to “undo the sexual revolution” (Leo 1982 p.62). The

dramatization of this virus had the effect of stigmatizing individuals living with the virus and shaming people for having sex for pleasure. Despite the rise of the sexual revolution in the 1960s, the article claimed that the risk of contracting herpes was changing social norms regarding sex once again and that the “Age of Herpes” was reverting us back to the “Age of Guilt” (Leo 1982 p.62) Leo wrote,

Spurred on by two decades of sexual permissiveness, the disease has cut swiftly through the ranks of the sexually active...with visions of herpes sores clouding each new encounter, would-be lovers who used to gaze romantically into each other's eyes now look for the telltale blink or averted glance of the dissembling herpetic. (Leo 1982 p.62).

Throughout the article, the virus was discussed as a result of sexual permissiveness and evidence of immorality and often betrayal. As seen in TIME Magazine's article, the sexual revolution did little to dispel myths about the type of people that contract STIs (Kinghorn 2001). The shock and shame that so often accompanies a HSV diagnosis is likely greatly impacted by these misconceptions and stereotypes perpetuated by Christian doctrine, the pharmaceutical industry, and media campaigns.

### **Feminist Perspective**

Breaking down hierarchical power structures is a central component to many feminist approaches (Harding 1995). These power structures don't just inform relations between men and women, but rather reflect larger institutional paradigms that are damaging in educational and healthcare spaces. Unequal power distributions perpetuate cycles of oppression and manifest in myriad ways.

Since shame and stigma are expressions of unequal power structures, providing culturally sensitive education and information in clinical and classroom settings can be one tool used to disrupt these power imbalances (Watkins and Whaley 2007).

Mariamme Whatley asserts that there must be a paradigm shift in the way sexual education is taught. She explains, “Sexual education that simply reinforces double standards of sexual behavior and restrictive sex role stereotypes may be worse than none at all” (Whatley 1987 p.60). Overcoming these double standards and stereotypes through open communication and dialogue regarding sexual health is one way to reduce STI stigma and shame.

Watkins and Whaley discuss how damaging it can be to diagnose a patient with a stigmatized infection without providing substantial information regarding that ailment:

Physicians’ failure to interact with patients in a courteous, informative fashion [is] a breach of ethics rather than a case of poor “bedside manner”...Most medical encounters constitute interviews in which patient-initiated questions are discouraged, thereby establishing the practitioner’s position of power. Such interactions prevent patients from taking charge of their own health (Watkins and Whaley 2007 p.343).

Medical professionals have a tradition of providing the bare bones information to their patients without regard for how their patients may experience that diagnosis on an emotional level. Environments where doctors’ focus solely on curing disease and eliminating physical pain fail to allow room for patients to break down hierarchal power dynamics and create an environment where patients feel comfortable asking questions and expressing their concerns (Watkins and Whaley 2007). Vivian Dickerson, the President of the American College of Obstetricians and Gynecologists outlined a Women’s Health Bill of Rights that incorporates the emotional, cultural, psychological and financial needs of all people and particularly women. She argues that the medical community is largely focused on curing disease and managing pain, but often fails to

acknowledge the pressing need to address how patients can heal from an emotional diagnosis (Dickerson 2007).

Another way in which these institutional power imbalances can be broken down is by making space for the voices of marginalized identities to be heard. Sandra Harding refers to this as feminist standpoint theory. She explains, "Standpoint theories argue that what we do in our social relations both enables and limits (it does not determine) what we can know. Standpoint theories...begin from the recognition of social inequality" (Harding 1995 p.341). She continues to explain, "institutionalized power imbalances give starting off from the lives of those who least benefit from such imbalances a critical edge for generating theoretically and empirically more accurate and comprehensive accounts" (Harding 1995 p.344). In keeping with this feminist perspective, I use the personal accounts of individuals living with HSV throughout this paper in order to showcase the narratives of a largely marginalized population and explore how stigma and knowledge are intimately connected.

## **Methodology**

This study examines the experiences of individuals over the age of eighteen who live with genital herpes. I conducted primary research using anonymous surveys (Appendix A) and topical interviews (Appendix B and C). The Clark University Institutional Review Board (IRB) approved the survey instruments and interview instrument prior to the start of the research.

The individuals interested in participating in the project were recruited primarily through my personal website, *The Full Disclosure Project*<sup>1</sup>. I posted the website on various online outlets such as Facebook, online herpes support groups, and sexual health blogs in order to garner attention and participants. The link to this website and survey was also sent out by email to the International Development, Community and Environment graduate students at Clark University. Lastly, a number of participants were recruited from an in-person HSV support group in Boston. Interview and survey participants were asked broad questions about their experiences living with the virus, factors they think contribute to HSV stigma, and how internalized shame affects their romantic and sexual lives.

Throughout the process, I took precaution to ensure participant anonymity. I omitted any names and identifiable information that participants noted throughout the interviews. Many participants admitted that prior to their interview with me they had told no one of their status, except for those in online or in-person support groups. Throughout the process, I omitted any names and identifiable information that participants noted throughout the interviews.

After collecting the surveys and conducting interviews, I employed theory-generated codes to organize the responses and discern common ideas and themes among participants in both the surveys and the interviews. The themes I employed in the coding process were: sexual health education, HSV misinformation, medical

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<sup>1</sup> <https://thefulldisclosureproject.wordpress.com/>

experiences while living with HSV, experiences of stigma, coping mechanisms, and romantic and non-romantic disclosures.

## Findings

### Quantitative Overview

**Table 1.**

<b>Gender Identity</b>		<b>Age</b>		<b>Race/Ethnicity</b>	
Female	92%	18-22	29%	Hispanic/Latino	11%
Male	8%	23-27	33%	Black or African American	7%
Other	0%	28-39	26%	White/Caucasian	80%
		40 or older	12%	Asian/Pacific Islander	2%
				Other	3%
<b>Sexual Orientation</b>		<b>Highest Level of Education</b>		<b>Length of time since HSV diagnosis</b>	
Straight	83%	Some high school	1%	Less than 6 months ago	25%
Gay/Lesbian	2%	High school degree	4%	Less than 1 year ago	13%
Bisexual	14%	Some college	31%	1-3 years ago	34%
Queer	3%	College degree	54%	4-6 years ago	12%
Other	1%	Other	11%	Over 6 years ago	16%

\*Table 1 displays the demographics of the 354 HSV+ individuals who completed the survey

### Qualitative Overview

**Table 2.**

<b>Gender Identity</b>		<b>Age</b>		<b>Length of time since HSV Diagnosis</b>	
Female	83%	18-22	39%	Less than 6 months ago	28%
Male	17%	23-27	17%	Less than 1 year ago	11%
		28-39	22%	1-3 years ago	33%
		40 or older	22%	4-6 years ago	17%
				Over 6 years ago	11%



\*Table 2 displays basic demographics about the HSV+ interview participants

## **STI Shaming and Misinformation in Institutional Settings**

### **Sexual Health Education**

The effect that the discourse regarding sex and sexually transmitted infections has on individuals can be dramatic. Sex and STI shaming is largely perpetuated by institutional structures such as sexual health programs in high schools as well as by medical practitioners in clinical settings. Sexual education varies widely state by state, district by district, and school by school. While the individuals I interviewed attended various types of sexual health programs, they all discussed how those sexual education programs failed to encourage honest and non-stigmatizing communication about sexual health. The majority of the interviewees discussed in detail how their initial knowledge from sexual education classes perpetuated STI stigma by labeling differences, linking these labels to negative stereotypes, and creating an ‘us’ vs. ‘them’ dichotomy. However, only 33% of the survey responders said that their HSV knowledge prior to their diagnosis came from sexual health education classes (See Figure 1). While this finding indicates the need to increase sexual health programs throughout the country, I focus primarily on the data attained from my surveys and interviews to support the claim that sexual education not only needs to be increased but also revamped.

A recent college graduate who contracted the virus in high school describes the difficult experience of going through sexual health class while living with an STI. This young woman describes how her teachers distinguished and labeled differences about people with STIs through the way in which they taught their lessons as well as by associating these differences with negative attributes:

That was probably the worst thing ever at the time for me. Sitting through that class, seeing those pictures blasted on the screen, it's crazy how even adults...talk about it...like in the most negative light. Even my health teacher had a demeaning tone in her voice talking about it. That's terrible. I'm sure I was not the only one in that high school going through something like that and to have an adult and someone you're supposed to respect make you feel like that...it was just crushing blows every turn. Sitting through that class, having all my classmates saying, "Ew, oh my god," reacting to those pictures, "that's so gross! Oh my god, your life sucks if you have that." And you just have to sit there...pretend. It's just a huge pretending game. (Female, 22)

This young woman's experience exemplifies that these programs can be damaging for young individuals. The assumption that educators make that their students do not have an STI marginalizes those living with them. These individuals carry the weight of this invisible stigma and learn how to navigate their lives while constantly hiding their true identity. Singling out these differences and labeling them as socially significant is the first component of Link and Phelan's stigma definition, while the second is associating these differences with negative attributes (2001). By broadcasting negative images on the screen in this woman's health class without a discussion on how people with STIs can and do live normal lives with romantic and sexual fulfillment distinguishes people with STIs as different. The demeaning tone that this woman describes of her teacher exemplifies the negative attributes attached to the stereotypes associated with STIs.

The ways in which sexual health programs teach about STIs leads to the emotional and negative reactions that often accompany a diagnosis. Many of the interviewees explain their negative views of HSV and other STIs prior to their own diagnoses. Two women explain:

I just knew that it was probably the worst STD you could get. It's not curable. And nobody wants to be with someone that has herpes. Basically that was my knowledge of it, I now see how ignorant and naïve I was because I didn't have it. It didn't pertain me. (Female, 22)

I knew you didn't want herpes and you didn't want genital warts because those stay forever and HIV you definitely don't want because that's not a good thing...I never really had the chance to have a discussion with anyone [about] the real importance of protecting yourself. I think that was lacking—my understanding of how easy it is to get herpes and how common herpes is. And it's so negatively viewed; people think it's the end of the world, but it's really easy to manage and what not when you have it. My understanding really just changed. (Female, 21)

The type of discussion that this second woman wished she had before her diagnosis is critical to changing the paradigm of partner communication regarding sexual health.

This interviewee identified how she had never had the opportunity before her diagnosis to engage in conversations about the tangible effects that an STI can have on one's life or about how they are a common result of engaging in sexual relationships. These sex education classes perpetuated stigma by emphasizing risks without discussing how common STIs are or how easy it is to minimize outbreaks and risk of transmission with proper medication.

Teaching students how to protect themselves from STIs without stigmatizing or avoiding those living with one is a critical step in breaking down this stigma. The 'us' versus 'them' dichotomy, which is the third component of Link and Phelan's (2001) definition of stigma illustrates the way agencies relied on for credible health information often render people with STIs as outcast individuals who pose a threat to society. The CDC states that the best way to lower one's chances of contracting the virus for sexually active individuals is to be "in a long-term mutually monogamous relationship with a partner who has been tested and has negative STD test results"

(Genital Herpes 2015). While the information is technically accurate, the CDC fails to provide adequate information about the effectiveness of preventing transmission through daily suppressive therapy or other alternative methods. Instead, it creates a distinction between people with and without genital herpes and provides a rationale for devaluing and rejecting those with a positive STI status.

According to the interviewees, many of these classes fail to teach students that some STIs, like herpes, can be contracted through skin-to-skin contact and that condoms do not always protect against them. One 21-year-old woman who was recently diagnosed explained, *“I thought using a condom I’m doing everything right. No one ever tells you that you can get things this way and you know dental dams aren’t really widely available or talked about.”* This lack of information leads to immense confusion for many people who thought they were effectively following the ‘safe sex’ practices.

### **Medical Practices**

Medical personnel commonly fail to recognize that their interactions with their patients influence the emotional reaction of a diagnosis. Since HSV is not a life threatening infection and generally not a serious physical health ailment, many doctors fail to give their patients much information about the virus. While this to a certain extent normalizes a diagnosis, it still fails to recognize the existence of STI stigma and the emotional aspect of the diagnosis. One interviewee who regularly attends an HSV support group, reflects on her medical experience:

I think that the lack of empathy, not even empathy, but the lack of time and effort that the medical community in general puts into this can also exacerbate a lot of those emotions because you wouldn’t believe some of the stories we’ve heard in the group over the years and just doctors and nurses in general are not very good at being able to

convey the information in a way that is compassionate but also provide some level of support for people when they get diagnoses. They pretty much just tell you and then usher you out of the office and then you're on your own. (Female, 41)

The leader of that same support group expands upon this idea:

And there's the bigger issue, which is the issue that I usually see more than the doctors, because doctors, they've got 7 minutes with their patient and then they've got to get to the next patient, right. The medical profession is just slammed these days. They can't sit with a patient crying and freaking out over the emotional aspect of this diagnosis, which...anyone associated with this legitimately knows is the real issue...Doctors directly lie to their patients concerning herpes and STIs. They say its not big deal, everyone has it, they say don't worry about it. They don't address the emotional component. And in my experience this is an area where doctors are not appropriate to the Hippocratic oath of do no harm. (Male)

A current college student explains her discomfort in asking questions at her school's health services:

I tried to ask questions to the people at health services, but...I didn't feel comfortable asking questions like that...They didn't seem very welcoming. I think it was just because I had to bring it up. (Female, 20)

As the young woman above explained, she failed to ask critical questions about outbreaks and transmission due to embarrassment and shame regarding her recent diagnosis.

Many interviewees commented that the medical community perpetuates misinformation regarding HSV. For many, the shock of a diagnosis is impacted by misperceptions about the virus. There is a lack of general knowledge about the virus in today's society as well as inaccurate information circulating in the medical and sexual health fields. While lack of knowledge about the virus heightens stigma, misinformation furthers the confusion and stigma as well. Nearly all of the interviewees expressed frustration about the lack of knowledge or misinformation perpetuated in clinic and/or in classrooms. A 20-year-old female explains, *"I also didn't know that you*

*could get herpes from having oral sex with someone who has a cold sore on their mouth, which is really frustrating that nobody told me about that, shouldn't everybody know that?"* This young woman's frustration highlights the limited attention placed on non-heteronormative, non-penetrative sex. The lack of information given to young people about other ways that STIs can be contracted is detrimental to people's knowledge and causes greater confusion when people are diagnosed.

One 23-year-old woman who was a former sex educator at her college explained that despite her background, even she was confused about how the virus was transmitted. This woman explained that she wrote the STI portion of her school's sexual health curriculum, but after she was eventually diagnosed with HSV she realized that a lot of the information she had been teaching was inaccurate. She explains, *"A lot of information out there says you can only get it if someone has an outbreak and then you read that that's not true."* She goes on to explain how when she asked her doctor if she could transmit HSV to partners they retorted by saying, *"As long as you practice safe sex and you don't have an outbreak you should be fine."* When she asked about disclosing to other partners, they told her, *"No, don't worry about it."* Since individuals are just as likely to shed the virus asymptomatically, this information is simply inaccurate (Ebel and Wald 2007).

The HSV support group leader spoke directly about the misconceptions perpetuated by the medical community:

There's a lot of old data that's going around. One of them is the aspect that if the virus is not present, invisible on your skin, you can go have sex [and] you can't transmit it. I'm still told of that, that someone was told that by their doctor in their last visit every other month.

The inaccurate information spread by the medical community about HSV transmission combined with STI stigma, is likely a significant cause of the fast spread of the virus and the lack of partner communication regarding sexual health.

While many of the interviewees commented on the lack of attention and misinformation they received from medical personnel, they also discuss feeling judged by practitioners because of their herpes positive status.

Honestly though, the nurses, people who dealt around, they were real awkward with me. They acted weird. They did. That was an uncomfortable experience actually. That was a bad moment. That was tough. They acted real awkward and they kind of treated me cold too. I didn't get the usual treatment I get when I'm getting a diabetes screening or something. (Male, 40 years old)

When I went to the doctor's office I was obviously panicking and freaking out because I had started to develop the blisters. I'm panicking and praying that it's literally anything else. To be completely honest my doctor was kind of a dick about it. She just wasn't very nice about it so when she left the room I was crying about it. (Female, 28)

This type of shaming from medical personnel is particularly significant since there is a stark power difference between doctors and their patients. This power difference is a significant component of Link and Phelan's stigma definition (2001). When doctors treat their patients differently because of their status, it amplifies the stigma experienced by STI positive individuals.

### **HSV Invincibility and Justifications**

Although half of all Americans contract an STI in their lifetime, open discussions about this topic rarely occur. STIs are highly stigmatized yet invisible, which makes it difficult to find a space for honest discussions about one's sexual health history. Many people associate contracting an STI with unsafe sex practices or promiscuity, which

feeds into feelings of shame after contracting one. According to my survey, 83% of participants (Figure 2) said they either strongly or moderately blamed themselves for contracting HSV following their diagnosis. One woman explains:

I felt really shitty...and also a little bit of shame, like if I hadn't slept with so many people in college maybe this wouldn't have happened. I was like, "You fucked around and you weren't always as safe as you could've been so this is what you get." (Female, 23)

The notion that promiscuity and immoral behavior cause people to contract STIs furthers the 'us' versus 'them' dichotomy. This woman was socialized to believe that her sexual behavior in college was excessive and unsafe, which therefore implied her difference and devaluation. This separation and stereotypes inferred on those with STIs leads many to blame themselves for contracting the virus, rather than understanding that it's a common byproduct of being sexually active.

However, many interviewees emphasized that prior to their diagnosis they had considered themselves invincible to contracting an STI due to their low-risk behavior. This rhetoric by people living with chronic STIs perpetuates misinformation about the likelihood of transmission and enhances STI stigma. Many interviewees explained how they ascribed to the sexual norms imposed on them by society, yet confusingly still contracted HSV. These individuals associated this virus with shame and embarrassment because they associated contracting it with violating sexual norms. According to the survey I distributed, 94% of participants said they felt either strongly or moderately ashamed of contracting HSV immediately following their diagnosis (See Figure 3). The lessons taught in school and perpetuated in the media teach that only those who engage in unsafe behaviors are at risk. Many of the individuals interviewed for this project felt



they “didn’t deserve” such a diagnosis because they had conformed to society’s expectations of how to behave in sexual relationships. Many of them justified past sexual behaviors, wondering how this could have happened to them. One participant explains her reaction following her diagnosis:

I thought my life was over. Oh my god...this doesn’t happen to someone like me. Like I did everything right, I was in a committed relationship, he was my first too, which made it even so much more devastating because [now you feel] tainted. You really truly feel invincible when you’re a young person...This was just the worst thing that could ever happen to me as a person. And like, why, why me? I don’t deserve this. I did everything right. I’m a good person. I don’t sleep around. (Female, 22)

Many women expressed feelings of devastation and frustration because they were following the societal scripts assigned to them yet they still contracted a sexually transmitted virus. This causes many individuals to feel a need to justify their behavior and make excuses for how they contracted HSV. This type of language, particularly the type that this woman uses, feeds into the STI shaming and sex shaming that we are socialized to believe and is used to control sexual behavior throughout American history (Shaw and Lee 2007).

Even those well versed in sexual health prior to their diagnosis had internalized this same STI and sex shaming that so many of the interview and survey participants expressed. I spoke with one woman who had been a peer sexual health educator on her college’s campus. Although she knew the facts about herpes before her diagnosis and felt comfortable talking about STIs, she realized she hadn’t fully internalized those messages she purported to teach. She explains:

I also absorbed a lot of feminist stuff in college. I was pro sex and pro health and pro choice and pro woman and all that good stuff. And I felt that I was really prepared for this kind of thing. And it still never occurred to me that this would happen to me. And

so when it did the blow to my ego and the blow to my confidence was like I should know better than that. If this happened to one of my friends I would be cheering them on, being like, “You’re going to be fine, you’re gonna be okay, like this is not a big deal.” I think that the way I took it so hard really surprised me. I thought I was better prepared for something like that. (Female, 30)

From the person who contracted herpes from her first sexual partner to the sexual health educator who thought she should have known better, there are a wide range of experiences and thoughts on why this should not have happened to them. Yet, these notions of invincibility stem from the misconceptions about what types of people contract STIs and how they can be transmitted.

### **Impact of Stigma on Individuals with HSV**

Stigma is the result of labeling, stereotyping, separation, status loss, and discrimination co-occurring (Link and Phelan 2001). According to the interviewees, labeling, stereotyping, and separation commonly occur in the classroom. Individuals with STIs are commonly labeled as “deviant” and stereotyped as promiscuous (East et. al 2011). While an ‘us’ versus ‘them’ mentality is fostered in educational settings, this dichotomy began much earlier. Beginning in the 1980s, herpes stigma heightened and people living with the virus were labeled as ‘herpetic’ (Leo 1982). This separation creates notions that people who contract STIs are fundamentally different than those who do not. This leads to the shame and internalized social psychological processes that so often impact a stigmatized individual’s self-esteem and mental health. Status loss and discrimination are the final two components of Link and Phelan’s definition of stigma (2001). This results in both individual and structural discrimination. For people living with herpes, individual discrimination is exercised when people openly reject, harass, or insult them because of their STI status. Structural discrimination of people

living with herpes, which was discussed earlier in this paper, occurs in both the classroom and in medical practices. These structural components of discrimination feed into the individual ones.

### **Individual Discrimination**

Individual discrimination results in stigmatized individuals undergoing social psychological processes that often leave them expecting and fearing devaluation and rejection. Discrimination occurs, although subtle, when those with stigma are deemed less trustworthy. According to Link and Phelan (2001), this type of discrimination often results in strained social interactions. One young woman describes how the real trauma of her diagnosis resulted from disclosing her status to her best friend.

And then also an old friend of mine, she didn't want to lay in the same bed with me even if we were fully clothed—share a bed, she wanted me to use toilet seat covers, and hand sanitizer. She just made me feel really gross and dirty. A friend I've known all my life. She was like, "Oh, I'm just trying to be careful. I've never known anyone with herpes before. I know it's really common but I've never known anyone with it and I have anxiety too. You should want to protect me. I'm your friend." I just kind of stopped talking to her. I blocked her on Facebook now. I just really haven't had any contact with her. I thought that was horrible and I couldn't believe she was doing that. Because in my experience, in general in these 6 months of having herpes, it's not really guys that reacted negatively, and that's the big fear that oh no one in heterosexual relationships is going to want me again. So it's always for a romantic interest. You never think our friends are going to be the ones to react like this. So that was, you know, what I think I was most surprised about. (Female, 21)

The unexpected nature of this type of rejection is a result of misconceptions and internalized stigma regarding the virus. This type of strained and uncomfortable social situations can often exacerbate feelings of stigma and isolation and make individuals with a stigmatized identity less likely to openly talk about their status.

According to my survey, 67% of respondents replied that their HSV diagnosis led them to avoid romantic and sexual relationships (See figure 4). Many individuals I

spoke with expressed how either past rejections or fear of rejection led them to keep their diagnosis private. Furthermore, some interviewees expressed how they had carried internalized herpes and STI stigma prior to their diagnosis. Being diagnosed shook them to their core because they had to reconsider their own identity. One woman explains:

I know that in high school everyone would crack jokes about so and so who has herpes and I would be like, what a skank, what a scumbag. I would talk so poorly about people who had herpes and really like they aren't skanks or scumbags. Like I look at myself and I'm like I'm not a skank. I don't think that I am. I got put into a situation where I slept with somebody, I had oral sex with somebody who had oral HSV 1 and I never expected to wake up and find herpes. That wasn't something that I anticipated. So that definitely sucks now because I'm like oh man I'm that girl that they talk about. Anytime somebody cracks one of those jokes I'm like ah man that's me. (Female, 22)

This woman was socialized from a young age to think poorly of those with STIs. She had to undergo many social psychological processes to understand herself after being labeled with an identity she had been taught to stigmatize. After being diagnosed with an STI, many people expect and fear rejection because of the way they were taught about those with that identity. Ninety-one percent of survey respondents said that they had either strong or moderate feelings of being tainted or unclean immediately following their diagnosis (See Figure 5). These fears can be detrimental to the emotional health of those labeled with a stigmatized identity. One young woman explained:

I had been fairly promiscuous throughout my late high school years and college and so immediately I felt guilty and shame and I just felt, my initial feeling was like I'm never going to get married, I'm never going to have kids, who's going to want me? Why do I deserve to be with anybody? Like I should just crawl in a cave and die basically. It was awful. (Female, 26)

Stigma has also been associated with higher levels of stress and constant fear of stigmatization can also lead to negative health effects (Link and Phelan 2001). One man explains that in order to avoid being rejected romantically, he unconsciously gained more weight in order to seem less attractive to others.

One of the coping mechanisms was I ate a lot. I actually put on quite a bit of weight after, which I'm now in the process of taking off. That was of them. And I sort of thought on that psychologically I think it was to make myself less attractive. I mean it sounds funny but it did impact a lot so that no one would approach me so I kind of put a wall up around me is what I did for romantic relationships. (Male, 40)

The coping mechanisms individuals employ to avoid re-stigmatization often result in more harmful health consequences than the physical health effects of living with herpes by enhancing secrecy and minimizing partner communication regarding sexual health.

### **Stigma and Partner Communication**

Individuals living with the virus must manage the information about their status.

As Goffman (1963) states, individuals with a discreditable stigma must decide, “*to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where*” (Goffman, 1963, 42).

Individuals with invisible stigmas have the privilege of being able to conceal their identity to some and therefore avoid overt discrimination. However, this often leads to greater psychological challenges as the cost of hiding an aspect of oneself can take an immense mental toll. This enhanced secrecy negatively impacts those living with the virus as well as the sexual partners of those people because the stigma leads so many to not pursue relationships, not disclose their status, or stay in problematic relationships out of fear that they will be unable to find a new romantic partner.

According to the survey distributed for this research, 43% of respondents admitted that they failed to disclose their STI status to at least one or more of their past sexual partners (See Figure 6). The primary reason respondents provided for non-disclosure practices were due to fear of rejection. It is this fear and shame that perpetuates herpes stigma and keeps this virus spreading. Many of the respondents discussed the difficulty of disclosing their status. Many of them said that it either led them to not pursue romantic relationships or to not disclose their status. One interviewee when asked how he felt about disclosing his status explained, "*Nervous. Nervous. Scared of rejection. So it makes me not pursue partners. So it's just like trying to put your hand on a hot stove type of thing, that's how it feels*" (Male, 40). Another woman explained, "*Having that conversation is terrifying and I wish that society would make it less terrifying*" (Female, 26).

Forty percent of survey respondents who did not disclose their status said they were concerned that either their partner would react badly or they were concerned that their partner would have rejected them. Another 21% explained they did not disclose their status due to feeling ashamed of their STI status (See figure 7). A number of survey participants wrote in about more specific reasons they chose not to disclose. One anonymous participant wrote, "*I had disclosed to potential partners with incredibly negative reactions, so I did not want to experience that again.*" Another person explained, "*It was a coworker and I didn't trust him not to tell others that we worked with about my status.*" Expecting or experiencing stigma greatly impacts individual's willingness to disclose their STI status to others (Ragins 2008).

### Stigma and Abusive Relationships

Another common theme that arose throughout the interviews was how being diagnosed with HSV led many individuals to stay in problematic or abusive relationships because they feared their ability to find a new partner. This finding appeared not only throughout the interviews, but also throughout other studies on the effects of herpes stigma. According to Marcia Inhorn, who conducted two months of fieldwork at a herpes self-help organization, many of the attendees stated that they stayed in problematic relationships because they were too scared to start new relationships and potentially face rejection (Inhorn 1986). While Inhorn's study was conducted 30 years ago, the individuals I interviewed confirmed that they continue to endure the same problems today. One woman I interviewed explains:

I feel trapped in [a] sense...I feel like I don't think I could handle the rejection of trying to find somebody else to be with and take the chance of them saying no...I know that me personally, previously, before the diagnosis and stuff, if I ever had to sit down and have [a potential partner] tell me that, I don't think that I would have been okay with it. I don't think I would have been like, "Yeah, yeah whatever, let's do it. Who cares?" I don't think I could've ever done that. (Female, 22)

A different woman explains:

I know that I stuck around with him longer than I should have because of that. You just have these feelings like no one else is going to want me, like I have this person [so] I might as well try to work it out with them. This is the only person who will ever understand...eventually him and I broke up once I realized I was not being treated right...just because you have this common thing with a person doesn't mean you need to stay with them. But that took a really long time for me to realize. (Female, 22)

Link and Phelan (2001) discuss how the social psychological processes that a stigmatized individual experiences dictates their outlook. It leaves them constantly wondering if people know of their stigmatized identity and fearful that they will be rejected by others because of their identity. This fear and internalization of stigma

illustrated by the above anecdotes keeps some HSV positive people in abusive or unhealthy relationships.

### **Participant Recommendations**

Throughout the interviews the respondents made a number of recommendations about how to breakdown the stigma associated with genital herpes. The recommendations address both structural and individual discrimination of people living with STIs. On the structural level, there was a predominant call to alter the way sexual health is taught in school as well as to change medical diagnostic practices. On the individual level, many believed it the responsibility of those living with the virus to openly discuss their status in order to shed light on how common it is and overcome this stigma.

### ***Shifting the Paradigm in Sexual Health Education***

Many interviewees discussed their minimal knowledge of HSV and STIs before their diagnosis. STIs were commonly discussed as a byproduct of behaving unsafely leading to their deviant label. STIs differ from other health issues because they are loaded with myriad taboos and preconceptions about what it means to be sexually active. Furthermore, because of the way these infections are contracted and the associated stigma, they are often perceived as more severe than health problems that may have greater physical ramifications on one's health. One 23-year-old female interviewee explained, *"I think the culture of sex ed. is really important for information, but also important to contributing to a culture where STIs can be discussed in a really transparent and mature way."* Negative notions and discussions on sexuality interfere with the recognition, prevention, and treatment of STIs (Gogna and Ramos 2000).



Teaching people from a young age about how to communicate about one's STI status as well as how to respond if a partner has one should be an essential component of sex education. One interviewee called for more resources on this topic:

It would be good to have more resources...about disclosing to partners...like how to have that conversation, how to bring it up, what phrasing and of course it's different for different relationships and different people. (Female, 23)

This inability to communicate due to fear of partner rejection perpetuates herpes stigma and keeps this virus spreading. It is this lack of communication that led so many people to a state of devastation immediately following their diagnosis. While it is legally the responsibility of those living with the virus to disclose their status to sexual partners, our society could ease those conversations by normalizing them and teaching that STIs are a normal and common result of being sexually active.

### *Shifting the Paradigm in Medical Practices*

Throughout the interviews, the interviewees expressed frustration at the medical system for not providing them with enough information at the time of their diagnosis both about the nature of the virus as well as linkages to resources and support services that would help them cope with the emotional aspect of the diagnosis.

That's something I want to address in the future is creating better cultures also in the clinical setting. I feel like having this empowers me in some ways where I feel like I know this is an issue that is mine, I have some ownership over it, where I can make something positive come of it. I definitely feel some empowerment because it's my issue. I know it's my issue but I also know it's not just my issue—it's thousands of people's issue around the world and thousands of people who don't have access to services or access to basic levels of care and comfort. People feel so shunned by this, by families, by their sexual partners, by themselves, so yea, it's just something that needs to be addressed. And also I feel like I hadn't really known about it before. I knew, I had heard about it, but I didn't really know. (Female, 23)

Addressing the climate in the clinical setting is a critical aspect in de-stigmatizing STIs. Christopher Whitty, an infectious disease specialist explains, “a public health strategy based upon stigmatizing individuals with sexually transmitted infections is not only unhelpful but also inevitably counterproductive” (Kinghorn 2001). When societal stigma exists, it inadvertently transfers onto individuals by the very people who are meant to offer services and care to the stigmatized population (Kinghorn 2001).

### *HSV Transparency*

Lastly, one of the primary recommendations expressed throughout the interviews was the desire to increase honest conversations and disclosure about the virus. Less than 10% of the survey respondents knew someone with HSV prior to their diagnosis (See Figure 1). While such a large percentage of the population lives with the virus, few people openly share their status with others. Interviewees wished that more people openly talked about their status in order to decrease anxiety during partner disclosures. Furthermore, participants, who had talked openly about their virus, viewed it much more positively than those who feared disclosure to friends and/or potential romantic partners. Studies show that individuals with chronic STIs are more likely to have a positive sense of sexual identity if they disclose their STI status to their sexual partner than if they choose to not engage in sexual behavior or if they have sexual relationships but keep their STI status secret (Newton and McCabe 2008). This finding was confirmed throughout the surveys. 77% of survey respondents who had disclosed their status to romantic partners noted that they were surprised by their partner’s positive reaction (See figure 8). The interviewees also confirm this finding:

For me it was like a blessing in disguise. It really helped me be better about communicating with my partners and saying what I need and what I want and asking for those things and it really challenged me to think about my value and my self-worth that has nothing to do with this diagnosis. You know, it's not tarnished by it and it shouldn't be. (Female, 30)

Honesty is I think, it is a blessing in disguise because it already sets you up for complete honesty in a relationship and if you can't be honest about this, where's your relationship really gonna go? (Female, 22)

The majority of the interview participants who had disclosed to romantic partners had positive or neutral experiences with those disclosure conversations. Most romantic partners felt comfortable being romantically involved with the person after being briefed on the nature of the virus and the likelihood of transmission:

I started dating someone in August and then I told them a month or so in because we hadn't been physical yet. And I just said it. I read all these different articles and like kind of like pumped myself up like the way that I brought it up, I was like it's not a big deal but I have to tell you this and this is the situation and I was still like, even though I acted like no big deal when I said it, I was nervous about it because this person was already very intimidating to me. I really liked him, he was like a professional athlete, very healthy, very fit. I was just like a mess on the inside. But he was super cool about it...I told him and he was like, "Okay," and that was that. Like nothing at all, I was just blown away, blown away. Just not an issue at all. It was incredible. I felt lucky. (Female, 30)

Obviously the diagnosis scared the shit out of me and my self-esteem definitely took a hit. But his reaction to it like really changed everything and not just his initial reaction, but the fact that it just hasn't really bothered him has helped. (Female, 26)

Shedding light on the unfounded nature of this stigma has the ability to decrease the strength associated with it, improve the self-esteem of those living with the virus, and decrease the risk of HSV transmission to more people. The Boston HSV support group leader ended our conversation with these words:

What better way to beat stigma than to shine the light on it. You've got to remember the 800-pound gorilla that sits on the shoulder of every person is the fear that they're going to be discovered and hated and never loved again. So every single time we shed light and we say to the 800-pound gorilla, "I'm not afraid of you. I'm going to tell someone who you are and what you are and that I have it"...that takes the weight and the pressure and the strength away from the fear and the stigma. (Male, Boston Herpes Support Group Leader)

Despite the fear that so many people face of potential rejection from sexual partners or isolation from friends and loved ones, the majority of people who disclose their status are surprised by the positive reaction that they gain from their sexual partners upon disclosure (Inhorn 1986). Out of the 18 individuals I interviewed, 15 of them had positive experiences disclosing to one or more sexual partners since their diagnosis.

## **Discussion and Analysis**

Incorporating a feminist approach to sexual health education and medical practices would foster a greater understanding of chronic sexually transmitted infections: from treatment, to transmission prevention, to living a fulfilling romantic and sexual life. Normalizing communication about sexual health and sexual preferences is key to teaching sexual health in a manner that promotes the rights of all people to make educated decisions regarding their bodies. There are myriad factors at play that contribute to both the perpetuation and experience of stigma that accompany an HSV diagnosis. It is evident from the survey data as well as the interview transcripts that this kind of diagnosis leads to shame, fear, and secrecy. While sexual health classes are designed, in part, to teach students how to protect themselves from contracting STIs, sexual health classes tend to perpetuate stigma by using fear-mongering tactics with the intention of scaring individuals from engaging in sexual behavior (Ford et. al 2013).

According to the interviewees, standardizing and normalizing conversations regarding sexual health prior to sexual activity is an essential component of breaking down HSV stigma. While interviewees participated in a range of sexual education

programs, none of the participants had been taught to normalize conversations regarding sexual health history or STIs. Sex education programs have the ability to continue teaching people how best to protect themselves from contracting an STI while simultaneously fighting STI stigma rather than perpetuating it. Perhaps if health programs taught how common STIs are and that practicing “safe sex” doesn’t eliminate all risk, then maybe those living with this virus might be more comfortable disclosing their status. Addressing the social and cultural meanings associated with STIs is key to providing effective sexual health programs. STI education programs are often insensitive to how these illnesses are experienced by people living with them (Gogna and Ramos 2000). This insensitivity illustrates the invisibility of herpes. Many people are unaware of how common STIs such as herpes are since it is easy to keep one’s status secret. Improving the culture of sexual education could minimize the risk of transmission and decrease stigma, which would ultimately lead to the decrease in STI rates.

Watkins and Whaley (2007) argue that incorporating a feminist approach would enhance medical practices. They argue that medical professionals must be trained how to support patients dealing with emotional diagnoses and help them feel comfortable asking questions and obtaining the information they need. Dickerson (2007) incorporates this approach into her Women’s Health Bill of Rights by focusing on easing the comfort of individuals in asking questions pertaining to their health and well-being. She explains that as part of an improvement in medical practices, doctors and

nurses should be proactively providing their patients with substantial information so that it is not solely left to the client to ask questions (Dickerson 2007).

In the absence of medical and educational discourse that include the standpoints of individuals living with HSV, many individuals living with HSV have created subversive online spaces to share their knowledge and change this discourse. Myriad online blogs and support groups exist for people living with HSV to anonymously share their stories and assist others with the virus to live fulfilling lives. Activists like Janelle Marie Davis of the STD Project<sup>2</sup>, blogger Ella Dawson<sup>3</sup>, and Adrial Dale of H Opportunity<sup>4</sup>, openly write about their experiences of living with HSV in order to create a culture that enhances communication around sexual health while simultaneously destigmatizing STIs. An individual's ability to overcome stigma and create personal knowledge often depends on the ways in which they experience stigma. This phenomenon reflects Sandra Harding's (1995) feminist standpoint theory. Individuals living with HSV are able to break away from oppressive discourse by embracing their own standpoints by sharing their own understandings and narratives with others.

### **Positionality and Limitations**

My positionality as an HSV positive woman has influenced this research. Due to my own status I was able to access and enter private support groups and establish greater credibility and trust from the interviewees that outside researchers would not have been able to obtain. Many of the participants expressed feeling comfortable and

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<sup>2</sup> <http://www.thestdproject.com/>

<sup>3</sup> <https://ellacydawson.wordpress.com/>

<sup>4</sup> <https://herpesopportunity.com/>

grateful to discuss the intimate details of their personal lives because of my own HSV status. While the trust I received from study participants due to my status was certainly an asset, my personal experience negotiating HSV stigma likely biased the questions I was interested in asking and the ways in which I analyzed this data.

This study also has several other limitations. First, genital herpes is a highly sensitive and stigmatized topic that many people living with the virus may not feel comfortable discussing openly. Therefore, my sample size is a self-selecting group of individuals living with HSV since I had to wait for participants to contact me directly after finding my website. A second limitation is that the majority of individuals who came across my study most likely found it on the support websites and therefore may either (a) have experienced greater shame and stigma which is why they sought out online groups, or (b), have a greater perspective on how herpes has affected their identity because they are dealing with their diagnosis directly. Despite these limitations, the narratives and responses from interviewees and survey respondents will provide high levels of insight into the experience of living with a stigmatized virus. A third limitation of this study is that 92% of the 354 respondents were female (See figure 9). While this data may imply either that women suffer from greater amount of trauma than males and therefore were seeking out support groups or are more willing to openly share their stories in survey or interview form than males, it also means that there is less validity in making generalizations about the male perspective of living with HSV.

## Conclusion

Being diagnosed with an STI is loaded with negative social connotations and often leaves people emotionally debilitated due to the shame and fear they experience. Those living with HSV are often labeled as herpetic, negatively stereotyped and viewed as a threat to society that necessitates separation. The stories that interviewees shared of discrimination and prejudice illustrate how society demonizes individuals with STIs. The language employed from religious rhetoric to pharmaceutical marketing campaigns conjures up images of those with STIs as sexually deviant. This rhetoric has been perpetuated in both sexual health education and medical diagnostic practices. The institutional structures that exist to provide accurate information about health and illness have failed. They have conjured up false notions of the ‘type’ of individual who contracts an STI, spread misinformation about modes of transmission, and inadequately responded to the emotional needs of patients.

The effects of these institutional failings leave many HSV+ individuals with feelings of shame and loneliness. This also leads to status loss and discrimination. Many fear the potential social repercussions that might ensue if they disclose their status to romantic partners, friends, and/or family. This fear often causes individuals to withdraw from romantic and sexual experiences altogether, engage in sexual relations without disclosing their status, or stay in unhealthy/abusive relationships.

A multifaceted approach is required to address the institutional and individual stigma of living with a sexually transmitted infection. Shifting the rhetoric in both sexual health education and medical practices is essential to decreasing stigma. Changing these norms has the potential to change the degree to which individuals



internalize STI stigma following a diagnosis. Shedding light on the innocuous nature of this virus is another critical step that can contribute to the de-stigmatization of herpes. The more the nature of the virus is understood and the more its presence is normalized, the less people will fear disclosure. Transparent discussions will help decrease fear and secrecy and will likely leave room for a society where conversations regarding sexual health are no longer filled with dread.

It is confounding that so many people live with this welled up shame when there are millions of people living with manageable STIs. While it is legally and morally the responsibility of those living with the virus to disclose their status to sexual partners, society could help ease these conversations. Teaching us that STIs are a normal and common byproduct of being sexually active must become a priority. Sexual health education programs and medical practitioners need to not simply teach avoidance of people with STIs, but rather how to communicate with those living with one and best practices to prevent contraction if choosing to be sexually active with them. Institutions that focus on sexual health have the opportunity to play a critical role in normalizing STI presence and teaching young people how to talk about these topics with romantic partners.

Sexual health conversations prior to sexual activity should not rest exclusively on the shoulders of those living with an STI. Formal sexual health education has failed to teach how to communicate effectively about this topic, leaving those living with STIs responsible to fill in this educational gap while simultaneously fearing the repercussions of STI stigma. The ways in which sexual health is taught in both classroom and medical

settings is in need of a new feminist approach in order to alter discussions on sexuality that forgo notions of morality and focus instead on the rights of individuals to make informed choices regarding their sexuality.

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## Appendices

### Appendix A. HSV Survey

**Intro The Experience of Living with Genital Herpes: Stigma, Self-Esteem, and STI Disclosure** This study is intended to gain a better understanding of how a genital herpes (HSV) diagnosis affects an individual's life. This is an anonymous survey and responses cannot be traced back to participants. All participation is voluntary. Please skip any questions that you feel uncomfortable answering. Participants may drop out of the study at any time. Please make sure not to put your name or any other identifying information on the survey. This survey should take about 5-7 minutes to complete. There is no monetary compensation for participation, but your responses may help shed light on the lived experiences of people with genital herpes.

For more information about this study please contact: Graduate Student Researcher: Mikayla Bobrow (607) 351-8976 mbobrow@clarku.edu Graduate Student Advisor: Ellen Foley (508) 421-3815 efoley@clarku.edu

This study has been approved by the Clark Committee for the Rights of Human Participants in Research and Training Programs (IRB). Any questions about human rights issues should be directed to the IRB Chair, Dr. James P. Elliot 508-793-7152.

**Survey Eligibility:** This survey is intended only for people who have genital herpes and are 18 years or older. You may continue only if you meet these requirements.

Q1 What is your gender?

- Male (1)
- Female (2)
- Other (3) \_\_\_\_\_

Q2 What best describes your sexual orientation? Check all that apply.

- Straight (1)
- Gay/Lesbian (2)
- Bisexual (3)
- Queer (4)
- Other (5) \_\_\_\_\_

Q3 What is your race/ethnicity? Check all that apply.

- Hispanic or Latino (1)
- Black or African American (2)
- White/Caucasian (3)
- Asian/Pacific Islander (4)
- Other (5) \_\_\_\_\_

Q4 How old are you?

- 18-22 (1)
- 23-27 (2)
- 28-39 (3)
- 40 or older (4)

Q5 What is your highest level of education?

- Some high school (1)
- High school degree (2)
- Some college (3)
- College degree (4)
- Other: (5) \_\_\_\_\_

Q6 How long ago were you diagnosed with genital herpes?

- Less than 6 months ago (1)
- Less than 1 year ago (2)
- 1-3 years ago (3)
- 4-6 years ago (4)
- Over 6 years ago (5)

Q7 Do you take daily suppressive herpes medication?

- Yes (1)
- No, but I take suppressive medicine when I notice a sign of an outbreak (2)
- No, but I have in the past (3)
- Other (4) \_\_\_\_\_
- No (5)

Q8 If yes, why do take medication? Mark all that apply.

- To protect myself from having an outbreak (1)
- To prevent genital herpes transmission to my sexual partners (2)
- Other: (3) \_\_\_\_\_
- N/A (4)

Q9 If no, why not? Mark all that apply.

- I think it's unnecessary for my overall health (1)
- I didn't know there was a daily medication (2)
- The medication is too expensive (3)
- Other: (4) \_\_\_\_\_
- N/A (5)

Q10 Where did your knowledge about HSV come from before your diagnosis? Mark all that apply.

- Sexual education program (1)
- Family or friends (2)
- Knew someone with HSV (3)
- Media/Web (4)
- No prior knowledge (5)
- Other: (6) \_\_\_\_\_

Q11 Do you know whom you contracted HSV from?

- Yes (1)
- No (2)

Q11a If you do know who you contracted HSV from, did that person disclose their status before having sex (oral, vaginal, or anal)?

- Yes (1)
- No (2)
- N/A (3)

Q11b If they did not disclose their HSV status, did they know that they had it at the time of your sexual activity?

- Yes (1)
- No (2)
- N/A (3)

Q12 Please mark the degree to which you agreed with any of the following statements IMMEDIATELY FOLLOWING your genital herpes diagnosis:

	Not experienced at all (1)	Mild (2)	Moderate (3)	Strong (4)
I felt ashamed (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt guilty (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blamed myself (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blamed others (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had low self-esteem (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was afraid of partner rejection (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt tainted/unclean (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about being alone (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt unworthy of love (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I deserved it (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt numb (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt neutral (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was able to educate others (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt empowered (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q13 Please mark the degree to which you NOW agree with any of the following statements in response to your genital herpes diagnosis:

	Not experienced at all (1)	Mild (2)	Moderate (3)	Strong (4)
I feel ashamed (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel guilty (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blame myself (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blame others (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have low self- esteem (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am afraid of partner rejection (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel tainted/unclean (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about being alone (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel unworthy of love (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I deserved it (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel numb (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel neutral (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I am able to educate others (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel empowered (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14 Has your HSV diagnosis led you to avoid sexual and/or romantic relationships?

- Yes (1)
- No (2)

Q14a If yes, does it still lead you to avoid sexual and/or romantic relationships?

- Yes (1)
- No (2)

Q15 How many sexual partners (oral, vaginal, or anal) have you had since your diagnosis? Please write in the number.

Q16 How many of those partners did you disclose your HSV status to? Please write in the number.

Q17 If you have ever disclosed your HSV status to any of your partners, how many of them had a positive reaction to your disclosure? Please write in the number.

Q18 Were you surprised by any of these positive partner reactions? Please explain.

- Yes (1)
- No (2)
- N/A (3)

Q19 How many of those partners had a negative reaction to your disclosure? Please write in the number.

Q20 Were you surprised by any of these negative partner reactions? Please explain.

- Yes (1)
- No (2)
- N/A (3)

Q21 If you did not disclose your HSV status to one or more of your past sexual partners, how do you imagine that they may have responded if you had disclosed?

- Very positively (1)
- Positively (2)
- Neutral (3)
- Negatively (4)
- Very negatively (5)
- N/A (6)

Q22 Do you think it is necessary to disclose your HSV status to sexual partners?

- Yes (1)
- No (2)
- Depends on the seriousness of the relationship (3)
- Depends on whether or not I'm having an outbreak at the time (4)
- Other: (5) \_\_\_\_\_

Q23 How do you expect FUTURE partners will react to finding out you have herpes?

- Very positively (1)
- Positively (2)
- Neutral (3)
- Negatively (4)
- Very negatively (5)

Q24 How have your past partners' reactions impacted your sexual confidence?

- Very positively (1)
- Positively (2)
- Neutral (3)
- Negatively (4)
- Very negatively (5)
- N/A (6)

Q25 If you have ever disclosed your HSV status to partners, why did you disclose?


Mark all answers that apply.

- I wanted to be honest (1)
- To protect my partner from getting herpes (2)
- It's my partner's right to know (3)
- Other: (4) \_\_\_\_\_
- N/A (5)

Q26 If you have ever not disclosed your HSV status to one or more partners, why did you not disclose? Mark all answers that apply.

- I was concerned my partner would react badly (1)
- I was ashamed (2)
- I was concerned that my partner would have rejected me (3)
- I thought it was unlikely my partner would contract the virus (4)
- My partner didn't ask (5)
- Other: (6) \_\_\_\_\_
- N/A (7)

## Appendix B. Interview Consent Form



**CLARK UNIVERSITY**  
CHALLENGE CONVENTION.  
CHANGE OUR WORLD.

**CLARK UNIVERSITY**

IRB Protocol #: 2015-022  
IRB Approval: [Signature]  
Approval Date: 1/22/2015  
Void After: 1/22/2016

**Interview Consent Form**

**Title of Research Study:** Navigating Stigma, Identity, and Disclosure: Genital Herpes and Partner Communication

**Person in charge of study:** Mikayla Bobrow, MA Candidate in Community Development and Planning at Clark University  
607-351-8976  
mbcbrow@clarku.edu

**Researcher supervisor:** Ellen Foley and Professor of International Development, Community and Environment at Clark University  
508-421-3815  
efoley@clarku.edu

The signing of this form constitutes consent to participate in a 45 minute interview being conducted by Mikayla Bobrow, a graduate student in the International Development, Community and Environment Department at Clark University. The purpose of this study is to better understand the effect that genital herpes has on partner communication. There is no monetary compensation for this interview, but your participation may help shed light on the lived experiences of people with genital herpes. The interview will be audio recorded and transcribed.

Your participation in this study is entirely voluntary. You are free to terminate your participation in this research at any time without penalty, or to refuse to answer any questions to which you don't want to respond. Your participation in this study is confidential. Neither recordings nor interview transcripts will contain names or any other information allowing identification of individual participants; participants will be identified by code number only. Participants may face possible discomfort while talking about their HSV experience. In case the interview causes psychological discomfort, a handout with counseling support services, HSV informational websites, and HSV advocacy resources are provided on the next page.

No other Clark students or Clark faculty will know who participated in the study. The Clark faculty supervising the project will not have access to the consent forms with names of participants, given that participating in the study discloses one's HSV status. Ellen Foley has provided me with a key to a locked storage area in her office that only I will have access to throughout the duration of the study. The consent forms will be kept separate from audio recordings and transcripts. Mikayla Bobrow will be the only individual transcribing interviews and all transcripts will be stored in electronic form only, in password protected files on her computer. Recordings will be destroyed upon completion of the research project. Password protected transcript files will be retained indefinitely. For more information about this study, please call or email Mikayla Bobrow or Ellen Foley.

By signing below, I agree to be audio recorded during this interview.

\_\_\_\_\_ (Signature)                      \_\_\_\_\_ (Date)

By signing below, I verify that I have read this consent form and agree to participate in this interview. I have been given a copy of this consent form.

By signing below, I verify that I have read this consent form and agree to participate in this interview. I have been given a copy of this consent form.

\_\_\_\_\_ (Signature)                      \_\_\_\_\_ (Date)

\_\_\_\_\_ (Printed Name)

*This study has been approved by the Clark Committee for the Rights of Human Participants in Research and Training Programs (IRB). Any questions about human rights issues should be directed to the IRB Chair, Dr. James P. Elliott (508) 793-7252.*

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## Appendix C. Interview Questions

1. Can you discuss how you came to know that you have HSV?
2. How long ago were you diagnosed with HSV?
3. Do you know how you contracted HSV?
  - 3a. If you know who you contracted it from, did that person communicate with you before hand?
4. Can you describe your initial reactions to your HSV diagnosis?
5. Have your emotions regarding your diagnosis changed over time?
6. Has your HSV diagnosis impacted your behavior? Please explain.
7. Has having an STI had any impact in your interactions with a sexual or romantic partner? Please explain.
8. Has contracting genital herpes led you to change your sexual behavior?
9. How do you feel about disclosing your STI status to sexual partners?
10. Can you discuss an experience where you chose to disclose or not to disclose your HSV status?
  - 10a. What factors impacted your decision?
11. Have you had a positive or negative experience of disclosing your HSV status?
  - 11a. Explain what made the encounter positive or negative.
  - 11b. Did that experience change your confidence in disclosing your status to future partners?

## Appendix D. Interviewee Characteristics

Respondent	Age	Sex	Relationship Status at Diagnosis	Current Relationship Status	Diagnosis Date
HSV Interview 1	23	Female	In a relationship	In a relationship	Less than 6 months
HSV Interview 2	30	Male	Single	Single	Less than 1 year
HSV Interview 3	41	Female	Single	Single	13 years ago
HSV Interview 4	40	Male	Single	Single	4 years
HSV Interview 5	45	Male	In a relationship	Single	25 years ago
HSV Interview 6	43	Female	Single	Single	5 months ago
HSV Interview 7	22	Female	In a relationship	Single	6 years ago
HSV Interview 8	30	Female	In a relationship	In a relationship	8 months ago
HSV Interview 9	30	Female	In a relationship	In a relationship	4 years ago
HSV Interview 10	28	Female	In a relationship	In a relationship	1 year ago
HSV Interview 11	23	Female	Single	Single	Over 1 year ago
HSV Interview 12	20	Female	In a relationship	In a relationship	1 year ago
HSV Interview 13	26	Female	Single	Single	3 years ago
HSV Interview 14	20	Female	In a relationship	Single	1 year ago
HSV Interview 15	21	Female	In a relationship	Single	3 months ago
HSV Interview 16	22	Female	In a relationship	In a relationship	2 weeks ago
HSV Interview 17	26	Female	Single	Single	2 years ago
HSV Interview 18	21	Female	Single	Single	6 months ago

Figure 1.

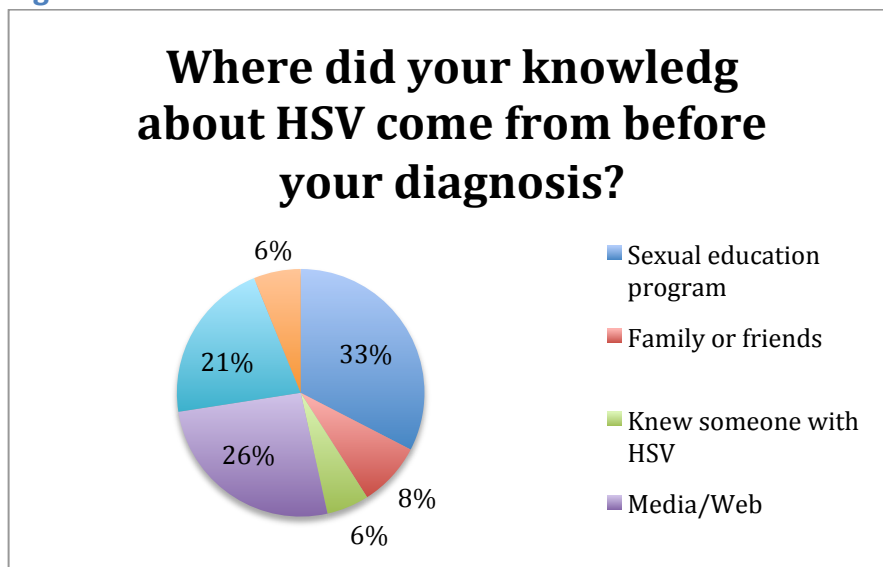


Figure 2.

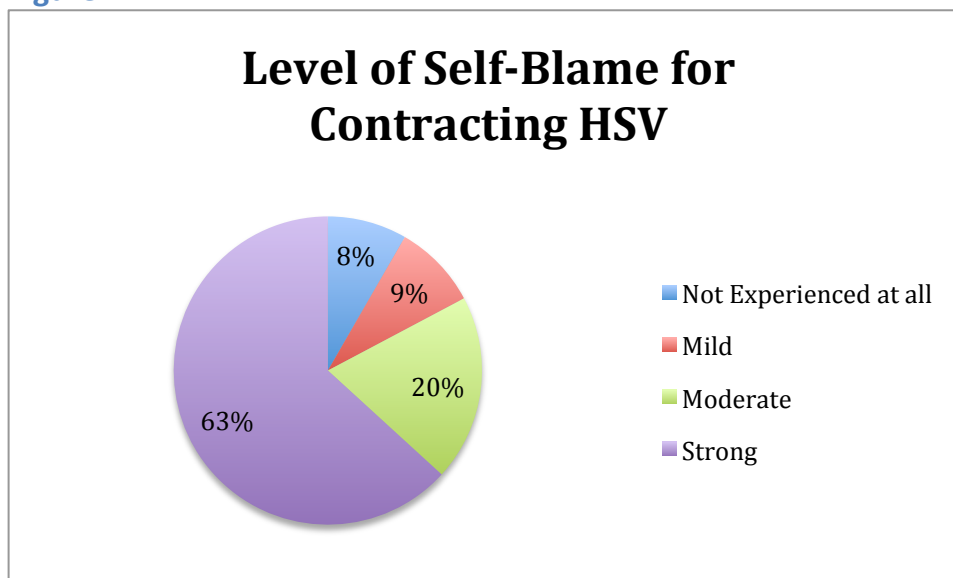


Figure 3.

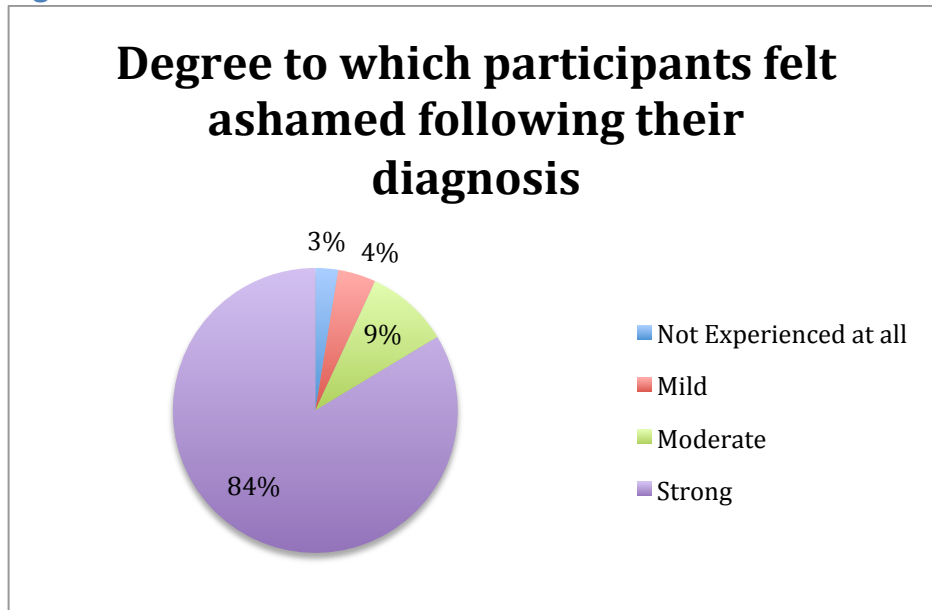


Figure 4.

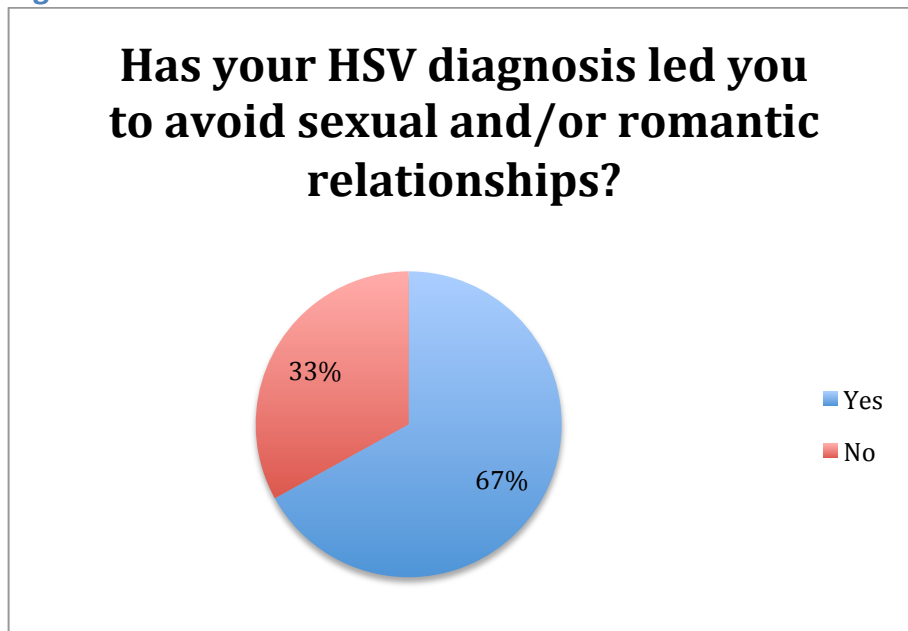




Figure 5.

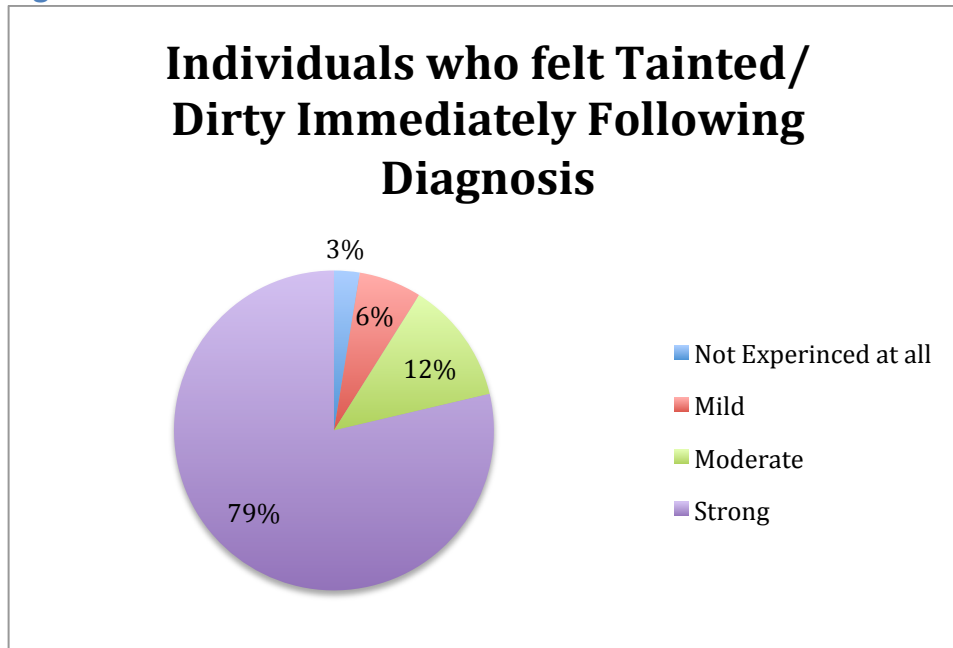


Figure 6.

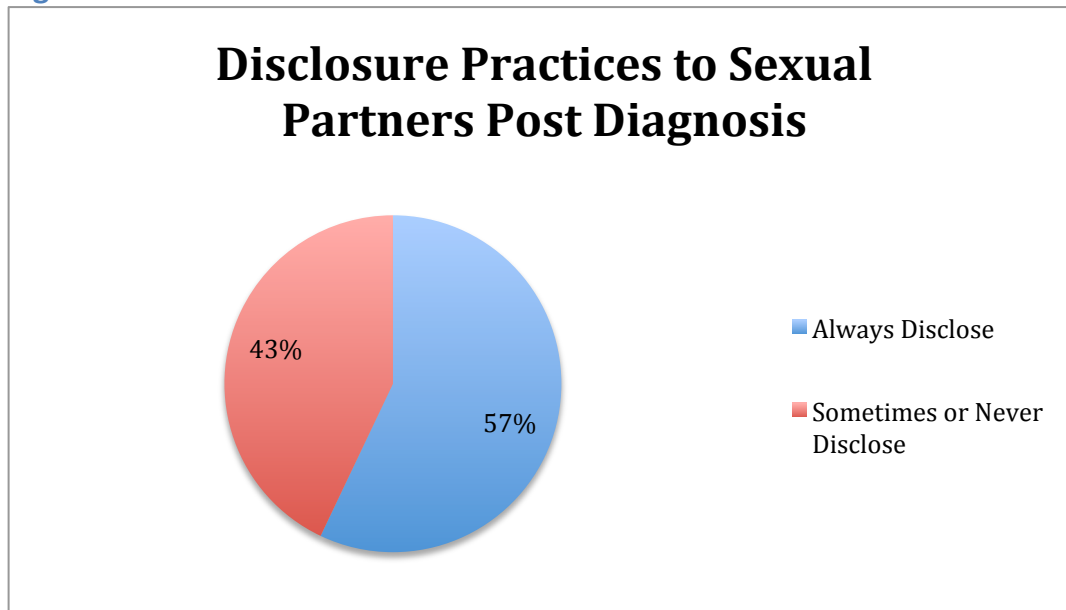


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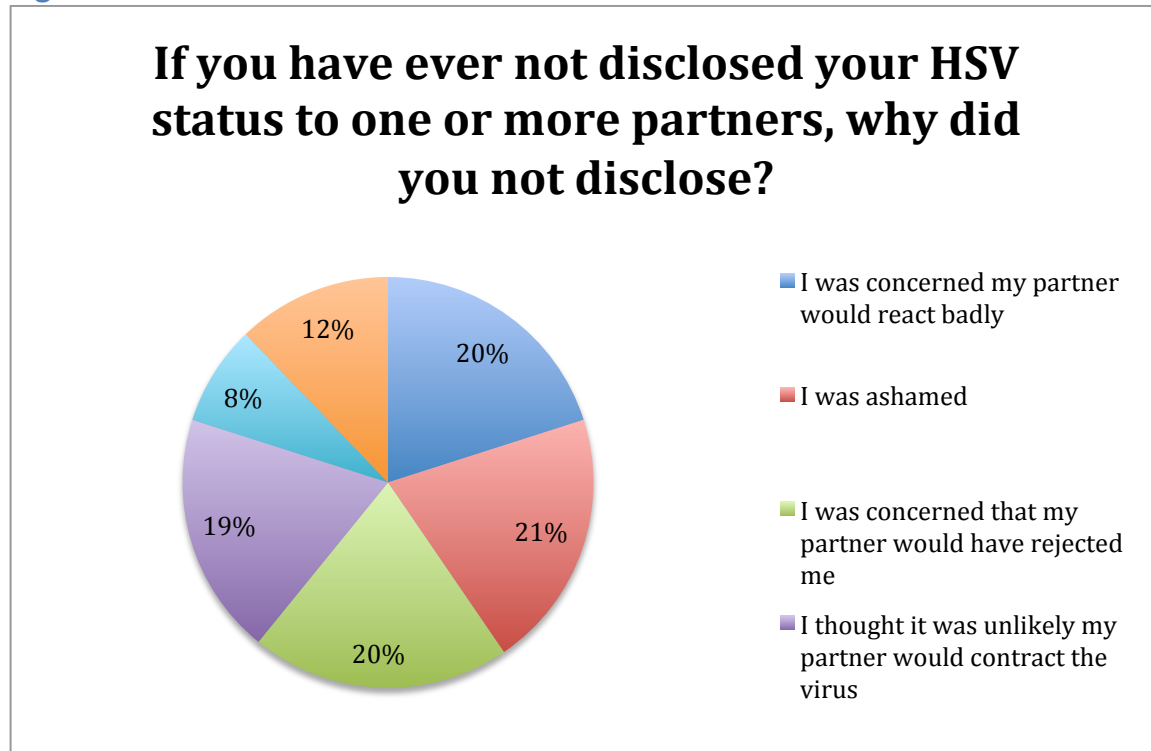


Figure 8.

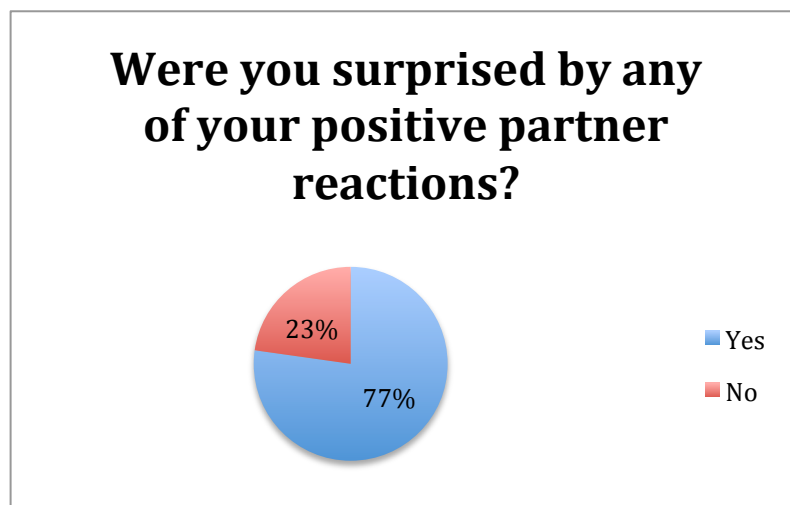


Figure 9.

