WHEN LIFE GIVES YOU HERPES: AN EXPLORATION OF HOW HERPES SIMPLEX STIGMA ON SOCIAL MEDIA IMPACTS PATIENTS AND THEIR RELATIONSHIPS WITH PROVIDERS

by

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ABSTRACT

Herpes simplex virus (HSV) is a prevalent and chronic sexually transmitted infection (STI) that is heavily stigmatized, rendering discussion of STIs between clinicians, patients, and sexual partners, more difficult. How an STI like HSV is discussed on social media sites, which have grown in prevalence and popularity, exemplifies societal beliefs related to STI stigma. The purpose of this study is to explore the intersection of HSV stigma, social media, and the patient-provider relationship. Specifically, the goal is to understand how HSV related social media content is interpreted in the context of stigma, whether interpretations differ depending on contextual factors (i.e. demographics, experiences with STIs, sexual education), and to understand the lived experiences of stigma and social media for those living as HSV positive.

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CHAPTER 1: INTRODUCTION

Sexual health is an oft overlooked aspect of patient health in primary care visits (Guilamo-Ramos et al., 2021). According to the World Health Organization (n.d.), sexual health encompasses biological, psychological, and social wellbeing related to sexuality and sex practices, and includes individual's rights to have "…pleasurable and safe sexual experiences free of coercion, discrimination, or violence." Thus, sexual health is an important and highly personalized aspect of holistic health. While reasons for overlooking sexual health in primary care visits are varied, lack of importance is not one of them. Rather, sexual health conversations between primary care providers and their patients are either non-existent, or limited in scope to the extent of rendering such conversations useless, due to non-biological reasons (Leyva-Moral et al., 2021).

Sexually transmitted infections (STIs) fall within the scope of sexual health and thus can be often overlooked in primary care settings (Leyva-Moral et al., 2021). STIs are a group of over 30 different bacterial, viral, and parasitic infections that are transmitted from oral, vaginal, or anal sex, with some STIs also being transmitted from mother to child in childbirth (World Health Organization, 2024). STIs can affect all sexually active people, with prevention of spread being dependent on education, testing, and use of protective measures like condoms (Garcia et al., 2024). Globally, STIs affect millions of people: 1 million new cases of curable STIs are diagnosed per day, with the number of people living with incurable STIs being estimated to be over a billion (World Health Organization, 2024).

Among the most common STIs both globally and in the United States is herpes simplex virus (HSV) (Garcia et al., 2024). HSV is an incurable STI with episodic symptoms most often affecting the oral or genitoanal regions with symptoms like sores, itching, or burning (World

Health Organization, 2023). There are two strains of HSV: HSV-1, the most common cause of oral HSV symptoms like cold sores, and HSV-2, the most common cause of genitoanal symptoms (World Health Organization, 2023). However, both strains are capable of causing symptoms in either location, or in more severe cases, other tissues like the brain, spinal cord, or eyes (World Health Organization, 2023). HSV can also be dangerous if passed from mother to child through childbirth, and can increase an individual's risk of contracting human immunodeficiency virus (HIV) (World Health Organization, 2023). However, most cases of HSV are asymptomatic, with many individuals unknowingly carrying and transmitting the virus, as the virus can be spread with or without symptoms (World Health Organization, 2023).

HSV can be psychologically distressing. If an individual receives a diagnosis as a result of seeking treatment for symptoms, psychological distress may have been present from the onset of symptoms and worsened by diagnosis (Johnston et al. 2024). If a person is serologically tested for HSV without symptoms, which is against CDC recommendations in the absence of symptoms or specific risk factors, asymptomatically carrying the virus can be shocking (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2022; Rosenthal et al., 2006). The distress from an HSV diagnosis originates not only from the biological illness, but also from the psychosocial implications of an incurable STI, like stigma.

Shame, Stigma and Social Distress

STIs, including HSV, are a sexual health topic especially burdened by stigma, shame, and fear. In healthcare settings, patients may be afraid to broach the specific subject of STIs unprompted with their providers due to internalized stigma, shame, or lack of trust in providers, even if other sexual health concerns like condom usage or contraception are discussed (Fisher et al., 2018; Wiegand et al., 2024; Zhang et al., 2020; Zimmaro et al., 2020). Providers in turn might believe that patients will broach STI related concerns on their own and not initiate conversation on the topic, leaving patients with legitimate needs in a gap between what is assumed and what is discussed (Zhang et al., 2020). Such a gap is problematic for public health initiatives, patient care outcomes, and overall health literacy.

STIS encompass a wide range of illnesses, from bacterial to viral, acute to chronic. The stigma associated with each STI, and how that stigma appears on social media platforms, may differ depending on the STI being studied. HSV is an incredibly common, chronic STI that is inundated with misinformation, including how it is spread, tested for, and treated. HSV is a good target for research seeking to understand the context of an illness, especially as it pertains to social media. As an STI, HSV is a social illness: more than one person must be present for the illness to be transmitted. It is an illness that many report being afraid of, and yet in most cases it is not fatal and results in nothing more than episodic skin symptoms, if any symptoms are present at all (World Health Organization, 2023). For many, the stigma surrounding an HSV diagnosis is far more severe than the biological effects of the illness.

BPSS, Sexual Health, and Distribution of Health Information Reliability

The biopsychosocial-spiritual (BPSS) theory of health, originally proposed as the biopsychosocial (BPS) theory of health by Engel (1977) and later expanded to add the spiritual dimension by Wright et al. (1996), posits that health encompasses not only biological wellbeing, but also psychological, social, and spiritual wellbeing, with all aspects being intertwined. Utilizing a BPSS lens to address sexual health is important for improving overall patient wellbeing as opposed to only treating physical symptoms, especially since many STIs, HSV included, are asymptomatic For primary care providers seeking to assist patients with multiple aspects of their health, a BPSS lens of STIs can help providers understand what services might be salient.

Primary care providers are defined as physicians, nurse practitioners, clinical nurse specialists, or physician's assistants who provide care and coordinate access to a variety of services depending on individual need (U.S. Centers for Medicare & Medicaid Services, n.d.) Providers who practice generally and cover a wide variety of health topics may be hesitant to broach sexual health with their patients for fear of offense and provider discomfort, and patients may be afraid of judgement from providers if they broach the topic themselves (Mendez et al., 2023; Newton-Levinson et al., 2016; Zimmaro et al., 2020). Additionally, providers may overlook sexual health if it is not initiated by patients due to increasing pressure to see more patients, attend to documentation, and care for other administrative duties within the same allotted time (Leyva-Moral et al., 2021; Woolweaver et al., 2023).

For patients seeking STI information yet unable to discuss STIs with their healthcare provider, other resources of information, including online resources like social media, might be a better option (Mulgund et al., 2021). Social media, also referred to as social networking, consists of online entities such as Instagram, TikTok, X, and Facebook, and are used for connection, entertainment, and information. Social media as a resource for health information has both pros and cons. Because social media sites are easily accessible for most, they present a quick way for patients seeking information to find answers and community with others. 2024 estimates suggest that 5.17 billion people use social media globally, indicating substantial potential for social media sites to act as a vehicle for the transfer of information from healthcare organizations and providers to patients (Singh, 2024). However, content may be of questionable quality, and social processes like stigma, shame, and rejection can be amplified on social media platforms (World

Health Organization, n.d.). Stigma is a process centered on social exclusion due to a trait or aspect that deviates from the perceived "norm" in a given culture (Goffman, 1986). In addition to social exclusion, stigma can be internalized and create long lasting mental, emotional, and physical distress if not managed (Goffman, 1986). As a particularly stigma-inducing topic, STIs present a unique opportunity for understanding the BPSS intersection of a sexual health topic with online public forums like social media platforms.

STI awareness, prevention, testing, and treatment are dependent on BPSS factors like accessibility to healthcare, willingness and ability to be forthright with symptoms and sexual practices, and knowledge of STIs (U.S. Department of Health and Human Services, 2020). Social media has become a potential option for increasing knowledge of STIs, but more research is needed to understand how STI stigma is expressed on social media (Gabarron & Wynn, 2016; Yeh et al., 2022). De-stigmatizing STIs would theoretically reduce the fear and shame that often inhibits conversations between both patients and providers, as well as between sexual partners (Devine et al., 2022; Myers, 2020).

Summary

For patients seeking education, testing, or treatment related to HSV, turning to providers can be a challenge due to time constraints, communication errors, and stigma (Mendez et al., 2023; Newton-Levinson et al., 2016; Zimmaro et al., 2020). When conversations about STIs like HSV don’t happen, patients, in an effort to meet a need, may turn to other sources of information, like social media (Mulgund et al., 2021). Social media has the potential to be a powerful tool for HSV education and awareness, but can also act as a conduit for stigma. There is a lack of research around how contextual factors shape perception of social media posts, and how providers can use social media as a tool for better care.

Purpose and Design

The purpose of this dissertation is to explore how stigma related to HSV intersects with social media, and how this impacts providers and patients. Specifically, this dissertation will attempt to provide more insight into the general questions of *how does HSV related content on social media reflect larger societal views? How do patients and providers view HSV related social media content? How do contextual factors shape views of HSV related social media content? How can social media be utilized by providers to better connect with, and care for, patients*?

Overview

Six total chapters will be utilized to address the research questions. Chapter 1 provides a brief introduction to STIs as a sexual health subject, including prevalence and introduction to a particularly common STI, HSV. The impact of those diagnosed with HSV is discussed from a BPSS perspective, including the roles of healthcare providers, stigma, and social media in access to education and service. Furthermore, research questions and an overview of the manuscript are presented. Chapter 2 is a more extensive literature review presenting current research pertaining to HSV, HSV stigma, stigma on social media, the patient-provider relationship, and the provider's role in HSV care. Implications and future directions following the presentation of literature are discussed. Chapter 3 is a content analysis of HSV related posts on the social media platform X (formerly Twitter) that begins with a literature review and culminates in an analysis of original social media content from X coded and analyzed both quantitatively and qualitatively for themes and trends. Additional recommendations for future research are discussed

Chapter 4 encompasses the proposed methodology for the original convergent study, the goal of which is to address the research questions by understanding the connections between the demographic and contextual factors of participants related to perception of X posts on HSV. Chapter 5 will present the findings from the original research outlined in Chapter 4, including relevant themes, correlations, implications for future research, and recommendations for providers. The final chapter, Chapter 6, is a discussion and overview of the dissertation in it's entirety, including how the dissertation adds to the existing body of literature, how each research questions was addressed o answered, and recommendations for both providers and researcher.

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CHAPTER 2: LITERATURE REVIEW

Globally, it is estimated that 1 million new infections of curable sexually transmitted infections (STIs) are acquired every day in those aged 15-49, while in the US alone rates of STIs reached an all-time high in 2021 across both gender and ethnicity (World Health Organization, 2024; Office of Infections Disease and HIV/AID Policy, 2024). While there are a multitude of different infections encompassed under the umbrella of STIs, herpes simplex virus (HSV) is one of the most prevalent incurable STIs and is estimated to effect over 4.1 billion people worldwide (World Health Organization, 2023). HSV is often overlooked for research due to its propensity to be asymptomatic, the low risk for life-threatening complications, and the minimal physical impact a diagnosis has on infected individuals (National Institute of Allergy and Infectious Diseases, 2023). While there are some more severe complications to an HSV diagnosis, such as increased risk for HIV infection and potential complications for pregnancy, for most of those diagnosed, HSV infections are either completely asymptomatic, which is extremely common, or a skin infection resulting in episodic blisters or sores in affected tissues (usually oral or genitoanal regions).

Even though HSV may not have as severe complications and outcomes as other STIs, HSV is an STI of interest for systemically oriented research because of the stigma that accompanies it, much like a socially rooted comorbidity (Matsunaga et al., 2023). An HSV diagnosis can change not only how others perceive the diagnosed individual, but also an individual’s sexual behaviors, coping strategies, substance use, perception of self or self-esteem, and overall quality of life (Barnack-Tavlaris et al., 2011; Davis et al., 2015). Individuals who were already predisposed to adverse mental health conditions may be the most at risk for adverse mental health and psychosocial effects following an HSV diagnosis, which is unfortunate considering populations most at risk for HSV are also those who are often at risk for adverse mental health conditions (Centers for Disease Control and Prevention, 2023; Provenzale et al., 2011; Sanchez et al., 2023). Previous risk for psychological and social distress is compounded by stigmatizing events following a diagnosis, with overall sexual wellbeing following an HSV diagnosis being predicted by experiences of stigma with others (Foster & Byers, 2016).

STIs in general are often targets of social stigma, where those infected with STIs are outcasts or "deviants" from the "norm" (Goffman, 1986). Stigma acts as a barrier for the prevention, testing, and treatment of STIs, as those infected may find it difficult to have conversations about their experiences or diagnosis with potential sexual partners and healthcare providers due to risk of ostracization or judgement of others (Devine et al., 2022; Myers, 2020). For STIs like HSV, finding accurate information about etiology, prevention, and treatment can be difficult for individuals who may find themselves affected but afraid to seek information for fear of stigma (Barnack-Tavlaris et al., 2011).

Healthcare providers (HCPs) are often sought after by patients as resources for information on a wide variety of topics, as they are often gatekeepers to the medical system and responsible for the testing and management of a wide variety of conditions. However, it can be difficult for providers and patients to discuss stigmatized topics like STIs because it may not be clear whose responsibility it is to broach the subject (Bonder et al., 2021; Coll et al., 2016; Einhorn et al., 2018; Ezhova et al., 2020; Fisher et al., 2018; Jahn et al., 2019; Pleasure et al., 2022). Additionally, providers operate within the same social contexts as patients and may be uncomfortable broaching topics like STIs with patients, or may exacerbate stigma through their interactions with patients (Chime et al., 2022).

For both patients and providers, larger questions of sexual education quality, including mandated education before the age of eighteen and education on sexual health in medical training programs, are also salient. Adults may find themselves lacking in knowledge of how to protect themselves from STIs, and healthcare providers may find that they are unsure how to handle sexual health concerns (Leyva-Moral et al., 2021; Woolweaver et al., 2023). Without quality education prior to the age of eighteen and without the ability to turn to healthcare providers for information in adulthood, patients may turn to other sources of information on STIs, including online sources of information and social networking like, social media. While increasing health literacy is advisable for any adult seeking to care for their own health, the quality of information that may exist on online platforms like social media sites is questionable, and could potentially contribute to further stigmatization, as social media sites are extensions of larger social climates. The purpose of this literature review is to understand current literature pertaining to HSV, social media, stigma, and the patient-provider relationship with the purpose of informing future research and recommendations for HCPs.

HSV Background

Herpes simplex virus (HSV) is a viral, chronic STI that is often asymptomatic. When HSV does result in symptoms, it most often affects the mouth, genital, or anal regions but can present with a wide range of clinical manifestations in other bodily locations as well, including the eyes, brain, or spinal cord (Johnston et al., 2024). How HSV is spread is location dependent, but is commonly transmitted through skin-to-skin contact, saliva, and genital fluids, including potential spread from mother to child via childbirth (World Health Organization, 2023). However, given that HSV is most often asymptomatic, the virus may be transmitted with or without symptoms (World Health Organization, 2023). There are two strains of HSV: HSV-1, the most common strain of HSV and most frequently associated with oral HSV symptoms (i.e. cold sores), and HSV-2, most commonly associated with genital HSV symptoms like genital or anal lesions (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2022a). It should be noted that although HSV-1 is commonly associated with oral HSV and HSV-2 is commonly associated with genital HSV, both strains can cause symptoms orally, genitoanally, or in other tissues (World Health Organization, 2023).

HSV is chronic and permanent, but symptoms are episodic and can be reduced in frequency and severity with daily antiviral medications (Johnston et al., 2024; World Health Organization, 2023). Aside from symptoms, other risks of HSV infection include heightened risk of acquiring HIV, rare complications such as neurological or ophthalmological infections, and the rare risk for pregnant women to expose newborns to HSV during birth (neonatal HSV), which can lead to severe disability or death for infants (World Health Organization, 2023). HSV is most often diagnosed via direct testing of sores but may be tested for serologically via a blood test in the absence of symptoms. Recommendations from the Centers for Disease Control and Prevention (CDC) are against diagnostic testing for the general population for HSV 1 & 2 via blood test in the absence of symptoms due to the tendency of blood tests to provide inaccurate results (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2022b).

BPSS Effects of HSV

Aside from the physical presentation and effects of HSV on infected individuals, HSV can have other long-lasting consequences for those diagnosed. Per Engel’s (1977) biopsychosocial (BPS) theory, later updated to the biopsychosocial-spiritual (BPSS) theory, the biological, psychological, social, and spiritual aspects of an individual are all interconnected and create a holistic definition of health (Mendenhall et al., 2021; Wright et al., 1996). Though HSV may be a biologically occurring illness, HSV poses a significant threat to aspects of health other than just physical wellbeing. For example, the initial presentation of symptoms can cause mental health effects like anxiety or depressive symptoms, as can seeking medical attention and discussing sexual health with an HCP (Johnston et al. 2024). For those experiencing HSV symptoms, Patel et al. (2001) found that work performance and overall mental health were considerably diminished due to HSV, with overall mental health decreased being greater in the HSV positive population than in populations of patients with asthma, chronic lung disease, or rheumatoid arthritis. Additionally, to reduce the severity of social impact, individuals may not inform potential sexual partners, affecting prevention of further spread, or the diagnosed individual may not tell other social supports, creating a sense of isolation post diagnosis (Myers, 2020). Spiritually, like other STIs, an HSV diagnosis may be viewed as a punishment for sexual "sin" by the individual or others or may bring spiritual beliefs into question as the individual grapples with the meaning behind their diagnosis (Reyes-Estrada et al., 2015).

For individuals diagnosed with HSV, the presentation of symptoms and experiences the diagnosed individual has with others may largely impact how that person experiences their own diagnosis. In one study from Foster and Byers (2016) on the sexual well-being of patients diagnosed with HSV or human papilloma virus (HPV), the most important predictor of sexual wellbeing was found to be experiences with stigmatization and the extent to which patients internalized stigmatizing beliefs. Rosenthal et al. (2006), indicated in another study that there may be differences in the psychological impacts of an HSV diagnosis depending on whether symptoms are present, noting that amongst newly diagnosed asymptomatic individuals, fear of rejection, shame, and anger were the most endorsed social and psychological impacts. Thus, the way an individual experiences an HSV diagnosis psychologically, socially, and spiritually is largely defined by both external experiences involving others, and internal reactions and processes.

Stigma, STIs, and HSV

Diving into how an HSV diagnosis effects individuals from a BPSS lens warrants further exploration of the “why” behind the potential BPSS effects. Stigma, particularly STI-specific stigma, is a social-exclusion process due to a biological illness, resulting in distressing mental health effects, and potentially impaired social functioning, involving all BPSS aspects of health (Scheinfeld, 2021). Per Goffman's (1986) theoretical framework of stigma, stigma is defined as the relationship between an attribute that deviates from a cultural norm, and the cultural stereotypes accompanied by that attribute. Those with highly stereotyped deviations are viewed by the non-deviants as worthy of less respect, with those possessing the deviant attribute rendered "spoiled" or tainted. The purpose of stigma has historically been for the protection and well-being of those living within a given system (Smith et al., 2008). Thus, STI stigma is a relational process of discrimination and oppression based upon STI status and rooted in cultural and societal beliefs, with the purpose of avoiding threats to the well-being of the societal system and those living within it (Goffman, 1986; Smith et al., 2008).

General STI stigma is well-documented as a barrier to treatment, testing, and sexual wellbeing, as fear of judgement, ostracization, or rejection accompanies stigma and can inhibit conversations about STIs (Scheinfeld, 2021; Thomas et al., 2022). While STIs in general may be considered stigmatized, the process of stigma may differ between STIs (Neal et al., 2010). For example, stigma may differ based on whether the STI is curable or incurable, the symptomology (e.g. genital lesions may be more stigmatized than infertility), and the way the STI was acquired (e.g. nonconsensual sexual activity vs. consensual). Literature examining differing attitudes has supported the idea that STIs are viewed differently when compared to other STIs. For example, a study by Sanchez et al. (2023) examined how perceptions of STI status of hypothetical partners impacted how likely participants were to proceed with a sexual or romantic relationship with the hypothetical partner. Findings suggested that participants were less likely to move forward with any type of relationship with hypothetical partners testing positive for HSV, even when compared to those testing positive for HIV or partners who had never received any type of STI testing.

Other studies have found differences in beliefs, attitudes, misconceptions, and stigma between STIs such as HIV, Hepatitis B, syphilis, and gonorrhea (Chitneni et al., 2024; Ndi, 2019; Reuter et al., 2018). Another study from Neal et al. (2010) comparing stigma of HIV to other STIs found differences in perception between the STIs on two different measures of stigma. Differing levels and processes of stigma between STIs could potentially indicate a need for interventions that are STI specific or tailored to each individual STI, and could offer a potential explanation for differing outcomes in STI interventions. Per Devine et al. (2022), research related to overall quality of life for HSV specifically has indicated that HSV related stigma not only causes psychological distress, but can also act as a deterrent to communication between sexual partners. However, the authors conclude that more up to date research on overall quality of life for people living with HSV is needed.

Patient-Provider Relationship

HCPs form unique relationships with patients that often eschew social norms in favor of efficiency and precision (Drossman et al., 2021). Social interactions outside of medical settings often do not delve into intimate details of a person’s life and health within the first fifteen minutes of meeting with the intention of making health-related decisions for one of the parties involved, and yet that type of interaction is often expected in medical settings. In recognition of the unique qualities of the patient-provider relationship, Siminoff and Step (2005) proposed a communication model of shared decision making (CDSDM), identifying three factors contributing to shared decision making (SDM): patient-provider antecedents, communication climate, and treatment decision. The patient-provider antecedents are the individual characteristics of both the patient and provider, characteristics that in turn create a communication climate in which there is ultimately the generation of a treatment decision. Utilizing this model, the patient-provider relationship can be broken down into parts that each party contributes to the overall relationship.

Provider Factors

Providers are increasingly called to eschew the traditional medical hierarchy that elevates providers as experts in favor of patient-centered approaches that uplift and empower patients to have a more central role in their own care (Drossman et al., 2021; Mohib & Turin, 2024). However, such approaches that empower patients do not necessarily subvert traditional power dynamics in the patient-provider relationship, as even the act of sharing power implies that one party has the power to decide to share or not. As Dubbin et al. (2013) succinctly stated, providers have the power to shape patient interactions by defining the parameters of what contextual factors the patient presents are important for care through their words and actions.

When providers communicate with patients verbally or non-verbally, they are overtly and covertly setting expectations for how patients can and should navigate medical settings (Dubbin et al., 2013). Thus, supplementing traditional medical training with communication skills training for healthcare providers may improve the patient-provider relationship and patient health outcomes (Cvetanovska et al., 2023; Drossman et al., 2021). Examples of provider factors that may improve the patient-provider relationship and increase patient wellbeing and act as suitable targets for provider education include empathy and knowledge of interpersonal communication theory (Bylund et al., 2012; Derksen et al., 2013). Given that the patient-provider relationship entails a great deal of trust between parties, teaching communication skills such as active listening, patient inclusion in agenda setting, empathy, and validation may build trust and further improve the effectiveness of the patient-provider relationship in promoting positive health outcomes (Drossman & Ruddy, 2020).

Aside from improving general communication skills to better build the patient-provider relationship, providers should be cognizant of their roles in improving the overall health literacy of patients. Part of empowering patients to take a more active role in their own care is assessing each patient's health literacy level and providing communication and education that are appropriate for each patient (Kamimura et al., 2020; Miller & Reihlen, 2023). However, current literature suggests that there is a gap between what providers think patients' health literacy level is and what patients actually know, suggesting that providers might benefit from training specific to assessing patient health literacy (Greaney et al., 2020; Sanchez et al., 2023).

Patient Factors

While providers are called to proactively involve patients in care decisions, patients are also responsible for communicating their needs with the provider. A patient's healthcare needs and involvement in care may change over the lifespan, especially as patients age and may have more or competing health concerns arise (Miller & Reihlen, 2023). Patients need to advocate for themselves when with providers despite their experience with the provider. Part of patients' ability to take an active role in care and communicate needs is their own trust in the provider. Trust is another factor that both providers and patients must provide for a beneficial patient-provider relationship. In a qualitative study from Kinchen et al. (2021), providers verbalized the need for patients to trust them as medical experts for improved adherence and acceptance of recommendations, going as far as stating that patients who do not trust their provider might need to seek care elsewhere. Therefore, while patients should make their own decisions about which providers to trust and seek care from, they should also seek alternative care if a provider is not someone they trust.

Patients seeking to form a relationship with their provider should seek to navigate the patient-provider relationship as they would any other relationship they were invested in: by treating the other party with appropriate respect and human decency. Providers often receive the brunt end of patients' frustrations with a variety of health-related issues that may not be related to the provider (Matthias et al., 2010). In a systematic review on abusive behavior in the patient-physician relationship from Chen et al. (2023), literature suggested that patients were more likely to be abusive in the relationship than physicians, and that such abuse can affect the care provided by the physician. Additionally, inappropriate and problematic patient behavior can lead to physician burnout and avoidance of patients exhibiting such behaviors (Shankar et al., 2019).

Systemic Impacts on the Patient-Provider Relationship

Changing the patient-provider relationship is not solely dependent on what each party contributes to the relationship, as there are other larger, systemic factors that impact the relationship. While HCPs are increasingly called to improve their communication skills and provider patient-centered care, systemic demands often make this a difficult task for providers seeking to balance the multitude of demands placed upon them (Chen et al., 2023). Providers are increasingly called to see more patients in the same amount of allotted time while also attending to the electronic medical record (EMR), communicating with other providers on the patient's healthcare team, and addressing other administrative tasks outside of direct patient care (Drossman et al., 2021; Kerluku et al., 2024). Thus, there are several systemically related barriers that make it difficult for HCPs to learn and implement patient-centered care approaches that might improve the patient-provider relationship. Leveraging systemic barriers to create a stronger patient-provider relationship is one potential subversion of increasingly larger constraints. As described by Shutzberg (2021), providers may seek to have a relationship with patients built on solidarity, in a relationship that pits the patient-provider relationship as a united front against larger systemic issues.

Larger systemic and cultural beliefs, biases, and stigma present another factor impacting the patient-provider relationship. Providers are embedded within the same beliefs, misconceptions, and biases as anyone else within a given culture. Researchers have consistently demonstrated that higher levels of implicit or explicit provider bias are associated with poorer patient outcomes, suggesting that improving patient care requires increased self-of-the-provider insight and education (Hagiwara et al., 2019; Maina et al., 2018). For patients, internalized bias, shame, and stigma may also prevent them from openly discussing their needs with their providers, especially related to culturally stigmatized topics (Wiegand et al., 2024).

The healthcare system is another larger-scale influence on the patient-provider relationship. While trust is an important contribution both providers and patients must make, trust in a single provider can be inhibited by beliefs patients have about the healthcare system as a whole (Elwood, 2023). For example, Cuevas and O’Brien (2019) demonstrated that in a sample of 220 African Americans, those reporting stronger ties to racial identify also had lower levels of trust in healthcare. In addition to lack of trust, patients may struggle to form relationships with providers due to restricted access to care due to financial constraints or lack of insurance (Noh et al., 2024).

Patient-Provider Relationship and STIs

Patient-centered skills that build trust and foster a positive patient-provider relationship may be difficult for providers to apply when working with stigmatized topics like STIs. While providers are integral to the provision of STI related services and knowledge, they are failing to initiate conversations about STI's, including prevention and safe sexual practices, necessitating more provider education and training (Bonder et al., 2021; Coll et al., 2016; Einhorn et al., 2018; Ezhova et al., 2020; Fisher et al., 2018; Jahn et al., 2019; Pleasure et al., 2022). As gatekeepers to medical services, providers hold more power within the patient-provider relationship, often taking on the role of the "expert" (Treichler et al., 2021). While collaborative and patient-centered models of care encourage providers to redistribute more power to patients, the power hierarchy necessitates providers to act as initiators of conversations regarding stigmatized topics as part of sharing power (Treichler et al., 2021; Ogden et al., 2017).

Providers may be hesitant or fail to initiate conversations about STIs with their patients due to inadequate formal training on STI transmission, prevention, and treatment (Guilamo-Ramos et al., 2021; Leyva-Moral et al., 2021). Formal sexual health training is required in only half of United States medical schools, and the topics encompassed under sexual health can vary widely, as there is no standardized curriculum (Beebe et al., 2021). In a report from the National Academies of Sciences, Engineering, and Medicine (2021), general providers (as opposed to STI specialists) were identified as potential ways to expand STI related services, but inadequate training, uncertainty about how to address STIs, and underestimates about the prevalence of STIs were barriers to general healthcare providers providing STI specific care. Though there are STI specific trainings available, such as free trainings offered by the CDC or the University of Washington, providers may not have time to engage in such trainings, and healthcare systems might not compensate providers for the time spent on training (Centers for Disease Control and Prevention, n.d.; University of Washington, n.d.).

When providers initiate conversations about STIs, patients have better access to services and better health outcomes, which in turn leads to improved population health. For example, Mendez et al. (2023) demonstrated that STI screening rates were higher when healthcare providers asked about a variety of patient sexual health practices, including sexual orientation, condom usage, and type of sexual intercourse. To better equip and empower providers to initiate conversations about STIs, education recommendations encompass sexual health specific topics, such as conception for women living with HIV, as well as population specific topics, such as STI prevention and sexuality in older adult populations (Coll et al., 2016; Ezhova et al., 2020). To exemplify the need for a broader competency of sexual health among healthcare providers, Jahn et al. (2019) found that in a sample of sexual minority cisgender women and nonbinary assigned female at birth individuals, healthcare providers who discussed sexual health topics lost patients' trust due to a focus on pregnancy and contraception, lack of knowledge about STI transmission in sexual minority populations, and the presence of heteronormative assumptions. Providers need to tailor sexual health and STI conversations to better suit the needs of specific populations.

Considering STIs disproportionately affect minoritized and/or stigmatized communities like gay and bisexual men, Black/African-American individuals, American Indian/Alaskan Native individuals, and youth of all demographics, additional training recommendations should include cultural sensitivity and self-of-the-provider awareness to decrease bias (Centers for Disease Control and Prevention, 2023). Current literature suggests that disparities exist regarding exposure to STI and sexual health conversations with providers, with populations such as older adults and individuals with disabilities (Agochukwu-Mmonu et al., 2021; Schmidt et al., 2022). STI services may also be more available to other populations, like those with unstable housing, females, and those between ages 15-34, which could potentially indicate that bias or provider assumptions of sexual risk increase the potential of a patient to be tested for STIs (Mick et al., 2023). While certain populations might have an increased risk of STIs, STI or sexual health needs should not be assumed, and other populations should not be excluded from sexual health services.

For providers working with individuals who have recently or previously received an HSV diagnosis, understanding the implications of diagnosis is important for accommodating all BPSS aspects of a patient's health. How a provider discusses HSV, including their knowledge level and effectiveness in communicating without increasing stigma, can have massive public health implications. For example, Romanowski et al. (2008) discovered that not only did both providers and patients underestimate the risk of asymptomatic transmission, but there were also huge gaps in communication between providers and patients regarding HSV, including discussions about antiviral therapy. Minoritized patients may have even greater difficulty than others discussing HSV due to the HSV stigma being compounded with bias or oppression. For example, Cazeau-Bandoo and Ho (2022) described the experiences of African-American women diagnosed with genital herpes as entrenched in racism and discrimination. Jackson and Arcelay-Rojas's (2021) qualitative study on the experiences of African-American women with HSV-2 described the difficulty African-American women have discussing sexual health with providers for fear of stigma and being seen as uneducated. If providers are not discussing the implications of and HSV diagnosis with HSV positive patients, including how to reduce outbreaks and transmission to others, patients may utilize other sources, like social media sites, to receive the information they need.

Social Media and STIs

In the absence of information from providers, patients seeking information about STIs may decide to seek online sources of information with questionable credibility (Mulgund et al., 2021). Social networking sites, such as Instagram, X (formerly Twitter), and TikTok serve as prevalent channels for individuals to access a wealth of information, community, and entertainment on an array of topics. Social networking sites, also known collectively as social media, are often globally available and easily accessible for most, positing an enticing option for disseminating information on highly stigmatized and controversial topics with the opportunity for anonymous access and content creation (Andalibi et al., 2018; Kesten et al., 2019). However, social media can also perpetuate harmful and inaccurate information necessitating policing of content, particularly health-centric content, to prevent harm to consumers (World Health Organization, n.d.). Given the power social media platforms allot users to circulate information quickly and across a global audience, understanding how social media impacts stigmatized health topics like STIs becomes abundantly important for public health.

Research exploring social media as a means for communicating STI related information supports both the potential for social media to positively impact patient outcomes, and the concurrent need for more research (Gabarron & Wynn, 2016). Some of the potential benefits of social media as a resource for STI information and services include accessibility for those who are not able to easily access healthcare, anonymity, and increased time to absorb information (Kesten et al., 2019). A systematic review from Yeh et al. (2022) concluded that STI services provided online, such as education, advertisement, and testing, may provide similar outcomes as services delivered in an offline format. Other studies on social media rooted STI interventions support the findings from Yeh et al. (2022), but continue to narrow the scope of research to include primarily HIV, men seeing men (MSM), or both (Argenyi & Kushalnagar, 2019; Cao et al., 2018; Kesten et al., 2019). Research in a variety of populations on social media and other STIs aside from HIV is lacking. More research is warranted to understand if all STIs, when present in an assortment of populations, involve the same type of discreditation and social exclusion on social media, or if different STIs evoke stigma on social media differently. For example, efforts to reduce the impact of the United States HIV/AIDS epidemic from the 1980's to present day, including social media campaigns, may have contributed to reduced stigma surrounding HIV/AIDS, while other STIs that have not had decades of destigmatizing efforts may continue to elicit more severe stigmatization (HIV.gov, 2023; Neal et al., 2010; Sanchez et al., 2023).

To better understand and conceptualize how social media, the patient-provider relationship, and social determinants of health effect STI stigma, Forgie et al.'s (2021) framework can be applied. According to Forgie et al. (2021), social media can assist patients with limited access to medical care due to social determinants of health with receiving health information. However, social media access is not feasible for everyone, and several populations who may be at risk for STIs, such as older adults, individuals with lower socioeconomic status, and those with less education may not have means to access social media (Forgie et al., 2021). While social media has many potential benefits, such as fostering community, providing support, and creating avenues for accessible STI information, there are other challenges as a result of social media to address, such as quality of information, privacy, and the potential for social media to reinforce stigmatizing STI narratives (Forgiet et al., 2021).

Implications and Future Directions

STIs like HSV are complex health conditions to navigate due to the interwoven nature of the BPSS aspects contributing to both living with the diagnosis and preventing further transmission (Engel, 1977; Wright et al., 1996). Inadequate sexual health education for the general United States population has only exacerbated the difficulty of circumnavigating STIs, leading to lack of information or, in worst-case scenarios, increased misinformation (Woolweaver et al., 2023). Healthcare providers are often sought out by patients for information on STIs, but the conversation between healthcare providers and their patients on STIs like HSV can be difficult to have due to stigma (Bonder et al., 2021; Coll et al., 2016). Stigma, a contributor to the psychosocial burden of STIs like HSV, adds another layer of complexity for those seeking to improve prevention, testing, and treatment. Stigma can act as a barrier to those who might seek STI services from healthcare providers, education, or open communication with potential partners about STI status (Scheinfeld, 2021; Thomas et al., 2022). Healthcare providers often feel underprepared and under educated to counsel patients on STIs, and may need assistance navigating conversations about a topic that can be complex to discuss (Guilamo-Ramos et al., 2021; Leyva-Moral et al., 2021). Social media as a potential intervention and avenue for STI-related services has shown promise, but many studies are limited in scope of STI studied and target population (Yeh et al., 2022).

Stigma and STIs do not affect all populations at the same rates. There are some populations who are more at risk for certain STIs than others, though all people are at risk for STIs if engaging in sexual activity (Cazeau-Bandoo & Ho, 2022; Jackson & Arcelay-Rojas, 2021). Due to the social nature of stigma, understanding how social media platforms transmit stigma can help inform potential interventions and resources, while also serving to give providers insight into how information on social media can shape health behaviors. When patients seek care, they do so within the context and cultural beliefs they are embedded in, and providers need to understand that context to provider culturally appropriate care for their patients.

Future directions for research incorporating stigma, social media, healthcare providers, and HSV specifically are needed to inform practice and improve quality of life for those diagnosed, as well as to assist others in getting the care and education they need without fear of ostracization. Additionally, future research targeting the efficacy of public health initiatives aimed to improve STI prevention, testing, and treatment outcomes using social media would be another potential area of interest. Sexual health education is another field that would benefit from more research related to HSV stigma, social media, and health care providers, as both sexual health provided as part of mandated schooling curriculum and sexual health during medical training.

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CHAPTER 3: A SORE SUBJECT: MANAGING STIGMA AND MISINFORMATION OF HSV ON X

On any single day in 2018, 20% of the United States population had a sexually transmitted infection (STI), costing the United States healthcare system over $16 billion dollars in healthcare costs alone (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2021). The United States STI epidemic continues to gain momentum, with the number of new STI cases increasing yearly (Centers for Disease Control and Prevention, 2023). There are over 30 different STIs, some curable and others incurable, with a diverse range of clinical presentations (National Academy of Sciences, Engineering and Medicine, 2021). While many individuals with STIs may be chronically or periodically asymptomatic, symptoms and health outcomes can range in severity, with the most serious cases resulting in permanent disability or death (National Academies of Sciences, Engineering, and Medicine, 2021). High prevalence, increasing incidence, and substantial healthcare costs situate STIs as a serious public health issue with potentially dire consequences for both individual and public health.

The questions of why and how STIs continue to plague the U.S. despite innovations in technology and medical care are especially salient, with answers to both questions being described as “multifaceted” by Leandro Mena, Director of the Center for Disease Control’s (CDC) Division of STD Prevention (Centers for Disease Control and Prevention, 2023). In addition to several social determinants of health (i.e. socioeconomic status, race/ethnicity, sexuality, etc.), lack of education and stigma are two facets behind the “how” and “why” of the STI epidemic (U.S. Department of Health and Human Services, 2020). In the United States, sex education during adolescence has been repeatedly found lacking, with adolescents often receiving education that does not meet minimum national goals (Lindberg & Kantor, 2021; Sao et al., 2023). Furthermore, adults may be less likely to initiate conversations regarding STIs with partners and healthcare providers due to the heavy stigmatization of STIs (Centers for Disease Control and Prevention, 2023; U.S. Department of Health and Human Services, 2020). To avoid direct conversations with others out of fear of stigma or judgement, the internet has become a popular source of information regarding STIs, including social media sites. Social media sites such as Facebook, X (formerly known as Twitter), TikTok, and Instagram, provide users with an abundance of information on a variety of topics, STIs included. However, the quality of such information is questionable, as users from all over the world can post anything at any time, inviting misinformation and further stigmatization (Nobles et al., 2019; Suarez-Lledo & Alvarez-Galvez, 2021; Tucker & Day, 2020).

STI stigma on social media presents an interesting opportunity to study how a health topic as old as human DNA intersects with the ever-changing world of technology, all while addressing larger sociocultural contexts. As social media sites continue to dominate discourse as primary communication channels, it is imperative that health sectors, particularly the fields of public health, mental health, and traditional health care, pay attention to the prevalence and type of messages consumers are exposed to regarding health-centric topics like STIs to create modern, better- informed initiatives, resources, and avenues for intervention that target the heart of STI pandemics: stigma and misinformation. The following review of literature is purposed to inform the present content analysis by providing context and relevant background for the variables of interest: STI stigma, providers and STI stigma, social media, and HSV.

STI Stigma

Despite the global prevalence of STIs, they remain a group of highly stigmatized health conditions in many countries, including the United States (World Health Organization, 2023).

Per Goffman's (1986) groundbreaking theoretical framework of stigma, stigma is defined as the relationship between an attribute that deviates from a given norm, and the cultural stereotypes accompanied by that attribute. Those with deviations that are highly stereotyped are viewed by the non-deviants as worthy of less respect, with those possessing the deviant attribute rendered "spoiled" or tainted. The purpose of stigma has historically been for the protection and well-being of those living within a given system (Smith et al., 2008). Thus, stigma is a relational process of discrimination and oppression rooted in cultural and societal beliefs, with the purpose of avoiding threats to the well-being of the societal system and those living within it (Goffman, 1986; Smith et al., 2008).

The existence of STI stigma is complex and multi-faceted, often varying depending on cultural beliefs surrounding sex and illness. Common STI beliefs that contribute to the existence of STI-related stigma in the United States include shame for sexual activity, implied lasciviousness, poor hygiene or sexual safety practices, and religious persecution (e.g. STI as a punishment for sexual sin). Stigmatizing beliefs about STIs are often furthered by a lack of information or blatant misinformation regarding the prevention, spread, and treatment of STIs (Earnshaw et al., 2021; Rusley & Chan, 2022; Scheinfeld, 2021). STI stigma can be further compounded by other stigmatized social locations, such as gender, socioeconomic status, race, ethnicity, and sexual identity, leading some groups to be doubly impacted by the intersection of an STI diagnosis with other marginalized identities (Lichtenstein, 2004; Valentine, 2022).

STI Stigma Research

Research pertaining to STI stigma, testing, and diagnosis will often use “STIs” as an umbrella term to encompass multiple STIs, creating discrepancies between studies concerning which STIs are being researched. For example, a study from Thomas et al. (2022) examining STI testing intention in college students utilized eight different STIs as part of their measures, while Armenta et al. (2021) qualitatively discussed barriers to STI testing in reservation-based American Indians, referring only to HIV specifically with no other STIs being specifically referenced, instead defaulting to “STIs” to encompass any of the 29 other STIs aside from HIV. The lack of specificity within STI research, aside from HIV, indicates a need for research targeting specific STIs, especially since prevalence rates, incidence rates, and screening recommendations can differ between demographic groups and between STIs (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2021, 2024)

Since stigma is a multifaceted process that involves specific stereotypes of attributes perceived as deviant, STI stigma may need to be decentralized and more personalized to each specific STI. The process of stigma for HIV may differ from HSV related stigma, for example. Empirically, the idea of differing levels of stigma for different STIs is supported. For example, a study by Sanchez et al. (2023) examined how perceptions of STI status of hypothetical partners impacted how likely participants were to proceed with a sexual or romantic relationship with the hypothetical partner. Findings suggested that participants were less likely to move forward with any type of relationship with hypothetical partners testing positive for HSV, even when compared to those testing positive for HIV or partners who had never received any type of STI testing. Other studies have found differences in beliefs, attitudes, misconceptions, and stigma between STIs such as HIV, Hepatitis B, syphilis, and gonorrhea (Chitneni et al., 2024; Ndi, 2019; Reuter et al., 2018). Differing levels and processes of stigma between STIs could potentially indicate a need for interventions that are STI specific or tailored to each individual STI, and could offer a potential explanation for differing outcomes in STI interventions.

STI Stigma and BPSS Effects

STI stigma is important to understand and address because of the effects it can have on affected individuals. Per Engel's (1977) biopsychosocial (BPS) theory, later updated to the biopsychosocial-spiritual (BPSS) theory, the biological, psychological, social, and spiritual aspects of an individual are all interconnected and create a holistic definition of health (Mendenhall et al., 2021; Wright et al., 1996). STI related stigma, which may have its origins in social and spiritual beliefs, has been associated with poor mental and physical health outcomes, including delay or avoidance of seeking treatment for STI exposure or symptoms, avoidance of notifying sexual partners of exposure, poor self-image and embarrassment, and depressive symptoms (Earnshaw et al., 2021; Morris et al., 2014; Reeves et al., 2023; Scheinfeld, 2021; Thomas et al., 2022). The psychological and social outcomes resulting from STI stigma can result in biological outcomes due to delays in seeking services for diagnosis or treatment. STIs left undiagnosed and untreated may not only further exacerbate the spread of STIs, but can also lead to individual health consequences such as infertility, blindness, paralysis, cancer, and death (World Health Organization, 2019). Spiritual beliefs regarding sexual and physical health may further exacerbate delays in treatment or negative mental health effects, as individuals may be afraid to seek treatment or STI prevention due to fear of spiritual or religious consequences. Aside from any physical symptoms or outcomes resulting from an STI, the stigma alone is enough to result in adverse health outcomes physically, socially, emotionally, mentally, and spiritually.

STI Stigma Reduction

Education, policy changes, and open conversations regarding sex and STIs amongst populations like the LGBTQIA community and adolescents have been touted as potentially helpful for reducing STI related stigma. Educational classes mandated by law for middle and high school aged adolescents, policies like The Ryan White Care Act (i.e., increases access to treatment interventions for STIs), and conversations between providers and their patients promoting STI testing are some of the historically offered interventions for reducing stigma (Hover & Bertke, 2017; Relf et al., 2021; Thomas et al., 2022). Reducing STI stigma is an ongoing endeavor that necessitates exploring potentially helpful routes for education, conversation, and policy with the ability to reach a much larger audience than some of the traditionally utilized methods. Additionally, targeting stigma as a process may differ between different types of STIs, necessitating exploration of how stigma may be eliminated for each individual STI.

Providers and STI Stigma

For many people, testing, diagnosis, and treatment of STIs occurs via healthcare providers. Healthcare providers are often positioned to be one of the first people to know a patient has an STI, and the conversation a provider has with a newly diagnosed patient can perpetuate or abrogate stigma (Garcia et al., 2021; Stangl et al., 2019). Thus, the role of the healthcare provider in preventing adverse mental health outcomes caused by an STI diagnosis becomes vital. This can be complicated because the conversation a healthcare provider has with a patient is impacted by a variety of factors, including the STI-related education level of both the provider and the patient, the beliefs and values about STIs of the provider and patient, and the level of internalized stigma surrounding STIs of both provider and patient. Thus, how a patient responds to or discusses STIs with their provider is extremely subjective and influenced by both provider and patient factors.

Provider Factors

Provider factors that are important for patient wellbeing in general include empathy and knowledge of interpersonal communication theory (Bylund et al., 2012; Derksen et al., 2013). The patient-provider relationship is unique in that it knowingly demands both parties violate common practices in communication to better address patient concerns (Bylund et al., 2012). For example, individuals may not be willing to disclose their sexual or medical history to others they don't know on a subjectively determined personal level, but medical providers, who occupy a different type of relationship to the patient, ask for such intimate details of a person's history within the first fifteen minutes of meeting. This forced proximity between patient and provider requires a certain tactfulness and sensitive approach from providers to effectively establish a working relationship with the patient (Bylund et al., 2012; Derksen et al., 2013).

Such tact and sensitivity may be difficult for providers to apply when working with stigmatized topics like STIs, especially considering STIs disproportionately affect minoritized and/or stigmatized communities like gay and bisexual men, Black/African-American individuals, American Indian/Alaskan Native individuals, and youth of all demographics (Centers for Disease Control and Prevention, 2023). Providers are human and therefore subject to operate within the same beliefs, misconceptions, and biases as anyone else within a given culture. Researchers have consistently demonstrated that higher levels of implicit or explicit provider bias are associated with poorer patient outcomes, suggesting that improving patient care for heavily stigmatized topics like STIs is not only a question of improving patient care, but also provider insight and education (Hagiwara et al., 2019; Maina et al., 2018)

Provider Power and Medical Hierarchy

While providers are integral to STI prevention and treatment access, they are failing to initiate conversations about STI prevention and sexual practices, prompting encouragement for more provider education and training (Bonder et al., 2021; Coll et al., 2016; Einhorn et al., 2018; Ezhova et al., 2020; Fisher et al., 2018; Jahn et al., 2019; Pleasure et al., 2022). As gatekeepers to medical services and leaders within the healthcare system, providers hold more power within the patient-provider relationship, often taking on the role of the “expert” (Treichler et al., 2021). While collaborative and patient-centered models of care encourage providers to share power with patients, the power hierarchy inherent within the United States healthcare system necessitates providers to act as initiators of conversations regarding stigmatized topics as part of sharing power (Treichler et al., 2021; Ogden et al., 2017). To better equip and empower providers to initiate such conversations, education recommendations encompass sexual health specific topics, such as conception for women living with HIV, as well as population specific topics, such as STI prevention and sexuality in older adult populations (Coll et al., 2016; Ezhova et al., 2020).

Social Media

If patients are unable to discuss STIs with their providers, they may decide to turn to online sources of information with questionable credibility to seek answers, understand symptoms, or receive prevention recommendations (Mulgund et al., 2021). Online social networking sites, such as Instagram, X (formerly Twitter), and TikTok serve as prominent sources of both information and conversation on a wide variety of topics. Social networking sites, also collectively referred to as social media, are often readily available and easily accessible for both consumers and content creators from a variety of different communities, posing an appetizing option for disseminating information regarding highly stigmatized and controversial topics with the opportunity for access and content creation to be anonymous (Andalibi et al., 2018). However, social media can also act as a virtual garden for the growth of harmful and inaccurate information, necessitating management of the different messages surrounding topics, particularly health-centric topics, to prevent harm to consumers (World Health Organization, n.d.). Therefore, given the power social media platforms allot users to disseminate information quickly and across a global audience, understanding how social media impacts conversations regarding stigmatized health topics like STIs becomes abundantly important for public health.

Social Media in Medical Contexts

Forgie et al. (2021) created a diagrammatic framework of social media use in context of the patient provider relationship to better understand the intersection of patients' social determinants of health, social media benefits and challenges, and physician perspectives on social media that can be applied to STI information on social media. According to Forgie et al. (2021), social media can assist patients who have difficulty accessing medical care due to various social determinants of health with receiving medical information. However, social media access is not feasible for everyone, and several populations who may be at risk for STIs, such as older adults, individuals with lower socioeconomic status, and those with less education may not be able to access information online (Forgie et al., 2021). While social media has many potential benefits, such as fostering community, providing support, and creating avenues for accessible STI information, there are other challenges to social media that need to be addressed, such as the quality of information, privacy, and the potential for social media to reinforce certain stigmatizing narratives regarding STIs (Forgiet et al., 2021).

Research on Social Media as an STI Intervention

Prior literature examining the role of social media in the dissemination of STI related information supports both the potential for social media to positively impact users, and the simultaneous need for more social media research (Gabarron & Wynn, 2016). A systematic review from Yeh et al. (2022) concluded that STI services provided over the internet, such as education, advertisement, and testing, may provide similar outcomes as services delivered in a non-internet format. Other studies examining the efficacy of interventions delivered over social media support the findings from Yeh et al. (2022), but continue to either focus on HIV, men seeing men (MSM), or both (Argenyi & Kushalnagar, 2019; Cao et al., 2018). Research examining the intersection of social media and STIs other than HIV in a variety of populations is lacking. More research is needed to understand if all STIs, when present in a multitude of populations and subject to potential social exclusion via social media sites, involve the same type of discreditation, or if different STIs evoke stigma on social media in different ways. For example, efforts to reduce the impact of the United States HIV/AIDS epidemic from the 1980's to present day, including social media campaigns, may have contributed to reduced stigma surrounding HIV/AIDS, while other STIs that have not had decades of destigmatizing efforts may still be subject to more severe stigmatization (HIV.gov, 2023; Sanchez et al., 2023).

HSV Background

One persistently stigmatized STI warranting further study is the herpes simplex virus (HSV). HSV is a chronic STI that is estimated to affect over 3.7 billion people globally (World Health Organization, 2023). HSV most often affects the mouth or genitoanal regions but can present with a wide range of clinical manifestations in other tissues as well, including the eyes, brain, or spinal cord. HSV is spread through skin-to-skin contact, saliva, and genital fluids depending on site of infection. HSV is most often asymptomatic and can be transmitted whether symptoms are present or not. Those who do experience symptoms most often experience recurrent outbreaks of sores either orally or genitoanally. There are two strains of HSV: HSV-1, the most common strain of HSV and the most frequent cause of oral herpes symptoms such as cold sores, and HSV-2, the most common cause of genital herpes symptoms such as genital or anal sores (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2022a). It should be noted that although HSV-1 is associated with oral herpes and HSV-2 is associated with genital herpes, both strains can cause symptoms orally, genitoanally, or in other tissues.

HSV is incurable, but symptom severity and recurrence can be reduced with antiviral medications taken daily or at the onset of symptoms. Aside from symptom outbreaks, other risks from HSV infection include increased risk for acquiring HIV, potential rare complications such as infections of the brain or eyes, and the rare potential for pregnant women to expose infants to HSV during birth, resulting in neonatal HSV that can lead to severe disability or death for infants (World Health Organization, 2023). HSV is most often diagnosed via virologic testing of oral or genitoanal sores but may be tested for via blood test as well in the absence of symptoms. The CDC recommends against testing the general population for HSV 1 & 2 via blood test for diagnostic purposes in the absence of lesions due to the propensity of blood tests to provide inaccurate results (National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2022b).

HSV and Stigma

For many, the mental health effects of an HSV diagnosis resulting from the high level of stigma surrounding the infection is far worse than the infection itself. Stigma, particularly HSV-specific stigma, is a social-exclusion process due to a biological illness, resulting in distressing mental health effects, and potentially impaired social functioning, involving all BPSS aspects of health. For example, Rosenthal et al. (2006) found that there may be differences in the psychological impacts of an HSV diagnosis depending on whether a person is asymptomatic or symptomatic, noting that amongst newly diagnosed asymptomatic individuals, fear of rejection, shame, and anger were the most commonly endorsed social and psychological impacts. Foster and Byers (2016) studied the sexual well-being of patients diagnosed with HSV or human papilloma virus (HPV) and discovered that the most important predictor of sexual wellbeing was experiences with stigmatization and the extent to which patients internalized stigmatizing beliefs.

Providers and HSV

For providers working with individuals who have recently or previously received an HSV diagnosis, understanding the implications of diagnosis is important for providing for all BPSS aspects of a patient’s health and for preventing further transmission. Given that providers demonstrate difficulty with initiating conversations about stigmatized topics, how a provider discusses HSV, including their knowledge level and effectiveness in communicating without increasing stigma, can have massive public health implications. For example, Romanowski et al. (2008) discovered that not only did both providers and patients underestimate the risk of asymptomatic transmission, but there were also huge gaps in communication between providers and patients regarding HSV, including discussions about antiviral therapy. If providers are not discussing ways HSV positive patients can reduce outbreaks and transmission to others, patients may utilize other sources, like social media sites, to receive information.

Study Aims and Purpose

The aim of the present study was to understand HSV related stigma on social media to better inform care within the patient-provider relationship. HSV was chosen over other STIs due to the need for more empirical support, the wide prevalence, and the high level of HSV-related stigma already present in the United States. Researchers sought to qualitatively describe HSV-related themes of social media posts and comments sections to understand the messages patients may be receiving about HSV on social media sites. The goal of the present study is to inform provider practice and public health initiatives of HSV stigma.

Methods

Data Source

X, formerly known as Twitter, was selected as the source for social media content due to the advanced search options available to search content for specific terms and phrases, transparent engagement statistics for posts and comments, and primarily text-based form of content. A text-based content source was chosen over video or image centric platforms due to the ease of access to literal meaning of posts and comments, and to better understand conversations as opposed to reactions to videos and images. Two independent coders created new accounts that had never been used to interact with or create content on X, to prevent skewing of results via the algorithm X employs to personalize search results based on user preferences and history. Four searches were completed utilizing the advanced search option and are depicted in Table 1. Two search terms, "herpes" and "herpes simplex", were each searched twice during two separate two-week time windows for a total of 200 unique posts coded. The search terms were selected to encompass both short and long form names for HSV.

Table 1

Search Descriptions

Search Term	Search Box Used for Search Term	Exclusions	Time Window Start	Time Window End	Number of Posts Coded
Herpes	"All of These Words"	English Only	2/1/24	2/14/24	50

Herpes	"All of These Words"	English Only	4/1/24	4/14/24	50
Herpes Simplex	"Exact Phrase"	English Only	2/1/24	2/14/24	50
Herpes Simplex	"Exact Phrase"	English Only	4/1/24	4/14/24	50

Data Coding

Two independent coders performed a content analysis utilizing the constant comparative method (CCM) of qualitative data analysis (Corbin & Strauss, 2014; Strauss, 1987). Data for each initial search was collected in Excel spreadsheets, with each coder ending with a total of four spreadsheets, one for each search. Initial independent data collection included multiple data points organized into four different categories: post analytics, post engagement, original post message and relationship to HSV, and comments message and relationship to HSV. Further breakdown of specific data included in each category and the purpose of inclusion is presented in Table 2. Objective data categories, including the post analytics and engagement categories, included data points that are not open to interpretation. Subjective data categories, including the original post message and relationship to HSV and comments message and relationship to HSV categories, included data points demanding interpretation of each data coder. For subjective data points, vague, working definitions of the data points were discussed by the coders prior to independent coding, but were left free to interpretation to better model how consumers might interpret posts. Demographic data concerning who created original posts and who commented on each post was not collected, as the purpose of the present study was to assess for the presence and characteristics of conversation as opposed to assessing who was facilitating or contributing to the conversation.

Table 2

Details of Initial Coding Data Categories

	Objective or Subjective Data	**Data Points**	**Purpose**
Post Analytics	Objective	1. Result Number 2. Why the post was pulled into the search (i.e. search term mentioned in text or link, etc.) 3. Image of post at time of analysis 4. Image of first comments at time of analysis 5. Date and time of original post 6. Date and time post was analyzed 7. Type of post content (i.e. text, image, repost, reply to a post, gif, link to external site, etc.)	1. Placement in the search results 2. Aspect of the post leading to it being pulled into each search 3. An image of the post at the time of analysis allowed coders to return to the post to discuss discrepancies 4. An image of the comments at the time of analysis allowed researchers to understand what comments were present during analysis 5. The date and time of the original post was included to record when the post was originally created 6. Date and time of analysis was recorded to account for how objective data about the post may change over time, as post engagement is in flux 7. Record how the message of the post was being conveyed to assess for trends between engagement and post type, as well as to assess how HSV conversations were being held
Post Engagement	Objective	1. Number of Comments 2. Number of Likes 3. Number of Reposts	1. Numbers 1-3 indicate active engagement with posts

		4. Number of Views	2. Number 4 indicates passive engagement with posts
Original Post Message and Relationship to HSV	Subjective	1. Category of post content (i.e. education with or without citations, insult, political, discussion, opinion, etc.) 2. Main message of the original post 3. Relationship of the main message of the original post to HSV (i.e. HSV positive, negative, neutral, ambiguous)	1. How each coder would categorize the original post content; posts allowed to inhabit more than one category 2. Understand the main message each post was conveying 3. Understand how each post related to HSV
Comments Message and Relationship to HSV	Subjective	1. Summary of the discussion within the first fifty comments 2. Relationship of the discussion in the comments section to HSV (i.e. HSV positive, negative, neutral, ambiguous)	1. Provide a concise description of the discussion happening concerning the original post 2. Understand how the comments section of each post related to HSV (overall)

Both coders began with the "herpes" February search, followed by the "herpes simplex" February search, continuing with the "herpes" April search, and ending with the "herpes simplex" April search. Once all data was collected by both coders, Coder 1 compiled the results of each search into a single spread sheet, totaling four combined spreadsheets. The combined spreadsheets were color coded to indicate whether the consensus between both coders for the main message and comments sections for each post was herpes neutral, herpes positive, or herpes negative. An additional color was utilized to indicate contention between each coder, suggesting differing opinions of the relationship post messages and/or comments had to HSV. Occasionally the search results differed, resulting in each coder having slight variation in the posts coded. With discrepancies, the posts from the search completed by Coder 2 were coded by Coder 1 prior to Coder 1 viewing Coder 2's coding, until fifty posts completed by both coders were compiled.

Additionally, in the combined spreadsheets, the average number of likes, comments, views, and reposts were compiled using the average function within Excel to generate the average number of post engagement for each search. Only posts that were coded by both coders within the original search time frames were utilized in compiling final averages and data results.

Coder Trustworthiness

Per Guba (1981) and Lincoln and Guba (1985), both coders followed four criteria to maintain trustworthiness in qualitative coding: credibility, transferability, dependability, and confirmability.

Credibility. To promote credibility, or congruence with reality, coders utilized methods outlined by Guba (1981), including triangulation, persistent observation, and prolonged engagement with content. Prior to coding, both coders discussed their own backgrounds and histories with the subject matter (HSV) to better contextualize each of their perspectives on the content. Additionally, once coding was finished, coders met once again to discuss their own findings, including how their individual contexts shaped coding. Multiple types of data were collected on each post and comment section, including each coder's reaction to and interpretation of observed content. Each coder spent hours of time reviewing content, exposing each coder to a significant amount of material and further familiarizing coders with HSV related discussion, beliefs, and ideas.

Transferability. Part of the rationale behind conducting four different searches within two different time windows was to increase transferability, or the ability of findings to be transferred to different contexts (Lincoln & Guba, 1985). Originally, both coders agreed to only two searches, one search for each search frame. However, after completing the original two searches, both coders agreed that another search window was needed due to the prevalence of cultural and context-specific HSV-related material to see if coding results were consistent across different time frames. Additionally, the point of examining both post and comment section material was to develop a “thick description” of the context surrounding HSV-related content (Guba, 1981).

Dependability. To create a data set that was dependable, or stable, stepwise regulation and the creation of an audit trail were utilized (Gupta, 1981). While both coders coded content independently, they regularly checked in with each other about the coding process, including ensuring all elements of the data were included for every piece of content, via text message and video conferencing. Both coders were aware that while both should journal their thoughts and interpretations freely, other authors of the manuscript may view the coding sheets at any given time. Additionally, during the final discussion of combined coding results, both researchers discussed how their own personal contexts may have influenced their coding.

Confirmability. Following the definitions of confirmability in Gupta (1981) and Lincoln and Gupta (1985), both coders acknowledged that neutrality was not possible with the subjective interpretation of social media content. Instead, both coders aimed to be transparent about how their contexts and identities may have biased their own interpretations of the data, deciding to disclose their various locations that may be relevant to how they interpreted data. Coder 1 (AB) identifies as a white, heterosexual, cisgender female in her late twenties from a middle-class socioeconomic status, and as of the writing of this article is currently finishing her doctoral degree in medical family therapy. Coder 1 is HSV-2 positive and has known her status since September of 2023. Due to Coder 1's STI status and area of research, Coder 1 would describe herself as having extensive knowledge of STIs, knowledge that began with abstinence-based curriculum received during her formative years in the late 2000's, developing slowly over the span of nearly 20 years and only peaking when diagnosed with an STI during her doctoral coursework. Coder 2 (GA) identifies as a white, bisexual, cisgender female in her early twenties from an upper middle-class socioeconomic status, and as of her participation in the data collection of the present study is completing her master's degree in marriage and family therapy. Coder 2 is unaware of her HSV status and describes herself as having moderate knowledge of STIs and having been predominantly exposed to abstinence only sex education.

Results

Post Analytics and Engagement

All 200 posts were included in each search due to the search term being included in the text of the post itself, as opposed to account names or hashtags. The order of posts differed slightly for each coder, with some posts of each given search being included in the top fifty results for one coder but not the other, and vice versa. While all posts included text, most posts also included other types of content, such as post content from other users via replies or reposts, links to external sources, and images.

Average post engagement statistics (likes, comments, views, and reposts) are depicted in Table 3. The number of comments, likes, and reposts indicate active engagement with each post beyond passive engagement (viewing). Each of the "herpes" searches generated more post engagement alone than the two "herpes simplex" searches combined. The largest active engagement average for every search was the average likes, but even the largest active engagement numbers paled in comparison to passive engagement for every search: February "herpes" average likes represented .42% of the average views, April "herpes" average likes represented 1.50% of the average views, February "herpes simplex" average likes represented .92% of the average views, and April "herpes simplex" average likes represented .57% of the average views. This indicates that for all four HSV-related searches, less than 2% of those viewing the post will interact with it using active engagement methods, such as likes.

Table 3

Post Engagement Averages

Search Term	Search Window	Avg. Likes	Avg. Comments	Avg. Views	Avg. Reposts
Herpes	2/1/24 - 2/14/24	47.12	7.88	11274.66	13.10
Herpes	4/1/24 - 4/14/24	91.16	4.46	6097.35	16.48
Herpes Simplex	2/1/24 - 2/14/24	12.34	1.12	1345.32	3.22
Herpes Simplex	4/1/24 - 4/14/24	28.2	1.88	4932.08	6.9
TOTAL AVG	N/A	44.71	3.84	5912.35	9.93

Post Message Relationship to HSV

Coding Results

Table 4 provides a summary of the combined coding of all posts for each search regarding the relationship of the main message of the post to HSV. Half of all posts were coded differently between coders, meaning each coder chose a different category than the other coder for that particular post. The search resulting in the most contention about how the main message related to HSV was the April “herpes simplex” search, with 84% of posts being coded differently between coders, followed by the February “herpes simplex” search with 58% of posts in contention. The two “herpes simplex” searches boasted significantly higher rates of contention between coders than the two “herpes” searches combined. The second highest category amongst all posts was herpes negative, with 36.5% of total posts agreed upon as negative by both coders. Herpes negative messaging disproportionately dominated the two “herpes” searches in comparison to the two “herpes simplex” searches. The incidence of herpes negative posts in the “herpes” search with the lowest percentage of herpes negative posts (54%) was still 5.4 times higher in herpes negative occurrence than the “herpes simplex” search highest in herpes negative messaging (10%).

Table 4

Post Message Relationship to HSV

Search Term	**Search Window**	**HSV Positive**	**HSV Negative**	**HSV Neutral**	**Contended**
Herpes	2/1/24 - 2/14/24	1/50 = 2%	27/50 = 54%	5/50 = 10%	17/50 = 34%
Herpes	4/1/24 - 4/14/24	0/50 = 0%	37/50 = 74%	1/50 = 2%	12/50 = 24%
Herpes Simplex	2/1/24 - 2/14/24	0/50 = 0%	5/50 = 10%	16/50 = 32%	29/50 = 58%
Herpes Simplex	4/1/24 - 4/14/24	0/50 = 0%	4/50 = 8%	4/50 = 8%	42/50 = 84%
TOTAL	N/A	1/200 = .5%	73/200 = 36.5%	26/200 = 13%	100/200 = 50%

Thirteen percent of all posts were coded as herpes neutral between both coders, with the February “herpes simplex” search having the highest occurrence of herpes neutral coded messaging (32%). Only a single post was coded as herpes positive for both coders in all 200 posts.

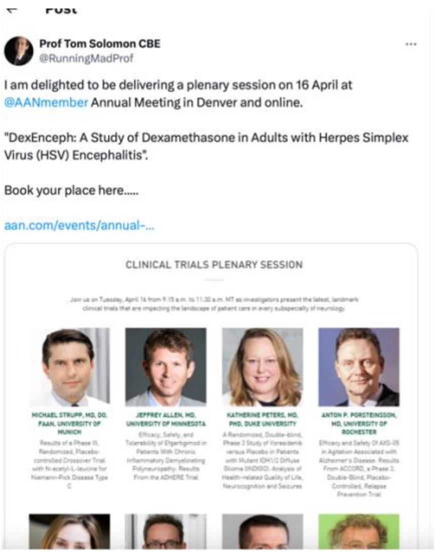
Themes

Themes Between Searches. There were differences in post messaging between the searches conducted with the term “herpes” and those conducted with “herpes simplex.” The search results for the “herpes” searches were much more pop-culture, entertainment, and current events oriented, whereas the two “herpes simplex” searches yielded results that were more scientific, such as links to external articles or responses to diagnostic challenges posted by others. While facts, scientific data, and education regarding HSV symptomology, prevention, treatment, and diagnosis were present in both searches, albeit with greater frequency in the "herpes simplex" searches, there was an overall lack of empirical evidence or citation provided to back up claims and literature, with external links to what appeared to be scientific articles often being difficult to judge for quality of information. Several posts across all four searches blatantly stated misinformation as fact, such as stating that HSV is a bacterial infection, insinuating that an allergy to HSV is what caused oral symptoms, and assertions that HSV is curable. In addition to being of questionable quality, many of the scientifically oriented posts concerned the intersection of HSV with other topics, such as Alzheimer's disease, cancer, and various vaccinations, suggesting that HSV-related social media content may have implications for other health topics.

Themes in Post Messaging. Examples of HSV negative, neutral, positive and contended post messages are included in Table 5. Among posts that were not contended, herpes negative messaging was the most coded of all 200 posts, occurring almost 3 times as often as neutral posts and 73 times as often as positive posts. Common themes among herpes negative coded posts included using HSV as an insult to public figures, including political, entertainment, and sports figures, as well as denouncing those who are HSV positive as disgusting, lascivious, and dirty. Additionally, negatively coded posts exhibited strong themes of racism and sexism, with posts such as "herpes is the white people std" and "safe to say she has herpes." The overall lack of posts where both coders concurred the message was herpes positive indicates a need for more positive information that reduces stigma to balance the negative information present in HSV related posts. Furthermore, of all two-hundred posts, only one post consisted of someone personally disclosing being HSV positive, with the disclosure being made anonymously through an account that posts anonymously submitted "confessions."

Table 5

Examples of Post Messaging Coding

	Examples From "herpes simplex" Search	Examples From "herpes" Search
HSV Negative	 **Slave Kun fayakũn** @JOnyilofor How can you pick up a prostitute from Figueroa street Los Angeles CA and sleep with her without condom? Some men are really mad!!! What a risky behavior. I hope your enjoying your herpes simplex virus now. This is exactly what you deserve for such risky enjoyment. 3:00 PM · Apr 11, 2024 · **1,349** Views 1	 **Tracey Taylor London** @traytaymakeup This woman is like a scorching case of herpes. She pops up periodically to bend the knee and suck the mushroom **Kelly Loeffler** @KLoeffler · Apr 11 President Trump has my full support - and the support of thousands of Georgians who are fed up with Bidenflation, open borders, and utter chaos. It's really that simple. 4:47 PM · Apr 12, 2024 · **749** Views 8 2 23
HSV Neutral	 **Prof Tom Solomon CBE** @RunningMadProf I am delighted to be delivering a plenary session on 16 April at @AANmember Annual Meeting in Denver and online. "DexEnceph: A Study of Dexamethasone in Adults with Herpes Simplex Virus (HSV) Encephalitis". Book your place here..... aan.com/events/annual-... CLINICAL TRIALS PLENARY SESSION Join us on Tuesday, April 16 from 9:15 a.m. to 11:30 a.m. MT as investigators present the latest, landmark clinical trials that are impacting the landscape of patient care in every subspecialty of neurology. MICHAEL STRUPP, MD, DO, FAAN, UNIVERSITY OF MUNICH Results of a Phase III, Randomized, Placebo-controlled Crossover Trial with N-acetyl-L-leucine for Niemann-Pick Disease Type C JEFFREY ALLEN, MD, UNIVERSITY OF MINNESOTA Efficacy, Safety, and Tolerability of Efgartigimod in Patients With Chronic Inflammatory Demyelinating Polyneuropathy: Results From the ADHERE Trial KATHERINE PETERS, MD, PHD, DUKE UNIVERSITY A Randomized, Double-blind, Phase 3 Study of Vorasidenib versus Placebo in Patients with Mutant IDH1/2 Diffuse Glioma (INDIGO): Analysis of Health-related Quality of Life, Neurocognition and Seizures ANTON P. PORSTEINSSON, MD, UNIVERSITY OF ROCHESTER Efficacy and Safety Of AXS-05 in Agitation Associated with Alzheimer's Disease: Results From ACCORD, a Phase 3, Double-Blind, Placebo-Controlled, Relapse Prevention Trial	 **Victor** @himbo_chico 1. Almost 70% of the population has Herpes. you probably have it. it so common doctors dont test for it in routine STI panels. I literally had to ARGUE with my doctor to get her to test me for it [without having symptoms] 2. You cant catch herpes like that Unpopular opinions (Uncensored **DGIRL THE** @doughgirldime · Feb 12 Idk I just wouldn't let anybody with herpes hug on me like this sorry not sorry x.com/hoodg3nius/sta... 4:11 PM · Feb 12, 2024 · **10.3K** Views 5 24 129 4

HSV Positive	N/A (No posts were coded as HSV positive in the “herpes simplex” searches)	 Thee Anime Guru Momocon @aprettyPR Herpes ruins lives? That's why we know you're uneducated and destigmatizing STDs is important so ppl aren't afraid to get tested and be honest about their status. There is a 100% chance you've been around ppl with herpes bc of how common it is. Which you would also know if you were more educated on the matter x.com/doughgirldime/... You're unable to view this Post because this account owner limits who can view their Posts. Learn more 5:24 PM · Feb 12, 2024 · **2,447** Views 3 11 22 2
Contended	 Sephania pius kasanga @Sephaniakasanga Risk Factors of cancer of cervix • Sexually Transmitted Infections o Human Papilloma Virus (HPV) Types 16, 18 o Herpes Simplex Virus (HSV) • Early age at first sexual intercourse • Multiple sexual partners (both M&F • Intercourse with uncircumcised male partner 4:03 PM · Apr 4, 2024 · **141** Views 1 1 1	 tytybronx2harlem @tytybronx2har Black women just don't care about gaydar no more. Or herpes. Down bad. Ashley White | Chicago Esthetician @skinclasshero · Feb 11 They'd have to pry Usher's wee wee out my mouth with wire cutters. 11:01 PM · Feb 12, 2024 · **6,462** Views 5 6 30 3

Between Coder Differences. Half of all posts were contended, meaning that there were differences in how coders coded the post content in relation to HSV, with the “herpes simplex” searched displaying the most contention. The higher levels of contention between coders present in the “herpes simplex” searches can be explained by the higher level of scientific information when compared to the “herpes” searches. Upon further discussion, both coders realized that their interpretation of scientific facts and data related to HSV stigma differed due to prior knowledge of HSV and HSV status. Coder 1, who is HSV-2 positive and has both personal and educational experience with HSV, coded scientific facts and findings as herpes neutral, while Coder 2, who does not know her HSV status and has not had HSV specific education, expressed facts and findings to be stigmatizing and fear-inducing.

Comment Section Relationship to HSV

Coding Results

Table 5 provides a summary of the combined coding of all posts for each search regarding the relationship of the comments section of each post to HSV. Only 52.5% of all posts contained a comments section at all. With the average comment section consisting of nearly four comments for all two hundred posts (see Table 3), there were approximately 800 comments that were reviewed in conjunction with the 200 original posts. Of the posts containing a comments section, 48.57% were coded differently between coders, nearly matching the 50% contention rate for post messages. Of the comments not under contention, 28.57% were coded as herpes negative and 20.95% were coded as herpes neutral. Additionally, there was a higher percentage, albeit still a low percentage, of herpes positive coded comments at 1.90%. While disparities in coding between the non-contented comments section messages still exist, the coding is more evenly distributed for the comments sections than it was for the relationship of the post messages to HSV. This is likely due to the contextual nature of how HSV is referenced in posts. For example, a search result utilizing HSV as an insult of a public figure (herpes negative) may yield a herpes neutral comment section, as commenters are more likely to discuss the subject of the HSV-related insult as opposed to HSV itself.

The two “herpes” searches yielded higher percentages of comments coded as herpes negative than the two “herpes simplex” searches, similarly to the coding of the post main messages. Additionally, the two “herpes simplex” searches had higher percentages of comment sections coded as herpes neutral than the two “herpes” searches. The only search yielding herpes positive comment sections was the February “herpes” search. Both comment sections that were coded as herpes positive were attributed to the same account posting on each of the two posts with misinformation correction that served to destigmatize HSV. However, it should be noted that both herpes positive comment sections were providing destigmatizing information without citations or empirical evidence.

In terms of post engagement, the two “herpes” searches continued to exhibit higher levels of active engagement indicators that the two “herpes simplex” searches via higher percentages of posts containing comments, demonstrating consistency with “herpes” searches resulting in more active engagement. The April “herpes” search boasted the lowest percentage of posts containing comments sections between the two “herpes” searches at 68%, which was still 1.89 times higher than either of the “herpes simplex” searches at 36% of posts containing comments section for each search. Interestingly, both “herpes” searches and both “herpes simplex” searches yielded similar percentages of posts containing comments between the two time frames for each search term, indicating that comment section results may be transferrable between differing time frames.

Table 6

Comment Section Relationship to HSV

Search Term	**Search Window**	**Number of Posts with Comments**	**HSV Positive**	**HSV Negative**	**HSV Neutral**	**Contended**
Herpes	2/1/24 - 2/14/24	35/50 = 70%	2/35 = 5.71%	9/35 = 25.7%	4/35 = 11.42%	20/35 = 57.14%
Herpes	4/1/24 - 4/14/24	34/50 = 68%	0/34 = 0%	18/34 = 52.94%	5/34 = 14.71%	11/34 = 32.35%
Herpes Simplex	2/1/24 - 2/14/24	18/50 = 36%	0/18 = 0%	2/18 = 11.11%	7/18 = 38.89%	9/18 = 50%
Herpes Simplex	4/1/24 - 4/14/24	18/50 = 36%	0/18 = 0%	1/18 = 5.56%	6/18 = 33.33%	11/18 = 61.11%
TOTAL	N/A	105/200 = 52.5%	2/105 = 1.90%	30/105 = 28.57%	22/105 = 20.95%	51/105 = 48.57%

Themes

Themes Between Searches. While the original posts had significant differences in post content between searches, the comment sections were a bit more evenly distributed in terms of the content contained within comment sections. Similarly to original post content, the comment sections of the two “herpes simplex” searches contained more scientifically oriented comments, as many comments were utilized as tools for the original post creators to elaborate on scientifically-oriented posts, or for others to post related scientific content. In contrast, the comment sections of the two “herpes” searches contained more emotionally or socially oriented reactions, such as laughter, judgment of the post creator’s content, or commenters expressing agreement with the original post creator’s sentiments.

Themes in Comment Section Messaging. Examples of HSV negative, neutral, positive, and contended comment section messages are included in Table 7. Of the comment sections coded as herpes negative, many continued to build on HSV-related negativity originating in the original post by either adding further negative comments or expressing agreement with HSV-negative sentiments. While there were plenty of comments further discrediting or stigmatizing those who are HSV-positive, and even two comment sections considered destigmatizing, there were no comments of the approximately 800 reviewed consisting of a personal HSV disclosure. However, there were a handful of comments where users disclosed experiences with others who were HSV positive, but many were careful to clarify they were not HSV positive themselves. The lack of personal disclosures indicates that HSV-related stigma on social media could be a potentially silencing narratives of individuals who are HSV-positive.

A theme for the comment sections coded as herpes neutral was the propensity for users in neutrally coded comment sections to ask for clarification, express confusion, or attempt to discuss what HSV related information they knew in relation to the original post. For example, a post accusing an entertainment figure of spreading HSV to black women resulted in a comment section coded as herpes neutral, as commenters shared there is no way to know who HSV was transmitted by and that the link that was shared in the original post was “shady,” or untrustworthy. This was coded as herpes neutral rather than herpes positive because while such a comment potentially corrects misinformation (no citation was provided), the context and other comments present in the same section neutralize the potentially positive comment by neither reducing or propagating HSV-related stigma.

Table 7

Examples of Comment Section Messaging Coding

	Examples From “herpes simplex” Search	**Examples From “herpes” Search**
HSV Negative	 **Paul Kimotho** @PaulKimotho13 · Apr 4 This is juju 😃 **Moses Jacksonville** @MosesJacksonvi1 · Apr 4 This same mouth you dey use pray to God naim you go use dey do oral.... Pleasure while it lasts.... **GoodnessOlayiwola** @Golden_Goodness · Apr 4 Jeeeesus Christ 😳 omoh this bad 🤦 **@Bumty** @mickmuller57611 · Apr 4 Pleasure, pleasure........... pressure! 	 **Sourmouth** @sourmouth100 · Apr 12 Lmao 🤣 ayo does he really have Herpes though!? **itsmyopinonokay** @myopinionokay_ · Apr 12 He has sex with so many whores he probably does Show replies **ConMan Gesundheit** @Gesundheit1111 · Apr 12 How do you know he spreads herpes? He pump and dump you or something? **itsmyopinonokay** @myopinionokay_ · Apr 12 🤮🤮 do you think I’ll let that monkey look alike nerd anywhere near me ??? **WeThePeople** @WeThePeopleX47 · Apr 12 I bet you’re ugly. **fuccbatman** @iknowitallbtc · Apr 12 That defamation you’re asking to be sued **itsmyopinonokay** @myopinionokay_ · Apr 12 That nigga ain’t gonna do shit

HSV **Neutral**	 **Ola not mide** @olacuteTunes · Feb 12 How true is it that this can be transmited and become an untreatable herpes? **Child HealthHero** @ChildHealthhero · Feb 12 Herpes infections are incurable, Antiviral medications are commonly prescribed to help speed up healing during outbreaks, lessen the severity of symptoms, and reduce the likelihood of future outbreaks. The medications are most effective when taken at the first sign of symptoms **Mayjorrity** @SirThosine · Feb 12 I always thought it's malaria oo **Child HealthHero** @ChildHealthhero · Feb 12 Not really, it's sometimes reactivated by a weakened immune system, so opportunistic infections can also occur **Mayjorrity** @SirThosine · Feb 12 😩😩😩, i learn another thing today, thanks to you **Digital Rev'd** @FanenBashi · Feb 12 Book no go kill me, abek	 **BTowne** @blaino70 · Feb 12 Im confused as to what to think about this. 🤷‍♂️ **Bunny** @BunnyConrad75 · Feb 12 I am too. But thanks to keyboards I almost spelled the wrong word **BTowne** @blaino70 · Feb 12 😂
HSV **Positive**	N/A (No HSV positive comments present in any "herpes simplex" searches)	 **Jo** @Jo09072005 · Feb 13 So you're terrified of 80% of America **Lilian Gee** @GeeLilian88924 · Feb 13 HSV is not a blood disease and therefore, individuals who carry the virus can test negative (false negative) with a PCR blood test since the HSV is not always present in the blood as HSV lives in the nervous system by @DrUyi2 he also cured differents types of disease
Contended	 **Martin Luther Prince Jr.** @Kaita26_27 · Apr 1 It is a sexually transmitted infection. It is often spread by skin-to-skin contact during sexual activity. Especially for those that are fond of putting penises/vaginas in their mouth.	 **N C** @LibraWife2010 · Feb 13 Sad she knew and didn't say anything. Ppl have it their whole lives and never know. **Larry Garner** @BedStuyJamaica · Feb 14 Only ting I can think of is you been had it and didn't know but you should've seein signs of it **Nova** @NomiMalone202 · Feb 14 She either not getting checked like you think or she gave it to you and didn't think you'd get checked yourself **Aerline** @Mari55430517 · Feb 14 Better question how often do YOU, get check ups? Seems like you were reliant on her to cover you, physical health when YOU are only responsible for that! **Uptown Yasuke'** @pythondalova · Feb 13 Sherlock you know exactly what it is. If you don't want to confront her move on. You know exactly what's up **Let'sBeClear** @MiDailyFix · Feb 13 Saying you "discovered" leads me to think it's definitely you and your not telling us the whole truth.

Between Coder Differences. Akin to the original post main messages, much of the contention present in the comments section coding was due to the differing opinions between coders of scientific data as sources of HSV-related stigma. Many comments, particularly those in the "herpes simplex" searches, consisted of original post authors elaborating on their posts with more scientific information, often presented as fact without citations or outside sources, leading to differences in coding per interpretive differences of HSV-related scientific data. Additionally, differences existed between coders in terms of how negativity expressed in the comments of HSV-related posts related to HSV. For example, the comment section of a post utilizing HSV to insult a political figure often elicited further insults to the political figure unrelated to HSV, which Coder 2 interpreted as stigmatizing to HSV for building off an HSV-related insult, and Coder 1 interpreted as neutral to HSV since further insults present in the comments did not mention HSV directly. Coders discussed the difference between them pertaining to comments not directly relating to HSV as a result of differing attitudes towards HSV: Coder 2, who does not know her HSV status, felt that HSV stigma or negativity was contagious, spreading from post content to associated comments, while Coder 1, who is HSV-2 positive, examined comments with more separation from post content.

Discussion and Implications

The results of this content analysis of HSV-related discussion on X suggests that not only is HSV stigma prevalent on social media, but that content varies widely and is subject to interpretation based on the background and intersectional identities of each consumer. Despite the wide variation in HSV-related content and discussion, there is a marked lack of HSV positive content on X, including content that is destigmatizing, empowering, or normalizing. Additionally, the high level of negativity, nearly non-existent incidence of personal disclosure of

HSV-positive status, and low level of content searching for or correcting misinformation in both posts and comments demonstrates that social media may be propagating HSV stigma, both through original posts and discussion. While the reach of posts is high with average views for each post at nearly 6000, the low ratio of active engagement with posts compared to the amount of people passively viewing posts warrants further exploration, as users may be hesitant or unwilling to interact with posts for fear of stigma and to preserve anonymity when searching for HSV-related information (Andalibit et al., 2018).

Nearly 50% of all posts and comment sections were coded as under contention with differences between coders, highlighting the importance of destigmatizing HSV in ways that make sense to different populations. For example, while scientific facts, data, and images may be destigmatizing and normalizing to some, they may be further stigmatizing and fear inducing for others. Considering that STI incidence and prevalence varies between different populations, understanding how STI stigma manifests in different populations may be prudent for correcting misinformation and disseminating HSV positive content that is also intentional in alleviating disparities (Centers for Disease Control and Prevention, 2023; Lichtenstein, 2004; National Center for HIV, Viral Hepatitis, STD, and TB Prevention, 2021, 2022).

Clinical and Public Health Implications

Providers seeking to discuss HSV with patients should be cognizant not only of the type of messages patients are exposed to on social media sites, but also reputable resources to provide to patients to increase health literacy without exposing patients, particularly vulnerable, newly diagnosed patients, to stigmatizing messages. Additionally, providers should aim to be cognizant of their own internal beliefs and biases regarding HSV to avoid communicating with patients about HSV in a stigmatizing way, as stigmatizing communication between patient and provider may further discourage patients from seeking care, disclosing status or sexual practices to providers and sexual partners, and result in further adverse outcomes (Garcia et al., 2021; Hagiwara et al., 2019; Maina et al., 2018; Stangl et al., 2019).

Providers who do not acknowledge and utilize social media in their patient interactions are competing with the breadth, accessibility, and questionable quality of HSV-related information available to patients on social media platforms. Providers should arm themselves with an understanding of how patients are utilizing social media, and how social media reflects societal beliefs concerning STIs like HSV, prior to initiating conversations about STIs. The presence of HSV conversation and information on social media should not dissuade providers from speaking with patients, but rather demonstrate how necessary it is for trained professionals to improve patients' health literacy, including equipping patients with resources, tools, and tactics (Bonder et al., 2021; Coll et al., 2016; Einhorn et al., 2018; Ezhova et al., 2020; Fisher et al., 2018; Jahn et al., 2019; Pleasure et al., 2022). Per Forgie et al.'s (2021) framework for social media in context of the patient provider relationship, providers seeking to engage in conversation about social media with patients should be open to discussing social media, engage in social media conversations themselves, collect social media resources pertaining to STIs, and provide patients with accurate information that can be used to evaluate information patients may see online.

Public health initiatives aimed at reducing the transmission of HSV, or negative effects of HSV in already-positive individuals, should seek to increase the ratio of positive to negative content, correct misinformation, and increase education levels of HSV-specific information, including normalizing HSV-positive persons as continuing to have healthy sex lives. While there was a significant amount of information related to HSV present, including scientifically oriented posts and discussion, the quality of information was difficult to discern. Public health initiatives should account for the average education level, including level of sex education, consumers may have when creating content for social media platforms.

Limitations and Future Directions

The present study had several limitations, with implications for future research. The first major limitation was the use of only two coders who were similar in several demographic features. Due to the highly subjective nature of social media content, future studies examining HSV-related social media content should seek to utilize more coders from diverse backgrounds, including coders with a variety of HSV statuses and levels of sex education. Exploring interpretation of social media posts in the personal context of each user would better inform how social media can be used in public health campaigns seeking to prevent, destigmatize, and normalize HSV, in addition to informing how clinicians may seek to better care for different populations. Another limitation was the exclusion of posts that were not in English. Future studies should seek to replicate the present study in non-English speaking populations, both within the United States and on a global scale.

A significant limitation of the current study was the use of a very vague working definition of post and comment relationships to HSV. While creating room for subjective interpretation within the coding process provided insight into how intersectional identities inform the decisions of each independent coder, utilizing a more standardized definition of each type of message content could be beneficial. By replicating the present study with a more standardized definition of each type of post content, a common working language could be created with which to categorize and analyze data on stigmatized health topics. Creating such a language could further inform public health policies and clinical practices by allowing for the creation of manualized or systematic intervention protocols that more readily identify content that may be helpful or harmful.

The current study briefly examined differences in passive and active engagement, but findings suggest that further research may be warranted, especially considering the empirically validated, negative effects stigma has on the propensity for individuals to discuss STIs with others (Earnshaw et al., 2021; Rusley & Chan, 2022; Scheinfeld, 2021). Future research should aim to understand driving factors or characteristics leading to active engagement, as well as how active and passive engagement affect consumers. For example, a study could aim to examine if active engagement with HSV-related social media content was associated with less HSV-related shame and more help seeking behaviors.

Additionally, the current study focused exclusively on HSV-related content and should be replicated utilizing other STIs. There is ample room to further understand if disparities in STI incidence and prevalence in different populations are related to different stigma processes, with the potential to develop a framework or theory specific to STI stigma. Additionally, more research targeting specific STIs as opposed to STIs in general may serve to better inform clinical practices and public health initiatives by allowing efforts to be targeted and specific for each STI. HIV is an excellent case example of how an STI that was highly stigmatized and feared was destigmatized over time utilizing specific and targeted campaigns and interventions, and perhaps utilizing that same process to target other STIs would serve to reduce incidence and prevalence (HIV.gov, 2017, 2023).

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CHAPTER 4: METHODOLOGY

Herpes simplex virus (HSV) is an incurable sexually transmitted infection (STI) estimated to effect over 500 million people globally (World Health Organization, 2023). Like most STIs, HSV can only be transmitted through oral, vaginal, or anal sex, or in rare cases during childbirth from mother to child (World Health Organization, 2023). HSV is an STI riddled with stigma, making an HSV diagnosis not only a biological health concern, but a psychological, social, and spiritual one as well (Devine et al., 2022; Johnston et al. 2024). Stigma is a social exclusion process where a trait, or health condition, flags an individual as “not normal” to other individuals in a given culture (Goffman, 1986). Some researchers suggest that such stigma effects how patients and providers interact, especially since individuals who may have concerns or symptoms must navigate obtaining services from their providers (Scheinfeld, 2021; Thomas et al., 2022). Patients may not feel comfortable discussing STIs with their provider, and providers may not initiate STI conversations with patients due to fear of offense and competing uses for visit time (Fisher et al., 2018; Jahn et al., 2019). Understanding contributing factors to HSV stigma is important for reducing transmission, improving access to both preventative and treatment services via the patient-provider relationship, and improving quality of life for those living with HSV (Devine et al., 2022; Romanowski et al., 2008).

Social media reflects the social climate and provides a place for individuals to share information, enjoy entertainment, and find community (Forgie et al., 2021). Such attributes make social media an excellent target for not only understanding a social process like stigma, but also for potentially increasing awareness and available information (Andalibi et al., 2018; Kesten et al., 2019). For STIs like HSV, preliminary research indicates that social media may be as effective as other methods for circulating information and increasing patient health literacy (Gabarron & Wynn, 2016; Yeh et al., 2022). However, more research is needed, especially research that covers a wide variety of STIs and patient populations. HSV is often overlooked for research due to the combination of how common it is, the tendency for the illness to be asymptomatic, and the often-minimal risk symptoms have for causing life-threatening or physically debilitating symptoms (National Institute of Allergy and Infectious Diseases, 2023). Social media interventions for stigmatized health conditions like HSV show promise but continue to need more empirical backing.

Research Questions and Hypotheses

The purpose of this study is to explore the intersection of HSV stigma, social media, and the patient-provider relationship. Specifically, the goal is to understand how HSV related social media content is interpreted in the context of stigma, whether interpretations differ depending on contextual factors (i.e. demographics, experiences with STIs, sexual education), and to understand the lived experiences of stigma and social media for those living as HSV positive. Given the exploratory nature of the study and lack of prior empirical findings, no specific hypotheses are proposed at this time.

Study Design

To better understand the impact of HSV stigma, social media-based patient information and the patient-provider relationship, a web-based, survey featuring both qualitative and quantitative questions will be employed using research electronic data capture (REDCap; Harris et al., 2009) hosted at East Carolina University. Researchers recommend using web-based, quantitative, surveys in social science research due to their convenience, cost-effectiveness, and accessibility (Connelly, 2016). The survey includes approximately 30 questions using Likert-type scales, open-ended questions, and dichotomous (e.g., yes/no) responses with additional room to free-type more applicable options outside of the dichotomy.

Participants

Participants will be limited to adults aged 18 and older in the United States capable of comprehending written English. Participants could identify as HSV positive or HSV negative, as no limits were placed on STI status. A sample size of 30-40 participants is the initial aim for recruitment (Cohen, 1988). Participants will be recruited utilizing two different social networking platforms and a professional listserv. A post advertising the study will be disseminated to the r/HSVPositive community on the social networking platform “Reddit,” a forum-based social networking site organized into over 100,000 different communities, where individuals subscribed to a community can post, comment, like, and share information. Additionally, the same post will also be disseminated in a Discord server exclusively for those who are HSV positive. Discord is another social networking platform utilizing voice, chat, video, and more for individuals organized into groups or communities to keep in communication with each other. Finally, the Collaborative Family Healthcare Association (CFHA) listserv will be utilized to disseminate the survey amongst subscribed professionals.

Procedure

Prior to data collection, we will receive approval from the Institutional Review Board of East Carolina University. Participants will be able to access the study survey through a link (embedded in a QR Code or in plain print) included in the distributed flyers. Prior to beginning the survey in REDCap there will be a short description of the study, followed by an informed consent outlining potential benefits and risks of participating in the study, limits to confidentiality, data management details, and voluntary status of study participation.

The survey consists of three parts. Part I asked all participants to independently code the same HSV-related Twitter posts as either HSV negative, HSV positive, or HSV neutral. Brief definitions of each of the three coding options were given at the beginning along with the instructions and were repeated next to each coding option on every post. Part II collected demographic and contextual factors from participants, including experiences with sexual health, sexual education, and sexual health experiences related to the patient-provider relationship, as well as measures of overall shame and stigma via the STI shame and STI stigma subscales (Fortenberry et al., 2022). Part III asked for participant impressions of the coding section and culminated in a list of HSV-related social media resources. The survey should take approximately 20 minutes to complete.

Measures

Due to the exploratory nature of the study, measures for all parts of the survey, with the exception of the STI related shame and STI related stigma scales, were created specifically for the survey. Measures utilized for parts I, II, and III of the survey were created to capture a wide range of demographic and background information to inform understanding of how HSV related social media posts are perceived, and how the lived experiences of those with HSV are shaped by stigma and social media. Prior to the start of data collection, three independent testers were utilized for a pilot study of the survey, with each tester giving feedback on clarity of instruction, order of questions, and overall quality of the survey. The complete survey is listed in Appendix D.

Part I: Definitions and X Post Coding

Instructions and Definitions

Following the informed consent process, Part I begins with instructions and working definitions for participants to enable them to code social media posts. A brief, easy to understand definition of stigma was provided before the instructions to code based on Goffman's (1986) theory of stigma. The instructions then asked participants to look at each post selected from X to code the post as either HSV positive, HSV Negative, or HSV neutral. An easy-to-read table of definitions of each category was provided. Definitions of each coding category were repeated as part of the answer selection process for every post.

X Post Coding

X posts pertaining to HSV falling within the time frame of August 1, 2024 through August 14th 2024 will be selected utilizing two different searches in X: one search using the term "HSV" and one search using the term "herpes." Five posts will be selected from each search for a total of ten posts. Post selection was completed utilizing data from the preliminary content analysis completed earlier in the year, where two independent coders coded a total of 200 X posts utilizing the same search methods employed in the current study. Posts were selected to be representative of the types of posts seen in the content analysis that were unanimously agreed upon as belonging to each category (HSV positive, HSV negative, HSV neutral), as well as to mirror the posts that were in contention between the two coders based on their own demographic and contextual factors.

Part II: Demographics, Contextual Factors, STI Related Shame, and STI Related Stigma

Demographic Questionnaire

The demographic questions utilized in Part I will capture the following data for each participant: age, gender, race, sexual identity/LGBTQ status, and religious/spiritual identification. All questions will have both pre-set options as well as an additional space to write in answers that better fit their identity. All participants will be asked the same demographic questions. Demographic questions are derived from a variety of studies to encompass a wide range of intersectional identities (Lindberg & Kantor, 2022; Mulgund et al., 2021; Scheinfeld, 2021).

Contextual Factors

Contextual factors will address level of sexual health education and sexual health education background, participant experience with STIs and STI status, STI information sourcing, participant experience with healthcare providers regarding STIs, fear/distress-based comparison of STIs, HSV specific word association, and an HSV hypothetical scenario. For all contextual questions, a variety of answers options will be utilized depending on the question.

STI Related Shame and STI Related Stigma

Two measures developed by Fortenberry et al. (2002) were utilized to measure participant levels of STI related shame and STI related stigma. The STI related shame scale consists of six items with α=.80, and the STI related stigma scale is a five item scale with α=.77. Correlation between the shame and stigma scales was moderate (r=.54), indicating that each scale measures a separate construct. The questions in each scale are depicted in Table 1. Every question in both scales is scored on a 5-point Likert scale ranging from “strongly disagree” to “strongly agree”.

Part III: Impressions and Resources

Impressions

Following the entirety of survey Parts I and II, participants will be asked a free response question of what their overall impressions were of the coding portion. To capture impressions, three questions will be asked: “Which post stood out to you the most? Why?”, “Based on the posts you coded, how do you think society in general views HSV and those living with it?", and "Based on the posts you coded, have your opinions, feelings, or views about HSV changed? Why or Why Not?". The purpose of these questions is to ascertain overall impressions of the posts, and their effects on participants.

Resources

Following the impressions, the survey will be concluded with a page thanking participants for taking time to take the survey, and providing a list of HSV-related social media users and page that are destigmatizing, educational, and promoting a positive, non-stigmatizing view of HSV on the platforms Instagram, X, and TikTok. The intention is to provide participants with more information should they need it given the posts they were exposed to during the survey. A disclaimer disclosing that social media resources are not an alternative to medical advice and that those needing testing, treatment, or prevention should seek medical care will be included at the end of the resource list.

Data Analysis Plan

Data analysis will be conducted using convergent methods. Convergent methods of data analysis collect qualitative and quantitative data independently but concurrently, seeking to analyze the qualitative and quantitative pieces separately during initial data analysis, and culminating in an analysis mixing the two types of data together (Katz-Buonincontro, 2024
The quantitative data analysis portion consisted of chi-square analyses with the goal of understanding how demographic and contextual factors correlated to STI experiences, HSV perception, and coding results. The qualitative analysis portion examined free response answers for common themes through the constant comparative method. The constant comparative method of data analysis was also employed via a triangulated researcher (Corbin & Strauss, 2014;

Strauss, 1987). The qualitative analysis portion will examine free response answers for common themes through the constant comparative method. The constant comparative method of data analysis will also be employed via a triangulated researcher (Corbin & Strauss, 2014; Strauss, 1987).

After finalizing the independent qualitative and quantitative analyses, both types of data will be analyzed together to create a more holistic view of participant experience. Quantitative information and factors will be utilized to understand how themes within the qualitative experiences of participants were shaped by background and contextual factors (Katz-Buonincontro, 2024). The goal of the convergent analysis is to see how qualitative experience differs based on quantitative information for different groups within the participant sample.

Ethical Considerations

The researchers were mindful of the sensitive nature of many of the survey questions, particularly those pertaining to sexual health, shame, and stigma. Therefore, to ensure participant comfort and safety, we will take the following steps: (a) construct a survey using REDCap (Harris et al., 2009), which is a secure, web-based, HIPAA (2010) compliant modality, (b) create informed consent materials that will clearly state that no identifiable information will be shared in any publications, and that all results will be shared via aggregate, non-identifiable statistics, (c) identify ourselves as researchers from East Carolina University and UT Southwestern, and (d) provide participants with social media resources, and encourage the seeking out of local resources (e.g., healthcare providers, public health departments), to assist with any sexual health concerns that may arise

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CHAPTER 5: “IT HURTS ALL THE SAME”: A MIXED METHODS EXPLORATION OF HSV STIGMA ON X

Over 30 different viruses, parasites, and bacteria are known to be transmitted sexually, making sexually transmitted illnesses (STIs) diverse in etiology and incredibly common (World Health Organization, 2024.). STIs may be symptomatic or asymptomatic, and while many are curable there are others that result in lifelong infection. One such STI, Herpes simplex virus (HSV), is a chronic, viral STI that often presents asymptomatically and affects billions of people globally (World Health Organization, 2023). In the United States in 2018, 18.6 million people were estimated to have genital HSV-2, a number not accounting for the prevalence of HSV-1 or non-genital HSV infections (Johnston & Wald, 2024). While HSV may be common, there are certain populations with higher prevalence of HSV, including women, African American individuals, Hispanic individuals, and older populations (McQuillan et al., 2018).

For many individuals within the United States seeking sexual health care, including testing, diagnosis, and treatment, care is dependent upon interacting with the healthcare system, specifically with medical providers. For example, for patients to get diagnosed with HSV they must schedule an appointment, which often involves specifying that the goal of the visit is STI testing, followed by interactions with a medical provider to receive testing, results, and management advice. Medical providers are often the first people who will know about a person's HSV status, placing undue importance on the attitude of the medical provider in discussing and conveying information, results, and ongoing care pertaining to HSV. However, many medical providers do not feel equipped to discuss such sensitive topics with their patients, whether due to a lack of HSV specific training, lack of time to adequately care for and educate their patients, or lack of patient centered skill training (Guilamo-Ramos et al., 2021; Leyva-Moral et al., 2021).

Aside from individual medical provider factors, other systemic factors, like stigma, can create barriers for patients attempting to care for their sexual health. Stigma is a process centered on exclusion based on a characteristic/trait that deviates from a population norm (Goffman, 1986). STIs like HSV are particularly vulnerable to stigmatization because the diagnosis is an indication of departure from "normative" sexual health, and because of the varying meanings attributed to diagnosis (e.g. HSV as a result of poor morals or lascivious behavior). While there is a greater body of research pertaining to STIs like HIV, other STIs like HSV have not garnered the same amount of attention (HIV.gov, 2023; Neal et al., 2010; Sanchez et al., 2023). HSV is an STI with a smaller empirical knowledge base regarding the social effects of the illness. As a chronic STI that cannot be cured but can be managed, HSV presents a unique intersection between a non-curable illness and an illness with social implications. Empirical evidence suggests that a diagnosis of HSV can result in impaired social functioning, decreased mental health, and isolation from others, but updated information on how changing sociopolitical landscapes, including technological advancements like social media sites, effects those with HSV (Bennett et al., 2022). Understanding the lived experiences of those with HSV is the first step to increase awareness of how sociocultural contexts intersect with a highly stigmatized, lifelong STI that requires healthcare involvement.

Literature Review

HSV From A Biopsychosocial-Spiritual Lens

HSV is incurable, viral STI. Route of transmission depends on the location of the infection, but is commonly transmitted through skin-to-skin contact, saliva, and genital fluids, including the potential, but rare, spread from mother to child during childbirth (World Health Organization, 2023). While transmission is more likely when symptoms are present, there is still a chance of transmitting the virus in the absence of symptoms (Johnston & Wald, 2024). Having HSV without symptoms, and therefore without a formal diagnosis, is common in the United States, with the 1988 to 2010 National Health and Nutrition Examination Survey data estimating that 87% to 90% of individuals aged 14 to 49 years with antibodies to HSV-2 not having a prior diagnosis of genital herpes (Johnston & Wald, 2024).

Aside from the physical presentation and effects of HSV on infected individuals, HSV can have other long-lasting consequences for those diagnosed The biopsychosocial-spiritual (BPSS) theory of health, originally proposed as the biopsychosocial (BPS) theory of health by Engel (1977) and later expanded to add the spiritual dimension by Wright et al. (1996), posits that health is the summation of not only biological wellbeing, but also psychological, social, and spiritual wellbeing, with all aspects being intertwined. Utilizing a BPSS lens to address sexual health is important for improving overall patient wellbeing as opposed to only treating physical symptoms, especially since STIs like HSV are often asymptomatic

HSV poses significant threats to aspects of health other than just physical wellbeing despite being a biological illness. For example, initial symptoms can result in mental health changes like anxiety or depressive symptoms, as can seeking medical attention and discussing sexual health with a healthcare provider (Johnston et al. 2024). For those experiencing HSV symptoms, Patel et al. (2001) found that work performance and overall mental health were considerably diminished due to HSV, with overall mental health decreases being greater in the HSV positive population than in populations of patients with other chronic illnesses. Additionally, to reduce the severity of social impact, individuals may not inform potential sexual partners thereby increasing the risk of further spread, or the diagnosed individual may not tell other social supports, leading to isolation post diagnosis (Myers, 2020). Spiritually, an HSV diagnosis may be viewed as a punishment for sexual “sin” by the individual or others, or may bring spiritual beliefs into question as the individual grapples with making meaning out of their new diagnosis (Reyes-Estrada et al., 2015).

HSV and Stigma

According to Goffman’s theory of stigma, stigmatized identities are identities deviating from the norm for a given population (Goffman, 1986). Despite the prevalence of HSV, normal sexual health is generally accepted as being negative for STIs, meaning that individuals who are HSV positive are at risk for being excluded and outcasted. Aside from biological deviations from normative sexual health, other facets of HSV exacerbating or affected by stigmatization can be further examined using BPSS theory. Though HSV is a biological, chronic illness, it can have detrimental psychological effects that can either be initially caused or further compounded by the social and spiritual implications of being diagnosed with the illness. For example, Foster and Byers (2016) studied the sexual well-being of patients diagnosed with HSV or human papilloma virus (HPV), finding that the most important predictor of sexual wellbeing was experiences with stigmatization and the extent to which patients internalized stigmatizing beliefs. Another study from Rosenthal et al. (2006) indicated there may be differences in the psychological impacts of an HSV diagnosis depending on the presence of symptoms, noting that amongst newly diagnosed asymptomatic individuals, fear of rejection, shame, and anger were the most endorsed social and psychological impacts. Thus, the way an individual experiences an HSV diagnosis psychologically, socially, and spiritually is largely defined by both external experiences involving others, and internal reactions and processes.

In addition to coming to terms with one’s new health status, including potentially uncomfortable symptomology, newly diagnosed HSV positive individuals find themselves suddenly belonging to a socially stigmatized group, which can change how they interact with others and how they feel about themselves. For individuals pursuing new or existing romantic or sexual relationships, an HSV diagnosis can be a hindrance. For example, a study by Sanchez et al. (2023) examining perceptions of STI status of hypothetical partners suggested that participants were less likely to move forward with any type of relationship with hypothetical partners testing positive for HSV, even when compared to those testing positive for HIV or partners who had never received any type of STI testing. Per Devine et al. (2022), research related to overall quality of life for HSV indicated that HSV stigma not only causes psychological distress but can also inhibit communication between sexual partners. With any chronic illness, how an individual creates meaning out of their diagnosis is an important part of navigating life following the diagnosis, and creating a narrative from an HSV diagnosis can be challenging.

Medical Providers

Patients who are concerned or are seeking to address their HSV status via testing, diagnosis, or treatment are required to speak with medical providers, placing undue importance on provider attitudes towards HSV. Due to the injurious BPSS factors and stigma surrounding HSV, conversations between patients and providers regarding HSV can be difficult to navigate. Patients may not feel comfortable discussing HSV with their provider, and providers may not initiate HSV conversations with patients due to fear of offense and competing uses for visit time (Fisher et al., 2018; Jahn et al., 2019). Higher levels of implicit or explicit provider bias are associated with poorer patient outcomes, suggesting that improving patient care for heavily stigmatized topics like STIs is not only a question of improving patient care, but also provider insight and education (Hagiwara et al., 2019; Maina et al., 2018). Increasing provider awareness of factors contributing to HSV stigma is important for reducing transmission rate, improving patient access to preventative and treatment services, and improving quality of life for those living with HSV (Devine et al., 2022; Romanowski et al., 2008).

While providers are integral to the provision of STI related services and knowledge, they are failing to initiate conversations about STI's, including prevention and safe sexual practices, necessitating more provider education and training (Bonder et al., 2021; Coll et al., 2016; Einhorn et al., 2018; Ezhova et al., 2020; Fisher et al., 2018; Jahn et al., 2019; Pleasure et al., 2022). Providers may be hesitant or fail to initiate conversations about STIs with their patients due to inadequate formal training on STI transmission, prevention, and treatment (Guilamo-Ramos et al., 2021; Leyva-Moral et al., 2021). Formal sexual health training is required in approximately half of United States medical schools, and the topics encompassed under sexual health can vary widely, as there is no standardized curriculum (Beebe et al., 2021).

When providers initiate conversations about STIs, patients have better access to services and better health outcomes, which in turn leads to improved population health. For example, Mendez et al. (2023) demonstrated that STI screening rates were higher when healthcare providers asked about a variety of patient sexual health practices, including sexual orientation, condom usage, and type of sexual intercourse. Considering STIs disproportionately affect minoritized and/or stigmatized communities like gay and bisexual men, Black/African-American individuals, American Indian/Alaskan Native individuals, and youth of all demographics, additional training recommendations should include cultural sensitivity and self-of-the-provider awareness to decrease bias (Centers for Disease Control and Prevention, 2023). Current literature suggests that disparities exist regarding exposure to STI and sexual health conversations with providers, with populations such as older adults and individuals with disabilities (Agochukwu-

Mmonu et al., 2021; Schmidt et al., 2022). STI services may also be more available to other populations, like those with unstable housing, females, and those between ages 15-34, which could potentially indicate that bias or provider assumptions of sexual risk increase the potential of a patient to be tested for STIs (Mick et al., 2023).

While certain populations might have an increased risk of STIs, STI or sexual health needs should not be assumed, and other populations should not be excluded from sexual health services. Minoritized patients may have even greater difficulty than others discussing HSV due to the HSV stigma being compounded with bias or oppression. For example, Cazeau-Bandoo and Ho (2022) described the experiences of African-American women diagnosed with genital herpes as entrenched in racism and discrimination. Jackson and Arcelay-Rojas's (2021) qualitative study on the experiences of African-American women with HSV-2 described the difficulty African-American women have discussing sexual health with providers for fear of stigma and being seen as uneducated. If providers are not discussing the implications of and HSV diagnosis with HSV positive patients, including how to reduce outbreaks and transmission to others, patients may utilize other sources, like social media sites, to receive the information they need.

Social Media

Patients who may not feel comfortable turning to their provider for HSV related information may turn to online platforms, creating a risk of exposure not only to harmful or inaccurate information, but also to stigmatizing and exclusionary content. Social networking sites, also known collectively as social media, are often widely available and easily accessible, positing an enticing option for disseminating information on highly stigmatized and controversial topics with the opportunity for anonymous access and content creation (Andalibi et al., 2018; Kesten et al., 2019). However, social media can also perpetuate harmful and inaccurate information necessitating policing of content, particularly health-centric content, to prevent harm to consumers (World Health Organization, n.d.). Given the power social media platforms allot users to circulate information quickly and across a global audience, understanding how social media impacts stigmatized health topics like HSV becomes abundantly important for public health.

Forgie et al.'s (2021) framework is a useful lens to better understand and conceptualize how social media, the patient-provider relationship, and social determinants of health effect STI stigma. According to Forgie et al. (2021), social media can assist patients with limited access to medical care due to social determinants of health with receiving health information. However, social media access is not feasible for everyone, and several populations who may be at risk for STIs, such as older adults, individuals with lower socioeconomic status, and those with less education may not have means to access social media (Forgie et al., 2021). While social media has many potential benefits, such as fostering community, providing support, and creating avenues for accessible STI information, there are other challenges to address, such as quality of information, privacy, and the potential for social media to reinforce stigmatizing STI narratives (Forgiet et al., 2021).

Aim of The Study

The aim of the current exploratory study is to explore the intersection of HSV stigma, social media, and the patient-provider relationship. Specifically, the goal is to understand how HSV related social media content is interpreted in the context of stigma, whether interpretations differ depending on contextual factors (i.e. demographics, experiences with STIs, sexual education), and to understand the lived experiences of stigma and social media for those living as HSV positive. Given the exploratory nature of the study and lack of prior empirical findings, no specific hypotheses are proposed at this time; rather three general, exploratory research questions were utilized as a guide: do contextual and demographic factors impact how participants interpret HSV related X posts, what have participants experienced concerning HSV related shame and stigma in healthcare, on social media, and in general societal contexts, and what is needed to reduce HSV related shame and stigma.

Methods

To better understand the impact of HSV stigma, social media based patient information and the patient-provider relationship, a web-based, survey featuring both qualitative and quantitative questions was employed using research electronic data capture (REDCap; Harris et al., 2009) hosted at East Carolina University. Researchers recommend using web-based, quantitative, surveys in social science research due to their convenience, cost-effectiveness, and accessibility (Connelly, 2016). The survey includes approximately 30 questions using Likert-type scales, open-ended questions, and dichotomous (e.g., yes/no) responses with additional room to free-type more applicable options outside of the dichotomy.

Participants and Sampling

Participants were limited to adults aged 18 and older in the United States capable of comprehending written English. Participants could identify as HSV positive or HSV negative, as no limits were placed on STI status. A sample size of 30-40 participants was the initial aim for recruitment (Cohen, 1988). Participants were recruited utilizing two different social networking platforms and a professional listserv. A post advertising the study was disseminated to the r/HSVPositive community on the social networking platform “Reddit,” a forum-based social networking site organized into over 100,000 different communities, where individuals subscribed to a community can post, comment, like, and share information. Additionally, the same post was also disseminated in a Discord server exclusively for those who are HSV positive. Discord is another social networking platform utilizing voice, chat, video, and more for individuals organized into groups or communities to keep in communication with each other. Finally, the Collaborative Family Healthcare Association (CFHA) listserv was utilized to disseminate the survey amongst subscribed professionals.

Procedure

Prior to data collection, approval was received from the Institutional Review Board (IRB) of East Carolina University. Participants were able to access the study survey through a link (embedded in a QR Code or in plain print) included in the distributed flyers and posts. Prior to beginning the survey in REDCap there was a short description of the study, followed by an informed consent outlining potential benefits and risks of participating in the study, limits to confidentiality, data management details, and voluntary status of study participation.

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Following the informed consent process, Part I begins with instructions and working definitions for participants to enable them to code social media posts. A brief, easy to understand definition of stigma was provided before the instructions to code based on Goffman's (1986) theory of stigma. The instructions then asked participants to look at each post selected from X to code the post as either HSV positive, HSV Negative, or HSV neutral. An easy-to-read table of definitions of each category was provided. Definitions of each coding category were repeated as part of the answer selection process for every post.

X Post Coding

X posts pertaining to HSV falling within the time frame of August 1, 2024 through August 14th 2024 were selected utilizing two different searches in X: one search using the term "HSV" and one search using the term "herpes." Five posts were selected from each search for a total of ten posts. Post selection was completed utilizing data from the preliminary content analysis completed earlier in the year, where two independent coders coded a total of 200 X posts utilizing the same search methods employed in the current study. Posts were selected to be representative of the types of posts seen in the content analysis that were unanimously agreed upon as belonging to each category (HSV positive, HSV negative, HSV neutral), as well as to mirror the posts that were in contention between the two coders based on their own demographic and contextual factors.

Part II: Demographics, Contextual Factors, STI Related Shame, and STI Related Stigma

Demographic Questionnaire

The demographic questions utilized in Part II captured the following data for each participant are picture in more detail in Table 1: age, gender, race, sexual identity/LGBTQ status, and religious/spiritual identification. All questions encompassed both pre-set options as well as an additional space to write in answers that better fit individual participant identity. All participants were asked the same demographic questions. Demographic questions were derived from a variety of studies to encompass a wide range of intersectional identities (Lindberg & Kantor, 2022; Mulgund et al., 2021; Scheinfeld, 2021).

Contextual Factors

Questions probing for potential contextual factors that could effect participant responses on other parts of the survey addressed participant level of sexual health education and sexual health education background, participant experience with STIs and STI status, STI information sourcing, participant experience with healthcare providers regarding STIs, fear/distress-based comparison of STIs, HSV specific word association, and an HSV hypothetical scenario. For all contextual questions, a variety of answer options were utilized depending on the question. The full survey is depicted in the Appendix.

STI Related Shame and STI Related Stigma

Two measures developed by Fortenberry et al. (2002) were utilized to measure participant levels of STI related shame and STI related stigma. The STI related shame scale consists of six items with α=.80, and the STI related stigma scale is a five-item scale with α=.77. Correlation between the shame and stigma scales was moderate (r=.54), indicating that each scale measures a separate construct. Every question in both scales is scored on a 5-point Likert scale ranging from a 1, indicating “strongly disagree,” to a 5, indicating “strongly agree”.

Part III: Impressions and Resources

Impressions

Following the entirety of survey Parts I and II, participants were asked free response questions of what their overall impressions were of the coding portion. To capture impressions, three questions will be asked: “Which post stood out to you the most? Why?”, “Based on the posts you coded, how do you think society in general views HSV and those living with it?”, and “Based on the posts you coded, have your opinions, feelings, or views about HSV changed? Why or Why Not?”. The purpose of these questions was to ascertain overall impressions of the posts, and their effects on participants.

Resources

Following the impressions, the survey concluded with a page thanking participants for taking time to take the survey, and a list of HSV-related social media users and pages that are destigmatizing, educational, and promoting a positive, non-stigmatizing view of HSV on the platforms Instagram, X, and TikTok. The intention was to provide participants with more information should they need it given the posts they were exposed to during the survey. A disclaimer disclosing that social media resources are not an alternative to medical advice and that those needing testing, treatment, or prevention should seek medical care will be included at the end of the resource list.

Data Analysis Plan

Data analysis was conducted using convergent methods. Convergent methods of data analysis collect qualitative and quantitative data independently but concurrently, seeking to analyze the qualitative and quantitative pieces separately during initial data analysis, and culminating in an analysis mixing the two types of data together (Katz-Buonincontro, 2024). The quantitative data analysis portion consisted of chi-square analyses with the goal of understanding how demographic and contextual factors correlated to STI experiences, HSV perception, and coding results. The qualitative analysis portion examined free response answers for common themes through the constant comparative method. The constant comparative method of data analysis was also employed via a triangulated researcher (Corbin & Strauss, 2014; Strauss, 1987).

After finalizing the independent qualitative and quantitative analyses, both types of data were analyzed together to create a more holistic view of participant experience. Quantitative information and factors were utilized to understand how themes within the qualitative experiences of participants were shaped by background and contextual factors (Katz-Buonincontro, 2024). The goal of the convergent analysis is to see how qualitative experience differs based on quantitative information for different groups within the participant sample.

Ethical Considerations

The researchers were mindful of the sensitive nature of many of the survey questions, particularly those pertaining to sexual health, shame, and stigma. Therefore, to ensure participant comfort and safety, we will take the following steps: (a) construct a survey using REDCap

(Harris et al., 2009), which is a secure, web-based, HIPAA (2010) compliant modality, (b) create informed consent materials that will clearly state that no identifiable information will be shared in any publications, and that all results will be shared via aggregate, non-identifiable statistics, (c) identify ourselves as researchers from East Carolina University, and (d) provide participants with social media resources, and encourage the utilization of local resources (e.g., healthcare providers, public health departments), to assist with any sexual health concerns that may arise.

Results

There were 125 total participants who started the survey. 24 participants were excluded due to failure to answer anything past the informed consent question. 101 participants completed the survey and were used for both quantitative and qualitative analyses. Missingness was addressed on a question-by-question basis due to overall low levels of missingness on examination of data. No participants were excluded due to degree of missingness as long as at least one answer was given past the informed consent portion.

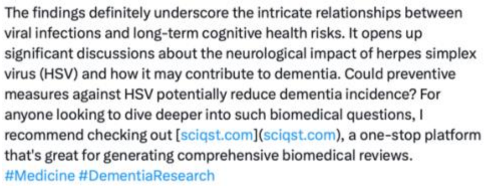
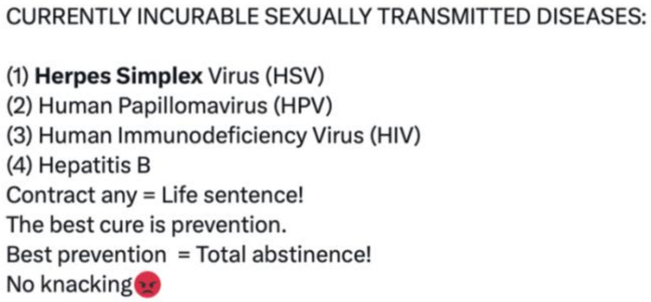
Part I: Definitions and X Post Coding

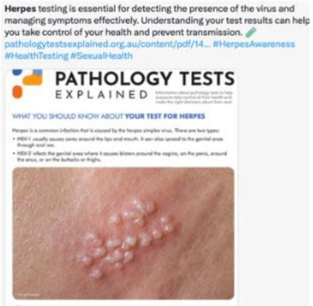
Frequencies for the coding portion of the survey featured in part 1 are displayed in Table 1 and are organized by category frequencies for each independent post, followed by the average responses in each coding category (HSV positive, HSV negative, HSV neutral) across all posts. The category with the greatest average percentage of responses across all posts was HSV negative at 43.7%, followed closely by HSV neutral at 40.2%. The average positive categorization across all posts was 15.8%, indicating that most posts were either interpreted as negative or neutral towards HSV by the overwhelming majority of participants. The posts with the highest participant categorization of HSV positive, HSV neutral, and HSV negative respectively were post 8 (Herpes Ed/Ignorant) at 44.6% positive, post 2 (What is Genital Herpes) at 83.1% neutral, and post 7 (Herpes/HIV) at 93% negative, while the posts with the lowest HSV positive, HSV neutral, and HSV negative categorization respectively were posts 1 (Lemons) and post 3 (Traffic Cones) tied at 1% positive, post 7 (Herpes/HIV) at 4% neural, and posts 2 (What is Genital Herpes) and 8 (Herpes Ed/Ignorant) at 3% negative. Trends in post categorization indicate that posts where HSV was mentioned in a joking matter (posts 1, 3, and 5) garnered primarily negative categorization, whereas posts focused on more scientific facts about HSV (posts 2, 4, and 9) were primarily neutral.

Table 1

Results of X Post Coding

Post	Coding Category	N	%	Picture
POST 1 (LEMONS)	HSV Positive	1	1%	 When life gives you lemons.... just be glad it wasn't **herpes**
	HSV Neutral	10	9.9%	
	HSV Negative	90	89.1%	
POST 2 (WHAT IS GENITAL HERPES)	HSV Positive	14	13.9%	 What is Genital Herpes? Genital herpes is an STI caused by the **herpes simplex** virus (HSV). There are two types of HSV: HSV-1 and HSV-2. While HSV-1 typically causes oral herpes (cold sores), it can also cause genital herpes. HSV-2 primarily causes genital herpes. https://projectredcap.org
	HSV Neutral	84	83.1%	
	HSV Negative	3	3%	
POST 3 (TRAFFIC CONES)	HSV Positive	1	1%	 They breed / spread like ... **herpes** 🤭😅
	HSV Neutral	29	28.7%	
	HSV Negative	71	70.3%	

Post	Coding Category	N	%	Picture
POST 4 (DEMENTIA)	HSV Positive	16	15.8%	 The findings definitely underscore the intricate relationships between viral infections and long-term cognitive health risks. It opens up significant discussions about the neurological impact of herpes simplex virus (HSV) and how it may contribute to dementia. Could preventive measures against HSV potentially reduce dementia incidence? For anyone looking to dive deeper into such biomedical questions, I recommend checking out sciqst.com, a one-stop platform that's great for generating comprehensive biomedical reviews. #Medicine #DementiaResearch
	HSV Neutral	63	62.4%	
	HSV Negative	62	61.4%	
	Missing	1	1%	
POST 5 (HERPES/ MURDER)	HSV Positive	12	11.9%	 Me: She never messaged me, so no need to worry about me getting **herp** or murdered!! My Little Sister: Yay! But also MURDER seemed more the worry thing
	HSV Neutral	26	25.7%	
	HSV Negative	62	61.4%	
	Missing	1	1%	
POST 6 (INCURABLE/ ABSITNENCE)	HSV Positive	2	2%	 CURRENTLY INCURABLE SEXUALLY TRANSMITTED DISEASES: (1) **Herpes Simplex** Virus (HSV) (2) Human Papillomavirus (HPV) (3) Human Immunodeficiency Virus (HIV) (4) Hepatitis B Contract any = Life sentence! The best cure is prevention. Best prevention = Total abstinence! No knacking😡
	HSV Neutral	20	19.8%	
	HSV Negative	79	78.2%	
POST 7 (HERPES/ HIV)	HSV Positive	3	3%	 Some infections are worse than Hiv Hope you know(**herpes** as example)
	HSV Neutral	4	4%	
	HSV Negative	94	93%	

Post	Coding Category	N	%	Picture
POST 8 (HERPES ED/ IGNORANT)	HSV Positive	45	44.6%	 Yes, it's active in the same way that if you got chicken pox (herpes zoster) the virus is still active in your body and you can develop shingles. It doesn't mean that someone with **herpes simplex** is contagious 24/7 but I'm not surprised that you're ignorant.
	HSV Neutral	52	51.5%	
	HSV Negative	3	3%	
	Missing	1	1%	
POST 9 (IMAGE OF HSV)	HSV Positive	34	33.7%	 **Herpes** testing is essential for detecting the presence of the virus and managing symptoms effectively. Understanding your test results can help you take control of your health and prevent transmission. 🧪 pathologytestsexplained.org.au/content/pdf/14... #HerpesAwareness #HealthTesting #SexualHealth
	HSV Neutral	56	55.4%	
	HSV Negative	11	10.9%	
POST 10 (TESTING)	HSV Positive	32	31.7%	 Facts. To add to this conversation, **Herpes simplex** virus is something you have to ASK to be included in yo test. Regular sex tests don't include this , nd I wasn't aware till a nurse I messed with asked me if I had herpes . I was like hmm .. I never thought to ask that on a test
	HSV Neutral	62	61.4%	
	HSV Negative	7	6.9%	
AVERAGE % OF RESPONSES ACROSS ALL POSTS	HSV Positive	16	15.8%	
	HSV Neutral	40.6	40.2%	
	HSV Negative	44.1	43.7%	
	Missing	.3	.3%	

Part II: Demographics, Contextual Factors, STI Related Shame, and STI Related Stigma

Participant Demographics

Participant characteristics are featured in Table 2. The average age of the 101 total participants was 29, with nearly half (49.5%) falling between the ages of 18 and 28. Most participants were white (66.3%), not Hispanic or Latino (79.2%), and identified as a woman (68.3%). A little over half of participants identified as heterosexual (56.4%) with no religious or spiritual affiliation (28.6%).

Table 2

Participant Characteristics

Characteristic	Category	Frequency	%
Race	White	67	66.3%
	BIPOC	31	30.7%
	Unknown/No Answer	3	3%
Ethnicity	Hispanic or Latino	14	12.9%
	Not Hispanic or Latino	80	79.2%
	Prefer not to Answer	4	4%
	Unknown	3	3%
Age	18-28	50	49.5%
	29-39	38	37.6%
	40-50	5	5%
	51-55	2	2%
	Missing	6	5.9%

Gender	Man	23	22.7%
	Woman	69	68.3%
	Other	8	8%
	Prefer not to Answer	1	1%
Sexual Orientation	Heterosexual	57	56.4%
	Gay/Asexual/Bisexual/Other/Pansexual/ Questioning	43	42.6%
	Unknown	1	1%
Religion/Spirituality	Spiritual but not Religious	27	26.7%
	None	39	38.6%
	Christian	21	20.8%
	Other	12	11.9%
	Prefer not to Answer	2	2%

Contextual Factors

Results from the STI knowledge and experience questions are depicted in Table 3. Most participants reported having had sexual health education as part of their mandated schooling prior to the age of 18 (82.2%) but having no formal sexual health education outside of the mandated education prior to 18 (69.3%). The majority of participants reported previously being tested for STIs (95%) and being previously diagnosed with an STI (88.1%). Nearly half (46.5%) of respondents self-rated their knowledge of STIs as being a 7 or an 8 on a 10-point scale, indicating moderate confidence in STI knowledge. A little over half of participants reported either feeling concretely (yes) or potentially (maybe) shamed by a provider due to a sexual health concern (51.5%), yet over half (63.4%) of participants reporting they would feel comfortable talking with a provider about STIs.

The hypothetical partner question indicated that 55.4% of participants would move forward with a relationship with a person who disclosed their HSV status in some capacity (35.6% with precautions and 19.8% without precautions), while 32.7% were more unsure about their course of action (23.8% would ask questions, 3% didn't know what they would do, and 5.9% indicated their course of action would depend on other factors). Considering that most participants were previously diagnosed with an STI, exploring why only a little over half of participants would move forward with the relationship despite having personal experience with STIs might be warranted. Potential explanations could be that participants themselves experience high levels of STI shame and stigma, that individuals who have previously been diagnosed with an STI are aware of how an STI diagnosis could affect a relationship, or that participants who were previously diagnosed with STIs other than HSV were less willing to engage in a relationship with an HSV positive person. Findings suggest further research is needed exploring hypothetical HSV scenarios while accounting for HSV status, as well as exploration into how previous experiences with STIs affect relationship behaviors.

Table 3

Participant Contextual Factors: STI Knowledge and Experience

Factor	Categories	Frequency	%
Sex Ed As Part of Schooling	Yes	83	82.2%
	No	15	14.9%
	I'm Not Sure	1	1%
	Missing	2	2%

Factor	Categories	Frequency	%
Formal Sexual Health Education	Yes	22	21.8%
	No	70	69.3%
	I'm Not Sure	9	8.9%
Previously Tested for STIs	Yes	96	95%
	No	5	5%
Self Rated Knowledge of STIS (1-10)	1-4	2	2%
	5-6	20	19.8%
	7-8	47	46.5%
	9-10	24	23.7%
	Missing	8	8%
Ever or Previously Diagnosed with an STI	Yes	89	88.1%
	No	7	6.9%
	Unsure	3	3%
	Prefer Not To Answer	1	1%
	Never Been Tested	1	1%
Ever Shamed or Discriminated Against by a Provider due to STI/Sex Health	Yes	40	39.6%
	No	46	45.5%
	Maybe	12	11.9%
	I Don't Know	2	2%
	No Response	1	1%

Factor	Categories	Frequency	%
Comfortable Talking with a Healthcare Provider about STIs	Yes	64	63.4%
	No	6	5.9%
	Maybe/It Depends	31	30.7%
What would you be the MOST likely to do if a potential sexual partner disclosed they were positive for herpes simplex virus (HSV) to you prior to sexual activity?	Move forward with the relationship with this person but take extra precautions	36	35.6%
	Move forward with the relationship with this person without extra precautions or like you would with any other partner	20	19.8%
	No longer see this person (cut the relationship off)	4	4%
	Ask questions or get more information before making a decision	24	23.8%
	I don't know	3	3%
	It depends	6	5.9%
	Missing	8	7.9%

The results for the next set of contextual questions are encapsulated in Table 4. These three questions utilized a five-point Likert scale to understand participant preferences for getting information about STIs from various sources, self-rated knowledge about different STIs, and participant distress levels for each listed STI. STI distress for diagnosis with any STI was rated as high for almost half of participants (49.7%), while the individual STIs with the most ratings of high distress were HIV (88.1%) and HSV (62.4%). The STIs with the greatest amount of low distress ratings were chlamydia (44.6%) and gonorrhea (41.6%). STI knowledge varied between STIs, with the most participants rating HSV with a high level of knowledge (79.2%) and syphilis and gonorrhea with a low level of knowledge (56.4% for both). Interestingly, the three STIs with the greatest number of participants reporting a high level of knowledge (HSV, HIV, and HPV) are also the three STIs participants rated as causing the most amount of distress upon diagnosis.

There are multiple potential explanations for these results. For example, incurable STIs (HPV, HSV, and HIV) incur a lifelong diagnosis and could therefore increase both participant distress and knowledge to prevent transmission, while curable STIs (syphilis, chlamydia, and gonorrhea) have decreased levels of distress and knowledge due to the presence of a cure. Participant perception of the severity of potential STI effects and symptoms is another possible explanation for results, especially since syphilis, a curable STI, showed similar distress ratings to HPV, an incurable STI. Additional potential explanations could be stigma and societal beliefs about each STI; however, more research is needed.

An additional point of note is that while 82.2% of participants reported having sexual education as part of their mandated schooling prior to age 18 in the demographic questions (Table 3) the average percentage of participants rating themselves as having a high level of knowledge across all STIs was only 28.7%. Considering that sampling methods heavily favored individuals who had experience with HSV, as reflected in the greater percentage of participants reporting a high level of knowledge for HSV, adjusting the average knowledge by removing HSV can paint a better picture of overall STI knowledge. The adjusted average with HSV removed indicates that an average of 18.6% of participants would rate themselves as having a high level of knowledge across the other five STIs, while 45.1% of participants would rate themselves as having a low level of knowledge on average across the other STIs. This could support previous evidence that mandated sexual health curricula for school-aged children is not adequately preparing individuals to be confidently competent about STIs.

Table 4

Participant Contextual Factors: STI Stress, Knowledge, and Info Sourcing

STI Distress				
STI	1-2 (Low Distress)	3 (Medium Distress)	4-5 (High Distress)	Missing
Syphilis	27 (26.7%)	18 (17.8%)	46 (45.5%)	10 (9.9%)
Chlamydia	45 (44.6%)	22 (21.8%)	26 (25.7%)	8 (7.9%)
Gonorrhea	42 (41.6%)	23 (22.8%)	28 (27.7%)	8 (7.9%)
HIV	2 (2%)	2 (2%)	89 (88.1%)	8 (7.9%)
HSV	17 (16.8%)	13 (12.9%)	63 (62.4%)	8 (7.9%)
HPV	22 (21.8%)	22 (21.8%)	49 (48.5%)	8 (7.9%)
AVERAGE	25.6%	16.5%	49.7%	8.2%
STI Knowledge				
STI	1-2 (Low Knowledge)	3 (Some Knowledge)	4-5 (High Knowledge)	Missing
Syphilis	57 (56.4%)	28 (27.7%)	12 (11.9%)	4 (4%)
Chlamydia	44 (43.6%)	33 (32.7%)	18 (17.8%)	6 (5.9%)
Gonorrhea	57 (56.4%)	28 (27.7%)	12 (11.9%)	4 (4%)
HIV	28 (27.7%)	43 (42.6%)	26 (25.7%)	4 (4%)
HSV	4 (4%)	12 (11.9%)	80 (79.2%)	5 (5%)
HPV	42 (41.6%)	29 (28.7%)	26 (25.7%)	4 (4%)
AVERAGE	38.3%	28.5%	28.7%	4.5%

STI Information Sourcing				
Source	1-2 (Not Likely Use)	3 (Maybe Use)	4-5 (Very Likely Use)	Missing
Google/Internet Based Source Other Than Social Media	7 (6.9%)	18 (17.8%)	72 (71.3%)	4 (4%)
Church or Religious/Spiritual Organization	95 (94.1%)	1 (1%)	0 (0%)	5 (5%)
Urgent Care	25 (24.8%)	23 (22.8%)	49 (48.5%)	4 (4%)
Healthcare Provider	9 (8.9%)	16 (15.8%)	72 (71.3%)	4 (4%)
Friend of Family Member	64 (63.4%)	17 (16.8%)	16 (15.8%)	4 (4%)
Social Media	58 (57.4%)	23 (22.8%)	15 (14.9%)	5 (5%)
AVERAGE	42.5%	16.2%	37.0%	4.3%

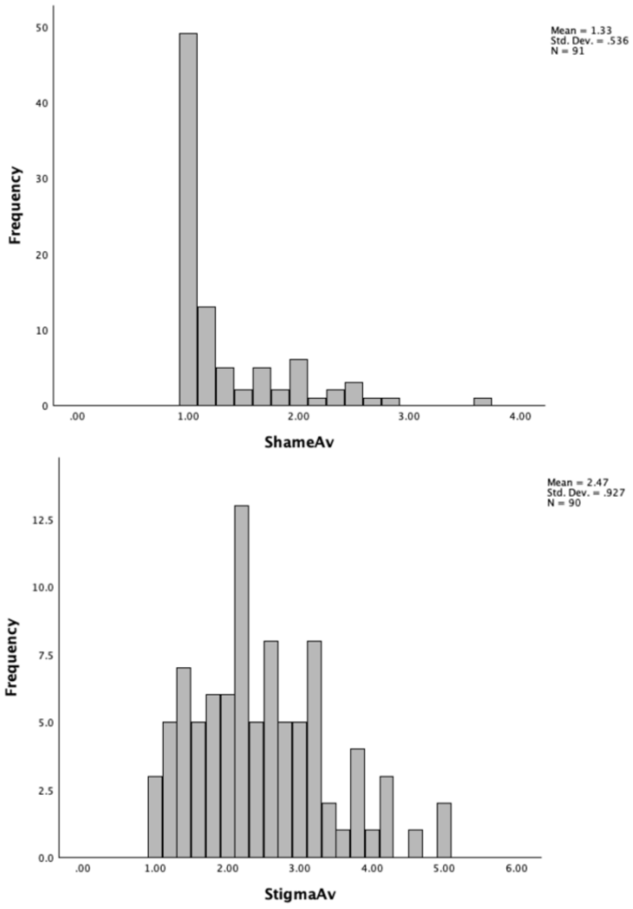
The greatest number of participants reported high likelihood for obtaining STI information for both internet-based searches and healthcare providers (71.3% for both). Almost all participants reported not being likely to use religious or spiritual organizations for STI information (94.1%), which is interesting considering that 59.4% of participants previously reported having some sort of spiritual or religious belief system in the demographic questionnaire. Over half of participants reported a low likelihood of using social media as a source for obtaining STI information (57.4%); however, this question did not consider where participants may be exposed to STI information regardless of choice of source.

STI Related Shame and STI Related Stigma

The average participant STI related shame and STI related stigma subscale scores distributions are pictured in Figure 1. Each participant's subscale scores were averaged to create one score for the overall subscale, with a higher average score on either subscale indicating a higher level of STI shame or STI stigma. Overall, participants had much lower levels of STI shame than STI stigma, indicating that internalized beliefs about STIs culminating in shame were not as prevalent as participant experiences with external STI beliefs indicative of stigma.

Figure 1

Score Distributions for Average STI Shame and Average STI Stigma



Qualitative Questions: Part II and Part III

Qualitative Question from Part II

Four total qualitative questions were utilized to better explore HSV experiences, one question in Part II and three questions in Part III. The first qualitative question in the survey featured in Part II asked "What words do you associate with Herpes Simplex Virus (HSV)? Write as many words or phrases as you'd like, separating words and phrases and with a comma between them. If you are unsure, put 'I am unsure.'" The word association question sought to understand the affective and perceptual realities of participants by prompting them to freely associate with the term HSV, as word association has often been used in multimodal approaches tasked with capturing experiential data (De Deyne et al., 2021). After removing filler words (e.g. like, and, I, think, feel), a word cloud was generated to create a better picture of what words were commonly used, and is depicted in Figure 2. 216 total words were utilized to generate the word cloud, with the cloud being limited to 100 words. The larger the word is within the cloud, the more the word was mentioned. The four most frequently mentioned words were "dirty" (19 mentions), "gross" (12 mentions), "common" (11 mentions), and "incurable" (11 mentions), with "sores," "contagious," and "stigma" following with 9 mentions each

Figure 2

Word Association Word Cloud

This question was placed earlier in the survey than the other qualitative measures as it was considered part of the collection process related to background STI knowledge and experience; whereas the other qualitative questions were more reflective of the survey itself (Etheridge, 2022). Participant answers indicated that many of the conjured experiences and associated words prompted by HSV revolve around repulsion, external perceptions, and the biological realities of

HSV. The top two words "dirty" and "gross" both indicate disgust, an emotion and reaction biologically designed to discourage living organisms from dangers associated with external threats (Curtis et al., 2004). Other words less prevalent in the word cloud such as "nasty," "contaminated," "cooties," and "unclean" further the image of HSV as something that others would be discouraged from encountering, which can have social, biological, and psychological implications for those diagnosed with it.

Additional associations in the word cloud indicate that HSV conjured meaning related to societal perceptions for participants. Words such as "stigma" or "stigmatized," "misunderstood," "jokes," "shame" or "shameful," and "rejection" have a connotation that others are involved in the conceptualization of HSV. For example, for HSV to be "shameful," which is defined as "…a painful emotion caused by consciousness of guilt, shortcoming, or impropriety" (Merriam Webster, n.d.) there would need to be external precedents for HSV to fall short of, precedents set by the social, medical, and psychological contexts in which HSV is embedded. Many of the words featured in the word cloud indicating a departure of HSV from societal norms also have a negative undertone, with HSV being seen by participants as something which warrants exclusion by others. Other strong associations within the cloud point to the biological realities of HSV, with word such as "sores" or "blisters," "contagious," "incurable," "virus," "infectious," and "skin" describing the etiology and symptomology of HSV. However, when combined with the other word associations, participants as a collective painted a picture of HSV as a true BPSS illness, with psychological, social, biological, and even spiritual associations.

Part III Qualitative Questions

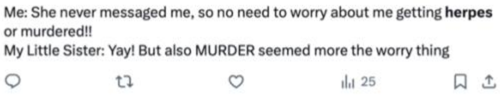
For the questions in Part III, longer responses were elicited from participants. These questions were reflective in nature and were put at the end of the survey to understand the overall experience of participants after taking the complete survey. The first question asked "Which post from Part I stood out to you the most? Why? (Try to describe the post as best you can)." The purpose of this question was to understand how impressionable different posts might be to participants, as other questions were asked to allow time to elapse between seeing the posts and reflecting on them. Social media users are often inundated with a large amount of content and knowing what kind of content leaves impressions on users, whether good or bad, is important for targeting stigmatizing posts for deletion or creating new content that is destigmatizing. The triangulated coder and principal investigator combed through each post to ensure that categorization was accurate and agreed upon by both parties. Table 5 depicts the post number and/or category title, a picture of the post, the percentage of respondents who named that post as standing out to them by the end of the survey, and sample responses from each category. 66 of the 101 participants put at least one word in the answer box for this question.

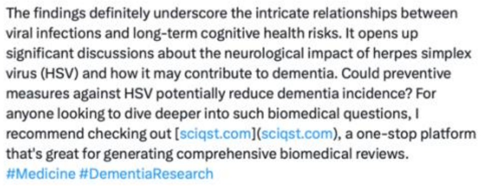
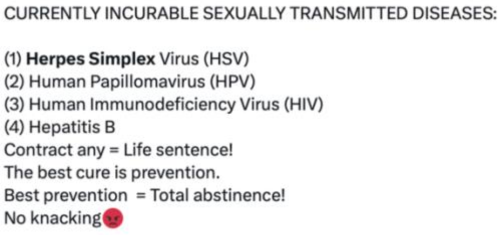
Table 5

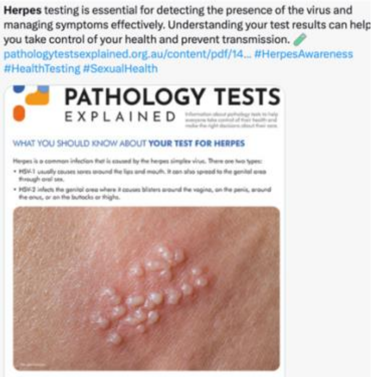
Part III Qualitative Question 1 Coding

Category/ Post Title	Image of Post	# of Respondents (%)	Example Answers
Multiple Posts Mentioned	N/A	14 (21.2%)	*"Sometimes jokes can be funny, but coming from people without the virus makes me uncomfortable and ashamed. As far as articles explaining the virus, I think they can help eliminate the stigma, however the article about cognitive studies (while it may be true) can definitely have negative mental effects on people who already are dealing with a lot. There also was an article with a picture of bluster bumps and while people's outbreaks can look like this, herpes comes in many forms and sizes and I feel it's vital that more examples are presented to people who may have it and not realize because they think that's the only form it takes."* *"It doesn't matter, all the posts with herpes as the butt of a joke hurts all the same"*

Category/ Post Title	Image of Post	# of Respondents (%)	Example Answers
Post 1 (Lemons)	 When life gives you lemons.... just be glad it wasn't **herpes** 	9 (13.6%)	*"The lemons one. Like herpes is the worst thing that could possibly happen to someone. The thing is after being diagnosed with HSV I see now how often people make "herpes" the butt of so many jokes. Like it isn't as "serious" as HIV so we don't whip that one out. I even think back now to how I made those kind of jokes, but it really just makes me feel bad. Not because I can't laugh about those jokes but because people really do treat you differently once you're HSV positive, and the jokes are just a bit of a reminder of that. Like people I really cared about have shamed me because of it, so seeing jokes like that... it isn't that I think bad about having it (which does take work..) but to know others might think bad of me just because they don't understand really sucks."* *"The lemons and herpes. I'd rather have lemons as well"* *"'When life gives you lemons, at least it's not herpes." While I can understand it's important to look on the bright side of everything and YES this disease does suck, the lack of education regarding herpes as a whole makes people think it's the worst diagnosis in the world, when it's really extremely manageable. "*
Post 7 (Herpes/ HIV)	 Some infections are worse than Hiv Hope you know(**herpes** as example) 	9 (13.6%)	*"The post about some STIs being worse than HIV stood out to me the most. HSV is not worse than HIV. People can and do frequently die of HIV. There is an epidemic of HIV in sub Saharan Africa and people there die due to lack of treatment options and stigma and shame. HSV is asymptomatic in most individuals and rarely causes serious illness except in cases of viral meningitis or neonatal herpes infection and those events are extremely rare."* *"One post said something about Herpes being worse than HIV, I think. That stood out the most for a couple of reasons: I instantly thought, "Actually, it's the other way around. I'm lucky that all I caught was Herpes instead of HIV." I thought, "This person must not know anything about Herpes or HIV if they're saying that." HIV has a long and notorious history, and I was playing into the stigma it has just by thinking that. Just as I wouldn't want people to say negative things about having Herpes, I shouldn't then go and say the same thing about HIV. They are both incurable, but I do believe people with HIV suffer much more mentally than people with Herpes do. It's not a contest as to which one is worse or better, but*

Category/ Post Title	Image of Post	# of Respondents (%)	Example Answers
			they are both unfortunate things that can happen while being human in this world. My thoughts only go to show just how heavy the stigma surrounding STI's is in this country. I consider myself progressive and accepting, but this line of thinking has been ingrained so deeply that it rears its ugly head every now and then. Luckily, though, I'm able to recognize it and question myself as to why I think that, and to change my line of thinking. In order for more people to do that, our system needs to change."
Nothing/ None/NA	N/A	8 (12.1%)	*"No response, ADHD brain "* *"can't remember "* *"Would I have dated someone who disclosed their status of having Hsv-1 or 2. I would've thought about being with that person and learning the extra precautions but honestly beforehand I'd say no because it's really painful"*
Reaction to All/Survey (Emotional/ Mental)	N/A	7 (10.6%)	*"Honestly I already don't really remember them. One of them made me feel sad because I have HSV-2 and the stigma sucks. People are ignorant of it and think it's some life ending thing, but it's really not a big deal to live with."* *"I think I expected there to be more humorous herpes memes, if current statistics peg it as one of the most common conditions to have worldwide, it's surprising to me somewhat that more people aren't making more jokes about it. "*
Post 5 (Herpes/ Murder)	 Me: She never messaged me, so no need to worry about me getting **herpes** or murdered!! My Little Sister: Yay! But also MURDER seemed more the worry thing 25	7 (10.6%)	*"The post about a girl never responded to OP so they wouldn't get herpes or murdered w a response from another person emphasizing the not getting murdered part. - Stood out to me because of the heavy stigma around HSV. It is about as bad as getting murdered. Those with HSV often want to die because of societal reaction and this post is a prime example of the problem."* *"Those are all pretty mild from what I've seen on my timeline but the "at least I didn't get murdered or herpes" stands out much more as I've almost been trafficked on a date and separately have herpes. 2 things I was deathly terrified of until they happened to me."* *"Comparing herpes equivalent or worse than murder It stood out because it's continuing the stigma that herpes is life ending... when it's just a skin condition "*

Category/ Post Title	Image of Post	# of Respondents (%)	Example Answers
Post 3 (Traffic Cones)	They breed / spread like ... **herpes** 🤭😅  	6 (9.1%)	*"Probably the one about the traffic cones spreading like herpes. I feel it's a phrase used casually that has the sort of same impact of saying oh the weather is so bipolar. You're not intentionally trying to be negative or shaming or anything, but it's thoughtless. "* *"The post about traffic cones because it was funny and viruses do spread"* *"The ones that said it spreads very easily, this hasn't been my experience"* *"The jokes people make about herpes like the one shown with traffic cones. It's already painful enough without the constant jokes at our expense. Not to mention how common it is. "*
Post 4 (Dementia)	 The findings definitely underscore the intricate relationships between viral infections and long-term cognitive health risks. It opens up significant discussions about the neurological impact of herpes simplex virus (HSV) and how it may contribute to dementia. Could preventive measures against HSV potentially reduce dementia incidence? For anyone looking to dive deeper into such biomedical questions, I recommend checking out sciqst.com, a one-stop platform that's great for generating comprehensive biomedical reviews. #Medicine #DementiaResearch	1 (1.5%)	*"I think the post about herpes and cognitive deficits; as someone currently diagnosed I have tried to do my best to learn about ways to keep myself healthy and acknowledge that I need to take care of myself and others. But I am past the part of being ashamed about it so some of the other posts did not affect me as much. "*
Post 2 (What is Genital Herpes)	 🔑 What is Genital Herpes? Genital herpes is an STI caused by the **herpes simplex** virus (HSV). There are two types of HSV: HSV-1 and HSV-2. While HSV-1 typically causes oral herpes (cold sores), it can also cause genital herpes. HSV-2 primarily causes genital herpes. 	1 (1.5%)	*"The one who said thats hsv1 is the same as hsv2 but different location, it makes feel better because its breaking a little bit the stigma, who dosent know it"*
Post 6 (Incurable/ Abstinence)	 CURRENTLY INCURABLE SEXUALLY TRANSMITTED DISEASES: (1) **Herpes Simplex** Virus (HSV) (2) Human Papillomavirus (HPV) (3) Human Immunodeficiency Virus (HIV) (4) Hepatitis B Contract any = Life sentence! The best cure is prevention. Best prevention = Total abstinence! No knacking😡	1 (1.5%)	*"People saying about abstaining from all sex in order not to get a sexually transmitted infection, like yes that's true but we all know most people aren't doing that so just be honest with yourself and say you're at risk just like everyone else and take care of your sexual health as best you can"*
Post 8 (Herpes Ed/ Ignorant)	 Yes, it's active in the same way that if you got chicken pox (herpes zoster) the virus is still active in your body and you can develop shingles. It doesn't mean that someone with **herpes simplex** is contagious 24/7 but I'm not surprised that you're ignorant. 	1 (1.5%)	*"The person with compassion explaining it is not contagious 100% of the time"*
Post 9 (Image of HSV)		1 (1.5%)	*"The image of the herpes because it was very visually jarring. "*

Category/ Post Title	Image of Post	# of Respondents (%)	Example Answers
	 **Herpes** testing is essential for detecting the presence of the virus and managing symptoms effectively. Understanding your test results can help you take control of your health and prevent transmission. pathologytestsexplained.org.au/content/pdf/14... #HerpesAwareness #HealthTesting #SexualHealth PATHOLOGY TESTS EXPLAINED WHAT YOU SHOULD KNOW ABOUT **YOUR TEST FOR HERPES**		
Post 10 (Testing)	 Facts. To add to this conversation, **Herpes simplex** virus is something you have to ASK to be included in yo test. Regular sex tests don't include this , nd I wasn't aware till a nurse I messed with asked me if I had herpes . I was like hmm .. I never thought to ask that on a test 5 2.8K	1 (1.5%)	*"the one about hsv not being included in most sti testing "*

Overall, respondents appeared to recall posts that resulted in strong emotional reactions or that related to their prior personal experiences with HSV. For example, one respondent shared that the posts that stood out to them were "The ones that would make jokes about HSV or compare it to something like murder. I think that is very degrading and does a lot of harm for a lot of people," while yet another respondent explained that they chose the single post that stood out to them because "…this hasn't been my experience." 21.2% of respondents mentioned multiple posts as standing out to them by the end of the survey, with many participants in this category reporting that recalled general themes amongst all the posts, such as posts where HSV was something that others joked about. Individual posts with the highest percentage of identification by respondents were the post 1 (Lemons) and post 7 (Herpes/HIV), with both being identified by 13.6% of respondents.

The second qualitative question in Part III asked, "Based on the posts you looked at in Part I, how do you think society in general views HSV and those living with it?" This question was purposed to improve understanding of how participants perceive systems-level reactions to HSV and individuals diagnosed with HSV. There were 71 total responses organized into three overarching categories based on the overall tone of the response: negative (68), neutral (1) and unknown/no answer (2). The 68 negative responses were thematically analyzed utilizing 13 different labels, with each answer receiving as many labels as necessary to fully encompass the answer. The triangulated coder and primary investigator went through each response and decided which labels would be appropriate, with the total number of labels reaching 149. Number of labels given per post ranged from one to six. The negative response labels were then organized into four different categories: general negativity towards HSV, having HSV indicates a character deficit (moral/behavioral/emotional), lack of understanding about HSV, and fear and exclusion towards HSV and those with it. The negative categorization and label breakdown is pictured in Table 6.

Table 6

Part III Qualitative Question 2 Coding

Category	# of Posts Based on Label (% based on 149 labels given)	Labels Assigned to Category	Example Posts
General Negativity Towards HSV	22 (14.80%)	Bad/Negative in General	*"They see it as a negative thing"* *"A typically negative view of those with HSV"* *"Like it's the worlds worst experience"*
Having HSV Indicates a Character	24 (16.10%)	Promiscuous/Lack of Sexual Control Lack of Morality	*"People who can't keep their legs closed"*

Category	# of Posts Based on Label (% based on 149 labels given)	Labels Assigned to Category	Example Posts
Deficit (Moral/Behavioral/Emotional)		Transmission Judgement	*"Society is very judgmental about herpes. Many people think it's a sign of bad morals"* *"I think they see people with HSV as dirty, hyper sexual, with low morals "*
Lack of Understanding About HSV	31 (20.80%)	Inadequate Education/Ignorance Comparison to Other Illnesses Reference to # of People Carrying it/Common HSV isn't that Bad	*"I think many people are very uneducated about it. I understand that is is scary in a way, but almost no one I have ever spoken to knows that about 90-95% of the population is a carrier of HSV, but they show no symptoms. I have started to become more comfortable just telling people that I have it (when the conversation lends itself for it) than I used to, so I think based on that society has improved a bit (or I have) "* *"I think it is easy to jump to the conclusion that anyone with HSV made a mistake and failed at being knowledgeable. When its definitely more likely that people have it but are not getting tested and are not telling others because they don't know that they have it."*
Fear and Exclusion Towards HSV and Those With It	72 (48.30%)	Fear Outcast/Exclusion/Shame/Stigma Joke Dirty/Disgusting/Gross	*"Shameful and ashamed "* *"A joke and a target of disdain."* *"I think there's a lot of casual jokes about HSV (i.e. glitter is herpes of the craft world), but ultimately people are either completely uneducated or academically educated. There doesn't seem to be a lot of in-between. education level doesn't seem to impact stigma - it's either an issue or non-issue for individuals in both groups."*

Category	# of Posts Based on Label (% based on 149 labels given)	Labels Assigned to Category	Example Posts
			"I think people don't take it seriously, but not in a nonchalant way. They don't take it seriously as a way to ostracize those living with it. People think they are generally invincible and that they're "careful" so they would never get it. They think those living with it deserve it and deserve to be joked about. Especially because it's a lifelong infection without serious health implications, that makes it easier to make fun of and exaggerate how "gross" it is. I think people that have it are more likely to be empathetic about other issues. "

The overwhelmingly negative categorization of most responses indicates that almost all participants believe that society has negative views of HSV or those with it based on the posts. Overall fear and exclusion accounted for half of negative post labeling, with 48.3% of all labels belonging to this category. Despite the high level of negativity expressed within qualitative question 1, during post coding many participants still coded some of the posts as being positive or neutral, which could potentially indicate that negative posts and narratives dominate even in the presence of positivity or neutrality. Additionally, while the question asked for reflections on societal views based exclusively on the posts participants coded in Part I, it is possible that participants utilized prior experiences while answering, especially considering the high number of participants who utilized personal stories and feelings in their answers.

The third and final question of the survey asked “Based on the posts you looked at in Part I, have your opinions, feelings, or views about HSV changed? Why or why not?” The goal of this question was to explore participants’ own experience of the posts they were asked to code, with an emphasis on understanding how coding the posts may have affected their own views of HSV or those diagnosed with HSV. There were 70 total responses that were organized into four categories by the triangulated coder and the primary investigator: no views have not changed, views changed since diagnosis with HSV but not as a result of the survey, N/A or no response or unsure, and yes views have changed as a result of the survey. Each category was then analyzed for common themes within the category. Results from qualitative question 3 are exhibited below in Table 7.

Table 7

Part III Qualitative Question 3 Coding

Category	# of Posts (%)	Themes Within Each Category	Example Responses
No Views Have Not Changed	46 (65.7%)	Confirmed or Amplified Previously Negative View/Feelings/Opinions Previously Educated "I've Seen Worse" Misinformation and Stigma are Prevalent--Shapes View of Self	*"No, I live this hell daily. "* *"No, my feelings haven't changed but I also have it. I still have the feelings and experience the judgement and rejection. I just learned to navigate through life a little better."* *"No, I've had it since I was about 5 or so (thanks, grandma :/) and both of my parents are doctors, so I've always had a very neutral/positive view about it. Thanks mom ♡"*
Views Changed Since Diagnosis with HSV but Not as a Result of the Survey	11 (15.7%)	Emotional Journey Accompanying Diagnosis Those Who Are HSV Positive Can Relate to Posts Due to How They Felt/Were Pre-DX Diagnosis Shifted Perspective or Changed How a Person Navigates/Sees the World	*"Since my diagnosis of HSV-1, I view jokes (that I once thought were funny) as hurtful. While I can still poke fun at myself, seeing others joke about or talk in a negative light about people who've been exposed or diagnosed with HSV makes me very uncomfortable now."* *"The posts didn't change my views, but being diagnosed with HSV did. There was a lot of information I was not given before diagnosis. "*

Category	# of Posts (%)	Themes Within Each Category	Example Responses
			"As I mentioned before, since I have been diagnosed I have a perspective shift. I never thought super negatively about others with STI's but having gone through it myself it made me feel like I failed and that I would never have meaningful relationships with other people because of the stigma. Now I just know what I need to do to take care of myself and make the choice to move forward with partners that will understand."
N/A, No Response, or Unsure	7 (10%)	Emotional Responses Generalized Responses to HSV/Not Answering the Question Unsure/No Response	*"Stigma and society make HSV sound horrible "* *"My opinion is that people with STD's don't deserve to be treated any different and people are ignorant and most likely have something themselves and don't even know it. "* *"I knew people were uneducated, but the post I mentioned in question 1 is really surprising. Not that those diagnosed with HIV are "worse" than those with HSV or are more "gross", but because HIV poses a much larger health risk factor."*
Yes Views Have Changed	6 (8.6%)	Worsened Previous Emotions Improved Empowerment/Protectiveness General Yes	*"It made me feel worse about HSV and more suicidal over the fact I was assaulted and got this STD without my consent. "* *"probably improved because now I feel more protective of those w an outbreak because I'm more aware of misinformed approaches."* *"made me feel more empowered to explain and destigmatize posts I come across demonizing HSV in the future"*

The majority of participants expressed feeling that the posts they saw did not change their views, with many participants expressing that they were very familiar with the type of stigmatizing content shown in the survey. In fact, several participants expressed feeling that they had seen worse social media content than what was provided for coding in the survey, indicating that societal discourse around HSV on social media is not only stigmatizing but also prevalent. Individuals belonging to both the “no change” and “changed since diagnosis” described education as a salient reason for why the posts in the survey did not affect them, as many cited having educated themselves on HSV either generally or because of diagnosis. This begs the question of why individuals are having to further educate themselves on a prevalent public health topic when most participants also reported having had sexual health courses previously as part of mandated schooling.

For those who did express feeling changed as a result of the survey posts, common themes were feeling more empowered to correct information due to increased awareness of misinformation present on social media and feeling more negatively as a result of the posts. Per participant answers, some may not have been as aware what kind of HSV specific content is on social media platforms like X as others, and therefore did not know the extent of the stigmatization and misinformation. However, some participants appear to have felt empowered by now knowing what kind of HSV content, beliefs, and ideas are out there, where others felt more defeated by it.

Convergent and Statistical Analyses

Aside from quantitative and qualitative frequency distributions, data, and associations based on observations of potential relationships between variables, chi-square analyses were employed in an attempt to find other statistically significant between-group differences amongst both the quantitative and qualitative variables. In order to run statistical analyses with the qualitative variables, two of the three qualitative questions featured in Part III of the survey were used: question 1 (“Which post from Part I stood out to you the most? Why? (Try to describe the post as best you can)") and question 3 ("Based on the posts you looked at in Part I, have your opinions, feelings, or views about HSV changed? Why or why not?"). Qualitative question 2 and the word association question from Part II were not utilized for statistical analyses due to the nature of the qualitative data analyses used for each question.

Demographic and Contextual Factor Relationships with Part I Post Coding

Chi-square analyses were utilized to explore potential relationships between background and contextual factors with how HSV related posts from X were coded by participants. The following background and contextual factors were examined for each post: spirituality/religion, age, gender, sexuality, race, average shame subscale score, average stigma subscale score, ethnicity, sexual health education prior to age 18, formal sexual health education, general STI knowledge, previous STI testing, previous/current STI diagnosis, comfort talking with a healthcare provider about STIs, and previous instances of discrimination by a healthcare provider. Table 8 displays variables with significant between group differences for each post's coding results.

Table 8

Chi-Squared Analysis of Posts Based On Demographic and Contextual Factors

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	$\chi 2$	DF	P Value
Post 1 (Lemons)	Ethnicity	Model				34.28	6	$P < .001$
		Hispanic	92.9% (13/14)	7.1% (1/14)	0% (0/14)			
		Not Hispanic or Latino	90% (72/80)	10% (8/80)	0% (0/80)			

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	χ2	DF	P Value
		Prefer Not to Answer	75% (3/4)	25% (1/4)	0% (0/4)			
		Unknown	66.6% (2/3)	0% (0/3)	33.3% (1/3)			
	Formal Sexual Health Education	Model				10.86	4	P < .05
		Unsure	77.8% (7/9)	11.1% (1/9)	11.1% (1/9)			
		No	91.4% (64/70)	8.6% (6/70)	0% (0/70)			
		Yes	86.4% (19/22)	13.6% (3/22)	0% (0/22)			
	Previous STI Testing	Model				20.24	2	P < .001
		No	60% (3/5)	20% (1/5)	20% (1/5)			
		Yes	90.6% (87/96)	9.4% (9/96)	0% (0/96)			
	Previous or Current STI diagnosis	Model				33.51	8	P < .001
		Unsure	66.7% (2/3)	0% (0/3)	33.3% (1/3)			
		Never Tested	100% (1/1)	0% (0/1)	0% (0/1)			
		No	85.7% (6/7)	14.3% (1/7)	0% (0/7)			
		Prefer not to Answer	100% (1/1)	0% (0/0)	0% (0/0)			
		Yes	89.9%	10.1%	0%			

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	χ2	DF	P Value
			(80/89)	(9/89)	(0/89)			
	Comfort with Healthcare Providers	Model				16.78	4	P < .05
		Maybe	87.1% (27/31)	12.9% (4/31)	0% (0/31)			
		No	83.3% (5/6)	0% (0/6)	1.7% (1/6)			
		Yes	90.6% (58/64)	9.4% (6/64)	0% (0/64)			
	Sexuality	Model				10.56	4	P < .05
		Heterosexual	91.2% (52/57)	8.8% (5/57)	0% (0/52)			
		LGBTQ	88.4% (38/43)	9.3% (4/43)	2.3% (1/43)			
		Unknown	0% (0/1)	100% (1/1)	0% (0/1)			
Post 2 (What is Genital Herpes)	Ethnicity	Model				15.23	6	P < .05
		Hispanic	0% (0/14)	92.9% (13/14)	7.1% (1/14)			
		Not Hispanic or Latino	2.5% (2/80)	83.8% (67/80)	13.7% (11/80)			
		Prefer Not to Answer	25% (1/4)	75% (3/4)	0% (0/4)			
		Unknown	0% (0/3)	33.3% (1/3)	66.7% (2/3)			

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	χ2	DF	P Value
	Sexuality	Model				34.40	4	P <.001
		Heterosexual	1.8% (1/57)	80.7% (46/57)	17.5% (10/57)			
		LGBTQ	2.3% (1/43)	88.4% (38/43)	9.3% (4/43)			
		Unknown	100% (1/1)	0% (0/1)	0% (0/1)			
Post 3 (Traffic Cones)	Formal Sexual Health Education	Model				14.59	6	P < .05
		Unsure	55.6% (5/9)	33.3% (3/9)	11.1% (1/9)			
		No	71.4% (50/70)	28.6% (20/70)	0% (0/70)			
		Yes	72.7% (16/22)	27.3% (6/22)	0% (0/22)			
	Mandated Sexual Health Education Prior to 18	Model				10.61	4	P < .05
		No Answer	50% (1/2)	50% (1/2)	0% (0/2)			
		Unsure	0% (0/1)	100% (1/1)	0% (0/1)			
		No	93.3% (14/15)	6.7% (1/15)	0% (0/15)			
		Yes	67.5% (56/83)	32.5% (27/83)	0% (0/83)			
Post 4 (Dementia)	None					-	-	-

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	$\chi2$	DF	P Value
Post 5 (Herpes/ Murder)	Ethnicity**	Model				53.92	9	P < .001
		Hispanic	92.9% (13/14)	7.1% (1/14)	0% (0/14)			
		Not Hispanic or Latino	60% (48/80)	27.5% (22/80)	12.5% (10/80)			
		Prefer Not to Answer	25% (1/4)	75% (3/4)	0% (0/4)			
		Unknown	0% (0/3)	0% (0/3)	66.7% (2/3)			
Post 6 (Incurable/ Abstinence)	Race	Model				25.13	4	P < .001
		White	80.6% (54/67)	17.9% (12/67)	1.5% (1/67)			
		BIPOC	74.2% (23/31)	25.8% (8/31)	0% (0/31)			
		Unknown	50% (1/2)	0% (0/2)	50% (1/2)			
Post 7 (Herpes/ HIV)	None					-	-	-
Post 8 (Herpes Ed/Ignorant)	Mandated Sexual Health	Model				33.51	9	P < .011

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	χ2	DF	P Value
	Education Prior to 18**							
		No Answer	0% (0/2)	50% (1/2)	50% (1/2)			
		Unsure	100% (1/1)	0% (0/1)	0% (0/1)			
		No	0% (0/15)	53.3% (8/15)	46.7% (7/15)			
		Yes	2.4% (2/83)	51.8% (43/83)	44.6% (37/83)			
Post 9 (Image of HSV)	Mandated Sexual Health Education Prior to 18	Model				14.16	6	P < .05
		No Answer	50% (1/2)	50% (1/2)	0% (0/2)			
		Unsure	100% (1/1)	0% (0/1)	0% (0/1)			
		No	6.7% (1/15)	73.3% (11/15)	20% (3/15)			
		Yes	9.7% (8/83)	53% (44/83)	37.3% (31/83)			
Post 10 (Testing)	Comfort with Healthcare Providers	Model				19.14	4	P < .001
		Maybe/It Depends	3.2% (1/31)	58.1% (18/31)	38.7% (12/31)			
		No	50% (3/6)	33.3% (2/6)	16.7% (1/6)			
		Yes	4.7% (3/64)	65.6% (42/64)	29.7% (19/64)			

			Between Group Coding Differences			Overall Factor Model Fit		
Post	Factor	Group	% Coding Negative	% Coding Neutral	% Coding Positive	χ2	DF	P Value
	Previous Healthcare Provider Discrimination	Model				16.14	8	P < .05
		No Answer	0% (0/1)	0% (0/1)	100% (1/1)			
		I Don’t Know	0% (0/2)	100% (2/2)	0% (0/2)			
		Maybe	25% (3/12)	41.7% (5/12)	33.3% (4/12)			
		No	0% (0/46)	73.9% (34/46)	26.1% (12/46)			
		Yes	10% (4/40)	52.5% (21/40)	37.5% (15/40)			
	Shame Subscale Average (Grouped)	Model				15.79	2	P < .001
		Between 1 and 2	4.9% (4/82)	69.5% (57/82)	25.6% (21/82)			
		Between 3 and 4	100% (1/1)	0% (0/1)	0% (0/1)			
	Race	Model				10.82	4	P < .05
		White	7.4% (5/67)	67.2% (45/67)	25.4% (17/67)			
		BIPOC	3.2% (1/31)	51.6% (16/31)	45.2% (14/31)			
		Unknown	50% (1/2)	0% (0/2)	50% (1/2)			

**Participants who did not code the post not included in these numbers

The presence of between group differences for several of the background and contextual factors in terms of post coding indicates that interpretations of HSV related social media posts are influenced by prior experiences and sociocultural identities. The between group differences for multiple posts due to education, whether formal or mandated prior to 18, indicate that education on BPSS topics like HSV can have some impact on HSV post interpretation. This could have applicability for public health initiatives focused on broadening quality and access to sexual health education, as well as for public health initiatives utilizing social media to reach populations unduly affected by STIs like HSV. This is especially salient considering that race, ethnicity, and sexuality were three other background factors that had between group differences for a number of the posts participants coded. If background factors and intersectional identities change how individuals interpret HSV content, including content that is stigmatizing, this could potentially indicate that broader approaches to lessening stigma that incorporate targeted communities would be most appropriate.

Demographic and Contextual Factor Relationships with Part III Qualitative Questions

Qualitative questions 1 and 3 were transcribed into quantitative coding based upon the categorization of participant answers. Chi-square analyses were utilized to examine if there were mean differences between groups based on contextual and demographic variables in how participants answered qualitative questions. Chi-square analyses indicated that there were significant between group differences for coding of qualitative question 1 for the following variables: sexual health education prior to the age of 18 ($\chi2$ (39) = 63.93, $p < .05$), prior shame or discrimination from a healthcare provider ($\chi2$ (52) = 125.46, $p < .001$), and religious or spiritual identification ($\chi2$ (52) = 87.62, $p = .001$). There were no significant between group differences for coding of qualitative question 3 based on demographic and contextual variables.

The presence of three different contextual factors as having significant differences for impressions post coding could indicate that a wide variety of content would be needed to reach audiences, and that stigma could vary depending on the context of the individual, which would align with Goffman's theory of stigma (1986) that excluded identities are based upon cultural norms. Additionally, prior experiences with sexual health do appear to influence social media interpretations, could indicate that educational experiences create differences in how individuals respond to HSV and stigma. However, if participants with different experiences with sexual health education prior to the age of 18 code posts differently, as indicated by the chi-square results for qualitative question 1, this could be indicative that more research is needed on the impact that several other sociodemographic factors, like socioeconomic status (SES) and access to quality of education, have on HSV stigma and social media interpretation.

While there were some background variables with significant between group differences for question 1, the overall lack of connection between background factors and qualitative answers could have several explanations. The large number of categories for qualitative question 1 could make it difficult to run statistical analyses without a large enough sample size, the contextual factors utilized for the quantitative portion could be unrelated to the qualitative process of change, and the sample could be too homogenous on certain key variables.

Discussion

The aim of the present study was to explore how contextual and background factors, including demographic variables, experiences with STIs and providers, and STI shame and stigma, shape how individuals interpret and reflect on HSV related X posts. The three exploratory research questions utilized to guide the study included: do contextual and demographic factors impact how participants interpret HSV related X posts, what have participants experienced concerning HSV related shame and stigma in healthcare, on social media, and in general societal contexts, and what is needed to reduce HSV related shame and stigma.

Prior research had indicated that HSV diagnosis can be distressing in a variety of BPSS ways, including anxiety and depressive symptoms, diminished work performance, and decreased communication with sexual partners and social supports (Johnston et al. 2024; Myers, 2020 ; Patel et al., 2001). Additional evidence suggested that HSV stigma is not only present in a variety of contexts, but is also detrimental to BPSS health (Devine et al., 2022; Foster & Byers, 2016). The present study confirmed prior research in that participants heavily endorsed HSV stigma as being prevalent and hurtful. For those who were able to share their story in the qualitative answers portion, many discussed how being diagnosed with HSV catapulted them into stigma, with most expressing a lack of surprise at seeing stigmatizing content due to how familiar and common it already is for them.

Findings echoed conclusions from prior research indicating that a positive HSV status would lead others to change their behavior in an exclusionary way towards the diagnosed individual (Sanchez et al., 2023). Many participants expressed that HSV and, by proxy, those diagnosed with it, are viewed with disgust and fear by others, as though HSV is akin to a death sentence indicating a personal deficit or moral failing. Several participants described the struggle and process of having to grapple with the stark contrast between the biological reality of HSV as a prevalent infection with occasional symptoms and the view that others appear to have of HSV. This is further reflected in the number of participants who identified the posts that stood out to them the most as the ones comparing HSV and HIV, HSV and murder, and HSV and metaphorical “lemons,” with “lemons” representing the unsavory hurdles that often happen in life. The overall exasperation with the lack of misinformation and understanding about HSV expressed by participants was palpable and appeared to create a divide between those who have HSV and know the reality of living with it, and those who don’t and fear contracting it.

Moreover, statistics from the Centers for Disease Control and Prevention (2020) indicate that sexual health education is declining and is not adequately preparing youth to care for their sexual health. The findings of the present study supported this by way of understanding how current adults, many of whom reported receiving sexual health education prior to 18, approach STIs. Participants reported low levels of knowledge of different STIs and moderate to high levels of STI distress, despite most participants reporting having had mandated sexual health education prior to the age of 18, further providing evidence that sexual health education prior to the age of 18 is lacking (Centers for Disease Control and Prevention, 2022). Additionally, participants’ descriptions of the changes they underwent as a result of being diagnosed with HSV, including having to educate themselves, indicates that HSV specific education was only pursued after diagnosis. This demonstrates a need for preventative education occurring prior to diagnosis.

It should be noted, however, that sexual health education should not be weaponized as a reason to categorize someone with HSV as having a personal deficit, or as having poor sexual health practices. As many participants highlighted in their own personal narratives, HSV is common and can be transmitted in a variety of scenarios, including those that are nonconsensual, deceitful, or a result of transmission at birth or as a child (World Health Organization, 2023). While more education is needed so that individuals can make informed decisions, sexual intercourse still carries risks without discrimination to method of transmission, education level, or any other sociodemographic identity, especially given than many STIs like HSV are often asymptomatic (World Health Organization, 2024). Therefore, part of improving sexual health information should include education on stigma and normalization of STIs as a communicable illness without moral underpinnings.

The current study also provided findings that can be useful when considering where and how to provide sexual health education. For participants of the current study, the two highest rated sexual health information sources for participants were google/internet sources and healthcare providers, both tied at 71.3% of participants rating a high likelihood of use. Ensuring that reliable, accurate information is accessible on the internet, as well as ensuring reliable access to quality healthcare, should be considered priorities for public health initiatives centered on increasing sexual health literacy and healthcare access (Mulgund et al., 2021). While social media was not rated high in likelihood for seeking sexual health information by the current sample of participants, sexual health content may still be appearing on platforms regardless, as indicated by participant’s lack of surprise towards the stigmatizing HSV X content.

Clinical Implications

Healthcare providers have a key role in STI testing, diagnosis, and treatment, necessitating healthcare providers to be equipped to discuss sexual health with patients. While efforts need to be pursued for medical education to be more inclusive of sexual health, current clinicians may need to change their practices to provide care accommodating different identities, backgrounds, and health literacy levels. For healthcare providers already in practice, implementing the Center for Disease Control and Prevention’s (2024) guidelines to taking a sexual history can be a good way to implement changes for better understanding and discussing patients’ sexual health. Additionally, providers should be prepared to answer questions related to disclosing STI status, as education is not only important for providing collaborative, patient-centered care, but also for reducing transmission rates and improving population health (Centers for Disease Control and Prevention, 2020). Providers should be cognizant of population trends concerning STIs and health literacy, especially considering that population disparities exist in STI prevalence and STI knowledge (Coll et al., 2016; Ezhova et al., 2020; Lederer et al., 2021).

The present study highlighted the need for healthcare providers to be aware of how both medical interactions and an STI diagnosis can affect individuals aside from biological presentation. Participants reported having had or having potentially had incidences of discrimination or shame from a healthcare provider, having high levels of comfort talking to healthcare providers, and being very likely to seek sexual health information from healthcare providers. These findings indicate that while participants are mostly comfortable turning to providers for information about sexual health, there still need to be efforts to reduce shame and discrimination in healthcare settings related to sexual health practices. Providers have power in the patient-provider relationship and are able to steer conversations depending on what information they see as salient to the visit, and increasing provider understanding of the BPSS implications of STIs could help reframe sexual health conversations to promote holistic wellness, as well as to improve the patient-provider relationship (Dubbins et al., 2013).

Conclusion, Future Directions, and Limitations

HSV is a wonderful example of a biological virus often treated in medical settings that has wider implications and meaning for the individuals who carry it. Reasons for the stigmatization of HSV, and the resulting exclusion and shaming of those positive for HSV, are multifaceted: lack of adequate sexual health education, implied moral and behavioral meanings, and fear of HSV are a few that have been targets of discussion in the present research. For individuals who receive a diagnosis like HSV, it can be difficult to separate individual identity from the diagnosis. Stigmatizing commentary evolves from fearing HSV as an illness to fearing the people afflicted with it, rendering stigmatizing commentary personal and injurious. More research could be beneficial to explore the role of identity integration of an HSV diagnosis to understand how perception of social media content is influenced by the degree to which individuals have integrated an HSV diagnosis into their overall person. Furthermore, the role that social media plays in stigmatization, education, and disseminating positive narratives needs continued exploration, especially with the continued evolution of technology.

The present study was limited in that the sample could still be too homogenous in background factors that could make more of a difference in post and qualitative coding. For example, most of the participants were white, not Hispanic or Latino, and have been previously or currently diagnosed with an STI. Finding a sample with more diversity in ethnicity, race, and STI status, as well as specifying STI status with specific STIs could be a beneficial direction for future research. Additionally, many participants were recruited on HSV specific forums on social media, indicating that participants could already heavily seek information and community related to HSV on social media. A potential future direction could be sampling based on geographic area, or repeating the study with a sample that is primarily STI negative. Overall, treating the stigmatization of sexual health topics like HSV as a threat to public health initiatives and individual wellbeing is paramount to reducing transmission rates and improving population health.

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CHAPTER 6: CONCLUSION AND FOUR WORLD IMPLICATIONS

The present dissertation sought to explore the intersection of the herpes simplex virus (HSV), stigma, social media, and the patient-provider relationship. Chapter 1 was a brief introduction to the variables while chapter 2 built on chapter 1 with a more in-depth literature review presenting current research pertaining to HSV, HSV stigma, stigma on social media, the patient-provider relationship, and the provider's role in HSV care utilizing a biopsychosocial-spiritual (BPSS) lens. Chapter 3 was a content analysis of HSV related X posts utilizing both quantitative and qualitative analyses, as well as two independent coders, while Chapter 4 proposed methodology for an original, exploratory study furthering the results of the content analysis. Chapter 5 utilized the methodology proposed in Chapter 4 to reveal the results of the original research exploring the connections between HSV, stigma, social media, and the patient-provider relationship. Chapter 6, the present chapter, is the concluding chapter of this dissertation and aims to present the overall findings of the dissertation in its entirety, as well as implications of the present research and future directions.

Research pertaining to HSV, stigma, social media, and healthcare providers has implications for healthcare systems best organized in a language catering to the system. Peek's (2008) Four World View is a framework for understanding healthcare systems by addressing the four interconnected and simultaneous "worlds" comprising such systems: the clinical, training, operational, and financial worlds. The clinical world revolves around direct patient care, the training world is centered around learners developing within the healthcare system, the operational world is concerned with productivity and efficiency of the system, and the financial world focuses on monetary exchange and budgetary adherence. While such a short summary briefly touches on the purpose of each world, it should be noted that there are many other functions and nuances to each world aside from what has been mentioned. By utilizing Peek's Four World View to present research findings and suggest avenues for change, systemic change can be pursued from a variety of angles.

Clinical Implications

One of the major advantages to the study in Chapter 5 was the large proportion of the sample that had previously been diagnosed with an STI, with many participants reporting that they had personally been diagnosed with HSV. When tasked with coding X posts related to HSV, many participants expressed feeling unsurprised by the amount of stigma, misinformation, and catastrophizing of HSV that they witnessed in the posts. Chi-square analyses examining between group differences in post coding based on demographic and contextual factors emphasized the role patients' backgrounds play in the interpretation of material related to HSV.

For healthcare providers and other clinicians working in healthcare contacts, such as medical family therapists, understanding the context and beliefs patients have about an illness can help address patient concerns while improving quality of care and empowering clinicians. Stigmatized illnesses like HSV that have strong narratives of stigma both on and off of social media platforms may require clinicians to proceed with extra caution regarding the language they use and the way they utilize visit time, as more time and attention may be needed to focus on health literacy and addressing the other BPSS effects of HSV as opposed to purely addressing biological symptoms.

Healthcare Provider Specific Implications

For healthcare providers who test, diagnose, and manage HSV, presenting an alternative narrative of HSV through patient interactions can help reduce some of the stigma and shame that may be associated with the virus. Many participants of the present study described their journey since diagnosis unprompted, with many describing several ways in which they changed as a result of being diagnosed with HSV. When providers give a diagnosis of HSV they are not simply telling patients that they have a chronic STI; they are telling patients that they now belong to a culturally stigmatized group, often resulting in adverse psychological, social, and spiritual outcomes. While healthcare providers, who are often facing increased demands on their time, may not have the time to fully address the implications of an HSV diagnosis with patients, connecting patients to resources, like medical family therapists, who can address systemic implications of a diagnosis can help alleviate some of the pressure for providers to address every BPSS aspect, especially if they don’t feel equipped by their training to do so.

Aside from connection to resources, providers can impact patients through the way in which they discuss HSV with patients. Providers may not have the extra time to fully understand a patient’s thoughts and feelings related to HSV, but they can impact patients in the way they communicate about it. In addition to following the Centers for Disease Control and Prevention’s (2024a) guidelines for taking a sexual history, normalizing HSV, briefly validating patient concerns, and addressing the rampant HSV misinformation can aid patients in joining with their provider and understanding HSV aside from narratives they may find in other arenas, such as social media.

Addressing health literacy shortcomings may also serve to assist patients with understanding their new diagnosis and the implications of it. Many participants in the study reported having low levels of knowledge with most STIs, and while participants reported higher levels of knowledge about HSV, many described only learning more about it once they received a diagnosis. Participants also described a high likelihood of seeking information online, which can vary in quality (Mulgand et al., 2021). Providers can ensure that their patients are getting adequate and valid information by providing patients with pre-selected materials and resources, or by explicitly having educational conversations with patients when patients are ready to hear more about it (Centers for Disease Control and Prevention, 2024a; Kamimura et al., 2020; Miller & Reihlen, 2023).

Medical Family Therapy Implications

Medical family therapists (MedFTs) are members of the healthcare team who utilize systemic and BPSS theories to partner with other members of the healthcare team, patients, and their families to provide holistic care (McDaniel et al., 2013; Hodgson et al., 2014). MedFTs are perfectly primed to address an issue like HSV due to the systemic and integrated nature in which they operate. The present study added to previous literature acknowledging the many BPSS effects of HSV by eliciting from participants their lived experiences, and by further demonstrating stigma and negative narratives of HSV through word associations, hypothetical situations, and social media post coding.

Training Implications

Both the original research study and the content analysis performed as part of this dissertation briefly highlighted the extent of HSV misinformation present on social media, as well as the lack of knowledge participants reported about multiple STIs. Such widespread knowledge inadequacies necessitate a serious reconsideration of current sexual health policies and programs (Centers for Disease Control and Prevention, 2020).

Sexual Health Education Programs for Adolescents

Per the National Conference for State Legislatures, as of October 1, 2020 instruction in sexual health education is required in only 30 states and the District of Columbia, while only 22 states require that sexual health and/or HIV education, if provided, must be “medically, factually or technically accurate." Displayed alongside adolescent and young adult STI facts, such as almost half (48.2%) of chlamydia, gonorrhea, and syphilis cases in 2023 being attributed to adolescents and young adults aged 15-24, the paucity of STI education across the United States moves from a shocking lack of literacy to a public health crisis (Centers for Disease Control and Prevention, 2024b).

According to the Center for Disease Control and Prevention's 2020 School Health Profile, dissemination of key sexual health education topics like STIs decreased for adolescents aged 15-19 decreased between 2011-2019, with major racial and gender disparities existing in students who were able to receive adequate sexual health topic education. Additionally, only 31% of lead health education teachers in secondary schools received training in the two years prior to the 2020 survey in "Building student skills in HIV, other STDs, and pregnancy prevention," indicating that continuing education for staff providing STI education to adolescents may be inadequate (Centers for Disease Control and Prevention, 2020).

For health topics with multiple BPSS implications like STIs, including STIs like HSV, educating individuals is a matter not only of reducing risk of transmission and rates of diagnosis, but also of ending stigma and shame. Both stigma and shame are parasitic to afflicted individuals in that once they take root within an individual or stigmatized identity, they proliferate and spread into larger and more concerning issues. Stigma and shame can lead to BPSS effects like social exclusion, adverse mental health effects, and spiritual turmoil, all of which can feed into each other to further exacerbate the other parts of the total BPSS health of an individual (Earnshaw et al., 2021; Morris et al., 2014; Reeves et al., 2023; Scheinfeld, 2021; Thomas et al., 2022).

Following the results of the original research conducted in prior chapters, it is recommended that sexual health become mandated starting in adolescence, medically accurate, and presented from an inclusive BPSS framework to encompass the systemic effects of sexual health. Utilizing existing guidelines, such as those found in the National Sexuality Education Standards from the Future of Sex Education Initiative (2012), can take away some of the initial work in implementing a new sexual health curriculum. The National Sexuality Education Standards provide a comprehensive breakdown of when a variety of sexual health topics, including STIs, should be covered from kindergarten through twelfth grade and includes recommendations in several BPSS oriented domains (Future of Sex Education Initiative, 2012).

Healthcare Providers

Recommendations for providers performing STI screenings on adolescents from the Centers for Disease Control and Prevention (2021) advocate for providers to integrate education on STIs, including prevention, risk reduction methodologies, and benefits of abstinence, into their clinical work. However, many providers report not feeling prepared or having adequate information to address STIs with adults, nevertheless adolescents (Guilamo-Ramos et al., 2021; Leyva-Moral et al., 2021). Saddling medical providers with education the general populace in addition to their other job duties, which often includes both clinical and administrative work amongst other tasks, is a poor substitute for adequate sexual health education for the general populace. Additionally, relying on clinically focused medical providers as one of the sole resources for health education further limits health literacy to those who currently have access to healthcare.

However, while medical providers continue to work within a culture that does not prioritize the sexual health literacy of its citizens, providers will continue to be burdened with filling sexual health education gaps when clinical matters arise. Given that over half of the participants of the present study, who were all aged 18 and older, had previous experiences of discrimination or shame from a healthcare provider for a sexual health concern, medical education needs to assist providers with talking about highly stigmatized topics to a variety of patient populations. Healthcare providers discussing STIs with patients are in a position of power given their expertise and role in the patient-provider relationship, with their power having the ability to abrogate or perpetuate stigma (Garcia et al., 2021; Stangl et al., 2019). It is therefore recommended that medical education encompass not only the biological aspects of STIs, but also the psychological, social, and spiritual meanings associated with diagnosis.

Additional recommendations would be to continue to develop provider's abilities to emotionally attune with patients while discussing difficult or stigmatized topics, as well as the ability to provide patient education on topics that are rampant with misinformation. Healthcare providers in training should be encouraged to process their experiences and to do self-of-the-provider work focused on reflecting on their interactions, beliefs, and reactions to their work and experiences. Teaching providers how to reflect and improve their overall quality of patient care creates a provider primed for a long career of learning and personal growth.

Medical Family Therapists

For systemically trained therapists seeking to work from an integrated care perspective using a BPSS lens, understanding the basic biological components of illnesses patients struggle with may be beneficial. Models such as the Family Systems Illness (FSI) model presented by Rolland (2018) should be an integral part of training and applied to a variety of issues, including illnesses like HSV. MedFTs should be trained to assist in the repair of relationships between patients, providers, and their families, as well as to assist healthcare providers with difficult and potentially stigmatizing conversations with patients when appropriate. Including education on healthcare systems, including the culture and hierarchy present in medical settings, would be beneficial for MedFTs seeking to balance the complex web of relationships often present in a medical examine room (Hodgson et al., 2014).

As a result of the present research, other recommendations for MedFT training include understanding the intersection of technology, culture, healthcare, and sexual health as an example of how topics that appear to be individual in nature have other, more complicated, systemic roots. Incorporating social media into MedFT education to encourage MedFTs to think about systemic beliefs, ideas, and information that providers, patients, and themselves are immersed in would be beneficial. Additionally, MedFTs should continuously engage in self of the provider reflection as part of their training to understand how their own implicit or explicit biases and stigmatizing beliefs, especially pertaining to STIs like HSV, may present in their work.

Operational Implications

To accommodate a BPSS intensive diagnosis like HSV, operational changes to clinic flow and structure may need to be considered. Adding in time to clinician schedules for patient education, creating a workflow that accounts for integrated care practitioners like MedFTs, and education employees on utilizing EMR systems in a non-stigmatizing way are all important potential changes for the operational “world” of any given healthcare system to consider. Making room for patient concerns and addressing issues outside of the purely biological implications of a diagnosis can appear inefficient, but for patients it can make the difference in their comfort level and health literacy.

Additionally, adding in providers like MedFTs to relieve some of the burden of addressing every BPSS aspect of diagnoses like HSV can potentially increase productivity for healthcare providers (Hodgson et al., 2014). By operationally employing providers who specialize in systems and BPSS to care for patients alongside providers, healthcare providers can then focus on other aspects of their work, creating more capacity for patient care.

Financial Implications

Providers and healthcare systems need proper reimbursement for time spent with patients, and the ultimate recommendation for the financial “world” would be to monetize the time providers spend with patients on tasks that are clinical adjacent. Providers spend a significant amount of time on administrative and patient centered tasks that are not always billable (e.g. answering patient electronic medical records, note taking, sending orders), and are often penalized when they don’t hit clinical benchmarks (Drossman et al., 2021; Kerluku et al., 2024). By monetizing provider time, the healthcare system would be incentivizing the time investment that providers holistically pour into patients.

If healthcare provider’s time cannot be monetized in other ways that encompass the holistic needs of patients, pulling in medical family therapists and behavioral health providers could be another avenue for decreasing financial burden. Preliminary findings indicate that utilizing medical family therapists can reduce healthcare utilization not only for the target patient, but also for other family members involved in the therapeutic process (Hodgsen et al., 2014). Additionally, as a therapeutic modality involving multiple people within a relational system, family therapy may be more cost effective than individual therapy, as multiple people are impacted within the same session (2014).

For HSV specifically, the economic burden is substantial, with the economic burden of HSV in the Americas reaching almost a billion in internationally equivalated currency in 2016 (Chaiyakunapruk et al., 2024). Economic costs of HSV include direct care costs like suppressive medications and provider visits, indirect costs like wages lost to transportation and seeking care, and other costs like providing HSV positive pregnant women with cesarean sections instead of vaginal delivery or treatment for neonatal HSV infections. Recommendations for the financial "world" would include improving HSV literacy, investing in transmission reduction initiatives, and co-locating multiple healthcare team members to address patient concerns utilizing less visits (e.g. an appointment with a healthcare provider accompanied by a brief visit with a MedFT).

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APPENDIX A: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
Willis Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **rede.ecu.edu/umcirb/**

Notification of Exempt Certification

From: Social/Behavioral IRB
To: Alexis Bruhn
CC: Damon Rappleyea
Date: 10/3/2024
Re: UMCIRB 24-001741
HSV, Social Media, and the Patient-Provider Relationship

I am pleased to inform you that your research submission has been certified as exempt on 10/2/2024. This study is eligible for Exempt Certification under category # 2AB.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
Email Flyer(0.01)	Recruitment Documents/Scripts
End Of Survey Resources/Disclaimer(0.01)	Surveys and Questionnaires
Flyer(0.01)	Recruitment Documents/Scripts
Informed Consent(0.02)	Consent Forms
InformedConsent_Dissertation.docx(0.01)	Information Sheet
Part I(0.01)	Surveys and Questionnaires
Part II(0.01)	Surveys and Questionnaires
Part III(0.01)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

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Amendment Approved

ID:	Ame1_UMCIRB 24-001741
Title:	Amendment 1 for IRB Study #UMCIRB 24-001741 HSV, Social Media, and the Patient-Provider Relationship
Description:	Your amendment has been approved. To navigate to the project workspace, click on the above ID.

APPENDIX B: RECRUITMENT FLYER, EMAIL, AND POST SCRIPTS

Let's Talk About Herpes!

QR

Scan Me!

Come join our research study about herpes and social media!

We want to hear what YOU think about herpes and STI stigma to help us improve care for sexual health!

WHO CAN JOIN?

-Anyone aged 18 years or older
-Healthcare providers also needed

WHAT WILL YOU DO?

Take a confidential 20 minute survey

For more information or questions please email Alexis Bruhn (PI) at bruhna22@students.ecu.edu

Hello,

I am seeking adults aged 18 or older capable of reading and writing English to participate in my research study on herpes simplex virus stigma and social media. I am seeking both healthcare providers (nurses, nurse practitioners, physicians, physician’s assistant) and non-healthcare providers for participation in this survey.

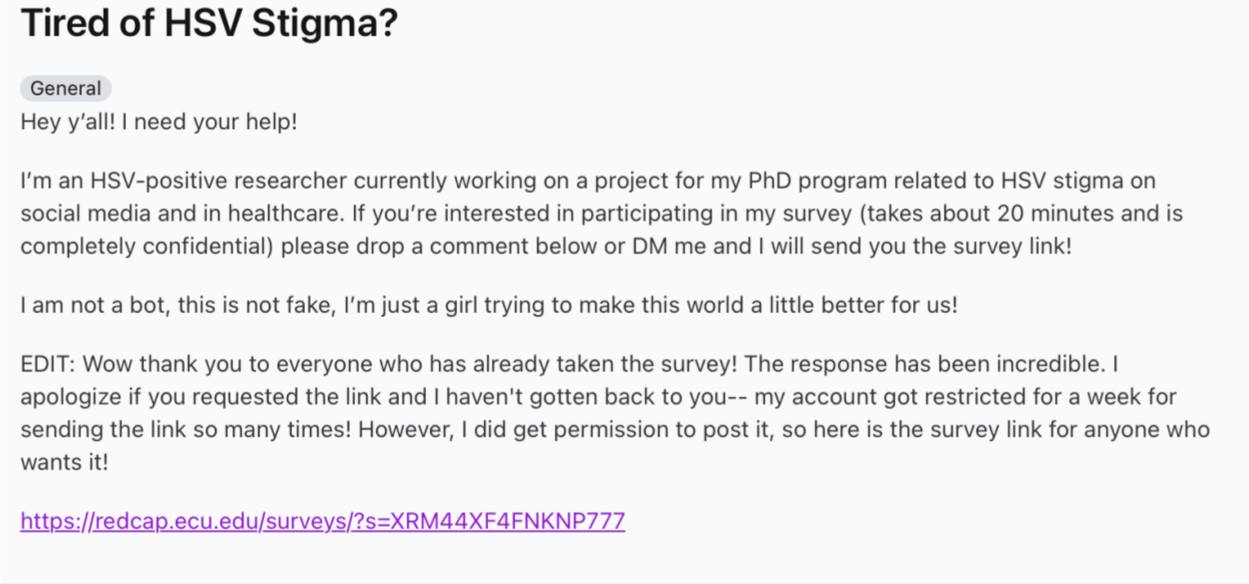
The purpose of this study is to understand how perceptions of social media posts related to stigmatized health topics like the herpes simplex virus differ based on individual background factors.

The survey includes both free response and multiple choice questions about sexual health, sexual education, and healthcare experiences. Participation is completely voluntary, the survey is anonymous, and your responses will be kept confidential.

I ask that you please fill out this survey by **October 14th**.

If you have any questions, feel free to contact me, the principal investigator, via e-mail. Your participation is greatly appreciated. Thank you in advance.

Alexis Bruhn, M.A., LMFTA
PhD Candidate, Medical Family Therapy
East Carolina University
bruhna22@students.ecu.edu
(she/her/hers)



Tired of HSV Stigma?

General

Hey y'all! I need your help!

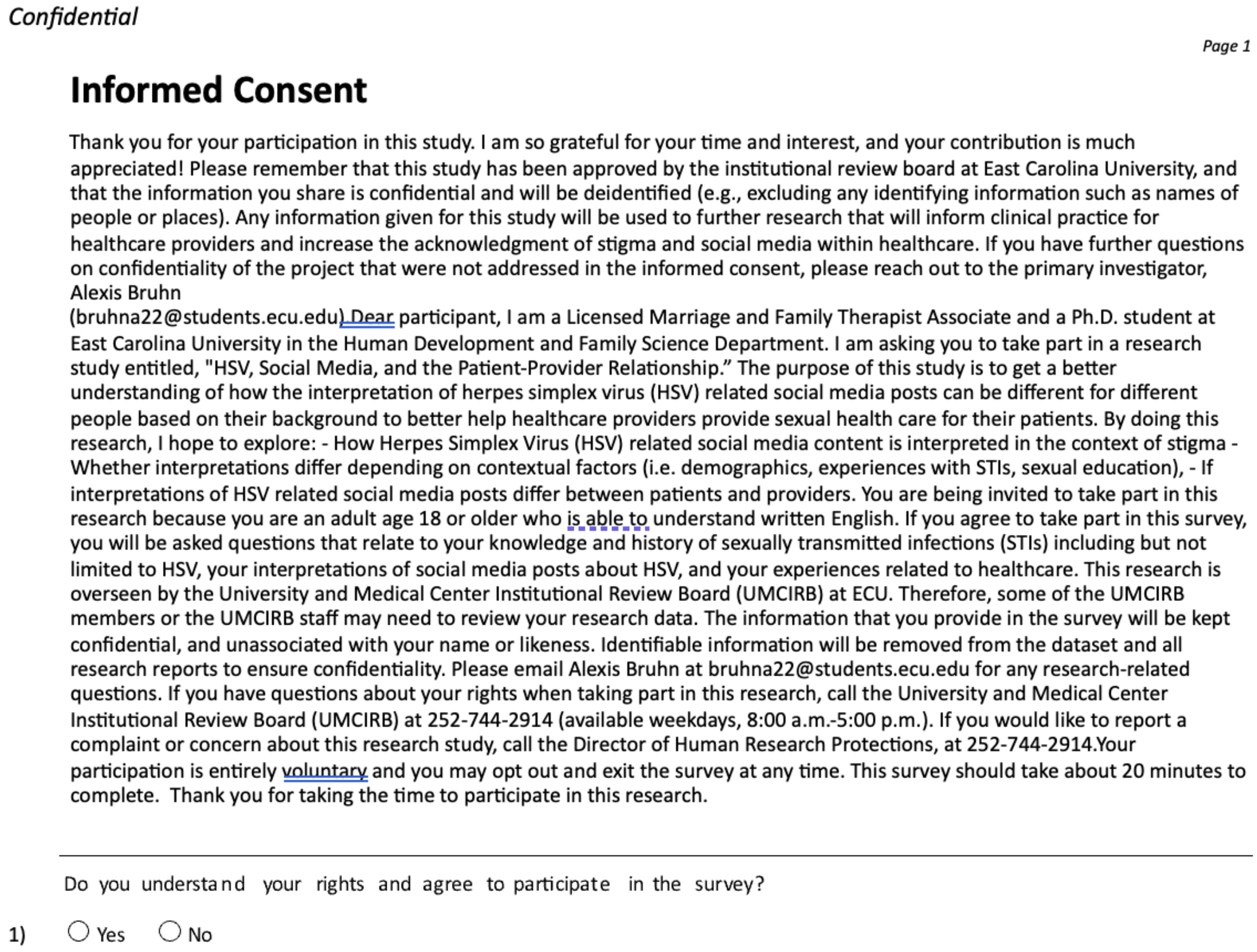
I'm an HSV-positive researcher currently working on a project for my PhD program related to HSV stigma on social media and in healthcare. If you're interested in participating in my survey (takes about 20 minutes and is completely confidential) please drop a comment below or DM me and I will send you the survey link!

I am not a bot, this is not fake, I'm just a girl trying to make this world a little better for us!

EDIT: Wow thank you to everyone who has already taken the survey! The response has been incredible. I apologize if you requested the link and I haven't gotten back to you-- my account got restricted for a week for sending the link so many times! However, I did get permission to post it, so here is the survey link for anyone who wants it!

https://redcap.ecu.edu/surveys/?s=XRM44XF4FNKNP777

APPENDIX C: INFORMED CONSENT



Confidential

Page 1

Informed Consent

Thank you for your participation in this study. I am so grateful for your time and interest, and your contribution is much appreciated! Please remember that this study has been approved by the institutional review board at East Carolina University, and that the information you share is confidential and will be deidentified (e.g., excluding any identifying information such as names of people or places). Any information given for this study will be used to further research that will inform clinical practice for healthcare providers and increase the acknowledgment of stigma and social media within healthcare. If you have further questions on confidentiality of the project that were not addressed in the informed consent, please reach out to the primary investigator, Alexis Bruhn
(bruhna22@students.ecu.edu) Dear participant, I am a Licensed Marriage and Family Therapist Associate and a Ph.D. student at East Carolina University in the Human Development and Family Science Department. I am asking you to take part in a research study entitled, "HSV, Social Media, and the Patient-Provider Relationship.” The purpose of this study is to get a better understanding of how the interpretation of herpes simplex virus (HSV) related social media posts can be different for different people based on their background to better help healthcare providers provide sexual health care for their patients. By doing this research, I hope to explore: - How Herpes Simplex Virus (HSV) related social media content is interpreted in the context of stigma - Whether interpretations differ depending on contextual factors (i.e. demographics, experiences with STIs, sexual education), - If interpretations of HSV related social media posts differ between patients and providers. You are being invited to take part in this research because you are an adult age 18 or older who is able to understand written English. If you agree to take part in this survey, you will be asked questions that relate to your knowledge and history of sexually transmitted infections (STIs) including but not limited to HSV, your interpretations of social media posts about HSV, and your experiences related to healthcare. This research is overseen by the University and Medical Center Institutional Review Board (UMCIRB) at ECU. Therefore, some of the UMCIRB members or the UMCIRB staff may need to review your research data. The information that you provide in the survey will be kept confidential, and unassociated with your name or likeness. Identifiable information will be removed from the dataset and all research reports to ensure confidentiality. Please email Alexis Bruhn at bruhna22@students.ecu.edu for any research-related questions. If you have questions about your rights when taking part in this research, call the University and Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 (available weekdays, 8:00 a.m.-5:00 p.m.). If you would like to report a complaint or concern about this research study, call the Director of Human Research Protections, at 252-744-2914.Your participation is entirely voluntary and you may opt out and exit the survey at any time. This survey should take about 20 minutes to complete. Thank you for taking the time to participate in this research.

Do you understand your rights and agree to participate in the survey?

1) ○ Yes ○ No

APPENDIX D: REDCAP SURVEY

HSV Stigma and Social Media Survey

Part I

For the first part of this survey, you will see ten different posts from X (formerly twitter) and asked to rate them individually based on how you think the posts talk about the herpes simplex virus (HSV) or those who might have it. You will be able to choose from three categories: - HSV positive-- the post talks positively about HSV, and if you saw this post you would think good/empowering thoughts, or feel good/happy emotions about HSV or those who have HSV - HSV negative-- the post talks negatively about HSV, and if you saw this post you would think bad/harmful/negative thoughts about HSV, or feel bad/sad/angry emotions about HSV or those with HSV - HSV neutral-- the post is neither negative or positive-- you do not think or feel bad or good emotions/thoughts in response to the postTry to go through the posts quickly: go with your gut reaction to each post as opposed to spending a lot of time thinking about each post!DISCLAIMER: The following twenty posts are real posts taken directly from X and posted between August 1st and August 14th 2024. Viewer discretion is advised: many of the following posts contain content that can be offensive, and that may be inaccurate or incorrect. Please do not judge the posts on how accurate or offensive they are, but rather how the posts talk about herpes. Resources for accurate information will be provided at the end of the entire survey.

When life gives you lemons.... just be glad it wasn't **herpes**

1)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)

🔑 What is Genital Herpes?

Genital herpes is an STI caused by the **herpes simplex** virus (HSV). There are two types of HSV: HSV-1 and HSV-2. While HSV-1 typically causes oral herpes (cold sores), it can also cause genital herpes. HSV-2 primarily causes genital herpes.

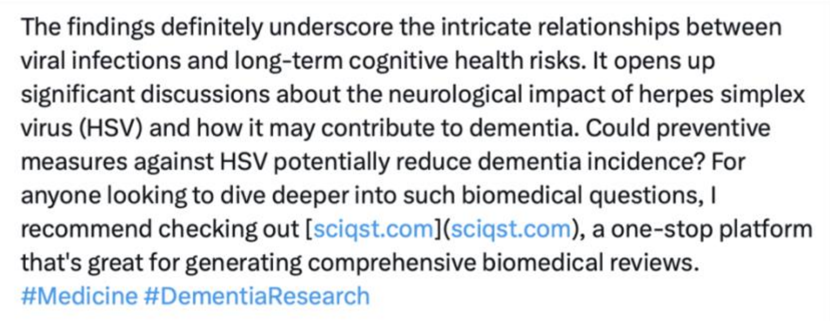
2)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)

They breed / spread like ... **herpes** 🤭😅

3)

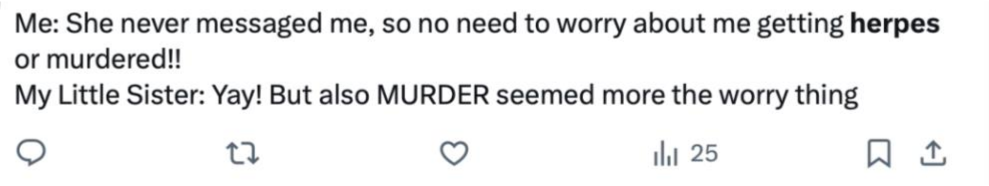
HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)



The findings definitely underscore the intricate relationships between viral infections and long-term cognitive health risks. It opens up significant discussions about the neurological impact of herpes simplex virus (HSV) and how it may contribute to dementia. Could preventive measures against HSV potentially reduce dementia incidence? For anyone looking to dive deeper into such biomedical questions, I recommend checking out sciqst.com, a one-stop platform that's great for generating comprehensive biomedical reviews. #Medicine #DementiaResearch

4)

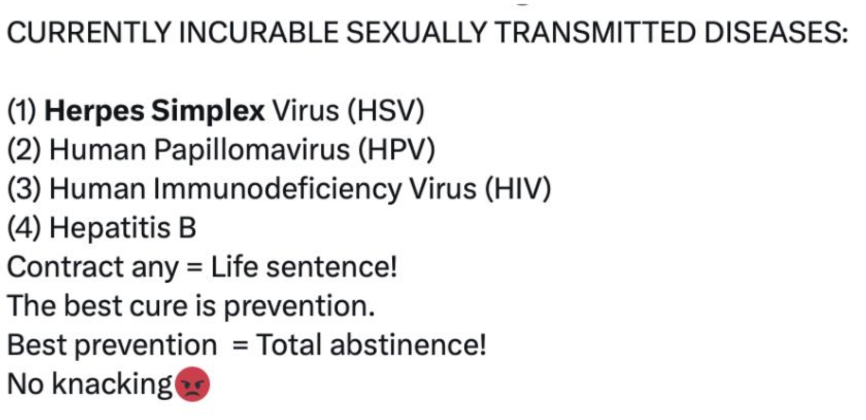
HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)



Me: She never messaged me, so no need to worry about me getting **herpes** or murdered!!
My Little Sister: Yay! But also MURDER seemed more the worry thing

5)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)

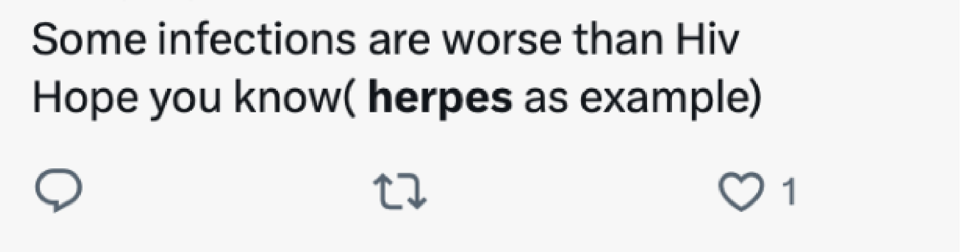


CURRENTLY INCURABLE SEXUALLY TRANSMITTED DISEASES:

(1) **Herpes Simplex** Virus (HSV)
(2) Human Papillomavirus (HPV)
(3) Human Immunodeficiency Virus (HIV)
(4) Hepatitis B
Contract any = Life sentence!
The best cure is prevention.
Best prevention = Total abstinence!
No knacking😡

6)

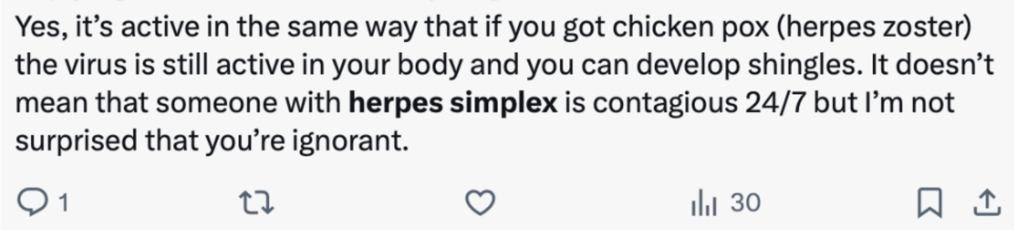
HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)



Some infections are worse than Hiv
Hope you know(**herpes** as example)

7)

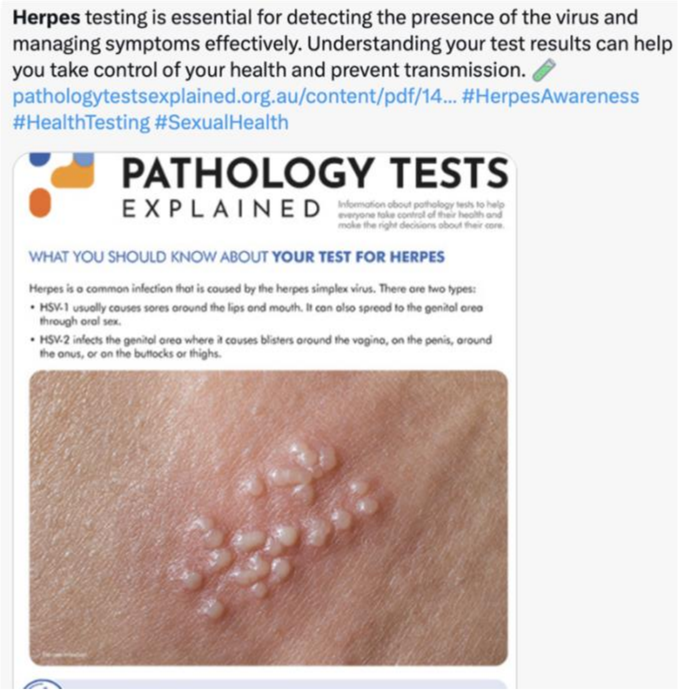
HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)



Yes, it’s active in the same way that if you got chicken pox (herpes zoster) the virus is still active in your body and you can develop shingles. It doesn’t mean that someone with **herpes simplex** is contagious 24/7 but I’m not surprised that you’re ignorant.

8)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)



Herpes testing is essential for detecting the presence of the virus and managing symptoms effectively. Understanding your test results can help you take control of your health and prevent transmission. 🧪 pathologytestsexplained.org.au/content/pdf/14... #HerpesAwareness #HealthTesting #SexualHealth

PATHOLOGY TESTS
EXPLAINED
Information about pathology tests to help everyone take control of their health and make the right decisions about their care.

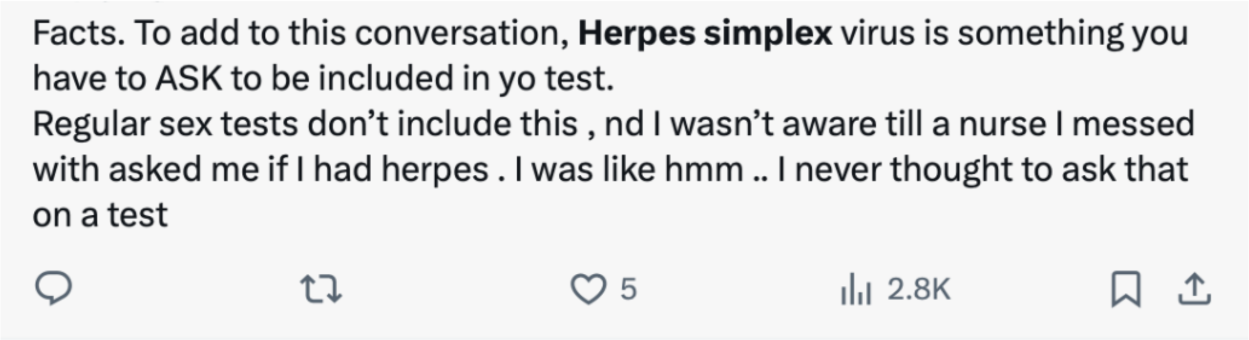
WHAT YOU SHOULD KNOW ABOUT **YOUR TEST FOR HERPES**

Herpes is a common infection that is caused by the herpes simplex virus. There are two types:

- HSV-1 usually causes sores around the lips and mouth. It can also spread to the genital area through oral sex.
- HSV-2 infects the genital area where it causes blisters around the vagina, on the penis, around the anus, or on the buttocks or thighs.

9)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)


Facts. To add to this conversation, **Herpes simplex** virus is something you have to ASK to be included in yo test.
Regular sex tests don't include this , nd I wasn't aware till a nurse I messed with asked me if I had herpes . I was like hmm .. I never thought to ask that on a test

10)

HSV Positive (I would think or feel good/positive/hopeful/happy thoughts/feelings about HSV or people who have HSV)
HSV Neutral (I would not think or feel any bad or good thoughts/feelings about HSV or people who have HSV)
HSV Negative (I would think or feel bad/negative/hurtful/mean thoughts/feelings about HSV or people who have HSV)

HSV Stigma and Social Media Survey

Part IIFor the second part of this survey, you will be asked a variety of questions about your background, including your experience with sexually transmitted infections (STIs) and sexual health. Please answer all questions to the best of your ability. Some of the questions have instructions that are different than others. Please make sure to read all instructions before answering.

What is your age in years?

____

Please select the option that best describes you

○ I am currently or was previously a physician, nurse practitioner, physician's assistant, or nurse
○ I have never been a physician, nurse practitioner, physician's assistant, or nurse

---

What term best describes your gender identity?

○ Woman
○ Man
○ Non-binary
○ Transgender man/Female-to-male (FTM)
○ Transgender woman/Male-to-female (MTF)
○ Gender non-binary/Genderqueer/Gender nonconforming
○ Agender
○ Bigender
○ None of these describe me
○ Prefer not to answer

Which racial category best describes you?

○ American Indian or Alaska Native
○ Asian
○ Black or African American
○ Native Hawaiian or Other Pacific Islander
○ White
○ More than one race
○ Other Race
○ Prefer not to Answer
○ Unknown

Which option best describes your ethnicity?

○ Hispanic or Latino
○ Not Hispanic or Latino
○ Prefer not to answer
○ Unknown

Which of the following options best describes you sexual orientation?

○ Lesbian
○ Gay
○ Heterosexual
○ Bisexual
○ Transexual
○ Pansexual
○ Asexual
○ Other
○ I don't know
○ I'm still figuring it out
○ I'd prefer not to answer

Please specify

____

Which of the following best describes your religious/spiritual identity?

○ None
○ Christian
○ Buddhist
○ Hindu
○ Jewish
○ Muslim
○ Sikh
○ Wiccan
○ Spiritual but not religious
○ Other, specify
○ I'd prefer not to answer

Please specify

____

Did you go through sexual health education courses as part of your schooling before the age of 18?

○ Yes
○ No
○ I'm not sure

Did you have any other formal sexual health education (i.e. medical school, elective courses, religious courses on sexual health)?

○ Yes
○ No
○ I'm not sure

Please describe the formal sexual education you received

How would you describe your knowledge of sexually transmitted infections (STIs)?

I don't know anything about STIs	I could protect myself but I'm not sure I could teach others	I know so much I could teach others and I feel comfortable protecting myself

☐☐

(Place a mark on the scale above)

Have you ever been tested for sexually transmitted infections (STIs)?

○ Yes
○ No
○ I'm not sure
○ Prefer not to answer

Have you ever or are you currently diagnosed with a sexually transmitted infection (STI)?

○ Yes
○ No
○ I've never been tested
○ I'm not sure
○ Prefer not to answer

Please rate each the following sources from 1 to 5 based on how likely you would be to seek STI information from that source, with 1 being a source you would least likely utilize and 5 being a source you would most likely utilize

	1-- I would likely not get STI information from this source	2	3	4	5-- I would most likely get STI information from this source
Healthcare Provider	○	○	○	○	○
Friend or Family Member	○	○	○	○	○
Social Media	○	○	○	○	○
Google/Internet Based Source Other Than Social Media	○	○	○	○	○
Church or Religious/Spiritual Organization	○	○	○	○	○
Urgent Care	○	○	○	○	○

Do you feel comfortable talking with a healthcare provider about sexually transmitted infections (STIs)?

○ Yes
○ No
○ Maybe/It Depends
○ I Don't Know

Have you ever felt shamed, discriminated against, or treated poorly by a healthcare provider due to a sexually transmitted infection (STI) or sexual health concern?

○ Yes
○ No
○ Maybe
○ I don't know

Please rate each sexually transmitted infection (STI) from 1 to 5 based on how much you know about each STI, where 1 means you know nothing about that STI and 5 means you have a strong knowledge of that STI

	1-- I know nothing about this STI	2	3-- I know a fair amount about this STI	4	5-- I know mostly everything about this STI
Human Immunodeficiency Virus (HIV)	○	○	○	○	○
Herpes Simplex Virus (HSV)	○	○	○	○	○
Human Papilloma Virus (HPV)	○	○	○	○	○
Gonorrhea	○	○	○	○	○
Chlamydia	○	○	○	○	○
Syphillis	○	○	○	○	○

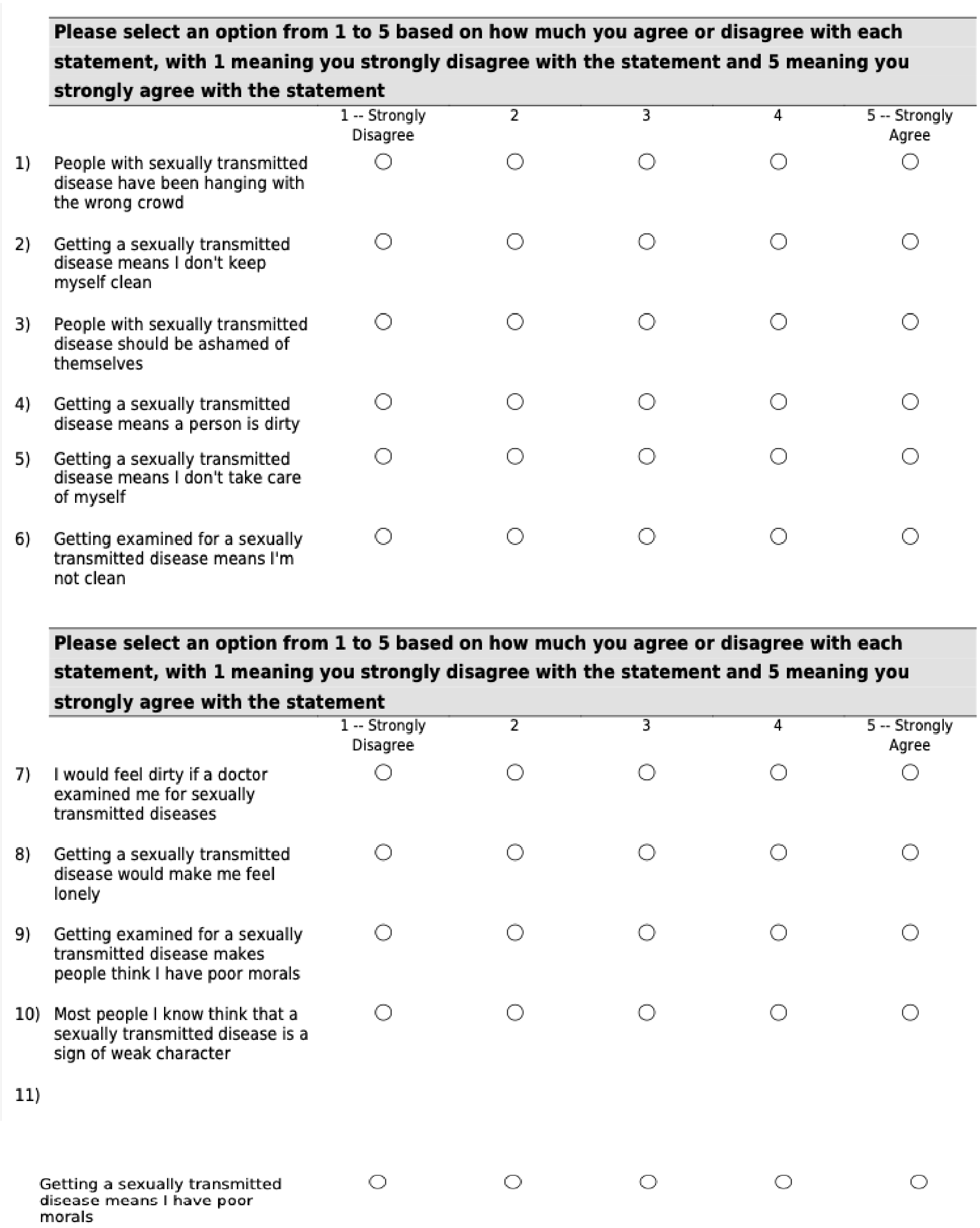
Please rate each STI from 1 to 5 based on how you feel about being diagnosed with that specific STI, with 1 meaning you would not feel distressed at all about being diagnosed with that STI, and 5 meaning you would be extremely distressed to be diagnosed with that STI

	1-- I would not feel distressed at all about being diagnosed with this STI	2	3-- I would feel some distress about being diagnosed with this STI	4	5-- I would feel extremely distressed about being diagnosed with this STI
Human Immunodeficiency Virus (HIV)	○	○	○	○	○
Herpes Simplex Virus (HSV)	○	○	○	○	○
Human Papilloma Virus (HPV)	○	○	○	○	○
Gonorrhea	○	○	○	○	○
Chlamydia	○	○	○	○	○
Syphillis	○	○	○	○	○

What words do you associate with Herpes Simplex Virus (HSV)? Write as many words or phrases as you'd like, separating words and phrases and with a comma between them. If you are unsure, put "I am unsure."

What would you be the MOST likely to do if a potential sexual partner disclosed they were positive for herpes simplex virus (HSV) to you prior to sexual activity?

○ Move forward with the relationship with this person but take extra precautions
○ Move forward with the relationship with this person without extra precautions or like you would with any other partner
○ No longer see this person (cut the relationship off)
○ Ask questions or get more information before making a decision
○ I don't know
○ It depends



Please select an option from 1 to 5 based on how much you agree or disagree with each statement, with 1 meaning you strongly disagree with the statement and 5 meaning you strongly agree with the statement

		1 -- Strongly Disagree	2	3	4	5 -- Strongly Agree
1)	People with sexually transmitted disease have been hanging with the wrong crowd	○	○	○	○	○
2)	Getting a sexually transmitted disease means I don't keep myself clean	○	○	○	○	○
3)	People with sexually transmitted disease should be ashamed of themselves	○	○	○	○	○
4)	Getting a sexually transmitted disease means a person is dirty	○	○	○	○	○
5)	Getting a sexually transmitted disease means I don't take care of myself	○	○	○	○	○
6)	Getting examined for a sexually transmitted disease means I'm not clean	○	○	○	○	○

Please select an option from 1 to 5 based on how much you agree or disagree with each statement, with 1 meaning you strongly disagree with the statement and 5 meaning you strongly agree with the statement

		1 -- Strongly Disagree	2	3	4	5 -- Strongly Agree
7)	I would feel dirty if a doctor examined me for sexually transmitted diseases	○	○	○	○	○
8)	Getting a sexually transmitted disease would make me feel lonely	○	○	○	○	○
9)	Getting examined for a sexually transmitted disease makes people think I have poor morals	○	○	○	○	○
10)	Most people I know think that a sexually transmitted disease is a sign of weak character	○	○	○	○	○
11)						
	Getting a sexually transmitted disease means I have poor morals	○	○	○	○	○

HSV Stigma and Social Media Survey

Part IIIThe last part of this survey contains three free response questions. Please type your answers in the text box under each question.

---

1) Which post from Part I stood out to you the most? Why? (Try to describe the post as best you can)

---

2) Based on the posts you looked at in Part I, how do you think society in general views HSV and those living with it?

---

3) Based on the posts you looked at in Part I, have your opinions, feelings, or views about HSV changed? Why or why not?

APPENDIX E: END OF SURVEY RESOURCES

Thank you for taking the survey!
Your input is very appreciated and helps make change happen! If you have any questions or concerns about the survey, please email the Primary Investigator Alexis Bruhn at bruhna22@students.ecu.edu.
As disucssed throughout the survey, some of the survey material may have been distressing. If you need to speak with someone, please seek mental health services in your area by visiting the website Psychology Today to locate mental health providers near you.
Below are some resources for Herpes Simplex Virus information. Please note that these resources have been evaluated as being positive towards the herpes simplex virus as of the making of this survey, and that online sources should not be used as a replacement for advice from healthcare professionals. This survey and the creators of it do not endorse or have any affiliations with any of the sources/creators listed below. If you are experiencing symptoms, please seek a healthcare provider.

WEBSITES

World Health Organization HSV Fact Sheet
U.S. Centers for Disease Control and Prevention HSV Fact Sheet
Johns Hopkins Medicine HSV Overview
Mayo Clinic Genital Herpes Overview

SOCIAL MEDIA PAGES

@sexelducation -- TikTok and Instagram
@suzbubs -- Instagram; @suzbub -- TikTok
@theonlyre._ -- Instagram; @Arie.4kk -- TikTok
@shanasingleton -- Instagram/TikTok; @cousinshanasing -- X
@pickeringfitness -- Instagram
@safe.slut -- Instagram, TikTok, X
@lifewithherpes -- Instagram and X
@DebunkedHerpes -- X
@HerpesUK -- X
@HerpesAdvocate -- X
@herpescouldnvr -- X
r/Herpes -- Reddit
r/HSVpositive -- Reddit