HSV+ and Proud: Does Illness Identity Mediate the Relationship Between Genital Herpes Stigma and Well-Being?

Nikolas Forest Priest

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HSV+ AND PROUD: DOES ILLNESS IDENTITY MEDIATE THE RELATIONSHIP BETWEEN GENITAL HERPES STIGMA AND WELL-BEING?

by

Nikolas Priest

A Dissertation
Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Major: Counseling Psychology

The University of Memphis
August 2024
Abstract

Genital herpes is a common, incurable, sexually transmitted infection that can be accompanied by significant social stigma that is associated with psychological distress, diminished quality of life, and diminished sexual well-being. How people incorporate chronic illnesses into their sense of self can also have significant effects on well-being. The illness identity model attempts to capture identity states that are more or less adaptive in adjusting to a chronic illness (Engulfment, Rejection, Acceptance, and Enrichment), but this model has not been studied in relation to stigmatized identities. The current study assessed if the different illness identity states mediated the relationship between perceived genital herpes stigma and two measures of well-being. A parallel mediation analysis was conducted with 204 participants diagnosed with genital herpes (HSV-1 or HSV-2). Measurement instruments included the Genital Herpes Stigma Scale (GHSS), Illness Identity Questionnaire (IIQ), Recurrent Genital Herpes Quality of Life Questionnaire (RGHQoL), and New Sexual Satisfaction Scale, Ego subscale (NSSS-Ego). Results revealed strong mediation by the engulfment illness identity and weaker mediation by the acceptance identity between stigma and measures of well-being. The present findings highlight the importance of identity in mediating the negative effects of genital herpes on well-being.
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Introduction

Genital herpes is a common, incurable, sexually transmitted infection that typically presents with minimal physical sequelae (Johnston, 2022). However, genital herpes carries significant social stigma that can result in psychological distress, psychosocial harm, diminished quality of life, decreased sexual behavior, and diminished sexual well-being (Brentjens et al., 2003; Devine et al., 2022; Foster & Byers, 2013, 2016; Gupta et al., 2007; Mindel, 1996; Newton & McCabe, 2008; Wang et al., 2018). As a stigmatized identity, genital herpes affects the person’s self-concept, interpersonal relationships, and ability to adapt to a chronic illness, which leads to decreased quality of life. The positive incorporation of a diagnosis of a chronic and incurable illness into one’s identity has been associated with better quality of life (O’Donnell & Habenicht, 2022; Van Bulck et al., 2019). Identity theory may provide a useful theoretical framework for understanding and managing the negative effects of genital herpes-related stigma.

Health-promoting behaviors (e.g., medication adherence and physician visits) and overall quality of life can be affected by how people incorporate chronic illness into their identity (Charmaz, 1995; Marcussen et al., 2021; O’Donnell & Habenicht, 2022; Van Bulck et al., 2018, 2019; Yanos et al., 2020). The illness identity model attempts to capture two states that successfully integrate an illness as part of the individual’s identity (acceptance and enrichment) and two states that do not (rejection and engulfment) (Andonian et al., 2021; Luyckx et al., 2018; Meyer & Lamash, 2021; Na et al., 2021; Oris et al., 2016, 2018; Peters & Brown, 2022; Rassart et al., 2022; Ross, 2018; Van Bulck et al., 2019). Previous studies have primarily applied the illness identity model to chronic illnesses with a focus on physical symptoms and have not assessed the role of stigma in their analyses (Luyckx et al., 2018). Additionally, much of the literature bridging illness identity and stigma theory is prospective or qualitative in nature (Lee &
Craft, 2002; Nack, 2000; O’Donnell & Habenicht, 2022; Rassart et al., 2022). The current study extends previous findings on the relationship between chronic illness and quality of life by assessing the relationship between genital herpes-related stigma and outcomes of well-being (i.e., quality of life and sexual satisfaction) with the four illness identity dimensions as potential mediators. Learning more about the underlying mechanisms of identity integration for individuals with genital herpes could inform more effective interventions for genital herpes-related stigma.

**Genital Herpes**

Genital herpes is an incurable sexually transmitted infection (STI) caused by herpes simplex virus 1 or 2 (HSV-1 or HSV-2) and is one of the most common STIs in the world (Gupta et al., 2007; James et al., 2020; Johnston, 2022; World Health Organization, 2016). It is estimated that 11.9% of persons 14 to 49 years of age in the United States (McQuillan et al., 2018) and 13.2% of persons 15 to 49 years of age in the world have an HSV-2 infection (James et al., 2020). Although HSV-2 is most commonly associated with genital herpes, an increase of genital infections caused by herpes simplex virus type 1 (HSV-1) likely increases the prevalence estimates cited above (Schiffer & Corey, 2009).

The physical symptoms of an initial genital herpes infection do not differ between HSV-2 and HSV-1 and can result in multiple lesions on the genitals or adjacent skin that resolve in about 2 to 3 weeks with systemic symptoms including headache, fever, malaise, dysuria, or tender lymph nodes in the groin area (Gnann & Whitley, 2016). Genital herpes is frequently characterized by recurrent outbreaks of painful ulcers, first appearing as one or more blisters on or around the genitals that break and then heal in about 5-10 days (Gupta et al., 2007; Johnston, 2022). A recurrent genital herpes infection will alternate between latent stages and symptomatic
recurrences with less frequent recurrences for HSV-1 genital infections compared to HSV-2 (Gnann & Whitley, 2016; Johnston, 2022). Serious physical complications associated with genital herpes infections, while rare, can include neonatal herpes infection (i.e., perinatal transmission from mother to infant and carrying a mortality rate up to 60% if untreated) and a three times higher increased risk of acquiring human immunodeficiency virus (Corey & Handsfield, 2000; Groves, 2016; Gupta et al., 2007; Johnston, 2022). Individuals with genital herpes are advised to abstain from sexual activities while lesions are present and genital herpes is most contagious (Gupta et al., 2007). Medical treatment for genital herpes generally consists of episodic and suppressive therapy with anti-viral medications with the goals of preventing outbreak recurrences, treating recurrences, and preventing transmission to sexual partners (Johnston, 2022).

At the same time, a majority of seropositive patients are unaware of their status because genital herpes infections can often be asymptomatic or so mild that subclinical symptoms go unnoticed or are attributed to a different skin condition (Brentjens et al., 2003; Groves, 2016; Gupta et al., 2007; Johnston, 2022; Schiffer & Corey, 2009; World Health Organization, 2016). For example, one study of women with genital herpes infections found 74% of HSV-1 infections and 63% of HSV-2 infections were asymptomatic (Bernstein et al., 2013). Another study found that only 10-25% with serologically confirmed HSV-2 infections were aware of their status (Gnann & Whitley, 2016). Furthermore, genital herpes may go undiagnosed because tests for genital herpes are not routinely conducted or recommended among asymptomatic individuals in the general population (Gupta et al., 2007; Johnston, 2022; US Preventive Services Task Force et al., 2016).
A genital herpes diagnosis is frequently associated with significant psychosocial complications such as negative psychological emotions (e.g., anger, depression, disbelief, fear of rejection) and lower levels of quality of life, sexual well-being, self-esteem, social interaction, sexual behavior, and personal relationships (Bobrow, 2016; Brentjens et al., 2003; Corey & Handsfield, 2000; Goldmeier et al., 1988; Gupta et al., 2007; Johnston, 2022; Melville et al., 2003; Merin & Pachankis, 2011; Wang et al., 2018; World Health Organization, 2016). Previous studies have found a strong relationship between physical and psychological health where increased severity of physical symptoms and frequency of outbreaks are associated with increased distress (Brentjens et al., 2003; Merin & Pachankis, 2011) and lower quality of life (Patel et al., 2001). Similarly, an absence of recurrent, symptomatic outbreaks is associated with decreased psychological distress (Carney et al., 1994; Rosenthal et al., 2006). The psychosocial consequences of diagnosis may be more clearly understood through examining the associated stigma (Bickford et al., 2007; Bobrow, 2016; Caspers, 2021; Devine et al., 2022; Newton & McCabe, 2008; Nicholson & O’Farrell, 2021; Royer et al., 2013; Wang et al., 2018).

**Genital Herpes-Related Stigma**

Stigma has been studied in the context of many illnesses that are associated with having a devalued identity (i.e., membership in a group that is devalued or associated with undesirable characteristics) such as mental illness, HIV, and other chronic illnesses such as cancer (Chime et al., 2022; Fife & Wright, 2000; Lee & Craft, 2002; Lucksted & Drapalski, 2015; Millen & Walker, 2001; Neal et al., 2010; O’Donnell & Habenicht, 2022; Overton & Medina, 2008; Wang et al., 2018; Yang & Mak, 2017). Both internalized stigma (i.e., internalizing the negative stereotypes about an identity) and experienced discrimination have been associated with increased psychological distress and lower psychological well-being (Quinn & Earnshaw, 2013).
Having a genital herpes diagnosis can be considered a concealable stigmatized identity as it is socially devalued, negatively stereotyped, and can be hidden within a social context until activated by disclosure (Quinn & Earnshaw, 2013; Wang et al., 2018). In a study on concealable chronic illnesses, O’Donnell and Habenicht (2022) found that stigma was generally associated with illness self-concept (i.e., increased preoccupation and perceived impact of the illness on the self). The individual with the concealable stigmatized identity must exercise cognitive preoccupation to suppress the stigmatized identity while also coping with psychological distress of anticipated rejection (O’Donnell & Habenicht, 2022; Quinn & Chaudoir, 2015; Quinn & Earnshaw, 2013; Wang et al., 2018).

Stigma related to STIs has been found to act as a barrier to STI prevention, testing, and treatment as well as negatively affect quality of life and health (Hood & Friedman, 2011). The stigma associated with genital herpes can result in adverse psychological symptoms and is related to significant negative outcomes (Merin & Pachankis, 2011; Patel et al., 2001) such as diminished self-concept (Newton & McCabe, 2005), diminished quality of life (Barnack-Tavlaris et al., 2011; Patel et al., 2001), anger, depression, shame, fear of discovery, and fear of rejection (Gnann & Whitley, 2016). Indeed, physicians are not encouraged to routinely screen for genital herpes in the general population as the concerns about the psychosocial harm of a positive diagnosis in an asymptomatic individual outweigh the benefits of potential reduction of transmission (Johnston, 2022; Miyai et al., 2004; Rosenthal et al., 2006; US Preventive Services Task Force et al., 2016).

In studying concealable stigmatized identity, Quinn and Chaudoir (2015) found increased psychological distress was predicted by greater centrality and increased salience of a stigmatized identity. The centrality of the stigmatized identity could be increased through any reminder,
positive or negative (e.g., frequent symptom outbreaks, sexual encounters, concerns about transmission, and health-promoting behaviors such as medical visits), that threatens to reveal the hidden identity while salience could be increased by stigma-related cues or situations that make the individual feel like a minority (Pachankis, 2007). The efforts to conceal the stigmatized identity have been found to lead to effortful cognitive preoccupation, related distress, and increased identification with the stigmatized group (Merin & Pachankis, 2011). Similarly, O’Donnell and Habenicht found that chronic illness affects one’s self-concept as the individual reconstructs a sense of self by incorporating the illness and that “stigma is associated with increased preoccupation and perceived impact of one’s illness on the self” (2022, p. 136). Lee and Craft (2002) interviewed 20 individuals from a genital herpes self-help group and found that a genital herpes diagnosis “threatens self-concepts and relationships to the extent that it, definitionally, widely implicates identities” (p. 267) and that respondents’ stigma management strategies were motivated by identity processes. Similarly, Caspers (2021) found a strong relationship between sexual self-concept and genital herpes-related stigma.

As noted earlier, the stigma related to a genital herpes diagnosis can result in significant psychological distress (Barnack-Tavlaris et al., 2011). Additionally, individuals who conceal their genital herpes diagnosis from others, possibly due to stigma, are subject to greater long-term psychological discomfort (Wang et al., 2018). Merin and Pachankis (2011) proposed that adverse, stigma-related psychological effects resulting from genital herpes perpetuate the associated distress from the physical symptoms. Similarly, successful disclosure to a sexual partner has been associated with more positive feelings about sexual self-concept (Newton & McCabe, 2008) and there is extensive literature on the use of disclosure as an intervention to counter stigma (Bickford et al., 2007; Merin & Pachankis, 2011; Wang et al., 2018).
Conversely, Provenzale et al. (2011) conducted a review of eight articles between 2000 and 2008 studying the psychosocial impact of a positive HSV-2 diagnosis on asymptomatic adults and found no evidence for a persistent adverse psychological impact following a diagnosis of HSV-2 in university students, individuals concurrent receiving HIV treatment, and a health maintenance organization population. However, they did not assess stigma. With such contradictory evidence as to the psychosocial effects of genital herpes, it is important to examine the stigma associated with a genital herpes diagnosis, outcomes that are expected to relate closely to that stigma, and potential mediating pathways that might explain the contradictory findings.

**Outcomes: Quality of Life and Sexual Satisfaction**

Previous studies (Bennett et al., 2022; Devine et al., 2022; Doward et al., 1998; Fisman, 2005; Wild et al., 1995) have examined associations between a genital herpes diagnosis with quality of life. While several instruments have been used to assess general health-related quality of life, the symptoms and effects of different illnesses can vary so much that it can be beneficial to use measures targeted for specific health conditions. The Recurrent Genital Herpes Quality of Life Questionnaire (RGHQoL) was developed from qualitative interviews of patients in the United Kingdom and subsequently validated in six countries (Doward et al., 1998). Bennet at al. (2022) found the RGHQoL to be the most frequently used condition-specific instrument (6 of 19 studies within a systematic review). Fewer studies have examined the association between stigma related to a genital herpes diagnosis and quality of life (Bennett et al., 2022; Devine et al., 2022) but findings generally support a negative relationship between stigma and quality of life. This study extends previous studies by using a genital herpes-specific quality of life measure that assesses the perceived emotional, social, and physical well-being of the individual.
Additionally, STI-associated stigma is characterized by an association with sex (also a stigmatized behavior) and genital herpes-associated stigma has been identified as a predictor of poor sexual well-being and sexual adjustment (Caspers, 2021; Foster & Byers, 2016; Hood & Friedman, 2011; Newton & McCabe, 2005, 2008). Since genital herpes stigma is related to sexual activity, stigma could lead to restrictions to sexual behavior, a decrease in the number of sexual experiences or a cessation of sexual behavior, or feeling less sexually desirable or attractive (Newton & McCabe, 2008). One study examining how women manage the stigma of STIs (referenced as STDs in the study) found that STI-related stigma only affected portions of self-concept related to sexuality and was compartmentalized away from the entire self-concept with the option of further distancing from their sexual role if the impact became too emotionally painful (Nack, 2000). Foster and Byers (2013) found lower levels of sexual satisfaction and higher levels of a distressing sexual problem in individuals diagnosed with herpes and human papilloma virus compared to individuals with no STIs. Sexual satisfaction has been found to be an important aspect of quality of life (Flynn et al., 2016). Despite the lower levels of sexual satisfaction, the Foster and Byers (2013) study found that participants reported high-quality sexual well-being overall. A later study found that lower sexual well-being was best predicted by experiences of stigmatization and was associated with perception of stigmatization by others and internalized negative social attitudes (Foster & Byers, 2016). Conversely, a few studies have found no significant differences in sexual behavior between individuals newly diagnosed with genital herpes and a control group (Carney et al., 1994; Conaglen et al., 2001).

Unfortunately, the above studies appear to comprise almost the entirety of the evidence linking genital herpes-related stigma and sexual satisfaction. This deficit is partially due to a recent shift away from measuring sexual function to measuring sexual satisfaction; the paucity of
research may also be attributed to the stigma associated with human sexuality that has limited
study in this area. Most instruments that were designed to measure sexual health and well-being
only measure sexual functioning (Esho et al., 2019). What evidence we do have is somewhat mixed, so this study will examine the theorized relationship between genital herpes-related stigma and broadly defined sexual satisfaction that includes sexual sensations, sexual awareness and focus, sexual exchange, emotional closeness, and sexual activity (Štulhofer et al., 2010).

Identity Theory and the Illness Identity Model

According to identity theory, people categorize themselves into social roles based on personal characteristics and self-relevant meanings and those same roles then guide motivation and behavior so that they act in agreement with their self-identity (Stets & Burke, 2000). Identity theory (Stets & Burke, 2000; Stryker & Burke, 2000) has not been widely utilized with the study of genital herpes but may provide a useful theoretical framework in how people incorporate a chronic and incurable illness, albeit one with fewer physical symptoms, into their self-identity and make meaning of their diagnosis. Some individuals may reject their diagnosis as not being consistent with their self-view while others may accept their diagnosis as a part of who they are and accept the necessary behaviors to maintain their health such as going to the doctor, taking medication, or using methods to prevent transmission to a sexual partner.

Recently, there has been a focus on understanding and assessing the construct of illness identity. Illness identity is defined as how much individuals integrate a chronic health condition into their identity, incorporating both illness perceptions and self-perceptions (Van Bulck et al., 2019). Oris et al. (2016) attempted to capture states that successfully and unsuccessfully integrated an illness into the individual’s self-identity and identified four such illness identity dimensions or states. The authors’ scale assessed two successful integration dimensions
(identified as acceptance and enrichment) and two dimensions with a lack of integration (identified as rejection and engulfment) related to a diagnosis of type 1 diabetes. Rejection is defined as when the chronic illness is viewed as unacceptable or as a threat to the self and is then rejected as part of that individual’s identity (Oris et al., 2018). Engulfment is defined as when an individual completely defines their identity and daily life in terms of their illness and at the expense of other important self-assets (Morea et al., 2008). Acceptance is defined as when an individual accepts the illness as part of their identity without allowing it to pervade all life domains (Morea et al., 2008). Enrichment is defined as the individual finding benefit or stress-related growth, specifically related to enriching the self of self or identity (Oris et al., 2018).

People may endorse aspects of several different illness identities while relying primarily on one illness identity state (Oris et al., 2016).

The four aspects of illness identity could capture various adaptation processes that account for differing physiological and psychological outcomes following diagnosis. Rejection could allow for compartmentalization or separation from the diagnosis that might decrease negative emotional reactions. However, rejection might also lead to decreased medical adherence (Oris et al., 2016) while acceptance of the diagnosis as part of who they are might facilitate the necessary behaviors to maintain health. Both acceptance and enrichment were related to greater quality of life and less depression, and acceptance was related to better treatment adherence whereas engulfment was related to lower quality of life and greater depression (Oris et al., 2016).

Researchers have applied the illness identity model toward chronic physical illnesses such as celiac disease (Meyer & Lamash, 2021), congenital heart disease and multisystem connective tissue disorders (Andonian et al., 2021; Na et al., 2021; Oris et al., 2018; Van Bulck et al., 2018), cystic fibrosis (Dell, 2021), inflammatory bowel disease (Peters & Brown, 2022;
Rassart et al., 2022), refractory epilepsy (Luyckx et al., 2018), type 1 diabetes (Rassart et al., 2021), and type 2 diabetes (Ross, 2018). In a study applying the illness identity model to adults with congenital heart disease and with multisystem connective tissue disorders, researchers found that “Rejection and engulfment were related to maladaptive psychological and physical functioning, whereas acceptance and enrichment were related to adaptive psychological and physical function” (Oris et al., 2018, p. 429). Similarly, patients who incorporated their illness as part of their identity were found to have fewer anxiety and depressive symptoms (Van Bulck et al., 2019). Researchers have also found that illness identity served as a strong mediating factor between the self-rated health of adults with congenital heart disease and psychological outcomes (Andonian et al., 2021). Associations between healthcare utilization, patient-reported outcomes such as quality of life, perceived health, and psychosocial functioning, and the four illness identity dimensions were found (Van Bulck et al., 2021).

**Illness Identity as a Mediator of the Stigma–Psychological Outcome Relationship**

Research has shown that the illness identity model has predictive value for adaptive functioning with numerous chronic illnesses characterized by primarily physical syndromes and therefore may provide a useful theoretical framework for understanding and managing the negative effects of genital herpes-related stigma. As a chronic illness, genital herpes shares characteristics of the illnesses above such as ongoing medical care, a need for treatment adherence, a striving for normalcy, and the subjective experience of stigma (Lambert & Keogh, 2015). Even when an illness is concealable, chronic illnesses can produce stigma, leading to a stigmatized identity (O’Donnell & Habenicht, 2022).

Lee and Craft (2002) proposed the use of modified labeling theory to link stigma to aspects of identity in a study of individuals with genital herpes attending a self-help group.
Modified labeling theory focuses on whether or not individuals internalize socially derived labels about a stigmatizing mark. At the same time, there may be variability in the meaning of a stigmatized person’s identities and an individual’s stigma may not affect each identity equally. The increased personal relevance of a stigmatized label then impacts self-perceptions and strategic behaviors designed to manage others’ perceptions such as secrecy, withdrawal, and preventive telling (Lee & Craft, 2002).

Luyckx et al. (2018) acknowledged that their study on young adults with refractory epilepsy neglected to incorporate stigma in the analysis of illness identity. They recommended that the illness identity model “should be explicitly linked to the notion of stigma…. Targeting patients’ illness identity alongside subjective feelings of stigma may help in breaking the vicious cycle in which experienced stigma and maladaptive illness integration may reinforce one another” (pp. 53-54). Thus, it seems likely that experiencing stigma associated with genital herpes is related to the development of different facets of an illness identity and that those illness identities might be differentially related to outcomes. Strongly internalized experiences of stigma might lead to either rejecting the illness identity and trying to conceal aspects of the illness from others (Rassart et al., 2022) or being consumed by the illness to the detriment of one’s quality of life or sexual satisfaction. Alternatively, individuals might counter the experience of stigma by accepting or finding benefit in their illness. The present study examined the evidence for how the different illness identities might mediate the relationships between stigma and quality of life and sexual satisfaction outcomes.

**Purpose of Study**

The primary goal of this study is to examine the relationship between genital herpes-related stigma and two measures of well-being (quality of life and sexual satisfaction) as
mediated by illness identities within individuals diagnosed with genital herpes. The illness identity model has been examined with other illnesses, but not with genital herpes, so this study extends the illness identity literature by examining the degree to which stigma associated with a diagnosis of genital herpes is related to the differing illness identity dimensions. Additionally, many of the existing studies on illness identity with other diagnoses have examined health-related quality of life or illness-specific quality of life so this study also examines whether there are similar relationships between the illness identity dimensions and quality of life specific to a genital herpes diagnosis as well as a measure of broadly defined sexual satisfaction since stigma related to other STIs has been related to facets of sexual wellbeing. Genital herpes differs from the previously studied chronic illnesses in that it is transmissible to others and the negative effects are primarily psychosocial effects symptoms associated with stigma rather than physical syndromes. Potential control variables in the mediation analysis include: 1) time since diagnosis to control for the initial spike in anxiety and stress (Gupta et al., 2007; Ross et al., 2011) as well as the most severe symptoms (Carney et al., 1994; Gupta et al., 2007; Ross et al., 2011) following a diagnosis and 2) presence, frequency, and intensity of genital herpes outbreaks to control for salience of ongoing genital herpes symptoms that are correlated with the proposed outcome variables. Figure 1 displays the hypothesized relationships of the main analysis.

**Research Hypotheses**

Hypothesis 1: Genital herpes stigma will be negatively associated with genital herpes-related quality of life and mediated by the dimensions of illness identity.

- Hypothesis 1a: The relationship between genital herpes stigma and genital herpes-related quality of life will be mediated by the enrichment dimension, resulting in higher levels of
genital herpes-related quality of life. In other words, lower levels of genital herpes stigma will predict more enrichment, which will predict higher quality of life.

- Hypothesis 1b: The relationship between genital herpes stigma and genital herpes-related quality of life will be mediated by the acceptance dimension, resulting in higher levels of genital herpes-related quality of life. In other words, lower levels of genital herpes stigma will predict more acceptance, which will predict higher quality of life.

- Hypothesis 1c: The relationship between genital herpes stigma and genital herpes-related quality of life will be mediated by the rejection dimension, resulting in lower levels of genital herpes-related quality of life. In other words, more genital herpes stigma will predict more rejection, which will predict lower quality of life.

- Hypothesis 1d: The relationship between genital herpes stigma and genital herpes-related quality of life will be mediated by the engulfment dimension, resulting in lower levels of genital herpes-related quality of life. In other words, more genital herpes stigma will predict more engulfment, which will predict lower quality of life.

Hypothesis 2: Genital herpes stigma will be negatively associated with sexual satisfaction and mediated by the dimensions of illness identity.

- Hypothesis 2a: The relationship between genital herpes stigma and sexual satisfaction will be mediated by the enrichment dimension, resulting in higher levels of sexual satisfaction. In other words, lower levels of genital herpes stigma will predict more enrichment, which will predict higher sexual satisfaction.

- Hypothesis 2b: The relationship between genital herpes stigma and sexual satisfaction will be mediated by the acceptance dimension, resulting in higher levels of sexual
satisfaction. In other words, lower levels of genital herpes stigma will predict more acceptance, which will predict higher sexual satisfaction.

- Hypothesis 2c: The relationship between genital herpes stigma and sexual satisfaction will be mediated by the rejection dimension, resulting in lower levels of sexual satisfaction. In other words, more genital herpes stigma will predict more rejection, which will predict lower sexual satisfaction.

- Hypothesis 2d: The relationship between genital herpes stigma and sexual satisfaction will be mediated by the engulfment dimension, resulting in lower levels of sexual satisfaction. In other words, more genital herpes stigma will predict more engulfment, which will predict lower sexual satisfaction.

**Figure 1.** Proposed parallel mediation model
Method

Participants

Participants were 204 adults ($X_{\text{age}} = 37.7$, $SD = 10.2$) living in the U.S. who self-identified as having a diagnosis of genital herpes. Participants were recruited from two internet resources, Reddit.com ($n = 128$) and CloudResearch’s Connect ($n = 76$). Almost half the participants ($n = 100$) were female, 97 were male, 2 identified as transmen, and 5 as non-binary or gender fluid. The majority were White ($n = 135$) with 48 identifying as Black/African American, 32 as Latinx, 19 as Asian/Pacific Islander, 3 as Native American as 1 as multiracial. The average time since diagnosis was 33.94 months ($SD = 60.95$ months) and 68.1% indicated that they experienced outbreaks, with a mean 5.74 outbreaks per year ($SD = 8.18$) and mean severity score of 4.14 ($SD = 1.64$) on a 7-point Likert scale ranging from 1 (no pain or discomfort) to 7 (very severe pain or discomfort). Additional descriptive information on the sample is presented in Table 1.

Table 1
Sociodemographic characteristics ($N = 204$)

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<td>Highest Educational Level</td>
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<tr>
<td>Some high school</td>
<td>3</td>
<td>1.5%</td>
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<tr>
<td>High school or GED</td>
<td>18</td>
<td>8.8%</td>
</tr>
<tr>
<td>Some college/ associate’s degree</td>
<td>49</td>
<td>24.0%</td>
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<tr>
<td>Four-year college degree/ bachelor’s degree</td>
<td>85</td>
<td>41.7%</td>
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<tr>
<td>Postgraduate or professional degree, including master’s, doctoral, medical or law degree</td>
<td>49</td>
<td>24.0%</td>
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<td>Sexual Orientation</td>
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<td>Heterosexual</td>
<td>161</td>
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<td>Gay/Lesbian</td>
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<td>Bisexual/Pansexual</td>
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<td>Queer</td>
<td>4</td>
<td>2.0%</td>
</tr>
<tr>
<td>Asexual</td>
<td>1</td>
<td>0.5%</td>
</tr>
<tr>
<td>Not listed above</td>
<td>1</td>
<td>0.5%</td>
</tr>
</tbody>
</table>
Table 1 (continued)

Sociodemographic characteristics (N = 204)

<table>
<thead>
<tr>
<th>Relationship Status</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>69</td>
<td>33.8%</td>
</tr>
<tr>
<td>Casual</td>
<td>20</td>
<td>9.8%</td>
</tr>
<tr>
<td>Dating</td>
<td>27</td>
<td>13.2%</td>
</tr>
<tr>
<td>Domestic Partnership</td>
<td>26</td>
<td>12.7%</td>
</tr>
<tr>
<td>Married</td>
<td>55</td>
<td>27.0%</td>
</tr>
<tr>
<td>Separated</td>
<td>2</td>
<td>1.0%</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>2.05</td>
</tr>
<tr>
<td>Non-monogamous</td>
<td>1</td>
<td>0.5%</td>
</tr>
</tbody>
</table>

Annual family income

<table>
<thead>
<tr>
<th>Annual family income</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $10,000</td>
<td>6</td>
<td>2.9%</td>
</tr>
<tr>
<td>$10,000 to less than $20,000</td>
<td>14</td>
<td>6.9%</td>
</tr>
<tr>
<td>$20,000 to less than $30,000</td>
<td>19</td>
<td>9.3%</td>
</tr>
<tr>
<td>$30,000 to less than $40,000</td>
<td>16</td>
<td>7.8%</td>
</tr>
<tr>
<td>$40,000 to less than $50,000</td>
<td>16</td>
<td>7.8%</td>
</tr>
<tr>
<td>$50,000 to less than $75,000</td>
<td>34</td>
<td>16.7%</td>
</tr>
<tr>
<td>$75,000 to less than $100,000</td>
<td>38</td>
<td>18.6%</td>
</tr>
<tr>
<td>$100,000 to less than $150,000</td>
<td>38</td>
<td>18.6%</td>
</tr>
<tr>
<td>$150,000 or more</td>
<td>23</td>
<td>11.3%</td>
</tr>
</tbody>
</table>

Measures

Descriptive Information

Demographic information was collected via self-report for all participants. Participants were asked to provide diagnosis status of genital herpes (i.e., yes/no), age, gender, race and ethnicity, sexual orientation, relationship status, highest level of education completed, household income level, and number of months since their genital herpes diagnosis. Participants were also asked if they experienced genital herpes outbreaks and, if so, about how many outbreaks they experience per year and the average severity of their pain and discomfort related to outbreaks.
Genital Herpes Stigma

The Genital Herpes Stigma Scale (GHSS) is an 18-item measure (Wang et al., 2018) adapted from the 37-item HIV Stigma Scale (Wright et al., 2007). The GHSS assesses the social and emotional aspects of having genital herpes using 4-point Likert scale items, with responses ranging between strongly disagree (1), disagree (2), agree (3), and strongly agree (4) (Wang et al., 2018).

The GHSS is separated into two parts with corresponding instructions for participants. The first section consists of 13 items and assesses how participants feel and how they are treated as people with genital herpes. Example items include: “I feel guilty because I have genital herpes” and “Some people who know I have genital herpes have grown more distant.” The second section consists of 5 items and assesses participants’ experiences surrounding the disclosure of genital herpes (Wang et al., 2018). If participants have not previously disclosed their genital herpes status, they are asked to imagine they have done so. Example items include: “I have been hurt by how people reacted to learning I have genital herpes” and “I have lost friends by telling them I have genital herpes.” Scores for all items are summed together to give a total for the measure (ranging from 18 to 72) with higher scores indicating higher genital herpes stigma (Wang et al., 2018).

A confirmatory factor analysis performed by Wang et al. (2018) yielded four subscales based upon the same structure in the HIV Stigma Scale: Personalized Stigma, Disclosure Concerns, Negative Self-Image, and Concern with Public Attitudes (Wang et al., 2018). Each subscale demonstrated good internal consistency, with Cronbach’s alphas of .82 for Personalized Stigma, .73 for Disclosure Concerns, .84 for Negative Self-Image, and .79 for Concern with Public Attitudes (Wang et al., 2018). It may be scored as either a total scale or separate
subscales. The total scale was used in the current study. Correlations with relevant psychosocial variables supported construct validity with all subscales correlated with rumination, most subscales positively correlated with negative affect, and most negatively correlated with perceived social support (Wang et al., 2018).

**Illness Identity**

The Illness Identity Questionnaire (IIQ) is a 25-item, self-report scale developed to assess the degree to which people integrate their illness into their lives and identity (Oris et al., 2016, 2018). The IIQ is designed so that it can be adapted to a specific illness by replacing the term “illness” in each item with the term more frequently used by the target population. The current study adapted it by substituting ‘genital herpes’ for illness. The IIQ items assess cognitions that describe various manners of illness identification. For each item, respondents are presented with a 5-point Likert type scale and asked to rate how agree with each statement, with responses ranging between *totally disagree* (1) to *totally agree* (5).

The initial confirmatory factor analysis of the IIQ was conducted with a sample of Dutch-speaking Belgians with type-1 diabetes and a 4-factor structure was found with Engulfment (IIQ-Engulfment), Rejection (IIQ-Rejection), Acceptance (IIQ-Acceptance), and Enrichment (IIQ-Enrichment) dimensions (Oris et al., 2016). The Engulfment dimension (8 items) captures a lack of illness integration and refers to the degree to which an illness dominates a person’s identity. The Rejection (5 items) dimension captures a lack of illness integration and refers to the degree to which an illness is rejected as part of a person’s identity. The Acceptance dimension (5 items) captures more adaptive illness integration and refers to the degree to which individual accepts an illness as part of their identity. The Enrichment dimension (7 items) captures more adaptive illness integration and refers to the degree to which having an illness results in positive life
changes, benefits one’s identity, and enables one to grow as a person. Engulfment and Rejection were associated with maladaptive psychological and physical functioning, whereas Acceptance and Enrichment were associated with adaptive psychological and physical functioning. Example items include: “I’d rather not think of my illness” (Rejection), “My illness is part of who I am” (Acceptance), “I am preoccupied with my illness” (Engulfment), and “Because of my illness, I have become a stronger person” (Enrichment). Item scores for each illness identity dimension scale are scored and summed individually, resulting in 4 dimension scores per participant (ranging from 5 to 25 for Rejection, 5 to 25 for Acceptance, 8 to 40 for Engulfment, and 7 to 35 for Enrichment) with higher scores in Acceptance and Enrichment and lower scores in Engulfment and Rejection indicating a more adaptive response (Oris et al., 2016, 2018).

Content validity of the subscales was ensured through the nature of the questionnaire development as the items were based on existing scales of illness identity (Oris et al., 2016). In the initial study with individuals with type-1 diabetes, internal consistency scores measured with Cronbach’s alpha were 0.90 for Engulfment, 0.84 for Rejection, 0.85 for Acceptance, and 0.90 for Enrichment (Oris et al., 2016). A subsequent study with individuals with congenital heart disease or multisystem connective tissue disorders found Cronbach’s alphas, respectively, of .92/.91 for Engulfment, .75/.75 for Rejection, .83/.85 for Acceptance, and .95/.90 for Enrichment (Oris et al., 2018). Similarly, a study of the IIQ among adolescents with celiac disease found Cronbach’s alphas ranging from 0.75 to 0.90 (Meyer & Lamash, 2021). Engulfment and Rejection were positively correlated and were both negatively associated with Acceptance. Acceptance and Enrichment were positively correlated (Oris et al., 2018).
Quality of Life

The Recurrent Genital Herpes Quality of Life Questionnaire (RGHQoL) is a 20-item measure assessing quality of life in genital herpes patients with a 4-point Likert scale with responses scored from 0 to 3 (Doward et al., 1998). The RGHQoL is a condition-specific quality of life instrument based upon the needs-based model of quality of life. This measure was initially developed from in-depth qualitative interviews in the United Kingdom and then used as part of an international clinical trial in the UK, USA, Italy, Germany, France, and Denmark (Doward et al., 1998). Example items include: “Herpes makes it difficult for me to plan ahead” with answers Yes, very difficult (3), Yes, quite difficult (2), Yes, a little difficult (1), and No, not at all difficult (0) and “I worry that sex will trigger an outbreak” with answers Yes, I worry a great deal (3), Yes, I worry quite a lot (2), Yes, I worry about it a little (1), and No, I don’t worry about it at all (0). The RGHQoL does not contain any subscales. Scores for all items are summed together to give a total for the measure (ranging from 0 to 60) with higher scores indicating better quality of life.

Test-retest reliability over a two-week period was calculated using Spearman rank correlations in six countries with coefficients ranging from .85 to .97 (Doward et al., 1998). Internal consistency scores of Cronbach’s alpha ranged from .91 to .96 at baseline and from .93 to .97 at time 2 among persons with genital herpes (Doward et al., 1998). Participants in Germany took the Nottingham Health Profile, a standardized measure of subjective health status, and moderate correlations (ranging from 0.19 to 0.55) were found (Doward et al., 1998). In a subsequent study, the RGHQoL has been shown to be significantly related to outbreak recurrence frequency and severity of pain and discomfort during outbreak recurrences (Patel et al., 2001).
**Sexual Satisfaction**

The New Sexual Satisfaction Scale (NSSS) is a 20-item, multidimensional self-report scale assessing sexual satisfaction (Brouillard et al., 2019; Štulhofer et al., 2010). The conceptual framework for the NSSS is derived from the sexuality counseling and psychotherapy literature and focuses on multiple aspects of sexual satisfaction (Brouillard et al., 2019). For each item, respondents are presented with a 5-point Likert type scale and asked to rate their level of satisfaction with their sex life in the preceding six months, with responses ranging between *Not at all Satisfied* (1), *A Little Satisfied* (2), *Moderately Satisfied* (3), *Very Satisfied* (4), to *Extremely Satisfied* (5).

The NSSS has two 10-item subscales: Ego-Centered, measuring the participant’s personal erotic or sexual experiences during intercourse, and Partner/Sexual Activity-Centered, measuring the perception of the partner’s erotic or sexual reactions to the participant and the general frequency and variety of sexual activities (Štulhofer et al., 2010). Example items include: “My focus/concentration during sexual activity,” “The frequency of my orgasms,” and “My body’s sexual functioning.” Scores for all items can be summed to yield either subscale scores or a total for the measure (ranging from 20 to 100) with higher scores indicating higher levels of sexual satisfaction (Brouillard et al., 2019). Participants responded to all questions, but only the Ego-Centered subscale (NSSS-Ego), reflecting the participant’s personal sexual satisfaction, was used in the analysis (with scores ranging from 10 to 50) since it is more central to the study hypotheses relating to identity.

Internal consistency of scores, measured with Cronbach’s alpha, was high, ranging from .94 to .96, with measures for the subscale scores ranging from .91 to .93 for Ego-Centered and .90 to .94 for Partner/Sexual Activity-Centered, in a sample of Croatian non-heterosexual men.
and women (Štulhofer et al., 2010). A subsequent study found a Cronbach’s alpha of .91 for the overall scale in a sample of US and Canadian participants (K. P. Mark et al., 2014). A Portuguese validation study found similar results with a Cronbach’s alpha of .94 for the scale and scores of .92 and .89 for the subscales (Pechorro et al., 2016). Test-retest reliability of the NSSS scores in a sample of Croatian students over a four-week period was found to be satisfactory with coefficients ranging from 0.72 to 0.84 (Štulhofer et al., 2010). The NSSS has been significantly positively associated with a general measure of life satisfaction, negatively correlated with the shorted Sexual Boredom Scale, and positively correlated with relationship intimacy, partner communication about sex, and relationship status (Brouillard et al., 2019).

Procedure

Following approval from the University of Memphis Institutional Review Board (IRB), participants were recruited from two online sources, Reddit and CloudResearch’s Connect. The goal was to obtain a U.S. based, nationwide sample of individuals with diagnoses of genital herpes. To be eligible for participation, individuals had to be at least 18 years old, living in the United States of America, and to have a previous diagnosis of genital herpes (HSV-1 or HSV-2). Participants needed to be able to read and understand English.

Reddit is an online message forum where users create posts including links, images, and videos in various communities (or subreddits) by subject matter. Posts detailing the study and requesting participation were made on Reddit forums dedicated to topics such as genital herpes, herpes, and sexually transmitted diseases. The text in these posts was previously approved by the IRB and included a brief description of the study, contact information for the study administrator, and IRB approval information. Participants who chose to participate clicked on a website link to the secure Qualtrics-hosted questionnaire. Participants obtained from Reddit were
entered into a raffle for six $25 gift cards as a “thank you” for participating in the survey.

CloudResearch’s Connect is a platform for online participant recruitment for online research studies. Users view posts detailing studies and associated payments. A post with the same IRB-approved text described above was created and individuals were paid $3, an amount recommended by CloudResearch, for completion of the survey.

Two quality checks were built into the online survey in order to assess whether participants were reading the survey questions and to promote quality responses. The first quality check was based on survey completion time. Average time of completion was 13.6 minutes and 41 individuals who completed the survey in less than 5 minutes or were identified by Qualtrics as completing the survey too quickly were deemed ineligible for inclusion in the final survey dataset since it was unlikely that they provided high quality data. The second quality check comprised three attention check questions. Individuals were prompted to select a specific response for that item. Individuals who failed two or three of the attention check questions (6 participants) were deemed ineligible for inclusion in the final survey dataset. Fourteen participants failed a single attention check but did not display any concerning response patterns and were included in the final sample. Participants who failed either quality check likely did not fully read and comprehend the questions and/or provided poor quality responses. Two hundred fifty-one participants completed all sections of the survey and 47 failed one or both of the quality checks above, leaving 204 participants deemed eligible for the final survey dataset (128 participants from Reddit and 76 from Connect).
Results

Preliminary Data Cleaning and Analyses

Prior to conducting the main analyses, all data were examined, and descriptive statistics were calculated using IBM SPSS version 29. Means, standard deviations, and ranges of all variables were examined for distributions and assumptions of normality, outliers, and homogeneity of variance. Variables fell within acceptable ranges for skewness (min = -.47, max = .30) and kurtosis (min = -1.04, max = .76). Although the Shapiro-Wilk test indicated non-normal population distributions, this is of little concern in large samples (N > 20) since the sampling distribution of the mean is normal. In order to identify multivariate outliers, an analysis of studentized residuals was carried out on the data and found one outlier (Std. Residual Min = -2.98, Std. Residual Max = 3.00), which was then removed. Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern as all tolerance values were above .50 and VIF values were below 1.98. The data met the assumption of independent errors (Durbin-Watson value = 1.95) where values close to 2 mean that the residual terms are uncorrelated. The normality of the distribution of standardized residuals was checked through visual inspection of histograms or the goodness of fit test. Homoskedasticity was assessed through visual inspection of scatterplots comparing the residuals to predicted values. The data also met the assumption of non-zero variances (GHSS, Variance = 92.95; RGHQoL, Variance = 251.21; NSSS-Ego, Variance = 122.86; IIQ-Enrichment, Variance = 52.52; IIQ-Acceptance, Variance = 22.36; IIQ-Rejection, Variance = 17.97; IIQ-Engulfment, Variance = 94.41). Means, standard deviations, and correlations among study variables are displayed in Table 2 below.
Table 2
Descriptive Statistics and Correlations for Study Variables (N = 204)

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GHSS</td>
<td>51.91</td>
<td>9.64</td>
<td></td>
<td></td>
<td>.88</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. RGHQoL</td>
<td>42.45</td>
<td>15.85</td>
<td>-.76**</td>
<td>.96</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. NSSS-Ego</td>
<td>54.81</td>
<td>21.44</td>
<td>-.37**</td>
<td>.63**</td>
<td>.95</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. IIQ Enrichment</td>
<td>21.57</td>
<td>7.25</td>
<td>-.21**</td>
<td>.24**</td>
<td>.28**</td>
<td>.90</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. IIQ Acceptance</td>
<td>14.28</td>
<td>4.73</td>
<td>-.33**</td>
<td>.46**</td>
<td>.44**</td>
<td>.46**</td>
<td>.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. IIQ Rejection</td>
<td>17.69</td>
<td>4.24</td>
<td>.34**</td>
<td>-.26**</td>
<td>-.07</td>
<td>-.11</td>
<td>-.32**</td>
<td>.65</td>
<td></td>
</tr>
<tr>
<td>7. IIQ Engulfment</td>
<td>27.15</td>
<td>9.72</td>
<td>.61**</td>
<td>-.84**</td>
<td>-.51**</td>
<td>-.15*</td>
<td>-.39**</td>
<td>.14</td>
<td>.94</td>
</tr>
</tbody>
</table>

Note. GHSS = Genital Herpes Stigma Scale; RGHQoL = Recurrent Genital Herpes Quality of Life; NSSS-Ego = New Sexual Satisfaction Scale, Ego subscale; IIQ Enrichment = Illness Identity Questionnaire, Enrichment subscale; IIQ Acceptance = Illness Identity Questionnaire, Acceptance subscale; IIQ Rejection = Illness Identity Questionnaire, Rejection subscale; IIQ Engulfment = Illness Identity Questionnaire, Engulfment subscale; Cronbach’s alpha coefficients on diagonal.
* p < 0.05, **p < 0.01

Based upon the literature review, time since diagnosis was assumed to be a potential covariate with the outcomes (i.e., a recently diagnosed person’s immediate response would likely spike with distress before stabilizing). A preliminary Pearson product-moment correlation was computed to assess if the number of months since diagnosis was associated with quality of life or sexual satisfaction. There was a weak, positive correlation with quality of life ($r = .059, n = 204$) that was not significant ($p = .403$) and a weak, negative correlation with sexual satisfaction ($r = -.092, n = 204$) that was not significant ($p = .191$). Because neither relationship was statistically significant with outcome measures, time since diagnosis was not included as a covariate.

Additional preliminary analyses were conducted to better understand relationships between other physical aspects of the diagnosis and the study variables. Independent t-tests
assessed gender differences on the main study variables and revealed no significant effects for gender on any measure. A preliminary Pearson product-moment correlation was computed to assess if participant age was associated with any of the main study variables. There was a weak, negative correlation with genital herpes stigma ($r = -.143, n = 204$) that was significant ($p < .05$); a weak, positive correlation with quality of life ($r = .211, n = 203$) that was significant ($p < .01$); and a weak, negative correlation with Illness Identity, Engulfment ($r = -.148, n = 204$) that was significant ($p < .05$). Correlations with the other main study variables were not statistically significant. Given the significant correlations above, age was included as a covariate in both analyses, but subsequently removed from the sexual satisfaction analysis when the initial mediation analyses indicated it was not significant.

Independent samples t-tests were run to assess if there were differences between individuals with and without reported outbreak recurrences. The 64 participants who reported no recurring outbreaks ($M = 47.94, SD = 14.97$) had statistically significant higher quality of life scores, $t (200) = 3.34, p < .01$ compared to the 138 participants who reported recurring outbreaks ($M = 40.14, SD = 16.67$). Similarly, the 64 participants who reported no recurring outbreaks ($M = 30.48, SD = 9.81$) had statistically significant higher sexual satisfaction (ego subscale), $t (201) = 2.89, p < .01$ than the 139 participants who reported recurring outbreaks ($M = 25.74, SD = 11.34$). There were no significant differences between groups on the four Illness Identity subscales or the Genital Herpes Stigma Scale. Given the significant differences found above, the presence of outbreaks was included in the model as a categorical covariate for both outcome variables.

Independent samples t-tests were run to assess if there were differences between individuals based upon relationship status. Reported relationship status was recoded into a binary
variable of being in a committed relationship or not. The 75 participants who were not currently being in a committed relationship ($M = 38.75, SD = 15.78$) had statistically significant lower quality of life scores, $t(200) = -2.54, p < .05$, than the 127 participants who reported a current committed relationship ($M = 44.48, SD = 15.37$). Similarly, the 75 participants who reported not currently being in a committed relationship ($M = 23.33, SD = 10.96$) had statistically significant lower sexual satisfaction (ego subscale), $t(201) = -3.85, p < .001$, than the 128 participants who reported having a committed relationship ($M = 29.34, SD = 10.58$). Given the significant differences found above, the presence of a committed relationship was included in the model as a covariate in both analyses but was removed from the quality of life analysis when the initial mediation analysis indicated it was not a significant predictor.

**Primary Analyses**

The primary objective of the current study was to examine the relationships between genital herpes-related stigma and two measures of well-being and assess whether the different illness identities mediated the relationship between genital herpes-related stigma and well-being. Simultaneous mediation was examined via parallel mediation analysis and two parallel mediational analyses were conducted, the first examined the mediating effects of the four illness identities on the relationship between genital herpes-related stigma and genital herpes-related quality of life and the second examined the mediating effects of the four illness identities on the relationship between genital herpes-related stigma and the ego subscale of sexual satisfaction. Age and presence of outbreaks were included as covariates for the analysis of genital herpes-related quality of life while outbreak occurrence and relationship status were included as covariates for sexual satisfaction.
Data were analyzed using IBM SPSS Statistics (version 29) predictive analytics software and the Hayes PROCESS macro (version 4.2, Model 4) for SPSS (Hayes, 2022; *IBM SPSS Statistics for Windows*, 2023). The PROCESS macro uses observed variable ordinary least squares regression with bootstrapping for interpretation of mediated or indirect effects. This type of analysis tests for the direct effects of genital herpes-related stigma on quality of life and sexual satisfaction as well as the indirect effects of genital herpes-related stigma via the Illness Identity subscales. The total effect of genital herpes-related stigma on genital herpes-related quality of life was statistically significant \((c_{total} = -1.22, SE = .08, t = -16.08, p < .001)\) as was the direct effect of stigma on quality of life after accounting for the effect of the illness identity variables and covariates \((c_{direct} = -0.58, SE = .07, t = -8.46, p < .001)\). The total effect of genital herpes-related stigma on sexual satisfaction ego subscale was also statistically significant \((c = -0.38, SE = .08, t = -5.05, p < .001)\), but the direct effect was not \((c_{direct} = -0.06, SE = .09, t = -0.67, p = .50)\).

The results displayed in Figure 2 and Figure 3 below revealed that genital herpes-related stigma had a significant association with all four Illness Identity subscales. As expected, stigma was negatively related to more adaptive aspects of illness identity (i.e., assessed by the IIQ-Enrichment and IIQ-Acceptance scales) and positively related to maladaptive illness identities (assessed by the IIQ-Rejection and IIQ-Engulfment scales). \(R^2\) values were calculated to measure the fit of the model, given the multiple parallel mediators. The \(R^2\) for quality of life was 0.61, which indicates that 61% of the variation in quality of life was explained by the independent variable of genital herpes-related stigma, the four illness identity mediators, and the two covariates. The \(R^2\) for sexual satisfaction was .19, which indicates that 19% of the variation in sexual satisfaction was explained by the stigma, illness identity, and covariate variables in this model.
The statistical significance of the indirect effects of genital herpes-related stigma on quality of life through the Illness Identity subscales was examined using 5,000 bootstrap samples with estimates taken at a 95% confidence interval. Indirect effects are determined to be statistically significant if the confidence interval does not include zero. As seen in Figure 2, there were significant indirect effects of genital herpes-related stigma on quality of life through IIQ-Acceptance (Effect = -0.043, SE = 0.022, CI: -0.089, -0.000) and IIQ-Engulfment (Effect = -0.555, SE = 0.069, CI: -0.697, -0.428). There were no significant indirect effects of genital herpes-related stigma on quality of life through IIQ-Enrichment (Effect = -0.015, SE = 0.012, CI: -0.044, 0.004) and IIQ-Rejection (Effect = -0.022, SE = 0.021, CI: -0.068, 0.014). Hypotheses 1b and 1d were supported while hypotheses 1a and 1c were not.

The statistical significance of the indirect effects of genital herpes-related stigma on sexual satisfaction through the Illness Identity subscales was examined using 5,000 bootstrap samples with estimates taken at a 95% confidence interval. Similar to the analysis of quality of life, there were significant indirect effects of genital herpes-related stigma on sexual satisfaction through IIQ-Acceptance (Effect = -0.085, SE = 0.031, CI: -0.152, -0.030) and IIQ-Engulfment (Effect = -0.250, SE = 0.055, CI: -0.363, -0.148). There were no significant indirect effects of genital herpes-related stigma on sexual satisfaction through IIQ-Enrichment (Effect = -0.014, SE = 0.016, CI: -0.051, 0.012) and IIQ-Rejection (Effect = 0.029, SE = 0.027, CI: -0.022, 0.086). Figure 3 displays the results of the analysis of sexual satisfaction. Hypotheses 2b and 2d were supported while hypotheses 2a and 2c were not.
Figure 2. Parallel mediation analysis showing the effect of genital herpes-related stigma on quality of life as mediated simultaneously by Illness Identity subscales of Enrichment, Acceptance, Rejection, and Engulfment

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$
Figure 3. Parallel mediation analysis showing the effect of genital herpes-related stigma on sexual satisfaction (ego subscale) as mediated simultaneously by Illness Identity subscales of Enrichment, Acceptance, Rejection, and Engulfment

* p < 0.05, ** p < 0.01, *** p < 0.001
Discussion

The main goal of this study was to examine the association between genital herpes-related stigma and two measures of well-being as mediated by illness identities within individuals diagnosed with genital herpes. As a component of the mediation analyses, relationships between genital herpes-related stigma and illness identities were examined, extending the literature on the connection between genital herpes as a chronic illness and illness identities. Additionally, relationships between genital herpes-related stigma and well-being were examined. Out of the eight mediation hypotheses tested in this study, the findings provided support for four of the hypothesized relationships.

Preliminary Analyses

Consistent with previous research and hypotheses above, genital herpes-related stigma was found to be significantly associated with lower quality of life and lower sexual satisfaction. The strong negative correlation found between genital herpes-related stigma (GHSS) and health-related quality of life (RGHQoL) concurs with much of the existing literature on the topic (Bennett et al., 2022; Brentjens et al., 2003; Devine et al., 2022; Johnston, 2022; H. Mark et al., 2009; Patel et al., 2001; Wang et al., 2018). This result appears to refute the contradictory evidence in the studies reviewed by Provenzale (2011) examining the impact of a positive HSV-2 diagnosis on quality of life, however, seven of those reviewed eight studies did not assess stigma using a quantitative scale and therefore could not identify the impact of genital herpes-related stigma. While Rosenthal and colleagues (2006) found a difference in stigma scores between asymptomatic HSV-2 positive participants and HSV-2 negative participants, stigma (assessed using an adapted STD stigma scale) was not a statistically significant predictor of quality of life, potentially due to lower stigma valence and/or higher quality of life scores due to
a lack of recurrent outbreaks. Therefore, the correlation found in the current study between genital herpes-related stigma and quality of life supports the existing literature while clarifying the few contradictory studies. Similarly, the moderate negative bivariate correlation found between genital herpes-related stigma and sexual satisfaction (NSSS-Ego) also concurs with much of the existing literature (Caspers, 2021; Foster & Byers, 2013, 2016; Hood & Friedman, 2011; Melville et al., 2003; Newton & McCabe, 2005, 2008; Wang et al., 2018). This finding expands the current limited research on the relationship between genital herpes-related stigma and the relatively new construct of sexual satisfaction.

The role of covariates, identified by preliminary correlations and t-tests, also contributes to and supports the current literature. Age has been previously found to be associated with lower levels of self-stigma (Mackenzie et al., 2019) and the weak, negative correlation here is consistent, meaning that older participants reported lower scores on the Genital Herpes Stigma Scale. It is possible that age either serves as a protective factor against stigma (e.g., additional or more solidified identities are more resistant to stigma), or the social aspect of stigma decreases over time. Similarly, it is possible that the weak, positive correlation of age with quality of life could be related to other factors such as increased resources or increased expertise due to experience attending to health behaviors. Regarding the presence of outbreaks as a covariate, the preliminary analysis was consistent with the literature that the presence of genital herpes recurrences is associated with decreased quality of life and poorer sexual satisfaction (Brentjens et al., 2003; Carney et al., 1994; Merin & Pachankis, 2011; Pachankis, 2007; Patel et al., 2001; Rosenthal et al., 2006).
Main Analyses and Mediation Effects

The findings provide valuable insights into how genital herpes-related stigma relates to various aspects of illness identity and how these, in turn, relate to quality of life and sexual satisfaction among individuals living with genital herpes. To date, illness identity has been studied with several chronic physical illnesses such as diabetes (Oris et al., 2016; Rassart et al., 2021; Ross, 2018), congenital heart disease and multisystem connective tissue disorders (Andonian et al., 2021; Na et al., 2021; Oris et al., 2018; Van Bulck et al., 2018), and inflammatory bowel disease (Peters & Brown, 2022; Rassart et al., 2022), but not among individuals diagnosed with genital herpes or with measures of stigma. The findings from this study extend the current literature on illness identity by noting that individuals experiencing higher levels of stigma reported greater identification with maladaptive illness identities of rejection and engulfment, while also exhibiting lower levels of adaptive illness identities of acceptance and enrichment. This aligns with previous research highlighting the detrimental impact of stigma on the self-perception and integration of illness into one's identity (Oris et al., 2016; Wang et al., 2018).

The results also revealed that illness identity subscales of acceptance and engulfment significantly mediated the relationship between genital herpes-related stigma and well-being outcomes. Specifically, acceptance of the illness (IIQ-Acceptance) was found to partially mediate the negative relationships between stigma and both quality of life and sexual satisfaction. This suggests that individuals who are more accepting of their genital herpes diagnosis may experience better overall well-being, even in the face of stigma. This underscores the importance of fostering acceptance and resilience in individuals living with stigmatized conditions like genital herpes.
The results also showed that feeling engulfed by the illness (IIQ-Engulfment) partially mediated the relationships between stigma and well-being by increasing the negative effects of stigma through the engulfment identity. This suggests that individuals who feel overwhelmed or consumed by their genital herpes diagnosis may experience poorer well-being, particularly in terms of quality of life and sexual satisfaction. Approximately 61% of the variance in quality of life was accounted for by the variables in this model, meaning that the data provide strong evidence for this theoretical model of the relationships between genital herpes-related stigma, illness identities, and quality of life while identifying that additional variables remain unidentified. In contrast, 19% of the variance in sexual satisfaction was explained by the variables in that model, meaning that the results provide some support for this theoretical model of the relationships between genital herpes-related stigma, illness identities, and sexual satisfaction but suggest that additional study is required to identify variables that are more closely related to sexual satisfaction.

The strength of the relationship between IIQ-Engulfment and outcome measures (as compared to the smaller relationship of IIQ-Acceptance and non-significant relationships of the other two illness identities) is a particularly notable finding in this study. Engulfment is the degree to which an illness completely defines a person’s identity and daily life (Luyckx et al., 2018; Van Bulck et al., 2018) and the stigmatized identity is therefore more likely to be central and salient (O’Donnell & Habenicht, 2022; Quinn & Earnshaw, 2013; Wang et al., 2018). These relationships align well with the present model and the integration of stigma theory and identity theory. The individual with an engulfment identity feels that genital herpes and the related stigma are all-consuming in terms of their identity and the rumination likely creates more frequent stigma reminders that could have a larger negative impact on well-being outcomes. At
the same time the Engulfment illness identity has been associated with less frequent use of healthcare and increased psychological distress (Andonian et al., 2021; Oris et al., 2018; Peters & Brown, 2022; Rassart et al., 2021; Van Bulck et al., 2018, 2019; Yanos et al., 2020). This is likely what Luyckx et al. (2018) was referencing when they expressed the concern that experienced stigma and maladaptive illness integration may reinforce one another in a vicious cycle.

Interestingly, the current study results did not show significant mediation effects for the other two illness identity dimensions, rejection and enrichment and only a small significant mediation effect for acceptance. This may suggest that these aspects of illness identity play a less significant role in the relationship between stigma and well-being in individuals with genital herpes. It is also possible that these results are more reflective of stigma theory (Quinn & Earnshaw, 2013); for example, IIQ-Rejection could result in lower levels of stigma valence and magnitude through denial and avoidance, which could then lead to a smaller effect of stigma on wellness outcomes. This pattern of results is also consistent with some of the previous illness identity literature finding the strongest results with engulfment and minimal relationships with the other illness identities (Luyckx et al., 2018; Na et al., 2021; Rassart et al., 2021; Van Bulck et al., 2018). These findings underscore the complex interaction between stigma, illness identity, and overall well-being among individuals with genital herpes.

Although the illness identities only partially mediated the direct effect of stigma on quality of life, the direct effect of genital herpes-related stigma on sexual satisfaction was completely mediated by the combination of the illness identities. The size of the relationships with sexual satisfaction were lower than those relationships with quality of life, a not unexpected finding since the quality of life measure was directly related to genital herpes as opposed to the
general measure of overall sexual satisfaction that did not reference genital herpes. Additionally, genital herpes-related stigma had a lower correlation with the sexual satisfaction measure than the quality of life measure. It seems likely that sexual satisfaction may be more strongly predicted by factors outside the present model such as experiences of discrimination, relationship satisfaction and frequency of sexual interactions (Rausch & Rettenberger, 2021) and such experiential evidence outweighs stigma or that individuals who are experiencing satisfying sexual encounters with partners have worked through any stigma they might have had. This highlights the importance of considering the psychological and emotional aspects of illness experience in understanding sexual satisfaction among individuals with genital herpes.

Clinical Implications

The findings of this study have several implications for clinical practice and interventions aimed at improving the well-being of individuals with genital herpes. It is currently unclear which interventions are most effective in improving health-related quality of life (Bennett et al., 2022). First, the degree and manner to which individuals diagnosed with genital herpes incorporate the diagnosis into their sense of identity may have an impact on their functioning from both a quality of life and sexual satisfaction standpoint. Interventions targeting stigma reduction such as psycho-education interventions, short term cognitive behavioral stress management groups, and community-level stigma interventions (Bennett et al., 2022; Rao et al., 2019) may have downstream effects on illness identity and subsequent quality of life and sexual satisfaction. Unfortunately, support for psychological therapy improving genital herpes-related well-being is currently mixed (Bennett et al., 2022). Second, the results underscore the importance of adopting a holistic approach to addressing the psychosocial needs of individuals with genital herpes as it affects overall well-being. Beyond managing physical symptoms,
interventions should also focus on promoting adaptive illness identity and addressing the emotional impact of stigma on overall well-being.

Additionally, the evidence in the present study could be used to argue that physicians can inform patients with non-engulfment identities (if identified) about a genital herpes diagnosis with little risk of negative psychosocial harm while improving public health transmission prevention efforts. The eight IIQ-Engulfment items could potentially be used to create a short screening instrument to be given to recently diagnosed individuals with genital herpes who present with emotional distress. A positive screen could mean that the individual would likely be processing their genital herpes diagnosis in a distorted manner, at increased risk of diminished genital herpes quality of life, and a good candidate for targeted interventions.

Limitations and Future Research

This study has some limitations that should be acknowledged. First, the cross-sectional design prevents identifying causal inferences from the results. Longitudinal studies or multi-wave designs are needed to identify causal relationships between stigma, illness identity, and well-being outcomes. Second, the current study’s use of the GHSS limited analysis to the role of internalized stigma on illness identity and omitted external experiences of stigma by participants. As such, it is possible that measures of external stigma and/or stigma experiences would alter the study results. Additionally, the use of self-report measures may be subject to biases such as social desirability bias, recall bias, or extreme responding. These biases may be more likely to occur with topics as sensitive as sexually transmitted infections. Participants in this study potentially differed from the general population as they were all willing to participate in a study on genital herpes and so may have either already addressed some stigma or, conversely, were actively distressed enough to seek help via online communities. It is likely that someone with
high stigma and/or low comfort addressing their illness would avoid participating in a study altogether and therefore be absent from this study. Although the numerical gender balance in the sample was a strength of the study, the racial balance of the participants was not representative of the population of the United States. Another weakness was the well-educated nature of the sample with roughly two thirds of the sample holding a bachelor’s degree or higher. As such, the generalizability of these results to more diverse populations are limited. It is possible that the stigma associated with a diagnosis of genital herpes carries could vary according to different cultural and racial groups or that more highly educated samples might be less prone to stigma resulting from low information regarding the disease. A larger sample size would likely be necessary to obtain a more representative sample and replicating this study in more diverse populations is necessary to ensure the robustness of the findings.

Future research could benefit from incorporating more objective indicators of well-being. Additionally, future research could explore other potential mediators and moderators of the relationship between stigma and well-being in individuals with genital herpes. Potential mediating factors could include coping skill deficits associated with stigma, internalized stigma beliefs, or personality characteristics that might affect identity development processes. For example, neuroticism (on the five-factor model) is often associated with poorer quality of life (Masthoff et al., 2007; Ozer & Benet-Martínez, 2006; Samartzis et al., 2014). It is possible that individuals higher in neuroticism might be more prone to develop a maladaptive illness identity of engulfment or rejection and exploring these pathways could shed light on effective ways to intervene at the illness identity development stage.

Additional mediators could include successful and unsuccessful disclosure attempts to sexual partners (Illic et al., 2014; Quinn & Earnshaw, 2013; Wang et al., 2018) as a positive
response from a sexual partner could provide counter-evidence to genital herpes-related stigma and reduce both the valence and magnitude of the stigma while a negative response from a potential sexual partner could reinforce the internalized stigma. Similarly, the use of suppressive antiviral therapy (Brentjens et al., 2003; Handsfield et al., 2007; Patel et al., 1999) is likely to reduce the number of recurrent outbreaks and subsequently reduce the valence and magnitude of genital herpes-related stigma reminders. Furthermore, future research would benefit from a larger sample size to obtain a more representative sample and replicating this study in more diverse populations is necessary to ensure the robustness and generalizability of the findings to a wider range of cultures that may have differing levels of stigma associated with genital herpes.

In conclusion, this study highlights the significant relationships between genital herpes-related stigma, illness identity, and well-being of individual living with genital herpes. It also sheds light on the role of illness identity in mediating these relationships. By understanding these relationships, it may help develop more targeted interventions or public health campaigns aimed at reducing the negative impact of stigma and improving the psychosocial well-being of individuals living with genital herpes. This study could assist mental and physical health clinicians in identifying and treating people diagnosed with genital herpes who may be at risk of worse well-being. These interventions or public health campaigns would need to be identified in further research. Despite the limitations, this study provided further evidence of the relationships between genital herpes-related stigma, illness identity, and well-being measures of quality of life and sexual satisfaction. Further studies are required to explore these relationships in more detail.
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