

You Are So Much More Than Your Diagnosis: Exploring Subjectivity and Sense of Self While
Living with a Chronic Sexually Transmitted Infection

by

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BA, Carleton University, 2020

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We acknowledge and respect the Ləkʷəŋən (Songhees and Esquimalt) Peoples on whose territory the university stands, and the Ləkʷəŋən and WSÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

This project focuses on stigma and sexual health by investigating the lived experiences of individuals diagnosed with a chronic sexually transmitted infection (STI). I explore how their STI diagnosis impacts their sense of self and their relationships. Data come from 21 semi-structured in-depth interviews with individuals living with chronic STIs (Herpes Simplex Virus, HIV, and HPV). Interview questions consisted of exploring particular experiences related to living with a chronic STI (i.e. process of diagnosis, disclosing STI status to sexual partners, etc.) and various thoughts and feelings associated with living with a chronic STI. The study found that being diagnosed with a chronic STI disrupts one's sense of self by forcing them to grapple with negativity and questions of self-worth, self-esteem, and identity disruption. This disruption was often intense and negative in the early stages of living with a chronic STI but improved significantly after rebuilding their sense of self and accepting the often-insignificant realities of living with a chronic STI. Several common themes emerged regarding the impact of being diagnosed with and living with an incurable STI such as impacts on romantic, platonic, and familial relationships. Informants reported the presence and discussions regarding STIs to have one of three impacts: 1) strengthening meaningful and caring dynamics; 2) damaging or ending weak and surface level connections; or 3) largely having no meaningful impact on solid pre-existing dynamics without sexual activity. Informants highlighted several positive impacts that they had not anticipated emerging from living with a chronic STI, including: forming deeper, higher quality connections with others; prioritizing self-love and self-care; dating more intentionally and with higher standards, and finding a special sense of community amongst other STI+ individuals. Overall, despite having intense emotional, personal, romantic, and social struggles associated with the initial process of being diagnosed and living with a chronic STI, most informants discovered that their STI had little-to-no meaningful negative impact on their lives.

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Chapter 1: **Introduction**

Sexually transmitted infections (STIs) are very common amongst sexually active individuals and are not as rare as public discourse (or lack thereof) might suggest. In fact, reports of sexual health statistics for 2018 in the United States reported that 1 in 5 Americans have an STI, totaling almost 68 million infections in that year alone; there were 26 million new STI cases in America that year; and almost half of all STI cases in America were among youth aged 15-24 (CDC, 2021). On a global scale, the World Health Organization (2019) reports that over 1 million STIs are acquired everyday worldwide; more than 500 million people are estimated to be living with genital herpes; and each year there is an estimated 376 million new infections of curable STI cases, which include chlamydia, gonorrhea, syphilis, and trichomoniasis. Although these numbers are quite high, the most common symptom of STIs are no symptoms at all, meaning that many individuals may have one without realizing it if they are not properly tested for them, they can still transmit them to other sexual partners, and that STIs may be even more prevalent than these numbers suggest (Nack, 2008; WHO, 2019). Even though these are only a few statistics, based on the high number of cases it is evident that STIs are not a rare occurrence, and this project aims to open a dialogue to discuss the implications of living with a STI.

Despite how common STIs are, when discussions around sexual health emerge, the topic of STIs is often elusive. In mainstream media, depictions of STIs are usually misrepresented, stigmatized, mostly neglected, or brushed over (Gabarron et al., 2014; Smith et al., 2008). Discussion of STIs is not much better in school based sex education either. School aged children and youth receive inadequate sexual health education (sex-ed), which is often detrimental to their

health and wellbeing (Fields, 2018). This is particularly the case when looking at sex education for queer and trans youth since school-based sex-ed lessons are commonly built on and reinforce heteronormativity (Garg & Volerman, 2021). School-based sex education often promotes risk-based models of pregnancy and STIs transmission and prevention, yet these discussions are often met with judgement and discomfort from both students and educators (Fosters & Byers, 2008). In terms of STIs and public perceptions, the most prominent topics of dialogue are medication, physical treatment, vaccines, and whether STIs are curable or chronic (Gottlieb et al., 2014).

When conversations of STIs arise outside of education spheres, we wade into the murky territory that constitutes our popular culture, personal, and public health perceptions of gender norms, sex, and sexuality. These conversations elicit alarming and negative messages – from shame, taboo, stigma, to fear, worry, embarrassment, and treatment – to name a few (Smith et al., 2008). Trickle down from the public sphere, this negative messaging can have many different impacts on an individual or personal level for sexually active people. For those diagnosed and knowingly living with an incurable STI, the stigma of STIs impacts one's sense of self and identity, self-presentation, as well as their interactions with others (Nack, 2008). This stigma can make individuals question their romantic and sexual appeal, their self-worth, and even their ability to be loved (Rosenthal et al., 1995). Since we know from the literature on living with chronic illness and sexual difficulties that events and experiences of managing illness or difficulties can be particularly distressing and overwhelming (Earnshaw et al., 2012; Hendrickx et al., 2016), we can safely assume then that being diagnosed with a chronic STI is a life-changing experience that may drastically challenge a person's sense of self and pose a considerable challenge to one's self-esteem and understanding of how they should present

themselves and interact with others. This project aims to investigate this in greater detail and depth.

Most of the dialogue or references to STIs in popular culture depicts them as scary, horrifying, life-ruining diseases that are a marker of ‘dirty people’ or ‘promiscuity’ (Smith et al., 2008). The prevalence of STI diagnoses is rarely acknowledged due to lack of mainstream attention, and a general absence of discussion regarding the experience of living with a chronic STI in public narratives. STIs, and sexual health in general, have largely been ignored or avoided in everyday life and mainstream discourse due to the notion that it is an awkward topic that makes some people uncomfortable. However, having normalized, ethical, non-judgmental discussions that challenge feelings of discomfort or awkwardness around these topics is crucial to demystify them and begin to eliminate the associated stigma and their dramatization (Schalet, 2000). There is a need to explore the social and personal impacts that chronic STIs have on people and create spaces for these individuals to share their experiences and normalize the topic. Thus, this project aims to create a safe and empowering space to do so and begin this dialogue.

While being diagnosed with a STI is a notable change, shock, and challenge to one’s life and personal experiences, the societal stigma, insensitive jokes in popular culture, and unnecessarily harmful discourse surrounding STIs likely poses unwarranted and distressing additional social challenges. Indeed, most STIs are curable and all STIs are manageable due to the various antibiotics and antiviral medications that are available to treat symptoms and alleviate associated pain. Yet, despite how manageable STIs are (WHO, 2019), what they represent (Nack, 2008), how health care or academic professionals discuss them (Stringer et al., 2015), and the social stigma and stereotypes attached to them make them extremely difficult and impactful on one’s life. This research aims to explore the everyday experiences of living with an

incurable STI. In doing this, I am able to evaluate whether there is a disconnection between the stigmatized public perception and the lived experiences of people living with chronic STIs. This project looks to go beyond the surface level dialogue of the importance of safer sex and avoiding STIs by investigating what happens when STIs still inevitably occur and examine what living with a STI might entail.

This research explores people's perceptions of sense of self and stigma associated with living with an incurable (chronic) STI, which refers to Herpes Simplex Virus (HSV), Human Papillomavirus (HPV), and Human Immunodeficiency Virus (HIV). Living with a chronic condition can have long lasting implications on how one thinks about themselves (Earnshaw et al., 2012) and is likely different from people's experiences with curable STIs such as chlamydia, gonorrhea, syphilis, and trichomoniasis. Although getting a curable STI causes experiences of shame, negativity, and stigma within the infected individual, these feelings may only occur for the short period of time that the individual is infected, with the possibility of these feelings quickly being resolved once the infection is effectively treated and cured (Foster & Byers, 2013). Alternatively, individuals with chronic STIs may not have this same opportunity to disconnect, resolve, or separate themselves from their feelings associated with a curable STI. Individuals living with chronic STIs may never have a clear resolution or feel 'finished' managing their STI as they may experience physical symptoms or forms of stigma for the rest of their lives (Foster & Byers, 2013). This research looks to explore these perceived lasting impacts and thus will only involve informants with incurable STIs.

In response to the various changes that being diagnosed and subsequently living with a chronic STI brings about in one's life, coupled with the societal stigma from lack of information and societal narratives around STIs, this project aims to explore the impact that living with a

chronic STI can have on an individual's life, sense of self, interactions with others, and their participation in society. The first research question guiding the current project is: how does being diagnosed with a chronic STI impact one's sense of self and how they understand themselves as a social being in the world? This question will explore both the internal (self-reflections, thoughts, and feelings towards 'the self') and the external (understanding of how one presents 'the self' to others) sense of self and will include topics such as constructing personal meanings, sense of worth or personal value, sexuality and sexual desires, and relationship to the body. Second, and in addition to understanding sense of self, this project will also focus on past and current relationships as well, and asks: how does living with a chronic STI come into play when understanding and navigating relationships with friends, family, and potential romantic or sexual partners?

Positionality Statement

In the current research, I explore how living with an incurable STI disrupts or alters one's daily life, as I aim to understand and analyze the many possible implications and impacts that may arise following the contraction of a chronic STI. Although managing a STI is arguably only a small piece of an individual's sexual health puzzle, as someone who has been living with a chronic STI for several years, this has not been my experience. I have found that being diagnosed with an incurable STI has deeply impacted various aspects of my life that I had not anticipated until being diagnosed and living this new reality, primarily due to the stigma I have been socially conditioned to maintain. For example, the stigma of living with a chronic STI has negatively impacted how I view myself as a person in terms of my value and purpose, my relationship with my body, how I look at relationships and potential partners, and even my future life aspirations – to name a few. I have felt that social implications of living with a STI have been the biggest

impact throughout my life and yet I feel that any meaningful dialogue surrounding STIs within my own life was extremely lacking until I myself was diagnosed. I recognize that my own experience is just one of many, and as a result I want to explore what this experience entails for other people living with chronic STIs. I want to understand the narratives of my informants in relation to how they understand and process their own experiences and identity after receiving their chronic STI diagnosis.

Chapter 2: **Background and Context**

Conceptual Context

The following chapter will cover information on sexual health, STIs, STI testing, illness, gender, sexuality, and other related topics that will provide the contextual foundation for the current research. In doing so, there are several conceptual and theoretical considerations that are central to this work that need to be discussed. Firstly, it is important to consider the notion of sexual health. Sexual health is a very broad term that can incorporate a wide variety of constantly changing themes, including but not limited to managing or avoiding sexually transmitted infections (STIs), reproductive health, mental health and intimacy, ongoing consent and mutual respect, sexual pleasure, and other emotional and social elements of being sexually active (Edwards & Coleman, 2004). Sexual health can be difficult to define and outline because there are many physical, mental, and emotional elements of sexual that can be difficult to differentiate without acknowledging how intertwined these elements are. Within the current context of this project, the primary focus of using the term sexual health is to identify and discuss the management of STIs, although many of the aforementioned elements of sexual health will inevitably arise and will be taken into consideration in order to best understand the lived experiences of the informants.

Current literature surrounding sexual health and STIs focuses on a range of important issues such as the logistics of safer sex, attitudes towards sexuality and sexual health, and indirect implications, such as STI testing (Barth et al., 2002; Lieber et al., 2006; Shoveller et al., 2009; Shoveller et al., 2010; Wong et al., 2012) , impacts on relationships (Hammerlund et al., 2007; Kershaw et al., 2010; Newton & McCabe, 2008; Reid et al., 2013), gendered differences

of experiencing a STI (Carpenter, 2010; Eiduson et al., 2021; Feinstein et al., 2018; Hammerlund et al., 2007; Jahn et al., 2019; Polzer et al., 2014; Rosenthal et al., 1995; Rosenthal et al., 2002; Scheim & Travers, 2017), sexual orientation (Lindley et al., 2008; Meyer, 1995; Scheim & Travers, 2017), perceptions towards sex (Gokengin et al., 2003; Le Espiritu, 2001; Newton & McCabe, 2008; Schalet, 2000; Sparling & Cramer, 2015; Wong et al., 2012), chronic illness (Bury, 1982; Charmaz, 1995; Earnshaw et al., 2012; Faircloth et al., 2004; Joachim & Acorn, 2000; Williams, 2000), community supports (Bush et al., 2018; Citron et al., 1999; Morales-campos et al., 2009), and identity and sense of self (Becker, 1963; Charmaz, 1995; Faircloth et al., 2004; Goffman, 1963; Hihara et al., 2019; Klawiter, 2004; Mäkelä, 2017; Perry, 2011; Polzer et al., 2014).

From these bodies of research, we learn that there are many personal, social, and structural challenges that individuals are subjected to that influence their overall perceptions on STIs and how they can impact or alter various parts of a person. In terms of perceptions towards sexual health and STIs in particular, the literature demonstrates that these perceptions are heavily influenced by experiences within health care systems or processes, cultural or family attitudes, and shame and stigma within interpersonal relationships (Barth et al., 2002; Gokengin et al., 2003; Hammerlund et al., 2007; Kershaw et al., 2010; Le Espiritu, 2001; Lieber et al., 2006; Reid et al., 2013; Schalet, 2000; Sparling & Cramer, 2015; Wong et al., 2012). The following section examines these influences that frame sexual health in order to contextualize where potential stigma surrounding STIs originates from. In this context, stigma directly refers to an undesirable quality or characteristic that one possesses and is then used to discredit them socially or morally (Goffman, 1963). Understanding the various themes and findings within the current

literature is essential to examine how all of these themes are simultaneously relevant in one person's life and shapes their overall narrative.

STI Testing

STI testing is the one of the first steps that someone can take in terms of checking in with their sexual health and STI status, yet it can be a very stressful and difficult step to take due to access issues, feelings of shame, lack of knowledge, or fear associated with the process (Barth et al., 2002; Lieber et al., 2006; Shoveller et al., 2009; Shoveller et al., 2010; Wong et al., 2012). It is also important to note that even for those who are able to overcome these barriers for testing, many people are not being screened for the full range of STIs as standard STI testing often excludes HSV and HPV (Nack, 2008). For those affected by mental and emotional barriers for STI testing, Barth et al. (2002) find that college students aged 18-23 often avoided or delayed getting tested for STIs for fear of receiving a positive diagnosis and the negative consequences, as well as a general lack of sexual health knowledge. Directly in line with the current study, Lieber et al. (2006), looking at participants living in Eastern China aged 18-46 who had engaged in some sort of stigmatized sexual acts (including sex work or contracting STIs), suggest that the biggest barriers for STI testing is the fear, shame, and embarrassment that is attached to having and being treated for STIs. Barth et al. (2002), Lieber et al. (2006), and Wong et al. (2012) suggest that a fear of being subjected to stigma and shame is a direct barrier for monitoring STI statuses and being informed about safer sexual health practices. Rather than seeking out sexual health information and becoming informed about their own health status, these studies suggest that avoiding or disengaging with STI testing is a common choice made by these young adults to avoid being confronted with stigma and dealing with negative consequences (Barth et al., 2002; Lieber et al., 2006; Wong et al., 2012).

In addition to shame, fear, and stigma, barriers to accessing affordable, good quality services can pose as an additional challenge for regular STI testing and sexual health check-ins (Shoveller et al., 2009; Wong et al., 2012;). Wong et al. (2012), working with women from disadvantaged neighborhoods in Toronto ages 16-24, find that individuals from less affluent neighborhoods have less access to STI testing within their neighborhoods and networks, and as a result had poorer sexual health outcomes and higher rates of STIs. Shoveller et al. (2009) find that young men and women ages 15-24 in British Columbia face challenges to accessing testing services that were welcoming and accessible to them in person, especially those from rural communities, as they felt judged while accessing services due to their age. Participants in this research demonstrated concern for accessing quality sexual health services that were physically accessible to them, which made them less likely to get tested regularly.

The process of STI testing can make patients feel self-conscious about themselves, their bodies, and their sexual activity within this context, particularly while considering worries related to gender and sexuality (Shoveller et al., 2009; Shoveller et al., 2010). Shoveller et al. (2010) find that young men ages 15-25 in British Columbia felt vulnerable in sexual health clinics, both physically as they feared getting erections during genital examinations, and emotionally as they felt they did not have permission to engage in sexual health discourse in order to uphold dominant ideas of masculinity. Participants also noted health providers were predominantly women and that the décor of the clinics were tailored towards being a safe space specifically for generalized women, creating additional barriers for men feeling comfortable in the clinics (Shoveller et al., 2009). Furthermore, discussing being sexually active and disclosing potentially 'risky' sexual behaviours is a notable challenge for patients, especially for queer youth who noted an additional fear of experiencing homophobia within sexual health clinics

(Shoveller et al., 2009). Personal fears and insecurities relating to identity and sexuality create additional barriers for proper STI testing.

We learn from this research that existing social and systemic barriers for STI testing can perpetuate stigma associated with both STIs and sexual health. Since much of the literature focuses on screening for STIs and potential STIs, it is crucial to further collect and examine the thoughts and narratives of those who receive positive diagnoses, especially for chronic STIs. The gap in this literature that I plan to address is to further unpack these social barriers to better understand the foundation of conceptions and attitudes that individuals with STIs have towards the process of being diagnosed and seeking treatment or support.

Identity and Sense of Self

Being diagnosed and living with a chronic STI is a major life event and can change how one views themselves and their place within the world around them. Because of this, it is important to explore how one's identity and sense of self are negotiated or change alongside an STI diagnosis. In this thesis, I conceptualize term "sense of self" as the way one understands and views themselves as an individual being. I use "sense of self" to capture and reflect my informants' expressions of emotions and feelings, thoughts about the kind of person they are and what they think of themselves, reflections on how they present themselves to others, perspective on their identity and how others view them, their sense of self-worth, and their relationship with their body. Many scholars have written about identity, and I in this thesis, I am conceptually guided by the notion of "negative identity" (Hihara et al., 2019), 'spoiled identity" and stigma (Goffman, 1963), labelling theory, and several related ideas. I introduce them and explore them below.

Hihara et al. (2019), who look at young female and male Japanese informants ages 18-25, find that people often develop a negative identity alongside an STI diagnosis. A ‘negative identity’ is an identity that forms during critical developmental stages and is an identity that is constructed as undesirable or dangerous and results in negative feelings towards the self. Importantly, developing a negative identity can impact psychosocial beliefs, social relationships, and participation in society. The social power of a negative identity is also supported through labelling theory, which suggests that those who are subjected to a certain stigmatized label in society will begin to internalize the label and present themselves and acts in a manner that aligns with their label and justifies their behaviour, which can be considered deviance amplification (Becker, 1963).

In a similar way, Goffman (1963) writes about a “spoiled identity”, which refers to the condition of an individual who is perceived by others as deviating from social norms and expectations, thus causing them a loss in social status and damaging one’s sense of self. Within Goffman’s (1963) theoretical framework of the “spoiled identity” and impression management, stigma is a product of an individual being viewed or labelled as an outsider to the ‘normal’ categorization of members of society, and is then reduced, tainted, or seen as damaged because of the quality or characteristics being stigmatized. Each characteristic or attribute in question is itself a stigma, as it is associated with a discredit, failing, or shortcoming of some kind which society produces judgement based upon (Goffman, 1963). When individuals experience negative self-perceptions or internalize stigma, it can negatively impact their behaviors, decision making processes, and daily activities because of their shame and believing that they deserve the shame and negativity.

External senses of rejection or alienation can be internalized and impact how one understands themselves based on the negative views of others. These negative perception or labels presented by others can alter how an individual thinks of themselves, and as a result of this shift in perception, encourages them to act in negative ways to align themselves with their social label (Becker, 1963; Goffman, 1963; Hihara et al., 2019). This can be understood in the context of STIs, as a person living with a chronic STI may internalize shame and stigma surrounding STIs and may perpetuate this stigma through their own beliefs and actions. An example of this stigma impacting the behaviors of individual living with HIV is a person choosing not to disclose their HIV status or disclosing in a very specific and intentional method in response to anticipated and previously experienced stigma (Block, 2009). As the current study will consider how identity and self-perceptions are influenced by having a STI, understanding negative external impacts on identity is crucial in the current study to recognize the role that stigma and negative perceptions have on interpreting the lived experiences of dealing with chronic STIs.

STI stigma can impact the way that one sees themselves and thus how they construct their own personal narrative, or rather, the way they understand themselves and their life experiences. The way that people construct their own individual narratives in relation to who they are is crucial to establish and validate, as all people experiencing the same illness or condition will still have unique experiences, outcomes, and perspectives (Faircloth et al., 2004). Personal narratives in the context of illness or disease can vary based on a wide variety of factors, including individual circumstances, particular characteristics of a disease or illness (including different strains or variations), as well as cultural, spatial, and social contexts that the individual is living through (Klawiter, 2004). Being diagnosed with a chronic illness changes one's personal narrative in countless ways as the illness may disrupts the harmony and

functioning of the body, may force the individual to adapt to a new impairment or set of treatments or accommodations, and may cause a change in identity (Charmaz, 1995). Personal narratives attempt to align the present self with the pre-illness or injury self, but in the case of chronic illness, this is not (normally) possible and thus the individual must renegotiate their altered identity and explore the implications of these changes (Mäkelä, 2017). The current research will look at how personal narratives are constructed around the disruption of being diagnosed with a chronic STI, and how this common experience has created various unique narratives and identities amongst each informant and their respective lives.

Navigating Romantic and Sexual Relationships

Relationships are central to navigating STIs since living with a chronic STI can impact relationship dynamics, introduce challenges for new partners, and create potential sexual health concerns or issues for couples (Hammerlund et al., 2007; Newton & McCabe, 2008; Reid et al., 2013). Reid et al. (2013), in their research with pregnant adolescent women and their male partners in Connecticut, find that one partner receiving a STI diagnosis during the relationship had more of a negative impact on the relationship than when couples received diagnoses prior to the relationship or when both partners were diagnosed with an STI, creating an imbalance in the relationship dynamic and opportunities for conflict. In terms of potential romances, Hammarlund et al. (2007), working with heterosexual Swedish men ages 19-31 living with genital warts, find that their informants viewed themselves as ‘disease carriers’, which made it more challenging for them to develop and engage in new meaningful emotional and physical connections. Newton and McCabe (2008), looking at 30 female and male adults living with herpes and 30 male and female adults with HPV, report that having a STI can make an individual scared of engaging in relationships and sexual activity due to feeling embarrassed or scared to discuss their STI with

potential partners and fear of transmitting their STI to their partner. These articles recognize the potential challenge of engaging with new partners who may be living with a chronic STI as well as the emotional obstacles present in romantic and sexual relationships for those living with STIs. Building on these insights and exploring the implications in greater detail, my research focuses on attitudes and perceptions regarding both the maintenance and formation of romantic and sexual relationships and how they can be impacted by STI diagnoses.

Perceptions Towards Sex

Perceptions towards sex is an important aspect of academic literature to consider when looking at STIs as these perceptions can be linked and identify whether someone will have a more negative and stigmatized view of STIs or whether they are likely to be more understanding and sex-positive (Gokengin et al., 2003; Le Espiritu, 2001; Schalet, 2000; Sparling & Cramer, 2015; Wong et al., 2012). Wong et al. (2012) find that social stigma and negative perceptions around STIs prevented young women from seeking STI prevention education, safer sex materials, early testing, and STI treatments, which negatively impacts their overall sexual health and perpetuates negative perception towards sex. Sparling and Cramer (2015), who look at female and male undergraduate students, discuss perceptions of sex through assessing sexual risk, as their informants believed having unprotected sex with a new or casual partner was more of a risk for contracting an STI than having unprotected sex with a regular partner, which is a common misconception. Gokengin et al. (2003), who surveyed first- and fourth-year university students in Turkey, find that student knowledge of transmission routes, signs and symptoms, and STI risks was low and in need of greater awareness. These misconceptions and fear of proper education affirm the negative perceptions toward sex and thus make it more likely to perpetuate stigma surrounding STIs based on misinformation.

Stigma and misconceptions about STI can make a person diagnosed with a STI feel personally guilty and ashamed of having contracted a STI, their perception towards having sex with a STI (Gokengin et al., 2003; Newtown & McCabe, 2008). Due to a lack of knowledge around STIs, informants identified their belief that contracting an STI was their own fault (Gokengin et al., 2003). Internalizing this guilt and shame from contracting a STI, informants identify feeling unworthy of romantic and sexual attention or desires, and as a result often feel the need to avoid or withdraw from romantic and sexual interactions (Newton & McCabe, 2008). These sources all identified perceptions and desires around avoiding acknowledging or contracting an STI, very few discuss perceptions of living with an STI. These studies focus primarily on the possibility of contracting STIs and discuss STIs theoretically, but very few acknowledge the reality of how common and manageable STIs are and thus do not normalize the fact that many individuals will contract a STI during their lifetime. The current study will bridge this gap and provide the perspective that STIs are frequently diagnosed and not as terrifying as some of the informants from these studies might think through exploring the lived experiences of this project's informants.

Further, perceptions of what is considered normal and appropriate sexual behaviour may also be impacted by one's cultural upbringing, cultural norms, or discussions with parents (Le Espiritu, 2001; Schalet, 2000). Schalet (2000) highlight the key differences between common perceptions of sexuality held by American parents and Dutch parents of teenagers. The American parents commonly saw teenage sex and sexuality as inappropriate, disruptive, sinful, and driven from shameful biological urges, whereas the Dutch parents understood teenage sexuality as normal, stemming from love, and being a normal teenage responsibility (Schalet, 2000). Le Espiritu (2001) finds that Filipinx Americans saw engaging in promiscuity and sexual behaviour

as a reflection of “loose morality”, as they believed that women who are passive and abstain from sex until well into adulthood were morally superior. Comparatively, these Filipinx Americans saw Americans as being overly promiscuous, irresponsible, and valuing sexual liberty over family and cultural values, making them morally inferior and deviant for acting on their sexuality and sexual desires (Le Espiritu, 2001). Understanding various cultural norms and expectations, especially how they compare to one another, demonstrate the various narratives of acceptable sexuality that become internalized and reinforced through family discussions and dynamics.

Gendered Experiences of STIs

Gendered norms and expectations also shape one’s experience with being diagnosed with an STI, as well as living with chronic STIs (Carpenter, 2010; Feinstein et al., 2018; Hammerlund et al., 2007; Nack, 2008). Indeed, there are gender-specific sexual scripts that impact sexual trajectory based on the gender norms and expectations (Carpenter, 2010). Although shame and stigma regarding sexual health can be identified for all genders, how people experience stigma and shame may vary. For example, studying heterosexual Swedish men living with genital warts, Hammerlund et al. (2007) found that men feel a considerable amount of shame associated with their diagnoses and feel a need to exert control over their STI as a coping mechanism. This internal conflict between need for control and low self-esteem resulting from their diagnosis negatively impacted their ability to establish and maintain healthy romantic and sexual relationships (Hammerlund et al., 2007). Comparatively, Feinstein et al. (2018), in their research with young men ages 18-29 who have sex with men who contracted STIs, report that men’s reactions to being diagnosed with STIs primarily consisted of shock, anger, worry, and annoyance. Men mainly focused on themselves and their impacts, and to a lesser extent some

informants considered the impact it would have on their partners (Feinstein et al., 2018). The male informants of these studies seemed to be more concerned with their own personal consequences rather than how it might impact others and seemed to desire a sense of control in their lives and their sexual health while coping with their STIs mostly independent of additional resources.

Rather than aiming to control their STIs and sexual health like men, women negotiate their identities as a result of their STIs and have more direct impacts on their romantic relationships and everyday life (Polzer et al., 2014). These negotiations of identity can be understood as women generally negatively accept their STI as their own responsibility and feel it needs to be managed individually. Accordingly, Rosenthal et al. (1995) focus on adolescent girls' coping mechanisms for living with an STI and find that young girls engaged more passive approaches to coping than the males exhibited in previous studies. These passive coping mechanisms included wishful thinking, social withdrawal, blaming others, self-criticism, and seeking social support (Rosenthal et al., 1995). These gendered beliefs surrounding both the stigmatized nature of STIs and feeling responsible for and having personally caused STIs is crucial in understanding how gender norms and societal narratives of gendered sexuality can impact the framing of personal experiences regarding STIs.

In a similar follow up study, Rosenthal et al. (2002) focus on the relationship between the STI locus of control and the STI acquisition amongst primarily African-American teenage girls. The female informants note feeling that their male partners were more in control of STI acquisition, as they believed male partners had more control in condom usage (Rosenthal et al., 2002). The literature demonstrate that women feel less in control of STIs and their diagnoses compared to men (Rosenthal et al., 1995; Rosenthal et al., 2002). Although women typically had

more passive attitudes towards STIs than men, women were more likely to feel comfortable seeking support from others as part of their coping mechanisms and were less socially isolated during this coping process than men (Feinstein et al., 2018; Rosenthal et al., 1995; Rosenthal et al., 2002). Academic knowledge and understanding regarding experiences of sexual health and STIs in relation to gender primarily focus on binary genders through comparing experiences of men and women, highlighting gaps in gendered analyses and the need for further research on identities outside of the gender binary.

When considering the current academic literature regarding gender, sexual health, and STIs, it is lacking extensive knowledge of the experiences of transgender and non-binary individuals (Eiduson et al., 2021; Jahn et al., 2019; Scheim & Travers, 2017). Eiduson et al. (2021) find that non-binary folks commonly experienced considerable barriers to high-quality healthcare both in their personal interactions with health care workers and on an institutional and systemic level, and thus needed to practice resiliency and intentionally engage in personal advocacy to have their sexual health needs met. Personal advocacy and resiliency strategies are noted as most commonly taking the form of actively seeking out additional sexual health education tailored specifically to their gender identity and seeking community supports from other non-binary folks experiencing similar barriers (Eiduson et al., 2021). Jahn et al. (2019) describe the sexual healthcare experiences from a sample of queer women and non-binary assigned female at birth (AFAB) individuals and emphasize that healthcare providers primarily use a heteronormative approach for sexual health that did not cater to their specific sexual health concerns, including focusing on pregnancy and STI prevention using external condoms. Healthcare providers generally treat patients and their sexual health needs as aligning with heterosexual experiences of their sex assigned at birth rather than considering the patient's

specific gender or sexual identities, reinforcing the need for self-advocacy and personal agency in healthcare settings (Eiduson et al., 2021; Jahn et al., 2019).

Nack (2008) has spoken in depth about the gendered differences that are often observed with individuals living with chronic STIs and has focused primarily on how women experience living with a chronic STI. Firstly, Nack (2008) points out that since women are encouraged to partake in annual gynecological exams, yet there is no comparable standard exam for men, there highlighting the gendered discrepancy for expectations surrounding testing and sexual health responsibility. Following the contraction of a STI, Nack (2008) argues that women suffer more than men in terms of both reproductive health concerns or consequences and social implications or self-concepts. When a woman receives a positive STI diagnosis, she is likely to be subjected to shame and ridicule for being perceived as promiscuous and thus suffering the consequences of it, yet men are often praised and experience an elevated social status due to engaging in the same behaviours (Nack, 2008). Nack (2008) asserts that receiving a STI diagnosis creates a “turning point” moment for women that damage their identity and initiates an “identity dilemma,” as the social constructions of female sexual morality intersect with STI stereotypes to present a threat to women’s *sexual self* (a woman’s view of herself as a sexual being in relation to general views of herself). As a result of these arguments, Nack (2008) explains the importance of considering gendered experiences regarding living with a chronic STI.

The multitude of encounters and interactions that individuals with chronic STIs may experience on interpersonal and institutional levels due to their gender identity is important to consider to understand how various aspects of identity can intersect and impact each individual differently in complex and nuanced ways. Gender norms and expectations impact the specific interactions that individuals have in their personal lives, the way they are perceived and treated

within institutions, and the internalized gendered expectations that individuals consciously or subconsciously hold themselves to (Carpenter, 2010; Eiduson et al., 2021; Feinstein et al., 2018; Hammerlund et al., 2007; Jahn et al., 2019; Polzer et al., 2014; Rosenthal et al., 1995; Rosenthal et al., 2002; Scheim & Travers, 2017).

Sexual Orientation and Sexual Health

People's experiences of living with chronic STIs can be shaped by social relations and inequalities associated with sexuality and sexual orientation (Eiduson et al., 2021; Lindley et al., 2008; Meyer, 1995; Scheim & Travers, 2017). Engaging in romantic or sexual relationships that align with an individual's identification with one or more sexual orientations or identities will likely impact both their prominent sexual health concerns and the type of sexual health knowledge and framework required for practicing safer sex (Eiduson et al., 2021). Lindley et al. (2008) focus on female sexuality and the various sexual orientations of their informants in relation to their likelihood of contracting an STI. Their findings suggested that bisexual women were at a greater risk of contracting an STI than lesbian women; women who had sex with multiple partners, including both male and female partners, were the most likely of the informants to contract a STI; and women who had sex with only men were more likely to contract a STI than women who only had sex with women (Lindley et al., 2008). This article suggests that women who have sex with men and women are the category of women at the highest risk of contracting an STI, which aligns with the findings of studies on queer men that suggest elevated STI risks for queer men (Lindley et al., 2008; Scheim & Travers, 2017).

Scheim and Travers (2017) look at the barriers and facilitators of STI testing for gay, bisexual, and transgender men, and indicate that men who have sex with other men are at higher risk of contracting HIV and other STIs and thus require more access to STI testing and treatment

services. They also highlight the discrimination, stigma, and additional challenges that transgender men face to access these same services, despite their risk being consistent with that of other men who have sex with men (Scheidt & Travers, 2017). Not only do queer individuals face challenges accessing education and resources, but they also experience what Meyer (1995) identifies as ‘minority stress’, which refers to the chronic stress that queer individuals experience due to the stigma, alienation, discrimination, internalized homophobia, and physical or emotional violence they endure while functioning in heteronormative structures in a heterosexist society. The additional burdens, stress, and necessity for self-advocacy that exists for queer people simply for existing as a queer person make it more challenging for them to manage personal, mental, and sexual health compared to heterosexual people.

The literature demonstrates the challenges that many LGBTQIA+ individuals face while being at higher risks for STIs due to a lack of available resources and education, as well as needing to overcome additional barriers for medical and emotional supports due to sexual orientation and systemic complications associated with queer identity (Eiduson et al., 2021; Lindley et al., 2008; Meyer, 1995; Scheim & Travers, 2017). Similar to how gender identity and norms shape one’s experiences and perspectives surrounding of sexual health and STIs, one’s sexual orientation can also impact sexual health risks, practices, education or knowledge, and barriers for navigating lived experiences of chronic STIs. The current study looks to engage with the topic of sexual orientation by investigating how chronic STIs may be framed, understood, treated, and dealt with differently depending on one’s personal and social identification.

Chronic Illness

While looking at themes outside of sexual health, engaging with illness narratives and considering how the disruption of being diagnosed with a chronic illness can impact one’s life

and identity is crucial in the context of the current research (Bury, 1982; Charmaz, 1995; Earnshaw et al., 2012; Faircloth et al., 2004; Joachim & Acorn, 2000; Klawiter, 2004; Williams, 2000). Chronic illness is a broad category that covers a wide range of personal illnesses or diseases that create customized and unique situations based on individual circumstances, interpersonal relationships and supports, and social contexts that can change throughout the course of one's life (Faircloth et al., 2004; Klawiter, 2004; Williams, 2000). Certain chronic illnesses may be received or perceived as more normal or acceptable than others, determining the severity of the impact on a person's life (Williams, 2000). Regardless of which chronic illness a person is diagnosed with, it presents a disruption to their sense of normalcy, may disrupt their daily activities and practices, and may challenge their sense of identity (Charmaz, 1995; Faircloth et al., 2004). However, this disruption of identity and routine creates the necessity of adapting to the new set of permanent circumstances and may create new opportunities for practicing resiliency through accessing resources and supports and communicating experiences and feelings surrounding pain or impairment (Bury, 1982; Charmaz, 1995). Chronic illness creates a new lifelong condition that is unique in its symptom presentation and social circumstance for each individual case, and because of this, it is importance to consider an individual's personal understanding of their own chronic illness and how they choose to (or not to) exercise personal agency within their circumstances.

Understanding the role that stigma plays in chronic illness is fundamental to interpreting experiences of chronic illness and exercising personal agency, as people who experience chronic illness will inevitably experience varying degrees and forms of both internal and external stigma (Earnshaw et al., 2012; Joachim & Acorn, 2000). Joachim and Acorn (2000) highlight the differing impacts of framing chronic illness through either a lens of stigma (the shame that

society places on those who are judged for being perceived as different) or a lens of normalization (the success that chronically ill individuals achieve after altering their daily or regular life practices to accommodate their illness), as those with a stigmatized lens suffered more from their chronic illness compared to those with a normalized or destigmatized lens. Anticipated or perceived stigma can also impact the quality of life of those living with chronic illnesses, as those who anticipated stigma in social networks were less willing to accept social support, experienced less satisfaction with health care providers, and were more likely to distance themselves socially and emotionally from others (Earnshaw et al., 2012). Joachim and Acorn (2000) and Earnshaw et al. (2012) suggest the importance of perspective and consideration of both normative and stigmatizing factors when analyzing the impacts of chronic illnesses. These studies demonstrate that the stigma that individuals living with chronic illness experience produce negative consequences on their mental health, their social interactions and networks, and the social presentation of the self (Earnshaw et al., 2012; Joachim & Acorn, 2000). The external stigma and associated consequences create and perpetuate a sense of internal stigma, as these individuals may experience lower self-esteem and self-doubt because of their chronic illness. The current research is rooted in themes emerging from literature on chronic illness, as this study aims to uncover and unpack prominent disruptive experiences of chronic STIs and explore how this disruption in one's life influences their sense of self and identity construction.

Support Groups

To situate the many individual experiences of STIs and chronic illness within a broader social narrative of sexual health and STIs, it is important to recognize how shared or common experiences are validated and managed within community supports settings (Bush et. al., 2018;

Citron et al., 1999; Morales-Campos et al., 2009). An impactful community support structure to examine is the support group, either for individuals who are sharing similar experiences, or for the friends and families of those individuals, allowing participants to develop relationships with others who they could relate to, giving them a platform to express themselves, and receive emotional support and peer-education about the disease (Bush et al., 2018). Morales-Campos et al. (2009) find support groups for Hispanic women who have experienced gender-based violence in Houston, Texas to be beneficial to participants as they fostered a sense of community and empowerment through the sharing of stories, allowing them to learn coping strategies from one another and develop confidence speaking up for themselves and sharing their personal narratives. Citron et al. (1999) report that support groups for families of persons with mental illness in Pennsylvania produce the following further benefits: learning to self-advocate, learning to better cope with stigma, releasing feelings of anger and negativity, and gaining tools to better maintain relationships with others. Overall, the literature highlights the beneficial effects of receiving support from peers and community members who can empathize and relate to circumstances or experiences surrounding a certain condition or illness.

However, scholars also indicate some notable barriers and shortcomings of support groups as well, including accessibility issues, reliving emotional trauma, and internalizing trauma of other participants (Bush et. al., 2018; Citron et al., 1999; Morales-Campos et al., 2009). Bush et al. (2018), in their research on support groups for Parkinson's disease in Rural America, reveal logistical challenges of organizing and running support groups, such as personal and financial barriers to joining or attending, low participation rates, and a general lack of accessibility due to physical limitations and lack of awareness or recruitment. Citron et al. (1999) discover an important potential downfall of support groups as they recognize that participants

can easily become overwhelmed about their individual situations while being in the presence of others experiencing similar challenges and feeling intense empathy. Morales-Campos et al. (2009) express concern about participants potentially feeling triggered from hearing about the experiences of peers and unintentionally reliving trauma through the narratives and perspectives presented by other participants. Yet, overall, the current literature on support groups and community supports generally suggest that they are primarily beneficial as they create a sense of community and inspire hope amongst one another to overcome the challenges they commonly experience (Bush et. al., 2018; Citron et al., 1999; Morales-Campos et al., 2009). Community supports help empower and heal participants through the comforting realization and validation that they are not alone during hard times and that others understand and personally relate to what they are going through. These findings are beneficial for the current research as they demonstrate how important human connection, communication, and relationships are to constructing and understanding sense of self and personal meaning.

Theoretical Framework: Goffman and Stigma

Goffman's concept of stigma is crucial to consider in the current study. Goffman defines stigma as an attribute or characteristic that one possesses which conflicts with identity norms and thus allows others to discredit them (Goffman, 1963; Jenson & Sandstrom, 2015). Within this discourse, Goffman examines identity as a basis for applying stigma, as a person who is understood as defying expectations in ways that are seen as undesirable are often judged and stigmatized. The following highlights relevant elements of Goffman's work to the current study.

Normal Versus Abnormal (Stigmatized)

Goffman (1963) highlights the importance of categorizing members of society in ways that label individuals as a dichotomy of either 'normal' or not. As a result, stigma is a product of

an individual being viewed or labelled as an outsider to the ‘normal’ (individuals who the stigmatized characteristic does not apply to) members of society, as thus is seen as isolated and abnormal. The individual in question is then reduced in our minds and seen as a tainted or damaged human because of the particular undesirable quality or characteristics that they possess. Goffman (1963) notes that the recognition of stigma is produced through language, and that not every characteristic or quality that may be stigmatized in one social setting will be stigmatized in another. Whether stigma is present in a specific instance depends on the constructions of what is inherently good or bad within the instance, as language is relational (Goffman, 1963).

Within Goffman’s (1963) definition of stigma, he identifies three different types of stigmas that can be applied to an individual, which are: abominations, blemishes, and tribal stigma. He identifies abominations as specifically pertaining to the physical body, taking the forms of various physical deformities (Goffman, 1963). Next, he defines blemishes as “blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty [which become known from things such as] mental disorder, imprisonment, addiction, alcoholism [etc.] (Goffman, 1963, p.4). The third type of stigma is tribal stigma, which refers to the race, nation, and religion; factors that he claims can be transferred through genetics and lineage and ‘contaminate’ the entirety of a given family (Goffman, 1963). Goffman (1963) defines those who he considers to be without stigma as ‘normals’, effectively applying the label of the isolated ‘other’ to those with stigma, discriminating against and dehumanizing them accordingly. Manzo (2004), as cited by Nack (2008), asserts that STIs fit Goffman’s (1963) criteria for generalized stigma due to STIs being contagious and often thought of as culpable when discussed in social settings.

Interactions of ‘Normals’ and The Stigmatized

When both ‘normals’ and the stigmatized are interacting within the same social situations, this is when the stigma and its implications are felt and experienced by both groups. The stigmatized are aware that they are different from the ‘normals’ because of their stigmatized characteristic, and the ‘normals’ are aware that the stigmatized can be ‘othered’ compared to them (without the stigmatized characteristic). The stigmatized characteristics are previously established as being abnormal or undesirable within social contexts; within the context of the current study, it is often established within popular culture and common societal discourse that contracting a chronic STI is undesirable and abnormal. The stigmatized individuals are aware that the concept of having a chronic STI is often stigmatized, even prior to interacting with the ‘normals’. Knowing this, the stigmatized may feel nervous, fearful, or unsure about how the ‘normals’ will experience or treat them within their interactions due to their stigma (Goffman, 1963). Due to this uncertainty, the stigmatized person is typically hyper-aware and self-conscious of how they are presenting themselves to the normal, as they focus on impression management. Social encounters provide opportunity for others to make quick judgements, profile others, and apply stereotypes to those who act in ways that are socially unacceptable (Jenson & Sandstrom, 2015). Due to regularly interacting with others, Goffman believes that all individuals must manage their identity and social interactions through limiting the attention drawn to their stigmatized characteristic as a way to avoid being discredited in society and thus stigmatized (Smith, 2011).

Overall, these concepts and theoretical framework will be crucial in understanding how my informants present themselves to others and in better understanding their intentions and decisions when interacting with others. This theory will also help understand perceptions of individuals with STIs and why they can be viewed as outside of social norms and stigmatized.

Chapter 3: Methods and Data Collection

This research involved in-depth semi-structured interviews with 21 informants who have been diagnosed with and are living with a chronic STI, such as HSV, HPV, and HIV.

Recruitment criteria for informants stated that they needed to be between the ages of 19-40, were living in Canada, were comfortable communicating in the English language, and were willing to have a one-on-one confidential interview. Recruitment occurred through posting a recruitment poster to Facebook, Instagram, and Reddit from my personal social media accounts, word of mouth, and snowball sampling. Additionally, I reached out to several sexual health Instagram accounts who generously agreed to post my recruitment material to their accounts. Informants were offered a small incentive of a \$10 gift card to thank them for their contributions to the current study. This project was supported by a Social Sciences and Humanities Research Council (SSHRC) research grant awarded in 2021.

Using semi-structured interviews (see Appendix A for interview guide) as the primary data collection method enabled discussion based on the topics that I wished to cover, while also allowing the informants the space and autonomy to contribute insight about my topic that I had not previously considered (Adeoye-Olatunde & Olenik, 2021). Semi-structured interviews allowed space for informants to direct conversation to what they felt is most important to focus on in regard to their own experiences, which produced data that I had not anticipated, yet was extremely impactful on the results of the study. The topics I covered with each informant in order to get a sense of how they experience certain elements of living with a chronic STI included the following: experience with being diagnosed, the impact of the diagnosis on

romantic and sexual relationships, the impacts on friendships, the impacts on attitudes towards sex, who they trust and confide in regarding their diagnosis, responses to their disclosures, forms of support, their ideas surrounding public perception, their own feelings towards their chronic STI, perceptions of STIs prior to being diagnosed, online supports, impact of the pandemic, and what they think are the most important aspects of their experiences.

Interviews were held over Zoom and ranged from 50 minutes to two hours each in duration. Each interview was audio-recorded with an external personal digital recording device and were subsequently uploaded to a password-protected USB. Interviews were then transcribed verbatim and anonymized by removing all names and personal identifiers, and informants were assigned random pseudonyms (Kaiser, 2009). Once transcribed, I coded my data for analysis by developing codes, categories, and relevant themes that emerged within the interviews. I used the coding software NVivo to support my analysis process. I identified broad or open codes, meaning that I created labels to help identify various units of data, and I did this by going through my transcripts line-by-line and pulling out meaningful sentences and quotes, key words, and reoccurring data in order to assemble a codebook (Mauthner & Doucet, 2003). The specific open codes that I identified for my analysis were: Diagnosis of STI, Family and Friends, Medical System, Romantic Relationships, Silver Linings, Social Media, Stigma, Support Systems, and the Self. Following the creation of these open codes, I then created focused categories based on each of the codes, and each category consisted of collections of similar codes that I compiled based on similar words or wording, shared experiences, and general overarching patterns between informants (Bradley et al., 2007). There were 80 focused codes in total used across the 10 open codes in order to organize and analyze data. Once the open and focused codes had been organized and the applied directly to the data, I sorted through the codes to highlight the most

common themes shared by multiple informants, as well as some interesting outliers that represented alternative or uncommon experiences amongst informants. The analyzed data were then reported and discussed within the finding chapters of this thesis.

Methodology

This research is methodologically guided by narrative inquiry. Narrative inquiry refers to the practice of studying lived experiences and how individuals understand the world through the hearing and interpreting of personal stories (Wang & Geale, 2015; Connelly & Clandinin, 1990). It is based on the concept that individuals construct meaning to their lives through stories, and these stories can then be studied and interpreted as data. Within narrative inquiry, the interviewer becomes a co-informant that works with the informant to co-construct knowledge and understanding of the topic at hand (Pino Gavidia & Adu, 2022). When the researcher is given the opportunity to hear in-depth stories from the informants, the researcher is then enabled to have more of an ‘insider view’ from gaining a deeper understanding of the perspective of the informants (Wang & Geale, 2015). Using stories as a primary form of data collection is also beneficial because both the researcher and the informant help construct a nuanced picture of a certain topic and how it is understood at a certain place or time, as well as how the certain topic may change or unfold over time (Pino Gavidia & Adu, 2022; Wang & Geale, 2015).

I have chosen to draw on narrative inquiry as my primary methodology because I wanted to explore the various nuances in the experience of living with a chronic STI. Each informant had a unique story, different from each other and from my own story, and therefore I wanted to be able to understand each person’s lived experience in greater specificity. Not only did I want to understand their own lived experiences in detail, but I also wanted to understand their distinctive

perspective and their thoughts on the common experiences that most of my informants shared with one another but had interpreted them in various ways. Focusing in on the stories that my informants shared with me has allowed me to gain a deeper understanding of how their thoughts and perspectives often changed over time, and allowed me to recount the common experiences and emotions that were most often associated with certain common experiences, such as being diagnosed, disclosing to partners, and learning to accept or at least manage their diagnoses. I was able to learn more about the thoughts and perspectives that were different from my own lived experiences, thus giving me a more complex insider view of the topic through being thoroughly informed by informants. Informants within this study were viewed as more than simply just participants in my research, as they co-constructed and helped shape my research through their own perspectives and understandings of living with a chronic STI.

Ethical Considerations

While prioritizing the wellbeing of my informants and considering any potential ethical considerations for this project, a few things were considered due to the sensitive nature of my topic. As previously mentioned, I ensured that I de-identified all of my data collection materials and randomized pseudonyms were used for each of my informants. All specific information that could be used to identify informants, such as hometown or current province, universities attended, partners' names, were changed or omitted in the interest of protecting confidentiality. Further, I recognized that it may be challenging for informants to identify themselves as living with a chronic STI and that it might bring up negative emotions by reliving troubling experiences. To mitigate this, I compiled a list of Canada-wide health and well-being resources to be readily available for informants to access if they feel it necessary. I reminded informants of this verbally at the start of the interview and at the end of the interview, and they also had access

to this information on their copy of the consent form. At the start of every interview, informants were made aware that if they felt uncomfortable at any time during the interview, they had the right to refuse to answer any question(s) they were uncomfortable with. They were also immediately informed of their right to withdraw from the study at any point and that they could request all data collected from them prior to the point of withdrawal be discarded. Although no informant did this, it was made clear to them that those who exercise their right to withdraw from the study during the interview would not be penalized and would still receive the monetary incentive offered. No informants expressed discomfort in answering the posed questions and were willing and seemingly enthusiastic to share their thoughts and experience on the matter. Several informants accepted the list of resources and expressed that they would keep it in case they needed it in the future, but no informant expressed feelings of distress or negativity at the time of their interview.

Informant Demographics

Out of the 21 informants involved in this process, 19 were living with a form of HSV (herpes), with six living with gHSV-1 (genital herpes, strain 1), nine living with gHSV-2 (genital herpes, strain 2), and four did not specify which strain of HSV they lived with. One informant was living with a multiple-year-long HPV flare up, and one informant was HIV+. Two of the HSV+ informants also identified experiencing HPV symptoms in the past as well. The age of informants ranged between 19 and 39 years old. Of the informants, 13 informants self-identified as cisgender women, five identified as men, two identified as non-binary, and one informant identified as currently questioning their gender identity. In terms of their sexuality, 10 informants self-identified as heterosexual, seven identified as bisexual, one identified as gay, one identified as pansexual, and two broadly identified as queer. In terms of relationship types or categories, 19

described pursuing monogamous relationships, and two described pursuing polyamorous relationship dynamics. In terms of race, 13 informants self-identified as white and/or settlers, four informants identified as Indigenous or Metis, two identified as Hispanic or Latino, one identified as Chinese, and one identified as Indian. Although all the aforementioned axes of identity were asked of each informant at the start of each interview, there was not enough data collected on how race or sexuality impacted experiences and thus were not a focus in data analysis.

In what follows, I introduce findings from this research. I start by exploring the diagnostic moments, detailing the initial reactions described by informants, which includes recounts of reactions from other people and societal forces that helped shaped these diagnostic moments. These external forces include reactions from health care workers, partner reactions, lack of STI knowledge, sex education shortcomings, and informants' understanding of STI stigma. Diagnostic moments demonstrate how emotionally difficult most informants experienced their STI diagnosis to be initially, but then begins to show an adjustment period where informants settle into their diagnosis and accept the reality of living with a chronic STI. Then, I explore how informants described their sense of self and identity as being disrupted, often temporarily, in connection to their new STI diagnosis. This disruption has implications for how informants describe their self-esteem, body image, and overall identity. Informants describe their diagnosis as being tied to a temporarily damaged sense of self and identity, but with some time and intentional effort, informants were able to repair their sense of self.

Next, I explore how informants described how their romantic, platonic, and familial relationships were influenced by their STI diagnosis. While there is a great deal of nuance and variation in the discussion regarding relationship dynamics, relationships were either

strengthened, weakened, or were largely unaffected by the acknowledgement and implications of the informant living with a chronic STI. I finish my exploring a topic that is often absent from a discussion of STIs, the discussion of what positive elements, or ‘silver linings’, informants identified as being connected to living with a chronic STI. These silver linings include an improvement in communication skills, a strong presence of community between others living with chronic STIs on social media platforms, higher quality connections with romantic partners and other loved ones, and an increase in self-care and -love, empowerment, and resiliency. The following chapters details these findings in greater specificity.

Chapter 4: Findings - STI Diagnosis

When I was diagnosed with a chronic STI, many thoughts ran through my head. How do I move forward now that the unthinkable happened? How do I cope with receiving a life-changing diagnosis that I assumed would end my sex life and complicate my dating life forever? Does getting a chronic STI change who I am and how I live my life? While these were some of my own reflections, many of my informants shared similar thoughts when they received their STI diagnosis. Most informants described in detail their painful and emotionally charged experiences of grappling with variations of these questions upon their initial STI diagnosis. Many informants could not believe they acquired a chronic STI and were both ashamed and disappointed with themselves as a result. Each informant had unique perspectives and challenges associated with their diagnosis. However, every single informant described experiencing negative feelings regarding their new STI and reported needing time to process this news given the personal implications they anticipated experiencing because of having an STI. Several informants stated that their experience acquiring a chronic STI was confusing and mentally consuming, as there were many unknown elements of living with a chronic STI. Few informants identified having other people in their lives who were open about having an STI, and many of them expressed feeling isolated during their initial diagnosis. Many informants reported feeling alone and heartbroken as they attempted to accept the reality of their new sexual health status.

Informants' initial diagnostic reactions were shaped by a number of external factors that are crucial to investigate in order to construct a more nuanced and full discussion of what it means to live with a chronic STI. These factors include interactions with health care workers, a lack of proper sex education received in school, partner reactions, and STI stigma as a broad

societal influence. In what follows, I explore these themes as they interacted with the diagnostic moments, from initial reactions with health care professionals, to sharing the diagnosis with partners, and making sense of the diagnosis oneself.

Initial Reactions

When describing their feelings and experiences of understanding that they have a chronic STI and subsequently receiving their diagnoses, informants most often used negative and emotionally charged language. They described experiencing intense feelings such as anger, depression, shock, anxiety, nervousness, frustration, disappointment, stress, confusion, and feeling suicidal in a few extreme cases. These feelings are consistent with Feinstein et al.'s (2008) findings wherein their participants commonly described feeling shocked and concerned, as well as Nack's (2008) findings that describe a STI diagnosis often being coupled with shame, blame, immorality, and irresponsibility. In the current study, informants described their overall experience of getting an STI as heartbreaking, isolating, devastating, traumatic, and difficult to process. Many informants recalled having never considered the possibility of acquiring an STI, so they lacked a clear sense of direction for processing this experience. Ivy, a 23-year-old woman diagnosed with gHSV-2, described grappling with this lack of knowledge and direction:

I like to think of myself as a fairly, like sexually open person, and really with it, and I don't know, but I guess that I was pretty uninformed in the beginning. I didn't know much beyond hey, don't get it, get tested regularly, and everyone says as long as you get tested regularly, you use protection, it'll be fine. But no one really tells you how to prepare for if one of those tests come back positive, no one really talks about that part of the story. And so I was really thoroughly unprepared to hear that positive diagnosis for

sure, and I was uninformed about STIs in general. So, I had to do a lot of learning in the past few months to kind of get up to speed.

As a result of lacking information or context about living with a chronic STI, informants expressed great worry and uncertainty around the implications of having a chronic STI on their social life, love life, and how it changes them as a person. Jerry, a 32-year-old man diagnosed with gHSV-2, expressed that, “it’s still an ongoing question, is what to do, like how this is gonna change things, and how should I start to adjust?” Informants experienced a notable adjustment period filled with many questions and concerns about their new STI diagnosis itself as well as how it would affect their lives moving forward.

Most informants described experiencing very negative, heartbreaking, upsetting initial reactions to acquiring their STI. Some informants felt restricted by uncertainty and thus immediately shut down and retreated from romantic and sexual endeavours as they began to process their diagnosis. This is illustrated by Danni, a 26-year-old woman diagnosed with gHSV-2:

Honestly, I just kind of thought my life was over, like I pulled away from everybody, anybody I had like any sort of intimate feelings for, like I just completely disconnected from, shut them down, I was like I’m not okay to be in a relationship right now, I kind of like battled with my whole outlook on relationships. I’m also polyamorous, so like at one point I was like can that even be a thing anymore? Like can that even happen? I was like I’m never gonna have sex again, unless I’m in like a committed relationship, like it was just a lot of like what ifs, like what is my life going to look like now, and for the longest time I didn’t think it looked good (laughs).

Danni's negative initial reactions were tied to romantic and sexual concerns as she questioned whether she would be able to engage in relationships the way she wanted to and anticipated that having herpes would now make her sex and love life more complicated, which was the case for many informants. This aligns with Newton & McCabe's (2008) findings of people withdrawing and avoiding romantic and sexual relationships following an STI diagnosis. In addition to anticipating difficulties in their relationships, some informants' negative initial reactions were connected to a fear of their diagnosis negatively changing them as an individual as well as their life as they had known it. Joan, a 24-year-old woman diagnosed with gHSV-1, demonstrated this fear as she described the exact day she received her diagnosis:

I remember just like bawling in the office, and then leaving and crying in my car, and feeling like, you know, my whole life is over. Like I radically changed as a person, and it's gonna have massive negative effects on like my life.

Similarly, Maya, a 19-year-old woman who had only received her gHSV-2 diagnosis a few months prior to our interview, said: "Oh, God! I felt like my world was ending, I was never gonna have sex again, I honestly didn't, I felt really like ashamed." Melissa, a 36-year-old woman with gHSV-1, echoed Maya's sentiments: "I thought life was, you know, ending, and just really felt like rock bottom, you know?" Melissa, similar to other informants, felt so ashamed and embarrassed about her new STI diagnosis that she could not bring herself to tell her therapist about her actual diagnosis while she used therapy to help process it:

Um, you know, I do go to therapy and stuff, like I never brought it up to my counsellor (embarrassed laugh), and we did a counselling session when I just kind of got the diagnosis, and you know, I cried and I said there is something I just can't tell you what it

is, but I need help with it, so we ended up talking about it that way. There was a lot of shame obviously.

Informants' initial reactions demonstrated the intensity of the negative emotions they experienced after receiving their diagnoses and illustrated the difficult personal journeys ahead of them to accept their new diagnoses and adjust to living with their new chronic STI.

Notably, some informants struggled with self-blame when initially diagnosed with their chronic STI. Rather than acknowledging STIs as a potential reality of being sexually active, some informants saw it as their fault because of their actions. Susan, a 20-year-old woman with gHSV-2, explained her initial thoughts:

I was mostly just like angry I guess, really, like cause I kind of felt like, because looking back, I did point something out, like I could have been smarter, and been like no or whatever but I chose to trust him, I guess, and I kind of blame myself a little bit. But then I, yeah, for like 6 months I think I kind of blamed myself and was kind of depressed.

Nora, a 22-year-old woman with gHSV-1, shared similar feelings of anger and blame towards herself: "how did I fuck up this bad? How did I fuck up my life that bad? Because it generally felt like a death sentence cause, it's the fact that it's like chronic, that was so scary to me, right?" Nora and Susan's sentiments are reflective of Gokengin et al., (2003)'s findings suggesting that their participants blamed themselves for contracting their STI. In addition to attempting to process a chronic STI diagnosis while grappling with the overarching societal stigma of STIs, many informants had an additional task of needing to overcome feelings of self-blame in order to move towards acceptance. As well, they needed to work through their now-altered identities and explore and accept the implications it would have on their lives. However, there were several other external factors that played a role within their initial diagnosis period that influenced their

feelings and overall perspective on the matter. The next section addresses a crucial factor at play within these circumstances, which is the reactions and interactions informants had with health care workers during the diagnostic process.

Health Care Workers' Reactions and Implications

For many informants, the first individuals they spoke to about their (potential) chronic STI was a doctor or nurse when they brought their initial concerns and symptoms forward to be examined by these health care workers. These interactions shaped how informants initially perceived their STI diagnosis, STIs in general, and what the reality of living with a chronic STI would actually look like for them. Nack (2008) describes how health care workers can be understood as social control agents due to their power to (or not to) assign moral statuses or judgements to different illnesses, especially STIs. Although each informant in the current research had unique experiences with health care workers, informants' retelling of these experiences can be understood as generally negative, neutral, or positive. Informants identified actions and conversations that they found helpful, things that actively harmed their perspectives, and experiences that did not do much of either. Informants typically noted how knowledgeable about STIs these professionals were, how much support and concern these professionals showed the informants, and their general reactions to STIs in general and even their specific reaction to the individual informant's situation. Some informants favoured support or knowledge over the other, while the others desired a combination of both. From examining and understanding these various experiences with health care workers, suggestions for best care and support practices emerge. The following section will discuss informant interactions with health care workers to explore how these interactions influenced how each informant viewed their STI diagnosis and set the stage for their overall perspective of what it means for them to live with a chronic STI.

Many informants described having negative interactions and experiences with health care workers during their diagnostic process. In these instances, informants described the doctors and nurses involved as unhelpful, lacking knowledge or compassion, being judgemental, engaging in limited discussion around the topic, not considering the informant's emotions and reactions of receiving a positive STI diagnosis, and not creating or holding space for the informants to process their emotions. For example, when Melissa (36-year-old woman with gHSV-1) recalled considering going to the doctors when she was initially experiencing symptoms, she expressed hesitation and worries about doing so based on her doctor's reputation with treating STI symptoms:

There are many friends I know that just don't like going to this doctor because sometimes he's just like, especially with STI diagnoses, he's usually like "you shouldn't be having this" or whatever, so he made me wait and then I was like hey, I need you to take a look at my anal area, so he brought in a nurse, and then, so I wait another 30-40 mins, he looks at is and he's like "this is herpes!" Like he screamed that, and then I was like oh my god! Then he was like, "well, I need to take this sample, I need to send it to you know, to get it checked out." Yeah, he didn't like counsel me or tell me anything about what it was.

The only accessible doctor to Melissa (described above) was known to judge patients in the past with STI symptoms which Melissa then experienced herself, in addition to his professional care shortcomings of proper knowledge, care, and compassion. Toni, a 36-year-old woman diagnosed with gHSV-2, shared a similar doctor experience that she described with notably intense emotions, hurt, shame, and anger. Toni depicted the process of receiving her STI results from her long-time family doctor:

[My] doctor came in in a flurry, and then she's like "oh, I don't have your results". So she opened the door, and she called across the waiting room that she needed my STI panel in front of everyone, and I was like, are you fucking kidding me? And then she comes in, and she's like "well, I told you, I told you so", like literally "I told you so" to my face. And then, so I'm like sobbing, I don't know what to do, she was like "you're probably gonna want to find someone to talk to because most people get dumped when they find out, when their partner finds out that they have herpes." So that was like her second line, that I'm going to get dumped. She gave me some dusty ass pamphlet that was so out of date, and I was like, well, what do I do with this? She's like, just like, nothing helpful [...] It was like immediately, already, like I'm a piece of trash, no one's going to want me, like this is ridiculous! [...] Just no education, no kind words, no like gentle way of like, easing me into it, the first time or the second time.

Toni felt her doctor was insensitive and unsupportive of her diagnosis and did not provide her with the medical information she desired in a compassionate manner, ultimately making Toni extremely unhappy with this interaction. Although Toni had seemingly made great progress in terms of accepting her STI status and not letting it affect her as much as it initially did, she still held that resentment and anger towards her doctor during our interview, which was over a decade after the described incident. Toni felt very strongly about how incorrectly and unprofessionally her doctor handled their interactions and even expressed the desire to confront that doctor about her experiences in hopes of both healing herself from that experience and further educating her doctor to have a more positive impact when diagnosing patients with STIs in the future. She felt she needed to advocate for herself and others who may find themselves in a similar position, which mirrors Eiduson et al.'s (2021) findings. For many informants, such as Melissa and Toni,

their doctors' negative reactions and interactions set them up for a rather negative and complicated perspective on living with a chronic STI and added an additional emotional barrier for them to overcome while they adjusted to this new element of their sexual health.

Alternatively, some informants described their interactions with their doctors in a more neutral manner compared to other informants. In rather neutral experiences, informants described their doctors as sharing straight-forward medical facts of their STI while having a relatively composed, relaxed, and unemotional demeanour. These health care workers seemed to be indifferent about STIs and simply treated them as any other part of their medical responsibilities. For instance, Taylor, a 28-year-old non-binary person with gHSV-2, casually recalled their experience with one of their doctors in a neutral manner:

The doctor honestly was pretty good about, you know, expressing what my options were, it was a different doctor this time, a nicer guy, and he was like we can put you on, you know, these 2 a day for 3 day thing when you get an outbreak, or you know, you can go the little more extreme, you know, way and take them every day twice a day, for like a few months, and see if it's suppresses anything.

They explained that their doctor had a helpful conversation with them about medical facts and options without being overly concerned or emotional. This casual approach to discussing STIs may be helpful when diagnosing a patient with a chronic STI as it does not suggest the patient should be overly stressed, worried, or concerned about their diagnosis; it demonstrates to patients that STIs are manageable and treatable. A casual or neutral approach is appropriate and likely the correct attitude to bring to the conversation when patients do not seem overly emotional or distraught about STI testing.

Finally, some informants described having positive, uplifting experiences with health care workers during their diagnostic period. These positive experiences contained doctors offering the informants lots of emotional support, an appropriate amount of medical knowledge, were free of judgement or STI stigma, and even involved a few doctors disclosing their own STI status. In Danni's (26-year-old woman with gHSV-2) case, she described an interaction with her doctor:

The doctor was actually like really assuring, I think it helped too that she actually disclosed with me that she also had herpes, so like it was kind of nice to have that bond, and then like when she broke down the statistics of how common it really is, it did help a little. I mean, it still is a lot of process, but just knowing how many people do actually have it kind of, you know, really helped. And she was really reassuring, she's like, "you can cry, you can ask me any questions, like whatever you're feeling, it's valid" (laughs).

The doctor provided sufficient STI knowledge, demonstrated emotional support, and held space for Danni to express whatever emotions she was feeling. The doctor immediately created positive STI representation by establishing herself as having the same chronic STI and reassuring Danni that it was common. This representation immediately made Danni feel less alone and set her up for a much more positive outlook on her diagnosis, especially compared to informants such as Toni (36-year-old woman with gHSV-2) or Melissa (36-year-old woman with gHSV-1).

The tone and outcomes of interactions with the health care system and health care workers are so important in shaping STI diagnostic periods for informants. Health care workers, who generally have a considerable amount of social and cultural capital, are often the first interactions they have surrounding their newly acquired STIs. Ivy (23-year-old woman with

gHSV-2) directly agreed with the importance of how health care workers react during the diagnostic process and noted that that they are often:

The first line of people that tell you and that know your status, and when they react negatively or curtly with you, that's really, really damaging when your self-esteem has already been, taken this huge hit. So having practical information and removing those biases from the medical community, I think would go a very long way in helping individuals with an STI. [...] Because doctors are someone that we regard, um we respect them in society, and we trust their opinion almost whole heartedly because they're supposed to be the professionals. And so, if the professional reacts negatively to this new lifelong status that you've acquired, I mean, if the PROFESSIONAL freaks out on you, can you imagine what the regular Joe down the street would do?

Informants often indicated that the doctor involved in diagnosing them and treating their STI greatly shaped their view on their new personal situation. Due to the power doctors held in this situation, some informants spoke of wishing they had received more direct and intentional knowledge and support from the doctors within these interactions. Nora (22-year-old woman with gHSV-1) verbalized this desire:

I definitely wish that the doctor gave me like a pamphlet instead of just telling me what it is. Maybe a pamphlet of like the transmission rate, what sex is gonna be like I guess. Like what they do when you get like get treated for chlamydia, like when I did, they gave me like a medication sheet of the symptoms you would get by taking the medication and all those things, like if you feel like this, side effects, were all those things, and with the chlamydia spreadsheet like they tell you like symptoms, how you can get it and everything, so like if I could get that with herpes, from what I got with chlamydia, that

would have been so much nicer. Just so I can just sit down and read and see if there's any more like websites I can go through for more information, or understand just like the transmission rate or anything, and understand the mental aspect of it as well.

Patients would benefit greatly from receiving resources on both medical and emotional aspects of living with a chronic STI to best set them up for being able to receive the level of support that they may need.

Partner Reactions

The diagnosis process does not begin and end with interactions at clinics and with health care professionals. Diagnosis moments continue into other relationships and spaces in people's lives. It extends beyond the clinical setting into one's everyday life. To that end, another important element connected to supporting informants in their diagnosis as well as influencing their initial reactions to acquiring their new chronic STI was how their sexual and romantic partner at the time of diagnosis reacted to the diagnosis. Although partner reactions varied considerably, most informants had identified their relationship status as being single at the time of diagnosis but had been recently involved with casual intimate partners. For those in a relationship of some kind, most people were scared to tell their current romantic or sexual partner as they were worried about their reactions. Despite this, most informants did inform their current partners of their STI diagnosis. In what follows, I outline those reactions and the impact the reactions had on how people made sense of their diagnosis as well as their sense of self. Some reactions were negative and some were supportive, even if trepidatious, from the start.

Negative Reactions

Many informants received negative reactions from casual sexual partners, even with partners whom informants believed they got the STI from. Many casual partners were generally

unsupportive, cut off communication, or even and ‘ghosted’ the informants meaning they just sort of disappeared from the person’s life. Ivy (23-year-old woman with gHSV-2), for example, described the reaction from her sexual partners at the time of her diagnosis recalling that he said: “‘Well, that sucks down and out.’ [He n]ever spoke to me again which is pretty hurtful and harmful for me especially being newly diagnosed. That really sucked.” Having a partner react poorly and withdrawing from the relationship made Ivy feel worse about her diagnosis and her dating prospects following her diagnosis.

Some informants dealt with intense and angry reactions from partners after informing them of their new STI diagnosis, which often led to the end of the relationship. Lennox, a 23-year-old woman with gHSV-1, explained that after she told her sexual partner at the time, “he screamed at me, and he was like, ‘how could you not tell me that you have, or you could have this?’” Natalie, a 21-year-old woman with gHSV-1, expressed similar negative responses from her sexual partner as she: “ended up telling the guy, of course, about it, and he freaked out. He ended it with me. [...] He actually had removed me and blocked me from the apps that we talked on.” These negative reactions from former sexual partners were not only difficult for informants to deal with and process in the moment but they also generated concern and worry for people, making them feel that this would be common reactions from future sexual partners for the rest of their lives. Natalie expressed this worry when she told me:

[At the time, I] was more so like focused on the whole boy drama, but (laughs), but I was just really hurt and upset that ... like is this what it’s gonna be like? Because it was just my first experience right off the bat like I was like is this, omg is everyone I’m gonna tell just gonna be like “no?” Like, I’m like, how was dating going to work? ... I was just so scared after that like, I like didn’t really want to date.

These negative reactions from partners made informants feel pessimistic and hopeless about their future relationship endeavours now that they live with a chronic STI. Some expressed that they felt like rejection might be a common and expected aspect in their future romantic lives. These feelings of hopelessness and anticipating rejection relating to their romantic and sexual lives shaped the diagnostic moment and how they processed their new diagnosis and sense of self.

Positive Reactions

When telling sexual and romantic partners about their new diagnosis and STI status, some informants experienced more positive and supportive reactions from partners. Most of these positive reactions came from committed partners, or partners that would soon become committed partners. Melissa (36-year-old woman with gHSV-1) acknowledged how much having her partner's continued support meant for her in her own journey of self-acceptance following her STI diagnosis. Recalling the moment she told her partner, she recalled:

[He] didn't cancel our relationship and that meant a lot to me, thank you so much, like you know, it helped me accept myself. I don't know what I would have done if he had said no in that moment when I first got diagnosed. So, that actually really helped me.

That was pivotal in me continuing to love, and you know, continuing to love and accept myself.

In contrast to the participants above who experienced negative reactions, which made the impact of their diagnosis more difficult to navigate, Melissa's response highlights how her partner's accepting and supportive response actually helped her process her diagnosis as well. Since her partner continued their relationship, she felt that she was still worthy of love and acceptance and made sure to treat herself accordingly. This contrasts with people who did not have this specific form of support because they did not have a relationship. For these folks, they often experienced

a particularly challenging diagnostic period. Nora (22-year-old woman with gHSV-1) expressed this when she explained how much harder she felt her diagnostic process was compared to others due to lacking a supportive partner: “I did feel like shit at first and with the fact that me not having a partner to talk to didn’t really make it feel better.” In sum, partners’ reactions, or the absence of a partner as a form of support, have the power to either help or further harm an individual dealing with a positive STI diagnosis in two ways. It seemingly shaped how people made sense of their ongoing diagnosis as it unfolded, and also shaped their sense of self.

Lack of Knowledge and Sex Education Shortcomings

One’s knowledge and education (and their partner’s knowledge) on the topic of STIs played a role in how they made sense of their diagnosis and experienced the diagnosis process. Many informants admitted being largely uneducated about the specific STI they had been diagnosed with and STIs in general. If they had been educated, it was mostly that they were something to avoid and that they are bad. They had no education on what do to if they did in fact get an STI.

A lack of knowledge on STIs shaped people’s sexual experiences and how people came to get STIs as well. For example, Joy, a 32-year-old woman with gHSV-1, expressed that her partner “would get cold sores, like oral cold sores, and we didn’t know, like I didn’t know that you could pass it on through like oral sex, I had no idea.” Many other informants expressed similar sentiments. Since they lacked this knowledge and information, they were unable to make educated choices regarding protection and barriers or abstaining from sexual activity while cold sores were present. This is consistent with Lindberg & Maddow-Zimet’s (2012) findings on the importance of comprehensive sex education on teaching safer sexual health practices and behaviours.

Many informants expressed that they did not receive good sex education during their school days but that they thought that having better information would have been beneficial for them in both their sexual practices and the ways that they communicated and understood sexual health. Joan (24-year-old woman with gHSV-1) theorized the impact that her insufficient formal sex education had on her experience of being diagnosed:

I think because I never learned how to talk about it in school. Like, I didn't have the language or the tools to understand what was happening inside of my body, so I didn't have the language to talk to myself about it, to like talk myself out of the mental spirals that I would go into. Nor did I have the tools to talk to my partners about it, or to anyone else who I may have needed, you know, comfort or reassurance from.

Joan felt that since she was not taught "comprehensive sex education" in school, she was lacking a proper understanding of the medical side of STIs and missing tools to communicate to her partners about the risks and safer sex practices available that could help protect them. Similarly, Danni (26-year-old woman with gHSV-2) shared her thoughts on how her sex (mis)education shaped her own initial reactions and internalized stigma:

They don't talk about it in school, so like right from a very young age, it's like ingrained to our brains that, you know, if you get an STI, it's something to look down upon. It's not a good thing, like they talk about it so negatively in school, and they basically say, you know, like either use a condom or don't have sex, because this is what could happen, and then they don't talk about it in some sort of like positive -- not a positive light, but like a reassuring light, but it's not like an end all be all kind of thing. So yeah, I think it starts right from education in the schools, like it's not talked about properly. [...] We're taught that all STIs are bad and that if you get one it's some sort of personal failings to be

looked down on for. They're made out to be so taboo and burned into our brains as a death sentence.

Danni and other informants expressed that their sex education was inadequate and riddled with shame. They also noted considerable struggles when processing their diagnosis and attempting to combat and unlearn stigma associated with living with a chronic STI.

Stigma

According to Goffman (1963), stigma is an attribute or characteristic that an individual is perceived to have that discredits them and separates them from others who do not possess the attribute. In order for stigma to be a powerful social force, Goffman (1963) stresses the importance of stigmatized individuals interacting with those he considers "normals", as stigma alienates the individual experiencing it by creates a clear divide between normal or correct social identities and attributes and those who are wrong or abnormal. Stigma can be external and felt from a variety of sources; informants note these sources include family, friends, TV shows and movies, stereotypes, and STI jokes in social settings. This external stigma can impact one's feelings or experiences and can also become internalized. Both internal and external stigma were discussed at length by informants.

Stigma played a big role in people's diagnosis and shaped how people made sense of their diagnosis and what it meant for them (in terms of their sense of self) and their imagined futures. Some people discussed that they personally experienced stigma from others because of having a chronic STI. However, several people also discussed the internalized stigma they felt-stigma that stemmed from their own preconceptions and stereotypes about STIs. In these instances, the internalized stigma shaped how participants felt others would view them and was often informed by tropes about STIs that are commonplace in pop culture, media, and everyday

jokes. These manifestations of stigma shaped how people experienced their diagnosis and how it shaped their sense of self. In what follows, I explore two of the main themes that participants discussed when talking about feeling stigmatized – stereotypes and pop culture. In doing this, I show how stereotypes and pop culture play a role perpetuating the stigma people felt and internalized, which subsequently shaped how they made sense of their diagnosis.

Stereotypes

Stereotypes of people with STIs were a key theme prevalent in creating and perpetuating stigma within informants. Some key words that emerged when asking informants about the terms and phrases tied to STI stereotypes they were aware of include: dirty, whore, villain, deviant, careless, reckless, deceptive, gross, not caring for oneself or sexual health, and sleeping around.

Erik, a 27-year-old man with gHSV-2, explained the reactions he expected to hear if he ever told anyone he was living with a chronic STI, as he assumed “everybody [would say] ‘oh, you caught it so you must be like dirty or gross.’ But yeah, that’s, that’s usually the stigma coming in.”

Although he had not actually had these reactions since he had not shared his status with anyone at the time of the interview, he assumed these would be the reactions based on the STI stereotypes he knew of combined with his understanding of STI stigma, perhaps illustrating an internalized stigma. Ivy (23-year-old woman with gHSV-2) noted something similar when she told me about the STI stereotypes she had observed:

those kinds of negative associations that come with having herpes, with having HSV is that like you must be sleeping around, you must not be taking care of your sexual health, you’re just some slut that doesn’t take care of yourself and so you should be avoided at all costs, you’re dirty. [...] Well, before I was diagnosed, I kind of felt immune to getting an STI because I’m like, you know, I sleep around but I practice safe sex. I get tested

regularly, [sarcastically] like I'm a good person, I don't get an STI, because somehow getting an STI means that you're a bad person, or a sexually deviant person, or a ho or something like that, which I'm a ho and I'm proud to be a ho!

Ivy worked hard to fight these stereotypes for herself and her own perspective, but when she was initially diagnosed, she understood that this is how society generally sees STIs and people who live with them. Most informants struggled with STI stereotypes and overcoming them, as they felt the weight of the stigma on their own sense of self and identity in the earlier stages of their diagnosis. Nora (22-year-old woman with gHSV-1) demonstrated the stereotypes that she intensely felt she embodied because of contracting an STI:

I will admit this, when I first got diagnosed, I was like on my phone with my friend, and I was like I kept calling myself a dirty skank, kind of thing. She was like, 'You gotta stop calling yourself that!' But it generally did feel like that.

Nora's self-description seemingly emerged from STI stereotypes leading her to feel shameful and negatively towards herself. These stereotypes contain many personal labels that translate to a negative identity (Becker, 1963) and several impactful negative feelings toward the self (Hihara et al., 2019). These stereotypes are upheld and hold significance amongst informants and within society, which heavily reflect Goffman's (1963) concept of stigma.

Many people's understandings of self were at odds with stereotypical understandings of "who gets STIs," which often led people to be surprised they had contracted an STI in the first place. For example, Toni (36-year-old woman with gHSV-2) was in such disbelief of contracting an STI, expressing that she is "not the person that this happens to." Joy (32-year-old woman with gHSV-1) shared a similar sentiment as she exclaimed, "I'm probably like an interesting person to have the face of somebody who has herpes because I don't have a story of going out there and

sleeping with a whole bunch of people.” Taylor (28-year-old non-binary person with gHSV-2) reflected this as well as they mentioned that they felt like they are “not necessarily someone people expect to have an STI, because when people think of, of someone who has an STI or like has herpes, they have an image of someone who’s like sexually irresponsible.” Each of these informants felt they did not align with common STI stereotypes while also demonstrating that STI stereotypes still exist and are deeply ingrained, even in the minds of those who live with chronic STIs. Although many informants demonstrated throughout the interviews that they actively challenge STI stigma and stereotypes, the stereotypes of who gets and who does not get STIs impacted their initial reactions to their diagnosis.

Pop Culture and STI Jokes

When informants referred to STIs in popular culture, they typically referred to the history of sex-negative and shameful attitudes they learned in school and in their social settings as the norm regarding STIs, as well as the STI jokes they recalled hearing both in media and in their real-life social situations. This could be part of why people do not see themselves as the type of person who gets an STI (as described above). Informants identified many sources of stigma in pop culture as they felt that is so ingrained in society. Talking to me about where she thinks STI stigma comes from, Joan (24-year-old woman with gHSV-1) expressed:

Ugh, the Judeo-Christian morality around sex, let’s like start there. I think historically you have to start there, because our whole education system came from the church. The whole thing has come from like Christian values around like morality and sinning. [...] I think it’s just, it’s bred into us as children to be stigmatized and to stigmatize other folks because of this and the education system just starts that and then we pick it up in our social groups and we talk to each other about it. You can’t escape it, it’s everywhere, but

it starts in school and it started with the church. [...] It just becomes so widespread, like it, I really think like if you were to do like a mind map of it, you know, like it starts with religion, and then it goes down to school, and then it goes down to your peers, and your peers grow up and they go into advertising or they go into television, and it just becomes part of our culture which is not ideal to say the least.

As previously mentioned, sex education within schools is lacking nuance and perpetuates stigma, but this stigma is also found in religious teachings, social settings, and media and marketing. In terms of marketing, a few informants specifically mentioned STI stigma in propaganda from “Big Pharma” that was prevalent several decades ago that was initially intended to sell HSV medication such as Valacyclovir. Taylor (28-year-old non-binary person with gHSV-2) explained their thoughts on the “fabrication” of the “herpes scare panic by Big Pharma” noting that:

Herpes is such an old infection, that you know, people have had literally forever, since we’ve been humans, kind of thing, like the ancient Greeks had it kind of deal, and they were chill with it, and it wasn’t until like the sixties or something like that, where Big Pharma was, you know, trying to create a marketable medication for people and manufacturing this health concern. [...] So I think it’s just these, these harmful narratives that get circulated around and around because certain people benefit, so like pharmaceutical companies benefit from this, and others just have no idea, so it just keeps going and is perpetuated.

Similarly, Jordan, a 36-year-old non-binary person with gHSV-2, demonstrated how these ideas strengthen and continue to form through other sources in popular culture. Jordan mentioned hearing about “Time Magazine when herpes medication came out, you know, like the scarlet H,

and it's something that is joked about, it's associated with having multiple partners, you know, like being dirty, slutty." These big and relatively respected sources in popular culture perpetuating STI stigma in various forms demonstrate how certain values and perspectives are maintained and evolve into powerful and influential ideals in society. Informants identified learning some of these ideals from their parents, who likely learned some of them from their own parents and from absorbing these ideals from pop culture themselves. Ivy (23-year-old woman with gHSV-2) eloquently described her understanding of this process:

You can think about it in like a cultural evolution or like a learning regard, right? What are your political affiliations? They likely line up with those of your parents, because the ideas, beliefs, and culture of your parents is passed down onto you. And so if they were taught that herpes is this lifelong disease that's going to ruin you, you probably got a little bit of that information from your parents, and then from the wider media as well growing up too, even if we weren't personally exposed to those campaign ads and this, that, and the other, that culture that it produced is still prevalent in society.

Ivy and other informants showed recognition of how STI stigma can be passed down through generations through teaching stigmatizing actions and values. These harmful and stigmatizing generational or parental influences align with the common perspectives of sex and sexuality of American parents as presented in Schalet's (2000) work. These negative, stigmatizing societal beliefs passed through generations (often subconsciously) helped shape their understandings of STIs and resulted in a more negative, shameful, and stigmatizing reaction to their diagnoses. These beliefs were yet again another obstacle that informants needed to overcome to accept their new chronic diagnosis and make peace with the impact it would have on them for the rest of their lives.

Another prominent source of STI stigma in popular culture that informants identified understanding and being impacted by was STI jokes. They were exposed to these jokes from friends, TV shows, movies, and simply coming across STI jokes in online and social settings. When hearing these jokes from friends, many of the friends were unaware of the informant's positive STI status and thus were unaware of the direct damage or harm they were doing by telling the joke. For example, Ivy recalled:

I was at a friend's party and it was only maybe a month after I first found out, maybe month and a half, and everyone have been drinking. We're hanging out and her Wi-Fi password happens to be "beavers have herpes" because apparently that's hilarious. Yeah, I have weird friends (laughs). And so somehow herpes became the topic of conversation after someone asked for the Wi-Fi Password and someone throws out, "Oh, you know 1 in 6 Canadians have herpes. It's crazy high!" And then we're in a room of six or eight people, so they go "Oh, someone here must have it. Ha, ha! ha!" Not realizing that, well, yeah, someone actually does, and I just found out a month ago. So I'm really sensitive about it, don't joke about it. And the jokes kept rolling. There was another guy sitting near me who was kind of flirting with me, and so one of the other friends said, "Hey, look out [name], that guy could have herpes!" Like straight to my face said "oh, look out, you know. Don't catch it!" And I kind of, I was so tempted to say, oh, well, it's too late, but I didn't have the balls yet.

Having her new STI status that she was still processing being the topic of ridicule and mockery made Ivy feel bad about herself and her STI status and made this process even more difficult and painful. Further, Toni (36-year-old woman with gHSV-2) discussed her feelings on situations like these and explained how:

when you're the butt of a joke, or when, not you, but like when someone's diagnosis, not the person, but when someone's diagnosis is the butt of a joke, and everyone thinks it's funny and doesn't take it seriously, and also doesn't understand the impact, that, I find that really frustrating.

Friends make these jokes while being unaware of the impact they have on these informants, but they continue to perpetuate STI stigma and establish that STIs are shameful, bad, and worth joking about.

In addition to hearing these jokes from friends, STI jokes are also prevalent in television shows, movies, and stand-up comedy specials. Nora (22-year-old woman with gHSV-1) recalled hearing a herpes joke in one of her favourite television shows, *New Girl*, shortly after she was diagnosed:

So like there is one where the guy, Schmidt, was talking to a girl, and then like he's like, "Oh, I have some bad news", and she was like "what is it?" And he said it, I forgot what it was, and she was like, "Oh, thank God, it's not herpes" kind of thing, right? And I was like well, okay.

Similarly, Lynn, a 28-year-old woman with gHSV-2, reflected on her experience with STI jokes in media:

it's almost like the butt of a joke, right? Like people often make jokes about it, like um, and you know, you see it in -- I was watching a stand-up comedy the other day, and the guy was like, made a joke about um, like this girl stopping him before sex, and he was like this bitch has herpes and I'm like oh my God, it's everywhere! Like people, it's a joke, like people make it as a joke, right, and things like "well, at least you don't have herpes!"

Faith, a 24-year-old woman with gHSV-2, further exclaimed, “in some films, like they literally just treat it like something gross of like, you know, like that girl’s got herpes!” Nora, Lynn, and Faith recalling these small specific STI jokes that they had heard in media throughout their life demonstrates the power those jokes had on them seeing as they stuck with these informants. Informants generally expressed frustration and annoyance around these jokes as they understood that these jokes continue to uphold and perpetuate STI stigma.

Finally, informants could not seem to avoid coming across STI jokes as they even passively encounter STI jokes in mundane places they did not expect. Jordan (36-year-old non-binary person with gHSV-2) recalls a specific incidence of going to a sexual health clinic and unexpectedly experiences STI stigma:

The office manager had printed off some comic strips where STIs were the punchline. So there was one where it shows a doctor talking to a patient, and the patient says, ‘so you know that’s saying like what happens in Vegas stays in Vegas,’ and then the punchline is, the doctor looks at the clipboard and says ‘you have herpes,’ and [they] had printed that off and taped it to the wall behind reception where anyone could see. And [the] registered nurse had that and other memes and cartoons that were jokes about STIs, and there was one with a guy, like a meme where a guy was looking really creepy, and it talked about him having, wanting to share chlamydia, and I saw it and was completely floored! [... This is] a sexual health clinic, these are sexual health jokes, [they thought] it’s fine, it adds, they actually thought it added color to the wall, meanwhile I’m horrified. [...] I thought it was a great example of here in a sexual health clinic, there’s a very clear picture of stigma in action, and people being uninformed about it.

Jordan felt that it was extremely inappropriate and upsetting that STI jokes were even being made in sexual health clinics that diagnose and treat individuals with STIs all the time. If even sexual health clinics make STI jokes that perpetuate stigma, then there must be some truth and validity to the stigma. Unfortunately, every informant mentioned struggling with stigma in some capacity, which contributed to their overall difficulties being diagnosed with a chronic STI and learning how to manage and cope with living with a chronic STI.

Chapter 5: Findings - Sense of Self

After receiving their chronic STI diagnosis, every informant expressed that they immediately felt a shift in their sense of self and how they viewed themselves as a social being. Informants often discussed how others see them, their perceptions of how they present themselves to others, their self-work, and their relationships with their bodies. In this thesis, I categorize and thematically treat those as one's sense of self. Specifically, my working concept of the *sense of self* includes elements of informants' personal thoughts, emotions, and feelings associated with understanding how others see them, perception of how they present themselves to others, their self-worth, and their relationship with their own bodies. Being newly diagnosed with a chronic STI influenced how each individual thought of themselves and their bodies and impacted how they assumed others would now perceive them too. For most informants, they commonly described that their positive STI diagnosis had detrimental and damaging impacts on their sense of self. Other scholars have found similar things. For example, Nack (2008) explored the implications of STIs meaning that an individual was promiscuous, irresponsible, naïve, lacking morals, and even stupid as a result of contracting a chronic STI. Nack (2008) argued that contracting a STI could be understood as a turning point in one's life as it brings upon implications to one's identity or sense of self that disrupts the previous understanding of them. At first, this shift in sense of self and identity can be confusing and difficult to navigate while processing a chronic STI diagnosis.

Many of the people in my research expressed a struggled to make sense of their self-worth as they explained their newly acquired STI made them feel less attractive and overall lowered their self-esteem. Many grappled with implications of negative STI stereotypes and how

these stereotypes influence their identity and how other people would see them. Although not necessarily forming in critical development stages, grappling with negative STI stereotypes and the implications they had on informants can be tied to Hihara et al. (2019) and their discussion of negative identity as these new images or perspectives can be understood as undesirable and harmful to informants' social relationships and participation in society. Informants described their mental health as impacted by the diagnosis as well, with many stating that their mental health was the worst it had ever been. Informants discussed what can be understood as a common learning curve while learning what living with a chronic STI means for them.

Despite the initial difficulties, most informants eventually worked to intentionally shift their perspectives and came to understand that having a chronic STI does not impact their value as a person because it does not meaningfully change who they are. Moreover, they began to understand that despite having an STI, it was a very small and mundane part of them that should not make them love themselves less, think less of themselves, or define who they are. Informants described this process of changing their unique perspectives and healing their sense of self as incredibly difficult and emotional, and it took various lengths of time and looked different for each informant. The following section describes and explores the initial damaging impacts to the sense of self and the painful, yet empowering, process of restoring self-confidence and healing the sense of self through topics of body image, self-esteem, and identity.

Body Image and Sense of Self

After receiving a diagnosis, most informants recalled experiencing a negative shift in their relationship to their bodies. They often expressed that they felt damaged and uncomfortable with their bodies, which made them feel unfamiliar and uncertain about their bodies and their worth. For some, this was the development of new body-image issues. For others, the diagnosis

heightened and added to pre-existing struggles with body image. When describing what they felt about themselves, informants used words like gross, dirty, diseased, self-conscious, unattractive, unworthy, inconvenient, lacking confidence and self-esteem, ashamed, guilty, ruined, worthless, frustrated, physically revolting, struggling, and upset. For some, these descriptions came in contrast to how they previously felt about themselves before the diagnosis. For example, Erik (27-year-old man with gHSV-2) mentioned:

Yes, before all of that happened, I was like cool with like, I was really confident with other people seeing my body and stuff, like I was, I could probably get naked pretty easily (laughs), if that makes sense, and not feel like self-conscious. And um, but now, not so much.

Erik noted that he became more self-conscious about his body following his herpes diagnosis, despite no real changes to his physical appearance. Informants discussed these (often) new negative feelings towards themselves and their bodies as if their STI diagnosis brought about real and noticeable changes to their body, even though most informants had no physical impacts on the body from their STI (aside from minimal physical symptoms for a few informants during an active outbreak). As a result of the negative labels and STI stereotypes that informants identified having an understanding of, they felt and understood the impacts of these stereotypes to be real and tangible on their individual bodies. This finding is consistent with labelling theory (Becker, 1963), as informants began to believe and internalize the STI stereotypes and labels they understood as being placed on them simply because of living with a chronic STI.

Alternatively, some informants discussed having pre-existing body image issues prior to their diagnosis. These informants explained that they felt their STI was an additional issue to

overcome and felt their looks needed to compensate for now having an STI, effectively increasing pressure to achieve conventional beauty standards. Joan (24-year-old woman with gHSV-1) discussed her previous body-image issues and the impact she felt that contracting herpes had on these issues:

I think I sometimes feel a level of anxiety about my weight and my appearance, it's like I feel this emotion of like well I can't be ugly and have herpes.[...] There's this feeling that like, well I'm already not super convenient and my body is already not super convenient, and so I can't be ugly, like I can't gain weight, I can't have pimples, I can't, you know, differ from this prescribed beauty norm because I'm already trying so hard to compensate for this thing that exists in my body.

Having a chronic STI made informants feel that they had more to prove to the world than the average person, as they now needed to compensate for an additional perceived bodily flaw in order to make themselves and the world see them as worthy and attractive again. They appeared to put additional pressure on themselves and their bodies following their diagnoses in order to feel that they would be good enough to be accepted by others despite the fact that they have a chronic STI.

While many informants were worried about how others would perceive them and their bodies now that they have a chronic STI, some informants discussed struggling with feeling a great sense of responsibility and personal blame. Mirroring Gokengin et al.'s (2003) findings amongst their participants, some of my informants were quite disappointed with themselves and felt a sense of personal responsibility and blame for acquiring their STI and the impact it had on their physical self. Joy (32-year-old woman with gHSV-1), for example, mentioned her struggles with personal blame as she mentioned, "I think maybe I felt like I let myself down, let my body down and my health down." She felt a sense of responsibility for her STI, which was tied to

negative feelings towards her body. Further, a few informants described feeling that they deserved it for either their behaviour or the fact that they were lacking something in their physical appearance. Often, this manifested in informants using negative and hurtful language towards themselves. For example, Toni (36-year-old woman with gHSV-2) said to herself: “Yeah, you fat fuck, like of course you’re diseased too!” Informants played into these negative self-perceptions and stereotypes often associated with STIs and validated their own negative thoughts of being gross, damaged, and diseased. Informants often initially felt a sense of personal responsibility or blame and viewed their STI as a punishment for who they are or their behaviours, rather than seeing STIs as a normal and sometimes unavoidable part of being sexually active.

Receiving an STI diagnosis impacted how some informants interacted with their own bodies. A few informants mentioned fearing directly interacting with their own bodies now that they live with a chronic STI. Ivy (23-year-old woman with gHSV-2) detailed how, “at the beginning I was, I was too afraid to even touch myself. I was washing my hands like mad, to the point where my skin was cracking and dry.” Not only were informants worried about interacting with themselves, but they also feared that their bodies were dangerous and posed a risk to other people due to the potential to transmit the STI. For example, Joan discussed this fear and her tools to cope with it:

I could take an anti-anxiety med (laughs) to deal with the anxiety that I’m feeling about like my body potentially being like dangerous to another person in that way, but I’m taking an antiviral to reduce the risk of it.

When it comes to her fear of transmission, Joan prioritized her partners’ wellbeing over her own as she opts for an antiviral medication over an anti-depression/anxiety medication. Informants

worried about how their body might impact others and were very cautious and aware of the potential to transmit their STI to others. Jerry (32-year-old man with gHSV-2) demonstrated this caution and awareness by reflecting on the fact that: “[herpes changes] what I can do or what I shouldn’t do with my body. I have to be mindful that I have a condition that if, if I don’t take the proper precautions, someone else could be implicated.” Informants worried about the impact they could have on others as a result of their STI, and thus it created layers of complexity regarding how they interact with their bodies and how they choose to have others interact with their bodies.

As informants disclosed the fear that their STI status made their bodies dangerous to themselves and others, it is evident that parts of their sense of self and body image were greatly tied to their perceived impact on others. Their sense of self was impacted by them perceiving that they were a risk to sexual partners and thus thought that no one would think they are good enough or ‘worth the risk’ of potentially getting an STI. Nora (22-year-old woman with gHSV-1) demonstrates these feelings as she vulnerably expressed:

It just felt like no one’s gonna sleep with me, I definitely felt like I was unfuckable or something, right? So it definitely felt like...I felt like I couldn’t have sex anymore, I felt like no one would want to have sex with me because they wouldn’t want to get herpes kind of thing. [...] So I felt like I was like, not touchable anymore when I got diagnosed.

Nora assumed that no matter how attractive someone may find her, they would not want to be physically intimate with her because she has herpes since they would not be willing to take the risk of contracting herpes themselves. This can be interpreted as her not feeling physically attractive enough or good enough as a sexual or romantic being to outweigh the fact that she has herpes. This finding is consistent with Hammarlund et al. (2007)’s data suggesting that their

participants thought of themselves as ‘disease carriers’, and with Newton and McCabe (2008)’s research, both suggesting fear of transmission created additional changes when engaging in sex and relationships. This new diagnosis disrupted informants’ relationships with their body and their self-worth and thus created an adjustment period where they had to work through these distorted self-images and learn how to live with themselves following their chronic STI diagnosis.

Despite feelings of negative body-image and a damaged sense of self that accompanied many informant’s STI diagnoses, they noted that their sense of self changed over time for the better. After an (indiscriminate) period of time in which informants had been facing the reality of what it means to now live with a chronic STI, many slowly began to accept their new STI status and the implications it has on their lives. Many informants noted a compassionate and empowering change tied to more self-confidence and more positive self-images. For example, Ivy (23-year-old woman with gHSV-2) explained how she overcame the personal challenges that she associated with her STI:

Through time [my body image/self-esteem] kind of built up again and I started just kind of not caring, and touching my body, it’s my body and this is who I am, so it’s going to be what it is.[...] I started masturbating again, and that was really helpful for me to just say like, oh hey, this is still your body, it can still experience pleasure. It still is normal, you’re fine, there’s nothing broken about it now.

Here we see how Ivy decided to be kinder to herself and show herself and her body the love and respect that she deserves. She decided to explore her body again which made her realize that she is still the same person that she was before. Informants noted making a conscious decision to start showing themselves care and compassion while they continued to process and accept their

STI status and the implications it would have on their lives. While showing themselves this well-deserved care and compassion, some informants even decided to use their STI as motivation to further work on themselves. A few informants identified their STI as a catalyst to overcome their previous discomfort with their own bodies and pre-existing body image issues. For instance, Joan expressed that her diagnosis empowered her to accept parts of herself that she used to take issue with:

I was not comfortable with my own vagina before I was diagnosed, like I think it's sort of forced me to like be comfortable with it. [...] I think that was a challenge for me was learning how to like become comfortable with my body.

Although it was difficult at first, Joan made intentional efforts to prioritize care and respect her body even more than she had prior to their diagnosis. Further, contracting an STI made informants realize their body was something they needed to take care of, love unconditionally, and be kind to. Joy (32-year-old woman with gHSV-1) demonstrated this realization as she said, "I was just like okay, I actually have to start thinking about my body as something to like care for." Reflecting these sentiments, Melissa (36-year-old woman with gHSV-1) asserted, "I invested in myself, I ended up taking regular therapy, you know, I started taking care of myself [...] I've been trying to fill myself with so much love." Informants were able to address and combat some of the body image issues they recognized as being connected to their STI through the intentional practice of self-care and self-love. This motivation to address and attempt to overcome pre-existing and exacerbated body image issues was identified by these informants as a positive outcome of contracting a chronic STI.

Not only did contracting an STI encourage informants to treat their bodies with more kindness and care, but it also empowered them to make access to their bodies more exclusive.

Living with a chronic STI encouraged them to prioritize their bodies and thus raise their own standards of communication and trust with potential sexual partners as a means of being more selective of sexual partners. Olivia, a 30-year-old woman with gHSV-2, embodied this empowered stance by stating:

I think it made me respect my body a little bit more in a way, like I shouldn't, you know, I don't have to have sex with someone for them to be interested in me, you know? [...]
It's made me think more about who I share my body with.

Olivia felt a new sense of respect towards her body following her herpes diagnosis that made her prioritize herself and her comfort over using sex as a tool to gain someone's affection, which she mentioned having struggled with previously. Her more positive perception of and relationship with her body following her diagnosis had a healing impact on some of her body image issues.

A final positive impact on body image that occurred post-STI diagnosis for some informants was that they felt a new sense of empowerment connected to having a new knowledge about their body. This newfound knowledge of their own bodies helped to restore some of the self-confidence and self-acceptance that they initially felt they lost following their diagnosis. This is seen in Taylor's (28-year-old non-binary person with gHSV-2) thoughts about their self-learning process tied to their diagnosis:

I think because I have the information, I just feel, like the diagnosis, I feel empowered because I like, I have an answer, like there's nothing uncertain. I feel resolved. So I think, that probably makes, that's probably what makes me feel cool, cause I'm like in the know, like I know things other people don't know about their bodies, I know for sure I have herpes, and I always will know that.

Here, we see how Taylor, like others, normalized having herpes as just another part of their life and their lived reality. They realized that having herpes did not negatively impact their self-worth, attractiveness, or worthiness to be loved and experience pleasure. In relation to the literature on chronic illness, the findings of the current study are consistent with that of Joachim and Acorn (2000) who assert that framing chronic illness through a lens of normalization and acceptance rather than stigmatization, alleviates some of the pain and suffering associated with the illness due to the power of perspective and positive mindsets.

Self-Esteem

One's self-esteem, which specifically refers to how one perceives their own abilities and self-worth within the context of this project, was also often impacted following an STI diagnosis. During the diagnosis period, many informants expressed feeling undesirable, insecure, shameful, anxious, damaged, inconvenient, unworthy, heartbroken, lacking confidence, abnormal, sensitive, gross, disappointed, frustrated, uncomfortable, awful, risky, rejected, worried, not enough, and like they had failed themselves. Some informants identified intense mental health challenges and discussed how damaging their STI diagnosis was to their self-esteem and sense of worth. Danni (26-year-old woman with gHSV-2) explained:

I spiraled so hard that I contemplated the worth of my own life and continuing to live. I tore myself apart and let myself down. I thought my life was over, no one would ever touch me again. And that if I ever told anyone, I'd be looked at like I have the plague. I've been verbally assaulted over this by vile people, and told my life was worthless, and how disgusting I am. We're so uneducated about these topics that people judge you, harm you, and shame you, and you shame yourself. You automatically think that you've done wrong.

Since Danni had several negative and emotionally abusive situations from partners stemming from her STI diagnosis, her self-esteem encountered a setback as a result of it. Danni internalized these negative words and experiences due to her STI status, which clearly negatively impacted how she viewed herself and her self-worth. She believed both her sex and love lives were over because of her STI and thus worried about how she would move forward. Other informants also felt that it was now much more difficult, if not impossible, to find someone to love them. Olivia (30-year-old woman with gHSV-2), who shared similar feelings to Danni, explained a painful instance where her damaged self-esteem was directly tied to being rejected romantically:

he didn't want to continue just because it was a risk he wasn't willing to take. So it was, honestly, it hit me really, really hard because that's the first time that I've been rejected by someone that I was actually interested in.

Olivia felt hurt about being romantically rejected by someone that she had been quite interested in, effectively challenging her self-esteem. Other informants mentioned having been in similar situations as well. Consequently, some individuals expressed feeling that they had no other choice but to settle in their romantic and sexual lives and engage with anyone who accepts their STI status regardless of their interest or attraction to the person. For example, David, a 34-year-old man with gHSV-2, expressed his own struggles with mental health, and self-esteem, and dating:

I had to deal with a lot of anxious thoughts and darkest night scenarios, where it's like well, nobody's ever gonna love me. Like I'm never going to be able to find the person that I want to spend my life with, and have the kind of sex that I wanna have with, and enjoy being with.

Olivia (30-year-old woman with gHSV-2) articulated similar thoughts:

I felt like I was going to have to settle, and I did settle for a little bit[...] I was also just frustrated and kind of emotional, and feeling like I'm never gonna date anybody, I'm never gonna find anybody I actually wanna be with.

Natalie's (21-year-old woman with gHSV-1) thoughts about being romantically rejected further demonstrates the power of rejection, as she expressed, "I guess that even though they like me, it's not enough apparently, like I'm not enough, you know? Like more that I can't be more than this diagnosis." David, Olivia, Natalie, and several other informants felt that they were no longer good enough to find quality partners to love them and make them happy as a direct result of contracting an STI. They felt they had no other choice but to settle for simply anyone who would accept their STI status since they were no longer capable of attaining the love and the high-quality relationships that they wanted.

Similar to the previous discussion on body image, the self-esteem of informants seemed to be very closely entwined with their romantic relationships, sexual identity, and their sexual self. Some informants searched for physical or sexual validation from others through engaging in more frequent casual sex as a way to help heal their damaged self-esteem. Illustrating this point, Susan (20-year-old woman with gHSV-2) explained her thought process regarding her sex life following her diagnosis:

I kind of looked for validation after I got my positive status because I was like, oh is my dating life over? Like is this it for me? So then I would go and I like kind of slept around and I, but I've disclosed, but I still slept around just because I felt the need to be validated to know that my dating life wasn't over, you know? But it was definitely a coping mechanism, for the first year 'cause I wanted to know that, you know, people would still accept me."

Susan, and other informants who described similar thoughts, wanted to prove to themselves that they were still worthy of dating and having sex with even after acquiring an STI. They appeared to attempt to mend their self-esteem struggles through placing importance and significance on sexual activity with others. The shift in self-esteem following an STI diagnosis seemed to be linked to their perceived new sense of unattractiveness to others and the understanding that an STI negatively changes their self-worth. These harmful beliefs seemed to encourage informants to feel ashamed and seek validation from others. Luckily, not many informants described feeling stuck in this negativity and shameful state for very long.

Consistent with body image, many informants discussed making a conscious decision to reframe their mindset through the realization or a reminder that ultimately having an STI does not destroy their self-worth or self-esteem. Demonstrating this, David (34-year-old man with gHSV-2) explained how he was able to reframe his mindset regarding his self-esteem for the better:

You learn tools to combat that kind of thinking, and you learn how to like self-talk much better, and how to interact with those emotions and realize, like, hey, like these are emotions I'm having, not reason, and I'm building reason around these emotions and that's not healthy because you can't be objective from an emotional place, and like you need to take like a step back, and just kind of leave your mind to do its own thing for a little bit and focus elsewhere, so that you know, when you do have the kind of clarity that you can approach it reasonably, you can get a clear answer, and so it's easier to contend with on that, I guess frame, but it takes practice and experience and you have to be able to recognize when you're being emotionally irrational as well.

For David, regaining his sense of worth and self-esteem came from learning skills that interrupted his negative self-talk and face emotions through what he described as reason. He described acknowledging his harmful thoughts as emotional rather than logical or real, and used tools to help talk himself out of negativity and back into a more positive and empowered state of self-esteem. David and other informants reported using their emotional skills and tools and having taken space from their initial emotional diagnoses reactions to work towards loving, accepting, and respecting themselves again. They described their powerful and compassionate realizations that they should love, accept, respect, and validate themselves and their own self-worth. Informants spoke about these realizations and shifts stemming from several different sources, including therapy, internal reflection, online research, online support communities, and other STI+ individuals. Danni (26-year-old woman with gHSV-2) demonstrated this intentionality to accept and validate herself as she said, “it wasn’t until recently that I became okay with myself and accepted myself. I know now this doesn’t change who I am. I’m still beautiful. I’m lovable and desirable. I’m still me.” Danni depicted attempting to reject negativity or hate through her own positive affirmations about her self-worth. Informants described a common realization that their STI status actually has no meaningful (negative) impact on who they are as a person, and thus, should not negatively impact their self-esteem.

As informants described trying to restore self-esteem, they reported the desire to take good care of themselves and their bodies. They depicted instances of realizing that they were still inherently and unconditionally worth of that love and care and that their STI did not change that. I saw them reminding themselves of the personal autonomy they had regarding their perspective and the potential actions they could take to empower themselves. For example, Joy (32-year-old woman with gHSV-1) expressed her desire to love and care for herself:

I deserve to have some control, I deserve treatment if I need it. I deserve to like have sex with somebody that I want to and not use it as a tool or separation. I deserve to treat my body in a healthy way for the first time in a couple of years, and that seems to work with me.

Joy reminded herself that she was worthy of support, care, and treatment and that she still deserved the love and affection she desired. In efforts to increase their self-esteem, informants felt the need to accept and truly believe that they were worthy and deserving of love and care, which helped positivity alter their damaged self-esteem. They expressed intentionally focusing on narratives of compassion, self-love, and self-care in order to restore or maintain self-esteem.

Despite reframing their thoughts and making the decision to love and care for themselves, many informants still struggled at times with the ideas of ‘darkness’, negativity, shame, and stigma that comes along with navigating living with an STI. For example, David (34-year-old man with gHSV-2) explained the challenges he faced as he worked to restore and better his self-esteem following his diagnosis:

You have to be able to recognize when you’re being emotionally irrational as well, and that’s not always successful, but it’s still always there, that emotion to tell yourself the worst possible things about yourself, is just kind of always lurking in the background looking for its opportunity.

Although David was clearly making efforts to be kinder to himself and shift his negative thoughts and mindset, it was undoubtedly challenging and an on-going process. However, since David and other informants had developed these aforementioned tools and used outside supports such as therapy, positive interpersonal relationships, and other people living with STIs as resources, they were able to work through that negativity. Combatting that negativity empowered

them to show up for themselves. Melissa (36-year-old woman with gHSV-1) explained this further by declaring, “I have a lot of self-love, you know, I live my life with dignity, so I’ve built up my life in many ways, right? But of course, this is some darkness in me, right, that still lives.” Melissa, like other informants, embodied narratives of self-love and compassion as a means to help restore her self-esteem. Even though informants worked hard to heal and improve their self-esteem, several expressed that they believed they would continue struggling with self-esteem and negative self-perceptions for the foreseeable future. For many of them, they were aware of the tools and resources available to them to help them tackle this and were willing to take on this challenge to better their overall well-being and self-esteem.

Identity

Identity was mentioned by most informants when discussing how their STI diagnosis influenced their perception of themselves. For most, they hoped that their STI status would not impact their identity or define them in the eyes of friends, family, and potential romantic or sexual partners. Ultimately, as Lennox (23-year-old woman with gHSV-1) put it, informants didn’t want people in their life to “see [them] any differently.” Similarly, Eric expressed his hope that romantic partners would “treat [him] like normal, like it never happened. But have that information in the back of their head.”

Most importantly, informants did not want to be treated like they were damaged or diseased.

Joan (24-year-old woman with gHSV-1) expressed this clearly when she said:

I want them to see me as not being damaged, like I think that feeling that I had about myself when I was initially diagnosed, I so desperately wanna keep them as far away from that perception of me. [...] I want to emphasize that like I’m still me. Like I’m still the person that you were attracted to, that you like wanted to sleep with, I’m still her.”

The hope for most, including Joan, was that friends, family, and potential romantic partners would understand that individuals living with STIs are still ‘normal’ and can live completely normal lives that are mostly unaffected by living with herpes. Ivy (23-year-old woman with gHSV-2) demonstrates this as she expressed, “hey, people exist, that live with this, and people with this still want to go out and date, they’re still normal, they still have regular lives. They can have kids. They get married.” Informants wanted others to understand that people with chronic STI can still live normal and happy lives, which appeared to be a helpful tool in getting them to believe this sentiment for themselves as well. They wanted to convince themselves and others that STI stereotypes were false and could easily be successfully challenged and disproven. Informants can also be understood as attempting to align their sense of self, identity, and life ambitions to their pre-diagnosis self.

Despite informants having established that they were painfully aware of existing STI stereotypes, many were hopeful that people did not even associate them specifically with these stereotypes. Some informants expressed that they did not align or embody the negative stereotypes such as being dirty, promiscuous, and irresponsible. Of course, the majority did at the time of diagnosis as part of their emotionally charged initial reactions, but this did not apply to everyone. A few informants specifically noted thinking more highly of themselves than someone who embodies an STI stereotype, and so they were hopeful that others thought more highly of them as well. For example, Taylor (28-year-old non-binary person with gHSV-2) expressed thinking that people hearing about their STI status might be shocked as they explained:

I feel like I’m not necessarily someone people expect to have an STI, because I think when people think of, of someone who has an STI or like has herpes, they have an image of someone who’s like sexually irresponsible.

Taylor believed they were not sexually irresponsible and therefore they challenge and disprove the STI stereotype of being sexually irresponsible. Some informants, however, were less direct in explaining that they wanted to specifically disprove STI stereotypes (dirty, damaged, promiscuous, sexually irresponsible, gross, diseased, etc.), rather, a few informants specifically described the desire to distance themselves from these stereotypes. For example, Toni (36-year-old woman with gHSV-2) wanted to distance herself from common STI stereotypes as she said, “it’s like I have to say words that prove I’m not a slut [...] to show them that I don’t fit the stereotype of the person who we think get STIs, right?” She wanted to prove that she did not fit the stereotype, but not necessarily that the stereotype did not exist or was explicitly wrong. Some informants assumed or worried that people would automatically apply these stereotypes to their personalities and identity, although they were quite upset with this thought. A few individuals internalized these stereotypes and truly believed they applied to them simply because they acquired an STI. Most individuals described engaging with forms of reputation management, either externally or internally, typically by distancing themselves from stereotypes or assuring themselves and others that having a chronic STI is not an important defining feature of their identity.

Although many informants believed their STI did not impact their identity, a few felt that it did impact their identity in a few different ways. In negative instances, a couple participants described their identity being reduced to their STI and experiencing bullying and harassment from others because of it. For example, David (34-year-old man with gHSV-2) explained how his STI status preceded him as a few women in his hometown who had been ‘warning’ others about him having herpes:

They had like huge posts about me and how much of a monster and a bad person I was [... saying] like “oh, he, he has herpes, and he’s spreading it around [...] you’re basically like writing up a, I don’t know, like an attack piece on me that only potential dating partners could read when like I have no agency or way to, way to disclose that information myself, like you’re not even giving me a chance to be a good person.

David struggled with having herpes as a large (negative) identity marker to people who he had not even chosen to tell and was particularly upset that he had no agency to keep his personal information confidential, demonstrate his personal growth, or to better his reputation to others.

Faith (24-year-old woman with gHSV-2) shared a similar story of others sharing her STI status without her consent and weaponizing it against her:

Well, someone at my work actually was taking it upon themselves to warn men about me, that I had HSV [...] But I just couldn’t work there no more because like I would literally talk to a guy one day like, just like, hey, it’s your first shift, how you doin? And then I’d come back and hear that somebody was like “Hey. Just to let you know, like [Faith’s] got herpes.

Faith expressed having her identity within her workplace reduced to her STI status as coworkers shared her STI status with others without her consent and shared it in order to deter others from becoming romantically (and perhaps platonically) involved with her. Faith’s coworkers wanted everyone to know that she had herpes as a way of bullying her and isolating her from other coworkers based on shame and ignorance. This reduction of identity to one’s STI status is consistent with Goffman’s (1963) work on stigma and spoiled identity, as Faith and David can be understood as being viewed as outsiders or “the stigmatized” compared to “normals” (those not living with any known STIs) and thus are stigmatized due to their STI. These informants

discussed the challenges that they endured when living with a chronic STI became a central part of their identity that they did not have control over sharing with others.

Despite having their STI status involuntarily shared with others, David and Faith both decided to own and embrace their STI as a way to normalize and destigmatize STIs. They described feeling that they could help normalize STIs by proudly identifying themselves as living with it to create representation in the lives of the people they know. They wanted people to think about them when they think about herpes – to be ‘the face of herpes’ – so that they could humanize STIs by demonstrating clear examples of people with herpes and some of the lived experiences of having an STI. For example, David shared his perspective on the matter:

I think it’s one of my personal beliefs about like kind of destigmatizing it is that like, if people need to put a face to that and need to say like, “Oh, ew, that guy’s got herpes” kind of thing like that, and I go yeah, me too! This is what it looks like. [...] So you know, this, this bad hypothetical person that you’re drawing in your head, I want you to put my face on that person so that you can humanize all these jokes.

David expressed wanting people in his life, who presumably thought highly of him, to think of him when they think of herpes to encourage them to challenge their own negative perceptions and internalized stereotypes that suggest STIs are bad and uncommon. David’s vocalness surrounding his STI status contradicts the implications from Shoveller et al. (2010)’s study suggesting that men felt they did not have permission to engage in emotional language, vulnerable behaviour, and sexual health discourses. Here we see David and other informants who discussed wanting to bring some positive STI representation to the folks in their life through having open dialogues about it. They claimed to want people to ask them questions about herpes in order to demystify STIs and to allow others to educate and inform themselves through them.

They wanted to make a difference by sharing their experiences with others for the sake of increasing awareness, knowledge, and representation.

Although some informants felt strongly about helping destigmatize and normalize STIs, other informants did not seem to feel as strongly and empowered to specifically create this change. In a more neutral sense, some people saw their STI as a part of their identity and who they are, but just *one* small part of them that did not change their worth or define them as a whole. They wanted others to understand that although they had an STI, it should not be a big part of their identity. For example, Ivy (23-year-old woman with gHSV-2) explained, “I can see myself with this as part of me, but also with me being a separate entity and that this doesn’t fully define my identity at all.” Similarly, Faith declared, “I want them to just realize that it’s still just me and it’s just something that I live with on the side.” Ivy and Faith recognized that their STI had an impact on their lives but that it is not their main defining feature. Ivy and Faith have both accepted their STI as a new part of them causing a slight shift in their identity, which aligns with Charmaz’s (1995) findings. As previously mentioned, it seems that their STI status impacted informants’ sense of self to certain extents, but that they did not think that it impacts their identity. Most informants believed that their STI was not an important or defining feature of their identity.

In concluding the discussion on STI status shaping identity, it is important to note that some informants actually hoped that the implications of their STI would positively contribute to their identity. They expressed their desire for others to see them as honest, transparent, communicative, ‘cool’, special, and trustworthy for being able to discuss this information with dignity and grace. Jerry (32-year-old man with gHSV-2) demonstrated this through stating, “Another trait that might be more important or interesting than this one is that I can have a hard

conversation and I can be transparent in this regard.” Similarly, Taylor (28-year-old non-binary person with gHSV-2) expressed, “I want them to think I’m cool (laughs), um for sharing with them, because I don’t know, I think it’s just a nice illustration of trust, so I like to think people feel closer to me.” Finally, Jordan (36-year-old non-binary person with gHSV-2) wanted to be seen as, “trustworthy, like honest, you know, and that I’m doing what I can to be a good sexual citizen.”

Jerry, Taylor, and Jordan hoped that showing others that they were able to communicate effectively about their sexual health demonstrated strength, courage, and vulnerability while also honouring their partner’s sexual health and well-being too. As Danni (26-year-old woman with gHSV-2) put it:

“I would hope like the way I just, the way I come about it and the way I talk about it, people would see me as somebody, you know, who is open and honest and vulnerable, not somebody that you know is like a walking STI, like somebody that’s like strong, like, and willing to talk about it, somebody that has like that courage, because it’s not talked about.”

Informants expressed wanting to share their most authentic self with others and felt that being honest and vulnerable about their sexual health and the personal challenges they have overcome is the best way to do so. Informants renegotiated their altered identities and explored some of the positive implications of these changes on their daily and romantic lives. Overall, informants hoped that their STI would not have any real impacts or consequences to their identity, but if it had to, they hoped it would be positive as demonstrated by their strength, communication skills, and vulnerability.

Chapter 6: Findings – Relationships

After informants either suspected or received confirmation that they had been diagnosed with a chronic STI, they contemplated and decided whether they would tell others. If they decided to tell others about their chronic STI, they decided who they would tell, when they would share this information, and sometimes reflected on why they would tell a specific person. Informants typically shared their STI status with friends, and some informants decided to tell their family members. All informants shared their STI status with any potential romantic or sexual partners. A few informants had not told any friends or family about their status and were still figuring out if they wanted to share this information with anyone and to whom. Every informant had a unique perspective on sharing their status and a different journey of sharing it with their loved ones. The following section analyzes the various common themes and patterns that emerged surrounding the sharing of informants' STI status and how it impacted their relationships.

Deciding to Share One's STI Status

There were several main reasons that informants decided to tell their friends and families about their STI status despite having no chance of transmission based on a lack of sexual contact. Often informants wanted to tell friends and family because they wanted to educate them and add positive representation of lived experiences with chronic STIs. For instance, Joan (24-year-old woman with gHSV-1) said she talks about her STI often to many people as she thinks “that it helps to sort of destigmatize for them what they think someone who lives with a chronic STI looks like.” Likewise, Natalie (21-year-old woman with gHSV-1) discussed her STI status and asserted:

I'm open about it, and I just I find I like to educate people as much as I can because that way if they're ever in a situation where maybe they're in contact with someone, they're not gonna be like super judgemental or something cause they're gonna remember, hey, one of my close friends or like one of my niece, or like my granddaughter or like whatever has it.

Natalie hoped that by sharing her own experiences and normalizing living with an STI to the people in her life, she would educate them and better prepare them to deal with STI disclosures in a more compassionate manner in the future. Some informants were very passionate about creating this representation and took every opportunity to do so. David (34-year-old man with gHSV-2) was one of these passionate advocates and explained:

I adopted a policy with friends and even coworkers that I became close with, that I don't hide my status. It's one, I think it's one of my personal beliefs about like kind of destigmatizing it is that like, if people need to put a face to that and need to say like, "Oh, ew, that guy's got herpes" kind of thing like that and I go yeah, me too! This is what it looks like. Like we've had beers together, we've laughed together, we play on the same sports team, you know, we go for motorcycle rides, you know, [...] this is what it looks like! So you know, this, this bad hypothetical person that you're drawing in your head, I want you to put my face on that person so that you can humanize all these jokes.

Informants worked to help destigmatize STIs in their lives by challenging stereotypes and demonstrating that you can live a 'normal' life with an STI. They choose to be vulnerable about their STI status to others in order to create positive representation in their social worlds.

Another motivating factor for informants wanting people in their lives to know about their STI status was to create more positive STI representation. Informants expressed that if

someone they knew contracted an STI, they hoped they would view them as a positive example and come to them for support. For example, Danni (26-year-old woman with gHSV-2) explained that she is always open and honest about her STI status so that if “something ever does happen to [someone] in the future or if something is happening to them that [she didn’t] even know about, you know, then they know that there is somebody they can come to that won’t judge.” David added to this by expressing his hope that “when people encounter it in the wild they can be like, ‘well but [David] doesn’t care [...] so if he’s fine with it, then maybe I can be fine with it too.’” Some informants wanted to do something positive with their positive STI status to make it easier for others in their lives to talk about sexual health and STIs and make living with a chronic STI more normal in their social settings.

Although some informants wanted to be open and vulnerable with others about their STI, there were a considerable number of informants who did not feel this way. Some informants were still contemplating who they wanted to share this with, if anyone at all. It was more common for informants to decide not to share their STI status with their family members. The exceptions to this were younger informants who needed their parents for support, and individuals who were close to the family members they decided to tell. Most informants felt uncomfortable discussing the topic of STIs with their families. Erik (27-year-old man with gHSV-2) explained that even though he thought his family would likely be supportive, “it feels really awkward to come to mom and dad about that.” Nora (22-year-old woman with gHSV-1) felt hesitant to discuss her STI with her family as she stated she was never close enough with her family to even have ‘the sex talk’ with them as a child. Nora did not feel it would be a welcome topic of discussion amongst her family as they had never spoken about sexual health or sex before. Toni

(36-year-old woman with gHSV-2) did not feel comfortable telling her family because she feared they would react poorly. Toni recalled past experiences that made her feel this way:

Even when my mom has cold sores, like my brother wouldn't let her hold the baby because he's like "oh, she might kiss him". I get it, like I, like it's contagious! It is, you can transfer it, like I understand but there's always like, there has always been that like, gross factor of cold sores, like it's just, it's something that I've always experienced, like in school and at home, like people think cold sores are disgusting."

Toni felt that if her family were stigmatizing and reacting poorly to cold sores, they would likely have an even worse reaction to genital herpes. Similarly, some informants felt it was none of their families' business. Ivy (23-year-old woman with gHSV-2), for example, explained that it should not impact her relationship with her family members and therefore there is no reason to tell them. Regardless of what informants cited as the reason, many informants did not end up sharing their status with family and said they have no future plans or desire to.

Another key reason as to why informants did not share their STI status with others was the fear of rejection or poor reactions. Several informants shared experiences of contemplating sharing their STI status with others, yet they worried that telling them would elicit a poor or stigmatizing reaction. For example, Lynn (28-year-old woman with gHSV-2) discussed wanting to share her status with a close friend (who was a former sexual partner), yet she was quite hesitant:

I'd love to tell him, but he's very squeamish about STIs, and I know that. So I'm like, I don't know how he would react, and I'm not prepared to deal with the fallout [...] Those, in those cases it's really hard, because you're like, you really want to be able to share with them, or I really want to share with him or other people, and then you just don't feel

supported because you're like [...] it doesn't feel like the end result might be worth the risk.

Lynn opted out of sharing her STI status with her friend as she anticipated a negative reaction from him. This decision reflects the desire to preserve harmony in their dynamic, yet it left her feeling unsupported in their relationship due to withholding this information. Toni (36-year-old woman with gHSV-2) expressed similar sentiments regarding fear of poor reactions:

What if I tell this person, and then I go over to their house, and I have to use their bathroom, and all they're thinking is that like, they can get herpes from the toilet seat, like I feel SO embarrassed.

Here, Toni is nervous about sharing her status due to the fear that a negative (stigmatized) reaction would make her feel ashamed. Both informants demonstrate the worries the many informants shared about having their STI status met with stigma, misinformation, and cruelty. Due to this fear, some informants decided not to share in order to avoid the possibility of negative reactions and harmful implications on their relationships.

Despite several informants fearing that sharing their status with friends, family, or partners would negatively impact their relationships, the informants who did share their status with others generally reported that it resulted in no meaningful negative impact on their relationships. Olivia (30-year-old woman with gHSV-2), for example, reported that living with herpes had no impact on her personal relationships at all. Ivy expressed this sentiment further by reporting: "my best friends have been extremely supportive, they say this doesn't change anything of course, and they're still here for me like anything else." Although Ivy's friends offer her support, the nature or strength of their relationship has not been negatively affected, but rather positively impacted. Ivy recognized that having herpes does not change how her friends

view her or her friendship. The following subsections further dissects the thoughts, experiences, and feelings that informants disclosed regarding how their STI shaped certain elements of their relationships with family, friends, and (potential) intimate partners.

Family and Friends

Disclosures

There was very little consensus amongst informants regarding who they disclosed their STI status to and how many people in total they felt comfortable disclosing to. Some informants only told one or two trusted people, while others told every person they had the opportunity to. Most commonly, informants told people they claimed to be comfortable with – most often with individuals who they considered friends, who they trusted, and who they believed would handle their disclosures with care and support. This was seen as a way to be transparent and not feel as if they are intentionally hiding their STI status from others. A few informants who described having close relationships with certain family members decided to tell those individuals, as they expressed grappling with anger and confusion, and thus were looking for support. Yet, more often than not, informants opted out of disclosing to family members. Generally, informants reported receiving positive or neutral reactions to their disclosures to friends and family. Nora described her typical reactions to her disclosures: “at first they’re like, “Oh, I’m so sorry!” And I’m like oh no it’s fine, like I know how it works and everything now. But other than that, they’re like “Cool!” Like they’re very neutral about it.” Even further, Toni (36-year-old woman with gHSV-2) expressed how grateful she was for all of the positive reactions that she has received to her disclosures: “I have been so fortunate, between intimate partners and good friends, not one person has been like ‘what the fuck’ or ‘I don’t, I don’t want to hang out.’ Like not one.” Despite informants having previously discussed their worries and fears regarding

sharing their STI status, most informants did not experience the negative reactions they had anticipated.

Support and Strengthening Relationships

Many informants received positive reactions from sharing their STI status with their family and friends, and they noted that sharing this information allowed for greater support from loved ones and stronger relationships. Numerous informants described bonding with both friends and family members over disclosures, especially with those who also disclosed they were also living with an STI themselves. For example, Danni (26-year-old woman with gHSV-2) shared an anecdote of her and her best friend finding out the other person had herpes. Danni's antivirals fell out of her purse while she and her best friend were at a bar and her best friend picked it up and asked her why she was on medication. Danni then told her best friend of her recent diagnosis, to which her best friend responded by pulling out the same bottle of antivirals from her own purse. Danni recalled the emotional implications that resulted from that experience:

We literally just sat in the middle of the bar crying together for a solid like 15 minutes.

And then we kind of like, just kind of told each other like our experiences and like how it happened and stuff, and it's yeah, and it's one of those things, as we kind of bonded over a lot of dark periods in our life.

As Danni and her best friend had similar lived experience based on both living with herpes, they were able to truly understand and support each other, further strengthening their bond and overall friendship. Taylor (28-year-old non-binary person with gHSV-2) experienced this situation in reverse, as they knew their friend had an STI prior to their own diagnosis and thus knew exactly who they wanted to discuss it with:

I went directly to one friend, who, I knew beforehand had herpes, so I had told her I was like, Oh, my gosh! [...] I have herpes too! It was like no way! (laughs) Yeah, like we're bonding over having herpes.

As informants such as Danni and Taylor were able to identify and utilize close friends who had shared lived experiences regarding a stigmatized topic that many informants struggled with, being able to lean on someone who has lived through the challenges associated with chronic STIs themselves made these friendships stronger and more rewarding. These strong connections from shared experiences mirror the benefits of support groups discussed within the work of Bush et. al. (2018), Citron et al. (1999), and Morales-Campos et al. (2009). Having an emotionally charged shared experience as a catalyst for deepening a bond with pre-existing relationships was one of the positive impacts that sharing one's STI status with loved ones had on informants. Informants discussed feeling validated and truly seen by these individuals who could relate to them, which helped them rebuild their confidence surrounding their STI. As Joan (24-year-old woman with gHSV-1) put it:

I think the really lovely thing that's come out of [getting herpes] has been realizing how many other people share the same experiences I do and being able to have those conversations because it just feels like someone is looking at you and really seeing you, for the first time in a long time.

Informants described these meaningful, deep feelings of connection to friends and family who were able to relate personally to their experiences, as well as with those who took the time to truly listen and try to understand what it is like for informants to live with a chronic STI.

Despite whether friends or family could personally relate to living with a chronic STI, informants who chose to share their status with loved ones most often received emotional

support from these loved ones after sharing. For example, Maya (19-year-old woman with gHSV-2) was having a difficult time with her diagnosis and thus decided to share it with her mother in order to receive the support from her that she desired:

One night, I was just having such bad issues, I finally just said I need my mom, so I kind of just broke down and told her and she's, like that's probably the best thing I ever did, was to tell my mom, because she's been nothing but supportive with it. [...] She actually gave me like lots of good tips that I still use to take care of myself when I'm having [flare ups]. [...] She bought me pads, she bought me diaper cream, she bought me an ice pack, she got me like a whole little like care kit, and was just like "try this out, maybe try, you know, this technique," this and that, like insanely supportive.

Maya turned to her mother, one of the most prominent and prevalent relationships in her life, in order to receive the emotional and physical support she needed to help process her diagnosis and support her adjustment to living with a chronic STI. Maya commented on the positive impact this emotional support had on her relationship with her mother: "I feel like it almost made our relationship a little bit stronger. Just, you know, being able to have her there with me." Danni (26-year-old woman with gHSV-2) shared a similar scenario in which she received support from her mother at the time of her diagnosis:

She was like, "it's not gonna be that, like don't put your mind at worst case scenario, like you don't know what it is" like trying to ease me, she was really, really good. And then, like when I came out of the clinic, and I told her I had it, she's like, "you know what, I was doing a whole bunch of research in the car while you were in the clinic on it, and like it doesn't sound as bad as like I thought it was like, you can definitely work through this." Like she was really supportive.

Danni was able to lean on her mother for emotional support during her diagnostic process as she had accompanied her to the doctor's office, reassured her that things would be alright, and helped her find some good information about her potential STI. Although informants did not necessarily need to disclose to family and friends, those who decided to were most often provided with emotional support that was crucial to assisting the informant process and accept their STI diagnosis, which in turn helped strengthen the bond between the informant and their loved one. For these reasons, most informants did choose to share their status with at least a few loved ones.

Judgement and Rejection

Although many informants experienced the strengthening of their relationships and specific emotional support as a result of disclosing their STI status to non-sexual loved ones, unfortunately, some informants noted anticipating receiving judgement and forms of rejection from sharing their STI status. Several informants mentioned friends and family having negative reactions to their disclosures. Melissa (36-year-old woman with gHSV-1) recalled a negative reaction from one of her friends who she claims had an ignorant response to her disclosure as she said to Melissa, "you obviously have to live with it now, like that's kinda gross." Erik (27-year-old man with gHSV-2), who had not actually told his friends about having herpes, avoided sharing this with them because he anticipated it would be met with negative reactions and teasing. The informants who received negative reactions from friends often became more selective about who they shared their status with, or in some cases, chose not to share their status at all, as Erik did. Although some informants shared stories of negative reactions from friends, more informants shared accounts of negative reactions from family members.

Many informants voiced feeling uncomfortable or worried about sharing their STI status with their families due to experienced or anticipated negative reactions. For those who worried what telling their family would be like, many expressed fears of negative reactions due to societal stigma surrounding STIs, regardless of their specific relationship with family members. Lynn (28-year-old woman with gHSV-2) explained her hesitations around telling her mother about her STI status: “I think if I told her now, like she probably wouldn’t be educated about it, so she probably just would have like a pretty severe reaction.” Since Lynn does not think her mother received comprehensive sex education, she assumed she would judge her and perpetuate existing STI stigma. Lennox (23-year-old woman with gHSV-1) described her hesitation about telling her sister to be a bit more centered on her sister’s specific personality, yet still rooted in stigma: “my older sister doesn’t know because I, she’s um, a very harsh person, and I feel like she um, would be very weird about it, like not accepting.” Lennox worried that her sister would have a harsh and judgemental reaction to her disclosure based on her understanding of her sister’s personality and general personal perspective, and therefore did not choose to share with her sister. Many informants such as Lynn and Lennox considered sharing their STI status with their family members but ultimately decided against it due to anticipated judgemental and stigmatized reactions.

Several informants who did choose to share their STI status with their family members did in fact receive negative and judgemental reactions that many informants feared they would. Dale, a 35-year-old man who is HIV+, described the negative reaction his father had to his diagnosis: “My father being a Hispanic Christian, we can all imagine how he reacted. Obviously, he made a big scene about it.” Dale partly attributed his father’s intense negative reaction to his diagnosis to both his religious and cultural background and upbringing. Dale also noted that he

and his father were estranged and did not have a good relationship, likely contributing to his negative reaction as well. Faith (24-year-old woman with gHSV-2) described her parents having a less-than-ideal reaction to her sharing her status with them as well: “when I first came home from getting diagnosed and like they knew what it was, my parents had me disinfecting the toilet seat after I used the bathroom. I was like come on!” From this anecdote, it is evident that Faith’s parents were not educated on how herpes is transmitted and thus acted in a stigmatized manner towards her due to their fear of transmission. Faith expressed that this lack of knowledge frustrated her. In a more blatantly stigmatized fashion, Jordan (36-year-old non-binary person with gHSV-2) shared an experience of their aunt asking them about their dating life and finding out that Jordan has herpes:

I told her I was actually taking a break from dating, and she asked why, and I said it was because I was recently diagnosed with genital herpes, and she was like, “Oh, no! Weren’t you using condoms?” Like if you look at like a list of what not to say. And then she was like, “who’s gonna wanna be with you now?”

Jordan’s aunt had an ignorant response to their disclosure as they put responsibility and blame on Jordan for contracting an STI, as well as perpetuating the stigmatized notion that those living with an STI will never find love. Informants who discussed receiving negative reactions to their disclosures often expressed having difficulties accepting their STI status and needing to overcome several additional barriers in order to do so.

Romantic Relationships

Dating and Romantic Love

When first diagnosed, most informants noted the belief that the biggest impact of having a chronic STI would be within their dating life. Many were unsure of how their new STI status

would impact their love lives, but most informants anticipated that it would to various extents. It was common amongst informants to fear that they would have challenges finding a quality partner because of their diagnosis and assumed they would have to settle for anyone who accepts their STI status. Ivy (23-year-old woman with gHSV-2) illustrates this sentiment while sharing how she felt about her romantic prospects following her diagnosis: “I’m going to go [through] life unloved. I’m never going to have a partner.” Similarly, Olivia (30-year-old woman with gHSV-2) expressed: “I was also just frustrated and kind of emotional, and feeling like I’m never gonna date anybody, I’m never gonna find anybody I actually wanna be with kind of thing.” Olivia, Ivy, and numerous other informants feared that they would no longer be capable of finding a quality romantic partner, which appeared to be directly connected to their internalized stigma. For most informants, their STI status added additional stressors to dating, including worries surrounding disclosing, fear of rejection, and fear of transmitting their STI to sexual partners. Some informants let these fears associated with their STI prevent them from putting out their truest, most authentic self in the dating world. For example, Theo, a 26-year-old man with HPV (who had experienced a genital warts flare up for more than two consecutive years), explained his hesitations surrounding his dating life: “I think probably losing some confidence too of like, you know, like a couple of times I was flirting with people, but then trying to, having to cut it off before we get too serious.” Theo would retreat from potential partners before even having the chance to disclose to them in order to avoid giving them the chance to reject him, as he assumed they all would reject him. These worries of rejection were shared by many informants.

When casually dating, informants expressed facing some challenges in forming solid, meaningful connections with potential partners that they connected to having an STI. For

instance, several informants communicated the sentiments of many potential partners being hesitant or less willing to commit to them, which many credited to the fear of potential partners contracting their STIs. Specifically, several informants recalled situations in which they disclosed to potential partners, who initially accepted their diagnosis, but then would “ghost” them, cutting off communication entirely without any sort of explanation. For example, Olivia recounted her thoughts about a situation in which she disclosed to someone who seemingly accepted it initially, but then stopped talking to her unexpectedly:

I kind of thought maybe my herpes diagnosis was why he didn't want to continue things, because initially, when we had been chatting, he said he was going to be around for a month, or so and wasn't wanting anything more serious than that, and I said look, this is, this is what it is, if you want to, you know, have a short term kind of thing, that's fine with me. But after that he just, after our first time he just kind of like ghosted me after a while, and I thought maybe that my herpes was why.

Despite both Olivia and this partner expressing interest in a short-term relationship, her potential partner suddenly pulled away from their relationship without warning or explanation, which Olivia believes is connected to her having genital herpes. Nora (22-year-old woman with gHSV-1) also described a situation where she was really interested in the person who she believes to have contracted genital herpes from, who ended up “ghosting” her after she disclosed to him:

Even when I asked him like do you still want to like hang out after the diagnosis, he said yes. And to have that herpes thing happen, and then have him just kinda ghost, that just really hurt, like it was more with wanting the closure of herpes as well like I just really liked him, and I thought like he felt the same way as well. So just to have that happen, like it's just like Wow! Was just kind of like a stab in the back.

Olivia, Nora, and several other informants shared stories of potential partners “ghosting” them, which not only discouraged them from continuing to be vulnerable and try to date, but also made them feel less confident in their ability to date freely. In fact, several informants believed that they could no longer date casually since potential partners would not think they are worth the risk of contracting herpes. Susan (20-year-old woman with gHSV-2) explained how a few potential partners conformed this:

The second guy he was like, “oh, like, I guess, I expect me to be the only one you’re sleeping with then?” And I was like, what do you mean? And he was like, “well, cause like if I get it, like I’d wanna be with you long term.” And I’ll say, oh, no, no, no, no, no! That’s not how this works. And some people do say that after I disclose, like “oh, well, that’s okay, like if we date.”

Although Susan was only interested in casual affairs, she claimed many potential sexual partners only wanted to accept the risk of possibly contracting herpes if it was in the context of a committed relationship. Other informants expressed similar experiences.

With this in mind, it is unsurprising that most informants, including Melissa (36-year-old woman with gHSV-1), Lynn (28-year-old woman with gHSV-2), and Theo (26-year-old man with HPV), declared that they were no longer interested in casual relationships and thus were looking for more of a serious relationship following their STI diagnosis. These informants often credited their STI diagnosis as their inspiration for choosing to date more intentionally and being more selective about who they choose to date and have sexual relationships with. For example, Joan (24-year-old woman with gHSV-1) explained:

I think that it has impacted who I have chosen as a partner, I think it has made me much more selective about who I choose to sleep with. Like I will literally look at people and

be like there's no way that you'll handle it, handle a disclosure well, and so, therefore I will not fuck you, like (laughs).

Similarly, Susan noted the following impact on her dating life:

I guess I'm more particular about like kind of feeling people out before I have to disclose, right? Whereas before I kinda wasn't as particular and I would go for anyone and like everyone (laughs), yeah. It's kind of like a blessing in disguise at the same time.

Many informants, such as Joan and Susan, felt that they needed to be more selective about who they choose to date, as they sought loving and accepting partners who would be open-minded about their STI status. They chose to pursue dating in this more intentional manner despite the often-discouraging obstacles they faced and anticipated continuing to face in terms of STI-based rejection.

Despite the initial fear of their STI status completely ruining their chances of ever finding love, almost every informant demonstrated that once they had found good partners who cared about them, their STI status had no meaningful effect on romantic relationships. Once informants disclosed to these partners, who truly did accept their STI status and the potential risk of transmission posed to them, the STI was rarely discussed. Joan demonstrated this notion as she discussed how her herpes status was discussed with her partner:

It hasn't come up since we initially started sleeping together, like he was just like, "yeah, okay, like this is a thing. It's up to you how you want to communicate about it with me. I don't want you to feel that I'm othering you or stigmatizing you, like here for whatever support that you may need, but it's really not a big deal and I don't want you to feel like it's being made into one.

Like Joan, Faith (24-year-old woman with gHSV-2) mentioned that the topic of herpes is not one that her and her partner discuss often, and in fact, he rarely thinks about it at all:

The man I'm with now, when I told him he was just like, "Um. Well you seem to know enough on it. I trust you." And like we just never talk about it. Like I asked him like two or three weeks ago, I'm like do you even think about it? And he's like no. And like I'll mention it like if I am having like an outbreak or whatever, he'll just say, you know, "feel better" or whatever.

Joan and Faith both had partners who accepted them and their STI status and did not seem to feel the need to discuss it at length, likely due to the truly accepting the informants and all that dating them entails, unlike many of the aforementioned casual partners. Many other informants shared similar sentiments to Joan and Faith.

This common experience suggests that healthy relationships involving one individual living with a chronic STI must include a discussion, acknowledgement, and acceptance of both the presence of an STI and the risk of transmitting the STI from the positive partner to the negative partner in order for the relationship to thrive. Without this acceptance, informants clearly demonstrated that relationships are destined to fail if they are not built on a solid foundation of genuine love, support, and care for one another. For strong, successful relationships, the informants were seen as more than just their STI status, they were a whole, complex, and unique person worthy of love and happiness. For the failed relationships, it seems that the potential partner was unable to view the informant as more than just their STI diagnosis. All informants, and everyone everywhere living with a chronic STI, are so much more than their diagnosis and deserve a chance to prove this and a chance to find fulfilling romantic relationships.

Disclosures

One of the most crucial elements to begin curating healthy, deep, and meaningful romantic connections for individuals living with chronic STIs is disclosing their STI to potential partners. All informants involved in this study confirmed that they disclosed their STI status to all potential sexual partners following their diagnosis. Informants shared many disclosure stories, each unique in the particular details they shared and the various responses they were met with. Many informants expressed often feeling nervous about disclosing to potential partners, no matter how often or much they did it. Maya (19-year-old woman with gHSV-2), Erik (27-year-old man with gHSV-2), and Taylor (28-year-old non-binary person with gHSV-2) all expressed fears of disclosing for the first time, as none of them had had the opportunity to disclose to a new potential romantic partner yet. Those who had experience with disclosing were typically quick to note that there is a learning curve that accompanies it, and that occasionally they still disclosed poorly even after doing them several times. These internal struggles with disclosing mirrors Hammarlund et al. (2007)'s findings that suggest their informants viewed themselves as "disease carriers" which made it more challenging to build and develop new connections due to this internalized stigma. Many informants within the current study openly discussed how they grappled with internalized stigma, which is tied to how they disclosed and discussed their STI status with potential partners. Informants contemplated when the right time to disclose was, what they should say, and how they should share this information. Should they disclose on a first date or a fifth date? Should they give them many statistics or just a few crucial facts? Should they disclose over text or in person? There is no one *right* way of disclosing as the responses of informants vastly varied, and informants typically found what works best for them specifically after gaining some experience with disclosing.

Once informants disclosed their STI status a few times and figured out when and what was the best way for them to do it, they typically created something of a ‘disclosure script’ that they would generally follow. Danni (26-year-old woman with gHSV-2) described her typical disclosure script as the following:

When I like disclose to people, it’s just like, I just lay it out like I’m very nonchalant with it, I’m like, hey by the way, like if we’re getting intimate there’s something you need to know, like I have this, this is what I do to take care of it, this is what this means for you, this is how we can protect it, if you have any questions like let me know. I’m just very open.

Jordan (36-year-old non-binary person with gHSV-2) detailed how they normally approach disclosing:

I’ll usually say I’m really interested in being sexual with you, you know, can we talk about sexual health stuff, and then I’ll say like how many partners they have, or this is, you know, testing, that kind of a thing. And then, and I need you to know, you know, last year I tested positive for genital Herpes, I take daily medication for it, I like to use condoms as well to lower risk to partners, and I’m happy to answer any questions about it. If you’re not interested in being sexual with me because of it, that’s okay, like I usually try to make it, I try not to like go on and on, and, but um, and I like to, I don’t, I’m not trying to like invite rejection, but I feel like if this is a deal breaker, that’s usually something I’ll say, but if this is a deal breaker, let me know, and I feel like that’s helped me get really positive responses, just kind of like inviting that, inviting the ‘no’ a little bit.

Jordan, Danni, and many other informants typically liked to start by disclosing their status, offer up various relevant information about transmission rates and the specific implications on their sex lives, ask if they have any questions, and then wait for a response. The many responses to disclosures discussed by informants varied greatly, but they can generally be classified as either rejections invoking various degrees of shame, or acceptance enabling informants to feel supported and safe.

Rejections and Shame

Most informants shared experiences of rejection and shame in the context of at least one disclosure over the course of living with their chronic STI. Informants recalled some of the rejections they experienced and shared how these rejections made them feel. For example, Ivy (23-year-old woman with gHSV-2) recalled some of her disclosures when she was first diagnosed:

I had to tell like some previous partners as well, just for safety purposes, and a lot of them just said, “Well, that sucks down and out.” Never spoke to me again, which is pretty hurtful and harmful for me, especially being newly diagnosed, that really sucked.

Informants such as Ivy were often putting themselves in a place of vulnerability while disclosing their chronic STI, something that holds a lot of stigma in society still, and thus their disclosures not being met with care and compassion but rather rejection made them feel bad about themselves. For informants such as Ivy who had to disclose to pre-existing partners (ones she had prior to her diagnosis), this experience can be linked to Reid et al. (2013)’s findings that suggest an STI diagnosis that occurs within pre-existing relationships can create an imbalance within the dynamic and often presents opportunities for various new conflicts. These conflicts and challenges demonstrate the intensity of the stigma as the diagnosis holds enough power to

disrupt functional relationship dynamics and lead to dysfunction or termination of the previous dynamic.

In addition to current or former partners demonstrating stigma in their responses, some informants shared stories of new or potential partners playing into stigma and stereotypes with their reactions as well. For instance, Taylor (28-year-old non-binary person with gHSV-2) recalled a conversation with their HSV+ friends who had bad experiences with disclosing: “they’ve also had not so great experiences where people have just sort of called them dirty, or you know, been uninterested afterwards, or, you know, said ignorant things that end up being harmful.” Jordan (36-year-old non-binary person with gHSV-2) shared an experience of one of their friends: “they had a terrible disclosure experience with someone that they were dating, who actually started swearing, got up and washed their hands, and acted like it was such a big deal.” The stories that Ivy, Taylor, Jordan, and many other informants shared of negative disclosures seemed to be quite common and appeared to have a lasting impact on informants and how they conceptualized living with a chronic STI. Receiving negative reactions from potential partners often made informants realize that they ‘dodged a bullet,’ as they mentioned it acting as a solid indicator of how the person handles conflict, how considerate they are of others, how open minded they are to educating themselves about sexual health and unlearning social stigma, and ultimately how much that person truly liked or care about them. Some informants took these rejections to heart and believed that these rejections reflected their self-worth (or lack thereof) and made them feel bad about themselves, reinforcing difficulties and stigma surrounding living with herpes.

One challenge in particular that informants identified surrounding living with a chronic STI was the possibility of transmitting their STI to a sexual partner, reinforced by most partners

who rejected them as they cited possible transmission as a key explanation for rejection. This fear of transmission was a central theme in Newton and McCabe (2008)'s work as well. In the current study, some potential partners simply were not willing to accept the small yet ever-present possibility that they could contract the chronic STI from engaging in any sexual contact with informants. Olivia (30-year-old woman with gHSV-2) recalled an instance in which she experienced this reaction from a potential sexual partner:

He told me that he's always been careful about not getting things and he just wanted some time to think about it. Then it was the next day that he told me that he wasn't, he didn't want to continue just because it was a risk he wasn't willing to take. So it was, honestly, it hit me really, really hard because that's the first time that I've been rejected by someone that I was actually interested in. [...] He said like he was interested in me, it just, he didn't want to take the risk and it does kinda hurt because I know the risk can be so small.

David (34-year-old man with gHSV-2) experienced a similar herpes-based rejection, as he recalled his brief relationship with a potential partner: "we started off really well and when I disclosed to her, you know, she was like 'I could see us having a huge future together, but I can't have herpes.'" Both Olivia and David's potential partners' reactions stem from existing herpes stigma, while seeming to be tied to a distorted, or perhaps absent, understanding of the reality of living with herpes as they both so intensely tried to avoid contracting it despite the potential of the relationship they missed out on as a result of it.

Some potential partners seemed to avoid overlooking the potential of their relationships with informants, as they initially accepted their status and the potential risks involved, but quickly revealed a more truthful negative reaction that ultimately ended in rejection and shame.

Faith (24-year-old woman with gHSV-2) explained a negative sexual encounter she had where she experienced this phenomenon:

My worst experience with a guy that I had told that I'd been intimate with, he then jumped in the bathtub right after to clean himself off and was googling the, he's like, "I've definitely got it. I've definitely, definitely got it." And was like googling on his phone and I'm like you're fine! You're fine! You're fine! And like yeah, we didn't work out (laughs).

Faith's sexual partner initially accepted her disclosure, yet following their sexual contact he proceeded to stigmatize Faith by acting in a way that can be interpreted as him implying that sleeping with her made him dirty or made him feel "dirty" (hence the shower). This particular partner was clearly not actually comfortable accepting the potential risk of transmission despite his previous agreement. Toni (36-year-old woman with gHSV-2) shared a memory of her ex-husband who she explained alluded to the fact that he loved her in spite of her herpes. David explained further about his previously mentioned partner who he had been dating for a considerable amount of time before they both accepted that she did not accept him having herpes or the potential risk of transmission:

I felt angry towards the end because I did want things to progress with her, but I had this, I remember having a conversation with her, and I was maybe a little more cruel than I should have been, but she was saying like, "I just can't, like I don't want that life" and blah blah blah, and I'm like yeah, well, I said the thing that you're afraid of is the thing that you're doing to me right now, and like, and that was like, yeah, I wouldn't want somebody to do this to me either, you know? And she was like well that's not fair. And I'm like, I think it is.

Faith, Toni, and David had all described uncomfortable situations in which their partners made them feel ashamed, guilty, or gross for having herpes despite them initially communicating that they were accepting of their status and willing to accept the risk of transmission. Informants seemed to internalize these rejections which presented in various ways unique to the specific informant. These presentations include feeling they were not worthy of love or affection, anticipating and assuming others would reject them based on their STI, using rejections as motivation to search for support and acceptance, and even reason to continue fighting STI stigma within their own lives. Most rejections were painful for informants to experience, especially in the moment of occurrence, but many informants used them as motivation to take better care of themselves and to even to create positive STI representation within their own social circles.

Support and Acceptance

While many informants shared experiences of rejection when disclosing, many informants also shared positive disclosure experiences in which they were met with support and acceptance. Several informants had potential partners respond with compassion, care, consideration, and were either already equipped with STI knowledge or were willing to educate themselves about it. Joan (24-year-old woman with gHSV-1) explained how her current partner had handled her disclosure with compassion, curiosity, and willingness to self-educate:

My current partner who didn't really ask questions so much as like he was like, "Yeah, no, that's really fine." And I thought he handled it a little too well. Come to find out he went home and like watched a whole like Netflix series, did a bunch of googling. And then when we started actually sleeping together, gave me this lovely talk about how he just implicitly trusts me to know my body and trust me to honor him in his body, and if there is anything I need to talk about with him, like he's there for me to talk about it, but

he's not going to ask any questions because he doesn't want me to feel stigmatized. And then asked if there was any aftercare he could, like that we could do. [...] Yeah, he was like, "well I didn't feel like it was your burden to educate me."

Natalie (21-year-old woman with gHSV-1) had a similar experience of her current partner demonstrating maturity through educating himself about herpes without being asked to: "my current partner, he even went online. He took the initiative because I didn't even send him the resources yet, but he took the initiative and looked it up and he decided he was fine with it."

Joan, Natalie, and other informants shared positive disclosure stories such as these ones, as their potential partners were not deterred by informants having herpes. Potential partners were willing to explore developing a relationship based on who the informant is rather than the potential risk of transmission present. This willingness to explore whether or not there was a meaningful connection between the informant and the potential partner often made informants feel supported and confirmed that they were more than just their STI and still worth loving.

In addition to potential partners simply accepting informants' STI status as a show of support and acceptance, some potential partners provided clear and direct support to the informants as well. Many informants shared experiences of feeling distressed and panicked but were comforted and supported by partners or potential partners in those moments. For example, Taylor (28-year-old non-binary person with gHSV-2) explained how their partner supports them while also recalling their experience of discussing their worries of having herpes just prior to receiving their diagnosis:

And now I feel like I have the support through, like having an accepting partner and having education and information. I would say those are the two biggest supports around the diagnosis. But I did have to have a little bit of a talk with my partner over like what

happened, because I was mostly just anxious, he didn't care at all, but I was really anxious, I was like what if it's herpes? And he was like "well, then it's herpes! Like I probably gave it to you!"

Taylor's partner's calm and caring response to the possibility of Taylor having herpes reinforced to them that having herpes was not a big concern and that getting herpes would not negatively affect their relationship. Joan also spoke about how their partner at the time of diagnosis was very reassuring and supportive when they experienced spikes of anxiety and panic surrounding her diagnosis:

For the first little while that I was diagnosed, I had a partner who was really lovely about it, and I used to have like a panic attack every week thinking I was having a flare up and he was gonna hate me, and he was like really lovely about it, but I remember sort of like not being able to verbalize that what I was scared of was passing it to him, and so it would come out as, oh, my god! I think I'm having a flare up, this is so terrible. And he would be really lovely and wonderful and reassuring about it, and be like, "you know, it's really fine. We'll go get the medication, like it's totally okay."

Joan's partner performed emotional labour and support for her during her initial stages of processing her diagnosis and easing her fears of transmitting it to others, which was a key source of support during her initial diagnostic period. The way that partners responded to the STI diagnosis and subsequently treated informants had a notable impact on informants' mental health and initial processing period.

Having understanding, compassionate, caring partners provide them with support following their diagnosis eased some of the distress, fear, and panic that almost every informant

(to various degrees) described experiencing. Partners' demonstrating care and support made it just a bit easier to live with an STI. As Melissa (36-year-old woman with gHSV-1) put it:

He didn't cancel our relationship and that meant a lot to me, it helped me accept myself, I don't know what I would have done if he had said no in that moment when I first got diagnosed. So, that actually really helped me, that was pivotal in me continuing to love, and you know, continuing to love and accept myself.

Since her partner continued loving her following her herpes diagnosis, Melissa was shown that she was still worthy and deserving of love, which she ensured to embody when showing herself the love and respect she deserved. Having partners who were able to accept the STI and look past it to start or continue meaningful relationships often made informants feel very loved, cared for, and taken seriously as romantic partners. Faith (24-year-old woman with gHSV-2) described the impact that her current partner accepting her STI status had on her own self-worth and the strength of their relationship:

I am so blessed that like even the fact that he accepted that, like, but it shows me he cares! Like he genuinely, genuinely cares because he takes, he knowingly takes that risk, and I'm, like I said, it might go in one ear and out the other, but he does take that risk, like, and to me that also shows he's committed, because if a man is taking that risk and knows that he might be coming out of it also positive, he's not thinking about going to be with anybody else, he's thinking about his future with you.

Faith's partner's willingness to accept the potential risk of contracting herpes demonstrates his loyalty and commitment to Faith, making her feel genuinely loved and cared for. Faith and other informants who had supportive and accepting partners often described these relationships as stronger and more meaningful than relationships with hesitant or non-accepting partners. These

caring and supportive relationships helped informants adjust to live with a chronic STI and encouraged more self-love and acceptance from the informants.

Chapter 7: Findings - Silver Linings

Despite informants identifying numerous negative experiences and challenges brought into their life by their STI diagnosis, most informants detailed some impactful and empowering silver linings that they believed they would not have otherwise experienced if they had not had to learn to manage their life with the addition of a chronic STI. They were able to pull out positive elements of their life that they attributed to their STI diagnosis and to then taking better care of themselves. As a result of getting a chronic STI, informants created deeper and sometimes new support systems that included various mixtures of other STI+ individuals, STI+ groups and social media, and the utilization of therapy. Many informants were able to overcome the loneliness that they expressed feeling upon their initial diagnosis as they used social media and shared their stories with others both in person and online to form a strong sense of community in their lives. Outside of their sense of community, they noticed improvements in their interpersonal relationships as well, as they realized they were developing higher quality interpersonal connections and stronger communication skills. Finally, many informants described the realization that they felt empowered and deserved to take good care of themselves, building up personal resiliency in the process. The following section explores these silver linings and positive outcomes that surprised many informants on their journey of processing and accepting their chronic STI diagnosis.

Communication

Many informants tied their chronic STI diagnosis to developing elevated communication skills. Since disclosing one's chronic STI to others can feel very intimidating and emotionally vulnerable, these informants identified their diagnosis as the catalysis for intentionally evolving

and improving their communication skills through the practice of having these difficult conversations. Informants identified the strengthening of their communication skills specifically in the context of having open, vulnerable, and well-articulated conversations about sexual health with potential partners. Lynn (28-year-old woman with gHSV-2) described this process:

Herpes is the best thing that ever happened to me, because it has changed the way that I look at relationships, the way I look at, like my sexual health and risk, as well as like, um how open and communicative I need to be with a potential partner like, I never would have had this conversation before and it would have like made me super uncomfortable. [...] I just didn't like have conversations about STIs or about like sexual health before, with like potential partners. And now, it kind of forces my hand because I, I wouldn't, I wouldn't sleep with somebody without disclosing so, yeah. It's like, in a weird way, it is a bit of a blessing, in a very weird, roundabout way.

As Lynn felt a responsibility to herself and the sexual health of potential partners, she learned how to overcome the fear of having uncomfortable conversations and be open and honest with others, which she notes she was unable to do prior to her diagnosis. Toni (36-year-old woman with gHSV-2) and Jordan (36-year-old non-binary person with gHSV-2) both closely echoed this sentiment, adding that Toni felt it was a good filtering system to see how well potential partners are able to communicate about vulnerable topics, and Jordan adding that their diagnosis encouraged them to have even more in-depth and intentional conversations about sexual health and safer sex with potential partners. Overall, informants felt the need to communicate about their STI, and their abilities to have these often difficult and vulnerable conversations allowed them to practice and improve on their overall communication skills that they could use in many other contexts as well.

Not only did disclosing their STI status allow them to improve their interpersonal communication skills, but it also helped several informants strengthen their advocacy skills. Living with a chronic STI encourages them to stick up for themselves and others, especially when it comes to matters surrounding sexual health and STIs. Joan (24-year-old woman with gHSV-1) illustrated this as she noted:

It's made me a very fierce advocate for folks who may live with chronic STIs who may not feel comfortable verbalizing it in social spaces. I'm very quick to like kind of step in if I feel like someone has said something inappropriate or hurtful.

Joan demonstrated finding an even stronger advocacy voice for herself and others living with chronic STIs, which she explains as a new development that accompanied accepting her STI status and wanting to make positive change for others living with STIs as well. Overall, being diagnosed with a chronic STI challenged informants' previous boundaries and comfort levels surrounding having difficult and vulnerable conversations as they now needed to advocate for themselves and help protect the sexual health of potential partners through sharing facts and equipped potential partners with all the necessary information to make informed decisions regarding sex and relationships.

Community and Social Media Platforms

As informants began to speak more openly about their chronic STI, many informants discussed the joy and connection they felt once they started to discover just how many people in their lives or their social circles were also living with that STI. These informants identified that discovering others in their lives who shared similar experiences helped validate and affirm their own experiences as they felt seen and heard. For example, Taylor (28-year-old non-binary person with gHSV-2) explained:

I've been able to connect with a couple of friends who are also, also have herpes and that's been really affirming [...] Not everyone's gonna get it, cause I think there's a, that feeling understood is another really big part of it, too, it's not just acceptance, it's like, "oh, yeah I also have herpes, so I literally know exactly what you're going through" kind of thing.

Taylor expressed feeling seen and affirmed by others who share similar experiences because it made them feel understood. Not only did informants discuss the power of having others relate to them and their own experience, they also felt validated and understood by being able to relate to the lived experiences expressed by others. Joy (32-year-old woman with gHSV-1) described how she felt like a part of a STI "club" or community based on all the adversity she felt she has overcome:

I understand what it feels like to like shame myself. I understand what it feels like to be the butt of like jokes like socially and culturally. I understand what it feels like to be afraid of passing it on to someone else or debating in your head like do I tell someone or don't I? And I know what it feels like to feel like I deserve this, I know what it feels like I feel like I'm a part of like a little club, to be like, hey, you too, hey? Like yeah, yeah, yeah, I have this. I feel in a small way like pretty lucky, like really fortunate.

Joy described feeling connected to others living with a chronic STI because they can both relate to experiencing and overcoming difficult experiences and feeling such as shame and ridicule. Informants felt connected to each other and to a wider community through both positive and negative shared experiences that most felt made them stronger.

In addition to feeling validated and seen through shared experiences, having this community of other STI+ individuals to relate to made many informants feel less alone. A key

source of this sense of community for numerous informants came from social media platforms such as subreddits on Reddit, STI-specific Instagram pages, and STI Facebook support groups. Being a part of these STI communities on social media allowed informants to share and compare similar experiences, ask for advice and information, and even form kinship and interpersonal connections with one another. Natalie (21-year-old woman with gHSV-1) explained what she felt she received as a result of being a part of a herpes subreddit:

I didn't know anyone that had herpes, it was just me, like I'd never met anyone else that was like "hey, I have herpes too" or like things like that. Like for me, like that Reddit post community is more so for me to be like yes, there are other people, it's not, it's not just me, (laughs) like there are others.

Since Natalie did not have this sort of community within her own social circle, she was able to find this community online, which affirmed that she was not alone and there were others with whom she could relate. Further, several informants shared fond tales of bonding with community members and developing rewarding interpersonal connections with them both within and outside of the direct community. Faith (24-year-old woman with gHSV-2) was one of these informants, as she passionately explained the relationships she formed with several community members and how much these relationships mean to her:

It feels really good, like really, really good cause like, and I even talked to like 2 or 3 of them on like a regular basis, like we're galpals now. So like they'll message me and be like just disclosed to this guy and like it went pretty well, and it's like, oh, yes, girl! Go get that d! (laughs) Like because like they turn into like actual friends and like you can actually talk about life with HSV and aside from it.

Faith felt so connected to these community members that they even connected on topics and experiences outside of HSV, which was their common tie. Faith explained that it was nice having friends who understood this part of her and the troubles that come along with living with herpes, but who she could discuss other elements of her life with as well. She identified these friendships as being very special, meaningful, and rewarding to her.

While this rewarding and meaningful sense of community allowed informants in the current study to feel connected to others with shared experiences, it also created a space for informants to share STI knowledge and information, as well as processing and directly working through various issues tied to living with a chronic STI. This aligns with findings presented by Bush et al. (2018) who emphasise the importance of having a platform to express oneself in support groups, as well as receiving emotional support and peer-education on the support group topic (in the case of the current study, STIs). As each informant within the current study was at a unique and personal place regarding their journey of acceptance or just simply coping with having a chronic STI, some informants felt it helped them to seek help for themselves, while others who had already overcome many of these same issues wanted to offer their help to others. In terms of informants still working through processing their diagnosis, Maya (19-year-old woman with gHSV-2) recalled an experience where she turned to the social media community for guidance:

When I like found the group or whatever, I posted like anonymously in there and I was like is there anyone that I can just like Facebook message, and kind of talk to? And luckily there was this one girl on there, she gave me all her tips and tricks, kind of just like in the community, saying she's there.

Maya felt supported and connected to other STI+ people through the sharing of knowledge and comfort provided by members of the community simply by being there for her. She felt a sense of guidance from community members, which she valued, as she was not yet fully comfortable or accepting of her herpes status. Other informants had previously done the work to accept and process their concerns tied to their STI status, and thus were at a place where they felt they could help others by offering that guidance and support that they had needed earlier on in their STI journey. When asked about the impact of being an active member of one of the existing herpes Facebook support group, Olivia (30-year-old woman with gHSV-2) reflected on this and shared that:

Since being in the group, I mean I guess I do think about [having herpes] a lot more, but I, when I see people, like especially the people who are like newly diagnosed, like I see it and I know how they're feeling, and I've always been a compassionate person and I like to help others so when I see someone and if I think I can, you know, share my experience and tell them like it does get better, (laughs), I just wanna help people because I didn't have that when I was first diagnosed, so I want to, you know, give some other people a chance to be able to feel better about it sooner than I did, you know?

Olivia had identified being in a much healthier and accepting mindset after successfully overcoming many of her own struggles regarding herpes and wanted to support others and assist them in overcoming their struggles more quickly and more easily than she had. She wanted to facilitate a space in which she could guide more-recently diagnosed individuals living with herpes through the often messy and difficult process of learning how to live with a chronic STI. This was a mutually beneficial situation for both those giving and receiving the advice and

support as it strengthened the community ties and bonds and made them feel like they were a part of something meaningful and bigger than just themselves. As Faith put it:

I never really felt like I had a sense of even belonging, and I know HSV, I didn't really have to pick that, I could've pick soccer or something else (laughs), but like, you know? But like it, it is a community, and it makes me feel like, like I'm categorized into something now, it might not be the most positive thing ever, but it's not bad either! Like I've made some of like my greatest friends, like I'll probably go out and see some of them girls in the states sometime, and, you know, like be friends for the next like 20 years, like so there's that.

One of the most powerful silver linings that many informants discussed was how finding some sort of STI community benefited their lives and made their journey in accepting and learning how to thrive while living with a chronic STI easier and even more enjoyable and pleasant. This finding of the importance of community and shared connections with other STI+ people emphasized the importance and benefits of support groups, heavily reflecting and affirming the findings of Bush et. al., (2018), Morales-Campos et al. (2009), and Citron et al. (1999). Many informants described the power of truly feeling understood by others in their STI community as they had finally been able to connect with others who had experienced variations of some of their most emotionally charged and painful experiences. This understanding of shared lived experiences made informants feel less alone in overcoming being diagnosed and living with a chronic STI, making them feel a particularly valuable and comforting connection with these other individuals. Many informants heavily relied on their STI communities to help them cope and process their chronic diagnosis and would likely have not found the same success in doing so without this crucial sense of community.

Higher Quality Connections

Another key silver lining that many informants described experiencing was that disclosing and dealing with their STI status within potential or current relationships lead to higher quality connections. On the side of the informant, they expressed feeling they now had to seriously reflect and consider whether they wanted to be vulnerable and pursue deep connections with someone as they were aware of the potential of STI-based rejection, and they had to decide whether this looming sense of potential rejection was worth it. For Susan (20-year-old woman with gHSV-2), she explained how it positively impacted her vetting process of potential partners:

I guess I'm more particular about like kind of feeling people out before I have to disclose, right? Whereas before I kinda wasn't as particular and I would go for anyone and like everyone (laughs), yeah. It's kind of like a blessing in disguise at the same time.

Lynn (28-year-old woman with gHSV-2) expanded on this idea of dating more intentionally:

Getting to know somebody a little bit better than I used to before, really like deciding whether or not I want to disclose to them, right? So um, it does kind of, it has helped me to like slow things down a tiny bit. [...] I'm actually really grateful for that, I think it's such a blessing because when I do decide to be with somebody, it's like, it is very intentional, and it's usually a healthier situation now.

Both Susan and Lynn describe a silver lining emerging from wanting to be more intentional and thoughtful about who they decide to use their time and emotional energy on, which as Lynn said, has led to more healthy romantic dynamics. Rather than giving just anyone a chance, as Susan had put it, informants often described having higher standards for potential partners and considered what they knew about a potential partner's empathy, willingness to learn, and overall ability to handle difficult conversations. If they got the sense that someone would not be

empathetic, caring, or kind to having to discuss and consider STI implications, they were less likely to give them a chance.

Alternatively, if informants decided to be vulnerable and give someone a chance and then got rejected, many felt it was actually a blessing in disguise and for the best in the long run. As Faith (24-year-old woman with gHSV-2) puts it:

You'll weed out anybody that never deserved you in first place, because if somebody can't genuinely love you for even like a small inconvenience as HSV, then they even deserve you in the first place, like it weaned out people right away.

Several informants described this impact from their STI status as an "asshole filter," meaning that if they were unable to see other "red flags" in potential partners, their disclosure being met with a bad reaction helped show potential partners' true colours. David (34-year-old man with gHSV-2) explained how a potential partner's poor reaction to his herpes status showed him that they were actually not a good match:

It was a good experience to have in the long run, because I learned, her reaction to that kind of showed me a lot of things about her personality and the way she is. And you get to know somebody where you're like oh okay, like we would not be compatible [...]. I feel like it is a strange like preclusive filter where you go through and if somebody's like "oh, it would force me to have to be compassionate and honest with people and I just can't have anything in my life that would force me to be compassionate and honest with people." And you're like wow, you're like not a good person.

Informants such as David and Faith explained that having to deal with rejection based on their STI status early on in a potential relationship spared them from being in relationships with people who did not truly care about them. These informants spoke about how something as

minor as having herpes would not stop the ‘right’ person from wanting to be with them, which many of them proved to be true through their current healthy relationships. Alternatively to those who had poor reactions or who informants anticipated would have bad reactions to an STI diagnosis, those who seemed empathetic, caring, and open minded were the ones that informants pursued, and many described healthy relationships forming from these dynamics.

Informants often described the ability to make deeper and higher quality connections with potential partners after sharing their STI status and being met with positive responses. Several informants attributed this to the idea that their ability to be vulnerable and open with potential partners attracts people who are interested in deeper connections and who demonstrate clear empathy and compassion. As Susan explained it:

The people that I do have longer relationships with tend to be, you know, more accepting and stuff like that instead of like judgmental, and maybe like more surface level relationships. I will like attract people that want a little bit more usually, so I like that (laughs).

Susan explained that partners who are accepting of her herpes status tend to be more kind, compassionate people in other elements of their relationship that are unrelated to herpes. Jordan (36-year-old non-binary person with gHSV-2) explained that positive disclosures showed them various positive skills and qualities that their partners possess: “I felt so reassured like this person is honest, they can have difficult conversations, and they care about my health.” The disclosure process even helped strengthen and solidify both pre-existing and in-progress relationships by overcoming adversity and difficulties. Ivy (23-year-old woman with gHSV-2) explained how her relationship with her pre-existing partner became even stronger after disclosing her herpes status to him:

My current partner, we were more casually dating at the time and so I think this actually really solidified our relationship more and made it more serious. He was extremely supportive and at the time when I told him, he obviously didn't know his status, and so he said, "regardless of what that test tells me, I'm here for you, I'm not leaving." And that was so nice to hear after being diagnosed and thinking that, you know, I'm going to go my life unloved. I'm never going to have a partner, and for him to say, "no matter what, I'm here for you." That was just, that meant the world to me.

When Joy (32-year-old woman with gHSV-1) was forming her relationship with her current partner after her herpes diagnosis, she explained how their mutual herpes disclosure brought them closer together and created a deeper shared sense of intimacy:

This might be stupid, but it is just sort of like exclusivity of like oh I have this thing, and it opens up a door to like you know, a more complicated, a more complex world, like it creates intimacy too in a way where, like my partner was completely relieved when he told me he has herpes, like I'm sure he was terrified, we talk afterwards and he was like "I was fucking scared to tell you" and I was like yeah me too, I was terrified to tell you, but it does create this like shared sense of intimacy that I'm really grateful for.

Informants such as Joy and Ivy demonstrated courage, strength, and vulnerability through openly disclosing and discussing their chronic STIs with their partners. Having their disclosures being met with compassion, love, care, and empathy made their respective bonds with their partners stronger. Informants demonstrated honesty, vulnerability, and concern for their partners by being open and transparent about the facts and risks surrounding their STI. Partners of informants demonstrated the depth of their interest, attraction, and commitment to informants through their warm, loving, and open-minded responses. Both partners bringing this respect for one another

into their dynamic through the disclosure process created and solidified a solid, healthy foundation to build a successful relationship on.

Other ways that informants connected living with a chronic STI to developing higher quality connections include experiencing additional care from partners surrounding their diagnosis, partners seeing them as a complex and valuable individual rather than simply their STI diagnosis, and ultimately partners showing informants that they are well-worth the risk of them contracting the STI as well. As Faith (24-year-old woman with gHSV-2) explained it:

I am so blessed that like even the fact that he accepted that, like, but it shows me he cares! Like he genuinely, genuinely cares because he takes, he knowingly takes that risk, [...] and to me that also shows he's committed, because if a man is taking that risk and knows that he might be coming out of it also positive, he's not thinking about going to be with anybody else, he's thinking about his future with you [...]. And it's silly to say, but he just, he loves me in the exact way that I need to be loved.”

Faith expresses here that she knows her partner is committed and serious about her, as his care and love for her coupled with his willingness to risk contracting a chronic STI proves that to her. Faith and many informants expressed feeling grateful to their STI for filtering out partners who were not genuinely interested in them and thus making room for partners who show up for them and love them the way they deserve to be loved.

Self-Love and Care, Empowerment, and Resiliency

Some final important silver linings (which have been discussed in greater detail above) that arose from informants living with a chronic STI is the increased awareness and importance they placed on self-love and care, as well as the ability to empower themselves and demonstrate resiliency. Many informants described that living with a chronic STI made them value

themselves more and intentionally take better care of their bodies and their minds. Jordan (36-year-old non-binary person with gHSV-2) talked about how living with herpes put the importance of their overall health into perspective:

A lot of people with herpes talk about is that having an outbreak forces a ton of self-care, slowing down, am I too stressed, how's my nutrition, you know, that kind of a thing. So, and I felt I've had to do that with, with injuries or mental health, and all of that. [...] I have been a little bit more motivated with taking care of myself, just like that, that little push, to take care of my health (laughs).

Jordan, similar to other informants, felt encouraged to take better care of themselves mentally and physically in order to alleviate the physical symptoms of their STIs, which ultimately empowered them to love themselves fully and to make changes to help them do so. Joy (32-year-old woman with gHSV-1) further demonstrated this by explaining the positive changes she made in her to life to better herself for herself:

I'm sorry that had happened of course, but like there's no changing it, so like how do I just keep myself, how do I just remove stress in my life and get better sleep? And like cut smoking out and like cut drinking out and stuff like that. It was, these are all good things, you know, like would I have come about that kind of, like would I have started doing yoga as much as I do? Would I be, would I have quit smoking? If it hadn't been for this, like actually probably not. I remember I quit smoking about a year ago because I was convinced it was giving me outbreaks [...]. And so I'm kind of grateful for that in like, you know, this has actually opened up a lot of opportunity for me to like take care of myself in ways that I probably wouldn't have thought before.

Joy directly attributes the several positive changes she made in her life in order to improve her health to her herpes diagnosis, as she wanted to find ways to take better care of herself in order to help minimize the impact that herpes has on her life.

Jordan, Joy, and many other informants demonstrated that although informants clearly and understandably encountered many challenges associated with living with a chronic STI, more surprisingly, they identified several silver linings. Informants had to learn how to better communicate with others in order to adequately inform others and discuss the impact that herpes has on their own lives, as well as the potential impact it could have on their partners. Informants found both online and in-person communities consisting of friends or even strangers that were living with the same chronic STI as them and could make themselves feel heard and seen based on understanding common shared experiences. They were able to see more clearly which potential partners were genuinely interested in developing meaningful connections with them, which helped them build and sustain higher quality relationships than they had prior to their diagnoses. Finally, informants were able to overcome many of the challenges they initially struggled with during their diagnostic period in order to realize that their STI does not make them unworthy of love and care and thus empowered them to treat themselves accordingly. Although every informant discussed various negative experiences and emotions associated with their STI, many of them left their interviews on an uplifting note as they realized that living with a chronic STI was not in fact the life-ruining, world-ending event they initially thought that it would be.

Chapter 8: Discussion and Conclusion

This thesis explored many aspects that accompany living with chronic STIs -- from diagnosis, to understandings of self, self-esteem, and identity, the impacts on relationships with friends, family, and romantic or sexual partners, to the surprising silver linings that people expressed.. Each informant described having difficulties initially processing and accepting their chronic STI diagnosis, but most of them also detailed working through these challenges and found various degrees of success in overcoming them. Several informants were even able to identify some positive outcomes associated with having a chronic STI, which is often absent within the discourses of living with a chronic STI. This study has chosen not to focus on the barriers to STI testing and the fears of contracting an STI in order to investigate what happens when one is diagnosed with a chronic STI and has to live with it for the remainder of their life. This work has utilized the unique experiences and words of 21 informants living with chronic STIs, primarily herpes, in order to construct a common narrative of what living with a chronic STI may look like to create greater insight on the topic.

This study has answered the two main research questions initially posed: 1) How does being diagnosed with a chronic STI impact one's sense of self and identity? 2) How does being diagnosed with a chronic STI impact both romantic and non-romantic relationships? Although the answers to these questions are neither simple nor straightforward, there were similarities and commonalities among what most informants shared. In terms of sense of self and identity, many informants described experiencing a (usually temporary) disruption to their sense of self and identity as they grappled with the external and internalized stigma they associated with STIs and the stereotypes of what kind of person contracts an STI. Many of them overcame the powerful

stigmatized notion that they described suggesting that those living with chronic STIs are dirty, diseased, promiscuous, worthless, unlovable, ugly, and deserving of an STI as a moral punishment. Many informants battled the idea that others would reduce them to STI stereotypes and treat them poorly as a result, and eventually overcame this battle in time. Through time, active work on reshaping their self-image, and the care and support of loved ones, most informants realized that having an STI does not actually change who they are; therefore, they should not think of themselves as damaged, alienated, or different as a result of their STI. In fact, many informants were able to use their chronic STI as a means to take better care of and be kinder to themselves, and seek higher quality connections in their relationships.

The impact that living with a chronic STI had on relationships differed between informants, but several common themes that emerged. Most informants suggested that sharing and discussing their STI status with others seemed to have various impacts on their romantic, platonic, and familial relationships. In cases of strengthening the relationship, both the informant and their loved one felt a stronger connection to one another based on the shared vulnerability between the two and the support that the informant received as a result. Some informants bonded with their loved ones based on shared experiences and developed even deeper levels of trust and connection. In cases where informants experienced a strain on their relationships, it was typically due to their loved one lacking knowledge about STIs and internalizing STI stereotypes, as well as initially not knowing how to compassionately respond to the diagnosis and support the informant. However, in the case of a strain on relationships, it often included the loved one doing some research and better informing themselves on sexual health before proceeding. In the case of ending relationships, some loved ones, typically casual sexual partners, simply could not overlook societal stigma surrounding STIs and were not willing to do the work to educate

themselves and destigmatize the topic for themselves. In fewer cases, some potential sexual partners were educated on the topic and chose not to risk contracting the STI from the informant. For relationships that were unaffected by the chronic STI diagnosis, loved ones were typically informed about STIs and were aware of the small or lack of impact it has on their relationship. For family members and platonic friends, the risk of transmitting the STI was non-existent, and for romantic partners, they were aware of the potential risk and accepted it. The reactions from loved ones and the impact on relationships were important to informants not only because it shaped the quality of their relationships, but it also helped shape how they thought of themselves and their diagnosis as a result.

When considering the importance of the diagnostic process on the lived experiences of those diagnosed with chronic STIs, the role of the health care professional was central. As highlighted by several informants within this study, the attitudes and reactions of health care workers have the potential to greatly influence the attitudes reactions of individuals receiving chronic STI diagnoses. These attitudes and reactions of health care workers matter a great deal to patients. They need to be carefully considered and approached with intentionality in order to offer patients the comfort and support they deserve in a difficult situation. Positive chronic STI diagnoses are difficult for most individuals, as communicated by the informants, and health care workers should aim to deliver the diagnosis with compassion and concern in order to best support patients. To best serve their patients, health care workers should be knowledgeable about both STIs and the impact that they can have on those living with them. They should also have easily accessible emotional (i.e., counselling materials) and medical resources available, while also being prepared to hold space for patients to have an emotional response in the moment of diagnosis.

Outside of the influence that doctors have on the informants' perspectives of living with chronic STIs, the initial reactions of both casual and committed romantic partners were also quite influential. When partners have positive, or at the very least neutral, reactions to a new STI status, it may allow individuals to feel a sense of normalcy and consistency amid a stressful period of adjustment. In addition to being an active support for someone who has just received a positive chronic STI diagnosis, a romantic partner can greatly influence the individuals' initial reactions based on how they treat their partner. If a partner is kind, caring, and loving towards the newly diagnosed individual, like Melissa's (36-year-old woman with gHSV-1) partner was, it demonstrates to that person that their STI status does not change their worth or who they are as an individual, which is important and reaffirming after being diagnosed with a chronic STI. If a partner reacts with anger, disgust, and rejection, the newly diagnosed individual may believe that they have done something wrong, are now "damaged" and deserve to be treated poorly. It is imperative to have positive support during the initial diagnostic period, and romantic partners may be the key determinative factor in this process.

The lack of comprehensive sex education that many informants described missing out on during their formal education also greatly shaped their initial reactions, the internalized stigma they experienced, and the struggles they faced while living with a chronic STI. Receiving better sex education in school prior to being diagnosed would likely help normalize STIs and help minimize the mental health struggles that many informants suffered from following their diagnosis. They would have learned sooner that living with a chronic STI was entirely possible and not the end of the world, which took most informants a considerable amount of time to learn for themselves. Informants discussed how much of their initial reactions came from their lack of knowledge coupled with the influence of the shameful way that STIs were discussed in sex

education classes. Regardless of the actual medical information that informants may or may not have received, informants recalled the shame and negativity surrounding STIs more than anything else. They remembered being told that contracting an STI was more of a personal failure and a reflection of one's character rather than a potential consequence of being sexually active. This negative, stigmatizing, and shameful narrative surrounding STIs that we hear from a very early age plays an important role in shaping the initial reactions to a positive STI diagnosis at a later time. If young people received sex education that openly discussed the facts surrounding STIs without stigmatizing them, not only could this aid with prevention due to greater knowledge of safer sex practices; but, more importantly, it would help emotionally prepare them for the possibility of a positive STI diagnosis in the future. Demystifying STIs and demonstrating the relatively mundane reality of living with a chronic STI is crucial to help break the stigma surrounding them. Unfortunately, many informants had to learn this for themselves while overcoming the various influences of stigma they experienced.

Within their personal interactions, popular culture, and media, most informants discussed experiences of feeling hurt, angered, or even dehumanized by hearing or being the target of STI related jokes. Even though informants expressed annoyance and frustration regarding these jokes, the prevalence of these jokes demonstrates that STI stigma is such an ingrained and powerful force in society. These jokes might make anyone who has any personal experience with STIs feel ashamed, abnormal, gross, and even guilty because of contracting an STI and thus adds further challenges to coping with and emotionally processing a positive STI diagnosis. From discussing with informants, it seemed STI jokes and stereotypes are often the result of a lack of good sexual health information and a lack of positive STI representation in pop culture. Therefore, challenging and dismantling STI stigma needs to come from better sexual health

education and from various sources (media, personal life, etc.) of people openly discussing living with STIs. Open informative discussions that perpetuate factual knowledge and positive STI representations would likely have helped every informant with processing their new STI and would have removed several of the previously discussed obstacles they were forced to overcome to make peace with their new chronic STI diagnosis.

Once informants decided to share their STI diagnosis with others in their life, the results from negative disclosures seemed to harm informants in several ways. Informants who experienced negative reactions from their family members often expressed suffering with mental health concerns and intense shame because of it. These negative reactions from family members also appeared to strain these relationships, although often only temporarily. Informants who noted experiencing rejection and judgement from their loved ones seemed to have a more difficult process of overcoming the personal struggles that came with their initial diagnosis and adjusting to life with a chronic STI compared to informants who received care and support. Accepting a new chronic STI diagnosis is difficult enough without negativity and judgement from loved ones, and thus informants had a more difficult time navigating their diagnosis when they did not have the clear and direct support from loved ones. Friends and family had the ability to make receiving a chronic STI diagnosis easier or more difficult depending on how supportive and open-minded they were about the situation, and whether they were willing to educate themselves and challenge their understanding of existing STI stigma.

Goffman's Stigma and Labelling Theory

The current study used Goffman's (1963) conceptualizations of the spoiled identity and stigma, as well as labelling theory, as foundational theoretical concepts to begin the analysis of the current study. However, the findings of this research did not directly align with these concept

and theories as presented by the respective theorists, but rather these concepts were challenged and expanded upon through the data analysis process. In terms of Goffman (1963) and stigma, his three types of stigma (abominations, blemishes, and tribal stigma) were helpful to guide this research and set up a theoretical foundation for analysis; however, conceptually, these three types of stigma were not clearly reflected within the data. Informants did not often speak about their STI as causing them to feel a physical deformity or of something that others could observe is clearly wrong with them, and therefore abominations do not quite fit. Blemishes could somewhat be applied to the current data, as informants occasionally mentioned stereotypes of STIs including individual character flaws, yet many informants were able to overcome these stereotypes and did not ultimately result in a sense of spoiled identity. Finally, tribal stigma was not applicable to the current data at all. Although stigma was crucial in theoretically framing this project, these particular types of stigma did not emerge within the current data.

In addition to stigma and spoiled identity, labelling theory was also initially a theory that was anticipated to be greatly related to the current findings, yet it did not quite have the social power over informants that was initially expected. The current study can help understand where labelling theory comes into play with STI diagnoses and how it changes over time. While informants were in the moment of diagnostic shock followed by their early experiences adjusting to living with a chronic STI, labelling theory appeared and informants did in fact internalize stigma. However, as they had more time to process their diagnosis and its implications, their illness experiences evolved as they exercised agency to push back against stigma or at least took away the power that STI stigma originally had on them. Although labelling theory is in fact relevant to the current study, the data demonstrates that the internalization of stigma is an ongoing process of engaging with sense of sense and subjectivity. Rather than simply

understanding a label to be completely solid or finalized, this study demonstrates that perhaps a label is just one stop on a moving train as labelling and internalized stigma does not need to be the end.

Key Takeaways and Suggestions for Improvement

The results from this study suggest that the initial diagnostic phase, heavily characterized by adjustment periods and learning to live with a new chronic STI, was the most difficult part of their experience with their STI. This appears to be due to a lack of proper sexual health education that frames the possibility of contracting an STI as a normal part of being sexually active. Some informants took all the precautions and engaged in safer sex and yet still contracted an STI. Sex education needs to be largely reformed in the way it handles discussing and teaching about STIs. If students receiving sex education were taught the reality of how many people contract chronic and curable STIs during their lifetime and this reality was normalized right from the start, it would make a chronic STI diagnosis later in life much more manageable and less daunting. Students would be taught about STIs without stigma and shame, which would make an STI diagnosis feel much less scary and life-ruining because they would have a better sense of the reality of living with a chronic STI. Although informants needed to disclose their status to potential sexual partners and often prioritized safer sex practices within their sex lives, most informants ultimately learned through their experiences that having a chronic STI has no meaningful impact on their life and does not change who they are as a person for the worst. In fact, many informants identified several positive impacts on their life that arose from learning to live with a chronic STI. However, it is crucial to prioritize a destigmatized approach to how we are teaching students about sexual health and STIs, such as addressing STIs as normal and manageable, as well as prioritizing easy access to quality social and emotional supports.

From the result of this study, one of the first emotional supports that should be in place are doctors and other health care workers, as these interactions within the health care system are often the first meaningful exposures to discourse surrounding STIs. A greater emphasis is needed on educating health care workers on the importance of tone and openness when treating STI cases. Since getting tested, diagnosed, and treated in health care settings are often the first interactions informants had with others regarding STIs, this research demonstrates how crucial and formative these interactions are in shaping one's perspective on their new diagnosis. Those receiving chronic STI diagnoses would greatly benefit from health care workers undergoing and utilizing additional training to deliver the diagnosis, medical facts about the STI, and offer resources and supports in a more caring and compassionate way. It would be greatly beneficial to provide health care workers with a more comprehensive education surrounding the various facts associated with different STIs, as we have seen here that knowledge amongst health care workers was inconsistent. In addition to being properly equipped with facts and medical knowledge about STIs, it is crucial for doctors and nurses to consider and challenge their own biases and internalized stigma associated with chronic STIs, which was often embedded in the experiences of the informants. If health care workers were given sensitivity training on how to discuss living with a chronic STI and were directly educated about STI stigma and the difficulties of living with one because of the stigma, they would likely reconsider the care and compassion that should go into these interactions with.

Since STI stigma was so prevalent within the study, I believe that creating more positive representation of individuals living with chronic STIs within pop culture would also be beneficial for those who receive chronic STI diagnoses. Most people that informants encountered who heavily stigmatized STIs or made STI jokes lacked information about STIs and how

common they are. When STIs are discussed in pop culture or the media, they are almost always villainized and used as a marker to ridicule or to “other” someone. To address this and demystify STIs on a broad scale, such as in pop culture or the media, creating and sharing stories of positive or even simply neutral experiences living with a chronic STIs would likely be effective in fighting STI stigma. Sharing fictional or real stories of people living normal and healthy lives while also living with a chronic STI — which is the reality of most informants — would help both those struggling with an STI diagnosis and those not living with a chronic STI normalize the existence of STIs and demonstrate how common and manageable they are. Celebrities, influencers, and other public figures sharing their real-life experiences of living with chronic STIs would also be helpful in changing the pop culture discourse surrounding STIs, as it would challenge several STI stereotypes by showing that even those who society regards as being the most beautiful, rich, and successful people can contract and live with chronic STIs, in addition to generally providing more positive STI representation.

Despite all the negativity, stereotypes, and stigma surrounding STIs, it was refreshing to hear informants speak about some of the unexpected positive moments and experiences they had due to living with their chronic STIs. Some informants felt they had been shaped for the better as a result of overcoming adversity, learning compassion and empathy, and connecting with others in a more intentional and kind manner. Since this element of living with a chronic STI is often overlooked within STI discourses, it was not originally a topic addressed within the initial interview guide used for this study. This topic was initially brought up in the second interview conducted for this study as the informant spoke about their own silver linings and suggested prompting others for their own thoughts on the matter. It was moving to hear informants describe how they made the best out of an unfortunate situation and allowed living with a chronic STI to

foster growth and self-care. A more in-depth analysis of the positive outcomes of living with a chronic STI would likely assist in destigmatizing STIs and making the initial diagnostic period less stressful.

Areas for Future Development and Research

Looking beyond the current study, future research on the impact that chronic STIs have on one's emotional well-being and social life might consider how different axes of identity might impact these experiences. In the original conceptualization of the current project, individual identity categories such as race, gender, and sexuality were considered for key points of analysis. However, due to a lack of diversity of informants, not enough data regarding race or sexuality were collected. Although some interesting data was collected in the current project about how gender might impact the experiences of informants, some of it was contradictory and thus in need of greater substantiation. In future research, obtaining a more representative sample of informants from various genders, races, and sexualities would likely produce rich data on intersectionality and lived experiences of those with chronic STIs.

Additionally, a few informants described their experiences of navigating polyamorous romantic relationships while living with a chronic STI. Discussing polyamorous relationships provided some variation to the more common experience of most informants who described navigating monogamous relationships, as polyamorous informants spoke about concern for and communication with their partners' other partners. Investigating how ethically non-monogamous individuals living with chronic STIs navigate their various relationship dynamics would be an important area of research to pursue to better understand the complex and nuanced nature of current relationships in society. Different axes of identities, such as race, gender, sexuality, and

relationship type, may be notable factors that impact how individuals understand how their STI impacts their sense of self and their relationships and should be studied further.

Final Remarks

In concluding this research, it is evident that living with a chronic STI does not meaningfully change or impact one's self-worth, beauty, ability to love, or ability to be loved. However, informants have demonstrated that it takes times and effort to feel that way following a chronic STI diagnosis. This project has argued that the emotional and social stressors and obstacles that one is faced with and tries to overcome when living with a chronic STI is worse than the physical symptoms. Although the chronic STIs discussed within this project are currently incurable, the social and emotional obstacles are curable and can be alleviated through access to more social and medical supports, better sexual health education, and more positive representation on a societal level. It is also crucial to acknowledge that although living with a chronic STI can be challenging, it can also be a catalyst for positive personal growth and for beginning to destigmatize STIs within one's personal world. Many individuals, including these informants, are already working to fight STI stigma, which helps make living with a chronic STI in today's world a bit easier. This project intends to aid in that fight. As this fight continues, it will hopefully make receiving a chronic STI diagnosis as mundane and manageable as learning you have eczema, or asthma, or any other common human condition that does not significantly impact or alter one's life or identity.

References

- Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semi-structured interviews. *Journal of the American college of clinical pharmacy*, 4(10), 1358-1367.
- Barth, K. R., Cook, R. L., Downs, J. S., Switzer, G. E., & Fischhoff, B. (2002). Social stigma and negative consequences: Factors that influence college students' decisions to seek testing for sexually transmitted infections. *Journal of American College Health*, 50(4), 153-159.
- Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758-1772.
- Becker, H. S. (1963). *Outsiders: Studies in the Sociology of Deviance*. Free Press.
- Block, R. G. (2009). Is it just me? Experiences of HIV-related stigma. *Journal of HIV/AIDS & Social Services*, 8(1), 1–19.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182
- Bush, E. J., Singh, R. L., Hidecker, M. J. C., & Carrico, C. P. (2018). Parkinson's disease support groups in rural america: Barriers, resources, and opportunities. *The Qualitative Report*, 23(6), 1381-1400.
- Carpenter, L. M. (2010). Gendered sexuality over the life course: A conceptual framework. *Sociological Perspectives*, 53(2), 155-178.
- Centers for Disease Control and Prevention. (2021, February 18). *Sexually Transmitted Infections: Prevalence, Incidence, and Cost Estimates in the United States*.

Sexually Transmitted Diseases (STDs) Statistics.

<https://www.cdc.gov/std/statistics/prevalence-incidence-cost-2020.htm>

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological quarterly*, 36(4), 657-680.

Citron, M., Solomon, P., & Draine, J. (1999). Self-help groups for families of persons with mental illness: Perceived benefits of helpfulness. *Community Mental Health Journal*, 35(1), 15-30.

Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational researcher*, 19(5), 2-14.

Earnshaw, V. A., Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness*, 8(2), 79-88.

Edwards, W. M., & Coleman, E. (2004). Defining sexual health: a descriptive overview. *Archives of sexual Behavior*, 33(3), 189-195.

Eiduson, R., Murchison, G. R., Agénor, M., Suarez, L., & Gordon, A. R. (2021). Sexual healthcare experiences of nonbinary young adults. *Culture, health & sexuality*, 1-17.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of health & illness*, 26(2), 242-261.

Fields, J. (2008). *Risky lessons: Sex education and social inequality*. Rutgers University Press.

Feinstein, B. A., Dellucci, T. V., Graham, S., Parsons, J. T., & Mustanski, B. (2018). Sexually transmitted infections among young men who have sex with men:

- Experiences with diagnosis, treatment, and reinfection. *Sexuality Research & Social Policy*, 15(2), 172-182.
- Foster, L. R., & Byers, E. S. (2008). Predictors of stigma and shame related to sexually transmitted infections: Attitudes, education, and knowledge. *The Canadian Journal of Human Sexuality*, 17(4), 193-202.
- Foster, L. R., & Byers, E. S. (2013). Stigmatization of individuals with sexually transmitted infections: effects of illness and observer characteristics. *Journal of Applied Social Psychology*, 43, E141-E152.
- Gabarron, E., Serrano, J. A., Wynn, R., & Lau, A. Y. (2014). Tweet content related to sexually transmitted diseases: no joking matter. *Journal of medical Internet research*, 16(10), e228.
- Garg, N., & Volerman, A. (2021). A national analysis of state policies on lesbian, gay, bisexual, transgender, and questioning/queer inclusive sex education. *Journal of School Health*, 91(2), 164-175.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. New York, NY: Simon & Schuster.
- Gokengin, D., Yamazhan, T., Ozkaya, D., Aytug, S., & al, e. (2003). Sexual knowledge, attitudes, and risk behaviors of students in turkey. *The Journal of School Health*, 73(7), 258-263.
- Gottlieb, S. L., Low, N., Newman, L. M., Bolan, G., Kamb, M., & Broutet, N. (2014). Toward global prevention of sexually transmitted infections (STIs): The need for STI vaccines. *Vaccine*, 32(14), 1527-1535.

- Hammarlund, K., Lundgren, I., & Nyström, M. (2007). To contract genital warts-A risk of losing love? experiences of Swedish men living with genital warts. *International Journal of Men's Health, 6*(2), 100-114.
- Hendrickx, L., Gijs, L., & Enzlin, P. (2016). Sexual difficulties and associated sexual distress in Flanders (Belgium): A representative population-based survey study. *The journal of sexual medicine, 13*(4), 650-668.
- Hihara, S., Umemura, T., & Sugimura, K. (2019). Considering the negatively formed identity: Relationships between negative identity and problematic psychosocial beliefs. *Journal of Adolescence (London, England.), 70*, 24-32.
- Jahn, J. L., Bishop, R. A., Tan, A. S., & Agénor, M. (2019). Patient-provider sexually transmitted infection prevention communication among young adult sexual minority cisgender women and nonbinary assigned female at birth individuals. *Women's Health Issues, 29*(4), 308-314.
- Jensen, T., & Sandström, J. (2015). Normal deviants and Erving Goffman: Extending the literature on organizational stigma. *Nordic Journal of Working Life Studies, 5*(4), 125-142.
- Joachim, G., & Acorn, S. (2000). Living with chronic illness: The interface of stigma and normalization. *CJNR: Canadian Journal of Nursing Research, 32*(3), 37-48.
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research, 19*(11), 1632-1641.
- Kershaw, T. S., Ethier, K. A., Niccolai, L. M., Lewis, J. B., Milan, S., Meade, C., & Ickovics, J. R. (2010). Let's stay together: Relationship dissolution and sexually

- transmitted diseases among parenting and non-parenting adolescents. *Journal of Behavioral Medicine*, 33(6), 454-465.
- Klawiter, M. (2004). Breast cancer in two regimes: the impact of social movements on illness experience. *Sociology of Health & Illness*, 26(6), 845-874.
- Le Espiritu, Y. (2001). "We don't sleep around like white girls do": Family, culture, and gender in Filipina American lives. *Signs: Journal of Women in Culture and Society*, 26(2), 415-440.
- Lieber, E., Li, L., Wu, Z., Rotheram-Borus, M. J., & Guan, J. (2006). HIV/STD stigmatization fears as health-seeking barriers in China. *AIDS and Behavior*, 10(5), 463-471.
- Lindley, L. L., Barnett, C. L., Brandt, H. M., Hardin, J. W., & Burcin, M. (2008). STDs among sexually active female college students: Does sexual orientation make a difference? *Perspectives on Sexual and Reproductive Health*, 40(4), 212-217.
- Mäkelä, P. (2017). "They brought you back to the fact you're not the same": Sense of self after traumatic brain injury. *Subjectivity*, 10(4), 358-373.
- Manzo, J. F. (2004). "On the Sociology and Social Organization of Stigma: Some Ethnomethodological Insights." *Human Studies* (24), 401-416.
- Mauthner, N. S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431.
- Meyer, I. H. (1995). Minority stress and mental health in gay men. *Journal of health and social behavior*, 38-56.
- Morales-Campos, D., Casillas, M., & Mccurdy, S. A. (2009). From isolation to connection: Understanding a support group for hispanic women living with

- gender-based violence in houston, texas. *Journal of Immigrant and Minority Health, 11*(1), 57-65.
- Nack, A. (2008). *Damaged Goods? Women Living with Incurable Sexually Transmitted Diseases*. Philadelphia: Temple University Press.
- Newton, D. C., & McCabe, M. P. (2008). Sexually transmitted infections: impact on individuals and their relationships. *Journal of Health Psychology, 13*(7), 864-869.
- Perry, B. L. (2011). The labeling paradox: Stigma, the sick role, and social networks in mental illness. *Journal of health and social behavior, 52*(4), 460-477.
- Pino Gavidia, L. A., & Adu, J. (2022). Critical narrative inquiry: An examination of a methodological approach. *International Journal of Qualitative Methods, 21*, 16094069221081594.
- Polzer, J., Mancuso, F. V., & Rudman, D. L. (2014). Risk, responsibility, resistance: Young women's negotiations of identity and healthy citizenship in human papillomavirus (HPV) vaccination narratives. *Narrative Inquiry, 24*(2), 281-308.
- Reid, A. E., Magriples, U., Nicolai, L. M., Gordon, D. M., Divney, A. A., & Kershaw, T. S. (2013). Associations of a sexually transmitted disease diagnosis during a relationship with condom use and psychosocial outcomes: (short) windows of opportunity. *American Journal of Community Psychology, 51*(3-4), 510-519.
- Rosenthal, S. L., Biro, F. M., Cohen, S. S., Succop, P. A., & Stanberry, L. R. (1995). Strategies for coping with sexually transmitted diseases by adolescent females. *Adolescence, 30*(119), 655-666.

- Rosenthal, S. L., Griffith, J. O., Succop, P. A., Biro, F. M., & al, e. (2002). The relationship between STD locus of control and STD acquisition among adolescent girls. *Adolescence*, 37(145), 83-92.
- Schalet, A. T. (2000). Raging hormones, regulated love: Adolescent sexuality and the constitution of the modern individual in the United States and the Netherlands. *Body & Society*, 6(1), 75-105.
- Schein, A. I., & Travers, R. (2017). Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men. *AIDS care*, 29(8), 990-995.
- Shoveller, J., Johnson, J., Rosenberg, M., Greaves, L., Patrick, D. M., Oliffe, J. L., & Knight, R. (2009). Youth's experiences with STI testing in four communities in British Columbia, Canada. *Sexually Transmitted Infections*, 85(5), 397-401.
- Shoveller, J. A., Knight, R., Johnson, J., Oliffe, J. L., & Goldenberg, S. (2010). 'Not the swab!' Young men's experiences with STI testing. *Sociology of health & illness*, 32(1), 57-73.
- Sparling, S., & Cramer, K. (2015). Choosing the danger we think we know: Men and women's faulty perceptions of sexually transmitted infection risk with familiar and unfamiliar new partners. *The Canadian Journal of Human Sexuality*, 24(3), 237-242.
- Smith, G., Mysak, K., & Michael, S. (2008). Sexual double standards and sexually transmitted illnesses: Social rejection and stigmatization of women. *Sex Roles*, 58(5-6), 391-401.

- Smith, R. J. (2011). Goffman's interaction order at the margins: Stigma, role, and normalization in the outreach encounter. *Symbolic Interaction*, 34(3), 357-376.
- Stringer, K. L., Turan, B., McCormick, L., Durojaiye, M., Nyblade, L., Kempf, M., Lichtenstein, B., & Turan, J. M. (2015). HIV-related stigma among healthcare providers in the deep south. *AIDS and Behavior*, 20(1), 115-125.
- Wang, C. C., & Geale, S. K. (2015). The power of story: Narrative inquiry as a methodology in nursing research. *International journal of nursing sciences*, 2(2), 195-198.
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of health & illness*, 22(1), 40-67.
- Wong, J. P., Chan, K. B. K., Boi-Doku, R., & McWatt, S. (2012). Risk discourse and sexual stigma: Barriers to STI testing, treatment and care among young heterosexual women in disadvantaged neighbourhoods in Toronto. *The Canadian Journal of Human Sexuality*, 21(2), 75-89.
- World Health Organization. (2019, June 14). *Sexually Transmitted Infections (STIs)*.
World Health Organization Newsroom. [https://www.who.int/news-room/fact-sheets/detail/sexually-transmitted-infections-\(stis\)](https://www.who.int/news-room/fact-sheets/detail/sexually-transmitted-infections-(stis))

Appendix A – Interview Guide

Demographic Questions

1. To start with, can you tell me a bit about yourself?

[Probes: How would you describe your gender? Sexual orientation? Race or ethnicity? Age?]

2. What made you interested in participating in this research?

Main Questions

1. What was your experience of finding out you had a STI?
 - a. How did you find out? How long ago?
 - b. Did you have any knowledge about STIs prior to this?
 - c. How do you feel medical professionals handled your situation?
 - d. How did you feel when you first found out? How do you feel now?

2. Do you feel your STI status impacts you at all? If so, how? (daily life, relationships, etc.)
 - a. Follow up – do you think having a STI impacts how you think about yourself? If so, how? If not, why not?
 - b. What are some of the personal challenges you face living with a STI?
 - c. Did this impact your relationship with your body?
 - d. Has this changed over time?

3. Who knows about your STI status? What made you choose to tell them and not others?
 - a. How have they responded? Have your disclosures generally been more positive or negative?
 - b. How do you want people to see you once you've disclosed?
 - c. How do you disclose? What information do you tell people when you tell them about your STI?

4. How does your STI status come into play within your past or current romantic or sexual relationships?
 - a. Are you currently in a romantic relationship(s)? If so, how do you
 - b. How does your STI status impact casual dating/sex?
 - c. Has living with a STI impacted your attitudes towards sex?

5. Does your STI status come into play within your friendships or relationships with family members? How so?
 - a. Do friends/family know about your diagnosis? How did they react?

6. Have there ever been times where you have felt or experienced stigma because of your STI? Where do you think this stigma comes from?
 - a. Are there any stereotypes about having a STI that you feel you have to overcome?
7. Do you seek any forms of support regarding your STI?
 - a. What do you get from having these supports in your life?
 - b. Are there ways you feel unsupported?
 - c. Are there other supports you wish you had available to you?
 - d. Do you know other people in your life with the same STI? How does this make you feel?
8. Is there anything related to living with a chronic STI that you are still working through or trying to overcome?
 - a. Are there any worries you still have about your STI status?
9. Are there any positive outcomes or ‘silver linings’ of living with a STI?
 - a. What do you wish more people would know about your STI or your experiences as a person living with a chronic STI?

Closing Questions

1. Was there anything that surprised you about the interview today?
2. Were there any questions or topics that you thought we’d talk about that we didn’t discuss?
3. Any final thoughts you would like to share with me before we wrap up?