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Original Research

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Experiences of African American Women Living With Herpes Simplex Virus 2

Cherlisa Jackson, PhD

Walden University, Minneapolis, Minnesota, United States

Yitza Arcelay-Rojas, EdD

Walden University, Minneapolis, Minnesota, United States https://orcid.org/0000-0002-7558-3111

Contact: cherlisa.jackson@waldenu.edu

Abstract

In the United States, the prevalence of herpes simplex virus 2 (HSV-2) continues to be the highest among African American women. Yet the perceived benefit of discussing sexual health, as well as recognizing a need to discuss HSV-2 with a health-care provider, is a gap in research. The purpose of this interpretive qualitative study was to understand the experiences of African American women who received an asymptomatic HSV-2 diagnosis. Semistructured interviews of seven participants were used to explore the experiences of African American women diagnosed with HSV-2, including barriers and challenges of discussing HSV-2 with health-care providers. Participants highlighted that a decrease in condom use arises when emotional commitment is established, and a lower perception of the severity of disease occurs when controlling symptoms with medication is understood and communicated. Results from the study also highlighted that not all participants preferred African American health-care providers, and participants were pleased that sexual partners were supportive of their diagnosis disclosures. African American women and their corresponding providers could benefit from sexual health education initiatives that address this information, as well as the results from this study.

Keywords: genital herpes, herpes simplex virus type 2, HSV-2, African American women, African American, African American female, Black, Black women, health education, health promotion, qualitative study

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Introduction

Genital herpes or HSV type 2 (HSV-2) has no cure, and it is the second more prevalent sexually transmitted infection (STI) in the United States (CDC, 2021c). HSV-2 is an infection spread by having vaginal, anal, or oral sex with someone who has the disease (CDC, 2017b; CDC, 2021a). A person can become infected when being in contact with herpes lesions; however HSV-2 also can be present on the skin even if there are no sores. If a person has contact with the virus on an infected person's skin, they can become infected (CDC, 2021a). It can

be transmitted through contact with saliva, genital secretions, contact with skin in the oral area, or contact with skin in the genital area if the partner has the infection (CDC, 2021a). Pregnant women are tested for HSV-2 because they can spread the infection to their babies, and it could be life-threatening to their newborn (CDC, 2017a; CDC 2021a). Genital herpes also increases the risk of getting HIV when exposed to it (CDC, 2017a; CDC 2021a).

African Americans are more likely to be infected by STIs, including HSV-2, than other demographics (CDC, 2017b, 2020, 2021b; Institute for Quality and Efficiency in Health Care, 2018). The latest statistical report on HSV-2 in the United States by the National Center for Health Statistics reveals that the overall prevalence for African Americans is the highest in the nation (CDC, 2021a; McQuillan et al., 2018). These statistics revealed that HSV-2 prevalence was highest among non-Hispanic Black persons (34.6%), followed by Mexican American (9.4%), non-Hispanic White (8.1%), and was lowest among non-Hispanic Asian persons (3.8%). The report also showed that among all ethnic groups, the prevalence was higher among female individuals (15.9%) than male individuals (8.2%) (CDC, 2021a; McQuillan et al., 2018). Women are more susceptible to infection during penile—vaginal sex because their mucous membranes are possibly more sensitive (CDC, 2021a; Institute for Quality and Efficiency in Health Care, 2018). Furthermore, the CDC (2017b) reported a nearly 50% HSV-2 seroprevalence among African American women—the most affected group with the highest HSV-2 prevalence in the nation. According to the CDC (2016), biological factors might increase women's susceptibility to STIs, and "racial disparities in HSV-2 infection are likely perpetuated because of the higher prevalence of infection within African American communities, placing African Americans at greater risk of being exposed to herpes with any given sexual encounter" (CDC, 2016, p.2).

The National Center for HIV, Viral Hepatitis, STD, and TB Prevention *AtlasPlus* database from the Centers for Disease Control and Prevention (2019) ranks Georgia among the first five states with more African American women's STI cases. Within the State of Georgia, the total number of STI cases reported in 2019 was 94,978, of which African Americans made up 60% (56,700) of the cases (Georgia Department of Public Health, 2021). This is an increase in STI cases in African Americans from 51% in 2018 to 60% in 2019 (Georgia Department of Public Health, 2021). The same statistics revealed that African American women represented 29,807 (53%) cases. The most recent available data outlined that the total number of STI cases reported during the time span of 1998–2019 has yielded over 1,433,033 cases and over 747,374 (52%) were reported for African Americans (Georgia Department of Public Health, 2021). Further, African American women represented 436,896 (59%) of the total cases among African Americans (Georgia Department of Public Health, 2021). These rates for Georgia support the prevalence and increase in STI infections among female African Americans (CDC, 2019; CDC, 2020; Georgia Department of Health, 2019; Henderson, 2015), which is why we focused on this state in this study.

African Americans often perceive that there are minimal treatments and cures for diseases, mistrust the health-care field, lack necessary knowledge for adequate decisions pertaining to health, and might not understand the level of risk that necessitates health screenings and interventions (CDC, 2021b; Hoffman et al., 2016; Pellowski et al., 2017; Wells & Gowda, 2020). When individuals believe an illness can be harmful enough to place them at risk, their likelihood of taking action to prevent it is high (Boslaugh, 2019), especially if the individual believes in the success and benefits of prevention (Green et al., 2020). The CDC (2021a) advises that patients have open conversations with their health-care providers about their sexual history; however, those discussions are often avoided due to a historical mistrust of health-care providers (Bronson & Nuriddin, 2014; Hoffman et al., 2016; Pellowski et al., 2017; Wells & Gowda, 2020) and a discomfort initiating conversations with health-care providers (Fray & Caldwell, 2017; Hagiwara et al., 2017; Shen et al., 2018). Female patients may also value emotional safety over disease prevention, thus avoiding HSV-2 discussions that could increase awareness (Bobrow, 2016). Other potential influential factors that could hinder prevention of STIs include lack of protective behaviors to preserve sexual relationships, lack of condom use when women want to establish trust in relationships, and African American culture influences regarding casual sex without

condoms (Andrasik et al., 2014; Bowleg et al., 2021; Broaddus et al., 2016; Caldwell & Mathews, 2015; Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020; Konkle-Parker et al., 2018; Wilson et al., 2014).

Although research has identified a significant disparity regarding the seroprevalence of HSV-2 among African American women (CDC 2017b; CDC 2020; CDC, 2021a; Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020; Operario et al., 2015), most studies have focused on HSV-2 comorbidity with gonorrhea, chlamydia, and HIV (McQuillan et al., 2018; Operario et al., 2015), with limited focus on HSV-2 lived experiences (Hendry, 2017; N'Diaye, 2014). Researchers have also highlighted that African Americans are likely to receive an HSV-2 diagnosis by a certain age and have comorbidity with other STIs (Kelly et al., 2016; Patel et al., 2016). There is a need to understand African Americans' knowledge and perceptions regarding protective behaviors for STI prevention and effective decision-making (CDC, 2021b; Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020). Therefore, exploring their lived experiences could offer insights into the context of their HSV-2 risk (Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020; Hoffman et al., 2016). Few researchers have focused on the perceived benefit of discussing sexual health with sexual partners or the need to discuss HSV-2 with a health-care provider (Fray & Caldwell, 2017; Royer et al., 2013). To fill this gap, we explored the overall perspectives African American women have about HSV-2, their personal understanding of STIs, experiences of an asymptomatic diagnosis of HSV-2, their perceptions of susceptibility to complications and comorbid infections directly associated with a diagnosis of HSV-2, and barriers they experienced regarding discussing HSV-2 with health-care providers.

Methods

Participants

We collected data within a geographical range, which was narrowed to only include the county in Georgia that had the highest number of STI cases. The Online Analytical Statistical Information System (OASIS), a database from the Georgia Department of Public Health (2021), was used to determine STI incidence in each county. We purposively selected Fulton County because it is the area of Georgia that reported more STI cases (16,175) for all races and the highest percentage of cases (18%) in African American persons in 2019 (Georgia Department of Public Health, 2021). For this interpretive qualitative study, we selected a purposive sample of women previously tested for HSV-2 with an asymptomatic diagnosis. The inclusion criteria were being African American; biological sex as a female; ages 18–59; living in, or diagnosed in, Fulton County, GA; and having received the results of the HSV-2 test.

We recruited the participants through local community-based organizations to which we provided a flyer to distribute. Data were collected through individual face-to-face virtual interviews with those who agreed to participate in this study. We obtained demographics regarding age, annual income, ethnicity, and employment status. Recruitment efforts were concluded after we interviewed seven participants.

To achieve adequate sampling based on the quality of the data, we used the concept of information power to guide our sampling. As defined by Malterud and colleagues (2016), information power states that "the more information the sample holds, relevant for the actual study, the lower amount of participants is needed" (p. 1). Information power is incorporated to achieve adequate sampling and quality in the data for studies that are interpretive in nature. The use of information power works best if the aim of the study is narrow with sample specificity and when the interview dialogue is robust yielding substantial narratives (Malterud et al., 2016). In this study, we incorporated sample specificity using specific participant selection criteria, and the interviewer provided participants the opportunity to promote an honest discussion of their experiences to allow for follow-up questions. Throughout the interviews, we implemented reflective listening to clarify researcher comprehension. At the end of all interviews, we performed an interpersonal process recall by reviewing the transcribed responses with the participants to illuminate any discrepancies with researcher interpretation.

Procedures

We emailed a recruitment flyer with the IRB approval number of 02-13-20-0387264 to lead community outreach liaisons for Atlanta-Metro community-based organizations. Potential participants had the opportunity to ask any questions they had about the study prior to being interviewed, and appointments for interviews were set up only after participants had reviewed the informed consent and indicated their willingness to be part of the study. We used the interview guide (see Appendix A for a list of interview questions) to align and maintain the focus on the research questions. We conducted the semistructured interviews virtually through a telehealth platform for video conferencing called Doxy.me. This platform requires the researcher to sign in and provide a unique link sent to each participant prior to the interview. Upon clicking the link, the participant is placed into a virtual waiting room only visible to the researcher. The duration of the interviews ranged from 45 to 60 minutes. We reviewed the content of all interviews multiple times to guarantee accuracy. Interviews were transcribed into separate Google Docs, a Google version of Microsoft Word, and we manually coded all interviews into Google Sheets, a Google version of Microsoft Excel.

Analysis

We used open codes, categories, and thematic analysis to scrutinize the interview transcripts. To see the layers of authenticity about the ideas expressed and ground the findings, the data analysis for this study was iterative and recursive. A journal was kept for field notes and all audio software. We reviewed transcripts and began coding at a low level, paying close attention to themes with no patterns. Using Google Sheets with the research questions in mind, we generated codes. We completed the coding in two documented cycles. After identifying common themes, codes were categorized into five main emergent themes. Table 1 presents an alignment of the research questions with the emergent themes.

Table 1. Emergent Themes Aligned With Research Questions

Research questions	Emergent themes
RQ1: What is the experience of herpes simplex virus 2 (HSV-2) for	Health risk perceptions
African American females, ages 18–59, living in, or diagnosed in, Fulton County, GA, who were asymptomatic prior to being diagnosed?	Prevention methods
	Feelings related to stigma and acceptance
<i>RQ2</i> : What barriers and challenges do African American females, ages 18–59, living in, or diagnosed in, Fulton County, GA experience during conversations with health-care providers about HSV-2?	Frustrations with testing Fear of judgment by health-care providers

Results

All participants identified as biologically born a female with no racial or ethnic identifiers other than African American. Most (four of seven participants) were between the ages of 33–51, and most (five participants) completed a master's degree. All participants were employed. Five participants (71%) reported an annual income of \$50,000–\$64,999. An equal number of participants reported dating (three participants, 43%) and being single. Table 2 displays sociodemographic data of all participants.

Table 2. Description of Participants' Demographics

Participant	Age	Level of School	Marital Status	
P1	34	Master's degree	Single	
P2	51	Master's degree	Divorced	
Р3	44	Master's degree	Single	
P4	33	Master's degree	Single	
P5	43	Master's degree	Dating	
P6	45	Some college	Dating	
P7	41	Doctoral degree	Dating	

The findings are organized into five main themes. These themes emerged from the coding and grouping of codes into categories. The first three themes correspond to the first research question related to exploring the experiences during and after being diagnosed: (a) health risk perceptions, (b) prevention methods, and (c) feelings related to stigma and acceptance. The themes (a) frustrations with testing and (b) fear of judgment by health-care providers correspond to the second research question related to challenges and barriers.

Theme 1: Health Risk Perceptions

The participants shared their perception of health risks and evaluated the diagnosis of previous STIs. Except for P4, all participants reported never considering the existence of HSV-2 prior to diagnosis. P4 responded that she knew she had a higher chance because of the commonality on her college campus and her previous STI history. P6 stated that it can happen "when you're not fully educated on what your partner has." P2, P3, and P5 reported that they were in monogamous relationships at the time of diagnosis and experienced infidelity. When asked if a previous STI determines receiving another, P2 responded, "Just because you encounter one thing does not mean you will encounter something else." P3 also spoke against inevitability and advocated, "I hope it would help someone think twice about sexual health."

Regarding perceptions of symptoms and complications, P1 called the diagnosis "the quiet one," with similar emphasis by P3, P5, P6, and P7 advising of its asymptomatic nature and dormancy. P4, P6, and P7 described the modalities for transmission as oral, vaginal, and anal sex, with P2 and P3 reporting that during pregnancy, "You can pass it to your baby." When directly asked about the signs and symptoms of HSV-2, all participants reported outbreaks and itching. P3 indicated "low-grade fever and back pain" coupled with instances reported by P7 of "pain in the lower back," alongside "pain while urinating, pain in the legs," and typically warning signs of the impending onset. Regarding possible sexual health complications, P2, P4, P6, and P7 stated that they were not aware of any complications. The likelihood of additional STIs in the future was mentioned by P4, and the possibility to pass it through childbirth was advised by P3 and P5. Risk reduction was discussed by P1 and P2, who reported abstinence during outbreaks, and P2 additionally mentioned the facilitation of medication as treatment.

Participants' perceptions of testing were also observed. P7 advised that annual testing is important "the younger you are and the more partners you have." P4 reported, "The body goes through changes as we get older. In a year, you may have only had a few partners, but if those partners have partners, the risks go up." P2 relayed that if she was not pregnant at the time, she would not have known her diagnosis. P1 emphasized that annual testing applies to those who are less sexually active, but everyone else should test every 3 to 6 months. P6 stated that annual HSV-2 testing is not necessary but did mention, alongside all other participants, the importance of testing for other STIs annually. P7 detailed, "I get tested when I go to my doctor, I have them run everything. We need to follow up with the PCP [primary care provider]." P3 also mentioned, "Annually,

women get that" when discussing testing by a health-care provider, and added, "Men don't do that unless that's a part of their yearly check-up." P5 enforced, "Even in a monogamous relationship, the only person you know what's happening with is yourself. You can't depend on someone else to take care of you. Their results are not your results."

In terms of susceptibility and risk, P5 stated that the modality or type of sexual activity places people at risk and "not necessarily the sexual preference." P5 further commented on the types of sexual activity, stating that "biological women who only have sex with other biological women are less likely than any other group to pass HSV-2 to each other based upon the mode of transmission." P7 reported, "I was about 26 or 27 when I actively started dating women," and defended that there is "a stereotype that lesbians do not have sexual risk." P1 also stated that "probably through heterosexual sex" is where higher risk is integrated into receiving or transmitting HSV-2. P4 elaborated by stating, "Most of us in my social circle, we have partners without relationships. The dating scene is set up to where people have multiple partners and often without condoms." P2 and P6 expressed that a previous or existing STI is not connected to experiencing another one. P1 advised of its inevitability, even in relationships. P7 proclaimed that HSV-2 lesions are direct sites for infection, which creates higher susceptibility, and P4 stated that the immune system is affected. P5 added that:

[I]t increases your chances because, more often than not, STDs [sexually transmitted diseases] do not have signs and symptoms that people can see. If you already have one and do not know that leaves you more open to something else, just based upon the nature of STDs.

All participants stated that African Americans are disproportionately affected by all STIs. P4 claimed, "The heavier hit STDs are HSV, HIV, and chlamydia." P2 advised that not only are African Americans at risk, but without the use of condoms, every racial group and ethnicity can experience STIs. When asked about beliefs regarding financial stability as a connection to HSV-2, both P2 and P7 believed this to be true. P2 stated, "If you're in a lower income level—especially now that people are out of work—women and men when you need money, you need money. Which means that you may do whatever you can to get it." P7 emphasized there are "disparities around income and the access to income. Females that do not go to the doctor put people at greater risk. Young adults are at greater risk from lack of resources, information, and prevention." Though the financial viewpoint of P7 indicated that there are disparities around income and the access to it, P1 suggested, "finances are not a big factor in how you pursue sexual relationships." P5 advised, "I don't believe how much money you make determines whether or not you would receive the infection. However, those with privilege may feel nothing will happen to them, sexually."

Theme 2: Prevention Methods

The participants discussed their perceptions and experiences regarding condom negotiation. Some participants mentioned that negotiation often happens in the beginning of a sexual relationship and if the partner seems unsafe. Other participants emphasized that negotiation would not take place when commitment is established if there is discomfort in having the discussion, if unprotected sex is enjoyed, and if they do not know how to negotiate. For instance, P2 narrated:

Growing up, sex was something that happened to a woman, and [she was] not responsible for it. It was something done to the woman not something she negotiated. My family members did not enjoy sex because they didn't know they could.

Both P1 and P4 advocated that both men and women need forms of protection. P4 stated, "Women should carry [male] condoms, and men should check on women using birth control." Similarly, P1 expressed, "we both need to have our own." P2 and P5 reported that they negotiate condoms, and both reported that it is a challenge but is necessary. In the practice of condom negotiation, P6 reported she uses condoms "in the beginning" but not once a commitment is established. P1 advised that her first encounter with removing a

condom resulted in contracting HSV-2 and she has since become celibate. P7 reported that she only negotiates condoms with men, and P3 reported a male condom latex allergy and often does not use condoms. P7 also mentioned that she will negotiate condoms if she cares about the person and will advise of the potential risks of unprotected sex.

Theme 3: Feelings Related to Stigma and Acceptance

Though all participants reported feeling acceptance at this time, immediately after the diagnosis there were feelings of hurt, regret, and shame. P2 and P6 both reported being pregnant at the time. P2 mentioned that she was married, and P4 stated she received it after a one-time encounter. Both P5 and P7 advised that they do not recall the source, and another participant stated that she received the diagnosis after sexual assault. But all participants advised that they have evolved beyond the initial feelings of being diagnosed. P5, P6, and P7 reported assumptions that future partners would shun them but have all received supportive responses that people still wanted to engage in romantic and sexual relationships. P5 mentioned, "My apprehension and fear was that my partners would be distraught, but I happened to have very understanding partners." P4 stated that she was 21 years old at the time and does not currently think about it. P6 mirrored P4, stating that she does not think about it daily and is currently in a relationship. However, P1 mentioned, "Relationships? I desire them but am not pursuing them. Because of having to have that conversation with someone who may not really be a safe place to have that, so I have avoided that." P2 said her diagnosis was more than 20 years ago and led to divorcing her husband:

There are times when I still struggle. I have accepted it for me. I am very thankful I met a man I could tell and he was accepting of it. I have girlfriends that have it. They date people and don't tell. I don't agree with that. It wasn't my choice to get it, so we should give others the option to say no. A lot of rejection comes from it which deepened that depression. Which is why most women do not share. The right thing to do is share. Something was put on me that I did not ask for. I am in a better place. It's a part of me now in terms of medical history. There's still a certain level of shame.

P4 added, "My thing is, I do not want to expose him at all. I did tell him from the beginning and made it his choice to go forward. I'm okay. I guess because I am in a relationship." P7 explained:

It definitely can be triggering when with a new partner. It makes oral sex complicated in a lesbian relationship. It's always interesting. I have almost 95% of the time gotten a positive response that it's not a baby and it's not AIDS. Talking about it is always uncomfortable.

All participants have talked about their diagnosis with someone within their trusted circle of friends, relatives, pastors, and therapists. P2 and P4 reported that unless sexual activity is happening, disclosures are withheld. P5 and P6 reported that disclosure only occurs with an exclusive commitment. P4 reported, "there is a 50% chance that I will tell" but mentioned that this step only happens if feeling emotionally safe and not feeling judged.

In response to notifying partners about the diagnosis prior to sexual activity—even without signs and symptoms—P7 reported, "I have other health conditions," so she discloses for reciprocated emotional wellness. P5 declared, "Both of us are obligated to take responsibility." P3 also indicated that she always opts for disclosure even without signs and symptoms. Sharing STIs annual results was reported as important for P2 and that she likes to give advance notice of any outbreaks. In response to addressing the likelihood for disclosure, P1 advised, "I want you to be sure," when elaborating that she wants anyone romantically and sexually interested in her to have the choice to choose a sexual relationship. P7 also stated, "I don't want to be responsible for you catching it," so she chooses to always disclose. P7 additionally said, "I don't need to discuss often" due to a regimen that suppresses outbreaks. In addressing the likelihood for diagnosis disclosure—even without signs and symptoms—P1 reported that she chooses to remain celibate to avoid

consistent explanations. P5 advised that disclosure is unlikely without commitment, and P6 reported "never" when asked.

Further, all participants indicated that there is a shared responsibility among them and their partners in protecting against STIs. P6 said that she now requests to see the test results of a partner, stating: "In the relationship I am in now, we see the sheets." P2, P5, and P6 all advocated against having their partners feel the negative emotion they personally felt after diagnosis. For instance, P6 advised, "I never want for anyone to go through what I have gone through. It is important for me to tell my partners. I don't want to put anybody in the position that I was in." Sharing similar views of other participants, P7 affirmed:

The price is really high for willful ignorance. We need to take care of our bodies and have challenging conversations that we can feel healthy about—lighthearted about—versus avoiding discomfort and then having a higher price to pay down the line or more turmoil.

A final response related to this theme is the role of religion in feeling stigma or acceptance. Apart from P3 and P6, all other participants felt religion is connected to sexual health perceptions. P1 stated:

For me, that has impacted how I pursue sex. The dark cloud hangs over you that says don't do it before marriage; it's a sin and you're going to burn in hell. For a long time, I thought that my diagnosis was a repercussion of not keeping my temple. A lot of mental anguish around that just because things that come from people in the ministry, or your own interpretation of the scripture.

Additional sentiments from P2 included, "I was having sex with a man at 23 and felt guilty that we were not married." P7 stated about religious beliefs, "Masturbation is a sin. Fornication is a sin. Just talking about it or having an option is considered punishment." P7 further elaborated, "The thing that shifted for me in college was God as punishing and God as wrathful [with vengeance]. I had to shed a wrathful, vengeful God to a loving, nurturing God." P4 reported, "[With] my religious background, we never talked about sexual health education. Me not having that safe space, or feeling shameful, I did sex how I wanted without proper information." Likewise, P5 expressed, "There is a certain level of shame attached to sexuality, and lack of sexual health education." P7 concurred that religion perpetuates a negative stigma and stated that, with religion, "there is something inherently wrong with any kind of sexuality. I think that pervades our society." P6 proclaimed, "There is a stigma it only happens to people who are loose or promiscuous." Further, P1 and P7 also emphasized that sexual education focuses on the symptomology of STIs and could perpetuate stigmatization. P7 clarified:

They were trying to scare kids with those terrible pictures... made me feel ashamed. "My body don't look like that." But if I tell people [I have HSV-2], that's what they are going to think my body looks like.

Theme 4: Frustration With Testing

All participants expressed frustration receiving an asymptomatic diagnosis. Further clarity in the responses outlined that the absence of symptomology and adequate prevention knowledge often placed barriers between them and early detection. Except for P5, all other participants had never been offered an HSV-2 test. P5 explained that "once" she "received an entire panel." Counter to the other participants, P5 and P7 stated that they were retested postdiagnosis. P5 advised, "I wanted to see what my titer for HSV-2 was. When I asked for it originally, they asked, 'Why?' I told them I felt I was exposed. Then they went ahead and tested me." She expressed frustration at only being offered HSV-2 testing one time in nearly 3 decades. The participants expressed questions on the testing process and when it should be requested. These feelings of frustration reflect these participants' need to understand testing guidelines and more education regarding recommendations about testing or retesting as well. P7 stated:

I have asked them to test for it and do visuals. I don't remember my diagnosis. I don't remember if it was a blood test, visual examining, or skin samples. I have asked before, particularly with active outbreaks, and they are reluctant to do any more than just look. Mine are so mild that it is not always visible to the eye. I can feel it and I can see it, because I know what the rest of my body looks like. I think I was in grad school the last time I got tested for everything at a public health clinic. I was shaping what communication and disclosure would look like.

All participants reported that before an HSV-2 diagnosis, testing for it or other STIs was never personally requested and that they were unaware of the exhaustive list of STIs to request. In probing further, participants expressed that before an HSV-2 diagnosis, they were unaware that all STIs are not automatically screened.

Theme 5: Fear of Judgment by Health-Care Providers

Participants often perceived judgment when discussing with health-care providers in the past, which often determined their level of engagement and discussion facilitation, in addition to their comfort level and perception of support received. In responding to possible outcomes or consequences when discussing HSV-2 with a health-care provider, P1, P4, P5, and P7 expressed varying levels of discomfort. P7 spoke to feelings of judgment:

I feel like speaking with the doctor is always a real concern. Moving through the world and presenting to the world as young, Black, unmarried—and you don't wear your degrees on your shirt. I've been treated like I'm a little crazy. Some of it is the lack of patient compassion and care. Particularly in Black and Brown communities. The absence of that is hard... interacting with doctors about sexual health. I have one primary doctor during my pregnancy that made me feel easy and light about it, and everyone else was pretty critical.

P4 affirmed, "I don't think there would be any direct issues. There is an uncomfortable question of why I need the test. It goes back to judgement." P2 similarly mentioned "Most physicians would look at you puzzled and ask more probing questions about why you need it. Most of this is due to stigma." P3 stated that she was not aware of any outcomes or consequences speaking with a health-care provider regarding questions about HSV-2, whereas P6 stated, "you just get more educated." P1 advised:

If you're not strong or confident, your mental health could suffer, just feeling that you have no outlet. I don't know any doctor right now that I would feel comfortable having the conversation with. It feels like a don't ask, don't tell situation.

P4 reported that, postdiagnosis, she decreased its priority to cope with the incurability, stating, "If I didn't feel I wasn't showing any symptoms, I didn't ask. I would not want it to be a priority. It's easier to stomach something you can manage rather than something you cannot get rid of." P3 also spoke to the discomfort and replied that she only mentions the diagnosis in the medical questionnaire on the intake form. P2 verified, "I was never tested again. I didn't think I could ask [them] to test me again." P6 also stated, "I did not know 13 years ago" that she could make that request.

All participants were asked about their comfort level discussing HSV-2 and other STIs with a health-care professional who is not African American. P5 reported, "I do it because I have to but not because I am comfortable with it. And this is just my experience. I have been to doctors and had conversations with them about it. I have felt judged." P6 similarly shared discomfort and mentioned, "My gynecologist is African American. Most times, it is whomever is available, but my preference is African American." P7 also verified discomfort, stating, "I don't, but I'll do it anyway."

Though some participants expressed preference for African American health-care providers, others were in opposition. P4 reported:

I felt comfortable with my White experiences. There was no connection, so I did not care what they thought. When someone is Black, it makes me feel like my aunt or my grandmother is talking to me, and I feel judged and shamed.

P7 expressed preference for someone African American but also stated:

I had to go to an internist who was an old White man, specifically about HSV during pregnancy, and I was like, "Really?" He was super-duper clinical and research-based in his approach. I appreciate expertise, but this is all very personal too.

P3 admitted, "I have had an African American male and an Indian woman but no White person just yet. I wouldn't have any issue." P1 expressed uncertainty about her comfort level, mentioning, "I haven't broached the subject. My therapist is Caucasian, and I felt comfortable that things would not leave the room, but I don't have that same feeling with a medical provider." P2 exclaimed, "The best gynecologist I ever had was a White woman," which was similar to P7, stating, "The one that made me feel comfortable was White—a White woman." P2 further mentioned, "I received a lot of knowledge about what I need to do, and she taught me how to ask more questions. I have mostly gone to Black women for gynecological services, and my most recent experience was not good."

Discussion

All participants in this study expressed a fear of judgment when discussing HSV-2 with a partner. They also mentioned that sexual health discussions are important; however, they expressed discomfort in discussing the onset of outbreaks, even in an established commitment. Previous studies have also shown the belief that discussing an HSV-2 diagnosis would violate trust and discourage longevity (Bobrow, 2016; Royer et al., 2013). In prediagnosis all participants expressed valuing monogamy more than preventing disease; however, in postdiagnosis, all participants reported facilitating sexual health discussions as a part of their emotional safety. Despite apprehension explaining the diagnosis to others, of the six participants who chose to have a sexual health discussion with new partners postdiagnosis, all participants reported feeling empowered to disclose, and four expressed feeling positively surprised with the support received from partners. In addition to conversations with partners, the participants expressed that they remove condoms when in a perceived monogamous commitment. This is similar to what other studies have found, where African American women have expressed that they may also be less likely to use condoms when perceived to be in a committed relationship (Andrasik et al., 2014; Bowleg et al., 2021; Broaddus et al., 2016; Caldwell & Mathews, 2015; Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020; Konkle-Parker et al., 2018). Sexual health education interventions could provide guidance on navigating the negative stigma of HSV-2 by encouraging disclosure conversations and by focusing on condom attitudes and condom negotiation behaviors (Bowleg et al., 2021; Broaddus et al., 2016; CDC, 2017a).

Discussions with health-care providers are important, even when patients are asymptomatic. Health-care providers choose STI tests based on the patient's sexual behaviors and on how common the infection is in the area where the patient lives (CDC, 2017a; CDC, 2021a). Women typically rely on the presence of HSV-2 symptoms to initiate discussions with health-care providers, but the reliance on symptomology delays action (Royer et al., 2013). Honest conversations with health-care providers are indispensable because they designate STI tests based on the sexual behaviors of the individual. Therefore, patients are expected to begin the discussion (CDC, 2017a; CDC, 2021a). African Americans often do not initiate the conversation because of feelings of discomfort with starting sexual health discussions (Fray & Caldwell, 2017; Hagiwara et al., 2017;

Shen et al., 2018). Similarly, the participants of this study expressed concern on how to initiate the conversation with their health providers and how to request testing. P4 reported that without a person showing any symptoms, discussions about HSV-2 with her health-care providers do not occur. Whereas P5 said she was met with suspicion and reported feeling judged for her inquiry to be tested.

African American men and women have higher rates of some STIs, including HSV-2 and HIV, than other racial or ethnic groups (CDC, 2021b). However, prior to diagnosis, all participants reported that conversations about STIs never came up during annual exams, regardless of the potential for risk, such as age or race, and they never knew to personally request more testing. Although HSV-2 might be considered an infection that does not cause serious outcomes, except to babies, it also increases the risk of getting HIV when exposed to it (CDC, 2017a; CDC 2021a). Testing is recommended particularly for at-risk populations with high infections rates (CDC, 2017a). African American women have a high risk of getting HSV-2 (CDC, 2017b; CDC, 2021a; McQuillan et al., 2018) and increased likelihood of comorbidity with HIV (CDC, 2021b; Operario et al., 2015).

All participants reported feeling ill-informed and misinformed about the asymptomatic nature possible for any STI and would have preferred adequate knowledge for prevention against HSV-2. In probing further, participants expressed that prior to an HSV-2 diagnosis, they were unaware that all STIs are not automatically screened and often made the presumption that within a relationship or established sexual commitment an annual exam was unnecessary.

Another barrier to sexual health conversations is fear of seeming uneducated. The findings from this current study outline that the lack of prevention knowledge or health literacy is not an automatic association with a lack of general knowledge or formal education. All participants had some college education or master or doctoral degree. P7 emphasized that being Black and unmarried with HSV-2 often has health-care providers judge that she is uneducated, which leads to discomfort in building rapport and hinders open communication. Lack of health literacy could be a barrier to open communication with health providers (Davis et al., 2019; Muvuka et al., 2020; Weekes, 2012). Limitations in health literacy are first experienced within family dynamics (Hovick et al., 2015) and then perpetuated with effects of post-slavery that are often dismissed in Westernized culture (Cooper, 2015). P2 highlighted that she learned from the women in her family that sex happens to a woman, and until receiving HSV-2 from her husband she was unaware that sexual health discussions with anyone were possible.

Another potential barrier to health provider discussions is the race of the provider. Research has outlined that when African Americans have health-care providers who are not African American, this can result in suspicion of their behaviors and thus a strong disbelief that those health-care providers will support their worldviews (Penner et al., 2017). Most participants desired an African American health-care provider but often accepted who was available. Other participants preferred someone of a different race or culture because there was perceived to be less shame. One participant reported shame speaking with African American health-care providers because it feels like an aunt or a grandmother. Three participants reported that they prefer someone African American but are often supplied with whoever is available. Though a preference for African American health-care providers was expressed by most participants, the other participants were open to other experiences, which have already yielded more discretion, empathy, professionalism, and connection.

Building awareness and seeking treatment relate to self-care and confidence in discussing an HSV-2 diagnosis (N'Diaye, 2014). All participants reported that they made the decision to build self-care and understand the diagnosis to make informed and confident sexual decisions. The level of confidence to act and prevent a disease is the cornerstone of self-efficacy, which is increased when feeling competent and appreciated (Skinner et al., 2015; Unis et al., 2015). Women with higher self-esteem have personal empowerment connected to healthier sexual decisions (Alexander et al., 2015). One participant explained that she lives in a house full of women that exude a positive sense of self, which keeps her aware of her own self-esteem. Additional participants expressed that in the absence of judgment when discussing the diagnosis, they would

be likely to maintain a positive sense of self when discussing it in the future. All participants expressed feeling more empowered postdiagnosis to lead sexual health discussions with partners. Further, two participants reported participating in mental health interventions postdiagnosis; three participants reported growing spiritual wellness, such as strengthening spirituality to manage wellness. Building sexual self-worth after an HSV-2 diagnosis is possible, and if adequate education on symptomology and prevention is provided, the result could be more confidence to act toward prevention, an increase in informed sexual decisions, and a better comprehension of sexual health (N'Diaye, 2014; Royer et al., 2013).

Implications and Recommendations

Having prevention knowledge is not an automatic correlation with better sexual decisions, but it can steer the conversation toward awareness (Fray & Caldwell, 2017). All participants, regardless of STI history, reported awareness of condoms and how condoms prevent the spread of HSV-2, but their decisions to not use condoms occurred when a commitment was established. The preservation of established relationships has also been shown in previous research as more important than STI prevention (Andrasik et al., 2014; Bowleg et al., 2021; Broaddus et al., 2016; Caldwell & Mathews, 2015; Crooks, King & Tluczek, 2020; Crooks, Wise & Frazier, 2020; Konkle-Parker et al., 2018). Condoms are rarely used when women are seeking to establish trust in relationships despite it being a method of risk-reduction for the transmission of HSV-2 (Caldwell & Mathews, 2015; Magaret et al., 2016).

There is no evidence that diagnosing HSV-2 with a blood test for asymptomatic individuals would change sexual behaviors to stop the virus, creating uncertainty that testing everyone would stop the spread (CDC, 2015; CDC, 2017a). However, testing information could encourage the patient's conversation with their health-care provider by asking questions about sexual health. These conversations might allow the health professional to educate the patient about what to expect in the future, which medications are available to help manage any symptoms, and how to lower the risk of spreading the infection. Conversations with health-care providers about sexual health need to be improved. They often exclude suggestions about HSV-2 (U.S. Preventive Services Task Force, 2016) and do not address the historical mistrust and discomfort that African Americans could feel for health-care providers (Bronson & Nurridin, 2014; Fray & Caldwell, 2017; Hagiwara et al., 2017; Shen et al., 2018; Wells & Gowda, 2020). Further, reliance solely on symptomology delays the cue to act (Nwankwo, 2014; Royer et al., 2013), and all participants expressed that prior to receiving a diagnosis while asymptomatic they felt no urgency to understand HSV-2 prevention.

The sense of seriousness about a disease can affect the cue to act toward prevention (Skinner et al., 2015). Actions to protect against a disease happen when individuals understand the severity, comprehend their vulnerability, acknowledge barriers and benefits, and can facilitate the techniques and resources for protection against it (Boslaugh, 2019; Tarkang & Zotor, 2015). Diagnosis is not necessarily a motivator for practicing safer sex (CDC, 2017a; Royer et al., 2013), but it is an opportunity for health-care providers to educate about STIs, including explaining HSV-2 testing guidelines for at-risk individuals.

In this study, we focused on the exploration of attitudes and beliefs that African American women hold of their susceptibility and severity to HSV-2. The implications of this study suggest that it is important to understand cultural sensitivity and cultural awareness when engaging with African American women. This understanding can provide comprehension for health-care professionals about the unique obstacles for African American women and emphasize the higher susceptibility to STIs and the absence of being tested. This study emphasizes the necessity for health messaging that speaks to the susceptibility of African Americans and the likelihood of comorbidity of HSV-2 and other STIs. This study may encourage the creation of health education programs that target educating patients on the necessity for engaging in prevention measures against transmission or contraction of HSV-2. Group discussions could be developed including the following topics promoting awareness of HSV-2: (a) How serious it is, and for whom; (b) race, gender, and a

lack of condoms (HSV-2 barriers); (c) stigmatized and silent (Should you have the talk?); (d) the confidence to prevent; (e) testing guidelines; and (f) relying on symptomology (unknowingly asymptomatic).

Future quantitative and qualitative studies, such as case studies, could be conducted to explore interventions that could guide health educators in formulating strategies and techniques that can decrease the stigma connected to discussing an HSV-2 diagnosis. Quantitative research that explores the connection between health-care professionals and patients when discussing STIs and healthier sexual decisions could also provide important insights into these issues.

Limitations of the Study

The results of this study can only describe the experiences of participants and cannot be generalized to the greater African American population. Though information power was reached with seven participants, the study consisted of a purposive sample in which the participants were chosen with inclusion criteria that lacks generalizability. Transferability was strengthened by the thick and descriptive language to provide comparison in other contexts; however, the variables outside of race, age, and geographical location could affect the overall outcome. Though these inclusion criteria present a challenge for generalizability, the results of this study helped to provide a voice to experiences of the African American women who participated in this study.

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Appendix A: Interview Questions

- A. What do you know about Herpes Simplex Virus-2?
- B. What are the symptoms and signs of HSV-2?
- C. What possible sexual health complications are you aware of that accompany HSV-2?
- D. Are you aware that HSV-2 can be transmitted and contracted without showing or having any signs or symptoms? Please explain.
- E. Have you ever negotiated condoms with your partner? Describe your experience.
- F. How likely are you to discuss HSV-2 with a partner even when no signs or symptoms are present?
- G. Have you told any partners after your diagnosis about the diagnosis before engaging in sexual activity, even if no signs or symptoms were present?
- H. Prior to diagnosis, did you feel you would ever become infected with HSV-2? Why or why not?
- I. After diagnosis, do you believe you can become infected with another STD or STI? Why or why not?
- J. What sexually transmitted diseases (STDs) and infections (STIs) affect African Americans?
- K. Do you believe females are more infected with HSV-2? Why or why not?
- L. Do you believe financial stability has anything to do with receiving or passing HSV-2? Why or why
- M. Do you believe religion has anything to do with receiving or passing HSV-2? Why or why not?
- N. Is a current or previous STD or STI a factor in whether an African American has an STD or STI?
- O. Do you believe you and your sexual partner(s) have a responsibility in protecting yourselves against STI's and STD's? Why or why not?
- P. How important is it to be tested annually for STDs and STIs?
- Q. Have you ever asked your healthcare provider to be tested for HSV-2, even if you did not have any symptoms? If so, describe your experience.
- R. Have you ever been offered an HSV-2 test by your healthcare provider, even if you did not have any symptoms?
- S. What might be the consequences or outcomes of speaking with a healthcare provider if you have concerns or questions about HSV-2?
- T. Do you feel comfortable or comforted speaking with a healthcare provider who is not African American regarding HSV-2 and other STDs and STIs? Why or why not?



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