Coping Strategies and Behavioral Changes Following a Genital Herpes Diagnosis Among an Urban Sample of Underserved Midwestern Women

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Abstract

Background: This study focused on understanding the coping strategies and related behavioral changes of women who were recently diagnosed with Herpes Simplex Virus Type 2 (HSV-2). In particular, we were interested in how coping strategies, condom use, and acyclovir uptake evolve over time.

Methods: Twenty-eight women screening positive for HSV-2 were recruited through a public health STD clinic and the Indianapolis Community Court. Participants completed three semi-structured interviews with a female researcher over a six-month period. The interviews focused on coping strategies for dealing with a diagnosis, frequency of condom use, suppressive and episodic acyclovir use, and the utilization of HSV-2 support groups. Interview data were analyzed using content analysis to identify and interpret concepts and themes that emerged from the interviews.

Results: Women employed a variety of coping strategies following an HSV-2 diagnosis. 32% of women reported an increase in religious activities, 20% of women reported an increase in substance use, and 56% of women reported engaging in other coping activities. 80% of women reported abstaining from sex immediately following the diagnosis, but 76% of women reported engaging in sex again by the six-month interview. Condom and medication use did not increase and HSV-2 support groups were not utilized by participants.

Conclusions: All participants reported engaging in at least one coping mechanism after receiving their diagnosis. A positive diagnosis did not seem to result in increased use of condoms for the majority of participants and the use of acyclovir was low overall.

Introduction

Herpes Simplex Virus Type 2 (HSV-2) is an extremely common sexually transmitted infection. The age-adjusted seroprevalence rate in the United States is 17.0%, with women having a seroprevalence rate almost double that of men (men 11.2% & women 23.1%).[1] The majority of people infected with HSV-2 experience no symptoms and thus may be unaware of their infection, despite shedding virus and potentially transmitting HSV-2 unintentionally to their sexual partners.[2] Diagnosis and treatment of HSV-2 infection is important given its association with increased susceptibility to other STIs, including HIV.[3-5] By expanding access to HSV-2 serological testing, community-level prevalence could be reduced, as asymptomatic individuals who know their serostatus may take measures to decrease the probability of transmission to uninfected partners through suppressive therapy, condom use and avoiding sexual contact during outbreaks.[6]

Previous research indicates that condom use can reduce the transmission of HSV-2.[7, 8] However, the extent to which a person changes their condom use behaviors after learning of their HSV-2 diagnosis is less known. The use of daily suppressive acyclovir also reduces asymptomatic viral shedding and transmission.[9-11] Acyclovir could be a useful tool in reducing HSV-2 transmission, but due to the difficulty in taking the medication regularly, it is not clear which women would be willing to use it.

A diagnosis of HSV-2 can be psychologically distressing; particularly for persons who have never experienced symptoms and are unaware they are seropositive.[12, 13]

However, severe, lasting negative emotional effects generally have not been found to be associated with an HSV-2 diagnosis.[14-17] Understanding women's coping strategies after receiving an HSV-2 diagnosis is necessary for the development of evidence-based resources for HSV-2 positive individuals. For example, HSV-2 support groups have been established in many areas in the US and may serve as a useful coping mechanism for individuals recently diagnosed with HSV-2.

The purpose of this study was to better understand the coping strategies and related behavioral changes of women who were recently diagnosed with HSV-2. We were interested in how coping strategies, condom use, and acyclovir uptake evolve over time. Findings from this study will provide increased understanding about coping mechanisms used by HSV-2 positive patients and may be informative for clinicians providing care to these patients.

Materials and Methods

Settings

From October 2009-June 2010, women screening positive for HSV-2 were recruited through two different venues: an STD clinic (Bell Flower Clinic) and the Indianapolis Community Court. Two of the most common charges among women at community court include prostitution and public intoxication. Because of the STI-risk associated with commercial sex and substance abuse, particular outreach efforts have been made to increase access to STI care for this population.[18] A few women had previously experienced HSV-2 symptoms, such as blisters or itching, but the majority of women

were asymptomatic prior to testing. Some women developed HSV-2 symptoms post-diagnosis.

Recruitment

Individuals attending the STD clinic were offered an HSV-2 serology test for a $30 fee.[19] Female defendants from the community court were offered no-cost HSV-2 serologic testing.[20] Fourteen women were enrolled from the STD clinic and fourteen were enrolled from community court. Participants recruited from both locations were given 90-day prescriptions for acyclovir and referred to their primary care physician for follow-up.

Procedures

Participants at both locations were female, 18 years of age or older and spoke English fluently. They completed three hour-long, face-to-face, semi-structured interviews with a female researcher. The first interview was conducted within two weeks of receiving an HSV-2 diagnosis. The second interview occurred 4-7 weeks later, and the final interview occurred approximately 6 months after diagnosis. The interviews explored how receiving an HSV-2 diagnosis affected participants' mental health and health behaviors over time. Items were grouped into 4 key domains including: coping strategies for dealing with a diagnosis, frequency of condom use, suppressive and episodic acyclovir use, and the utilization of HSV-2 support groups. Table 1 provides a list of key domains and related exemplar items to elicit participant response. During the interviews, participants were provided basic educational information about HSV-2, including how HSV-2 is transmitted, the use of condoms and daily suppressive therapy in reducing

transmission, and the management of symptoms. All participants were compensated with a $40 gift card upon completion of each interview. The institutional review board at Indiana University approved the study, and each participant provided written informed consent.

Analysis

We focused on changes in women's attitudes and behaviors over time. Because interviews were individually tailored, not every participant was asked about their experience with each domain at all three time points. To conduct our analyses, we organized the transcripts in chronological order by participant and read the transcripts of each participant one-by-one, which allowed us to focus on factors related to change at the individual-level. This strategy is recommended by Saldaña for analyzing qualitative data for change over time.[21] We included data from women for whom there was a response to key items in two or more of the interviews for each domain. Of the 28 enrolled, 3 were excluded because they completed only one interview.

Data from this study were analyzed using content analysis to identify and interpret concepts and themes that emerged from the interviews.[22] This method involved multiple readings of transcripts and analytical induction via open and axial coding of data using NVivo software (version 10, Doncaster, Australia) to thematically organize transcripts. To describe the sample, descriptive analyses were conducted. To assess behavioral change over time for sexual behavior, condom use, and acyclovir use, repeated

measures ANOVA was used. All quantitative analyses were conducted using SPSS statistical software (version 21, Durham, NC).

Results

Participants

In total, 25 women completed more than one interview and were included in the analyses (15 black, 9 white, 1 American Indian). Participant ages ranged from 21-61 years (median, 38 years; IQR = 33-47 years). Most participants reported engaging in sexual behaviors with male partners only (88%; n=22). Of the 13 women recruited from community court, 5 reported previous involvement in exchanging sex for money or living needs. . There were no statistically significant differences in recruitment group composition by race or age. However, women recruited from the community court were significantly more likely to be unemployed (p=.03), have lower educational attainment (p=.03), and report exchanging sex for money or living needs (p=.02).

Coping Strategies for dealing with an HSV-2 diagnosis

Women employed a variety of coping strategies following an HSV-2 diagnosis. Most women expressed initial shock and psychological distress. (*"Oh my god, it felt like a nightmare. It was the worst day of my life."*) Women were most concerned about how they had contracted HSV-2 and that HSV-2 could not be cured. Women reported engaging in a variety of behaviors to cope with their diagnosis, including an increase in religious activities, reaching out to friends or family for support and an increase in consumption of alcohol and drugs. Below we explore each coping strategy in detail.

The role of religion & spirituality

For some women (32%, n=8), their diagnosis caused them to increase the frequency of prayer and religious service attendance. Participants stated that spiritual activities helped them alleviate feelings of guilt (*"I went to church and felt relief. I got to clear my conscience for a little while, and I felt like that was important because I needed that."*), better understand what happened (*"I just prayed about it for the most part. Sometimes I just try to get an understanding of what happened."*) and receive support (*"I pray a lot, and if I miss going to church, wherever I am I stop to pray. Lord, help me deal with this."*).

Information seeking, staying busy, and social support

Fifty-six percent of women (n=14) reported engaging in other activities to help themselves cope with their diagnosis (*"I do tasks or listen to the radio, find music that I can sing along with. If I'm at home, I find a conversation to have with my kids and forget about it."*), receive support (*"I've got a couple of really good friends I talk to and they're telling me life's not over, you can still have meaningful relationships with people."*) or find out more information ("*I've read the brochures on it and tried to get some information about how it came about, what you do to treat it, when not to have sexual intercourse and stuff like that."*)

The role of substance use

Nearly 20% of women mentioned an increase in alcohol and drug use following their HSV-2 diagnosis. Reports of alcohol and drug use were similar between participants recruited from community court (n=3) and the STD clinic (n=2). Participants stated the substance use helped them forget about their diagnosis (*"I drink, smoke marijuana, try to forget about it."*), or feel better (*"Weed, wine, whatever I feel is best at that time. More drugs, more prescriptions, NyQuil, anything to just make me sleep or make me feel better, that's what I do."*).

Coping over time

Coping behaviors seemed to be more important for women at the initial interview than at the last interview, which indicates the need for coping mechanisms may decrease as time progresses and women adjust to their diagnosis. Interestingly, although women engaged in a variety of coping mechanisms, none of the participants reported an interest in attending support groups for people diagnosed with HSV-2, even though participants were given extensive information about a local group.

Preventing transmission to partners: Sexual activity

In addition to examining coping methods, we examined women's sexual behavior, condom use and medication use over time. There was a significant increase in the number of women reporting sexual activity over time ($F(1, 20) = 22$, $p \leq 0.01$, $\eta^2 = .524$). The majority of women (80%; n=20) reported abstaining from sex immediately after their diagnosis. However, as time progressed, most women reinitiated sexual relationships. By the six-month interview, 76% of respondents had engaged in sexual behavior again.

We use narrative data from one participant to illustrate this progression. At the first interview, one woman stated, *"I'm having the trust issue, and I feel like maybe I want to [have sex], but I just can't bring myself to right now. I'm not on that level yet. There's just so many things that I have to iron out before I even go there."* In an interview weeks later, she said, *"We've not been intimate yet. We're sticking to the dating process…sort of like starting over. We do a lot of kissing like we did when we were first dating. It's working out."* Six months later, she reported, *"Yes, we have [had sex]. In the beginning, it was rough. Now, we have become closer. There's more communication."* This process was similar across participants. Thus, in this sample, it does not appear that there were long-term negative effects on the women's sexual lives.

Preventing transmission to partners: Condom use

A few women reported an increase in condom use immediately following their diagnosis, but this change was inconsistent over time ($F(1, 18) = .321$, $p=0.58$, $\eta^2=.018$). Women who reported an increase in condom use stated that their diagnosis had made them more cautious, *"Now I'm very cautious about not spreading it… I make that my first priority. I know there are still other diseases like HIV and AIDS. I don't want to die, so it's a must that I use condoms."* However, most women reported no change in condom use. Several were already in long-term monogamous relationships in which they did not use condoms because they suspected their partner had already contracted HSV-2 (*"No, we don't use protection. I know we should, but me and him don't use protection 'cause I feel it's already too late."*). Some women stated that their sexual partners didn't want to use condoms, even though they knew the woman had HSV-2 (*"It's complicated. They*

know that I have it, but they don't want to use condoms… they act like it don't phase them."). Thus, patient and partner knowledge of seroprevalence status alone was not sufficient to increase condom use.

Preventing transmission to partners: Acyclovir use

Medication use was low overall; 13 reported initiating treatment and uptake did not increase over time ($F(1, 20) = .656$, $p=0.43$, $\eta^2=.032$). Some participants reported they were not aware their prescriptions would run out after 3 months, *"I felt like ya'll should have said that after three months you're not getting suppressive therapy anymore. I didn't know. I'm thinking, shit, if you're diagnosed with it, they're gonna give it to you until you stop needing it."* In Indianapolis, the cost for a 30-day regimen of suppressive therapy (400mg twice per day) ranged from $35.88 USD to $125 USD without health insurance (personal communication with pharmacy technicians at Kroger, Marsh, CVS, Kmart and Walmart in Indianapolis, IN). Some participants reported cost to be a barrier and found it a hardship to pay for medication. For example, a participant receiving Medicaid stated, *"I have a three dollar co-pay, and I don't have three dollars, but I got to come up with something. I got to get it filled so I can start feeling better. I am willing to go through the treatment and the things I have to do to have normal living."*

Others assumed that medication was only necessary for an outbreak and didn't realize they would be shedding virus and potentially transmitting HSV-2 to sexual partners. (*"I still have not went to get the medicine because I don't feel that I really have any symptoms."*) Reportedly, this erroneous belief was validated by their primary physicians,

"My doctor said just to see, and if I have another break out, she'll put me on it, but I haven't had one." Several participants also expressed resistance to taking pills two times a day every day, *"I hate taking pills. I don't want to take those pills every day."* Given the lack of financial resources to maintain a lifetime of suppressive therapy, limited physician support and the daily dosage regimen, acyclovir may not be an effective tool in preventing HSV-2 transmission, especially among asymptomatic women of low socio-economic status.

Discussion

Our study results suggest that an HSV-2 diagnosis results in short-term behavioral changes for many women. This study adds a unique contribution to the literature because of its 3-time-point longitudinal qualitative design that enabled an in-depth exploration of participants' behavioral changes, including how women cope with an HSV-2 diagnosis, as well as condom and medication use. Additionally, this study provides some insight into differences between two high-risk groups, those recruited from a clinical setting and those receiving community based testing.

Most women expressed initial shock and psychological distress. However, as in other studies, this distress waned over time.[14, 23] A large proportion (32%) of participants increased religious activities. While further research would be needed to explore the role of religiosity post-HSV-2 diagnosis, it is possible that religious organizations could be a mechanism for engaging women in care. Women also reported an increase in the consumption of alcohol and drugs (20%). A majority of women (56%) reported engaging

in other types of coping behaviors, such as talking with family and friends, writing poems, listening to music or working. Despite being given information about a local HSV-2 support group, no participants attended. This study indicates that most women engage in healthy behaviors to cope with their HSV-2 diagnosis, but some women may need additional support to refrain from negative coping mechanisms.

Most participants did not report a change in condom usage following their HSV-2 diagnosis. This study found that HSV-2 positive individuals in long-term partnerships may not feel the need to use condoms. In fact, some men reportedly did not want to use condoms, even when they knew their female partner was HSV-2 positive. Given the role condoms play in reducing the transmission of HSV-2, further research should be conducted to determine ways to increase condom use among HSV-2 positive individuals and their sexual partners.

Medication use was low. Most participants showed little interest in taking acyclovir and felt it was only necessary for outbreaks. This belief was supported by their primary care physicians. A number of participants expressed difficulty in obtaining acyclovir due to a lack of financial resources. This set of findings indicates a need for additional education and for services that make acyclovir more accessible to high-risk populations.[18, 19]

Our findings are limited by the fact that this was a small, exploratory study of women residing in one city in the Midwestern United States. The majority of our sample participants were low income and their experiences may not be generalizable to women

from more privileged backgrounds. Research should be conducted among women recently diagnosed with HSV-2 in a private practice. Additionally, 40% of women were symptomatic. This is much higher than the literature reports (10-25%).[24] Further exploration may be needed to see how symptomatic versus asymptomatic women react and the potential types of resources they may need. Furthermore, we relied on self-reported experiences and behaviors provided by participants. Given the nature of face-to-face interviews, social desirability reporting may have occurred. Women in this study were only followed for six-months, so it is unclear how an HSV-2 diagnosis affects women over a longer time period. However, we interviewed women at regular intervals, and even with our small sample size, we were still able to detect trends.

In sum, all participants reported engaging in at least one, if not several, coping mechanisms after receiving their diagnosis, both adaptive and maladaptive. A positive diagnosis did not result in increased condom use for the majority of participants and the use of acyclovir was low overall. For this sample, additional resources would be needed to provide women with acyclovir for long-term suppressive therapy. In addition, there is a need for educational interventions regarding viral shedding, the value of condom use, and strategies to enhance adherence to suppressive medication. No participant was interested in attending an HSV-2 support group. Additional studies to identify alternative support resources for HSV-2 patients would be useful. While it may seem counterintuitive, our findings suggest partnering with church services may be one potential recruitment and service provision venue.

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Conflict of Interest: BVDP reports receiving consulting and honoraria, not related to this work, from BD Diagnostics, Cepheid, Melinta, Rheonix and Roche Molecular Diagnostics.

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Table 1:

Table 1: Key Domains	
Domain	*Exemplar Item*
Coping strategies	*"How are you dealing with being diagnosed with herpes?"* *"If it bothers you, what do you do to help stop thinking about it?"*
Sexual activity	*"How has your diagnosis affected your intimate relationships?"* *"Do you feel your sex life is different now than it was before the diagnosis?"*
Condom use	*"When do you use condoms with your partner?"* *"Have you altered your condom use since this diagnosis?"*
Use of acyclovir	*"Are you planning to take medication for HSV-2?"* *"Have you been using suppressive therapy? How often do you use it?"*
Support groups	*"Would you be interested in attending a herpes support group? Why or why not?"*

Table 2:

Table 2: Demographic Characteristics by Recruitment Location			
	Community Court N=13 N (%)	**STD Clinic** N=12 N (%)	*Sig.*
Race			.57
African American	7 (54%)	8 (67%)	
White	5 (38%)	4 (33%)	
American Indian	1 (8%)	0 (0%)	
Age			.85
18-39 years	7 (54%)	6 (50%)	
40 years and older	6 (46%)	6 (50%)	
Homeless	3 (23%)	0 (0%)	.08
History of transactional sex	5 (38%)	0 (0%)	***.02***
Employment	2 (15%)	7 (58%)	***.03***
Educational Attainment			***.03***
High School or less	10 (77%)	4 (33%)	
Some college or higher	3 (23%)	8 (67%)	
Symptoms			.51
Symptomatic	6 (46%)	4 (33%)	
Asymptomatic	7 (54%)	8 (67%)	