

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

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This is the author's manuscript of the article published in final edited form as:

Davis, A., Roth, A., Brand, J. E., Zimet, G. D., & Pol, B. V. D. (2016). Coping strategies and behavioural changes following a genital herpes diagnosis among an urban sample of underserved Midwestern women. *International Journal of STD & AIDS*, 27(3), 207–212. <http://doi.org/10.1177/0956462415578955>

1 **Abstract**

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

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

13 **Results:** Women employed a variety of coping strategies following an HSV-2 diagnosis.  
14 32% of women reported an increase in religious activities, 20% of women reported an  
15 increase in substance use, and 56% of women reported engaging in other coping  
16 activities. 80% of women reported abstaining from sex immediately following the  
17 diagnosis, but 76% of women reported engaging in sex again by the six-month interview.  
18 Condom and medication use did not increase and HSV-2 support groups were not  
19 utilized by participants.

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

23

24 **Introduction**

25 Herpes Simplex Virus Type 2 (HSV-2) is an extremely common sexually transmitted  
26 infection. The age-adjusted seroprevalence rate in the United States is 17.0%, with  
27 women having a seroprevalence rate almost double that of men (men 11.2% & women  
28 23.1%).<sup>1</sup> The majority of people infected with HSV-2 experience no symptoms and thus  
29 may be unaware of their infection, despite shedding virus and potentially transmitting  
30 HSV-2 unintentionally to their sexual partners.<sup>2</sup> Diagnosis and treatment of HSV-2  
31 infection is important given its association with increased susceptibility to other STIs,  
32 including HIV.<sup>3-5</sup> By expanding access to HSV-2 serological testing, community-level  
33 prevalence could be reduced, as asymptomatic individuals who know their serostatus  
34 may take measures to decrease the probability of transmission to uninfected partners  
35 through suppressive therapy, condom use and avoiding sexual contact during  
36 outbreaks.<sup>6</sup>

37

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

44

45 A diagnosis of HSV-2 can be psychologically distressing; particularly for persons who  
46 have never experienced symptoms and are unaware they are seropositive.<sup>12, 13</sup>

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

53  
54 The purpose of this study was to better understand the coping strategies and related  
55 behavioral changes of women who were recently diagnosed with HSV-2. We were  
56 interested in how coping strategies, condom use, and acyclovir uptake evolve over time.  
57 Findings from this study will provide increased understanding about coping mechanisms  
58 used by HSV-2 positive patients and may be informative for clinicians providing care to  
59 these patients.

## 60 61 **Materials and Methods**

### 62 Settings

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

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

72

### 73 Recruitment

74 Individuals attending the STD clinic were offered an HSV-2 serology test for a \$30 fee.<sup>19</sup>

75 Female defendants from the community court were offered no-cost HSV-2 serologic  
76 testing.<sup>20</sup> Fourteen women were enrolled from the STD clinic and fourteen were enrolled  
77 from community court. Participants recruited from both locations were given 90-day  
78 prescriptions for acyclovir and referred to their primary care physician for follow-up.

79

### 80 Procedures

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

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

97

### 98 Analysis

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

108

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

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

117

## 118 **Results**

### 119 Participants

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

129

### 130 Coping Strategies for dealing with an HSV-2 diagnosis

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

138

139 *The role of religion & spirituality*

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

148

149 *Information seeking, staying busy, and social support*

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

158

159 *The role of substance use*



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

167

#### 168 Coping over time

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

175

#### 176 Preventing transmission to partners: Sexual activity

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

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

193

#### 194 *Preventing transmission to partners: Condom use*

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

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

209

#### 210 *Preventing transmission to partners: Acyclovir use*

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

224

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

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

236

## 237 **Discussion**

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

245

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

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

257  
258 Most participants did not report a change in condom usage following their HSV-2  
259 diagnosis. This study found that HSV-2 positive individuals in long-term partnerships  
260 may not feel the need to use condoms. In fact, some men reportedly did not want to use  
261 condoms, even when they knew their female partner was HSV-2 positive. Given the role  
262 condoms play in reducing the transmission of HSV-2, further research should be  
263 conducted to determine ways to increase condom use among HSV-2 positive  
264 individuals and their sexual partners.

265  
266 Medication use was low. Most participants showed little interest in taking acyclovir and  
267 felt it was only necessary for outbreaks. This belief was supported by their primary care  
268 physicians. A number of participants expressed difficulty in obtaining acyclovir due to a  
269 lack of financial resources. This set of findings indicates a need for additional education  
270 and for services that make acyclovir more accessible to high-risk populations.<sup>18, 19</sup>

271  
272 Our findings are limited by the fact that this was a small, exploratory study of women  
273 residing in one city in the Midwestern United States. The majority of our sample  
274 participants were low income and their experiences may not be generalizable to women

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

285  
286 In sum, all participants reported engaging in at least one, if not several, coping  
287 mechanisms after receiving their diagnosis, both adaptive and maladaptive. A positive  
288 diagnosis did not result in increased condom use for the majority of participants and the  
289 use of acyclovir was low overall. For this sample, additional resources would be needed  
290 to provide women with acyclovir for long-term suppressive therapy. In addition, there is  
291 a need for educational interventions regarding viral shedding, the value of condom use,  
292 and strategies to enhance adherence to suppressive medication. No participant was  
293 interested in attending an HSV-2 support group. Additional studies to identify alternative  
294 support resources for HSV-2 patients would be useful. While it may seem  
295 counterintuitive, our findings suggest partnering with church services may be one  
296 potential recruitment and service provision venue.

297

298 **Acknowledgments:** The authors would like to thank the participants, the Community  
299 Court of Indianapolis, and the Marion County Health Department for their invaluable  
300 support in conducting this study.

301

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

305

306 **Source of Funding:** Funding for this study was provided by the Center for Translational  
307 Science Institute (CTSI), Indiana University Purdue University Indianapolis and NIDA  
308 T32 DA 023356.

309

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376

377

**Table 1:**

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

**Table 2:**

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