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Special Edition

"HIV-related Stigma across
the Lifespan"

Brief Research

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Perceptions of HIV-Associated Stigma in the U.S. Virgin Islands

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ABSTRACT

Introduction: The U.S. Virgin Islands (USVI) has one of the highest HIV rates in the U.S. to date. In order to understand the high prevalence of HIV, it is important to identify the factors that contribute to HIV, especially those with relevance to the specific culture of the USVI.

Aim and Methods: Quantitative surveys and qualitative in-depth interviews were conducted to examine the socio-cultural factors that contribute to the high rates of HIV in the USVI. The study included a sample size of 52 participants, including community members, healthcare providers, and people living with HIV. The purpose of this secondary analysis was to identify the stigmas about HIV that persist in the USVI.

Results: Qualitative analysis of in-depth interviews using NVivo software (version 10) found that the most prevalent stigma was the *Fear of Gossip and Being Labeled* by the community. This stigma referred to the fear of being labeled as HIV-positive or gossiped about if an individual had been seen near an HIV-related health facility. Others types of stigma included: *Fear of HIV; Invincibility and Appearance; Preferred Ignorance and Denial; Cultural Resistance to Change; Sexual Expectations Based on Gender or Age; Resistance to Condoms or other Contraceptive Use; and <i>Prejudice against members of the LGBTQA+ Community.*

Conclusions/Implications: Several different categories of stigma were identified and the results show that the stigma surrounding HIV in the USVI is not limited to one overarching stigma. A possible implication of HIV/AIDS-related stigmas are that they may discourage those who are HIV positive from getting treatment or disclosing their HIV status to sexual partners. These results also have implications for HIV prevention and HIV care in the USVI and similar areas.

KEYWORDS: HIV; Stigma; Communities.

ABBREVIATIONS: WHO: World Health Organization; IRB: Institutional Review Board; CAPI: Computer Assisted Personal Interview; ACASI: Audio-Computer Assisted Personal Interview; QDS: Questionnaire Development System; SPSS: Statistical Package for the Social Sciences.

INTRODUCTION

For over a decade, the U.S. Virgin Islands (USVI) has consistently had one of the highest per capita prevalence rates of HIV infection in the nation, despite a total population of only approximately 110,000. By the end of 2014, the USVI was ranked as having the third highest

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rate of people living with HIV/AIDS in the US.¹ HIV-related stigma is among one of the socio-cultural factors that may help explain these high rates due to serving as a barrier to HIV testing and disclosure. According to the Joint United Nations Program on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), HIV/AIDS-related stigma is a barrier is to treat HIV and there is a need for research that provides better conceptual and operational definitions of stigma and that identifies different types of HIV/AIDS-related stigmas.^{2,3} Past research in the Caribbean region also identified stigma as a barrier to accessing HIV care,⁴ but few published studies have been conducted in the USVI. The purpose of this research study was to explore the perceptions of HIV/AIDS-related stigma and identify the most common stigmas in the USVI.

LITERATURE REVIEW

Review of relevant literature and past studies regarding HIV related stigma demonstrate the issues regarding stigma as a barrier to care. Studies confirmed the presence of a strong stigma in the Caribbean Basin and the USVI related to sexual health, as well as in other geographic locations across the United States including Illinois, Missouri, Wisconsin, Kansas, Michigan, Arizona, New York, and Texas. The literature suggested that those most affected by the HIV stigma included communities of color and women.

A study conducted in the Carribean Basin⁴ analyzed surveillance data from nearly 7 million residents in relation to AIDS and HIV. In that study, the concept of stigma was described by one study participant saying "Everybody on this island knows everybody else, and if someone sees you go to the part of the health department where they do the HIV test, by the end of the day every soul from Christiansted to Frederiksted and from one end of the island to the other is saying that you have AIDS". This stigma that was described through this study was shown to have implications in the lives of those who may be engaging in sexual activity, as "the consequence is that few people seek out voluntary testing".⁴

This reluctance to seek medical care and medical testing was found to be an associated risk behavior and a barrier to safe sex. The article synthesized the surveillance data and from it discovered how the socio-cultural practices and religious taboos in the Caribbean Basin lead to stigma, shame, and denial. This stigma and denial was found to prevent issues such as HIV from being discussed or addressed in the community.⁴

Other studies have further described HIV stigma in the USVI.^{6,8} One created a Community Readiness Model (CRM) which could be used to assess the recognition of stigma and other key data related to HIV.⁸ This study found that such a stigma was prevalent in the Caribbean. A notable quote from a study participant from the study conducted by McCoy, Malow, Thurland and Rosenberg that exposes this stigma explicitly states that "There is a stigma, people think AIDS is a curse, a sin from god;

people think that it won't happen to them. I think we are in denial about the impact of AIDS". Problems in reducing this stigma have also been studied. Through a review of 22 studies that attempted to reduce AIDS stigma, it was found that stigma does not decrease with the increased visibility of HIV in a community. This literature review included studies conducted in places other than the USVI and Caribbean region, which indicated that other communities in differing geographical locations have experienced the negative effects of the stigma related to HIV. In addition, the results from the study suggest that other methods than simply increased visibility of the disease must be taken in order to reduce the effects of stigma in a community where HIV stigma is prevalent.

Another research study created an HIV/AIDS stigma scale that assessed the stigmatizations experienced by those with HIV. This study included 19.6% African-Americans and 8% Hispanics as part of the primarily male sample. This study found 4 factors that contributed to stigma: personalized stigma, disclosure concerns, negative self-images, and concern with public attitudes towards people with HIV. These 4 themes were found to be correlated with depression and feelings of guilt or shame, which have consequences for the mental health and quality of life for those living with HIV. This study also showed that communities of color other than those in the Caribbean have been affected by the stigmas surrounding HIV.⁵

This impact of AIDS and HIV on African-American women was also examined in 2 prior research studies.^{7,9} One focused primarily on childbearing women, and revealed that women in the USVI more frequently reported related to HIV in their families, churches, and communities. This study revealed 6 themes that categorized the data about the women's attitudes to HIV and the impact of the disease.⁹ Another qualitative study focusing on women of color described social stigmas and their relations to culture and women.⁷ The findings of this study suggest that by "integration of services to include confidentiality" stigma as a barrier to care among African-American women could be reduced.⁷ Both of these studies imply that communities of colored people (especially women) are those who are most affected by the stigmas of HIV.^{7,9}

RESEARCH APPROACH

This mixed methods, but primarily qualitative study, used individual interviews and computerized questionnaires to assess HIV/AIDS-related stigma among residents of the USVI.

Procedures and Sampling

The target population was adult age residents of the USVI. Participants were recruited from the community, the USVI Department of Health (DoH), and local healthcare facilities, using approved study flyers and referrals. Study flyers included a brief description of the study including the purpose, procedures, duration, potential risks and benefits, and study team contact





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information. The flyer also clearly indicated that there was no monetary or non-monetary compensation for participation and that participation was voluntary. Interested people living with HIV contacted project staff by telephone or in person at the DoH to learn more about the study and to indicate their interest in participating. ¹⁰ The project's purpose, procedures, potential risks and benefits were explained over the phone or in person and oral or written consent was obtained from interested participants who met initial eligibility screening.

Eligibility was determined in person or *via* telephone using a brief screening survey. To be eligible, participants had to: (1) be between the ages of 18-65 years; (2) and reside in the USVI during the previous 9 months. Individuals who were not currently residing in the USVI or did not reside in the USVI within the previous 9 months were ineligible. The study protocol was approved by the University Institutional Review Board (IRB) and all participants provided written informed consent prior to participating in the study. A unique study ID number was assigned once consent had been given.

Data Collection

Questionnaires were completed on password-protected laptop computers either using computer assisted personal interview (CAPI) or audio-computer assisted personal interview (ACASI). Both CAPI and ACASI are designed using the Questionnaire Development System (QDS).

Sociodemographics: A 25-item questionnaire was used to assess information regarding each participants age range, educational level, marital status, religious background and practices and HIV testing.

Individual interviews: Individual interviews with participants were conducted using a semi-structured interview guide. Each interview lasted between 30-60 minutes. Interviews were conducted in person by two team members (one to ask questions and one to take notes). Interviews were conducted in a private area at an agreed upon location. Each interview was audio-recorded using a digital recorder and transcribed verbatim by project team members. Participants were asked to use a pseudonym to protect their identity on audio-recordings and transcripts. Team members reviewed transcripts for any transcription or grammatical errors.

Data Management and Analysis

Quantitative data: The principal investigator and trained project team members conducted the analyses using the Statistical Package for the Social Sciences (SPSS) software (IBM SPSS Statistics for Windows, Version 23.0). Alpha level was set at a p<.05. Descriptive statistics were conducted to describe the sample.

Qualitative data: Qualitative analysis was conducted by trained project team staff using NVivo software version 10 (QSR International, Melbourne, Australia). Trained study staff uploaded

and systematically catalogued and stored transcript data in the NVivo 10 qualitative data management and analysis software program for qualitative data analysis. Content and thematic analysis and coding were used to identify themes and sub-themes related to HIV/AIDS-related stigma in the USVI. Each transcript was analyzed as one (grouped) text using constant comparative, thematic line-by-line analysis to identify salient themes. Once an understanding of the overall text was obtained, phrases in the text were highlighted and theme names were assigned to the text. The researchers examined this data line by line, and all-important phrases were labeled with tentative theme names. Analysis of the data included elements or categories within themes. We used a precise definition for each theme in order to enable consistent recognition of when they are present, especially because of the possibility of the theme not being explicitly mentioned by an exact name. This facilitated the development of a coding scheme or structure that was used to code concepts and themes and identify the overall relationship between the codes.11

In the attempt to reduce bias, the coders maintained an audit trail of research activities and decisions and performed member checking by asking some participants to review a list of identified themes that were presented at the community forum in the USVI. Leaders from the Department of Health and an HIV specialist in the USVI were asked to review main themes and provide feedback.

In order for a theme or category to be included, it needed to meet the following criteria: (1) mentioned by 15% or more of participants; and (2) recognized as a problem by each category of participants, including: community members, healthcare providers, and people living with HIV. Using SPSS software and Excel, these categories were further analyzed to identify their relative frequency.

RESULTS AND DISCUSSION

Sample Characteristics

A description of the sample is presented in Table 1. The original sample consisted of 52 participants. Forty-three of these participants completed in-depth interviews and are the focus of this paper. Participants included community members, healthcare providers, and people living with HIV, who resided in the USVI. Participants ages and levels of education varied.

The demographic breakdown of the study participants shows that the majority of the participants were female, and that the majority of them were adults. The largest age group included those participants in mid to late adulthood, with 23.3% of the sample being over the age of 55. Few participants were of high school age or lower, and the highest level of education achieved by the majority of the sample was either having had some college experience (20.9% of participants) or a college degree (44.2%). Participants were nearly equally divided among St. Thomas and St. Croix. The majority of participants (83.7%) described themselves as having had prior HIV testing. Among





Demographics of Participants		%	n
Categories	Community Members/Leaders	55.8%	24
	Health-care Providers	27.9%	12
	People Living with HIV	16.3%	7
Island	St. Thomas	48.8%	21
	St. Croix	51.2%	22
Gender	Female	67.4%	29
	Male	32.6%	14
Age	13-19	11.6%	5
	20-24	16.3%	7
	25-23	16.3%	7
	35-44	16.3%	7
	45-54	16.3%	7
	55+	23.3%	10
Ever had an HIV Test	No	16.3%	7
	Yes	83.7%	36
Level of Education	8 th grade or lower	9.3%	4
	High School	14%	6
	Associate Degree	11.6%	5
	Some College	20.9%	9
	College Graduate	44.2%	19

Table 1: Demographics of participants in this study

the 3 categories described, the majority of participants (55.8%) were community members or community leaders. Health-care providers comprised of 27.9% of the sample, and 16.3% of the sample included people living with HIV (PLHIV).

Qualitative Findings

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Qualitative analysis of the in-depth interviews regarding stigma indicated that there were multiple subcategories of stigma in the USVI. Coding for stigma yielded the following eight types of HIV/AIDS-related stigmas: (1) Fear of Gossip and Labeling; (2) Fear of HIV; (3) Invincibility and Appearance; (4) Preferred Ignorance and Denial; (5) Cultural Resistance to Change; (6) Sexual Expectations Based on Gender or Age; (7) Resistance to Condoms or other Contraceptive Use; and (8) Prejudice against members of the LGBTQA+ Community. The coding frequency for each stigma is presented in Figure 1 and exemplar quotes for each are presented in Table 2.

The primary stigma found was the fear of gossip in the community and labeling, which typically would occur if an individual was seen around an HIV related healthcare facility. This was related to the fear of labeled if seen around an HIV health related facility, a concern for 5% of participants. The stigma was mentioned 59 times, which is nearly twice as much as the 2nd highest stigma. Living in a small, tight-knit community, 24 participants described how unwanted gossip was spread quickly.

Because of this, some participants said that they did not seek out HIV testing because they were worried about others

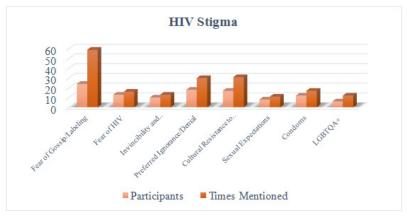


Figure 1: The number of times HIV/AIDS-related stigmas were mentioned.



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Themes and Example Quotes			
Category	Example Quotes		
	"A lot of time people don't want to walk into HOPE's, uh, facility because they know that it's testing for HIV and it's in an area where anybody could see you go through the door." (Healthcare Provider)		
Fear of Gossip and Labeling	"We need something more mobile, where people could really feel more secure about their information. Because from the time you walk into the clinic, everybody's assuming you have some kind of STD or something like that." (Person Living with HIV)		
	"It is a small community and I think they're scared that they will be labeled and if you tell one person that person might tell somebody that person might tell you know so, it's a, it's a fear of being labeled and frowned upon because it's a very small community everybody knows everybody." (Health Provider)		
Fear of HIV	"I think because so many people are just afraid of the disease that they don't want to even talk about it." (Community Member, Female)		
	"UmI feel like the people in the community need to takelike find out about HIV and like not be afraid to talk about it. Because I think like they're afraid to talk about it." (Community Member, Female)		
	"People are too afraid or too proud to get tested and know their status and they judge people on looks, like Ooh! She's hot! She probably doesn't have anything." (Community Member, Male)		
Invincibility and Appearance	"Yeah. And um I've heard people say, 'Oh I'm too black I can't get it,' and then they're positive." (Health-care Provider, Female)		
	"Because in the Virgin, like in the islands people don't really think like they could catch whatever. Like they don't think they could catch HIV, they don't think they could catch AIDS, anything. They just don't. They have like the, I don't want to say like they blind, but they blind to like stuff that everybody else have they eyes open to." (Community Member, Female)		
Preferred Ignorance and Denial	"I can say all the ways of contacting people, and it's like certain people don't want to know their status because it's a kind of scary thing, to know that you have HIV" (Person Living with HIV)		
	"People are afraid to get tested because, because they don't want to know. Um. People feel that it just couldn't happen to them, and I think a big problem here is denial." (Community Member, Male)		
Cultural Resistance to Change	"Um, lack of resources because we tend to be, I would say, ten years behind. Um, any kind of research or um, implementation of uh new measures. It's a very hard culturein reference to change; they don't adapt quickly, like that (audible snapping) to change." (Healthcare Provider, Female)		
	"And um, I come from the perspective of protecting our culture and the environment um, and at the same time being open to change. Um, which we're not at the moment. I think our culture is very important because there are some value systems that we have in place that I don't find on the mainland that I think is beneficial to our, um, our sense of community and growth." (Healthcare Provider, Female)		
	"Um, women don't have a lot of power here, and often end up in relationships for economic reasons, or sugar daddy kind of relationships, or, you know, I know numbers of women who get food, you know, bags of food come in and that's the exchange that she makes." (Healthcare Provider, Female)		
Sexual Expectations Based on Gender or Age	"And, uh, that people practice unsafe sex because many women in this community feel that getting pregnant is a good way to honor or keep a man." (Community Member, Male)		
	"But it was never routinely offered because I guess they feel people our age don't have sex, you know? Um and a lot of the um males on the island have multiple partners and a lot of the older men are with younger women that are prostitutes." (Healthcare Provider, Female)		
	"There's still a lot of um cultural prohibitions around condom use for example, around being honest about our sexual practices including you know multiple partners and um so on." (Healthcare Provider, Female)		
Resistance to Condoms or other Contraceptive Use	"UmmA lot of people think condoms interfere with the feeling or the pleasure of sex. UmmOther people, they think it ruins the mood of the moment. Some people just, you know, like I said before, they're afraid to be seenummpicking them up in the store or at the clinic or whatever. So they don't pick them up. UmmMaybe they're pressured into not using them. Maybe their partner pressures them into not using them or their friends tell them, you know, it feels better without using one so they listen to other people." (Community Member, Male)		
	"Like I told you before, the MSM population that are still in the closet. They, they're not coming out because they might either get killed, or get shunned from the family and what not. They are being judged and what not. So they're going to keep it to themselves and don't tell their partners." (Healthcare Provider)		
Prejudice against members of the LGBTQA+ Community	"Um it's not very progressive about homosexuality. Do you guys know what the word is for a gay man here? "Anti-man". Not like "aunty" but like "anti-man". And kids call each other that on the playground. Um so there's like, um a lot of, you know, this is an island that has already come even close to it having large campaigns to prohibit gay marriage here. It's a very anti-gay place. So that's hard for young men who are gay here, um and I think gay teenagers are having a difficult time with that, because I know of two of them who are HIV-infected and are having trouble negotiating and feeling like they have any power." (Healthcare Provider, Female)		
	"I think that also, um, homophobia is pretty rampant here, so a lot of men don't feel comfortable being in a homosexual relationship, so they'll do it in secret, and sometimes they'll pass on, uh, diseases from that risky sexual behavior to their heterosexual partner." (Community Member, Male)		

Table 2: Quotes from in-depth interviews displaying each category of stigma.

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thinking that they had HIV, simply by being tested. Healthcare providers also mentioned this stigma as being a barrier to care, as some HIV positive patients would not receive care to avoid being seen. Due to the high prevalence of being mentioned by participants, the *fear of gossip and being labeled* was found to be the primary stigma in the USVI and a barrier to healthcare services for HIV.

Fear of HIV or the fear of contracting HIV was mentioned by 13 participants, which was most correlated with a lack of education (which was analyzed using data analysis in primary research in conjunction with stigma).

Invincibility and appearance, is based upon the idea that people who are good-looking, a certain skin color, or religious are unable to contract HIV. Some community members believe that they are "too black" to get HIV. Others are assumed to not have HIV because they are "too good-looking", or consider their religious beliefs to protect them from HIV, despite unsafe sexual practices. While being religious is not based on appearance, it did represent a factor in perceived invincibility. Some community members mentioned that their religious faith could save them from HIV and others believed they could cure themselves of their HIV positive status using forms of black magic or ancient rituals.

Preferred ignorance and denial was mentioned by 18 participants as being a barrier to care. Individuals said that they would rather not know if they were infected with HIV. Health-care providers described this stigma by many who were already found HIV positive choosing to deny their status and thereby resist care or treatments for HIV. Some participants who were HIV positive explained the stigma by saying that it was better for one to ignore their HIV-positive status to avoid being treated differently by family and friends.

The cultural resistance to change stigma is explained by the culture of the USVI being very conservative and resistant to change. This phenomenon is described by previous research as illustrated by a community readiness model, which could be utilized to assess the willingness of a community to accept change. Seventeen participants described how the communities in the USVI were resistant to change based on long-standing cultural practices and societal norms that kept the USVI "10 years behind" other countries, as stated by one participant.

Sexual Expectations Based on Gender or Age

In the USVI there are sexual expectations, primarily for females or the elderly. Females have significantly less power as a societal norm and therefore do not have much ability or say in relationships, such as the ability to convince her sexual partner to wear a condom or be tested for HIV. Men are expected to engage in sexual activity regularly without using a condom, and doing so is an important part of the culture. The lack of female empowerment in the USVI was mentioned as being a barrier to a woman's

ability to decline sexual activity, or convince her sexual partner to use a condom by many participants. The more elderly members of the population are perceived as not engaging in sexual activity, and therefore there is less outreach to get such members of the community tested for HIV as was described by several elderly members of the community. These sexual expectations are embedded in the culture and may be culturally specific to the USVI.

Resistance to Condoms or Other Contraceptive Use

The stigma against condom use was described as being a barrier to safe sex by 12 participants. Younger members of society stated that they did not feel comfortable going out and buying condoms, and it was a common perception that sexual activity "does not feel as good with one". Unprotected sexual activity is widely accepted among members of a younger generation, and the lack of female power in sexual relationships was seen as typically resulting in a woman being unable to convince her partner to use a condom.

Prejudice against Members of the LGBTQA+ Community

Members of the LGBTQA+ community are not accepted and therefore often hide their sexual orientation, making it hard for those who engage in risky sexual behaviors to be identified and treated. Individuals who are not heterosexual may live a "double life" and be married to a partner of the opposite sex, as well as engage in sexual activity with other partners that are hidden from their spouse, which is often risky sexual behavior. This may put themselves and their domestic partner (spouse) who believes he/she is engaging in safe sexual activity at risk for HIV. Because sexual orientation considered deviant in the USVI is hidden, there is an additional barrier for healthcare providers who do not know which members of the population to reach out to in order to give proper education and healthcare services to those who are not heterosexual.

DISCUSSION AND CONCLUSIONS

From secondary data analysis conducted in this study, it was found that HIV related stigma exists in the USVI, which was consistent with several past studies. The data analysis also found that HIV related stigma was a barrier to care, which was consistent with past research. While this study only looked at perceptions on HIV in the USVI, it was found that the results were also consistent with studies conducted in the United States itself, indicating that the results of this study could be generalizable to other geographic locations. The findings of this study further aid current research on stigma by providing a more indepth analysis of the concept within a culture that has a relatively high rate of HIV per capita, which may help with the creation of HIV treatment and education that can target the different stigmas within the USVI or other communities in the future.

Much like the study conducted by Njie-Carr and

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Sharps, multiple aspects of stigma were noted that participants mentioned as being a barrier to care. The eight categories analyzed in this study correlated and overlapped with the four found by Njie-Carr and Sharps, such as their category of *concern with public attitudes towards people with HIV* being very similar to the primary stigma found in this study, which was *fear of gossip and labeling*. The possible implication of this stigma is that community members may choose not to pursue care in order to avoid stigma, which was described by several participants in this study, and in many others. In order to counteract this stigma, increased medical confidentiality in the USVI could reduce the fear of gossip among the community.

A review of 22 studies related to HIV stigma found that other methods than simply increased visibility of the diseases would be needed in order to reduce the effect of stigma as a barrier to care. This result was also seen in this study; the presence of several different categories of stigma as found in this study could mean that a variety of tactics to reduce or eliminate these stigmas would be needed in the USVI and in similar populations.

This study, being comprised of most African-Americans (as is the population of the USVI), found that these communities of color were affected by the HIV stigma. It was also found that there are specific stigmas that mainly affect women, as shown through the category of stigma described as *Sexual Expectations Based on Gender or Age*. As women in USVI have less social status and less social power than the men do, they were shown to be more at risk to be subject to stigma in this specific category than men were. The effects of HIV stigma on women has also been studied through past research, the results of which suggest that women of color are at a higher risk for stigmatization than other populations. ^{7,9} Because of the different ways that men and women are affected by stigma, gender-specific treatment methods may be needed to target specific populations at higher risk than others.

Limitations of this study include that not all participants who completed the survey also completed the in-depth interview. Another limitation is that the community members primarily consisted of young adults, therefore certain stigmas could be more prevalent in the older community members (for example, the socially accepted *prejudice against LGBTQA+members* could be present in a different proportion or strength in the older population than the primarily younger population studied). *Cultural resistance to change* could be another stigma affected by the age discrepancy in the study to the actual population.

Certain stigmas may also have prevented some members from discussing their sexual activity, opinions, or answering questions truthfully. Because the research only studied the USVI, stigmas (especially those based on culture) may not be applicable or generalizable to other populations. Members were primarily African-American (as is the population of the USVI)

so the results may differ among those of other ethnicities in other countries.

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CONFLICTS OF INTEREST

The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be construed as a conflict of interest

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