

# Applying the Social Ecological Model to Explore HIV-Related Stigma in the Southeastern United States: A Qualitative Study

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## Research article

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# Abstract

**Background:** Although evidence suggests HIV-related stigma directly affects health and behaviors, we have a limited understanding of stigma's influence beyond the individual-level. We aimed to describe HIV-related stigma and strategies to reduce it in the Southeastern U.S. within the context of the social ecological model (SEM).

**Methods:** Qualitative surveys were distributed in-person at community events, conferences, and via email to persons affected by HIV periodically over 8 months. The final sample size included 87 participants (33 persons living with HIV, 54 without HIV). A directed content analysis was used to code responses into five levels of the SEM (individual, interpersonal, community, institutional, and structural).

**Results:** Multiple themes emerged within each level: Individual – knowledge, fear, internalization; Interpersonal – social network; Community – judgements, discrimination, community organizations, norms; Institutional – competent providers, healthcare services; and Structural – systemic barriers, language, education.

**Conclusions:** The findings exemplify the need for a multi-level approach to intervene and reduce HIV-related stigma. Based on the experiences and suggestions of people affected by HIV, future interventions should include substantial consideration from persons affected by HIV.

## Background

Despite great progress that has been made over the past decade, the human immunodeficiency virus (HIV) care continuum has not seen remarkable improvement [1]. One reason for this may be due to HIV-related stigma, which has been cited in multiple studies as an impediment to successful HIV care engagement across the continuum [2–4]. In 2018, the Southern United States (U.S.) accounted for approximately 52% of new HIV diagnoses despite making up only 38% of the U.S. population [5, 6]. Although the HIV diagnosis rate in the South (15.7 cases per 100,000) is not drastically higher than the national rate (11.4 per 100,000 people), some Southeastern states (e.g., Florida, Georgia) have diagnosis rates twice that of the national rate [5]. In early 2019, the U.S. Department of Health and Human Services announced a plan to end the HIV epidemic to reduce HIV transmission by 90% by 2030 [7]. This plan targets 48 counties that account for 50% of new HIV diagnoses, 48% of which are Southern states [7, 8]. The plan calls to reduce HIV transmission through early diagnosis, treatment to achieve sustained viral suppression, protection for people at risk for acquiring HIV, and rapid response to HIV outbreaks [7].

HIV-related stigma is conceptualized as a social devaluation associated with persons living with HIV (PLWH) [9]. HIV-related stigma may operate at an individual-level such as: (1) enacted (i.e., stereotyping, discrimination) [10–12], (2) anticipated (i.e., expectations of negative treatment) [10, 13], and (3) internalized stigma (i.e., negative assumptions about one's own character) [10, 14]. Although evidence suggests HIV-related stigma directly affects health and behaviors, we have a limited understanding of stigma's influence beyond the individual-level.

# Conceptual Framework

The conceptual model of this research incorporates concepts from the Social Ecological Model (SEM). The SEM is based on the assumptions that health behaviors are shaped by the interactions across multiple levels of influence (individual, interpersonal, community, institutional, and structural) and can provide a framework for integrating the multiple levels for studying and intervening on HIV-related stigma [15].

The complexity of HIV-related stigma can be attributed not only to its unique differences in cultural and geographical contexts, but also its variations on an individual, interpersonal, community, institutional, and structural level [16]. These differences have led to incongruencies in the definition, assessment, and reduction of HIV-related stigma [16]. This is an important gap in the literature because the SEM suggests that stigma may have a much broader impact beyond the individual-level. As communities consider interventions to address HIV-related stigma, we need more information about what is contributing to stigma, and suggestions to intervene. Community insights on factors associated with HIV-related stigma in the Southeastern U.S. are unknown. To bridge this gap, we sought information to (1) describe experiences and examples of HIV-related stigma and (2) describe strategies to reduce stigma in the Southeastern U.S. within the context of the SEM.

## Methods

### Study Population

Qualitative interviews were conducted among participants who attended the Rural HIV conference in Southern Georgia. Purposive sampling was used to recruit individuals affected by HIV (e.g. people living with and without HIV, individuals working in HIV prevention, and individuals interested in learning about HIV) in Florida and Georgia. We developed and distributed a survey at a rural HIV conference in southern Georgia (September 2018), a pride parade in Florida (October 2018), and an HIV-related comprehensive planning meeting in Florida (November 2018). In May 2019, we distributed an online link through the Florida Department of Health to share with potential participants. Individuals were eligible to participate if they were 18 years or older and fluent in English. Participants were excluded if they were not from Florida or Georgia or had missing information on state of residence (n = 8).

### Study instrument

We created an anonymous 11-item survey consisting of 4 open-ended questions (Table 1) and 7 demographic questions specifically for this study (Supplementary file 1). The open-ended questions sought to define and identify examples of HIV-related stigma as well as recommendations to reduce it. The survey took approximately 5 minutes to complete.

## Ethics

The study was approved by the University of Florida Institutional Review Board with a waiver of obtaining written informed consent.

## Analysis

A total of 87 surveys were collected from persons living in Florida and Georgia. We obtained qualitative data using surveys and a directed content analysis approach for data analysis. With a directed approach, an established theory guides initial coding. This method is appropriate when an existing theoretical framework (i.e., SEM) exist to explain the phenomenon (i.e., HIV-related stigma) in a new context [17]. All text was initially coded by two researchers (VR and RW) independently using the five levels of the SEM (individual, interpersonal, community, institutional, structural). Following this, each response was coded to address specific areas within each level (Table 2). Given the complexity of HIV-related stigma, responses could be coded in more than one level and were grouped by PLWH and people not living with HIV (PNLWH). In the event of a discrepancy in coding, a third researcher (NS or SC) resolved conflicts. We used a deductive process of group discussion and recoding and developed a codebook collaboratively. Finally, an audit trail was generated by VR, and RW checked the audit trail to capture thought processes and reflection of the text and to interpret personal reactions or biases. While each question was analyzed separately, the results from questions 1 and 2 were combined to describe: Experiences and examples of HIV-related stigma and questions 3 and 4 were combined to describe: Strategies to reduce HIV-related stigma (Table 1).

Table 1  
Community Stigma Survey Open-Ended Questions

Question 1	"In your own words, define HIV-related stigma (2 sentences or less)"
Question 2	"Give one example of what you have seen or heard about to help reduce HIV-related stigma"
Question 3	"Give one example of what you have seen or heard about to help reduce HIV-related stigma"
Question 4	"What would you recommend to be the most important strategy to reduce HIV-related stigma in your state? Please be specific. (Example: policy, media, types of education, health services or providers, etc.)"

Table 2

Responses about HIV-related stigma according to the Social Ecological Model from persons affected by HIV\*

Levels of the Social Ecological Model	Themes About HIV-Related Stigma	Definitions
<b>Individual</b>	Knowledge	Understanding HIV transmission
	Fear	Unpleasant emotion surrounding consequences of HIV status disclosure and transmission
	Internalization	Negative beliefs about one's own HIV status
<b>Interpersonal</b>	Social Network	A network of interactions and personal relationships among a close group of individuals
<b>Community</b>	Judgements	How persons view PLWH negatively, involving prejudice and stereotyping
	Discrimination	Actions of prejudice directly at PLWH
	Community Organizations	Groups working to reduce stigma
	Norms	Changing how HIV and related prevention methods are viewed
<b>Institutional</b>	Competent Providers	The ability for professionals to provide care to PLWH free from judgment
	Healthcare Services	Integrative and patient-centered services provided for PLWH
<b>Structural</b>	Systemic Barriers	Laws, policies, and structures that make it difficult for PLWH to receive equal treatment
	Language	Words used to describe PLWH
	Education	Increase in knowledge through systematic instruction targeted to a variety of groups (e.g., students, healthcare professionals)
*including persons living with HIV, healthcare providers, researchers, and allies		

## Results

The sample consisted of 33 PLWH and 54 PNLWH. The average age for PLWH and PNLWH were 50 years (SD=13) and 46 years (SD=16), respectively. Most participants were female (54%), non-Hispanic (80%), White (69%), and lived in Florida (87%). Themes that encapsulate experiences and examples of HIV-related stigma and recommendations to reduce stigma in Florida and Georgia are summarized in Table 2. Furthermore, we incorporated our findings into a model of the SEM to address HIV-related stigma, illustrated in Figure 1.

# Experiences and Examples of HIV-Related Stigma

## Individual

### Knowledge

Sentiments expressed by participants included perceptions of HIV transmission. For example, one person shared that, “many people still don’t know how HIV is spread and treat [people living with] HIV as if they have a contagious disease”.

### Fear

Participants tended to describe HIV-related stigma as a fear to disclose status. One person wrote, “...fears of disclosing status because of potential violence”, another said, “people are afraid that if people find out they have HIV they will suffer negative consequences such as isolation; loss of job or housing; physical harm”. Participants also described fears related to risk perceptions, “fear of contracting HIV simply by being close to an HIV+ person...”

### Internalization

Participants brought up similar examples of internalization, including, “HIV-related stigma is the stigma that we put upon ourselves. We have to accept ourselves as who we are with HIV first.”

## Interpersonal

### Social Network

Participants described instances of family members and friends not wanting to share items such as food or utensils with a PLWH. One respondent remarked, “families are still giving people who are *HIV+ different things to eat on*”. Two PLWH also brought up the concept of dating being a source of HIV-related stigma, for example, “I’ve seen people still afraid to date someone HIV+”.

Other instances involved rejection by people close to them. Another example was, “an older person who has been going to her church for many years and eventually she felt comfortable enough to share her diagnosis with one of her closest friends. Soon after that the friend stopped coming to her house and stop hugging her and uses hand sanitizer after she awkwardly shakes her hand.”

## Community

### Judgements

Judgements was the most commonly cited example of HIV-related stigma in our sample. Many responses involved stereotyping: “that the person afflicted was promiscuous or on drugs” and “only gay people get HIV”, religion: “you got what you deserved, God’s wrath on gays”, and more general negative opinions: “prejudice against people infected with HIV in all facets of life” and, “the negative and often hurtful attitudes and ideas that people have about those of us living with HIV.”

Judgments came mostly from interactions with others. Only one person (without HIV) described media as an example of HIV-related stigma, writing, “[HIV medication] commercial. Although it depicts multiple races, it still insinuates HIV is a white, gay man's disease.”

## **Discrimination**

Responses ranged from avoidance to violence. Examples included, “...hate crimes against people living with HIV and AIDS”, “not allowing an individual to participate in sports events”, and “people avoiding, not talking and not wanting to be with you.”

## **Institutional**

### **Competent Providers**

Examples described providers who were not sufficiently able to treat PLWH. There was not one predominant provider type in which this occurred. One participant shared an experience that exemplified competency in providers in which they described as, “an orthopedic surgeon saying he cannot perform a total hip replacement on me because he has never done one on a person with my condition.” Another person described their experience as someone who works with PLWH, “When I was giving birth the nurse had to get another person to start my IV because she couldn't get it started, I heard her down the hall telling the other nurse that I was high-risk because I work in the HIV department.”

### **Healthcare Services**

Participants described healthcare services as an example of HIV-related stigma, but one person described the setup of a health department: “...having to walk into a county health facility to get my meds at a special window in a crowded room full of people.”

## **Structural**

### **Systemic Barriers**

Participants discussed HIV-criminalization laws, citing the, “increased penalties in the ‘justice system’... levied at people who are HIV positive”. Multiple respondents also mentioned challenges with our laws, such as, “.... I would also like to see Florida modernize its HIV-related and sex work laws. I am excited

that syringe exchange may finally be an option in Florida counties outside of Miami-Dade sometime this year.”

## **Strategies to Reduce HIV-related Stigma**

### **Individual**

#### **Knowledge**

Participants expressed that informing individuals about HIV transmission, treatment, and prevention could be one strategy to reduce HIV-related stigma. For example, one participant noted, “Explaining that you're unable to catch HIV - through hugs, handshakes, or holding hands.”

PLWH specifically noted that telling their own stories and learning from peers living with HIV would increase knowledge and reduce stigma. One respondent stated, *“Knowing an HIV positive individual or friend... Get some knowledge!! Always correct people especially kids who are mocking or joking about the situation”*

#### **Fear**

Two PNLWH remarked fear needed to be addressed to dispel misinformation about HIV. One person described, “Open communication to continue to assist with the fear associated with HIV. Many people have knowledge but somehow do not believe all of it to be true.” No PLWH in our sample commented that fear was an issue.

### **Interpersonal**

#### **Social Network**

Several participants believed we should focus our attention on families. For example, “We are a tight knit community that places emphasis on our family units. The moment the older generation opens up and changes their minds about their attitudes towards the disease the easier it will be for the younger generations to be open and feel comfortable getting tested and talking about HIV”.

### **Community**

#### **Judgements**

Respondents generally described that a barrier to HIV-related stigma interventions refers to judgement from and within specific communities. For example, “Reducing HIV-related stigma needs to focus on the

religious community where the language used by religious leaders need to be more inclusive, so people don't keep on perpetuating hate language in their homes.”

Media was also described as a mode of decreasing judgments. Mediums such as diverse websites, commercials, and billboards would be useful to increase awareness about HIV. Respondents detailed, *“Increasing your voice, being seen by way of billboards, brochures at every medical facility.....depicting all kinds of people old, young, white, black, brown, Asian, the disabled in brochures and prevention messages HIV does not discriminate anyone.”*

## **Community Organizations**

Respondents agreed that inclusive, respectful organizations such as peer-led community-based organizations as well as government-funded agencies would decrease HIV-related stigma. “Agencies that make an effort to let people know they treat all persons with respect and dignity, and then actually do so.”

## **Norms**

Participants noted that HIV should be normalized as a chronic illness where people could feel comfortable disclosing their status or get tested without being judged, mentioning:

“Messaging here is difficult but not impossible. Too many people still think HIV is a death sentence. It isn't. I may very well outlive many of my HIV negative friends. HIV is a treatable, manageable condition. We need to get that out there. At the same time, we don't want people to let their guard down too much. HIV is still serious”.

PLWH also noted this approach could normalize HIV if peers living with HIV could tell their story.

## **Institutional**

### **Competent Providers**

Respondents also explained how HIV-related stigma could be perpetuated among providers. Although the type of provider was not specified, participants tended to agree that support, education, and communication could be improved, in other words, “HIV providers and Case Managers provide education using simple terms, in everyday words that people can understand and empathize rather than sympathize.”

### **Healthcare Services**

Respondents agreed that resources such as increased testing, providers, and healthcare centers are needed. Respondents noted that facilities should not be identified as HIV-specific, rather they should provide a gamut of services. Specifically, respondents commented, “Create a safe non-descriptive clinic that is not just for PLWH so they can access care without feeling singled out.”

# Structural

## Systemic Barriers

Participants discussed criminalization laws, discriminatory practices, and policies that could increase testing efforts, citing, “For example, not having a patient sign special consent forms saying they want HIV testing” and, “*Modernize the outdated, unscientific, discriminatory HIV specific laws.*” PLWH specifically mentioned engaging communities as a whole such as, “...Allow them [people living with HIV] to sit at the decision-making table.”

## Language

PLWH described language as meaningful, stating, “People or patient first language being used to take the impact of harm from the intent behind describing people living with HIV.”

## Education

Participants often cited education focusing on HIV transmission, particularly geared towards school-aged children, “For my state/city, I think it could be helpful if we provided more information to the youth about HIV, in a conducive way. Implement a course on it.” One respondent noted, “...Renewed community HIV/AIDS education prevention efforts targeting high risk communities utilizing real leaders in the community.”

## Several Approaches

It should be noted that a couple of respondents indicated that strategies to reduce HIV-related stigma should not be a single approach citing, “Any strategy to overcome HIV-related stigma must be multi-pronged, it must involve policy, media, specific education, and health services integration”.

## Discussion

This is one of the first studies to qualitatively describe examples of HIV-related stigma and strategies to reduce HIV-related stigma in the Southeastern U.S. within the context of the SEM. In this study, participants identified that HIV-related stigma encompasses individual (knowledge, fears, internalizations) interpersonal (social networks), community (judgement, discrimination, community organizations, norms), institutional (competent providers, healthcare services) and structural levels (systemic barriers, language, education) of the SEM which have been supported in previous studies [18] [19]. These findings demonstrate that a multi-component intervention that encompasses each of the levels of the SEM simultaneously could be useful to reduce HIV-related stigma in the Southeastern U.S.

Examples and experiences of HIV-related stigma were most commonly noted as instances of enacted stigma. Many of these experiences occurred on a community and institutional level which entailed

judgments and discrimination from friends, family, and the community at large highlighting fears of sharing utensils, stereotyping, and violence. These findings are consistent with a similar qualitative study, in which a representative sample of families in care for HIV in the US described enacted stigma as the most common theme [20]. A smaller number of respondents in our sample described structural stigma related to education, HIV-criminalization laws, and housing discrimination. Examples of HIV-related stigma were also experienced at an individual level (i.e., internalized negative attitudes about HIV, misconceptions about HIV transmission), and institutional level (i.e., anticipated stigma from healthcare providers). The present study's results have implications for the design of HIV-related stigma interventions. Although researchers mainly consider individual-level interventions, our results demonstrate that further research is needed on interventions that include all levels of the SEM.

Our findings were similar to results of studies done in other settings which further support that a cross-cutting approach may support an efficient, effective response to reduce HIV-related stigma in the Southeastern U.S. [21–24]. Most interventions to-date focus on a single social ecological level targeting individual levels of influence [25]. While these studies address the knowledge, fears, and attitudes of individuals, these interventions may not adequately address HIV-related stigma manifestations on a community (e.g., community attitudes) interpersonal (e.g., social isolation from family and friends), institutional (e.g., healthcare worker discrimination of PLWH), or structural-level (e.g., discriminatory laws). Specifically, fewer community, institutional, and structural-level interventions have been tested in a North American context.[25] HIV-related stigma interventions that fail to address all of the social ecological levels may not sustain long-term health seeking or preventative behaviors [25]. More research is needed to explore combinations of strategies at multiple social ecological levels for PLWH affected by HIV-related stigma in North America.

The use of purposive sampling served as a major limitation in this study, as our sample does not reflect the full diversity of the Southeastern U.S. Purposive sampling, however, is a common method for recruiting participants into qualitative research [26]. Furthermore, the sample was predominantly White and non-Hispanic, and more input from Black and other racial/ethnic groups could provide additional examples. Although, it is possible that the survey did not reach the people who experience the greatest amounts of stigma who may be less likely to participate in HIV-related research studies, we felt that including the perspective of both PLWH and PNLWH who worked with a larger population would help us to understand those experiences. Additionally, because this was a self-administered survey that only allowed short answers, we were unable to follow-up on responses that lacked clarity or warranted further explanation. Lastly, because this was a qualitative study, we are not able to make formal comparisons in attitudes or specific suggestions in PLWH compared to PNLWH.

Despite these limitations, the study has several strengths. Participants were able to describe their experiences in an open-answer format, allowing them to expand on their thoughts. Additionally, this study recruited in different environments to attempt to include a variety of persons affected by HIV, including both people with and without HIV. This was one of the first studies to qualitatively assess HIV-related

stigma in the Southeastern U.S., thus provides a novel explanation of the experiences of HIV-related stigma and recommendations to combat it.

## **Conclusions**

HIV-related stigma exists within every level of the SEM. Our findings exemplify the need and potential benefits from a multi-level approach to intervene and reduce HIV-related stigma in the Southeastern U.S. The data suggest that such an approach includes the following: (1) increasing knowledge by addressing fears, attitudes and beliefs about HIV (2) talking openly with family, friends, and partners to correct misconceptions (3) normalizing HIV through media campaigns and inclusive community organizations (4) structured education and training, specifically for school or healthcare settings and (5) updating current federal and state policies with the input of PLWH. Future HIV-related research and intervention development may further benefit from incorporating the experiences of all persons affected by HIV and their advocates not living with HIV while considering all levels of the SEM. Additional studies that use in-depth interviews and include more minority groups may be able to expand and provide insight on the optimal methods to reduce HIV-related stigma in the Southeastern U.S.

## **Abbreviations**

HIV- Human immunodeficiency virus

PLWH- People living with HIV

PNLWH- People not living with HIV

SEM- Social ecological model

## **Declarations**

### **Ethical Approval and Consent to Participate:**

The Institutional Review Board of the Florida Department of Health approved the analysis of this study. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. A waiver of informed consent was received for this study.

### **Availability of Data and Material:**

The full survey used for this study is included within the article.

## Competing of Interests:

The authors declare that they have no conflict of interest.

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## Author Contribution:

All authors contributed to the study conception and design. Data analysis and literature search were performed by RW and VR. VR, RW, NS, and SC contributed to interpreting the data. The first draft of the manuscript was written by RW and VR. NS, SC, AA, CC, RL, ES, and RC contributed to critically reviewing the first draft and offered substantial revisions of subsequent drafts of the manuscript. All authors read and approved the final manuscript.

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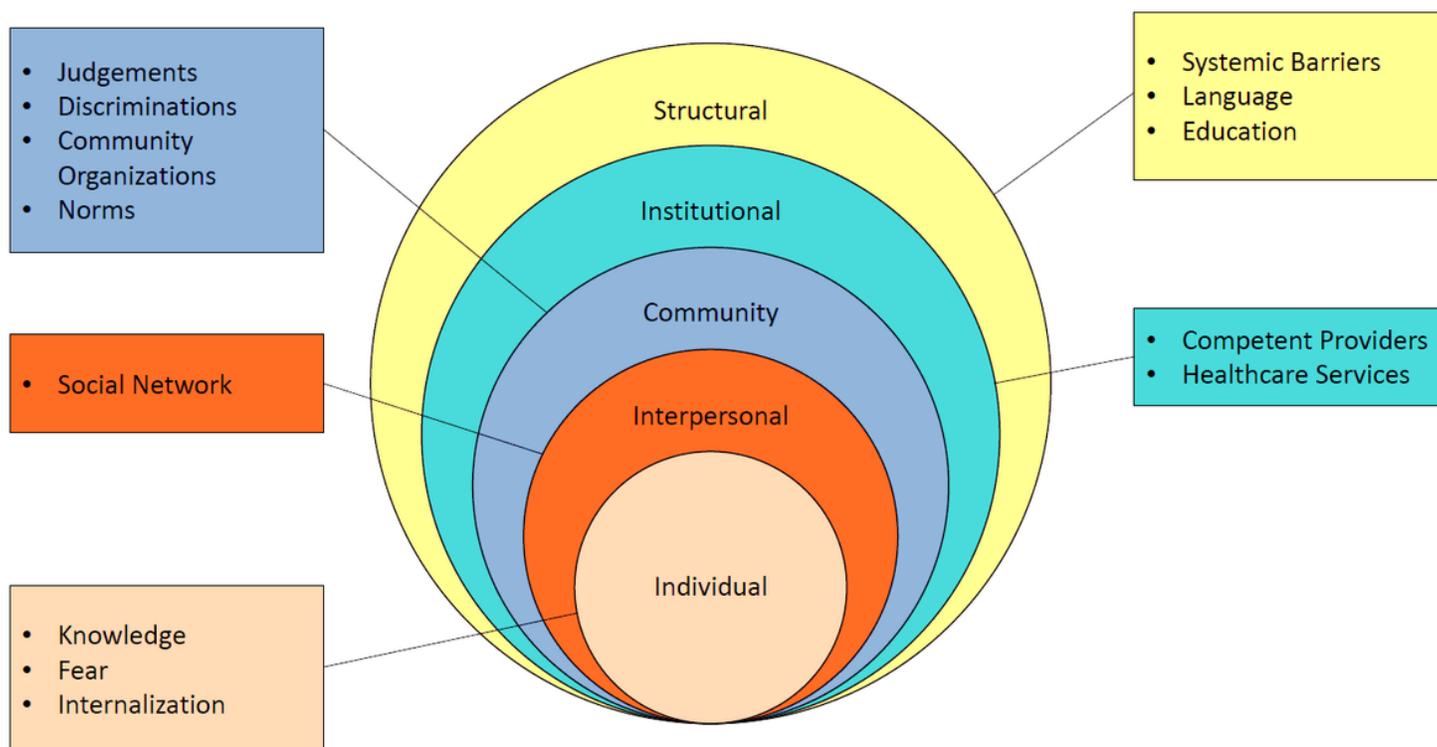
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## Figures



## Figure 1

Social Ecological Model to Explain HIV-Related Stigma

## Supplementary Files

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- [stigmasurveycomplete.docx](#)