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Risk and resiliency: the syndemic nature of HIV/AIDS in the indigenous highland communities of Ecuador

L.U. Đào [a,*], E. Terán [b], S. Bejarano [a], I. Hernandez [c], M. Reina Ortiz [a], V. Chee [a], M. Flores [b], R. Izurieta [a], J. Baldwin [d], D. Martinez Tyson [a]

[a] University of South Florida, College of Public Health, Tampa, FL, USA
[b] Universidad San Francisco de Quito, Colegio de Ciencias de la Salud, Quito, Ecuador
[c] Pontificia Universidad Católica del Ecuador, Facultad de Enfermería, Quito, Ecuador
[d] Northern Arizona University, Center for Health Equity Research, Flagstaff, AZ, USA

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ABSTRACT

Objectives: This community-based study explores the syndemic nature of HIV/AIDS risk and resilience among Indigenous Kichwa communities in the province of Imbabura, Ecuador. This study elucidates individual and community-level factors that serve to exacerbate HIV/AIDS risk, as they relate to underlying macrolevel, structural forces. Critically, this study also elicited opportunities for community-based opportunities for resiliency from HIV/AIDS.
Study design: Exploratory qualitative study.
Methods: Guided by syndemic theory, a qualitative study was conducted to explore HIV risk and resilience among Indigenous Kichwa communities in the Northern Andean highlands of Ecuador. Eight focus groups ($n = 59$) with men and women from two communities were conducted. The data were analyzed using applied thematic analysis techniques.
Results: Identified risk factors for HIV/AIDS centered around the following themes: (1) parents leaving the community for work, (2) alcohol and drug consumption, (3) unprotected sex, and (4) barriers to health care. Identified HIV/AIDS resiliency factors included the preservation of Indigenous culture and family-focused interventions.
Conclusions: The identified risk factors for HIV/AIDS are interrelated within a complex syndemic relationship. The mutually reinforcing individual-level risk factors of substance abuse and risky sexual behavior coalesce with violence to exacerbate the risk for HIV/AIDS acquisition among Ecuadorian Highland Indigenous communities. Moreover, HIV/AIDS risk prevails in the macrolevel context of disproportionate unemployment among Indigenous peoples and a systematically fragmented healthcare system. It is critical that public health professionals work to revolutionize the systematic discrimination that underpins indigenous health disparities at-large.

* *Corresponding author*. 13201 Bruce B. Downs Blvd, MDC56, Tampa, 33612-3805 FL, USA. Tel.: +1954 873 9214.
E-mail address: LDAO@health.usf.edu (L.U. Đào).
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Introduction

Globally, there are approximately 36.7 million people living with HIV/AIDS,[1] with about 2.1 million living in Latin America and the Caribbean (LAC).[2] The Joint United Nations Program on HIV/AIDS (UNAIDS) reported immense strides made to mitigate the HIV/AIDS epidemic in LAC stating that HIV/AIDS treatment coverage reached 55%, and rates of new adult HIV infections have remained relatively static.[1] While there have been advancements made in HIV/AIDS prevention and care in the LAC, these advancements have not been equitably distributed with many left behind including Indigenous communities. In Ecuador, evidence indicates a higher risk of HIV transmission among Indigenous populations.[3] In general, Indigenous people disproportionately experience high levels of HIV/AIDS because of a coalescing of oppressive social, political, and economic forces including poverty, a lack of access to education, inadequate social services, destruction of Indigenous economies, forced displacement, and the degradation of their customary lands and resources. Said forces are exacerbated by structural racism and discrimination.[4] With over one million people in Ecuador's population who self-identify as Indigenous peoples, it is critical that public health researchers elucidate the concurrent factors that serve to exacerbate the HIV/AIDS epidemic among Indigenous Ecuadorian communities.[5] The purpose of this study is to identify both individual and community level factors for HIV/AIDS risk and resiliency among two Indigenous communities in the highlands of Ecuador. This study explores the syndemic nature of HIV/AIDS among Indigenous communities in the province of Imbabura, Ecuador. Community and individual level factors are discussed as they relate to underlying macro-level, structural forces that may compound the HIV/AIDS epidemic. Critically, this study also elicits examples of and opportunities for community resiliency from HIV/AIDS. This study operationalizes 'community resiliency' as it relates to 'how people overcome stress, trauma, and other life challenges by drawing from the social and cultural networks and practices that constitute communities.'[6]

Methods

This study is part of a larger multinational study that assessed the syndemic nature of HIV/AIDS in three Indigenous communities in LAC: Panama, Ecuador, and Belize. Guided by syndemic theory, a qualitative, community-engaged research design was implemented to explore HIV/AIDS risk and resiliency among Indigenous communities in the Imbabura province located in the highland region of Ecuador. A purposive sampling technique was utilized for the recruitment of eight focus groups ($n = 59$). Focus groups are a qualitative data collection technique that can be used to understand perceptions and beliefs about disease and illness such as HIV/AIDS and provide insights on HIV/AIDS-related behavior.[7–9] Participants were identified through in-country existing partnerships with Indigenous community leaders and community-based organizations based in the Imbabura province. A total of eight focus groups were conducted in two communities. Focus group data were analyzed using Applied Thematic Analysis.[10] Sociodemographic data were also collected from focus group participants. Each focus group discussion lasted between 1 and 1.5 h. To be eligible for focus groups, participants had to be over 18 years of age and reside and receive their health care in the province of Imbabura, Ecuador. Focus groups were stratified by age (e.g. younger generation and elders) and gender (e.g. males and females).

Syndemic theory

Syndemic theory was used as the guiding framework for this study. Syndemic theory posits that co-occurring diseases and health problems are a result of social, economic and political inequities that work synergistically to increase the negative health consequences of one another.[11–14] This study applies a syndemic framework which emphasizes the identification of underlying social, economic, political, and environmental factors that impact the health and well-being of an Indigenous community. Syndemic theory has been applied in previous HIV research with Latino populations to elucidate ways social determinants have contributed to disease clustering and interaction as well as to vulnerability.[12,15,16]

Results

Focus group participants included 31 females and 28 males. Their ages ranged from 18 to 74 years of age with an average of 35 years. The majority of participants ($n = 28$) completed secondary school. All participants spoke Spanish, while the majority ($n = 48$) also spoke the Indigenous Kichwa language. Overall, participants demonstrated interest and engaged in conversation with each other easily despite the fact that many had just been introduced to each other during the focus group. Most of the participants self-identified as Indigenous ($n = 48$). A demographic summary of the focus group participants is shown in Table 1.

Participants displayed an overall understanding of HIV/AIDS and attributed their knowledge of HIV/AIDS to education provided during primary and secondary school. Participants were knowledgeable about several high-risk behaviors for HIV/AIDS. For instance, participants knew that people are at higher risk for HIV/AIDS when not using condoms, having multiple partners, having sexual relationships prior to disclosing HIV/AIDS status, and using injection drugs. Participants also mentioned that getting tattoos is a high risk when using the same needle for multiple people.

While participants had a general understanding of HIV/AIDS, they also identified multiple, interconnected HIV/AIDS risk factors in their communities which centered around the following themes: (1) parents leaving the community for work, (2) alcohol and drug consumption, (3) unprotected sex, and (4) barriers to health care. Factors for HIV/AIDS resiliency were also identified in the form of prevention efforts. The following

Table 1 – Demographic summary of focus group participants ($n = 59$)[a] in the Indigenous communities of Otavalo and Cotacachi in the highland of Ecuador.

Demographics	n	%[b]
Gender		
Male	28	46.5
Female	31	52.5
Age		
Average		35 years
Range		18–74 years
Education		
Illiterate	1	1.7
Primary	19	32.2
Secondary	28	47.5
University	5	8.5
Second level university	1	1.7
Language spoken		
Kichwa	32	81.4
Spanish	59	100
English	1	1.7
Other	1	1.7
Ethnicity		
Indigenous	48	81.4
Mestizo	9	15.3

[a] Not all participants reported their full demographics.
[b] Unless stated otherwise.

section describes said themes in greater detail and provides illustrative quotes. To ensure anonymity, the following illustrative quotes are labeled as Community A or Community B to denote where they came from.

Leaving the community for work

Adults leaving the community for work was one of the most salient themes that emerged throughout the focus groups. Parental absence because of leaving the community for work was linked to loss of parental authority, lack of guidance for adolescents, and ultimately led to adolescents engaging in risky sexual behavior which placed them at risk for HIV/AIDS. The time parents spent away from their families ranged from weeks or months to years at a time. Upon leaving the community, relatives (usually grandparents) or friends often become the caregivers of their children. Participants reported that these children felt abandoned and did not want to obey their new caregivers. Adolescents engaged in alcohol and drug use as a result of the disconnected parent–child relationship. Participants also linked a lack of parental guidance to adolescents initiating early sexual behaviors. One woman participant recounts how she feels that parents leaving their children for work leads adolescents adopting bad influences:

> *It is mostly mom and dad who work, and children are left alone. In my opinion, this is the biggest problem. They [i.e., the children] no longer have someone behind them, watching over them, so I think it is because of that… The issue is that children are not taught clearly about things starting in their early years… they may go around and seek refuge in their friends… that are a bad influence for them—Focus group # 1 with young women in Community A*

Alcohol and drugs

Alcohol and drugs were topics often discussed by the participants. Participants mentioned that alcohol use is a general problem in the community. Teenage boys have initiated alcohol use at a younger age in comparison to previous generations. As previously stated, participants reported that the adolescents often felt abandoned when their parents left the community for work. During a discussion on the lack of parental control, a participant linked it with adolescent substances use:

> *…once boys are free with no [parental] control at all, they soon begin with vices. For example, here [in this community, it] is alcohol, in teenagers …and this new generation starts [alcohol consumption] very early—Focus group # 2 with young men in Community A*

Participants cited alcohol use is a pervasive problem found among all ages. For adults, alcohol use was reported to be more common among men than women. Participants reported that when intimate partner violence (IPV) in heterosexual relationships or public fights between males occurred, it was usually a consequence of alcohol use. Furthermore, the majority of alcohol-related violence reported was violence against women (VAW). Related alcohol use in excess was reported as acceptable and normalized during festivals. Participants identified festivals and parties as a time where IPV and VAW occurred between heterosexual couples, which was usually a repercussion of excessive alcohol consumption as alcohol was more readily available. One participant referred to IPV in the context of parties with alcohol stating:

> *I have seen that when there is a party, the majority [of people] drink, husband and wife sometimes [drink]. Then they become drunk and the husband beats up his wife, but probably he is not aware about what he is doing. He does it due to the alcohol effects. I have seen husband and women fighting in the streets—Focus group # 1 with young women in Community A*

Participants reported that visitors from neighboring communities would walk back to their communities in the dark after parties and that many times VAW occurred in the form of sexual abuse during their walk back to their community. Participants also mentioned that women do not want to denounce these acts because of victim shaming. Furthermore, participants reported that drug use among adolescents was a complex, growing concern that is interconnected with gang membership and violence. Particularly, participants reported that some adolescents are members of gangs and are using and selling drugs, primarily marijuana.

Unprotected sex

Condom use was reported as a generally uncommon practice. Participants also explained that negotiation of condom use was not discussed between couples because of suspicions of infidelity. Participants mentioned that unprotected sex occurred between spouses and other partners outside of the relationship. During all focus groups, unprotected sex was

discussed in the context of a heterosexual relationship. Women reported that men may have many partners regardless of whether they are married or not because they go to the brothels and do not use protection. It was reported that the men go home and have sex with their wives which puts their wife at risk for HIV/AIDS. Participants expressed a need for young men to be educated on fidelity because if they do not understand the importance of being loyal then they are at high risk of transmitting HIV/AIDS and other sexually transmitted infections (STIs) to their wives. Participants gave explicit examples of ways in which unprotected sex and infidelity leads to STIs. For example, one participant stated:

> *…what I know, of this illness, it's transmitted by him… and sexual relations. They didn't tell us (women) that, women that work at the cabaret, that …men are practically not using anything, condoms… it's easier to infect their wives at home—Focus group # 7 with older women in Community B*

Participants also reported that parents had limited communication with their adolescent children regarding safe sex. Some fathers said they have talked to their sons about using protection. For example, a male participant stated that he told his son, '*You better use protection*' but that was the extent of the discussion. When asked if they spoke to their sons about safe sex, women participants said they tell their sons to make sure they '*buy protection*'. Again, this was also the extent of the discussion. Women participants said that they do not talk to their daughters about safe sex or using protection stating that adolescent girls are learning about sexual relationships at school so they already know about sex.

Barriers to health care

Participants cited a mistrust of health professionals, limited access to healthcare resources, and discrimination as barriers to care. Participants believed that health professionals were not sanitary with the medical instruments they used on patients. Women participants reported that they only receive information on HIV/AIDS if they are pregnant. Also, participants explained that condom dispensers were placed at the center of the waiting area in their local healthcare facility which was seen as highly indiscrete. Overall, there was a reported distrust of the providers and limited access to resources for HIV/AIDS.

Lastly, participants felt that they did not have much support for HIV/AIDS stating that they only knew of one hospital where they could receive help for HIV/AIDS or get tested. However, this hospital is located outside of their rural community. In addition, public healthcare services opened during hours that were largely at odds with the community's schedule. Also, Indigenous community members felt that the staff was mostly Mestizo which lead to discrimination. Moreover, participants reported a sense of mistreatment when seeking care:

> *I had to use the health center only one time, I was treated badly and never went back again…—Focus group # 2 with young men in Community A*

Factors for HIV/AIDS prevention and resiliency

The preservation of Indigenous Kichwa cultural practices and lifeways were cited by participants as a factor for resiliency from HIV/AIDS and its interrelated adverse consequences. A participant discussed the need to find ways to preserve Kichwa identity, culture, and language.

> *I think we have to preserve our identity or our culture, in fact in this community I am not sure if the majority or exactly what percentage of us are indigenous but that is something that is losing progressively. It is happening slowly in some sense … here the majority of us speak Kichwa [i.e., the local Indigenous language] but talking about the new generations they do not speak that language; maybe they can understand but it is like they have fear and then say 'no no, I do not speak Kichwa'. I really do not know what to do to preserve our culture, maybe we should look for strategies to do it as it is something important because the culture is the nucleus where we came from as persons—Focus group # 2 with young men in Community A*

Participants also shared several potential ways to prevent HIV/AIDS in their communities. Participants suggested that doctors give '*charlas*' (i.e. talks) about HIV/AIDS prevention. '*Radio Iluman,*' a local radio station with contents in Kichwa, was identified as a platform to broadcast educational information as many Indigenous community members listen to this station. Participants also suggested that HIV/AIDS education efforts be implemented through signs at bus stops. Churches were also identified as a community locale in which HIV/AIDS could be addressed. Additionally, women suggested having community meetings where couples could talk about being faithful and highlight the consequences that come with not being faithful, including HIV/AIDS. Lastly, participants also discussed a desire to learn how to appropriately talk to their adolescents in situations where there is an estranged parent–child relationship.

Discussion

The identified risk factors for HIV/AIDS are interrelated within a complex syndemic interaction. Results of this exploratory research indicate that multiple mutually reinforcing risk factors coalesce to exacerbate the risk for HIV/AIDS acquisition among highland Indigenous communities. As shown in Fig. 1, the HIV/AIDS risk factors include (1) parents leaving the community for work, (2) alcohol and drug consumption, (3) unprotected sex, and (4) barriers to health care.

This study's findings of the individual-level HIV/AIDS risk factors of (1) alcohol and drug consumption and (2) unprotected sex align with previous studies on the substance abuse, violence, and AIDS (SAVA) syndemic.[16–25] The conceptualization of the SAVA syndemic was a landmark study[24] that pioneered holistic conceptualizations of the complexities of HIV/AIDS interaction with substance abuse and violence. These three closely linked and interdependent threats to health and well-being are referred to as the single term SAVA to emphasize their interrelatedness. Previous research on the

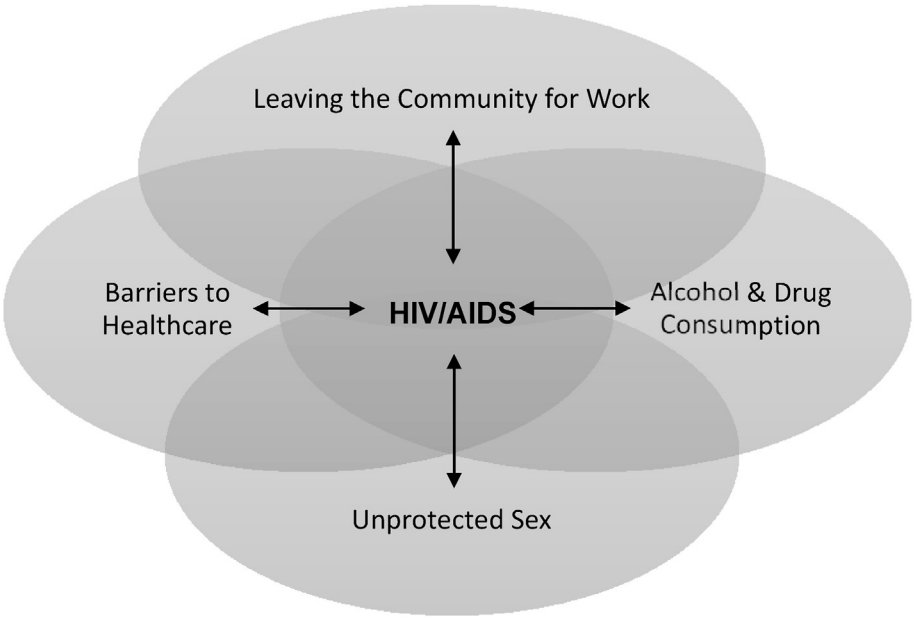

Fig. 1 – A visualization of the syndemic nature of HIV/AIDS among indigenous communities in Imbabura, Ecuador.

SAVA syndemic shows that there are multiple pathways between substance abuse and violence that link to HIV/AIDS risk and acquisition.

Study participants identified VAW as an issue in their communities. These findings are congruent with a review of the SAVA syndemic among women which shows substantial evidence for a bidirectional relationship between VAW and HIV/AIDS risk.[25] In this bidirectional relationship between VAW and HIV/AIDS risk, earlier sexual risk taking was associated with subsequent IPV, and inversely IPV experienced earlier in life was associated with subsequent sexual risk taking.[25] Participants also reported IPV and general violence in the community often was the result of alcohol use. These finding also align with evidence for the SAVA syndemic and the interrelated relationship between substance abuse, violence, and HIV/AIDS. A syndemic framework accounts for the milieu of inequality that serves to exacerbate negative health outcomes and impede survival.

Evidence from a global review assessing the underlying causes of health disparities between Indigenous and non-Indigenous people highlights that Indigenous people worldwide have been historically marginalized, with little respect for their customary cultural life ways and their autonomy which underpin poor health outcomes.[26] In this study the community-level HIV/AIDS risk factors of (1) leaving the community for work and (2) barriers to health care are reflective of macro-level oppressive contextual factors that are faced by Indigenous communities worldwide: disproportionate unemployment and a fragmented healthcare system. Unemployment among Indigenous peoples is linked to discrimination, poverty, poor education, family instability, and residential instability.[26] According to the 2015 National Survey of Employment, Unemployment, and Underemployment, only 29.44% of Indigenous Ecuadorians were reported as having suitable jobs.[27] Unemployment and lack of opportunities for economic growth within Indigenous highland communities in Ecuador may have led to Indigenous peoples leaving the community for work as found in our study. Leaving the community for work, in turn, placed Indigenous Ecuadorians at higher risk for HIV/AIDS.

Regarding barriers to health care, the global review assessing the underlying causes of Indigenous health disparities also indicates that services and support for health and social programming for Indigenous populations are typically fragmented in which different levels of government, departments, and divisions all generally work without collaboration.[26] This fragmentation is documented to result in the isolation of symptomatic issues (i.e. HIV/AIDS, substance abuse, IPV, unemployment, etc.) followed by the development of siloed programs that manage each issue separately, overlooking the syndemic nature of disease and illness.[26] Applying a syndemic framework to program and policy formation would allow for co-occurring and mutually reinforcing health issues to be addressed in multidimensional programs rather than stand-alone programs. Multidimensional programs holistically address the syndemic nature of HIV/AIDS (e.g. concurrently addressing prevention, treatment, and sustainable development).[28]

Study strengths included a qualitative research design that allowed for in-depth observation and narrative engagement with the community. Furthermore, standardized data collection and analysis procedures were employed to minimize bias. Study limitations include the scope of the study which was limited to perceptions of HIV/AIDS solely from the perspective of heterosexual relationships. In addition, emergent community-identified health issues such as VAW, IPV, and healthcare discrimination were inquired about only briefly during focus groups as HIV/AIDS was the focus of this study. VAW, IPV, and healthcare discrimination are urgent public health issues, and it is urgent that future research done with

Indigenous Kichwa communities address these community-identified issues related to violence and health.

In closing, this study not only identified HIV/AIDS risk factors but also elicited community-identified protective factors and areas for HIV/AIDS prevention and resiliency. Most notably, study participants stated that the preservation of Indigenous Kichwa cultural practices and lifeways is critical to protect local communities from the syndemic issues related to HIV/AIDS. These findings are corroborated by studies that rethink resiliency from an Indigenous perspective stating that resiliency in the Indigenous context include but are not limited to '… Narratives of historical identity and continuity along with [the] revitalization of culture, language, and tradition [which] can help repair the ruptures of cultural continuity that have occurred with colonization and the active suppression of indigenous cultures and identity'.[29] Based on community-identified factors for resiliency, future work with Ecuadorian Highland Indigenous communities should focus on prevention efforts in the form of HIV/AIDS, sexual education, and family-focused interventions. Concurrent with community-level efforts, it is critical that public health professionals encompass cultural context[30] from an Indigenous perspective to develop health interventions and to revolutionize the systematic discrimination that underpins indigenous health disparities. Social, political, economic, and environmental changes must be made from the community to structural level to have sustainable improved health outcomes for Indigenous peoples living with or at risk for HIV/AIDS.

Author statements

Ethical approval

This study was approved by the "Comité de Ética en Investigación en Seres Humanos" (Ethics Committee on Human Research) of the Universidad San Francisco de Quito, Ecuador (ID: 2015-122IN). This study was also approved by the University of South Florida's Institutional Review Board (ID: Pro00020635).

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Competing interest

None declared.

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