18th International Conference on
HIV TREATMENT AND PREVENTION ADHERENCE

Tujuane Tujiamini: Community perspectives of stigma and recommendations from people living with HIV in Obunga, Kenya

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TUJUANE TUJIAMINI

LET'S KNOW EACH OTHER
LET'S BELIEVE IN OURSELVES

Background

- The **2030 UNAIDS ending the AIDS epidemic is off track**

- **Where you reside and seek services for HIV matters**, for both prevention and treatment

- Not only where, but **what one's experience is in treatment settings** matters (e.g., stigma)

Background

- **Stigma** has been highlighted as **problematic in achieving equity in health and well-being**
  - Research in Kenya has similarly highlighted the **disruptive effects of stigma** on progress towards **Kenya's HIV strategy**
- Stigma in its various forms **contribute to poor mental health**, **avoidance of health care**, and **compromises self-care efforts**:
  - Internalized stigma
  - Enacted stigma
  - Anticipated stigma

Background

- **Intersectional stigma**, the compounded impact of multiple stigmatized identities, has increased relevance in efforts to mitigate barriers to care in HIV

- Intersectional stigma was assessed in rural Kenya and Uganda to understand **implications for care outcomes**
    - Stigmas took the form of **HIV, gender, poverty, and other marginalized identities**

- Research has captured the impact of anti LGBTQ+ Kenyan legislation on health outcomes and public safety
    - Recent news…

Kenya's LGBTQ community wins bittersweet victory in battle for rights

Supreme court rules for freedom of association but landmark decision sparks backlash from government and churches

OPINION
Opinions

How an LGBTQ court ruling sent Kenya into a moral panic

The legal pushback against Kenya's anti-LGBTQ colonial-era laws has unleashed vicious homophobia in the public space.

AFRICA

Kenyan anti-homosexuality bill would expel LGBTQ refugees

Kakuma and Dadaab refugee camps are located in the country

Published 2 weeks ago on April 26, 2023
By Sam Kisika

Objective of current research:

Community-driven conceptualizations on how intersectional stigma is experienced by LGBTQ+ members who belong to other stigmatized communities
AND
how these compounded stigmas impact critical health outcomes…

Today's focus being on LGBTQ+ PLWHIV

Method

- Community consultations with 5 key population groups
  - *Abstract focus is on PLWH group*
- Facilitated by CBO staff using semi-structured guide
- Field notes included direct quotes recorded and thematically analyzed
- Adapted group concept mapping

Inclusion criteria:

- Age 18 or older
- Resident of Obunga, Kisumu, Kenya
- PLWH – *self report*
- LGBTQ+ community member

Demographics:

- 13 participants
- Sex
  - 7 men (5 cisgender, 2 transgender)
  - 6 women (4 cisgender, 2 transgender)

Tugutuke Jamii Facilitated Community Consultations

| GBMSM | GBMSM Sex Work | Lesbian | PLWH | Transgender |

Community Map of Stigma Experienced by PLWH in Obunga, Kenya

"I am stigmatized and discriminated by people because they believe I acquired HIV due to multiple frequent sexual activities."

"I am stigmatized and discriminated because of my HIV status; my peers say I should not waste my time having fun because I am almost heading to the grave just like our other friends we have buried."

IS EXPERIENCED AS
- Misinformation
- Exclusion
- Rejection
- Abusive language
- Disenfranchisement

Recommendations
- Expanded resources for PLWH
  - Self-awareness sessions
  - Guidance around practice of self-disclosure
- Sensitization and training offered to:
  - Tracers
  - Chief Barazas
  - Health care workers
  - Community members
- Increased visibility of PLWH
  - Put on educational skits/dramas
  - Participation in community events

IS PROMOTED/ CAUSED BY
- Lack of Information / Sensitization in Community
- Prevalence of HIV/AIDS Myths

"Some people still believe in myths about HIV and AIDS. They don't believe that HIV exists and so, they see us as bewitched"

STIGMA

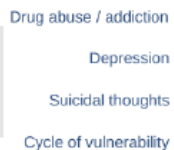"Stigma promotes poor adherence of ARVs"

"Some decide to be lost to follow ups because of the continuous stigma faced when they go for medication."

Health Care Challenges
- Adherence issues
- Lost to follow-up

RESULTS IN

"Disclosure to friends who have not been sensitized about HIV go ahead to use my status against me when we have misunderstandings"

Social Networks
- Use of nonconsensual HIV status disclosure as a threat in relationships

"It leads to drug abuse and addiction in order to cope with challenges"

Mental Health Challenges
- Drug abuse / addiction
- Depression
- Suicidal thoughts
- Cycle of vulnerability

Privacy Challenges
- Impact on clientele — Loss of clientele
- Sex work — Sensitization of clientele
- Lack sense of freedom to be oneself
- Chronic anxiety around disclosure

"I engage in sex work for a living and one time my work mate disclosed my status to one of my clients, this ended up so bad because my client panicked and got stressed up a lot even though we used a condom."

Residential Challenges
- Eviction threats
- Relocation to escape stigma

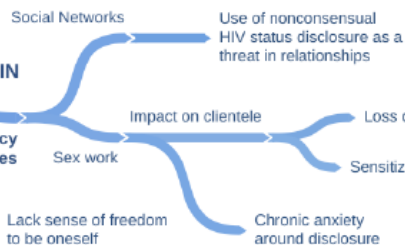"Stigma leads to one getting abused and harassed because they are not in the right state of mind due to depression"

"It prevents us from being free at our resident areas because our neighbors stigmatize us a lot especially when our HIV status is known"

"I get stigmatized a lot where I stay because of my sexual identity and again because I am HIV positive... We share one washroom with all my neighbors so they don't always like sharing the washrooms because they believe I will transmit the virus to them and sometimes they end up telling the landlord to vacate me because I am a threat to them"

Community Map Breakdown

HIV stigma is experienced as…

"I cannot share utensils with my family members because they believe I will transmit the virus to them."

"I am stigmatized and discriminated by people because they believe I acquired HIV due to multiple frequent sexual activities."

"I am stigmatized and discriminated because of my HIV status; my peers say I should not waste my time having fun because I am almost heading to the grave just like our other friends we have buried."

Misinformation
Exclusion
Rejection
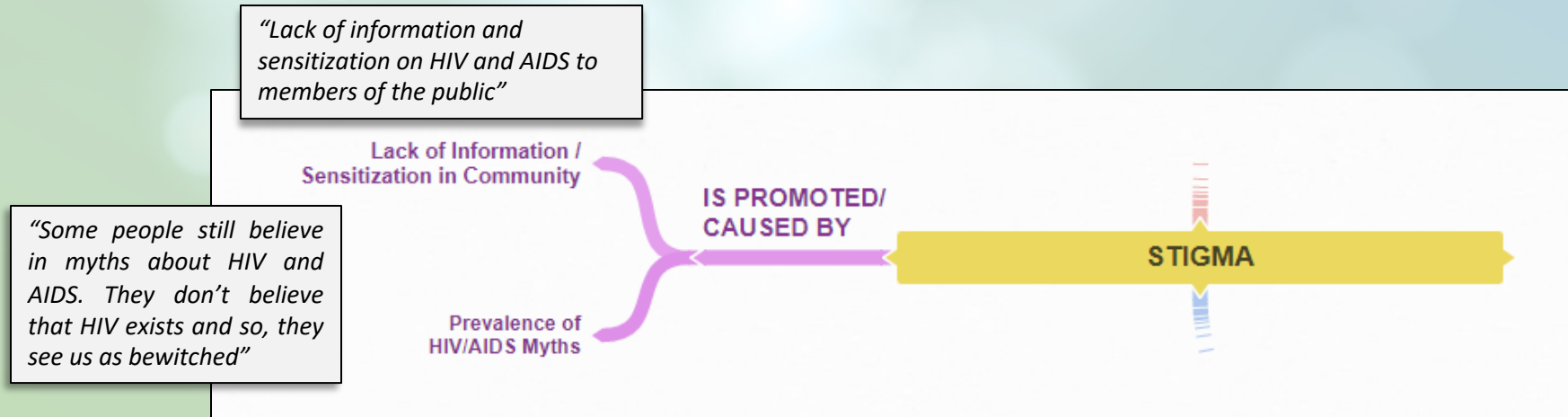Abusive language
Disenfranchisement

IS EXPERIENCED AS

STIGMA

Community Map Breakdown

HIV stigma is promoted and caused by...

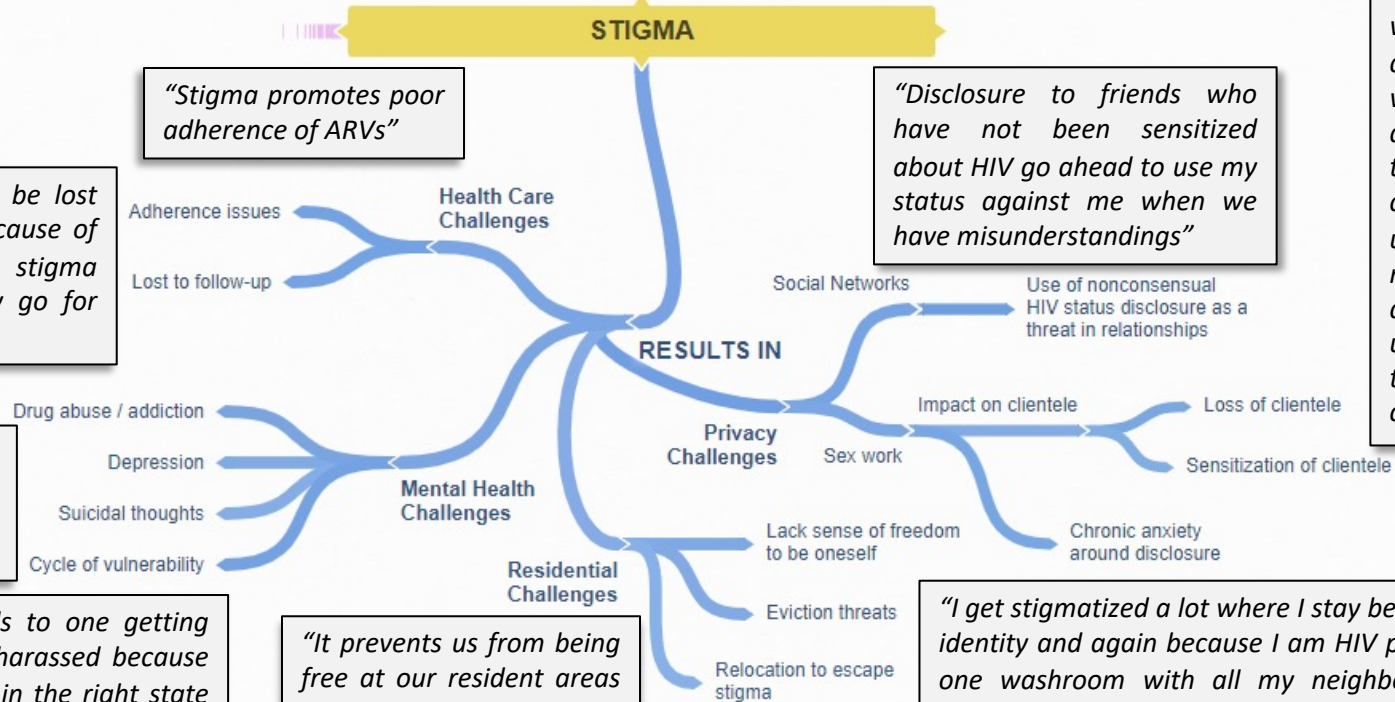"Lack of information and sensitization on HIV and AIDS to members of the public"

"Some people still believe in myths about HIV and AIDS. They don't believe that HIV exists and so, they see us as bewitched"

Lack of Information / Sensitization in Community

IS PROMOTED/ CAUSED BY

Prevalence of HIV/AIDS Myths

STIGMA

Community Map Breakdown

Stigma results in…

STIGMA

"Stigma promotes poor adherence of ARVs"

"Disclosure to friends who have not been sensitized about HIV go ahead to use my status against me when we have misunderstandings"

"Some decide to be lost to follow ups because of the continuous stigma faced when they go for medication."

"I engage in sex work for a living and one time my work mate disclosed my status to one of my clients, this ended up so bad because my client panicked and got stressed up a lot even though we used a condom."

Adherence issues — Health Care Challenges

Lost to follow-up

Social Networks → Use of nonconsensual HIV status disclosure as a threat in relationships

RESULTS IN

Drug abuse / addiction

Depression

Suicidal thoughts

Cycle of vulnerability

Mental Health Challenges

Privacy Challenges

Impact on clientele → Loss of clientele

Sex work → Sensitization of clientele

Lack sense of freedom to be oneself

Chronic anxiety around disclosure

Residential Challenges

Eviction threats

Relocation to escape stigma

"It leads to drug abuse and addiction in order to cope with challenges"

"Stigma leads to one getting abused and harassed because they are not in the right state of mind due to depression"

"It prevents us from being free at our resident areas because our neighbors stigmatize us a lot especially when our HIV status is known"

"I get stigmatized a lot where I stay because of my sexual identity and again because I am HIV positive… We share one washroom with all my neighbors so they don't always like sharing the washrooms because they believe I will transmit the virus to them and sometimes they end up telling the landlord to vacate me because I am a threat to them"

Recommendations

- **Expanded resources for PLWH**
  - Self-awareness sessions
  - Guidance around practice of self-disclosure
- **Sensitization and training** offered to:
  - Tracers
  - Chief Barazas
  - Health care workers
  - Community members
- **Increased visibility of PLWH**
  - Put on educational skits/dramas
  - Participation in community events

Next Steps

- Creation of self-empowerment tools for those entering health care settings

- Group therapies

- Integrate findings internally – *peer educators*

- Target sources of stigma (e.g., sensitization of religious leaders, surveying Boda Boda drivers)

Advocating for Your Health

Self-Affirmation Statements

Advocating for yourself starts with loving yourself and remembering that you matter. When you're feeling low, practice sayings like this:

"I am going to this health facility because I love myself and I want to be well."

"My opinions, expressions, and health matter."

"Even if the doctor doesn't respect me, that does not mean I don't deserve respect."

You are **not** alone
You are **not** at fault

Gratitude

References

- James SL, Abate D, Abate KH, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet.* 2018;392(10159):1789-1858.

- Bekker L-G, Alleyne G, Baral S, et al. Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society Lancet Commission. *The Lancet*. 2018;392(10144):312-358.

- Dwyer-Lindgren L, Cork MA, Sligar A, et al. Mapping HIV prevalence in sub-Saharan Africa between 2000 and 2017. *Nature.* Jun 2019;570(7760):189-193.

- UNAIDS. Global AIDS strategy 2021-2026: end inequalities. *End AIDS*. 2021.

- United Nations. Sustainable Development Goals. 2022; https://sdgs.un.org/#goal_section. Accessed September 29 2022, 2022.

- Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, Turan JM. Framing Mechanisms Linking HIV-Related Stigma, Adherence to Treatment, and Health Outcomes. *American journal of public health*. 2017;107(6):863-869.

- Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ open*. 2016;6(7):e011453.

- Yebei VN, Fortenberry J, Ayuku DO. Felt stigma among people living with HIV/AIDS in rural and urban Kenya. *African health sciences*. 2008;8(2).

- Kingori C, Reece M, Obeng S, et al. Impact of internalized stigma on HIV prevention behaviors among HIV-infected individuals seeking HIV care in Kenya. *AIDS patient care and STDs*. 2012;26(12):761-768.

- Rankin WW, Brennan S, Schell E, Laviwa J, Rankin SH. The stigma of being HIV-positive in Africa. *PLoS medicine*. 2005;2(8):e247.

- Akatukwasa C, Getahun M, El Ayadi AM, et al. Dimensions of HIV-related stigma in rural communities in Kenya and Uganda at the start of a large HIV 'test and treat' trial. *PloS one*. 2021;16(5):e0249462.

- Musyoki H, Bhattacharjee P, Sabin K, Ngoksin E, Wheeler T, Dallabetta G. A decade and beyond: learnings from HIV programming with underserved and marginalized key populations in Kenya. *Journal of the International AIDS Society*. 2021;24(S3):e25729.

References

- Goffman E. Stigma: Notes on the management of spoiled identity: Simon and schuster; 2009.
- Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: moving toward resilience. *The American psychologist*. May-Jun 2013;68(4):225-236.
- Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and behavior*. 2013;17(5):1785-1795.
- Yigit I, Bayramoglu Y, Weiser SD, et al. Changes in internalized stigma and HIV health outcomes in individuals new to HIV care: The mediating roles of depression and treatment self-efficacy. *AIDS patient care and STDs*. 2020;34(11):491-497.
- Graham SM, Micheni M, Secor A, et al. HIV care engagement and ART adherence among Kenyan gay, bisexual, and other men who have sex with men: a multi-level model informed by qualitative research. *AIDS care*. 2018/08/23 2018;30(sup5):S97-S105.
- Thirikwa JW. Emergent momentum for equality: LGBT visibility and organising in Kenya. Downloaded from the Humanities Digital Library. 2018:307.
- Müller A, Daskilewicz K. Mental health among lesbian, gay, bisexual, transgender and intersex people in East and Southern Africa. European *Journal of Public Health*. 2018;28(suppl_4):cky213. 794.
- Andersson GZ, Reinius M, Eriksson LE, et al. Stigma reduction interventions in people living with HIV to improve health-related quality of life. *The Lancet HIV*. 2020;7(2):e129-e140.

Questions?