

Measuring and addressing stigma

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HIV LEARNING NETWORK
The CQUIN Project for Differentiated Service Delivery

Outline

- **Defining Stigma**
- **Measuring Stigma**
- **Addressing Stigma**

Setting the Scene

Patrick: ‘The CLAD leader talks about people he picks drugs for, so I opt to travel long distances to pick my drugs from the health centre’

Patience: ‘I cannot be seen picking drugs from my neighbor’s compound!’

Maureen: ‘My family members are very supportive but I fear to be seen. I am ashamed to be HIV+’

Mark: ‘Over my dead body! I cannot disclose to my wife that I am HIV positive, she will leave me!’

Student leader: ‘This student is HIV+ so we should burn her up, she must be infecting us’

Winnie: ‘I am not sure when and how I will disclose to my children, they may reject me’

What is Stigma?

A Social Process that Occurs in the Context of Power

1. Distinguishing and Labeling Differences

(person living with HIV, person who injects drugs, gay man, sex worker)

2. Associating Negative Attributes

(irresponsible, immoral, promiscuous, untrustworthy)

3. Separating “Us” from “Them”

(physical and social isolation)

4. Status Loss and Discrimination

(denial of health care, verbal & physical abuse, loss of respect)

Types of Stigma

Experienced	Stigma that is enacted through interpersonal acts of discrimination
Perceived	Perception of the prevalence of stigmatizing attitudes in the community, amongst health care workers or other groups
Anticipated	Fear of stigma, whether or not it is actually experienced
Internalized (self)	Acceptance of experienced or perceived stigma as valid and/or justified

Key Effects of Stigma & Discrimination

- Failure to seek medical attention/honour appointments
- Isolation/exclusion from social events/gatherings
- Inability to join and access care and treatment e.g. CDDPs
- Sexual rejection
- Loss of employment
- Psychological pressure/manipulation

Measuring Stigma – 1

- Stigma among PLHIV is measured by the **PLHIV Stigma Index**
 - Cross sectional, one point at a time, by, for and with PLHIV
 - > 90 countries, involving > 100,000 PLHIV, have rolled out the survey
- Developed by the Global Network of PLHIV (GNP+), UNAIDS, ICW and IPPF in 2008
 - Validated in 2017 in Uganda, Senegal and Cameroon to capture recent developments such as Viral Load.
 - Tool available as Stigma Index 2.0 (stigmaindex.org)



Measuring Stigma – 2

- The tool captures experiences of stigma of PLHIV in the last one year through examining forms and trends. Added was capturing resilience levels and KP specific experiences to understand stigma intersectionality
- Variables capture experiences of internal and external stigma, disclosure, resilience, access to health care (testing, ART, VL), rights, laws & policies, effecting change.



Why the PLHIV stigma index?



Measures/quantifies HIV Stigma and discrimination related experiences

Describes the stigma and discrimination as perceived by PLHIV

Measure and document stigma to develop evidence-based, responsive strategies

Provides for evidence-informed advocacy, policy reform and service delivery

Broadens understanding of the extent and forms of stigma and discrimination

Roll out of stigma index in CQUIN countries

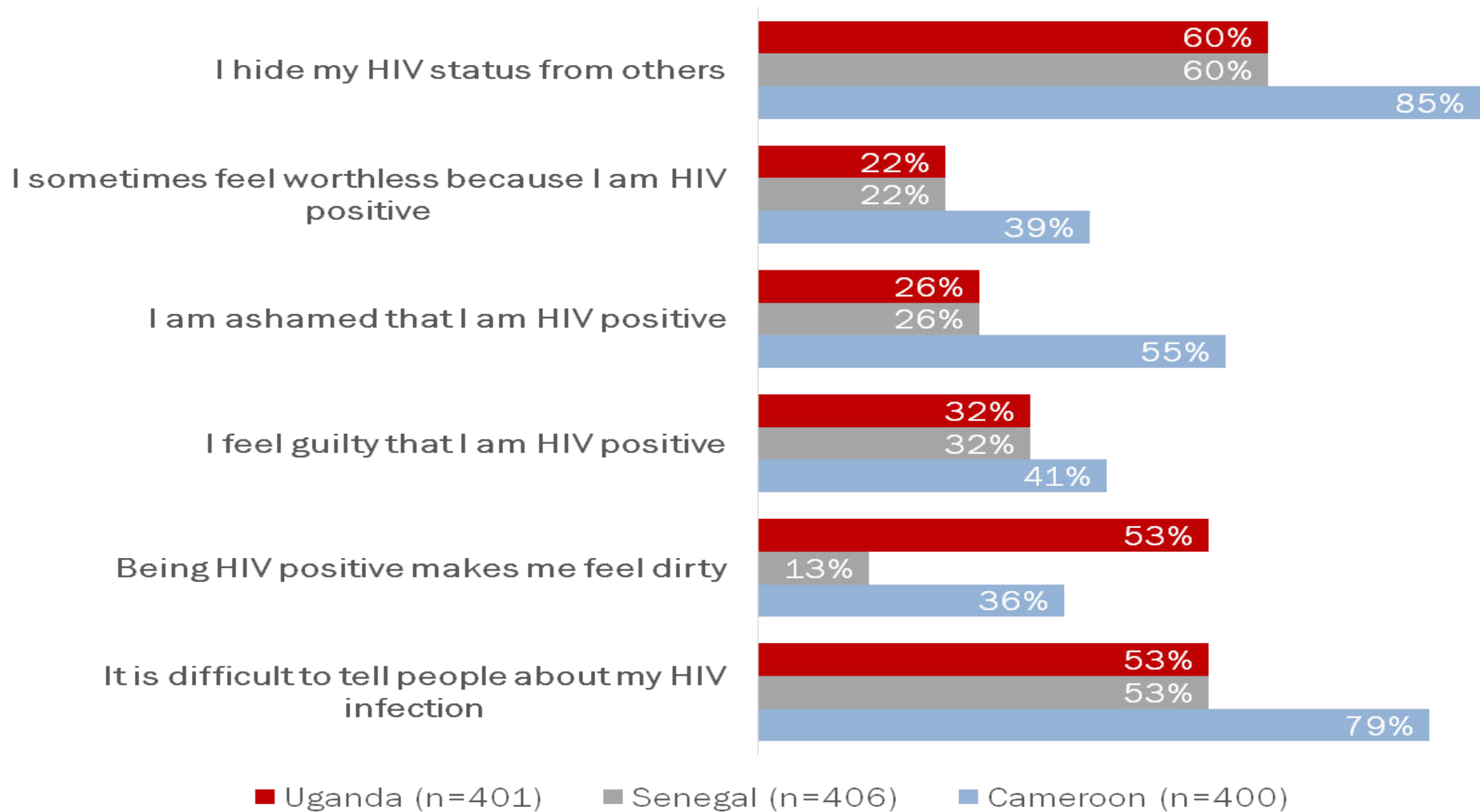
Country, year, number	Country, year, number
Uganda (2013 n1110, 2019 n1398)	South Africa (2014 n10,473)
Kenya (2011 n 1086)	Eswatini (2011 n1233, finalizing 2019 survey report)
Tanzania (2013 n2205)	Zambia (2012 n854)
Ethiopia (2011, n3360)	Zimbabwe (2014 n1905)
Ivory Coast (2016 n1230)	Mozambique
Malawi (2016 n4504, 2012 n2266)	

Manifestations of Internal stigma – CQUIN countries

Variable %	Eth	Ky	Ug	SA	Esw	Zam	Zim	Mal '16	'12	IV	Moz	Tz
Ashamed	45.5	43	50	29	13	45.1	21.8	13.4	14.2	33.2	34.8	29.2
Guilty	44	44	50	28	13.2	44.1	18.6	28.7	24.9	30.8	32.8	14.6
Blame self	53	49	50	31	13	39.9	16	19.6	26	26	60	30.6
Blame others	26	27	50	19	15.5	29.2	19.7	13.5	10.2	10.2	36	13.1
Low self esteem	52	45	67	22	12.5	33.7	19	9.8	13.6	13.6	35.5	43.7
Should be punished	28	8	50	11	2.5	10.3	4	14.9	7	7	6.1	5.4
Feeling Suicidal	19	14.5	55	11	3.5	12.1	7	3.2	8.7	8.7	10	6.4

Pilot study – internal stigma (n=1207; 401 in Uganda) - 2017

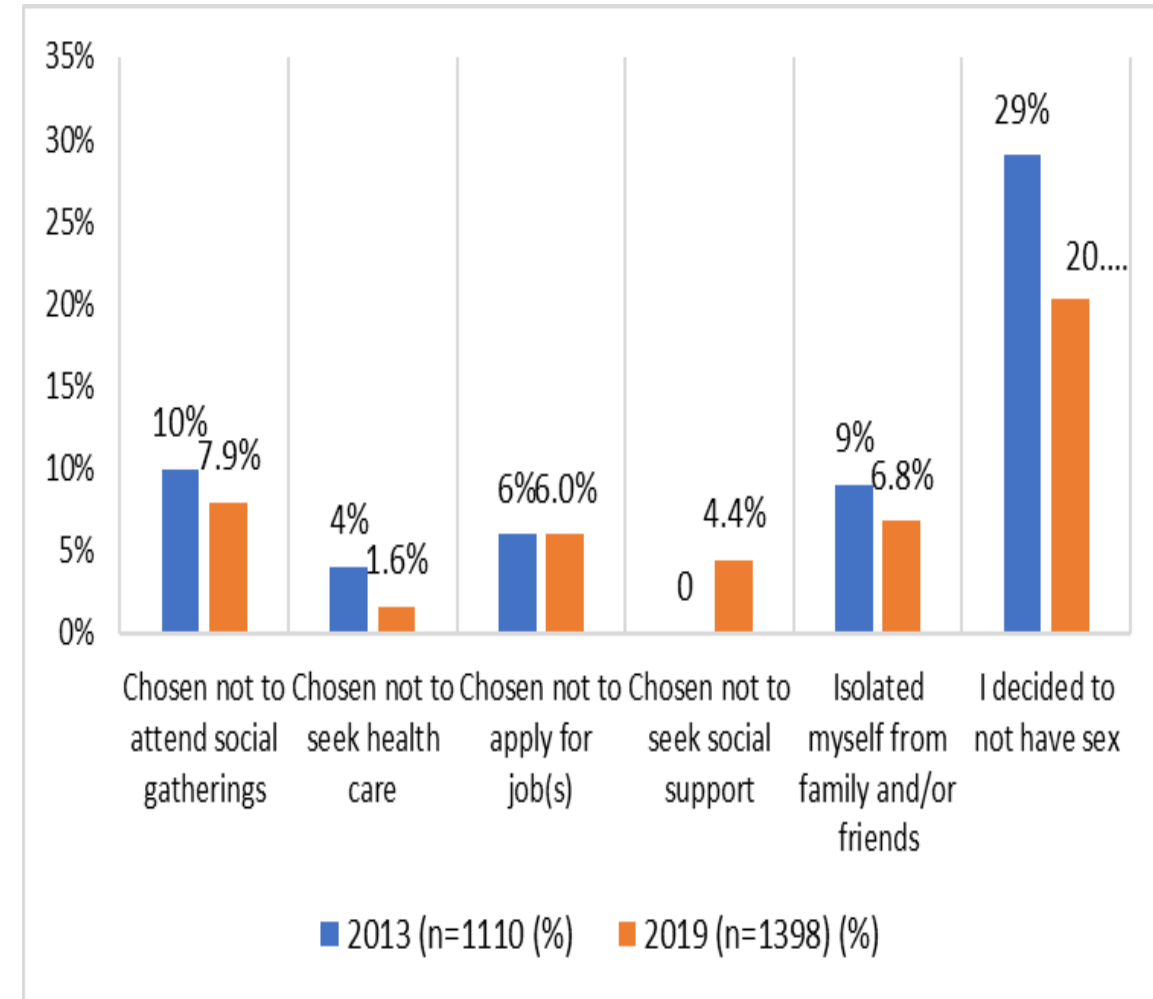
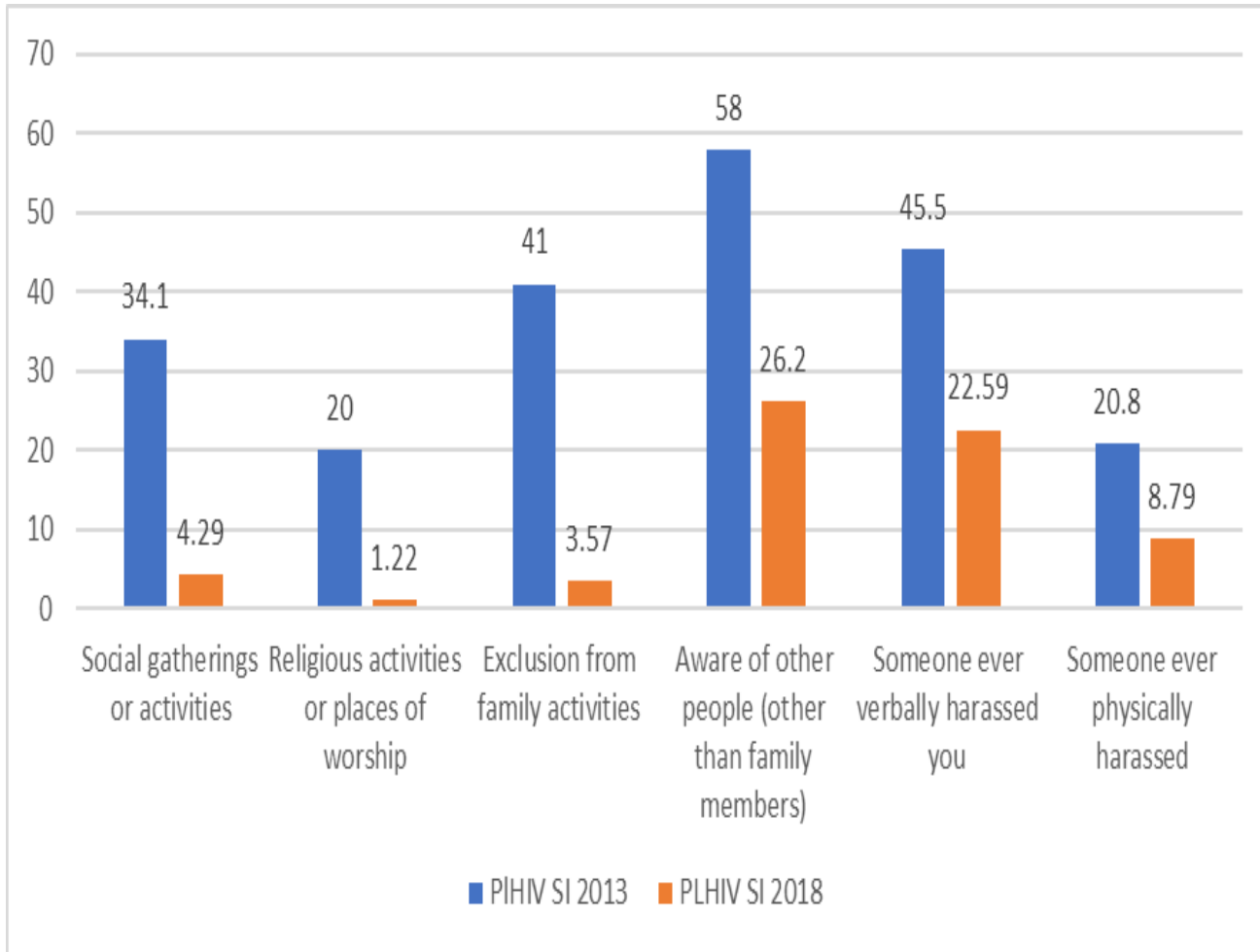
6-question internal stigma scale



Uganda – Internal Stigma 2019

Specific experiences				
	Response	Female n (%)	Male n (%)	Total n (%)
It is difficult to tell people about my HIV infection	Disagree	557(63.73)	328(62.60)	885(63.33)
	Agree	314(35.93)	195(37.21)	509(36.38)
Being HIV positive makes me feel dirty	Disagree	755(86.38)	467(89.12)	1222(87.40)
	Agree	117(13.39)	55(10.50)	172(12.29)
I feel guilty that I am HIV positive	Disagree	650(74.37)	399(76.15)	1049(75.05)
	Agree	221(25.29)	119(22.71)	340(24.30)
I am ashamed that I am HIV positive	Disagree	675(77.23)	424(80.92)	1099(78.60)
	Agree	197(22.54)	100(19.08)	297(21.23)
I sometimes feel worthless because I am HIV positive	Disagree	694(79.41)	433(82.63)	1127(80.60)
	Agree	169(19.34)	86(16.41)	255(18.23)
I hide my HIV status from others	Disagree	593(67.85)	356(67.94)	950(67.90)
	Agree	281(32.15)	167(31.87)	448(32.02)

Uganda: External Stigma and PLHIV Choices 2013 vs 2019



Uganda 2019: Key Populations

Concept of **double stigma** because of belonging to some groups as well as stigma associated with living with HIV

- **Transgender** (more of verbal harassment at 28.5)
- **MSM** (more of discriminatory remarks at 24.2%)
- **Gay/homosexual** (discriminatory remarks at 16.6%)
- **Gay/lesbian** (discriminatory remarks/gossip at 39.9%)
- **Sex workers** (discriminatory remarks at 28.7% and verbal harassment at 26.3%)
- **People who inject/use drugs** (discriminatory remarks at 28.9%)

All countries: why stigmatised?

Largely due to;

- Afraid/fear to contract HIV
- Ignorance
- Considered shameful to be HIV+
- Religious/moral judgment
- Disapproval of lifestyles
- Having AIDS symptoms
- Others were not sure why

Addressing Stigma – 1

- Stigma affects service delivery when the beneficiaries cannot freely access and utilize the available services
- The longer the person lives with HIV, the lesser the stigma, the more the resilience. In context of Test and Treat and DSD, newer cases must be supported to absorb shocks!
- Use the findings to plan for stigma reduction strategies at all levels

Addressing Stigma – 2

- Fund stigma studies to monitor trends and reduction strategies that address stigma as a structural barrier if quality and QI are to be attained
- AIDS competency trainings for health workers
- Target male involvement, over 65% of respondents were women

Addressing stigma to achieve quality care

Protect

- Anti discrimination laws
- Decriminalisation
- Challenging violence

Include

- Key population in healthcare service design and implementation
- Stigma and discrimination reduction as a goal in national strategies

Empower

- To understand rights
- To act on violations

Educate

- To address fears
- To change attitudes

To achieve quality care, an effective response to the HIV epidemic must tackle the root causes of stigma and ensure services are inclusive and accessible in a stigma free environment

Closing the scene

As Edwin Cameron observes, “...if we do not appreciate the nature of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatised disease.”

