



Implication of Self-Stigma on PLHIV in Jamaica

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Implications of **Self-Stigma** on Dignity of PLHIV in Jamaica



JN+
Jamaican Network of Seropositives

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- THE JAMAICAN NETWORK OF SEROPOSITIVES (JN+)

WHO ARE WE?

The Jamaican Network of Seropositives (JN+) is a community-led national non-profit advocacy organization established in 1996 and formally registered on October 1, 1999.

JN+ represents and advocates on behalf of persons living with and affected by HIV in Jamaica and is the largest network of persons living with HIV in Jamaica.



Key Terms

- **Dignity**

An intrinsic feeling of worth that is received at birth and developed and maintained by the psychosocial environment.

- **Guilt & Shame Self-conscious**

‘moral’ emotions, which arise in response to an evaluation of the self.

- **Self Stigma**

Negative views that individuals hold about themselves and dignity was defined as a sense of pride in oneself.

Objectives

- To assess how perceived/self-stigma affects PLHIV accessing HIV treatment and care services
- To understand what interventions and programmes are available for PLHIV for the care and treatment of self-stigma and the enabling of their dignity
- To share PLHIV lived experiences relevant to the impacts of stigma and discrimination on their desire to access and adhere to HIV treatment and care

Background and Context

- The first case of HIV in Jamaica was documented in 1982 and at present there is an estimated 32,000 people in Jamaica that are living with HIV
- The Jamaican Network of Seropositives (JN+) in 2020 published its Jamaica Stigma Index 2.0 survey for persons living with HIV (PLHIV) and it indicated that (53%) of the respondents reported experiencing self-stigma.
- More specifically, respondents indicated that they felt **guilty (42%)**, **ashamed (36%)**, **worthless (29%)**, or **dirty for living with HIV (27%)**.
- In addition, over half of respondents reported engaging in at least one self-isolating behaviour in the past 12 months—for example, self-isolation from friends and family.
- Additionally, approximately half of the respondents reported experiencing anxiety and depression.

Methodology

- Participatory Action Research (PAR) approaches were used for this research looking at the impact of self-stigma on PLHIV accessing care in Jamaica.
- A total of 267 questionnaires were administered via JN+ community Facilitators and Retention Navigators who are PLHIV.
- Five (5) focus group discussions were conducted with:
 - 2 groups - 9 women participants living with HIV,
 - 1 group - 4 cisgender men living with HIV,
 - 1 group - 5 MSM/Trans persons living with HIV
 - 1 mixed group - cis-men and ciswomen living with HIV
- Secondary data was informed from the body of work obtained from the 2020 Stigma Index 2.0.

Key Findings

Table 1: Table showing the demographic variables of survey respondents (N=267)

	Variable	Proportion of Respondents
Gender	Male	32%
	Female	65%
	Transgender Women	1%
	Unspecified	2%
Parish	Kingston/St. Andrew	20%
	St. Catherine	13%
	Clarendon	14%
	Manchester	8%
	St. Elizabeth	4%
	Westmoreland	4%
	Hanover	3%
	St. James	9%
	Trelawny	5%
	St. Ann	6%
	St. Mary	9%
	Portland	4%
	St. Thomas	2%
	Age Group	18-24
25-34		29%
35-44		31%
45-54		24%
55+		8%
HIV Duration	Less than 10 years	42%
	Greater than 10 years	58%

Key Findings

Table 2: Table showing the number and proportion of respondents who report feeling guilt because of their HIV status disaggregated by gender, age and length of time living with HIV (N=267)

	Feeling of Guilt					p-value
	Always	Most Times	Sometimes	Never/Rarely	Not Anymore	
Gender						0.21
Male	10 (12%)	13 (15%)	37 (44%)	9 (11%)	16 (19%)	
Female	22 (13%)	20 (12%)	59 (34%)	34 (20%)	39 (22%)	
Transgender Women	0 (0%)	1 (33%)	1 (33%)	1 (33%)	0 (0%)	
Other	1 (20%)	0 (0%)	0 (0%)	3 (60%)	1 (20%)	
Age Group						< 0.01
18-24	2 (10%)	4 (20%)	10 (50%)	3 (15%)	1 (5%)	
25-34	16 (21%)	14 (18%)	32 (41%)	5 (6%)	11 (14%)	
35-44	7 (9%)	10 (12%)	28 (34%)	21 (26%)	16 (20%)	
45-54	5 (8%)	4 (6%)	19 (29%)	15 (23%)	22 (34%)	
55+	3 (14%)	2 (9%)	8 (36%)	3 (14%)	6 (27%)	
HIV Duration						< 0.001
Less than 10 years	22 (20%)	20 (18%)	49 (43%)	12 (11%)	10 (9%)	
Greater than 10 years	11 (7%)	14 (9%)	48 (31%)	35 (23%)	46 (30%)	



Figure 01: Graph Showing How a HIV Positive Diagnosis affected the Lives of PLHIV disaggregated by Sex assigned at Birth, Length of Time Living with HIV and Age (N=267)

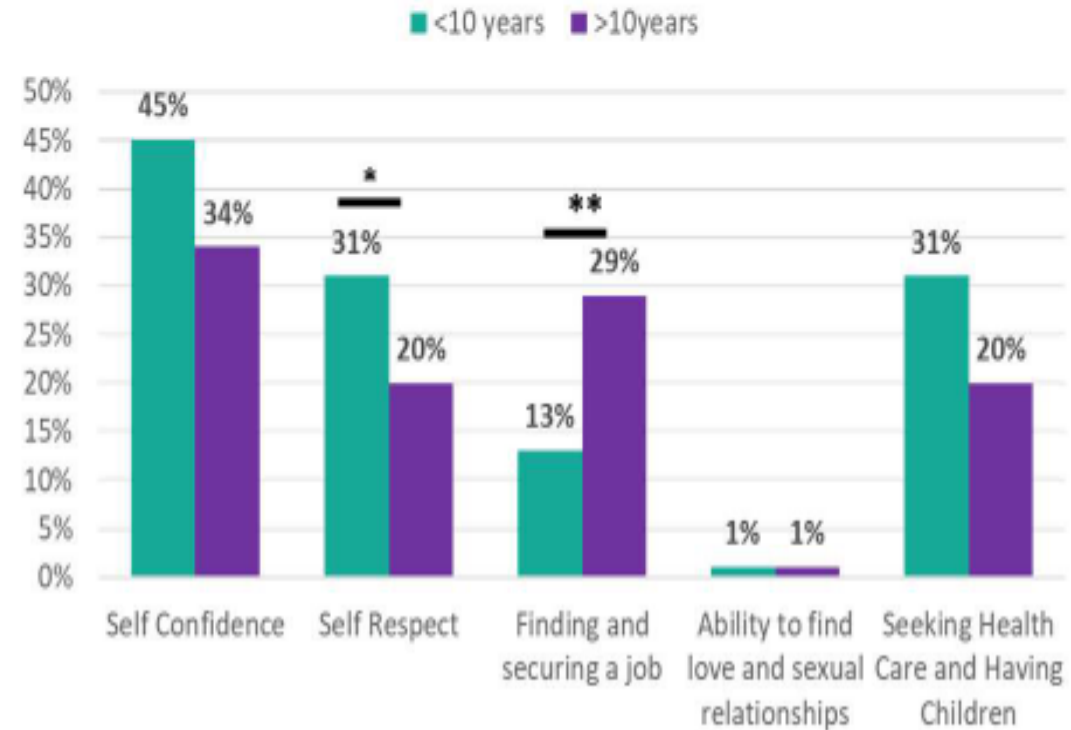
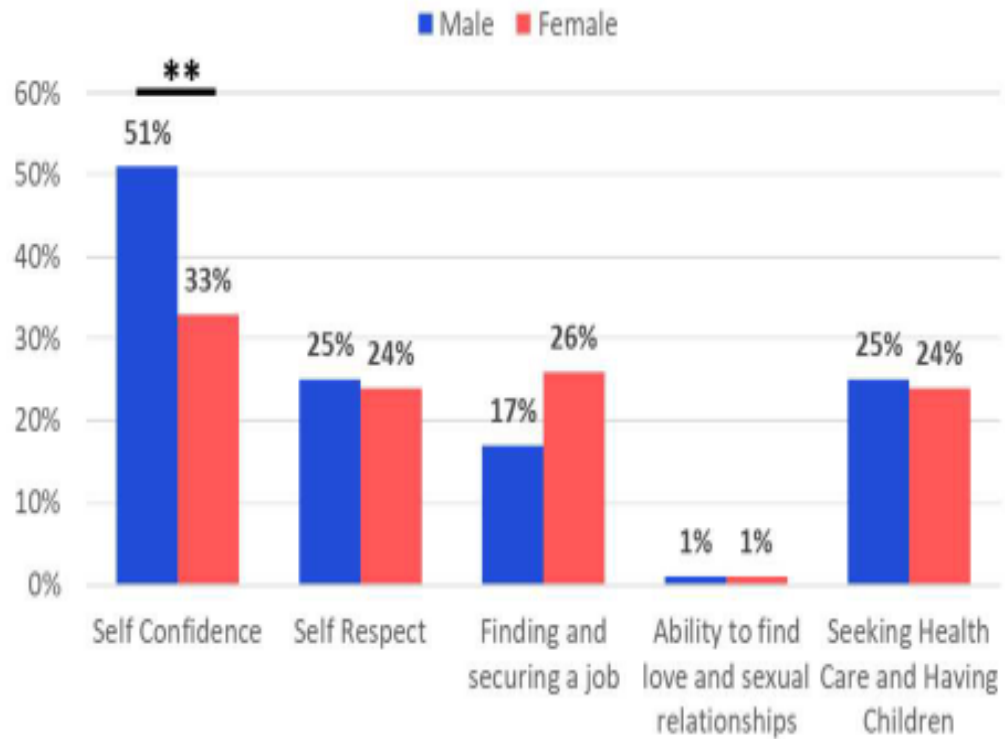
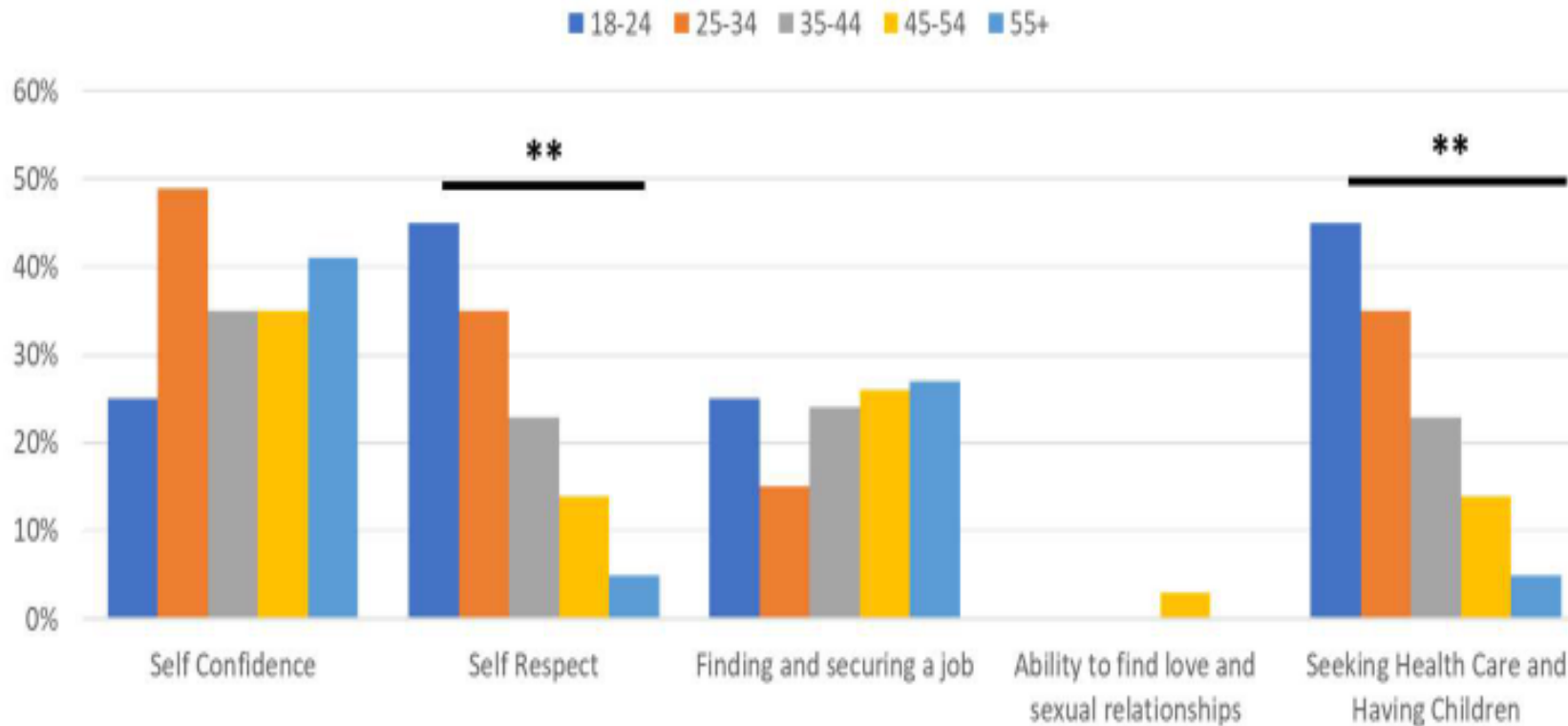


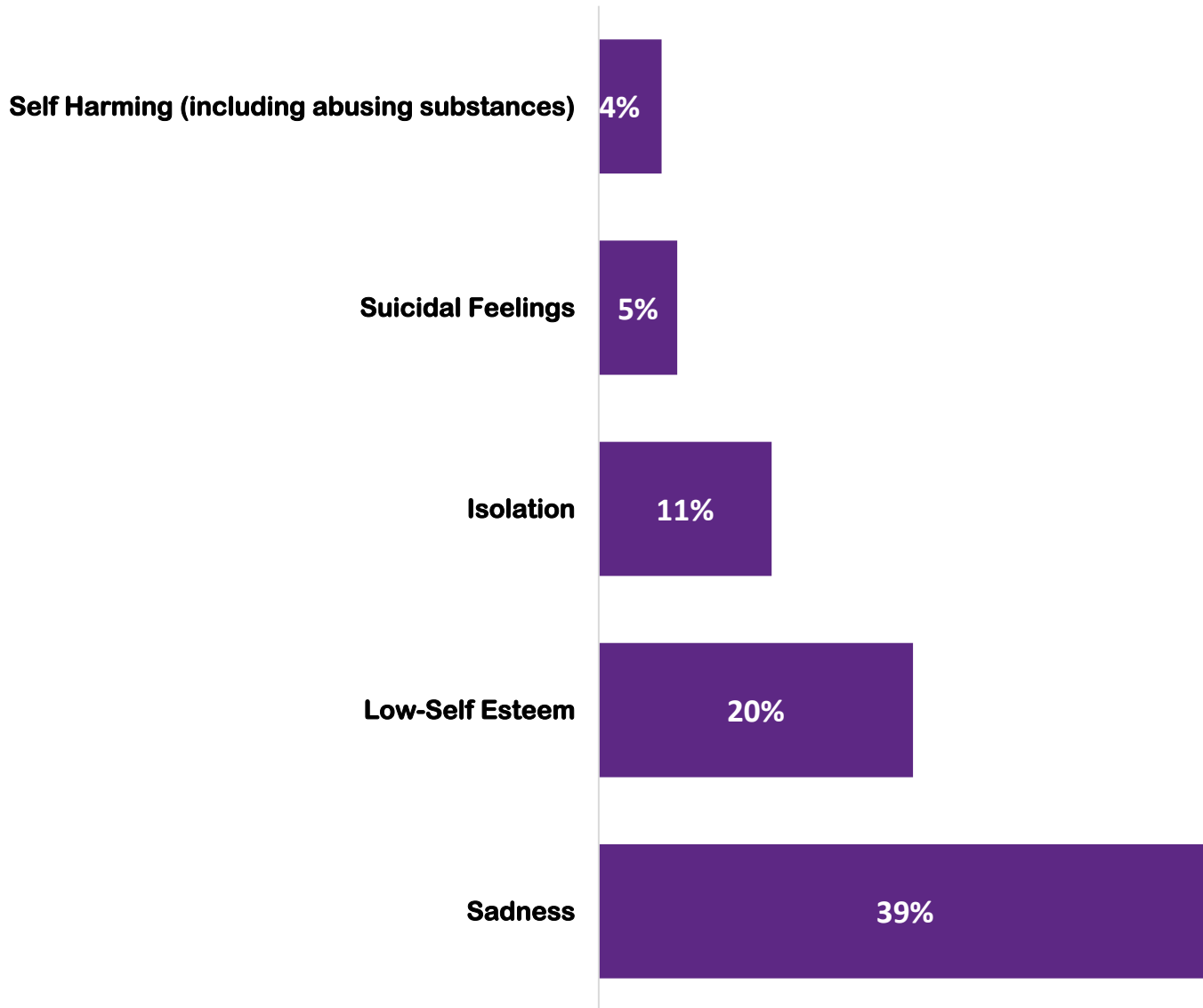
Figure 01: Graph Showing How a HIV Positive Diagnosis affected the Lives of PLHIV disaggregated by Sex assigned at Birth, Length of Time Living with HIV and Age (N=267)



Key Findings

Table 03: Table showing the number and proportion of respondents who report feeling shame because of their HIV status disaggregated by gender, age and length of time living with HIV (N=267)

	Feeling of Shame					p-value
	Always	Most Times	Sometimes	Never/Rarely	Not Anymore	
Gender						0.41
Male	8 (9%)	5 (6%)	30 (35%)	30 (35%)	12 (14%)	
Female	28 (16%)	17 (10%)	43 (25%)	50 (29%)	36 (21%)	
Transgender Women	0 (0%)	1 (33%)	1 (33%)	1 (33%)	0 (0%)	
Other	1 (20%)	0 (0%)	1 (20%)	1 (20%)	2 (40%)	
Age Group						< 0.01
18-24	3 (15%)	5 (25%)	6 (30%)	5 (25%)	1 (5%)	
25-34	18 (23%)	9 (12%)	22 (28%)	14 (18%)	15 (19%)	
35-44	9 (11%)	7 (8.5%)	21 (26%)	36 (44%)	9 (11%)	
45-54	4 (6%)	2 (3%)	18 (28%)	21 (32%)	20 (31%)	
55+	3 (14%)	0 (0%)	8 (36%)	6 (27%)	5 (23%)	
HIV Duration						< 0.001
Less than 10 years	27 (24%)	14 (12%)	34 (30%)	25 (22%)	13 (12%)	
Greater than 10 years	10 (7%)	9 (6%)	41 (27%)	57 (37%)	37 (24%)	



Key Findings

Graph Showing the Most Common Emotions experienced by PLHIV Due to their Positive Status (N=267)

The Feeling of Guilt:

When participants were asked the question “how did you feel about yourself when you were first diagnosed with HIV?”, a variety of responses were provided. Among both men and women, the responses associated with guilt are reflected below:

1. Man – “I am only sorry for the number a girls weh mi get involved with”
2. Man – “I can’t run the streets again like one time”
3. Man – “Felt a darkness come over my life”
4. Man – “Me did feel guilty but never take no long long time to get over about 4 or 5 months. Get more comfortable over time. The support that I have around me helped me realize I need to take my meds to stay alive. I have my kids to live for.
9. Woman – “I do not want my child to be discriminated against because of my positive status.”
10. Transwoman – She felt guilty because she knew her partner had HIV but continued to engage in unprotected sex.

The Feeling of Shame

Shame came up in response to the question of “how did you feel about yourself when you were first diagnosed with HIV?” Respondents' expressions of shame are reflected in the responses below:

1. Man– “More time mi feel a way cause people see you a visit the hospital a collect your meds. Mi comfortable in myself now. Is ten years I have it.. You haffi do it to survive”.
4. Woman– “I attempted suicide because of my positive status.”
5. Woman– “Felt ashamed and it made me afraid thinking I would have to disclose HIV status when applying for a job.”
8. Woman– “I am a disaster.”
9. Woman– “I could have done better.”
10. Woman– “I couldn’t tell my children, I was embarrassed.”

Results of Open-Ended Questionnaire Questions and Focus Groups

Participants were asked, ‘What more do you believe can be done to reduce self-stigma among PLHIV?’

The respondents were able to provide multiple responses. The frequency of response occurrence appears in brackets. The top responses from participants were:

1. public education and awareness (59)
2. education and sensitization of PLHIV themselves (28)
3. peer to peer/ PLHIV support groups (20)
4. PLHIV empowerment (18)
5. PLHIV self-acceptance (12)
6. better laws and legal protection (10)

Recommendations

1

Additional studies to better understand the impact of self-stigma on younger populations.

2

Scaling up of community-led initiatives and peer-to-peer engagement, including support groups for newly diagnosed PLHIV and those struggling with adherence.

3

Using this data and other evidence driven approaches to implement psychosocial and mental health support programmes for PLHIV in Clinics.

4

Greater use of the Positive Health, Dignity and Prevention Framework in the National HIV-related programmes to build capacity of PLHIV.

5

Continuous engagement and sensitization of health care workers around rights and responsibilities especially around human rights and stigma and discrimination.

Recommendations

Public relations campaigns around the redress systems available to PLHIV.

Increased advocacy around the passing of anti-discrimination laws.

A comprehensive psychosocial Programme for Women of reproductive age living with HIV to deal with issues such as disclosure, pregnancy, breastfeeding, and the psychosocial challenges of vertical transmission.

Further research and programmatic exploration on the realities of older persons living with HIV.

Scaling up of Community led and people-centred approach programmes for PLHIV especially those in and out of care and those from more vulnerable populations.

Thank you for Listening

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