Implications of Self-Stigma on Dignity of PLHIV in Jamaica

Jamaican Network of Seropositives

Table of Contents

Acronyms & Abbreviations

ART	Antiretroviral therapy
ARV	Antiretroviral
GBV	Gender-Based Violence
HIV	Human Immunodeficiency Virus
JN+	Jamaican Network of Seropositives
JASL	Jamaica AIDS Support for Life
MSM	Men who have sex with men
PLHIV	People living with HIV

Acknowledgement

The Jamaican Network of Seropositives (JN+) would like to thank the persons who played a part in actualizing the ***Implication of Self Stigma on Dignity of PLHIV in Jamaica*** Study.

The study was made possible through the contribution of several individuals and organizations who helped to mobilize the community but also more importantly the PLHIV community who so willingly participated to provide the rich data.

Important to the results presented in this study is the community of people living with HIV who were willing to share their realities on the impact of self-stigma in their lives.

Additionally, we would like to thank our team of researchers; Dr. Alisha Robb-Allen and Dr. Tiffany Butterfield from the Ministry of Health and Wellness for their expert guidance through the execution of the study. We would also like to extend our appreciation to Jomain McKenzie who offered his services as Rapporteur for the compilation of the of the report.

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Executive Summary

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[1]. HIV is a highly stigmatized virus, and for many decades social scientist and researchers have been theorizing as to the reason for enacting stigma as well as different social protection programs that could HIV related reduce stigma and discrimination. However, we have not seen much empirical data on self-stigma and strategies that have been proven to reduce self-stigma and empower persons living with HIV. To further clarify, there isn't much data available as it relates to how self-stigma affects adherence to ART and the relationship between self-stigma and disclosure. The Jamaican Network of Seropositives released the report for Stigma index findings in 2020 and the reports indicated that **53%** of the respondent indicated that they are ashamed, guilty and dirty because of their HIV Status. As a result, JN+ decided to investigate the findings from the stigma index report and identify strategies to address self-stigma.

The Implications of Self-Stigma Study gathered information from **267** persons from the community of people living with HIV across Jamaica. The information was gathered using google forms. Additionally, five focus group sessions were conducted with Cis gender Men and Women, Men who have sex with Men (MSM) and Transgender persons. Most of the correspondents are from the parishes of Kingston, St. Andrew **(20%),** St. Catherine **(13%)** and Clarendon **(14%)**. Sixty-Five Per cent **(65%)** of the respondents identified as Women, thirty-two per cent (32%) identified as men, one per cent **(1%)** identified as trans women, and two per cent **(2%)** did not specify their gender.

The results from the study indicated that sixty one per cent **(61%)** of the respondents' experienced feelings of guilt due to their HIV Status, and fifty one per cent **(51%)** of the respondents experienced feelings of shame. Seventy-eight per cent **(78%)** of the respondents expressed that their lives were negatively impacted by their positive status, with the most common area being self-confidence. Many of the respondents reported voluntary disclosure to healthcare professionals and families. Sixty-six per cent (**66%)** of the respondents shared that their ability to negotiate condom use was not affected by their feelings of guilt and shame.

From the focus group discussions, the participants expressed their belief that public education and awareness as well as sensitization of PLHIV could be instrumental in the reduction of self-stigma among the community. The participants also called for better legal and social protection for members of the community.

Considering the findings from the study, JN+ made the following recommendations:

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[1] HIV IN JAMAICA – HISTORICAL TIMELINE. Ministry of Health Wellness National HIVSTITB Programme. (n.d.). Retrieved March 23, 2023, from https://hstu.moh.gov.jm/information-on-hiv-sti-tb/hiv-in-jamaica-historical-timeline/#:~:text=HIV%2FAIDS%20became%20an%20issue,This%20represents%20about%2027%2C000%20people.

- Additional studies to better understand the impact of self-stigma on younger populations.
- Scaling up of community-led initiatives and peer-to-peer engagement, including support groups for newly diagnosed PLHIV.
- Evidence Driven approaches to psychosocial and mental health support programmes for PLHIV and scale up of these programmes.
- Greater use of the Positive Health, Dignity and Prevention Framework in the National HIV related programmes.
- Continuous engagement and sensitization of health care workers around human rights and stigma and discrimination.
- Public relation 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 is the realities of older persons living with HIV.
- Scaling up of people centered approach programmes for PLHIV especially those in and out of care and those from more vulnerable populations.

Background

In 2020, The Jamaican Network of Seropositives published a Stigma Index for persons living with HIV (PLHIV). The PLHIV Stigma Index 2.0 gathered information on stigma and discrimination faced by PLHIV, with the intention of improving policymakers' understanding of PLHIV experiences and empowering PLHIV involved in the study design and implementation. The sample for the 2019 survey included 557 PLHIV in Jamaica, selected through a purposive (i.e., non-random) process. All participants were over the age of 18 and provided informed consent to participate. The sample included 290 cisgender women, 211 cisgender men, and 56 transgender or nonbinary people. Ninety-one participants were non-bisexual MSM, 60 were non-bisexual women who have sex with women (WSW), and 35 were bisexual.

The data from the study indicated that fifty-three per cent (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. More interestingly, approximately half of the respondents reported experiencing anxiety and depression. However, the PLHIV stigma index did not investigate how self-stigma affected the dignity of PLHIV.

Consequently, from these findings, JN+ desired to investigate the implications of self-stigma on the dignity of PLHIV across the country. For the purposes of the study, self-stigma was defined as the stigmatizing views that individuals hold about themselves and dignity was defined as a sense of pride in oneself. Even further, the study will investigate how one's view of themself, because of their HIV-positive status, affects the frequency of PLHIV accessing health care, adherence to their ARVs and disclosure.

Objectives

1. To assess how perceived/self-stigma affects PLHIV accessing HIV treatment and care services
2. To understand what interventions and programmes are available for PLHIV for the care and treatment of self-stigma and the enabling of their dignity
3. 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

Research Questions

1. As someone living with HIV in Jamaica, how has self-stigma affected you personally and your relationship with other PLHIV, friends and family?

2. Since being HIV+, what has changed in terms of behaviour, attitude and activities in your life and how have your family and friends been supporting you as someone living with HIV?

3. How have the providers of HIV treatment and care services been supporting you as a PLHIV with interventions and activities that would be beneficial and helpful as someone living with HIV dealing with Self Stigma?

Definition of Key Terms

Dignity	An intrinsic feeling of worth that is received at birth and developed and maintained by the psychosocial environment[2].
Guilt & Shame	Self-conscious, 'moral' emotions, which arise in response to an evaluation of the self[3].
Self-stigma	The perception of oneself as inadequate or weak [4]

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[2] Chummar, P. (2009). HIV/AIDS in Africa: A bioethical hard blow to human dignity and human rights. Proceedings of the International Conference on Bioethics, Njoro, 12-14 August 2008.

[3] Sheehy, K., Nouree, A., Khaliq, A., Dhingra, K., Husain, N., Pontin, E., Cowley, R., & Taylor, P. (2019). An examination of the relationship between shame, guilt and self-harm: A systematic review and meta-analysis. Clinical psychology review. Retrieved February 2, 2023, from https://pubmed.ncbi.nlm.nih.gov/31707184/

[4] Mittal, D., Sullivan, G., Chekuri, L., Allee, E., & Corrigan, P. (n.d.). Empirical studies of self-stigma reduction strategies: A critical review of the literature. Psychiatric services (Washington, D.C.). Retrieved February 2, 2023, from https://pubmed.ncbi.nlm.nih.gov/22855130/

Relevance to the Response

Stigma and Discrimination have caused a significant disruption in HIV services, especially for persons experiencing lower socio-economic conditions that rely heavily on the public healthcare system[5]. Data from the Stigma Index 2.0 study indicated that fifty-three per cent (53%) of respondents reported experiencing self-stigma and over half of the respondents reported engaging in at least one self-isolating behaviour in the past 12 months—for example, self-isolation from friends and family[6]. This research is relevant to further interrogate these findings towards the implementation of interventions and programmes that would help to reduce these gaps and challenges. Additionally, with the limited research and data available on this topic, this research aims to achieve the following and provide context and baseline for further studies to be conducted:

1. Bring attention and understanding to the experiences and challenges of the PLHIV participants on the issues they face due to self-stigma

2. Enable the participation of PLHIV participants to increase knowledge and awareness and ultimately an improvement in treatment and care services for them

3. Explore how PLHIV can create social change through advocacy using their own voices and capabilities to create change in programmes, interventions, and practices to meet their needs as users of HIV treatment and care services.

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[5] Fauk, N. K., Hawke, K., Mwanri, L., & Ward, P. R. (2021, May 19). Stigma and discrimination towards people living with HIV in the context of families, communities, and healthcare settings: A qualitative study in Indonesia. International journal of environmental research and public health. Retrieved February 2, 2023, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8159085/

[6] Jamaican Network of Seropositives and Health Policy Plus. 2020. The People Living with HIV Stigma Index: Jamaica. Washington, DC: Palladium, Health Policy Plus.

Research Design, Methodology and Data Collection

The study design and methodology followed community research approaches for achieving the most representative and valid body of evidence to test and query the research questions. The study utilized a mixed-methods approach. Primary data collection was done using quantitative as well as quantitative approaches through the administration of a questionnaire tool and focus group discussions. Secondary data was informed from the body of work obtained from the 2020 Stigma Index 2.0. The qualitative approaches through focus groups sought to unearth the lived realities of PLHIV and the nuanced expressions and impacts of self-stigma. The questionnaire process efficiently provided rapid results with an opportunity for analysis that would be relatively free of researcher bias (Johnson and Onwuegbuzie 2004). Cross-tabulations and chi-square analysis were utilized.

Researcher Positionality

In conducting this research, it was paramount that the researcher JN+, immediately re-established itself as a PLHIV community-led response organization that works predominantly with PLHIV across Jamaica. It was also key that the researcher recognized how this position, privilege and presence in the research process could potentially influence and impact the research outcomes. The position of JN+ as a PLHIV-led and operated organization, heightened its ability to appropriately and accurately articulate and reflect the views and lived experiences of the PLHIV participants. This insight, capacity, and advantage enabled the researcher to effectively facilitate a participatory approach to data gathering. JN+'s positioning allowed participants of this community study to co-lead discussions and conversations that ensured the rich unearthing of ideas and issues pertinent to the research objectives.

In alignment with positionality, the researcher placed significant importance on the willingness and ability to, at all times during the process of the research, constantly reflect and assess stance, presence and awareness in the researched space to ensure no impartiality. Reflexivity according to Argyris and Schon (1976), is the process in which you are able to reflect upon the ways, your own assumptions and actions influence a situation, and thus change your practice as a direct result of this reflective process in that context. Therefore, being acutely aware of this the researcher periodically assessed these principles and relationship dynamics to effectively reduce and sufficiently eliminate the possibility of the researcher's personal assumptions, values and experiences that would shape the research process and outcomes.

Research Design Type and Justification

Participatory Action Research (PAR) approaches were used for this research looking at the impact of self-stigma on PLHIV accessing care in Jamaica. The purpose of PAR is to minimize power differences between researcher and constituents, increase the knowledge of participants, and promote social change. Participatory Action Research relies on developing and trusting relationships among members, especially for a consensus about research project goals, data collection methods, and analysis of findings, and recommendations can be reached. Based on the JN+'s positionality the research intended to enable and empower the PLHIV community to be vocal about their experiences and thereby take proactive action in advocating for personal and social change and transformation.

Recognizing the body of evidence which speaks to the impact of stigma and discrimination on HIV globally and locally, it was critical that the researcher collected information about the problem/issues faced by PLHIV, directly from PLHIV – having lived experiences. This PAR study required direct contact and engagement through dialogues with the PLHIV community to develop an understanding of the relationship between self-stigma and PLHIV wellness and survival in a personal, social, and economic context. Identifying the issues allowed for opportunities to interrogate, theorize and collect data and information related to the origin and parameters of their problems and to generate possible solutions to address them.

In-depth questionnaire Tool

A total of 267 questionnaires were completed. The tool comprised a total of 22, mostly closed-ended, questions. The questionnaires were primarily self-administered via a Google Forms Survey tool. This allowed for maximum uptake and the wide geographical reach of participants from urban and rural parishes. During the active COVID-19 pandemic, using the questionnaire tool also enabled adherence to protocols and ensured participants' and facilitators' safety. A small cohort of participants was assisted by staff with the completion of the questionnaire. This provided support where there were challenges of reading/writing literacy as well as inadequate access to the internet. The questionnaires included limited open-ended questions to aid in gleaning experiential feedback while providing the opportunity to generate some level of free-thinking from the sample that would not participate in focus group discussions. To further ensure the wide geographical reach of the questionnaire, JN+ staff, and members, already with representation in each parish of the island, were engaged in its snowball dissemination. This included, but was not limited to community facilitators, JN+ Board, and JN+ volunteers tasked to share widely among their peers and networks of PLHIV.

Focus Group Discussions

Five (5) focus group discussions were conducted and co-facilitated with two sets of 9 women participants living with HIV, one group of 4 cisgender men, one group of 5 MSM/Trans persons and one mixed group of cis-men and ciswomen. The five focus group discussions explored issues from the perspective of gender, age, urban and rural living, as well as the perspectives of PLHIV living with other health challenges. The discussions were coordinated by JN+ staff and conducted primarily, for efficiency and cost, on the heels of existing programmatic interventions such as support group sessions. Independent sessions for MSM and transgender persons were organized and conducted together due to the cordial familiarity of the participants.

The data collection process was completed over a two-month period.

Sampling Approaches

The study's geographical focus included PLHIV participants living and accessing HIV care across Jamaica. The Ministry of Health and Wellness (Spectrum estimates, 2019-revised) reports that there is an estimated 32,000 PLHIV in Jamaica with an adult prevalence of 1.5%.

The sampling approach used for this research was a non-probability purposive sample to support the adequate recruitment of PLHIV participants across Jamaica that were willing and able to adequately support and participate in the research. The sample group was pulled from the active database of JN+ members and their peers. Using the snowballing techniques, the participants were also invited to share the questionnaire link/tool with peers. This was ideal to ensure appropriate representation, the sharing of lived experiences and the facilitation of the empowerment of participants to be thoroughly vocal about how, what, and where changes were needed to better support them as PLHIV impacted by self-stigma.

Data Analysis

The data responses from questionnaires and focus groups were carefully reviewed, listened to, transcribed and analyzed. Quantitative data was collated and analyzed using Excel and PSPP statistical software. Frequencies were calculated and cross-tabulations and the chi-square test were utilized to determine associations and establish relationships between their HIV status and internal and external stigma. A p-value of < 0.05 was considered significant.

Focus group recordings were transcribed and coded. Themes and codes were generated in relation to the questions and study objectives. Rapporteur and discussion facilitator notes as well as recording transcriptions were analysed to generate these codes and themes. The qualitative and quantitative data were triangulated to ensure that the data analysis provided valid information.

Results

Demographics of Survey Respondents

The majority of respondents identified as women (65%) followed by men (32%) with a smaller proportion of transgender women (1%) and unspecified gender(s) (2%). Most respondents were from Kingston & St. Andrew (20%) followed by Clarendon (14%) and St. Catherine (13%). There was a higher proportion of respondents from rural areas (58%) compared to urban (42%) (Kingston & St. Andrew, St. Catherine, & St. James). Thirty-one per cent (31%) of respondents were aged 35 – 44 years followed by 29% and 24% of respondents being aged 25 – 34 years and 45 – 54 years respectively. There was a higher proportion of respondents (58%) living with HIV for greater than 10 years.

Table 01: 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	8%
	25-34	29%
	35-44	31%
	45-54	24%
	55+	8%
HIV Duration	Less than 10 years	42%

Greater than 10 years	58%

Feelings of Guilt and/or Shame

Sixty-one per cent (61%) of respondents indicated feeling guilt due to their HIV status at least sometimes and 51% reported feeling shame. The feeling of guilt and shame due to their HIV status was significantly associated with age (χ^2 = 33.64, df = 16, p = *0.006*; χ^2 = 39.05, df = 16, p = *0.001* respectively) and length of time living with HIV (χ^2 = 33.63, df = 4, p < *0.001*; χ^2 = 27.92, df = 4, p = *0.001* respectively) among the survey respondents. Most persons aged 18 – 44 reported feeling guilt because of their HIV-positive status (18 – 24, 80%; 25 – 34, 80%; 35 – 44; 54%) while the majority of persons aged 45 – 54 (57%) reported never or rarely feeling guilt and not feeling guilt any more because of their HIV status.

Table 02: 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)

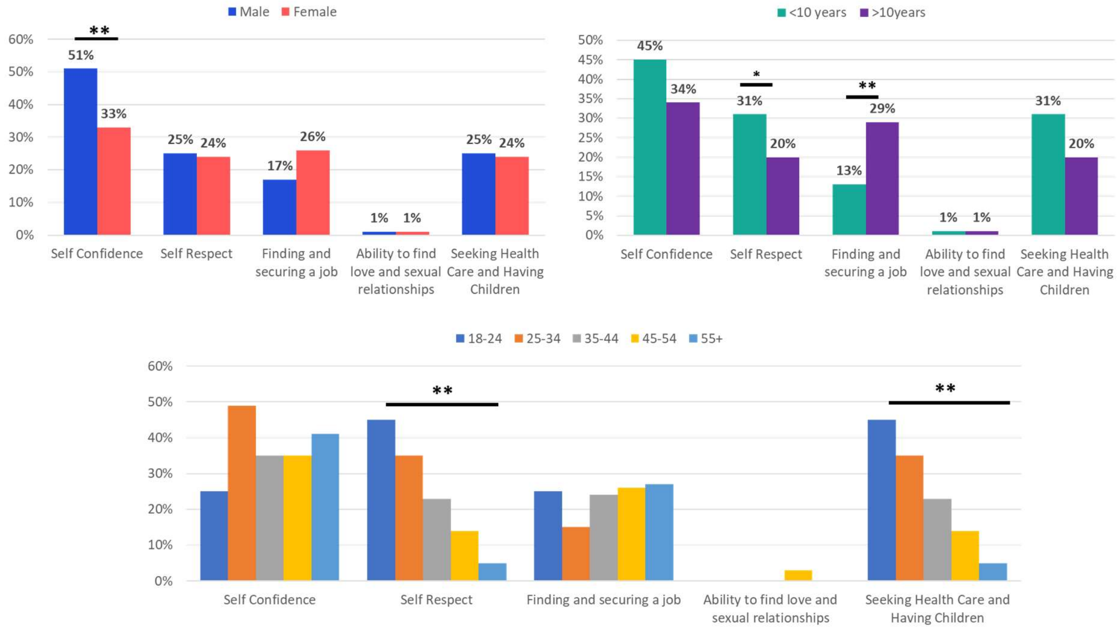
	Feeling of Guilt					
	Always	Most Times	Sometimes	Never/Rarely	Not Anymore	p-value
Gender						0.21
Male	10 (12%)	13 (15%)	37 (44%)	9 (11%)	16 (19%)	
Female	22 (13%)	20 (12%)	59 (34%)	34 (20%)	39 (22%)	
Transgender Women	0 (0%)	1 (33%)	1 (33%)	1 (33%)	0 (0%)	
Other	1 (20%)	0 (0%)	0 (0%)	3 (60%)	1 (20%)	
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%)	

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					
	Always	Most Times	Sometimes	Never/Rarely	Not Anymore	p-value
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%)	

Seventy-eight per cent (78%) of respondents have indicated that their HIV status has negatively affected their lives with the most common being a negative effect on their self-confidence. Male respondents were more likely to indicate that their self-confidence is negatively affected by their HIV status (χ^2 = 13.10, df = 3, p = *0.004*). Younger age was significantly associated with reporting that their self-respect was negatively affected by their HIV status (χ^2 = 17.73, df = 4, p = *0.001*). Also, those living with HIV for less than 10 years were more likely to respond that their self-respect was negatively affected by HIV (χ^2 = 4.67, df = 1, p = *0.04*).

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)



Reports of feeling guilt or shame because of HIV status is significantly associated with the reporting that HIV negatively affected their life. Persons who report feeling guilt and/or shame are more likely to indicate that their self-confidence, self-respect and seeking health care are negatively affected by their HIV status.

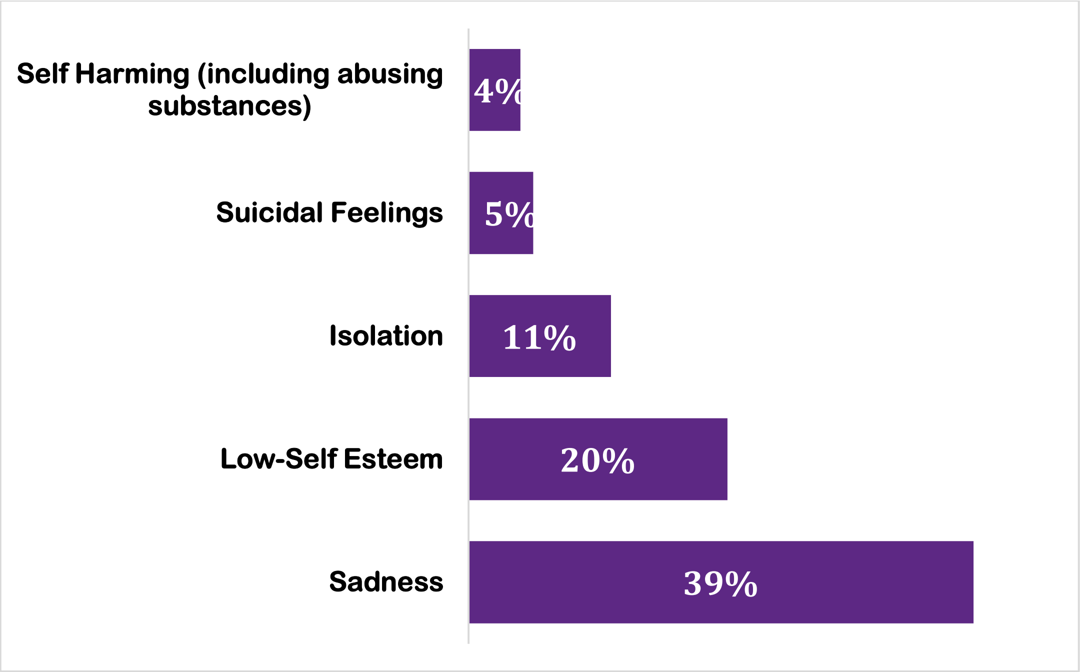
Table 04: Table showing the number and proportion of respondents who report feeling guilt because of their HIV status disaggregated reports on life being negatively affected by HIV status.

		Feeling of Guilty					
	N	Always	Most Times	Sometimes	Never/Rarely	Not Anymore	p-value
Self Confidence	104	16 (15%)	18 (53%)	49 (51%)	8 (17%)	13 (23%)	***< 0.001***
Self Respect	65	11 (17%)	15 (23%)	24 (37%)	7 (11%)	8 (12%)	***< 0.01***
Finding and Securing a Job	60	1 (2%)	1 (2%)	9 (15%)	27 (45%)	22 (37%)	***< 0.001***
Seeking Health Care and Having Children	65	11 (17%)	15 (23%)	24 (37%)	7 (11%)	8 (12%)	***<0.01***

Table 05: Table showing the number and proportion of respondents who report feeling shame because of their HIV status disaggregated by reports on aspects of life being negatively affected by HIV status.

	N	Feeling of Shame					p-value
		Always	Most Times	Sometimes	Never/Rarely	Not Anymore	
Self Confidence	104	14 (14%)	11 (11%)	45 (43%)	16 (15%)	18 (17%)	***< 0.001***
Self Respect	65	14 (22%)	9 (14%)	22 (34%)	13 (20%)	7 (11%)	***0.01***
Finding and Securing a Job	60	2 (3%)	1 (2%)	4 (7%)	36 (60%)	17 (28%)	***< 0.001***
Seeking Health Care and Having Children	65	14 (22%)	9 (14%)	22 (34%)	13 (20%)	7 (11%)	***<0.001***

Figure 02: Graph Showing the Most Common Emotions experienced by PLHIV Due to their Positive Status (N=267)



The most common emotion reported by respondents who indicated feeling guilt because of their HIV status was sadness (39%) followed by low self-esteem (20.3%). Women were more likely to report feeling sadness, while men were more likely to report low self-esteem (χ^2 = 29.77, df = 15, p = *0.013*). Also, persons living with HIV for less than 10 years were more likely to report sadness and low self-esteem and less likely to report isolation compared to those living with HIV for greater than 10 years (χ^2 = 19.13, df = 5, p = *0.002*).

Disclosure

Most respondents who reported voluntary disclosure have disclosed to health care professionals (70%) and family (68%). Voluntary disclosure to main partners, peers and health care professionals is significantly associated with reporting feeling guilt with voluntary disclosure more likely to occur for those who report never/rarely or not anymore ($\chi^2 = 21.53$, df = 4, $p < 0.001$; $\chi^2 = 22.82$, df = 4, $p < 0.001$, $\chi^2 = 12.98$, df = 4, $p = 0.011$ respectively). Additionally, persons who report never/rarely or not anymore feeling shame because of their HIV status are more likely to disclose to their main partners and peers ($\chi^2 = 19.44$, df = 4, $p = 0.001$, $\chi^2 = 18.31$, df = 4, $p = 0.001$ respectively).

Twenty-six per cent (26%) of respondents indicated that their status had been disclosed without their consent. Respondents who reported feeling guilt and/or shame at some time, because of their HIV-positive status were also more likely to indicate that their status had been disclosed without their consent ($\chi^2 = 13.13$, df = 4, $p = 0.011$; $\chi^2 = 17.01$, df = 4, $p = 0.002$ respectively). Disclosure without consent occurs more frequently from family members and friends than in the workplace, community or church.

Collection of and Adherence to ARV

The majority of respondents indicated that the feeling of guilt and shame has never deterred them in the collection of ARVs (71%) and adherence to ARVs (72%). For those who have indicated that their feelings of guilt and/or shame have influenced their collection of ARV, 46% reported never missing an appointment with 37% report missing an appointment every 3 to 6 months, 15% missing an appointment once every year and only 1% missing every month. For those who have indicated that their feelings of guilt and shame influence their adherence to ARVS most (60%) report missing their ARVs once every 3 to 6 months with 18% reporting they have never missed their ARVs, 13% missing once every year and 10% report missing their ARVs every month. Persons living with HIV for less than 10 years are more likely to be influenced by their feelings of guilt and shame in collection of and adherence to ARVs ($\chi^2 = 15.78$, df = 3, $p = 0.001$; $\chi^2 = 8.44$, df = 3, $p = 0.038$ respectively).

Sexual Relationships and Behaviour

Most participants (66%) report that their negotiation of condom use within a relationship is not affected by any feeling of guilt and/or shame because of their HIV status. Additionally, most respondents (52%) believe they are solely responsible for practising safe sex because of their positive status. Those who do not believe it is solely their responsibility to practice safe sex were more likely to report 'never/rarely' or 'not anymore' to feeling guilt and/or shame because of their HIV status.

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)

The majority of participants stated that public education and awareness is the primary tool for reducing self-stigma among PLHIV. Ideas around public education through the sensitization of religious communities and the sharing of messages through social and traditional media as well as influencers could be featured. Some participations who spoke about public education and awareness articulated that the education of rural area persons is key. It was offered that education and public awareness should also be formalized through coursework in secondary and tertiary-level educational systems. A small number of participants highlighted that information around advances in HIV prevention and treatment (injectables, etc.) provides hope and an elevated sense of self. Public education on HIV must also be provided within a framework that understands the generally insensitive Jamaican society that includes homophobia. Factual information about modes of HIV transmission must be reflected within public education. Some participants' feedback includes:

- *"Educate more persons that HIV is not a death sentence."*
- *"Education of the wider public… ensure a proper explanation about HIV is given… about how you catch the virus"*
- *"Go into community and schools and teach them about HIV"*
- *"Get more people educated about HIV"*
- *"Education, we live in a homophobic country where HIV and gay is a double murder… People need to be properly educated to surpass this."*
- *"Educate the country Jamaica."*
- *"Also, the sharing of real-life stories to the general population who are suspected or reported of stigmatizing and discriminating PLHIV should become a regular practice [approach] from the PLHIV community."*

The education and sensitization of PLHIV themselves was the second most popular suggestion for reducing self-stigma among PLHIV. The education of PLHIV was often described as being more optimally provided within support groups and meetings. Some participants shared:

- *"Knowledge will empower us holistically to overcome challenges to be in the know about making the right decisions."*
- *"[PLHIV] Sensitization can't be too much..."*
- *"Help them PLHIV to be better educated."*

Participants highlighted peer-to-peer or PLHIV support groups as a tool for reducing self-stigma. They suggested that support groups should be continued or scaled up. PLHIV coming together through support groups and the sharing of experiences in these settings helps to build confidence and a heightened sense of self. Some participants shared:

- *"Coming together through support groups."*
- *"Just continue to have more support groups meetings that will help them to be better educated."*
- *"Join support groups safe space for PLHIV to help the process"*
- *"More getting together with our support groups."*
- *"As a PLHIV, I do [wish] that we get more support groups for men... women get more support than men…"*

To reduce self-stigma, participants called for better laws and legal protection and spoke to specific legislation for the protection against forced/ involuntary disclosure. Participants also suggested laws to protect PLHIV when stigmatized. Some participants shared:

- *"I think since the inception of HIV there have been so much sensitization sessions on stigma and discrimination, especially in the health sector and it doesn't seem to work. My opinion is for stricter penalties for healthcare workers who breach confidentiality to face some form of accountability."*
- *"Laws to protect the rights of PLHIV."*
- *"Laws to protect PLHIV."*
- *"[Ability to file] Lawsuit."*
- "DJs should be banned from saying 'hand inna the air if you nuh have HIV."

Participants highlighted that the empowerment of PLHIV is an approach to reducing self-stigma. These are ideally presented through workshops they said. Some participants shared:

- *"Empowered PLHIV taking the initiative to share their stories and use their achievements to help motivate peers."*
- *"More empowerment."*
- *"We would like if the men got the opportunities to empower themselves."*
- *"Empowerment sessions in rural areas."*
- *"More empowering workshops."*

Participants highlighted that PLHIV self-acceptance is a tool for reducing self-stigma. Some participants shared:

- *"For PLHIV to accept the fact that it's not the end of the world and we didn't commit a crime where we need punishment [because] we did nothing wrong, sometimes we are pressured into things that we don't want to be a part of."*
- *"Self-acceptance."*
- *"Encourage PLHIV to accept their status hence they will become more empowered and reduce self-stigma."*
- *"Acceptance."*

Other suggestions for reducing self-stigma included: support for the employment of PLHIV, the re-education of health care providers and their provision of stigma-free services, support from government organizations and support from 'other NGOs', family support as well as advocacy for laws and policies.

Results of Focus Group Discussions

The following responses emerged from two focus group discussions. One of 3 heterosexual men and a homosexual man, one of 7 heterosexual women and another group of 8 heterosexual women, One group of 3 Transgender women and 2 homosexual men and a mixed group with 9 heterosexual women and 2 heterosexual men. Where sexual identity is not given the respondent is represented as heterosexual.

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.
5. Man – "You feel guilty in yourself because you see people talking about you but you nah hear weh dem a say and them a point finger. You just haffi nuh pay dem no mind. If you hear what dem say, its most times dem a say see him deh him dead long time, him have AIDS".
6. Woman– "When the doctor says to me, I have to take this pill for the rest of my life it rests on your mind"
7. Woman– "I still feel guilty even though I have done nothing wrong".
8. Woman – "Every time mi look pan him mi feel away, Mi feel guilty" in relation to her son to whom she transmitted HIV.

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”.
2. Woman– “Me did shame and I didn’t want to express to spouse why I couldn’t breastfeed.”
3. Woman– “Me did shame and afraid that people would see me and call mi “AIDS gyal.”
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.”
6. Woman– “I wondered and said to myself how did I manage to get myself into this?”
7. Woman– “I would leave the baby feeding formula over the neighbour’s house (neighbour is her aunt) because I didn’t want my spouse to know that I was HIV positive.”
8. Woman– “I am a disaster.”
9. Woman– “I could have done better.”
10. Woman– “I couldn’t tell my children, I was embarrassed.”
11. Woman– “I couldn’t say HIV, I would refer to HIV as ‘the something’ when I first got pregnant and was first diagnosed positive.”
12. Woman– “When going to the clinic I would tell my children “Mi a go a Western Union go sort out something, mi soon come back.”

13. Woman– “I attempted suicide (drank bleach) because I was ashamed of my status. How mi fi allow this fi happen to mi clean body?”
14. Transwoman – “Me did shame to take ARVs while at work so sometimes I would miss it until I changed the time I take the medication.”
15. Man– “Me feel like garbage the first time. Mi did waan tek weh miself.”
16. Man– “I started buying lunch for them (his 7 staff) because I did not want to cook for them in case one of them say dem nuh waan eat from me. One day dem say put on the pot.”
17. Woman– “Mi did cry and feel bad fi what happen. It did bother me for a year. It did have me way. It did stress me out and confusing. Almost lost my mind.”
18. Man– “I was nervous. It was bad news to me. I was sweating, I panicked and only could tell fiancé.”
19. Man– “Did feel like garbage. Not being sure how people ago treat me. I isolate myself.”

Support Received as PLHIV

Within each of the focus group sessions, participants were asked to share information on the types of persons who are aware of their positive status, how did the awareness/sharing happen and if it was a personal choice to disclose and what were the motivations behind the decision to disclose. These guiding questions highlighted the types of support that participants were receiving from different persons and in different spaces. The responses below reflect the support received by PLHIV:

1. Man– “Mi baby mother and persons at clinic [where] I get treatment
2. Man– “My sister. She was the first person I disclose to. It means a lot. Makes me feel good. Me and her are so close. My mother is alive, and I don’t want her to know because I do not want her to feel any way. Bigger brother also knows, he is a doctor, he says mi fi go doctor.
3. Man– “My baby mother as she is someone I love and can trust and rely on
4. Man– “A PLHIV Peer. Me use to absent and not going clinic, and a tek too much pill, pill dem big. When I was assigned to a peer, and we work together, and mi come back. Mi nah tell no body bout me status

5. Woman– “Mi glad for the doctor that hold me down and put the tube inna mi nose and give me the medicine. If a never fi him me would a never be here.
6. Woman– “My father’s side of the family is good. Get on with her son. My mother is my support.
7. Woman– “Ainsley & Anisha – were her support seeing them as advocates in advertisement made her understand you could live long.”
8. Unspcecifed gender – “Support from my friends helped me to accept my status and take my meds.”
9. Transwoman – “I find it easy to adhere to my medication because I live among other PLHIV-transwomen.”
10. Man– “My friends and family show me love. Mother always see and say ‘see your water here.’”
11. Woman– “Mi glad for the doctor that hold me down and put the tube inna mi nose and give me the medicine. If a never fi him me would a never be here.”

Disclosure

Participants were asked in the focus group discussions to share information on the types of persons who are aware of their positive status, how did that awareness/sharing happened and if it was a personal choice to share/disclose what was the reason for the decision. The responses below are in direct relation to disclosure.

1. Man– “I would disclose to me girl, but I would a haffi have her inna mi arms, on mi shoulder. But nah tell nobody”
2. Man– “No – I would only disclose to my partner when they disclose to me.”
3. Man(MSM) – “No. Not going to be comfortable telling anyone unless its someone who is also positive.”
4. Woman– “My status was Involuntary disclosed. My status was disclosed by the doctor to my family because they thought I was going to die. Doctor called a meeting with my family. My Aunt also forced me to disclose to my daughter.”
5. Man– “Disclosed to my Fiancé. Been living with HIV for 18 years. She was upset but she did her research, and she is alright now. She inna it already.”

6. Woman– "Another PLHIV disclosed my status to her partner because she was jealous of the relationship we had."
7. Woman– "My mother disclosed my status at my daughter's school. After I was different and suicidal – started to take pills and alcohol. I had to move my daughter from the school. My daughter is very supportive. Reminds me to take my meds."
8. Woman– "My sister disclosed my status to the community I live in, and I had to leave because it affected me psychologically."

Attending Clinic Appointments and Collecting ARVs

The participants were asked questions to ascertain whether they were attending clinics, doctors' appointments and ARV collection. Based on the responses given, follow-up questions were asked to inquire why or why not, as well as the frequency of going or not going.

1. Man– "Don't feel comfortable collecting meds because people out there a watching you. Dem see you a go down there so then go pharmacy. Walking with brown bag."
2. Man– "Mi nuh business wid people, me still go."
3. MSM – "Don't feel comfortable collecting meds because a particular section of the hospital is known for HIV treatment, hence they would often be discriminated against us."

Challenges and Limitations

While the study provided an assurance of privacy and confidentiality this had to be reiterated to participants to gain and strengthen buy-in. In some instances, some participants were unwilling to be open, and share lived personal experiences due to discomfort and little ownership commitment to the research process.

The study results and recommendations must be viewed and assessed through the lens that JN+, as the researcher, maintains a multifaceted power and support relationship with the participants. While the study demands strict independence, it also calls for duty of care. The researcher, aware of positionality took great care to not interrupt, interject and make interventions during the research process, especially during the data collection stage. This was important to prevent critical information from being lost or withheld back.

The COVID-19 pandemic meant that protocols related to social distancing had to be maintained and programme design adjusted to account for these. The researcher pivoted to a largely online questionnaire tool approach versus the initial research design which intended to glean data through largely face-to-face discussions. This however proved more cost-effective and facilitated a larger and geographically wider data set.

Discussion

The qualitative and quantitative results support the thesis that persons living with HIV are adversely affected by self-stigma to various degrees. The study suggests that while self-stigma was less-likely to impact PLHIV adherence to medication, self-stigma was very much more likely to impact their social, mental, and emotional well-being – and access to care. The impact on their emotional and social status is more affected when compared to access to care and adherence.

A significant portion of the study participants was or have been exposed to adherence-counselling or related interventions with a focus on treatment adherence facilitated by JN+. This could, in part, explain the level of impact on PLHIV's social/ emotional wellbeing versus medication pick-up. In addition, time remained a significant and intersecting factor contributing to persons' ability to resolve self-stigma and their willingness to disclose. Both likely factors however are worthy of further exploration.

Within this study, most persons have disclosed from HIV-positive status to their health care providers and one or more family members. Additionally, it could be surmised that persons who have resolved self-stigma are more likely to disclose to peers and their primary sexual partners.

From the results, there was an early indication that experiences of coerced, involuntary or forced disclosure and feelings of guilt and shame. Where disclosure without consent had occurred in the past, this was a noted factor influencing sustained medication pick-up habits and patterns.

Participants' majority recommendations proffered changes to their external environment to support the reduction of self-stigma. Changes offered included an end to discrimination from society through the mass education of the public. It appears that this relationship between societal discrimination and PLHIV self-stigma and how this is expressed warrants further exploration. Secondarily, peer-to-peer support-based Interventions in various forms and contexts have helped to address self-stigma and facilitate a sense of empowerment.

It must be noted that from the study, there was a unique gendered nuance to the expressions of self-stigma among PLHIV. Women of reproductive age were more likely to be impacted by self-stigma, especially if they were diagnosed during pregnancy. While not the core study question, the impact on women and their children cannot be negated. Rapporteur notes from focus group discussions also highlighted observations of negative interactions including verbally abusive discourse from women towards their infant children. Other manifestations of self-stigma in this group included but were not limited to forced breastfeeding, poor management of disclosure, establishing multiple family residences, travelling across health providers, challenges with or rejection of clinic commodities for pregnant and lactating PLHIV as well as exposure to gender-based violence.

These adverse impacts of self-stigma, particularly in social and family life, were more evident in women of the 18-34 age group and those who, from this group, were living with HIV for less than 10 years.

Recommendations

The study results highlight several areas and opportunities to invest and grow the body of knowledge around PLHIV self-stigma as well as the unique expressions of its manifestations across the diverse gender and age differences.

Recommendation One: There is a need to further explore and invest in additional studies to understand better the impact of self-stigma on younger populations of PLHIV, those living with HIV for less than 10 years and those within the cohort of clients who began treatment upon the implementation of Jamaica's 'test and start' protocols. There is also a need to study further the influence of stigma and discrimination within the wider society on personal empowerment, and self-stigma and how these public attitudes may inspire or fuel feelings of guilt and shame.

Recommendation Two: In light of the data, it augurs well for the HIV response to scale-up community-led responses and increase peer-to-peer engagement including support groups for newly diagnosed PLHIV and those PLHIV struggling with treatment adherence. the institutions for comprehensive treatment and care of PLHIV should seek to increase and integrate PLHIV-led support programmes within government healthcare facilities to quickly target and reach persons who stand to benefit the most from community safe spaces for managing their diagnoses and adherence.

Recommendation Three: Participants did not always refer to their psychological states and their emerging responses as issues of emotional wellbeing and mental wellness. However, even a minimal review of the data points to the urgency of the need for a technically sound and evidence-driven approach to psychosocial and mental health support programmes for PLHIV. Mental health support programmes are critical to the effective treatment adherence and care of any potentially chronic or lifelong communicable infection. As such further investment and scale-up of accessible mental health support services are needed across public and private clinics providing HIV treatment and care. The is a clear need to also lend focus to addressing self-stigma (guilt and shame) as well as stigma and discrimination within the context of mental health.

Recommendation Four: The study points to the need for the greater and expanded use of existing resources such as the Positive Health, Dignity and Prevention framework and its accompanying curricula and intervention. The PHDP-focused messages and interventions are currently infrequent in clinics and other spaces where PLHIV occupy. The tools remain useful for crafting messages and sensitization/ educating and reminding people including PLHIV of their inalienable respect and the inherent value of their lives. Also, within this context, the U=U framework should be promoted and adopted by the public health system with messages and direct interventions that aid and support PLHIV. The U=U message promotes positive health and dignity for PLHIV through the uptake and adherence to HIV treatment. Its utility and value offer the potential to impact self-stigma and other effects of stigma and discrimination.

Recommendation Five: A majority of participants identified being negatively impacted by stigma and discrimination with the allusions that their expressions of self-stigma were due in large part to how society views them. In this regard, consistent and sustained advocacy and public education, which engages the community of people living with HIV, must be prioritized by the public and civil society systems for health. The building and sustained facilitation of an enabling and supportive environment for PLHIV is essential to ending self-stigma and its repercussions. Participants also expressed an appetite for public education to also include faces and examples of PLHIV living positively. This would counter the negative stereotypes that PLHIV should look ‘sick.’ Engaging and interactive public information campaigns would support a shift in narrative and promote a culture of change.

Recommendation Six: Public education should utilise traditional and social media and should also include face-to-face community education where rural area communities are prioritized. Leveraging the agency of macro and micro-influencers from social and traditional media should be a key feature of a modern-day public education initiative.

Recommendation Seven: Self-stigma is also undoubtedly fueled by the mistreatment or inadequate service delivery of health professionals. Civil society data including the Stigma Index 2.0 point to stigma and discrimination being drivers of reluctance in treatment adherence. Clinics and treatment sites should be engaged in continuous education and staff capacity programmes that bring awareness and attention to human rights and stigma and discrimination. This will aid in fostering an environment where clinical and non-clinical staff are better equipped to be more supportive and inclusive when providing treatment and care services. Enforcing guidelines and standard operating procedures around stigma and discrimination should also be a feature of the capacity-building and accountability mechanisms of healthcare providers.

Recommendation Eight: With the reality of stigma and discrimination within the public and the healthcare system, managing and reducing self-stigma and its effects are aided by the promotion of existing mechanisms for the protection and preservation of the rights and privacy of PLHIV. The education of persons into the accessible opportunities and mechanisms for client complaints and redress is known to not only improve quality outcomes of service providers but access to sound mechanisms may empower and heighten patients' health-seeking behaviour.

Recommendation Nine: There is a need to improve the enabling environment for PLHIV, including access to justice. Increased advocacy around as well as the passing of anti-discrimination laws is one way to legislate fair treatment of all persons with protections for health status, gender and sexual identities. A legislative framework would support holding everyone accountable within the law.

Recommendation Ten: A comprehensive programme is needed for women of reproductive age living with HIV to deal with the issues that arise with disclosure around pregnancy and breastfeeding as well as their own psycho-social challenges associated with passing on the virus to children as well as the dynamic family relations. The adverse impacts of self-stigma were noted to uniquely impact the social and family life, of women living with HIV aged 18-34 years group. In this regard, there is a need for focused and tailored interventions for these women and the children within their care. Based on the impacts observed include but are not limited to their establishing multiple residences, travelling across health providers, challenges with or rejection of clinic commodities for pregnant and lactating PLHIV as well as exposure to gender-based violence it would behove the response to ensure that GBV response and the economic empowerment of this target group is a core part of the support and care interventions. Income-generating programmes could also be scaled up through partnerships with other government and private sector organizations to bolster economic opportunities for PLHIV to drive empowerment and resiliency.

Recommendation Eleven: Warranting further research and programmatic exploration is the realities of older persons living with HIV. An 'ageing with HIV' programmatic response is needed to support those persons across Jamaica, particularly those in rural and hard-to-reach areas of the country. The ageing population living with HIV continue to be marginalized - with their reduced access to support and care services. Further, with age, this group is often time isolated and not prioritized. Their food and job security come into high risk of jeopardy with time as well as the associated challenges of climate change, COVID, crime and economic inequity.

Recommendation Twelve: Scaling up People-Centered Approach Programmes for PLHIV who are inconsistent with accessing care and more vulnerable populations. This would allow for an individualized approach to wholistic care that seeks to deal with self-stigma and improve the number of persons who a retained in care.

Conclusion

The community study exploring the implications of self-stigma on the dignity of PLHIV in Jamaica was carried out through a mixed methods approach which collected data directly from Jamaican PLHIV themselves.

The results highlighted that self-stigma affects PLHIV in varying degrees and spheres of their lives, especially within the first 10 years of their diagnosis. Persons experiencing socio-economic challenges especially women and girls of reproductive age are uniquely affected in part because of their bio-social relationships with their families and children. Ageing populations also require the attention necessary to mitigate against their loss to treatment, care, job and food security as a result of their ageing. Self-stigma was reported influenced by public stigma and discrimination, public attitudes towards PLHIV, and experiences of forced disclosure among other factors. Participants as well as the body of related evidence proffer some recommendations to resolve self-stigma within PLHIV. Some of these include: public education, scale-up of peer support groups, increases mental health interventions, the socio-economic empowerment of women, addressing gender-based violence, improved capacity of healthcare providers, enactment of anti-discrimination legislation as well as the promotion of existing mechanisms for reporting and redress of discrimination complaints. These including further research are necessary to better understand and address this universal occurrence.

The study, while worthy of further exploration, highlights the experiences and challenges of PLHIV and amplifies the need for additional targeted interventions for their treatment, care and support. The research methodology, results and recommendations, consider the proximity and positionality of JN+ to the participants and their treatment, care and support.

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