Undoing the Unseen: Stigma and its reduction among African, Caribbean and Black People Living with HIV in Ontario—A Population Profile at Baseline

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BACKGROUND

HIV-related stigma exacerbates pre-existing social inequities based on race, class, gender, and sexual orientation.[1] While most stigma research has focused on individual factors implicated in producing stigma, there is a shift of focus toward structural factors in stigma analyses.[1-2] However, most research has examined HIV-related stigma, racism and sexism separately. As a result, there is little evidence of interventions that aim to address the intersecting forms of marginalization in order to promote health equity for African, Caribbean and Black (ACB) people living with HIV in Ontario.

Women's Health in Women's Hands (WHIWH) CHC, Black Coalition For AIDS Prevention (Black CAP) and Africans in Partnership Against AIDS (APAA) have formed a Community Alliance with the aim of better understanding the intersectionality of stigma, culture, and HIV positive status that African, Caribbean and Black (ACB) people living with HIV experience.

OBJECTIVES

1. Develop and pilot test an intervention to reduce internal stigma and to better support ACB people living with HIV, using an intersectional approach and
2. Adapt the intervention for other demographics and settings so it can be rolled out nationally and help decrease the stigma around living with HIV.

METHODS

The Stigma Reduction Intervention pilot study was launched in the Greater Toronto Area (GTA) from January 2020 – March 2020.

A mixed sampling method was used for recruitment to ensure a diverse sample of participants was obtained. Participants were recruited through networks of community-based organizations and service providers working with PHAs, including AIDS Service Organizations, shelters, social workers, and primary care health care providers. Participants were screened for eligibility prior to participating. ACB individuals were eligible to participate if they: identified as an ACB person living with HIV, 18 years of age or older, lived in the GTA, experience internalized stigma due to their HIV status, and could speak and understand English.

Two interventions were identified through a systematic literature review that addressed internalized stigma experienced by African American women living with HIV. Through the facilitation of in-depth interviews (n=20) with ACB women living with HIV (WLWH), their service providers (n=18), and a community consultation (deliberative dialogue), the UNITY Study[3] and STEP-AD intervention[4] were adapted to a Canadian context and implementated among ACB WLWH, ACB MSM and ACB heterosexual men. The intervention structure included workshops which were meant to foster social support, skills building, and reduction of internalized stigma. The workshops were implemented for 11 weeks consecutively, with follow-up booster sessions at 6-month and 12-month marks post-intervention. Each workshop lasted 3 hours and addressed the following topics:

Week 1: What is Stigma?
Week 2: What is Stigma? (Part 2)
Week 3: Mental Health & HIV Stigma
Week 4: Building Self-Esteem
Week 5: Coping Strategies for Racial & HIV Discrimination
Week 6: Migration & HIV Stigma
Week 7: Building Resiliency
Week 8: Sexuality & HIV Stigma
Week 9: Reproductive Health & HIV Stigma
Week 10: Disclosure
Week 11: Living Positively

A randomized prospective cohort with a pre-test /post-test survey design with follow-up was developed. Baseline data was collected before the implementation of the intervention.

RESULTS

Due to COVID-19 prevention measures, the final workshops were cancelled and thus post-test data was not collected. The results presented here provide a snapshot of the population at baseline and shed light on the prevalence of stigma among ACB populations in Toronto.

Demographic Characteristics of Participants

Table 1. Participant Demographics N=46

Characteristics	N	%
Age M(SD)	43.67 (6.29)	
Ethnoracial Identity		
Black	5	10.87
Black African	32	69.57
Black Canadian	8	17.39
Black American	0	0
Black Latin American	0	0
Residency Status		
Canadian Citizen	6	12.77
Landed Immigrant or Permanent Resident	13	27.66
Refugee	8	17.02
Refugee Claimant	20	42.55
Gender Identity		
Man	25	53.19
Woman	20	42.55
Non-binary	1	2.13
Intersex	1	2.13
Sexual Orientation		
Gay	10	21.74
Lesbian	2	4.35
Heterosexual	26	56.52
Bisexual	6	13.04
Marital Status		
Single	23	48.94
Married	14	29.79
In a steady relationship (not living together)	3	6.38
Widowed	2	4.26
Separated	4	8.51
Divorced	1	2.31
Education level		
No formal Schooling	2	4.26
High school	14	29.79
College, CEGEP	14	29.79
University	12	25.53
Graduate School	4	8.51
Employment Status		
Employed/Self-employed Full-time	8	17.02
Employed or Self-employed Part-time	4	14.89
Volunteering	12	25.53
Unemployed	11	23.40
Student	4	8.51
Not working due to disability	5	10.64
Income		
None	7	15.22
$1 - $19,999	16	34.78
$20,000 - $39,999	9	19.57
$40,000 - $59,999	4	8.70
$60,000 - $79,999	0	0.00
$80,000 - $99,999	0	0.00
$100,000 or more	2	4.35
Don't know	6	13.04
Prefer not to answer	2	4.35

Depression Scores at Baseline

Table 2. Depression Scores at Baseline N=46

	M	SD	Range
CES-D Score	23.17	11.69	0-53

Stigma Scores at Baseline

Table 3. Stigma Scores at Baseline N=46

Dimension	M	SD	Range
Personalized Stigma	2.80	0.24	2.38 - 3.18
Disclosure Sub-Scale	3.09	0.16	2.80 - 3.32
Negative Self-Image	2.61	0.28	2.24 - 3.23
Public Attitudes	2.88	0.28	2.38 - 3.23

Health Related Quality of Life at Baseline

Table 4. Health Related Quality of Life at Baseline N=46

		N(%)
Health Status	Fair, Good, Very Good, Excellent	44 (95.65)
	Poor	2 (4.35)
Number of Days of Poor Physical Health	0	14 (30.43)
	1 - 5	6 (13.00)
	6 - 10	4 (8.70)
	11 - 20	2 (4.35)
	21- 30	1 (2.17)
	Don't know	14 (30.43)
	Prefer not to answer	13 (28.26)
Number of Days of Poor Mental Health	0	8 (17.02)
	1 - 5	6 (12.80)
	6 - 10	5 (10.64)
	11 - 20	8 (17.02)
	21 - 30	4 (8.51)
	Don't know	12 (25.53)
	Prefer not to answer	4 (8.51)
Number of Days Inactivity due to Illness	0	21 (44.68)
	1 - 5	6 (12.77)
	6 - 10	5 (10.64)
	11 - 20	6 (12.77)
	21 - 30	2 (4.26)
	Don't know	5 (10.64)
	Prefer not to answer	2 (4.26)

Results continued:

- Respondents ranked moderate to high on the Berger Stigma Scale[5] (measured on a scale of 1-4 with 4 being the highest)
- The highest average stigma score (3.09) was on the disclosure sub-scale.
- Respondents also reported clinically significant scores on the CES-D scale >16 on a scale of 0-60.[6]

Regarding access to services:

- 86% (n=38) of respondents reported using social support services
- 69% (n=30) of respondents reported using health promotion or education programs
- 67% (n= 30) of respondents reported food banks or meal services
- 54% (n=23) reported using case management (social worker) services
- Overall, low report on services related to substance us, mental health and street or sexual assault services.

DISCUSSION

- Further analysis upon the completion of the post-test data will look at differences between the various randomized groups.
- The impact of stigma on access to care as well as the relationship between gender and intersectional stigma will also be examined
- There may be implications for the generalizability of the intervention outcomes due to limited representation of non-binary and trans identifying participants in the intervention
- A randomized control study design typically homogenizes participant characteristics and thus does not highlight intersectionalities of participants. Qualitative data collected through post-implementation focus groups will provide an opportunity to bring context and adequately capture the impact of the stigma reducing intervention.

CONCLUSION & RECOMMENDATIONS

Many participants experience internalized stigma and depression which is an indication that more comprehensive, wrap around health care provision is required. These findings suggest that ACB people living with HIV need an intervention that combats intersectional stigma using a culturally relevant approach. The proposed intervention presented here will be followed up with an evaluation of its acceptability, feasibility and satisfaction. Further adaptation of the Stigma Reduction Intervention will occur before a province wide and national roll-out.

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