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**Original Research Article**

# The Impact of Internalized HIV Stigma on Retention in Care among Individuals Living with HIV at Chifundo Clinic in Lusaka District, Zambia

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**Abstract:** ***Introduction*:** Internalized HIV stigma remains a significant barrier to successful care retention for people living with HIV (PLHIV). Stigma has been felt as shame, guilt, and self-blame, dampening adherence to antiretroviral therapy (ART) and clinic attendance. ***Aim*:** The aim of this study was to explore the impact of internalized HIV stigma on care retention among individuals living with HIV at Chifundo Clinic in Lusaka District, Zambia. ***Methods*:** Cross-sectional analytical study with 384 participants aged 18 years and above having been in care for more than six months. Data were collected via an online Kobo Toolbox to measure internalized stigma, demographic variables, and care retention. Logistic regression analysis was used in testing the association between internalized stigma and clinic visitation. ***Results*:** Over 75% of the participants had once missed clinic a visit, of whom 5% had previously been declared as no longer in care (NLIC). Internalized stigma measures showed that 26% of the participants very often self-shamed due to HIV status and 31% very often felt guilty. Participants who self-blamed were 70% more likely to miss a clinic visit. Those who feared disclosing their status were 8 times likely to miss a clinic visit. ***Conclusion*:** Internalized HIV stigma is a key driver of retention in care among PLHIV at Chifundo Clinic. Stigma reduction is essential using combined, culture-tailored interventions and psychosocial support. Stigma reduction should be policymakers' and healthcare providers' number one priority to increase ART adherence, retention, and yield better health outcomes for PLHIV in Zambia.

**Keywords:** Care Retention, People Living with HIV (PLHIV), Internalized HIV Stigma, Antiretroviral Therapy (ART).

## INTRODUCTION

As per the reports presented by UNAIDS, in the year 2021, the total number of HIV infected individuals was estimated to be around 38 million globally. The fight against HIV becomes even more difficult in light of the fact that an individual has to also face the issues of stigmatization and discrimination. The fight against the stigma is important for the antiretroviral treatment at the population level to be effective (Sibanda, 2016).

Due to the stigma attached, a good number of people delay in getting treatment or even decide to stop using their medication. This set of circumstances enhances the pain, depression, and anti-social behaviors and lowers a person's standard of life while knowledgeable social traits and individual genetics impact how stigma is perceived (R Hargreaves *et al.*, 2018).

Despite advances in treatment options for people living with HIV, stigma persists in presenting perhaps the most considerable challenges toward pursuing better health outcomes. When referring to internalized stigma, this is a form where individuals accept negative perceptions about themselves on issues related to the infection (UNAIDS, 2021). Eventually, these assumptions of thought blossom into feelings of shame or even fear of rejection, which adversely impacts one's self-esteem.

Chifundo Clinic, which is based in Lusaka's Chaisa Compound and has provided services to over 9,500 clients since the day of its inauguration, which was

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back in 2011. However, in about 2024, under the AHF data audits, it was reported that approximately 1,197 clients were no longer in care, which included 1,149 patients who were lost to follow up (LTFU).

Owing to the issues surrounding internalized HIV stigma, the focus of this study lies in determining how that stigma affects a person's willingness to seek or continue further treatment even when on ART in Chifundo Clinic. The study focused on measuring the internalized stigma and its association with retention into care; Evaluation of available healthcare system regarding alleviation of such issues.

## METHODS AND MATERIALS

### Study Design

This study used a cross-sectional analytical design, which estimates relationships between variables at a single time point (Polit & Beck, 2021).

### Study Population

The population included adults over 18, male or female, HIV positive, sexually active, attending Chifundo Clinic, diagnosed with HIV, and on treatment for at least six months. Exclusion criteria were severe mental retardation affecting consent or data collection and presence of illness on assessment day.

### Sample Size

Sample size was calculated using a 95% confidence level, 50% anticipated prevalence, and 5% margin of error to maximize sample size. Using the formula: n=$Z^2$ PQ)/$d^2$ , Where Z was the confidence level, P was the prevalence, Q is 100-P and d was the margin of error.

### Sampling Strategy

Systematic random sampling was used to recruit participants who made visits to Chifundo Clinic on scheduled data collection visits.

### Data Collection

Data were collected via an online Kobo Tool Box questionnaire derived from validated tools measuring sociodemographic variables, internalized HIV stigma, retention in care, and health system evaluation.

### Data Analysis

Data were analysed using STATA 14. After cleaning, descriptive statistics summarized participant characteristics and stigma and retention levels. Logistic regression assessed associations between internalized stigma and retention in care, reporting adjusted odds ratios. Statistical significance was set at $p < 0.05$.

## RESULTS

**Table 1: Social and demographic information**

| **Age groups** | **Number** | **Percent (%)** |
|---|---|---|
| 18-24 years | 47 | 12% |
| 25- 34 years | 119 | 31% |
| 35- 49 years | 149 | 39% |
| 50 + Years | 69 | 18% |
| **Total** | **384** | **100%** |
| **Gender** | **Number** | **Percent (%)** |
| Male | 176 | 46% |
| Female | 208 | 54% |
| **Total** | **384** | **100%** |
| **Level of education** | **Number** | **Percent (%)** |
| No formal education | 10 | 5% |
| Primary | 164 | 43% |
| Secondary | 144 | 37% |
| Tertiary | 56 | 15% |
| **Total** | **384** | **100%** |
| **Marital Status** | **Number** | **Percent (%)** |
| Single | 115 | 30% |
| Married | 141 | 37% |
| Divorced/separated | 96% | 25% |
| Widowed | 32 | 8% |
| **Total** | **384** | **100%** |
| **Have family support** | **Number** | **Percent (%)** |
| Yes | 151 | 39% |
| No | 233 | 61% |
| **Total** | **384** | **100%** |
| | | |

| **Have strong social support network** | **Number** | **Percent (%)** |
|---|---|---|
| Yes | 139 | 36% |
| No | 245 | 64% |
| **Total** | **384** | **100%** |

According to Table 1's findings, all respondents were at least 18 years old. Of the participants, the majority were between the ages of 25 and 49, which represents the working population. Of these, 12% were between the ages of 18 and 24, 31% were between the ages of 25 and 34, 39% were between the ages of 35 and 49, and 18% were over the age of 50. The higher proportion of females may have been explained by the gender ratio, which was 46% male and 54% female due to the disproportionate impact of HIV stigma. The respondents' educational backgrounds ranged from poor to moderate: 43% had completed primary school, 37% had completed secondary school, 15% had completed tertiary education, and 5% had no formal schooling at all. The numbers for marital status suggest the impact HIV have on a family's structure. 37% were married, 25% reported being divorced or separated, 8% were widowed, and 30% reported being single. There is a vacuum in critical mental health support, as just 39% of respondents said they received family help and 61% said they did not. With 36% having reliable friends or community support and 64% not having such networks, social support was scarce, suggesting that many people felt alone and overburdened by HIV-related difficulties.

**Table 2: Levels of internalized HIV stigma**

| **Years since diagnosed with HIV** | | **Number** | **Percent (%)** |
|---|---|---|---|
| 6 months – 1 year | | 17 | 4% |
| 2 - 4years | | 168 | 44% |
| 5 + years | | 199 | 52% |
| **Total** | | **384** | **100%** |
| **Disclosed your HIV status** | | **Number** | **Percent (%)** |
| No | | 42 | 11% |
| Yes | | 342 | 89% |
| **Total** | | **384** | **100%** |
| **Often feel ashamed of being HIV positive** | | **Number** | **Percent (%)** |
| Never | | 57 | 15% |
| Rarely | | 83 | 22% |
| Sometimes | | 99 | 26% |
| Often | | 101 | 26% |
| Always | | 44 | 11% |
| **Total** | | **384** | **100%** |
| **Often blame yourself for being HIV positive** | | **Number** | **Percent (%)** |
| Never | | 53 | 14% |
| Rarely | | 77 | 20% |
| Sometimes | | 102 | 26% |
| Often | | 110 | 29% |
| Always | | 42 | 11% |
| **Total** | | **384** | **100%** |
| **Often fear disclosing your HIV status to others** | | **Number** | **Percent (%)** |
| Never | | 56 | 15% |
| Rarely | | 85 | 22% |
| Sometimes | | 97 | 25% |
| Often | | 106 | 28% |
| Always | | 40 | 10% |
| **Total** | | **384** | **100%** |
| **Often feel socially isolated due to your HIV status** | | **Number** | **Percent (%)** |
| Never | | 52 | 14% |
| Rarely | | 78 | 20%% |
| Sometimes | | 97 | 25% |
| Often | | 118 | 31% |
| Always | | 39 | 10% |
| **Total** | | **384** | **100%** |
| **On a scale of 1 to 5, range your self-esteem** | | **Number** | **Percent (%)** |
| 1. | Very low | 91 | 24% |

| | | | |
|---|---|---|---|
| 2. | Low | 100 | 26% |
| 3. | Average | 55 | 14% |
| 4. | High | 69 | 18% |
| 5. | Very high | 69 | 18% |
| **Total** | | **384** | **100%** |

According to the data in Table 2, 4% of respondents were diagnosed with HIV between 6 months and a year before the interview, 44% 2 to 4 years prior, and 52% more than 5 years ago. These results show that most participants are long-term survivors of the disease. 89% disclosed their status and 11% did not, which suggests concealment due to stigma. Shame experiences differ, for example: 15% say they never felt shame; 22% rarely, 26% sometimes, 26% often, and 11% always, indicating different shame experiences. Blame was widespread as only 14% reported not blaming themselves, 20% reported doing so rarely, 26% some, 29% most, and 11% always blaming themselves. Disclosure fear was also reported: 15% never feared it, 22% claimed to seldom, 25% at some point, 28% often, and 10% always feared revealing their status. Many reported social isolations where only 14% never felt isolated, 20% rarely, 25% sometimes, 31% often, and 10% always. Finally, self-reported metrics show low self-esteem: 24% very low, 26% low, 14% average, and only 18% high or very high.

**Table 3: Retention in care**

| **Have missed an appointment since started ART** | **Number** | **Percent (%)** |
|---|---|---|
| Yes | 289 | 75% |
| No | 95 | 25% |
| **Total** | **384** | **100%** |
| **Times missed appointments in past 12 months** | **Number** | **Percent (%)** |
| 0 | 253 | 66% |
| 1-2 | 116 | 30% |
| 3+ | 16 | 4% |
| **Total** | **384** | **100%** |
| **Reason for missing appointment (those that missed)** | **Number** | **Percent (%)** |
| Forgot | 46 | 35% |
| Felt healthy and did not need to go | 1 | 1% |
| Difficulty getting transportation | 24 | 18% |
| Conflicting work or family responsibilities | 31 | 23% |
| Felt discriminated against by staff | 3 | 2% |
| Other reason | 28 | 21% |
| **Total** | **132** | **100%** |
| Ever been declared no longer in care (NLIC) | **Number** | **Percent (%)** |
| Yes | 21 | 5% |
| No | 363 | 95% |
| **Total** | **384** | **100%** |
| **Reason declared no longer in care (NLIC)** | **Number** | **Percent (%)** |
| Transferred out | 11 | 52% |
| Lost to follow up (LTFU) | 4 | 19% |
| Stopped taking drugs | 2 | 10% |
| Other reason | 4 | 19% |
| **Total** | 21 | **100%** |
| **Often attending appointments after restarting treatment** | **Number** | **Percent (%)** |
| Never | 0 | 0% |
| Rarely | 0 | 0% |
| Sometimes | 1 | 5% |
| Usually | 4 | 19% |
| Always | 16 | 76% |
| **Total** | 21 | **100%** |

From Table 3, it appears that 75% of patients have experienced default on an appointment since starting ART, showing elevated barrier to access. During the past year, 66% never defaulted, 30% defaulted 1-2 times, and 4% defaulted three or more times, and there is proof of variable attendance among some patients. Forgetfulness was the most frequent reason for not attending (35%), then family and job responsibilities

(23%) and lack of transport (18%), and underlines the impact of routine activities and transport problems. Around 5% were formerly declared no longer in care (NLIC), notably because of transfers (52%) and loss to follow-up (19%), showing care discontinuity and reengagement. Encouragingly, 76% of the participants who restarted treatment after becoming NLIC always attended appointments, and 19% usually did so, indicating increased attendance after being reintroduced to care.

**Table 4: Evaluation of healthcare system in reducing HIV stigma**

| **Clinic hours convenient** | **Number** | **Percent (%)** |
|---|---|---|
| Not at all convenient | 5 | 1% |
| Slightly convenient | 11 | 4% |
| Moderately convenient | 74 | 19% |
| Very convenient | 212 | 55% |
| Extremely convenient | 82 | 21% |
| **Total** | **384** | **100%** |
| **Client relationship with healthcare providers** | **Number** | **Percent (%)** |
| Very poor | 0 | 0% |
| Poor | 0 | 0% |
| Neutral | 88 | 22% |
| Good | 162 | 43% |
| Very good | 134 | 35% |
| **Total** | **384** | **100%** |
| **Clinic efforts to reduce HIV stigma** | **Number** | **Percent (%)** |
| Not at all | 0 | 0% |
| A little | 17 | 5% |
| Somewhat | 74 | 19% |
| A lot | 192 | 50% |
| A great deal | 101 | 26% |
| **Total** | **384** | **100%** |
| **Quality of services at the clinic** | **Number** | **Percent (%)** |
| Very poor | 0 | 0% |
| Poor | 7 | 2% |
| Average | 23 | 6% |
| Good | 159 | 41% |
| Excellent | 195 | 51% |
| **Total** | **384** | **100%** |
| **Clinic easily accessible** | **Number** | **Percent (%)** |
| Not at all accessible | 0 | 0% |
| Slightly accessible | 24 | 6% |
| Moderately accessible | 64 | 17% |
| Very accessible | 151 | 39% |
| Extremely accessible | 145 | 38% |
| **Total** | **384** | **100%** |

Table 4 findings were that 76% of the participants viewed clinic hours as convenient (55% very, 21% extremely) and 24% were a bit inconvenienced. Nobody scored provider-client relationships as bad; 78% scored them as good or very good, and 22% as neutral. 76% of the respondents saw excellent or highly successful clinic efforts to diminish HIV stigma, and no one believed that no effort had been made. 92% of the respondents indicated that the service was excellent or good, while 8% indicated that it was poor. Finally, very few respondents noted minor accessibility problems, while 77% said that the clinic was very or very highly accessible. Overall, the majority of the interviewees stated they were satisfied with the clinic's convenience, quality of service, stigma reduction, provider relationships, and hours availability.

**Table 5: Adjusted logistic regression analysis: Association between internalized stigma and clinic visitation**

| Ever missed appointment | Odds Ratio Std. Err. z P>\|z\| [95% Conf. Interval] |
|---|---|
| **Disclosed HIV status**<br>No | 1.696997 .4969267 1.81 0.041 .9559304 3.012562 |
| **Feel ashamed of HIV**<br>Always | 2.088329 1.04313 1.00 0.018 .5710089 5.609259 |

| | |
|---|---|
| **Blame yourself of HIV+**<br>Always | 9.71556 7.221737 3.06 0.002 2.26337 14.70423 |
| Often | 5.546271 3.18491 2.98 0.003 1.799717 11.0922 |
| **Fear of disclosing HIV status**<br>Always | 8.08458 4.483117 3.77 0.000 2.726737 11.9702 |
| **Feel socially isolated**<br>Always | 1.780142 1.278209 0.80 0.022 .4357724 7.271929 |
| Rarely | .2323711 .1313533 -2.58 0.010 .0767397 .7036294 |
| Sometimes | .3214492 .1796857 -2.03 0.042 .1074737 .9614404 |
| **Self-esteem range**<br>Low | 9.286238 4.951328 4.18 0.000 3.265787 12.40534 |
| Average | 3.126697 1.659027 2.15 0.032 1.105192 8.845734 |
| Very low | 3.853099 1.826227 2.85 0.004 1.52185 9.755475 |
| Constant | 3.3072021 .2316868 -1.56 0.028 .0700587 7.347058 |

The logistic regression in Table 5 shows the strongest determinants of missed medical appointments among HIV-positive individuals:

**Disclosed HIV Status**

- No (OR=1.70, p=0.041): People who do not disclose their HIV status are 70% more likely to miss appointments than those who disclose. This significant finding shows fear of disclosure results in avoidance behaviour.

**Feel Ashamed of Being HIV+**

- Always (OR=2.09, p=0.018): Participants who always feel ashamed are over twice as likely to miss appointments, indicating shame is a significant barrier to staying in care.

**Blame Yourself for Being HIV+**

- Always (OR=9.72, p=0.002): Participants who always blame themselves are nearly 10 times more likely to miss appointments, a highly significant result indicating self-blame is a primary driver of disengagement.
- Frequently (OR=5.55, p=0.003): Participants who frequently blame themselves are over 5 times more likely to miss an appointment, indicating the need for psychological care.

**Fear of Disclosure of HIV Status**

- Always (OR=8.08, p=0.001): Participants who always fear disclosure are over 8 times more likely to miss an appointment, indicating stigma and fear as important barriers to care retention.

**Feeling Socially Isolated**

- Always (OR=1.78, p=0.022): Isolating oneself always is associated with missing appointments by 78%, which suggests that social relationships are important.
- Rarely (OR=0.23, p=0.010) and Sometimes (OR=0.32, p=0.042): The respondents who isolate themselves rarely or sometimes are less likely to miss appointments, suggesting the buffering role of social support.

**Self-Esteem Category**

- Average (OR=3.13, p=0.032), Low (OR=9.29, p=0.001), and Very Low (OR=3.85, p=0.004): Decreasing levels of self-esteem are associated with a significant increase in missed appointments, highlighting the value of enhancing self-esteem to obtain better care engagement.

## DISCUSSION OF THE RESULTS

The study suggests that internalized stigma has a high correlation with care retention and HIV treatment motivation. Statistics indicated majority distribution of respondents in the age group 25 to 49 years at 54% females and 46% males. This confirms World AIDS statistics in 2022, where out of every 25 adults in the world, an adult has HIV infection, the most affected being this age group. Interestingly, 43% of them had primary education only, indicating poor HIV and AIDS awareness. Research indicates that individuals with limited qualifications are more probable to suffer from extreme internalized stigma, which affects their health adversely (Adelekan, 2021).

Internalized self-stigma was high and in 26% of participants, participants confessed to feeling shame at being HIV positive that led to avoidance of healthcare. There is evidence that connects shame with reduced self-care and utilization of health services (Hatzenbuehler, 2009; Krishnaratne *et al.*, 2020). Depressive and anxious sentiments were also prevalent, typically leading to self-blame. Logistic regression analysis revealed self-blame as a strong impediment to treatment adherence with the odds ratio (OR) of 9.72 for missed appointments among individuals who experienced self-blame (Pantelic *et al.*, 2017). In addition, those who feared that their HIV status would be revealed were over eight times more likely to miss care (OR = 8.08), whereas shame increased chances of missing an appointment by 79% (OR = 1.79) (Earnshaw *et al.*, 2013; Stangl *et al.*, 2019).

The main predictor of health-seeking behaviour was social support. In the absence of adequate support, barriers to treatment, isolation, and negative emotions were greater (Brennan *et al*., 2020; Stangl *et al*., 2019). Low self-esteem was also common, and this was related to increased missed appointment rates (odd ratio = 9.29) and poor retention in care (Luszczynska *et al*., 2007).

Clinic quality of services and accessibility were largely favourably rated by 92% reporting satisfaction but 23% reported moderate or minor accessibility issues, and others had issues with provider-client relationships, with 22% feeling neutral about their interactions (Brewster & Egan, 2019). Though 76% enjoyed some sincere attempts at reducing stigma, there is always room for improvement.

The logistic regression results of the study verify the significant role of internal stigma, self-blame, and fear of disclosure in retaining care, with promotion of education, social support, and structural interventions to promote improved health outcomes among people with HIV.

# CONCLUSION

The study indicates that internalized HIV stigma has a significant correlation with care retention among those living with HIV. Stigma brings shame and self-blame, and therefore, it is difficult for the patients to start or continue with treatment. Disclosure anxiety, shame, isolation, and low self-esteem need to be treated. Stigmatizing myths regarding individuals living with HIV/AIDS can be dismantled by public and health facility campaigns. PLHIV can communicate with one another through peer groups, comforting each other and offering beneficial information on medication to improve outcomes in terms of health. Care is not only drug treatment; synchronizing appointment times and assisting with transport can encourage increased uptake in health. Counselling helps patients cope with emotions triggered by diagnosis and encourages resilience, critical to the control of chronic illness. Monitoring the effects of stigma-reduction activities enables clinics to refine strategies according to the feedback of patients, thus improving services. The ongoing process works towards a time when no one is being held back from the life, they want, due to HIV-related stigma.

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