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Evaluating layered stigma from comorbid HIV and epilepsy among Zambian adults

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ABSTRACT

Background and purpose: Stigma hinders care for patients with neurologic illness. Layered stigma due to comorbid disease is common yet poorly characterized due to lack of instruments. Epilepsy and HIV are prototypical stigmatized conditions widespread in sub-Saharan Africa.

Methods: We assessed layered stigma among people with HIV and epilepsy (n = 21), epilepsy only (n = 88), and HIV only (n = 40) in Zambia. Epilepsy-associated stigma was assessed using the Stigma Scale of Epilepsy and Jacoby's Stigma Scale. HIV-related stigma was assessed using the HIV/AIDS Stigma Instrument-People Living with HIV/AIDS and Jacoby's Stigma Scale. Stigma was compared across groups using χ^2 tests.

Results: 55% (60/109) with epilepsy reported some epilepsy-associated stigma and 20% (12/61) with HIV reported HIV self-stigmatization. Those with HIV and epilepsy were more likely to associate seizures with fear (OR 6.1 [95% CI: 1.3–27.9]) and epilepsy with dependence (OR 4.6 [1.1–19.6]), controlling for age, gender, marital status, and employment. Those with comorbid disease were more likely to report they were "no longer a person" and felt "blamed" for their HIV. Controlling for age and gender, the difference in depersonalization remained (OR: 6.4 [1.1–36.1]).

Conclusion: Individuals carrying the burden of one stigmatized condition may be more vulnerable to stigma from a comorbid disease.

1. Introduction

Disease-associated stigma is a fundamental cause of population health inequity that substantially affects quality of life [1]. Stigma, and its manifestations as interpersonal discrimination and self-stigmatization, remains one of the greatest barriers to improving the availability of care and preventing mortality associated with neurologic conditions [2]. Social scientists have long maintained that stigma disproportionately affects individuals who are already disempowered [3] and substantial research has sought to identify factors associated with stigma. Greater disease-associated stigma has been associated with other vulnerabilities, such as female gender [4], minority ethnicity [5], and low income [6], but little research has examined how stigma from comorbid medical conditions affects the experience of stigma. While quantitative instruments are available to assess stigma from a sole condition, none have been validated to assess stigma resulting from comorbid conditions. Neglecting this "layered stigma" may result in an underestimation of the impact of stigma on individuals with multiple conditions and may adversely affect our ability to design interventions to reduce stigma [7].

As the burden of non-communicable neurologic diseases continues to grow in low- and low-middle income countries, understanding layered stigma experienced by individuals with comorbid infectious and non-communicable diseases will become increasingly relevant. Epilepsy and HIV are prototypical stigmatized conditions [8,9]. Epilepsy-associated stigma has been associated with decreased medication

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adherence [10] and decreased quality of life [11], whereas HIV-related stigma has been associated with decreased disclosure of disease and decreased health seeking behaviors [12]. In addition, both conditions disproportionately affect sub-Saharan Africa. Half of the world's population living with HIV reside in eastern and southern Africa [13]; 85% of the 70 million people with epilepsy are in low and lower-middle income countries, including sub-Saharan Africa [14]. In Zambia, 13.3% of the population is HIV-positive [15] and a door-to-door survey using a conservative definition for epilepsy identified an epilepsy prevalence of 14.5/1,000 adults [16]. While the number of people with comorbid HIV and epilepsy in Zambia is unknown, the high prevalence of both of conditions suggests there is substantial overlap among those affected.

We used existing epilepsy-associated and HIV-related stigma measures to assess layered stigma among people with epilepsy only, HIV only, and both HIV and epilepsy. We hypothesized that layered stigma would be present in individuals with comorbid disease and that this would manifest as these individuals reporting a greater stigma burden than individuals with HIV or epilepsy alone. We anticipated that there would be a complex interaction between HIV-related and epilepsy-associated stigma that would be neither multiplicative nor additive.

2. Materials and methods

Interviews were conducted with patients receiving routine outpatient care for HIV or epilepsy at two urban health care centers in Zambia. Five clinics were sampled for eligible participants: adult infectious disease, neurology, general medicine, psychiatry and epilepsy. Eligible participants were Zambian adults age 18 years and older with documented HIV infection, epilepsy, or both diagnosed at least one year prior to the date of interview. A duration of at least one year since diagnosis was selected as this has been positively correlated with stigma [17]. The Zambian Mini-Mental Status Exam (zMMSE), an adapted version of the standard Mini-Mental Status Exam for limited literacy populations, was used to screen for severe cognitive impairment and individuals with scores < 18 were excluded [18].

Eligible patients were approached while waiting to be seen at the clinic. The study consent form was read aloud and discussed with participants before obtaining written, informed consent in their preferred language (Nyanja, Bemba, or English). All interviews were conducted in private rooms by trained Zambian nurses who were fluent in English as well as the participant's preferred language. Due to numerous non-standard dialect variations, staff were trained to master the intent for each question in English so it could be translated for each participant. Staff were also provided phrases in local languages reflecting the content of the questions. Participants were reimbursed 20 kwacha (~4 USD) for transportation.

This study was granted ethical approval by the University of Zambia's Biomedical Research Ethics Committee (UNZA BREC) and Michigan State University's Biomedical Institutional Review Board (MSU BIRB). Written informed consent was obtained from all participants included in the study.

2.1. Measures

Data were collected regarding basic demographic characteristics, household wealth, housing quality, educational attainment, and employment as these factors have been inversely associated with stigma [4,19]. Wealth was assessed by enumerating the value of common household items [20–22]. Housing quality was assessed using household construction materials (roof, floor and walls; summed score range 0–15) and access to running water and a toilet [21]. Educational attainment was determined using the highest grade level completed by participants and employment was defined as a regular source of income.

Psychiatric morbidity was assessed with the Shona Symptom Questionnaire (SSQ). Developed in neighboring Zimbabwe, the 14-item SSQ has been used successfully in Zambia to query culturally-relevant symptoms of psychologic morbidity [20,22].

Disease-specific interview questions assessed the time since initial diagnosis, disease severity, medication usage, disclosure status, and stigma. For participants with epilepsy, time since diagnosis was defined as time since first seizure, whereas for participants with HIV, this was defined as time since first positive HIV test. Among participants with epilepsy, disease severity was ascertained using seizure frequency, time since most recent seizure, and interviewer report of physical stigmata of epilepsy, primarily burn scars. For HIV-infected participants, $CD4^+$ T-cell count was used to assess disease severity. Participants were not asked about mode of HIV acquisition as heterosexual transmission is overwhelmingly the most common mode of HIV infection in Zambia [23].

As there are currently no validated instruments for evaluating layered stigma, separate instruments were used to assess HIV-related and epilepsy-associated stigma. Each instrument asked participants to report stigmatizing experiences and personal thoughts related to either HIV or epilepsy. Epilepsy-associated stigma was assessed among participants with HIV and epilepsy and epilepsy only using the Stigma Scale of Epilepsy (SSE) and Jacoby's 3-item Stigma Scale. HIV-related stigma was assessed among participants with HIV and epilepsy and HIV only using the HIV/AIDS Stigma Instrument-People Living with HIV/AIDS (HASI-P) and Jacoby's 3-item Stigma Scale. The SSE is a 24-item Brazilian instrument designed to assess individual perception of discrimination and self-stigmatization using four-point Likert-type responses [25]. Validation of this instrument in Zambia indicated that the instrument adequately assessed two underlying latent traits – one reflecting difficulties associated with epilepsy and the other encompassing epilepsy-related emotions [26]. The HASI-P is a 33-item instrument with four-point Likert-type responses developed in five neighboring sub-Saharan countries to assess HIV-related discrimination and self-stigmatization [24]. Developed among populations that are culturally similar to Zambia, validation indicated that the HASI-P assessed five underlying latent traits related to felt and enacted stigma [24]. Jacoby's 3-item Stigma Scale consists of three dichotomous items that assess an individual's perception of differential treatment because of their condition and has been found to adequately assess epilepsy-associated and HIV-related stigma in Zambia [20,22]. Participants with HIV and epilepsy were asked Jacoby's 3-item Stigma Scale twice – once regarding their HIV infection and once regarding their epilepsy.

2.2. Statistical analysis

Individuals were grouped per medical condition (HIV and epilepsy, epilepsy only, or HIV only) and group frequencies and means were assessed for categorical and continuous items, respectively. Differences in demographic characteristics across the three groups were compared using ANOVA and χ^2 tests, or their non-parametric equivalents, as appropriate. HIV and epilepsy-specific clinical characteristics were compared using t-tests or χ^2 tests. We opted not to compare group responses to the SSE and the HASI-P using their underlying latent traits as it was not clear whether these traits would be sufficiently sensitive to detect layered stigma. In addition, the latent traits of the HASI-P have not been assessed in Zambia. Due to the small sample size, Likert-type responses to stigma questions were dichotomized and χ^2 tests were used to assess the association between comorbid HIV and epilepsy and reported stigma. SAS software was used for all analyses (version 9.4, SAS Institute Inc., Cary, NC).

Adjusted odds ratios for stigma-related measures were calculated, controlling for variables that have been previously associated with disease-associated stigma. A p-value < 0.05 was considered statistically significant.

Table 1
Demographic characteristics of study population.

	Epilepsy (n = 88)	HIV (n = 40)	HIV & epilepsy (n = 21)	p-Value
Women	34 (39)	28 (70)	9 (42)	**0.004**
Age in years	29.2 (9.1)	43.2 (9.3)	37.0 (9.2)	< **0.0001**
Marital status				
Currently married	53 (61)	17 (43)	10 (48)	< **0.001**
Never married	33 (38)	8 (20)	8 (38)	
Divorced/ separated/ widowed	1 (1)	15 (38)	3 (16)	
Currently employed	23 (28)	33 (82)	12 (57)	< **0.0001**
Years of education completed	8.5 (3.4)	9.5 (3.7)	9 (3.2)	0.341
Housing quality	9.9 (2.8)	12.5 (0.9)	11.9 (1.3)	< **0.0001**
Household light source[a]				
Electricity	66 (75)	38 (95)	15 (75)	**0.038**
Kerosene, gas, or paraffin	2 (2)	1 (3)	1 (5)	
Candles	19 (22)	1 (3)	4 (16)	
Cooking method[a]				
Electric stove	59 (67)	35 (88)	14 (67)	0.110
Charcoal	26 (30)	5 (13)	6 (29)	
Wood	3 (4)	0 (0)	1 (5)	
Water source				
Running water in home	32 (37)	19 (48)	10 (48)	0.063
Community tap or pump	53 (61)	18 (45)	8 (38)	
Well/borehole	2 (2)	3 (8)	3 (15)	
Toilet facility				
In home	44 (50)	31 (79)	13 (62)	**0.017**
Toilet nearby	8 (9)	2 (5)	3 (14)	
Pit latrine	36 (41)	6 (15)	5 (24)	
Wealth, USD, mean	1,963 (3,512)	3,457 (3,265)	1,692 (1,563)	**0.004**
Median	1,000 (459, 1,741)	1,820 (1254,4,686)	1,431 (414,2,032)	

Data expressed as number (%), mean (standard deviation), or median (25th, 75th percentile). Percent's may not sum to 100 due to rounding.
Bolded values are considered statistically significant.
[a] More than one allowed. USD, US Dollars.

3. Results

3.1. Demographic and clinical characteristics

One-hundred forty-nine participants were interviewed to assess layered stigma (21 HIV and epilepsy, 88 epilepsy only, and 40 HIV only). A greater number of participants with epilepsy only were intentionally recruited as epilepsy-associated stigma measures may have a ceiling effect in this setting. Six other individuals were ineligible due to severe cognitive impairment as determined by the zMMSE (four men with epilepsy only, one man with HIV only, and one woman with HIV only). Of all the individuals approached for participation, eight patients refused (three men with HIV only who had not disclosed their status, three men with epilepsy only who denied their epilepsy diagnosis, and two women with HIV only for unknown reasons) and two men with epilepsy only declined to answer most of the stigma questions; therefore, these surveys were discarded. This yielded an overall participation rate of 90% (data analyzed from 149/165 eligible participants).

Individuals in the HIV only group were older and more likely to be women than individuals in the epilepsy only and HIV and epilepsy groups ($p < 0.0001$ and $p = 0.004$ using ANOVA, respectively) (Table 1). Participants with HIV only were also more likely to be employed (HIV: 82% versus HIV and epilepsy: 57% and epilepsy: 28%, $p < 0.0001$) with greater household wealth ($p = 0.042$). Housing quality was significantly worse among people with epilepsy ($p < 0.0001$). Individuals with epilepsy only were more likely to rely on candles for household lighting (epilepsy: 22% versus HIV and epilepsy: 16% and HIV: 3%, $p < 0.038$).

$CD4^+$ T-cell counts were comparable between the HIV and epilepsy and HIV only groups (Table 2). While frequency of seizures was not significantly different between groups, participants in the HIV and epilepsy group were more likely to report a breakthrough seizure in the previous week or month than participants in the epilepsy only group. A greater percentage of individuals in the HIV and epilepsy group had experienced seizures in the previous month than individuals in the epilepsy only group (HIV and epilepsy: 85% versus epilepsy: 66%, $p = 0.028$). Thirteen participants in the epilepsy only group (15%) did not know their HIV status. Of the 21 participants in the HIV and epilepsy group, 12 (57%) were diagnosed with epilepsy before they were diagnosed with HIV. In addition, 14 (67%) were taking antiepileptic and antiretroviral drug combinations that may affect the therapeutic efficacy of both regimens [27].

Psychiatric morbidity was high in all three groups, with over half of participants scoring sufficiently high on the SSQ to warrant additional psychiatric assessment and support (Table 2). Thirteen participants (9 epilepsy only; 3 HIV only; 1 HIV and epilepsy) reported contemplating suicide in the previous week and were assisted with accessing psychiatric care. Comorbid HIV and epilepsy was neither associated with increased psychiatric morbidity nor the need for psychiatric support.

3.2. Disease-associated stigma

Reported epilepsy-associated stigma was high for both the HIV and epilepsy group and the epilepsy only group (Table 3). Using the SSE, 17/21 participants with HIV and epilepsy (81%) and 52/88 participants with epilepsy only (66%) associated epilepsy with feelings of shame. Using Jacoby's 3-question Stigma Scale, 8/21 of participants with HIV and epilepsy (38%) and 27/88 of participants with epilepsy only (31%) thought that other people preferred to avoid them because of their epilepsy. Participants with comorbid HIV and epilepsy were more likely to associate seizures with feeling scared and with fear than people with epilepsy only. They were also more likely to associate epilepsy with prejudice and indicate that people with epilepsy feel dependent on others. After controlling for age, gender, employment, and marital status, participants with HIV and epilepsy were more likely to associate seizures with fear (OR: 6.1 [95% CI 1.3–28.0], $p = 0.019$) and epilepsy with feelings of dependence (OR: 4.6 [95% CI 1.1–19.6], $p = 0.039$) than participants with epilepsy only.

Generally, few experiences of overt discrimination were reported by participants. Despite this, using Jacoby's 3-item Stigma Scale, 4/20 (20%) of participants with HIV and epilepsy and 2/40 (5%) with HIV only reported feeling that people treated them like an inferior person because of their HIV infection (differences across groups not significant). Participants in both groups reported self-stigmatization due to their HIV diagnosis (Table 4, HASI-P items 29–33). Twenty participants with HIV (10 HIV only, 10 HIV and epilepsy) felt ashamed about their HIV status. Participants in the HIV and epilepsy group were more likely to report feeling that other people blamed them for their HIV status than participants in the HIV only group (OR: 5.3 [95% CI 1.2–24.1]). Participants with HIV and epilepsy were also more likely to report feeling like they were “no longer a person” because of their HIV status compared to participants with HIV only (OR: 5.3 [95% CI 1.2–24.1]). After controlling for age and gender, the association between comorbid disease and depersonalization remained significant (OR: 6.4 [95% CI 1.1–36.1], $p = 0.044$).

4. Discussion

Accurate assessment of stigma is essential to both characterize the complexity of stigmatization and design interventions to decrease

Table 2
Clinical characteristics of study population.

	Epilepsy (n = 88)	HIV (n = 40)	HIV & epilepsy (n = 21)	p-Value
SSQ score	4.6 (3.0)	4.1 (3.0)	3.8 (2.6)	0.414
Requiring additional evaluation[a]	54 (6)	22 (55)	10 (48)	0.478
HIV characteristics				
cART	–	40 (100)	18 (86)	**0.037**
First-line therapy	–	34 (87)	14 (82)	–
More than once daily dosing	–	18 (46)	5 (29)	–
Forced disclosure of HIV status	–	2 (5)	1 (5)	1.0
Years with HIV, mean	–	5.8 (3.0)	5.2 (3.3)	0.448
Age at diagnosis, mean, years	–	37.4 (9.2)	32.0 (8.0)	**0.028**
$CD4^+$ T-cell count, mean (cells/uL)	–	205 (222)	181 (191)	0.725
Median		135 (49, 277)	112 (68, 20)	–
Epilepsy characteristics				
Seizure-related burns	23 (26)	–	2 (10)	0.149
AED	88 (100)	–	20 (100)	–
More than once daily dosing	28 (32)	–	7 (33)	
Seizures in the past 3 months				
> 1 per week	7 (8)	–	0 (0)	0.284
1 per week	4 (5)	–	0 (0)	
1–3 per month	22 (25)	–	9 (43)	
< 1 per month	55 (63)	–	12 (57)	
Most recent seizure	27 (31)	–	3 (14)	**0.028**
≤ 1 week ago				
> 1 week ago to ≤ 1 month ago	31 (35)	–	15 (71)	
> 1 month ago to ≤ 1 year ago	20 (23)	–	2 (10)	
> 1 year ago	10 (11)	–	1 (5)	
Forced disclosure of epilepsy	46 (52)	–	14 (67)	0.234
Years with epilepsy, mean	10.6 (8.2)	–	10.0 (7.5)	0.747
Age at diagnosis, mean, years	18.7 (11.7)	–	27.3 (14.6)	**0.008**

Data expressed as number (%), mean (standard deviation), or median (25th, 75th percentile).
SSQ, Shona Symptom Questionnaire; cART, combination antiretroviral therapy; AED, antiepileptic drug.
Bolded values are considered statistically significant.
[a] SSQ score > 4.

stigma [28]. Although the burden of stigma has been fairly well characterized for isolated medical conditions and literature suggests that stigma is affected by the presence of other stigmatized identities such as race and gender [5], few investigations have addressed layered stigma experienced by individuals with multiple stigmatized medical conditions [28].

In this study, patients with comorbid epilepsy and HIV experienced some aspects of HIV-related and epilepsy-associated self-stigmatization (felt stigma) more frequently than people with either condition alone. This suggests that individuals already stigmatized by one health-related condition are more vulnerable to stigma from a second condition. This finding is analogous to a study in Ethiopia which showed greater HIV-related stigma among patients with comorbid tuberculosis infection [29]. In our study, participants with HIV and epilepsy were more likely to report feelings of depersonalization due to HIV even after controlling for factors associated with increased stigma. Stigma literature suggests that depersonalization is a manifestation of societal efforts to segregate those with a condition from those without in order to stigmatize those affected [30]. Participants with HIV and epilepsy were also more likely to associate seizures with fear and epilepsy with feelings of dependence than participants with epilepsy alone. In Zambia, a public seizure often forcibly reveals a diagnosis of epilepsy. Increased fear among participants with HIV and epilepsy suggests these individuals may anticipate greater stigmatization from their community and, as a result, actively limit their own activities to avoid revealing their diagnosis [30].

This study also highlighted some of the challenges faced by people living with HIV and epilepsy in a resource-limited setting. Participants with comorbid epilepsy were diagnosed with HIV at a younger age than participants with HIV only, possibly due to previously described sexual vulnerability in this population [21]. Participants with HIV and epilepsy were also more likely to have experienced a breakthrough seizure than participants with epilepsy only. Seizure severity and frequency have been repeatedly associated with stigma among people with epilepsy and appropriate management with antiepileptic drugs has been associated with decreased felt stigma [19]. Understanding the etiology of seizure, particularly among people with comorbid HIV and epilepsy, may be key to addressing reported stigma. Among people with HIV and epilepsy, seizures may be a result of more severe underlying neurologic disease than among people with epilepsy only; poorer medication adherence in the setting of polypharmacy; or antiepileptic drug treatment failure due to interactions with antiretroviral drugs. As most participants with comorbid HIV and epilepsy in this study (57%) were diagnosed with epilepsy prior to HIV, their underlying seizure etiology is unlikely to differ substantially from those with epilepsy only. Therefore, antiepileptic drug failure due to drug interactions or decreased medication adherence due to pill burden may be the more likely causes of seizure breakthrough rather than disease etiology. After a comprehensive literature review, Birbeck et al. [27] recommended pharmacokinetic monitoring among HIV-positive patients taking enzyme-inducing antiepileptic drugs with protease inhibitors or non-nucleoside reverse transcriptase inhibitors due to possible drug interactions resulting in treatment failure. However, as pharmacokinetic assessment is often absent in resource-limited settings and these medication combinations are frequently the only therapy available, the risk of treatment failure may be unavoidable.

This study suggests that further investigation into layered stigma is warranted as it may affect efforts to decrease stigma. The association between order of disease diagnosis and reported stigma also deserves further attention. It may be that stigmatized conditions “sensitize” individuals to experience a second stigma insult differently based on the order in which the stigma burdens are encountered. An individual with a highly-stigmatized condition, such as epilepsy, may experience such a significant initial stigma burden that the addition of another stigmatized condition may have less of an effect than it would in an individual with a less stigmatized pre-existing condition.

The generalizability of this study may be limited. Study participants

Table 3
Reported epilepsy-associated stigma and association with comorbid HIV.

	Group	Number (%)		Odds ratio [95% CI]	Adjusted OR [95% CI][b]
		No	Yes		
Stigma Scale of Epilepsy					
Do you think that people with epilepsy feel able to control their own epilepsy?[a]	Epilepsy	44 (50)	44 (50)	1.3 [0.5–3.5]	0.8 [0.3–2.3]
	HIV & Epilepsy	12 (5)	9 (43)		
How would you feel when you see an epileptic seizure?					
Scared	Epilepsy	48 (56)	37 (44)	**4.2 [1.4–12.4]**	3.6 [1.0–13.3]
	HIV & Epilepsy	5 (24)	16 (76)		
Fear	Epilepsy	43 (51)	42 (49)	**6.1 [1.7–22.4]**	**6.1 [1.3–28.0]**
	HIV & Epilepsy	3 (14)	18 (86)		
Sadness	Epilepsy	26 (31)	59 (69)	2.6 [0.7–9.8]	3.3 [0.6–16.8]
	HIV & Epilepsy	3 (14)	18 (86)		
Pity	Epilepsy	12 (14)	76 (86)	3.2 [0.4–25.8]	4.4 [0.5–39.8]
	HIV & Epilepsy	1 (5)	20 (95)		
Which difficulties do you think people with epilepsy have in their daily lives?					
Relationships	Epilepsy	12 (14)	76 (86)	3.2 [0.4–25.8]	1.5 [0.5–4.8]
	HIV & Epilepsy	1 (5)	20 (95)		
Work	Epilepsy	26 (30)	61 (70)	1.8 [0.6–5.9]	1.8 [0.5–6.9]
	HIV & Epilepsy	4 (19)	17 (81)		
School	Epilepsy	21 (25)	63 (75)	1.9 [0.5–7.1]	2.3 [0.5–11.5]
	HIV & Epilepsy	3 (15)	17 (85)		
Friendships	Epilepsy	39 (45)	48 (55)	1.1 [0.4–2.8]	0.9 [0.3–2.7]
	HIV & Epilepsy	9 (43)	12 (57)		
Sexual	Epilepsy	48 (55)	39 (45)	0.6 [0.2–1.7]	0.8 [0.3–2.5]
	HIV & Epilepsy	14 (67)	7 (33)		
Emotional	Epilepsy	28 (32)	59 (68)	1.2 [0.4–3.4]	1.2 [0.4–3.8]
	HIV & Epilepsy	6 (29)	15 (71)		
Prejudice	Epilepsy	28 (33)	58 (67)	**0.3 [0.1–0.8]**	0.4 [0.1–1.3]
	HIV & Epilepsy	13 (62)	8 (38)		
How do you think that people with epilepsy feel?					
Worried	Epilepsy	12 (14)	76 (86)	1.0 [0.2–3.7]	1.3 [0.3–6.1]
	HIV & Epilepsy	3 (14)	18 (86)		
Dependent	Epilepsy	35 (40)	52 (60)	**4.0 [1.1–14.7]**	**4.6 [1.1–19.6]**
	HIV & Epilepsy	3 (14)	18 (86)		
Incapable	Epilepsy	31 (36)	55 (64)	1.8 [0.6–5.4]	2.1 [0.6–7.5]
	HIV & Epilepsy	5 (24)	16 (76)		
Fearful	Epilepsy	29 (34)	57 (66)	3.1 [0.8–11.2]	2.6 [0.6–10.8]
	HIV & Epilepsy	3 (14)	18 (86)		
Depressed	Epilepsy	23 (26)	64 (74)	1.5 [0.5–5.0]	1.2 [0.33–4.58]
	HIV & Epilepsy	4 (19)	17 (81)		
Ashamed	Epilepsy	35 (40)	52 (60)	2.9 [0.9–9.2]	3.5 [0.9–12.8]
	HIV & Epilepsy	4 (19)	17 (81)		
The same as those without epilepsy[a]	Epilepsy	30 (34)	57 (66)	1.3 [0.5–3.7]	1.4 [0.4–4.6]
	HIV & Epilepsy	6 (29)	15 (71)		
In your opinion, the prejudice in epilepsy will be related to?					
Relationships	Epilepsy	32 (37)	55 (63)	1.2 [0.4–3.2]	1.1 [0.3–3.5]
	HIV & Epilepsy	7 (33)	14 (67)		
Marriage	Epilepsy	40 (48)	44 (52)	1.4 [0.5–3.7]	1.6 [0.5–5.0]
	HIV & Epilepsy	8 (40)	12 (60)		
Work	Epilepsy	21 (25)	64 (75)	1.1 [0.3–3.2]	1.3 [0.3–5.0]
	HIV & Epilepsy	5 (24)	16 (76)		
School	Epilepsy	14 (17)	68 (83)	0.4 [0.1–1.2]	0.4 [0.1–1.3]
	HIV & Epilepsy	7 (33)	14 (17)		
Family	Epilepsy	50 (59)	35 (41)	0.5 [0.2–1.3]	0.6 [0.2–2.2]
	HIV & Epilepsy	16 (76)	5 (24)		
3-Item Stigma Scale					
Because of my epilepsy					
I feel that some people are uncomfortable with me	Epilepsy	50 (57)	38 (48)	0.9 [0.4–2.6]	1.0 [0.3–3.1]
	HIV & Epilepsy	12 (60)	8 (40)		
I feel some people treat me like an inferior person	Epilepsy	52 (59)	35 (40)	1.1 [0.4–2.9]	1.2 [0.4–3.6]
	HIV & Epilepsy	12 (57)	9 (43)		
I feel some people would prefer to avoid me	Epilepsy	60 (69)	27 (31)	1.4 [0.5–3.7]	1.2 [0.4–3.9]
	HIV & Epilepsy	13 (62)	8 (38)		

OR: odds ratio for HIV and Epilepsy group vs epilepsy only group with the response of 'yes' to the stigma question evaluated.
CI: confidence interval.
Bolded values are considered statistically significant.
[a] Categories inverted for analysis to indicate greater stigma.
[b] Adjusted for age, gender, marital status and employment.

were selected through clinics where they were accessing care for their HIV and/or epilepsy. As there are significant treatment gaps (disparity between the number of people needing versus accessing treatment) for both epilepsy and HIV in Zambia [9,31] participants may be healthier and less stigmatized than individuals who are not seeking care. Since the stigma instruments validated in this setting are disease-specific, we

Table 4
Frequencies of HIV-related stigma and association with comorbid epilepsy.

	Group	Number (%)		Odds ratio [95% CI]	Adjusted OR [95% CI][a]
		No	Yes		
HIV/AIDS Stigma Instrument-PLWA					
In the past 3 months, how often did the following events happen because of your HIV status?					
1. I was told to use my own utensils.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	19 (95)	1 (5)		
2. I was asked not to touch someone's child.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
3. I was made to drink last from the cup.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
4. Someone mocked me when I passed by.	HIV	38 (95)	2 (5)	2.1 [0.3–16.2]	4.1 [0.5–35.8]
	HIV & Epilepsy	18 (90)	2 (10)		
5. I stopped eating with other people.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	19 (90)	1 (5)		
6. I was asked to leave because I was coughing.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
7. Someone stopped being my friend.	HIV	39 (97)	1 (3)	6.9 [0.7–71.0]	8.7 [0.7–108.7]
	HIV & Epilepsy	17 (85)	3 (25)		
8. A friend would not chat with me.	HIV	39 (98)	1 (3)	2.1 [0.1–34.6]	3.9 [0.2–70.7]
	HIV & Epilepsy	19 (90)	1 (5)		
9. I was called bad names.	HIV	34 (85)	6 (15)	0.3 [0.03–2.7]	0.2 [0.02–2.0]
	HIV & Epilepsy	19 (95)	1 (5)		
10. People sang offensive songs when I passed by.	HIV	38 (95)	2 (6)	1.0 [0.1–11.7]	0.9 [0.1–12.9]
	HIV & Epilepsy	19 (95)	1 (5)		
11. I was told that I have no future.	HIV	36 (90)	5 (13)	1.6 [0.3–7.9]	1.3 [0.2–7.7]
	HIV & Epilepsy	17 (85)	3 (15)		
12. Someone scolded me.	HIV	38 (95)	2 (6)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
13. I was told that God is punishing me.	HIV	33 (82)	8 (31)	0.8 [0.2–3.6]	0.8 [0.2–4.1]
	HIV & Epilepsy	17 (85)	3 (15)		
14. I was made to eat alone.	HIV	39 (97)	1 (3)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
15. Someone insulted me.	HIV	37 (92)	3 (8)	0.7 [0.1–6.7]	1.1 [0.1–12.5]
	HIV & Epilepsy	19 (95)	1 (5)		
16. People avoided me.	HIV	36 (90)	4 (10)	0.5 [0.1–4.5]	0.4 [0.03–4.2]
	HIV & Epilepsy	19 (95)	1 (5)		
17. People cut down visiting me.	HIV	35 (87)	5 (13)	0.4 [0.04–3.4]	0.2 [0.02–2.6]
	HIV & Epilepsy	19 (95)	1 (5)		
18. People ended their relationships with me.	HIV	35 (87)	5 (13)	0.8 [0.1–4.4]	0.7 [0.1–4.8]
	HIV & Epilepsy	18 (90)	2 (10)		
19. I was blamed for my HIV status.	HIV	37 (92)	3 (8)	**5.3 [1.2–24.1]**	5.1 [1.0–26.2]
	HIV & Epilepsy	14 (70)	6 (30)		
20. Someone tried to get me fired from my job.	HIV	38 (95)	2 (5)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
21. My employer denied me opportunities.	HIV	39 (97)	1 (3)	2.1 [0.1–34.6]	1.8 [0.1–39.2]
	HIV & Epilepsy	19 (95)	1 (5)		
22. I was denied health care.	HIV	39 (97)	1 (3)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
23. I was refused treatment because I was told I was going to die anyway.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
24. I was discharged from the hospital while still needing care.	HIV	39 (97)	1 (3)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
25. I was shuttled around instead of being helped by a nurse.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
26. At the hospital/clinic, I was made to wait until last.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
27. At the hospital, I was left in a soiled bed.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
28. At the hospital or clinic, my pain was ignored.	HIV	40 (100)	0 (0)	–	–
	HIV & Epilepsy	20 (100)	0 (0)		
29. I felt that I did not deserve to live.	HIV	34 (85)	6 (15)	1.0 [0.2–4.5]	1.0 [0.2–5.1]
	HIV & Epilepsy	17 (85)	3 (15)		
30. I felt ashamed of having this disease.	HIV	30 (75)	10 (25)	3.0 [0.9–9.3]	3.2 [0.9–11.6]
	HIV & Epilepsy	10 (50)	10 (50)		
31. I felt completely worthless.	HIV	36 (90)	4 (10)	3.9 [0.9–15.8]	3.3 [0.7–15.0]
	HIV & Epilepsy	14 (70)	6 (30)		
32. I felt that I brought a lot of trouble to my family.	HIV	27 (67)	8 (20)	1.7 [0.6–5.1]	1.5 [0.4–5.4]
	HIV & Epilepsy	11 (55)	9 (45)		
33. I felt that I am no longer a person.	HIV	37 (92)	3 (8)	**5.3 [1.2–24.1]**	**6.4 [1.1–36.1]**
	HIV & Epilepsy	14 (70)	6 (30)		
3-Item Stigma Scale					
Because of my HIV status:					
I feel that some people are uncomfortable with me	HIV	34 (85)	6 (15)	1.0 [0.2–4.5]	1.1 [0.2–5.4]
	HIV & Epilepsy	17 (85)	3 (15)		

(*continued on next page*)

Table 4 (*continued*)

	Group	Number (%)		Odds ratio [95% CI]	Adjusted OR [95% CI][a]
		No	Yes		
I feel some people treat me like an inferior person	HIV	38 (95)	2 (5)	4.8 [0.8–28.6]	3.8 [0.5–27.0]
	HIV & Epilepsy	16 (80)	4 (20)		
I feel some people would prefer to avoid me	HIV	29 (97)	1 (3)	2.1 [0.1–34.6]	2.1 [0.1–46.2]
	HIV & Epilepsy	19 (95)	1 (5)		

Bolded values are considered statistically significant.

[a] Adjusted for participant age and gender; CI: confidence interval; OR: odds ratio for HIV and Epilepsy group vs HIV only group with the response of 'yes' to the stigma question evaluated.

were unable to assess whether layered stigma from comorbid HIV and epilepsy was additive or multiplicative as not all participants could be asked all the stigma questions. Lastly, given our relatively small sample size in this first-ever evaluation of layered stigma in the setting of pre-existing stigma from another chronic disease, we did not have sufficient power to correct for multiple testing.

4.1. Conclusions

As access to care continues to improve for conditions like HIV and epilepsy in resource-limited settings and HIV-positive individuals continue to live longer, the burden of layered stigma will become increasingly relevant. Although layered stigma is an often-overlooked aspect of stigma research, this study suggests that an existing stigma burden from one condition predisposes individuals to being more vulnerable to the effects of stigma from a second condition. Additional investigations into layered stigma among people with HIV and epilepsy, including the development of instruments to examine stigma resulting from comorbid medical conditions, are warranted.

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