

Community-Level HIV Stigma and Projected Quality of Life: A Cross-Sectional Evaluation of Societal Stereotyping in a Malaysian University

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Abstract

Background

HIV-related stigma remains a formidable public health barrier, compromising the social integration, treatment adherence, and psychological well-being of people living with HIV (PLHIV). While actual Health-Related Quality of Life (HRQoL) among PLHIV is well-documented, public assumptions and stereotypes regarding the lived experiences of PLHIV are rarely quantified. This study evaluated community-level HIV stigma and the public's projected HRQoL for PLHIV within a university campus in Malaysia.

Methods

A cross-sectional survey was conducted among university students and employees at the International Islamic University Malaysia (IIUM) Centre for Natural and Health Sciences (CNHS). Data were collected using the validated HIV Stigma Questionnaire, which evaluates six conceptual domains: anticipated stigma, fear of infection, discrimination, perceived stigma, social judgement, and experienced stigma. Concurrently, respondents completed the WHOQOL-HIV BREF from the imagined perspective of PLHIV to assess empathic projection. Chi-square tests of independence assessed associations between sociodemographic characteristics and stigma domains, while descriptive statistics evaluated the transformed QoL domain scores.

Results

406 respondents showed high levels of community stigmatization, with anticipated stigma emerging as the most prevalent domain (91.9%, $n = 373$) followed by fear of infection (83.5%, $n = 339$). Gender was significantly associated with social judgement ($p = 0.001$), experienced stigma ($p = 0.005$), and discrimination ($p < 0.01$). Employment status showed significant associations with social judgement ($p < 0.001$), whereas general educational qualification yielded no statistically significant impact on stigma reduction. Projected WHOQOL-HIV BREF scores were strikingly depressed across all dimensions. Respondents estimated the lowest QoL in the Spirituality, Religion and Personal Beliefs domain (Mean = 33.5 ± 23.3 out of 100), followed by the Psychological domain (Mean = 45.4 ± 22.9).

Conclusion

HIV-related stigma remains highly prevalent within higher education communities, driven primarily by persistent transmission fears and moral judgment rather than a lack of general academic attainment. The severely depressed projected QoL scores, particularly within the spiritual domain, highlight a pervasive community stereotype that HIV inevitably destroys an individual's spiritual peace and psychological stability. Public health interventions must transcend biological education, combining health literacy with faith-aligned community engagement to challenge moral stereotypes and foster social pardoning of PLHIV.

Introduction

The Human Immunodeficiency Virus (HIV) remains a major global public health challenge, presenting persistent social and psychological hurdles for individuals living with the virus. The advent of highly active antiretroviral therapy (ART) has fundamentally transformed the clinical trajectory of HIV, transitioning it from a universally fatal illness to a manageable chronic condition¹. In Malaysia, national surveillance data from the Global AIDS Monitoring Report indicated an estimated 86,142 people living with HIV (PLHIV) by the end of 2022, with 81% aware of their diagnosis and 68% actively receiving ART^{2,3}. Although annual new HIV notifications in Malaysia dropped by 65.8% between 2002 and 2022 (from 28 to 9.7 cases per 100,000 individuals), the epidemic maintains a prominent male preponderance, exhibiting a male-to-female ratio of 7.5 in 2021²⁻⁴. Despite these biomedical advancements, the psychosocial landscape for PLHIV remains fraught with isolation, systemic discrimination, and barriers limiting engagement with the care cascade⁵.

The World Health Organization (WHO) defines Quality of Life (QoL) as “individuals' perceptions of their position in life in relation to their goals, expectations, standards, and concerns within the context of the culture and value systems in which they live”⁶. Evaluating QoL has gained widespread recognition as a crucial health outcome that supplements traditional clinical markers such as mortality and CD4 + T-cell counts, aiding healthcare providers in tracking functional changes over time and evaluating therapy effectiveness⁷⁻¹⁰. For PLHIV, actual Health-Related Quality of Life (HRQoL) is shaped by a complex interplay of physical symptoms, treatment adherence, personal beliefs, education, employment security, and social support networks¹¹⁻¹⁵. Recent literature indicates that when PLHIV achieve viral suppression, their actual HRQoL can be highly comparable to the general population¹⁶⁻¹⁸. Furthermore, HRQoL in PLHIV is increasingly viewed as the vital “fourth 95” in the UNAIDS 95-95-95 targets, ensuring that individuals do not merely survive but thrive¹⁹⁻²¹.

However, a major barrier directly eroding the actual QoL of PLHIV—and a primary driver of the epidemic's hidden burden—is HIV-related stigma^{22,23}. The Joint United Nations Programme on HIV/AIDS (UNAIDS) defines HIV-related stigma as “a process of devaluation of people either living with or associated with HIV and AIDS”¹⁹. Stigma frequently originates from public ignorance regarding transmission pathways, unfounded fears of casual contact, and persistent associations of HIV with socially condemned or immoral behaviors. In societies strongly influenced by traditional cultural and religious values, hostility toward PLHIV often manifests as acute moral judgment and prejudice. This continuous hostility inflicts profound damage on patients; PLHIV routinely experience social judgment, forced isolation, and emotional disturbances²²⁻²³.

While the actual QoL of PLHIV is extensively documented, an underexplored dimension of HIV research is the societal projection of QoL—how the uninfected public assumes a PLHIV lives. When community members interact with PLHIV, their behavior is largely dictated by cognitive stereotypes regarding the patient's physical capability, mental stability, and spiritual worth. Measuring this empathic projection provides a unique window into the subconscious stigma held by a community. Understanding both explicit community-held stigma and the implicit stereotyping of PLHIV's lived experiences is critical for designing targeted public health interventions and anti-discrimination policies. Public attitudes directly shape the

social environment in which PLHIV seek care, maintain employment, and access community support. Therefore, this study aims to comprehensively evaluate the specific domains of explicit stigma present within a university cohort and to quantify the community's empathic projection of a PLHIV's QoL.

Methodology

Study Design and Setting

This study utilized a cross-sectional, quantitative survey design to simultaneously measure community-level stigma and projected HRQoL towards PLHIV. The research was conducted among students and employees within the International Islamic University Malaysia (IIUM) Centre for Natural and Health Sciences (CNHS), serving as a sample of an educated, predominantly young adult population within a conservative sociocultural setting.

Participant Selection and Sample Size

The target population comprised approximately 3,000 members of the IIUM CNHS community. To ensure statistical reliability and adequate power, the minimum required sample size was calculated using Slovin's formula²⁴, yielding a target sample size of 400. Eligible participants included individuals currently studying or employed at IIUM CNHS. Those who had communication barriers, were neurologically or psychologically unwell were excluded from the final analysis.

Study Instruments

A self-administered Google form was developed and deployed through emails and WhatsApp® groups. The form consisting of three primary sections: demographic profiling, an explicit stigma evaluation, and a projected QoL assessment.

The first quantitative tool utilized was the HIV Stigma Questionnaire. Originally developed by the Global Stigma and Discrimination Indicator Working Group (GSDIWG), this questionnaire evaluates community stigma across six distinct conceptual domains: anticipated stigma, perceived stigma, fear of infection, social judgement, experienced stigma, and discrimination. The questionnaire utilising 'Yes or No' answer in which the positive answers results in a high stigma. There are six questions representing each key conceptual domain²⁵. The instrument has demonstrated strong content validity and internal consistency in previous Malaysian population research^{26,27}.

The second quantitative tool was the WHOQOL-HIV BREF, a highly validated 31-item instrument designed to assess QoL across six domains. Participants use a 5-point Likert scale, with 1 denoting "not at all" and 5 denoting "an extreme amount", to score their feelings on various life elements over the last two weeks. The ratings for each domain vary from 4 to 20, with higher values denoting improved QoL^{6,10}. Previous validation studies of the Malay version of the WHOQOL-HIV BREF have demonstrated excellent

psychometric properties^{28,29}. While standard applications evaluate generic physical conditions and clinical outcomes³⁰, in a methodological departure, this study explicitly utilized the WHOQOL-HIV BREF to measure the "proxy-patient perspective" and "affective forecasting"^{31–33}. Participants were explicitly instructed to answer the 31 items from the imagined perspective of a person living with HIV^{31,32}. This captures the respondents' affective forecasting—their ability to predict how someone would feel in a hypothetical health state—thus quantifying societal stereotyping³³. The raw item scores were then mathematically transformed onto a standardized 0–100 scale according to the WHO scoring protocol^{6,10}.

Data Collection, Ethical Considerations, and Statistical Analysis

A pilot study was conducted prior to primary data collection to evaluate readability, response burden, and questionnaire completion time³⁴. The pilot study showed that participants preferred the English version of the questions for simplicity and clarity with no further changes to any of the questionnaires. This study was conducted in strict accordance with the Declaration of Helsinki and was formally approved by the IIUM Research Ethics Committee (IREC No: (UG) 2024-089). Informed consent of participations was collected from all participants prior to answering the questionnaire.

Raw data were imported, cleaned, and analyzed using IBM SPSS Statistics version 29.0 and Jamovi version 2.5 by the Jamovi Project. Continuous data were evaluated for normal distribution, and subsequently expressed as means, standard deviations, skewness, and kurtosis to understand the distribution shape of

public projections³⁵. Chi-square (χ^2) tests of independence were utilized to determine significant associations between sociodemographic variables and the six HIV Stigma Questionnaire domains.

Results

Sociodemographic Characteristics of Respondents

The final analytical sample comprised of 406 participants. The study cohort demonstrated a significant female preponderance (71.2%, n = 289). The respondents represented a young adult demographic, with a mean age of 21.2 years. Evaluating employment status revealed that the overwhelming majority of participants were students (87.7%, n = 356), and 69.0% (n = 280) were actively pursuing undergraduate degrees. Complete sample characteristics are shown in Table 1.

Table 1
Sociodemographic of the participants of the study
population (N = 406)

*	Mean	SD	Range
Age (Years)	21.2	3.32	16–54
	n		%
Gender			
Female	289		71.2
Male	117		28.8
Employment Status			
Employed	30		7.4
Freelancer	4		1.0
Student	356		87.7
Unemployed	16		3.9
Education Level			
Undergraduate	280		69.0
Diploma	27		6.7
Postgraduate	14		3.4
Do not have degree	85		20.9

[Table 1]

Prevalence of Community HIV Stigma Domains

The application of the HIV Stigma Questionnaire revealed exceptionally high levels of explicit community stigmatization. Anticipated stigma emerged as the most universally held belief, endorsed by an overwhelming 91.9% (n = 373) of respondents. Fear of infection through casual contact was the second most prevalent domain, reported by 83.5% (n = 339). Over half of the participants acknowledged the presence of structural discrimination (60.8%, n = 247), perceived societal stigma (58.1%, n = 236), and harsh social judgement (56.9%, n = 231). Only experienced stigma was reported by less than half of the participants (43.1%, n = 175).

Sociodemographic Associations with HIV Stigma

Significant statistical associations were identified primarily concerning gender and employment status. Gender exhibited a profound impact, with respondents differing significantly in their likelihood to endorse

social judgement ($p = 0.001$), experienced stigma ($p = 0.005$), and awareness of discrimination ($p < 0.01$). Employment status also showed a strong statistical association exclusively with the domain of social judgement ($p < 0.001$). Crucially, educational qualification demonstrated no statistically significant association with any of the six stigma domains (all p -values > 0.05). Full reported significance values are summarised in Table 2.

Table 2
Association between sociodemographic characteristics with HIV Stigma Questionnaire

Variables	Fear of infection	Social judgement	Anticipated stigma	Perceived stigma	Experienced stigma	Discrimination
Gender	$p = 0.496$	$p = 0.001$	$p = 0.838$	$p = 0.826$	$p = 0.005$	$p < 0.01$
Male						
Female						
Employment status	$p = 0.366$	$p < 0.001$	$p = 0.679$	$p = 0.083$	$p = 0.235$	$p = 0.497$
Employed						
Unemployed						
Student						
Freelancer						
Education Level	$p = 0.386$	$p = 0.942$	$p = 0.525$	$p = 0.168$	$p = 0.072$	$p = 0.405$
Do not have a degree						
Undergraduate						
Diploma						
Postgraduate						

[Table 2]

Empathic Projection: Estimated Quality of Life (WHOQOL-HIV BREF)

To quantify community stereotyping, the WHOQOL-HIV BREF items were transformed into six standardized domain scores, and overall QoL and general health perception (0–100 scale). The descriptive statistics expose a uniformly pessimistic societal view. The most severe projected impairment occurred in Domain 6 (Spirituality, Religion and Personal beliefs), which yielded a mean score of only 33.5 (SD = 23.3). The Psychological domain (Domain 2) and Social Relationships domain (Domain 4) yielded highly depressed mean scores of 45.4 (SD = 22.9) and 46.2 (SD = 22.2), respectively. The complete projection scores of each domain are shown in Table 3.

Table 3
Descriptive Statistics of Projected Transformed WHOQOL-HIV BREF Scores (0-100 Scale) (N = 406)

Domain or Item	Item Number	N	Mean	SD	Skewness	Kurtosis
Overall QoL/ General Health		406	53.1	27.9	-0.264	-0.821
Overall Quality of Life	Q1		3.16	1.15	-0.243	-0.819
General health perception	Q2		3.09	1.22	-0.248	-0.951
I. Physical health		406	49.3	20.1	0.222	0.154
Pain and discomfort	Q3		2.98	1.35	-0.093	-0.597
HIV symptoms	Q4		3.16	1.35	-0.39	-1.04
Energy and fatigue	Q14		2.98	0.97	0.0835	-0.069
Sleep and rest	Q14		2.98	0.97	0.0665	-0.069
II. Psychological health		406	45.4	22.9	0.158	-0.517
Positive feelings	Q6		3.05	1.23	-0.008	-0.916
Concentration	Q11		2.88	1.13	0.0679	-0.72
Bodily image and appearance	Q15		2.84	1.10	0.0665	-0.572
Self-esteem	Q24		2.85	1.21	0.144	-0.953
Negative feelings	Q31		3.54	1.21	-0.376	-0.863
III. Level of Independence		406	51.1	22.8	-0.019	-0.38
Dependence on medication or treatment	Q5		3.24	1.30	-0.342	-0.94
Activities of daily	Q20		3.33	1.15	-0.377	-0.702
Work capacity	Q22		3.07	1.08	-0.012	-0.679
Mobility	Q23		3.02	1.08	-0.072	-0.716
IV. Social relations		406	46.2	22.2	0.164	-0.386
Social support	Q17		2.98	1.07	-0.071	-0.526
Sexual activity	Q25		2.79	1.20	0.17	-0.926
Personal relationships	Q26		2.42	1.13	0.388	-0.513
Social inclusion	Q27		3.19	1.15	-0.166	-0.826
v. Environmental health		406	54.7	19.9	-0.063	0.0977
Physical safety and security	Q12		2.92	1.18	-0.014	-0.883
Home environment	Q13		3.13	1.14	-0.33	-0.492

Domain or Item	Item Number	N	Mean	SD	Skewness	Kurtosis
Overall QoL/ General Health		406	53.1	27.9	-0.264	-0.821
Financial resources	Q16		2.97	1.02	-0.001	-0.308
Opportunities to acquire new skills and information	Q18		3.28	1.03	-0.293	-0.301
Participation in and opportunities for recreation and leisure activities	Q19		3.11	1.06	-0.164	-0.521
	Q28		3.24	1.16	-0.182	-0.853
Physical environment	Q29		3.49	1.12	-0.518	-0.44
Health and social care	Q30		3.36	1.09	-0.306	-0.573
Transport						
VI. Spirituality, Religion and Personal beliefs		406	33.5	23.3	0.586	-0.315
	Q7		3.14	1.23	-0.12	-0.868
Religion, spirituality and personal beliefs	Q8		3.6	1.48	-0.708	-0.907
Forgiveness and blame	Q9		4.06	1.11	-1.11	0.573
Concern about the future	Q10		4.12	1.13	-1.25	0.794
Death and dying						
	N			%		
Poor Quality of Life	227			56.03		
Good Quality of Life	178			43.96		

[Table 3]

The data distributions was fairly normal as the Skewness/SE values for five domains were < 1.96 (except domain six it was 4.84)³⁵. Complete values are reported in the appendix material, supplementary 1.

Discussion

This study undertook a comprehensive evaluation of community-level stigma toward PLHIV alongside an innovative assessment of the public's empathic projection of HIV-related QoL. The synthesized findings reveal a dual crisis of profound misinformation: alarmingly high levels of explicit community stigmatization are inextricably linked to severe, pessimistic stereotyping of the lived experience of PLHIV.

The extraordinarily high prevalence of anticipated stigma (91.9%) alongside fear of infection (83.5%) underscores deep-seated community anxieties. A major conceptual driver of HIV-related stigma is the lack of accurate public knowledge regarding transmission pathways^{5,22,23}. This is exacerbated by a widespread lack of public awareness regarding the Undetectable = Untransmittable (U = U) consensus^{4,5,19}.

This baseline of fear correlates directly with the dismal QoL projections measured by the WHOQOL-HIV BREF, which heavily underscores the phenomenon known as the "disability paradox"^{36–38}. The disability paradox occurs when outsiders assume the quality of life for individuals with a chronic illness or disability is exceptionally low, whereas the affected individuals actually report high levels of adaptation and life satisfaction^{36–38}. When uninfected individuals try to imagine life with HIV, they frequently fall victim to affective forecasting errors and focalism, overestimating the persistence of negative emotions and fixating solely on clinical limitations while entirely ignoring human resilience and coping mechanisms^{33,39}. The community assumes an HIV diagnosis results in immediate and permanent incapacitation, projecting severe impairments with mean scores of 49.3 for Physical and 45.4 for Psychological well-being^{31,33}. This projection stands in stark contrast to contemporary clinical reality, where actual HRQoL utility scores frequently exceed 0.80 on standardized indices^{7,16}.

Nowhere is this societal stereotyping more evident than in the evaluation of the Spirituality, Religion and Personal Beliefs domain. In conservative, faith-oriented societies, community stigmatization is heavily influenced by cultural values^{40–42}. The public clearly operates under the assumption that an HIV diagnosis inevitably precipitates profound spiritual turmoil. However, this assumption represents a secondary form of moral prejudice—the belief that PLHIV are spiritually illegitimate. Empirical literature definitively refutes this, demonstrating that religion frequently functions as a primary source of psychological resilience and coping for PLHIV^{41,42}. Studies centered on Muslim PLHIV demonstrate that many actively employ religious coping strategies, strengthening their relationship with God to find tranquility, meaning, and acceptance⁴⁰. The community's failure to recognize spiritual resilience indicates that interventions must prioritize dismantling the moral and religious stigmatization surrounding the disease.

The inferential statistics drawn from the χ^2 tests further elucidated the demographic contours of this stigma, demonstrating that gender and differing baseline exposures to health information alter how individuals regulate social responses²⁶. Furthermore, the lack of association between general educational qualification and stigma domains ($p > 0.05$) proves that higher general academic attainment does not automatically neutralize HIV-related prejudice^{4,5}.

Strengths, Limitations, and Future Directions

This study features several notable strengths, primarily its innovative methodological approach combining direct explicit stigma evaluation with the indirect measurement of stereotyping through projected WHOQOL-HIV BREF scores. Furthermore, utilizing an anonymous, self-administered digital format successfully mitigated social desirability bias.

However, the study is subject to specific limitations. The reliance on purposive sampling within a single university community inherently limits the generalizability of the findings. Additionally, by using the WHOQOL-HIV BREF to measure the proxy-patient perspective, the findings quantify public assumptions rather than clinical outcomes. In this Limitations section, it is firmly acknowledged that proxy reporters systematically misjudge well-being^{31,32}. Because self-reports and proxy reports differ systematically, the QoL data in this study reflect affective forecasting errors and societal stereotyping rather than the true health states of PLHIV^{31–33}. The cross-sectional nature of the research design precludes the establishment of definitive causal relationships.

Conclusion

The findings confirm that explicit stigmatization, propelled by unfounded transmission fears, remains deeply entrenched within the community, completely unaffected by general educational attainment. Crucially, by measuring projected QoL, this study uncovered a profound societal stereotype: the public erroneously assumes an HIV diagnosis guarantees total physical destruction, psychological despair, and spiritual ruin. Translating these findings into highly targeted, myth-busting, and faith-aligned anti-stigma campaigns is essential for public health policy to foster a scientifically literate and genuinely compassionate social environment.

Declarations

Declaration of Generative AI and AI-assisted technologies in the writing process:

During the preparation of this work the authors used generative AI to improve the structure, wording, and linguistic flow of the manuscript, as well as to assist with the thematic reframing of methodological approaches based on existing behavioral science literature. After using the tool, the author(s) reviewed and edited the content as needed and take full responsibility for the content of the publication.

Clinical trial number:

not applicable

Ethical Approval Statement / Consent to Participate)

The study was conducted in accordance with the 1964 Declaration of Helsinki and its later amendments. Ethical approval was obtained from the IIUM Research Ethics Committee (IREC No: (UG) 2024-089). Informed consent of participations was collected from all participants prior to answering the questionnaire.

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Author Contribution

A.M.Y.O. (Ahmad M. Y. Osman) Conceptualisation, Methodology development, Project administration, Writing – final draft, Writing – review & editing. S.A: (Sofea 'Aisyah Aminondin) Google form development, data acquisition, data curation, Statistical analysis, Writing – original draft, Writing – review & editing. A.M.F.N.: (Abdul Rahman M. Fata Nahas) Methodology development, Scientific advisory, Validation, Writing – review & editing

Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Supplementary Files

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