Development and Psychometric Evaluation of the HIV–Related Stigma in Health Facilities (HIV–SHF) Scale

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Abstract:

Objective: The literature presents a variety of Human Immunodeficiency Virus (HIV) stigma scales focused on the self, social aspects, and health worker issues. Scarcity was noted on instruments developed to assess HIV-related stigma in health facilities. This paper aims to present the rigors in designing and developing a psychometrically reliable and valid scale to assess HIV-related stigma in health facilities.

Material and Methods: A sequential exploratory mixed method design was utilized following a Qual–Quan approach. Key informant interviews were used to gather first–hand experience of stigma in health facilities among key populations and persons living with HIV. Thematic analysis was utilized to analyze the narratives and pick out statements for item generation in the scale. The quantitative phase was done through item and scale validation, exploratory factor analysis, and reliability assessment using Cronbach's alpha.

Results: Two factors were extracted which were categorized as (1) Facility Structure and Protocol, and (2) Health Personnel. The scale has very high internal consistency as per Cronbach's alpha value of 0.91, suggestive of its high reliability in measuring HIV-related stigma in health facilities.

Conclusion: The scale may be utilized by health facilities to assess and evaluate their health service provision, particularly on their client's perception of health facility-related stigma.

Keywords: health facilities, HIV stigma, scale development, sequential exploratory mixed-method

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Introduction

Human immunodeficiency virus (HIV) continues to be a dreaded medical condition and has claimed so many lives across the globe. As of 2020, the Joint United Nations Programme on HIV/AIDS (UNAIDS) recorded 37.7 Million people living with HIV, of which 680,000 have died from AIDS-related illnesses¹. Despite the number of efforts implemented in mitigating the number of cases, there is an increasing trend in the number of estimated adults and children living with HIV².

Stigma in the context of HIV

The breadth of reports of stigma and discrimination coming from scholars across the globe mirrors the seemingly complex means to achieve the 90-90-90 goals for 2020 and ending HIV and AIDS. Various scholars have attributed the constraints in HIV mitigation to stigma and discrimination. Stigma is defined as personal, psychoemotional, and social remarks devaluing and discrediting a person³. This can be from the inner self, social circle, or by overt exclusion in society^{4,5}. A variety of scholars agree to this, pointing to the detrimental effects of stigma on patient outcomes. For instance, patients would prefer not to seek medical attention out of fear of confirming the disease's presence and being seen by their peers⁶. Other patients would prefer to discontinue treatment because of having a degrading experience when visiting their health providers. Likewise, dropouts are common, especially when persons living with HIV (PLHIVs) feel threatened about their safety. Similarly, there are reports where routine procedures in the facility may be perceived as offensive and intimidating^{7,8}. Unquestionably, the literature is clear in regards to the ill effects of stigma, as it leads to compromised physical and mental deterioration and a reduction in life guality⁹.

Measurements in HIV stigma

HIV Stigma has long been studied and discussed in the literature. The desire to fully understand and capture

stigma is evidenced by the number of instruments developed by various scholars and adapted in different cultural settings. For example, Berger's HIV Stigma Scale, originally from the United States of America¹⁰, has been validated in assessing stigma in children¹¹, and perinatal adolescents¹². Likewise, it has been used to assess stigma among adults in China¹³, India¹⁴, Sweden¹⁵, and Spain¹⁶. Additionally, the scale has been validated to assess other stigma inducing situations such as Hepatitis C infection¹⁷, and stigma related to preexposure prophylaxis¹⁸.

Other psychometrically tested scales were created to assess different dimensions of stigma. For instance, there are scales developed to measure internalized stigma¹⁹ and anticipated stigma²⁰ in both adult and young PLHIVs²¹. Similarly, scales were developed to assess the entire four stigma dimensions, including enacted and resisted stigma in addition to the first two aforementioned²². Additionally, there are also HIV stigma scales developed for exclusive use among the Asians in an American setting²³, and a measure to assess culturally-induced stigma²⁵, and HIVrisk associated stigma²⁵.

Health facilities, which refer to establishments providing health services, are the most frequently identified places where stigma and discrimination are experienced by clients seeking reproductive and sexual health-related support.

Additionally, healthcare workers were a major factor in the perception of stigma and discrimination, and this potentially could be measured through the use of an instrument measuring behavior²⁶. Assessing the possible presence of health facility-related stigma, especially among the key population, is vital to evaluate whether health centers facilitate healing and restoration or are perceived as stigma-inducing. Despite a large number of instruments in existence that are developed to measure HIV stigma, there is a scarcity of scales measuring specific to healthfacility-related HIV stigma.

Study aims

This study aims to develop and psychometrically test an instrument to measure HIV-related stigma in health facilities.

Material and Methods

Design

This study utilized a sequential exploratory mixedmethod design. The study's first phase used a descriptive qualitative approach followed by exploratory factor analysis (EFA) as the quantitative method used in the study's second phase (Figure 1 and Table 1).

Phase 1: Qualitative phase

The participants' experience of stigma was assessed using a descriptive qualitative approach. The narratives centered on the overarching question, "What stigmatizing experiences on HIV did you encounter in health facilities?"

Participant Recruitment and Sampling

Due to the nature and sensitivity of the topic, the researchers implemented criterion sampling to recruit participants. The researchers coordinated with existing HIV support and advocacy groups in the region to invite participants to the study. The support group leaders cascaded the invitation to participants willing to join in a focus group discussion (FGD). A total of 15 informants joined

Qualitative Phase

Thematic
Analysis
Instrument
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Quant
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in the FGD session. There were two types of participants invited to participate. The first group was composed of young adults who were identified to have risky sexual behaviors but had a negative diagnosis, and the other was clinically diagnosed as HIV positive. Inclusion criteria included only those who had an experience feeling stigmatized in a health facility for a sexual and reproductive health concern. Likewise, they must have been voluntarily willing to share their experiences with the researchers. Excluded are those who are in the advanced stage of HIV disease.

Setting and data collection

Fifteen willing participants were gathered in a private room for a face-to-face FGD. The researchers secured informed consent before initiating the discussion, ensuring that the participants understood the purpose, benefits, and risks of the study. The participants were allowed to raise queries that facilitated clarity about their roles. The researchers oriented the participants in regards to the discussion flow and informed them about the need to utilize a recorder throughout the session.

Data analysis

The recorded FGD session was transcribed and analyzed using Braun and Clark's²⁷ thematic analysis. The transcripts underwent a reading and re-reading process to identify any embossed patterns. The researchers

Quantitative Phase

- Exploratory Factor Analysis
- Instrument Reliability Assessment

Figure 1 Sequential exploratory process

grouped narratives that shared the same meaning and listed them as a pool for items to be used to develop the Human Immunodeficiency Virus-Stigma in Health Facility (HIV-SHF) Scale. The raw instrument derived 15 items that underwent subject matter expert (SME) validation for face and content validity assessment. The invited SMEs were composed of health practitioners in HIV/AIDS care, a nurse professor whose expertise is on HIV care, a tool development expert, nurse theorists, academicians in health science, a statistician and a language expert.

Trustworthiness

Trustworthiness in this phase of the study was established following the Lincoln and Guba²⁸ framework. Consistent reflexive journaling throughout the inquiry met credibility, transferability, and authenticity standards. The participants' narration of their experience was done to the point of meeting data saturation. Likewise, intercoder reliability checks maintained the veracity, confirmability, and groundedness of transcripts on the participants' experience of stigma in health facilities. Member checking was done to achieve the dependability of this study.

Phase 2: Quantitative phase

This phase involved the content validity and reliability assessment of the raw questionnaire.

Content and face validity assessment

Subject matter expert validation was done to assess the face and content validity of the raw instrument composed of fifteen initial items. Eleven experts took part in the validation process. Using the item and scale assessment, content validity (CVI) was computed following the standard CVI computation. Items were assessed based on relevance. Items with a 'very relevant' score were summed and divided by the total number of experts who rated (I-CVI). Scale Content Validity Index (S-CVI) was computed by averaging the item score from the total number of items in the scale. The final version of the validated HIV– SHF scale is composed of 11 items.

Sampling and sample size

Based on DeVellis's²⁹ standard of 1:5 item-sample ratio, for the 11-item raw version, a total of 55 samples will suffice to run an EFA. We utilized 180 samples to run an exploratory factor analysis of the final version of the scale.

Participant Recruitment and Setting

Using SurveyMonkey, the researchers forwarded the instrument to several HIV support and advocacy groups for field-testing. The researchers coordinated with a representative from the mentioned groups who served as the link to the participants. The researchers trained the representative in selecting respondents, informed consent, and other relevant steps about data gathering and retrieval. Included were individuals who had an experience being stigmatized and discriminated against in a health facility for a sexual or reproductive health concern. These include PLHIV, high-risk groups (not limited to MSM or high-risk behaviors). Likewise included were those who declared willingness to voluntarily participate. Excluded as samples were those in their advanced stage of HIV disease. A total of 180 responses were retrieved.

Statistical data analysis

To analyze the data, we utilized STATA v15.1 software. Bartlett's Test of Sphericity and the Kaiser Meyer Olkin (KMO) test were used to assessing the suitability of the samples for exploratory factor analysis. Factor extraction was done using the Principal Component Factor method. Kaiser's Criterion estimated the eigenvalues to determine the number of retained factor solutions. Those whose eigenvalues were >1 were retained. Likewise, we utilized the Varimax rotation to interpret the items retained per factor

easily. Cronbach's alpha was used to assess the internal consistency and reliability of the identified factors and the entire scale.

Ethical considerations

This study is technically and ethically reviewed and approved by the St. Paul University Philippines Ethics Review Committee with protocol code number 2018–01– PhDNS–11. The researchers observed proper ethical procedures, especially in regards to participant selection and securing informed consent before data collection.

Results

Qualitative findings

During the focused group discussion, the qualitative responses with participants unearthed several experiences of being stigmatized and discriminated against, in health facilities. The narratives were categorized into three themes: facility structure, protocols, and personnel. The narratives of each theme were utilized for the item development of the HIV-SHF scale.

Profile of interview participants

The participants were composed mainly of men (80.0%) aging 21–30 years old (53.0%). Most of the participants were able to complete high school as their highest educational attainment (80.0%) (Table 2).

Quantitative results *Profile of participants (survey)*

The survey participants were composed mainly of males (85.56%), aged between 25–24 years old (53.8%). Most of the participants were unmarried (92.78%), attained a university degree (78.33%) and were employed (60.56%). (Table 3)

Content and face validity

A content and face validity assessment was able to cull five irrelevant and redundant items from the raw instrument. The final 11-item scale's I-CVI ranged from 0.80 to one, suggesting the high relevance of the items in connection to the construct that the scale intends to measure. The S-CVI revealed a score of 0.94 based on averaging, which indicates a high-scale content validity.

Assessment of strength of item-correlations

Bartlett's Test of Sphericity and Kaiser–Meyer– Olkin (KMO) Measures were done to determine the strength of inter–correlations among the items. Bartlett's tests suggested a very high significance (p–value 0.000). Moreover, KMO results revealed 0.909, a value very close to 1, indicating a sufficient amount of shared variance among items in the final HIV–SHF Scale (Table 4).

Table 1 Implementation matrix

	Phase I: Qualitative	Phase II: Quantitative
Study aims	To explore the stigma experience of PLHIV and high-risk individuals in health facilities	To develop a valid and reliable instrument to measure HIV Stigma in health facilities
Type of data	Narrative data	Survey data
Period of collection	January–June 2019	July–December 2019
Participants	9 Persons Living with HIV; 6 individuals with high-risk sexual behaviors	180 Persons living with HIV and individuals on high-risk sexual behaviors

HIV=human immunodeficiency virus

PLHIV=persons living with HIV

Tab	le	2	Participants	profile	(qualitative	interviews)
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Profile variables (n=15)	Frequency	Percentage
Age (years)		
Below 20	3	20.0
21–30	8	53.0
31–40	3	20.0
41–50	1	7.0
Sex		
Male	12	80.0
Female	3	20.0
Civil status		
Married	1	10.0
Single	14	90.0
Highest educational attainment		
Elementary	1	7.0
High school	12	80.0
College	2	13.0
HIV status		
Clinically diagnosed positive	9	60.0
Negative	6	40.0

Table 3 Participant's profile (quantitative survey)

Category (n=180)	Count	Percentage
Age (years)		
15–24	24	13.33
25-34	97	53.8
35-44	47	26.11
45–54	10	5.56
55 and older	2	1.11
Sex		
Male	154	85.56
Female	26	14.44
Marital status		
Married	13	7.22
Unmarried	167	92.78
Educational attainment		
Elementary	1	0.56
High school	12	6.67
College	141	78.33
Post graduate	26	14.44
Employment status		
Unemployed	42	23.33
Employed	109	60.56
Self-employed	29	16.11

Table 4 Intercorrelation coefficients of the final human immunodeficiency virus-stigma in health facility (HIV-SHF) scale

Coefficients	Value
Determinant of the correlation matrix	0.001
Bartlett's test of sphericity	
Chi-square	1179.665
Degrees of freedom	55
P-value	0.000
Kaiser-Meyer-Olkin	
Measure of sampling adequacy	0.909

Factor extraction

To extract the factors in the scale, we utilized the Principal Component Factor method. The Kaiser's criterion through the eigenvalue ruling and Catell's Scree test were used to decide factor retentions. There were two factors retained based on their eigenvalues of 6.12297 and 1.07801 for factors 1 and 2, respectively (Table 5). A two-factor solution explains 65.4% of the total variance of the scale. These were visually verified using Catell's Scree test (Figure 2).

Reliability score

The validated HIV-SHF scale showed high to very high-reliability scores on the two identified factors. The scale showed very high internal consistency based on Cronbach's alpha value of 0.91 (Table 6)

Discussion

This study aims to design and develop a valid and reliable instrument that can assess the presence of HIV stigma in health facilities. The use of a sequential exploratory approach, specifically the Qual–Quan method, was essential in extracting items that represent authentic claims of stigma and discriminatory experiences as care recipients in a health facility. Likewise, SME validation is an integral process in culling or enhancing the raw items of the instrument, particularly in regards to its relevance, readability, coherence, and structure³⁰. The experts' evaluation of face and content validity is an essential and objective process that significantly improved the validity of the developed HIV-SHF scale.

It is also essential to attain the appropriate itemsample ratio for the scale eligible for factor analysis. Based on the results derived from the quantitative phase of the study, the HIV-SHF scale is a valid and reliable instrument to measure HIV stigma in health facilities.

Table 5 Factor loadings of the human immunodeficiency virus-stigma in health facility (HIV-SHF) scale

Variable	Communalities	Factor 1	Factor 2
Health care personnel			
The health care team are sources of discrimination and stigma	0.812	0.84	
Health workers are afraid to care for persons with HIV	0.778	0.78	
The health workers' lack of awareness of HIV care are prone to discriminate against persons with HIV	0.825	0.76	
Heath workers gossip about gay person with HIV	0.732	0.71	
The disclosures to selected health workers only promote gossip, fear, and tension in the workplace	0.715	0.70	
Health workers make jokes on patients with HIV	0.589	0.64	
Health workers use excessive PPE in caring for persons with HIV	0.628	0.63	
Health workers does not maintain confidentiality	0.703	0.61	
Health workers' approach are judgmental towards HIV	0.645	0.50	
Facility structure and protocols			
The health facility does not support privacy and confidentiality	0.831		0.85
Protocols and procedures do not provide privacy and confidentiality	0.745		0.84
Eigenvalue		6.12	1.70
Explained variance (%)		55.66	9.80
Cumulative variance (%)		55.66	65.46

PPE=Personal Protective Equipment

Table 6 Human immunodeficiency virus-stigma in health facility (HIV-SHF) psychometric properties

	Average inter-item covariance	No. of items in the scale	Scale reliability coefficient	Interpretation
Facility structure and protocol	0.74	2	0.70	High reliability
Health personnel	0.87	9	0.90	Very high reliability
All items	0.76	11	0.91	Very high reliability

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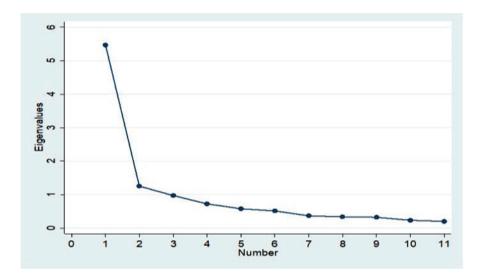


Figure 2 Scree test on the human immunodeficiency virus-stigma in health facility (HIV-SHF) scale

The HIV-SHF scale contents and structure

The HIV-SHF scale is a valid and reliable tool to assess stigmatizing factors in a health facility. It is composed of two subscales: Health personnel and the facility structure and protocols.

Health personnel. There are nine items classified under this factor that describe behaviors exhibited by health workers considered stigmatizing and discriminatory. For instance, items pertaining to denial of treatment, gossiping, and joking about a patient's HIV status are deliberate discriminatory remarks that stigmatize clients. This is related to reports indicating some personal experiences of health workers discriminating against PLHIV through refusal to care³¹ and, to some extent, labelling it as promiscuity, homosexuality, and immorality^{6,8}. The items in this subscale are negatively worded suggesting that higher scores revealed higher stigmatizing experiences with healthcare personnel in health facilities.

Facility structure and protocols. Under this factor are items describing stigmatizing experiences related to the health facility structure and its protocol. Notably, items

included here relate to the lack of confidentiality. The literature presented a breadth of studies discussing patients' reluctance to seek medical attention because of their fear of being seen in an HIV facility^{6,8}. Similarly on this subscale, there are negatively worded statements indicating higher stigma experience toward the health facility's structure and protocols.

Scoring procedure

The scale will utilize a 5-point Likert scale with a point system using agreement descriptions as follow: 1 (strongly disagree); 2 (disagree); 3 (neutral); 4 (agree), and 5 (strongly agree). The scale is answerable within three to five minutes. The highest possible score for this scale is 55. Specifically, the scores will be described as:

11-25 points: a low presence of stigmatizing and discriminatory factors in the health facility.

26-40 points: a moderate presence of stigmatizing and discriminatory factors in the health facility, and

41-55 points: a high presence of stigmatizing and discriminatory factors in the health facility.

Tool utilization

The HIV–SHF Scale is a valid instrument to measure the presence of health facility related stigma as perceived and experienced by clients of health facilities. The scale may serve as a useful instrument for clients to evaluate stigmatizing and discriminatory behaviors of care providers working in facilities and to determine the presence of any other stigmatizing protocols and structures within the health facility.

Integrated mixed-method findings

The Qual–Quan sequence utilized in this study was an authentic and logical process in designing and developing the HIV–SHF scale. A qualitative exploration, as recipients of care in health facilities, is a legitimate source of actual experiences of stigma among high–risk and PLHIVs. These narratives of authentic experiences provide valuable items in the scale tested that were found to be reliable after rigorous examination of the scale's psychometric properties.

Implications for nursing practice

Considering that HIV and AIDS are sensitive and oftentimes considered a taboo due to the possibility that it touches on perceptions about morality, stigma can be an undeniable reality. The development of the HIV-SHF Scale may be essential in identifying which stigmatizing or discriminatory factors are present in a health facility as perceived and experienced by clients seeking care. In comparison to other existing HIV Stigma scale measurements, the HIV-SHF scale is concise and specific in regards to measuring tripartite health-facility related, stigma inducing factors such as in connection to health personnel, structures and policies being implemented. In regards to most available stigma-related scales, the purpose is on identifying the degree of stigmatization and determining the type of stigma experience which limits the measurement of other existing stigma-inducing factors that are found in health-facilities. The development of the HIV-SHF scale will help produce a more evidencebased approach in destigmatizing HIV by streamlining stigma reduction strategies and interventions anchored on the responses of the developed instrument. Although the process of destigmatization of HIV is a holistic approach, the interventions should be made relevant and responsive to the identified needs of the health facility as determined by the care recipients. By using the HIV-SHF scale as an assessment and evaluation tool to assess the presence of HIV stigma in a health facility, health professionals will be made aware of what specific areas they need to improve on. The scale will serve as a helpful instrument among program implementers of the Department of Health, through the local government units, in assessing compliance with countrywide laws and guidelines in zeroing HIV stigma in catchment centers such as local and rural health facilities.

Limitations of the study

The study is limited to the following. First, the HIV–SHF scale was prepared in the Philippine context; future researchers need to determine its applicability in their setting. Additionally, the limited number of sample participants where this study was derived may limit the generalizability and utility of the questionnaire. Furthermore, the use of EFA is also limited only to the determination of latent factors present in the scale. Future researchers are likewise encouraged to perform Confirmatory Factor Analysis (CFA) for verification purposes and hypothesis testing among elements in the scale.

Conclusion

The rigorous process of tool development using a sequential exploratory mixed method design is high-quality procedure for instrument development. The narrative accounts of the actual experience of stigma among care recipients, followed by a quantitative approach using

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exploratory factor analysis, is a reliable biphasic approach in tool development. The HIV-SHF Scale developed in the study is a valid and reliable instrument to assess and evaluate the presence of HIV Stigma in health facilities.

Conflict of interest

No conflicts of interests are declared.

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