# Development of internalized and personal stigma among patients with and without HIV infection and occupational stigma among health care providers in Southern China

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**Background:** HIV/AIDS-related stigma is a major barrier of access to care for those infected with HIV. The aim of this study was to examine, validate, and adapt measuring scales of internalized, personal, and occupational stigma developed in Africa into a Chinese context.

**Methods:** A cross-sectional study was conducted from January to September 2015 in Kunming, People's Republic of China. Various scales were constructed on the basis of the previous studies with modifications by experts using exploratory and confirmatory factor analyses (EFA+CFA). Validation of the new scales was done using multiple linear regression models and hypothesis testing of the factorial structure invariance.

**Results:** The numbers of subjects recruited for the development/validation samples were 696/667 HIV-positive patients, 699/667 non-HIV patients, and 157/155 health care providers. EFA revealed a two-factor solution for internalized and personal stigma scales (guilt/blaming and being refused/refusing service), which were confirmed by CFA with reliability coefficients (r) of 0.869 and 0.853, respectively. The occupational stigma scale was found to have a three-factor structure (blaming, professionalism, and egalitarianism) with a reliability coefficient (r) of 0.839. Higher correlations of factors in the HIV patients (r=0.537) and non-HIV patients (r=0.703) were observed in contrast to low-level correlations (r=0.231, 0.286, and 0.266) among factors from health care providers.

**Conclusion:** The new stigma scales are valid and should be used to monitor HIV/AIDS stigma in different groups of Chinese people in health care settings.

**Keywords:** HIV/AIDS-related stigma, exploratory factor analysis, confirmatory factor analysis, guilt, blaming, being refused, refusing service

#### Introduction

With the pandemic of HIV/AIDS¹ predominantly characterized by sexual transmissions² and in the People's Republic of China, the majority of people living with HIV/AIDS (PLWHA) are faced with HIV/AIDS-related stigma (HIV/AIDS stigma) – a major barrier for access to prevention, care, and treatment services. Studies have shown that HIV/AIDS stigma is a barrier for PLWHA-seeking health care due to lack of community HIV/AIDS knowledge, lack of understanding supportive clinic environments, absence of personal financial resources,³ and lack of employment opportunities.⁴ Although attention to stigma has steadily increased, it is especially important to comprehensively understand HIV/AIDS stigma under a measurable conceptual framework from different individuals' perspectives in order to improve access to HIV health care.

Correspondence: Lin Lu Yunnan Center for Disease Prevention and Control, 158 Dongsi Street, Xishan District, Kunming 650022, Yunnan Province, People's Republic of China Email Iulin@yncdc.cn The concept of HIV/AIDS stigma is often not explicitly defined – it usually refers to discrimination and violation of human rights as "a mark of disgrace." Stigma linked to the reproduction of social differences in special settings will intimately contribute to existing inequalities. Existing theories have already delineated a framework to understand how stigma impacts individuals on their psychology, health, and behaviors. Some other existing theories have demonstrated concepts to understand how stigmatization as a social control mechanism impacts the HIV/AIDS epidemic and communities. However, existing conceptual frameworks have not clearly identified how HIV-positive patients experience HIV/AIDS stigma in health care settings.

Because of time- and context-specific characteristics of stigma, a stigma instrument needs to address the specific nature of people's perceptions in each local context. 10,11 For an individual not infected with HIV, personal stigma can be manifested in three predominant ways toward PLWHA,12 including negative emotions/feelings toward HIV-infected people (prejudice), <sup>13,14</sup> prejudiced behavioral expressions to PLWHA (discrimination), and stereotyping as group-based beliefs about PLWHA (stereotype). 15 For HIV-positive individuals, internalized stigma refers to the degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves. Moreover, the health care sector is one of main environments where HIVpositive individuals experience stigma and discrimination. 16,17 Stigma toward PLWHA can lead to lower access to care 18 by PLWHA. Additionally, Chinese culture is more collectivist<sup>19</sup> compared to western cultures. Individuals in the People's Republic of China tend to maintain the same opinions with the mainstream rather than to go against it. Therefore, development of scales simultaneously to measure internalized stigma, personal stigma, and occupational stigma are necessary in the same health care setting.

In the People's Republic of China, previous studies have shown that keeping social distance based on fears of stigmatization<sup>20</sup> and negative feelings toward PLWHA<sup>21</sup> may act as barriers for seeking health care services among PLWHA. Two equivalent stigma scales measuring internalized and personal stigma<sup>22</sup> match the two core elements. However, the stigma scales were built on a series of shared beliefs that HIV is associated with immoral behavior, religious punishment, and lack of adherence to cultural norms.<sup>23,24</sup> It is similar to the HIV/AIDS stigma in the People's Republic of China, but different in the expression form of specific perceptions and behaviors. Therefore, exploration of the latent levels of these two scales is necessary. Additionally, other studies have revealed that Chinese service providers'

stigmatizing attitude and behavior are a key barrier for HIV testing and treatment such as differential treatment and denial of care, their perception of social norms, and concerns about their occupational safety.<sup>25,26</sup> A Chinese scale<sup>27</sup> measuring stigma among service providers has already been developed. However, it mainly focuses on occupational stigma in general hospitals at different levels rather than infectious disease hospitals that are responsible for HIV care in the Chinese health care system. Thus, there is a need to further improve it for the assessment of HIV/AIDS stigma in special hospitals among different groups of people in order to target key populations to improve quality of HIV/AIDS care.

This current study aims to develop and validate scales for measuring individual HIV-related stigma among HIV patients, non-HIV patients, and health care providers. The study was divided into two stages. The first stage aimed to modify the scales and examine the factor structure using exploratory factor analysis (EFA). In the second stage, the construct validity was evaluated using confirmatory factor analysis (CFA), and the discriminative validity was assessed in another group of subjects. In addition, difference in stigma perceived by HIV versus non-HIV patients was also examined and covariates with the stigma were identified.

### Framework for HIV/AIDS stigma

Our understanding of HIV/AIDS stigma framework in hospital settings stems from previous studies. <sup>12,22,27</sup> Earnshaw and Chaudoir <sup>12</sup> in 2009 developed the conceptual framework for HIV stigma mechanisms from HIV-infected and non-HIV people. Visser et al <sup>22</sup> in 2008 developed a parallel scale among HIV-infected and non-HIV people while Stein and Li<sup>27</sup> in 2008 developed a multidimensional scale of HIV-related stigma among Chinese service providers. Figure 1 shows the conceptual framework of the study. Internalized stigma and personal stigma were developed using parallel scales for HIV-positive and non-HIV patients, while occupational stigma was developed for health care providers using a separate scale.

### **Methods**

# Study settings

A cross-sectional study was conducted in the infectious disease departments of Kunming Infectious Disease Hospital and Kunming General Hospital, Yunnan Province, People's Republic of China. These two hospitals serve both HIV/AIDS and non-HIV patients at out- and in-patient departments. HIV status was confirmed by Western blot test. The majority of the non-HIV patients were diagnosed with viral hepatitis or other infectious diseases. Although this group could not

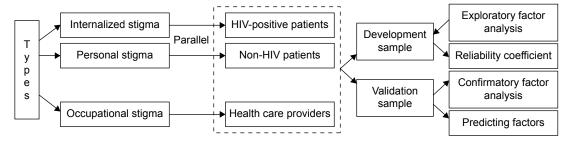


Figure I Conceptual framework of the study.

represent general non-HIV patients, they were served by the same hospital and were worthwhile to compare with the HIV group.

### Study subjects

All HIV and non-HIV patients aged  $\geq$ 15 years consecutively attending the study hospitals were consecutively screened for eligibility. Patients with tuberculosis were excluded in order to avoid confusion from tuberculosis stigma. Those who were too ill to be interviewed were also excluded. Doctors, nurses, and experimenters attending HIV and non-HIV clinics of the study hospitals were also recruited.

The first group of HIV patients, non-HIV patients, and health care providers was enrolled during January 1 to February 15, 2015, and was used to develop the scale. EFA was used to identify the underlying stigma constructs. The second group of HIV patients, non-HIV patients, and health care providers was enrolled between July 20 and September 10, 2015, and was used to validate the scale. The same questionnaires were applied for both the groups. Any subject who was involved in the development sample was excluded from the validation sample. CFA was conducted on the basis of the model developed from the first part.

# Sample sizes

The required sample size needed for EFA is usually 5–10 times the number of questionnaire items. <sup>28</sup> Initially, each of the three scales contained 17 items. A sample size of ~85–170 HIV and non-HIV patients per group was determined to be sufficient. For CFA, the recommended sample size required is 15–20 times the number of questionnaire items, <sup>28</sup> and there were 10 and 11 items in internalized stigma scale and personal stigma scale, respectively. The required sample size was thus determined to be at least 150 HIV and non-HIV patients per group.

# Study instruments

Internalized stigma and personal stigma scales developed by Visser et al<sup>22</sup> were translated from English into Chinese by

JL, and the Chinese version was checked for accuracy against the original English version by two other researchers. All the three scales were modified by the main researcher to suit the local hospital context. For example, one item about "Do not drink from the same tap with PLWH" changed to "Do not eat together with PLWH." A team of health care experts including two chief physicians from the infectious departments of two hospitals and an expert of HIV/AIDS prevention in the Centre for Disease Control of Yunnan Province reviewed and finalized the Chinese version. Finally, five HIV and 10 non-HIV patients were individually requested to complete the questionnaires and comment on the understandability of the questions and on whether the intent of each question was accurately conveyed. The respondents were also asked to elaborate on the reasons why a particular response category was chosen for a question. According to their suggestions, the scales were further modified for clearer comprehensibility and cultural suitability.

The contents of the questionnaire items for HIV (internalized stigma) and non-HIV patients (personal stigma) were the same, but worded according to the perspective of the HIV status of the reader, for example, HIV group: "Do you think that you should be ashamed of yourself due to HIV/AIDS?"; non-HIV group: "Do most people think that PLWH should be ashamed of themselves?" A total of 17 parallel items were framed as two positive and 15 negative statements. Responses were rated on a scale of 1–4 where 1= strongly disagree, 2= disagree, 3= agree, and 4= strongly agree. Questions in two scales were worded from different perspectives.

The occupational stigma scale<sup>27</sup> completed by service providers also consisted of 17 items with the similar 1–4 rating scale reflecting the level of prejudicial attitudes. These items are listed in Tables 1 and 2.

# Analysis of stigma scales

Mean scores for each item among the three scales were compared using Student's *t*-tests, and two-way analysis of variance was used to compare items adjusting for the type of sample (development and validation). The total scores of the

Table I Summary of stigma items among HIV-positive and non-HIV patients in development and validation sample

Items for HIV and non-HIV patients	Developm (mean, Sl	nent sample D)	е	Validation (mean, Sl	•		P-value**
	HIV	non-HIV	P-value*	HIV	non-HIV	P-value*	
I. PLWH should be ashamed of themselves	2.62 (0.9)	2.00 (0.6)	<0.001	2.71 (0.9)	2.18 (0.6)	<0.001	<0.001
2. PLWH must have done something wrong to deserve it	2.27 (0.9)	2.00 (0.6)	< 0.001	2.40 (0.9)	2.11 (0.7)	< 0.001	< 0.001
3. It is the fault of PLWH that they got HIV	2.43 (0.9)	2.08 (0.6)	< 0.001	2.49 (0.9)	2.19 (0.7)	< 0.001	0.006
4. Be uncomfortable around people with HIV	2.87 (0.8)	2.49 (0.6)	< 0.001	3.00 (0.8)	2.43 (0.7)	< 0.001	0.166
5. Getting HIV is a punishment for bad behavior	2.13 (0.9)	2.14 (0.6)	0.872	2.29 (0.9)	2.20 (0.8)	0.058	< 0.001
6. Be afraid to be around people with HIV	2.56 (0.9)	2.53 (0.6)	0.533	2.54 (0.9)	2.56 (0.7)	0.597	0.796
7. Not like to be friends with someone with HIV	2.67 (0.9)	2.59 (0.7)	0.048	2.59 (0.9)	2.49 (0.7)	0.022	0.003
8. Do not like someone with HIV to be living next door	2.58 (0.8)	2.55 (0.7)	0.402	2.55 (0.9)	2.50 (0.7)	0.196	0.15
9. Do not like to sit next to someone with HIV	2.68 (0.9)	2.46 (0.6)	< 0.001	2.68 (0.9)	2.28 (0.7)	< 0.001	0.003
10. Do not eat together with PLWH	2.56 (0.8)	2.73 (0.6)	< 0.001	2.52 (0.8)	2.48 (0.7)	0.428	< 0.001
II. Less of PLWH because of their HIV status	2.45 (0.8)	2.53 (0.6)	0.048	2.51 (0.9)	2.25 (0.7)	< 0.001	0.166
12. Most employers would not employ me because I am HIV-positive	2.81 (0.8)	2.75 (0.6)	<0.001	2.81 (0.8)	2.71 (0.7)	0.011	0.542
13. Getting HIV was just a matter of bad luck	2.46 (0.9)	2.13 (0.7)	< 0.001	2.53 (0.9)	1.98 (0.7)	< 0.001	0.156
14. It is safe for me to handle other people's children (R)	2.84 (0.8)	2.04 (0.6)	< 0.001	2.80 (0.8)	2.14 (0.6)	< 0.001	0.172
15. Have a lot to teach people about life through having HIV (R)	2.66 (0.8)	2.64 (0.6)	0.699	2.64 (0.8)	2.46 (0.7)	<0.001	<0.001
16. Do not like to date with PLWH	2.66 (0.8)	2.57 (0.6)	0.022	2.58 (0.8)	2.59 (0.7)	< 0.001	0.227
17. PLWH deserves as much respect as anyone else	3.36 (0.6)	3.14 (0.5)	< 0.001	3.40 (0.7)	3.09 (0.6)	< 0.001	0.795

Notes: \*Student's t-test for HIV/non-HIV effect; \*\*Student's t-test for sample effect. Abbreviations: PLWH, people living with HIV; R, reversed items; SD, standard deviation.

three stigma scales were obtained by adding the scores of the 17 items for each scale. All four responses were summed to obtain a total score for each scale, with a possible range of 17-68, where higher scores indicate higher stigma toward HIV/AIDS.

EFA was done on the three scales using principal components analysis with oblimin rotation to allow for possible correlation among factors and thus obtain more interpretable factors.<sup>29</sup> Scree plots were used to identify the optimum number of factors. Items that had a factor loading of >0.4 were considered part of a factor. Items that did not have a factor loading of  $\geq 0.4$  were not included on any factor. Cronbach's alpha coefficient was used to assess the internal consistency of scores.

CFA was used to validate the construct suggested by EFA in the development sample. Goodness-of-fit was

Table 2 Summary of stigma items among health care providers in development and validation sample

Items for health care providers	Sample I	Sample 2	P-value#
	Mean (SD)	Mean (SD)	
I. PLWH through sex and drug use got what they deserved	2.08 (0.8)	2.33 (1.0)	0.018
2. People infected through commercial sex deserve sympathy	2.11 (0.8)	2.34 (1.0)	0.026
3. People infected through drug use deserve sympathy	1.98 (0.8)	2.32 (1.0)	0.001
4. People who behave promiscuously should be blamed for AIDS	2.09 (0.9)	2.25 (1.0)	0.126
5. Deserve good care – blood donation (R)	2.10 (1.0)	2.27 (1.0)	0.132
6. Deserve good care – commercial sex (R)	1.75 (1.0)	1.94 (1.1)	0.113
7. Deserve good care – drug use (R)	1.73 (0.9)	2.08 (1.2)	0.003
8. If I worked with HIV-positive patients, I would want to change my job	1.82 (0.7)	1.96 (0.9)	0.138
9. I feel ashamed if I know someone with AIDS	2.15 (0.7)	2.25 (0.9)	0.251
10. I feel ashamed if a relative got HIV/AIDS	2.13 (0.7)	2.17 (1.0)	0.683
II. I am afraid of PLWH	2.04 (0.8)	2.30 (1.1)	0.017
12. I would not buy from a vendor who has HIV/AIDS	1.97 (0.9)	1.94 (1.0)	0.756
13. I would not share utensils with PLWH	1.96 (0.9)	2.02 (0.9)	0.530
14. I am willing to work with HIV-positive patients (R)	1.68 (0.8)	1.76 (1.0)	0.443
15. I am willing to provide same care to all patients (R)	1.62 (0.9)	1.86 (1.0)	0.029
16. I am willing to perform a physical examination of HIV-positive patient (R)	1.49 (0.8)	1.72 (1.0)	0.022
17. I am willing to interact with HIV-positive patients in the same way as other patients (R)	1.60 (0.9)	1.81 (1.0)	0.053

Note: #Student's t-test for sample effect.

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Abbreviations: PLWH, people living with HIV/AIDS; R, reversed items; SD, standard deviation.

assessed using a chi-square test of exact fit (non-significant P-value as a good fit), root mean square errors of approximation (RMSEA: <0.08 as a good fit), comparative fit index (CFI: >0.90), and Tucker Lewis index (TLI: >0.90).<sup>30</sup>

Among the internalized stigma scale, seven items were dropped in EFA and confirmed in CFA; six items were dropped in EFA and another item was dropped in CFA among personal stigma scale; and in terms of occupational stigma scale, there were six items dropped in EFA and confirmed in CFA.

Finally, univariate analyses were performed separately for each factor of HIV/AIDS stigma after EFA and CFA in order to assess their independent association with demographic and socioeconomic variables. Variables having a P-value of <0.05 were considered significant. All analyses were performed using R language and environment.<sup>31</sup>

#### Ethical considerations

The ethical aspects of this study were approved by Prince Songkla University Faculty of Medicine Institutional Review Board (57-246-18-5) and Kunming Medical University. Anonymity of the data was assured, and written informed consent was obtained from the participants to participate in the survey, after providing them with detailed information on the survey procedures.

### **Results**

Out of 800 consecutive eligible HIV patients approached in both the groups, 696/800 (87%) in the first group and 667/800 (83%) in the second group consented to join the study, whereas 699/1,059 (66%) in the first group and 667/1,059 (63%) in the second group among the invited non-HIV patients agreed to join the study. The development/validation samples included 696/667 HIV patients, 699/667 non-HIV patients and 157/155 health care providers, respectively.

### Sample characteristics

Table 3 presents the sociodemographic characteristics of the patients in each sample. The majority was male, of Han ethnicity, married or cohabiting, and employed. Most reported having no religious affiliation. About half achieved a junior high school level of education, had a monthly household income of ≤5,000 RMB, and were living in a family with 2–4 members. HIV-positive patients were more likely to belong to a minority ethnicity, have a religious affiliation, live in rural areas, have a higher education level, be separated, divorced, or widowed, have a lower household income, live with fewer family members, and be self-employed.

Table 4 shows the demographic characteristics of the health care providers in the exploratory and validation samples. The majority was female, of Han ethnicity, married or cohabiting, employed at the elementary level, working as nurses, achieved a university or equivalent level of education, and had a household income ranging from 5,000 to 8,000 RMB.

Tables 1 and 2 show the distribution of items of the three scales in the exploratory and validation phases. In the patient scales, the item "PLWH deserves as much respect as anyone else" had the highest score reflecting positive attitude toward PLWH by HIV and non-HIV patients. In 12 items, the HIV group had significantly higher mean scores compared to the non-HIV group (10 items in both development and validation samples, one item in the development sample alone, and one item in the validation sample alone). The mean (standard deviation) scores of stigma scales among HIV patients, non-HIV patients, and health care providers were 45.0 (7.9), 40.7 (6.1), and 35.3 (9.6), respectively. Thus, internalized stigma was generally stronger than personal stigma. Stigma scores in the validation sample were generally higher than those in the development sample for all items. The same applied for items among health care providers.

#### **EFA**

#### Patient scales

The scree plots from both the analyses shown in Figure 2 suggested two factors. Among the HIV group, the first factor loaded highly on seven items and reflected a feeling of "being refused." The second factor loaded highly on three items and reflected a feeling of "guilt." Among the non-HIV group, the first factor loaded highly on seven items reflecting a feeling of "refusal" and the second factor loaded highly on three items and reflected a feeling of "blaming" (Table 5).

#### Health care providers' scale

EFA identified three factors (Figure 2) reflecting feelings of "blame," "professionalism," and "egalitarianism" among the health care providers (Table 5).

#### Internal consistency

Cronbach's alpha coefficients for all factors were >0.85, except for egalitarianism, which had a value of 0.78, thus reflecting a high level of inter-item consistency (Table 5).

# Correlation among factors

Table 6 summarizes correlation coefficients among factors within each group of subjects. The absolute values ranged from 0.23 to 0.70, indicating that the factors had a low to moderate correlation.

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Table 3 Distribution of characteristics among HIV and non-HIV patients

Variables	Developm	ent s	ample (n=1	,395)			<b>Validation</b>	samp	ple (n=1,334	<b>l</b> )		
	Total		HIV		non-HIV		Total		HIV		non-HIV	
	n	%	n	%	n	%	n	%	n	%	n	%
Age (mean, SD)	38.8 (12.0)		38.1 (11.0)		39.5 (13.0)		38.8 (14.0)		38.9 (12.1)		39.7 (15.6)	
Gender												
Female	516	37.9	270	38.8	590	84.4	493	37.0	246	36.9	505	75.7
Male	847	62.I	426	61.2	109	15.6	841	63.0	421	63.I	162	24.3
Ethnic group												
Han	984	72.2	504	72.4	590	84.4	985	73.8	480	72.0	505	75.7
Other	379	27.8	192	27.6	109	15.6	349	26.2	187	28.0	162	24.3
Religious belief												
No	1,027	75.3	522	75.0	627	89.7	1,068	80.I	505	75.7	563	84.4
Yes	336	24.7	174	25.0	72	10.3	266	19.9	162	24.3	104	15.6
Place of residence												
Rural	960	70.4	490	70.4	268	38.3	725	54.3	470	70.5	255	38.2
Urban	403	29.6	206	29.6	431	61.7	609	45.7	197	29.5	412	61.8
Marital status												
Single	334	24.5	159	22.8	123	17.6	336	25.2	175	26.2	161	24.1
Married/cohabiting	741	54.4	383	55.0	552	79	817	61.2	358	53.7	459	68.8
Separated/divorced/widowed	288	21.1	154	22.1	24	3.4	181	13.6	134	20.1	47	7.0
Size of family												
ı	88	6.5	52	7.5	6	0.9	42	3.1	36	5.4	6	0.9
2–4	1,042	76.4	535	76.9	495	70.8	990	74.2	507	76.0	483	72.4
≥5	233	17.1	109	15.7	198	28.3	302	22.6	124	18.6	178	26.7
Education												
Primary school or less	283	20.8	144	20.7	162	23.2	298	22.3	139	20.8	159	23.8
Junior high school	635	46.6	296	42.5	372	53.2	627	47.0	339	50.8	288	43.2
Senior high school	335	24.6	158	22.7	153	21.9	364	27.3	177	26.5	187	28.0
University or equivalent	110	8.1	98	14.1	12	1.7	45	3.4	12	1.8	33	4.9
Occupational status												
Government-employed	126	9.2	62	8.9	67	9.6	167	12.5	64	9.6	103	15.4
Enterprise-employed	503	36.9	256	36.8	243	34.8	437	32.8	247	37.0	190	28.5
Self-employed	195	14.3	172	24.7	37	5.3	40	3.0	23	3.4	17	2.5
Unemployed	539	39.5	206	29.6	352	50.4	690	51.7	333	49.9	357	53.5
Household income (CNY)												
<800	294	21.6	163	23.4	81	11.6	196	14.7	131	19.6	65	9.7
801-2,000	340	24.9	177	25.4	145	20.7	258	19.3	163	24.4	95	14.2
2,001–5,000	409	30	184	26.4	233	33.3	447	33.5	225	33.7	222	33.3
5,001–8,000	165	12.1	88	12.6	151	21.6	234	17.5	77	11.5	157	23.5
≥8,001	155	11.4	84	12.1	89	12.7	199	14.9	71	10.6	128	19.2
HIV/AIDS stigma score (mean, SD)												
Internalized stigma			44.6 (8.0)						45.0 (7.9)			
Personal stigma			(0.0)		41.3 (5.8)				13.0 (7.7)		40.7 (6.1)	

Abbreviations: SD, standard deviation; CNY, Chinese Yuan.

### Confirmatory and validation analyses

After testing the validity of the factors on the corresponding validation sample, the factor loadings from the validation sample are shown in the last column of Table 5. In general, the coefficients were moderate for HIV and non-HIV patients (between 0.41 and 0.67), whereas those for health care provider's validation sample were high (between 0.50 and 1.04). For test statistics, all RMSEA were <0.08, all CFI were >0.90, and all TLI were >0.90. Thus, CFA confirmed that the factors identified from the development samples

fit the validation sample. However, all P-values from the chi-squared goodness-of-fit tests were <0.001.

# Covariates for each domain of stigma

Table 7 presents the results of the univariate analysis to predict each domain of stigma. Age was associated with feelings of being refused among HIV patients; those being >40 years of age were more likely to feel refused by others. Age was also associated with a tendency to refuse and blame HIV patients among non-HIV patients; those >40 years of age

 Table 4
 Distribution of characteristics among health care providers

Variables	Developm		Validation	
	sample (n=		sample (n	
	n	%	n	<u>%</u>
Age (mean, SD)	34.5 (10.6)		32.5 (10.1)	
Gender				
Female	141	50.7	137	88.4
Male	16	10.2	18	11.6
Ethnic group				
Han	133	84.7	131	84.5
Other	24	15.3	24	15.5
Religious belief				
No	129	82.2	130	83.9
Yes	28	17.8	25	16.1
Marital status				
Single	48	30.6	69	44.5
Married/cohabiting	103	65.6	81	52.3
Separated/divorced/widowed	6	3.8	5	3.2
Size of family				
1	3	1.9	3	1.9
2–4	123	78.3	125	80.6
≥5	31	19.7	27	17.4
Employment level				
Elementary	89	56.7	101	65.2
Intermediate	37	23.6	41	26.5
Advanced	31	19.7	13	8.4
Years of professional	13.7 (10.8)		10.3 (9.7)	
experience (mean, SD)	(,		( , , ,	
lob title				
Doctor	55	35.0	43	27.7
Nurse	88	56.1	101	65.2
Other	14	8.9	11	7.1
Education				
High school or less	27	17.2	39	25.2
University or equivalent	130	82.8	116	74.8
Household income (CNY)				
<2,000	П	7.0	13	8.4
2,001–5,000	34	21.7	55	35.5
5,001–8,000	66	42.0	62	40.0
8,001–13,000	32	20.4	14	9.0
≥13,001	14	8.9	11	7.1
		0.7		7.1
HIV/AIDS stigma score	32.3 (8.8)		35.3 (9.6)	
(mean, SD)				

Abbreviations: SD, standard deviation; CNY, Chinese Yuan.

were more likely to refuse and blame HIV patients. Health care providers who were aged >40 years were more likely to adhere to professionalism when they treated HIV patients. HIV patients who were married often felt that they were refused and felt guilty, whereas non-HIV patients who were married also had a tendency to refuse and blame HIV patients. Health care providers who were married were less likely to be professional. Health care providers who had higher education levels were less inclined to blame HIV patients and were more professional and egalitarian. Gender

was also significantly associated with being refused, while ethnicity and household income were associated with guilt among HIV patients. Among non-HIV patients, religion was associated with refusing. Among health care providers, marital status was associated with professionalism while gender and household income were significantly associated with egalitarianism.

#### **Discussion**

This study revealed that stigma scales developed in Africa can be modified for use in a Chinese setting. EFA suggested two latent factors for HIV-positive and non-HIV patients, which were confirmed by CFA. With small differences, items in each factor of the two scales among HIV patients corresponded well with those among non-HIV patients. Two factors were identified in each group: being refused and guilt among HIV patients and refusing and blaming among non-HIV patients. Among health care providers, three factors that reflected feelings of contradiction between social norms (blaming) and professional values (professionalism and egalitarianism) were identified. There were significant relationships between various demographic characteristics and these latent factors. However, there was no consistent pattern among the three groups.

Being refused versus refusing and guilt versus blaming were two latent factors among internalized and personal stigma scales suggested by EFA and CFA. Perceptions of guilt and shame are two self-conscious emotions. Some researchers have repeatedly confirmed their distinctiveness.<sup>32,33</sup> Guilt is associated with self-blame related to one's own behavior, whereas shame is associated with self-blame at a deeper level where the individual sees their global self as being at fault.34 One of the common characteristics associated with shame and guilt is the desire to hide or withdraw from social situations, in part to avoid situations that may elicit further guilt.<sup>35</sup> Thus, guilt-prone individuals may utilize more avoidant strategies such as abandoning utilization of health care in order to avoid social interactions. It may also help to explain the characteristics of individual internalizing symptoms among HIV-positive patients who may have faced a significantly higher level of internalized stigma and participation restriction.

Being refused for HIV patients and refusing for non-HIV patients were powerfully associated with internalized and personal stigma among HIV and non-HIV patients, respectively. Due to guilt- and shame-proneness of HIV patients, they frequently tended to withdraw from social situations<sup>36</sup> so as to avoid further refusal. Being refused is also manifested

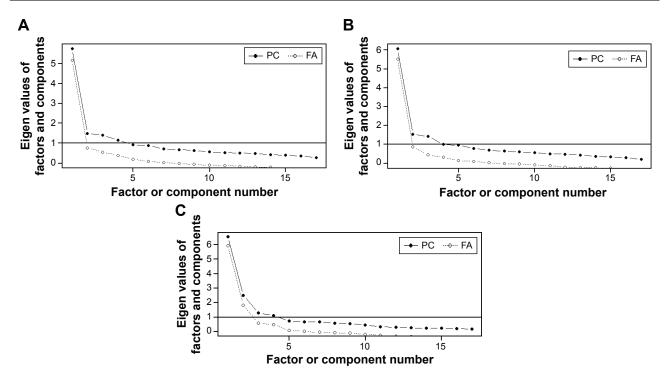


Figure 2 Scree plots for the three scales of internalized stigma, personal stigma, and occupational stigma. Notes: (A) Internalized stigma among HIV-positive patients. (B) Personal stigma among non-HIV patients. (C) Occupational stigma among health care providers. Abbreviations: FA, exploratory factor analysis; PC, principal component analysis.

in the forms of social isolation<sup>37</sup> from family, friends, and community. Correspondingly, non-HIV patients also mainly tend to refuse infectious subjects for the same reason.

Two items namely "people would not date me due to HIV/ AIDS" and "neighbors would not like to live next door to me" were included in our results among patients who were not included in the African study.<sup>22</sup> This implies that Chinese tend to refuse HIV-positive patients more compared to the African context which is known to be the epicenter of HIV/ AIDS. Feelings of refusing and blaming not only come from non-HIV patients but are also stemmed from community members who reside near PLWHA.

Our study found consistent blaming factors among non-HIV patients and health care providers. Struening et al<sup>38</sup> showed that strained, distant relationships with family members or friends or both were a source of shame. Based on the labeling theory of Scheff,<sup>39</sup> the application of deviant stereotypes makes those who are faced with changed self-perceptions and social opportunities devalue and be labeled. The majority of the general population does not want to employ PLWHA or be their neighbor, friend, or intimate partner and tends to regard them as being less trustworthy, intelligent, and competent. Once a person is labeled, powerful social forces come into play to encourage a stable pattern of stigma.

Guilt and feelings of being refused had a relatively higher correlation among HIV patients (0.54) than among health care providers (0.23–0.39). The correlation between blaming and refusing was even higher (0.70) among the non-HIV group. These correlations resulted from our use of oblimin rotation of the factors. While changing the viewing angle of space by oblimin, two interpreted factors indicated the delicate difference among guilt and being blamed in internalized stigma as well as among blaming and refusing in personal stigma. Just as mentioned earlier, those who had perceptions of guilt- and shame-proneness inclined to be refused or refuse infectious patients. Factors of guilt/blaming primarily emphasized the perceptions of patients, while being refused/refusing mainly focus on behaviors.

Low levels of correlation among stigma factors found in health care workers in our study reflect independence. A previous study<sup>27</sup> identified internalized shame among health care providers, a contrast to our study. The attitude of health care providers toward HIV patients is mainly built on a mainstream culture of associations between HIV/ AIDS and immoral behaviors. A coexistence of blaming on one hand and professionalism<sup>40,41</sup> and equalitarianism<sup>42</sup> on the other hand indicated a contradiction between knowledge/competence in care and attitudes toward HIV/ AIDS patients. 25,43,44 It also reflected a contradiction between stigmatized attitudes acquired from the community and professional knowledge and competence on HIV/AIDS care.

Among the three study groups, each of the subscales associated with measures of sample characteristics further validated

Table 5 Factor loadings among HIV and non-HIV patients and health care providers in development and validation samples

Items	Factor loa	adings		
	Developn	nent sample		Validation
	Factor I	Factor 2	Factor 3	sample
I) Items of internalized stigma among HIV patients (α=0.869)				
Being refused ( $\alpha$ =0.880)				
7. I would understand if people rejected my friendship because I am HIV-positive	0.82			0.67
8. My neighbors would not like me living next door if they knew I had HIV	0.81			0.58
16. Because of my HIV, people would not date me	0.81			0.58
12. Most employers would not employ me because I am HIV-positive	0.73			0.56
13. If I was on public or private transport and someone knew I had HIV, they would not sit next to me	0.70			0.54
14. If I eat around a restaurant and people knew I had HIV, they would not eat in the same place	0.69			0.61
4. When people know I have HIV, I feel uncomfortable around them	0.66			0.44
Guilt ( $\alpha$ =0.709)	0.00			0.11
3. I feel that it is my fault that I got HIV		0.84		0.63
5. Getting HIV is a punishment for bad behavior		0.78		0.53
2. I must have done something wrong to deserve getting HIV		0.68		0.63
2) Items of personal stigma among non-HIV patients (α=0.853)		0.00		0.03
Refusing ( $\alpha$ =0.810)				
7. I would not like to be friends with someone with HIV	0.88			0.54
8. I would not like someone with HIV to be living next door	0.80			0.49
9. If I was in public or private transport, I would not like to sit next to someone with HIV	0.76			0.42
16. I would not date with a person if I know that he/she has HIV	0.76			0.41
6. I feel afraid to be around people with HIV	0.74			0.45
4. I feel uncomfortable around people with HIV	0.69			0.45
II. I think less of someone because they have HIV	0.67			*
Blaming ( $\alpha$ =0.852)				
2. If you have HIV, you must have done something wrong to deserve it		0.85		0.51
I. People with HIV should be ashamed of themselves		0.81		0.45
3. People with HIV/AIDS have only themselves to blame		0.79		0.43
5. I think getting HIV is a punishment for bad behavior		0.61		0.42
3) Items of stigma from health care providers ( $\alpha$ =0.839)				
Blaming (α=0.872)				
I. People who got HIV/AIDS through sex and drug use, got what they deserved	0.89			0.79
4. People who behave promiscuously should be blamed for AIDS	0.86			0.79
3. Infected through drug use deserve sympathy	0.86			0.84
Infected through commercial sex deserve sympathy	0.82			0.80
Professionalism* ( $\alpha$ =0.893)				
15. Willing to provide same care (R)		0.92		0.94
16. Willing to do physical examination of HIV-positive patients (R)		0.88		0.85
17. Willing to interact same as other patients (R)		0.83		0.89
14. Willing to work with HIV-positive patients (R)		0.70		0.60
Egalitarianism* ( $\alpha$ =0.780)				
6. Deserve good care – commercial sex (R)			0.90	1.04
7. Deserve good care – drug use (R)			0.88	0.95
5. Deserve good care – blood donation (R)			0.68	0.50

**Notes:** The items are ranked by the value of factor loadings from largest to smallest in the same factor. The numbers represent items in accordance with numbers in Table 1. \*Means that the coefficient for that item is <0.4, so it was omitted from validation sample.

**Abbreviation:** R, score reversed before loading.

Table 6 Correlation of latent factors in three scales

Stigma types	Internalized stigma	Personal stigma	Occupational stigma of	f health care providers
	Guilt	Blaming	Professionalism	Egalitarianism
Internalized stigma				
Being refused	0.54			
Personal stigma				
Refusing		0.70		
Occupational stigma				
Blaming			0.23	0.39
Professionalism				0.27

 Table 7 Crude coefficients (95% CI) of HIV/AIDS stigmas and sample characteristics

Variables	Internalized stigma of HIN	na of HIV patients	Personal stigma of non-HIV patients	f non-HIV	Occupational stigma		
	Being refused	Guilt	Refusing	Blaming	Blaming	Professionalism	Egalitarianism
Age (years): >40 vs ≤40	<b>0.18 (0.05, 0.32)</b> 0.14 (-0.01, 0.28)	0.14 (-0.01, 0.28)	0.27 (0.13, 0.40)	<b>0.23 (0.09, 0.37)</b> -0.18 (-0.54, 0.18)	-0.18 (-0.54, 0.18)	-0.33 (-0.67, 0.01)	0.02 (-0.30, 0.34)
Gender: male vs female	0.22 (0.08, 0.35)	-0.05 (-0.20, 0.10)	0.01 (-0.13, 0.15)	-0.13 (-0.27, 0.02) 0.06 (-0.42, 0.54)	0.06 (-0.42, 0.54)	-0.23 (-0.69, 0.24)	0.75 (0.28, 1.22)
Ethnicity: other vs Han	0.07 (-0.08, 0.21)	0.22 (0.06, 0.38)	0.10 (-0.06, 0.25)	0.11 (-0.06, 0.27)	0.06 (-0.37, 0.48)	0.15 (-0.27, 0.56)	0.29 (-0.13, 0.72)
Religious belief: yes vs no	0.04 (-0.11, 0.19)	0.10 (-0.06, 0.27)	0.23 (0.04, 0.42)	0.14 (-0.05, 0.34)	0.17 (-0.25, 0.59)	0.35 (-0.06, 0.75)	-0.06 (-0.49, 0.36)
Marital status: married vs single	0.13 (0.00, 0.26)	0.26 (0.12, 0.41)	0.21 (0.06, 0.36)	0.29 (0.14, 0.44)	0.13 (-0.18, 0.44)	0.40 (0.11, 0.70)	0.19 (-0.12, 0.5)
Education: $\geq$ university vs $<$ university 0.37 (-0.12, 0.87)	0.37 (-0.12, 0.87)	-0.08 (-0.62, 0.45)	0.04 (-0.28, 0.35)	0.05 (-0.27, 0.38)	-0.71 (-1.05, -0.37)	$-0.56 \ (-0.90, -0.23)$	-0.40 (-0.75, -0.05)
Household income: $\geq$ 5,000 vs $<$ 5,000 $-0.14~(-0.30,0.02)$	-0.14 (-0.30, 0.02)	<b>-0.28 (-0.45, -0.11)</b> -0.01 (-0.15, 0.13) 0.03 (-0.11, 0.17)	-0.01 (-0.15, 0.13)	0.03 (-0.11, 0.17)	0.16 (-0.15, 0.47)	0.06 (-0.24, 0.36)	0.42 (0.12, 0.73)

**Note:** Bold values indicate statistical significance. **Abbreviation:** CI, confidence interval.

the independence of each factor reflecting that they are representative of an independent sub-stigma mechanism.<sup>6–8</sup>

Marital status was the strongest covariate across all latent factors of internalized and personal stigma among both the patient groups. Marital status strongly influences disclosure of HIV status<sup>45</sup> and is also known to have a significant association with quality of life.<sup>46</sup> The association may stem from relationships between marital status and psychology reflecting unmet inner needs and emotional frustrations. Based on social cognitive theory,<sup>47</sup> symbolic communication influences human thought and action as the link of their marriage. Thus, a perception of betrayal of marriage was associated with being refused, refusing, guilt, and blaming.

Education was significantly associated with blaming, professionalism, and egalitarianism among occupational stigma of health care providers. Those having a higher education were less likely to blame patients and more likely to treat patients professionally and equally. One study<sup>48</sup> suggested that poor knowledge of HIV resulted in more blaming toward PLWHA. A spirit of professionalism and excellence of patient care provided a strong foundation for the planning and delivery of health services.<sup>49</sup> Furthermore, egalitarianism of health care providers should compensate for those who were HIV-positive including the sufficient magnitude of health care providers for HIV patients in order to close inequalities.

The World Health Organization and other international organizations such as The Joint United Nations Programme on HIV/AIDS (UNAIDS) and The South African National Aids Council (SANAC) have advocated "zero discrimination" since 2011. Overall, our study has highlighted that HIV/AIDS stigma is still common in 2014. In the People's Republic of China, the strategy to control HIV indeed achieves universal health coverage and promotes a peoplecentered approach grounded in principles of human rights and health equity. However, for over 10 years, >50% of PLWHA were still fearful of disclosing their infectious status, whereas ~80% were afraid of being blamed or being refused in 2013. More efforts are still needed to achieve these goals, especially in health settings.

#### Limitations

Some limitations should be noted in our study. First, patients were recruited from only two hospitals, thus generalizability is limited. Second, the sample size of health care providers was rather small, thus it is possible that the situation in other institutes may be different. Third, a poorer response rate among the non-HIV group may have affected the internal

validity of the study. Fourth, the non-HIV patient group in our study cannot represent all PLWHA, so generalizability of personal stigma is limited.

#### **Conclusion**

In terms of construct and discriminative validity, it could be said that the current stigma scales developed so far are valid and should be used to monitor HIV/AIDS stigma in different groups of Chinese people in health care settings.

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