Comparison of Health System Responsiveness and HIV/AIDS Stigma among HIV and Non-HIV Patients in Healthcare Settings in Yunnan, China: a Series of Surveys

Jing Li

A Thesis Submitted in Partial Fulfilment of the Requirement for the Degree of
Doctor of Philosophy in Epidemiology (International Program)
Prince of Songkla University
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Author	Mrs Jing Li
Major Program	Epidemiology (International Program)

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This is to certify that the work here submitted is the result of the candidate's own investigations. Due acknowledgement has been made of any assistance received.

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I hereby certify that this work has not already been accepted in substance for any degree, and is not being concurrently submitted in candidature for any degree.

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ABSTRACT

Background: The health service of China has encountered significant challenges due to inequalities in socio-economic determinants of health. HIV patients are known to suffer from social stigma, and may receive inadequate responsiveness from health providers. Before assessing the responsiveness they receive, it is important to know their expectations. We aimed to compare levels of expectation and experience of health system responsiveness between HIV and non-HIV patients adjusted for patients' expectations. Due to the lack of a valid and reliable HIV/AIDS stigma scale in healthcare settings, our aim was to examine, validate and adapt measuring scales of internalized, personal and occupational stigma developed in Africa into a Chinese context. Finally, the changes of HSR and HIV/AIDS stigma by time were explored, and associations between health system responsiveness and HIV/AIDS stigma were identified.

Methods: A cross-sectional study was conducted from January to September, 2015 among two consecutive groups of HIV positive and non-HIV patients in two hospitals in Kunming, China. Two cross-sectional surveys were conducted. Patients' expectation towards eight domains of health system responsiveness was measured using 40 vignettes; five per domain. Each vignette was ranked from 1 "very good" to 5 "very bad", and the responses were summed to obtain a total score for each domain. Differences in total scores were compared between the two groups and adjusted for other factors using multiple linear regression. Patients' experience was measured using a self-reported questionnaire containing items of seven domains and using 35 vignettes for patients` expectation. Each item was ranked from 1 “very good” to 5 “very bad”. B-scales were built based on the difference between experience and the vignettes for each domain. Ordered probit and censored ordered probit regression models were constructed to compare health system responsiveness experience between the two groups adjusted for socio-economic factors. Construction of the scales was based on previous studies with modification by experts using exploratory and confirmatory factor analyses. Validation of the new scales was done using multiple linear regression models and hypothesis testing of the factorial structure invariance. Chi-squared tests were used to compare changes of health system responsiveness and HIV/AIDS stigma by time. Linear regression models were conducted to explore the association between responsiveness health system r and HIV/AIDS stigma.

Results: The numbers of subjects recruited for the first and second samples were 696/667 HIV, non-HIV patients and 157/155 health providers. The first and second samples were used as the development and validation samples respectively. The majority of HIV patients were at clinical stage 1, infected via unprotected sexual contact and had CD_4 count less than 500cells/μl. Exploratory factor analysis revealed a two-factor solution for internalized and personal stigma scales (guilt/blaming and being refused/refusing service), which were confirmed by confirmatory factor analysis with reliability coefficients 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 subjects (r=0.703) were observed in contrast to low level correlations (r=0.231, 0.286 and 0.266) among factors from healthcare providers. Among eight domains of patients’ expectation, three domains with the highest scores, reflecting high expectation, were prompt attention, basic amenities and choice. Adjusted for other factors, HIV patients had significantly lower levels of expectation in all domains compared to non-HIV patients. Age was associated with the basic amenities domain, with young adults having higher expectations than other age groups. Minority ethnic groups had lower expectation towards dignity, prompt attention and autonomy domains compared to Han ethnicity. Those who lived in a home with 2-4 family members had higher expectations towards confidentiality than those who lived alone. After adjustment by socio-economic factors, HIV patients had better experiences of HSR in six out of the seven health system responsiveness domains, prompt attention being the only domain that non-HIV patients had better experiences. There was no significant association between health system responsiveness and HIV/AIDS stigma.

Conclusion: The new stigma scales are valid and should be used to monitor HIV/AIDS stigma in different groups of Chinese people in healthcare settings. Patients with HIV have significantly lower levels of expectations even after adjusting for socio-economic factors. Perceptions of health system responsiveness experience were better among HIV patients except for prompt attention, which could not be explained by socio-economic factors. Current healthcare receives low expectations from HIV patients. Assessment of healthcare quality based on their perception should therefore be supplemented by experience measures. A reform is needed to push the current healthcare system into the right direction to meet the demands of patients.

Keywords: Expectation; HIV patients; Socio-economic factors; Health system responsiveness; Experience; anchoring vignettes; HIV care; Healthcare; HIV/AIDS stigma, scales, internalized stigma; personal stigma; occupational stigma; HIV positive patients, non-HIV patients, healthcare providers; China.

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Jing Li

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CHAPTER 1

INTRODUCTION

1. Background

1.1 Study background

1.1.1 Magnitude of HIV problems globally and locally

With the broad utilization of antiretroviral therapy (ART) for treatment and prevention, still, about 34.2 million individuals were presently living with HIV worldwide in 2010 [1]. The coverage of HIV counselling and testing rose from 8% in 2005 to 35% among pregnant women in 2010. Nevertheless, the majority of people living with HIV/AIDS (PLWHA) still do not know their serostatus in low- and middle-income countries. The number of health facilities to provide antiretroviral therapy expanded from 7,700 in 2007 to 22,400 at the end of 2010, a threefold increase, reflecting expansion capacity of delivery treatment in health system. Access to antiretroviral therapy increased from 400 000 in 2003 to 6.65 million in 2010, 47% coverage of people eligible for treatment, resulting in substantial declines in the number of people dying from AIDS related causes during the past decade[2,3]. Mounting scientific evidence shows that increased access to antiretroviral therapy is also contributing to declines in the number of PLWHA. According to 2013 WHO antiretroviral (ARV) drug guidelines[4], it recommends earlier initiation of ART for people diagnosed with HIV (at CD4 $\leq$500 cells/mm^3) and immediate ART for sero-discordant couples, pregnant women living with HIV and children living with HIV aged younger than five years. These recommendations increase the potential number of people eligible for ART to an estimated 25.9 million in 2013, which amounts to 9.2 million more people than were eligible under the previous 2010 WHO ARV during guidelines [5].

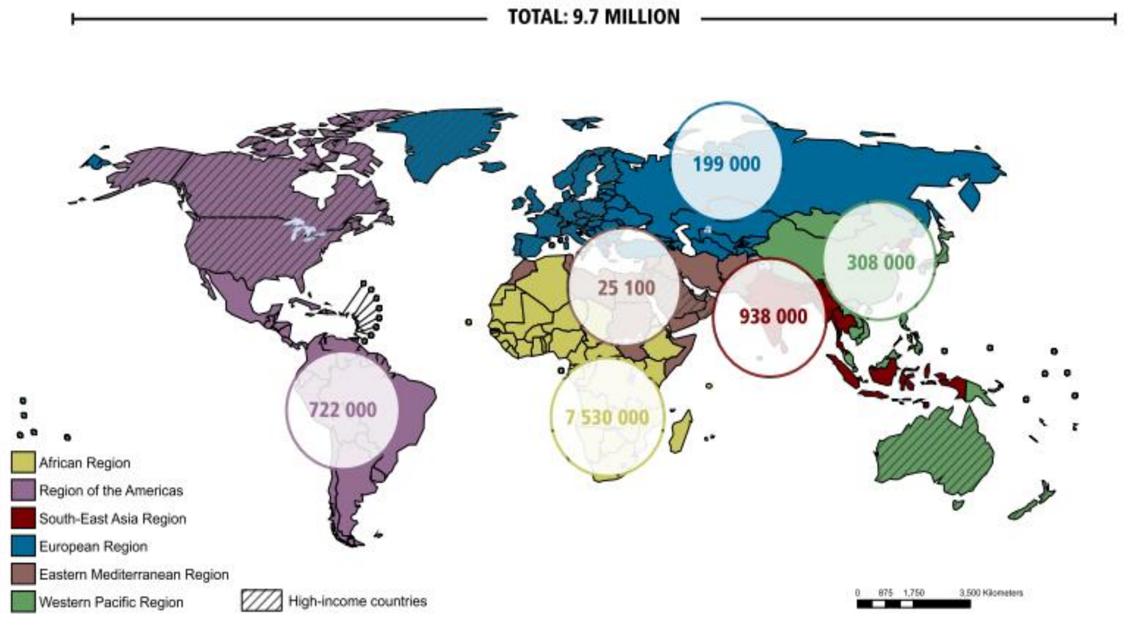


Figure 1 Number of people receiving antiretroviral therapy in low- and middle-income countries, by WHO region, 2012(Sources: [2])

The prevalence of HIV/AIDS in China still maintains a rapid growing trend. At the end of 2015, there were 575 000 cases of people living with HIV/AIDS, and 177 000 deaths in China. In Yunnan, the highest-prevalence province, there were 33 412 cases of HIV/AIDS, and 26 510 deaths[6]. Under the policy of “Four Frees and One Care” from 2004, over 140,000 HIV/AIDS patients had been treated nationwide by the end of 2011. There were about 49,000 people living with HIV in Yunnan in 2007, which is the highest ranked province in China. Between 1989 and 2006, 3.2 million blood samples were tested in Yunnan, in which 48,951 HIV-1 cases, 3,935 AIDS patients, and 1,768 resultant deaths were identified representing about 25%, 8% and 13% of the national totals[7]. There was a sharp increase in 2004 due to 13,486 new cases arising. It is comparable to the total number identified in the previous 16 years. After that, an average 10,000 new cases emerged each year in Yunnan. Drug users had the highest incidence rate, varying between 2.2% and 8.0% per year, whereas that for outpatients attending sexually transmitted infection (STI) clinics was 0.3–1.0% per year and for pregnant women it was about 0.1% per year. Whereas the Dai and Jing-po minorities were the most affected ethnic groups in 1989–95, Han Chinese over- took these minorities in 1996 and up to 2006 accounted for around 60% of infections. Although on average more than 95% of infected individuals have been aged 20–40, HIV-1 prevalence has increased among the 30–59 groups and decreased among the 20–29 group. Nonetheless, high prevalence in the 20–29 and younger than 20 age groups suggests ongoing infection within the young population.

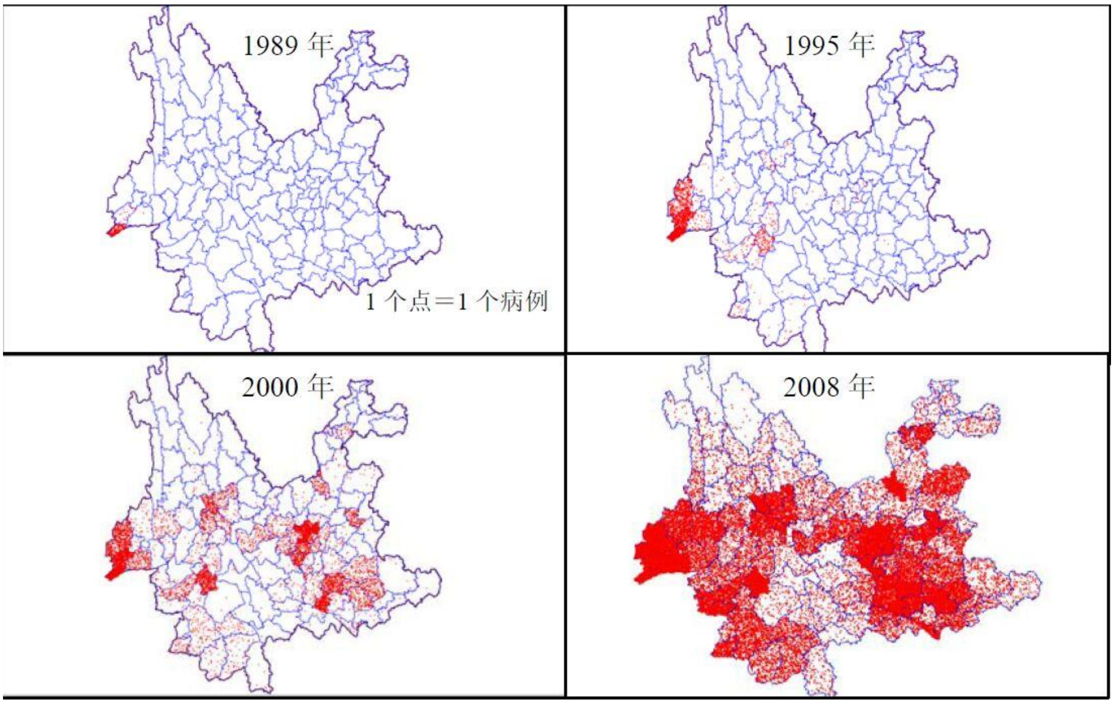


Figure 2 Number of people living with HIV/AIDS in Yunnan Province, China, by years: 1989, 1995, 2000 and 2008

1.1.2 Current situation of HIV care in China and/or Yunnan province

Policymakers of China announced a change of focus from purely economic goals to increasing the focus on health and social wellbeing for HIV/AIDS care and, as a result, increased support for public-health agencies due to the challenge of managing the severe acute respiratory syndrome (SARS) epidemic in 2003. Firstly, programme scale-up such as HIV care was based on case finding. The rapid expansion of testing infrastructure has been largely prompted by the introduction of provider-initiated routine testing campaigns to identify infected individuals and put them in contact with treatment services. Client-initiated testing was failing to identify most infected individuals, so campaigns to screen high-risk groups, including drug users, commercial sex workers, prisoners, and former plasma donors, were commissioned to link patients to treatment services. However, even with this effort, only about 22% of the estimated 650 000 HIV-infected individuals living in China at the end of 2005 have been identified[8]. Secondly, the AIDS Regulations[6] have outlined requirements at the county level and above, including educational establishments, customs, health providers, businesses and border control, and the media to promote HIV/AIDS education and social marketing. A number of schools now include sex, drug, and HIV education for their pupils, especially in high-risk areas such as Yunnan, Guangxi, and Guangdong. An important part of HIV education is targeting behaviour to reduce stigma towards people with HIV/AIDS. Thirdly, through the China CARES programme[9], provision of free antiretroviral therapy to rural residents and the urban poor became policy in 2003 under the Four Free and One Care policy[10]. National HIV/AIDS Clinical Taskforce took the lead in establishing the program, and set up a database to monitor it. At the end of 2006, more than 30,640 patients have been treated in 800 counties in all 31 provinces.

In Yunnan, the Centre for Disease Control and Prevention (CDC) is the key point responsible for HIV care. When patients visit the doctors, HIV screening test is conducted according to the status of patients. Once the test reveals a positive result the patient is referred to Yunnan CDC for an HIV confirmatory test. When making a definite positive diagnosis, HIV patients enter into the monitoring system of HIV/AIDS. All HIV-related healthcare services are provided in this monitoring system including referral to different designative specialists and special hospitals under the management of Yunnan CDC. When CD4 count is less than 200/mm^3, patients can enter into the free treatment under the policy. Before that, regular monitoring is provided by HIV Voluntary Counselling & Testing (VCT) clinics per six months.

1.1.3 Health system responsiveness and HIV/AIDS stigma

Health system responsiveness

Health system responsiveness (HSR) is a promising measurement of quality of health system, and focuses on a healthcare system`s ability to satisfy patients` expectations in terms of non-financial aspects of health care and non-clinical health domains such as dignity, confidentiality, autonomy, prompt attention, quality of basic amenities, social support and choice of provider[11,12]. It in turn may promote utilization of services[13,14], ultimately promoting health. One study from Ethiopia found that HSR was independently associated with satisfaction of HIV care[15], while another suggested that HSR was related to increasing visit adherence[16]. Some domains of HSR such as prompt attention, autonomy and communication were identified as priority areas for actions to improve responsiveness of healthcare services[17,18]. HSR is determined not only by patients' perceptions but also by their expectations.

Patient expectations prior to seeking healthcare services and their perceptions of the care after consuming the service positively affect their satisfaction of the service and confirm or refute their re-visits of the service[19,20]. Expectations of healthcare systems are proportional to their attractiveness. Patient's expectations of medical care are linked to the cost of treatment[21], assessments and satisfaction[22,23]. When the perception of patients towards healthcare meets the expectation of patients**[24]**, a healthcare system will arrive at the perfect level, which appeals to patient-centred medical services[25].

HSR also demonstrates that patients play a dominant role in the process of access to healthcare called patient-centred medical services with fairness of financial contribution. The definition can be viewed broadly from two perspectives, in which one is that the greater responsiveness comes from healthcare system, the more consumers of healthcare system are attracted. Another one is that responsiveness is seen as safeguarding the rights of patients to adequate and timely care[26]. Although traditionally patients' views have been sought on the quality of care provided and satisfaction with health services, the World Health Organization (WHO) has proposed the concept of responsiveness as a more desirable measure by which a health systems can be judged[27].

HSR needs to contribute to the enhancement of health by creating a favourable environment such as seeking care earlier and openness in interactions with providers, and to the reduction of barriers to utilization of healthcare. Across different socio-economic status (SES), responsiveness measures patient’s experience with the health care system to reflect the health disparities. Perception of the patients has been shown with high patient satisfaction correlated with increased compliance, decreased latency to care seeking, and improved understanding and retention of the medical information.

Table 1 Elements as defined in the WHO responsiveness concept

Element	Question Handles (Sub-elements)
Dignity	The element implies that individuals are treated with respect by being welcomed at the healthcare unit and addressed respectfully. It also implies being treated with concern, and being examined in a manner that respects the client's privacy and the right of individuals with infectious diseases such as HIV to be safeguarded.
Autonomy	This element deals with involvement in decision making, and assumes that this can only happen if the users are provided with relevant information, consulted on preferences, and that patients' consent is sought before any proceeding. It also implies that respect is observed on the right of patients of sound mind to refuse treatment.
Confidentiality	This element of responsiveness is related to high maintenance of confidentiality of any information that is provided by the patient, confidentiality of medical records and information about individuals, and privacy during consultations by health providers.
Prompt Attention	This element is defined as care provided readily and as soon as necessary. It includes short waiting-times for treatment or consultations, short-lists for consultations, reasonable waiting-times for appointments, fast care for emergencies as well as the accessibility of the health facility.
Quality of Basic Amenities	This element deals with the extent to which the health facility's physical infrastructure is welcoming and pleasant. It mainly includes clean surroundings, maintenance, adequate furniture, sufficient ventilation, clean water, clean toilets and clean linen.
Choice of Provider	This element is related to the health-care institutions and health providers. It is defined as the power or opportunity to the selection of a provider which requires more than one option. It deals with patients being able to access health services without much difficulty, ability to choose a health-care provider within a health-care unit, individuals being able to get a second opinion, and ability of individuals to get appropriate specialist care.
Social Support	In Hospitals: visits, having special foods, religious practices.

HIV/AIDS stigma

HIV/AIDS related stigma (HIV/AIDS stigma) is invoked as a persistent and pernicious problem in any discussion about effective responses to HIV prevention and treatment programs. HIV/AIDS stigma is cited as a major barrier to accessing prevention, care, and treatment services [28,29] due to devastating the familial, social, and economic lives of individuals. The concept of stigma is often not explicitly defined, but rather, is referred to cursorily as "a mark of disgrace"[30]. The conceptualization of HIV/AIDS stigma is utilized for a broader set of health and social issues, such as mental illness or unemployment. Conceptualizing stigma as a combination of individual and social phenomenon underscores the importance of addressing self-imposed, individual, as well as structural (or institutional) discrimination[30]. Discrimination is a consequence of stigma and defined as "when, in the absence of objective justification, a distinction is made against a person that results in that person being treated unfairly and unjustly on the basis of belonging or being perceived to belong, to a particular group" [31].

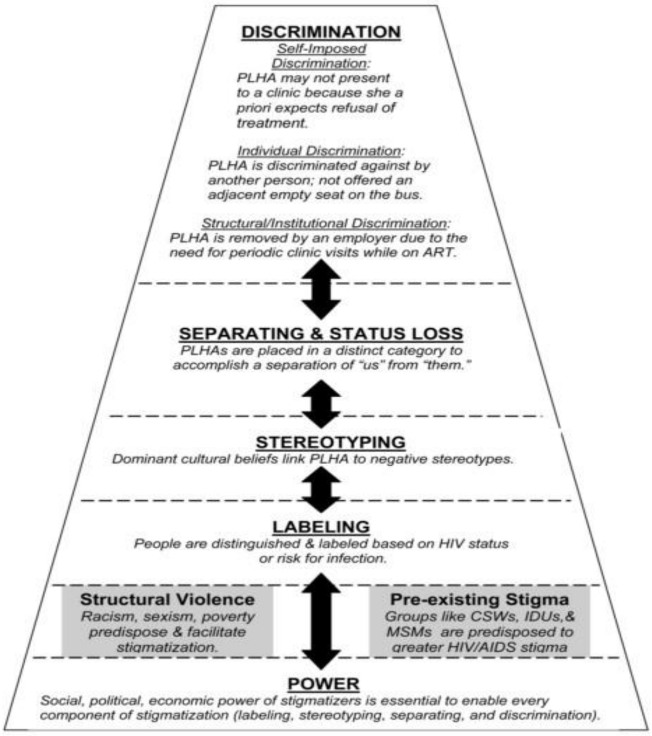


Figure 3 Comprehensive conceptual framework for HIV/AIDS related stigma (Source: Bruce Link and Jo Phelan)

There are different HIV stigma effects for different individuals. Stigma mechanisms are manifested in three predominant ways among HIV uninfected individuals: prejudice, stereotyping, and discrimination towards people living with HIV/AIDS (PLWHA)[32]. Prejudice refers to negative emotions and feelings such as disgust, anger, and fear that HIV uninfected people feel toward HIV infected people[33,34]. Stereotypes refer to group-based beliefs about HIV infected people that are often applied to specific individuals living with HIV/AIDS[35]. Discrimination refers to behavioural expressions of prejudice by HIV uninfected people directed at HIV infected people[19]. By the pathways, the existence of a stigma can impact a variety of psychological, behavioural, and health outcomes for both people. As for HIV infected people, at the individual level there are at least three important stigma mechanisms: enacted stigma, anticipated stigma, and internalized stigma. Enacted stigma refers to the degree to which PLWHA believe they have actually experienced prejudice and discrimination from others in their community. Anticipated stigma refers to the degree to which PLWHA expect that they will experience prejudice and discrimination from others in the future[36]. Internalized stigma refers to the degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves[37]. These three mechanisms have been previously defined as central, distinct processes through which members of other stigmatized groups experience stigma[37,38]. Each mechanism is highly relevant to the experiences of HIV infected people. Ultimately, PLWHA face a variety of often deleterious outcomes such as mental health, social support and HIV symptoms.

1.1.4 Stigma and HSR with relevance to HIV patients

HIV positive patients are the population facing with healthcare inequity such as barriers for access to healthcare. Not surprisingly, there is an overlap between system factors associated with lower adherence to care and those associated with low patient satisfaction with care and low HSR. These include long wait times, long distance of clinic from the patient’s home, and health care worker shortages that are incorporated elements of HSR[39-41]. Socio-economic status (SES) may explain the common co-occurrence of risk factors among HIV and sexually transmitted diseases (STDs). The differences across the different SES groups are significant approaches to compare general health indicators to monitor healthcare equity and variety of some sensitive problems such as gender and incomes among HIV and STDs. According to literature review, the relationship between HSR and adherence to HIV care has not been well described. Some patients reported high levels of satisfaction with care received[42], but others held opposite opinions. Therefore, the relationship between HSR and adherence to HIV care is not explicitly clear. With the promising efficacy of antiretroviral therapy, and the policy for all HIV positive patients in China to have free access to them, there is a need to examine the quality of healthcare and whether it meets their expectations. In addition, stigma is well recognized as a major barrier to HIV control, because it prevents people from seeking services for testing and treatment, and discourages people from practicing safer behaviours. Despite the progress in treatment and management of HIV infection, the disease remains a concern regarding the issue of inequity due to social stigma and the tendency of the disease to affect marginalized populations. Stigma is not only the HIV positive patient`s perception of being discriminated but also the perception of others, including care providers towards HIV positive patients. Perceived stigma among PLWHA is associated with stress, depression, and lower perceived quality of life[43,44]. More directly, health service providers’ stigmatizing attitudes and avoidance behaviours toward PLWHA hinder people for seeking HIV testing and counselling, participating in prevention programs, accessing HIV treatment, and adhering to antiretroviral therapies[28,45-50]. Factors contributing to stigmatizing and discriminatory responses among service providers include a lack of appropriate knowledge and training[51]; the perception that HIV/AIDS is incurable[52,53]; insufficient institutional support and perceived societal discrimination against HIV[54]; lack of knowledge and supply of universal precautions and post exposure prophylaxis[55]; and legislative or policy gaps including health controls, quarantine, compulsory internment, and/or segregation in hospital[56]. In addition, stigma among providers is not clear[57], and also without robust measures of such institutional stigma and the identification of potential levels to affect change by time, effective stigma reduction interventions cannot be designed.

1.2 Study setting background

1.2.1 Study area

Located in southwest China, Yunnan has a total of 16 prefectures including 129 counties and cities with an estimated total population of 46.31 million covering 39.41 million square meters. With a 4060 km border with Myanmar, Laos and Viet Nam, Yunnan province has become the province with the highest number of HIV/AIDS cases in China with all of its 16 prefectures affected. Yunnan's ethnic diversity is unsurpassed with 25 different ethnic minority groups representing one third of the province's population. Yunnan has a long history of opium/heroin trade, and the vast majority of illicit drugs in China are trafficked through Yunnan from the 'Golden triangle' of illicit opium production, encompassing Laos, Thailand, Myanmar and Vietnam (Figure 4)[3].

HIV-1 was detected in intravenous drug users in Yunnan in 1989. It then also spread among other populations. Between 1989 and 2006, 3.2 million blood samples were tested in Yunnan. This testing identified 48,951 HIV-1 cases, 3,935 AIDS patients, and 1,768 resultant deaths accounting for 25%, 8% and 13% of national quantity respectively[7]. Prefectures bordering Myanmar and Vietnam were the first and the most severely affected. Although the cumulative HIV-1 case load rose gradually from 1989 to 2003, there was a sharp rise in 2004 when 13,486 new cases were seen. This total is comparable to the number identified in the previous 16 years. After that, an average of 10,000 new cases emerged each year till 2013. Intravenous drug users had the highest incidence rate throughout the study, varying between 2.2% and 8.0% per year, whereas that for outpatients attending sexually transmitted infection clinics was 0.3～1.0% per year and for pregnant women it was about 0.1% per year[7].

1.2.2 Study sites

Kunming city has the highest prevalence of HIV/AIDS in all districts of Yunnan. Kunming is classified as a highly developed area, which is the centre of political, economic and cultural development and activities in Yunnan province. It covers an area of 21,473 square kilometres and with 2,622 square kilometres being urban area. Kunming has population of 6,432,212, including 3,583,429 in the built-up area made up of 4 urban and 1 suburban districts. Its economic importance derives from its geographical position near the border with South-east Asian countries, serving as a transportation hub in Southwest China, linking by rail to Vietnam and by road to Myanmar and Laos.

Figure 4 Geographic location of Kunming district in Yunnan province

2. Literature Review

About comparisons between HSR and HIV care services among HIV patients, there is an overlap between system factors associated with lower adherence to care and those associated with low patient satisfaction with care and low HSR. These include long wait times, time-consuming distance of clinic from the patient's home, and healthcare worker shortages that are incorporated elements of HSR[39-41]. SES may explain the common co-occurrence of risk factors among HIV and sexually transmitted diseases. In addition, the relationship between HSR and adherence to HIV care has not been well described. Some patients reported high levels of satisfaction with care received[42], but others hold opposite opinions. In summary, it is not explicitly clear about the association between HSR and HIV care among HIV patients because most of the published studies were cross-sectional and lacked generalizability and causality, which limited in reflection the healthcare equality.

As for the literatures of stigma among HIV patients, perceived stigma among PLWHA is associated with stress, depression, and lower perceived quality of life[43,44]. More directly, health service providers' stigmatizing attitudes and avoidance behaviours toward PLWHA hinder people seeking HIV testing and counselling, participating in prevention programs, accessing HIV treatment, and adhering to antiretroviral therapies[28,45-50]. Factors contributing to stigmatizing and discriminatory responses among service providers include a lack of appropriate knowledge and training[51]; the perception that HIV/AIDS is incurable[52,53]; insufficient institutional support and perceived societal discrimination against HIV[54]; lack of knowledge and supply of universal precautions and post exposure prophylaxis[55]; and legislative or policy gaps including health controls, quarantine, compulsory internment, and/or segregation in hospital[56]. In addition, stigma among providers is not clear[57], and also without robust measures of such institutional stigma and the identification of potential levels to affect change by time, effective stigma reduction interventions cannot be designed. Obviously, there is a lack of a measurement by time.

2.1 HIV/AIDS stigma as a barrier to access healthcare services

With the pandemic of HIV/AIDS[58] predominantly characterized by sexual transmissions[59] and chronic tendency in China, the majority of PLWHA are faced with HIV/AIDS stigma — a major barrier for access to prevention, care, and treatment services. Some studies showed that stigma was significantly associated with poor access to care, which were not regular source of HIV care or ART adherence. However, one study suggested that patients with high levels of stigma were more likely to report poor access to care, regular source of HIV care, and ART adherence[60] , and may be a result of different cultural and contextual settings.

In terms of reasons of HIV/AIDS stigma as a barrier, studies have shown that HIV/AIDS stigma is a formidable barrier for PLWHA seeking healthcare due to less positive attitudes[61], lack of community HIV/AIDS knowledge, lack of supportive or understanding clinic environments, absence of personal financial resources[62], lack of employment opportunities[63], and less optimistic perceptions of policy enforcement[64]. Additionally, limited clinical and cultural competency of public clinic staff also were barriers of access to healthcare services. Negative attitudes from PLWHA or healthcare providers significantly correlated with limited access to healthcare services. Besides these, HIV/AIDS stigma as barriers identified to include fears of HIV disclosure, distancing, blaming, and discrimination.

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 healthcare (Table 2).

Table 2 Summary of access to healthcare associated with HIV/AIDS stigma among PLWHs or healthcare providers

Author/Published year	Research purpose	Subjects/Region/Scales/ study design	Results	Limitations
[65]Elwell K 2016	To understand women's perspectives in order to meet patients' needs.	Women living with HIV for potion B+; In Malawi	Barriers included HIV/AIDS stigma, fears of HIV disclosure to husbands, and poor communication with healthcare providers; Facilitators have desire to remain healthy and quality of lives.	Selective bias due to qualitative study.
[66]Yakob B, Ncama BP, 2016	To investigate the impact of socio-ecological factors on access to and acceptability of HIV/AIDS treatment and care services	111 people involved in HIV care; In Wolaita Zone of Ethiopia;	Four socio-ecological factors: 1) awareness, experiences, family, HIV disclosure, expectations, income, food availability and employment; 2) stigma and discrimination, care and support, and traditional healing; 3) availability of care, interactions with care providers, distance, quality of care, affordability, follow up and service administration, logistics availability; 4) service standards, healthcare financing, policy documents and implementation manuals.	Selective bias due to qualitative study.
[67]Cange CW, et al. 2015	To investigate the effect of stigma and discrimination on MSM of HIV treatment.	Men who have sex with men (MSM); In Cameroon.	MSM participants reported experiences of discrimination and physical violence in seeking health services; Majority observed limited clinical and cultural competency of public clinic staff; Lack of social support; Alienation discouraged to seek HIV service and treatment.	Selective bias due to qualitative study.
Eugene W. Farber et al. 2014	To investigate short-term outcomes in HIV stigma in HIV **mental health services.**	Adult PLWHs; South eastern United States; HIV stigma scale; A cohort study.	Self-reported perceived HIV stigma over time reduced for the distancing, blaming, and discrimination dimensions of stigma; Subjects of HIV mental health services have a favourable impact on HIV stigma.	Reduction for participants.
[68]Wen, Y., et al.,2013	To evaluate the medical and psychosocial needs of HIV/AIDS patients after **initiating HAART**	H/A patients from study sites for regular ART; Yunnan, China; Quality of life (SF-36); Family functioning; Physician-patient relationship; Perceived HIV-related stigma; Family/community support.	Patients on HAART by drug use and current smokers typically had poorer physical health. Better financial status and physician-patient relationship were associated with physical and psychological health. Family awareness was negatively associated with patient's psychological health. Higher levels of HIV-related stigma were associated with poorer psychological health and family functioning.	Selection bias; Information bias; Causality and generalization;
[63]Lazarus L et al.2012	To evaluate relationship to barriers to accessing health services	252 female street-based sex works; Vancouver, Canada.	Associations: occupational sex work stigma and interpersonal/work environment risks.	No causal relationships; No generalizability.

Author/Published year	Research purpose	Subjects/Region/Scales/ study design	Results	Limitations
[69]Lin, C., et al. 2012	To investigate healthcare providers' empathy levels and its association with **avoidance in providing service to PLWHA**	Healthcare providers: doctors, nurses and lab technicians; Yunnan and Fujian, China; Jefferson Scale of Physician Empathy; HIV-related avoidance; A cross-sectional study	Association: empathy and medical degree. Healthcare providers with lower education tended to avoid contact with PLWHA. A higher level of attitude negatively association with outcomes.	No causality built.
[70]Feyissa GT, Abebe L, Girma E., et al., 2012	To explore stigma and discrimination against PLWHA amongst **healthcare providers**	Healthcare providers; Jimma zone, Southwest Ethiopia; HIV case load; HIV knowledge; Stigma and discrimination; Perceived institutional support.	Mean stigma scores are high. Risk factors: unnecessary referral to healthcare institutions, refusal to treat clients. Negative predictors of stigma: perception of institutional support, educational level of degree or higher, attending training on stigma and discrimination, the presence of ART service and high HIV case loads.	Ignore the levels factors.
[71]Fox MP., et al. 2010	To identify barriers to and facilitators of ART uptake.	400 patients on ART and patients accessing home-based care (HBC); In two rural and two urban sites in Zambia.	Stigma was common; Urban HBC patients more likely to pay to travel to the clinic; more to pay a fee at the clinic.	Selective bias: Target sample opted out of treatment.
[60]Sayles, J.N., et al. 2009	To estimate the association between HIV stigma and self-reported access to care, **regular source of HIV care, and antiretroviral therapy adherence**; To test whether mental health mediates these associations.	PLWHs; Los Angeles County, USA; Internalized HIV stigma scale; HIV Cost and Services Utilization Study (HCSUS); Self-reported Regular Source of HIV care and ART adherence; Mental health composite scores.	High levels of stigma; poor access to care; suboptimal ART adherence; no regular source of HIV care. High level of stigma more likely to report poor access to care, regular source of HIV care, and ART adherence. Association between stigma and poor access to care, no regular source of HIV care or ART adherence. Relationship between stigma and ART adherence.	No causality; Ascertainment bias; Be lack objective measures of access to medical care.
[72]Genberg BL.,et al.2009	To compare levels of HIV/AIDS stigma at differing levels of HIV	14,203 participants in Sub-Saharan Africa (Tanzania, Zimbabwe and	Relationship between negative attitudes and no tested for HIV, lacking knowledge of ARVs, and no discussed HIV/AIDS. More negative attitudes with the lowest HIV prevalence;	Underestimate the true levels of negative attitudes;

Author/Published year	Research purpose	Subjects/Region/Scales/ study design	Results	Limitations
	prevalence and ARV coverage.	South Africa) and northern Thailand.	More perceived discrimination against PLHA with the lowest ARV coverage.	
[73]Rutledge SE., et al. 2009	To contextualise the experience of AIDS stigma in health services	in the Caribbean, sub-Saharan Africa	AIDS stigma among marginalized populations. PLWHA are scorned by some service providers, especially when they are perceived to be gay or bisexual. PLHA and providers identified passive neglect and active refusal by hospital and clinic staff to provide care to PLHA.	Sample size vary: some may find our sample small.
[74]Pulerwitz J., et al, 2008	To test the associations between stigma, service utilization and status disclosure.	1,775 truck drivers crossing Southern borders in Brazil	Less stigma (both individual items and grouped as a scale) was significantly correlated with VCT use (p<or=0.001), knowing where to get tested (p<or=0.001) and willingness to disclose HIV-positive test results (p=0.013).	Generalizability is difficult to other population.
[75]Li, L., et al.,2007	To assess the impact of the AIDS epidemic on **medical care systems** and service providers.	Doctors, nurses, and lab technicians working with PLWHA; Yunnan, China	Correlation analyses showed significant association between internalized shames reported by service providers and their perception of being stigmatized due to working with PLWHA. Multivariate analyses revealed that perceived level of institutional support for AIDS care was significantly related to the stigmatization and shame reported by the service providers.	Institutional support based on self-report and without data on institutional indicators such as equipment.
[76]Wong V.,et al, 2006	To examine management strategies among older people living with HIV/AIDS to conceal their positive status in healthcare settings	a total of seven male older PHAs aged 55 or above	Older PHAs did exercise their own agency in preventing against and managing stigma in their access to and use of health care services; Two more specific themes around "sign of disapproval" and "discriminatory practice" as barriers to access were also identified.	The small sample size

2.2 Theories of HIV/AIDS stigma

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”[30]. The absence of an explicit conceptualization of stigma precludes appraisal and comparisons of study findings and also limits the ability to design effective interventions[77]. Based on the “significantly discrediting” attributes, 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 behaviours[78,79]. Some other existing theories have demonstrated concepts to understand how stigmatization as a social control mechanism impacts the HIV/AIDS epidemic and communities[77,80]. However, existing conceptual frameworks have not clearly identified how HIV positive patients experience HIV/AIDS stigma in healthcare settings.

2.3 Development of HIV/AIDS stigma scales among HIV/AIDS relative population

Due to time- and context-specific characteristics of stigma, a stigma instrument needs to address the specific nature of people’s perceptions in each local context[81,82]. For an individual not infected with HIV, personal stigma can be manifested in three predominant ways towards PLWHA[32], including negative emotions/feelings toward HIV infected people (prejudice)[33,34], prejudiced behavioural expressions to PLWHA (discrimination), and stereotyping as group-based beliefs about PLWHA (stereotype)[35]. 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 healthcare sector is one of main environments where HIV-positive individuals experience stigma and discrimination [83,84]. Stigma towards PLWHA can lead to lower access to care[85] by PLWHA. This stigma can be manifested through the careers of healthcare professionals and quality of health services. Culture is another significantly important characteristic in the framework of HIV/AIDS stigma. Chinese culture is more collectivist[86] compared to western cultures. Individuals in 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 healthcare setting.

In China, previous studies have shown that keeping social distance based on fears of stigmatization[87], negative feelings towards PLWHA[88], such as deservingness or being shamed with risky behaviours[89], may act as barriers for seeking healthcare services among PLWHA. Two essential core elements of HIV/AIDS stigma have been identified in China: keeping social distance based on fear, and negative feelings or behaviours of blame or being shamed. Because of internalized and personal stigma from different groups of people, HIV/AIDS stigma should be measured in parallel from HIV-infected and non-infected individuals, using similar items that are worded from a specific perspective to capture the meaning of different types of stigma. Two equivalent stigma scales measuring internalized and personal stigma[90] match the two core elements. However, they were developed in a South African context. Stigma in an African context is built on a series of shared beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms, resulting in blame for contracting the disease [91,92]. It is similar to the HIV/AIDS stigma in China in some ways but significantly different in the expression form of specific perceptions and behaviours. Therefore, exploration of the latent levels of these two scales is necessary. Additionally, other studies have revealed that Chinese service providers’ stigmatizing attitude and behaviour such as differential treatment and denial of care, their perception of social norms and concerns about their occupational safety[93,94] are a key barrier for HIV testing and treatment. A Chinese scale[95] 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 departments of hospitals that are responsible for HIV care in the Chinese healthcare system, especially in the background of increasing coverage of ART. Thus, there is a need to further improve it for assessment of HIV/AIDS stigma at the individual level in hospitals caring for HIV patients and among different groups of people, and also facilitate targeting key populations to improve quality of HIV/AIDS care (Table 3).

Table 3 Summary of development of HIV/AIDS stigma scales among HIV/AIDS relative population

Author/Published year	Research purpose	Subjects/Region	Construct	Dimensions	Limitation
[96]Smith EA et al. 2014	To assess a theoretically and culturally informed multi-dimensional, HIV/AIDS-related, stigma scale for measurement invariance across a sample drawn	South Africa's diverse population: Limpopo and Western Cape area	The scale consisted of twelve items selected based on their fit with the overall conceptualization of stigma indicated through qualitative research and pilot testing.	Three distinct domains: government support, shame and Rejection, and individual Support.	Sampling did not capture all regions of South Africa; Purposive sampling limited the generalizability of this study.
[97]Liu, H. et al. , 2014	To develop a scale to measure the degree of stigma among both PLWHAs and their HIV-uninfected family members at the family level.	PLWHAs and their HIV-uninfected family members; Anhui and Guangxi, China	Chinese Courtesy Stigma Scales (CCSSs); Centre for Epidemiologic Studies Depression Scale(CES-D); General self-efficacy scales;	Two facets of stigma: public and self-perceived stigma; Provide concurrent validity evidence for the newly developed instrument.	Generalizability to different populations
[98]Wagner AC et al.2014	To create an empirically supported scale of HIV stigma from	Four focus groups And 234 medical and nursing students; North America	AIDS Attitude Scale, AAS; The Marlowe-Crowne Social Desirability Scale Short Form (MC-SF)(Ninety-three items)	The final three-factor: Prejudice subscale (13 items); Stereotypes subscale (11 items); Discrimination subscale (6 items)	Use of a self-selecting sample. Self-report of discriminatory behaviours may be particularly notable,
[99]Ebrahimi-Kalan M et al.2013	to adapt the HIV/AIDS Stigma Instrument (HASI) to the Iranian People Living with HIV/AIDS (PLWHA)	PLWHAs/ Iran	To evaluate linguistic validity, assess content validity by a panel of nine experts, and explore construct validity.	-	To use sample without random process; Its generalizability to Iranian PLWHA is limited.
Seth C. K et al.2009	To develop a psychometric scale to measure internalized AIDS-related stigmas among PLWHAs.	PLWHAs; South Africa/Swaziland/ USA	Internalized AIDS-Related Stigma Scale(IA-RSS); Cognitive and Affective Depression; Social support from social support questionnaire; HIV/AIDS discrimination experiences	Self-blame and concealment of HIV status; Symptoms of depression; Perceived tangible and emotional support; Discrimination-related events	To examine other affective dimensions as well as social processes with stigma; To explain more association magnitude by other constructs.
[95]J. A. Stein et al. ,2008	To develop a multidimensional scale to measure HIV-related stigma	Doctors, nurses, and lab technicians	Outlines assessing stigma in a variety of healthcare settings or other venues relevant to H/A	Discrimination Intent at Work (4 items) Prejudiced Attitudes (4 items)	Generalizability to different populations especially

	among Chinese service providers	working with PLWHA; South-western province, China	provided by USAID including five dimensions.	Opinion about Healthcare for H/A patients (3 items) Internalized Shame (3 items) Fear of PLWHA (3 items)	among HIV+ patients, non-HIV patients and health providers.
[100] Sayles JN et al. 2008	To develop and evaluate internalized HIV stigma.	A sample of 202 PLWHAs	A 28-item measure of internalized HIV stigma scales	Four factors: shame, social support, mental health, and supported construct.	Selection bias and convenience sampling strategy
[101]Visser, M. J. et al.2008	To assess stigma, stigma attributed to others, and internalised stigma experienced .	A community sample of 1,077 respondents and 317 HIV-infected pregnant women	A two-factor structure to moral judgment and interpersonal distancing.	The internal consistency of the scales was acceptable and evidence of validity is reported.	Only HIV positive pregnant women who attended antenatal care.
[102]Van Rie A et al.2008	To develop scales to measure tuberculosis and HIV/AIDS stigma.	56 tuberculosis and 47 HIV/AIDS stigma-related statements; in South Thailand	A revised 56 potential tuberculosis stigma items and 47 potential HIV/AIDS stigma items.	Two sub-scales associated with both tuberculosis and HIV/AIDS stigma	No generalizability of the scales.
Carla E. Zelaya et al.2007	Development and psychometric testing of an HIV/AIDS stigma scale	200 men aged 18–40 years of unknown HIV status; in Chennai, India	Domain 1 “fear of transmission and disease”; Domain 2 “association with shame, blame and judgment”; Domain 3 ‘support of discriminatory actions 10–15 per domain.	The final 24-item scale with four separate domains: 1) fear of transmission and disease; 2) association with shame, blame and judgment; 3) personal support; 4) perceived community support.	Only surveyed men.

2.4 Healthcare equity on utilization, access and dissemination across socioeconomic groups

SES is an important factor that influences the healthcare equity. Some studies showed that socio-economic inequalities in provider-patient interaction could be an important mechanism by which inequalities in access to medical specialists' arise. Higher SES groups used more of public and private hospitals while lower SES groups used more of traditional healers for adult patients[103]. Lower SES and being male correlated with negative experiences among healthcare providers. However, other studies showed that the level of education-related inequity in access to specialists was not sensitive[104]. The diverse outcomes from the previous studies may have resulted from measurements or study designs, whereas factors associated with inequity vary significantly depending on the context.

Access to adequate health services that is of acceptable quality is important in the move towards universal health coverage. Previous studies have revealed inequities in health care utilization in the favour of the rich. Moreover, those with the greatest need for health services are not getting a fair share. Furthermore, differences across different socio-economic groups are valuable to compare general health indicators to monitor healthcare equity and variety of some sensitive problems such as gender and incomes. Most importantly, socio-cultural barriers to care were identified at the organizational (leadership/workforce), structural (processes of care), and clinical (provider patient encounter) levels (Table 4). Additionally, international evidence indicates consistently lower rates of access and use of healthcare by international immigrants. Some studies suggested that perception of healthcare by patients was an important factor influencing quality of healthcare.

In summary, health inequity is universal resulting in quality of healthcare across different socio-economic groups, but there is litter literature about perception of healthcare by patients to estimate quality of healthcare.

Table 4 Summary of Healthcare equity on utilizations, access and dissemination across socioeconomic groups

Author/Published year	Research purpose	Subjects/Region/ Methods/Study design	Results	Limitations
[105]Phiri, J. and J.E.Ataguba,2014	To assess socioeconomic related inequalities or inequities in public health service utilization	19,398 households (i.e., 102,882 individuals) in nationally representative survey; Zambia;	The concentration indices was low; Pro-poor distribution at primary facilities and with pro-rich distribution at hospitals; The horizontal equity indices for health post and clinic was different;	Recall biases; Limited capabilities to measure 'need' of healthcare; No quality of healthcare between facilities.
Seeberg, J., et al.,2014	To investigate the individual-, household- and community-level factors that affect Women's use of maternal health care services in Turkey.	A nationally representative survey of ever married women 15 to 49 years of age	Urban women have at least one prenatal care consultation than rural women. Rural women have traditional home deliveries than urban women. Factors: parity level, educational attainment, ethnicity, health insurance coverage, geographic region and household wealth.	Recall bias.
Rodriguez -Alvarez, E., et al.,2013	To identify social factors to explain differences in knowledge with regards to HIV/AIDS among immigrants in Spain.	754 immigrants from 86 China, 368 Latin America, 237 the Maghreb and 74 Senegal; A cross-sectional study.	Associations between inadequate knowledge and place of birth, sex, a lower level of education, immigration status, difficulties. To promote equity through clinical guidelines.	Potential selection bias; Small sample size.
[104]Vikum, E., et al. 2013	To investigate socioeconomic inequalities in experiences with general practice in access to specialist services	6,067 participants	Associations between low SES/male gender and negative experiences. Associations between patient experiences related to referrals and probability/quantity of specialist utilization. Associations between perception of low subjective influence on decisions about choice of medical care and lower specialist utilization. No strong education-related inequity in access to specialists.	Reliance on self-reported health for needs-adjustment.
[103]Onwujekwe, O., et al.2011	To determine the differences in the quality of treatment for presumptive malaria received by different SES groups in Nigeria	2250 people	Higher SES groups used more of public and private hospitals; Lower SES groups used more of traditional healers (adult); Higher SES used more of healthcare centres and private hospitals; Lower SES groups used more of pharmacy shops (children); The quality of treatment services decreased as SES decreased.	Selection bias; Lack of use of consumer perceptions to adjudge quality of services.
[106]Cabieses, B., et al. 2006 and 2009	To explore healthcare provision entitlement and use of healthcare services by	268,873 people in 73,720 households (44, 854 urban and 28,866 rural ones) in 2006;	A decrease in the rate of immigrants without healthcare provision; An increase in reporting of private healthcare provision entitlement. Disabled immigrants without healthcare provision compared to the disabled Chilean-born.	Need adjust for legal status, health status, stigma and discrimination, and others;

Author/Published year	Research purpose	Subjects/Region/ Methods/Study design	Results	Limitations
	immigrants in Chile and compare them to the Chilean-born.	246,924 people in 74,339 households (47 044 urban and 27 295 rural ones) in 2009.	Factors associated with immigrants’ access to, and use of, healthcare: sex, education, urban/rural status and country of origin.	Self-report bias.
[107]Onwujekwe, O., et al.2008	To investigate the link between SES with differences in perceptions of ease of accessing.	1,351 health providers in four malaria-endemic communities in Enugu state, southeast Nigeria.	Vendors were the most perceived accessible providers; Inequities in perception of accessibility and use of different providers. Inequity in treatment-seeking for malaria; The poor spend more to treat the disease.	Quantitative study cannot built causation.
[108]Casalino, L.P., et al.,2007	To explore consequences between pay-for-performance and public reporting programs on disparities; To explain how to reduce disparities.	15 major performance incentive programs in the United States;	Influencing factors: income, education, acculturation to the United States, and English language ability, similar unintended consequences of external incentive programs. Low-income and poorly educated white patients are not included in the term "minority patients";	Without a great deal of attention to their possible effects on health care disparities.
[109] Onwujekwe, O. 2005	To investigate the socio-economic inequities in healthcare seeking in the treatment of common communicable endemic diseases.	A total of 1620 households was selected from the four LGA using simple random sampling.	The poorest quartile tend to use low-level providers; The concentration indices were low in use of herbalists, patent medicine dealers, community-health workers, PHC centres and hospitals. A decrease in the amount of user fees enhanced physical access.	A cross-sectional study.
Gill, R. and D.E.2011	To explore relationship between gender-sensitive policies and the empowerment of women.	A list of 17 gender-sensitive policy and 17 general health indicators from four documents under the umbrella of the WHO and UN;Second-hand data analysis.	Several gender-sensitive policies that were measurable by indicators that contribute to health. Large gender inequities due to examination of political and economic status, illiteracy rates, maternal mortality rates, birth sex ratios, human trafficking, fertility rates, contraception prevalence, access to skilled birth attendants, knowledge of HIV/AIDS prevention, and microfinance.	Secondary data sources; Gender-sensitive indicators are provided little information on the wider social patterns.

2.5 Healthcare equity in different social groups among people living with HIV

Health disparities in HIV, viral hepatitis, sexually transmitted diseases, and tuberculosis have been documented for racial and ethnic minority groups, sexual and gender minority groups, young people, females, and incarcerated people[110]. Social determinants of health may explain the common co-occurrence of risk factors among these groups and, thus, the co-occurrence of HIV diseases. Equity in access to health care among PLWHA has not been extensively studied despite the fact there is significant social diversity within this group. Utilization and access to HIV care as well as social determinants, impact on the morbidity and mortality rates among those affected by the HIV/AIDS epidemic. However, little is known about the association of within-PLWHAs and between-non HIV positive group socioeconomic inequalities and HIV care such as voluntary counselling and testing. HIV care providers and program managers play important roles to further characterize the barriers to healthcare access and develop strategies to resolve them. However, little is focused on HIV care providers to reduce the barriers for HIV positive patients’ access to HIV care (Table 5).

Social inequalities in provider-patient interaction could be an important mechanism by which inequalities in access to medical specialists arise.

Table 5 Healthcare equity in different social groups among people living with HIV

Author/ Published year	Research purpose	Subjects/Region/ Methods/Study design	Results	Limitations
[111]Onwujekwe, O. E., et al. 2016	To examine magnitude of economic burden of HIV/AIDS to different population groups; in Nigeria.	1200 PLWHA based household survey.	Average expenditures was US$6.1 across SES and urban-rural residence; Majority households spent money on transportation to a treatment facility and on food; Urbanites paid more medical expenditures than rural dwellers; Rural dwellers incurred more catastrophic medical expenditures.	Restriction of survey respondents; No qualitative component.
[112]Silva-Santisteban, A., et al.,2013	To assess the extent to which health care provision to PLHA, including ARVT.	863 individuals from PLWHA organizations ; four cities of Peru; Respondent driven sampling (RDS) other than convenience recruitment;	Majority of PLWHA access to HIV-related health service and receiving at a public facility. Most of those access to care received ARV. 36% percent reported out-of-pocket expenses within the last month among those on ARV, Transgender identity and age younger than 35 years old, were associated with lower access to health care.	Over-estimating access among PLHA; Clinical indicators maybe have affected our understanding of other barriers to health care access.
[113]Tao G, Hoover KW.2013	To examine differences in access to healthcare and HIV and STI related health services.	MSM and non-MSM in the United States aged 15-44 years who have ever had sex;	No significant differences between MSM and non-MSM in the three access measures; MSM more receive HIV counselling and STI testing.	A cross-sectional study.
[114]Larose, A., et al.,2011	To examine the degree in low socioeconomic groups in developing countries.	106,705 individuals in 49 countries from data of the 2002 to 2003 World Health Survey; Individual income based on country-specific income quintiles; Second-hand data analysis.	VCT was more likely among higher income quintiles and in countries with higher GDP/c; Associations between individual income and VCT were greater in countries with lower GDP/c; Individual socio-demographic characteristics were also associated with the likelihood of a person having VCT.	Self-rated HIV/AIDS status; Selections bias.

Author/ Published year	Research purpose	Subjects/Region/ Methods/Study design	Results	Limitations
[115]Wouters, E., et al.,2007	To examine how and to what extent public sector ART is related to the physical and emotional health. .	371 AIDS patients on ART or medically certified for ART;	Patients with a higher personal income and a larger dwelling were more likely to enter the programme at this early stage; Initial months of ART associated with improvements in physical QoL; Patients on ART had higher levels of emotional well-being; ART is associated with emotional QoL and mediating variable physical QoL.	selections' bias; Inequities in care uncovered.
[116]Tsai, A.C., et al.,2009	To determine socioeconomic differences in the community and hospital-based HIV positive outpatient for HIV/AIDS care and related services	776 HIV-infected persons aged 18–35 years, 534 consecutive patients at a hospital-based outpatient HIV clinic, and 242 persons living in the community; Limpopo Province, South Africa	Higher overall socioeconomic profile among HIV people. Have completed matric or tertiary education among HIV people; Less l to be unemployed among HIV people; More likely to live in households with access to a private tap water supply among HIV people.	Limit to individuals between 18 and 35 years;
[117]Posse M., et al2008	To present a review of barriers PLWHA in developing countries.	A total of 19 studies (7 articles and 12 abstracts) in English were reviewed.	The barriers: lack of information about antiretroviral therapy, perceived high costs for ART and stigma, long distance from home to the health facility, lack of co-ordination across services and limited involvement of the community.	Literature Review.
Zhou, Y.R.,2007	To explore how HIV/AIDS is understood as a social construct	Chinese PLWHA's illness experiences; A qualitative study;	Experiences by their of interacting with their families, friends, and health workers influenced perceptions responses to this disease among PLWHA.	Small sample size; Expansions of AIDS education.

2.6 HSR among HIV positive patients and healthcare providers

Responsiveness measures the patient's experience with the healthcare system in different social groups to reflect the health disparities, which the importance of the patient's perspective has been shown with high patient satisfaction correlated with increased compliance, decreased latency to care seeking, and improved understanding and retention of the medical information. As aforementioned, HIV positive patients are the vulnerable population facing with healthcare equity such as barriers for access to healthcare. Not surprisingly, there is an overlap between system factors associated with lower adherence to care and those associated with low patient satisfaction with care and low HSR. These include long wait times, long distance of clinic from the patient's home, and health care worker shortages that are incorporated elements of HSR[39,40]. Moreover, the relationship between HSR and adherence to HIV care has not been well described. Some patients reported high levels of satisfaction with care received[42], but others hold opposite opinions. Domains of Confidentiality, communication, and respect in HSR generally were significantly associated with overall rating of health care, but sometimes provider skills and communication were not significantly associated. Therefore, there is a significant gap about the relationship between HSR and adherence to HIV care (Table 6).

Table 6 Summary of healthcare system responsiveness among HIV+ patients and healthcare providers

Author/Published year	Research purpose	Subjects/Region/ Methods/Study design	Results	Limitations
[41]Miller JS, et al, 2014	To examine HSR in private clinics serving HIV patients;	640 HIV patients 18 or older receiving care at one of 10 participating clinics; Dares Salaam, Tanzania; Cross-sectional study.	High levels of satisfaction with care received; Higher rating in confidentiality, communication, and respect were particularly highly rated; Lower ratings in timeliness. Associations between respect/confidentiality/promptness and overall rating of health care among providers.	Generalizability; Small number sites; Lack of qualitative data.
[118]Gabriela Poles et al.,2014	To explore relationship between HSR, patient factors, and visit non adherence in AIDS Relief-supported HIV/AIDS clinics	720 patients staying at least 6 months in 16 HIV/AIDS clinics; Tanzania; A cross-sectional study	Gaps in care were more common; Influencing factors: younger age, no explanation of side effects, and ART duration. No visit in last quarter and low visit constancy was associated with younger age, poor healthcare worker communication, and less time on ART.	Patient's ratings were balanced against their expectations.
[119]Makoae, M. and K. Jubber,2008	To analyse challenges between home-based care and access to medical treatment.	21 family caregivers aged between 23 and 85 years: 16 females and 5 males; A qualitative study: in-depth interviews.	There was continuity of care where the caregivers obtained hospital support; Confidentiality was adhered to the caregivers by lack of information, disrupted treatment, and exclusion of their perspectives in medical care, failure to secure hospitalization, ambiguous goals and non-responsiveness.	External validity due to a small sample; A knowledge gap regarding the demand and utilization of inpatient care services.

2.7 Measurement of HSR

2.7.1 Measurement of HSR by Multi-Country Survey

Multi-Country Survey had as its first objective the assessment of health in different domains using self-reports by people in the general population. Responsiveness is one of the central parameters in healthcare performance[26], making surveys measuring responsiveness instrumental in providing evidence that can guide resource allocation and management strategies. Two major components have been defined by WHO in attempts to measure responsiveness, namely respect for persons, which captures aspects of individual interaction with the health system, and client orientation, which includes several aspects of consumer satisfaction[24,26,120]. WHO also developed 8 elements as the central elements needed to measure the responsiveness of a health system and consequently validated a questionnaire that was used to measure levels of responsiveness in surveys[26,120]. This tool has since been employed in several studies[121-123]. Most samples were selected from nationally representative sampling frames with a known probability so as to make estimates based on general population parameters.

2.7.2 Measurement of HSR by World Health Survey (WHS)

The current WHS modules address different aspects of health and health systems, and are organized in two sections, the household and individual questionnaire. Household surveys have an important role to play in national health information systems. They represent a low-cost method of addressing the selection bias inherent in provider registries and effective coverage of health interventions. The responsiveness module consisted of 5 sections: "Needing Health Care and General Evaluation of Health Systems", "Importance", "Seeing Health Care Providers", "Outpatient and Care at Home", and "Inpatient Hospital". While there exists evidence on variation in reported levels of health system responsiveness across countries[124,125], there has been little investigation of the determinants of responsiveness, particularly of system-wide determinants[11]. There is a gap about the investigation of individual questionnaire.

Table 7 individual questionnaire of modules of the WHS instrument in 2002-2003

The Individual Questionnaire	
	Socio-demographics
	Health state description
	Health state valuation
	Risk factors
	Mortality
	Coverage of health interventions
	Health system responsiveness
	Health system goals and social capital
	Interviewer observations

2.7.3 Measurement of HSR by Key Informant Survey

The key informant survey is part of an important WHO initiative. It is a survey of informed opinions on the responsiveness of health systems. The name “Key Informant” is based on the origin of the survey methodology, which is used extensively in other spheres of social, political and anthropological research. A key informant about a health system is defined as someone knowledgeable about the health system. While the primary goal of the health system is improving health, another important goal is ensuring the responsiveness of the health system to the legitimate expectations of the population.

2.7.4 Continuous development of the instruments

In multi-country survey and world health survey, both of them include the health state description and responsiveness modules including panels of anchoring vignettes, along with modules on mortality, socio-demographics, health system goals, and mental health. Multi-country survey as a baseline in 2000-2001 had been developed. Kappa`s and intra-class correlation coefficients allowed identification of items with particularly low test-retest reliability. Data on item missingness also provided insights into the psychometric properties of items or groups of items. Formal item and domain reduction methods were used on the survey data to suggest ways to decrease substantially the overall length of these modules. Between February and April 2002, revised modules for health state description, health state valuation, responsiveness, and health system goals, along with new draft items for modules on health expenditures, health insurance, health occupations, indicators of permanent income, risk factors, and health intervention coverage, were fielded in a 12-country WHS pilot study. The final WHS wave I instrument was available in August 2002 (Table 8).

2.7.5 Application of HSR measurement in China

In China, these surveys have been only conducted in some provinces. There is only one household questionnaire of WHS in Chinese version, however the individual questionnaire is not available. This would provide the opportunity for routine evaluation and for benchmarking service systems with results being fed back to service providers. The concept of responsiveness can offer new controllable guidelines for service development and can help better achieve meeting patients' expectations and strengthening them within the system.

Table 8 Summary of surveys by HSR measurement in different type questionnaires of HSR by WHO

Author/ Published year	Research purpose /Study design	Subjects/Region/ Methods	Results	Limitations
[123]Ugurluoglu, O. and Y. Celik, 2006	To support the perspective of the responsiveness level of Turkish health care system, and satisfies the citizens' expectations.	172 hospital managers; KIS by WHO;	Turkish health care system satisfies Turkish citizens' expectations id better than any other expectations; The financial situation, population structure, culture, and some other regional and country factors should be taken into account by estimating and responsiveness level of the health care systems;	No take into account of culture and values; Focus on dignity, autonomy, and confidentiality.
[122]Bramesfeld, A., et al.,2007	To evaluate responsiveness for inpatient and outpatient mental health care by a standardized questionnaire	221 outpatients and 91 inpatients; Germany; MCSS by WHO.	Inpatient service users' responsiveness is 22% which is more often than outpatients (15%). It was notable for the domains dignity and communication. Best performing: confidentiality and dignity Worst performing: choice, autonomy and basic amenities (only inpatient care). Autonomy was the most important domain, followed by attention and communication. Less money and less well educated people rate the responsiveness within outpatient care. Both higher level educated people and people who were not so well educated rate the inpatient responsiveness. 23% of participants can differentiate mental health care during the past 6 months. The attention expectations and autonomy expectations are not met satisfactorily in inpatient and outpatient care.	Motivation for reform has slowed down in recent years; MCSS of instrument is complicated, and are not good at application.
[121]Hsu, C.-C., et al.,2006	Assessing whether WHO seven dimensions can measure responsiveness are applicable in evaluating the health system.	132 key informants by email; Taiwan ;(The key informants included health professionals, members of civil society groups and academics, among others.)	Five factors (respect, access, confidentiality, basic amenities, and social support) produced by Principal component analysis which explained 63.5% of the total variances. Four of five factors (except social support) were significantly. Health providers' communication ability and medical ethics were also highly appraised by interviewed by focus group.	A globally accepted assessment framework for responsiveness has not been theoretically formulated; Key informant survey may be biased

Author/ Published year	Research purpose /Study design	Subjects/Region/ Methods	Results	Limitations
		KIS by WHO;		by theoretical prejudgment.
[126]Robone, S., [127]N. Rice, and P.C.Smith, 2011	To explore the potential health system responsiveness of country-level drivers.	Information on country-level characteristics from UNDP; World Health Survey(WHS)	After controlling for potential confounding factors, there is positively association between health care expenditures per capital and responsiveness. Aspects of responsiveness Negatively association: public sector spending Positively association: educational development	Across sectional study are difficult to draw strong inferences about causality from this study
[128]Malhotra, C. and Y.K. Do, 2013	To assess the magnitude of socio-economic disparities in health system responsiveness in India	Outpatients by household survey conducted in 2002-04; World Health Survey (WHS)	Individuals from the lowest wealth group, for example, were less likely than individuals from the highest wealth group to report ‘very good’ on the dignity domain by 8% points (10% vs 18%); Stratified analysis showed that such disparities existed among users of both public and private health facilities.	Outpatients; Recall bias; Substantial variation among individual public and private facilities;
[129]Njeru, M.K., et al.,2009	To assess the applicability of the responsiveness tool developed by WHO when applied in the context of voluntary HIV counselling and testing services (VCT) at a district level	VCT counsellors or VCT users; Kenya; HSR questionnaire; Mixing quantitative and qualitative methods; A concurrent nested study	Most users and health providers regards confidentiality and autonomy very important; Confidentiality and autonomy were highly observed in the VCT room; Three aspects, social support, continuity and follow-up, quality of counselling and testing that were not captured by HSR tool of WHO; Striking examples were inappropriate location of the VCT centre, limited information provided, language problems, and concern about the quality of counselling.	To identify potential weaknesses in responsiveness tool; Dimensions could be incorporated in the WHO tool.

3. Rationale

3.1 Knowledge gaps

Health system responsiveness as non-clinical expectation of patients towards providers is seen as a key strategic characteristic in health service systems. HSR needs to contribute to the enhancement of health by creating a favourable environment such as seeking care earlier and openness in interactions with providers, and to the reduction of barriers to utilization of healthcare. Across different social groups, responsiveness measures patient’s experience with the health care system to reflect the health disparities. Patient’s perspective, HSR, has been shown with patient satisfaction correlated with increased compliance, decreased latency to care seeking, and improved understanding and retention of the medical information. However, as a more desirable measure by which health systems can be judged, almost there is short age of studies about HSR reflecting the perception of patients towards service providers to meet the expectation of patients, especially among HIV positive patients in China. With the promising efficacy of antiretroviral therapy, and the policy for all HIV positive patients in China to have free access to them, there is a need to examine the quality of healthcare and whether it meets their expectations.

Despite the progress in treatment and management of HIV infection, the disease remains a concern regarding the issue of inequity due to social stigma and the tendency of the disease to affect marginalized populations. Stigma is not only the HIV positive patient`s perception of being discriminated but also the perception of others, including care providers, towards HIV positive patients. Studies on HIV/AIDS stigma have provided descriptive information about how individual providers think about and serve PLWHA but have not revealed how the prevalence and determinants of stigma and discrimination vary by institutional or social context[57]. Moreover, there is a gap without robust measures of such institutional stigma and the identification of potential levels to affect change. In China, there have been several studies concerning the impact of HIV on social, economic and access to care aspects. However, further studies on the relationship between stigma and responsiveness of the health system and interventions to reduce stigma among healthcare providers are still limited.

3.2 Rationale

Understanding of the magnitude of HIV/AIDS stigma, responsiveness of healthcare systems and how to reduce stigma to improve responsiveness among HIV positive patients, non-HIV patients and healthcare providers is crucial. The results of the patients' perceptions of stigma and healthcare system responsiveness can be used as a feedback to the providers and evaluated providers' performance by time. Furthermore, it could help to reflect healthcare equity between HIV and non-HIV patients of different socio-demographic and economic backgrounds and levels of care. A process to diminish the stigma could lead to elimination of inequitable HSR that HIV patients receive.

4. Research questions

We hypothesize that among the HIV patients the non-clinical responsiveness of the healthcare providers towards them is different across socio-economic groups and disease statuses, that the responsiveness is different between different levels of healthcare and that it is influenced by patients and providers' stigma on HIV/AIDS. We also hypothesize that among the non-HIV patients the non-clinical responsiveness of the healthcare providers towards them is different across socio-economic groups and disease types and that the responsiveness is different between different levels of healthcare. Between HIV and non-HIV patients there is a difference in their perception of the responsiveness of the health service providers towards them. This HSR disparity is believed to be due to the stigma of providers towards the HIV positive people. After healthcare providers know the results of patients' perceived HSR towards them, we hypothesize that the difference of responsiveness and HIV/AIDS stigma between HIV positive and non-HIV patients will change.

The research questions of the study are:

1) What are the levels of perceived HSR among HIV and non-HIV patients in Yunnan, China?

2) What are the levels of HIV/AIDS stigma among HIV patients, non-HIV patients and healthcare providers in Yunnan, China?

3) Is perceived HSR towards healthcare providers among HIV patients equal across different socio-economic and disease statuses in Yunnan?

4) Is there a difference in perceived HSR of healthcare providers between HIV and non-HIV patients?

5) What are factors associated with perceived HSR among HIV and non-HIV patients in Yunnan?

6) Is there an association between patients' HIV/AIDS stigma and perceived HSR among HIV patients and non-HIV patients in Yunnan, China?

7) Is there a change of HIV/AIDS stigma among HIV, non-HIV patients and healthcare providers by time in Yunnan, China?

5. Objectives

5.1 General objectives

In this study, we aim to examine the level of HIV/AIDS stigma among HIV and non-HIV patients and their healthcare providers, to compare the level of perceived HSR between HIV patients and non-HIV patients, to identify predictors of perceived HSR and to measure the change of perceived HSR and HIV/AIDS stigma after providing a feedback of the HIV/AIDS stigma and HSR to the providers. The ultimate goal of the study is to improve the level of HSR to HIV positive patients and reduce disparities of responsiveness between HIV and non-HIV patients and between those with different socio-demographic backgrounds in Yunnan, China.

5.2 Specific objectives

1) To assess the level of perceived HSR among HIV and non-HIV patients;
2) To compare scores of expectation of HSR between HIV and non-HIV patients across different socio-economic statuses;
3) To compare proportions of experience of HSR between HIV and non-HIV patients across different socio-economic statuses;

4) To determine factors associated with perceived experience of HSR in consideration of expectation among HIV and non-HIV patients separately;
5) To explore the change of perceived HSR among HIV and non-HIV patients by time;
6) To assess the magnitude of HIV/AIDS stigma among HIV, non-HIV patients and healthcare providers;
7) To explore the latent factors of HIV/AIDS stigma among HIV, non-HIV patients and healthcare providers;
8) To explore the change of HIV/AIDS stigma among HIV, non-HIV patients and healthcare providers by time;
9) To determine the association between patients' HIV/AIDS stigma and perceived HSR among HIV patients and non-HIV patients.

CHAPTER 2

RESEARCH METHODOLOGY

1. Conceptual Framework

A mixed quantitative and qualitative study was carried out from 1st January to 15th September 2015. A series of two repeated cross-sectional quantitative surveys were conducted to measure the baseline stigma and HSR and examine the changes of these variables at two points in time, among HIV, non-HIV patients and their healthcare providers. A focus group discussion was used in the first round to validate HSR questionnaires and HIV/AIDS scales with some of these patients and providers to refine the Chinese version of HIV/AIDS stigma and perceived HSR as well as to elaborate the quantitative findings. An in-depth interview was also conducted among HIV positive patients to further explore the reasons of their perceived experience of HSR so as to improve quality of HIV care.

Quality of healthcare included two aspects: clinical and non-clinical aspects. HSR is the main aspect to predict non-clinic aspects of quality of healthcare from eight domains: dignity, prompt attention, communication, quality of basic amenities, confidentiality, choice of provider, social support and autonomy. Due to heavy HIV/AIDS stigma among HIV patients, HIV/AIDS stigma with demographic and socio-economic status as factors may impact quality of healthcare. HIV/AIDS stigma is also as another important aspect which may influence HSR. In summary, HSR and HIV/AIDS stigma as two significant components impact quality of care whereas HIV/AIDS stigma may influence HSR independently. Figure 5 presents the conceptual framework of this study.

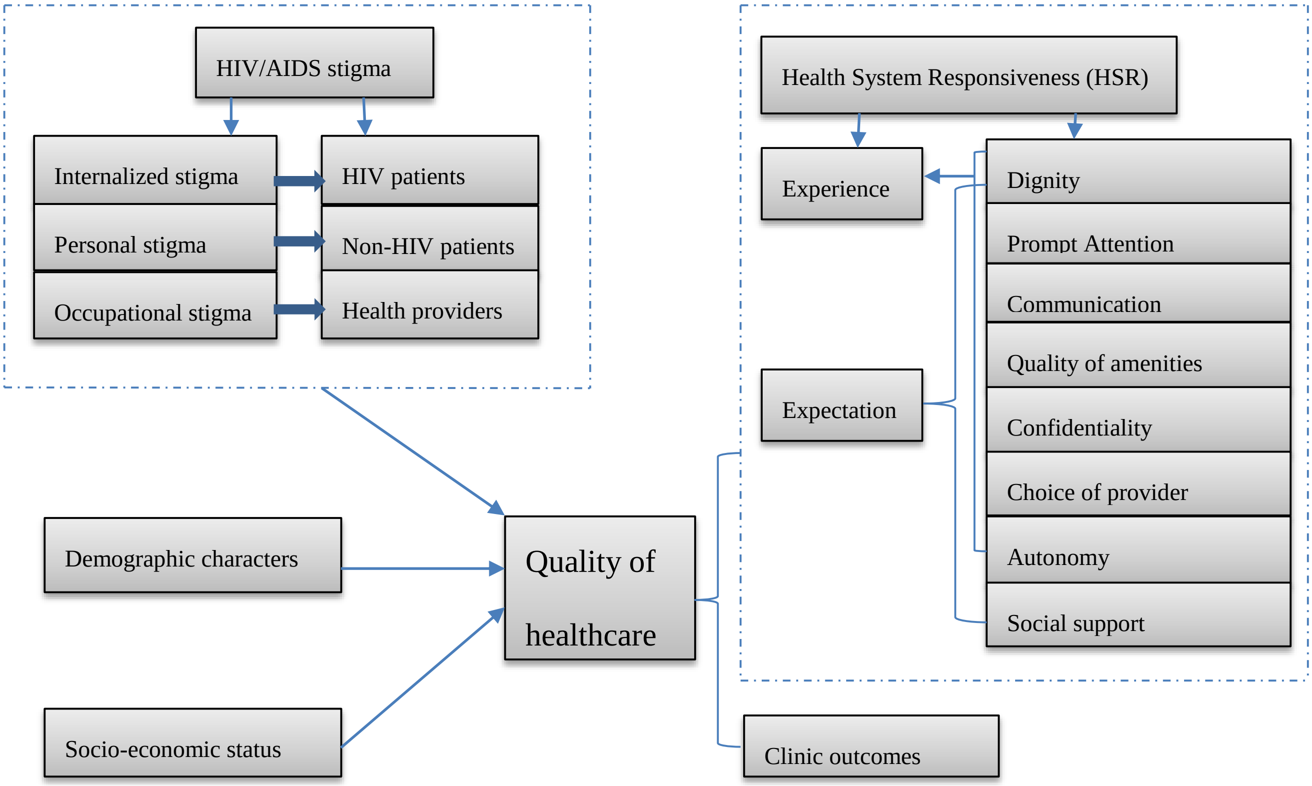


Figure 5 Conceptual framework of our study

2. Methodology

A mixed quantitative and qualitative study was carried out from 1st January to 15th September 2015. A series of two repeated cross-sectional quantitative surveys were conducted to measure the baseline stigma and HSR and examine the changes of these variables at two points in time, among HIV, non-HIV patients and their healthcare providers. A focus group discussion was used in the first round to validate HSR questionnaires and HIV/AIDS scales with some of these patients and providers to refine the Chinese version of the HIV/AIDS stigma and perceived HSR scales as well as to elaborate the quantitative findings. An in-depth interview was also conducted among HIV positive patients to further explore the reasons of their perceived experience of HSR so as to improve quality of HIV care. Figure 6 presents flow process of the study.

2.1 Quantitative study

2.1.1 Study setting

The study was conducted in the infectious departments of two large hospitals: a special infectious hospital and a general hospital in Kunming, the capital city of Yunnan Province, China. The two hospitals have the largest admissions of HIV positive and non-HIV patients in Yunnan. One hospital is located in the North-west of Kunming and the other is in the prefecture level that is located in the South-east. Both of the infectious departments of two hospitals are the only hospitals that admit HIV and non-HIV patients simultaneously.

2.1.2 Study subjects

All HIV and non-HIV patients aged 15 years or more attending the study hospitals were screened for eligibility. Patients with tuberculosis were excluded to avoid confusion from tuberculosis stigma and also as they received different services from non-HIV healthcare. The majority of non-HIV infectious patients suffer from hepatitis. Those who could not communicate in Chinese or were too ill to be interviewed were also excluded. Consecutive sampling was used to recruit study subjects. All staff attending HIV and non-HIV clinics of the study hospitals were also recruited. The same questionnaires were applied. Any subject who was involved in the development sample was excluded from the validation sample.

2.1.3 Study sample and sampling methods

HIV patients attending the study hospitals from 1st January to 15th February in 2015 in the first survey were recruited. Non-HIV patients who attended the same hospital at the same period were also recruited. The feedback (to be explained in section 2.1.6) was given in the two study hospitals at different time, the first time in the first selected hospital from 28th June to 19th July, 2015, and the second time in the other hospital from 10th to 29th August, 2015. The second survey was carried out after the feedback separately from 20th July to 9th August and from 30th August to 15th September, 2015. Healthcare staff of the study hospitals was included in the study in the first and second surveys.

Figure 6 shows the flow process of a series of repeated studies. This study totally was divided into three phrases. The first phrase was mainly development of HSR questionnaires and HIV/AIDS stigma scales before data collection. The second phase was data collection for two rounds. After data collection of the first survey, the results were also given feedback to healthcare providers in target hospitals one by one. When finished feedback in one hospital, half of data collection in the second survey was conducted in both hospitals. Similarly, another half of data collection was carried out after the second feedback to the second hospital.

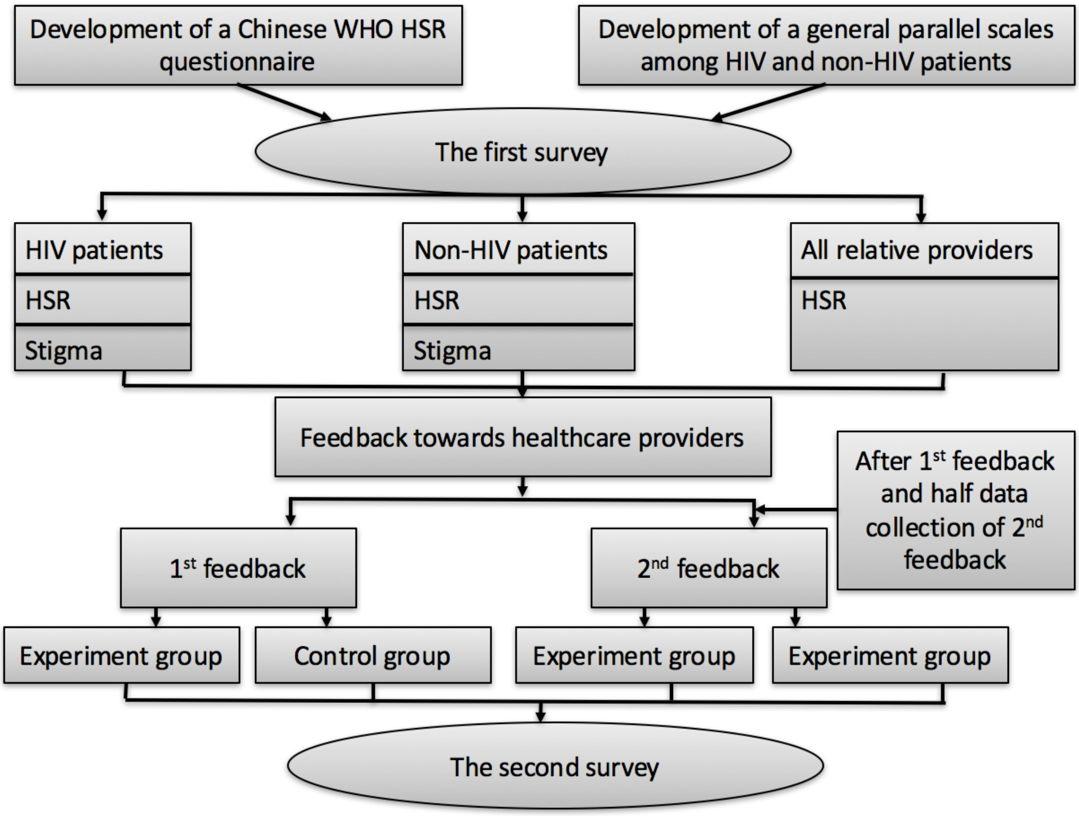


Figure 6 Flow process of a series of repeated studies

2.1.4 Sample size

Calculation of sample size for estimating the proportion of HIV patients who rate the health system responsiveness as good with a given precision.

The formula is given by:

$$n = \frac{Z_{\frac{\alpha}{2}}^{2} p(1-p)}{d^{2}}$$

α=Type I error (0.05)

p= Expected proportion of study outcome

d=Precision (±0.1 or ±0.05, see Table 9)

According to a previous study[41]: the proportion of HIV positive patients who rated each domain of HSR as good is shown in Table 9.

Table 9 Estimated proportions for calculation of sample size among PLWHAs

Indicator	Populations	Promptness	Communication	Confidentiality	Quality of facilities
Percentage of responsiveness	p_1=HIV patients	0.46	0.67	0.70	0.94
Required precision		0.1	0.1	0.1	0.05
Total number		96	85	93	87

From the above table, the highest sample size needed is 96. The suggested sample size is 107 among HIV patients after the compensation for 10% non-response.

Calculation of sample size for estimating means of HIV/AIDS stigma in HIV and non-HIV patient groups with a given precision.

Scores of the parallel HIV/AIDS stigma scales[25] measured in our pilot study were used as an indicator of the level of HIV/AIDS stigma among HIV and non-HIV patients. The full range of stigma scores are 4-68.

$$n = \left(\frac{\sigma Z_{\frac{\alpha}{2}}}{d}\right)^2$$

α=Type I error (0.05)

σ = Standard deviation from pilot study outcome

d = Maximum tolerated error (1.0)

Sample sizes based on mean scores of HIV/AIDS stigma scales among HIV+ patients and non-HIV patients are listed below:

Table 10 Estimated means for calculation of sample sizes in HIV and non-HIV groups

Score of internalized stigma among HIV+ patients			Score of personal stigma among non-HIV patients		
mean	sd	n	mean	sd	n
44.6	8.0	246	41.3	5.8	130

The required sample sizes are at least 246 for the HIV patients and 130 for the non-HIV patients or 274 and 145 after compensation for 10% non-response.

Calculation of sample size to compare the proportions of patients who rated the HSR as good between HIV patients and non-HIV patients with a given power.

Based on our pilot study, the percentages of patients who rated communication domain as “good” among HIV and non-HIV patients were 50.8% and 59.1%, respectively. With these parameters, the number of subjects required to detect this difference of 8% in the proportion of rating communication as “good” between the two groups, with 95% confidence and 80% power, would be 587 per group.

$$n = \frac{(Z\alpha/_2\sqrt{2p(1-p)} + Z_\beta\sqrt{p_1(1-p_1)+p_2(1-p_2)})^2}{(p_1-p_2)^2}$$

$$p = \frac{(p_1+p_2)}{2}$$

α=Type I error (0.05)

Z_β: Type II -error (not more than 20%)

p_1: Proportion of outcome in HIV patients who rated the HSR as good

$p = (p_1 + p_2)/2$

p_2: Proportion of outcome non-HIV patients who rated the HSR as good

To compensate for an estimated 10% incomplete response rate, 653 were required in each group.

Calculation of sample size for the change in HIV/AIDS stigma by time with a given power.

We hypothesized that the mean scores of HIV/AIDS stigma scale among HIV, non-HIV patients and healthcare providers would change by time. Meanwhile, the two samples are totally composed of different patients. Then, we hypothesized that at least one item of HIV/AIDS stigma scale would change over time. Finally, mean scores of the sample in the second round compared to the first round among HIV patients would be reduced to 2, and sd. is 8.0. Accordingly, among non-HIV patients with mean scores of personal stigma would be reduced to 2, and sd. is 5.8.

$$n = \frac{2\sigma^2(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta})^2[\sigma_1^2 + \frac{\sigma_2^2}{r}]}{(\mu_1-\mu_2)^2}$$

$Z_{\frac{\alpha}{2}}$=standard normal deviate (1.96)

Z_β =Type II error (not more than 20%) (0.84, if power=80%, β=0.2)

σ_1= Standard deviation of HIV/AIDS stigma scale in the first round

σ_2= Standard deviation of HIV/AIDS stigma scale in the second round

μ_1 =mean of HIV/AIDS stigma scale in the first round

μ_2 = mean of HIV/AIDS stigma scale in the second round. $(\mu_1 - \mu_2 = 2)$

r = n_2/n_1 = 1

Table 11 Hypothesis testing for means to calculate sample size among two groups

	Score of internalized stigma among HIV+ patients			Score of personal stigma among non-HIV patients		
	mean	Sd.	n	mean	Sd.	n
The first round	44.6	8.0	252	41.3	5.8	133
The second round	42.6	8.0	252	39.3	5.8	133

To compensate for an incomplete follow up rate of 10%, a sample size of 280 is needed for the HIV group and 148 for the non-HIV and provider groups**.**

Calculation of sample size for identification of the associated factors for HSR among HIV patients

No standard method could be found for calculation of sample size consist with censored order probit regression.

Calculation of sample size for development of HIV/AIDS stigma scales in HIV, non-HIV patient and healthcare providers groups

The required sample size needed for exploratory factor analysis (EFA) is usually 5-10 times the number of questionnaire items[31]. Initially, each of the three scales contained 17 items. A sample size of about 85 to 170 HIV and non-HIV patients per group was determined to be sufficient. For confirmatory factor analysis (CFA), the recommended sample size required is 15-20 times the number of questionnaire items[31] 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.

Overall, 653 individuals were enrolled per group of HIV and non-HIV patients in each hospital. All healthcare providers working in the infectious departments of the study hospitals were recruited.

2.1.5 Development and modification of research instruments

There are two parts of research instruments: HSR questionnaire and HIV/AIDS stigma scales. The HSR part of the WHO Health Responsiveness Survey with anchoring vignettes was developed in Chinese under the study`s cultural context. HIV/AIDS stigma scales were constructed based on our understanding of HIV/AIDS framework of HIV/AIDS stigma.

Measurement of HSR was divided into two parts, the first one measured the perceived experience using self-rated items on seven domains: prompt attention, dignity, communication, quality of amenities, confidentiality, choice of provider and autonomy. The second part measured expectations of HSR using anchoring vignettes among eight domains; five vignettes per domain. Anchoring vignettes have an extra domain of social support. Figure 7 presents the flow process of development and modification of HSR.

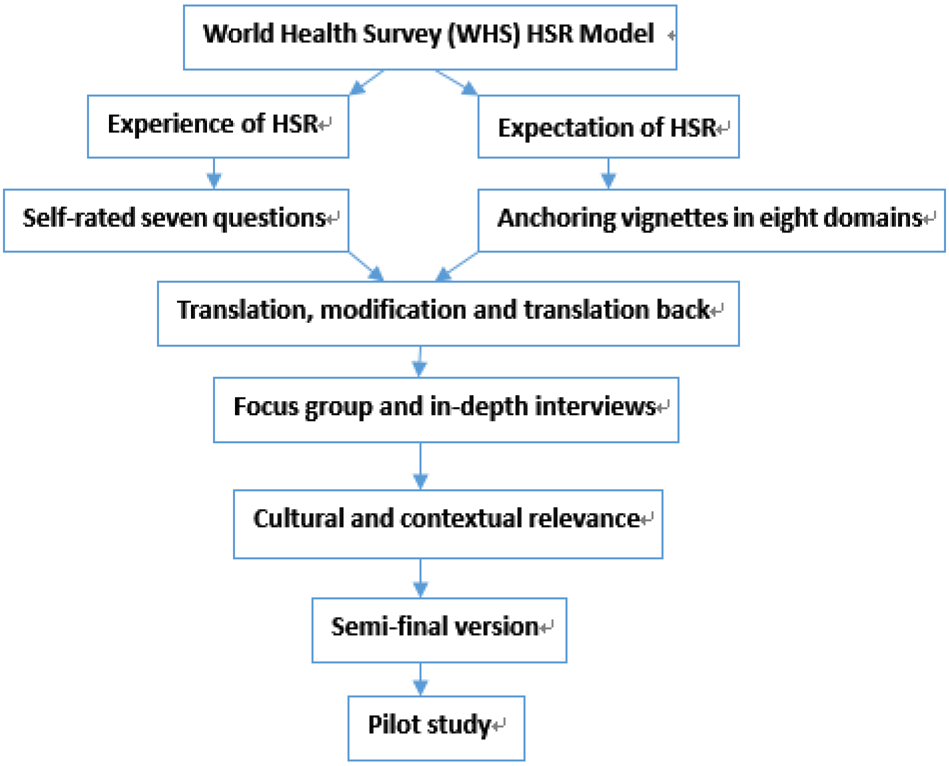
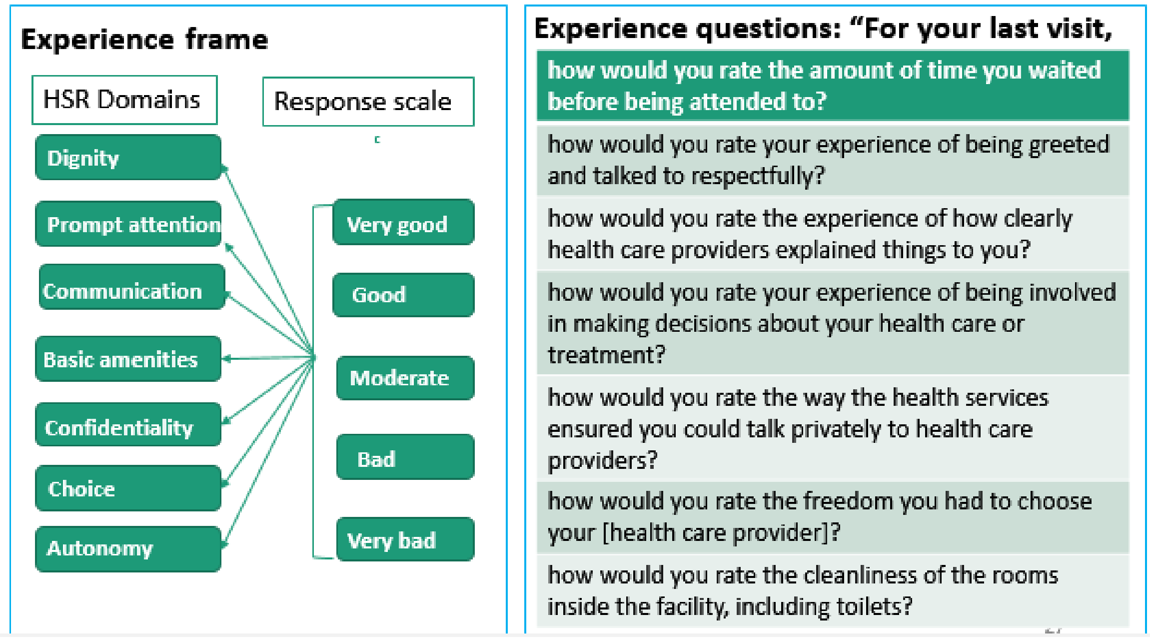


Figure 7 Flow process of development and modification of HSR

Development and modification of experience of HSR

Figure 8 presents the framework of experience of HSR in seven domains, and also gives the seven questions, together with the questions asked. A rating scale of 1 to 5, representing "very good" to "very bad", was used for each question.

The self-rated questions were translated into Chinese and modified by the main researcher to suit the Chinese context. An English-Chinese group translated them back into English for validating the translation.



Experience questions: "For your last visit,

how would you rate the amount of time you waited before being attended to?

how would you rate your experience of being greeted and talked to respectfully?

how would you rate the experience of how clearly health care providers explained things to you?

how would you rate your experience of being involved in making decisions about your health care or treatment?

how would you rate the way the health services ensured you could talk privately to health care providers?

how would you rate the freedom you had to choose your [health care provider]?

how would you rate the cleanliness of the rooms inside the facility, including toilets?

Figure 8 Framework of experience of HSR

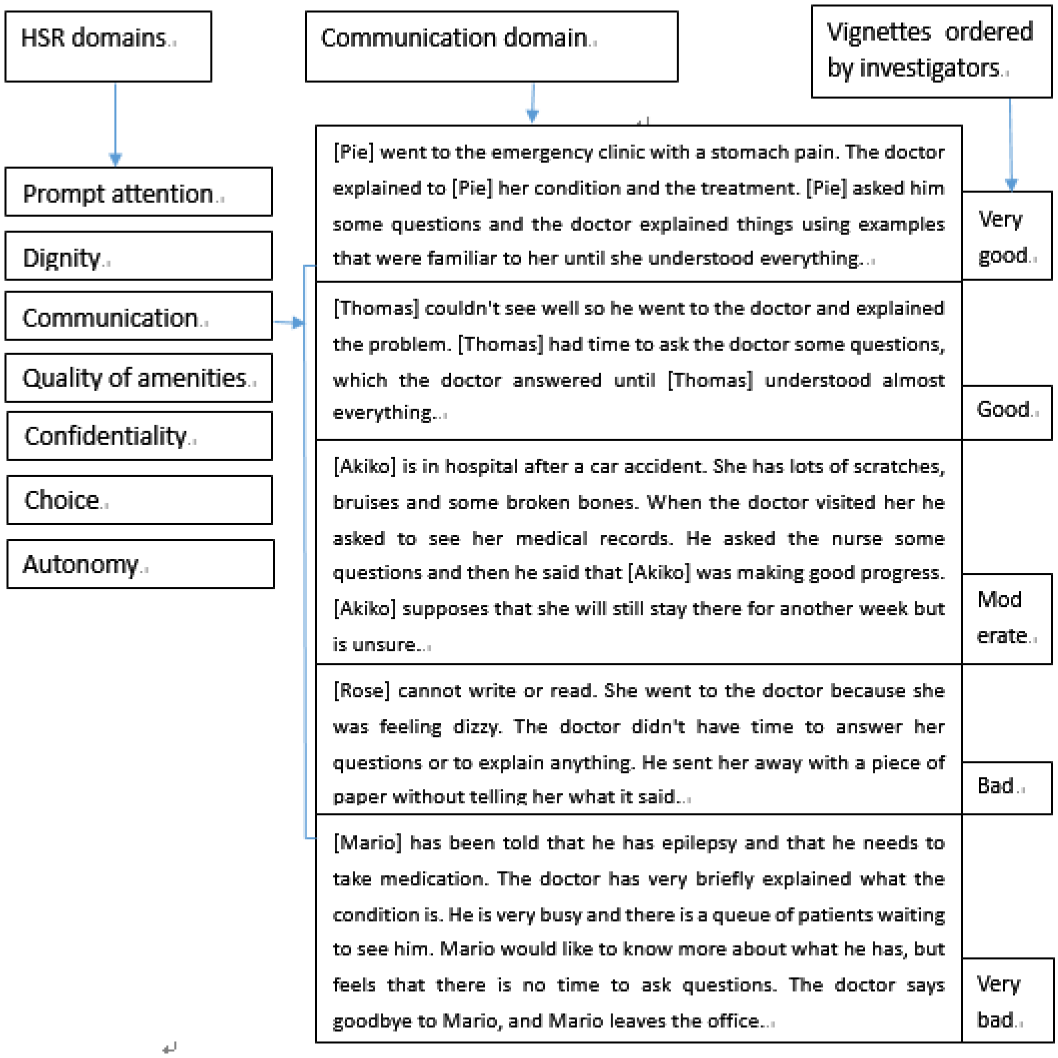
Development and modification of vignettes

The vignettes were developed using a standardized protocol from the World Health Survey responsiveness module (short version), Set A to Set D. Domains in these vignettes included: Set A - respective treatment and prompt attention, Set B - clear communication and quality of basic amenities, Set C - confidentiality and choice of care provider, and Set D - social support to patient and autonomy. Each set includes ten vignettes, five for each domain. Each vignette simulates patient visits and healthcare provider’s responsiveness to the patient in the relative domain. In each set, ten vignettes of the two domains were mixed in random order. A rating scale of 1 to 5, representing "very good" to "very bad", was used for each question.

The vignettes were translated into Chinese and modified by the main researcher to suit the Chinese context. A team of healthcare experts including two chief physicians of infectious departments of the two hospitals, and an expert of HIV/AIDS prevention in the Centre for Disease Control of Yunnan Province, reviewed the Chinese version of the vignettes. A bilingual (English-Chinese) group translated them back into English for validation. To check appropriateness of the vignettes, a focus group discussion consisting of ten non-HIV patients was assembled, and in-depth interviews were conducted with five HIV patients to obtain cultural and contextual relevance. The respondents were asked to determine whether each question was understandable and the message was accurately conveyed. They were also asked to elaborate on the reasons why a particular response category was chosen for a question.

Figure 9 shows the framework of HSR in seven domains, and also gives an example domain of communication including five vignettes on behalf of scales from “very good” to “very bad”.

The semi-final version of the vignettes were achieved in November 2014. In December of 2014, a pilot study was conducted among 45 HIV and non-HIV patients in both hospitals. It took 60 to 70 minutes for a patient to complete the questionnaire. The finalized instrument was then shortened to between 40 to 60 minutes duration.



[Pie] went to the emergency clinic with a stomach pain. The doctor explained to [Pie] her condition and the treatment. [Pie] asked him some questions and the doctor explained things using examples that were familiar to her until she understood everything.

[Thomas] couldn't see well so he went to the doctor and explained the problem. [Thomas] had time to ask the doctor some questions, which the doctor answered until [Thomas] understood almost everything.

[Akiko] is in hospital after a car accident. She has lots of scratches, bruises and some broken bones. When the doctor visited her he asked to see her medical records. He asked the nurse some questions and then he said that [Akiko] was making good progress. [Akiko] supposes that she will still stay there for another week but is unsure.

[Rose] cannot write or read. She went to the doctor because she was feeling dizzy. The doctor didn't have time to answer her questions or to explain anything. He sent her away with a piece of paper without telling her what it said.

[Mario] has been told that he has epilepsy and that he needs to take medication. The doctor has very briefly explained what the condition is. He is very busy and there is a queue of patients waiting to see him. Mario would like to know more about what he has, but feels that there is no time to ask questions. The doctor says goodbye to Mario, and Mario leaves the office.

Figure 9 Framework of HSR, vignettes example of communication domain, and vignettes ordering

Development and modification of HIV/AIDS stigma

Framework, samples and scales of HIV/AIDS stigma

Our understanding of HIV/AIDS stigma framework in hospital settings stems from previous studies [14,25,30]. Valerie A et al[14] developed the conceptual framework for HIV stigma mechanisms from HIV infected and non-HIV people. Maratha J et al[25] developed a parallel scale among HIV infected and non-HIV people while Judith A et al[30] developed a multidimensional scale of HIV-related stigma among

Chinese service providers. Figure 10 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 healthcare providers using a separate scale.

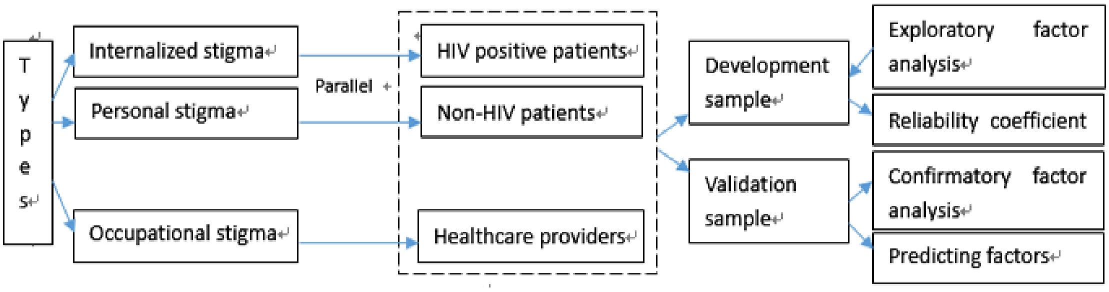


Figure 10 **Conceptual framework of the study**

The development sample of HIV patients, non-HIV patients and healthcare providers in the first survey came from the data in the first survey by exploratory factor analysis (EFA) to identify the underlying stigma constructs. Validation sample of the three groups derived from the second survey of subjects by confirmatory factor analysis (CFA) based on the model developed from the first part.

Internalized stigma and personal stigma scales developed by Maratha J[25] 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 three scales were modified by the main researcher to suit the local hospital context. A team of healthcare 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 questions and 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. A total of 17 parallel items were framed as two positive and 15 negative statements. Responses were rated on a scale of 1 to 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[30] completed by service providers also consisted of 17 items with the similar 1 to 4 rating scale reflecting the level of prejudicial attitudes. These items are listed in Tables 24 and 25.

Analysis of stigma scales for reliability and validity

Comparisons of mean scores for each item among the three scales were done using t-tests and two-way analysis of variance was used to compare items adjusting for the type of sample (development and validation).

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[130]. Scree plots were used to identify the optimum number of factors. Items that had a factor loading of > 0.4 and did not load on multiple factors were considered part of a factor. Items that did not have a factor loading of 0.4 or greater or items that had a factor loading of > 0.4 on multiple factors 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 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)[131].

Finally, univariate analyses were performed separately for each factor of HIV/AIDS stigma after EFA and CFA to assess their independent association with demographic and socio-economic variables. Variables having a *P* value of less than 0.05 were considered as significant. All analyses were performed using R language and environment[132].

2.1.6 Recruitment and training

The team of interviewers consisted of the main research investigators, HIV/AIDS specialists and local medical students. Prior to data collection, all interviewers were given training based on concepts of HSR, dimensionality of each domain, meaning of each vignette, concepts of HIV/AIDS stigma, difference of types of HIV/AIDS stigma, common symptoms of HIV/AIDS, psychological supports and investigation skills and protocol for emergency situations.

2.1.7 Feedback

Results of the first survey was given to the healthcare providers prior to the second survey. Based on the diffusion of innovation (DOI) theory[133], a subset of providers who are popular opinion leaders was selected. These individuals were asked to transfer messages derived from the first survey to their peers during their work together. This is considered better in sustaining advocacy activities and building cultural context-specific strategies rather than traditional training each service provider in the hospitals. The DOI model has successfully been used towards service providers in the United States[134,135].

Feedback settings

The two hospitals were randomly assigned into feedback and control groups after the first survey. The second survey was done immediately after the feedback activity, the results of which were used as a material for the second feedback activity. The two hospitals were switched to receive or not receive feedback for the activity.

The feedback activity totally lasted three weeks. The feedback activity was carried out in the first randomly selected hospital from 28th June to 19th July, 2015, while the second feedback was carried out in the second hospital from 10th to 29th August, 2015.

Steps of feedback

Identification of potential popular opinion leaders

We targeted totally 15 popular opinion leaders from the hospital, which covered about 10% of all the providers. The leaders were department directors and charge nurses who are trusted by their co-workers and are willing to make an effort to improve the service quality.

Training of popular opinion leaders

The leaders attended half day training sessions, which were held in a conference room where they affiliate. The participants were seated in a circle, and results including HIV and non-HIV patients' perceived HSR and HIV/AIDS stigma among HIV, non-HIV and healthcare providers were given to them. The training covered activities such as discussion, games and role playing to encourage the trainees' full participation and refine their communication skills so that they can comfortably deliver messages. Discriminatory language and behaviours, especially in medical settings, was avoided.

Dissemination of feedback messages from popular opinion leaders to peer providers

To ensure broad message diffusion, the leaders were encouraged to talk to their co-workers, not only within the same department, but also from other departments. They were asked details about who they communicated with, under what circumstances, the contents of the conversation, challenges encountered and possible solutions. Investigators also asked for the related contents of results to peer providers, recorded the knowledge of each providers and diffused these messages to them if they did not know.

2.1.8 Variables and measurements

Independent variables

Dependent variables included perceived experience of HSR among patients, expectation of HSR among patients, internalized stigma among HIV patients, personal stigma of non-HIV patients and occupational stigma among healthcare providers.

The total expectation scores for HSR in the eight domains were measured by five vignettes per domain among patients. All five responses were summed to obtain a total score for each domain, with a possible range of 5 to 25, where higher scores indicate higher expectation towards that domain.

HIV/AIDS stigma is the second study outcome. The total scores of internalized stigma among HIV patients, personal stigma of non-HIV patients and occupational stigma among healthcare providers were measured by the parallel scales and occupational stigma scale (Tables 23 and 24). All four responses were summed to obtain a total score for each HIV/AIDS stigma, with a possible range of 17 to 68, where higher scores indicate higher stigma towards HIV patients.

Dependent variables

Demographic variables, measured by a self-reported questionnaire, included age, gender, ethnicity, religion, place of residence, marital status, family size, education, occupation, and household income. For comparability with other studies, age was grouped into three categories: (i) 40 years old or less (young adults); (ii) 41 to 60 years old (middle-aged); (iii) more than 60 years old (elderly). The nine ethnic groups were classified into two categories: Han and other ethnicity. Place of residence was classified as either rural or urban based on their insurance type. Family size was grouped into 3 categories: (i) single; (ii) 2-4; (iii) 5 or more family members. SES factors included education, occupation, and household income per month. Education was grouped into four levels: (i) primary school or less; (ii) junior high school; (iii) senior high school, and (iv) university or more. Occupation was grouped into four categories: (i) government-employed; (ii) enterprise-employed; (iii) self-employed; (iv) unemployed. Household income was categorized into five levels according to distribution of household income by place of residence in China[136]: (i) 800RMB or less; (ii) 801～2000RMB; (iii)2001～5000RMB; (iv) 5001～8000RMB; (v) 8001RMB or more.

Access to HIV care were measured using six items for access to care, one item for regular source of HIV care and another one for ART adherence among HIV patients. Access to care among the non-HIV patients were measured using six items for access to care, one item for hepatitis care and another for medication compliance respectively.

The medical records of the HIV patients were reviewed and additional information was asked from the patients to capture some information about HIV care and disease status, including ART adherence, CD_4 cell count, viral load, stage of HIV/AIDS, route of transmission of HIV/AIDS and number of follow-up visits.

2.1.9 Data collection

Data collection of the first round was conducted among HIV, non-HIV patients and healthcare providers from 1st January to 15th February 2015. After the first feedback, the second data collection was conducted among these three groups from 20th July to 9th August 2015, while the another part of second data collection was carried out during the period from 30th to 15th September, 2015 after the second feedback.

Eligible patients were interviewed face-to-face using an individual questionnaire, while information from healthcare providers was obtained using a self-administered questionnaire. Experiences of HSR were self-reported, whereas vignettes were read by the investigators among HIV and non-HIV patients. HIV/AIDS stigma scales, and demographic and socio-economic questionnaires were applied among HIV, non-HIV patients and healthcare providers. The instrument used in the second surveys was the same as the one used in the first survey.

Because the whole instruments take about 60-70 minutes each patient, those who already took part in the investigation would not like to answer them for the second time. Thus, the two round surveys consisted of different patients. The relevant clinical characteristics of the patients were collected from the clinical records. Each subject was given a gift valued at 20 RMB.

2.1.10 Data management

A database with suitable edit checks and validation was developed using EpiData 3.1. Double entry for structure questionnaires was performed. Integrity and validity of data was checked on day of survey.

2.1.11 Data analysis

Comparison of sample characteristics between HIV positive and non-HIV patients was performed using Chi-square goodness-of-fit tests for categorical variables, and t-tests for continuous variables. All analyses were performed using R language and environment[137].

Scores of eight domains as outcome variables

Comparisons of mean scores for the eight domains were done using t-tests or analysis of variance as appropriate. Multiple linear regression models were conducted separately for each domain to assess their independent association with demographic variables and socio-economic factors. Variables having a p-value less than 0.05 were considered as significant.

Percentages of experience and expectation of HSR in seven domains as outcome variables

B-scale computation

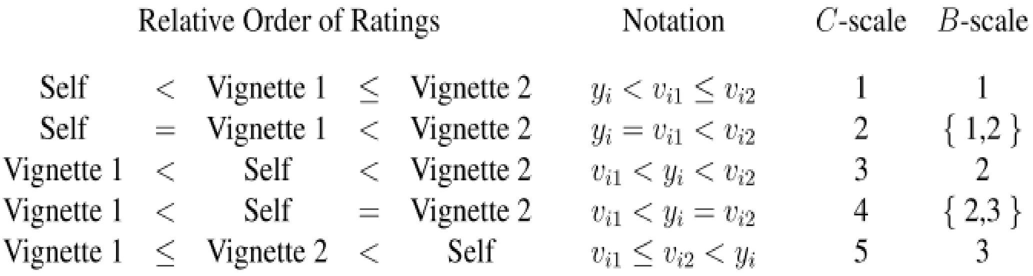
One approach was used to calculate the proportions of HSR: setting the scale of self-assessments relative to vignettes in a non-parametric setting**.**

Let y_i be the self-assessment HSR and $z_{i1}, \ldots, z_{iJ}$ be the J vignette HSR, for the ith respondent. For respondents with consistently ordered rankings on all vignettes ($z_{j-1} < z_j$, for $j = 2, \ldots, J$), we create the Difference Items Function (DIF)-corrected self-assessment Ci:

$$
\mathrm{C}_i = \begin{cases} 1 & \text{if } yi < zi1 \\ 2 & \text{if } yi = zi1 \\ 3 & \text{if } zi1 < y < zi2 \\ \vdots & \\ 2J+1 & \text{if } yi > zij \end{cases}
$$

Values of C that are intervals represent the set of inequalities. Under two assumptions of response consistency and vignette equivalence, C-scale is used to ensure credible comparisons[138].

Based on the same method as the C-scale, the B-scale is built. The difference between the values of them lies in information that exist when a self-rating is tied with the rating of an anchoring object, $y_i = v_{ij}$. The C-scale makes strict comparisons with adjacent rank orderings in such cases. The B-scale states less information in the occurrence of a tie, represented as a set of B-scale values rather than a single index value[139]. If $y_i = v_{i1}$, then $\mathrm{B_i} = \{1, 2\}$, if $y_i = v_{i2}$, then $\mathrm{B_i} = \{2, 3\}$ (Figure 11). The advantage of B-scale is that it does not rely on cut point locations, and as a result provides credible comparisons without the requirement of interval equivalence or vignette equivalence.



Relative Order of Ratings					Notation	C-scale	B-scale
Self	<	Vignette 1	≤	Vignette 2	$y_i < v_{i1} \leq v_{i2}$	1	1
Self	=	Vignette 1	<	Vignette 2	$y_i = v_{i1} < v_{i2}$	2	{ 1,2 }
Vignette 1	<	Self	<	Vignette 2	$v_{i1} < y_i < v_{i2}$	3	2
Vignette 1	<	Self	=	Vignette 2	$v_{i1} < y_i = v_{i2}$	4	{ 2,3 }
Vignette 1	≤	Vignette 2	<	Self	$v_{i1} \leq v_{i2} < y_i$	5	3

Figure 11 correspondent values of C-scale and B-scale

Vignette ordering

The ordering of the vignettes is needed to fix before construction of B-scale. It is normally chosen by the researchers, and also possible to draw upon a consensus ordering by the respondents, so long as only one ordering is used for all respondents for the analysis. However, differences between hypothesized ordering by the researchers and the consensus ordering may be used for diagnosing problems in the survey instruments, particularly when translating the questions for use in different languages. Thus, we confirmed the vignette ordering for construction of B-scale and censored ordered probit regression models.

Ordered probit and censored ordered probit regression

Figure 12 shows the subsequent analysis of experience and HSR vignettes. After vignette ordering (Figure 8), distributions of experience and B-scales of HSR was described, and ordered probit regression models (OPR) and censored ordered probit regression models (COPR) were conducted. OPR models were constructed separately for each domain to compare differences of self-reported experience of HSR between HIV and non-HIV patients before and after adjustment of demographic and socio-economic factors. COPR models were used to compare B-scale values of HSR before and after adjustment of demographic and socio-economic factors.

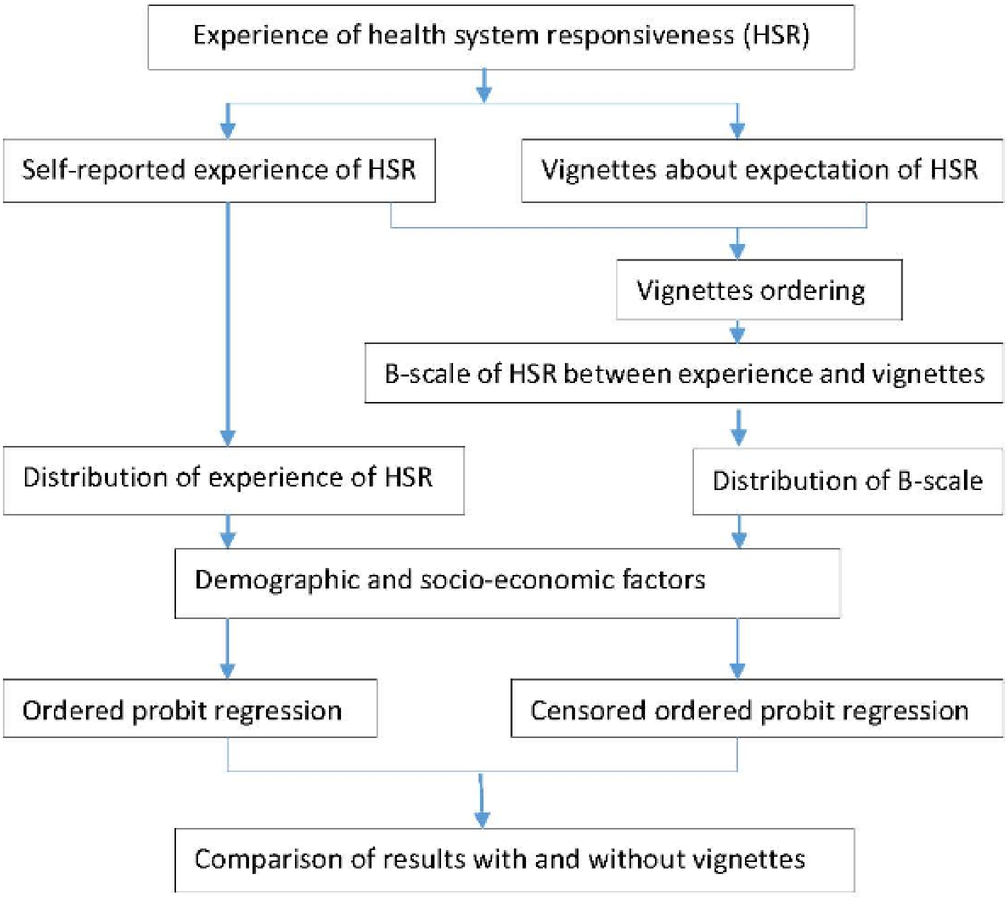


Figure 12 Framework of measurement and analysis about HSR experience and vignettes

HIV/AIDS stigma scores

Comparisons of mean scores for three kinds of HIV/AIDS stigma were done using t-tests or analysis of variance as appropriate. Multiple linear regression models were conducted separately for each HIV/AIDS stigma to assess their independent association with demographic variables and socio-economic factors. Variables having a p-value less than 0.05 were considered as significant.

Changes of perceived experience, expectation of HSR and HIV/AIDS stigma

Comparisons of mean scores for expectation of HSR and HIV/AIDS stigma were done using t-tests or analysis of variance as appropriate, while comparisons of proportions for perceived experience of HSR were conducted by Chi-square goodness-of-fit tests. Variables having a p-value less than 0.05 were considered as significant.

2.1.12 Quality assurance

Pre-interview, a two-day training course was arranged for interviewers. The course facilitated interviewer understanding exactly the objective of survey, the meaning of each item, the procedure of interview, as well as some interview skills.

Agreement of participation was acquired from Kunming Medical University. Enough time and comfortable environment was ensured to conduct interview. Appropriate introduction was needed to help guardian respond to each item objectively, and confidentiality was assured to all participants.

Post-interview, integrity and validity checking was done immediately. Coding of items was completed in the field.

2.2 Qualitative study

2.2.1 Study setting, design and sample size

The qualitative study was performed during the same period as the quantitative study. A saturation sampling method was used to recruit HIV patients to attend individual-based in-depth interviews after they completed questionnaires. A total of 21 HIV patients participated in the interviews, which was based on HSR theory framework. This simplified approach helps us to deeply analyse and understand HSR systematically. It consists of three elements: perception of living with HIV/AIDS, perception of experiences of HSR, and accessibility to HIV care.

2.2.2 Data analysis

Qualitative content analysis was conducted following the steps given by Mayring [140] and recommendations of Schreier[141]. All data were transcribed verbatim and translated into English by the principle investigator. Transcripts were read and checked against the contents to confirm or correct errors. Contents were then reduced to the main ideas based on explicit definitions and coding rules for each deductive category. Those category definitions were put together within a coding agenda. Finally, results were subsequently anonymized and inserted by impressions from observations and field notes. Ethnography v6 was used data organization, condensation and analysis.

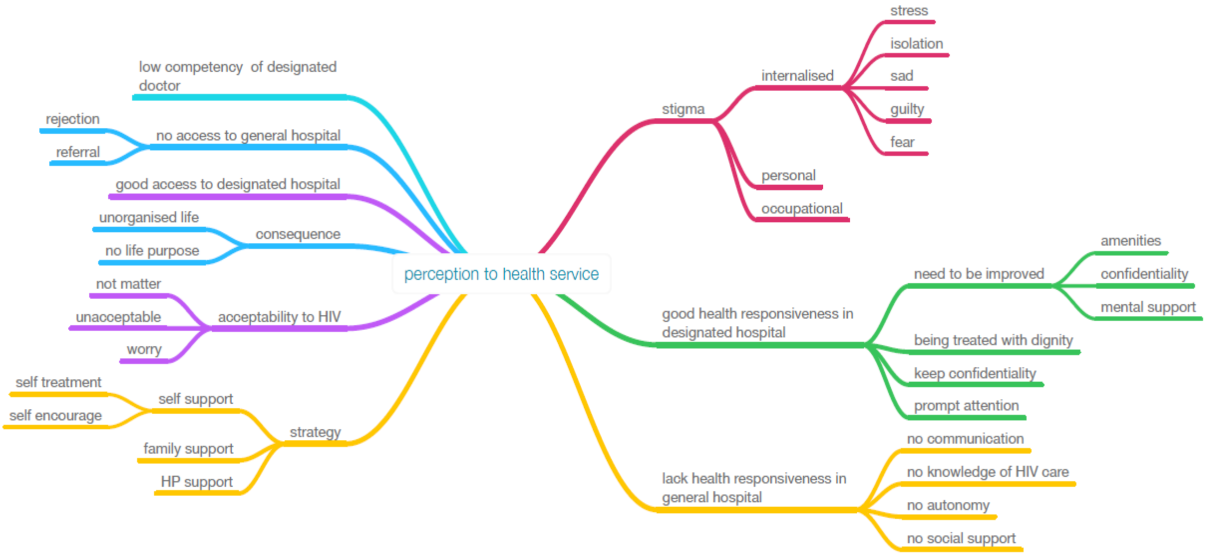


Figure 13 Framework of perception to healthcare service among HIV positive patients

Figure 13 presents the framework of perception to healthcare service among HIV positive patients, including HIV/AIDS stigma, health system responsiveness among designated and general hospitals, accessibility to HIV care and strategies to copy with HIV status.

3. Ethical considerations

The ethical aspects of this study were approved by Prince Songkla University Institutional Review Board and Kunming Medical University. Anonymity of the data was assured and the participants were requested to give their consent to participate in the survey by signing an informed consent form, after providing them with detailed information on the survey procedures

CHAPTER 3

RESULTS

1. Quantitative study

1.1 Sample characteristics

The first round data were used as the development sample. While the data in the second survey were used as the validation sample. In the first survey, two consecutive groups containing 696 HIV and 699 non-HIV patients were included in the first round survey. The response rate was 87% and 66% among HIV and non-HIV patients, respectively. 157 and 155 health providers were also included in the development and validation samples, respectively.

1.1.1 Distribution of socio-demographic variables among HIV and non-HIV patients in the first and second surveys

Table 12 shows the distribution of demographic and socio-economic variables among HIV and non-HIV patients in the first and second survey. In the first survey, the majority of patients were 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 and had a monthly household income of 5000 RMB or less and living in a family of size 2-4 members. Both groups were closely matched on gender; however, 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. In the second survey, comparison of the two groups was similar to the first survey. Age, gender and ethnic group were closely matched among HIV and non-HIV patients.

For the two samples of the first and second surveys, 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 5000 RMB or less and were living in a family with 2-4 members. Both groups were closely matched on gender; however, 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.

The two HIV groups in the two surveys were closely matched except for education and occupation. Patients in the survey achieved university level of education or more than accounting for 14.1%, while 1.8% in the sample in the second survey. Patients in the first survey were mainly enterprise-employed (36.8%), whereas unemployed (49.9%) of patients in the second survey.

Table 12 Distribution of socio-demographic variables among HIV and non-HIV patients in the first and second surveys

	First survey (n=1 395)							Second survey (n=1 334)								
	Total		HIV (696)		non-HIV (699)			Total		HIV (667)		non-HIV (667)				
	n	%	n	%	n	%	*P**	n	%	n	%	n	%	*P**	*p***	*p****
Age (Mean, SD)	38.8 (12.0)		38.1 (11.0)		39.5 (13.0)		0.039$^{\#}$	38.8 (14.0)		38.9 (12.1)		39.7 (15.6)		0.761$^{\#}$	0.205$^{\#}$	0.912$^{\#}$
Gender							0.709							1.000	0.502	0.211
Female	549	39.4	270	38.8	279	39.9		493	37	246	36.9	505	75.7			
Male	846	60.6	426	61.2	420	60.1		841	63	421	63.1	162	24.3			
Ethnic group							**<0.001**							0.135	0.901	**0.006**
Han	1094	78.4	504	72.4	590	84.4		985	73.8	480	72	505	75.7			
Other	301	21.6	192	27.6	109	15.6		349	26.2	187	28	162	24.3			
Religious belief							**<0.001**							**<0.001**	0.809	0.135
No	1149	82.4	522	75	627	89.7		1068	80.1	505	75.7	563	84.4			
Yes	246	17.6	174	25	72	10.3		266	19.9	162	24.3	104	15.6			
Place of residence							**<0.001**							**<0.001**	1.000	1.000

	First survey (n=1 395)							Second survey (n=1 334)								
	Total		HIV (696)		non-HIV (699)			Total		HIV (667)		non-HIV (667)				
	n	%	n	%	n	%	*P**	n	%	n	%	n	%	*P**	*p***	*p****
Rural	758	54.3	490	70.4	268	38.3		725	54.3	470	70.5	255	38.2			
Urban	637	45.7	206	29.6	431	61.7		609	45.7	197	29.5	412	61.8			
Marital status							**<0.001**							**<0.001**	0.304	**0.003**
Single	282	20.2	159	22.8	123	17.6		336	25.2	175	26.2	161	24.1			
Married/Cohabiting	935	67	383	55	552	79.0		817	61.2	358	53.7	459	68.8			
Separated/Divorced/Widowed	178	12.8	154	22.1	24	3.4		181	13.6	134	20.1	47	7			
Size of family							**<0.001**							**<0.001**	0.135	**<0.001**
1	58	4.2	52	7.5	6	0.9		42	3.1	36	5.4	6	0.9			
2-4	1030	73.8	535	76.9	495	70.8		990	74.2	507	76	483	72.4			
≥5	307	22	109	15.7	198	28.3		302	22.6	124	18.6	178	26.7			
Education							**<0.001**							**0.001**	**< 0.001**	**0.001**
Primary school or less	306	21.9	144	20.7	162	23.2		298	22.3	139	20.8	159	23.8			

	First survey (n=1 395)							Second survey (n=1 334)								
	Total		HIV (696)		non-HIV (699)			Total		HIV (667)		non-HIV (667)				
	n	%	n	%	n	%	*P**	n	%	n	%	n	%	*P**	*p***	*p****
Junior high school	668	47.9	296	42.5	372	53.2		627	47	339	50.8	288	43.2			
Senior high school	311	22.3	158	22.7	153	21.9		364	27.3	177	26.5	187	28			
University or equivalent	110	7.9	98	14.1	12	1.7		45	3.4	12	1.8	33	4.9			
Occupational status							**<0.001**							**<0.001**	**<0.001**	**<0.001**
Government-employed	129	9.2	62	8.9	67	9.6		167	12.5	64	9.6	103	15.4			
Enterprise-employed	499	35.8	256	36.8	243	34.8		437	32.8	247	37	190	28.5			
Self-employed	213	15.3	172	24.7	37	5.3		40	3	23	3.4	17	2.5			
Unemployed	554	39.7	206	29.6	352	50.4		690	51.7	333	49.9	357	53.5			
Household income (RMB)							**<0.001**							**<0.001**	**0.052**	**0.008**
<800	244	17.5	163	23.4	81	11.6		196	14.7	131	19.6	65	9.7			
801-2000	322	23.1	177	25.4	145	20.7		258	19.3	163	24.4	95	14.2			
2001-5000	417	29.9	184	26.4	233	33.3		447	33.5	225	33.7	222	33.3			

	First survey (n=1 395)							Second survey (n=1 334)								
	Total		HIV (696)		non-HIV (699)			Total		HIV (667)		non-HIV (667)				
	n	%	n	%	n	%	*P**	n	%	n	%	n	%	*P**	*p***	*p****
5001-8000	239	17.1	88	12.6	151	21.6		234	17.5	77	11.5	157	23.5			
≥8001	173	12.4	84	12.1	89	12.7		199	14.9	71	10.6	128	19.2			
Internalized/personal stigma (17 items)			44.6	(8.0)	41.3	(5.8)				45.0	(7.9)	40.7	(6.1)			
Internalized/personal stigma (10 items)			25.7	(5.6)	23.4	(4.4)				25.9	(5.6)	23.5	(4.5)			

*P**: T-test or Chi-square test for HIV/non-HIV effect; *p***: T-test or Chi-square test for two HIV sample effect; *p****: T-test or Chi-square test for two sample effect.

1.1.2 Clinical characteristics among HIV patients

Table 13 presents the clinical characteristics of HIV patients. The route of HIV transmission among HIV positive patients was mainly sexual transmission, accounting for 77.7%, 66.5% of which were from heterosexual transmission. The majority were at clinical stage 1, were not tested for virus load, and missed their ART dose in the last seven days. In almost 90% of patients, the CD_4 count was less than 500 cells/µl, and patients were followed up between 2-4 times in the first three months after confirmation of HIV/AIDS. The median virus load was 89 377.5 copy/ml among those who were tested, and the median number of days between HIV diagnosis and receiving the first dose of ART was 292.6. In contrast, the majority of non-HIV patients had hepatitis (85.7%).

Table 13 Clinical status among HIV positive patients in the first survey

	n	%
Days between HIV diagnosis and ART		
Median (min., max.)	292.6	(0,4745)
Route of transmission		
Intravenous injection of drug abuse	107	15.4
Homosexual	78	11.2
Heterosexual	463	66.5
Mother-to-child	22	3.2
Not clear	26	3.7
Clinical stage		
Stage 1	389	55.9
Stage 2	160	23.0
Stage 3	100	14.4
Stage 4	47	6.8
CD_4 count		
<200	305	43.8
200-499	337	48.4
>=500	54	7.8
Whether test Virus load		
No	558	80.2
Yes	138	19.8
Distribution of virus load		
Median (min., max.)	89377.5	(50, 7060000)
Treatment of opportunistic infections		

	n	%
No	624	89.7
Yes	72	10.3
Numbers of follow up in the first three months		
0	15	2.2
1	51	7.3
2	240	34.5
3	193	27.7
4	197	28.3
Whether missed ART in latest seven days		
No	223	32.0
Yes	473	68.0

1.1.3 Distribution of sample characteristics in the first and second surveys among healthcare providers

Table 14 shows the demographic characteristics of healthcare providers in the first and second surveys. 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 5000 to 8000 RMB.

Table 14 Distribution of characteristics among healthcare providers

	First sample (n=157)		Second sample (n=155)	
	n	%	n	%
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

	First sample (n=157)		Second sample (n=155)	
	n	%	n	%
Years of professional experience (Mean, SD)	13.7 (10.8)		10.3 (9.7)	
Job 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 (RMB)				
<2000	11	7.0	13	8.4
2001-5000	34	21.7	55	35.5
5001-8000	66	42.0	62	40.0
8001-13000	32	20.4	14	9.0
≥13001	14	8.9	11	7.1
HIV/AIDS stigma score (Mean, SD)	32.3 (8.8)		35.3 (9.6)	

1.2 Expectation and perceived experience of HSR

Mean scores in eight domains of patients' expectation of HSR were presented based on vignettes between HIV and non-HIV patients. Proportions of perceived experience of HSR were shown before and after adjustments of percentages of vignettes in seven domains and socio-economic factors. Comparisons between two samples by time were given in expectation and perceived experience, respectively.

1.2.1 Differences of HSR in eight domains between HIV and non-HIV patients

Table 15 presents mean scores of eight domains of patients' expectation of healthcare between HIV and non-HIV patients, based on the vignettes. In all domains, HIV patients had significantly lower mean expectation scores than non-HIV patients.

Table 15 Distributions of patients` expectation scores based on vignettes

	Total	HIV patients	Non-HIV patients	*p**
	(n=1395)	(n=696)	(n=699)	
Dignity	14.0 (2.5)	13.9 (2.7)	14.2 (2.2)	0.024
Prompt attention	15.9 (2.8)	14.9 (3.0)	17.0 (2.2)	<0.001
Communication	14.4 (2.2)	14.1 (2.5)	14.6 (1.7)	<0.001
Basic amenities	15.5 (2.2)	15.2 (2.6)	15.8 (1.7)	<0.001
Confidentiality	17.0 (2.7)	16.8 (3.3)	17.2 (2.0)	0.004
Choice	15.7 (2.6)	15.3 (3.0)	16.2 (2.0)	<0.001
Social support	14.1 (2.2)	13.8 (2.5)	14.4 (1.9)	<0.001
Autonomy	14.3 (2.2)	14.2 (2.6)	14.5 (1.8)	0.004

*: *p* values from independent t-test.

1.2.2 Differences in expectation by HIV status and socio-demographic factors

HIV status was associated with all domains. After adjustment for demographic and socio-economic variables, HIV status remained significantly associated with lower expectations of all health system domains (Table 16). Age was significantly associated with basic amenities, with young adults having a higher expectation. Compared to Han people, minority ethnic groups had lower expectations towards dignity, prompt attention and autonomy. Those who lived in a family containing 2-4 members had a higher expectation than those who lived alone.

Table 16 multiple linear regression of patients` expectation based on vignettes among eight domains

	Dignity		Prompt attention		Communication		Basic amenities		Confidentiality		Choice		Social support		Autonomy	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
HIV status: Non-HIV vs. HIV	0.252 (-0.009,0.513)	**0.027**	2.106 (1.826,2.386)	**< 0.001**	0.532 (0.302,0.762)	**< 0.001**	0.587 (0.354,0.821)	**< 0.001**	0.397 (0.102,0.692)	**0.003**	0.928 (0.662,1.195)	**< 0.001**	0.543 (0.308,0.778)	**< 0.001**	0.288 (0.052,0.524)	**0.0046**
Age: ref.=16-40								**0.0177**								
41-60							-0.35 (-0.598,-0.102)									
61-85							-0.29 (-0.78,0.201)									
Ethnic group: other vs. Han	-0.333 (-0.65,-0.016)	**0.0398**	-0.412 (-0.752,-0.071)	**0.0178**											-0.415 (-0.701,-0.128)	**0.0046**
Family size: ref.=1										**0.0389**						
2-4									0.912 (0.179,1.644)							
>=5									0.74 (-0.045,1.525)							

1.2.3 Comparisons in expectation by HIV status

Figure 14 compares the crude and adjusted coefficients from the linear regression models among each domain, reflecting the differences in expectation scores between HIV positive and non-HIV patients. Prompt attention had the highest coefficient reflecting a relatively higher expectation by non-HIV patients. Non-HIV patients also had higher expectations towards basic amenities, choice of provider, confidentiality, communication, autonomy, social support and dignity.

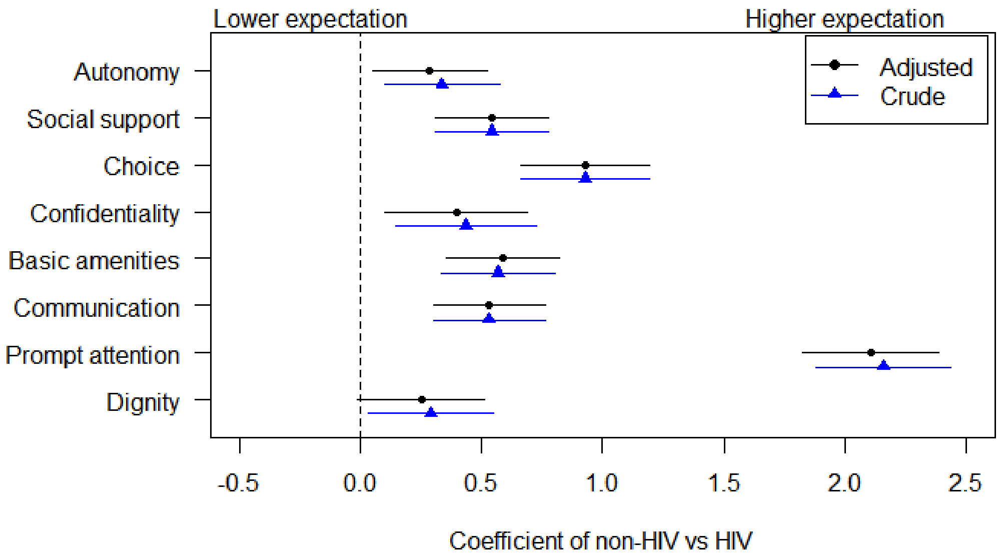


Figure 14 Differences in health service expectation between HIV and non-HIV patients

1.2.4 Experience of HSR among HIV and non-HIV patients

Figure 15 presents the distribution of experience of HSR among HIV and non-HIV patients The highest percentages of HSR in all seven domains were “good” ranging from 44.0 to 52.0% among HIV patients, while the corresponding percentages among non-HIV patients were “good” in prompt attention, dignity and communication about 65% and “moderate” scale in quality of basic amenities, confidentiality, choice and autonomy, ranging from 63.7 to 70.7%.

Table 17 shows the coefficients of experience of HSR among HIV and non-HIV patients before and after adjustment for socio-demographic factors among patients. Differences of proportional trends were significant in six domains except for prompt attention. There were significant associations in four domains with higher odds ratio (OR) from 19.9 to 25.1, and they were quality of basic amenities, confidentiality, choice and autonomy. After adjustment for socio-demographic factors, the differences were still significant among the same six domains.

Table 17 Distribution and ordered probit regression results of experience of HSR before and after adjusted for socio-demographic factors among patients

HSR domains	Patients	Very good		Good		Moderate		Bad		Very bad		Before				After			
		n	%	n	%	n	%	n	%	n	%	β	se	OR	95%C.I.	β	se	OR	95%C.I.
Prompt attention	HIV	83	11.9	306	44.0	228	32.8	67	9.6	12	1.7	-0.11	0.13	0.90	(0.70,1.15)	-0.16	0.11	0.85	(0.69,1.05)
	non-HIV	21	3.0	442	63.2	206	29.5	21	3.0	9	1.3								
Dignity	HIV	168	24.1	362	52.0	129	18.5	25	3.6	12	1.7	**0.69***	0.13	1.99	(1.54,2.58)	**0.63***	0.12	1.88	(1.48,2.40)
	non-HIV	42	6.0	483	69.1	163	23.3	9	1.3	2	0.3								
Communication	HIV	179	25.7	352	50.6	139	20.0	19	2.7	7	1.0	**0.58***	0.13	1.79	(1.39,2.31)	**0.6***	0.11	1.83	(1.48,2.27)
	non-HIV	49	7.0	455	65.1	177	25.3	13	1.9	5	0.7								
Quality of amenities	HIV	135	19.4	335	48.1	180	25.9	33	4.7	13	1.9	**3.16***	0.16	23.65	(17.35,32.54)	**2.99***	0.14	19.88	(15.11,26.43)
	non-HIV	10	1.4	26	3.7	445	63.7	201	28.8	17	2.4								
Confidentiality	HIV	169	24.3	352	50.6	145	20.8	21	3.0	9	1.3	**3.36***	0.16	28.66	(20.87,39.76)	**3.21***	0.14	24.85	(18.81,33.16)
	non-HIV	10	1.4	43	6.2	491	70.2	149	21.3	6	0.9								
Choice	HIV	136	19.5	332	47.7	192	27.6	30	4.3	6	0.9	**3.14***	0.16	23.01	(16.80,31.83)	**3.16***	0.15	23.68	(17.57,32.24)

HSR domains	Patients	Very good		Good		Moderate		Bad		Very bad		Before				After			
		n	%	n	%	n	%	n	%	n	%	β	se	OR	95%C.I.	β	se	OR	95%C.I.
	non-HIV	11	1.6	32	4.6	494	70.7	152	21.7	10	1.4								
Autonomy	HIV	167	24.0	354	50.9	138	19.8	29	4.2	8	1.1	**3.27***	0.16	26.39	(19.25,36.54)	**3.22***	0.15	25.05	(18.87,33.62)
	non-HIV	11	1.6	31	4.4	479	68.5	165	23.6	13	1.9								

HSR: Health system responsiveness. *: Significance.

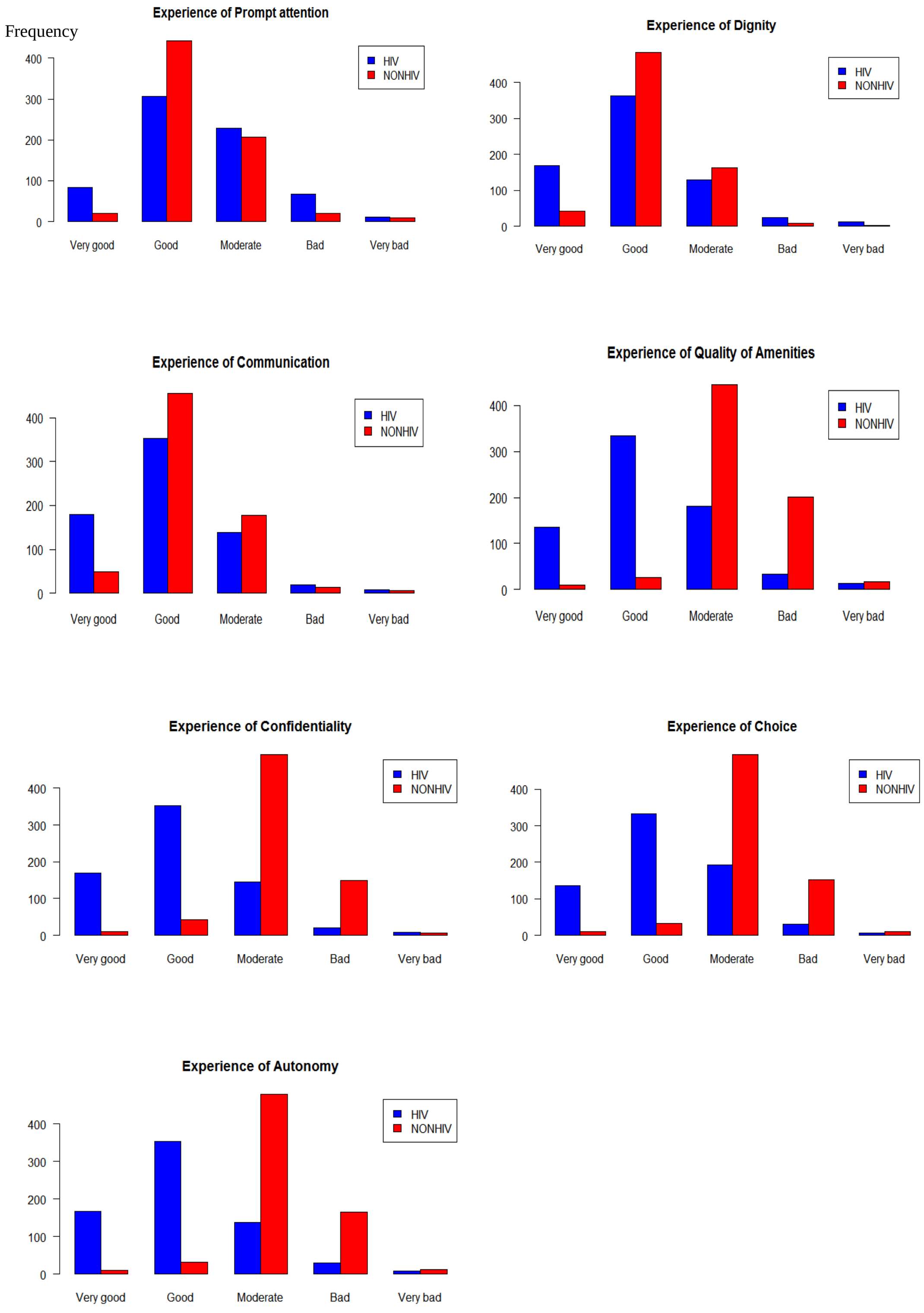


Figure 15 Distribution of experience of HSR among HIV and non-HIV patients

1.2.5 Experience of HSR after adjusting for vignettes among HIV and non-HIV patients

Figure 12 shows B-scale values of experience adjusted for vignettes in seven domains between HIV and non-HIV patients. Among HIV patients, the highest proportions mainly concentrated around B-values of 2 reflecting the experience between the scale of “very good” and “good” for four domains: prompt attention, dignity, communication and confidentiality. The highest proportions of basic amenities and autonomy domains had B-scale values of 3 reflecting the experience between the scale of “good” and “moderate”, and 1 reflecting an experience more than “very good”.

Table 18 presents distribution of B-scales and coefficients from the censored ordered probit regression adjusted for vignettes before and after adjustment for socio-demographic factors. B-values ranged from 1 to 6, since there are 5 vignette scales, reflecting more than “very good” to less than “very bad” experience of HSR. The experience of HSR after adjusting for vignettes among non-HIV patients generally were lower than HIV patients. The differences of proportions were significant in all seven domains before and after adjusting for socio-demographic factors. B coefficients reflect the difference in z-scores between non-HIV patients and HIV patients (referent group), thus positive values indicate that non-HIV patients have a worsening HSR experience compared to HIV-positive patients. In prompt attention, non-HIV patients had a better experience than HIV patients. However, non-HIV patients had a worse experience than HIV patients in domains of dignity, communication, quality of basic amenities, confidentiality, choice and autonomy.

Table 18 Distribution and censored ordered probit regression results between experience and vignettes of HSR before and after adjusted for socio-demographic factors among patients

		B-value												**COPR**			
		1		2		3		4		5		6		Before		After	
		n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	β	se	β	se
Prompt attention	HIV	49	0.070	493	0.710	35	0.050	88	0.130	0	0.000	31	0.040	**-0.44***	0.09	**-0.52***	0.08
	non-HIV	33	0.048	575	0.840	55	0.080	2	0.003	1	0.001	17	0.020				
Dignity	HIV	63	0.091	485	0.697	18	0.026	104	0.149	7	0.010	19	0.027	**0.38***	0.09	**0.33***	0.07
	non-HIV	21	0.030	471	0.684	33	0.048	97	0.141	65	0.094	2	0.003				
Communication	HIV	85	0.122	483	0.694	71	0.102	39	0.056	4	0.006	14	0.020	**0.25***	0.09	**0.23***	0.08
	non-HIV	95	0.141	28	0.041	529	0.783	8	0.012	1	0.001	15	0.022				
Quality of basic amenities	HIV	116	0.167	25	0.036	527	0.757	4	0.006	2	0.003	22	0.032	**1.13***	0.10	**1.08***	0.08
	non-HIV	2	0.003	20	0.029	581	0.854	4	0.006	59	0.087	14	0.021				
Confidentiality	HIV	148	0.213	517	0.744	7	0.010	1	0.001	0	0.000	22	0.032	**1.16***	0.10	**1.03***	0.08

		B-value												**COPR**			
		1		2		3		4		5		6		Before		After	
		n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	β	se	β	se
	non-HIV	22	0.032	603	0.874	3	0.004	0	0.000	18	0.026	44	0.064				
Choice	HIV	535	0.769	121	0.174	-	-	10	0.014	-	-	30	0.043	**1.60***	0.10	**1.44***	0.08
	non-HIV	24	0.034	117	0.167	-	-	520	0.744	-	-	38	0.054				
Autonomy	HIV	155	0.223	6	0.009	513	0.737	5	0.007	0	0.000	17	0.024	**1.64***	0.11	**1.50***	0.09
	non-HIV	10	0.015	4	0.006	569	0.827	21	0.031	2	0.003	82	0.119				

HSR: Health system responsiveness. -: Calculation of B-scale not possible. *: Significance.

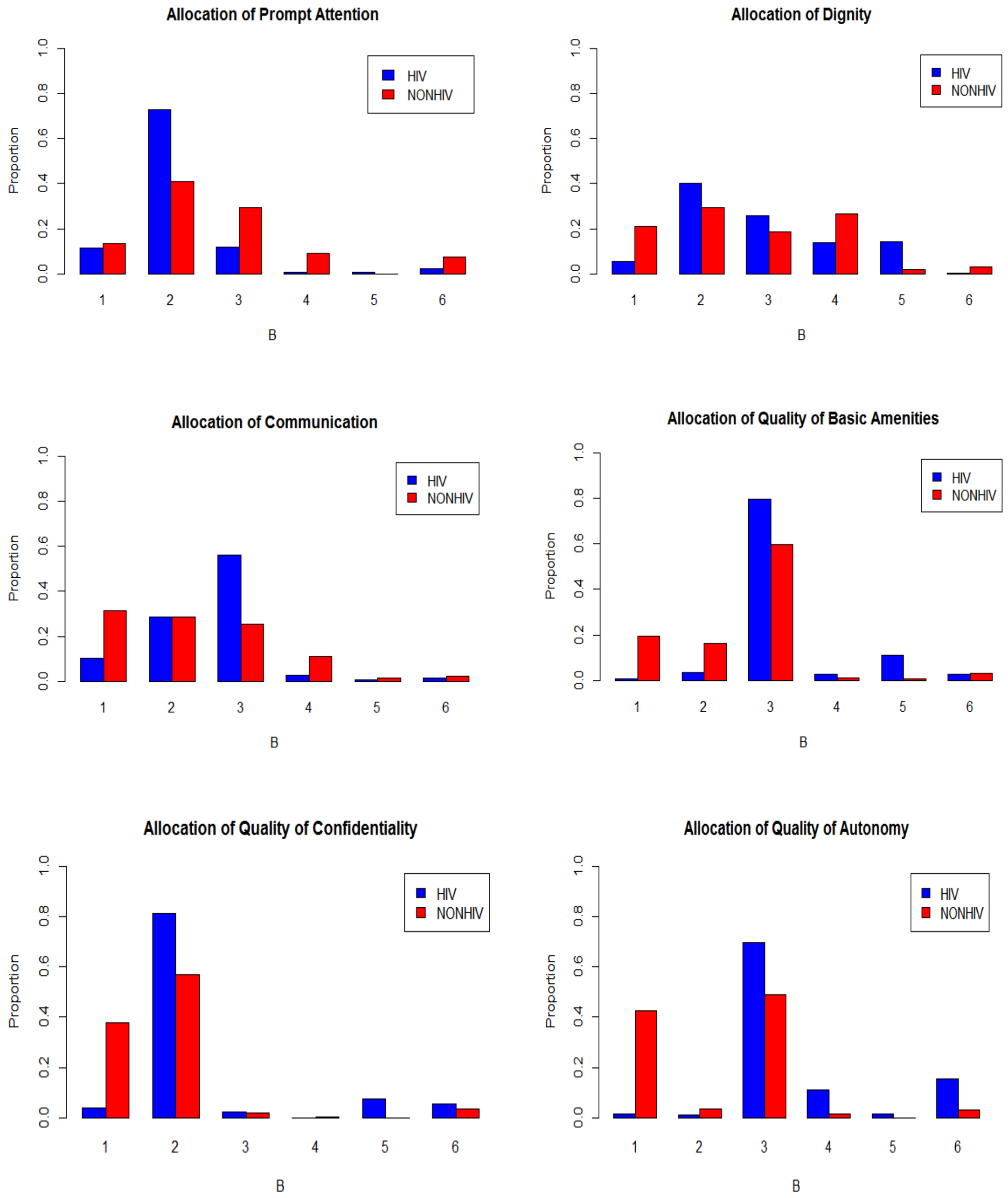


Figure 16 Comparison of B-values between HIV and non-HIV patients in seven domains

1.2.6 Associations between HSR and demographic and socio-economic factors adjusted for anchoring vignettes

Table 19 presents associations between HSR and socio-demographic factors after adjustment for anchoring vignettes. HIV status was associated with perceived experience in all seven domains adjusting for anchoring vignettes. Gender, ethnic group and occupation were also significantly associated with perceived experience in prompt attention. In the dignity domain, those who received the education in senior high school and university or more had a worse experience than those in primary school, whereas in quality of amenities domain those who received education in junior high school had a worse experience. Those who lived in the family of 2-4 people had a worse perceived experience in communication domain than those who lived alone.

Table 19 Censored ordered probit regression (COPR) of HSR among patients on demographic and socio-economic variables

	Prompt Attention		Dignity		Communication		Quality of amenities		Confidentiality		Choice		Autonomy	
	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE
HIV status: NONHIV vs. HIV	**-0.52**	0.08	**0.33**	0.07	**0.23**	0.08	**1.08**	0.08	**1.03**	0.08	**1.44**	0.08	**1.50**	0.09
Gender: Male vs. Female	**0.16**	0.08												
Ethnic group: Minority vs. Han	**0.23**	0.09												
Family size: Ref: 1														
2-4					**0.59**	0.21								
>=5					0.60	0.22								
Education Ref: <=Primary school														
Junior high school			0.11	0.09			**-0.20**	0.10						
Senior high school			**0.25**	0.11			-0.19	0.11						
>=University			**0.31**	0.15			0.22	0.16						

	Prompt Attention		Dignity		Communication		Quality of amenities		Confidentiality		Choice		Autonomy	
	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE
Occupation Ref: Government-employed														
Enterprise-employed	**-0.37**	0.13												
Self-employed	**-0.31**	0.15												
Unemployed	-0.25	0.13												

1.2.7 Comparisons of HSR by time

Comparisons of perceived experience of HSR by time

Table 20 and Figure 13 show percentages of perceived experience of HSR by time among HIV patients. The majority of proportions in HSR were “good” accounting for 44.0-52% in the first survey, while the corresponding percentages accounted for 51.9-68.1% in the second survey. Overall, the distribution of responsiveness were significantly different in seven domains. HIV patients appear to have better experiences after the feedback for most HSR domains. Choice of provider maybe worse.

Dignity, prompt attention, communication, quality of basic amenities, confidentiality and autonomy domains were rated more favourably (after the feedback) since the proportions of both “very good” and “good” experiences increased in the second survey except for choice domain.

Table 20 Experience of health system responsiveness in HIV sample in the first and second survey

	Total sample (n=1363)	First survey (n=696)	Second survey (n=667)	*p**
Experience of dignity				**< 0.001**
very good	309(22.7)	168(24.1)	141(21.1)	
good	816(59.9)	362(52.0)	454(68.1)	
moderate	191(14.0)	129(18.5)	62(9.3)	
bad	32(2.3)	25(3.6)	7(1.0)	
very bad	15(1.1)	12(1.7)	3(0.4)	
Experience of prompt attention				**< 0.001**
very good	188(13.8)	83(11.9)	105(15.7)	
good	698(51.2)	306(44.0)	392(58.8)	
moderate	360(26.4)	228(32.8)	132(19.8)	
bad	101(7.4)	67(9.6)	34(5.1)	
very bad	16(1.2)	12(1.7)	4(0.6)	
Experience of communication				**< 0.001**
very good	306(57.4)	179(25.7)	127(19.0)	
good	783(22.5)	352(50.6)	431(64.6)	
moderate	225(16.5)	139(20.0)	86(12.9)	
bad	38(2.8)	19(2.7)	19(2.8)	
very bad	11(0.8)	7(1.0)	4(0.6)	
Experience of basic amenities				**< 0.001**
very good	221(16.2)	135(19.4)	86(12.9)	
good	755(55.4)	335(48.1)	420(63.0)	
moderate	325(23.8)	180(25.9)	145(21.7)	
bad	44(3.2)	33(4.7)	11(1.6)	

	Total sample (n=1363)	First survey (n=696)	Second survey (n=667)	*p**
very bad	18(1.3)	13(1.9)	5(0.7)	
Experience of confidentiality				**0.001**
very good	299(21.9)	169(24.3)	130(19.5)	
good	763(56.0)	352(50.6)	411(61.6)	
moderate	251(18.4)	145(20.8)	106(15.9)	
bad	36(2.6)	21(3.0)	15(2.2)	
very bad	14(1.0)	9(1.3)	5(0.7)	
Experience of choice				**< 0.001**
very good	216(15.8)	136(19.5)	80(12.0)	
good	678(49.7)	332(47.7)	346(51.9)	
moderate	369(27.1)	192(27.6)	177(26.5)	
bad	83(6.1)	30(4.3)	53(7.9)	
very bad	17(1.2)	6(0.9)	11(1.6)	
Experience of autonomy				**< 0.001**
very good	281(20.6)	167(24.0)	114(17.1)	
good	764(56.1)	354(50.9)	410(61.5)	
moderate	258(18.9)	138(19.8)	120(18.0)	
bad	51(3.7)	29(4.2)	22(3.3)	
very bad	9(0.7)	8(1.1)	1(0.1)	

*: *p* values on Chi-squared test.

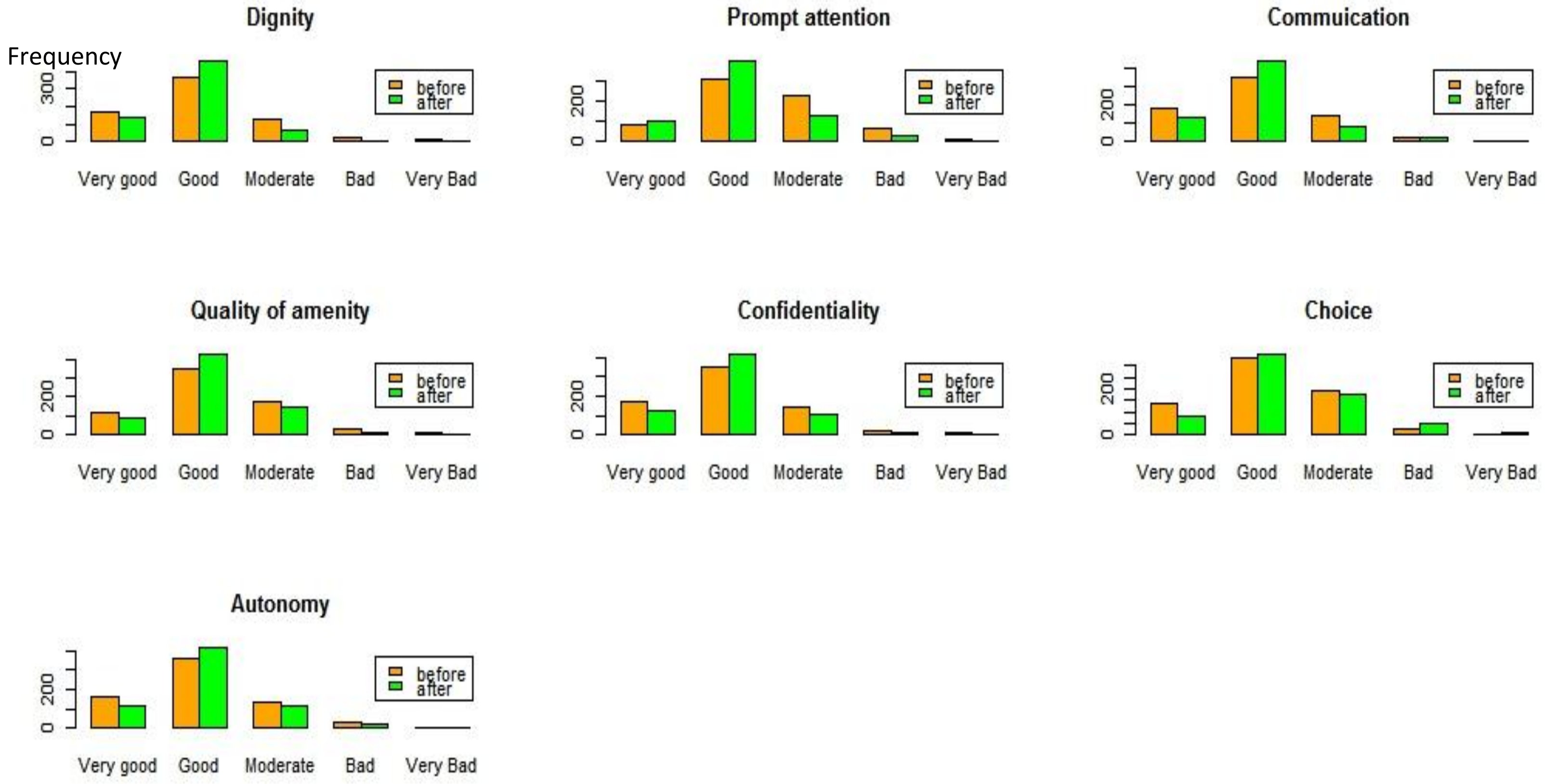


Figure 17 Comparison of perceived experience of HSR by time among HIV patients

Comparisons of expectation of HSR by time

Table 21 presents mean scores of vignettes in eight domains among HIV patients by time. Mean scores in the first survey ranged from 13.8 to 16.8, while in the second survey ranged from 13.2 to 16.1. Mean scores significantly increased in dignity, prompt attention, communication, quality of basic amenities, confidentiality, and choice domains, indicating that HIV patients had better expectations of these HSR domains after the feedback, whereas they decreased in social support and autonomy domains.

Table 21 Expectation based on vignettes among HIV positive patients in the first and second survey

	Total sample (n=1363)	First survey (n=696)	Second survey (n=667)	*p**
Score of dignity [Mean(SD), Range]	14.0 (2.5) (5,25)	13.9 (2.6) (5,24)	14.2 (2.2) (5,25)	**0.005**
Score of prompt attention [Mean(SD), Range]	15.1 (2.7) (5,24)	14.9 (3.0) (5,24)	15.4 (2.3) (5,23)	< **0.001**
Score of communication [Mean(SD), Range]	14.3 (2.3) (5,25)	14.1 (2.5) (5,21)	14.6 (2.0) (5,25)	< **0.001**
Score of basic amenities [Mean(SD), Range]	15.6 (2.4) (5,25)	15.2 (2.6) (5,25)	16.1 (2.1) (5,25)	< **0.001**
Score of confidentiality [Mean(SD), Range]	17.1 (2.9) (5,25)	16.8 (3.3) (5,25)	17.4 (2.4) (5,25)	< **0.001**
Score of choice [Mean(SD), Range]	15.6 (2.7) (5,25)	15.3 (3.0) (5,24)	15.9 (2.2) (5,25)	< **0.001**
Score of social support [Mean(SD), Range]	13.6 (2.3) (5,22)	13.8 (2.5) (5,22)	13.4 (2.1) (5,20)	**0.004**
Score of autonomy [Mean(SD), Range]	13.7 (2.5) (5,21)	14.2 (2.6) (5,21)	13.2 (2.4) (5,20)	< **0.001**

*: *p* values on independent t-test.

1.2.8 Multivariate analysis of HSR experience of HSR before and after feedback

Table 22 presents results of the multivariate linear regression models for all HSR experience in domains of prompt attention, choice and autonomy domains, Non-HIV patients had a worse HSR experience after the feedback but better experiences in domains of dignity, quality of basic amenities and confidentiality.

Table 22 Final multivariate linear regression models for HSR experience

	Prompt Attention		Dignity		Communication		Quality of amenities		Confidentiality		Choice		Autonomy	
	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE
Time: After vs. Before	**0.26**	**0.09**	**-0.47**	**0.08**	-0.15	0.09	**-0.20**	**0.08**	**-0.41**	**0.07**	**0.20**	**0.09**	**0.62**	**0.08**
HIV status: Non-HIV vs. HIV	**-0.58**	**0.09**			**-0.27**	**0.10**			**-0.16**	**0.08**	**0.44**	**0.09**		
Religious belief: Yes vs. No					**0.28**	**0.11**								
Ethnic group: Minority vs. Han											**-0.29**	**0.11**		
Age: ref.=16-40									-0.07	0.08				
41-60									**0.28**	**0.14**				
61-85														
Place of residence: Urban vs. Rural									**0.18**	**0.08**				
Marital status: Ref: Single														
Married/Cohabiting			**-0.25**	**0.10**	**-0.25**	**0.11**								
Separated/Divorced/Widowed			**-0.28**	**0.15**	-0.10	0.15								
Education: Ref: <=Primary school														
Junior high school													0.08	0.09
Senior high school													**-0.26**	**0.11**
>=University													-0.26	0.18
Occupation Ref: Government-employed														
Enterprise-employed	**-0.41**	**0.14**												
Self-employed	-0.27	0.19												
Unemployed	-0.23	0.14												

1.3 HIV/AIDS related stigma

This part presented results of the development of HIV/AIDS stigma scales, and also showed associations of internalized stigma among HIV positive patients, personal stigma among non-HIV patients and occupational stigma among healthcare providers adjusting for demographic and socio-economic factors.

1.3.1 Comparisons of items in HIV/AIDS stigma scales among three groups

Tables 23 and 24 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 towards 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, 1 item in the development sample alone and 1 item in the validation sample alone). The mean (standard deviation) scores of stigma scales among HIV, non-HIV and healthcare 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 healthcare providers.

Table 23 Summary of stigma items among HIV positive and non-HIV patients in development and validation sample

Items for HIV and non-HIV patients	Development Sample (Mean, SD)			Validation Sample (Mean, SD)			*p***	*p****
	HIV	non-HIV	*p**	HIV	non-HIV	*p**		
1. 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	0.036
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	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	0.222
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	<0.001
5. Getting HIV is a punishment for bad behaviour	2.13 (0.9)	2.14 (0.6)	0.872	2.29 (0.9)	2.20 (0.8)	0.058	<0.001	<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	0.695
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	0.063
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	0.150	0.448
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	0.855
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	0.239
11. 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	<0.001
12. Most employers would not employ me because I am HIV+	2.81 (0.8)	2.75 (0.6)	<0.001	2.81 (0.8)	2.71 (0.7)	0.011	0.542	0.840
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	0.122
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	0.386
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	0.724
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	0.043
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	0.247

* T-test for HIV/non-HIV effect; ** T-test for sample effect; *** Two way ANOVA for sample effect adjusted by the HIV status effect; R=reversed items. PLWH: people living with HIV.

Table 24 Summary of stigma items among healthcare providers in development and validation sample

Items for healthcare providers	Sample 1	Sample 2	$p^{\#}$
	Mean (SD)	Mean (SD)	
1. 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 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
11. 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 wouldn’t share utensils with PLWH	1.96 (0.9)	2.02 (0.9)	0.530
14. I am willing to work with HIV + 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 exam of HIV + patient (R)	1.49 (0.8)	1.72 (1.0)	0.022
17. I am willing to interact with HIV + patients in the same way as other patients (R)	1.60 (0.9)	1.81 (1.0)	0.053

#: t-test for sample effect. R=reversed items. PLWH: people living with HIV/AIDS.

1.3.2 Exploratory factor analysis

Patients' stigma scales

The scree plots shown in Figure 18 from both analyses suggested two factors. Among the HIV group, the first factor loaded highly on 7 items and reflected a feeling of "being refused". The second factor loaded highly on 3 items and reflected a feeling of "guilt". Among the non-HIV group, the first factor loaded highly on 7 items reflecting a feeling of "refusal" and the second factor loaded highly on 3 items and reflected a feeling of "blaming" (Table 25).

Healthcare providers' stigma scale

Figure 18 also showed that exploratory factor analysis identified three factors reflecting feelings of "blame", "professionalism" and "egalitarianism" among the healthcare providers (Table 25).

1.3.3 Internal consistency

Cronbach's alpha coefficients for all factors were above 0.853, except for egalitarianism which had a value of 0.780, thus reflecting a high level of inter-item consistency (Table 25).

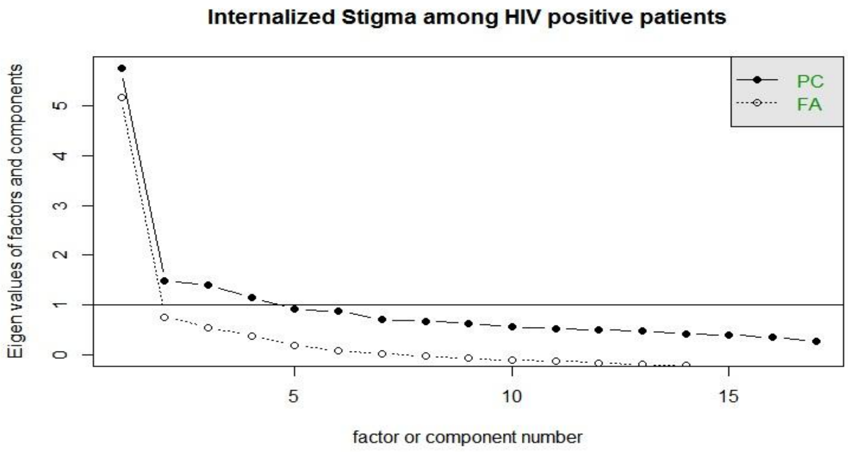
Table 25 Factor loadings among HIV, non-HIV patients and healthcare providers in development and validation samples

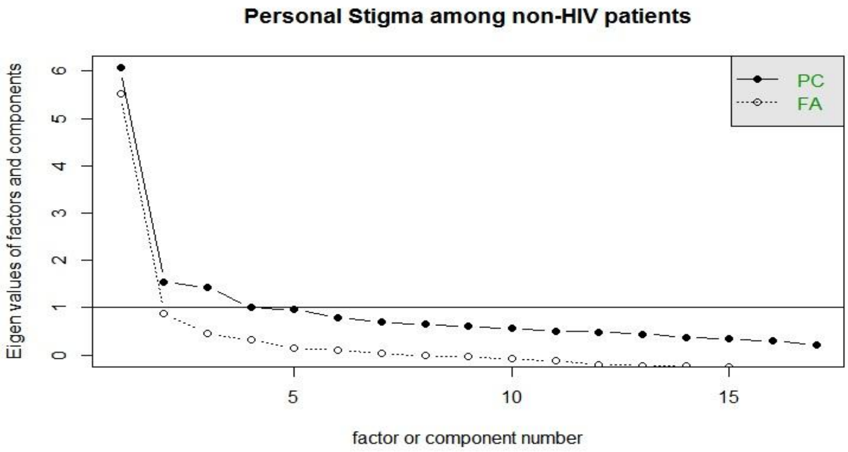
	Factor loadings			
	Development sample			Validation sample
	Factor 1	Factor 2	Factor 3	
1) Items of internalized stigma among HIV patients (α=0.869)				
Being refused (α=0 .880)				
7. I would understand if people rejected my friendship because I am HIV+	0.82			0.674
8. My neighbours would not like me living next door if they knew I had HIV	0.81			0.584
16.Because of my HIV people would not date me	0.81			0.580
12.Most employers would not employ me because I am HIV+	0.73			0.556
13.If I was in public or private transport and someone knew I had HIV they would not sit next to me	0.70			0.544
14.If I eat around a restaurant and people knew I had HIV they would not eat in the same place	0.69			0.614
4. When people know I have HIV I feel uncomfortable around them	0.66			0.444
Guilt (α=0.709)				
3. I feel that it is my fault that I got HIV		0.84		0.633
5. Getting HIV is a punishment for bad behaviour		0.78		0.529
2. I must have done something wrong to deserve getting HIV		0.68		0.631
2) Items of personal stigma among non-HIV patients (α=0.853)				
Refusing (α=0.810)				
7. I would not like to be friends with someone with HIV	0.88			0.543
8. I would not like someone with HIV to be living next door	0.80			0.487

	Factor loadings			
	Development sample			Validation sample
	Factor 1	Factor 2	Factor 3	
9. If I was in public or private transport, I would not like to sit next to someone with HIV	0.76			0.422
16. I would not date a person if I know that he/she has HIV	0.76			0.405
6. I feel afraid to be around people with HIV	0.74			0.446
4. I feel uncomfortable around people with HIV	0.69			0.447
11.I think less of someone because they have HIV	0.67			-
Blaming (α=0.852)				
2. If you have HIV you must have done something wrong to deserve it		0.85		0.507
1. People with HIV should be ashamed of themselves		0.81		0.445
3. People with HIV/AIDS have only themselves to blame		0.79		0.425
5. I think getting HIV is a punishment for bad behaviour		0.61		0.420
3) Items of stigma from healthcare providers (α=0.839)				
Blaming (α=0.872)				
1. People who got HIV/AIDS through sex and drug use, got what they deserved	0.89			0.791
4. People who behave promiscuously should be blamed for AIDS	0.86			0.785
3. Infected through drug use deserve sympathy	0.86			0.839
2. Infected through commercial sex deserve sympathy	0.82			0.798
Professionalism* (α=0.893)				
15. Willing to provide same care (R)		0.92		0.944
16. Willing to do physical exam of HIV + patient (R)		0.88		0.853

	Factor loadings			
	Development sample			Validation sample
	Factor 1	Factor 2	Factor 3	
17. Willing to interact same as other patients (R)		0.83		0.893
18. Willing to work with HIV + patients (R)		0.70		0.599
Egalitarianism* (α=0.780)				
6. Deserve good care-commercial sex (R)			0.90	1.042
7. Deserve good care-drug use (R)			0.88	0.951
5. Deserve good care-blood donation (R)			0.68	0.497

- means that the coefficient for that item < 0.4. R=reversed item.





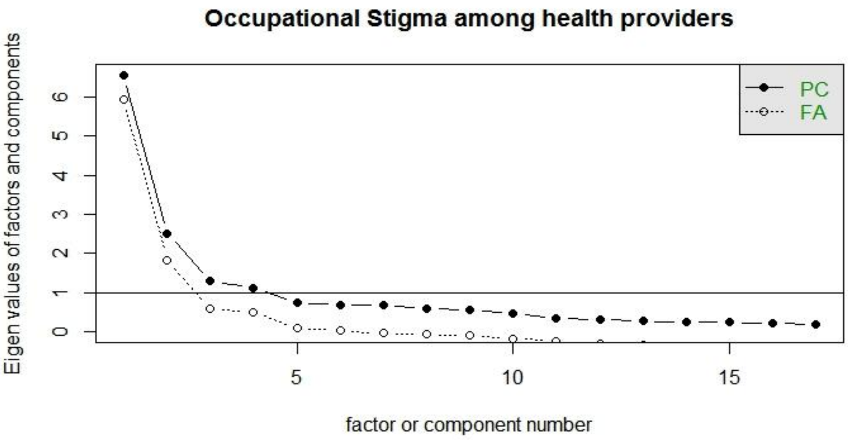


Figure 18 Scree plots for the three scales of internalized stigma, personal stigma and occupational stigma

1.3.4 Correlation among factors

Table 26 summarizes correlation coefficients among factors within each group of subjects. The absolute values ranged from 0.231 to 0.703 indicating that the factors had a low to moderate correlation.

1.3.5 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 25. In general, the coefficients were moderate for HIV and non-HIV patients (between 0.405 and 0.674), while those for healthcare provider's validation sample were high (between 0.497 and 1.042). For test statistics, all RMESA were less than 0.08, all CFI were more than 0.90 and all TLI were more than 0.90. Thus, confirmatory factor analysis suggested 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 less than 0.001.

Table 26 Correlation of latent factors in three scales

		Internalized stigma	Personal stigma	Occupational stigma of providers	
		Guilt	Blaming	Professionalism	Egalitarianism
Internalized stigma	Being refused	0.537			
Personal stigma	Refusing		0.703		
Occupational stigma	Blaming			0.231	0.386
	Professionalism				0.266

1.3.6 Predictors for each domain of stigma

Table 27 presents results of the univariate analysis to predict each domain of stigma. Age was associated with feelings of being refused among HIV patients; those being older than 40 years 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 older than 40 years were more likely to refuse and blame HIV patients. Healthcare providers who were aged more than 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, while non-HIV patients who were married also had a tendency to refuse and blame HIV patients. Health providers who were married were less likely to be professional. Health 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 providers, marital status was associated with professionalism while gender and household income were significantly associated with egalitarianism.

Table 27 Crude coefficients (95% CI) of HIV/AIDS stigmas and sample characteristics

	Internalized stigma of HIV patients		Personal stigma of non-HIV patients		Occupational stigma		
	Being refused	Guilt	Refusing	Blaming	Blaming	Professionalism	Egalitarianism
Age (years): >40 vs. ≤40	**0.18 (0.05, 0.32)**	0.14 (-0.01, 0.28)	**0.27 (0.13, 0.40)**	**0.23 (0.09, 0.37)**	-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)	-0.23 (-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: ≥University vs. < University	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: ≥5000 vs. < 5000	-0.14 (-0.30, 0.02)	**-0.28 (-0.45, -0.11)**	-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)**

CI: confidence interval.

1.3.7 Comparisons and associations of HIV/AIDS stigma by time

Comparisons and associations of internalized stigma among HIV patients by time

Table 28 shows results of multiple linear regression of internalized stigma by time. The difference of mean score of internalized stigma by time was not significant. Age, ethnic group, marital status and occupation were significantly associated with internalized stigma among HIV patients. Those who were aged 41-60 years old had higher internalized stigma than those aged 15-40 years old. Those who were separated, divorced or widowed had higher internalized stigma than those who were single. Additionally, those who were self-employed and unemployed had higher internalized stigma than those who were employed by government. Ethnic group, marital status and household income were associated with feeling “refused”, while gender, marital status, occupation and education were associated with feeling “guilty”.

Table 28 multiple linear regression of internalized stigma among HIV patients

	Internalized stigma		Refused		Guilt	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
Time: second vs. first	0.278 (-0.342,0.898)	0.422	-0.050 (-0.509,0.410)	0.653	0.327 (0.086,0.567)	**0.002**
Gender: Male vs. female					0.665 (0.428,0.902)	< 0.001
Age: ref.=15-40		< 0.001				
41-60	0.946 (0.279,1.612)					
61-85	0.455 (-0.780,1.690)					
Ethnic group: Other vs. Han	0.797 (0.136,1.458)	0.002	0.769 (0.254,1.284)	< 0.001		
Marital status: ref.=Single		< 0.001		< 0.001		< 0.001
Married/Cohabiting	1.210 (0.455,1.964)		1.136 (0.566,1.706)		0.399 (0.109,0.689)	
Separated/Divorced/Widowed	1.153 (0.232,2.073)		1.086 (0.387,1.784)		0.363 (0.017,0.709)	
Occupation: ref.=Government-employed		0.016				0.002
Enterprise-employed	0.904 (-0.180,1.988)				0.398 (-0.020,0.816)	
Self-employed	1.472 (0.180,2.764)				0.663 (0.152,1.173)	
Unemployed	1.620 (0.529,2.711)				0.743 (0.317,1.169)	

	Internalized stigma		Refused		Guilt	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
Education: ref.<=Primary school						0.002
Junior high school					-0.358 (-0.650,-0.066)	
Senior high school					-0.458 (-0.814,-0.101)	
>=University					-0.431 (-0.928,0.066)	
Household income(Yuan): ref.=<800				0.002		
801-2000			-0.118 (-0.793,0.557)			
2001-5000			-0.737 (-1.390,-0.084)			
5001-8000			-1.325 (-2.150,-0.499)			
>=8001			-1.185 (-2.036,-0.333)			

Comparisons and associations of personal stigma among non-HIV patients by time

Table 29 shows changes of personal stigma among non-HIV patients by time. There was not significant among mean score of personal stigma by time. Religious affiliation, marital status and education were significantly associated with personal stigma among non-HIV patients. Those who were single had lower personal stigma towards HIV patients than others. Those who received junior and senior high school education had lower personal stigma towards HIV patients than those who educated in primary school.

At the level of factors, “refusing” was negatively associated with time, whereas “blaming” was positively associated with time. Marital status and education were also associated with “refusing”, while religious affiliation, marital status, education and household income were significantly associated with “blaming”.

Table 29 multiple linear regression of personal stigma among non-HIV patient

	Personal stigma		Refusing factor		Blaming factor	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
Time: second vs. first	0.265 (-0.203,0.733)	0.480	-0.258 (-0.581,0.064)	**0.038**	0.502 (0.292,0.712)	**< 0.001**
Religious affiliation: Yes vs. No					0.332 (0.019,0.645)	0.017
Marital status: ref.=Single		< 0.001		< 0.001		< 0.001
Married/Cohabiting	1.238 (0.638,1.837)		0.827 (0.414,1.240)		0.396 (0.129,0.664)	
Separated/Divorced/Widowed	1.835 (0.692,2.978)		0.841 (0.053,1.628)		0.939 (0.423,1.454)	
Education: ref.<=Primary school		< 0.001		< 0.001		< 0.001
Junior high school	-1.052 (-1.638,-0.466)		-0.680 (-1.084,-0.277)		-0.409 (-0.676,-0.142)	
Senior high school	-2.000 (-2.690,-1.311)		-1.283 (-1.758,-0.807)		-0.805 (-1.133,-0.476)	
>=University	-0.695 (-2.072,0.682)		-0.430 (-1.379,0.520)		-0.472 (-1.113,0.170)	
Household income(Yuan): ref.=<800						0.049

	Personal stigma		Refusing factor		Blaming factor	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
801-2000					0.409 (0.009,0.809)	
2001-5000					0.205 (-0.162,0.572)	
5001-8000					0.171 (-0.222,0.565)	
>=8001					0.557 (0.124,0.989)	

Comparisons and associations of occupational stigma among healthcare providers by time

Table 30 presents changes of occupational stigma among healthcare providers by time. There was a significantly change in mean score of occupational stigma by time. Age, gender and education were significantly associated with occupational stigma among healthcare providers. Those who were aged more than 33.5 years old had lower occupational stigma than those who were younger. Male healthcare providers had higher occupational stigma than females. Those who received a tertiary education had lower occupational stigma than those without a tertiary education. “Blaming” was significantly associated with time, years of professional experience and job title. Other predictors including job title and years of professional experience were significantly associated with “blaming”. “Professionalism” were significantly associated with time, age and education, while time, gender and household income were associated with “egalitarianism”.

Table 30 multiple linear regression of occupational stigma among healthcare providers

	Occupational stigma		Blaming		Professionalism		Egalitarianism	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
Time: second vs. first	2.096 (0.656,3.537)	< **0.001**	0.970 (0.277,1.663)	**0.005**	0.614 (-0.082,1.31)	**0.033**	0.682 (0.103,1.261)	**0.014**
Age: >33.5 vs. <=33.5	-1.764 (-3.257,-0.270)	0.0107			-0.712 (-1.428,0.004)	0.010		
Gender: male vs. female	3.365 (1.035,5.695)	0.010					0.937 (0.013,1.861)	0.041
Years of professional experience: >7 vs.<=7			-1.105 (-1.844,-0.366)	0.004				
Education: >=University vs. <University	-2.654 (-4.458,-0.850)	0.004			-1.283 (-2.152,-0.415)	0.004		
Job title: ref:=Doctors				0.025				
Nurses			-0.141 (-0.952,0.67)					
Others			1.668 (0.296,3.040)					
Household income(Yuan) ref:<2000								0.046
2001-5000							-0.396 (-1.554,0.762)	
5001-8000							0.466 (-0.648,1.579)	
8001-13000							-0.69 (-1.957,0.577)	
>=13001							-0.089 (-1.519,1.342)	

1.4 Associations between HIV/AIDS stigma and HSR experiences

1.4.1 Associations between internalized stigma and HSR experiences

Table 31 shows associations between seven domains of HSR and internalized stigma after adjusting for anchor vignettes. There was no significant association between internalized stigma and experience in domains of prompt attention, dignity, communication, quality of basic amenities, confidentiality and choice. However, There was a significantly association between autonomy and internalized stigma.

The time was a significantly influencing factor across five domains: prompt attention, dignity, communication, confidentiality and choice. Those who were in the second survey have a better experience compared to the first survey in domains of prompt attention, dignity, communication and confidentiality, whereas in choice domain those who were in the second survey have a worse experience. Age group was significant across three domains, which those who were at more than 60 years old had worse perceived experience in prompt attention, dignity and communication domains than those less than or equal to 40 years old.

Table 31 associations between seven domains of HSR and internalized stigma by censored ordered probit regression adjusted ordering vignettes

	Prompt attention		Dignity		Communication		Quality of basic amenities		Confidentiality		Choice		Autonomy	
	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se
Score of internalized stigma: High vs. Low	-0.01	0.07	0.12	0.08	0.03	0.07	0.03	0.08	-0.03	0.08	0.07	0.08	**0.21**	**0.08**
Time: Second vs. First survey	**-0.35**	**0.07**	**-0.49**	**0.08**	**-0.37**	**0.07**			**-0.28**	**0.08**	**0.34**	**0.08**		
Age: ref.=16-40 (years)														
41-60	-0.08	0.08	**-0.20**	**0.08**	-0.11	0.08								
61-85	**-0.47**	**0.15**	**-0.69**	**0.20**	**-0.62**	**0.17**								
Religious affiliation: No vs. Yes			**0.18**	**0.08**										
Education: ref. <=Primary school														
Junior high school													-0.18	0.10
Senior high school													**-0.33**	**0.12**
>=University													**-0.42**	**0.16**

	Prompt attention		Dignity		Communication		Quality of basic amenities		Confidentiality		Choice		Autonomy	
	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se	Coeff.	se
Occupation: ref.=Government-employed														
Enterprise-employed			-0.10	0.13										
Self-employed			-0.09	0.16										
Unemployed			**-0.27**	**0.14**										

se = Standard error.

1.4.2 Associations between personal stigma and HSR experience

Table 32 shows associations between seven domains of HSR and personal stigma adjusted for ordering vignettes. There was no significant association between personal stigma and domains of dignity, communication, quality of basic amenities, confidentiality and choice. However, prompt attention and autonomy were significantly associated with scores of personal stigma.

The time was a significantly influencing factor across five domains: prompt attention, dignity, communication, choice and autonomy, but there was no increasing or decreasing trends among these domains. Those who were in the second survey have a worse experience compared to the first survey in domains of prompt attention, dignity, choice and autonomy, whereas in communication domain those who were in the second survey have a better experience. Ethnicity and place of residence were significant across two domains. Those who lived in rural area had worse experience among prompt attention and dignity.

Table 32 associations between seven domains of HSR and personal stigma by censored ordered probit regression adjusted ordering vignettes

	Prompt attention		Dignity		Communication		Quality of basic amenities		Confidentiality		Choice		Autonomy	
	Coeff.	se	Coeff.	se	Coeff.	se	Value	se	Coeff.	se	Coeff.	se	Coeff.	se
Score of stigma: High vs. Low	**-0.22**	**0.07**	-0.05	0.07	0.03	0.07	0.13	0.09	0.04	0.08	0.001	0.08	**0.21**	**0.08**
Time: Second vs. First	**0.67**	**0.07**	**0.28**	**0.07**	**-0.37**	**0.07**					**0.917**	**0.08**	**0.54**	**0.08**
Age: ref.=16-40														
41-60					-0.11	0.08								
61-85					**-0.62**	**0.17**								
Ethnicity: Han vs. Other	**0.25**	**0.09**									**-0.209**	**0.10**		
Place of residence: Rural vs. Urban	**-0.21**	**0.07**	**-0.16**	**0.07**										
Education: ref.=<=Primary school														
Junior high school							-0.02	0.11			-0.042	0.10		
Senior high school							**0.25**	**0.12**			0.086	0.11		
>=University							0.21	0.25			**-0.677**	**0.26**		

	Prompt attention		Dignity		Communication		Quality of basic amenities		Confidentiality		Choice		Autonomy	
	Coeff.	se	Coeff.	se	Coeff.	se	Value	se	Coeff.	se	Coeff.	se	Coeff.	se
Occupation: ref.=Government-employed														
Enterprise-employed	-0.50	0.11												
Self-employed	-0.50	0.20												
Unemployed	-0.33	0.10												

se = Standard error.

2. Qualitative study

A total of 21 HIV patients participated in the study, of which 7 were female and 14 were male, while 10 were single or separated or divorced or widowed, and 11 were married or cohabiting in marital status, respectively. 8, 8 and 5 of participants were in the age group <=40 years, 41-60 years and >=61 years, respectively. Ten participants had been taking antiretroviral therapy for less than one year, while 11 were those who took medicine more than or equal to one year.

2.1.1 Feeling and HIV/AIDS stigma among HIV positive patients

The majority of participants had strong reactions when they knew their HIV status, including fear, anger, and a sense of being overwhelmed. Most of them felt lonely, helpless, sad, anxious stressful, and guilty.

> *"I stay alone and feel lonely."*(Participant 5)
>
> *"I felt stigma from people around me without comfort and communication….Now I muddle along, but worried about Wawa (child)."* (Participant 7)
>
> *"I couldn't find work (due to HIV status) and felt despair of life."*(Participant 1)
>
> *"I feel HIV stigma, but just here is the 3rd hospital to receive me."*(Participant 13)
>
> *"There are a lot of patients in Kunming, and we are very helpless. We don`t know how to deal with the disease from the humble beginnings."* (Participant 10)
>
> *"My husband infected to me, and I was so angry…. I just don't understand why I have this disease. My life is indecent. I cannot talk about others because of getting this kind of HIV/AIDS…. It is so sad that I cannot make my friends know (my situation)….Press is very large (for me). It is so sad! ... I am upset. …The society is too LaoHuo (heavy), and too bad. Why does society take the disease?... The society is too CaoNai (disgusting), and to messy."* (Participant 11)
>
> *I am very much grieved over HIV/AIDS.* (Participant 12)

I have psychological burden, because this disease cannot be cured.(Participant 14)

"When the doctor was doubtful HIV/AIDS, I felt a little afraid, and a little surprised."(Participant 16)

"I am not be affordable."(Participant 19)

"(I feel) the guilt." (Participant 6)

Finally, they suffered from heavy social stigma from their families, friends and even healthcare providers.

"The Chinese people have discrimination toward this disease. (HIV patients) will lose friends (in the hometown). I can only develop (my career) in Kunming." (Participant 3)

"Social stigma is very big." (Participant 4)

"When local people find out (some have) HIV, all of local people will know it. They are afraid of me. I drink the water that they used." (Participant 6)

"I cannot say, if I say that others will annoy me….There are a lot of patients in Kunming, and we are very helpless. …The whole family and girlfriend look at me with the sight of discrimination and stigma. …In the general people, this is a disease that cannot contact with others and others reject (us)."(Participant 10)

"I felt stigma from people around me without comfort and communication." (Participant 7)

2.1.2 Better perceived experience of HSR in designated hospitals

The majority of participants found out their HIV/AIDS positive infection due to other diseases diagnosis especially surgeons. Most positive attitude to healthcare responsiveness in the HIV/AIDS monitor system such as treatment with dignity, keeping confidentiality, and providing social support, although there still are some shortages such as insufficient communication, lacking basic amenities and choice of provider.

> *"I just see a doctor in the 3rd hospital, although regular illness can be treated in another hospital."*(Participant 12)
>
> "*I have got the medicine in the centre for Disease Control of Xishan District, and (they) have good service attitude. (However, I) must get the medicine in B Hospital for one year. ...Sometimes, I want to have a good communication. Environment is not good (in designated hospital), and (there are) too many people and motley crew. (Under this environment, I) cannot communicate (with doctors). The doctor seldom explain condition of the disease."* (Participant 3)
>
> *"After the first hemorrhoids surgery, I found out HIV in a traditional Chinese medicine hospital (designated hospital). (I lived in) often follow up after the operation (surgeon), and (doctors had a) good job for confidentiality. ...Psychological dredge is too low. I hope the doctor can communicate with me."* (Participant 5)
>
> *"The doctor Xue in the 3rd hospital and the other doctor in Second people's Hospital give me the maximum support."*(Participant 4) *"He (the doctor of 3rd hospital) spoke detailed, and (also said) living with HIV also is not so bad."*(Participant 13)
>
> *"I am seldom sick, and sometimes I fever and transfused. When I go to hospital to get the medicine, their attitude is very good except for one doctor who is substituted for a prescription."* (Participant 17)
>
> *"...Medical treatment environment is too small."* (Participant 4)
>
> *"Our country have management of district attribution (no much choice to hospitals and doctors)..."* (Participant 6)

2.1.3 Bad perceived experience of HSR even inaccessibility to general hospitals

By contrast, perception of HSR in the general hospital was mainly negative responsiveness such as indignity, betrayal of patients' condition and poor interactions with healthcare providers. Once disclosure of their HIV status, rejection or referral were the normal situation that they faced.

> "*Life is a mess because doctor of surgeon Leak to (my) advisor. The Surgeon doctor is no moral. Chief physician has been nervous (when knowing HIV/AIDS status). The advisor hope (that I) send the positive physical report to him, and also review blood routine test report."*(Participant 2, a medical master student.)
>
> "*My husband was sick, then found out HIV positive. After that, I also found out. Hospital A (general hospital) rejected my husband, and then transferred him to the designated hospital. (I) felt stigma from people around me without comfort and communication. ... (I) held up by myself step by step...*" (Participant 7)
>
> *"His (a locum doctor) attitude is very scurvy. He abused him who did not abide by* orders*. He said to another patient: "you are those who don't save your lives." ..."Having HIV/AIDS is Zuo (acted silly or daring) by yourself."... "In Kunming, it is normal when I see a doctor."*(Participant 1, MSM)
>
> "*All of other hospitals do not receive me. There is no other place to see a doctor. It is good in the 3rd hospital (designated hospital).*" (Participant13)
>
> *If (I) need surgeon, it will not be convenient because others will know my HIV status".* (Participant 10)

Majority of HIV patients worry about the HIV/AIDS care that cannot be affordable when catastrophic illnesses coming.

"I couldn't find work (due to HIV status) and despair of life. ... Worry about no place to see a doctor (when disease is heavy). When I need surgeon, whether can we do in other hospital?" (Participant 1)

"The Chinese people to this disease have discrimination. (HIV patients) will lose friends (in the hometown). I can only develop (my career) in Kunming." (Participant 3)

"There are a lot of acquaintance in hometown, and there is no infectious department in state hospital. So, I choose to take medicine in Kunming. ...All diseases (among our HIV patients) are treated by doctors of infectious departments, but they cannot deal all kinds of illness. So, I worry about no doctors and diagnosis when I had a catastrophic illness."(Participant 9)

"(Although) it is convenient to see a doctor in designated hospital.... If (I) need surgeon, it will not be convenient because others will know my HIV status". *(*Participant 10)

2.1.4 HIV/AIDS stigma as a barrier to access to healthcare

Majority of HIV patients firstly chose the hospital or treatment by themselves due to heavy HIV/AIDS stigma, although these hospitals generally are lack of excellent experts and amenities compared to comprehensive hospitals. It was a formidable barrier for PLWHA seeking healthcare due to less positive attitudes and dignity, lack of communication with HIV/AIDS condition, lack of supportive or understanding, absence of good clinic environments and lack of confidentiality especially in the general hospital.

"*If I need surgery, I will choose the designated Hospital (rather than the local hospital). When local people find out (some have) HIV, all of local people will know* *it. They are afraid of me. I drink the water that they used, (I will feel) the quilt. …Our country have management of district attribution…*" (Participant 6)

"The attitude of doctors made me think suicide… When my husband got meningitis, they (doctors) just gave him medicine. I treated him for half a year by IV fluids. Now I muddle along, but worried about Wawa (child)." (Participant 7)

"Communication environment is not good (in designated hospital), and (there are) too many people and motley crew. (Under this environment, I) cannot communicate (with doctors). Doctors seldom explain condition of my disease." (Participant 3)

"*(The words that) the doctor said were very bluntly, and (they) depended me on the experimental animal with casual adjust medicine… The doctor in a County hospital (general hospital) unexpectedly wrote HIV/AIDS in (records of) discharge diagnosis to announce my condition without confidentiality."* (Participant 8)

"I feel HIV stigma, but just here is the 3rd hospital to receive me." (Participant 13)

"(I) am ostracized by my advisor (of a medical master student) duo to my HIV status."(Participant 2)

"The attitude of doctors made me think suicide…" (Participant 7)

The most worry is that when I go to see a doctor, I will suffer from HIV stigma. …I dare not find the doctors that I knew. I just can find the doctors that I did not know. …I baffled. " (Participant 11)

2.1.5 Re-entry into Life

There were kinds of methods to support HIV/AIDS patients, including self-support, family support and healthcare providers support. The majority of Participants took care for themselves, and also support from their family and healthcare providers. Several people ended up their negative feelings, and remained healthy to go on living well.

> "*I ever had a boyfriend drug used, and he died maybe due to HIV/AIDS. ...A lot of friends suspected me of having HIV/AIDS. ...I need live well to wipe their suspects and tell everyone (that I am good). ...I need save myself in the range of my ability. ...I already clear their suspects in ten years. I am very well now. ...My husband* is non-*HIV infection, and he also know my condition. We want to have a child. ...The universal knowledge is too deficient, and the knowledge that we want to get also is too insufficient."* (Participant 9)

> *"Face with reality (having HIV). ...Look far from the target; Look far from lives. Do not hate yourself; forgive yourself. Happy every day!*"(Participant 10)

> *"There is no a curative method. After my death, I will donate myself to Medical profession for anatomy and researches".* (Participant 10)

> *"Sometimes I study from the life, sometime call doctor li to ask."*(Participant 4)

> *"I held up by myself step by step. …When my husband (also HIV/AIDS patients) got meningitis, they (doctors) just gave him medicine. I treated him for half a year by IV fluids."* (Participant 7)

> *"I need be cautious to choose spouse, and have a new friend who does not know my HIV status. I will do protective measures."*(Participant 17, MSM)

> *"I comfort myself."*(Participant 11)

> *"Thing happened, I just head on."* (Participant 19)

> *"My husband is non-HIV infection, and he also know my condition. We want to have a child."* (Participant 9)

> *"My husband is the only one who know my situation. He did not blame me, and make me take medicine well.*" (Participant 11)

> *“Sometimes I study from the life, sometime call doctor li to ask.*(Participant 4)

> *Supports of hospitals come from the 3rd hospital and KunShan hospital of Anning.*(Participant 20)

2.1.6 Competency in clinical aspects

Although there were better perceived experience of HSR, the doctors were perceived as lack of competency in clinical aspects.

> *“The universal knowledge is too deficient, and the knowledge that we want to get also is too insufficient.”* (Participant 9)

> *“Their hospital (3^rd^ hospital) is not good at treat a disease although HIV stigma is not obvious.”*(Participant 11)

> *“However, medical condition in the 3^rd^ hospital is limited. If they can treat, I will receive treatment.”* (Participant 13)

> *“We need doctors who have high quality and majored in difficult and complicated disease.”*(Participant 17)

CHAPTER 4

DISCUSSION AND CONCLUSIONS

1. Discussion

1.1 Expectation and perceived experience of HSR

HIV patients had lower expectation scores in all health system domains even after adjustment by demographic and socio-economic factors, reflecting lower expectations of the healthcare system. Additionally, HIV patients had better perceptions of experiences about self-rated healthcare responsiveness in six HSR domains, prompt attention being the only exception, after adjustment for demographic and socio-economic factors. After adjusting for anchoring vignettes, HIV patients still had better perceptions of experiences about healthcare responsiveness in these six domains. Compared to OPR models without anchoring vignettes, all the coefficients reduced in COPR models reflecting more narrow and valid differences among HIV and non-HIV patients without bias due to reporting heterogeneity.

After adjustment for anchoring vignettes, gender, ethnic group and occupation were significantly associated with perceived experience in prompt attention. In dignity domain, those who received the education in senior high school and university or more had a worse experience than those in primary school, whereas in quality of amenities domain those who received education in junior high school had a worse experience. Those who lived in a family of size 2-4 people had a worse perceived communication experience than those who lived alone.

There were significant increases in seven proportions of “good” perceived experience of HSR by time. However, increasing and decreasing trends could not find in the proportion of “very good” and “bad” or “very bad”. In terms of expectation of HSR, increasing changes existed in dignity, prompt attention, communication, quality of basic amenities, confidentiality, and choice domains except for social support and autonomy domains by time.

1.1.1 Lower expectation of HSR in eight domains among HIV patients

HIV patients had lower expectation scores in all health system domains even after adjustment by demographic and socio-economic factors, reflecting lower expectations of the healthcare system. Compared to non-HIV patients, they were slightly younger, belonged to a minority ethnic group, more religious affiliation, more educated, self-employed, more likely to be single or separated and had lower household incomes. Thus, on top of having a lower SES, HIV positive patients in this study were further oppressed by their own HIV status.

Not many studies have focused on differences in expectations of healthcare system between HIV and non-HIV patients across socio-economic status. One study showed that patient's satisfaction with nursing care was associated with younger age, being male, being non-white and having HIV[142]. However, that study did not find an independent effect of being HIV positive after adjustment for socio-economic factors.

Among the eight health system domains, prompt attention was found to have the highest difference of expectation between HIV positive and non-HIV patients. The low expectation by HIV patients confirmed that there is a shortage of human resources and a lack of an efficient mechanism to uniformly cooperate in HIV/AIDS care. Additionally, quality of basic amenities is linked to health facilities. One study confirmed that this domain is not strongly correlated with clinical quality, and depends on different hospitals in terms of productivity based on instrumental variables [143]. The lower expectation of HIV patients towards basic amenities reflects their helplessness about dissatisfaction with designated hospitals because of not only limited medical resources but also "logistic choices"[144] to hospitals or providers. Another study[145] considered consulting the same healthcare provider to be a source of comfort in provider-patient relationships. However, the comforting affection from seeing the same provider is on the premise that patients have free choice[146,147] rights. The monitoring and evaluation system of China cannot equally share the whole medical resources, and there is lack of effective operational mechanisms to respond timely to the patient's needs. Under this system, the free choice rights of HIV patents have not been taken into account.

The lower HIV patient expectation in confidentiality can sometimes create a dilemma for health professionals or family members because there is a fine line between safeguarding their privacy and the need to inform other people about their illness. Some studies documented the benefit to patients, especially those with HIV/AIDS, based on human-rights, but others hold the opposite view[148-150]. Besides these, some suggested to identify boundaries of confidentiality[151]. Only in the safe context can "silences" be broken. The majority of people living with HIV/AIDS (PLWHA) often avoid naming themselves in public, to their neighbours, and even sometimes to their own family members. As a marginalized population, they are more vulnerable because of the heavy HIV/AIDS stigma[28,152], especially discrimination by healthcare providers, so they keep "silent" in unsafe contexts. When disclosing their HIV status, the majority of providers in non-appointed hospitals will refuse to examine and treat them and transfer them to special HIV unit. The majority of HIV positive patients must tolerate the negative talk and stigmatizing attitudes by healthcare providers. During their care, there was no dignity[153] given to them because of a lack of effective communication, and lack of prompt attention and respect for individual autonomy[154] such as self-decisions and meaningful participation. Thus, elimination of stigma is an important goal in the struggle against HIV/AIDS for subsequent HIV testing and counselling, and adherence to antiretroviral therapy. Additionally, confidentiality, choice of provider, dignity and clarity of communication are deserved rights of HIV positive patients. Adopting a human rights-based approach towards care of HIV/AIDS patients can be very helpful to improve access to HIV prevention, care and treatment.

In terms of social support, HIV patients had a lower expectation compared to their counterparts. Most HIV positive patients expect that they will stay by themselves in hospital, but other patients expect care and contact from their family and friends. The fact that HIV patients abandon their right of access to family and community support may be a consequence of social stigma. Other evidence has shown that decision-making interventions[155] can improve quality of healthcare. This suggests that empowerment of HIV patients within the healthcare system will strengthen quality of healthcare.

1.1.2 *Perceived experience of HSR in seven domains among HIV patients*

HIV patients had better perceptions of experiences about self-rated healthcare responsiveness in six HSR domains, prompt attention being the only exception, after adjustment for demographic and socio-economic factors. After adjusting for anchoring vignettes, HIV patients still had better perceptions of experiences about healthcare responsiveness in these six domains. Compared to OPR models without anchoring vignettes, all the coefficients reduced in COPR models reflecting more narrow and valid differences among HIV and non-HIV patients without bias due to reporting heterogeneity.

Better experience of HSR in six domains among HIV patients

Perception about experience of dignity, communication, quality of basic amenities, confidentiality, choice and autonomy among HIV patients were better compared to their non-HIV counterparts. Many studies among HIV patients showed "logistic choices"[144] to providers or hospitals and lack of dignity[153] without respect for individual autonomy[154] such as medical participation and self-decisions in HIV care. HIV patients kept more appointments when treated with dignity and patient-centred communication[156,157], because of communication preferences[158] and patient satisfaction[159]. Meanwhile, providers also need to recognize boundaries of confidentiality[151]. Conversely, one study showed that HIV patients were highly satisfied with pharmaceutical services[160]. A possible explanation for the finding that HIV patients perceived better HSR than non-HIV patients in this study may be as follows:

Our findings that the perceived HSR among HIV participants was significantly better than the non-HIV counterparts may reflect the successful evolvement of HIV care in the country. Good care to HIV participants is a part of the attempt to control HIV such as good treatment efficacy of highly active antiretroviral therapy[161] and integrations of community and public HIV services[162]. HIV prevention has steadily been supported first by internal findings such as Global Fund[163,164] and currently become internalized. Studies in China recently focused on scale-up[165,166] to increase the number of individuals knowing their HIV status and development[167,162] for access to HIV-related services. On the other hand, non-HIV healthcare is overwhelmed by several problems including inequalities of health care utilization[168] and high out-of-pocket payments[169] due to high care load and inadequate finance. In 2012, the wealthiest 20% of urban and rural population contributed 49.7% and 55.8% of total health expenditure, respectively, while the poorest 20% took only 4.7% and 4.4% in China[170]. This finding indicates a need to improve care for patients in general.

Worse experience of HSR in prompt attention among HIV patients

HIV patients had worse perceptions about experience of prompt attention domain compared to their counterparts. There has been no study comparing the experience of HSR between HIV and non-HIV patients. One study in South Africa showed that prompt attention had the lowest degree of perceived responsiveness among older adults in the inpatient care[17]. Prompt attention may be seen as a priority domain to improve HSR. There is probably a shortage of human resources[54,171] and a lack of an efficient mechanisms for HIV/AIDS personal to uniformly cooperate with each other[24].

1.1.3 Valid method of anchoring vignettes for obtaining perceptions of HSR

Anchoring vignettes were used to narrow differences of perception about experiences of HSR between HIV and non-HIV patients, thus controlling for patients` own expectations. Our results using vignettes are consistent with a study by Hanna etc[172]. This indicates that using anchoring vignettes to adjust for self-rated HSR is valid: our vignettes were comprehensible to our patients and showed minimal violation of the method`s measurement assumptions. Thus, using anchoring vignettes may be a valid method to measure perceptions of HSR to control for differential item functioning so as to avoid incorrect research findings.

1.2 HIV/AIDS related stigma

In our study, 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 healthcare providers, three factors were identified reflecting feelings of contradiction between social norms (blaming) and professional values (professionalism and egalitarianism). There were significant relationships between various demographic characteristics and these latent factors. However, there was no consistent pattern among the three groups.

Differences of mean scores of internalized and personal stigma were not significant by time. However, there was a significant difference of occupational stigma by time among healthcare providers. Age was significantly associated with internalized and occupational stigma among HIV patients and healthcare providers. There was an association between marital status and internalized, personal stigma, respectively, while education was significantly associated with personal and occupational stigma.

1.2.1 Two latent factors in internalized and personal stigmas and three latent factors in occupational stigma

Our finding 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 healthcare providers, three factors were identified reflecting feelings of contradiction between social norms (blaming) and professional values (professionalism and egalitarianism). There were significant relationships between various demographic characteristics and these latent factors. However, there was no consistent pattern among the three groups.

Being refused vs. refusing and guilt vs. blaming were two latent factors among internalized and personal stigma scales suggested by EFA and CFA. Perceptions of guilt and shame are two painful self-conscious emotions. Some researchers have repeatedly confirmed their distinctiveness[35,36]. Guilt is associated with self-blame related to one's own behaviour, whereas shame is associated with self-blame at a deeper level where the individual sees their global self as being at fault[37]. 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[38]. Thus, guilt-prone individuals may utilize more avoidant strategies such as abandoning utilization of healthcare in order to avoid social interactions. It also may 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.

Powerful "being refused vs. refusing" factor associated with internalized and personal stigma

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[39] so as to avoid further refusal. Being refused is also manifested in the forms of social isolation [40] 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 "neighbours would not like to live next door to me" were included in our results among patients that were not included in the African study[25]. This implies that Chinese tend to repel HIV positive patients more so than people from Africa, a country known to be the epicentre of HIV/AIDS. Feelings of refusing and blaming come not only from non-HIV patients but are also stemmed from community members who reside near PLWHA.

Consistent blaming factor among non-HIV patients and providers

Our study found consistent blaming factors among non-HIV patients and healthcare providers. One study[41] showed that strained, distant relationships with family members or friends or both were a source of shame. Based on the labelling theory of Scheff [42], the application of deviant stereotypes makes those who are faced with changed self-perceptions and social opportunities devalue and be labelled. The majority of the general population doesn't want to employ PLWHA, or be their neighbour, friend, or intimate partner, and tend to regard them as being less trustworthy, intelligent, and competent. Once a person is labelled, powerful social forces come into play to encourage a stable pattern of stigma.

1.2.2 Higher and lower correlation among HIV patients and healthcare providers

Guilt and feelings of being refused had a relatively higher correlation among HIV patients (0.54) than among healthcare 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. When changing 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 above, 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 behaviours.

Low levels of correlation among stigma factors found in healthcare workers in our study reflect independence. A previous study[30] identified internalized shame among healthcare providers, a contrast to this study. The attitude of healthcare providers towards HIV patients is mainly built on a mainstream culture of associations between HIV/AIDS and immoral behaviours. A coexistence of blaming on one hand and professionalism[43,44] and equalitarianism[45] on the other hand indicated a contradiction between knowledge/competence in care and attitudes towards HIV/AIDS patients[28,46,47]. It also reflected a contradiction between stigmatized attitudes acquired from the community and professional knowledge and competence on HIV/AIDS care.

1.2.3 Subscales strongly associated with marital status and education

Among the three study groups, each of the subscales associated with measures of sample characteristics further validated the independence of each factor reflecting that they are representative of an independent sub-stigma mechanism[8-10].

Marital status was the strongest predictor across all latent factors of internalized and personal stigma among both patient groups. Marital status strongly influences disclosure of HIV status[48], and is also known to have a significant association with quality of life[49]. The association may stem from relationships between marital status and psychology reflecting unmet inner needs and emotional frustrations. Based on social cognitive theory[50], 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 healthcare providers. Those having the higher education were less likely to blame patients and more likely to treat patients professionally and equally. One study [51] suggested that poor knowledge of HIV resulted in more blaming towards PLWHA. A spirit of professionalism and excellence of patient care provided a strong foundation for the planning and delivery of health services [52]. Furthermore, egalitarianism of healthcare providers should compensate for those who were HIV positive in order to close inequalities based on Luck Egalitarian theory[53].

1.3 Difference of HSR and HIV/AIDS stigma by time

There was almost no change in levels of HSR and multitude of internalized and personal stigma between the first and second surveys. There are few studies about changes of health system responsiveness and HIV/AIDS stigma by time. A study found that stigma in the baseline was significantly related to decreased adherence over time[173]. Another showed that proportion of 84% of reported HIV-stigma events declined to 64.9% after one-year intervention[174] among PLWHA. These were inconsistent with our results. The first reason may be due to the study design, which is a repeated cross-sectional study so that different people consisted of two rounds.

Although characteristics of two surveys were similar, the effect over time still cannot show precisely. Longitudinal studies are needed to follow up the same HIV patients.

Another reason possibly came from our weak feedback, which was toward healthcare providers measured by patients. A Chinese study found that intervention towards market workers successfully reduced the level of HIV-related stigmatizing attitudes[175] among them using the community-based diffusion. It suggested that intervention and measurement toward the same population should be implemented in future studies.

After feedback there was an increased trend of occupational stigma among healthcare providers. Some studies showed that interventions using diffusion of innovation theory successfully reduced HIV/AIDS stigma to PLWHA among healthcare providers[176,177] and communication workers[175]. The content of feedback should focus on target population so as to improve the effect of intervention. The method of feedback based on diffusion of innovation theory maybe was not well adapted to this study. It also suggested that the root reason of healthcare inequity probably came from the healthcare system itself rather than healthcare providers or patients.

1.4 Polices to suggestion

1.4.1 Policies towards lower expectation of HSR among HIV care

Policies in China such as “Four Frees and One Care” has had a great success on expanding the coverage of prevention of mother-to-child transmission and antiretroviral therapy. Another policy called “HIV/AIDS regulation” first highlighted human rights’ protection in early 2006[178]. However, the effects of empowering these marginalized people in China is lacking. Evidence has shown that empowerment of PLWHA has resulted in policy changes, especially regarding access to free antiretroviral therapy. For example, Thailand’s response to HIV/AIDS is considered one of the best success stories due to civil society groups[179] as networks at different levels promoted the efficient coordination of activities. Free access to antiretroviral therapy has brought massive relief, restoring people’s health and enabling them to care for families, providing hope for the future and allowing PLWHA to participate in community activities[180]. In addition, success of Treatment Action Campaign in South Africa, a powerful force in converting donor perceptions of universal access to treatment into a moral imperative[181], led to policy changes for a global impact in 2004. However, free access to antiretroviral therapy cannot replace empowerment of PLWHA in which human rights and fundamental freedoms can be realized.

1.4.2 Policy of Zero discrimination

WHO and other international organizations such as UNAIDS and SANAC have advocated “zero discrimination” since 2011. Overall, our study has highlighted that HIV/AIDS stigma is still common in 2014. In China, the strategy to control HIV indeed achieves universal health coverage and promotes a people-centred approach grounded in principles of human rights and health equity. However, for over ten years more than 50% of PLWHA were still fearful of disclosing their infectious status, while almost 80% were afraid of being blamed or being refused in 2013[54]. More efforts are still needed to achieve these goals, especially in health settings[55].

1.5 Limitations

There are some limitations in our study, which should be acknowledged. Firstly, we could not involve patients-family-friends relationships during the decision-making process of seeking health care services in our vignette because there are various roles that family or friends play in Chinese culture. Moreover, selection bias was unavoidable since those who did not seek healthcare services or did not know their HIV status were not recruited into this study. Thirdly, a poorer response rate among the non-HIV group may have affected the internal validity of the study. However, this imbalance was in the same direction of the main results in which non-HIV patients perceived poorer HSR. Despite the findings in favour of HIV care, the generalizability of this study is still limited due to the fact that the data were collected from only two hospitals in one province of China. Finally, the sample size of healthcare providers was rather small, thus it is possible that the situation in other institutes may be different.

2. Conclusion and recommendations

2.1 Conclusion

This study compared the perceived experience and expectation of health system responsiveness separately between HIV positive patients and non-HIV patients by adjustments of demographic and socio-economic factors. Using anchoring vignettes, this study re-compared the perceived experience of HSR by adjustments of demographic and socio-economic factors. Predictors of perceived experience and expectation of HSR were identified through ordered probit regression (OPR) and censored ordered probit regression (COPR) models. This study also compared the trends of HIV/AIDS stigma and perceived experience of HSR by time. HIV/AIDS stigma included internalized stigma among HIV positive patients, personal stigma among non-HIV patients and occupational stigma among healthcare providers in healthcare setting. Before comparisons of HIV/AIDS stigma, our study firstly developed and validated scales for measuring individual HIV related stigma among the three groups. Exploratory factor analysis (EFA) was used to examine factor structure. Then, construct validity was evaluated using confirmatory factor analysis (CFA) and the discriminative validity was assessed in another group of subjects.

HIV patients had lower expectation scores in all health system domains even after adjustment by demographic and socio-economic factors, reflecting lower expectations of the healthcare system. On top of having a lower SES, HIV positive patients in this study were further oppressed by their own HIV status. Additionally, HIV patients had better perceptions of experiences in six HSR domains, prompt attention being the only exception, after adjustment for demographic and socio-economic factors. After adjusting for anchoring vignettes, HIV patients still had better perceptions of experiences in these six domains. Compared to OPR models without anchoring vignettes, all the coefficients reduced in COPR models reflecting more narrow and valid differences among HIV and non-HIV patients without bias due to reporting heterogeneity. EFA and CFA revealed a two-factor solution for internalized and personal stigma scales (guilt/blaming and being refused/refusing service) and a three-factor structure (blaming, professionalism and egalitarianism) of occupational stigma scale. Marital status was the strongest predictor across all latent factors of internalized and personal stigma among both patient groups. Education was significantly associated with blaming, professionalism and egalitarianism among occupational stigma of healthcare providers.

2.2 Recommendation

Comparison between health system responsiveness and HIV/AIDS stigma among HIV and non-HIV patients may explore effective strategies to evaluate quality of healthcare in our study. Our HIV/AIDS stigma scales are valid to measure different types of stigma, whereas anchoring vignettes may be valid to measure healthcare quality. HIV status oppressed HIV patients to express lower expectation and better perceived experience than non-HIV patients.

2.2.1 Clinical implications

The current stigma scales developed so far are reliable and valid for evaluation of different types of HIV/AIDS stigma from different perspectives in clinical settings. These scales should be used to monitor HIV/AIDS stigma in different groups of Chinese people in healthcare settings. Using anchoring vignettes to adjust for self-rated health system responsiveness may be a valid method to measure perceptions of HSR to control for differential item functioning so as to avoid incorrect research findings. Thus, methods of anchoring vignettes should be included in questionnaires which evaluate non-clinical quality of healthcare service in other Chinese healthcare settings.

2.2.2 Public health implications

HIV patients had lower expectation scores in all health system domains even after adjustment by demographic and socio-economic factors, reflecting lower expectations of the healthcare system. On top of having a lower SES, HIV positive patients in this study were further oppressed by their own HIV status. During HIV care, the majority of HIV positive patients tolerate the negative talk and stigmatizing attitudes by healthcare providers. Elimination of stigma is an important goal in the struggle against HIV/AIDS for subsequent HIV testing and counselling, and adherence to ART. Additionally, confidentiality, choice of provider, dignity and clarity of communication are deserved rights of HIV positive patients. Adopting a human rights-based approach towards care of HIV/AIDS patients can be very helpful to improve access to HIV prevention, care and treatment. Empowerment of HIV patients within the healthcare system will strengthen quality of healthcare.

In addition, HIV patients had better experiences of HSR in six domains, prompt attention being the only exception, after adjustment for demographic and socio-economic factors using anchoring vignettes to adjust for self-rated HSR. Better perceived HSR experience may reflect the successful evolvement of HIV care in China. The successful strategies such as steady support by the Global Fund and internalized effective results should be implemented consistently. On the contrary, non-HIV healthcare is overwhelmed by several problems, which include inequalities of health care utilization and high out-of-pocket payments due to high workloads and inadequate budgets. It suggests a need to improve care for ordinary patients in general to eliminate inequity of healthcare so as to meet the expectation and demands of patients.

2.2.3 Research implications

According to the results of this study and considering previous studies, anchoring vignettes can be a good approach for estimation of health system responsiveness in healthcare settings. In consideration of influences of healthcare-seeking behaviour by family and friends in a Chinese culture, an additional qualitative data collection for patients-family-friends relationship may be an alternative way to establish stronger and more comprehensive domains in anchoring vignettes for further causal relationship or otherwise.

Documenting development of HIV/AIDS stigma scales, our scales are reliable and valid to measure different types of HIV/AIDS stigma in healthcare settings. Studies on HIV/AIDS stigma in China are lacking especially data in healthcare settings. Further studies should use the scales to monitor HIV/AIDS stigma in different groups of Chinese people in healthcare settings in order to eliminate HIV/AIDS stigma for improvement of quality of healthcare.

Exploring risk factors of expectation of health system responsiveness, HIV status was the single factor to oppress HIV patients on top of having a lower SES. Even after adjustments of patients own expectations, perceived experience of HIV positive patients were still oppressed by their own HIV status. Further studies in this area to evaluate the non-clinical aspects of healthcare service quality are needed to confirm these findings elsewhere and in other settings.

Examining trends of health system responsiveness and HIV/AIDS stigma by time, there were no obvious changes in this study. Cohort studies are conducted to observe deep cause-and-effect relationships and provide a confirmation on the trends by over time. Intervention studies can also be carried out to explore effective strategy to close the inequity of healthcare service. The follow-up data will provide deep relationship and effective strategy to improve health system responsiveness and eliminate HIV/AIDS stigma in healthcare settings.

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ANNEXS

Annex 1: Information sheet and informed consent form for interview

"Comparison of health system responsiveness and HIV/AIDS stigma among HIV and non-HIV patients in healthcare settings in Yunnan, China: a series of surveys"

Part 1 Information sheet

Dear Participant,

(I will invite doctors` patient to another clinic room, where there is nobody except me. I will close the door to ensure there is no one who will hear us from outside. Before that, explanation why I close the door in order to make him/her feel comfortable and free. Then, I will introduce myself and explain the research to candidates for consent to take part in our research.)

My name is Li Jing. I work in Kunming Medical University as a lecturer. I am also a PhD student of Epidemiology in Prince of Songkla University, Hat Yai, Thailand. I will introduce you the study and invite you to take part in. I am principal investigator of the study.

Understanding of the magnitude of health system responsiveness (HSR) and comparison of differences among HIV positive and non-HIV patients could help to reflect healthcare equity controlled by clinical outcomes and other possible associated factors. Due to the lack of the magnitude and differences of HSR among HIV and non-HIV patients, the results of HSR as a strategy will increase health equity and quality of life. In this study, we aim to examine the level of stigma and responsiveness for HIV and non-HIV healthcare system and identify predicators of HSR among HIV positive and negative patients in Yunnan, China. In addition, the study is aimed to develop scales of patients' perceived stigma and HSR to relevant healthcare providers of the study hospitals.

It is freely to you to join this study. Whether you join this study will not alter the kind of care you will get at the hospital. If you agree to join this investigation, I will inquire you about your personal and socioeconomic characteristics, your family and health provider`s characteristics associated with HIV/AIDS stigma and health system responsiveness. The survey will last about forty to sixty minutes.

The risk by joining this study is negligible. However, you may feel uneasy in talking about some aspects associated with family characteristics and your perception about health system responsiveness and HIV/AIDS stigma. You can refuse to answer any questions if you think it makes you uneasy.

When you take part in the project and complete the questionnaires, you will get 10 RMB as compensation. Your participation will be valuable to provide useful information for healthcare services and policy formulation.

Approvals: Written and signed approval from Prince of Songkla university ethical review board and Kunming Medical University ethical review board also were accomplished before embarking any data collection or research activities.

Confidentiality: All the information will be kept anonymously. No identification contents will be used. A written certificate of consent will be signed by both the researcher and you.

Right to refuse: You have the right to either agree or disagree to take part in this study. Where you agreed on the participation of study and then you have right to refuse any question to answer or terminate the study. When you agreed on the participation at the beginning, you also have right to stop or withdraw the research without consequence at any time. All the participation will volunteer and no incentive will be given for study.

Contact person: For any question before making a decision to join in the study, you can contact with Li Jing in Kunming Medical University, Kunming, Yunnan, China

Mobile number: 13708857880; E-mail:1518556986@qq.com

You also can contact Kunming Medical University ethical review board via telephone number: 0871-65922935.

Address: Kunming Medical University 1168 West Chunrong Road, Yuhua Avenue, Chenggong District, Kunming 650500, Yunnan, P.R.China.

I am fully understood the above information concerning to intervention study.

I have read or been informed of the above information. Any question concerning to this research has been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to refuse the study at any time.

Data: / /

Part 2 Certificate of informed consent form

I have been asked to join in study on “Comparison of health system responsiveness and HIV/AIDS stigma among HIV and non-HIV patients in healthcare settings in Yunnan, China: a series of surveys”

I have read the foregoing information, or it has been read to me. I have had the chance to quest about it and the questions have been replied to my satisfaction. I agree to join this study.

Name of participant________________________________

Signature of participant ________________________________

If illiterate

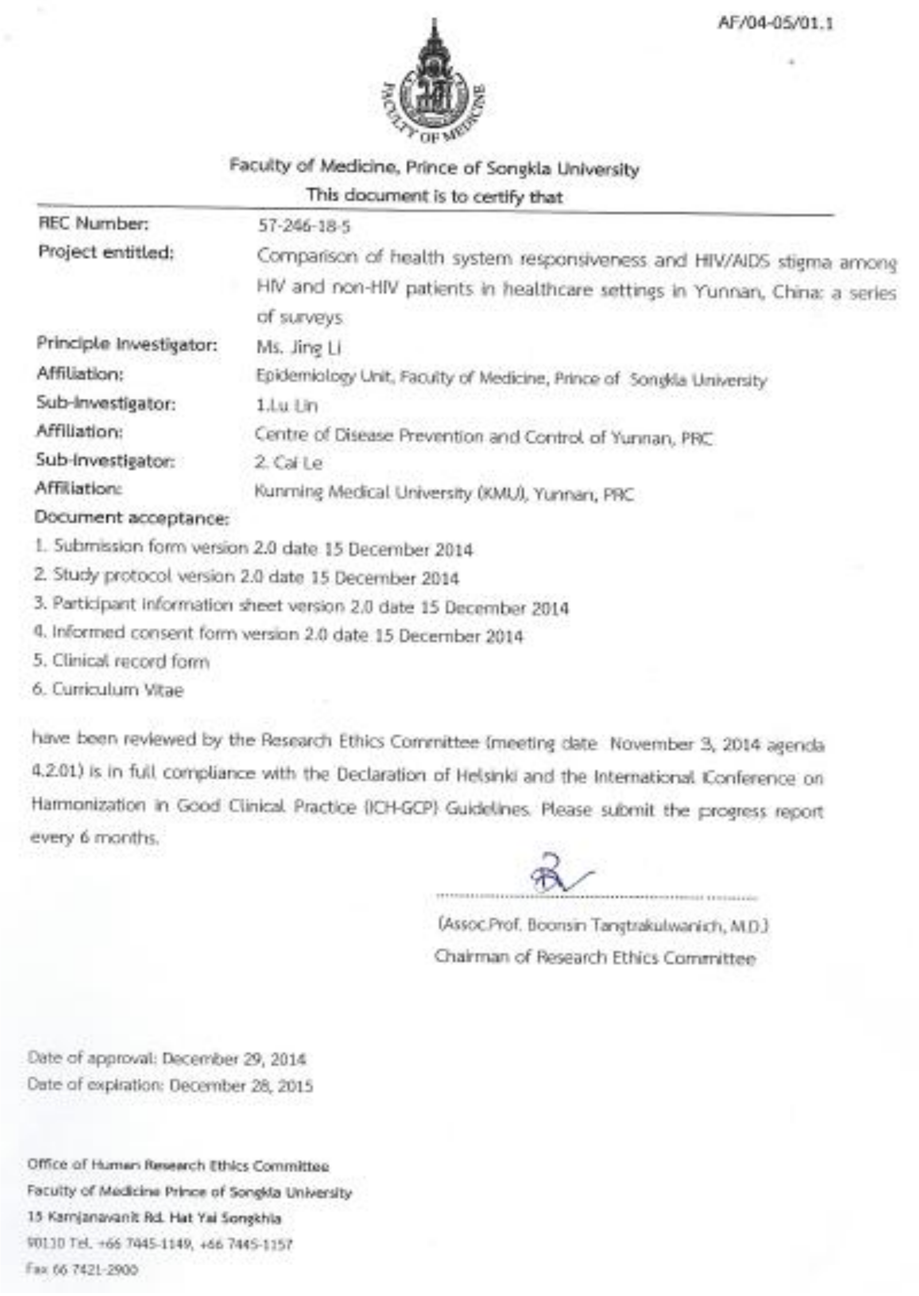
Left	Right

Date ________________________________

Place ________________________________

Signature of researcher _______________________________

Part 3 **Ethical Approval Document**



AF/04-05/01.1

Faculty of Medicine, Prince of Songkla University

This document is to certify that

REC Number:	57-246-18-5
Project entitled:	Comparison of health system responsiveness and HIV/AIDS stigma among HIV and non-HIV patients in healthcare settings in Yunnan, China: a series of surveys
Principle Investigator:	Ms. Jing Li
Affiliation:	Epidemiology Unit, Faculty of Medicine, Prince of Songkla University
Sub-Investigator:	1.Lu Lin
Affiliation:	Centre of Disease Prevention and Control of Yunnan, PRC
Sub-Investigator:	2. Cai Le
Affiliation:	Kunming Medical University (KMU), Yunnan, PRC

Document acceptance:

1. Submission form version 2.0 date 15 December 2014
2. Study protocol version 2.0 date 15 December 2014
3. Participant information sheet version 2.0 date 15 December 2014
4. Informed consent form version 2.0 date 15 December 2014
5. Clinical record form
6. Curriculum Vitae

have been reviewed by the Research Ethics Committee (meeting date November 3, 2014 agenda 4.2.01) is in full compliance with the Declaration of Helsinki and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP) Guidelines. Please submit the progress report every 6 months.

(Assoc.Prof. Boonsin Tangtrakulwanich, M.D.)
Chairman of Research Ethics Committee

Date of approval: December 29, 2014
Date of expiration: December 28, 2015

Office of Human Research Ethics Committee
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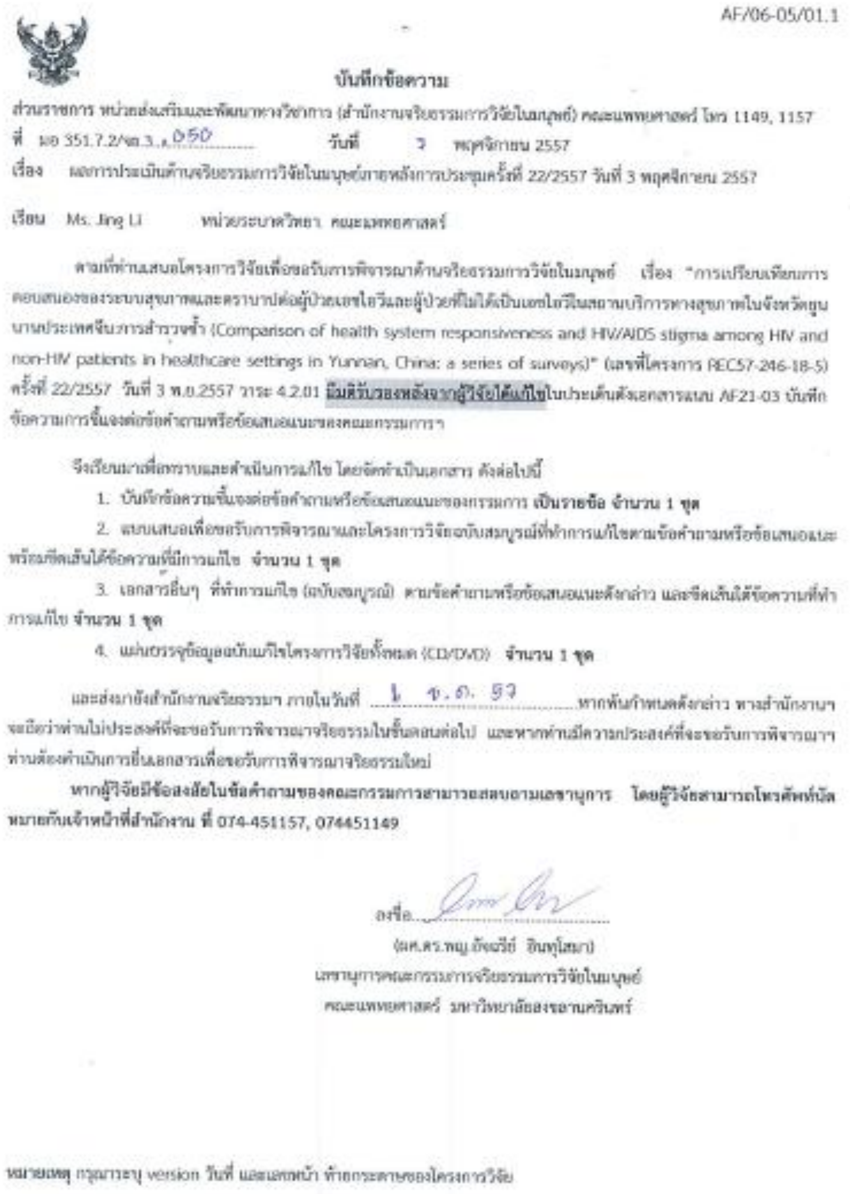

AF/06-05/01.1

บันทึกข้อความ

ส่วนราชการ หน่วยส่งเสริมและพัฒนาทางวิชาการ (สำนักงานจริยธรรมการวิจัยในมนุษย์) คณะแพทยศาสตร์ โทร 1149, 1157
ที่ มอ 351.7.2/จต.3..050 **วันที่** ๖ พฤศจิกายน 2557
เรื่อง ผลการประเมินด้านจริยธรรมการวิจัยในมนุษย์ภายหลังการประชุมครั้งที่ 22/2557 วันที่ 3 พฤศจิกายน 2557

เรียน Ms. Jing Li หน่วยระบาดวิทยา คณะแพทยศาสตร์

ตามที่ท่านเสนอโครงการวิจัยเพื่อขอรับการพิจารณาด้านจริยธรรมการวิจัยในมนุษย์ เรื่อง "การเปรียบเทียบการตอบสนองของระบบสุขภาพและตราบาปต่อผู้ป่วยเอชไอวีและผู้ป่วยที่ไม่ได้เป็นเอชไอวีในสถานบริการทางสุขภาพในจังหวัดยูนนานประเทศจีน:การสำรวจซ้ำ (Comparison of health system responsiveness and HIV/AIDS stigma among HIV and non-HIV patients in healthcare settings in Yunnan, China: a series of surveys)" (เลขที่โครงการ REC57-246-18-5) ครั้งที่ 22/2557 วันที่ 3 พ.ย.2557 วาระ 4.2.01 **มีมติรับรองหลังจากผู้วิจัยได้แก้ไข**ในประเด็นดังเอกสารแนบ AF21-03 บันทึกข้อความการชี้แจงต่อข้อคำถามหรือข้อเสนอแนะของคณะกรรมการฯ

จึงเรียนมาเพื่อทราบและดำเนินการแก้ไข โดยจัดทำเป็นเอกสาร ดังต่อไปนี้

1. บันทึกข้อความชี้แจงต่อข้อคำถามหรือข้อเสนอแนะของกรรมการ **เป็นรายข้อ จำนวน 1 ชุด**
2. แบบเสนอเพื่อขอรับการพิจารณาและโครงการวิจัยฉบับสมบูรณ์ที่ทำการแก้ไขตามข้อคำถามหรือข้อเสนอแนะ พร้อมขีดเส้นใต้ข้อความที่มีการแก้ไข **จำนวน 1 ชุด**
3. เอกสารอื่นๆ ที่ทำการแก้ไข (ฉบับสมบูรณ์) ตามข้อคำถามหรือข้อเสนอแนะดังกล่าว และขีดเส้นใต้ข้อความที่ทำการแก้ไข **จำนวน 1 ชุด**
4. แผ่นบรรจุข้อมูลฉบับแก้ไขโครงการวิจัยทั้งหมด (CD/DVD) **จำนวน 1 ชุด**

และส่งมายังสำนักงานจริยธรรมฯ ภายในวันที่ ๖ ธ.ค. ๕๗ หากพ้นกำหนดดังกล่าว ทางสำนักงานฯ จะถือว่าท่านไม่ประสงค์ที่จะขอรับการพิจารณาจริยธรรมในขั้นตอนต่อไป และหากท่านมีความประสงค์ที่จะขอรับการพิจารณาฯ ท่านต้องดำเนินการยื่นเอกสารเพื่อขอรับการพิจารณาจริยธรรมใหม่

หากผู้วิจัยมีข้อสงสัยในข้อคำถามของคณะกรรมการสามารถสอบถามเลขานุการ โดยผู้วิจัยสามารถโทรศัพท์นัดหมายกับเจ้าหน้าที่สำนักงาน ที่ 074-451157, 074451149

ลงชื่อ..........................
(ผศ.ดร.พญ.อังณวีย์ อินทุโสมา)
เลขานุการคณะกรรมการจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

หมายเหตุ กรุณาระบุ version วันที่ และเลขหน้า ท้ายกระดาษของโครงการวิจัย

Annex 2: Records and Questionnaires

1.1 Records of patients` condition and treatments (ART) for HIV patients

Code of treatment facility	
Number of ART	
Number of patients	
Number of questionnaire	
Interviewer code	

1. Date of Diagnosis of HIV positive [ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	H3ddi [ ]
2. Place at HIV diagnosis [ ] write name	H4pdg [ ]
3. Date at ART started [ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	H5dtt [ ]
4. Transmitted from [ ] 0. Husband [ ] 1. Wife [ ] 2. Female sex workers [ ] 3. Male sex worker [ ] 4. Blood donation [ ] 5. Injection sharing	H6trs [ ]
5. HIV status of spouse [ ] 0. Negative [ ] 1. Positive	H7sts [ ]
6. Route of infection [ ] 0.Transfusion of blood [ ] 1.Apheresis plasma [ ] 2. Intravenous drug [ ] 3. Homosexual transmission [ ] 4. Heterosexual transmission [ ] 5. MTCT [ ] 6. Uncertainty [ ] 7. Other	H8rou [ ]
7. Clinical stage [ ] 0. Stage I [ ] 1. Stage II [ ] 2. Stage III [ ] 3. Stage IV	H9 Hst [ ]
8. Known morbidities [ ] 0. None [ ] 1. T.B. [ ] 2. Chanced of infection	H10kHo [ ]
9. Known Symptoms [ ] 0. Never [ ] 1. Cough [ ] 2. Fever [ ] 3. Chest pain [ ] 4. Vomiting [ ] 5. Night sweats [ ] 6. Diarrhoea [ ] 7. Nausea [ ]8. Difficulty breathing [ ] 9. Headache [ ] 10. Cough [ ] 11. Decreased vision [ ] 12. Rash [ ] 13. Blurred vision [ ] 14. Lymphadenopathy [ ]15. Expectoration	H11sym [ ]
10. Known relative Symptoms [ ] 0. Never [ ] 1. Skin lesions [ ] 2. Thrush [ ] 3. Oral hairy leukoplakia [ ] 4. Persistent diarrhoea (>1 month) [ ] 5. Continuous or intermittent fever(>38° ,>1month) [ ] 6. Severe recurrent bacterial infections [ ] 7. Disseminated mycobacterial infection of non-binding [ ] 8. Oesophageal candidiasis [ ] 9. Cryptococcus infection outside the lungs [ ] 10. Yarrow Pneumocystis infections [ ] 11. Disseminated fungal disease [ ] 12. Cytomegalovirus infection [ ] 13. Pulmonary tuberculosis [ ] 14. Recurrent severe bacterial pneumonia [ ] 15. Chronic herpes simplex virus infection [ ] 16. Herpes zoster [ ] 17. Toxoplasmosis [ ] 18. Kaposi's sarcoma [ ]19. Brain lymphatic tumour or cell non-Hodgkin's lymphoma [ ]20. Other opportunistic infections / tumours [ ]21.Uncertainty	H12rsy [ ]
11. CD4 count [ ]	H13HdH [ ]
12. Viral load [ ]	H14vld [ ]
13. Several previously received antiretroviral therapy programs [ ] 0. 0 [ ] 1. 1 [ ] 2. 2 [ ] 3. 3 [ ] 4. 4and more than	H15dis [ ]

14. Whether received cotrimoxazole prophylaxis of opportunistic infection treatment? [ ] 0. No [ ] 1. Yes	H16dsp [ ]
15. The sources of the cost for ART [ ] Free medical care by nation [ ] your own expense [ ] Socialized medicine [ ] Medicare [ ] Other______________________	H17 Hos [ ]
16. How many times for HIV medical care visit within three months of HIV diagnosis? [ ] 0. 0 [ ] 1. 1 [ ] 2. 2 [ ] 3.3 [ ] 4. >=4	H18 tim [ ]
17. Times of follow-up ____________________	H19tfo [ ]
18. How many doses of ART did you miss in recently seven days? ________________________	H20tdo [ ]

1.2 Records of patients` condition and treatments for non-HIV patients

Code of treatment facility	
Number of treatment	
Number of patients	
Number of questionnaire	
Interviewer code	

1. Type of disease [ ] write name	N1tyd [ ]
2. Date of Diagnosis of disease [ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	N2ddi [ ]
3. Place at disease diagnosis [ ] write name	N3pdg [ ]
4. Clinical stage [ ] write name	N4Cst [ ]
5. Date at treatment started [ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	N5dtt [ ]
6. Complications [ ] write name	N6com [ ]
7. How many times for HIV medical care visit within three months of HIV diagnosis? [ ] 0. 0 [ ] 1. 1 [ ] 2. 2 [ ] 3.3 [ ] 4. >=4	N7tim [ ]
8. Times of follow-up ____________________	N8tfo [ ]
9. How many doses of medicine did you miss in recently seven days? ____	N9tdo [ ]

1.3 Scales/Instruments for healthcare providers

Preliminaries

Interview date : yyyy-mm-dd	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]
Data entry period	Baseline	The second survey	The third survey
	1	2	3
Target population	HIV patients	Non-HIV patients	Healthcare providers
	1	2	3
Interviewer code			

Part P1: Socio-economic and demographic

P1.1 Date of birth [ ][ ]/[ ][ ]/[ ][ ][ ][ ]	P1.1age [ ]
P1.2 Sex [ ] 0.Female [ ] 1. Male [ ] 2. Transgender	P1. 2sex [ ]
P1.3 Ethnicity [ ] 0. Han [ ] 1. Bai [ ] 2. Hani [ ] 3. Yi [ ] 4. Hui [ ] 5. Wa [ ] 6. Dai [ ] 7. Zhuang [ ] 9. Other	P1. 3eth [ ]
P1.4. Religion [ ] 0. No [ ] 1. Christianity [ ] 2. Buddhism [ ] 3. Muslin [ ] 4.Others	P1. 4rel [ ]
P1.5. Occupation [ ] 0. Clinic doctors [ ] 1. Nurses [ ] 2. Laboratory Personnel [ ] 3. Public health physicians [ ] 4. Others	P1. 5occ [ ]
P1.6. Education [ ] 0. No formal schooling [ ] 1. Less than primary school [ ] 2. Primary school completed [ ] 3. Junior high school completed [ ] 4. Senior higher school(or equivalent) completed [ ] 5.College/pre-university/University completed [ ] 6. Post graduate degree completed [ ] 7. PhD. Degree completed	P 1.6edu [ ]
P1.7 Professional titles [ ] 0. Technician/ Nurse Practitioner [ ] 1. Residencies/assistants /nurse [ ] 2. Doctor/lecturers/assistant professors/ senior nurse [ ] 3. Deputy Chief Physician/associated professors/ Nurse-in-charge [ ] 4. Chief Physician/professors	P1.7tit [ ]
P1.8 Practitioners of the time________________________________	P1.8tim[ ]
P1.9 Marital status [ ] 0. Never married [ ] 1. Currently Married [ ] 2. Separated [ ] 3. Divorced [ ] 4. Widowed [ ]6.Cohabiting	P1.9mrt [ ]
P1.10 Children [ ] 0. No [ ] 1. Yes	P1.10chd [ ]
P1.11 Number of Children [ ]	P1.11ncd [ ]
P1.12 Number of family members [ ]	P1.12nfm [ ]
P1.13Forms of your residence living [ ] 0. Renting [ ] 1. Free using [ ] 2. Purchase [ ] 3. Donation/ inheritance [ ] 4. Others	P1.13fom [ ]
P1.14Structure of your residence living [ ] 0. Single room [ ] 1. Double rooms [ ] 2.One-bedroom apartment [ ] 3. Two-bedroom apartment [ ] 4. Three-bedroom apartment [ ] 5. Four or above bedrooms apartment	P1.14sre [ ]

[ ] 6. Skip-floor Residence [ ] 7. Row dwelling [ ] 8. Single villa	
P1.15 Monthly personal income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6.>20001RMB	P1.15inc [ ]
P1.16 Monthly household income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6.>20001RMB	P1.16hic [ ]

Part P2: HIV/AIDS healthcare providers’ relative stigma

P2.1I would be willing to work with HIV positive patients [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.1pun [ ]
P2.2I would be willing to provide the same healthcare no matter HIV+ or HIV- patients [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.2sit [ ]
P2.3I would be willing to do physical exam of HIV+ patients [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.3luc [ ]
P2.4I would be willing to interact HIV+ patients same as other patients [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.4con [ ]
P2.5People who got HIV/AIDS through sex and drug use, got what they deserved [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.5doo [ ]
P2.6Infected through commercial sex deserve sympathy [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.6fri [ ]
P2.7Infected through drug deserve sympathy [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.7loo [ ]
P2.8People who behave promiscuously should be blamed for AIDS [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.8sol [ ]
P2.9People who got infected with HIV/AIDS through blood donation deserve good quality medical care [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.9dat [ ]
P2.10People who got infected with HIV/AIDS through commercial sex deserve good quality medical care [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.10afr [ ]
P2.11People who got infected with HIV/AIDS through drug use deserve good quality medical care [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.11fau [ ]
P2.12If you work with HIV positive patients, you would want to change job [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.12des [ ]
P2.13If you know some with AIDS, you would feel ashamed [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.13emp [ ]
P2.14If your relative got HIV/AIDS, you would feel ashamed [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.14tap [ ]
P2.15You feel afraid of PLH [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.15wro [ ]
P2.16You do not buy from vendor with HIV/AIDS [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.16ash [ ]
P2.17You would not share utensils with PLH [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	P2.17pub[ ]

1.4 Scales/Instruments for HIV patients

Interview date : yyyy-mm-dd	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]
Data entry period	Baseline	The second survey	The third survey
	1	2	3
Target population	HIV patients	Non-HIV patients	Healthcare providers
	1	2	3
Interviewer code			

Part H1: Socio-economic and demographic

H1.1 Date of birth [ ][ ]/[ ][ ]/[ ][ ][ ][ ]	H1.1age [ ]
H1.2 Sex [ ] 0.Female [ ] 1. Male [ ] 2. Transgender	H1. 2sex [ ]
H1.3 Ethnicity [ ] 0. Han [ ] 1. Bai [ ] 2. Hani [ ] 3. Yi [ ] 4. Hui [ ] 5. Wa [ ] 6. Dai [ ] 7. Zhuang [ ] 9. Other	H1. 3eth [ ]
H1.4. Religion [ ] 0. No [ ] 1. Christianity [ ] 2. Buddhism [ ] 3. Muslin [ ] 4.Others	H1. 4rel [ ]
H1.5. Current job [ ] 0. Government employee [ ] 1. Non-government employee [ ] 2. Self-employed [ ] 3. Employer [ ] 4. Not working for pay If not working: Go to H1.23	H1. 5job [ ]
H1.6 Education [ ] 0. No formal schooling [ ] 1. Less than primary school [ ] 2. Primary school completed [ ] 3. Junior high school completed [ ] 4. Senior higher school(or equivalent) completed [ ] 5.College/pre-university/University completed [ ] 6. Post graduate degree completed [ ] 7. PhD. Degree completed	H1.6edu [ ]
H1.7 Main occupation during the last 12 months [ ]0. Legislator, senior official, or manager [ ] 1. Professional (engineer, doctor, teacher, clergy, etc.) [ ] 2. Technician or Associate Professional (inspector, finance dealer, etc.) [ ] 3. Clerk (secretary, cashier, etc.) [ ] 4. Service or sales workers (cook, travel guide, shop salesperson, etc.) [ ] 5. Agricultural or fishery worker (vegetable grower, livestock producer, etc.) [ ] 6. Craft or trades worker (carpenter, painter, jewellery worker, butcher, etc.) [ ] 7.Plant/machine operator or assembler (equipment assembler, sewing-machine operator, driver, etc.) [ ] 8. Elementary worker (street food vendor, shoe cleaner, etc.) [ ]9. Armed forces(government military)	H1.7occ [ ]
H1.8 The weight [ ] [ ]. [ ] kg	H1.8wei [ ]
H1.9 The height [ ] [ ] [ ] cm	H1.9hei [ ]
H1.10 Marital status [ ] 0. Never married [ ] 1. Currently Married [ ] 2. Separated [ ] 3. Divorced [ ] 4. Widowed [ ]6.Cohabiting	H1.10mrt [ ]

H1.11 Children [ ] 0. No [ ] 1. Yes	H1.11chd [ ]
H1.12 Number of Children [ ]	H1.12ncd [ ]
H1.13 Number of family members [ ]	H1.13nfm [ ]
H1.14Forms of your residence living [ ] 0. Renting [ ] 1. Free using [ ] 2. Purchase [ ] 3. Donation/ inheritance [ ] 4. Others	H1.14fom [ ]
H1.15Structure of your residence living [ ] 0. Single room [ ] 1. Double rooms [ ] 2.One-bedroom apartment [ ] 3. Two-bedroom apartment [ ] 4. Three-bedroom apartment [ ] 5. Four or above bedrooms apartment [ ] 6. Skip-floor Residence [ ] 7. Row dwelling [ ]8. Single villa	H1.15sre [ ]
H1.16 Monthly personal income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6.>20001RMB	H1.16inc [ ]
H1.17 Monthly household income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6. 20001～40000RMB [ ]6. >40001RMB	H1.17hin [ ]
H1.18 Monthly payment for total healthcare by out-of-pocket payment [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	H1.18hep [ ]
H1.19 Monthly payment for ART by out-of-pocket payment [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	H1.19arp [ ]
H1.20 Monthly payment for total healthcare by other free sources such as Medicare and socialized medicine [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	H1.20hef [ ]
H1.21 Monthly payment for ART by other free sources such as Medicare and socialized medicine [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	H1.21arf [ ]
H1.22 Monthly family living standards (household spending) [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	H1.22fls [ ]
H1.23 Main reason that you are not working for pay [ ] 0. Homemaker/caring for family [ ] 1. Looked but cannot find a job [ ] 2. Doing unpaid work/voluntary activities [ ] 3. Studies/training [ ] 4. Retired/too old to work [ ] 5. Ill health [ ] 6. Other	H1.23rea [ ]

Part H2: Access to care, regular source of HIV care and ART adherence at individual level

H2.1You am able to get medical care whenever you need it: [ ] 0. No [ ] 1. Yes	H2.1med [ ]
H2.2 Places where you can get medical care are very conveniently located: [ ] 0. CDC [ ] 1. MCH [ ] 2. Special hospital [ ] 3. General hospital [ ] 4. Private clinics [ ] 5. Handle by myself	H2.2whe [ ]
H2.3 You have never gone without the medical care you needed because it is too expensive [ ] 0. No [ ] 1. Yes	H2.3exp [ ]
H2.4You have easy access to the medical specialists that you need [ ] 0. No [ ] 1. Yes	H2.4spe [ ]

H2.5 It is easy for you to get medical care in an emergency [ ] 0. No [ ] 1. Yes	H2.5eme [ ]
H2.6 If you need hospital care, you can get admitted without any trouble [ ] 0. No [ ] 1. Yes	H2.6tro [ ]
H2.7 Do you currently have a regular place to go for your HIV medical care? [ ] 0. No [ ] 1. Yes	H2.7pla [ ]
H2.8 How often during the past week were you able to take your antiretroviral medications exactly as your doctor or nurse told you to [ ] 0. No [ ] 1. Yes	H2.8tak [ ]
H2.9Do you know someone in their family or a close friend with HIV? [ ] 0. No [ ] 1. Yes	H2.9kno [ ]

Part H3: HIV/AIDS parallel stigma scales (Internalized stigma of HIV patients)

H3.1Getting HIV is a punishment for bad behaviour [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.1pun [ ]
H3.2If I was in public or private transport and someone knew I had HIV they would not sit next to me [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.2sit [ ]
H3.3I think my getting HIV was just a matter of bad luck [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.3luc [ ]
H3.4I think less of myself because I have HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.4con [ ]
H3.5My neighbours would not like me living next door if they knew I had HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.5doo [ ]
H3.6I would understand if people rejected my friendship because I am HIV+ [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.6fri [ ]
H3.7I feel it is completely safe for me to handle other people's children (reverse) [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.7loo [ ]
H3.8I have a lot to teach people about life through having HIV (reverse) [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.8sol [ ]
H3.9Because of my HIV people would not date me [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.9dat [ ]
H3.10People are right to be afraid of me because I have HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.10afr [ ]
IH3.11 1 feel that it is my fault that I got HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.11fau [ ]
H3.12 Although I have HIV I am a person who deserves as much respect as anyone else [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.12des [ ]
H3.13Most employers would not employ me because I am HIV+ [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.13emp [ ]
H3.14 If I drank from a tap and people knew I had HIV they would not drink from the same tap [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.14tap [ ]
H3.15 I must have done something wrong to deserve getting HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.15wro[ ]
H3.16 I feel ashamed that I have HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.16ash[ ]
H3.17 When people know I have HIV I feel uncomfortable around them [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	H3.17pub[ ]

Part H4: Questionnaire of Health System Responsiveness and vignettes (See the next part)

1.5 Scales/Instruments for non-HIV patients

Interview date : yyyy-mm-dd	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]	[2[0[1][ ][ ][ ][ ][ ]
Data entry period	Baseline	The second survey	The third survey
	1	2	3
Types of patients	HIV patients	Non-HIV patients	
	1	2	
Interviewer code			

Part N1: Socio-economic and demographic

N1.1 Date of birth [ ][ ]/[ ][ ]/[ ][ ][ ][ ]	N1.1age [ ]
N1.2 Sex [ ] 0.Female [ ] 1. Male [ ] 2. Transgender	N1. 2sex [ ]
N1.3 Ethnicity [ ] 0. Han [ ] 1. Bai [ ] 2. Hani [ ] 3. Yi [ ] 4. Hui [ ] 5. Wa [ ] 6. Dai [ ] 7. Zhuang [ ] 9. Other	N1. 3eth [ ]
N1.4. Religion [ ] 0. No [ ] 1. Christianity [ ] 2. Buddhism [ ] 3. Muslin [ ] 4.Others	N1. 4rel [ ]
N1.5. Current job [ ] 0. Government employee [ ] 1. Non-government employee [ ] 2. Self-employed [ ] 3. Employer [ ] 4. Not working for pay (If not working: Go to N1.23)	N1. 5job [ ]
N1.6 Education [ ] 0. No formal schooling [ ] 1. Less than primary school [ ] 2. Primary school completed [ ] 3. Junior high school completed [ ] 4. Senior higher school(or equivalent) completed [ ] 5.College/pre-university/University completed [ ] 6. Post graduate degree completed [ ] 7. PhD. Degree completed	N1.6edu [ ]
N1.7 Main occupation during the last 12 months [ ]0. Legislator, senior official, or manager [ ] 1. Professional (engineer, doctor, teacher, clergy, etc.) [ ] 2. Technician or Associate Professional (inspector, finance dealer, etc.) [ ] 3. Clerk (secretary, cashier, etc.) [ ] 4. Service or sales workers (cook, travel guide, shop salesperson, etc.) [ ] 5. Agricultural or fishery worker (vegetable grower, livestock producer, etc.) [ ] 6. Craft or trades worker (carpenter, painter, jewellery worker, butcher, etc.) [ ] 7.Plant/machine operator or assembler (equipment assembler, sewing-machine operator, driver, etc.) [ ] 8. Elementary worker (street food vendor, shoe cleaner, etc.) [ ]9. Armed forces(government military)	N1.7occ [ ]
N1.8 The weight [ ] [ ]. [ ] kg	N1.8wei [ ]
N1.9 The height [ ] [ ] [ ] cm	N1.9hei [ ]
N1.10 Marital status [ ] 0. Never married [ ] 1. Currently Married [ ] 2. Separated [ ] 3. Divorced [ ] 4. Widowed [ ]6.Cohabiting	N1.10mrt [ ]
N1.11 Children [ ] 0. No [ ] 1. Yes	N1.11chd [ ]

N1.12 Number of Children [ ]	N1.12ncd [ ]
N1.13 Number of family members [ ]	N1.13nfm [ ]
N1.14Forms of your residence living [ ] 0. Renting [ ] 1. Free using [ ] 2. Purchase [ ] 3. Donation/ inheritance [ ] 4. Others	N1.14fom [ ]
N1.15Structure of your residence living [ ] 0. Single room [ ] 1. Double rooms [ ] 2.One-bedroom apartment [ ] 3. Two-bedroom apartment [ ] 4. Three-bedroom apartment [ ] 5. Four or above bedrooms apartment [ ] 6. Skip-floor Residence [ ] 7. Row dwelling [ ] 8. Single villa	N1.15sre [ ]
N1.16 Monthly personal income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6.>20001RMB	N1.16inc [ ]
N1.17 Monthly household income before tax [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～13000RMB [ ]4. 13001～16000RMB [ ]5. 16000～20000RMB [ ]6. 20001～40000RMB [ ]6. >40001RMB	N1.17hin [ ]
N1.18 Monthly payment for total healthcare by out-of-pocket payment [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	N1.18hep [ ]
N1.19 Monthly payment for total healthcare by other free sources such as Medicare and socialized medicine [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	N1.19hef [ ]
N1.20 Monthly family living standards (household spending) [ ]0.<2000RMB [ ]1. 2001～5000RMB [ ]2. 5001～8000RMB [ ]3. 8001～11000RMB [ ]4. >11001RMB	N1.20fls [ ]
N1.21 Main reason that you are not working for pay [ ] 0. Homemaker/caring for family [ ] 1. Looked but cannot find a job [ ] 2. Doing unpaid work/voluntary activities [ ] 3. Studies/training [ ] 4. Retired/too old to work [ ] 5. Ill health [ ] 6. Other	N1.21rea [ ]

Part N2: Access to healthcare and treatment adherence at individual level

N2.1You am able to get medical care whenever you need it: [ ] 0. No [ ] 1. Yes	N2.1med [ ]
N2.2 Places where you can get medical care are very conveniently located: [ ] 0. CDC [ ] 1. MCH [ ] 2. Special hospital [ ] 3. General hospital [ ] 4. Private clinics [ ] 5. Handle by myself	N2.2whe [ ]
N2.3 You have never gone without the medical care you needed because it is too expensive [ ] 0. No [ ] 1. Yes	N2.3exp [ ]
N2.4You have easy access to the medical specialists that you need [ ] 0. No [ ] 1. Yes	N2.4spe [ ]
N2.5 It is easy for you to get medical care in an emergency [ ] 0. No [ ] 1. Yes	N2.5eme [ ]
N2.6 If you need hospital care, you can get admitted without any trouble [ ] 0. No [ ] 1. Yes	N2.6tro [ ]
N2.7 Do you currently have a regular place to go for your medical care? [ ] 0. No [ ] 1. Yes	N2.7pla [ ]
N2.8 How often during the past week were you able to take your medications exactly as your doctor or nurse told you to [ ] 0. No [ ] 1. Yes	N2.8tak [ ]
N2.9Do you know someone in their family or a close friend with HIV?	N2.9kno [ ]

[ ] 0. No [ ] 1. Yes	

Part N3: HIV/AIDS parallel stigma scales (Personal stigma for non-HIV patients)

N3.1. I think getting HIV is a punishment for bad behaviour [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.1pun [ ]
N3.2. If I was in public or private transport, I would not like to sit next to someone with HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.2sit [ ]
N3.3. Having HIV is just a matter of bad luck [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.3luc [ ]
N3.4. I think less of someone because they have HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.4con [ ]
N3.5. I would not like someone with HIV to be living next door [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.5doo [ ]
N3.6. I would not like to be friends with someone with HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.6fri [ ]
N3.7. It is safe for a person with HIV to look after somebody else's children (reverse) [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.7loo [ ]
N3.8. People with HIV can teach us a lot about life (reverse) [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.8sol [ ]
N3.9. I would not date a person if I know that he/she has HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.9dat [ ]
N3.10. I feel afraid to be around people with HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.10afr [ ]
N3.11. People with HIV/AIDS have only themselves to blame [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.11fau [ ]
N3.12. People with HIV deserve as much respect as anyone else (reverse) [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.12des [ ]
N3.13. I would not employ someone with HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.13emp [ ]
N3.14. I would not drink from a tap if a person with HIV had just drunk from it [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.14tap [ ]
N3.15. If you have HIV you must have done something wrong to deserve it [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.15wro [ ]
N3.16. People with HIV should be ashamed of themselves [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.16ash [ ]
N3.17. I feel uncomfortable around people with HIV [ ] 1. Strong disagree [ ] 2. Disagree [ ] 3.agree [ ] 4.Strong agree	N3.17pub [ ]

Part N4: Questionnaire of Health System Responsiveness and vignettes (See the next part)

1.6 Questionnaire of Health System Responsiveness and vignettes

Part 1: Health State Descriptions **Time Begin: __ __: __ __**

Overall Health

The first questions are about your overall health, including both your physical and your mental health.

Q2000	In general, would you rate your health today as?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Q2001	Overall in the last 30 days, how much difficulty did you have with work or household activities?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Now I would like to review different functions of your body. When answering these questions, I would like you to think about the last 30 days, taking both good and bad days into account. When I ask about difficulty, I would like you to consider how much difficulty you have had, on an average, in the past 30 days, while doing the activity in the way that you usually do it. By difficulty I mean requiring increased effort, discomfort or pain, slowness or changes in the way you do the activity. Please answer this question taking into account any assistance you have available. (**Read and show scale to respondent).**

Mobility

Q2010	Overall in the last 30 days, how much difficulty did you have with moving around?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2011	In the last 30 days, how much difficulty did you have in vigorous activities, such as running 3 km (or equivalent) or cycling?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Self-Care

Q2020	Overall in the last 30 days, how much difficulty did you have with self-care, such as washing or dressing yourself?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2021	In the last 30 days, how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking neat and tidy etc.)	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Pain and Discomfort

Q2030	Overall in the last 30 days, how much of bodily aches or pains did you have?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2031	In the last 30 days, how much bodily discomfort did you have?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Cognition

Q2050	Overall in the last 30 days, how much difficulty did you have with concentrating or remembering things?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2051	In the last 30 days, how much difficulty did you have in learning a new task (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Interpersonal Activities

Q2060	Overall in the last 30 days, how much difficulty did you have with personal relationship or participation in the community?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2061	In the last 30 days, how much difficulty did you have in dealing with conflicts and tensions with others?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Vision

Q2070	Do you wear glasses or contact lenses? **(If Respondent says YES to this question, preface the next 2 questions with "Please answer the following questions taking into account your glasses or contact lenses".)**	**1.** Yes			**5.** No	
Q2071	In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do
Q2072	In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme/Cannot do

Sleep and Energy

Q2080	Overall in the last 30 days, how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme

Q281	In the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g. feeling tired, not having energy)?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme

Affect

Q2090	Overall in the last 30 days, how much of a problem did you have with feeling sad, low or depressed?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme
Q2091	Overall in the last 30 days, how much of a problem did you have with worry or anxiety?	**1.** None	**2.** Mild	**3.** Moderate	**4.** Severe	**5.** Extreme

Part 2: Health System Responsiveness

Time Begin: __ __ : __ _

1) Importance

Q 7100	How important is "respectful treatment" to you. This means being shown respect when greeted by and when talking to health care providers having physical examinations conducted in a way that respects your cultural norms Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q 7101	How important is "confidentiality of personal information" to you. This means: having information about your health and other personal information kept confidential having conversations with health care providers without other people overhearing Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q7102	How important is "convenient travel and short waiting times" to you. This means having short travel times and convenient access to health care facilities having short waiting times for consultations and hospital admissions Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q7103	How important is "choice of health care providers" to you. This means being able to choose your health care providers (place or person) being able to consult for a second opinion or with a specialist if so desired Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q7104	How important is "involvement in decision making" to you. This means being involved as much as you want in deciding about your health care	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important

	freedom to discuss other treatment options or care regimes if you want Would you say it is:					
Q7105	How important is “good quality surroundings” to you. This means having enough space, seating and fresh air in the waiting rooms, examination rooms and hospital words having a clean facility (including clean toilets) Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q7106	How important is “contact with the outside world” to you. This means having family and friends visit you as much as you want when you are a patient in hospital being able to keep in contact with family and friends and to have information about what is happening outside the hospital Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important
Q7107	How important is “convenient travel and short waiting times” to you. This means having the health care providers explain things in a way you can understand having enough time to ask questions if you don`t understand something Would you say it is:	1.Extremely Important	2.Very Important	3. Moderately Important	4.Slightly Important	5.Not important

2) Experience

Q7300	For you last visit, how would you rate the amount of time you waited before being attended to?	**1.** Very good	**2.** Good **3.** Moderate	**4.** Bad	**5.** Very Bad	
Q7301	For your last visit, how would you rate your experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad

Q7302	For your last visit, how would you rate the experience of how clearly health care providers explained things to you?	**1.** Very good	**2.** Good		**3.** Moderate	**4.** Bad	**5.** Very Bad
Q7303	For your last visit, how would you rate your experience of being involved in making decisions about your health care or treatment?	**1.** Very good	**2.** Good		**3.** Moderate	**4.** Bad	**5.** Very Bad
Q7304	For your last visit, how would you rate the way the health services ensured you could talk privately to health care providers?	**1.** Very good	**2.** Good		**3.** Moderate	**4.** Bad	**5.** Very Bad
Q7305	For your last visit, how would you rate the freedom you had to choose your [health care provider]?	**1.** Very good	**2.** Good		**3.** Moderate	**4.** Bad	**5.** Very Bad
Q7306	For your last visit, how would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad	**9.** Not applicable, home care

3) Vignettes for Health System Responsiveness

Q7400	**RECORD SET (A, B, C, D):**	

I am now going to read you stories about people's experiences with health care services. I want you to think about these people's experiences as if they were your own. Once I have finished reading each story, I will ask you to rate what happened in the story as very good, good, moderate, bad or very bad.

Vignette 1						
Q7401	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 2						
Q7402	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 3						
Q7403	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 4						
Q7404	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 5						
Q7405	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 6						
Q 7406	Question 1	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad

Vignette 7						
Q7407	Question 1	**1.**Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 8						
Q7408	Question 1	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 9						
Q7409	Question 1	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad
Vignette 10						
Q7410	Question 1	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very Bad

VIGNETTES FOR HEALTH SYSTEM RESPONSIVENESS: Set A

I am now going to read you stories about people's experiences with health care services. I want you to think about these people's experiences as if they were your own. Once I have finished reading each story, I will ask you to rate what happened in the story as very good, good, moderate, bad or very bad.

Respectful Treatment and Prompt Attention

[Niles] woke up with a sore back so he decided to go to the clinic. It took 30 minutes to travel to the clinic and he was seen within 5 minutes.

Q7401	How would you rate the amount of time he waited before being attended to?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Anya] took her baby for a vaccination. The nurse said hello and but did not ask for [Anya's] or the baby's name. The nurse also examined [Anya] and made her remove her shirt in the waiting room.

Q7402	How would you rate her experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Stan] broke his leg. It took an hour to be driven to the nearest hospital. He was in pain but had to wait an hour for the surgeon and was only operated on the next day.

Q7403	How would you rate the amount of time he waited before being attended to?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Conrad] had bad flu. He went to the clinic. The nurse expressed concern about [Conrad]'s cough and called the doctor, who gave [Conrad] a full chest examination behind a large screen that hid him from the view of other patients.

Q7404	How would you rate his experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Astor] broke his hand. He walked to the clinic because there was no transport and the journey took him several hours. He had to sleep near the clinic for two days before seeing the doctor.

Q7405	How would you rate the amount of time he waited before being attended to?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Julia] was pregnant and went to the hospital coughing blood. A nurse welcomed her gently and helped her to a private room. A female doctor came to examine her and gave her a clean gown to replace her blood-stained clothes.

Q7406	How would you rate her experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Carla]'s child became seriously sick. [Carla] called an ambulance that arrived after 10 minutes and within 5 minutes they were at the hospital and the doctors were treating the child.

Q7407	How would you rate the amount of time she waited before being attended to?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Patricia] went to a crowded clinic. At first, no-one greeted her but after waiting for 5 minutes a nurse called her to the examination area where she was examined behind a small screen that mostly hid her from the other patients.

Q7408	How would you rate her experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Karen] needed a blood test. It took her 45 minutes by bus to get to the clinic and she waited d for 30 minutes to see the nurse.

Q7409	How would you rate the amount of time she waited before being attended to?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Said] has AIDS. When he goes to his health center the nurses do not talk to him and deliberately ignore him. During examinations, his clothes are removed and he is made to wait, half-naked in the waiting room.

Q7410	How would you rate his experience of being greeted and talked to respectfully?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

VIGNETTES FOR HEALTH SYSTEM RESPONSIVENESS: Set B

I am now going to read you stories about people's experiences with health care services. I want you to think about these people's experiences as if they were your own. Once I have finished reading each story, I will ask you to rate what happened in the story as very good, good, moderate, bad or very bad.

Communication and Quality of Basic Amenities

[Thomas] couldn't see well so he went to the doctor and explained the problem. [Thomas] had time to ask the doctor some questions, which the doctor answered until [Thomas] understood almost everything.

Q7401	How would you rate his experience of how clearly health care providers explained things to him?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Wing] had his own room in the hospital and shared a bathroom with two others. The room and bathroom were cleaned frequently and had fresh air.

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Q7402	How would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Pie] went to the emergency clinic with a stomach pain. The doctor explained to [Pie] her condition and the treatment. [Pie] asked him some questions and the doctor explained things using examples that were familiar to her until she understood everything.

Q7403	How would you rate her experience of how clearly health care providers explained things to her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Shard] was hospitalized last year for a hip operation. Her private room had its own bathroom and was comfortable and spacious. It was cleaned by the hospital staff daily. The bed was comfortable and the sheets were changed daily.

Q7404	How would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Akiko] is in hospital after a car accident. She has lots of scratches, bruises and some broken bones. When the doctor visited her he asked to see her medical records. He asked the nurse some questions and then he said that [Akiko] was making good progress. [Akiko] supposes that she will still stay there for another week but is unsure.

Q7405	How would you rate her experience of how clearly health care providers explained things to her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Kamal] has a nervous breakdown and had to spend 3 months in the past year in the local hospital. He had to sleep on an uncomfortable mattress with no sheets. There were 30 other patients in the same dormitory style ward and the toilets would smell, because they were not cleaned. He came back with a skin infection, because he couldn't wash regularly and there were insects in the bed.

Q7406	How would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Rose] cannot write or read. She went to the doctor because she was feeling dizzy. The doctor didn't have time to answer her questions or to explain anything.

He sent her away with a piece of paper without telling her what it said.

Q7407	How would you rate her experience of how clearly health care providers explained things to her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Hans] shared his small hospital room with five other patients with no partitions between beds. The five patients shared a toilet, which was cleaned every second day and sometimes smelt.

Q7408	How would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

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[Mario] has been told that he has epilepsy and that he needs to take medication. The doctor has very briefly explained what the condition is. He is very busy and there is a queue of patients waiting to see him. Mario would like to know more about what he has, but feels that there is no time to ask questions. The doctor says goodbye to Mario, and Mario leaves the office.

Q7409	How would you rate his experience of how clearly health care providers explained things to him?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[José] shared a hospital room with four other persons. There was a toilet for his ward located along the outside corridor. The room was only occasionally dusty and hot, but without any fan.

Q7410	How would you rate the cleanliness of the rooms inside the facility, including toilets?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

VIGNETTES FOR HEALTH SYSTEM RESPONSIVENESS: Set C

I am now going to read you stories about people's experiences with health care services. I want you to think about these people's experiences as if they were your own. Once I have finished reading each story, I will ask you to rate what happened in the story as very good, good, moderate, bad or very bad.

Confidentiality and Choice

[Simon] was speaking to his doctor about an embarrassing problem. There was a friend and a neighbor of his in the crowded waiting room and because of the noise the doctor had to shout when telling [Simon] the treatment he needed.

Q7401	How would you rate the way the health services ensured [Simon] could talk privately to health care providers?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When the clinic is not busy, [Marabou] can choose which doctor he sees. But most often it is busy and then he gets sent to whoever is free.

Q7402	How would you rate [Marabou’s] freedom to choose her health care provider?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Rebecca] usually spoke to her doctor about her illness in complete privacy. Once [Rebecca] heard that the doctor spoke to [Rebecca's] friend about her illness. She asked her doctor not to do it again. He did not do it again.

Q7403	How would you rate the way the health services ensured [Rebecca] could talk privately to health care providers?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

In [William]’s town there is a large day clinic where there are several doctors and nurses. When [William] has a sensitive health problem he can see a male rather than a female doctor or nurse.

Q7404	How would you rate [William's] freedom to choose his health care provider?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Elma] was asked to describe a serious health problem to the doctor in the middle of the waiting room. The doctor repeated everything to the nurse and all the other patients, many of whom knew her family, could overhear everything.

Q7405	How would you rate the way the health services ensured [Elma] could talk privately to health care providers?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Penelope] had fertility problems, she had to travel from her small village to the closest town where they only had one male doctor. [Penelope] wanted to see a female doctor but she had no choice.

Q7406	How would you rate [Penelope's] freedom to choose her health care provider?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Alanine] had his consultation in a small private room. During the consultation, a nurse occasionally walked in and listened to the conversation. Sometimes she forgot to close the door so people in the waiting room could overhear parts of their conversation.

Q7407	How would you rate the way the health services ensured [Alanine] could talk privately to health care providers?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

The national health service assigns all the people in [Ibrahim's] community to the local clinic. At the clinic they have a choice of 3 doctors. If they want to change clinics, they need to get permission.

Q7408	How would you rate [Ibrahim's] freedom to choose his health care provider?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Ken] visited the doctor regularly. His doctor always took [Ken] to a private room before discussing his illness. The doctor was aware that [Ken] was very sensitive about his health condition and would never talk about it to anyone or in front of anyone without Ken's permission.

Q7409	How would you rate the way the health services ensured [Ken] could talk privately to health care providers?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Nathan] lives in a town where there are lots of doctors and clinics. He tried one doctor but he didn't like him so he changed doctors. This was easy to do because he could go where he wanted.

Q7410	How would you rate [Nathan's] freedom to choose his health care provider?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

VIGNETTES FOR HEALTH SYSTEM RESPONSIVENESS: Set D

I am now going to read you stories about people's experiences with health care services. I want you to think about these people's experiences as if they were your own. Once I have finished reading each story, I will ask you to rate what happened in the story as very good, good, moderate, bad or very bad.

Social Support to Patient and Autonomy

[Sally]'s husband could only visit her in hospital in the evenings because of the visiting hours and because he had to look after their children. Once he brought the children with him and the nurse, who was reading a newspaper, said she could not watch them for him. This meant [Sally] had fewer visits from her husband.

Q7401	For [Sally's] last hospital stay, how would you rate the ease of having family and friends visit her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Jazmine’s] had treatment for infertility, the doctor gave he r some pills and asked her to return in two weeks. He didn't ask her whether she wanted to know anything about her health condition nor suggest different alternatives that might have suited her better.

Q7402	How would you rate [Jazmine’s] experience of being involved in making decisions about her health care or treatment?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Joseph] was in hospital he could have no visitors nor could he receive any presents from friends or relatives. The hospital had no telephones and he could not get any news from outside.

Q7403	For [Joseph's] last hospital stay, how would you rate the ease of having family and friends visit him?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Mark] had a serious health problem. The doctor prescribed the best treatment for Mark but without telling him the implications on his quality of life or the cost. [Mark] felt powerless and was not given any information to help him to feel more in control.

Q7404	How would you rate [Mark's] experience of being involved in making decisions about his health care or treatment?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Tamara] was in hospital for two weeks, her family visited her every few days during the evening visiting hours, but she was alone the rest of the day. There was little to read or do in the hospital. Every few days, the nurses brought her a portable radio to listen to for a few hours.

Q7405	For [Tamara's] last hospital stay, how would you rate the ease of having family and friends visit her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Bob] had a broken arm. The doctor explained different ways of fixing it and then ordered some blood tests. [Bob] didn't know why he needed blood tests and was worried until the doctor explained what they were for.

Q7406	How would you rate [Bob's] experience of being involved in making decisions about his health care or treatment?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Carol] was in hospital, she was allowed visitors at any time of the day. Whenever she needed to contact her family, work or friends, she could easily get a message delivered to them.

Q7407	For [Carol's] last hospital stay, how would you rate the ease of having family and friends visit her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

When [Sarah] wanted treatment for her swollen limbs, the nurses at her clinic discussed many possible treatments with her. They discussed all the pro's and con's of each treatment with her and then recommended one to her.

Q7408	How would you rate [Sarah's] experience of being involved in making decisions about her health care or treatment?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

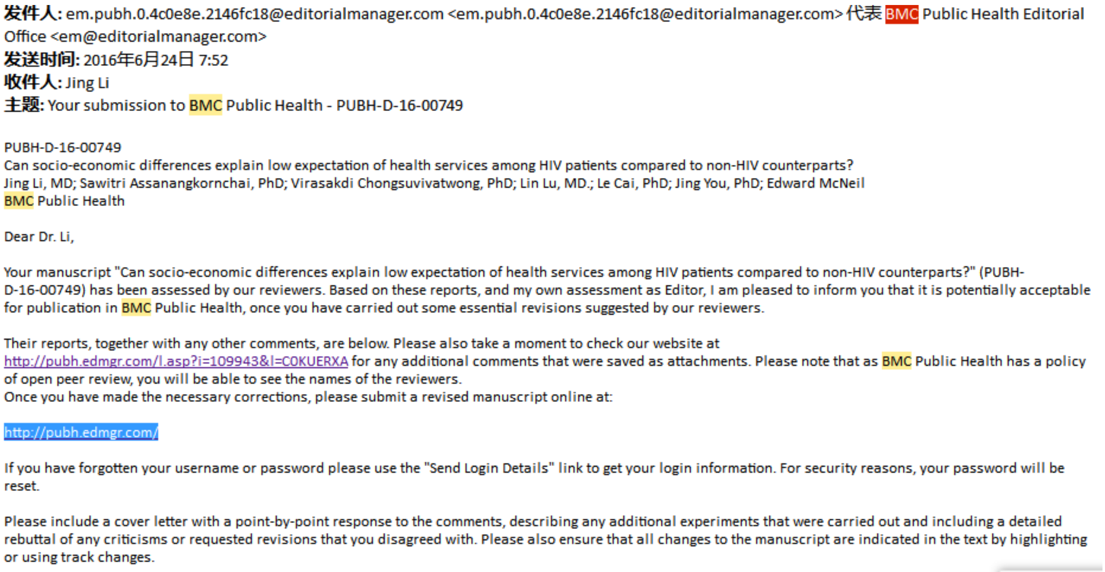
[Jane] gave birth in hospital. Her husband was permitted to visit her every morning and evening. [Jane] was able to contact her family and friends once a day.

Q7409	For [Jane's] last hospital stay, how would you rate the ease of having family and friends visit her?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

[Tara] is unhappy and has no energy. She gave birth to a baby girl two months ago and the doctor has told her that she may be suffering from depression. The doctor discussed her condition with her and then suggested that she could either try some medication or, if she prefers, talk to a counsellor.

Q7410	How would you rate [Tara's] experience of being involved in making decisions about her health care or treatment?	**1.** Very good	**2.** Good	**3.** Moderate	**4.** Bad	**5.** Very bad

Annex 3: Manuscript I



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PUBH-D-16-00749
Can socio-economic differences explain low expectation of health services among HIV patients compared to non-HIV counterparts?
Jing Li, MD; Sawitri Assanangkornchai, PhD; Virasakdi Chongsuvivatwong, PhD; Lin Lu, MD.; Le Cai, PhD; Jing You, PhD; Edward McNeil
BMC Public Health

Dear Dr. Li,

Your manuscript "Can socio-economic differences explain low expectation of health services among HIV patients compared to non-HIV counterparts?" (PUBH-D-16-00749) has been assessed by our reviewers. Based on these reports, and my own assessment as Editor, I am pleased to inform you that it is potentially acceptable for publication in BMC Public Health, once you have carried out some essential revisions suggested by our reviewers.

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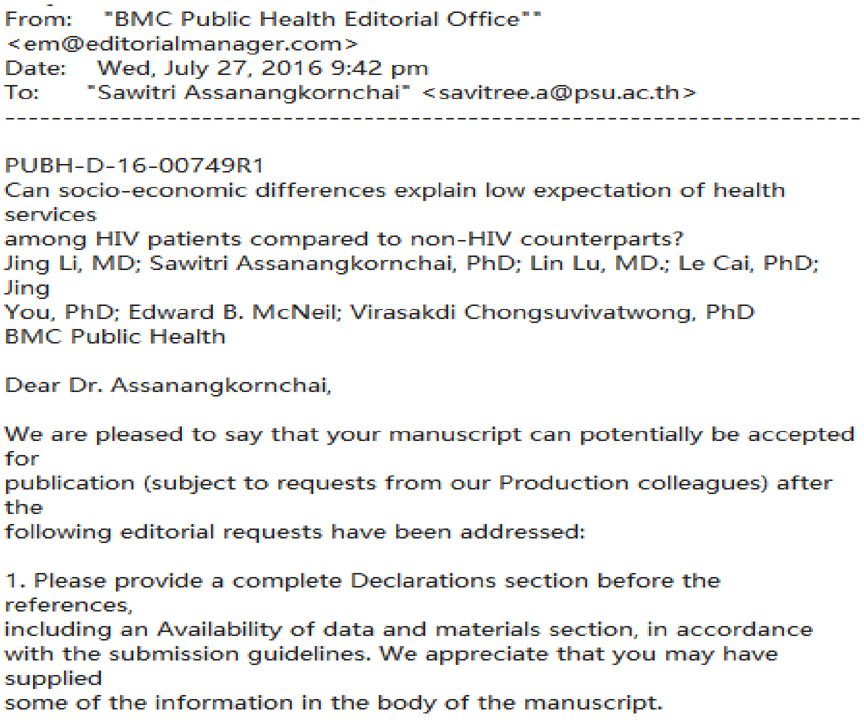

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PUBH-D-16-00749R1
Can socio-economic differences explain low expectation of health services among HIV patients compared to non-HIV counterparts?
Jing Li, MD; Sawitri Assanangkornchai, PhD; Lin Lu, MD.; Le Cai, PhD; Jing You, PhD; Edward B. McNeil; Virasakdi Chongsuvivatwong, PhD
BMC Public Health

Dear Dr. Assanangkornchai,

We are pleased to say that your manuscript can potentially be accepted for publication (subject to requests from our Production colleagues) after the following editorial requests have been addressed:

1. Please provide a complete Declarations section before the references, including an Availability of data and materials section, in accordance with the submission guidelines. We appreciate that you may have supplied some of the information in the body of the manuscript.

Can socio-economic differences explain low expectation of health services among HIV patients compared to non-HIV counterparts?

Abstract

Background: The health service of China has encountered significant challenges due to inequalities in socio-economic determinants of health. HIV patients are known to suffer from social stigma, and may receive inadequate responsiveness from health providers. Before assessing the responsiveness they receive, it is important to know their expectations. We aimed to compare levels of expectation towards the healthcare service among HIV and non-HIV patients with adjustment for socio-economic factors. ***Methods:*** A cross-sectional study was conducted during January and February, 2015 among two consecutive groups of HIV positive and non-HIV patients in two hospitals in Kunming, China. Patients' expectation towards eight domains of health system responsiveness was measured using 40 vignettes; five per domain. Each vignette was ranked from 1 "very good" to 5 "very bad", and the responses were summed to obtain a total score for each domain. Differences in total scores were compared between the two groups and adjusted for other factors using multiple linear regression. ***Results:*** The three domains with the highest scores, reflecting high expectation, were prompt attention, basic amenities and choice. Adjusted for other factors, HIV patients had significantly lower levels of expectation in all domains compared to the non-HIV group. Age was associated with the basic amenities domain, with young adults having higher expectations than other age groups. Minority ethnic groups had lower expectation towards dignity, prompt attention and autonomy domains compared to Han ethnicity. Those who lived in a home with 2-4 family members had higher expectations towards confidentiality than those who lived alone. ***Conclusion:*** Patients with HIV have significantly lower levels of expectations even after adjusting for socio-economic factors. Assessment of health system responsiveness based on their judgments above may give biased results toward favourable service quality.

Keywords: Expectation; HIV patients; Socio-economic factors; Health system; Chin

1. Introduction

Patient expectations prior to seeking healthcare services and their perceptions of the care after consuming the service positively affect their satisfaction of the service and confirm or refute their re-visits of the service[19,20]. Expectations of healthcare systems are proportional to their attractiveness. Patient's expectations of medical care are linked to the cost of treatment[21], assessments and satisfaction[22,23]. When the perception of patients towards healthcare meets the expectation of patients[24], a healthcare system will arrive at the perfect level, which appeals to patient-centered medical services[25]. However, there has been little research on the expectation of patients with HIV/AIDS in comparison to other patients. With the rapid economic development in China, equity of health services faces significant challenges due to a vicious cycle of factors such as inequalities of socio-economic determinants of health[182-184] and growing dissatisfaction about health system fairness[185,186] among the public. The high prevalence of HIV/AIDS[187], broad utilization of antiretroviral therapy (ART) and inadequate access to health services[188,189] combine to create parallel challenges of the HV/AIDS healthcare system. Health systems of China are facing reforms with aims to expand access to more healthcare services and enhance the quality in terms of non-clinical aspects in order to meet the people's new expectations[190].

According to the WHO framework for assessing the performance of health systems[24], patients' expectations of healthcare services are categorized into eight domains of health system responsiveness (HSR): dignity, confidentiality, autonomy, prompt attention, quality of basic amenities, social support and choice of provider[11]. These domains are related to patient rights, and reflect their expectation of healthcare services according to their perception of healthcare.

In the measurement of expectation, bias due to reporting heterogeneity among survey respondents from different groups with different preferences and cultural norms make cross-cultural comparison of ordinal response categories invalid[191]. A clinical vignette is a short and clear scenario presenting a hypothetical clinical situation, and can resolve this "response-category differential item functioning"[192]. The response of patients to each scenario thereby reveals their perceptions, values, social norms or impressions of clinical events. Such vignettes have been used to assess opinions or preferences across countries, health care systems, and specialties[193,194]. As a marginalized population, HIV/AIDS patients are more vulnerable in healthcare compared to other patients due to the heavy HIV/AIDS stigma and discrimination. However, there is no study focusing on their expectations compared to their counterparts in healthcare setting especially based on vignettes.

Patients' expectations are affected not only by age[195,196] and sex, but also by occupation[197,198], education[198], and income-conventional indicators of socio-economic status (SES). Although different socio-economic indicators have comparable effects on patients' expectations, a convincing causal relationship between SES indicators and patients' expectation towards quality of HIV/AIDS healthcare remains to be established.

The presence of socio-economic disparities among HIV patients compared to their non-HIV counterparts may be damaging not only from a human rights perspective but also in sustaining confidence in the system. Identifying the extent of such socio-economic disparities can be the first step in improving the quality of health services and patient satisfaction with services within HIV/AIDS health systems. In this current paper, we aimed to compare levels of expectation of HIV and non-HIV patients in eight domains separately adjusted for different socio-economic factors. The results could be useful for the ongoing healthcare reform process in order to improve the quality of HIV/AIDS care.

2. Methods

2.1 Study setting and design

A cross-sectional quantitative study was conducted from 1st January 2015 to 15th February 2015. The study was conducted in the infectious departments of two large hospitals: a special infectious hospital and a general hospital in Kunming, the capital city of Yunnan Province, China. The two hospitals have the largest numbers of HIV patients in Kunming. In these hospitals, both HIV/AIDS and non-HIV patients visit the infectious departments. The majority of non-HIV patients have viral hepatitis or other infectious diseases without tuberculosis. All HIV and non-HIV in- and out-patients aged 15 years old or more attending the infectious department of the two study hospitals were eligible to join the study. Patients with tuberculosis were excluded because tuberculosis is one of the most common opportunistic infections of HIV patients. Those who could not communicate in Chinese or were too ill to be interviewed were also excluded. Consecutive sampling was used to recruit study subjects.

2.2 Sample size

Sample size estimation used the formula for comparing two population means. The mean scores (SD) for confidentiality among HIV and non-HIV in pilot study were 16.77 (3.29) and 17.21 (2.13). With these parameters, the number of subjects required to detect a difference in mean confidentiality score between two groups, with 95% confidence and 80% power, would be 624 per group. To compensate for an estimated 10% incomplete response rate, 694 were required in each group.

2.3 Development and modification of vignettes

The vignettes were developed by using a standardized protocol from the World Health Survey (WHS) responsiveness module (short version). We firstly selected vignettes for health system responsiveness of Set A to Set D involved in eight domains. Vignettes of Set A focus on two domains: respective treatment and prompt attention, Set B: clear communication and quality of basic amenities, Set C: confidentiality and choice of care provider, and Set D: social support to patient and autonomy. Each set includes ten vignettes, five for each domain. Each vignette simulates patient visits and healthcare provider's responsiveness to the patient in the relative domain. In each set, ten vignettes of the two domains were mixed in random order.

The vignettes were translated into Chinese and modified by the main researcher to suit the Chinese context. A team of healthcare experts including two chief physicians of infectious departments of the two hospitals, and an expert of HIV/AIDS prevention in the Centre for Disease Control of Yunnan Province, reviewed and finalized the Chinese version of the vignettes. A focus group discussion consisting of ten non-HIV patients was assembled, and in-depth interviews were conducted with five HIV patients to obtain cultural and contextual relevance. The respondents were asked specific questions in order to determine whether questions were understandable and whether the intent of each question was accurately conveyed. They were also asked to elaborate on the reasons why a particular response category was chosen for a question. According to their suggestions, we modified the vignettes for clearer comprehensibility and cultural suitability. In December of 2014, a pilot study was conducted among 45 HIV and non-HIV patients in both hospitals. It took 60 to 70 minutes for a patient to complete the questionnaire. The instrument was then shortened to 40 to 60 minutes duration.

A sample of five vignettes on the dignity domain was as follows:

- [Xiao Zhang] was pregnant and went to the hospital coughing blood. A nurse welcomed her gently and helped her to a private room. A female doctor came to examine her and gave her a clean gown to replace her blood-stained clothes.
- [Xiao Qu] had bad flu. He went to the clinic. The nurse expressed concern about [Xiao Qu]'s cough and called the doctor, who gave [Xiao Qu] a full chest examination behind a large screen that hid him from the view of other patients.
- [Xiao Ting] went to a crowded clinic. At first, no-one greeted her but after waiting for 5 minutes a nurse called her to the examination area where she was examined behind a small screen that mostly hid her from the other patients.
- [Wang Li] took her baby for a vaccination. The nurse said hello and but did not ask for [Wang Li's] or the baby's name. The nurse also examined [Wang Li] and made her remove her shirt in the waiting room.
- [Luo Ping] has AIDS. When he goes to his health center the nurses do not talk to him and deliberately ignore him. During examinations, his clothes are removed and he is made to wait, half-naked in the waiting room.

All questions for the dignity domain were: “How would you rate his/her experience of being greeted and talked to respectfully?” A rating scale of 1 to 5, representing "very good" to "very bad", was used for each question.

2.4 Study variables and measures

Dependent variables were the total scores of the eight domains as measured by five vignettes per domain. All five responses were summed to obtain a total score for each domain, with a possible range of 5 to 25, where higher scores indicate higher expectation towards that domain. Demographic variables, measured by a self-reported questionnaire, included age, gender, ethnicity, religion, place of residence, marital status, family size, education, occupation, and household income. For comparability with other studies, age was arbitrarily grouped into three categories by mean and 20 year's old interval: (i) 40 years old or less (young adults); (ii) 41 to 60 years old (middle-aged); (iii) more than 60 years old (elderly). The nine ethnic groups were classified into two categories: Han and other ethnicity. Place of residence was classified as either rural or urban based on their insurance type. Family size was grouped into 3 categories: (i) single; (ii) 2-4; (iii) 5 or more family members. SES factors included education, occupation, and household income per month. Education was grouped into four levels: (i) primary school or less; (ii) junior high school; (iii) senior high school, and (iv) university or more. Occupation was grouped into four categories: (i) government-employed; (ii) enterprise-employed; (iii) self-employed; (iv) unemployed. Household income was categorized into five levels according to distribution of household income by place of residence in China[136]: (i) 800RMB or less; (ii) 801～2000RMB; (iii)2001～5000RMB; (iv) 5001～8000RMB; (v) 8001RMB or more.

2.5 Data analysis

Comparison of sample characteristics between HIV positive and non-HIV patients was performed using Chi-square goodness-of-fit tests for categorical variables, and t-tests for continuous variables. Comparisons of mean scores for the eight domains were done using t-tests or analysis of variance (ANOVA) as appropriate. Multiple linear regression models were conducted separately for each domain to assess their independent association with demographic variables and SES factors. Variables having a p-value less than 0.05 were considered as significant. All analyses were performed using R language and environment[137].

2.6 Ethical considerations

The ethical aspects of this study were approved by Prince Songkla University Institutional Review Board and Kunming Medical University. Anonymity of the data was assured and the participants were requested to give their consent to participate in the survey by signing an informed consent form, after providing them with detailed information on the survey procedures.

3 Results

Two consecutive groups containing 696 HIV and 699 non-HIV patients were included in the study. The response rate was 87% and 66% among HIV and non-HIV patients, respectively.

3.1 Demographics and socio-economic status

Table 1 shows the distribution of demographic and socio-economic variables. The majority of patients were 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 and had a monthly household income of 5000 RMB or less and living in a family of size 2-4 members. Both groups were closely matched on gender; however, 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.

3.2 Differences in eight domains between HIV and non-HIV patients

Table 2 presents mean scores of eight domains of patients' expectation of healthcare between HIV and non-HIV patients, based on the vignettes. Of all domains, HIV patients had significantly lower mean expectation scores than non-HIV patients.

3.3 Multivariate analyses

After adjustment for demographic and socio-economic variables, HIV status remained significantly associated with lower expectations of all health system domains (Table 3). Age was significantly associated with basic amenities, with young adults having a higher expectation. Compared to Han people, minority ethnic groups had lower expectations towards dignity, prompt attention and autonomy. Those who lived in a family containing 2-4 members had a higher expectation than those who lived alone.

Figure 1 compares the crude and adjusted coefficients from the linear regression models among each domain, reflecting the differences in expectation scores between HIV positive and non-HIV patients. Prompt attention had the highest coefficient reflecting a relatively higher expectation by non-HIV patients. Non-HIV patients also had higher expectations towards basic amenities, choice of provider, confidentiality, communication, autonomy, social support and dignity.

4 Discussion

HIV patients had lower expectation scores in all health system domains even after adjustment by demographic and socio-economic factors, reflecting lower expectations of the healthcare system. Compared to non-HIV patients, they were slightly younger, belonged to a minority ethnic group, more religious affiliation, more educated, self-employed, more likely to be single or separated and had lower household incomes. Thus, on top of having a lower SES, HIV positive patients in this study were further oppressed by their own HIV status.

Not many studies have focused on differences in expectations of healthcare system between HIV and non-HIV patients across socio-economic status. One study showed that patient's satisfaction with nursing care was associated with younger age, being male, being non-white and having HIV[142]. However, that study did not find an independent effect of being HIV positive after adjustment for SES factors.

Among the eight health system domains, prompt attention was found to have the highest difference of expectation between HIV positive and non-HIV patients, and the low expectation by HIV patients confirmed that there is a shortage of human resources and a lack of an efficient mechanism to uniformly cooperate in HIV/AIDS care. Additionally, quality of basic amenities is linked to health facilities. One study confirmed that this domain is not strongly correlated with clinical quality, and depends on different hospitals in terms of productivity based on instrumental variables [143]. The lower expectation of HIV patients towards basic amenities reflects their helplessness about dissatisfaction with designated hospitals because of not only limited medical resources but also “logistic choices”[144] to hospitals or providers. Another study[145] considered consulting the same healthcare provider to be a source of comfort in provider-patient relationships. However, the comforting affection from seeing the same provider is on the premise that patients have free choice[146,147] rights. The monitoring and evaluation system of China cannot equally share the whole medical resources, and there is lack of effective operational mechanisms to respond timely to the patient’s needs. Under this system, the free choice rights of HIV patents have not been taken into account.

The lower HIV patient expectation in confidentiality can sometimes create a dilemma for health professionals or family members because there is a fine line between safeguarding their privacy and the need to inform other people about their illness. Some studies documented the benefit to patients, especially those with HIV/AIDS, based on human-rights, but others hold the opposite view[148-150]. Besides these, some suggested to identify boundaries of confidentiality[151]. Only in the safe context can “silences” be broken. The majority of people living with HIV/AIDS (PLWHA) often avoid naming themselves in public, to their neighbours, and even sometimes to their own family members. As a marginalized population, they are more vulnerable because of the heavy HIV/AIDS stigma[28,152], especially discrimination by healthcare providers, so they keep “silent” in unsafe contexts. When disclosing their HIV status, the majority of providers in non-appointed hospitals will refuse to examine and treat them and transfer them to special HIV unit. The majority of HIV positive patients must tolerate the negative talk and stigmatizing attitudes by healthcare providers. During their care, there was no dignity[153] given to them because of a lack of effective communication, and lack of prompt attention and respect for individual autonomy[154] such as self-decisions and meaningful participation. Thus, elimination of stigma is an important goal in the struggle against HIV/AIDS for subsequent HIV testing and counselling, and adherence to ART. Additionally, confidentiality, choice of provider, dignity and clarity of communication are deserved rights of HIV positive patients. Adopting a human rights-based approach towards care of HIV/AIDS patients can be very helpful to improve access to HIV prevention, care and treatment.

In terms of social support, HIV patients had a lower expectation compared to their counterparts. Most HIV positive patients expect that they will stay by themselves in hospital, but other patients expect care and contact from their family and friends. The fact that HIV patients abandon their right of access to family and community support may be a consequence of social stigma. Other evidence has shown that decision-making interventions[155] can improve quality of healthcare. This suggests that empowerment of HIV patients within the healthcare system will strengthen quality of healthcare.

Policies in China such as “Four Frees and One Care” has had a great success on expanding the coverage of prevention of mother-to-child transmission and ART. Another policy called “HIV/AIDS regulation” first highlighted human rights' protection in early 2006[178]. However, the effects of empowering these marginalized people in China is lacking. Evidence has shown that empowerment of PLWHA has resulted in policy changes, especially regarding access to free ART. For example, Thailand's response to HIV/AIDS is considered one of the best success stories due to civil society groups[179] as networks at different levels promoted the efficient coordination of activities. Free access to ART has brought massive relief, restoring people's health and enabling them to care for families, providing hope for the future and allowing PLWHA to participate in community activities[180]. In addition, success of Treatment Action Campaign in South Africa, a powerful force in converting donor perceptions of universal access to treatment into a moral imperative[181], led to policy changes for a global impact in 2004. However, free access to ART cannot replace empowerment of PLWHA in which human rights and fundamental freedoms can be realized.

Limitations

There are some limitations in our study, which should be acknowledged. Firstly, we could not involve patients-family-friends relationships during the decision-making process of seeking health care services in our vignette because there are various roles that family or friends play in Chinese culture. Moreover, selection bias was unavoidable since those who did not seek healthcare services or did not know their HIV status were not entered into our study.

Conclusion

Lower expectation of healthcare services was independently associated with HIV status, which could not be explained by any socio-economic indicators. Assessment of health responsiveness based on HIV patient's judgments may give biased results toward favourable service quality. Therefore, assessment of healthcare quality based on their perception should be supplemented by other measures in order to improve quality of HIV/AIDS healthcare service. In addition, a human rights-based approach to HIV/AIDS patients should be implemented.

Acknowledgements

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Table1 Distribution of socio-demographic variables

	Total sample (n=1395)		HIV patients (n=696)		non-HIV patients (n=699)		*p**
	n	%	n	%	n	%	
Age							
<=40	803	57.6	422	60.6	381	54.5	**0.048**
41-60	502	36.0	236	33.9	266	38.1	
>=61	90	6.5	38	5.5	52	7.4	
Gender							
Female	549	39.4	270	38.8	279	39.9	0.709
Male	846	60.6	426	61.2	420	60.1	
Ethnic group							
Han	1094	78.4	504	72.4	590	84.4	**<0.001**
Other	301	21.6	192	27.6	109	15.6	
Religious affiliation							
No	1149	82.4	522	75.0	627	89.7	**<0.001**
Yes	246	17.6	174	25.0	72	10.3	
Place of residence							
Rural	758	54.3	490	70.4	268	38.3	**<0.001**
Urban	637	45.7	206	29.6	431	61.7	
Marriage							
Single	282	20.2	159	22.8	123	17.6	**<0.001**
Married/Cohabiting	935	67.0	383	55.0	552	79.0	
Separated/Divorced/Widowed	178	12.8	154	22.1	24	3.4	
Family size							

1	58	4.2	52	7.5	6	0.9	**<0.001**
2-4	1030	73.8	535	76.9	495	70.8	
>=5	307	22	109	15.7	198	28.3	
Education							
<=Primary school	306	21.9	144	20.7	162	23.2	**<0.001**
Junior high school	668	47.9	296	42.5	371	53.3	
Senior high school	311	22.3	158	22.7	152	21.8	
>=University	110	7.9	98	14.1	11	1.6	
Occupation							
Government-employed	129	9.2	62	8.9	67	9.6	**<0.001**
Enterprise-employed	499	35.8	256	36.8	243	34.8	
Self-employed	213	15.3	176	25.3	37	5.3	
Unemployed	554	39.7	202	29.0	352	50.4	
Household income(Yuan)							
<800	244	17.5	163	23.4	81	11.6	**<0.001**
801-2000	322	23.1	177	25.4	145	20.8	
2001-5000	417	29.9	184	26.4	233	33.3	
5001-8000	239	17.1	88	12.6	151	21.6	
>=8001	173	12.4	84	12.1	89	12.7	

*: All p values in the column were from Chi-squared tests.

Table 2 Distributions of patients` expectation scores based on vignettes

	Total	HIV patients	Non-HIV patients	*p**
	(n=1395)	(n=696)	(n=699)	
Dignity	14.0 (2.5)	13.9 (2.7)	14.2 (2.2)	0.024
Prompt attention	15.9 (2.8)	14.9 (3.0)	17.0 (2.2)	<0.001
Communication	14.4 (2.2)	14.1 (2.5)	14.6 (1.7)	<0.001
Basic amenities	15.5 (2.2)	15.2 (2.6)	15.8 (1.7)	<0.001
Confidentiality	17.0 (2.7)	16.8 (3.3)	17.2 (2.0)	0.004
Choice	15.7 (2.6)	15.3 (3.0)	16.2 (2.0)	<0.001
Social support	14.1 (2.2)	13.8 (2.5)	14.4 (1.9)	<0.001
Autonomy	14.3 (2.2)	14.2 (2.6)	14.5 (1.8)	0.004

*: *p* values from independent t-test.

Table 3 Multiple linear regression of patients` expectation based on vignettes among eight domains

	Dignity		Prompt attention		Communication		Basic amenities		Confidentiality		Choice		Social support		Autonomy	
	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*	Coeff.(95%CI)	*p*
HIV status: Non-HIV vs. HIV		**0.027**		**< 0.001**		**< 0.001**		**< 0.001**		**0.003**		**< 0.001**		**< 0.001**		**0.0046**
	0.252 (-0.009,0.513)		2.106 (1.826,2.386)		0.532 (0.302,0.762)		0.587 (0.354,0.821)		0.397 (0.102,0.692)		0.928 (0.662,1.195)		0.543 (0.308,0.778)		0.288 (0.052,0.524)	
Age: ref.=16-40								**0.0177**								
41-60							-0.35 (-0.598,-0.102)									
61-85							-0.29 (-0.78,0.201)									
Ethnic group: other vs. Han		**0.0398**		**0.0178**												**0.0046**
	-0.333 (-0.65,-0.016)		-0.412 (-0.752,-0.071)												-0.415 (-0.701,-0.128)	
Family size: ref.=1										**0.0389**						
2-4									0.912 (0.179,1.644)							
>=5									0.74 (-0.045,1.525)							

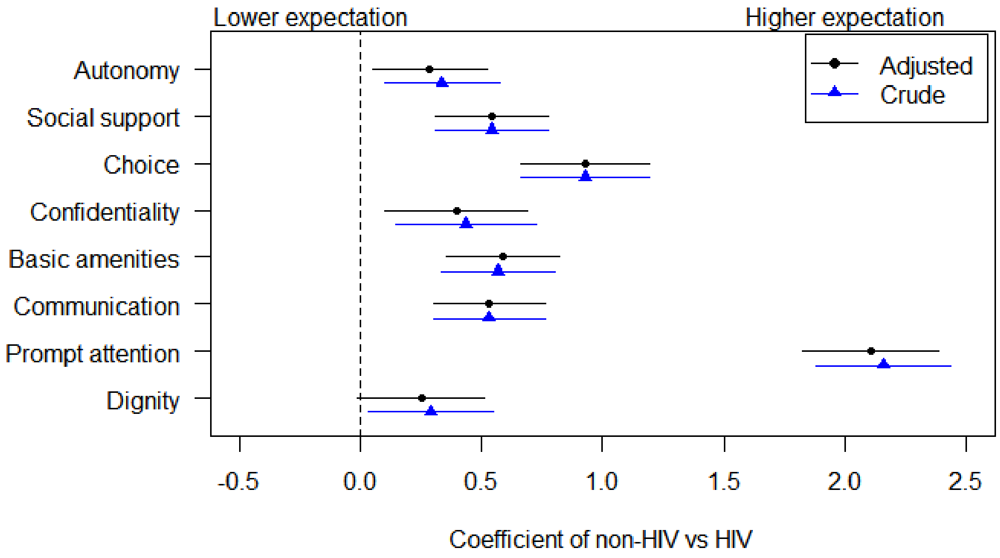
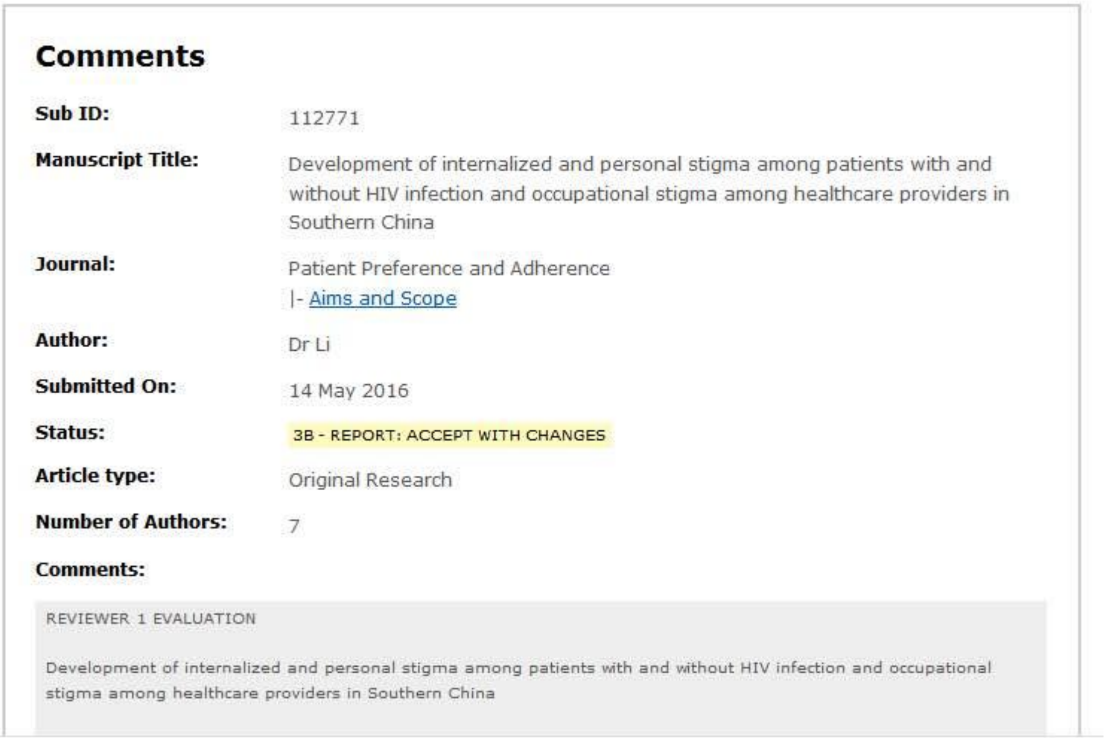


Figure 1 Differences in health service expectation between HIV and non-HIV patients

Annex 3: Manuscript II



Comments

Sub ID:	112771
Manuscript Title:	Development of internalized and personal stigma among patients with and without HIV infection and occupational stigma among healthcare providers in Southern China
Journal:	Patient Preference and Adherence |- Aims and Scope
Author:	Dr Li
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Number of Authors:	7
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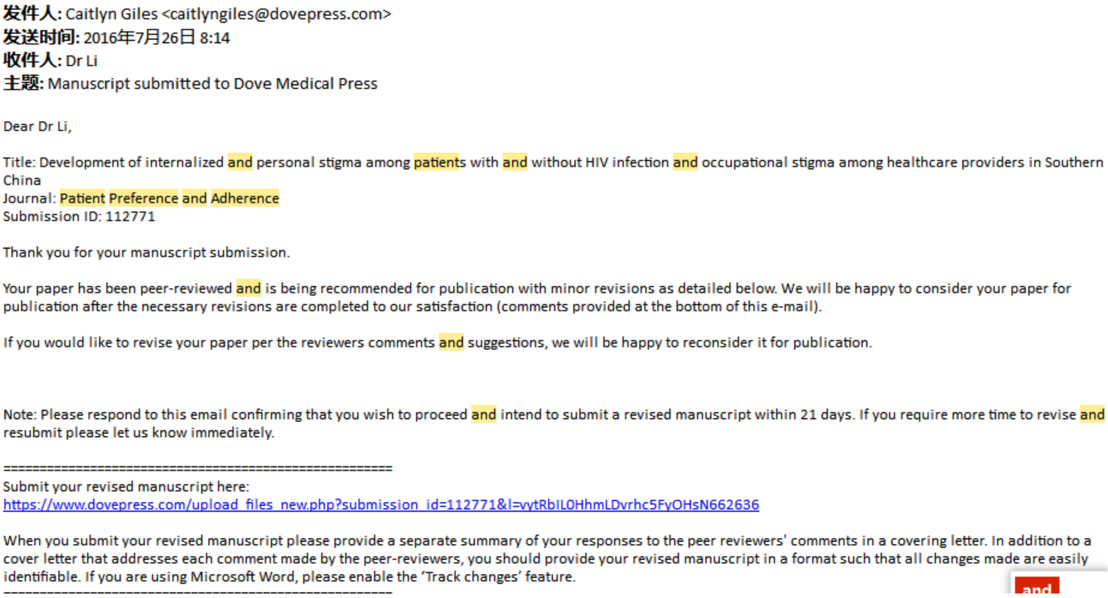
REVIEWER 1 EVALUATION

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



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

Abstract

Background: HIV/AIDS related stigma is a major barrier of access to care for those infected with HIV. Our aim 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, China. Construction of the scales was based on previous studies with modification 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, 699/667 non-HIV patients and 157/155 health 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 subjects (r=0.703) were observed in contrast to low level correlations (r=0.231, 0.286 and 0.266) among factors from healthcare providers. **Conclusions**: The new stigma scales are valid and should be used to monitor HIV/AIDS stigma in different groups of Chinese people in healthcare settings.

Keywords: HIV/AIDS related stigma, scales, HIV positive patients, non-HIV patients, healthcare providers

Introduction

With the pandemic of HIV/AIDS[58] predominantly characterized by sexual transmissions[59] and chronic tendency in 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 formidable barrier for PLWHA seeking healthcare due to less positive attitudes[61], lack of community HIV/AIDS knowledge, lack of supportive or understanding clinic environments, absence of personal financial resources[62], lack of employment opportunities[63], and less optimistic perceptions of policy enforcement[64]. 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 healthcare.

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"[30]. The absence of an explicit conceptualization of stigma precludes appraisal and comparisons of study findings and also limits the ability to design effective interventions[77]. Based on the "significantly discrediting" attributes, 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 behaviours[78,79]. Some other existing theories have demonstrated concepts to understand how stigmatization as a social control mechanism impacts the HIV/AIDS epidemic and communities[77,80]. However, existing conceptual frameworks have not clearly identified how HIV positive patients experience HIV/AIDS stigma in healthcare settings.

Due to time- and context-specific characteristics of stigma, a stigma instrument needs to address the specific nature of people's perceptions in each local context[81,82]. For an individual not infected with HIV, personal stigma can be manifested in three predominant ways towards PLWHA[32], including negative emotions/feelings toward HIV infected people (prejudice)[33,34], prejudiced behavioural expressions to PLWHA (discrimination), and stereotyping as group-based beliefs about PLWHA (stereotype)[35]. 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 healthcare sector is one of main environments where HIV-positive individuals experience stigma and discrimination [83,84]. Stigma towards PLWHA can lead to lower access to care[85] by PLWHA. This stigma can be manifested through the careers of healthcare professionals and quality of health services. Culture is another significantly important characteristic in the framework of HIV/AIDS stigma. Chinese culture is more collectivist[86] compared to western cultures. Individuals in 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 healthcare setting.

In China, previous studies have shown that keeping social distance based on fears of stigmatization[87], negative feelings towards PLWHA[88], such as deservingness or being shamed with risky behaviours[89], may act as barriers for seeking healthcare services among PLWHA. Two essential core elements of HIV/AIDS stigma have been identified in China: keeping social distance based on fear, and negative feelings or behaviours of blame or being shamed. Because of internalized and personal stigma from different groups of people, HIV/AIDS stigma should be measured in parallel from HIV-infected and non-infected individuals, using similar items that are worded from a specific perspective to capture the meaning of different types of stigma. Two equivalent stigma scales measuring internalized and personal stigma[90] match the two core elements. However, they were developed in a South African context. Stigma in an African context is built on a series of shared beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms, resulting in blame for contracting the disease [91,92]. It is similar to the HIV/AIDS stigma in China in some ways but significantly different in the expression form of specific perceptions and behaviours. Therefore, exploration of the latent levels of these two scales is necessary. Additionally, other studies have revealed that Chinese service providers' stigmatizing attitude and behaviour such as differential treatment and denial of care, their perception of social norms and concerns about their occupational safety[93,94] are a key barrier for HIV testing and treatment. A Chinese scale[95] 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 departments of hospitals that are responsible for HIV care in the Chinese healthcare system, especially in the background of increasing coverage of ART. Thus, there is a need to further improve it for assessment of HIV/AIDS stigma at the individual level in hospitals caring for HIV patients and among different groups of people, and also facilitate targeting 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 healthcare 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. The findings from this study can be used to set a priority for future interventions among groups who face a high level of stigma.

Framework for HIV/AIDS stigma

Our understanding of HIV/AIDS stigma framework in hospital settings stems from previous studies[32,90,95]. Valerie A et al[32] developed the conceptual framework for HIV stigma mechanisms from HIV infected and non-HIV people. Maratha J et al[90] developed a parallel scale among HIV infected and non-HIV people while Judith A et al[95] developed a multidimensional scale of HIV-related stigma among Chinese service providers. Fig 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 healthcare 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, China. These two hospitals serve both HIV/AIDS and non-HIV patients at out- and in-patient departments. The majority of the non-HIV patients were diagnosed with viral hepatitis or other infectious disease.

Study subjects

All HIV and non-HIV patients aged 15 years or more consecutively attending the study hospitals were consecutively screened for eligibility. Patients with tuberculosis were excluded to avoid confusion from tuberculosis stigma. Those who were too ill to be interviewed were also excluded. All staff attending HIV and non-HIV clinics of the study hospitals were also recruited.

The first group of HIV patients, non-HIV patients and healthcare providers was enrolled during 1st January to 15th February, 2015 and used to develop the scale. Exploratory factor analysis (EFA) was used to identify the underlying stigma constructs. A second group of subjects, similar to the first, was enrolled between 20th July and 10th September, 2015 and used to validate the scale. The same questionnaires were applied. Any subject who was involved in the development sample was excluded from the validation sample. Confirmatory factor analysis (CFA) was conducted based on 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[199]. Initially, each of the three scales contained 17 items. A sample size of about 85 to 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[199] 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 Maratha J[90] 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 three scales were modified by the main researcher to suit the local hospital context. A team of healthcare 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 understand ability of the questions and 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. A total of 17 parallel items were framed as two positive and 15 negative statements. Responses were rated on a scale of 1 to 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[95] completed by service providers also consisted of 17 items with the similar 1 to 4 rating scale reflecting the level of prejudicial attitudes. These items are listed in Tables 3 and 4.

Analysis of stigma scales

Comparisons of mean scores for each item among the three scales were done using t-tests and two-way analysis of variance was used to compare items adjusting for the type of sample (development and validation).

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[130]. Scree plots were used to identify the optimum number of factors. Items that had a factor loading of > 0.4 and did not load on multiple factors were considered part of a factor. Items that did not have a factor loading of 0.4 or greater or items that had a factor loading of > 0.4 on multiple factors 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 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)[131].

Finally, univariate analyses were performed separately for each factor of HIV/AIDS stigma after EFA and CFA to assess their independent association with demographic and socio-economic variables. Variables having a P value of less than 0.05 were considered as significant. All analyses were performed using R language and environment[132].

Ethical considerations

The ethical aspects of this study were approved by Prince Songkla University Faculty of Medicine Institutional Review Board and Kunming Medical University. Anonymity of the data was assured and the participants were requested to give their consent to participate in the survey by signing an informed consent form, after providing them with detailed information on the survey procedures.

Results

The development/validation samples included 696/667 HIV patients, 699/667 non-HIV patients and 157/155 health providers.

Sample characteristics

Table 1 presents socio-demographic 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 5000 RMB or less and were living in a family with 2-4 members. Both groups were closely matched on gender; however, 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.

Table1 Distribution of characteristics among HIV and non-HIV patents

	Development sample (n=1 395)						Validation sample (n=1 334)					
	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	62.1	426	61.2	109	15.6	841	63.0	421	63.1	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	1027	75.3	522	75.0	627	89.7	1068	80.1	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												
1	88	6.5	52	7.5	6	0.9	42	3.1	36	5.4	6	0.9
2-4	1042	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 (RMB)												
<800	294	21.6	163	23.4	81	11.6	196	14.7	131	19.6	65	9.7
801-2000	340	24.9	177	25.4	145	20.7	258	19.3	163	24.4	95	14.2
2001-5000	409	30	184	26.4	233	33.3	447	33.5	225	33.7	222	33.3
5001-8000	165	12.1	88	12.6	151	21.6	234	17.5	77	11.5	157	23.5
≥8001	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					41.3 (5.8)						40.7 (6.1)	

Table 2 shows the demographic characteristics of healthcare 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 5000 to 8000 RMB.

Table2 Distribution of characteristics among healthcare providers

	Development sample (n=157)		Validation sample (n=155)	
	n	%	n	%
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 experience (Mean, SD)	13.7 (10.8)		10.3 (9.7)	
Job 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 (RMB)				
<2000	11	7.0	13	8.4
2001-5000	34	21.7	55	35.5
5001-8000	66	42.0	62	40.0
8001-13000	32	20.4	14	9.0
≥13001	14	8.9	11	7.1
HIV/AIDS stigma score (Mean, SD)	32.3 (8.8)		35.3 (9.6)	

Tables 3 and 4 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 towards 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, 1 item in the development sample alone and 1 item in the validation sample alone). The mean (standard deviation) scores of stigma scales among HIV, non-HIV and healthcare 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 healthcare providers.

Table 3 Summary of stigma items among HIV positive and non-HIV patients in development and validation sample

Items for HIV and non-HIV patients	Development Sample (Mean, SD)			Validation Sample (Mean, SD)			*p***	*p****
	HIV	non-HIV	*p**	HIV	non-HIV	*p**		
1. 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	0.036
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	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	0.222
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	<0.001
5. Getting HIV is a punishment for bad behaviour	2.13 (0.9)	2.14 (0.6)	0.872	2.29 (0.9)	2.20 (0.8)	0.058	<0.001	<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	0.695
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	0.063
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	0.150	0.448
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	0.855
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	0.239
11. 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	<0.001
12. Most employers would not employ me because I am HIV+	2.81 (0.8)	2.75 (0.6)	<0.001	2.81 (0.8)	2.71 (0.7)	0.011	0.542	0.840
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	0.122
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	0.386
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	0.724
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	0.043
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	0.247

* T-test for HIV/non-HIV effect; ** T-test for sample effect; *** Two way ANOVA for sample effect adjusted by the HIV status effect; R=reversed items. PLWH: people living with HIV.

Table 4 Summary of stigma items among healthcare providers in development and validation sample

Items for healthcare providers	Sample 1	Sample 2	$p^{\#}$
	Mean (SD)	Mean (SD)	
1. 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 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
11. 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 wouldn’t share utensils with PLWH	1.96 (0.9)	2.02 (0.9)	0.530
14. I am willing to work with HIV + 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 exam of HIV + patient (R)	1.49 (0.8)	1.72 (1.0)	0.022
17. I am willing to interact with HIV + patients in the same way as other patients (R)	1.60 (0.9)	1.81 (1.0)	0.053

#: t-test for sample effect. R=reversed items. PLWH: people living with HIV/AIDS.

Exploratory factor analysis

Patient scales

The scree plots shown in Fig 2 from both analyses suggested two factors. Among the HIV group, the first factor loaded highly on 7 items and reflected a feeling of "being refused". The second factor loaded highly on 3 items and reflected a feeling of "guilt". Among the non-HIV group, the first factor loaded highly on 7 items reflecting a feeling of "refusal" and the second factor loaded highly on 3 items and reflected a feeling of "blaming" (Table 5).

Table 5 Factor loadings among HIV, non-HIV patients and healthcare providers in development and validation samples

	Factor loadings			
	Development sample			Validation sample
	Factor 1	Factor 2	Factor 3	
1) Items of internalized stigma among HIV patients (α=0.869)				
Being refused (α=0 .880)				
7. I would understand if people rejected my friendship because I am HIV+	0.82			0.674
8. My neighbours would not like me living next door if they knew I had HIV	0.81			0.584
16.Because of my HIV people would not date me	0.81			0.580
12.Most employers would not employ me because I am HIV+	0.73			0.556
13.If I was in public or private transport and someone knew I had HIV they would not sit next to me	0.70			0.544
14.If I eat around a restaurant and people knew I had HIV they would not eat in the same place	0.69			0.614
4. When people know I have HIV I feel uncomfortable around them	0.66			0.444
Guilt (α=0.709)				
3. I feel that it is my fault that I got HIV		0.84		0.633
5. Getting HIV is a punishment for bad behaviour		0.78		0.529
2. I must have done something wrong to deserve getting HIV		0.68		0.631
2) Items of personal stigma among non-HIV patients (α=0.853)				
Refusing (α=0.810)				
7. I would not like to be friends with someone with HIV	0.88			0.543
8. I would not like someone with HIV to be living next door	0.80			0.487
9. If I was in public or private transport, I would not like to sit next to someone with HIV	0.76			0.422
16. I would not date a person if I know that he/she has HIV	0.76			0.405

6. I feel afraid to be around people with HIV	0.74			0.446
4. I feel uncomfortable around people with HIV	0.69			0.447
11.I think less of someone because they have HIV	0.67			-
Blaming (α=0.852)				
2. If you have HIV you must have done something wrong to deserve it		0.85		0.507
1. People with HIV should be ashamed of themselves		0.81		0.445
3. People with HIV/AIDS have only themselves to blame		0.79		0.425
5. I think getting HIV is a punishment for bad behaviour		0.61		0.420
3) Items of stigma from healthcare providers (α=0.839)				
Blaming (α=0.872)				
1. People who got HIV/AIDS through sex and drug use, got what they deserved	0.89			0.791
4. People who behave promiscuously should be blamed for AIDS	0.86			0.785
3. Infected through drug use deserve sympathy	0.86			0.839
2. Infected through commercial sex deserve sympathy	0.82			0.798
Professionalism* (α=0.893)				
15. Willing to provide same care (R)		0.92		0.944
16. Willing to do physical exam of HIV + patient (R)		0.88		0.853
17. Willing to interact same as other patients (R)		0.83		0.893
18. Willing to work with HIV + patients (R)		0.70		0.599
Egalitarianism* (α=0.780)				
6. Deserve good care-commercial sex (R)			0.90	1.042
7. Deserve good care-drug use (R)			0.88	0.951
5. Deserve good care-blood donation (R)			0.68	0.497

- means that the coefficient for that item < 0.4. R=reversed: it means the description of the reverse.

Healthcare providers' scale

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

Internal consistency

Cronbach’s alpha coefficients for all factors were above 0.853, except for egalitarianism which had a value of 0.780, 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 0.231 to 0.703 indicating that the factors had a low to moderate correlation.

Table 6 Correlation of latent factors in three scales

		Internalized stigma	Personal stigma	Occupational stigma of providers	
		Guilt	Blaming	Professionalism	Egalitarianism
Internalized stigma	Being refused	0.537			
Personal stigma	Refusing		0.703		
Occupational stigma	Blaming			0.231	0.386
	Professionalism				0.266

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 0.405 and 0.674), while those for healthcare provider's validation sample were high (between 0.497 and 1.042). For test statistics, all RMESA were less than 0.08, all CFI were more than 0.90 and all TLI were more than 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 less than 0.001.

Predictors for each domain of stigma

Table 7 presents results of the univariate analysis to predict each domain of stigma. Age was associated with feelings of being refused among HIV patients; those being older than 40 years 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 older than 40 years were more likely to refuse and blame HIV patients. Healthcare providers who were aged more than 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, while non-HIV patients who were married also had a tendency to refuse and blame HIV patients. Health providers who were married were less likely to be professional. Health 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 providers, marital status was associated with professionalism while gender and household income were significantly associated with egalitarianism.

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

	Internalized stigma of HIV patients		Personal stigma of non-HIV patients		Occupational stigma		
	Being refused	Guilt	Refusing	Blaming	Blaming	Professionalism	Egalitarianism
Age (years): >40 vs. ≤40	**0.18 (0.05, 0.32)**	0.14 (-0.01, 0.28)	**0.27 (0.13, 0.40)**	**0.23 (0.09, 0.37)**	-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)	-0.23 (-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: ≥University vs. < University	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: ≥5000 vs. < 5000	-0.14 (-0.30, 0.02)	**-0.28 (-0.45, -0.11)**	-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)**

CI: confidence interval.

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 healthcare providers, three factors were identified reflecting feelings of contradiction between social norms (blaming) and professional values (professionalism and egalitarianism). There were significant relationships between various demographic characteristics and these latent factors. However, there was no consistent pattern among the three groups.

Being refused vs. refusing and guilt vs. blaming were two latent factors among internalized and personal stigma scales suggested by EFA and CFA. Perceptions of guilt and shame are two painful self-conscious emotions. Some researchers have repeatedly confirmed their distinctiveness[200,201]. Guilt is associated with self-blame related to one's own behaviour, whereas shame is associated with self-blame at a deeper level where the individual sees their global self as being at fault[202]. 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[203]. Thus, guilt-prone individuals may utilize more avoidant strategies such as abandoning utilization of healthcare in order to avoid social interactions. It also may 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[204] so as to avoid further refusal. Being refused is also manifested in the forms of social isolation [205] 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 “neighbours would not like to live next door to me” were included in our results among patients that were not included in the African study[90]. This implies that Chinese tend to repel HIV positive patients more so than people from Africa, a country known to be the epicentre of HIV/AIDS. Feelings of refusing and blaming come not only 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 healthcare providers. One study[206] showed that strained, distant relationships with family members or friends or both were a source of shame. Based on the labelling theory of Scheff [207], the application of deviant stereotypes makes those who are faced with changed self-perceptions and social opportunities devalue and be labelled. The majority of the general population doesn't want to employ PLWHA, or be their neighbour, friend, or intimate partner, and tend to regard them as being less trustworthy, intelligent, and competent. Once a person is labelled, 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 healthcare 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. When changing 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 above, 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 behaviours.

Low levels of correlation among stigma factors found in healthcare workers in our study reflect independence. A previous study[95] identified internalized shame among healthcare providers, a contrast to our study. The attitude of healthcare providers towards HIV patients is mainly built on a mainstream culture of associations between HIV/AIDS and immoral behaviours. A coexistence of blaming on one hand and professionalism[208,209] and equalitarianism[210] on the other hand indicated a contradiction between knowledge/competence in care and attitudes towards HIV/AIDS patients[93,211,212]. 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 the independence of each factor reflecting that they are representative of an independent sub-stigma mechanism[77-79].

Marital status was the strongest predictor across all latent factors of internalized and personal stigma among both patient groups. Marital status strongly influences disclosure of HIV status[213], and is also known to have a significant association with quality of life[214]. The association may stem from relationships between marital status and psychology reflecting unmet inner needs and emotional frustrations. Based on social cognitive theory[215], 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 healthcare providers. Those having a higher education were less likely to blame patients and more likely to treat patients professionally and equally. One study [216] suggested that poor knowledge of HIV resulted in more blaming towards PLWHA. A spirit of professionalism and excellence of patient care provided a strong foundation for the planning and delivery of health services[217]. Furthermore, egalitarianism of healthcare providers should compensate for those who were HIV positive in order to close inequalities based on Luck Egalitarian theory[218].

WHO and other international organizations such as UNAIDS and SANAC have advocated “zero discrimination” since 2011. Overall, our study has highlighted that HIV/AIDS stigma is still common in 2014. In China, the strategy to control HIV indeed achieves universal health coverage and promotes a people-cantered approach grounded in principles of human rights and health equity. However, for over ten years more than 50% of PLWHA were still fearful of disclosing their infectious status, while almost 80% were afraid of being blamed or being refused in 2013[219]. More efforts are still needed to achieve these goals, especially in health settings[220].

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 healthcare providers was rather small, thus it is possible that the situation in other institutes may be different.

Conclusion

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 healthcare settings.

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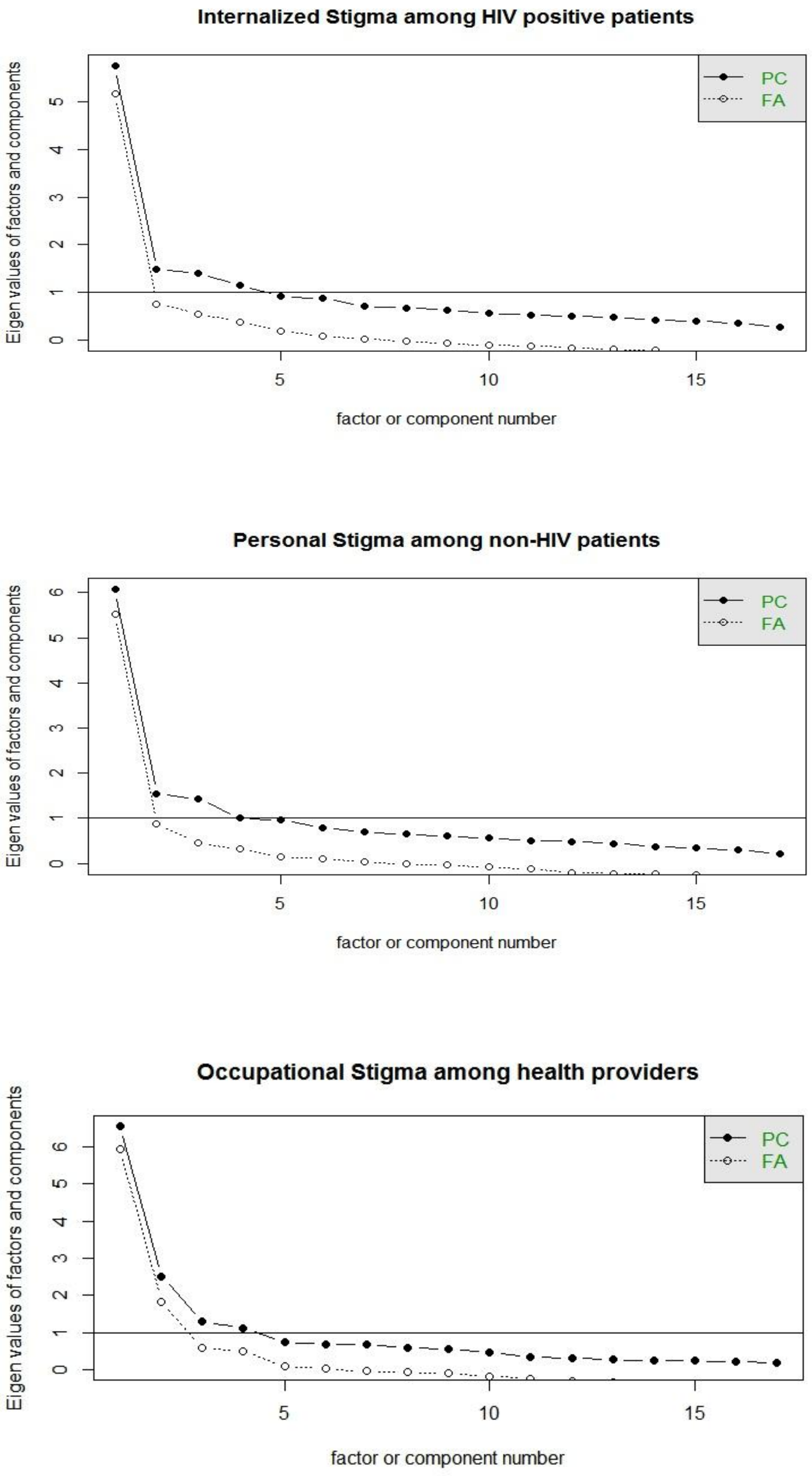


Figure 1 Scree plots for the three scales of internalized stigma, personal stigma and occupational stigma

Annex 3: Manuscript III

Comparison of health system responsiveness between HIV and non-HIV patients at infectious disease clinics in Yunnan, China

Abstract

Background: China is in an epidemiologic transition period. Health system responsiveness (HSR) has become an increasing concern in China. With the burden of increasing HIV/AIDS, responsiveness of HIV care is urgently needed. We aimed to compare experience of HSR between HIV and non-HIV patients. ***Methods:*** A cross-sectional study was conducted in Yunnan, China from January to February, 2015 among two consecutive groups of HIV positive and non-HIV patients in two hospitals with the largest HIV admissions. Patients' experience and expectation of HSR were measured using a self-reported questionnaire containing items of seven domains and 35 vignettes; five per domain. Each item and vignette were ranked from 1 "very good" to 5 "very bad". B-scales were built based on the difference between experience and the vignettes for each domain. Ordered probit and censored ordered probit regression models were constructed to compare HSR experience between the two groups adjusted for SES factors. ***Results:*** The majority of HIV patients were at clinical stage 1, infected via unprotected sexual contact and had CD_4 count less than 500cells/μl. After adjustment by SES factors, HIV patients had better experiences of HSR in six out of the seven HSR domains, prompt attention being the only domain that non-HIV patients had better experiences. ***Conclusion:*** Perceptions of HSR experience were better among HIV patients except for prompt attention, which could not be explained by SES factors. A reform is needed to push the current healthcare system into the right direction to meet the demands of patients.

Keywords: Experience of HSR; anchoring vignettes; HIV care; Healthcare; China**.**

Introduction

China is in an epidemiologic transition period. Quality of healthcare faces with noteworthy challenge especially due to non-clinical determinant such as perception of patients experience in clinics. Public perceptions of responsiveness, trustworthiness and quality is low[221]. About 55% of residents from the lowest and highest income quintile groups are not satisfied with inpatient services[185]. Quality of mental healthcare have been showed to be significantly associated with dignity and basic amenities[222]. With the serious burden of increasing human immunodeficiency virus infections and acquired immune deficiency syndrome (HIV/AIDS), responsiveness of HIV care is an urgent public health concern.

On one hand, there are low levels of responsiveness in HIV care. A study from China showed that healthcare providers did not offer adequate emotional support to HIV patients, whereas nurses could not provide normative HIV care[223]. On the other hand, there have been attempts to improve the quality of HIV/AIDS care. Another study suggested that an expert system for HIV voluntary counselling could increase patients' self-efficacy and knowledge[224]. However, HIV patients still suffer from indignity and incompetent service and lack the required social support.

Since 2011, there has been an advocacy of “zero discrimination” to eliminate discrimination and stigmatization[225]. However, more than 50% of people living with HIV/AIDS are still fearful of disclosing their infectious status, while almost 80% are afraid of being blamed or being refused healthcare[219]. For HIV patients who bear psycho-social problems such as discrimination, HSR has rarely been addressed in HIV care, especially in China. It is important to comprehensively compare HSR among HIV and non-HIV patients to meet patients` needs.

HSR is a promising measure of the quality of a health system, and focuses on a healthcare system`s ability to satisfy patients` expectations in terms of non-financial aspects of healthcare and non-clinical health domains such as dignity, confidentiality, autonomy, prompt attention, quality of basic amenities, social support and choice of provider[11,12]. It in turn may promote utilization of services[13,14], and ultimately promote health. One study from Ethiopia found that HSR was independently associated with satisfaction of HIV care[15], while another suggested that HSR was related to increasing visit adherence[16]. Some domains of HSR such as prompt attention, autonomy and communication were identified as priority areas for actions to improve responsiveness of healthcare services[17,18]. However, there has been a lack of studies comparing differences of HSR between HIV and non-HIV patients.

The self-rated behaviour of HSR is systematically biased by demographic, socio-economic or cultural factors. A challenge to comparing self-reported responsiveness results is known as "reporting behaviour heterogeneity"[226], "differential item functioning (DIF)"[227], and "response category cut-point shift"[228]. Anchoring vignettes have been proposed to address these problems[192,228,229]. Although anchoring vignettes have been applied to HSR in different settings[230,231], it has not been used to assess HSR across HIV and non-HIV patients to measure equity of outpatient services.

The main aim of this study was therefore to compare experiences of HSR between HIV and non-HIV patients. It is well known that the two groups are different in terms of SES and expectations on health system responsiveness, the comparison thus adjustment for these two factors was implemented.

Methods

Study setting and design

A cross-sectional study was conducted in infectious departments of two large hospitals in Kunming, Yunnan province. These two hospitals have the largest number of admissions of HIV and non-HIV patients in Yunnan.

Subjects

Eligible patients in this study were HIV and non-HIV in- and out-patients aged 15 years old or more. The majority of non-HIV infectious patients had hepatitis. HIV patients with tuberculosis were excluded as they received different services from non-HIV healthcare. Those who could not communicate in Chinese or were too ill to be interviewed were also excluded. Consecutive sampling was used to recruit study subjects.

Sample size

Sample size estimation used the formula for comparing two population proportions. The percentages of patients who rated communication domain as “good” among HIV and non-HIV patients in a pilot study were 51% and 59%, respectively. With these parameters, the number of subjects required to detect this difference of 8% in the proportion of rating communication as “good” between the two groups, with 95% confidence and 80% power, would be 631 per group. To compensate for an estimated 10% incomplete response rate, 694 were required in each group.

Development and modification of vignettes

The vignettes were developed using a standardized protocol from the World Health Survey (WHS) responsiveness module (short version), Set A to Set D. Domains in these vignettes included: Set A - respective treatment and prompt attention, Set B - clear communication and quality of basic amenities, Set C - confidentiality and choice of care provider, and Set D - social support to patient and autonomy. Each set includes ten vignettes, five for each domain. Each vignette simulates patient visits and healthcare provider’s responsiveness to the patient in the relative domain. In each set, ten vignettes of the two domains were mixed in random order. A rating scale of 1 to 5, representing "very good" to "very bad", was used for each question.

The vignettes were translated into Chinese and modified by the main researcher to suit the Chinese context. A team of healthcare experts including two chief physicians of infectious departments of the two hospitals, and an expert of HIV/AIDS prevention in the Centre for Disease Control of Yunnan Province, reviewed the Chinese version of the vignettes. A bilingual (English-Chinese) group translated them back into English to improve the accuracy of the translation. To check appropriateness of the vignettes, a focus group discussion consisting of ten non-HIV patients was assembled, and in-depth interviews were conducted with five HIV patients to obtain cultural and contextual relevance. The respondents were asked to determine whether each question was understandable and the message was accurately conveyed. They were also asked to elaborate on the reasons why a particular response category was chosen for a question. Based on these results, the semi-final version of the vignettes were achieved in November 2014. In December of 2014, a pilot study was conducted among 45 HIV and non-HIV patients in both hospitals. It took 60 to 70 minutes for a patient to complete the questionnaire. The finalized instrument was then shortened to between 40 to 60 minutes duration.

Figure 1 shows the framework of HSR in seven domains on the left. Details of the vignettes are in the annex.

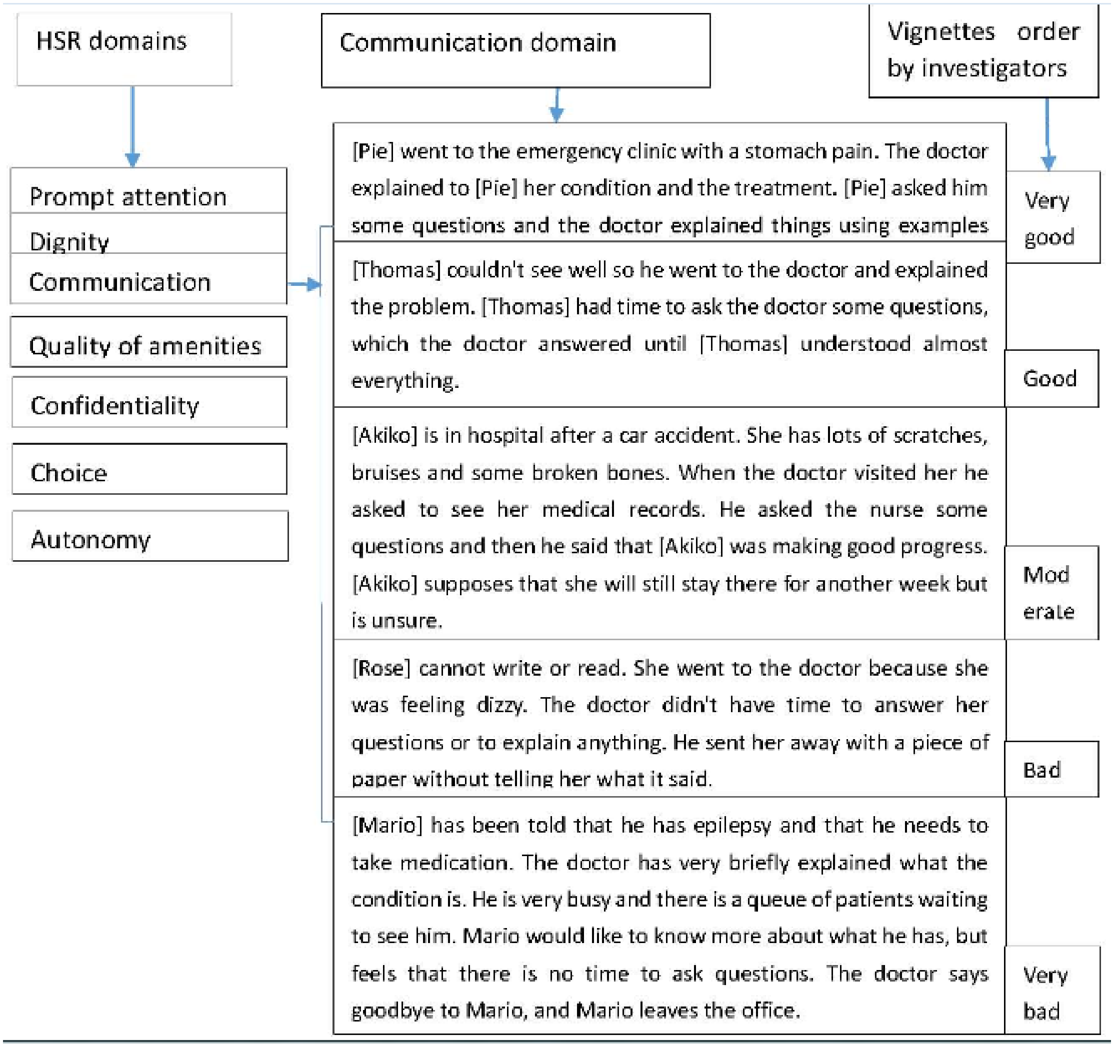
Data collection

HSR data were collected from 1st January to 15th February 2015. The team of interviewers consisted of the main research investigators, HIV/AIDS specialists and local medical students. Prior to data collection, all interviewers were given training based on concepts of HSR, dimensionality of each domain, meaning of each vignette, common symptoms of HIV/AIDS, psychological support and investigation skills and protocol for emergency situations. Then, eligible patients were interviewed face-to-face using an individual questionnaire. Among them, experiences of HSR were self-reported, whereas vignettes were read by the investigators. Each patient was given a gift valued at 10 RMB.

Study variables and measurements

The dependent variable was the self-rated experience of HSR in seven domains.

The main independent variable was HIV status confirmed by Western Blot test. Demographic and socio-economic variables collected included age, gender, ethnicity, religious affiliation, place of residence,



[Pie] went to the emergency clinic with a stomach pain. The doctor explained to [Pie] her condition and the treatment. [Pie] asked him some questions and the doctor explained things using examples

[Thomas] couldn't see well so he went to the doctor and explained the problem. [Thomas] had time to ask the doctor some questions, which the doctor answered until [Thomas] understood almost everything.

[Akiko] is in hospital after a car accident. She has lots of scratches, bruises and some broken bones. When the doctor visited her he asked to see her medical records. He asked the nurse some questions and then he said that [Akiko] was making good progress. [Akiko] supposes that she will still stay there for another week but is unsure.

[Rose] cannot write or read. She went to the doctor because she was feeling dizzy. The doctor didn't have time to answer her questions or to explain anything. He sent her away with a piece of paper without telling her what it said.

[Mario] has been told that he has epilepsy and that he needs to take medication. The doctor has very briefly explained what the condition is. He is very busy and there is a queue of patients waiting to see him. Mario would like to know more about what he has, but feels that there is no time to ask questions. The doctor says goodbye to Mario, and Mario leaves the office.

Figure 1 Framework of HSR, vignette example, and vignette ordering by investigators

Statistical methods

B-scale computation. One approach was used to calculate the proportions of HSR: setting the scale of self-assessments relative to vignettes in a non-parametric setting**.**

Let y_i be the self-assessment HSR and $z_{i1}, \ldots, z_{iJ}$ be the J vignette of HSR, for the ith respondent. For respondents with consistently ordered rankings on all vignettes ($z_{j-1} < z_j$, for $j = 2, \ldots, J$), we create the DIF-corrected self-assessment Ci:

$$\mathrm{C}_i = \begin{cases} 1 & \text{if } yi < zi1 \\ 2 & \text{if } yi = zi1 \\ 3 & \text{if } zi1 < y < zi2 \\ & \vdots \\ 2J+1 & \text{if } yi > zij \end{cases}$$

Values of C that are intervals represent the set of inequalities. Under two assumptions of response consistency and vignette equivalence, the C-scale is used to ensure credible comparisons[138].

Based on the same method as the C-scale, the B-scale is built. The difference between the values lies in information that exist when a self-rating response is tied with the rating of an anchoring object, $y_i = v_{ij}$. The C-scale makes strict comparisons with adjacent rank orderings in such cases. The B-scale states less information in the occurrence of a tie, represented as a set of B-scale values rather than a single index value[139]. If $y_i = v_{i1}$, then $\mathrm{B}_\mathrm{i} = \{1, 2\}$, if $y_i = v_{i2}$, then $\mathrm{B}_\mathrm{i} = \{2, 3\}$. The advantage of B-scale is that it does not rely on cut point locations, and as a result provides credible comparisons without the requirement of interval equivalence or vignette equivalence.

Vignette ordering. The ordering of the vignettes is important before construction of the B-scale. It is normally chosen by the researchers, and also possible to draw upon a consensus ordering by the respondents, so long as only one ordering is used for all respondents in the analysis[139]. However, differences between hypothesized ordering by the researchers and the consensus ordering may be used for diagnosing problems in the survey instruments, particularly when translating the questions for use in different languages. Thus, we confirmed the vignette ordering for construction of B-scales and censored ordered probit regression models.

Data analysis

Comparison of sample characteristics between HIV positive and non-HIV patients was performed using Chi-square goodness-of-fit tests for categorical variables. Figure 2 shows the subsequent analysis of experience and HSR vignettes. After vignette ordering (Figure 1), the distributions of experience and B-scales of HSR were described, and ordered probit regression models (OPR) and censored ordered probit regression models (COPR) were conducted. OPR models were constructed separately for each domain to compare differences of self-reported experience of HSR between HIV and non-HIV patients before and after adjustment of demographic and socio-economic factors. COPR models were used to compare

B-scale values of HSR before and after adjustment of demographic and socio-economic factors. Variables having a p-value less than 0.05 were considered as significant. All analyses were performed using R language and environment[137].

Ethical considerations

The ethical aspects of this study were approved by Prince Songkla University Institutional Review Board and Kunming Medical University. Anonymity of the data was assured and the participants were requested to give their consent to participate in the survey by signing an informed consent form, after providing them with detailed information on the survey procedures.

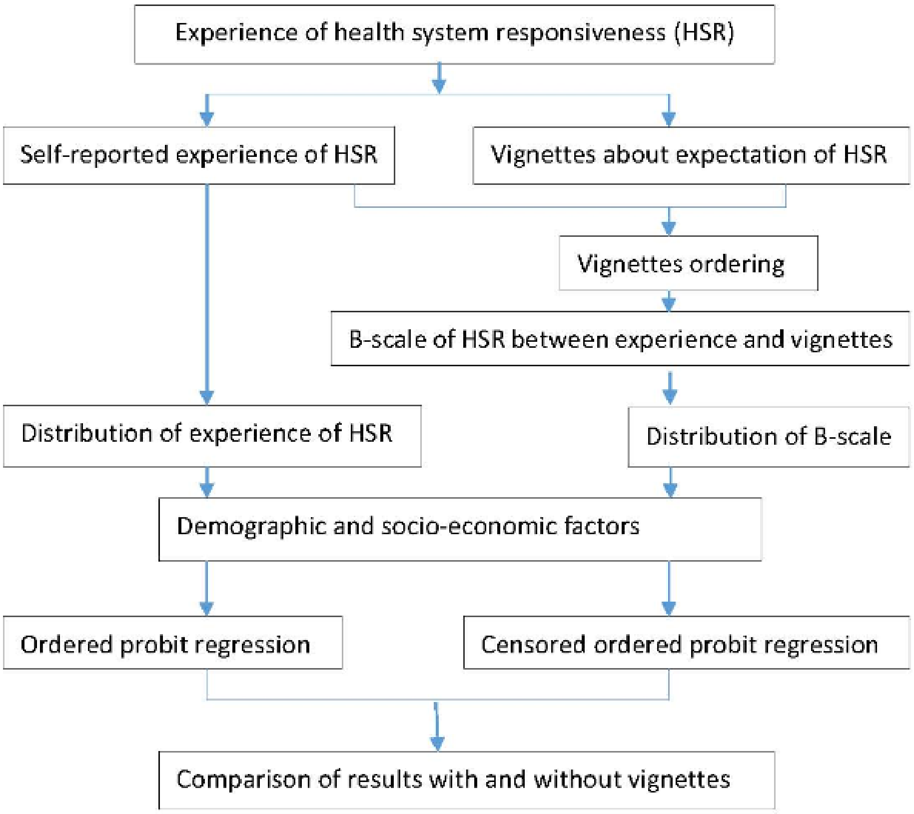


Figure 2 Framework of measurement and analysis about HSR experience and vignettes

Results

Out of 800 consecutive eligible HIV patients approached, 696 (87%) consented to join the study, while 699 (66%) of 1059 non-HIV patients invited agreed to join the study. Most of the HIV patients who refused to participate stated heavy internalized stigma, as the reason for not joining, whereas their counterparts refused because they thought the study was not relevant to them.

Demographic and socio-economic characteristics

Table 1 shows the distribution of demographic and socio-economic variables. The majority of both groups of patients were male, of Han ethnicity, married or cohabiting, employed, and had no religious affiliation. About half achieved a junior high school level of education, had a monthly household income of 5000 RMB or less and were living in a family of size 2-4 members. Both groups were closely matched on gender; however, HIV positive patients were more likely to belong to a minority ethnicity, have a religious affiliation, live in a rural area, have a higher education level, be separated, divorced or widowed, have a lower household income, live with fewer family members and be self-employed.

Clinical and characteristics

Table 2 presents the clinical characteristics of HIV patients. The route of HIV transmission among HIV positive patients was mainly via unprotected sexual contact, accounting for 77.7%. The majority were at clinical stage 1, were not tested for virus load, and missed their ART dose in last seven days. In almost 90% of patients, the CD_4 count was less than 500 cells/µl, and the majority were followed up between 2-4 times in the first three months after confirmation of HIV/AIDS. The median virus load was 89,377.5 copy/ml among those who were tested, and the median number of days between HIV diagnoses and receiving the first dose of ART was 292.6. In contrast, the majority of non-HIV patients had hepatitis (85.7%).

Experience of HSR among HIV and non-HIV patients

Table 3 shows the distribution of experiences of HSR among HIV and non-HIV patients.

The majority of HIV patients perceived having a “good” experience in all seven HSR domains. The majority of non-HIV patients perceived having a “good” experience in three HSR domains: prompt attention, dignity and communication, while four domains were perceived as “moderate”: quality of basic amenities, confidentiality, choice and autonomy. The difference of proportional trends from the ordered probit regression models were significant in all domains except for prompt attention, indicating that non-HIV patients were more likely to have a worse experience for these HSR domains.

After adjustment for socio-demographic factors, the differences were still significant among the same six HSR domains.

Experience of HSR after adjusting for vignettes among HIV and non-HIV patients

Table 4 presents B-scale values between self-rated HSR and vignettes in seven domains. B-values ranged from 1 to 6, since there are 5 vignettes, reflecting more than "very good" to less than "very bad". Among HIV patients, the highest probabilities mainly concentrated around B-values of 2 reflecting experiences between "very good" and "good" for four domains: prompt attention, dignity, communication and confidentiality. The highest probabilities of basic amenities and autonomy domains had B-scale values of 3 reflecting experiences between "good" and "moderate", and 1 reflecting experiences more than "very good". In contrast, the experience of HSR after adjusting for vignettes among non-HIV patients were generally lower than HIV patients. The differences of rank probabilities were significant in all seven domains before and after adjusting for socio-demographic factors. In prompt attention, non-HIV patients were less likely to have a worse experience than HIV patients. However, non-HIV patients were more likely to have a worse experience than HIV patients in dignity, communication, quality of basic amenities, confidentiality, choice of providers and autonomy domains.

Discussion

HIV patients had better experiences about self-rated health system responsiveness in six HSR domains, prompt attention being the only exception, after adjustment for demographic and socio-economic factors. After adjusting for anchoring vignettes, HIV patients still had better perceptions of experiences about health system responsiveness in these six domains. Compared to OPR models no adjustment for vignettes, all the coefficients reduced in COPR models reflecting more narrow and valid differences among HIV and non-HIV patients without bias due to reporting heterogeneity.

Perceptions about experience of dignity, communication, quality of basic amenities, confidentiality, choice of provider and autonomy among HIV patients were better compared to their non-HIV counterparts. Many studies among HIV patients showed "logistic choices"[144] to providers or hospitals and lack of dignity[153] without respect for individual autonomy[154] such as medical participation and self-decisions in HIV care. HIV patients kept more appointments when treated with dignity and patient-centred communication[156,157], because of communication preferences[158] and patient satisfaction[159]. Meanwhile, providers also need to recognize boundaries of confidentiality[151]. Conversely, one study showed that HIV patients were highly satisfied with pharmaceutical services[160]. A possible explanation for the finding that HIV patients perceived better HSR than non-HIV patients in this study may reflect the successful evolvement of HIV care in the country. Good care given to HIV patients such as good treatment efficacy of highly active antiretroviral therapy (HAART)[161] and integration of community and public HIV services,[162] is part of an attempt to control the spread of HIV. HIV prevention has steadily been supported first by internal findings such as Global Fund[163,164] and has recently become internalized. Studies in China recently focused on a scaling-up[165,166] to increase the number of individuals knowing their HIV status and improving[167,162] access to HIV-related services. However, non-HIV healthcare is overwhelmed by several problems including inequalities of health care utilization[168] and high out-of-pocket payments[169] due to high workloads[223] and inadequate budgets. In 2012 in China, the wealthiest 20% of the urban and rural populations contributed 49.7% and 55.8% of the total health expenditure respectively, while the poorest 20% contributed only 4.7% and 4.4%[170]. This finding indicates a need to improve care for ordinary patients in general.

However, HIV patients had worse perceptions about experience of prompt attention compared to their counterparts. There has been no study comparing the experience of HSR between HIV and non-HIV patients. One study in South Africa showed that prompt attention had the lowest degree of perceived responsiveness among older adults admitted to hospital[17]. Prompt attention may be seen as a priority domain to improve HSR. There is probably a shortage of human resources[54,171] and a lack of an efficient mechanism to allow health personnel to uniformly cooperate with each other[24] in HIV/AIDS care.

Anchoring vignettes were used to narrow the differences in perceptions of HSR experiences between HIV and non-HIV patients, thus controlling for patients` own expectations. Our results are consistent with a study by Hanna et al[172], indicating that using anchoring vignettes to adjust for self-rated HSR is valid. Our vignettes were comprehensible to the patients and showed minimal violation of the assumptions. Thus, using anchoring vignettes may be a valid method to measure perceptions of HSR to control for differential item functioning so as to avoid incorrect research findings.

There are certain limitations in our study. Firstly, a poorer response rate among the non-HIV group may affect the internal validity of the study. However, this imbalance was in the same direction of the main results in which non-HIV patients perceived poorer HSR. Despite the findings in favor of HIV care, the generalizability of this study is still limited due to the fact that the data were collected from only two hospitals in one province of China.

Conclusion

Perceptions about experiences of health system responsiveness were better among HIV patients than non-HIV patients in all domains except for prompt attention, even after adjusting for differences in socio-economic indicators and patients own expectation. Further studies are needed to confirm these findings elsewhere and in other settings.

Table 1 Comparison of demographic and socio-economic characteristic between HIV positive and non-HIV patients

	Total sample (n=1395)		HIV patients (n=696)		non-HIV patients (n=699)		*p**
	n	%	n	%	n	%	
Age							
<=40	803	57.6	422	60.6	381	54.5	**0.048**
41-60	502	36.0	236	33.9	266	38.1	
>=61	90	6.5	38	5.5	52	7.4	
Gender							
Female	549	39.4	270	38.8	279	39.9	0.709
Male	846	60.6	426	61.2	420	60.1	
Ethnic group							
Han	1094	78.4	504	72.4	590	84.4	**<0.001**
Other	301	21.6	192	27.6	109	15.6	
Religious affiliation							
No	1149	82.4	522	75.0	627	89.7	**<0.001**
Yes	246	17.6	174	25.0	72	10.3	
Place of residence							
Rural	758	54.3	490	70.4	268	38.3	**<0.001**
Urban	637	45.7	206	29.6	431	61.7	
Marital status							
Single	282	20.2	159	22.8	123	17.6	**<0.001**
Married/Cohabiting	935	67.0	383	55.0	552	79.0	
Separated/Divorced/Widowed	178	12.8	154	22.1	24	3.4	
Family size							
1	58	4.2	52	7.5	6	0.9	**<0.001**
2-4	1030	73.8	535	76.9	495	70.8	
5 or more	307	22	109	15.7	198	28.3	
Education							
Primary school or less	306	21.9	144	20.7	162	23.2	**<0.001**
Junior high school	668	47.9	296	42.5	371	53.3	

Senior high school	311	22.3	158	22.7	152	21.8	
University or higher	110	7.9	98	14.1	11	1.6	
Occupation							
Government-employed	129	9.2	62	8.9	67	9.6	**<0.001**
Enterprise-employed	499	35.8	256	36.8	243	34.8	
Self-employed	213	15.3	176	25.3	37	5.3	
Unemployed	554	39.7	202	29.0	352	50.4	
Household income (Yuan)							
<=800	244	17.5	163	23.4	81	11.6	**<0.001**
801-2000	322	23.1	177	25.4	145	20.8	
2001-5000	417	29.9	184	26.4	233	33.3	
5001-8000	239	17.1	88	12.6	151	21.6	
>=8001	173	12.4	84	12.1	89	12.7	

*: Chi-squared test.

Table 2 Clinical status among HIV positive patients

	HIV patients	
	n	%
Days between HIV diagnosis and ART		
Median (range)	292.6	(0,4745)
Route of transmission		
Unprotected sex	541	77.7
Sharing injection equipment	107	15.4
Mother-to-child	22	3.2
Unknown	26	3.7
Clinical stage		
Stage 1	389	55.9
Stage 2	160	23.0
Stage 3	100	14.4
Stage 4	47	6.8
CD4 count		
<200	305	43.8
200-499	337	48.4
>=500	54	7.8
History of virus load testing		
No	558	80.2
Yes	138	19.8
Distribution of virus load		
Median (range)	89 378	(50, 7 060 000)
Treatment of opportunistic infections		
No	624	89.7
Yes	72	10.3
Number of follow up visits in the first three months		
0	15	2.2
1	51	7.3

2	240	34.5
3	193	27.7
4	197	28.3
Missed ART in last seven days		
No	223	32.0
Yes	473	68.0

Table 3 Distribution and ordered probit regression results of experience of HSR before and after adjusting for socio-demographic factors among HIV positive and non-HIV patients

HSR domain	Patient group	Perceived experience										Ordered probit regression							
		Very good		Good		Moderate		Bad		Very bad		Crude				Adjusted			
		n	%	n	%	n	%	n	%	n	%	β	se	OR	95% C.I.	β	se	OR	95% C.I.
Prompt attention	HIV	83	11.9	306	44.0	228	32.8	67	9.6	12	1.7	-0.11	0.13	0.90	(0.70,1.15)	-0.16	0.11	0.85	(0.69,1.05)
	non-HIV	21	3.0	442	63.2	206	29.5	21	3.0	9	1.3								
Dignity	HIV	168	24.1	362	52.0	129	18.5	25	3.6	12	1.7	**0.69**	0.13	1.99	(1.54,2.58)	**0.63**	0.12	1.88	(1.48,2.40)
	non-HIV	42	6.0	483	69.1	163	23.3	9	1.3	2	0.3								
Communication	HIV	179	25.7	352	50.6	139	20.0	19	2.7	7	1.0	**0.58**	0.13	1.79	(1.39,2.31)	**0.6**	0.11	1.83	(1.48,2.27)
	non-HIV	49	7.0	455	65.1	177	25.3	13	1.9	5	0.7								
Quality of amenities	HIV	135	19.4	335	48.1	180	25.9	33	4.7	13	1.9	**3.16**	0.16	23.65	(17.35,32.54)	**2.99**	0.14	19.88	(15.11,26.43)
	non-HIV	10	1.4	26	3.7	445	63.7	201	28.8	17	2.4								
Confidentiality	HIV	169	24.3	352	50.6	145	20.8	21	3.0	9	1.3	**3.36**	0.16	28.66	(20.87,39.76)	**3.21**	0.14	24.85	(18.81,33.16)
	non-HIV	10	1.4	43	6.2	491	70.2	149	21.3	6	0.9								
Choice of providers	HIV	136	19.5	332	47.7	192	27.6	30	4.3	6	0.9	**3.14**	0.16	23.01	(16.80,31.83)	**3.16**	0.15	23.68	(17.57,32.24)
	non-HIV	11	1.6	32	4.6	494	70.7	152	21.7	10	1.4								
Autonomy	HIV	167	24.0	354	50.9	138	19.8	29	4.2	8	1.1	**3.27**	0.16	26.39	(19.25,36.54)	**3.22**	0.15	25.05	(18.87,33.62)
	non-HIV	11	1.6	31	4.4	479	68.5	165	23.6	13	1.9								

HSR: Health system responsiveness

Table 4 Distribution and censored ordered probit regression results between experience and vignettes of HSR before and after adjusting for socio-demographic factors among HIV positive and non-HIV patients

HSR domain	Patient group	**B-value**												**COPR**			
		1		2		3		4		5		6		Before		After	
		n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	n	Pr.	β	se	β	se
Prompt attention	HIV	49	0.070	493	0.710	35	0.050	88	0.130	0	0.000	31	0.040	**-0.44***	0.09	**-0.52***	0.08
	non-HIV	33	0.048	575	0.840	55	0.080	2	0.003	1	0.001	17	0.020				
Dignity	HIV	63	0.091	485	0.697	18	0.026	104	0.149	7	0.010	19	0.027	**0.38***	0.09	**0.33***	0.07
	non-HIV	21	0.030	471	0.684	33	0.048	97	0.141	65	0.094	2	0.003				
Communication	HIV	85	0.122	483	0.694	71	0.102	39	0.056	4	0.006	14	0.020	**0.25***	0.09	**0.23***	0.08
	non-HIV	95	0.141	28	0.041	529	0.783	8	0.012	1	0.001	15	0.022				
Quality of basic amenities	HIV	116	0.167	25	0.036	527	0.757	4	0.006	2	0.003	22	0.032	**1.13***	0.10	**1.08***	0.08
	non-HIV	2	0.003	20	0.029	581	0.854	4	0.006	59	0.087	14	0.021				
Confidentiality	HIV	148	0.213	517	0.744	7	0.010	1	0.001	0	0.000	22	0.032	**1.16***	0.10	**1.03***	0.08
	non-HIV	22	0.032	603	0.874	3	0.004	0	0.000	18	0.026	44	0.064				
Choice	HIV	535	0.769	121	0.174	-	-	10	0.014	-	-	30	0.043	**1.60***	0.10	**1.44***	0.08
	non-HIV	24	0.034	117	0.167	-	-	520	0.744	-	-	38	0.054				
Autonomy	HIV	155	0.223	6	0.009	513	0.737	5	0.007	0	0.000	17	0.024	**1.64***	0.11	**1.50***	0.09
	non-HIV	10	0.015	4	0.006	569	0.827	21	0.031	2	0.003	82	0.119				

HSR: Health system responsiveness -: Calculation of B-scale not possible.

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