

Original Article

Perceived stigma of HIV patients receiving task-shifted primary care service and its relation to satisfaction with health service

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Abstract

Introduction: HIV stigma is the remaining challenge to end the global epidemics of HIV. Whether stigma may form a barrier to the provision of ART within the community-based, primary care setting was not studied yet. Therefore, this study intended (1) to compare the levels of ‘perceived stigma’ in PLHIV attending district hospital and primary care units (PCUs), and (2) to measure the relation between HIV stigma and the satisfaction of patients with their health service.

Methodology: In this cross-sectional study, two matched PLHIV attending district hospitals were recruited for every PLHIV attending a PCU, within a pilot project, until the end of 2014. 198 informed and consented participants were recruited. We used validated Thai version instruments to measure the levels of ‘perceived stigma’ and ‘internal shame’ and the Patient Satisfaction Questionnaire 18 (PSQ18) to measure patients’ satisfaction with the health service. Analysis applied MANOVA and multivariate robust regression.

Results: The level of ‘perceived stigma’ and ‘internal shame’ levels were not significantly different between district hospitals attendants and PCU attendants ($P > 0.05$ MANOVA). Moreover, the more patients were satisfied with the health service, the less likely to have ‘perceived stigma’ ($\beta -5.9$, 95% confidence interval -7.7 to -4.1) and ‘internal shame’ ($\beta -5.7$, 95% CI -8.3 to -3.2), $P < 0.001$).

Conclusions: HIV associated stigma would be minimized through the attempt to promote PLHIV’s satisfaction with ART service. There is ample role of health professional education and training to improve patients’ satisfaction. It may contribute to the aim of zero discrimination.

Key words: HIV; Thailand; perceived stigma; internal shame; health professions.

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Introduction

HIV is a highly stigmatized disease. Over the last three decades of the HIV epidemic, there has been both qualitative and quantitative evidence revealing the negative impact of HIV-related stigma, such as avoidance of HIV testing, delayed seeking and non-utilization of HIV services, missing pills for anti-retroviral therapy (ART), and ultimately poor HIV outcomes [1-3]. Being stigmatized, people living with HIV (PLHIV) may feel shame and a fear of discrimination, resulting in social inequality and exclusion from access to antiretroviral therapy [4-6]. Without minimizing stigma, therefore, it will be difficult to eradicate this epidemic [7]. Research that provides a better understanding of HIV stigma and

suggested ways to overcome its negative impact is required.

Nowadays, ART grants almost normal life expectancy to PLHIV [8]. Hypothetically, expanding its accessibility might bring less fear and discrimination amongst PLHIV, allowing them to experience years of well-being and improved HIV outcomes. Although many researchers have reported the impact of stigma on the health seeking behaviors of PLHIV, literature is still lacking on how HIV stigma is affected in relation to ART services.

HIV is heavily stigmatized in many countries such as Thailand, a country with the highest burden of HIV infection in Southeast Asia [9]. In Thailand, ART coverage is provided to more than two thirds of PLHIV who require it with hopes for “zero new transmission”

via expansion of access to ART [10]. Task-shifting HIV services to primary healthcare is an important strategy within this expansion of access to ART. [11], with a recent study in northern Thailand reporting greater accessibility and convenience for PLHIV receiving a task-shifted service at primary health care centers [12]. However, anecdotal evidence among healthcare professionals and policy makers has led to concern about the existence of HIV stigma in the communities where PLHIV reside.

Thailand is the most highly HIV-prevalent country in Southeast Asia [13,14]. There, ART is universally accessible to all Thai citizens within the Thai health system [15]. ART coverage reached to almost 80% of PLHIV until recently. Newer ART guidelines, effective in Thailand since 1 October 2014, proposed initiation of ART in all HIV-infected individual whatever is the CD4 count [16,17]. Practicing new guideline, the number of PLHIV who will receive ART has increased by 26% in Thailand [15,17]. Therefore, task-shifting model of ART services became urgently required to ensure health professional needs in delivering ART, in addition to the physician-centered healthcare model [18]. Research assessing the challenges of task-shifted ART services is not yet undertaken in Thailand and Southeast Asia. Therefore, study such as current one measuring HIV stigma, an important challenge of task-shifted ART services in a pilot project is practically required for future extension of ART and health service delivery to PLHIV in an evidence-based approach.

There is limited research reporting whether PLHIV's stigma levels differ based on the location of their ART services. It is of interest, therefore, to compare the level of HIV stigma perceived by PLHIV attending primary health care centers, located in the vicinity of their homes, with that perceived by those attending HIV clinic at their district level hospital.

Thus, the objectives of this study were (1) to measure and compare the levels of stigma perceived by PLHIV accessing ART services task-shifted to primary health care centers with those accessing routine HIV clinic care at district hospitals; (2) to measure the gender difference in HIV stigma levels; and (3) to test the relation between HIV-related stigma and the satisfaction of patients with their HIV healthcare service.

Methodology

Study site, sample size and sampling

The study was conducted in the community setting of a district in Chiang Mai province, northern Thailand. The study population was composed by applying the

inclusion criterion of “PLHIV accessing ART at the district hospital or task-shifted primary health care centers”. The exclusion criterion of “refusal to participate in the study” was applied.

All PLHIV receiving ART at seven primary health care clinics in a pilot project were recruited. The PLHIV with matched CD4 counts, age, sex and ART regimens, attending the district hospital were recruited as the control group, amounting to twice the number of those accessing the task-shifted service. The final sample consisted of 198 PLHIV. It included 66 patients receiving task-shifted ART service, all such patients at the time of data collection and matched controls in a ratio of 1:2 to ensure the power of the study. Study period was from 2013 April to 2014 August.

Instrument for HIV stigma measurement

An instrument to measure the level of stigma among PLHIV and which had been validated in Thailand was used. Literature recommends separating the notions of ‘internal shame’ and ‘perceived stigma’ when measuring and analyzing HIV stigma levels [19]. In the current study separate sets of scales, validated in a previous Thai study [5], were applied to measure participants’ ‘perceived stigma’ and ‘internal shame’ levels. In relation to the current study population, the reliability coefficient for the ‘perceived stigma’ instrument was 0.83, and for the ‘internal shame’ instrument it was 0.87.

Instrument for satisfaction with health service

The short form Patient Satisfaction Questionnaire 18 (PSQ-18) was applied to measure the patients’ satisfaction [20,21]. This five-level Likert scale consists of seven constructs: 1) ‘general satisfaction’; 2) ‘technical quality’; 3) ‘interpersonal manner’; 4) ‘communication’; 5) ‘financial aspects’; 6) ‘time spent by service provider’; and 7) ‘accessibility and convenience’ [21]. PSQ 18 underwent transcultural translation: forward translation, back translation, and pilot test for cognitive test and comprehension. Research assistants were trained to deliver interviewer-administered questionnaires. The reliability coefficient of the Thai version PSQ-18 was 0.78 [22].

The clinical status of PLHIV was assessed by means of their CD4 count as well as AIDS defining events after one year of receiving the service. CD4 counts and AIDS diagnoses were reviewed in the medical record [23].

Statistical analysis

Descriptive analysis was applied to describe the distribution of the participants' 'perceived stigma', 'internal shame' and satisfaction levels. A multivariate model of robust regression was applied to test the relation between (1) the 'perceived stigma' of PLHIV and satisfaction with their HIV healthcare service, and (2) the 'internal shame' of PLHIV and satisfaction with their HIV healthcare service. Unstandardized beta was applied. In these multivariate models possible confounders were included such as age, gender, education, and income. Levels of 'perceived stigma' and 'internal shame' were measured using two different instruments and analyzed using two different regression models.

STATA version 11SE was used for the data analysis. Statistical significance was defined as a P value of less than 0.05 ($P < 0.05$), and a confidence interval of 95% (95% CI). Signed-ranked test, multivariate analysis of variants (MANOVA) and robust regression analyses were applied.

Results

The response rate for the questionnaires measuring 'perceived stigma' and 'internal shame' were both 100%. The response rate for the PSQ-18 was 96%. The median age of the study participants was 46 years, with

females comprising two thirds. The median duration of ART for the study participants was 8 years (Table 1.).

The task-shifted service group comprised a higher proportion of females and a higher proportion of those educated to just a primary education level. There was no significant difference in HIV service parameters between the two groups, such as age, CD4 count at baseline or duration of ART. There was no AIDS defining events (Table 2.).

Overall, the magnitude of 'internal shame' amongst the study participants was higher than that of 'perceived stigma' (Table 3.).

'Perceived stigma'

Exploring the participants' 'perceived stigma', in the present study, has led to a greater understanding of this notion. What the participants fear most is to be isolated from society. They worry about being gossiped about by other people. They worry about how their family members are being treated because of their HIV status, with this worry perceived more significantly amongst PCU attendants. They are afraid of being discriminated against by healthcare workers when they access medical care, this fear being significantly higher amongst the hospital attendants than those receiving task-shifted services at PCU's.

Table 1. Socio-demographic characteristics of the participants.

	Task-shifted service at primary health care center	Routine service at district hospital	Male	Female	Total
Number, n (%)	66 (33.33)	132 (66.67)	98 (49.49)	100(50.51)	198 (100)
Age, years Med (iqr)	47.5 (43-53)	46 (41-50)	47 (41-51)	46 (42-52)	46 (42-51)
Gender Male, n (%)	75(56.82)	23 (34.85)	-	-	98 (49.49)
Income, Thai-baht Med (iqr)	4000 (2000-6000)	6000 (4000-9000)	6200 (4000-9000)	4250 (3000-6000)	6000 (3000-8000)
Education					
-Primary and lower, n (%)	57(86.36)	69 (52.27)	54 (55.1)	72 (72)	126(63.64)
-Secondary and higher n (%)	9 (13.64)	63 (47.73)	44 (44.9)	28 (28)	72 (36.36)
Distance to the health facility, Kilometers, Mean (SD.)	2.91(6.43)	7.67 (4.66)	5.63(6.02)	5.07 (4.57)	5.33 (5.31)
Duration of ART, years Mean (SD.)	8.89 (4.39)	8.76 (4.66)	8.25 (4.36)	9.35 (4.70)	8.81 (4.56)
Regimens started with GPO vir	83.33%	72.73%	69.39%	83.00%	76.26%
Current CD4 counts Mean (SD.)	481.5 (192.45)	473.45 (212.79)	423.52 (217.59)	526.72 (180.47)	476.16 (205.61)
AIDS events	0	0	0	0	0
Patients' satisfaction, Mean (SD.)	3.83 (0.47)	3.90 (0.47)	3.84(0.50)	3.90 (0.43)	3.88 (0.47)

Med: Median; Iqr: Interquartile range; SD.: Standard deviation; ART: Antiretroviral therapy; GPO vir: stavudine, lamivudine, and nevirapine.

Table 2. Stigma among the HIV patients.

Questions answered on a scale of 1 to 5	Total Mean, (SD)	Task-shifted service Mean, (SD)	Hospital Mean, (SD)	Male Mean, (SD)	Female Mean, (SD)
1. I am accused by others of being the spreader of AIDS in the community	1.91 (0.98)	1.81 (1.08)	1.96 (0.94)	1.94 (0.98)	1.89 (0.99)
2. People gossip about my HIV status	2.44 (1.14)	2.59 (1.25)	2.36 (1.07)	2.42 (1.18)	2.46 (1.10)
3. People look down on me	2.27 (1.14)	2.13 (1.21)	2.34 (1.09)	2.26 (1.14)	2.29 (1.13)
4. The community isolates me	2.77 (1.15)	2.27 (1.22)	2.3 (1.12)	2.26 (1.14)	2.29 (1.17)
5. I feel discriminated by health workers	1.71 (0.91)	1.55 (0.84)	1.80 (0.93)*	1.75 (0.97)	1.67 (0.85)
6. I feel my life in the community is lonely	2.07 (1.17)	1.93 (1.19)	2.14 (1.17)	2.06 (1.20)	2.09 (1.16)
7. I worry about how other children treat my children in school as a result of my HIV	2.43 (1.22)	2.56 (1.25)	2.20 (1.15)	2.48 (1.23)	2.4 (1.21)
8. I worry about how others will treat my family members as a result of my HIV	2.30 (1.20)	2.18 (1.22)	2.35 (1.19)	2.27 (1.23)	2.32 (1.18)
Perceived stigma	16.42 (6.3)	15.91 (6.66)	16.86 (6.12)	16.23 (6.62)	16.61 (6.00)
9. I am punished by the devil	2.74 (1.37)	3.03 (1.48)	2.60 (1.30)	2.47 (1.29)	3.01 (1.41)*
10. My life is tainted	3.01 (1.30)	3.28 (1.22)*	2.87 (1.32)	2.73 (1.33)	3.28 (1.30)*
11. I am angry with myself for getting HIV	2.68 (1.38)	2.68 (1.37)	2.67 (1.43)	2.56 (1.40)	2.79 (1.37)
12. I am a disgrace to society	2.34 (1.04)	2.15 (1.04)	2.43 (1.07)	2.39 (1.18)	2.29 (0.89)
13. My life is filled with shame	2.39 (1.23)	2.19 (1.24)	2.48 (1.22)	2.34 (1.21)	2.43 (1.22)
14. I feel guilty for being the source of disruption in the family	2.61 (1.30)	2.41 (1.28)	2.71 (1.31)	2.63 (1.34)	2.59 (1.27)
15. I feel my life is worthless	2.10 (1.15)	2.18 (1.18)	1.95 (1.10)	2.10 (1.14)	2.11 (1.18)
16. I feel my reputation is lost	2.29 (1.15)	2.11(1.23)	2.39 (1.10)	2.29 (1.18)	2.3 (1.15)
17. If possible I want to conceal my HIV status for life	2.45 (1.42)	2.06 (1.29)	2.65 (1.43)	2.6 (1.48)	2.31 (1.34)
'Internal shame'	22.62 (8.10)	21.87 (7.41)	22.99 (8.43)	22.12* (8.10)	23.11 *(7.63)

* Statistical significant difference P < 0.05.

Table 3. Disclosure status of PLHIV patients.

	Task-shifted group	District hospital	Male	Female	Total
	n (%)	n (%)	n (%)	n (%)	n (%)
Disclosure to family					
Yes	64 (96.97)*	111 (84.09)	83 (84.69)	92 (92)*	175 (88.38)
No	2 (3.03)	15 (11.36)	9 (9.18)	8 (8)	17 (8.59)
Living alone	0 (0)	6 (4.55)	6 (6.12)	0(0)	6 (3.03)

* Statistical significant difference P < 0.05.

Table 4. Robust regression models predicting 'perceived stigma'.

'Perceived stigma'	Coef.	Std. Err.	P value	95% CI	
				Lower	Upper
Overall PSQ	-6.04	0.89	<0.01	-7.80	-4.27
Female gender	1.28	0.87	0.15	-0.44	3.00
CD4	0.002	0.002	0.43	-0.002	0.00
Primary education	0.38	0.95	0.69	-1.49	2.25
Task-shifted service	-1.66	0.93	0.08	-3.50	0.18
Age	-0.09	0.05	0.09	-0.20	0.01

Coef: Coefficient of regression; Std. Err.: Standard Error of the Estimate; CI: Confidence interval; PSQ: patient satisfaction questionnaire (PSQ18); CD4: CD4 count at the last follow up.

Table 5. Robust regression models predicting ‘internal shame’.

‘Internal shame’	Coef.	Std. Err.	P Value	95% CI	
				Lower	Upper
Overall PSQ	-6.16	1.23	<0.01	-8.59	-3.73
Female gender	2.70	1.20	0.02	0.33	5.07
CD4 count at last follow up	-0.00	0.003	0.72	-0.01	0.01
Primary education	-0.69	1.30	0.59	-3.26	1.88
Task-shifted service	-2.36	1.28	0.07	-4.89	0.16
Age	-0.16	0.07	0.04	-0.30	-0.01

Coef: Coefficient of regression; Std. Err.: Standard Error of the Estimate; CI: Confidence interval; PSQ: patient satisfaction questionnaire (PSQ18); CD4: CD4 count at the last follow up.

Overall, however, the participants’ ‘perceived stigma’ was not significantly different according to the location and setting of the health service, whether it was at the task-shifted primary health care unit or at the district hospital-based HIV clinic. There was also no significant difference amongst men and women (Tables 2 and 3).

‘Internal shame’

Responses to the constructs in Table 2 saw a higher level of stigma amongst women. Among the constructs of ‘internal shame’, the feeling of being tainted by being HIV infected represented the highest level of stigma. The levels of two constructs- ‘I am punished by the devil’ and ‘My life is tainted’- were significantly higher among the women than the men. Overall, however, the level of ‘internal shame’ did not differ significantly between men and women (P = 0.69). Furthermore, the level of ‘internal shame’ was not significantly different among the PCU attendants and the hospital attendants.

Both ‘perceived stigma’ and ‘internal shame’ were compared in a MANOVA model. There was no significant difference between task-shifted primary care attendants and those attending the district hospital (P=0.63). Neither was there a significant difference between the two genders (P=0.69).

There was a significant association between patients’ satisfaction with their health service and the level of their HIV-related stigmata (Figure 1). The more the participants were satisfied with their health service, the less was their ‘perceived stigma’ (beta -6.04, 95% CI -7.80 to -4.27), (Table 4). Likewise, the more the participants were satisfied with their health service, the less they felt ‘internal shame’ (beta -6.16, 95% CI -8.59 to -3.73) (Table 5). These findings were made from the results of different regression models for ‘perceived stigma’ (Table 4) and ‘internal shame’ (Table 5).

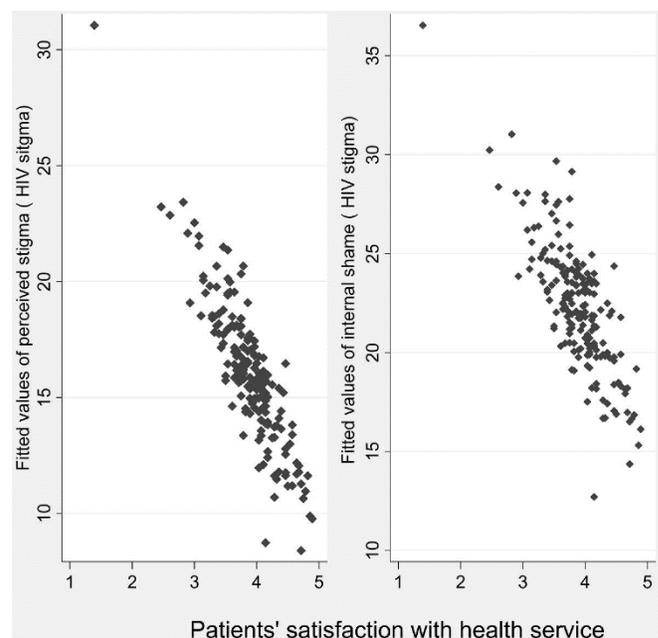
Discussion

Stigma is recognized as a challenge that remains to be tackled in the fight against HIV epidemics [24].

UNAIDS has urged a global commitment of “zero discrimination” towards PLHIV, a policy which Thailand has integrated into its national strategic healthcare framework [10,24].

The nature of HIV stigma is very complex and diverse. Nowadays HIV-related stigma is conceptualized as a social process which may be resisted and challenged via social action such as through assistance from families, communities and health care services [6,7,25]. This concept allows for analysis of the possible influences and actions which may relate to HIV-stigmata. In this study, the ‘perceived stigma’ and ‘internal shame’ of the PLHIV were measured and compared among those attending task-shifted ART services and those attending the HIV clinic at a district hospital in northern Thailand [5].

Figure 1. Inverse relation of patients’ satisfaction with health service and the level of HIV-related stigmata multivariate robust regression models.



Findings of the current study relating to stigma

Overall, the magnitude of ‘internal shame’ was higher than that of ‘perceived stigma’. However, the levels of both ‘perceived stigma’ and ‘internal shame’ were less than the level reported in a previous study conducted in the northern part of Thailand.[5] Moreover, one of the findings of the current study showed that attending different HIV service facilities, whether at task-shifted primary care units or at the HIV clinic in the district hospital, did not make a significant difference in terms of either the ‘perceived stigma’ or the feeling of ‘internal shame’ of PLHIV. Therefore, stigma may not be the factor hindering the task-shifting of HIV services (Table 2).

The current study also assessed the relation of the participants’ satisfaction with their HIV health care service to the stigma perceived by the PLHIV in the community health care setting of northern Thailand. Multi-variate robust regression models included independent variables such as age and sex of the participants, their immunological status, the site of the service, their satisfaction as an indicator of health care, and socio-economic indicators including the participants’ education and income (Table 4). Results showed that the higher the level of satisfaction experienced by the participants, the lower the level of their ‘perceived stigma’ (Table 4) and the less their ‘internal shame’ (Table 5).

The fear of being known as HIV-positive in the community where one is living is a barrier to accessing HIV health services [4]. A clear finding from the present study is that the stigma related to non-disclosure of HIV is more common among PLHIV attending district hospital HIV clinics than those receiving task-shifted HIV services at PCU’s (Table 3), whilst the majority of district hospital attendants did not want to reveal their status for life (Table 2). Findings in the multivariable analysis (Table 4) may provide clues as to how to reduce such fear.

The present study also found that the higher the level of satisfaction experienced by the participants, the less ‘internal shame’ they felt. It is very likely that a highly satisfactory HIV service will reduce the PLHIV’s fear of being discriminated against by doctors and nurses, their fear of their families being looked down upon within the community as well as the shame and guilt they feel inside. These findings indicate the great potential that quality ART services have in reducing the stigma in PLHIV.

Health service provision represents a process of interaction between service providers and patients. The nature of this health service is usually personal,

sensitive and emotional. The instrument used to measure the level of patient’s satisfaction in the current study comprised seven domains: 1) general satisfaction; 2) the health care provider’s technical quality; 3) interpersonal relations; 4) communication; 5) time given to the patient; 6) financial aspects; and 7) convenience and accessibility.

Likewise, ‘perceived stigma’ is related to the interaction between the care provider and the PLHIV. After adopting the new HIV guidelines calling for the earlier commencement of ART regardless of CD4 status, HIV clinics in Thailand will be required to serve a higher number of PLHIV newly eligible for ART [10,20]. This necessitates a strengthening of the health system, with a faster logistical supply of diagnostics and medicine, as well as a greater number of competent health professionals.

As long as the PLHIV’s experience with their health service is a healing and satisfactory one, no one will feel discriminated against. Without this fear of discrimination, PLHIV may be able to experience equal access to ART, and within such social equality, the shame inside will diminish leading to individuality and the goal of ‘zero discrimination’. In a high HIV-burdened country like Thailand, which invests in the sustainability of expanded access to ART and the consolidation of ‘test and treat strategy’, there is an urgent need to tackle stigma [26]. We believe that the findings of the current study provide practical hints as to how to create interventions that promote HIV service satisfaction that in turn can relieve HIV-related stigmata.

Strengths and limitations of the study

To our knowledge, this study would be the first of its kind exploring the relation between the level of stigma and satisfaction of PLHIV with health service. The number of PLHIV receiving task-shifted ART services at the primary care units was limited as it was a pilot project. However, the sample size was calculated and ensured, according to a ratio of 1:2, to ensure adequate power of the finding, and overcome this limitation. Moreover, the study was carefully designed to avoid bias and confounding factors in both the design phase and the analysis phase. Matching HIV and CD4 status when recruiting the control group sought to prevent bias caused by the health status. Table 1 showed that there was a balance of prognostic factors between the two groups. Moreover, the internal validity of the research was secured by taking measures to ensure the reliability and validity of the instruments used.

Conclusion

‘Perceived stigma’ and ‘internal shame’ of PLHIV may be reduced through satisfaction with their health service. In fact, stigma may not be the factor hindering the task-shifting of HIV care services to primary health care centers in Thailand, given that the different study participant groups were equally satisfied with their health care services. Rather, this study recommends that a health professional education package should be introduced for primary care providers, focusing on improving interpersonal communication and technical quality that may serve as an effective intervention to tackle HIV stigma.

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Authors’ contribution

MNA, SY and TK designed the study. YS, PT, CK, HO, MF and ON contributed to instrument development and validation. All authors contributed to data collection. MNA and SY analyzed the data. TK, JD and VK contributed to interpret the finding and advised MNA to develop the manuscript. Every authors participated in drafting, revising and finalizing the article.

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