

Stigmatization and shame: Consequences of caring for HIV/AIDS patients in China

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Abstract

Using a representative sample of 478 doctors, nurses, and lab technicians working with people living with HIV/AIDS (PLWHA), a cross-sectional study was conducted to assess the impact of the AIDS epidemic on medical care systems and service providers in China. Correlation analyses showed significant association between internalized shame reported by service providers and their perception of being stigmatized due to working with PLWHA. Multivariate analyses revealed that the perceived level of institutional support for AIDS care was significantly related to the stigmatization and shame reported by the service providers. The study findings suggest that improved institutional support for AIDS care at the facility level and HIV-related stigma reduction intervention are crucial to maintain a high quality performance by the workforce in the health care system.

The HIV/AIDS epidemic has increased the demand for medical care worldwide. Health service workers play an important role in the battle against HIV/AIDS by providing testing, care, and treatment for people living with HIV/AIDS (PLWHA). Service providers face significant occupational challenges such as work-related infection risks, increased demand for services, inefficiency in the HIV care financing system, and the lack of appropriate training for HIV/AIDS treatment (Unger et al., 2002). The HIV pandemic also indirectly affects the health workforce in terms of increasing physical and emotional stress for care providers working with PLWHA (Marchal et al., 2005). Service providers who have physical contact with PLWHA may experience misunderstanding and avoidance from their social connections and families (Bennett, 1992a; Bennett, 1992b), which undoubtedly adds to worker stress and often results in burnout and drop out. Therefore, maintaining optimal performance by the health care workforce becomes an urgent task for meeting the increasing needs of AIDS patients.

Ross and Seeger's study (1988) suggests that there are significant stresses and burnout associated with caring for AIDS patients; the determinants were reported to be situational rather than personality-based. From a study of oncology and AIDS nurses, Bennett et al. (1991) concluded that the longer the time spent in either treatment situation, the greater

the likelihood of burnout. Another study, however, reported that burnout among service providers was more related to the intensity of the work than its duration (Nesbitt et al., 1996). Burnout was grouped into three categories: job activities, organizational structure, and personal characteristics (Cordes & Dougherty, 1993). Barbour (1995) reported that personal employment history was relevant to the demand of the work, suggesting that the training and support for service providers need to be personalized. Claxton et al. (1998) also investigated factors associated with psychological distresses related to AIDS care; they reported that being younger, gay, male, better educated, and employed were associated with a higher level of emotional exhaustion. Organizational factors, such as satisfaction with training, were positively related with personal accomplishment but negatively related with emotional exhaustion, depersonalization, anxiety, and depression (Claxton et al., 1998).

While there is a large body of literature that examines the difficulties, stressors, and burnout associated with caring for PLWHA, there is a paucity of research investigating discrimination and the internalized shame experienced by AIDS care providers. One notable exception reported that HIV-related stigma was significantly related to social withdrawal, internal coping, grief, and powerlessness (Bennett et al., 1994).

It is probable that AIDS impacts the health care systems and settings in resource-limited countries such as China. Since the first case of AIDS in China was identified, the number of reported HIV infections has greatly increased (Zhang et al., 2004). The latest estimation results indicate that as of late 2005, 650,000 people in China are currently living with HIV/AIDS (UNAIDS, 2005). These figures, however, are believed to constitute only a small percentage of the true HIV infections in the country (Yang et al., 2005). Steps have been taken to curb the transmission of the disease. In 2004, China started a new policy to offer free treatment for rural and poor urban residents, free and voluntary HIV screening tests, and free education for the orphans of PLWHA (Shen & Yu, 2005). For service providers in China, the new policy has led to improved standards, updated procedures, and a transformation of the doctor-patient relationship. Under these circumstances, it is crucial to understand providers' perceptions of the possible impact of HIV/AIDS care on their professional and personal life. Does caring for HIV patients lead to internal shame and societal discrimination for service providers in China? Knowing what factors are associated with the perceived impact will help China improve the working conditions of the many health care workers who will be needed to meet the demands of the country's newly expanded AIDS health care programme.

Methods

Sample and procedure

This study was conducted in Yunnan Province, which has 40% of all reported HIV cases, the highest range of reported HIV infection in China (State Council AIDS Working Committee Office and U.N. Theme Group on HIV/AIDS in China, 2004; U.S. Embassy, 2000). The study received Institutional Review Board (IRB) approval from both the University of California, Los Angeles (UCLA) and the China Center for Disease Control and Prevention (CCDC). The data were collected between January and August, 2005. In order to obtain a representative sample, we gathered staffing information from local hospitals and clinics before sampling. Three out of nine provincial hospitals, four out of seven city/prefecture hospitals, 10 out of 35 county hospitals, 18 out of 90 township health clinics, and 54 out of 573 village clinics were randomly selected using a random number table. The staff list of each facility was obtained, and doctors and nurses were sampled proportionally to the doctor-nurse ratio of each hospital or clinic. Lab technicians were over-sampled in order to include an adequate representation in the analysis.

A total of 1,101 participants were randomly selected from 3,579 eligible health care providers. They voluntarily participated in an anonymous survey, with a refusal rate of less than 8%. Before the survey, project researchers introduced the purpose of the study, procedures, potential risks, and benefits. Oral informed consent was obtained from each of the participants before the study. To ensure anonymity, respondents were instructed not to place any personal identifiers on the questionnaire, which took, on average, an hour to complete. No monetary incentive was offered at the completion of the survey. All participants were asked if they had ever treated or interacted with any HIV-positive patients in their hospital/clinic. Only those who gave positive responses to this question ($n=478$) were included in this study.

Instruments and measures

The self-administered survey questionnaire contained questions about age, ethnicity, education, profession, HIV-related training, and the length of service. The second part of the survey consisted of several measurement scales from previous studies. One of the scales, the Impact Scale, was based on a study in which five items were identified to measure discrimination and stigma due to working with HIV/AIDS (Bennett et al., 1994).

Five items were used to measure perceived impact of working with PLWHA, with each item scored from 1 (strongly disagree) to 5 (strongly agree):

1. You suffer discrimination or stigma outside of work due to the fact that you work in an HIV/AIDS-related field.
2. Some friends have had less contact with you since you started working with HIV/AIDS patients.
3. People move away from you at social functions when they hear that you work in the field of HIV/AIDS.
4. Your family is unhappy that you are working in the field of HIV/AIDS.
5. You suffer discrimination or stigma from other staff at the hospital due to the field in which you work.

A higher score indicated a higher level of negative impact on the service providers' life and social network as a result of working with PLWHA. The inter-item reliability of the Impact Scale is high (Cronbach's $\alpha=0.86$), with an alpha value of 0.72 (Bennett et al., 1994).

The Internalized Shame Scale was used to measure how the providers felt about their work with HIV-positive patients. It includes the following two

items with responses from 1 (strongly disagree) to 5 (strongly agree) for each item:

1. If you worked with HIV-positive patients, you would feel embarrassed to tell other people about it.
2. If you worked with HIV-positive patients, you would wish that you could change your job so that you would never have to deal with PLWHA.

A higher score reflects greater internalized humiliation reported by service providers because of work with HIV-positive patients. Cronbach's alpha for the variable was 0.67, indicating acceptable inter-item reliability for this two-item scale.

We also assessed the respondents' stress, their perceived societal stigma associated with HIV/AIDS, knowledge of HIV/AIDS, and their perception of institutional support for HIV/AIDS care. The stress scale was based on a global measure of the Perceived Stress Scale to measure the level of stress felt in the past month (Cohen et al., 1983). In this study, we used two items from the original scale, with responses ranging from 1 (never) to 5 (very often). A higher stress score indicates greater stress suffered by the providers (alpha = 0.61).

1. In the last month, how often have you felt that you were unable to control the important things in your life?
2. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Service providers' perception of societal stigma associated with HIV/AIDS was assessed with a 5-item measure. This scale was adapted from UNAIDS (2004) to assess the extent to which the participant personally knew someone who had been unfairly treated because of HIV/AIDS. Acceptable consistency and reliability was supported by an alpha of 0.85. The number of positive answers (participant replied 'yes') was calculated for a total score of perceived societal stigma. The questions include:

1. Do you personally know someone who has lost or been denied a job because of HIV/AIDS?
2. Do you personally know someone who has lost or been denied education because of HIV/AIDS?
3. Do you personally know someone who has lost or been denied health care services because of HIV/AIDS?
4. Do you personally know someone who has lost or been excluded at a social gathering because of HIV/AIDS?

5. Do you personally know someone who is no longer visited at home or by others because of HIV/AIDS?

Institutional support for HIV/AIDS care was developed by asking 13 questions. This scale measures the respondents' perception of support resources provided by their workplace for HIV/AIDS care. Example statements in this scale are: '*There are always sterile rubber gloves available at your health care facility when you need them at work.*' '*There are always written HIV/AIDS treatment regimens available at your worksite.*' '*You would have sufficient health insurance coverage if you were infected by HIV on your job.*' The participants reported yes or no based on their agreement with each of the statements. The positive answers were added for a total score of perceived institutional support for HIV/AIDS care. The inter-item reliability of this scale was also acceptable (alpha = 0.70).

We used a 10-item measurement scale to assess the knowledge of HIV/AIDS. The measure included questions such as: '*Can HIV be transmitted through breast-feeding?*' '*Is an HIV vaccine already available?*' For each item, the response was coded as 1 (correct answer) or 0 (incorrect answer or unknown). The scale for knowledge of HIV/AIDS was constructed as a sum of the 10 questions.

Data analysis

SAS statistical software (version 9.1) was used to perform all analyses. First, we descriptively analysed the distribution of age, gender, education, care facility, and profession of the sample. Second, Pearson correlation coefficients were calculated to investigate relationships between age, gender, medical degree, HIV knowledge, stress, perceived institutional support, perceived societal stigma, impact of working with HIV/AIDS, and internalized shame. Third, two multiple regression analyses were performed with the Impact Scale and the Internalized Shame Scale, respectively, controlling for the simultaneous effects of participants' HIV knowledge, perceived institutional support, perceived societal stigma, stress, as well as demographics. Standardized regression coefficients and their significant levels are reported.

Results

The study sample was primarily female (72.8%) and Han ethnicity (68.2%), the racial majority in China. Approximately 23% of the respondents were younger than 30 years old and 31% were 41 years or older. Approximately one-third of the sample worked in provincial hospitals or city hospitals, and

about 45% of the participants were doctors, 42% were nurses, and nearly 13% were lab technicians. At the time of the survey, about 40% of the sample had a four-year medical education or higher. The demographics of our participants are comparable to the 2003 data reported by the National Bureau of Statistics of China (2004).

Correlation coefficients of identified variables are reported in Table I. The level of reported stigma and discrimination caused by working with PLWHA was significantly positively associated with internalized shame ($r = 0.32$), stress ($r = 0.14$), age ($r = 0.10$), and perceived societal stigma ($r = 0.10$). The Impact Scale had a significant negative relationship with knowledge of HIV ($r = -0.10$) and institutional support ($r = -0.14$). The level of internalized shame was found positively correlated with age ($r = 0.11$) and stress ($r = 0.15$), and negatively associated with knowledge of HIV ($r = -0.12$) and institutional support ($r = -0.10$). The stress scale was significantly associated with age ($r = -0.11$), knowledge of HIV ($r = -0.10$), institutional support ($r = -0.24$), and perceived societal stigma ($r = 0.12$). Institutional support was also significantly associated with the respondents' age, gender, and knowledge of HIV. Younger providers and providers with a medical degree reported a higher level of perceived societal stigma. It was also noted that having a medical degree was positively correlated with more HIV knowledge ($r = 0.10$).

The results of multiple regression analyses are presented in Table II. The first column of the table summarizes findings from the regression model for perceived stigma and discrimination due to caring for PLWHA, controlling for all the selected independent variables. Those who reported better

institutional support for AIDS care in their work tended to report a lower level of negative impact on their life ($\beta = 0.13$). Age was also found to be an important predictor for perceived discrimination against caring for PLWHA ($\beta = 0.15$). Providers who perceived more societal stigma towards PLWHA ($\beta = 0.1$) and who felt more stressed in the past month ($\beta = 0.1$) also reported a higher level of negative impact of caring for HIV/AIDS patients. It is interesting to note that the correlation of knowledge of HIV and perceived negative consequences of working with PLWHA became insignificant when other variables were held constant.

Multiple regression of internalized shame by service providers working with HIV/AIDS is shown in the second column of Table II. Stress ($\beta = 0.14$) was significantly associated with the Internalized Shame score when other variables were under control. The providers who reported less institutional support ($\beta = -0.10$) and were older ($\beta = 0.14$) experienced a higher level of internalized shame for their work with PLWHA. The knowledge of HIV remained significantly negatively related to the Internalized Shame score ($\beta = -0.10$) while other variables were held constant.

Discussion

This study examined the negative consequences of caring for PLWHA reported by providers at both individual and institutional levels. Service providers' feelings of being stigmatized and discriminated against due to working with HIV-positive patients and the related internalized shame were the primary foci of this study. Although we could not demon-

Table I. Correlation coefficients among selected variables.

Variable	Age	Gender (1 = male, 2 = female)	Medical degree (1 = yes, 2 = no)	Impact scale	Internalized shame	Stress scale	Knowledge of HIV	Institutional support
Gender	-0.05626							
Medical degree (Yes or No)	0.2230	-0.42431						
Impact scale	0.09891	-0.06872	0.04853					
Internalized Shame	0.0321*	0.1344	0.2907	0.32847				
Stress	0.11285	0.04434	-0.07410	<0.001***				
HIV Knowledge	0.0143*	0.3333	0.1057	0.14502	0.15642			
Institutional Support	-0.10820	-0.00143	0.04942	0.0015**	0.0006***			
Perceived societal Stigma	0.0190*	0.9752	0.2814	0.0015**	0.0006***			
	-0.01283	0.05748	0.09423	-0.10955	-0.12862	-0.09122		
	0.7414	0.2102	0.0397*	0.0169*	0.0049**	0.0467*		
	0.19390	0.13165	-0.08118	-0.14937	-0.10259	-0.24055	0.09787	
	<0.001***	0.0039**	0.0762	0.0011**	0.0249*	<0.001***	0.0326*	
	-0.12855	-0.03031	0.09190	0.10246	0.06490	0.12571	-0.03728	-0.06886
	0.0052**	0.5085	0.0446*	0.0254*	0.1566	0.0060**	0.4166	0.1327

* $P < 0.05$ ** $P < 0.01$ *** $P < 0.001$.

Table II. Estimation results from multiple regressions.

Parameter	Impact scale	Internalized shame
Age	0.14772**	0.13960**
Female	-0.03030	0.03810
Medical degree	0.01951	-0.07111
HIV knowledge	-0.08427	-0.10299*
Institutional support	-0.13015**	-0.10313*
Perceived societal stigma	0.10058*	0.06390
Stress score	0.10364*	0.13696**
R-square	0.0717	0.0724

* $P < 0.05$ ** $P < 0.01$.

strate the causations of perceived stigmatization and internalized shame, the findings of the study help elucidate the negative consequences of caring for PLWHA reported by service providers in China and potential approaches to reduce them and maintain optimal performance of health care workers.

This study provides clear evidence that institutional support is a central factor to reducing service providers' perceived negative consequence of caring for PLWHA and minimizing their internalized shame. With access to more preventive measures such as sterile rubber gloves, HIV-related training, and sufficient health insurance coverage, service providers would feel more protected and comfortable about their work. Good institutional support will promote a positive psychological state and prevent burn out and departure from the workforce. This finding is consistent with studies in other countries reporting the importance of adequate support with AIDS health workers in reducing personal distress and the role of that distress in reducing dropout (Ross et al., 1999; Claxton et al., 1998).

In China, investments in AIDS prevention and control from the Chinese government and international society have been increasing rapidly. However, a gap between needs and available resources still exists because of China's large population, the need for rapid scale-up, and the continually increasing number of HIV/AIDS cases. This study suggests the need for more attention to the area of institutional support for HIV/AIDS care, and it is incumbent on the government to ensure HIV/AIDS resources are effectively allocated. The reinforcement of universal precautions at all levels of care, appropriate health insurance for health care providers, an efficient supply of sterile materials, and specialized medical training are all important steps in maintaining a stable workforce and improving the quality of care for PLWHA.

As described earlier, those service providers who observed a higher level of discrimination against PLWHA in the society were more likely to report also being a victim of stigmatization and discrimination. This suggests that social norms and environment play an important role in the negative feelings

reported by the providers. Service providers are part of the general society, and their perceptions and attitude toward HIV/AIDS are expected to be influenced by societal norms and attitudes. If AIDS were viewed as a normal disease in society, the health providers could feel more comfortable when they treat AIDS patients. This finding also implies that stigma reduction in the general population is essential to promoting high quality care for PLWHA by service providers.

In this study, HIV knowledge was not significantly associated with the feeling of being stigmatized due to working with PLWHA; however, service providers with better HIV knowledge reported less internalized shame. HIV training and knowledge might help the providers to understand better the level of risks associated with caring for HIV/AIDS patients, and therefore reduce their stress and shame. This effect is likely to lead to a greater willingness to care for PLWHA. Thus, as suggested in other studies (Wu et al., 2002; Anderson et al., 2003), HIV education might be a necessary intervention component to maintain a healthy psychological state among providers and to increase their productivity

Although the findings of this study are interesting, there are some limitations. First, the study relied entirely on self-report data. Issues surrounding recall accuracy can be raised, especially in the assessment of institutional support. Since we assessed institutional support based on self report and without data on institutional indicators, such as equipment and regulations in each hospital or clinic, the implications for future policy are limited. Second, the cross-sectional analysis limited our ability to identify cause and effect relations. Third, the data were collected from a region with the highest reported HIV cases in China. Service providers and the general population in this area may exhibit characteristics related to HIV issues that are different than people in other parts of China. Nevertheless, even with the limitations noted, our findings are clear enough to identify essential elements for design of effective interventions and policy formulation.

In conclusion, there is an urgent need to attract, train, and retain health care providers to meet the challenge of the HIV/AIDS epidemic. It is essential that policy makers and health administrators recognize and respond to the support needs of the health care workforce.

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