

Discrimination Against People living with HIV Within Health Settings in China

The HIV Program

ILO Beijing Office for China and Mongolia

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By Wu Rulian, Lv Fan, Xu Peng and Lin Hong

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1. Background

The Chinese government has already issued a set of laws and policies to protect the legal rights of people living with HIV. These include the *Act on the Prevention and Treatment of Infectious Diseases* (2004), the *Regulation on the Prevention and Treatment of HIV/AIDS* (2006) and the *Tort Liability Law of the People's Republic of China* (2010). However, in recent years there has been a surge of stories about people living with HIV experiencing difficulties accessing medical services in general hospitals. In some cases, this was associated with adverse mental and physical consequences.¹

In order to identify the key factors behind differential access and treatment of people living with HIV to medical services, the STD and AIDS Prevention and Control Center of the Chinese Center for Disease Control and Prevention (NCAIDS) and the International Labour Organization (ILO) undertook a joint qualitative research project in August 2010. In-depth interviews were conducted with 20 medical professionals from four designated HIV hospitals and seven non-designated hospitals in five provinces (Henan, Beijing, Guangxi, Yunnan and Gansu). Based on the interview responses and related documents, this report describes the current state of discrimination by medical institutions against people living with HIV, analyses the underlying factors behind this discrimination and provides a set of policy recommendations designed to better protect the medical rights of people living with HIV.

2. Definitions

2.1 Discrimination

According to the *UNAIDS Protocol for the Identification of Discrimination against People Living with HIV*, the primary forms of HIV-related discrimination in health care settings are:

- Refusal of treatment – refusal to provide medical services to people living with HIV;

- Differential treatment – treating people living with HIV differently than other patients with similar conditions who do not have HIV or AIDS;
- Mandatory testing – conducting compulsory HIV tests; and,
- Disclosure of information – not informing people who have been tested of the result after an HIV test and/or disclosing information about HIV status to others without consent.

This report will focus on refusal of treatment and differential treatment. For further information related to disclosure of information and mandatory testing, please refer to the report '*Protecting the Privacy of People living with HIV in China*'.²

2.2 The medical rights of people living with HIV

According to *The National Hospital System and Staff Job Responsibilities (2010)*³, people living with HIV should enjoy equal medical rights. This report defines the medical rights of people living with HIV as follows:

- Patients have the right to enjoy polite, patient, reasonable and consistent treatment services regardless of gender, nationality, ethnicity, beliefs, social status or stage of illness;
- Patients have the right to access higher quality diagnosis, treatment and nursing conditions if necessary;
- Patients have the right to a clean and quiet medical environment;
- Patients have the right to know all information related to diagnosis, prognosis and treatment;
- Patients have the right to make decisions regarding their treatment and surgery; and,
- Patients have the right to know all information about possible treatment options.

All patients enjoy equal medical rights. If the medical rights of a patient have been violated, the patient has every right to question and criticize medical organizations and staff as well as to ask for mistakes to be corrected and for treatment to be provided.

3. Main findings

Government policies have clearly defined the medical rights of patients (including those of people living with HIV). However, despite the presence of these definitions, people living with HIV still encounter difficulties when attempting to access medical services.

In 2005, Yan Zhihua from the Chinese Center for Disease Control and Prevention described the severity of this problem in his master's thesis entitled *A Study on HIV and AIDS Related Stigma and Discrimination and Its Influence on Behavior Intervention*.⁴ In this thesis he explained that, 'Discrimination by medical organizations is very serious, and primarily includes: refusal of treatment and the use of some equipment; forced referral or isolation of people living with HIV to a single ward regardless of the patients health condition; disposal of non-disposable items used by people living with HIV, or forcing them to pay extra money; and, differential treatment when confronted by people living with HIV'. This research clearly describes medical organizations depriving people living with HIV of their right to know, their right to make decisions and their right to privacy. This has the potential to cause people living with HIV serious mental and physical anguish.

Five years later, our research has found that these issues still exist and that solutions to the problem are extremely difficult to come by.

3.1 Denial of surgery for people living with HIV by medical institutions

Current practices surrounding denial of surgery for people living with HIV by medical institutions are best illustrated by the 103 interviews with people living with HIV conducted by Marie Stopes International China (MSIC).

"...I was going to get the surgery after my car accident. But I was tested positive before the surgery. The doctors told me that they couldn't do the surgery and

asked me to leave... I was transferred to an infectious disease hospital... The surgery was put on hold at the hospital for three months... The experts invited were all the doctors of the provincial or city level, but they all refused to perform the surgery, claiming that it was too difficult.” (A 29-year-old woman in Shanxi Province)

“In 2007, I was waiting for anal fistula surgery at a hospital and I was tested HIV positive before the surgery...The hospital said, in consideration of other patients, they could not do my surgery, and they had already discharged me... Later I went to several specialized and general hospitals, but they all refused me. I was very desperate at that moment and even wanted to give up the treatment...” (A 28-year-old man in Anhui Province)

“When I went back to my ward, I found that all my stuff that was in the ward was gone... The department director said, ‘We cannot treat you here. Now go and get discharged.’” (A 30-year-old man in Xi’an)

“...Friends took him (the speaker’s husband) to a TCM hospital. The hospital said he needed surgery for his lumbar disc protrusion. But he had been tested before the surgery, so the hospital knew he was HIV positive and refused to take him... He didn’t have the surgery in the end...” (A 43-year-old woman in Xinjiang Province)

“...I had a problem with my eyes and it was operable. But the hospital said they couldn’t do it... I went to many hospitals including the ones in the capital city of the province and Beijing. At the beginning they all said they could do it, but later...they said they couldn’t.” (A 37-year-old man in Henan Province)

“I had a lump in my stomach... Each hospital advised me that I should be hospitalized immediately for surgery, but when they heard that I was HIV positive, none were willing to accept me. They asked me to go to the infectious disease hospital... The hospital did not agree to let me use the operating theatre. They said if other patients knew that an HIV person had used the operating theatre, it would badly influence the hospital’s reputation...” (A 37-year-old man in Shaanxi Province)

Yan Zhihua provided a similar example in his thesis⁵ where an interviewee recalled:

“The doctor said, you only have two options. One option is that you move upstairs (to the TB department); another option is that you move out of the hospital. I was worried that I would be infected with TB if I moved upstairs, because they had taken x-rays and told me that I was not infected with TB. I considered for a while, and then discharged myself. When I was going through the discharge procedures, the hospital asked me to write a clarification to prove that I was discharged voluntarily... they asked me to state in writing that... because of competing demands on my time, I left the hospital voluntarily.”

These kinds of responses were supported by the findings of a visit to a hospital in Guangxi. This hospital had 28 HIV positive cases detected during pre-surgery tests conducted over the first, second and third quarters of 2009. However, only 21 patients had case files and as many as 15 of these did not receive surgery (71.4% of the patients with case files). Hospital records showed that these individuals did not receive surgery because they were either discharged, “they gave up the treatment” or they were transferred to a designated hospital. The six patients who did receive surgery all had acute diseases.

A further 20 interviews conducted with healthcare workers and management personnel in hospitals confirmed the difficulties people living with HIV have in accessing medical services.

“...We will never operate on HIV positive people if we are aware of their status. Some surgeries were performed when we were not aware of their positive status... We will handle the case by transferring the patient to the infectious disease hospital...”
(Health care worker at a 3A general (top-class) hospital in Beijing)

“...Now if patients test positive they will be immediately transferred out...”
(Health care worker at a 3A general hospital in Beijing)

“...If (the patient) is found to be HIV positive in the pre-surgery test, we will first report to the Medical Affairs Department. If the Medical Affairs Department instructs us to transfer the patient, then we will discharge the patient and ask him or

her to go to an infectious disease hospital... The patient's condition was really bad, so judging from the treatment and diagnostic competence of the eye department in the infectious disease hospital, the patient was likely to go blind...If he had the surgery here, this would have been avoided. But this is the rule of the hospital and the decision to transfer the patient was made based on the medical care conditions here" (Health care worker at a 3A general hospital in Beijing)

"...If we discover such patients, our hospital will transfer the patient to somewhere else in principle. If they are tested positive before the surgery, we will not perform the surgery. They will be transferred to the infectious disease hospital in general even for alternative treatment." (Health care worker at a 3A general hospital in Gansu Province)

"...One patient went to XX General Hospital and was refused treatment after the patient was tested positive..." (Health care worker at a 3A general hospital in Gansu Province)

"We have to operate on those in need of emergency and urgent surgeries and will decline those in need of elective surgery so long as we can..." (Health care worker at a 3A general hospital in Gansu Province)

"...I know among the 50 people living with HIV/AIDS in need of surgery, 20 of them did not get it due to various reasons. Other (general) hospitals made all kinds of excuses and said there was no indication for the surgery. All of them would advise surgery as the first option if the patients did not have HIV..." (Health care worker at a designated hospital in Beijing)

A review of the literature indicates that it is very common for health care workers to be reluctant to provide services for people living with HIV. For example, in a 2005 survey, Sheng Yu⁶ found that approximately 91.9% of nurses were worried about contracting HIV when nursing HIV positive patients, 64% of doctors believed that they had the right to decide whether or not they provided treatment to people living with HIV and 50% of doctors and nurses believed it was acceptable to refuse treatment to people living with HIV. Similarly, a 2008 survey⁷ that targeted 658 health

care workers in 14 hospitals in Guangzhou found that 20% of health care workers were reluctant to provide medical services for people living with HIV. Another recent survey conducted by Xiang Nan College (Hunan Province)⁸ interviewed 343 quasi-medical staff and found that approximately 83.4% of interviewees believed that HIV positive patients should be transferred to specialized infectious disease hospitals while only 35.6% were willing to treat a hand injury on a person living with HIV and AIDS.

3.2 Differential treatment towards people living with HIV by healthcare workers

Differential treatment towards people living with HIV by healthcare workers typically comes in three primary forms, namely, delayed treatment, poor service quality and high service charges. Other types of differential treatment involve the use of a discriminatory attitude and discriminatory language towards people living with HIV/AIDS.

“During my hospital stay, the nurse would give me the IV injection every time before the HIV test. After I was confirmed HIV positive, the nurse put an IV set for multiple drips on me. The worst was when I had to call the nurse many times before one would show up to replace my drip. The nurse even transferred all my roommates to another room... The doctor refused to come to my ward when I needed him. ” (A 40-year-old man in Hebei Province)

“After the surgery, the nurses in the Infectious Disease Department didn’t know how to take care of the wound and she had to ask for help from the nurses from the Surgical Department each time. But more often than not, the nurses from the Surgical Department were just too ‘busy’ to come.” (A 37-year-old man in Shaanxi Province)

“There was a Bone Surgery Department in the hospital, but the doctor always said the surgery was too difficult and technically challenging. So they needed to invite

an expert from outside for the consultation... I waited for three months...and I was told that they found one doctor for the surgery, but the exact date was still uncertain...and the cost of the surgery would be 150,000 RMB... ” (A 29-year-old woman in Shaanxi Province)

“...When I was going through the discharge procedures...people from the hospital said, ‘The total cost for the bed clothing was 260 RMB. No one else will use the blanket and the sheet you used. If you want, just take all these home.’ ” (A 30-year-old man in Xi’an)

“I had to pay for the thermometer and the rubber band used to tie up my wrist for the IV drip. My pyjamas and bed clothing were put in a separate plastic bag when I didn’t use them, not with everyone else’s. They put all of my stuff separately... ” (A 40-year-old woman in Henan Province)

“...It was a shock to me that the doctor wrote ‘HIV’ in front of my bed, so that all the doctors and nurses knew it and discussed it outside my ward...The doctor wouldn’t let me use the toilet in my ward and they asked me to use a public toilet at the end of the corridor. It was December and January. It was so windy and such a long walk through the corridor...” (A 40-year-old woman from Henan Province)

“...I was four months pregnant and I asked the doctor what I should note, where I could get medicine to prevent mother to child transmission, or if there would be free milk powder. Guess what the doctor said? He said: ‘You don’t have any money? Then don’t have a child; you people with HIV/AIDS cannot even take care of yourselves, needless to say a child; it’s just a burden to your family and society.’ ” (A 29-year-old woman in Guangxi Zhuang Autonomous Region)

“...One nurse was really terrible. I was staying in the ICU after the cesarean and she was supposed to send me back to my ward. She held my baby in her arms, but didn’t say my name, instead, she said, ‘that HIV’.” (A 24-year-old woman in Xinjiang Uyghur Autonomous Region)

Interviews conducted by NCAIDS and the ILO with healthcare workers in designated and general hospitals supported these statements.

“Generally in hospital, it is impossible that there is no discrimination at all, there is almost always some kind of discrimination.” (Health care worker at a designated hospital in Henan Province)

“Our department received an HIV positive patient this year... we moved him to separate room, fearing that he would affect other patients. We also burnt the blanket and the sheet he used, specially disinfected the bed and fumigated the room after he was discharged.” (Health care worker at a 3A general hospital in Gansu Province)

“There is a fear of AIDS from the doctor’s point of view... (We) eye doctors believe that there would be a risk of infection in sharing faucets and public washrooms with HIV/AIDS patients.” (Health care worker at a 3A general hospital in Beijing)

In one interview conducted as part of the joint NCAIDS/ILO study on protecting the privacy of people living with HIV, the HIV Division Chief of District CDC stated, *“Before 2006 and 2007, doctors and nurses wouldn’t even allow the epidemiological survey form to be put on their table. They would wear gloves to get it... Doctors and nurses felt very negative about this disease, and with such an attitude towards the patients, they were reluctant to take their blood...”* This illustrates a long-standing culture of discrimination and fear on the part of healthcare workers towards HIV and AIDS.

Of the 103 people living with HIV interviewed by MSIC, a total of 6 were from medical institutions. After finding out about their infection, their fellow health care workers exhibited a distinct fear of HIV and AIDS.

“...Some co-workers were very irrational. They asked the department leaders to

test everyone who had contact with me... Then they asked my department chief to replace all the uniforms, and throw away my desk and chair.” (Male doctor in Sichuan Province)

“...The routine physical examination in the hospital where I worked didn’t include an HIV test. After I was confirmed positive, the news shocked the whole hospital. All healthcare workers took the HIV test, and since then the HIV test has been listed in the routine examination. I lost my job since then although I love working as a doctor. My case has been made known to the whole medical system in this city. It is impossible to work again.” (Female doctor in Shanghai)

“...I was confirmed positive in a screening test under a different name in the hospital where I worked, but very soon the news spread to my department...I felt so stressed... I was still working on my PhD. They even sent for my mentor and said this and that to him.”(Male doctor in Shanghai)

“After I was infected, my hospital transferred me from nursing to the logistics department, and forced me to move, because I lived near the outpatient department of the hospital.” (Female nurse in Guangxi Zhuang Autonomous Region)

“My colleagues thought I must have messed around to get infected. This was humiliating to me.” (Male doctor in Henan Province)

3.3 Practical problems surrounding access to medical services by people living with HIV

During the interviews, many healthcare workers compared HIV surgery to Hepatitis B (HB) surgery. These respondents believed that providing surgery for people living with HIV is in no way different to providing surgery for people living with HB.

“HB surgery is no different to surgery for patients with other infectious diseases like HIV and AIDS. This kind of surgery is always arranged at the end of the day and after the surgery we do a final disinfection. We use disposable supplies as often as we can, and all non-disposable supplies are recycled” (Health care worker at a 3A

general hospital in Gansu Province)

“Surgery for people living with HIV is arranged after others... all items are specifically allocated for that person, and we use specialized equipment in the operating room. After the surgery we do a big disinfection... HB surgery needs disinfection too, we have many HB surgeries each day, so it feels normal now”
(Health care worker at a 3A general hospital in Gansu Province)

Although providing surgery for people living with HIV initially seems uncomplicated, in reality it is very difficult to solve the problems involved with accessing surgery and other medical services. Currently, people living with HIV can obtain surgery through two primary channels – either through a consultation process or through the intervention of a health administrative bureau. However, the consultation process is typically very difficult to go through.

“To be able to invite a doctor for consultation usually depends on your personal relationship. It is very hard to go through medical administrative departments. No hospital is willing to come” *(Health care worker at a designated hospital in Beijing)*

Obtaining surgery through the health administrative bureau can be even more complicated.

“Through the intervention of the city health bureau, I was finally hospitalized in the infectious department of XX hospital...at the end, with my parents’ pleading and the intervention of the unit in charge, the hospital finally agreed to do my surgery”
(HIV-positive man from Xi’an)

When faced with this situation, both healthcare workers and administrative staff indicated that they felt helpless.

“There have been cases of medical institutions turning patients away in the past few years, and even now. We have dealt with the complaints against relevant medical

institutions. We talked to the president of the hospital or directly went to work at the hospital to help the patients... Although this issue shows some improvement, it will still be around for a long period of time.” (Section Chief of a Provincial Health Administrative Department)

“There was this pregnant woman. Every hospital turned her away. In the end, the Health Administrative Department stepped in and made the final decision: the patient could choose whichever hospital she pleased and the chosen hospital had to take her in. She gave birth to the child in our hospital in the end.” (Doctor at a 3A general hospital in Gansu Province)

“General hospitals can do hepatitis surgery, so why can’t they do HIV surgery? Seeking administrative intervention is one way. Maybe the first time is OK, and the second, but we cannot seek an administrative intervention every time” (Doctor from a designated hospital)

4. Underlying factors behind the denial of treatment

Based upon our literature review and the interviews, the following four key factors were identified as contributing to the denial of medical treatment for people living with HIV.

4.1 Perceived responsibility to other patients

In many cases, healthcare workers justified denial of treatment for people living with HIV and their transfer to designated hospitals on the grounds that they needed to better protect other patients.

“In order to protect other patients, we will never carry out surgery on HIV positive patients if we are aware of their HIV status.” (Health care worker at a 3A general hospital in Beijing)

“Other patients would be uncomfortable and even panic if they had to stay in the same room as HIV patients. No one is willing to stay with them and we are short

of wards.” (Health care worker at a 3A general hospital in Beijing)

“The greatest problem is that we are short of rooms. We must have separate rooms for HIV patients, as other patients wouldn’t like to share a room with them. That’s the current situation.” (Health care worker at a 3A general hospital in Beijing)

“Currently, there is no special ward in the general hospital, so other patients will panic.” (Health care worker at a 3A general hospital in Gansu Province)

Similar stories were recounted in the master’s thesis affiliated with the Chinese Center for Disease Control and Prevention.⁹ In one interview, a person living with HIV explained *“They didn’t do the gastroscopy for me... They said that the equipment was very expensive and that if I used it then other patients could not use it anymore... They were afraid that I would transmit HIV to others...”*

4.2 Lack of hospital resources

In other cases, health care workers reported that people living with HIV were denied treatment because their hospitals were not equipped to provide the required medical care by HIV positive patients.

“Now we are short on operating theatres, wards and equipment in the operating theatres. We will need special instruments and training to do this. For example, we will have special instruments for Hepatitis B patients only. For HIV, I think we would need a separate set of surgical instruments like what we have for Hepatitis B patients.” (Health care worker at a 3A general hospital in Beijing)

“It should be done through isolation treatment, but this involves discrimination and human rights issues. If not, we will have hospital infection concerns. We don’t have specialized wards, and the infectious disease department doesn’t have the capacity to do so.” (Health care worker at a 3A general hospital in Gansu Province)

“We need to purchase a separate set of surgical instruments like we did for hepatitis B patients. That needs investment. Despite disinfection, we will be held responsible if iatrogenic infection happens. ” (Health care worker at a 3A general hospital in Beijing)

4.3 Profit-driven hospitals

During the interviews, many respondents put forth their view that hospitals are primarily driven by profit. These respondents believed that the pursuit of profit occurs regardless of both hospital resources and responsibilities to other patients. The rationale here is that in an environment where consumers have free choice, hospital management is worried that prospective patients will go elsewhere if they know that the hospital provides services for people living with HIV. In addition to this, providing surgery for people living with HIV is typically more expensive and thus may also impact hospital revenue.

“The issue here is that if other patients know about the surgery when it’s performed, they will leave. This will affect the income of the hospital.” (Health care worker at a designated hospital in Gansu Province)

“Other patients will panic and leave” (Health care worker at a 3A general hospital in Gansu Province)

“Doctors are able to accept it due to advocacy and education efforts in recent years. Almost no doctor would refuse to treat them due to fear of infection. However, hospital management cannot take it. They are worried about the revenue for the hospital.” (Health care worker at a designated hospital in Beijing)

“Surgical costs of HIV positive patients are two to three times that of normal surgery. This is when the number of staff involved in the surgery is strictly controlled.” (Health care worker at a designated hospital in Gansu Province)

4.4 Poor feasibility of policies and mechanisms

Poor feasibility of policies and mechanisms is one of the key factors behind the difficulties faced by people living with HIV when accessing medical services. This is exemplified by the poor implementation of the *Regulation on the Prevention and Treatment of HIV/AIDS* issued by the State Council in 2006 and other related laws.

The *Regulation on the Prevention and Treatment of HIV/AIDS* explicitly prohibits

discrimination against people living with HIV. For instance, Article 3 provides that, “Employers and individuals should not discriminate against people living with HIV, AIDS patients and their family members. The rights and interests of people living with HIV, AIDS patients and their family members concerning their marriages, employment, healthcare and education are protected by law”. Article 41 of the same document also states, “medical institutions should provide services of counseling, diagnosis and treatment to people living with HIV. They should not turn people living with HIV away or refuse treatment on the grounds that the people seeking medical assistance live with HIV or AIDS”.

Similar provisions are seen in other regulations. For example, the *Notification of the State Council on Strengthening the Prevention and Treatment of HIV/AIDS* issued in 2004 requires, “enhancing the occupational training and medical ethics education of medical personnel, improving the quality of medical services, timely and effectively providing medical services for HIV and AIDS patients.” In addition to this, the fifty-seventh article of the *Tort Liability Act* enacted in 2009 provides that, “when activities of medical personnel during the diagnosis procedure do not fulfill the medical treatment obligations in correspondence to the appropriate level of medical capability, resulting in patient harm, the medical institutions should bear the liability”.

The State Council has also issued a number of regulations surrounding hospital management including *The Hospital System* (1982), *Hospital Staff Job Responsibilities* (1982) and *Supplementary Provisions on the Hospital System* (1992). These regulations were revised in 2008 and 2010 to form the *National Hospital System and Staff Job Responsibilities* regulation. The twenty-seventh article in the administrative management section of the latest version states that, “hospitals should safeguard patients rights in accordance with law” and that patients “enjoy equal medical rights. Regardless of gender, nationality, ethnicity, belief, social status and the state of illness, patients have the right to enjoy polite, patient, reasonable and consistent treatment services.” The thirteenth article in the medical section establishes

“the system of hospitals and divisions transferral” and acknowledges that, “when the hospital cannot provide diagnosis and treatment for patients due to limited technology and equipment conditions, patients can be transferred to other hospitals after discussion within the division or as proposed by the director of the division, and having gained approval by the hospital administrative department or the vice president in charge of hospital business, or having gained approval by the hospital general duty, and advance agreement of the transfer hospital.”

Unfortunately, these laws and regulations have limited influence on the behavior of hospitals. When people living with HIV who are in need of medical treatment are forced to transfer to lower level hospitals, their medical rights cannot be protected. The situation is highlighted by the fact that there are no reports to show that any hospital has ever been reprimanded for avoiding or refusing to treat people living with HIV.

Interviews with healthcare workers and health department chiefs revealed the full extent of the situation.

“Every hospital knows that according to the law they cannot reject HIV positive patients. But there are no rules on what action you can take when you are rejected by the hospital. Without concrete punishment, hospitals do not consider the law as a restriction on their behavior. ” (Doctor working in a designated hospital)

The fact that many hospitals and health administrative departments simply do not understand the designated hospital system only compounds matters. For instance, many medical workers at general hospitals believe that all people living with HIV should be transferred to a designated hospital. During the interviews, many doctors located in general hospitals explained, “The way of coping with people living with HIV is to transfer them to infectious disease hospitals. To perform surgical operations in the infectious disease hospital is quite reasonable...”

The designated hospital system was first described in the 1999 *Proposal on the Management of People Living with HIV and AIDS*. This document asserts that, “health administrative departments at all levels should designate medical institutions to provide medical services for people living with HIV and AIDS”. However, no definition of ‘medical services’ is ever provided.

The specifics of the designated hospital system gradually became clearer in later regulations. For instance, in 2004 the Ministry of Health and the State Administration of Traditional Medicines jointly issued the *Suggestion and Advice on ARV Management of HIV/AIDS*. This document states, “Health administration departments above the city level should designate infectious disease hospitals or general hospitals with an infectious disease department to treat AIDS patients who are critically ill, or with severe opportunistic infection, associated diseases or complications, based upon the local AIDS incidence rate and AIDS patient distribution”. In the same year, another document entitled *Management Approach for Relieving and Reducing Costs of Drug Therapy for Common Opportunistic Infection of HIV and AIDS* reiterated, “the management of treatment for people living with HIV and the set of designated hospitals should be in accordance with the *Suggestion and Advice on ARV Management of HIV/AIDS* jointly issued by the Ministry of Health and the State Administration of Traditional Medicines.”

These two regulations partially clarify the responsibilities of designated hospitals with regards to providing medical assistance for people living with HIV. However, they are not comprehensive enough and the possibility of misinterpretation remains.

Currently, the *Administration of Clinical Treatment for HIV/AIDS in Yunnan (Trial)* issued in September 2005 by the Yunnan Provincial Health Department is the only policy that defines “HIV/AIDS clinical treatment” provided by designated hospitals. In this policy, “HIV/AIDS clinical treatment” is defined as: “to provide HIV/AIDS antiretroviral therapy, treatment of opportunistic infections of HIV/AIDS, prevention

of mother to child transmission, Chinese traditional therapy and Chinese-Western integrative therapy for HIV/AIDS.”¹⁰ By clarifying the responsibility of designated hospitals in this way, medical institutions no longer have grounds to avoid or refuse to provide medical services for people living with HIV who are in need of medical treatment for other diseases.

During the course of the interviews, we found that some healthcare workers had a very clear understanding about the role of designated hospitals.

“I think we should categorize the cases when HIV positive people come for treatment. If the patients require treatment that is not related (to HIV), the 3A general hospitals must take them according to the regulations. If they come for treatment for HIV, they should be transferred to the infectious disease hospitals.” (Health care worker at a 3A general hospital in Gansu Province)

“(General) hospitals should take care of the initial treatment and when it comes to antiretroviral treatment, they can transfer the patients to designated hospitals.” (Health care worker at a 3A general hospital in Gansu Province)

The designated hospital system was designed to provide more professional and efficient antiretroviral therapy to people living with HIV. However, it appears to have simply become an excuse for general hospitals to transfer people living with HIV to designated hospitals regardless of the medical assistance they require.

“Nowadays once the patient is tested HIV positive in the general hospital, no operation will be carried out. They will all be transferred to infectious disease hospitals like You’an, Ditan and No.302 etc, simply because they are HIV positive.”(Health care worker at a designated hospital in Beijing)

“With specialized and designated hospitals, a large number of patients with infectious diseases have been transferred here, when they actually need treatment for common diseases. The designated hospitals have no such capacity.” (Health care worker at a designated hospital in Beijing)

5. Underlying factors behind differential treatment

The primary reasons behind differential treatment of PLHIV by healthcare workers were concerns about occupational exposure and a lack of knowledge about HIV and AIDS.

5.1 Concerns about occupational exposure

A review of the literature reveals that occupational exposure is very common among healthcare workers. For instance, a study published in *China Hospital Management*¹¹ found that 60.5% of healthcare workers had had their skin pierced by medical instruments at least once and 45.2% had had blood or fluid come into contact with their broken skin or mucosa; a further 20.04% of healthcare workers were unaware of what pathogens they had been exposed to and 77.22% of surgical staff had suffered needle stick injuries - much higher than other medical divisions. Another study published in *Soft Science of Health*¹² found that 52.9% of healthcare workers hurt their fingers every three months on average and that the occupational exposure risk rate reaches 31.8% for healthcare workers working on HIV prevention and control. This is significantly higher than in some western countries, where the average is around 0.3-0.5%.

In many instances, reports of occupational exposure in China are specifically related to HIV/AIDS. This was illustrated by an article from the *Journal of Nursing*¹³, which reported that in 2001 the Beijing You An Hospital had 5 cases of occupational exposure to HIV while the First Affiliated Hospital of Kunming Medical College had 8 cases within 2 years. At the latter hospital, healthcare workers did not use any form of occupational protection whilst treating 4 HIV positive patients with skin damage. Similar situations were also reported for the People's Hospital of Zhanjiang city (7 cases of occupational exposure to HIV in 2002-2005), the Central Hospital of Nanyang city (7 cases of occupational exposure to HIV in 2003-2004) and the Province of Sichuan (25 cases of occupational exposure to HIV in 2001-2004).

The lack of any systematic training on occupational protection against HIV within hospitals is one of the most important factors behind these high rates of occupational exposure among healthcare workers. One survey conducted by Zhang Hong on 199 healthcare workers found that 85% had not completed any HIV related occupational training during the past year.¹⁴ Another survey conducted by He Xiaoqi *et al.* reported that 42.35% of healthcare workers worked for hospitals that never organized training on occupational protection.¹⁵

The situation is compounded by the absence of protective equipment. For instance, a survey conducted by Lu Linqing *et al.* on 60 clinical staff found that most healthcare workers did not wear protective glasses. This was largely because they were simply not equipped with them.¹⁶

Interviews conducted by NCAIDS and the ILO with healthcare workers highlighted these findings.

“...It’s not that I look down on them (people living with HIV). I’m just afraid of occupational exposure...” (Health care worker at a designated hospital in Henan Province)

“I’ve worked here for 7 or 8 years and have not yet received any specialized training on dealing with HIV. If I get exposed to HIV, I really don’t know what to do...” (Health care worker at a 3A general hospital in Gansu Province)

“We have had one case of occupational exposure to HIV, but that person didn’t get infected.” (Health care worker at a 3A general hospital in Gansu Province)

“We have had one case of occupational exposure. The person got stuck by a needle and later tested negative.” (Health care worker at a designated hospital in Henan Province)

“The national regulations include a clear definition of occupational exposure and a detailed description on the assessment and post-assessment treatment for occupational exposure... As a special hospital for infectious diseases, we deal with

lots of these cases and are more familiar with these situations than general hospitals... So far, we have had 5 cases of (HIV) occupational exposure, including three cases of needle stick injury and two cases of mucosal exposure.” (Health care worker at a designated hospital in Gansu Province)

Occupational exposure to HIV is not currently classed as an occupational injury or disease under Chinese law. As such, there are no applicable laws or regulations in China designed to provide compensation or subsidies for healthcare workers who contract HIV through occupational exposure¹⁷ and there are no reporting systems in place within hospitals for monitoring occupational exposure. This situation was underlined by a survey conducted by He Xiaoqi *et al.*, which found that 86.2% healthcare workers did not report occupational exposure in a timely fashion. The main reasons behind this were that 51% of interviewees did not know who they should report to, 60.7% had no reporting or monitoring systems for occupational exposure in place at their hospitals and 57.7% of interviewees believed that their hospitals were not interested in occupational exposure and the protection of healthcare workers.¹⁸

5.2 Poor awareness of HIV and occupational protection measures among healthcare workers

In many cases, HIV-related awareness among healthcare workers remains poor. This was highlighted by a 2005 study published in the *Preventative Medicine Forum*, which surveyed 109 clinical workers from various medical specialties and found that only 67.89% of interviewees knew how HIV is transmitted, while as few as 11.92% knew the correct protocol to treat injuries caused by contaminated equipment.¹⁹ Similarly, a study conducted by Rou Keming *et al.* found that knowledge of the universal precaution rule among healthcare workers was between 12.5% and 24.4%²⁰ and a 2007 survey published in the *China HIV and STD Journal* found that of the 1,292 healthcare workers in Beijing, only 39.7% had received HIV related training and 24.7% received such training in 3A hospitals²¹.

The interviews conducted by MSIC with people living with HIV who were also former healthcare workers confirm these findings.

“...People feel that it (HIV and AIDS) is something far away from us, including me... If I put it on a 100-point scale, I would have only scored 10 points in terms of knowledge of HIV. I really knew nothing about HIV except for the three modes of transmission and that it was dangerous.” (28 year old, female, former nurse, Fujian Province)

These accounts were supported by the NCAIDS and ILO interviews conducted with current healthcare workers.

“Even doctors... fear HIV.” (Health care worker at a 3A general hospital in Beijing)

“(The day when I did the operation) I was more careful about the protection...I was more nervous than usual. I had also checked online the protection and prophylaxis measures against HIV before the operation.” (Health care worker at a 3A general hospital in Gansu Province)

5.3 Misinterpretation of routine procedures by people living with HIV

Some healthcare workers disputed alleged cases of discrimination by claiming that they were actually misunderstandings or misconceptions held by the person living with HIV. For instance, some people living with HIV felt that their treatments had been intentionally delayed because of their HIV status when in reality the hospitals had legitimate reasons for their actions.

“Patients need to be tested before the operation. If they test positive, they will be moved to a special operating theatre and then transferred to the infectious disease department afterwards... When we find positive cases, we need to contact the infectious diseases control office and then CDC. CDC will in turn get back to the office. It will take as long as three days... If it’s an emergency surgery and it can’t wait,

we just have to make sure that we get all the necessary protection ready and do it.”
(Health care worker at a designated hospital in Henan Province)

“The patient came in on December 1st but didn’t get the operation done until December 7th because we had to wait for the materials...” (Health care worker at a 3A general hospital in Gansu Province)

In other cases, healthcare workers did not believe that the differential treatment reported by people living with HIV amounted to discrimination.

“Treating them differently is not the same as discriminating against them. The patients may feel this way but it’s not necessarily true... Sometimes they don’t understand that we assign them single rooms for their own good. We are actually trying to protect them from discrimination from other patients and to protect the doctors as well.” (Health care worker at a designated hospital in Henan Province)

“We have special rooms (for HIV positive patients), and if they don’t understand why, it’s the doctor’s job to help them understand...” (Health care worker at a County MCH Center in Henan Province)

“According to the patients condition, some of them do not need hospitalization, so we suggest they not be hospitalized, but this could be mistaken by patients as discrimination... In this situation, doctors should communicate with patients and explain to them” (Health care worker at a county level designated hospital in Henan Province)

These kinds of misunderstandings may stem from a lack of trust between healthcare workers and patients. This is supported by data that shows that 80% of medical disputes are caused by a lack of communication between healthcare workers and patients.²²

6 Recommendations

6.1 Improve relevant policies, including to clarify hospital responsibilities

During the course of our interviews, many healthcare workers proposed that a guideline for the implementation of the *Regulation on the Prevention and Treatment of HIV/AIDS* should be developed in order to improve the effectiveness of the regulation. Any such guideline would need to define terms such as ‘medical services’, ‘employment’, ‘privacy protection’ and ‘refusal and avoidance’ whilst also outlining the penalties to be imposed if relevant laws are breached.

Based on the findings of our survey, we recommend conducting an assessment of the *Regulation on the Prevention and Treatment of HIV/AIDS* over the past five years. This assessment should focus on identifying the difficulties involved in implementing the regulation and lay the foundations for the development of detailed guidelines for implementation.

This could be complemented by the development of a policy by the health administration department that clarifies the responsibilities of designated and non-designated hospitals with regard to the provision of medical services for people living with HIV. This will help to further clarify the medical rights of people living with HIV at the policy level.

6.2 Promote awareness among hospital management about the rights of people living with HIV/AIDS to access medical services

During the course of this survey, healthcare workers continually noted the importance of hospital management in deciding whether to accept HIV positive patients. This indicates that raising awareness within hospital management will be integral to resolving issues surrounding access to medical services by people living with HIV. To help achieve this, we propose the following three courses of action: 1) strengthen

awareness among hospital management of the *Regulation on the Prevention and Treatment of HIV/AIDS*, *Tort Liability Act* and *National Hospitality System and Staff Job Responsibilities*; 2) promote understanding of the medical rights of people living with HIV among hospital management; and 3) list ‘provision of treatment for people living with HIV’ as a performance management indicator for hospital administration in the evaluation systems of health administrative departments. Hospital presidents should be held accountable for this indicator and reprimanded if denial of treatment occurs.

6.3 Strengthen implementation of the universal precaution principle

Interviews conducted with healthcare workers revealed that many had a very poor awareness of HIV and the universal precautions that can be taken to prevent contraction of the disease. As Xiao-Jun Ma, director of the Hospital Infection Control Office in Beijing Union Medical College Hospital said, “The worst things are those which are unknown, but adhering to principles of universal precaution prepares us for all possibilities”.²³

At the international level we can look to the *Joint ILO/WHO Guidelines on Health Services and HIV/AIDS* issued in 2005. These guidelines treat HIV/AIDS as a workplace issue and propose full implementation of the principles of universal precaution in order raise occupational health and safety standards in healthcare settings and, in so doing, better protect the rights of healthcare workers. To achieve this, training on the principles of universal precaution and other issues raised in these Guidelines should be integrated into pre-existing training for health care workers. This could be complemented by the development of policies that enable people who have contracted HIV to continue working in their jobs.

Turning to the national level, China has already issued a series of laws and regulations designed to protect occupational health and safety, including the *Regulation on*

Infection Control (2002), the *Occupational Disease Prevention Law* (2005) and *Hospital Infection Control Measures* (2006). In 2004, the Ministry of Health also issued the *HIV Prevention Guidelines for Occupational Exposure among Healthcare Workers (Trial)*. These guidelines require all health administrative departments and healthcare institutions to strengthen measures designed to prevent HIV infection through occupational exposure and specify that all healthcare workers must adhere to principles of universal precaution.

However, the reality is that many healthcare workers are unclear about the principles of universal precaution.²⁴ For example, a 2008 study published in the *Journal of Nursing Management* found that adherence to these principles by nurses is quite poor and implementation of individual protective requirements appears to vary significantly.²⁵ This is primarily due to low awareness of the principles of universal precaution among health care workers and a lack of capital investment from hospitals.

To address this situation, we recommend that:

- Training on the principles of universal precaution is integrated into existing training for healthcare workers;
- Existing training on preventing occupation exposure is strengthened;
- Policies are developed to enable healthcare workers who have become infected with HIV to continue working; and,
- All hospitals establish a program on HIV/AIDS prevention and treatment whilst also taking steps to reduce the level of stigma and discrimination held by health care workers towards people living with HIV. This program may comprise of training on HIV/AIDS, the medical rights of people living with HIV and the related laws and regulations (particularly the *Regulation on the Prevention and Treatment of HIV/AIDS*, the *Tort Liability Act* and the *National Hospital System and Staff Job Responsibilities*).

6.4 Improve protection mechanisms for healthcare workers who have been subject to occupational exposure

In 2005, China had nearly 400 incidents of occupational exposure to HIV. These primarily occurred in hospitals, immunization centers and during the course of police work.²⁶ Although there have been no formally reported cases of HIV infection through occupational exposure in China to date, the risk of this occurring in the future is likely to grow due to an increase in the rates of occupational exposure. However, China does not currently have any support systems for healthcare workers who contract HIV through occupational exposure.

Despite the lack of regulations, it is clear that many healthcare workers support improved protection mechanisms around occupational exposure. This was illustrated in a 2008 study targeting 658 healthcare workers at 14 hospitals in Guangzhou city.²⁷ This study found that 78.7% of respondents supported the development of regulations to ensure the legal rights of people who contract HIV through occupational exposure and 76.7% believed HIV/AIDS should be integrated into work injury insurance coverage or critical illness insurance. In addition to this, 66.1% of respondents believed HIV/AIDS should be considered an occupational disease or covered by the social protection scheme and 74.2% supported the establishment of a special fund to provide compensation for pain, costs of living and medical treatment.

The ILO has already revised the *Recommendation Concerning the List of Occupational Diseases and the Recording and Notification of Occupational Accidents and Diseases (No. 194)* in order to add HIV and AIDS to the list of infectious diseases.²⁸ Given the risks of occupational exposure faced by healthcare workers, HIV and AIDS should also be included in the social security coverage for healthcare workers who contract the disease through occupational exposure.

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