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# Coping Strategies for HIV-Related Stigma in Liuzhou, China

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# Keywords

HIV-Associated Stigma; Coping; HIV in China

### Introduction

Previously, most efforts to quell the HIV epidemic in China have focused on primary HIV prevention (1). As the HIV prevalence in China has grown, however, increasing attention is also being paid to the experiences of people living with HIV (PLHIV) in China, such as HIV-associated stigma (2,3). Such stigma not only interferes with HIV prevention efforts, like voluntary counseling and testing, needle exchange, and condom promotion programs, but also can reduce the abilities of PLHIV to access treatment and care (4–11). HIV-associated stigma and discrimination also cause substantial psychological distress (e.g., severe depression, anxiety, and poor self-esteem) among PLHIV (12–16).

These effects, however, have been shown to be moderated by the abilities of PLHIV to cope with their illness and its associated stigma, as well as by the amount of social support they have available (12–14,17,18). Serostatus disclosure both affects and is affected by the quality and amount of available social support (14,18–20). While garnering social support can serve as one coping strategy to reduce stigma, the role of family and community, as well as stigma, are highly contextually based. Hence, coping strategies to address stressors that arise from an HIV diagnosis may be different in China than other countries (1,15,21–25). The interrelationships among HIV-associated stigma, serostatus disclosure, coping, available social support, and well-being have been studied extensively and shown to be complex,

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dynamic, important, and contextually based (12–14,17–20) but have not been well-studied in China.

Stigma has been defined as the act of being negatively judged by others based on a specific identifiable attribute (26). Stigmatization has been conceptualized as a process with four related components: 1) distinguishing and labeling differences (stigmatizing features); 2) associating negative attributes with these differences; 3) separating 'us' from 'the other' or stigmatized group; and 4) enacted stigma resulting in loss of status for the stigmatized group and discrimination (9,27–29). PLHIV throughout the world experience both felt and enacted HIV stigma. Felt or perceived stigma represents the negative attitudes PLHIV perceive from their partners, friends, family, community, and society in general (30–33). Enacted stigma or discrimination is a behavior carried out as a result of these attitudes, such as the denial of rights to health care, education, and employment. Enacted stigma may also involve social distancing, such as isolation by family and community, or loss of respect (30,34–36). Because HIV-associated stigma, which is often embedded in a society's culture, is difficult to eliminate from communities and society, one critical component of assisting stigmatized individuals and groups is to identify helpful coping strategies to counter or mitigate its effects.

The coping styles most likely to enhance well-being, however, may vary based on the context in which stressors, such as HIV illness and HIV-associated stigma, occur (37). Coping has been defined as the process by which individuals regulate stressors that they face (38). Being diagnosed with a serious illness like HIV represents a substantial stressor that incites a process of coping. Lazarus and Folkman were the first to document that the process of coping begins with cognitive appraisal both of the stressor and of the resources one has available to address that stressor (38). When an individual's cognitive appraisal determines that the illness holds both significant personal relevance and represents a challenge (rather than only a threat), s/he then initiates coping strategies to regulate the stressful situation. Coping strategies have been categorized into two general types: 1) those that are "active/ problem-focused strategies" versus 2) those that are "passive/avoidant" strategies (38,39). Specific strategies offer a means to reduce distress caused by HIV-associated stigma (39,40). In U.S. studies in general, PLHIV who use problem-focused tactics have been shown to be less distressed than those using passive coping approaches (20,22). In non-Chinese populations, coping strategies used to address HIV-associated stigma have been found to change over time after initial diagnosis (18).

While several studies in China have documented the severity of stigma that PLHIV face and its detrimental effects on their and their families' senses of well-being (1,2,21,41), only a few studies have assessed the coping strategies of PLHIV. Zhou (42) found that, to cope with their illness, PLHIV in China reconstructed their conception of time to emphasize the facets of life they found most salient in the course of living with this disease. Another study of PLHIV showed that in central China, acceptance/resignation and avoidant coping styles were associated with increased distress while confrontation, which was most commonly used by PLHIV, was beneficial (14), although all of the individuals in this study had been infected via plasma donation, which had an impact on the context of their infection and, therefore, stigma. Li and colleagues (23) identified a complex interrelationship among

PLHIV's depressive symptoms, those of their family, available social support, and family relationship features. In the current journal issue, Hua and her colleagues found qualitatively that PLHIV in China often self-isolate to cope with anticipated stigma (2) but that such coping seemed to lead to loneliness and depressive symptoms.

Because the inter-relationships between coping and stigma are contextually-based and understudied in China, we explored stigma-related coping strategies of PLHIV in Liuzhou, China, to fill this gap.

#### Methods

### **Study Overview**

We conducted a face-to-face in-depth qualitative study of 47 PLHIV from Liuzhou, China, including participants in different high-risk groups (intravenous drug users, female sex workers, and men who have sex with men) between September 2009 and April 2011. The project was approved by the Ethics Committee of Renmin University in Beijing, China, and all subjects provided written informed consent.

# Setting

The study was conducted in Liuzhou, a medium-sized city in southwest China, with a population of approximately 1.5 million. It borders Myanmar, Vietnam, and Laos, along a main route for drug trafficking. It has four urban administrative districts and six counties. The cumulative total of PLHIV in Guangxi Province is the second highest in China, and Liuzhou ranks first among the regions in Guangxi Province. Liuzhou (including the urban and rural units and resident migrants) reported 11,323 total HIV cases by 2012. HIV data from 2012 showed that the primary route of HIV transmission in Liuzhou is heterosexual contact (89%), followed by injection drug use (6%), men who have sex with men (1%), and mother-to-child transmission (<1%).

#### Recruitment of participants

We used recruitment methods established in previous studies conducted in Liuzhou targeting high risk populations ("Reducing HIV Transmission among and from Vulnerable Groups and Alleviating its Impact in Seven Provinces in China," Global Fund Round 4; "Mobilizing Civil Society to Scale Up HIV/AIDS Control Efforts in China," Global Fund Round 6). Purposive sampling was utilized to recruit PLHIV from three different high-risk groups (People Who Inject Drugs [PWID], female sex workers [FSW], and men who have sex with men [MSM]) to select representative numbers from each group. Other PLHIV identified who did not report being in a high-risk group were also included in the sample and labeled as "Other." We structured the sample to ensure the inclusion of women, older people, and ethnic minorities. The study inclusion criteria were as follows: confirmed diagnosis of HIV infection for at least six months; age 18 years or older; having the mental competence to provide informed consent and answer questions; currently living in Liuzhou; and not having taken part in an HIV-related interview or survey in the prior two months.

Staff at local community-based organizations helped us recruit participants, including at needle exchange and methadone treatment centers for PWID, non-governmental organizations for MSM, and a women's health clinic for FSW. Other PLHIV who are not MSM, PWID, or FSW were recruited by primary care workers and infectious disease specialists at Longtan Hospital, where HIV care is provided (Table 1).

## **Qualitative data collection**

Five students (three male and two female) from Guangxi Industrial University Sociology Department were trained to conduct the interviews. After obtaining informed consent, the interviewers conducted semi-structured, face-to-face interviews lasting one to two hours in a private area. Interviewers audio-recorded the interviews with each participant's permission and took notes during the sessions. Each participant received 50 RMB (equivalent to \$7.30 USD) as compensation for their time.

The data collection instrument was semi-structured and modified from a published interview guide that explores coping strategies of PLHIV (43). The guide, made up of four main questions, with optional follow-up probes, assessed three primary *a priori* domains: 1) experienced and felt stigma; 2) strategies individuals used to cope with HIV-related stigma; and 3) programs they thought might help reduce stigma toward PLHIV.

### Qualitative data analysis

After the interviews were transcribed to text, they were independently coded by three different researchers in Chinese. Specifically, after conducting a "first pass" of the transcripts, the research team developed a codebook according to the interview outline and the interview data in consultation with collaborators at the University of North Carolina. Three researchers then independently coded each of the transcripts simultaneously, using the codebook and making additions to the codebook as needed when previously unidentified codes emerged. After completing the coding, the researchers met to discuss the codes until they came to a consensus on each code. After a consensus was reached, the researchers analyzed the data using theme-based analysis to identify emergent themes that reflected overarching ideas about ways of coping in the coded transcripts and associated quotes.

# Results

# **Description of sample**

From September 2009 through April 2011, we interviewed 47 out of 65 PLHIV approached, until we achieved data saturation; eighteen people declined to participate. Reasons for nonparticipation included: concerns that participation would disclose their HIV diagnosis, and lack of time or interest. Among the 47 participants (Table 2), 28 were men and 19 were women, and included nine PWID. The mean age of participants was 42 and all six participants over 50 years old were men. Most participants had at least a middle school education and were unemployed. Additional participant characteristics are presented in Table 2.

### Means of Coping among PLHIV in Liuzhou, China

Our analysis identified four main categories of strategies that participants used to cope with HIV-associated stigma. Two approaches were interpersonal and two intrapersonal in nature. Of the two interpersonal approaches, one was consistent with passive/avoidant coping, while the other represented an active/problem-focused coping approach. Similarly, among the two intrapersonal approaches people used to deal with experienced stigma, one was passive and the other an active coping method. Each is described below in turn with accompanying illustrative quotes.

# Interpersonal Coping Strategy Category 1. Compassionate Approaches: Seeing the world through the eyes of uninfected people who stigmatize

Some participants described using passive coping to help them handle the pain they felt from being stigmatized. Several felt, particularly when others who discriminated against them due to fear of infection, that it helped them to try to empathize with those who discriminated against them. Using compassion to understand why people felt afraid of PLHIV helped participants take the discrimination less personally. The key narrative was that because HIV is contagious, it is fathomable that people holding inaccurate perceptions of HIV transmission risk would fear becoming infected. PWID most commonly endorsed this strategy.

"I can understand why people discriminate against us ... they are afraid of being infected. Once you get HIV, everyone must keep away from you."

(Participant A, 38-year-old male PWID)

"The main people who show discrimination to me are my neighbors. It is normal that they look down on me. After all, it's an infectious disease."

(B, 39-year-old female PWID)

While some participants believed that empathizing with those who stigmatized them reduced their emotional stress due to stigma, for others, this coping strategy had the opposite effect. Instead, it served to reinforce self-blame and reduce self-esteem which led to more distress.

"It's very sad to be misunderstood and be without my family's concern and support at the beginning, but I can't blame them. After all, it is the way I chose by myself."

(C, 26-year-old female PWID)

As these statements demonstrate, participants, especially drug users, experienced stigma from family, neighbors, and more broadly, within the community. However, they showed tolerance and understanding toward those who stigmatized and discriminated against them; in fact, consistent with some passive coping styles, they often blamed themselves and their behaviors for getting HIV, internalizing the stigma they felt from others. Some also thought that fear of infection was an understandable reaction among people who lacked information about HIV transmission routes.

# Interpersonal Coping Strategy Category 2. Social Support Approaches: Seeking support from family, peers, or close friends

Some participants used a more active problem-focused interpersonal coping style: they reached out to important people to develop a supportive environment. The groups of people from whom they sought support and the ways in which they sought support varied across individuals.

Several participants spoke poignantly about their close family members' positive reactions when they disclosed their infection to them. Instead of discrimination, these participants reported receiving understanding and strong emotional and tangible support. One participant whose wife was also infected reported that they provided each other with mutual support and understanding.

"My parents didn't say anything about the situation, and I am their only son after all. My mother knows a little about AIDS and hopes I'll be cautious in the future. My wife is also HIV positive and knows my situation. But she thought that partners should understand each other."

(D, 38-year-old male PWID)

"I feel better because my good friends gave me a hand when I was diagnosed with HIV. We communicate about health and matters that need attention."

(E, 24-year-old MSM who disclosed to his partner)

Another source of social support is community-based organizations designed for PLHIV. Quite a few participants spoke about the saliency to them of peer support, particularly as an important way for them to cope with stigma. Relying on friends who were also receiving care for HIV, met through a peer organization, helped participants create a safe environment conducive to developing new caring, accepting, and helpful relationships. As one person described:

"I took part in hospital activities after my HIV diagnosis. There are many HIV patients in the organization and I met some patient-friends. We all communicate with each other, which is helpful for us. I can learn a lot after discussion."

(F, 60-year-old male heterosexual)

For many participants, seeking and receiving support from family, friends, and peers helped them maintain a positive attitude, which they believed enhanced their well-being. Some participants described receiving the most support from those with whom they already had a close relationship. Other participants found it easier to garner support from other PLHIV rather than non-infected people.

#### Intrapersonal Coping Strategy 1. Hiding HIV status to reduce feelings of despair

Some participants expressed extreme feelings of despair related to their HIV diagnosis and the resulting stigmatization. HIV was talked about as a "fatal blow" that left them feeling isolated and hopeless. They often chose to keep their status a secret as a way to avoid discrimination or stigma, yet such individuals described a sense of loneliness that they felt as

a result of their secrecy. Discussion of suicide was not rare during our interviews. Stigma and discrimination also made some participants contemplate revenge although they all eventually decided that revenge was not a good option.

Participant L, a young male PWID, told us that he had considered suicide because he "felt alone" with "no one to speak to." Others expressed similar hopelessness:

"This is no way to live. I cannot see any hope and sometimes I just want to start over. With other diseases, sometimes you can, but not with AIDS. The pain of this disease is so intense, maybe I'll die suddenly one day. I feel a lot of pressure and just want to die."

(M, 26-year-old female PWID)

"I...feel great despair."

(K, 54-year-old female heterosexual)

"Because of this disease, I can't live much longer anyway, so I have low selfesteem and feel great despair."

(K, 24-year-old MSM)

All participants were very afraid of disclosure of their HIV-positive status. They believed that HIV-related stigma would be inevitable once they were exposed, and they would inevitably face discrimination. They did not want their status known by anyone but people they knew well.

"If it is known by strangers, they will tell more people about it. You can't expect that all of them will care about you. They will stay away from you. So do you want to disclose your HIV infection to 100 people in order to get just one person's support? I say absolutely not."

(N, 25-year-old FSW)

Another older woman, married with three children, said, "I don't trust anyone and there is no one I can tell about it at my work or life. In fact, I dislike talking to anyone." (O, 53-year-old female heterosexual)

Some participants, both male and female, were more concerned about the stigma directed toward their family and children than toward themselves and thus chose to hide their HIV status, often even among their families.

"My children will not come back home if they know the truth. They will think that many of their classmates and friends will discriminate against them and say, 'That one's father is an HIV patient.'...I can't face the consequences."

(P, 41-year-old male heterosexual)

Thus, while hiding HIV status was a passive coping response, the relationship among disclosure, stigma, and well-being were complex: hiding one's serostatus did often protect PLHIV's mental and physical health, at least in the short term. In the long term, however,

the fear and consequences of stigma and discrimination may continue to have serious negative and isolating effects.

# Intrapersonal Coping Strategy Category 2. Self-Care: Physical and mental health activities to improve well-being

Some participants expressed despair over the prospect of living with HIV, but some described drawing upon their inner resources rather than seeking external support to address such despair. Physical exercise and psychological treatment were two specific coping strategies described as salient in helping them deal with stigma.

For example, Participant H said, "I usually calm myself down by staying at home, drinking, walking, and swimming" (38-year-old male PWID). He found that exercise was an effective way to get rid of hopeless feelings. Likewise, a 50-year-old woman who contracted HIV from unprotected sex told us that "it is very important to have a mental balance generally. You'd better go out for exercise, such as singing, dancing when you can. More exercise [means] more health." (50-year-old female heterosexual).

Some older participants believed their more advanced age made it easier to garner inner strength to face their HIV diagnosis and its associated stigma.

"When I look at those younger HIV patients, I can get a balance. I am already over 50, so compared with them, I am much luckier. I really feel sorry for those young patients. Because they are young and have AIDS, otherwise they would live longer, they are so poor and unfortunate."

(I, 53-year-old female heterosexual)

Another talked about maintaining a positive outlook as a means of coping with her diagnosis:

"We should live well for as long as possible. It is no use to feel depressed. We should keep a cheerful mind, whether healthy or not. I do not want to wait for death by sitting. I have fought to live for five years."

(J, 50-year-old female heterosexual)

#### Discussion

This qualitative study of nearly fifty PLHIV in Liuzhou, China, revealed several noteworthy findings. First, every participant described experiencing or fearing severe HIV-related stigma or discrimination. Individuals were concerned not only of the effects of such stigma and discrimination on themselves, but also on their family members. These reported experiences and fears of HIV-associated stigma are consistent with several previous studies of HIV in China (1,14,15,25), including two in this issue (2,3). Similar to data reported in other recent research about PLHIV in China (1,2,4,14,15,22–25,44–46), participants in this study described experiencing serious stigma from a broad range of sources: family, neighbors, health professionals, including doctors, and other people in the community. PLHIV perceived that the stigma they experienced was compounded by stigma associated with HIV-acquisition behaviors, such as intravenous drug use and sex work. Abler and

colleagues documented the high level of stigma that exists in the general public in Liuzhou toward PLHIV (3). In Hua and colleagues' study of 27 PLHIV in Liuzhou, the vast majority of participants were highly isolated, rejected, unemployed, and impoverished as a result of their disclosure of their diagnosis (2).

Our study goes beyond those that simply document experiences of HIV-associated stigma in China to assess how PLHIV respond to these experiences. While, like Hua and her colleagues (2), we identified socially and emotionally isolated individuals, our findings documented a broader range of responses to HIV diagnosis and its associated stigma. In our study, PLHIV reported using numerous strategies to deal with the stress they experienced due to their diagnosis. Although most PLHIV reported using negative strategies, such as hiding their HIV status or living with a negative attitude, several positive strategies were also described in the interviews.

The varied strategies discussed by participants in this study were grouped along two dimensions: the degree to which they were interpersonal versus intrapersonal approaches; and the degree to which they were passive/avoidant versus active/problem-focused. Hence, looking across both of these dimensions together, the strategies that participants used to cope with their diagnosis and its associated stigma fell into four general types: compassion, social support, hiding HIV status, and self-care (Table 3).

These categories are consistent with and build upon existing theories of stress and coping. As suggested by Lazarus and Folkman (38), participants in this study considered their HIV diagnosis to both hold a great deal of personal salience and represent a highly significant challenge in their lives. Each means of coping with such a salient challenge as HIV was easily identified as either "active/problem-focused strategies" or "passive/avoidant" strategies as purported by coping theory. In addition, we noted that within these categories, some strategies used were more focused on relationships the participants had with other individuals, while other strategies drew upon their inner resources, without relying on social relationships.

We found that support from family, peers, and close friends was the most important resource that facilitated a positive attitude toward an HIV diagnosis and related stigma. Therefore, establishing a supportive environment with reduced stigma among important people (especially family and close friends) is critically important (47) to reduce the felt stigma experienced by PLHIV and encourage more positive coping strategies toward HIV-related stigma.

It is not clear from our findings what drove the use of different approaches and several participants reported using more than one approach. Because this was a cross-sectional study, we were not able to identify changes or patterns of strategies that individuals used as their disease progressed, however, use of these strategies is likely to shift as a person's symptoms develop (18). In the CHAI (Coping, HIV, and Affect Interview) Study, researchers followed PLHIV over time and identified four patterns of coping related to approaches to disclosure during nine months of follow up with narrative interviews (20). Similarly, Kotze and colleagues (18) followed 224 HIV-infected women in an antenatal

clinic over two years. They found that both active and passive coping increased over time although more women used active coping. Those who had increased active coping over 21 months had decreased internalized stigma and depression and improved social support, self-esteem, physical and financial well-being. Future studies are needed to explore further changes in the use of inter- and intrapersonal approaches over time.

While studies of coping with HIV-associated stigma are uncommon, it is noteworthy that our findings differed in some respects from those reported in other international settings, such as Africa. For example, Makin and colleagues (48) found that, despite the common perception that PLHIV often do not disclose their HIV status, the majority (81%) of HIVinfected pregnant women they studied told at least one person within three months of diagnosis. Makoae and colleagues (43), in a study of strategies for coping with HIV stigma in five African countries (Lesotho, Malawi, South Africa, Swaziland, and Tanzania), found that some participants (21%) were open about their diagnosis and served as spokespersons for others. They disclosed their HIV status to reduce gossip and rumors, whereas others disclosed their HIV status to gain support from loved ones and community members. That study also reported that a few participants (18%) actually saw themselves as normal and courageous in the face of the illness and stigma and refused to withdraw from social contact when they experienced stigma. Instead they sought support from health workers, counselors, or peers. Like the participants in our study, however, such counseling and support helped them feel better and understand more about their illness. Less common positive coping strategies included helping others (9%), mainly those with HIV-related problems, and changing their lifestyle (6%), so that such positive changes then became the focus of their lives rather than the negative diagnosis (43). Therefore, social environment, including medical services and insurance, as well as society's attitude toward HIV is clearly a key structural factor that influences people's coping strategies. This kind of support is a critical need in China, as most PLHIV feel severe stigma and are very fearful of disclosure.

In China, many mass education programs address HIV stigma and stigma reduction through education about the disease. However, public attitudes, including those in Liuzhou, remain quite negative (49). In the research reported by Hua and colleagues in this issue (2), PLHIV reported experiencing discrimination due to a fear of casual transmission and that even some medical workers, who should be knowledgeable about HIV, treated them badly due to such fear. The only recourse that seemed available to some PLHIV was to adopt the negative strategies described above. At the same time, a minority of individuals were able to draw upon positive experiences from their family and peers and garner an inner strength that led to lifestyle changes in self-care habits. This observation suggests that positive coping strategies can be developed and enhanced in the Chinese setting.

Our findings require reflection on the lack of effectiveness of existing mass education programs for reducing stigma. Identifying better programs to strengthen effective coping strategies for PLHIV in China could serve to enhance their physical and psychological wellbeing, as has been shown to be effective in other settings (39,50).

# Conclusion

HIV-related stigma has the potential to markedly harm the health and well-being of PLHIV. Hence PLHIV must be able to use effective coping strategies to overcome such HIV-related stigma. To achieve that goal, both structural and individual factors need to be addressed. For better social environments, necessary medical and psychological consultations need to be available for PLHIV and their potential support networks. Social workers, for PLHIV who do not have easy access to them, could help establish supportive social networks by bringing in family members, close friends, and peers for HIV education and stigma prevention efforts. Providing targeted HIV education for people in PLHIV's circles will be crucial to their development. New media methods utilizing the internet and smart phones may provide an improved method of disseminating tailored education for both HIV infected and uninfected people. These intervention measures are of key importance not only to reduce stigma but also to help PLHIV face the stigma with more positive attitudes instead of relying on negative coping strategies.

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Table 1

Number of PLHIV participants recruited by recruitment site

PLHIV Recruitment			
Recruitment Site	Recruiters	# of Participants Recruited	
Needle Exchange Center	Staff and drug users	6	
Methadone Maintenance Treatment	Staff and drug users	14	
Women's Health Center	Staff	3	
MSM Group	NGO Volunteers	6	
Other PLWHA	Doctors	18	
Total		47	

Table 2

Number of PLHIV participants recruited by participant characteristics

PLHIV Participant Characteristics		
Mean Age	42 years (range: 24–74)	
Gender		
Female	19 (7 PWID)	
Male	28 (2 PWID)	
Route of Infection		
Contaminated Blood Exposure	20 (9PWID)	
Heterosexual Contact	21	
Men who have Sex with Men	6	
Ethnicity		
Han	36	
Zhuang	8	
Other	3	

Table 3
General approaches to coping with a HIV diagnosis and its associated stigma

	Level of Coping Approach	
Coping Style	Interpersonal	Intrapersonal
Passive/Avoidant	Compassion	Hiding HIV Status
Active/Problem-Focused	Social Support	Self-Care