Expressions of HIV-Related Stigma among Rural-to-Urban Migrants in China

Yan Hong, Ph.D.,¹ Xiaoming Li, Ph.D.,² Bonita Stanton, M.D.,² Xiaoyi Fang, Ph.D.,³
Danhua Lin, Ph.D.,³ Jing Wang, M.A.,⁴ Rong Mao, Ph.D.,⁴ and Hongmei Yang, Ph.D.⁵

Abstract

In China, HIV-related stigma is considered as a formidable barrier in the combat against the HIV epidemic. There have been few qualitative investigations on HIV-related stigma in China, especially among a vulnerable population of rural-to-urban migrants. Based on 90 in-depth interviews conducted in 2002–2003 with rural-to-urban migrants in Beijing and Nanjing, China, this study examines the forms and expressions of HIV-related stigma from migrants' perspectives regarding HIV infection and individuals at risk of HIV infection. Consistent with the general framework on stigma, Chinese rural-to-urban migrants' attitudes toward HIV infected individuals take forms of denial, indifference, labeling, separation, rejection, status loss, shame, hopelessness, and fear. These stigmatizing attitudes were mainly derived from fears of AIDS contagion and its negative consequences, fears of being associated with the diseases, and culturally relevant moral judgments. In addition to universal AIDS stigma, both traditional Chinese culture and socially marginalized position of rural migrant population have contributed to culturally unique aspects of stigmatizing attitudes among rural-to-urban migrants. These multifaceted manifestations of HIV-related stigma suggest that HIV stigma reduction intervention needs to address multiple aspects of HIV stigma and stigmatization including personal, cultural, institutional, and structural factors.

Introduction

ALTHOUGH THERE IS GREAT VARIATION in conceptualizing a health-related stigma, stigma is generally considered to be a discrediting attribute that reduces an individual's status in the eyes of others.^{1,2} The status reduction process implies a process of devaluation and discrimination against the stigmatized individuals or groups.³ Globally, the epidemic of HIV/AIDS has been accompanied by the epidemic of stigmatization against people living with HIV/AIDS (PLWHA).⁴ HIV-related stigma refers to "prejudice, discounting, discrediting directed at people perceived to have HIV/AIDS, as well as individuals, groups and communities with which they are associated."⁵ HIV-related stigma has been recognized not only for its persistent existence but also for its complexities in formations and expressions.^{1,6}

HIV/AIDS is characterized as an illness that is unalterable or degenerative. Since the earliest days of the epidemic, HIV/AIDS has been widely perceived to be a fatal condition. Being diagnosed with such a disease, both before and after highly active antiretroviral therapy (HAART) became available, has been often regarded as the equivalent to dying, and those who are diagnosed may represent a reminder—or even the personification—of death and morality.⁷ Therefore, one important universal expression of stigma may be fears: fear of illness, fear of contagion, and fear of death.⁸ Although in some cases these fears are warranted, in many instances the fears of HIV/sexually transmitted disease (STD) may be based on an inaccurate understanding of how HIV is transmitted.^{9,10} Denial and silence may be other forms of stigma.¹¹ For individuals who perceive themselves at low risk of infection, their denial is often exhibited by dis-

¹Department of Social and Behavioral Health, Texas A&M Health Science Center School of Rural Public Health, College Station, Texas.

²Carman and Ann Adams Department of Pediatrics Prevention Research Center Wayne State University School of Medicine, Detroit, Michigan.

³Institute of Developmental Psychology, Beijing Normal University, Beijing, China.

⁴Institute of Mental Health, Nanjing University, Nanjing, China.

⁵Population Services International, Washington, D.C.

tancing themselves from the problem or refusing to acknowledge the individual or societal risk. The denial of the risk of and vulnerability to HIV can further lead to indifference to gaining knowledge about HIV or caring for HIV-infected individuals.¹²

According to Link and Phelan¹³ the process of stigma requires identification. Stigma occurs not just because of its linkage with a disease but also due to its association with particular social groups who are usually already marginalized in society. Given that HIV/AIDS is a fatal contagion and often associated with some socially disapproved behaviors (e.g., homosexuality, injection drug use, and commercial sex), people with HIV/AIDS are often double-stigmatized. They are stigmatized not only for having a deadly infectious disease but also for having a disease that has been most prevalent among high-risk groups such as drug users, homosexuals, and sex workers who were already targets of prejudice in most societies.¹⁴ Literature suggests that stigma is often gradient in which the degrees and forms of discrimination and blame are attached to how the person is infected.¹⁵ The process of double or gradient stigmatization takes effect through labeling and separation.

A core concept of HIV-related stigma is the perception that PLWHA are members of an "outgroup" threatening social identity of the nondeviant "ingroup."¹⁶ Such a social separation of "us" versus "them" is through the belief that sense of self as psychosocially healthy and moral can be maintained by favoring those perceived to be similar, and by discrediting those perceived to be different. In the process of relating perceived differences of "outgroups" with negative stereotypes, stigmatized individuals are considered the ones to be blamed and condemned. A strong sense of shame or guilt thus prevails among those being infected, and such feelings are often extended to their families or immediate communities, or prevent those infected from making appropriate disclosures or seeking care.¹⁷

An almost immediate consequence of negative labeling and stereotyping is a general downward placement of a person in a status hierarchy.¹³ The most typical forms of stigmatization are rejection and status loss.¹⁸ Due to the impenetrable boundary of "ingroup" versus "outgroup" and the blame placed on those infected, if someone from the "ingroup" unfortunately gets infected, she or he will be rejected without any sympathy. Status loss sometimes may be elevated to more extreme forms of discrimination, which can severely disrupt lives of those infected.^{5,12}

Although some aspects of HIV-related stigma may have universal causes (e.g., fears of AIDS contagion), their manifestations or expressions may vary considerably from culture to culture, and from population to population. This variation across culture and population is shaped in each society by multiple factors, including local HIV epidemic and pre-existing prejudice within the local culture or subcultures.⁵ These postulations regarding the relationship between culture and HIV-related stigma have highlighted the importance to disentangle HIV-related stigma within its specific cultural settings. As noted by Parker and Aggleton,¹⁴ a good understanding of the manifestations of stigma and its related factors are critical in designing and implementing interventions to reduce stigma or mitigate the negative impact of the stigma. Qualitative studies of HIV-related stigma have documented the culturally unique aspects of stigma and their

related social factors in the Western nations.^{16,19} However, such efforts in many developing countries, including China, have been limited.

China is experiencing a rapid increase in its HIV epidemic. As of 2005, the government estimated that there were 650,000 individuals living with HIV or AIDS.²⁰ Many of the HIV-infected individuals in China are believed to be among the nation's 130 million rural-to-urban migrants. The migrant population has been reported to have a higher rate of HIV risk behaviors and higher STD infection rates.^{21,22} Some experts warned that this large mobile population could become the tipping point in the HIV epidemic in China, to rapidly transform a local epidemic to a national pandemic, if no effective prevention is taken.²¹

Similar to the observations in many other countries, HIV infection in China is a highly stigmatized disease; HIV-related stigma is considered as one of the most resistant forces in combating the HIV epidemic in China.²³ Studies on HIV-related stigma in China have found strong stigmatizing attitudes toward PLWHA or people who are at risk of HIV infection among the general population, college students, health care providers, and rural-to-urban migrants.²⁴⁻³⁰

Stigmatizing attitudes delayed treatment and partner notification among male patients with STDs.¹⁷ Studies conducted among rural-to-urban migrants found a significant relationship between an individual's perceptions of HIV-related stigma and his/her HIV-related risk behaviors.³¹ However, the existing studies have generally been limited to quantitative approaches, which quantified the degree of stigmatizing attitudes along a numerical scale. These survey data might not capture the complexities and unique aspects of HIV-related stigma within the Chinese culture, which could be addressed through qualitative investigation.

Accordingly, this qualitative study, utilizing data from a larger HIV/AIDS prevention intervention feasibility study, attempts to fill the literature gap by examining perceptions of the HIV-related stigma from the perspective of the rural-to-urban migrants, a growing population that has been considered to be at risk of HIV/AIDS in China.^{21,22} Given the lack of conceptual framework specific to HIV/AIDS stigma in China, we bring together a framework that integrates various research findings from the literatures and explore the forms and expressions of HIV-related stigma and stigmatization among the rural-to-urban migrant population. The main objectives of the current study are to examine forms and expressions of stigma among rural-to-migrants in terms of their personal reaction and perceived public attitudes toward HIV infection and HIV infected individuals and to explore the culturally unique aspects of HIV stigma in Chinese culture as well as among this socially marginalized migratory population.

Materials and Methods

Research site

The data used in this study were derived from a larger HIV/AIDS prevention intervention feasibility study conducted in 2002–2005 among rural-to-urban migrants in two major Chinese cities, Beijing and Nanjing.^{22,32} The qualitative inquiry of the larger study included a total of 90 semi-structured and open-ended individual interviews. The cur-

rent study was a secondary data analysis of these 90 interviews that were designed to collect qualitative data regarding HIV/STD risks and perceptions and related social and cultural factors. Beijing, the capital city of China, has a population of 13.82 million and more than 3 million rural-to-urban migrants.³³ Nanjing, with a population of 5.6 million and approximately 800,000 migrants, is the capital city of Jiangsu Province in east China.³⁴

Interview guide

Prior to conducting individual interviews, project staff developed an interview guide with input from young migrants, local community leaders (both formal and informal), health care providers and government officials, regarding topics and themes for the individual interviews among migrants. The interview guide covered several broad topics including demographic information, history and patterns of migration, working and living experiences in the cities, sexual attitudes and behaviors, as well as attitudes and perceptions on HIV/STD.

Migrants were probed on their awareness and understanding of HIV prevention, transmission and treatment, their attitudes toward HIV/STD as diseases and social problems, and their attitudes toward people living with HIV/STD or individuals/groups at risk of HIV/STD infection. The sample questions contained in the interview guide included, "What you have heard or read about HIV/AIDS"; "What are some ways that a person might put him/herself at risk of contracting HIV/STDs"; and "If a person were infected with HIV, how would that affect his/her work [his/her family life; his/her relationship with friends or spouse]?" The interview guide used open-ended questions to encourage extended responses. The guide, however, was a means of ensuring that all of the relevant topics were covered during the interview. The semistructured, open-ended interviews were conducted in a conversational style, so questions were not always asked in the same order or worded in the same manner.

Interview procedures

A purposeful sample of 90 participants (50 in Beijing and 40 in Nanjing) were recruited from their work places, labor markets, or homes. Local community leaders (both formal and informal) in the migrant settlements and workplaces served as facilitators for the recruitment process. These community leaders mainly spread the words of our research to migrants in their premises and introduced migrants to the local research team. However, none of these community leaders participated in the actual recruitment and consenting process. A total of eight interviewers were recruited and trained to conduct the interviews in Beijing and Nanjing. All interviewers were graduate students or faculty members in the field of psychology and education in Beijing Normal University and Nanjing University. Each participant was assured of his/her confidentiality in the study, and a written informed consent form was signed before the interview started. During the consenting process, participants were asked about their preference for the location and time for interviews and the interviews were conducted in time and private places (homes or private rooms at workplace) established as convenient for the interviewees. During the

interview, each participant was asked to provide some basic demographic information which included age, gender, marital status, education attainment, age of first migration to urban areas, and the total duration of their stay in cities. Each interview took about 60 to 90 minutes; all interviews were audiotaped and transcribed verbatim. Both tape recordings and interview transcripts were kept anonymous without participant's name or other identifiable personal information. The Institutional Review Boards at West Virginia University in the United States, Beijing Normal University, and Nanjing University in China approved the study protocol.

Participants

The 90 participants ranged in age from 16 to 37 years and consisted of approximately equal proportions of males ($n = 44$) and females ($n = 46$). Nineteen of the participants were married, 2 were divorced, and 69 were single. Fourteen of the participants had no more than primary school education, 36 had completed middle school, 9 had graduated from high school, and 30 had post-secondary education (including vocational school, 3-year colleges, etc.). Forty-six had first migrated to cities between the ages of 16 and 19. The duration of their stay in Beijing or Nanjing varied from 1 year to more than 11 years.

Data analysis

Data analysis was guided by the constant comparative method used in grounded theory.³⁵ Original interview transcripts and field notes were read line by line and analysis was performed by reading and rereading the transcripts, identifying the themes and coding the texts. Coding themes were developed drawing upon the constructs from the theoretical frameworks of stigma, the domains from the interview guide, and new themes emerging during the interview and coding process.^{5,12-14,36,37} Text coding and analysis were then conducted in Chinese by members of the research team who are Chinese-English bilingual. Following the procedures outlined in the recent qualitative literature,^{38,39} word processing functions in Microsoft Word (Microsoft, Redmond, WA) were used to mark themes in texts and retrieve themes on demand. The transcript texts were coded for recurring themes. New themes were identified and added during the coding process. Transcripts were recoded if either a new code was developed or an existing code was revised.

Detailed summaries with substantial retention of original quotes were prepared in English to facilitate further discussion and elaboration among both the U.S. and Chinese investigators. The accuracy and relevancy of translations of the summaries and original quotes were verified independently by two more investigators who were Chinese-English bilingual. Discrepancies in translation were resolved through group discussions. Quote excerpts and summaries were then categorized by participant characteristics and the coding domains; they were further compared and reviewed for interrelationships and correspondence with coding and conceptual framework.^{37,40} The findings presented in this manuscript reflect the range of responses, with some indication of the consistency of the responses. The findings mainly describe multifaceted manifestations of HIV-related stigma by unfolding the distinctive but interconnected expressions of stigma.

Results

The participants in the current study had identified or expressed a number of stigmatizing attitudes associated with HIV/AIDS. These expressions are mainly derived from three broad, but interrelated sources of perceptions and attitudes: fear of being associated with HIV/AIDS or with groups at risk of HIV/AIDS (e.g., expressions of denial, indifference, labeling, separation); fear of AIDS contagion and its negative social consequences (expressions of fear, status of loss, shame, loss of hope); and moral judgment (expressions of rejection, gradient stigma, separation, labeling).

Denial

In our interviews, nearly all the participants were aware of STD and HIV. However, the initial response of many participants to the topics regarding STD or HIV was to decline further comments and to distance themselves from the problem. Some typical responses were: "I have heard about it [STD], but once they talk about it, I am not happy. I don't like to talk about that stuff; I just don't like to talk about it" (25-year old male). Similarly, "I have heard of it [AIDS], but don't know much about it. I think if a person has a messy relationship with others, he will get it. I don't know the rest" (30-year old female).

They were even reluctant to mention the words "STD" or "AIDS"; they used such terms as "that disease," "that thing," "that stuff" to refer to STD or AIDS. Vague terms instead of explicit expressions were used to describe sexual relationships. For instance, "the messy relationship" means having multiple sexual partners or casual sex; "dubious people" for people who have such "messy relationship" or clients of commercial sex, "miss" for female commercial sex worker, "mommy" for the woman who supervised and arranged business for "misses," "those places" or "dirty places" for entertainment establishments where "misses" and "mommies" worked.

Some migrants justified their denial by their perceptions of cultural avoidance of topics regarding sex or sex-related issues: "From ancient time till now, for us Chinese, we have always placed a mysterious veil on anything related to sex, a very mysterious veil. It is a quite private thing" (21-year old male); "Chinese people might talk about sex issues with the same gender or close friends, but not with other people. They just won't let you know what is going on regarding those things" (24-year old female).

Indifference

Coupled with reluctance to discuss STD or HIV, several participants expressed aversion to learning any information about these diseases including modes of transmission or means of prevention: "These things are on the newspaper, but I don't like to read them" (21-year old female); "The folks from my hometown often talk about pretty 'misses', I heard AIDS from them. I don't know how it is transmitted. I don't care about that" (20-year old male).

Consistent with their indifference to learn about HIV, most of the participants had some degree of misconceptions or inaccuracy regarding the symptoms of infections. Examples of such misconceptions include: "STD patients will feel itchy"; "AIDS symptoms are nausea"; "You can tell HIV patients at

first sight"; "The HIV infected [individuals] are all very skinny, all like drug users"; "I heard it [HIV] can affect people's body, the skeleton will change, and will affect the next generation."

Some attributed their indifference to their busy life in the cities: "I don't want to know about it [HIV], and I don't care about it. We all work very hard every day. Who the heck will pay attention to that? You got time not to work? What's that for?" (20-year old male).

Labeling

During the interview, almost all of the migrants quickly linked STD or HIV infection with specific "groups." The most frequent responses revealed from interviews regarding people at risk of HIV were: "Only those who go to dirty places will get that disease" (20-year old male); "For STD or HIV, it mainly comes from the 'misses'. If you don't go to misses, it is impossible to get that kind of diseases" (20-year old male); and "Only a person who has a messy relationship will get HIV" (30-year old female).

Because of the fear of being labeled, some migrants actually attempted to hide how they became infected; however, such attempts often encountered suspicion. A 21-year-old male migrant shared a story of his friend:

He is a little bit older, in his 30s. He went to work in XX [name of a city], and got an STD. He said he went to a sauna and got it, and he didn't go to the "misses." Nobody knew, and he spent a lot of money and has not got any better.

Another migrant told us the story of his neighbor in the city:

I know a [truck] driver; he said that he never had sexual relationships with women. But once he was on a business trip, he stayed in a roadside restaurant, and got it [STD]. Later on, it [the infection] was so serious that he even could not wear his pants, and had to hang them on the rear-view mirror. It was hard. He said he only slept in the roadside restaurant, but never had that thing [sexual intercourse] (34-year old male).

Separation of "us" versus "them"

In this study, STDs or HIV were perceived by most of the participants to be restricted to certain groups or social classes, and the risks always belonged to "others." Most of the participants did not believe that they were vulnerable to infection with HIV or STDs because they were not part of these groups or social classes. Many respondents expressed such a distinction with a sense of self-righteousness. For example, a young woman 20 years of age saw no connection at all between herself and STD even though she was engaged in premarital sex:

For those people [STD or HIV infected], some of them are quite complicated. But like me and people around me, although we live together [with boyfriend or girlfriend], we give people quite a good impression. We don't have dubious friends. Only those with dubious friends will have those diseases.

In contrast, HIV has been linked to certain groups of people. Common remarks included: "I am most afraid of people from Henan [Province]. There is an 'AIDS Village' in Henan" (21-year old male); "Those who have AIDS are rich people" (24-year old male); "I think homosexuals will have HIV; transmission between men and women is least likely" (30-year old male); and "I know there are three AIDS patients, all African students; they were at XXX University. Because AIDS was from Africa" (21-year old male).

Fear

A strong sense of fear of HIV/STD prevailed among these migrants: "Oh, AIDS, I have heard about it. I feel—how can I say it—I think it is terrible, horrible" (21-year old male). Likewise, one 35-year old female migrant told the interviewer:

I know STDs are very dangerous. It can pass from one person to another, some people even die. But as for AIDS, I don't know its symptoms at all. Anyhow, it is the most dangerous disease, and anybody who has it will die. So everybody should avoid it, should keep far away from it. I am so scared of it.

While a majority of participants understood that HIV/STD could be transmitted by sex, many also thought STD or HIV could also be transmitted by sharing dinnerware, saliva, personal items, touching, or even by talking. Fear of transmission goes beyond the personal items of the HIV infected individuals, and even extends beyond their death: "After the patient dies [of AIDS], you cannot bury him; you have to burn him. You know, the virus and bacteria will spread in the air" (24-year old female).

Status of loss

Despite the denials or dismissals of the idea that AIDS could possibly happen to them, many participants in our interviews acknowledged that they actually knew individuals with an STD infections, including their villagers, their bosses, their friends, or even family members. The disclosure of infection status (usually unintentionally) was always accompanied by rapid decline in their quality of life. One 30-year-old female participant told the interviewer a story about one of her fellow villagers:

He [the interviewee's fellow villager] caught syphilis, now nothing good is happening to him. He could not have a second child . . . Later on, all people in the village knew what had happened to him. People said he paid a life-time of regret for a short term of happiness and he lost his reputation. He was not able to do anything good for himself.

Not only were those infected ostracized by their communities, so too were their family members. Another 23-year-old male migrant also shared a story about a fellow villager in his hometown:

He caught that disease [STD], his wife still lived with him. People in my village like to visit each other, and people were afraid if she [the wife] went to visit them.

They dared not let her sit in on their bed . . . But people all cared about [saving] their faces, so they had to let her in, because she herself didn't get it but her husband had it. But people were still very afraid that she carried the virus to their houses.

Shame

In our interviews, participants indicated that if they ever were to become infected, they would feel shame about telling the truth or seeking treatment. They would not go to see doctors, nor even talk to family or friends about their illness. One 26-year-old woman reiterated the point: "For AIDS, it is even worse than cancer. For cancer, you still can talk about it; for AIDS, you can't talk with your family or friends, it will be a big loss of face [upon them or their families]." Sometimes, the shame caused by the infection and disclosure could lead to family tragedy:

He did not tell his wife [he was infected] when he returned home. So his wife got it, and later on, their child got it too. What a big loss of face! His wife had a big fight with him and they fought every day. Later on, they divorced. His wife was really upset; she was so upset that she drank pesticide. She drank the poisonous pesticide!! There was no way out [for them] . . . (30-year-old female).

The compelling sense of shame and fear of being identified or blamed kept some people from seeking appropriate treatment. Sharing experiences of his friends who were infected with an STD, a young migrant 19 years of age told the interviewer: "They didn't get treatment in the big hospitals, neither in the small hospitals; actually, it was the small clinics, the underground ones."

Another 29-year-old male migrant offered observations of STD patients visiting such an underground clinic in his neighborhood: "I used to rent a room in XXX [name of a community in Beijing]. There was a fake STD doctor two doors next to my room. Several times when I was off work and went home, I saw he was posting the ads—'cure with one shot', for syphilis and all kinds of those things [STDs]. And his patients came at midnight, 2 or 3 AM in the morning . . . They were afraid to be recognized, so they came to knock on the door at midnight."

Loss of hope

In our study, many participants indicated that being infected with HIV is considered the equivalent to a loss of hope in a person's life: "For the HIV patient, to a great extent, it is a psychological disease. He [the HIV patient] will think it is all over now; his life is hopeless, there is nothing hopeful." (21-year-old male); "If I get it [HIV], I will choose to die. Because there is no cure, why bother to torture myself?" (19-year-old female).

Some participants reported that this sense of hopelessness was also shared by other members of the society such as health care providers. One 25-year-old male participant described a scene he had witnessed in a hospital:

When my wife delivered our baby, I was waiting outside the delivery room. There was also a girl, about 15 years

old, and she was delivering a baby too. That baby had syphilis because the girl had syphilis. The doctor said the baby's whole life was ruined. The girl worked in a hair salon, only 15. She ruined herself and the baby. The girl was quarantined, and the doctors helping her deliver the baby all wore long gloves. It was quite horrible.

Rejection

Because of the impenetrable boundary of "us versus them," and the blame placed on those infected, some migrants perceived that if some of their friends or villagers unfortunately get infected, she or he will keep a distance, either physically or psychologically, from them. One 19-year-old female participant stated: "[If my friend is infected,] I may let him in [to my house], but in my heart, I will think, ugh, he is sick. AIDS is certainly horrible. Even if he does come, being honest, I will keep a big distance from him." Another 27-year-old female participant also shared the view: "We should keep a distance from them [HIV infected], especially for breathing. When we talk or do something, we'd better keep far away from them."

Some migrants shared their experiences of dealing with HIV/STD infection. For example, one 24-year-old male migrant working in a sauna and massage parlor shared his observation: "All the cups and towels are used only once, we change the sheet every day. We also have a warning sign at the entrance and it says 'STD or HIV patients stop here.'"

The rejection and distance are not merely because of fear of contagion, but often are due to feelings of abhorrence: "I know it [HIV] will not be transmitted by touching, but I still will not let him [an HIV-infected person] come to my house, because I would feel dirty in my heart" (21-year-old male).

Gradient stigma

During our interviews, some participants expressed a sense of tolerance and sympathy for individuals who were infected with HIV through blood transfusion, but reserved no mercy for those who were infected through sexual contacts or drugs.

A 21-year-old female migrant stated: "I think for HIV, if it is infected by blood, or from mother to child, I will not discriminate against them. But if he gets it from sex, I will look down on him; and I won't talk to him anymore."

Another 22-year-old male participant elaborated: "If he got it [STD or HIV] from a hospital, he deserves sympathy. But if he is caused by having relationships with dubious people, he will receive blame from people, and he deserves no sympathy at all."

Still the majority of the migrants believed that the STD- or HIV-infected individuals should be blamed for their affliction, if their behaviors are deemed immoral and deserve blame: "It is all personal conduct. You belong to yourself, if you don't cherish yourself, you deserve it. If you don't deserve yourself, you will have the retribution coming to yourself" (27-year-old male).

Sympathy was not even spared for family members. A 35-year-old woman related that when her sister-in-law was infected with an STD, all people including family members blamed her: "I said to her, 'you should lead a life like a decent person, and should not do those kinds of dirty things. See now, you got this disease, you really deserve it.'"

Discussion

The findings in the current study demonstrate the multifaceted expressions of HIV-related stigmatizing attitudes among rural-to-urban migrants in China. While the forms of migrants' attitudes toward HIV/AIDS (e.g., denial, indifference, labeling, separation, rejection, status loss, shame, and hopelessness) are consistent with the theoretical framework on stigma, the expressions of HIV-related stigma in the current study need to be analyzed within the context of Chinese culture or rural-to-urban migrant population.^{5,12-14} Although all forms of stigma reported in this study represent individual perceptions and attitudes, they are actually manifestations of global HIV stigma, existing cultural beliefs that are linked with gender, sexuality, morality, social class, and HIV-related policies.^{12,13} The possible sources of HIV-related stigma among rural-to-urban migrants can be explored along two interrelated lines: culturally unique aspects of HIV stigma and population specific aspects of HIV stigma.

Some of the expressions of HIV stigma by rural-to-urban migrants are global HIV stigma (e.g., those derived from the fears of AIDS contagion). Researches in the United States, Africa, and China have suggested that stigmatizing attitudes toward PLWHA might be associated with an inaccurate understanding of the modes of HIV transmission.^{7,30,41} While this phenomenon is universal, particularly low HIV/AIDS awareness and knowledge among rural-to-urban migrants in China might have further elevated the fears and resulting stigmatizing attitudes associated with HIV/AIDS among this population. Most of the young migrants originated from rural areas where there is limited HIV/STD prevention or education. As acknowledged by the Chinese Ministry of Health, two thirds of the reported HIV/AIDS infections in China were in rural areas, but there was no AIDS education in many rural towns and villages.^{20,42} In some rural villages where AIDS was already a serious problem, only 34% of the people had ever heard of HIV/AIDS.⁴³ Previous studies among rural-to-urban migrants in China also suggested an inadequate level of knowledge regarding preventive measures among migrants.^{22,32}

Some aspects of HIV-related stigma among rural-to-urban migrants (e.g., those derived from morality or value judgment) are rooted in and possibility aggravated by traditional Chinese culture. As indicated by Liu et al.,⁴⁴ Chinese culture values collectivism, group dignity and centrality of family, and rejects any individuals or behaviors that may disgrace the family and the community. In addition, traditional Chinese culture denounces premarital or extramarital sex. Women's virginity and sexual fidelity are considered vital for a woman and her family. Even though young people have more tolerant sexual attitudes and more open sexual behaviors, there is still a cultural taboo on the topics about sex, and homosexuals are still not accepted by the majority of Chinese.⁴⁵

Therefore, stigma in Chinese culture is gradient in which the degrees and forms of discrimination and blame are attached to how the person is infected. Migrants expressed less tolerant and more punitive attitudes toward those infected with HIV or STD through sex and drugs than through blood collection or transfusion. Therefore, stigma occurs not just because of its linkage with a deadly disease, but also because of its association with particular social groups who are at

risk. Furthermore, the boundary between “us” and “them” was clearly drawn within the collectivist culture of China.

In addition to traditional Chinese value orientation, some early and current HIV-related policies and practices by Chinese government and media might have served to reinforce the moral-based stigmatization against those at risks. The first Chinese case of HIV infection was confirmed in 1985, but for quite some time, HIV was considered a disease of “foreigners” or a “disease of imperialism”, and the government ignored and denied the growing HIV epidemic.⁴⁶ When the HIV infection rate climbed among the high-risk groups (e.g., sex workers, drug users), prevention intervention programs were still serving the purpose of “social sanitation.” The Chinese government has been making substantial progress in HIV prevention and education in recent years; however, the Chinese government consistently considers the elimination of prostitution and drug use (two social “evils”) as the essential strategy of HIV/STD control.^{47,48} In 2003, the Chinese premier shook hands with a patient with AIDS, which had significant symbolic meaning for reducing HIV-related stigma.⁴⁹ However, the Chinese media delivered a mixed message in its report of the event by emphasizing that the patient was infected through blood transfusion (instead of through sex or drug use). Furthermore, the government issued a statement in the same year on HIV prevention strategies, which called for continuing to “fiercely crack down” on sex work and drug use.⁵⁰ Law enforcement agencies organize periodic clampdowns on commercial sex. Sex workers and their clients are fined or jailed if arrested. Drug users are sent to rehabilitation centers for forced detoxification treatment. A recent public humiliation of female sex workers in Shenzhen, the birthplace of China’s economic reform and an industrial boomtown bordering Hong Kong, demonstrated the institutionalized stigma against female sex workers in China. On November 29, 2006 (2 days before the World AIDS Day), Shenzhen police forced more than 100 arrested female sex workers, all handcuffed and dressed in identical yellow smocks, to march in public while their names were announced in front of a crowd of thousands of bystanders.⁵¹ Such measures and practice might have further augmented the individual level stigma and made the general public believe that such groups deserved no sympathy, but blame and punishment.

In China, laws were passed to protect PLWHA, but there was a big gap between legislation and practice. The problem was particularly evident at the provincial and local levels.²⁹ People with an STD or HIV were also practically banned from the right to education, marriage, child-bearing, military services, and employment in service related occupations.²³ Only a small proportion of PLWHA were receiving any treatment.⁵² In some regions, some PLWHA had to undergo segregated medical treatment, which could, if necessary, be “forcibly implemented by public security authorities.”²³ Such restrictive and punitive practices, targeting those who were HIV positive or were vulnerable to HIV infection, could exacerbate the existent stigma, and negatively impact HIV treatment and prevention. Some recent studies in China also showed persistence of HIV-related stigma among current or future health care providers (e.g., medical students), the very groups that might be called upon in attempts to alleviate HIV/AIDS-related discrimination.^{24,26,28}

The marginalized status of rural-to-urban migrants in Chi-

nese society might also contribute or aggravate the stigmatizing attitudes toward HIV infected individuals. Rural-to-urban migrants have been distinctly labeled and negatively stereotyped because of their migratory status and low socioeconomic status in Chinese society.⁵³ The common images of rural migrants created by the media are poor, dirty, ignorant, and prone to violence and disease.⁵⁴ Rural-to-urban migrants have been frequently blamed for the increasing commercial sex, drug use, drug trafficking, crime, and social instability in the cities.⁵⁴ As a matter of fact, in the early stages of the HIV epidemic, rural-to-urban migrants (as a whole group) were blamed in large part for the HIV/STD epidemic in China. For example, the Chinese Minister of Health publicly exclaimed in 1996 (with no seroprevalence statistics on which to base his assertion) that “the 80–120 million people in the ‘floating population’ which moves throughout the country in search of work carry the HIV virus into China’s population centers”.⁵⁵ Therefore, the primary reason for migrants’ denial of the HIV problem, indifference with HIV knowledge, or separation of themselves from certain “risk groups,” may well be the fear of being linked to HIV infection or HIV-related risk behaviors, which would add additional unfavorable “labels” to their socially marginalized migratory identity.

There are several limitations to this study. First, because we did not have a comparison group for these migrants, we did not know if or how some of the perceptions of these migrants differed from those of nonmigrant urban or rural residents. Second, because none of our participants self-identified as HIV or STD infected, no data were available on HIV stigma or stigmatization from the perspective of PLWHA. Third, because of the qualitative nature of the inquiries, we were not able to accurately assess whether the perceived stigma or stigmatizing attitudes differed by any key demographic characteristics such as age gender, education attainment, and marital status.

Despite these limitations, our data provide valuable information regarding HIV-related stigma among young rural-to-urban migrants in China, which serves as a necessary basis for designing HIV stigma reduction measures. The widespread stigmatizing attitudes against HIV/STD infected individuals that were already enacted in migratory communities suggest the vulnerability among the migrants. Quantitative data from Chinese rural-to-urban migrants have also found that this population is at high risk of HIV and STD infection.²² Our findings suggest that HIV-related stigma might negatively affect their preventive behaviors including participating in prevention intervention activities, communicating with family/partners about infection and prevention, accessing voluntary counseling and testing, and seeking appropriate and timely treatment and care.

Current HIV education programs targeting general population in China primarily focus on “knowledge education,” based on the assumption that better knowledge will prevent HIV risk and reduce stigma.⁴⁷ However, even in societies that have greater information and understanding of HIV, HIV-related stigma still persists.⁵⁶ Also evident from the findings in the current study, an individual who understands the modes of HIV transmission would still refuse to sit next to a HIV infected individual, because “I would feel dirty in my heart.” Future efforts on reducing stigma need to go beyond “knowledge education” and to address the cultural

norms and personal feelings such as fears of HIV infection and its negative social consequences or fears of being "double stigmatized." Because of the multi-faceted characteristics of HIV-related stigma, the approach to reduce stigma must address multiple causes and mechanisms that can lead to the formation and action of HIV stigmatization.

More importantly, the intervention to reduce stigma needs to go beyond the individual level, and must consider and appreciate the political, social and cultural contributors of the HIV-related stigma. Global literature indicates that the institutional and structural manifestation of stigma is always more pervasive and persistent than stigma manifested at the individual level.⁵⁷ International experiences suggest the importance of structural approaches to reduce HIV-related stigma.^{11,58-60} HIV stigma reduction efforts in China should include the establishment and enforcement of legislative protection of PLWHA, assurance of the rights of PLWHA to health care, education, marriage, and employment, promotion of positive social norms on safe sex and harm reduction strategies in drug use, and empowerment of the socioeconomically disadvantaged population such as sex workers and rural-to-urban migrants.

Acknowledgment

This study was supported by the National Institute of Mental Health (NIMH; grant #R01MH064878). We would like to thank colleagues and graduates from Beijing Normal University, Nanjing University, and West Virginia University for their participation in instrument development and data collection. We also want to thank Dr. Ambika Mathur and Ms. Joanne Zwemer for assistance in manuscript preparation.

References

- Stafford MC, Scott RR. Stigma deviance and social control: Some conceptual issues. In: *The Dilemma of Difference*. New York: Plenum Publications, 1986:7791.
- Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall, 1963
- Gilmore N, Somerville MA. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming "them" and "us". *Soc Sci Med* 1994;39:1339-1358.
- Varas-Díaz N, Serrano-García I, Toro-Alfonso J. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qual Health Res* 2005;15:169-187
- Herek GM. AIDS and stigma. *Am Behav Sci* 1999;42:1106-1116.
- Alonzo AN, Reynolds N. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Soc Sci Med* 1995;41:303-315.
- Herek GM. Thinking about AIDS and stigma: A psychologist's perspective. *J Law Med Ethics* 2002;30:594-607.
- Goldin CS. Stigmatization and AIDS: critical issues in public health. *Soc Sci Med* 1994;39:1359-1366.
- Meisenhelder JB, LaCharite CL. Fear of contagion: A stress response to AIDS. *Adv Nurs Sci* 1989;11:29-38.
- UNAIDS. HIV and AIDS-related stigmatization, dissemination and denial: Forms, contexts and determinants. UNAIDS Best Practices Collections. Geneva: UNAIDS, 2000.
- Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Educ Prev* 2003;15:49-69.
- Malcolm A, Aggleton P, Bronfman M, Galvao J, Mane P, Verrall J. HIV-related stigmatization and discrimination: Its forms and contexts. *Crit Public Health* 1998;8:347-370.
- Link BC, Phelan JC. Conceptualizing stigma. *Ann Rev Sociol* 2001;27:363-385.
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Soc Sci Med* 2003;57:13-24.
- Herek GM, Capitanio JP. AIDS stigma and sexual prejudice. *Am Behav Sci* 1999;42:1130-1147.
- Devine PG, Plant EA, Harrison K. The problem of "us" versus "them" and aids stigma. *Am Behav Sci* 1999;42:1212-1228.
- Liu H, Detels R, Li X, Ma E, Yin Y. Stigma, delayed treatment, and spousal notification among male patients with sexually transmitted disease in China. *Sex Transm Dis* 2002;29:335-343.
- Herek G.M, Glunt EK. AIDS-related attitudes in the United States: A preliminary conceptualization. *J Sex Res* 1991;28:99-123.
- Herd G. Stigma and the ethnographic study of HIV: Problems and prospects. *AIDS Behav* 2001;5:141-149.
- UNAIDS/WHO. *AIDS Epidemic Update*. Geneva: WHO, 2006
- Anderson AF, Qingsi Z., Hua X, Jianfeng B. China's floating population and the potential for HIV transmission: A social-behavioral perspective. *AIDS Care* 2003;15:177-185.
- Li X, Fang X, Lin D, et al. HIV/STD risk behaviors and perceptions among rural-to-urban migrants in China. *AIDS Educ Prev* 2004;16:538-556.
- UNAIDS. *HIV/AIDS: China's Titanic Peril*. Geneva: UNAIDS, 2002
- Cai G, Moji K, Honda S, Wu X, Zhang K. Inequality and unwillingness to care for people living with HIV/AIDS: A survey of medical professionals in Southeast China. *AIDS Patient Care STDs* 2007;21:593-601.
- Lee MB, Wu Z, Rotheram-Borus MJ, et al. HIV-related stigma among market workers in China. *Health Psychol* 2005;24:435-438.
- Li L, Wu Z, Wu S, Zhaoc Y, Jia M, Yan Z. HIV-Related stigma in health care settings: A survey of service providers in China. *AIDS Patient Care STDs* 2007;21:753-762.
- Lieber E, Li L, Wu Z, et al. HIV/STD stigmatization fears as health-seeking barriers in China. *AIDS Behav* 2006;10:463-471.
- Lonn E, Sahlholm K, Maimaiti R, Abdukarim K, Anderson R. A traditional society in change encounters HIV/AIDS: Knowledge, attitudes, and risk behavior among students in Northwestern China. *AIDS Patient Care STDs* 2007;21:48-56.
- Yang Y, Zhang KL, Chan KY, Reidpath DD. Institutional and structural forms of HIV-related discrimination in health care: A study set in Beijing. *AIDS Care* 2005;17:S129-S140.
- Zhang L, Li X, Mao R, et al. Stigmatizing attitudes towards people living with HIV/AIDS among college students in China: Implications for HIV/AIDS education and prevention. *Health Educ* 2008;108:130-144.
- Liu H, Li X, Stanton B, et al. Relation of sexual risks and prevention practices with individuals' stigmatizing beliefs towards HIV infected individuals: an exploratory study. *Sex Transm Infect* 2005;81:511-516.
- Hong Y, Stanton B, Li X, et al. Rural-to-Urban Migrants and the HIV Epidemic in China. *AIDS Behav* 2006;10:421-430.
- Beijing Municipal Bureau of Statistics (BMBS). *Migrant Population Development and Corresponding Policies*. Beijing, China: BMBS, 2002

34. Nanjing Municipal Bureau of Statistics (NMBS). Statistical Report of Economic and Social Development in Nanjing. 2002. Nanjing, China: NMBS, 2003
35. Strauss AL. Qualitative Analysis for Social Scientists. New York: Cambridge University Press, 1987
36. LeCompte MD, Schensul J. Analyzing and interpreting ethnographic data (Ethnographer's Toolkit, Book 5). Walnut Creek, CA: Altamira Press, 1999.
37. Ryan GW, Bernard HR. Data management and analysis methods. In: Handbook of Qualitative Research, 2nd ed. Thousand Oaks, CA: Sage Publications, 2000:769–802.
38. Ryan GW. Using a word processor to tag and retrieve blocks of texts. *Field Methods* 2004;16:109–130.
39. La Pelle N. Simplifying qualitative data analysis using general purpose software tool. *Field Methods* 2004;16:85–108.
40. Rubin HJ, Rubin IS. Qualitative Interviewing: The Art of Handling Data. Thousand Oaks, CA: Sage Publications, 1995
41. Letamo G. Prevalence of, and factors associated with, HIV/AIDS-related stigma and discriminatory attitudes in Botswana. *J Health Population Nutr* 2003;21:347–357.
42. China Ministry of Health, UNAIDS, and WHO. Update on the HIV/STD Epidemic and Response in China 2005. Beijing, China; January 24, 2006.
43. Tie P. Survey of risk factors among migrants. *Dis Monit* 1999;14:229–230.
44. Liu H, Hu Z, Li X, Stanton B, Naar-King S, Yang H. Understanding interrelationships among HIV-related stigma, concern about HIV infection, and intent to disclose HIV serostatus: A pretest posttest study in a rural area of eastern China. *AIDS Patient Care STDs* 2006;20:133–142.
45. Zhang K, Li D, Li H, Beck EJ. Changing sexual attitudes and behavior in China: Implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999;11:581–589.
46. Gil VE. An ethnography of HIV/AIDS and sexuality in People's Republic of China. *J Sex Res* 1991;28:521–534.
47. Wu Z, Sullivan SG, Wang Y, Rotheram-Borus MJ, Detels R. Evolution of China's response to HIV/AIDS. *Lancet* 2007;369:679–690.
48. China Public Science and Technology Network. Be Self-clean and self-respect is the key to preventing HIV/AIDS [in Chinese]. 2003. <http://database.cpst.net.cn/popul/focus/article/31205111347.html> (Last accessed June 29, 2005).
49. Xinhua News Agency. Chinese Prime Minister Shook Hands with HIV/AIDS infected the First Time [in Chinese]. December 1, 2003. http://news.xinhuanet.com/newscenter/2003-12/01/content_1207962.htm (Last accessed February 26, 2006).
50. China Population Development Research Center. State Council's Notice on Strengthen Prevention on HIV/AIDS [in Chinese]. 2004. www.cpic.org.cn/zcfg/zcfg_detail.asp?id=2867 (Last accessed February 26, 2006).
51. The International Herald Tribune. Shenzhen's public humiliation of sex workers provokes a backlash. December 8, 2006. www.iht.com/articles/2006/12/8/news/shenzhen.php (Last accessed December 10, 2006).
52. World Health Organization. Stigma and Discrimination: Live and Let Live. Geneva: World Health Organization, 2002
53. Zhang L. Strangers in the city: Reconfigurations of space, power and social networks within china's floating population. Stanford, CA: Stanford University Press, 2001.
54. Li X, Stanton B, Fang X, Lin D. Social stigmatization and mental health among rural-to-urban migrants in China: A conceptual model and some future research needs. *World Health Population* 2006;6:1–18.
55. US Embassy Beijing. HIV/AIDS—What Chinese experts say (Fourth of seven reports). Beijing, China: U.S.Embassy, 1997.
56. Valdiserri RO. HIV/AIDS stigma: An impediment to public health. *Am J Public Health* 2002;92:341–342.
57. Reidpath DD, Brijnath B, Chan KY. An Asia Pacific six-country study on HIV-related discrimination: Introduction. *AIDS Care* 2005;17:S117–127.
58. Busza JR. Promoting the positive: Responses to stigma and discrimination in South East Asia. *AIDS Care* 2001;13:441–456.
59. Castro A, Farmer P. Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *Am J Public Health* 2005;95:53–59.
60. Rutledge SE, Abell N. Awareness, acceptance, and action: An emerging framework for understanding AIDS stigmatizing attitudes among community leaders in Barbados. *AIDS Patient Care STDs* 2005;19:186–199.

Address reprint requests to:

Xiaoming Li, Ph.D.

Prevention Research Center

Carman and Ann Adams Department of Pediatrics

Wayne State University School of Medicine

4201 St. Antoine Street, UHC 6D

Detroit, MI 48201

E-mail: xiaoming_li@wayne.edu