Published in final edited form as:
AIDS Behav. 2014 February ; 18(0 2): 203–211. doi:10.1007/s10461-013-0637-3.

The Experience of Living with HIV in Liuzhou, China

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Abstract

Objective—To describe emergent stigma-related themes from individual descriptions of living with HIV in Liuzhou, China.

Materials and Methods—Qualitative interviews were conducted with 23 people living with HIV (PLHIV). To provide contextual information, 14 public health personnel and 4 community workers in Liuzhou were also interviewed.

Findings—PLHIV experienced enacted, anticipated, and internalized HIV-related stigma, which resulted in negative affective, behavioral, and physical health outcomes, including barriers to health care, preemptive self-isolation, suicidal ideation, and poverty.

Conclusions—To lessen stigma, future programs should aim to increase HIV knowledge and empathy for PLHIV among family members, community workers, and health professionals. HIV programs should also include suicide risk assessment for PLHIV, especially immediately after diagnosis and at the onset of HIV-related symptoms.

Keywords

HIV/AIDS; Stigma; China; People Living with HIV; Qualitative Research; HIV Stigma Framework

INTRODUCTION

The AIDS epidemic in China has been increasing rapidly, spreading from primarily high risk groups to the general population ([1]). Between 2006 and 2011, the percentage of new HIV cases due to heterosexual sex almost doubled from 32% to 62%, respectively ([2]). Liuzhou, a city of 3.6 million people located in Guangxi Zhuang Autonomous Region in China's southwest, is among the areas with the fastest growing number of new

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heterosexually acquired HIV infections, having increased from 2% of new infections in 1998 to 66% in 2009 ([3]). Nearly 10,000 people in Liuzhou have been diagnosed with HIV, reflecting one of the highest prevalence rates in China.

The increase of HIV in China has been partly attributed to the hesitancy of many people living with HIV (PLHIV) to disclose their HIV serostatus to friends or family for fear of stigmatization ([4,5]). This fear may also deter them from seeking HIV testing, education, or treatment ([6]). In other countries, PLHIV who do not access such services are more likely to transmit the virus to others ([7]) and the same phenomenon likely occurs in China.

Previous studies show that HIV-associated stigma is a legitimate concern in China, including within families of PLHIV. Family members of PLHIV in China have reported feeling angry at and ashamed of their HIV positive relative, even refusing to eat with them ([8]). After disclosing their status at their workplace, PLHIV have been ostracized or fired ([8]). In several different studies, nearly two-thirds of HIV negative individuals were unwilling to interact with PLHIV ([9–11]). Rural PLHIV reported being discriminated against by other villagers ([12]). In a recent study, 42% of PLHIV reported facing HIV-related stigma ([13]), and in another, 36% of government officials interviewed said they would not dine with a PLHIV and 56% would not purchase any food produced by the family of a PLHIV ([14]). Thus, not only PLHIV, but also their families may experience stigma and discrimination. In fact, families of PLHIV may even be blamed for an adult member's HIV infection ([15]). In this study, we sought to explore the presence and impact of stigma and discrimination among PLHIV.

METHODS

We used the HIV Stigma Framework developed by Earnshaw and Chaudoir ([16]) to structure our findings and analysis. Interviews with PLHIV from a qualitative study that initially focused on understanding factors influencing social support for PLHIV were conducted and analyzed using methods of content analysis. Select health providers were also interviewed to provide contextual understanding of the lives of PLHIV. However, powerful data emerged during the analysis concerning experiences of HIV-related stigma and discrimination, which were compelling and robust on their own. As a result, this publication reports our findings related to stigma.

Participants and Recruitment

In July 2009, we recruited 23 of 25 PLHIV approached in the Liuzhou CDC (public health) clinic while they were attending a routine medical visit. Four members of two seroconcordant HIV positive couples were included in the sample. Eligibility criteria included: HIV diagnosis; having lived in Liuzhou for at least five years; willingness to disclose their HIV serostatus to interviewers; and not engaging in commercial sex. Demographic characteristics of the PLHIV in our sample are listed in Table I.

For contextual information, we approached 14 Liuzhou CDC employees, all of whom agreed to participate, and five community workers, one of whom declined. To be eligible, these workers had to have worked with PLHIV in Liuzhou for at least five years. We interviewed one senior CDC manager; four mid-level staff; six doctors; a counselor; a nurse; a needle exchange staff member in charge of HIV prevention and control; and the four community workers.

Data Interview Guide

A semi-structured interview guide was used to conduct interviews approximately two hours long with PLHIV. Originally developed to assess three primary categories of social support:

emotional, instrumental, and informational ([17]), the interviews sought information about the psychological needs of PLHIV (including relationships, discrimination experiences, and feelings about the future) and physical needs (including employment, daily life, health, and medical care). Other topics included HIV-related public policy, HIV knowledge, and sources of HIV education. We developed a parallel but streamlined version of the interview to use with community workers (CW) and public health workers (PHW).

Data Collection

The Renmin University of China's Institutional Review Board approved the study, informed consent procedures, and all interview guides prior to the commencement of the project. Four Nanjing Normal University sociology graduate students were trained to obtain written informed consent and collect data.

We interviewed PLHIV in private hotel rooms to ensure confidentiality. CW and PHW were individually interviewed in a Liuzhou CDC conference room. The qualitative data for this study were comprised of audio-recorded interviews, interview notes, and team notes that were compiled daily.

Data Processing and Analysis

The interviews were conducted in Mandarin Chinese, transcribed into Chinese MS Word, and reviewed by multiple project members for accuracy. We imported data into ATLAS.ti 5.0, where we conducted thematic coding in Chinese and developed exploratory codes. We analyzed the frequency of emergent codes, both overall and by type of interviewees, to assess the data from PLHIV, CW, and PHW. Stigma and fear of stigma were ubiquitous in our interview data. To better understand these emergent findings in our data, we turned to a framework that would provide relevant analytic tools: the HIV Stigma Framework ([16]).

HIV Stigma Framework

This framework describes the mechanisms by which HIV-associated stigma produces specific outcomes, and does so separately for HIV positive and HIV negative populations. Stigma mechanisms that are identified to have an impact on PLHIV include enacted (i.e., experiencing discrimination), anticipated, and internalized (i.e., beliefs and attitudes) stigma ([18]). Stigma mechanisms manifest among HIV negative people as emotions (i.e., prejudice), thoughts (i.e., stereotypes), and behavior (i.e., exhibiting discrimination), all of which represent efforts to distance the HIV negative person from the stigmatized PLHIV. All types of stigma mechanisms can impact affective, behavioral, and physical health outcomes within the HIV-infected population ([16]).

RESULTS

Stigma Mechanisms

Enacted Stigma—Stigma within a PLHIV's immediate and extended family was the most commonly discussed topic in our interview data. In fact, reports of family conflict were nearly universal. After serostatus disclosure, close family members frequently expressed anger, disappointment, and fear toward the PLHIV which led them to distance themselves both emotionally and physically from the PLHIV. Such distancing is common among HIV negative people; the HIV Stigma Framework includes "social detaching" as an outcome of stigma within that population.

PLHIV named fear as the most commonly expressed emotion that led to enacted stigma from family members, who were often afraid of HIV transmission from casual contact. In addition, family members feared being stigmatized themselves due to being related to a

PLHIV. In fact, it was reported that PLHIV's family often feared stigma even more than PLHIV did, providing additional anger and motivation for withdrawing from the PLHIV. Translated into action, a family's fear of stigma frequently limited the care and support they provided their family member unless the PLHIV's serostatus was secret, or else the local community had already treated another PLHIV well. When their diagnosis was concealed from the community, PLHIV often reported a greater ability to get material support from parents and siblings. Overall, our interviews document that if PLHIV received any support from family at all, it was more likely to be financial and tangible rather than emotional support or understanding, and often provided from a distance.

When siblings learned of a PLHIV's diagnosis, they commonly discriminated against their infected sibling; many ended all interactions with the PLHIV. A 48-year-old male PLHIV experiencing enacted stigma reported, "I have three brothers who I have helped a lot in the past. Now that I am sick, they neither give me any food nor talk to me." However, his sister did provide assistance, but she kept his illness a secret from her husband and daughter:

> "If I had no sister then I would have died… She is a tower of strength to me… My sister has an empty apartment (70 M^2). She gave me a key to this apartment, but she won't let me live there. When I need something, I may call her. She prepares the things I need and puts them in the apartment, then calls me to take them away from the apartment. She said, 'If you need something, let me know, but you can never go to my home and you can never see my husband and my daughter.'"

Several PLHIV reported that even though siblings were willing to help them, they feared for their children's safety. The 37-year-old husband in a seroconcordant HIV positive couple explained: "My parents left a large house for me and my siblings. Unfortunately, my sisters and brothers will not allow us to live with them… We dine with my brothers, sisters, and their children every day but we never hug the children."

One 48-year-old male PLHIV reported, "My brother and sister-in-law not only refused to give me any help, but also told other people in the community that I have HIV and asked them not to help me either." The man living with HIV believed that they had disclosed his diagnosis to others to garner public support for themselves and lessen their guilt about their discrimination toward him.

Relationships between PLHIV and their adult children were also often strained after serostatus disclosure and involved discrimination. PLHIV's adult children sometimes were angry and considered it unforgivable that the PLHIV became infected through risky behavior. PLHIV also stated that their adult children believed that casual contact would put them at high risk for infection themselves. Discrimination usually followed as they eventually ended all interactions with their HIV positive parents. One father said, "My son is very healthy, and successful in his career. I am very proud of him, but he never visits me. When I called him… he changed his phone number." (50-year-old male PLHIV)

HIV-related discrimination also occurred within marital relationships. In our sample, divorce followed HIV diagnosis disclosure to a PLHIV's uninfected spouse in six of 17 married PLHIV participants. As one PHW explained, "A female PLHIV used to date someone who was infected with HIV through drug use. After she became infected, she married another man. But after her husband learned her HIV status, he divorced her." The family of a 47-year-old PLHIV's wife became involved in a case of discrimination: "After discovering my HIV status, my wife and her relatives demanded a divorce. She got custody of our child." Giving up or losing a child was common. However, when a spouse learned of a PLHIV's diagnosis and remained in the marriage, they usually offered care to their HIV positive spouse even if they were not living together. “My wife and I are living separately, but she still comes to cook for me from time to time.” (33-year-old male PLHIV)

Only one interviewee, among all, believed that his spouse still loved him. He had disclosed his diagnosis to his wife only after she had become HIV positive as well. The husband said, “She can be with me so that I won’t be lonely, and we can share everything. We are not lonely.”

Among all family members, parents of PLHIV were reported to be the most reliable supporters, both financially and personally. “I am closest to my father and never contact any other family members besides him. I am thankful that he’s been by my side for all these years, not abandoning me, and supporting me financially.” (36-year-old male PLHIV)

A parent was sometimes described as a PLHIV’s sole source of support. “My father’s the only one who takes care of me. He has financial difficulties too. He doesn’t go to the doctor when he himself is sick, saving all his money and spending it on me.” (31-year-old female PLHIV)

PLHIV also reported experiencing enacted stigma in the context of employment. Those who disclosed their status were often refused employment or fired. Employment was widely acknowledged in our data as crucial to one’s financial status and mental health, making this type of discrimination particularly salient. Fifteen of the 23 participants had become unemployed since their HIV diagnosis.

Financial challenges were nearly universal among PLHIV. In addition to unemployment, the vast majority described other economic hardships that resulted from their HIV diagnosis, including inadequate medical care, housing shortages, insufficient food, and lack of clothing. A PHW reported, “One PLHIV… sold everything at home to pay for treatment, the methadone clinic, and life necessities. He owned only a bowl when we visited him… There was just a little rice soup in the pot that he cooked days ago.” Another PHW described the situation faced by a divorced, unemployed female PLHIV with a young child. “Her application for subsistence allowance was denied. She cried and was in great despair. We pitied her, but there was nothing much we could do.”

Anticipated Stigma—PLHIV expected, often accurately (as described above), feelings of repugnance from family and community members. As a result, protecting their children from stigma was a common concern among PLHIV. When a spouse was not HIV-infected, anticipated stigma sometimes caused a PLHIV to initiate a divorce to protect a child. “For our child’s sake, I insisted on divorcing my wife in order to give my son and wife a normal life. Otherwise, their lives would be ruined by me.” (48-year-old male PLHIV)

PLHIV also faced difficult choices when trying to protect themselves from anticipated stigma. For example, even though they were eligible for financial subsidies provided by the government, fears of stigma and discrimination stopped some PLHIV from applying for the minimum subsistence allowance to avoid disclosure of their HIV status. They described their daily life as “rough, lost, and helpless.” Some PLHIV even reported knowing others who avoided changing their risk behaviors and seeking treatment for fear of people learning of their diagnosis and the resulting stigma.

Anticipated stigma caused a fear of disclosure that shaped many areas of PLHIV’s lives. For example, employment was often seen to depend on maintaining secrecy. As one female PLHIV said, “The hotel requires every employee to get an HIV test. I have found various excuses to avoid it, [because if they find out about my HIV infection] I will lose my job as a janitor in the hotel." Employed PLHIV who concealed their diagnosis more often reported being able to keep their jobs and avoid enacted stigma.

Internalized Stigma—

Many PLHIV described internalized stigma, expressing feelings of guilt and self-recrimination. In some cases they appeared to internalize the fear of transmitting HIV to others via casual contact, and expressed a view of themselves as dangerous, dirty, or contagious. One woman confessed that, before her diagnosis, she had discriminated against PLHIV; "I used to look down on [PLHIV] because they are dirty." (28-year-old female PLHIV) After her HIV status was confirmed, she was shocked: "My world crashed." Others expressed guilt about letting down their family members. One father told us, "What I cannot bear anymore is the guilt I feel about my son." (47-year-old male PLHIV)

Parents who were living with HIV reported worrying especially about transmitting HIV to their children. A grieving 32-year-old female PLHIV said: "After being diagnosed as HIV positive, I gave custody of my daughter to my parents and my sister because I was afraid of transmitting HIV to her." A 28-year-old PLHIV was also concerned for her eight-year-old son's safety: "Before I was diagnosed, I was able to sleep with my son by my side. Now, I can no longer stay close to him. Our daily supplies have to be separated out." She was afraid that she might infect him or that he might discover her diagnosis.

PLHIV feared transmitting to other individuals beyond their own children. During a previous summer when she had skin lesions, the 28-year-old mother wore heavy clothes in extremely hot weather because she was terrified of infecting others or revealing her serostatus. In addition, a PHW described a male PLHIV who asked him to arrange a marriage for him with a female PLHIV because he did not want to infect "ordinary people."

Stigma Outcomes

Affective Outcomes—

PLHIV described feeling lonely and bored. They were often not even allowed to do household chores because family members feared they would transmit HIV to others. Free time often led them to focus their thoughts on their HIV infection and the many ways it might affect them. "After being diagnosed, I was extremely lost and scared, not knowing what to do, what's going to happen, and when I am going to die. I had a lot of thinking and regrets."(27-year-old female PLHIV) One 36-year-old male PLHIV told us, "I… kill time by watching TV or staring blankly. I am just waiting for death." In fact, "waiting for death" was mentioned 11 times in PLHIV and PHW interviews. The concept was also described using different words: "I was scared about HIV/AIDS before I got infected. After four years of infection, I still panic and am very pessimistic about my future." (36-year-old male PLHIV)

Grief at the loss of close family relationships was common. "[My son] despises me… My biggest wish is to obtain his forgiveness and hear him call me 'Dad' one more time before I die." (47-year-old male PLHIV)

Suicidal thoughts were frequently mentioned in the interviews, including by PWH, CW and PLHIV, both those who had and who had not considered suicide themselves. The two reasons most commonly reported for suicidal ideation were HIV-related stigma and the PLHIV's lack of confidence in getting adequate treatment. Two peak periods of suicidal ideation were discussed in our data: soon after diagnosis and when CD4 counts dropped to low levels and physical health and self-care abilities significantly declined. At this time of health decline, suicide was seen as a viable option to end the physical and emotional pain of the disease and its resulting discrimination.

Behavioral Outcomes

Suicide: While suicidal thoughts were described in many interviews, one 28-year-old female PLHIV reported that she actually attempted suicide, repeatedly, after diagnosis. A 36-year-old male PLHIV reported knowing other individuals who had attempted suicide: “I feel trapped, lost and hopeless, like I am sentenced to death. Many other people just gave up and asked for death.”

Ending relationships with significant others: While many PLHIV experienced rejection and discrimination by their spouse or partner (as described above), other PLHIV chose to end relationships with their HIV negative spouse or partners. They stated that their objective in “breaking up” was to protect their partner from infection, stigma, or both.

> “After being diagnosed with HIV, I broke up with my boyfriend, because I was afraid that I might transmit HIV to him. But I don’t have the guts to tell him the truth. Years have passed. I am still terrified at the thought of asking him about his health. I couldn’t stand hearing that he got infected.” (28-year-old female PLHIV)

Preemptive self-isolation: Many PLHIV (18/23) reported preemptively isolating themselves almost completely to avoid stigma, including enacted stigma from other people. Strained relationships, exclusion from family, and PLHIV’s psychological defenses were often reported as reasons for this isolation. Most PLHIV interviewees (17/23) lived alone or with just one family member, and reported few opportunities for meaningful interactions. Fifteen PLHIV rarely left their living quarters except to go to work, if employed. While such choices were isolating, participants expressed a preference for self-imposed loneliness over that dictated by the actions of others.

As a result, PLHIV often reported having a great deal of spare time. They usually stayed home and chose inexpensive, solo activities, such as watching television, which allowed them to avoid others. They also refused to engage in in-depth conversations with others, even when given the opportunity. Those with jobs often feared disclosure and casual transmission to coworkers, which caused them to withdraw whenever possible. They reported declining social invitations with various excuses.

> “[PLHIV] are in fear of seeing other people. We usually go out with our heads hanging down… We also suffer from enormous social pressure. Gradually, some of us can’t live under the pressure; we take things too hard, become reclusive, and refuse treatment.” (47-year-old male PLHIV)

Seeking friendships with other PLHIV: When making new friends, PLHIV tried to avoid anticipated or enacted stigma by reaching out to people with whom they shared specific HIV-related characteristics. For example, PLHIV who were infected through injection drug use sought friendships with other HIV positive drug users. “My friends and I now share the same experience. We all used to be rich, used drugs, and got HIV infected… We are not like those poor people with whom we don’t have common language.” (48-year-old male PLHIV) A 28-year-old female PLHIV reported, “I like talking to other PLHIV with similar experiences. We understand each other. After hanging out with them, I feel much better, and much more relieved. But I don’t like hanging out with drug users, they are scary.” Similar experiences strengthened the bonding and mutual understanding between PLHIV and helped them build new supportive relationships to replace their old broken relationships. As a 47-year-old male PLHIV said, “When I am sick, my family never visits me. Patients take care of each other.”

Crime: Sometimes, because of the many financial burdens imposed by living with HIV, living within the law became too difficult. As a 36-year-old male PLHIV said, “When life becomes hard, the only way I can think of to survive is stealing.” He hoped that “society can encourage the government to take better care of us, to feed us, so that I no longer need to steal.” Similarly, two PLHIV who lost their ability to work due to the side effects of antiretroviral therapy began stealing to support themselves. Both were caught by the police and disclosed their HIV status, but when they disclosed their status, they were released. “The policemen were afraid that we would infect criminals and staff in the prison.” (37-year-old male PLHIV)

A few PLHIV in Liuzhou had recently established a criminal gang, working together to steal, commit fraud, and threaten other people. Many study participants told us that the gang’s misconduct was the primary reason that a local self-help center for PLHIV had collapsed. The gang’s notoriety also deepened the stigma and discrimination against PLHIV within the larger community, as voiced by one PHW: “They don’t cherish themselves. How do they expect other people to understand, care for, and forgive them?”

Repeated testing: PLHIV sometimes reported disbelief in their HIV test results, which led to repeated testing, especially among those who did not engage in such high risk behaviors as injection drug use and commercial sex. Two women who lost their husbands years ago were still frequently repeating HIV testing, in the hopes that they would find that they actually were not infected and prove that they had not engaged in stigmatizing high risk behaviors.

Limited disclosure of diagnosis: Some individuals who disclosed their HIV status did so actively, while for others it occurred passively or involuntarily. PLHIV who were still independent and did not yet need HIV-related care were more likely to successfully conceal their diagnosis. Those who did disclose often actively chose cautious, limited disclosure to health professionals and others who could potentially provide care and support, to protect the individual and family from stigma and discrimination. Passive disclosure within the community occurred either accidentally or inadvertently through the provision of care and support.

Risk Behaviors: After diagnosis, most PLHIV participants responded well to treatment and reported deliberately modifying their risk behaviors and physical contact with others to avoid spreading HIV. However, two female PLHIV in our study were infected by their partners (husband and cohabitant) who had each known but not disclosed his HIV status. The cohabitant did not tell his partner that he had been infected before she was. In addition to this partner, he reported unprotected sex with 16 other women after he was diagnosed with HIV, justifying his actions by saying, “if most people in society suffered from AIDS, discrimination against PLHIV would disappear.”

Physical Health Outcomes

Stigma’s most common effect on the physical health of PLHIV involved health care. Seven of 23 PLHIV reported experiencing discrimination by health care providers at an undesignated hospital, in which health care workers refused to provide non-HIV related treatment after their status was disclosed. This finding was in contrast to the satisfaction with the CDC and their designated HIV hospitals, where all but two PLHIV reported having a harmonious relationship with the CDC and its staff.

PHW and CW both reported that PLHIV could not access timely treatment for HIV. While HIV testing and medications were covered by comprehensive medical insurance, PLHIV were required to pay 70% of all non-HIV related medical costs. Also, as a CW explained, “When PLHIV go to doctors, they have to pay first and then get reimbursement. If they can’t afford to see the doctor in the first place, their treatment will be affected.” A 38-year-old male PLHIV said, “I am resigned to fate and have decided not to see the doctors.”

The most dire effect on PLHIV’s physical health was caused by attempting or successfully committing suicide, as explained by a PHW: “Many PLHIV feel extreme fear and became suicidal, which may cause them more harm than HIV/AIDS does.” However, losing supportive relationships due to stigma was also very painful. “The harm from family is the most hurtful. I have seen some cases where PLHIV couldn’t face losing family relationships and ended up dying soon after.” (36-year-old male PLHIV) Damaged family relationships worsened the financial conditions for PLHIV which could in turn affect their health, for example, by a lack of food, shelter, or medical treatment.

DISCUSSION

PLHIV in our study anticipated, experienced, and internalized stigma in health care and social interactions that caused them to withdraw from society, which is consistent with other research in China ([19]). As in our study, a quantitative study of PLHIV in Liuzhou ([20]) also noted severe discrimination toward PLHIV, including among health providers: 48% (n=21) of PLHIV experienced discrimination in hospitals, including contemptuous language, leaking of confidential medical records, and refusal to give treatment. Discrimination in health care settings has been linked to shame and perceptions of stigma experienced by health care providers who treat PLHIV ([21]).

In our study, we discovered an important behavioral outcome of anticipated and enacted stigma: preemptive self-isolation. As part of this self-isolation, PLHIV seldom sought help when needed or participated in community activities. The self-isolation also affected their personal relationships, which can lead to increased psychological distress ([22]). PLHIV reported avoiding social support, which led to depression. However, when social support was sought, it was often primarily from other PLHIV with shared HIV-related characteristics.

In addition to preemptive self-isolation, PLHIV described experiencing denial (leading to repeated re-testing), feeling extremely afraid, and considering suicide. A handful of previous studies have specifically reported suicidal ideation among Chinese PLHIV. In one quantitative study with a similar sample of 2,000 PLHIV in China, over half of the women and 40% of the men thought about committing suicide after being diagnosed ([13]). In a cross-sectional study of rural and urban residents and students in China that assessed 25 distressing situations in which suicide might be considered acceptable, the one in which respondents were overall most likely to consider suicide was having AIDS ([23]). A small study of PLHIV and matched HIV negative controls in China found that significantly more PLHIV reported having had a major depressive disorder (MDD) during their lifetime (78% vs. 4%) ([24]). Of the 21 PLHIV in that category, only one had an MDD before HIV diagnosis. Only two (9%) had received mental health treatment, although four (18%) had ongoing suicidal thoughts. In a study of 176 HIV positive former blood/plasma donors in rural China, 34% had considered suicide and 8% attempted suicide in the previous year ([25]).

HIV/AIDS not only undermined the most basic relationships with community members and professionals ([26]), but more importantly, also threatened family relationships. Previous research has demonstrated that HIV-related stigma deeply affects families of PLHIV in China ([15,27]). Our findings indicated that family members were often perceived as feeling vulnerable or ashamed to be associated with HIV (emotion/prejudice in the HIV Stigma

Framework), and choosing to distance themselves emotionally and physically from the PLHIV (behavioral outcome). They feared experiencing stigma within their community from being known as a family member of a PLHIV and therefore hid this connection. Two of our respondents were known within the community as PLHIV; as a result, they rarely received familial support. Such abandonment and resentment from family members caused PLHIV despair and further isolation. People who were infected through injection drug use often already had unstable relationships with their families, which frequently resulted in even less support after diagnosis. Families of PLHIV whose serostatus was unknown within their communities treated them simply as sick relatives and, hence, generally better than those widely known to be HIV positive. However, their families appeared to be emotionally conflicted, hiding their association with HIV while still giving material support as well as some care and comfort to PLHIV.

Study Limitations

Because we did not interview PLHIV infected through commercial sex or blood donation, MSM, or PLHIV outside of Liuzhou, our data are not generalizable to all PLHIV in China. Further, PLHIV were not randomly selected. In addition, some participants may have been reluctant to talk frankly because the interviewers (university students) were young.

CONCLUSIONS

Keeping the above limitations in mind, we believe some tentative conclusions can be drawn. These data support other studies that demonstrate that PLHIV in China experience significant stigma. This stigma is related to depression in PLHIV, and social support can provide some protection against depression ([28]). Chinese culture places particular emphasis upon the importance of family, which is often the most influential force in the lives of Chinese PLHIV. Therefore, social support and education for family members, with the aim of reconciling PLHIV with their sources of potential social support, would be an important goal.

Learning about family members' perceptions of PLHIV will be critical to the successful planning of future interventions. While families are logical sources of social support for PLHIV in this culture, we must understand their perspectives in order to incorporate them into an effective social support intervention. If a widespread deep-seated negativity toward PLHIV exists among their families, such a program would surely fail unless family attitudes were first recognized and targeted for change. A belief that was reported to be pervasive among both PLHIV and their family members was that HIV can be transmitted via casual contact. Education programs that simply correct such misinformation could go a long way to reducing fear and its associated stigma toward PLHIV in China.

Future strategies should also emphasize training for health professionals to reduce stigma and discrimination and increase empathy, thereby creating a more supportive clinical environment for PLHIV ([20,29,30]). Li and colleagues ([31]) found that stigma reduction was an unintended consequence of an HIV prevention program conducted among community popular opinion leaders. If such programs succeeded in decreasing stigma among health care workers and/or communities, PLHIV health care and available social support could be positively affected. This change, in turn, could have an impact on Chinese PLHIV's preemptive self-isolation, suicidal thoughts and attempts, and quality of life and health care.

PLHIV need systematic visits and coordination with their medication and daily needs, especially given the isolation described in our data. In the future and with additional training, CW could potentially play a crucial role in establishing this systematic visit policy.

Finally, recognizing the connection between self-isolation and suicidal thoughts may help PHW and clinicians develop suicide risk reduction programs for PLHIV. This study provides particularly helpful new information by suggesting specific times when PLHIV may be at highest risk for suicidal thoughts and attempts, namely, immediately after diagnosis and again once CD4 counts drop and symptoms intensify.

Acknowledgments

The authors wish to express their appreciation to the PLWHA, their families, the health personnel, and the community workers who participated in this study, and following individuals for their support at different stages of this research project: Dr. Xiangsheng Chen, at National Center for STD Control, CDC China; Dr. Yingxia Zhang, Mingqiang Li, Weidong Feng at Liuzhou CDC in China; Dr. Yingying Huang and Professor Suiming Pan at Renmin University of China; Professor Zhen Pan at Business school of Nanjing Normal University; Drs. Gail Henderson, Sohini Sengupta, Suzanne Maman, and Laurie Abler; Ms. Qianlai Luo, Ms. Kumi Smith, and Ms. Malena Rousseau at the University of North Carolina at Chapel Hill; Ms. Rachel Emrick; and the UNC Center For AIDS Research (NIH P30 AI50410). We also thank the journal reviewers for their insightful comments.

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Table I

Demographic information of PLHIV (n=21)

Demographic Characteristics	**Number**
Gender	
Male	14
Female	7
Education	
Primary School	3
Middle School	12
High School	5
College	1
Employment	
Unemployed (including 3 thieves)	15
Provider of PLHIV services	2
Retired	1
Salesman and agent	3
Marital Status	
Not married	7 (3 single, 3 unmarried cohabitation, 1 lives with family)
Married	8
Divorced	6
Route of infection	
Drug use	13
Non-marital sexual transmission	6
Spouse	2
Years of infection	
< 3 years	4
3-10 years	10
>10	7
HIV Status Disclosure	
Public health workers only	2 (1 male, 1 female)
Public health worker & family	16 (12 male, 4 female)
Public health worker, family & acquaintances	3 (3 male)
Financial support	
Government assistance	10
Salary	5
Help of relatives	2
Theft	3
Help of partner	1