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## Family Relations in the Context of HIV/AIDS in Southwest China

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### Abstract

In China, an estimated 780,000 people have been infected with HIV (China AIDS, 2012). Even as this stigmatized population rapidly grows, with the majority of reproductive age (20–40 years old), information about their daily experiences in the domestic sphere has been scarce. Because the family remains a central unit of social and ethical organization in China, the current qualitative study examines family relations among people living with HIV (PLWH) with the goal of identifying the effect of HIV on family relations and, conversely, the effect of family relations on those with HIV. We analyzed data from 90 in-depth interviews with PLWH and people around them (i.e., their children, health care providers, other community members) in southwest China (Guangxi province). Through analyzing the families' experiences with illness, three themes emerged: how individuals with HIV interact with their community; how they cope with stigma alongside and against their family; and how families can support those with HIV. Our data ultimately showed the critical role of family in the quality of PLWH's well being. Because concealment of their serostatus was the primary coping strategy, stigma manifestation was most obvious in the domestic spheres. Yet when help was received, PLWH regarded family support as the most helpful, as those who received empathy from their families remained more optimistic. Thus, there is an urgent need for developing efficacious intervention programs that could lead to maximize family support, involving the families of PLWH, with a particular attention to family dynamics in daily interactions. Despite our awareness of the significance of family in China, this study reveals a particular kind of role of family that has rarely been considered, namely the role of family in healing and sustaining social bonds within the context of stigmatization, when those bonds might otherwise be broken.

### Keywords

HIV; PLWH; family relations; stigma; China

## INTRODUCTION

Pharmaceutical development and the increased availability of highly active antiretroviral therapy (HAART) has improved the health and longevity of HIV-positive patients globally, including in China (Qiao, Li, Stanton, 2014). Although HIV has become a chronic disease (Bunting 2001), stigma against people living with HIV (PLWH) persists and remains closely

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related to the mental, emotional, and physical well being of HIV-affected people and their families.

Researchers have long studied stigma across many fields, including psychology, anthropology, and sociology. The majority of researchers have studied stigma related to diseases (e.g., leprosy, TB, HIV) and disabilities, and have pointed out that stigma is essentially an experience of rejection (e.g., Miller & Kaiser 2001). In his monumental work, Erving Goffman (1963) defined stigma as a “spoiled” or devalued identity that discredits an individual. In particular, HIV stigma usually results in social isolation (Fife & Wright 2000), psychological distress (Chaudoir et al. 2012), problems of adherence to medical treatments (Castro & Farmer 2005), impaired quality of life (Greef et al. 2010), and an increased likelihood of engaging in risky sexual practices (Wegner et al. 1994).

Previous studies of HIV stigma have also argued that collectivism or familism, which is very strong in the Asia-Pacific regions, exacerbates the HIV-related stigma that family members of PLWH experience (e.g., Chin & Kroesen 1999; Mason et al. 1995). For example, even as family structures and norms have significantly changed in China over the past few decades (Li et al. 2006; Li et al. 2008), it remains a family-oriented society with family at the center of household life. Thus, the families of HIV-infected individuals in China must often share the HIV stigma (Li et al., 2009). This makes the burden of HIV a shared one, and thus makes a study of stigma more complicated. As they experience the stigma as a family, as a community, research shows family can come to offer a primary source of support for relatives with serious illness such as HIV (Li et al. 2006; Li et al. 2008; Grant et al., 2013).

The existing literature has shown a considerable level of HIV stigma in China (e.g., Hyde 2007). Since HIV infection is perceived as a result of violating moral and cultural taboos, someone who contracts it comes to be seen as a threat to a society (Yu, 2013; Das, 2001). Although this stigmatized population has seen rapid growth—with an estimated 780,000 people who have been infected with HIV (China AIDS, 2012)—and is largely of reproductive age, information regarding their daily lives remains scarce. In particular, there have been few qualitative studies on the domestic lives of PLWH and their families, especially in low to mid-income countries such as China. Given the substantial level of stigma against HIV in the context of familism in China (e.g., the familial culture or value system in an extended family), we suggest that understanding family relationships is critical in thinking about an effective intervention program.

The current study examined familial relations of PLWH by drawing upon 90 in-depth interviews with PLWH and those around them (i.e., their children, health care providers, and other community members) in the Guangxi province, which currently ranks second in HIV prevalence among the nation’s 31 provinces (Zhou et al., 2013). Specifically, we examined family dynamics among HIV-affected families to assess how families react and respond to an HIV-infected member, identify the realities of daily domestic life, and evaluate the impact of HIV status upon family relationships. Attaining a deeper understanding of PLWH’s (and their families’) lived experiences has the potential to both provide useful insights in the production of intervention programs as well as augment the qualitative literature of HIV by furthering research in China.

## METHODS

### Research Site and Participants

The current study was designed to analyze interview data regarding experiences and perceptions of PLWH. This qualitative research was conducted in Guangxi, China, where HIV prevalence has maintained substantial growth since its first case in 1996 (Qi et al., 2013).

Using a purposive sampling method, we recruited four groups of 90 participants who participated in a parental HIV disclosure intervention trial (i.e., 42 or 46.7% were parents living with HIV, 20 or 22.2% were children who were aware of parental serostatus, 18 or 20.0% health care providers, and 10 or 11.1% were other community members). Our participants were largely from rural areas of the Guangxi province (46 or 55.1% of participants were from rural areas, 31 or 34.4% were from suburban areas, and five or 5.6% were from urban areas), consisting of 28 men (31.1%), 42 women (46.7%), and 19 children (21.1%). The majority of the sample was of *Zhuang* minority ethnicity (70.0%) whereas 13.3% was of *Han* ethnicity (see Table 1).

### Procedures

In-depth interviews with participants were conducted in 2012. Our interview guide was informed by existing literature as well as the informal discussions we conducted with PLWH, community leaders, health care workers, and regional government officials. The resulting interview guide included four key components: (1) demographic data regarding the population; (2) daily experiences resulting from HIV infection; (3) existing as well as “missing” resources available to PLWH; and (4) our recommendations for HIV disclosure intervention programs. Wayne State University in the United States approved the study protocol, as did the Guangxi Center for Disease Control and Prevention (CDC) in China.

In order to protect the confidentiality of the participants, we conducted all interviews in a private room at a local CDC office. Prior to the start of interviews, we asked participants to provide a written informed consent (parental informed consent and assent from children). Our interviews inquired about local perceptions, daily experiences, and general attitudes toward PLWH regarding domestic relations, stigma manifestation, and coping strategies; each interview lasted a minimum of 30 minutes. With regard to compensation, we presented each participant with 50 CNY (equivalent to 8 USD). All interviews were audiotaped and transcribed.

### Data Analysis

Qualitative data analysis followed the procedure outlined by Ryan and Bernard (2000): identifying themes, building codebooks, marking texts, constructing models, and testing these models against empirical data. Coding themes were first developed from theoretical frameworks (Herek, Gillis, Cogan, 2009), and were expanded to include other themes that emerged during the interviews and the coding process (Rubin & Rubin, 1995; Silverman, 1993). Two team members independently coded all transcripts based on our coding

directory, using qualitative data analysis software called *Dedoose*. Coding differences were reconciled through group discussion.

We adopted thematic content analysis (Green & Thorogood, 2013) for the qualitative data analysis. Quotes, excerpts, and summaries were further categorized by participant characteristics and coding domains while being compared and reviewed for interrelationships and correspondence with the coding and theoretical framework (Ryan & Bernard, 2000). Relevant quotes were grouped together, which allowed us to develop interpretive memos (Saldana, 2012) for a deeper understanding of familial dynamics regarding PLWH in their daily lives. Finally, we conducted cross-case analysis (Hult et al., 2012) by discussing, summarizing, and comparing cases. The major themes were divided into sub-themes and enhanced with representative quotes by participants (see Table 2).

## RESULTS

### Coping with from the Community

Our interviews suggested a considerable level of HIV stigma in the region; PLWH were often seen as immoral, contagious, and terminal. As shown in Table 2, our findings showed that PLWH and their families generally experienced a substantial level of stigma and shame, which made it more difficult for them to accept reality.

Because of such strong stigma, PLWH and their family members largely chose not to share the information with community members outside of the family, instead opting to keep HIV status within the domestic sphere. The justifications for concealing diagnoses were multitudinous. The family members in China did not expect practical help or interactions with other families of PLWH. Further, because children that revealed the HIV status of family members often faced discrimination from peers, parents with HIV often concealed their illness from their children; they believed that concealment would protect their children from experiencing extended stigma. PLWH tended to inform siblings more easily than either parents or children. Due to the prevalence of the concealment strategy, it was difficult for both PLWH and their families to get help from other community members.

Substantial HIV stigma often caused PLWH and their families—especially those who maintained relationships with HIV-infected individuals—to minimize their social contacts with others, thus resulting in a shrinkage of their own networks. In light of fear at revealing the “shameful” information, minimizing social interactions was a safe way to maintain secrecy. This tendency was particularly clear among children who continued to live with their HIV-positive parent(s). The children were not exceptions in actively working to conceal their parents’ HIV infections.

### Coping with Stigma Alongside and Against Family

Post-diagnosis, many of our participants documented experiencing significant exclusion and a lack of empathy in their domestic relationships. Perceived as a “malfunctioning” member of the family, an important rationale behind such considerable exclusion was the potential stigma by association. Many feared HIV stigma being extended to people close to PLWH

(e.g., family, relatives, caregivers), as it was generally extended to the families of HIV-infected individuals in the region.

Another central reason generating HIV stigma in family relations was fear and discomfort regarding the potential contagion through daily interactions. Many participants reported the primary manifestation of stigma was their exclusion experiences from the families who feared contagion; PLWH often lived alone. In response to experiencing rejection from their family, PLWH expressed a deep sense of disappointment and isolation. While PLWH were frequently excluded in domestic spheres, their family members often took care of their children in order to protect them from “possible HIV infections.” Even more accepting families still changed daily interaction practices with HIV-infected members. Some of these changes were useful (e.g., encouraging condom use) and others were useless (e.g., eating separately). The most frequent practices among our participants were minimizing daily contacts such as washing clothes separately and using separate utensils. Those who stayed with their family also tended to divide the living space. Beyond physical disruption, HIV-stigma extended into emotional disruption as well.

Most family members did not ask PLWH about their health conditions, feelings, or transmission routes. Furthermore, PLWH also lacked a desire to share their suffering or details regarding their infection. Both parties thought that bringing up such an issue would be embarrassing and would not practically help improve the status quo. Even though some intimate family members communicated with PLWH, the communications were quite limited and lacked variety; the sharing of struggles, emotions, or thoughts was rare. As a result, domestic communications often failed to help the emotional well being of PLWH. However, it is noteworthy to mention that attitudes and support can vary from within a single family, as family member attitudes were also shown to be inconsistent. In the process of care, family members were often trapped between family obligations and social stigma.

### **Families that Support**

While many families chose to exclude or isolate PLWH, some families chose to embrace their HIV-infected family members. Our participants often described the understanding and supportive families as educated and relatively well off. Accepting family members were evaluated as helpful through providing financial support. When a spouse was diagnosed, some PLWH generally concluded that divorce or separation would not be a practical choice.

Furthermore, our data showed that PLWH whose families closely provided care perceived and reported that their family was the most helpful resource for the vulnerable population; those with dedicated family care felt more relieved regarding their infections. Dedicated spouses appeared particularly helpful, even though marriage often failed when only one spouse had the infection. When both partners were infected, they tended to remain married, supported each other, and dealt with challenging conditions better. A few couples even reported that they conceived and delivered healthy children (though others gave up pregnancy).

Interestingly, most of our participants mentioned that their children, if they were aware of the parental infection, not only understood and showed deep concern, but also provided the

utmost emotional support in addition to practical help in their daily lives. While children did not usually ask questions about their illness, they reminded the HIV-infected parents to take the medicine and helped with daily household chores.

## DISCUSSION

This qualitative paper examined the familial relations of PLWH in southwest China. Drawing upon 90 interviews with PLWH and those around them, our findings pointed to the critical role the family plays in supporting the quality of PLWH's wellness. We have demonstrated three themes regarding the lived experiences of the HIV affected families: coping with from the community; coping with stigma alongside and against family; families that support.

Our findings also showed that education and socio-economic status affected relationships in PLWH families. Those family members who had garnered more education and financial resources in urban settings were generally more supportive of their HIV-infected family members. That said, the majority of family members in Guangxi did not have this level of education or financial success. As a result, the majority of HIV positive people there experienced physical exclusion and a lack of family support. This situation differs from previous findings in the Yunnan province where *most families provided extensive and a wide dimension of support* to the PLWH such as financial assistance, support in daily routines, medical assistance and psychological support (Li et al. 2008; Li et al. 2006). This discrepancy may be because of the characteristics of our participants' demographics (e.g., mostly *Zhuang* minority from resource-poor settings in rural and suburban areas) or because Yunnan's government has been not only the most open in China when it comes to confronting AIDS but has also successfully cooperated with international NGOs on AIDS assistance (Hyde, 2007). However, given the wide spectrum of acceptance of HIV in the domestic sphere among our participants, there would seem to be a real possibility of improving the well being of PLWH through various approaches, including social support and intervention programs (e.g., a stigma reduction program involving family members of PLWH).

While counterparts in other western societies tended to blame the larger society and government for HIV infections (e.g., Kelly & Sykes, 1989), many families of PLWH in southwest China blame the infected individuals, feeling those with PLWH brought shame to the family. Those individuals with PLWH, in turn, often blamed themselves and felt guilty before their family members. To address this, we suggest that health professionals develop a more effective program that does not place blame on HIV-infected individuals. A comprehensive intervention program needs to include consultation with professionals for the sake of decreasing fear and empowering self-esteem, financial support, service policy, and the legal system (e.g., legal protection from abuse and discrimination).

Our findings indicate that, when helping PLWH, relevant government agencies and health professionals should pay more attention to family dynamics. Because of concealment as a coping strategy, stigma manifestation was most frequent in domestic relationships; when help was received, however, PLWH regarded their family's support as the most helpful



resource, evinced in the way those who received understanding from their families remaining more hopeful and optimistic. Our findings suggest that HIV-affected families are in great need of assistance. Families experienced shock and shame once they learned about their family member's HIV infection. This pattern parallels previous findings among the wives of HIV-infected people in India (D'Cruz, 2003) and among the families of African American PLWH (Tolliver, 2001). Additionally and consistent with previous findings (Zhou, 2007), the level of distress the families expressed to PLWH concerning the fear of contracting HIV was considerable through daily interactions. Given the substantial level of concern regarding contagion, the distribution of HIV knowledge on the safety of daily interactions and potential transmission routes seems urgent, especially among families in rural areas. Furthermore, deeper communications within domestic spheres should be encouraged to both support PLWH as well as share information.

Many family members appeared to be struggling between social stigma and their family obligation to take care of infected family members. In line with previous findings (e.g., Li et al. 2007), then, the families of PLWH experienced significant changes in their own lives as they were burdened with stigma and family obligation. However, many families of PLWH in southwest China did not generally receive social support or interact with other families. Hence, culturally tailored programs should be considered to help the families form networks, supporting home visit services and psychological consultation, and providing financial support (e.g., care-giving, hospice, funerals).

Among family members, children seemed to bring the most hope to their HIV-infected parents. Our participants acknowledged that interactions with children were the most helpful for their emotional (e.g., loneliness) and physical wellness (e.g., medical adherence), in addition to relieving daily burdens (i.e. contributing to household chores). However, such burdens may interrupt children's academic achievement and healthy development; the healthy development of children, such as personality, grades, education, and emotional hardship were not issues of the highest concern to HIV-positive parents. Thus, we suggest that intervention programs should be built in the direction of supporting co-habitation of PLWH and their children, providing a strong support system for the children's healthy development and education. Some of our participants also reported that they could not move to an urban area with the rest of their families that were seeking out of higher quality education for the children, as they needed to stay for HIV treatments; medical coverage did not extend beyond their localities and so they were left alone following their family's move. This indicates that the health insurance system will need to incorporate the needs of PLWH with regards to cohabitation with their families.

These findings should be interpreted with caution because of the following limitations. First, the current findings regarding family dynamics were largely based on the perspectives of PLWH and their children. Future studies should be inclusive of family members beyond spouses and children in order to effectively explore family dynamics and rationales behind the exclusion and discrimination of HIV-infected family members. Second, no data were collected regarding the family dynamics prior to their HIV diagnosis. There is a possibility that the low level of family support found in this study may have partly originated from pre-HIV family relations rather than from their HIV diagnosis alone. Third, the current study

drew upon one-time interviews. Further studies need to adopt longitudinal ethnographic research methods in order to gain a deeper understanding of the daily process of family relations among PLWH and the broader cultural and political contexts in which HIV stigma is constructed.

Despite these limitations, the findings of this study are meaningful in understanding the cultural uniqueness of HIV, as it is experienced in southwest China, and the resulting lived experiences of both PLWH and their family members in the domestic realm. Not only does this study add to the very limited literature on the lived experiences of PLWH, but by focusing on family dynamics in daily interactions and by including various network members (i.e., their children, health care providers, other community members), this study also reveals the critical role of family in healing and sustaining social bonds in cases of stigmatization, particularly in resource-poor settings such as Guangxi, China.

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**Table 1.**

Demographic characteristics of survey participants

Characteristics	Number	Percentage
<u>Composition</u>		
Parents	42	46.7%
Children	20	22.2%
Health care providers	18	20.0%
Other community members	10	11.1%
<u>Geographic origin</u>		
Rural	46	55.1%
Suburban	31	34.4%
City	5	5.6%
<i>missing</i>	8	8.9%
<u>Ethnicity</u>		
Majority ( <i>Han</i> )	12	13.3%
Minority ( <i>Zhuang</i> )	63	70.0%
<i>missing</i>	15	16.7%

**Table 2.**

## Family relations among PLWH in southwest China

## (1) Coping With From the Community

*Substantial level of local stigma:*

- (28-year-old rural woman) - "People in our area say that it [HIV/AIDS] is really terrible. They say it's really terrible!"
- (33-year-old rural woman) - "My mom said 'your infection is somewhat difficult to accept.'"
- (34-year-old suburban woman) - "Alas... I'm afraid that, afterwards, others will know that we have this disease [AIDS]...and despise us... we carry this kind of idea around with us..."

*Concealment of an HIV/AIDS diagnosis as a coping strategy:*

- (36-year-old urban man) - "I didn't tell after all, this is a terrible disease, and it causes discrimination."
- (40-year-old suburban woman) - "People who actually have this disease like us are afraid of telling others because people don't usually accept it. If they find out you have this kind of disease, some don't understand it and think that they could get infected by eating with you. I have this idea in my mind."
- (38-year-old rural woman) - "Once the doctor told me that I was HIV positive, my whole body became powerless. At that time, my child wasn't around, and I cried every night. I had to go to work in the morning, and when I was at work I didn't say anything. My colleague asked me why I didn't talk at all. I said I was upset and didn't dare talk to others. I was afraid that people wouldn't understand or accept me, so I said I had something upsetting happen at home. Every evening for the whole week, I went to sleep alone and didn't dare to tell others. I didn't even tell my son."

*Minimization of social interactions and shrunken networks:*

- (31-year-old suburban woman) - "I'd feel uncomfortable [to talk to others]. I'm reluctant to contact anyone, for the sake of escaping the feeling. I rarely even contact my friends."
- (14-year-old girl) - "Whenever my classmates want to visit me and play at my house, I say I don't have time this week or give another excuse. Yes [I don't want to let them play at my home]... [cry]..."

## (2) Coping with Stigma Alongside and Against Family

*Exclusion, lacking empathy, substantial discrimination:*

- (37-year-old rural woman) - "When I did not have the disease [AIDS], everyone [in the family] was good to me, but now that I have the disease, everyone is distant."
- (37-year-old man) - "Whenever my mom sees me, she asks me to 'get out' and 'die,' saying it's meaningless that I live in this world and that I have no contribution to the family...while she speaks these kinds of words. I can also understand her, so I don't fight with her or care about what she says either. I already became like this [an AIDS patient]... it's fine to let her talk if it makes her feel comfortable."
- (12-year-old boy) - "No [other people know about my mom's infection], probably just three of us [immediate family] know. My uncle's family doesn't care about us. We just need to live stronger."

*Willingness to distance themselves from family members:*

- (33-year-old rural woman) - "Usually, our family was very nice to me, and was concerned about me. Now, after I got this disease, I also don't want to interact with them...I also don't give things I've eaten to him [her son] 'cause I'm afraid... There was a change in family relationships after my infection...I don't want to have contact with them much. We washed all of the clothes and other stuff together before, but after knowing my diagnosis we separated them. We're afraid just in case there is a bloodstain on it or something."

*Replacing the parental care of infected family member's children:*

- (28-year-old rural woman) - "My mother is good to my child. She's afraid that my child would get infected, so she doesn't want me to bring up the child."

*Daily exclusions, despite greater acceptance:*

- (39-year-old rural man) - "It's true that people don't eat together, he [son] wakes me up to eat, but nobody eats with us [PLWH]."

*Too embarrassed to share suffering:*

- (40-year-old man) - "Usually we can't talk about this kind of thing [AIDS]. Sometimes, I ask a bit about it, but basically she [daughter] won't take the initiative and talk about it."

*Minimized communications:*

- (28-year-old rural woman) - "My daughter asks me if I had a meal, and if my health condition is better. No more details than that."
- (40-year-old suburban man) - "We haven't talked about anything specific, we don't know how to talk, and we have nothing to talk about. I take my medicine on time, she [his mother] has nothing to ask, and she knows this disease is hard to cure. I take the medicine and it's nothing more than a temporary control to put off the date of falling ill. She probably just knows about this, so she doesn't ask anything."

*Inconsistent attitudes within a single family:*

- (33-year-old rural woman) - “She [sister] helps me, and also, if the price of milk powder gets too high, she gives me some money. My parents won’t usually give me a penny...”
- 

(3) Families that Support

*Knowledgeable, better-off and supportive families:*

- (33-year-old rural woman) - “My uncle and I are like brother and sister. My uncle is fifty some years old, but he understands me very much, and he shares some knowledge because he’s been all over the country. He said it’s nothing; he often gives me a call as well and asks me how much my CD4 has increased.”
- (31-year-old suburban woman) - “... I take care of my little brother’s child. My brother also knows that I have this kind of problem... To speak of our family’s perception, their awareness is quite strong, and the kind of knowledge is quite broad, so they think it’s nothing, and I still take care of my nephew.”

*Staying married through HIV/AIDS:*

- (39-year-old rural man) - “... When I first learned of the fact [HIV infection], I simply couldn’t accept it. But, later I thought that I already had the disease, it’s useless to blame her [his wife]. We just need to live well, two people need to live well together, and divorce is useless. If I marry another person, I’ll harm the person, and she’ll blame me. This is how it is.”

*Family care as the most helpful resource for wellness:*

- (31-year-old suburban woman) - “Consolation at home is quite valuable, and my family helps me.”
- (35-year-old woman) - “My family members help me. Speaking of which, I’m nevertheless lucky, my big brother and the family are very nice to me... If my family was like that of that woman [referring to an AIDS patient violently discriminated against by her family], I probably would’ve been dead as well. I know I wouldn’t still be alive today.”

*Children provide the utmost emotional and practical support:*

- (39-year-old rural man) - “...Originally, I had no hope. Now I look at the situation for my son’s sake and my heart becomes relaxed.”
- (11-year-old suburban girl) - “I became more concerned about my dad [after his infection]. I know he has to take medicine on time every day, and when I help him I feel more comfortable.”
- (38-year-old rural woman) - “... My kid is concerned about me a lot. Sometimes I don’t take medicine in the evening, then she says, ‘Mom, it’s time, why don’t you take the medicine?’ Sometimes she asks, ‘Mom, have you taken the medicine?’ ... I shop and cook dishes, and she cooks rice, does laundry, sweeps the floor, etc.”

*Concerns about children: lacking the ability to support:*

- (36-year-old rural man) - “Yes, I’m worried [about my child]. I don’t worry about anything else. It’s nothing even if I die, but I just worry about my child.”
  - (31-year-old suburban woman) - “I don’t have a way out, my salary is too little, and I can’t bring her [daughter] around... We [the couple] rent a room and it’s somewhat difficult to raise a child. We can’t support her.”
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