



Bearing the Stigma of HIV: Experiences and Coping Strategies in Southwest China



Yeon Jung Yu, PhD
Department of Anthropology, Western Washington University
Bellingham, WA

Xiaoming Li, PhD
Arnold School of Public Health, University of South Carolina
Columbia, SC

Shan Qiao, PhD
Arnold School of Public Health, University of South Carolina
Columbia, SC

Yuejiao Zhou, MD
Guangxi Center for Disease Prevention and Control
Guangxi, People's Republic of China



Correspondence may be directed to:
Yeon Jung Yu, Department of Anthropology, Western Washington University,
516 High St, Bellingham, WA 98225; E-mail: Yeon.Yu@wwu.edu.



Abstract

Even as the number of people living with HIV (PLWH) is rapidly increasing in China, qualitative studies investigating the effect of HIV stigma on daily lives remain limited. The current study aims to fill this gap in research with attention to not only the experiences but also the coping strategies of PLWH in southwest China. We conducted 90 in-depth interviews in Guangxi, China. Our participants included both PLWH and individuals in their surrounding community (e.g., spouse, children,

health workers). Our interview data showed an intense manifestation of HIV stigma in domestic spheres. Other close community members (e.g., relatives, friends, neighbours) also worked both to discriminate against PLWH and simultaneously thwart possible stigma by association. By explaining how stigma affects both PLWH and their family members, the current study seeks to help both citizens and health practitioners better understand the effects of stigma on PLWH, their friends and their families.

Introduction

Approximately 501,000 people living with HIV (PLWH) are currently reported in China (UNAIDS, MoH. 2015). In recent years, the trajectory of HIV has changed considerably, with the pharmaceutical advent of medical treatments, including antiretroviral therapy (ART), which prolongs longevity and improves the quality of life for those who are living with the virus (Kalichman 2000; Qiao et al. 2014). As a result, AIDS has become a chronic disease and stigma against PLWH has become an increasingly important issue. Thus, development of evidence-informed stigma interventions with cultural sensitivity will greatly benefit the mental and physical well-being of PLWH and their families. To design and implement such interventions, we first need an in-depth understanding of the very experience of being stigmatized.

Stigma is generally a response to social differences (e.g., class, race, gender) in the context of particular culture and power structures (Parker and Aggleton 2003). Stigma has long been studied in many fields, from psychology and sociology to anthropology. Most researchers have studied stigma in terms of diseases (e.g., leprosy, TB, HIV) and disabilities—chronic statuses that can affect individual identity through an experience of rejection (Krzban and Leary 2001; Miller and Kaiser 2001). In his pivotal work, Goffman (1963) defined stigma as a “spoiled” or devalued identity that discredits an individual. Jones et al. (1984) interpreted stigma as an unwanted attribute that is associated with a bias. Shamos and her colleagues (2009)

added a dynamic component to the perception of stigma – as a social process (stigmatization) that allowed labelling and distinction, which leads to discrimination, loss of status and decreased social power. Drawing upon these previous scholars, we understand the stigma of HIV as a dynamic social mechanism through which individuals with HIV become labelled, discriminated against and then must work at coping within a particular culture and power structure. Therefore, it is imperative to understand the specific social setting in which stigma is produced and reproduced.

Stigma can lead to a severe decrease in self-esteem (Crocket and Quinn 2000) and cause symptoms of depression, anxiety, decreased satisfaction with life (Link et al. 1997), psychological distress and self-hatred (Crandall and Coleman 1992). In particular, the stigma of HIV usually leads to social isolation (Fife and Wright 2000), psychological distress (Chaudoir et al. 2012; Morrison et al. 2002; Reichert 2007; Steward et al. 2008), problems adhering to medical treatments (Abadia-Barrero and Castro 2005; Castro and Farmer 2005), impaired quality of life (Greef et al. 2010; Holzemer et al. 2009; Jurgens 2004; Neely-Smoth 2003) and an increased likelihood of engaging in risky sex (Wegner et al. 1994). HIV stigma is usually extended to and shared by the families of PLWH as well (e.g., Haber et al. 2011; Li et al. 2008; Yu et al. 2016). This phenomenon is conceptualized as “courtesy stigma” (Goffman 1963), “secondary stigma” (Bond et al. 2003) or “association stigma” (Holzemer et al. 2007). Coping strategies to

overcome the stigma of HIV can vary, moreover, according to socio-cultural differences (Yoshioka and Schustack 2001).

Despite the fact that the PLWH population is rapidly growing in Asia, empirical studies of daily experiences and coping strategies for facing the stigma of PLWH have been concentrated in the West, limiting available data from low and mid-income countries such as China; a qualitative, in-depth understanding of lived experiences and daily coping strategies of PLWH has been scant. In addition, previous empirical studies exploring the experience of stigmatization largely drew upon quantitative approaches. The current study examines the experience of HIV stigma, drawing upon in-depth interviews with 90 people in the Guangxi province – both HIV-infected individuals and the people they are close to (e.g., spouse, children, health workers). Our field site presented an ideal site to examine the stigma of HIV, as the province currently ranks second in HIV prevalence in the nation, constituting a 30.12% increase since the end of 2009 (Guangxi CDC, 2011; Zhou et al., 2013).

Drawing upon the interview data, we explored local HIV stigmas, the experience of being stigmatized and individual coping strategies. Through our work, we sought to address the following three questions: First, what is the general attitude towards HIV and PLWH? Second, what are the daily experiences of HIV stigma among PLWH? And, finally, what are the coping strategies of HIV stigma among PLWH and their family members? A more comprehensive understanding of these vulnerable people's daily experiences could both contribute useful insights for future stigma interventions and enrich the literature around stigma by adding a China-based study.

Methods

Research site

This current study is a secondary analysis of data originally designed to study parental

HIV disclosure, a study which yielded much information regarding the experiences and perceptions of PLWH. The qualitative study was conducted in a province (Guangxi) in southwest China. HIV prevalence has increased substantially in the province since its first case in 1996 (Qi et al. 2013). Furthermore, Guangxi ranks second among China's 31 provinces in the number of documented HIV seropositive cases – and the epidemic is still growing steadily in the province (Zhou et al. 2013). As of October 30, 2015, Guangxi reported a total of 106,001 HIV/AIDS cases, which represented a 52.41% increase since June 2011 (69,548 HIV/AIDS cases) (Zhang 2014).

Participants

We conducted in-depth interviews with 90 people in Guangxi, China, in 2012. To obtain a comprehensive understanding of HIV experience, our data were collected from multiple groups of people (e.g., HIV-infected individuals, their children, healthcare workers and community leaders). The number of participating parents who disclosed their HIV infection status to their children was equal to parents who did not. We interviewed 42 (46.7%) parents living with HIV, 20 (22.2%) children, 18 (20.0%) healthcare providers and 10 (11.1%) other community members. The majority of the participants were of ethnic minority (*Zhuang*) (70.0% vs. 13.3% *Han* majority). As to the household registration, 46 participants were from rural areas (51.1%), 31 were from suburban areas (34.4%) and 5 were from urban areas (5.6%) (8 [8.9%] were missing). Twenty-eight participants were men (31.1%), 42 were women (46.7%) and 20 were children (22.2%) (Table 1). We interviewed the children who were knowledgeable about their parents' HIV status. The children's age ranged from 6 to 15 years old. Unfortunately, the routes of infection were not asked.

Table 1. Demographic characteristics of survey participants

Characteristics	<i>n</i>	%
Composition		
Parents	42	46.7
Children	20	22.2
Healthcare providers	18	20.0
Other community members	10	11.1
Gender (adults)		
Men	28	31.1
Women	42	46.7
Geographic origin		
Rural	46	51.1
Suburban	31	34.4
City	5	5.6
Missing	8	8.9
Ethnicity		
Majority (<i>Han</i>)	12	13.3
Minority (<i>Zhuang</i>)	63	70.0
Missing	15	16.7

Study procedures

Our semi-structured interview guide was developed based on literature reviews, informal discussions with PLWH, local community leaders, healthcare providers and government officials. The final interview guide consisted of questions covering: (1) demographic information; (2) experiences related to HIV infection; (3) resources used or perceived to be of need and (4) personal preference for HIV interventions. We received IRB approval from Wayne State University, USA, and the Guangxi Center for Disease Control and Prevention (CDC) in China.

To ensure confidentiality for these vulnerable people, we conducted all interviews in a private room at a local CDC office in Guangxi. Each participant provided a written informed consent (parental informed consent and assent from children) before each interview. As our interviews were designed to be semi-structured, we were able

to inquire about interviewees' perceptions, experiences and attitudes towards PLWH in multiple realms such as stigma, disclosure, social support and coping strategies. Each interview lasted a minimum of 30 minutes. Each participant or parent-child dyad received 50 CNY (equivalent to US\$8) to compensate for their time.

Data Analysis

All of the 90 interviews were audiotaped and transcribed. 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. Preliminary coding started with reading and re-reading the Chinese transcripts by research team members. Coding themes were developed from the theoretical framework of stigma (Herek et al. 2009), and new themes emerged during the interviews as well as the coding process (Rubin and Rubin 1995).

In order to analyze the interview data, we adopted thematic content analysis (Green and Thorogood 2013). According to a coding directory, two team members first independently coded all transcripts before coding differences were discussed and reconciled. Detailed summaries with substantial retention of original quotes were prepared in English to facilitate further discussion and elaboration among both American and Chinese investigators. Quotes, excerpts, and summaries were then categorized by participant characteristics and coding themes; they were further compared and assessed for interrelationships and correspondence with coding and the theoretical framework (Rubin and Rubin 1995; Ryan and Bernard 2000). We used qualitative data analysis software (*Dedoose*) for coding, as it had some unique features that fit with our analytic plan and budget (e.g., more appropriate and effective for our team collaboration and data integration during

coding and analysis). Relevant quotes were then grouped together, which enabled us to develop interpretive memos (Saldana 2012) for a greater understanding of the stigmatic experiences of Chinese PLWH. We then conducted cross-case analysis (Hult et al. 2012) by discussing, comparing, and summarizing cases. Most of the research team members are fluent in both English and Chinese, so translations were often discussed among the team members to ensure the accuracy of the translations between the two languages. There is an equivalent and mostly accepted translation of “stigma” in Chinese (*qishi*).

Results

Local context of HIV stigma

HIV stigma was so prevalent in this region that, as in many other parts of China, people generally heard, observed and internalized the stereotype prior to getting infected with HIV. Our interviewees mentioned that the concept of HIV stigma was closely associated with high contagiousness and fatality, which makes people fear contact with PLWH. In addition, the locals presented the idea that PLWH somehow deserved suffering given the immoral behavior that caused the illness.

For example, a 39-year-old rural man who was HIV-positive commented, “People around me are usually afraid when they hear about this kind of disease [AIDS]. It’s normal, because if they know you have the disease, they’ll usually not interact with you.” Another 39-year-old rural male patient added, “When you have a contagious disease, who’d not be afraid of contacting you!” Misunderstandings of the routes of HIV infection translate into stigmatization of PLWH. In many locals’ minds, PLWH were immoral people who deserved their intense suffering. Often, PLWH first learned about the stigmatization from their local networks and thus predicted strong HIV stigma and discrimination against them.

Experiences of HIV stigma

Indirect experiences of HIV stigma
According to our data, a clear sense of HIV stigma usually developed from either hearing or observing secondary experiences of patients’ peers or relatives. Many of our participants observed intense HIV stigma, which reinforced their internalized stigma of HIV. The observed experiences were expressed as “being neglected,” “excluded” and “displaced.” For instance, a 33-year-old rural woman pointed out that family was not an exception in exerting HIV stigma,

... Anyway I have a friend, after he got the disease [AIDS], his family knew it and really treated him this way. When he ate, they wouldn’t dare to eat together. He was 30 years old, used drugs, and his family isolated him. When eating, he ate by himself. He took a stool and went off to one side; and every time this happened he felt very lonely; during holidays he was especially lonely. When he spoke [about this], tears fell down.

Among our participants, such preemptive experiences were more prominent than first-hand experiences because many of them did not disclose their status. The examples and stories of their peers made PLWH feel depressed and confirmed their anticipation of strong stigma if their status was revealed. Consequently, these indirect experiences of strong HIV stigma against others shaped their coping strategy of concealment.

Domestic experience of HIV stigma

The most distinctive experience of stigma among our participants was the intense HIV stigma – exclusion and discrimination – exerted by family members. The level of stigma within families in the current study was substantial; nearly every participant who reported experiencing the manifestation of stigma discussed being discriminated

against and excluded by their families. A 33-year-old rural woman explained, “Everyone [in the family] ignores me, dislikes me a lot. My mother in-law even advised my husband to divorce me.” A 37-year-old rural woman explained her lack of family support:

[The biggest difficulty] should be being ill, being sick with no one to help. At the time I got sick not a single person dared to stay with me; I couldn’t walk, but I still had to grab and take medicine myself. At that time my brother said he’d ask my mom to come. Later they learned I had this kind of disease [AIDS], and my brother didn’t even let my mom come to take care of me.

While HIV-infected people expressed their understanding of family members’ discrimination, within the local context of strong HIV stigma, they also expressed disappointment at their loved ones’ attitudes. A 35-year-old rural man expressed his loneliness saying, “I live alone in our courtyard. They [family members] all moved out. Whoever was able moved out, and kept away from me.”

In particular, encounters with exclusion in daily activities, such as sharing meals and utensils, space/housing sharing, chatting, shaking hands and family gatherings were frequently mentioned in our interviews as especially painful experiences for PLWH. A 28-year-old rural woman commented, “My clothes are washed in another washer, even clothes can’t be cleaned together.” In the families’ eyes, the possibility of “polluting” or transmitting the fatal infection to other family members posed a threat to the fundamental unit of the society – making it necessary to isolate the infected individuals. A 39-year-old rural woman expressed her deep sense of isolation and exclusion originating from HIV stigma in domestic spheres:

Everyone in my family knows. But they don’t understand this. Even when we have meals or something, no one dares to eat with me or include me. When they get married, they don’t ask me to come. They bring out dishes and let me eat alone. I really feel very lonely, very uncomfortable, very uncomfortable!

Patients with HIV were indeed shocked, saddened and felt abandoned by close and personal rejections from those relationships that were once their most-trusted, intimate or romantic.

Ubiquitous encounters of HIV stigma
While families are the primary source of stigma against PLWH, there were also other sources that motivate this stigma. According to our participants, friends, colleagues and neighbours were the quickest actors in rejecting and excluding PLWH. Close acquaintances were often the least ambivalent about ending the relationship while reinforcing HIV stigma in the region. For example, a 28-year-old rural woman infected with HIV said, “They [friends and colleagues] estranged themselves from me ...” A 36-year-old rural man also shared this idea, saying:

In the past I lived in the countryside and cut cane. We did it as a group. But later I got this disease [AIDS], and folks didn’t engage with me in the group anymore. Now I don’t grow cane. No one dares to be with you, people don’t visit, you eat at home yourself. How can you do it without others? I have no way to grow cane, I mean. Things you can do by yourself, do it yourself. Don’t be with others or work together, I mean.

Given this corroborating and sustained stigmatization from the community, very few

participants reported maintaining relationships with their friends and neighbours after their diagnoses.

HIV stigma exerted by medical practitioners was also reported; the health professionals in the area may be torn between following the social norm (i.e., HIV stigma) and acting on the basis of their professional role/knowledge. A 33-year-old rural woman complained about her doctor's discrimination against patients with HIV:

But doctors also discriminate against people with this kind of disease [AIDS]. They really do ... at the time I knew a doctor. She [doctor] said, "If it wasn't for my job, I'd certainly discriminate against you." ... I don't know why she talked like that at that time. I wanted to ask her then, but she's a doctor after all. I thought, then why are you still doing this. You want to do this, you shouldn't discriminate ...

A 34-year-old woman from a city also complained about the phenomenon saying: "Even some doctors, when they know you have this kind of disease [AIDS], they won't see you." Such HIV stigma enacted by health professionals both confused and upset patients with HIV profoundly. These responses indicate a need for further research into care providers' struggles with strong HIV stigma in China.

Coping with HIV Stigma Coping strategies of PLWH

The great majority of our participants reported concealment as their predominant coping strategy, a strategy explicitly in response to the substantial level of HIV-related stigma in the region. A 39-year-old rural man said, "I dare not, dare not to talk to people ... If everyone knew that I have AIDS, they wouldn't want to deal with me, and if they don't want to interact with me, my life will be over!"

One concealment strategy was to misinform people regarding their illness.

A 38-year-old rural woman attempted to thwart stigma by (mis)representing her illness as something other than AIDS:

They don't know I have AIDS. When I take medicine, I don't want to let them know and I take it secretly. If they see me and ask why I take the medicine, I say my throat hurts because my voice is not good, I need a surgery but have no money. I want to take my medicine, but I don't tell people I take AIDS medicine.

The most concerning issue among the PLWH was the way its stigma extends to their children. Efforts to protect their children from possible HIV stigma by association catalyzed concealment strategies and made this concern the dominant motive among our participants. The strategies included hiding HIV infection from the children themselves, as the parents were concerned their children may accidentally reveal their parents' infection to peers. Female patients were also worried about losing custody once their infection was revealed.

It is worth mentioning that, other than concealment, some participants took a more adaptive coping strategy to normalize HIV and PLWH. For instance, a 37-year-old rural man mentioned that he had a more proactive perspective to decrease HIV stigma: "I advocate for propaganda, disseminate more vigorously, let everyone understand this kind of disease is not fearful at all and won't be contagious. This way we won't get supplanted or discriminated."

Coping strategies of family members

HIV stigma was a critical issue for families of HIV individuals as well as for HIV-infected individuals themselves. Our participants made it clear that their families had experienced extended HIV stigma

by association. Intense HIV stigma in the region often forced the family members and relatives of PLWH to distinguish their health status from the patients and thus prevent themselves from the possibility of extended HIV stigma. In this sense, family members became active agents in crystallizing stigma in daily lives. Only a few participants mentioned that their families were appropriately educated about HIV (e.g., routes of infection) and continued the close relationship with them; they also added that the level of HIV stigma in domestic spheres (e.g., exclusion) also depended on their previous relationships and individual context (e.g., only child).

The children who were aware of their parents' infection largely chose a concealment strategy for avoiding association stigma as well. In particular, they were most concerned about the possibility of exclusion from their peers. Depending on age, the children had heard of negative social discourse about HIV and tended to be distressed at the prospect of relatives or neighbours judging their parents. For instance, a 14-year-old rural girl commented:

A schoolmate wanted to play at my home, so I said I didn't have time this week or gave other excuses ... [cry] ... Since my junior-high years, I have known my dad was like this; I didn't want to let my classmates know. [cry] ... When I was in class, my dad came to see me and asked me to come out. I don't know if my classmates would ask me something ... Classmates could ask, and I don't know how to answer them [cry]. They may ask who it was, and what he came for ... So I don't know how to answer the questions. And a classmate may look at me with unusual sight [cry].

A 16-year-old son of an HIV-infected parent from a rural area pointed to

association stigma saying, "No one knows. I can't tell. If I tell, people won't interact with my family, even kids will be criticized." Another 16-year-old son of HIV-infected parents also commented on concealing his parents' illness saying:

I can't tell others about the disease. If you do, they'll look down upon your family. Even a little kid won't play with you. How can you dare to say? You can't talk about this kind of thing ... If you got a disease like TB and tell others, they might help you a bit, but this kind of disease, people will distance themselves from you.

The considerable degree of HIV stigma realized by family members may be rooted in the familism prominent in Chinese culture. Family members (e.g., grandparents) of our participants often took the children of the HIV-infected individuals from their parents to protect the future generation from those deemed "extremely contagious." Beyond having to cope with losing their children, critical support was also lost as the children did not generally hold or exert stigma against their HIV positive parents and expressed pain because of their illness.

Discussion

In this paper, we have demonstrated that PLWH in southwest China suffer substantially from HIV stigma exerted by close community members. In particular, given the dominant concealment strategy, the dynamic process of HIV stigma in domestic spheres represents the manifestation of HIV stigma in the daily lives of PLWH in China. Because the concept of HIV stigma in the region was closely associated with high contagiousness and fatality, which led to fear and exclusion of PLWH in the community, intervention programs should focus on stigma reduction through spreading knowledge of HIV. At the same time, they

will need to address the prevalent practice of blaming infected individuals by dismantling the understanding of HIV infection as a result of immoral behavior.

The current study indicates that family dynamics are a key component when examining the mechanism of HIV stigma. Some researchers have suggested culture as an important factor in determining the level of HIV stigma in a location. They argued that HIV stigma was stronger in Asian cultures because of the traditions of collectivism and familism (Chin and Kroesen 1999; Mason et al. 1995). As a result, PLWH in Asia usually conceal their infections to protect their families from shame and stigma, as it extends to the family and the larger local community (Yoshioka and Schustack 2001). Some previous studies also found that family members who took care of HIV-infected individuals suffered from stigma, such as ostracism, rejection and loss of friends (Scott 2009). As a result, families of PLWH were generally afraid of extended stigma (Bogart et al. 2008). A few studies conducted in other parts of China also showed that families of PLWH felt shame and humiliation (Songwathana and Manderson 2001), experienced exclusion from their neighbours (Alubo et al. 2002; Busza 1999) and felt stigma-driven shame towards HIV-affected families; this led to the families' social networks shrinking (Li et al. 2008). In the context of southwest China, which has a strong tradition of familism, an individual member could very likely bring shame and HIV stigma to the whole family.

However, the extended stigma of HIV problematizes a helpful link to aiding PLWH, as family can be the best source of social support for HIV-infected individuals in the cultural context of familism. Thus, outreach programs for the families of patients with HIV should be perceived as critical in the region. Previous studies have pointed to the positive effects of family support for patients with HIV. For instance, supportive

relationships with family members could reduce the level of HIV stigma that patients face (Lee et al. 2002) and families are the most important resource for female patients (Lekganyane and du Plessis 2012). In the same vein, the few cases of reduced HIV stigma within families among our participants indicate the possibility of alleviated HIV stigma in China. In addition, PLWH who are ostracized by their family have a higher level of internalized stigma and tend to have severe anxiety-related symptoms (Lee et al. 2002). Compared to other cultural contexts, the prevalence of families excluding HIV-infected family members as a proactive strategy to thwart extended HIV stigma seems considerably high in the Chinese cultural setting with its strong tradition of familism. Thus, the development of outreach programs targeting families is urgently needed.

Furthermore, culturally tailored programs need to be designed and implemented so that healthcare providers can completely overcome HIV stigma in the region. Some of our interviewees suggested that people in the region highly respected the opinions of medical doctors and commented that it would be very useful if these professionals talked to families. A few interviewees also mentioned positive effects of media, propaganda and education. Consequently, an effective HIV stigma reduction program will need to include various parties such as medical practitioners, health workers and schoolteachers.

While concealment appealed to the majority of our PLWH participants as the most feasible strategy in the social context, it posed various difficulties in the process, such as psychological distress, emotional hardship and mal-adherence to medicine regimens. Simultaneously, the fear of HIV stigma made people withdraw from possible social interactions and alienate themselves further, often leading to critically inadequate amounts of social support (Herek 1999; Holt et al. 1998). Our interviews indicated that

networking with other patients with HIV helped PLWH to normalize their disease and provided a certain level of relief. Because concealment of HIV infection usually leads patients into an isolated state (Herek 1999), creating a support system for PLWH seems necessary. A few studies have suggested the positive effects of networking among patients with HIV (e.g., Makoae et al. 2008), such as reducing the level of stigma (Lee et al. 2002); men who have sex with men (MSM) often have support networks and experience reduced levels of stigma as a result (Lichtenstein et al. 2002). PLWH in southwest China are also in need of help in forming their own networks. HIV stigma intervention programs in the future will need to focus on creating a strong support network for this marginalized population.

Loss of employment and a lack of social support further exacerbate the negative psychological effects of stigma (Altman 1986). Adequate social functioning and support has been shown to be vital for the healthy development of all human beings (Simon 2002). HIV-affected people often face economic difficulty, especially given the lack of support from their families and their societies (e.g., insurance, employment). Patients with HIV tend to experience exclusion from economic activity and thus experience financial instability (Braveman et al. 2006; Martin et al. 2003). Free distribution of ART to patients with HIV who are unable to pay for treatment will help to eliminate a critical component of HIV stigma – fatal mortality – and thus diminish the public perception that HIV is a chronic disease.

Given the current substantial level of HIV stigma and that patients' preference for concealment and isolation is unlikely to change soon, we need to develop services that can ensure patient confidentiality. Our interviews showed that PLWH were very sensitive and did not feel secure, even at local CDC offices. To that end, the adoption of new technologies, such as mobile devices (e.g., cell

phone, internet, phone services) as a means of outreach services (e.g., reminders for medical adherence, tracing health conditions, information about welfare and networking) may be a useful way to closely monitor whether patients take their medicine as well as support their mental health in the context.

While these conclusions stand, we need to be cautious with interpreting the results of the current study because of several limitations. First, the current study was a secondary analysis of data that was originally designed to study parental HIV disclosure. Consequently, the data might not be comprehensive about different experiences of stigma and various strategies for responding to HIV stigma. As pointed out in previous studies (Crandall and Coleman 1992; Bunn et al. 2007; Lee et al. 2002), there may be varying levels of perceived stigma among individuals affected by HIV in China. Second, our sample in this rural area may not be representative of PLWH in other regions (especially big cities in China). Third, our interviews were subject to reporting or recall bias. Despite these limitations, the current study is one of the few qualitative studies on HIV stigma experiences among family members in China and thus provides important insights for possible intervention strategies. More studies that clarify the link between HIV stigma and risk and protective behaviors for intervention, are needed.

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30
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Leadership in Nursing Management, Practice, Education & Research

Addressing Gaps in Mental Health and Addictions Nursing Leadership	23
Public Health Nursing in Promoting Infant and Early Childhood Mental Health	43
Using Technology to Assist with Transitional Care for Persons with Dementia	54
Digital Mental Health – Innovations in Consumer-Driven Care	63
Lessons Learned After Losing my Brother to an Overdose	73
Nurses Taking the Lead: Community Engagement and Knowledge Exchange	80
Patient Partnership: One Organization's Journey	93

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