

Understanding Family Support for People Living with HIV/AIDS in Yunnan, China

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Published online: May 31, 2006

This study examines how family support affects people living with HIV/AIDS (PLHA) in China. In-depth, semi-structured interviews ($n = 30$) were conducted with people living with HIV/AIDS who were infected through different routes (e.g., intravenous drug use, sex) and of different age groups. Findings showed that all of the participants were in great need of help and the primary source of support came from their families. Family support included financial assistance, support in the disclosure process, daily routine activities, medical assistance, or psychological support. This study illustrates that the support provided by family makes multiple levels of positive impact on people living with HIV/AIDS, suggesting the importance of including families in HIV/AIDS interventions.

KEY WORDS: family support; HIV in China; qualitative study.

INTRODUCTION

China has over one million people living with HIV/AIDS (PLHA). By the year 2010, China will have nearly 10 million PLHA, an anticipated growth of 30% each year (China Xinhua News Agency, 2002; France-Presse, 2002; Rosenthal, 2002). With one-fifth of the world's population (1.4 billion persons) and massive population migration (Tucker *et al.*, 2005; Wu and Zhou, 1996), the risk of a pandemic is substantial in China. In recent years, the Chinese government has recognized the substantial risk of HIV and has allocated resources to fight its spread (China State Council, 2001; State Council AIDS Working Committee Office and U.N. Theme Group on HIV/AIDS in China, 2004). Viable ways of delivering HIV interventions and culturally appropriate

intervention programs, however, still need to be identified and developed (Wang *et al.*, 2005).

Previous studies have demonstrated that when one member of the family has HIV/AIDS, the whole family feels the impact (Bor *et al.*, 1993; Pequegnat *et al.*, 2001; Rotheram-Borus and Lightfoot, 2000). The impact usually shows in many different aspects. First, economic hardships associated with HIV/AIDS can be devastating (U.N. General Assembly, 2005). Previous studies in China showed that companies fired employees because they tested HIV-positive (Cao *et al.*, 2005). The combination of the increasing cost of healthcare for PLHA and decreasing family income caused by unemployment may even hinder access to basic goods such as food, housing, medication, and education for children (China Nanfang Zhoumo News, 2004; Li, 2002).

In addition to economic hardship, families living with HIV usually face tremendous social pressure and discrimination. In Nigeria, when one member of the family becomes HIV-positive, the whole family will be called an "AIDS family" by other villagers (Alubo *et al.*, 2002). Everyone in the family experiences shame when being treated discriminatorily by members in their social network. In Thailand, if the status of a PLHA is disclosed, the whole family fears

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losing face (Songwathana and Manderson, 2001). This is especially true in a family-oriented society like China.

When facing societal discrimination and other hardships related to HIV/AIDS, a strong and supportive family is one of the first lines of defence. Bor *et al.* (1993) suggested that when parents are too sick to take care of children themselves, the grandparents usually become the primary caregiver for their grandchildren. In Thailand, as well as many other countries, families affected by HIV/AIDS provide psychological and economic support to their infected family members (Manopaiboon *et al.*, 1998). On the other hand, in a study conducted in Mexico, Castro *et al.* (1998) argued that the majority of family members displayed negative responses to a family member's HIV diagnosis. In this case, HIV became a catalyst of pre-existing family conflicts.

Studies have shown that disclosure of HIV-positive serostatus can result in greater social support (HDN Moderation Team, 2005), which in turn has positive effects on psychological well-being (Ostrow *et al.*, 1989; Zich and Temoshok, 1987). Sethosa and Peltzer (2005) found that social support, especially family support, was significantly related to disclosure of HIV status in South Africa. In a cohort study in the southern United States, greater family support at baseline was found to be predictive of positive changes in physical health and social functioning among PLHA who were on highly active antiretroviral therapy (HAART) (Jia *et al.*, 2005). Burgoyne (2005) found that PLHA consistently taking HAART, experienced better clinical benefit if they perceived available social and family support. Another study has shown that family support is predictive of reduced risk behaviors among HIV-positive gay men (Kimberly and Serovich, 1999). However, to date there has not been a paper published in an English journal showing the role of family support for PLHA based on systematically collected data from China.

China is a family-oriented society. Given the potential risk of a HIV/AIDS pandemic in China (The U.N. Theme Group on HIV/AIDS in China, 2002), and the important role families play in the life of PLHA, the need to study families living with HIV is clearly presented. A good understanding of the role of families in the lives of PLHA can better inform the design of an HIV-related intervention, and also make existing programs become more accessible to the targeted population (Bor *et al.*, 1993).

This study takes the first step toward understanding the role of family support in the lives of PLHA in China. If the family is supportive, what are the dimensions of such support, and what positive impact does family support have on PLHA? Finally, we explore the role of families in the development of an effective HIV intervention targeting PLHA in China.

METHOD

Procedures and Participants

The study collected qualitative data from three different sites in Yunnan province, China. Bordering Myanmar, Laos, and Vietnam, Yunnan has the highest number of reported HIV infections in China (40% of all reported HIV cases) (State Council AIDS Working Committee Office and U.N. Theme Group on HIV/AIDS in China, 2004; U.S. Embassy, 2000). The recruitment procedures were built upon experience gained from previous and ongoing projects in the area. Informational materials about the study were made available in local clinics/hospitals that treat HIV patients. Service providers who treat HIV-positive patients were also informed of the study. A Community Advisory Board was formed to provide consultation on cultural appropriateness, applicability of the study design for the population, and administration. The Board was composed of officials from the provincial Health Bureau, health providers from the Department of Infectious Diseases of provincial hospitals, administrators from local Centers for Disease Prevention and Control (CDC), PLHA, and their family members. Before interviews were conducted, revisions were made according to suggestions provided by the Board.

Thirty in-depth interviews with PLHA were conducted between March and July, 2004. Each interview was conducted in a private room on a one-on-one basis for 1–2 hrs. At the time of interviews, all HIV-positive participants knew about their serostatus for a minimum of 3 months. During the interviews, participants were asked open-ended questions about personal and family experiences with HIV/AIDS, disclosure, HIV-related stigma and response, and health/treatment services. To allow flexibility and spontaneity as new content was revealed during interviews, interview questions were not required to be asked in the same order

or wording as in the interview guide. However, all questions in the interview guide were covered during the course of each interview.

All interviews were transcribed by one project staff member and the quality of the transcription was cross-checked by another staff member. A local project staff member, fluent in the local dialect, transcribed the interview when local dialect was used. Transcripts were then translated into English for data analysis.

Study participants were recruited by referral from different organizations, such as local non-governmental organizations (NGOs) (13%), hospitals that treat HIV patients (27%), and through snowball recruitment (7%). The majority of the participants were recruited through HIV clinics at provincial and local CDC sites (53%).

The majority of HIV-positive participants were between the age of 20 and 39 (93.4%), and about a third were women (36.7%). Most of the PLHA attended junior high school (70%), only one-fourth of the participants were married, 63% of the PLHA were unemployed, and the majority (76.7%) were from urban areas. Over 73% of the participants reported that they were infected through injection drug use. Based on the 2003 Yunnan CDC sentinel surveillance report (Yunnan Center for Disease Prevention and Control, 2004), the characteristics of the interview participants and PLHA in the general population were comparable in terms of gender, age, employment status, and HIV infection route.

Data Analysis

The research team developed a code list for data analysis. A total of 63 codes and 18 code “families” (a group of codes with the same theme) were created based on the questions in the interview guides and examination of the actual content of a number of interview transcripts. In order to reach better inter-coder reliability, one transcript was coded by the team together and the definitions of code categories were then fine-tuned (Sandelowski, 1986).

To facilitate theme development, the transcripts were organized into smaller groups. Groups were created for people who were infected through drug use and for people of the same gender, age (20–29, 30–39, 40 and older), and marital status (single, married, divorced). These groups were helpful in comparing differences within and between groups. For example, the kind of family support female

participants received was compared to the family support male participants received. Consistency of experiences within each group was also examined. For example, one injecting drug user (IDU) participant’s description of discriminatory experience could be compared to another IDU participant’s. ATLAS.ti (version 5.0) (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to analyze the data (Muhr, 1997).

RESULTS

Examining the interview transcripts through the code and text search, three central themes relevant to the study objectives were identified: (a) Need of family support, (b) dimensions of family support, and (c) benefits of family support on PLHA as well as on the family. All of the participants were in great need of help. The primary source of support came from their family. The family usually went through different stages in the process of providing support. When the HIV status of a family member was revealed, the family as a whole would experience shame, social and psychological pressure. The shame and pressure in turn influenced family relations. Participants mentioned limited or restrained interaction with family members, e.g., “[my family members] are afraid to hurt me. But I, myself, also try to avoid even common contacts in everyday life” (Single male, age 34).

In many cases, increased psychological burden on family members pushed the family to stay closer together than ever before and at the same time provided a wide dimension of support to the PLHA. Family support starts with the disclosure process and helping PLHA to cope with HIV/AIDS. The families also provided financial assistance, support in daily routines, medical assistance, and psychological support.

Evidently, the support provided by families made multiple levels of positive impact on the PLHA. As a result of family support, PLHA made important decisions, such as being tested for HIV, taking medication regularly, and enrolling in HIV-training programs. On the other hand, the positive impact on PLHA also benefited family relations. PLHA regained hopes for their future and valued their families more. One single male participant (age 31) said, “I feel that [my family members] support and help me so much. I could have died without them.”

Need of Family Support

We identified several areas related to the need of family support for PLHA. First, the whole family experiences shame both within and outside the family when one member is HIV-positive. Most families were afraid of being discovered and discriminated against. In order to keep the secret within the family, the family usually made a collective effort to face outside pressure. In some cases, family members who knew the situation also kept it a secret from other family members. Consequently, family relations changed, causing family members to feel isolated and/or restricted when they interacted. For example, some PLHA demanded to use their own set of eating utensils and put their food in separate bowls. Considering Chinese culture is family-oriented, and eating is a principal gathering activity for many families, eating from separate dishes can put the PLHA in an awkward position.

Family Shame

In most Asian cultures, a widespread social phenomenon is the presence of a “face” mentality (inclination to put up a front to save face). Songwathana and Manderson (2001) found that in Thailand, both the PLHA and their family members were afraid of losing face and bringing shame to the family because one member of the family was HIV-positive. The situation is similar in China. To most people in China, HIV/AIDS is associated with promiscuous sex and drug abuse, both of which are considered to represent low moral status. A sense of family shame is referred to in many interviews with our participants, and a common strategy to avoid it is to keep it a family secret:

I have worries. I really have worries about my family. People like my mom living in those small towns, the education level... must be lower... in small cities, I think, usually even when nothing happened, people would talk about you, spread rumors of you, criticize and gossip you. If you really have such a thing now, I don't know what to do (single male, age 37).

People in our village like gossip, don't they? Once they talk about it, my family will be influenced. My parents are still there! My family will be discriminated and influenced, and will be looked down. So I never told them, I didn't tell my friends either (married female, age 22).

My psychological pressure is big in this aspect. I first considered what effects this will have on my offspring, my children... If the thing [that she is HIV positive] was spread, it would be a huge problem. My children would be affected at work and all other aspects too. It is certain that they would be affected. I think... I think so (married female, age 56).

In addition to family shame in the community, in some cases, the sense of family shame is also present within the family itself. One woman who was a drug user mentioned that she did not want to disclose her HIV status to her family:

Because I had been using drugs for many years, I've already hurt my family members too much. I don't want to... Now I have just stopped [using drugs] for two years, my parents are proud of my little achievement. I can't give them another attack. They have just felt relieved. This attack, I think, is more brutal than my drug using (single female, age 28).

A female participant was told by her family not to disclose her serostatus to her younger brother.

It was my families who told me not to tell [my brother], because he is now over 30 years old and not married yet, and he does not have a good job either, no achievement. They were afraid that if I told him the thing [her serostatus] it would affect his job and his life. So they told me not to tell him. Yeah, because he is not married yet, if he knows, or some of his friends know, if he wants to have a girlfriend, I think it will certainly affect him (single female, age 30).

Family Relations

HIV also impacts the family on how the members interact with one another. Some families try to avoid discussion of HIV/AIDS-related topics and the family members feel uneasy when HIV-related words were mentioned.

Before... for instance, with my families, say my mother and my sister, I was laughing and joking and had no worries and I told them what I thought. But now I try to avoid... as if they also avoid talking about this sensitive topic [HIV] on purpose. They are afraid to hurt me. But I myself also try to avoid even common contacts in day-to-day life. These things are invisible. It could be that we are all trying to protect each other. But somehow this invisible force has created something between us. I just can't quite describe the feeling (single male, age 34).

Many participants expressed concerns of accidentally infecting their family members. They

requested to eat alone although their family members did not ask them to do so, and they understood that eating together would not spread the virus.

For example, at home, that day, I brought it up by myself, that is, including my own bowls and chopsticks, I put them on other places. I don't want to put them with my parents' and my sister's. Originally, we put them together. Washing dishes, they always did so for me. . . Now I thought it over, and I want to try to avoid what could be avoided (single female, age 26).

I don't live with my parents, but I go there often, I go to my parents' home often. We use bowls and utensils separately. I just use my own bowls and utensils, I use my own. I suggested that by myself. They are not afraid (married male, age 38).

In addition to affecting interactions between family members, having an HIV-positive family member also affected the way the family interacted within its community.

My mom said that because she knew I had the disease, when there were guests at home, she would prepare a special pair of chopsticks for me. That is to say, when I got dishes, I would use another pair of chopsticks, use the public chopsticks. It doesn't matter whether it's transmittable, once they know that someone with the disease used the chopsticks to get food from the same dish, they dare not to touch it. Anticipating this, we do these things ahead of time. It doesn't matter whether they know or not, I just do so. [This way] even if they know, they won't blame me. It's not a big deal, but I would be uncomfortable in the heart if I heard [them blaming me] (single male, age 26).

Dimensions of Family Support

Most of the family members knew the participant's HIV status by the time the interviews were conducted. All of the 30 participants reported the benefits of family support from their immediate family members (parents and siblings). In some cases it took some time for the family to process the information about the HIV status of the family member and adjust to the change, but at the end they were always supportive. This is true across participants of different infection routes, gender, and age. Many of the families that the study participants came from were providing a wide range of support to their HIV-positive family member. In our analysis, we categorized several dimensions of family support: Support during the disclosure process, financial assistance,

daily activities, medical care, and psychological support.

Support During the Disclosure Process

Because of belief in strong family support in coping, many service providers first inform PLHA's family members of their HIV status (Li *et al.*, 2005). Then in some cases, instead of the service provider, it is the family member's responsibility to inform PLHA.

[The doctors] didn't inform me when they found out [of my serostatus]. They only informed my families, which were my elder sister and my mother, my father, and my younger brother. They all knew it. . . They didn't tell me at that time, and didn't tell me for a long time. I didn't know. . . Until about four months later. . . I remember it was my mother, my mother who told me (divorced female, age 39).

After learning the status of the PLHA, family members tried to find a way to inform the PLHA about their HIV status and support them. One female participant's family members knew about her HIV status 1 year before she did. During this 1 year, her brother, who was also HIV-positive, disclosed his status to her. The participant consoled her brother when he was depressed and learned more about HIV/AIDS. A year later, she finally learned that she was also HIV-positive:

I never imagined I could be that desperate when I knew I was also infected. But anyway, because my younger brother was worried that I couldn't accept it, he had told me about his situation first. This helped me prepare myself psychologically. At the end, it was better. It wasn't [like what they thought that I] couldn't accept it all at once (married female, age 34).

When PLHA participants are the first to know, most of them first disclose their status to a "key" family member, usually a spouse if married, sisters and brothers, but not parents, and then the "key" family member will inform the rest of the family:

[Only one of] my sisters knew it. . . At first, I didn't want to tell her, but I thought about it later that after all she is my sister, so I told her. . . Now my all three sisters know it (single male, age 37).

Financial Assistance

Nearly 65% of our participants were unemployed and were supported financially by their families (living expense, cost for medication, etc.). One married female participant (age 34) explained, “I found my income was too little to support myself. I still need my family to make up the difference for me.” Another single man (age 27) said, “My economic condition is really bad now. . . I’m totally dependent on my parents’ income.”

I heard from my sisters, it’s in last week, or last month, that they told my mother about my situation. I called [my mom] one day, and she said she knew what happened to me. She said she did not blame me. But she said that as I was in this situation. . . she’s decided to sell the house in order to get treatment for me (single male, age 37).

Support in Daily Activities

The majority of study participants lived with family members, and the family members took care of them: “My parents are. . . whatever I want to eat, they always, they always satisfy me, just like this kind of painstaking caregiving. . .” (divorced female, age 39). Families living with PLHA who have kids sometimes also provide regular childcare: “After my child was one year old, I took him, took him to [city X, he was] brought up by my mother and father. . . [my parents] often take care of my child” (divorced female, age 39). “[My daughter] was taken care of by my parents” (divorced male, age 42).

Medical/Healthcare

Family support also included assistance with regular medical and healthcare. Participants were accompanied by their family members to the doctor’s office for viral load testing and other medical tests. “My sister, my sister usually comes [to treatment clinic] with me” (divorced female, age 39). Many family members exhausted all means looking for a medical cure for PLHA.

My mom was very desperate at the beginning. She always cried when my dad and I were not present. They had discussed how to find cure for me, and help me. They tried every method shown on TV and newspapers. . . They looked for new medicines for me, and went to wherever there were therapies of lymphoma. Ah, my parents, I owe them a lot, but I

have little chance to pay them back (single male, age 32).

Some family members tried to accompany the PLHA to the hospital when they were sick. “Since my husband knew I was infected with the disease, he stayed in the hospital with me every day” (married female, age 56). Family members also helped PLHA to pick up prescriptions in order to help them comply with their medication.

Generally my younger sisters come to help me [with medicines]. . . My younger sisters help me resolve problems of medicine. . . Sometimes, that is to say, they go to get the prescriptions. Sometimes, they get the prescription, and then call me to pick it up. . . Even before I ask for, [my sisters] have already got the prescription and ask me to pick it up. It’s always like this (divorced male, age 42).

Psychological Support

Families also provided psychological support and always let PLHA know they were loved and important.

Our family has two houses. The one we are living in now is the new one. I told them. . . , “I have the disease, and I’m afraid to transmit to you.” [I feel] I should protect them. I was afraid of staying together every day. It’s enough I myself had it. I told them that I wanted to live in the old house by myself. They refused resolutely. [My parents] said, “You are my son. No matter what disease you have and how you are, we won’t dislike or abandon you” (single male, age 25).

My mom, since I got the disease, has accompanied me all the time. (Participant started crying.) Though her hair is grey. . . she is almost seventy, she told me ‘you must be strong. For us, for your child, you have to live with strong mind’ . . . my mother and my family all understand me very well. They said, ‘You have to be strong, you have to be brave. . . You are also a victim. You are innocent’ (divorced female, age 39).

Positive Impact of Family Support

The support provided by families made multiple levels of positive impact on our participants. As a result of family support, PLHA made important medical and treatment decisions. Conversely, the positive impact on PLHA also benefited the family relationship. PLHA regained hopes for their future and a positive attitude toward life in general. One married female participant (age 34) said, “My family treats

me very well. I think people like us can't live without the family's care. Really, I can't be here today without my family's love."

Impact on PLHA

With family support, many of our participants expressed positive behavioral and attitude changes in their lives. Family members persuaded several participants to be tested for HIV. One female participant explained how initially she did not want to take the HIV test, and her father convinced her to do so:

It may be because what my father said [I took the HIV test]. My dad said, 'you can know what is going on if you have a test. If you were infected, we should have a family meeting with all the family members, ourselves, parents, and sisters, should have a meeting to discuss how to protect them.' Starting from this point, I thought, I should have a test, if I was infected, at least I could know how I should protect my family in my daily living. So I finally agreed to take the test (single female, age 28).

Many PLHA enrolled in HIV-training programs because of the support of family members. One female participant had a negative view of the healthcare field, and she tried to avoid any interaction with the healthcare professional and self-support groups. Because of her father's persuasion, she overcame her prejudice and enrolled in an HIV-training program:

I was not very proactive [participating in HIV-related programs] at that time. At that time I still took it as a taboo. Forget about the people from Red Cross, the people from CDC, I hated them. I could become disturbed even when they looked at me. I didn't want that. I didn't want to contact them. . . . But later, my dad said that you could go [to the HIV training sessions] because they would teach you knowledge about how to take better care of yourself. I felt good after I joined the session. (married female, age 34).

Family members took care of many of the PLHA when they were sick. This made an enormous difference, both psychologically and physically, on PLHA. A divorced female participant (age 39) described how she recovered from an illness because of the care of her family members:

They. . . my elder sister and my younger brother, took one month off to accompany me all the time because last year, in last September, my condition worsened again. After I got to Hospital X, the doctor said it was incurable and already in late stage. So [my families] tried to comfort me, and accompany

me. . . they encouraged me. . . they all encouraged me. As a result, after I fought with the disease for two months, gradually, I recovered.

Impact on Family Relations

One participant described how her relationship with her husband was improved as a result of her disclosure. Her husband knew about her serostatus before she did, but both kept it a secret from each other for a year. Because of this secrecy, their relationship suffered. After she finally disclosed her status to her husband, her husband also felt relief and their relationship improved:

[Before] We had slept separately and [my husband] hadn't taken much care of me. Then I realized when I told him I was HIV-positive, he could throw away many of his worries. Contrary [to common beliefs], we had better relationship. Because then we knew how to face it in the right way. For example when we had sexual contact, we could wear condoms above-board, unlike what we had done before. I hadn't known I was HIV-positive and he hadn't dared to tell me. If he wanted to have sex with me, he would fear transmission. I would have felt strange if he wanted to wear condom. . . . So, I think it's better to tell him, and since then we always use condoms. I felt we had much better relationship than before when I hadn't told him (married female, age 34).

More importantly, the family support helped PLHA to develop a sense of responsibility, and therefore changed their thoughts about HIV and their future. One male participant infected his wife before he realized that he was HIV-positive. He recalled:

Tearfully my wife told me, 'we are husband and wife, this is determined by our fate.' Shared misfortune brought our hearts closer. It was because of this altruistic love from my family, I was able to build up confidence to continue living my life. . . . Then later, I heard [my wife] was infected by me. If I left the world, what could she do? What could she do? She may live with me, so she has a little hope; if I left the world, she was really. . . . Considering this, I regained my strength [to live] (married male, age 32).

DISCUSSION

Past research has demonstrated that HIV/AIDS is a family disease: When one member of the family has HIV/AIDS, the impact radiates through the entire family (Bor *et al.*, 1993; Pequegnat *et al.*, 2001;

Rotheram-Borus and Lightfoot, 2000). When facing hardship related to HIV/AIDS, a strong and supportive family is one of the first lines of defence. In this paper, we examined the need for family support, dimensions of family support, and positive impact of family support on families affected by HIV in China.

To most people, HIV/AIDS is still associated with promiscuous sex and drug abuse, both of which are considered representative of low moral status. In Chinese culture, it is socially acceptable to treat people of low moral status disrespectfully and sometimes even discriminatorily. Consistent with previous research findings from other countries (Bor *et al.*, 1993; Songwathana and Manderson, 2001), most Chinese families living with HIV experienced shame both within and outside of their families. During difficult times, it becomes particularly important for families to stay close and to help and support each other. As our study shows, families in China indeed provide a wide range of support to HIV-positive family members. Family support starts with the disclosure process, and may include financial assistance, help with daily activities, medical assistance, and psychological support.

Family support benefited our participants in many different ways. Family members helped PLHA make important decisions, such as taking an HIV test and enrolling in HIV-training programs. Family support can also have significant implications for HIV interventions and programming. Recently, the Chinese government launched the “Four Free One Care” national campaign aimed at providing free medical assistance to PLHA who cannot afford to buy AIDS drugs (State Council AIDS Working Committee Office and U.N. Theme Group on HIV/AIDS in China, 2004). Regardless of its intentions, the policy will also face the challenges of participant recruitment and medication compliance (State Council AIDS Working Committee Office and U.N. Theme Group on HIV/AIDS in China, 2004). Based on the findings of this study, the government can achieve a higher rate of participation and compliance from PLHA by recruiting and educating family members to facilitate the process. Potentially, family members can act as advocates for the policy and encourage PLHA to participate in interventions and take medications on a regular basis.

Furthermore, as HIV/AIDS is a family experience, a family-focused intervention is needed in China. Our data revealed family members often are the first ones to be informed of a loved one’s HIV status. This suggests the need to include components

such as teaching families how to deal with HIV disclosure within the family and community and how to cope with stress and the burden of being a caretaker. Our data show that when PLHA voluntarily disclosed their HIV status, participants usually disclosed to their spouse if they were married and siblings if they were single, rather than their parents. This finding is consistent with a study conducted in Virginia, United States, which showed that PLHA are more likely to seek help from and less likely to display avoidance behavior with intimate partners than parents (Derlega *et al.*, 2003). This suggests that siblings and spouses of PLHA are probably a good target audience for a family-focused intervention.

Our findings seem to suggest major differences in PLHA’s support network in China versus the United States. Contrary to studies conducted in the United States among HIV-positive gay men (Bor *et al.*, 2004), families, rather than a social support network, played an essential role in the life of PLHA. At the same time, PLHA in China also rely heavily on their families for material and psychological support. The difference may be a result of a different target population. While many of the studies done in the United States are focused on the gay community, only one of our participants was a homosexual man. IDU participants in our study were also more reliant on their family support, rather than a social support network, as has been proven in the United States. For example, Smith and Rapkin (1996) reported that HIV-positive injecting drug users in the U.S. relied on friends and family almost equally. Our data suggest, however, that IDU participants rely more on their family for support than on their social network. Of the 19 IDU participants, 63% of them voluntarily disclosed their status to their family members and only 37% of them disclosed to someone other than a family member. Contrary to the findings of Derlega *et al.* (2003), participants in this study were more likely to seek support from family members than from friends.

There are some limitations to our research. The study was conducted in Yunnan province in China, with most participants infected through intravenous drug use (over 73%). Since drug use is highly stigmatized in Chinese society, it is likely the families affected by HIV had already experienced stigma as a result of the PLHA’s drug use. This stigma placed double burden on these families, and it may have differentiated these families from other families who were only affected by HIV; therefore, one should be cautious when generalizing the results to other

populations. Despite the disparities, the general family dynamic still applies to most families living with HIV in China, and the findings are important for designing future HIV interventions.

ACKNOWLEDGMENTS

This paper was completed with the support of National Institute of Mental Health grant R01MH070931.

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