Published in final edited form as:
Fam Syst Health. 2008 December ; 26(4): 431–442.

Impacts of HIV/AIDS Stigma on Family Identity and Interactions in China

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Abstract

This study examines the impact of HIV-related stigma on families living with HIV/AIDS in China. In-depth, semistructured interviews were conducted with 30 people living with HIV/AIDS and with 15 of their family members, including spouses, parents, and siblings. Findings show that HIV-related stigma is associated with bringing shame to the family, losing family “face,” and damaging within-family relations and broader family social networks. HIV/AIDS stigma was reported to have major impacts on family identity and interactions. In order to cope with these pressures, families reported joining self-support programs, educating family members, and helping other families. This study illustrates that HIV-related stigma is an issue faced by entire families in China, points to specific aspects of family life in which these impacts take place, and suggests the importance of including families in HIV/AIDS and stigma reduction interventions.

Keywords

HIV/AIDS; stigma; family relations; China; qualitative research

Worldwide, people living with HIV/AIDS (PLWHA) have multiple sources of stress: the disease itself, financial burdens, stigma and discrimination, pressure from worrying about family, and so on. Clinical and empirical findings suggest that family can be a significant source of stress to women with HIV (Joseph & Bhatti, 2004), with the burden associated with family stress being second only to that of the disease itself (Jones, Beach, Forehand, & Foster, 2003; Rotheram-Borus, Robin, Reid, & Draimin, 1998; Semple, Patterson, Temoshok, & McCutchan, 1993). To better understand and improve the well-being of PLWHA, it is important to study their families.

Families of individuals living with HIV/AIDS often experience HIV-related stigma and discrimination because of their association with the infected family member. The stigma results not only from being HIV positive, but from risk behaviors that bring the disease (such as drug use and commercial sex), a concept often referred to as *double stigma* in the literature. However, this pattern is less likely to hold for other non-infectious illnesses. In Nigeria, when one member of a family becomes HIV positive, the whole family is called an *AIDS family* by

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other villagers (Alubo, Zwandor, Jolayemi, & Omudu, 2002). In Indonesia, entire families have reported experiencing rejection by their local communities because of the positive HIV serostatus of one member (Busza, 1999). A study by Songwathana and Manderson (2001) in Thailand showed that if the status of a PLWHA is disclosed to the community, the entire family fears losing face. The social network in Thailand often treats entire families discriminatorily because one member is HIV positive. As a result, a whole family, in addition to the PLWHA, often feels shame and humiliation. Other studies have also reported similar findings regarding the impact of HIV on the whole family (Boyd-Franklin, Steiner, & Boland, 1995; Pequegnat et al., 2001; Pequegnat & Szaponick, 2000; Rotheram-Borus, Flannery, Rice, & Lester, 2005; Schuster et al., 2000). Bor, Miller, and Goldman (1993) pointed out that a strong understanding of the role of family in the lives of PLWHA can better inform the design of HIV-related interventions and make it easier for PLWHA to access existing programs. More and more studies have shown that in order to be successful, services and programs for PLWHA need to appropriately and effectively involve their families (Harvey & Wenzel, 2002; Joseph & Bhatti, 2004; Rotheram-Borus et al., 2005; Zhou et al., 2004).

Because China is a family-oriented society, many individual experiences become, or are inseparable from, family matters. It is unfortunate that the whole family is often stigmatized because family is held responsible for the behaviors and lifestyles of individual members. As a result, unhealthy behaviors may be considered to be traits shared by the entire family, or more often the case, the family is blamed for not correcting the risk behaviors before they led to HIV infection.

This characteristic is exemplified by the attribution of responsibility related to injection drug use, one of the dominant routes of HIV infection in China. Drug use is commonly seen as a primarily individual decision and a more personal experience in most Western cultures (Derlega, Winstead, Oldfield, & Barbee, 2003). The case is very different in China. Zhang and Chen (1996) reported that most parents of injection drug users (IDUs) in China took personal responsibility for the fact that their children were using drugs. Many of the parents reported feeling psychological pressure and shame in front of their neighbors and friends. Similarly, HIV status disclosure, commonly viewed as a personal decision in Western cultures (Fehr, 1996; Gaines, 2001; Levinger, 1980; Rawlins, 1992), is considered more a family matter in China (L. Li et al., 2007). Consequently, an individual’s infection status becomes a source of stigmatization for the whole family. In China, PLWHA often depend on financial and psychological support from their family, as well as assistance in daily activities. At the same time, PLWHA worry about bringing shame and harm to their family, a complicated and challenging dilemma for the individual and the family (L. Li et al., 2006).

HIV-related stigma has been recognized as a major barrier to HIV prevention, treatment, and care. HIV-related stigma and discrimination have a direct negative impact on the quality of life for PLWHA (Lieber et al., 2006; UNAIDS, 2003). However, most research on HIV-related stigma has focused on discriminatory attitudes toward PLWHA, under the assumption that stigmatization is about individuals or groups who share similar undesirable attributes. This study takes the first step in understanding the dimensions of HIV-related stigma in a family context in China. Beyond focusing only on individual PLWHA, we explore the experiences with and impact of HIV-related stigma on the family and various coping strategies used by families living with HIV/AIDS.

METHOD

Study Setting and Procedures

This study was conducted in three districts in Yunnan, an area with the highest number of HIV infections in China. The first epidemic of HIV infection was identified in Yunnan along the

Myanmar border in 1989 (Ma et al., 1990). By the end of 2005, Yunnan had more than 40,000 reported HIV cases distributed over 115 counties (Yunnan Center for Disease Control and Prevention, 2006). Among the reported cases, 88% had been infected through sharing of needles, and 75% were ages 15 to 29 years old (J. H. Li, 2002). The three study district sites have populations ranging from 500,000 to 45 million. At two of the sites, the Han ethnic group comprises a majority of the residents; the third site was primarily populated by minority ethnic groups (National Bureau of Statistics of China, 2004).

A community advisory board (CAB), consisting of officials from the provincial health bureau, service providers and administrators from local hospitals, family members of PLWHA, and local advocates, provided consultations on the study's cultural appropriateness, applicability of design for the target population, and administration. PLWHA were recruited from local clinics and hospitals that treat HIV patients and local nongovernmental organizations (NGOs) through flyers and informational materials. PLWHA who expressed interest in participating were referred to project staff members for more information. Family members of PLWHA were referred by participating PLWHA to project staff members for participation. The study fulfilled all human subject guidelines, including the use of informed consent to obtain participation, and was approved by the Institutional Review Board (IRB) at China Center for Disease Control and Prevention (CDC) and University of California, Los Angeles (UCLA).

One-on-one interviews were conducted with 30 PLWHA and 15 family members of PLWHA between March and July 2004. All PLWHA participants had known their serostatus for a minimum of 3 months at the time of the interview and all family member participants had learned of their family members' HIV status prior to the interview. Interviews were held in private rooms and lasted approximately 2 hr. The interview guides were developed by project staff, with feedback from the CAB. The interview consisted of open-ended questions about personal and family experiences with HIV/AIDS, disclosure, health and treatment services, HIV-related stigma and their responses to the stigma, and discrimination. To allow flexibility as new content was revealed during interviews, interviewers were not required to ask all questions in the order they appeared in the guide, but assured that every question was asked of every participant. The interviews were audiotaped and transcribed, with an independent staff member cross-checking each transcript for quality assurance. For those interviews conducted in the local dialect, a staff member fluent in the local dialect transcribed the interview. Transcripts were translated into English before data analysis.

Study Participants

The majority of HIV-positive participants were between the ages of 20 and 39 (93.4%), and about a third were women (36.7%). Most of the PLWHA had attended junior high school (70%), only one fourth of the participants were married, and 63% of the PLWHA were unemployed. The majority (76.7%) of the PLWHA lived in an urban area, and about one third of them had children.

Fifteen PLWHA family members agreed to be interviewed, and about one half of them were female (53%). More than half of the participating family members were parents of a PLWHA (53%), about 20% were siblings, and 13% were spouses. The average age of the family members was 51, and more than one half of them had an education of junior high school or below. Almost all of the family members were married.

These PLWHA families are often marginalized even before the detection of HIV/AIDS, because certain household members, or in some cases the whole family, are involved in drug use. These families are disproportionately drawn from those with inferior socioeconomic status. As a result, poverty usually represents one of the problems facing these families.

However, these are our speculations based on the literature. The data do not provide adequate information to further examine the PLWHA families.

Over 73% of the participants reported that they were infected through injection drug use (IDU); 23% were women, and 50% were men. On the basis of the 2003 Yunnan Center for Disease Control sentinel surveillance report (Chinese Center for Disease Control & Prevention, 2004), the proportion of IDU transmission was comparable with PLWHAs in the general population. Less than one quarter (23%) of the participants were infected through sexual contact, by spouses or heterosexual partners. Of the 30 participants, only 1 was infected through homosexual contact. Many of the IDU participants had used drugs for more than 4 or 5 years. No case was contracted through blood transfusions. Of the 11 female IDU participants, only 1 mentioned her husband’s drug use as the reason for her infection. In our sample, the average length of participants knowing their HIV status was 17 months for male IDU participants and 39 months for female IDU participants. Male non-IDU participants knew their status for an average of 19 months and female non-IDU participants for 23 months.

Data Analysis

The qualitative data were explored for content that identified and elucidated the key issues expressed by the study participants. A coding system was developed through an iterative process involving the definition of core themes and an evaluation of how the themes captured the content of the actual interview transcripts; the code system was constructed. Intercoder reliability was developed via a consensus approach. Coding was done first as a team until each code definition and application criterion was documented and understood consistently across team members. Once consistent application of codes by all coders was demonstrated, the remaining transcripts were coded (Sandelowski, 1986). ATLAS.ti, version 5 (Muhr, 2004), was used to manage, code, and analyze the data. Analyses were performed by identifying and coding meaningful and consistent themes across transcripts and then exploring the subtleties within each. Our focus is to provide a general picture of HIV stigma and related issues at the family level. We do not further distinguish between different modes of transmission because of the lack of sufficient data in each category, in particular with respect to homosexuality and blood transfusion.

RESULTS

This study provided further evidence that HIV-related stigma goes beyond individuals’ experiences and affects the whole family. It is so powerful and pervasive that it influences a family’s identity, family relations, and social networks in the community. While some families succumb to the damage that the stigma can cause, other families respond with resilience and do their best to overcome the barriers caused by the stigma. Three main themes related to stigma emerged in the data analyses: issues of (a) family identity, (b) family network, and (c) social support seeking. All reports of the stigmatization experience were based on self-reports that include actual experience and fear.

Stigma and Family Identity

Stigma impacting on family identity was understood through two dimensions: shame and “face.” Traditional Chinese collective culture calls for self-sacrifice for parents and ancestors and emphasizes an individual devotion to the family (Tsui, 1989). Just as a family is judged to be responsible if a child has bad manners, family is also considered responsible if an adult member contracts HIV. For a family living with HIV/AIDS, shame is a shared burden. HIV/AIDS is a disease that causes the entire family to lose face in the community. This shame can alter their family identity and cause the family to become too ashamed to go out and socialize. While in China, family identity is also constructed on the basis of other socioeconomic elements such as education, occupation, and wealth, having a HIV-positive family member does not necessarily jeopardize these aspects of the family unit. The impact of stigma is mostly felt with respect to shame and “face” because of the belief that HIV is associated with “bad” behaviors.

Bringing Family Shame—One of the major fears reported by PLWHA was bringing shame to their family. Family shame was reported to be relevant to (a) a societal belief of the immorality of behaviors of PLWHA, including drug use and promiscuity and (b) a belief that AIDS is a “terrible disease” that is incurable and easy to transmit. In the collective culture of China, the community commonly holds the family responsible for the behaviors of the individual members of the family. That is, when one member violates a social norm, the whole family will be blamed. Consequently, fear of bringing shame to family becomes a heavy psychological burden to PLWHA. The following are some examples.

> My psychological pressure is big in this aspect. I first considered what effects this will have on my offspring, my children. . . . (Married female PLWHA, age 56)

> People would try to avoid you as soon as they know. How could I tell them? Nobody would talk to you then, and nobody would visit your home, either . . . . They would probably say, “hmm, this girl is not good, otherwise how could she be infected?” They would not talk to you. (Married female, age 57; mother of a single female PLWHA, age 30)

Some PLWHA participants mentioned that if other people knew of their status, it would be “bad” and “difficult” for their family to continue living in the same place, and other people would avoid and “look down” on the family. Their reported concern for family well-being appears an overwhelming experience, and protecting family identity becomes a major concern.

> I’m just worried—worried that after [our neighbors in the village] knew, it would be bad and inconvenient to my family, family or relatives around, right? It would make them . . . hum, anyway, anyway, most villagers, that is, some, that is, couldn’t accept the problem. If they knew, oh, the whole village would know. It would be difficult to live there [for my family], right? (Married female PLWHA, age 56)

A younger brother of a PLWHA even suspected that the neighbors would manipulate his family shame when in conflict with his family:

> I live on the upper floor. If I made some noise and disturbed [my neighbor], they would go upstairs and say: “please be quiet.” But for the people who are not so nice, they would go directly to mentioning [your family’s] disease in order to take advantage of our shortcomings. (Married male, age 45; younger brother of a female PLWHA, age 56)

Losing Family “Face”—Most families in China care deeply about issues of “face” at both individual and family levels (Zhang & Chen, 1996). Many family members tried to provide help to the PLWHA, but at the same time, some family members felt ashamed of their close association with the PLWHA. PLWHA are sensitive about their families’ feelings, and they believe that some family members try to avoid being seen with them in public and or even mentioning their names.

> Well, I think my parents, when they are in front of people, if they talk about me . . . my parents try not to stay with the topic. Because, they don’t want, don’t want to talk about their own children like this [infected by HIV]. They feel ashamed. (Single male PLWHA, age 25)

At the same time, family members of PLWHA are worried about inadvertent disclosure and therefore avoid interaction with other people in society.

> The biggest change in my life is that I no longer want to interact with people since I learned of the infection of my family members. Some people like to discuss it behind your back; I don't want to interact with them. (Married male, age 30; husband of a female PLWHA, age 34)

Having one HIV positive family member was considered a dreadfully "unfortunate" event for the entire family. PLWHA worried that the disclosure of their HIV status to the community would negatively affect their family in terms of employment and the amount and level of social support they would receive. Many family members discussed how their neighbors, coworkers, and friends gossiped about their families living with HIV. One single female PLWHA described why her family did not want her to disclose her status to her brother because of fears ranging from employment issues to difficulty in finding a date:

> It was my family 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 [my serostatus], it would affect his job and his life. So they told me not to tell him. Yes, because he is not married yet. If he finds out, or if some of his friends find out—if he wants to have a girlfriend, I think it will certainly affect him. (Single female PLWHA, age 30)

Most parent participants mentioned their worries for their children. They expressed concerns about their children not being able to go to school like other "normal" children, not being accepted by society, and not having a promising future.

> The biggest pressure . . . I have a child . . . If [her mother] passes away, I really don't know how to live. If people were to find out that she died from [AIDS], probably, they would . . . and in the future, our child will be affected. I don't dare to think [about it]. (Married male, age 31; husband of a PLWHA, age 30)

Stigma and Family Networks

The stress caused by HIV-related stigma was also reported to have a huge impact on relations within the family and the community. Some families reported feeling uncomfortable discussing topics related to HIV/AIDS among family members. This discomfort and desire for secrecy prevents good communication and can generate bitterness between family members. Stigma pressures can also trigger finger-pointing and blame as families try to find a cause for their sudden marginalization from society. Some PLWHA were told by their family members not to reveal their status to certain family members in order to protect them from discrimination. Families also changed their social interaction and network. Many family members mentioned living a more isolated lifestyle and reported that their "social circle" became smaller because of HIV/AIDS.

Affecting Family Relations—HIV-related stigma impacts the family in how the members interact with one another. Some families tried to avoid discussion of HIV/AIDS-related topics, and the family members felt uneasy when HIV-related words were mentioned. This secrecy and taboo surrounding certain topics created new barriers between family members.

> 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, too, 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 PLWHA, age 34)

Some family members reported losing faith in the PLWHA, and they did not believe that the PLWHA could find a job or live a normal life:

> [The PLWHA] just wanted to find a job to be able to earn his own living and to be able to work and have the disease treated. But I told him, “You have this disease, so nobody will pay you. For normal people, maybe they will consider. But for a person like you, they won’t hire. They won’t hire you absolutely. So you won’t find a job easily. You cannot have a job again.” (Widowed female, age 61; mother of a single male PLWHA, age 26)

A 61-year-old mother of a PLWHA blamed her son for the difficulties he brought to the family. The tremendous social pressure and feeling of shame was thought to have contributed to both of the parents becoming ill.

> He makes it very difficult for the family and [brings a lot of] shame [to the family]. People discriminate [against] us and think our family is more terrible than robbers. Robbers also bring damage to the society, but robbers will run away after robbing. [His dad and I] fell sick several times just because of him . . . that is . . . he was the reason his dad was sick. (Widowed female, age 61; mother of a male PLWHA, age 26)

Weakening Family Networks—Stigma has also impacted how the family interacts with other people in the community, with friends, coworkers, and neighbors. Because of feelings of family shame and stigmatization, many family members reported changing their behavior. Some family members of PLWHA felt ashamed and tried to avoid interaction with others.

> Now I just live my days . . . I always bow my head; awfully low-key . . . I used to be very outgoing. Now in many people’s eyes, I’ve become narrow-minded. (Married male, age 31; husband of a PLWHA, age 30)

> Comparing to before [I learned of his serostatus], I don’t like to make friends with anybody [now]. Because these friends . . . including my relatives and good friends, they all discriminate against us. (Widowed female, age 61; mother of a male PLWHA, age 26)

One 26-year-old male PLWHA mentioned how his mother made him use designated chopsticks when guests visited at home. In China, it is very uncommon for people to use designated chopsticks. The PLWHA was therefore forced to change his behavior. Even if he followed his mother’s word, the uncomfortable feelings about the arrangement remained:

> 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 just for me. That means when I got dishes, I had to use another pair of chopsticks, the public chopsticks. It doesn’t matter whether it will transmit or not . . . is not a big deal, but still I feel uncomfortable in my heart. (Single male PLWHA, age 26)

Most of the families expressed efforts to hide the HIV status of the PLWHA because of fear of social discrimination and ostracism. When the HIV status was disclosed, voluntarily or involuntarily, the entire family experienced major changes in their interactions within their community and their social networks.

> [We experienced] a big difference . . . [Neighbors] very much excluded us [after they found out] . . . Before [they found out], they always liked to visit us at our home. They came to visit and chat. They didn’t come afterward. None of them came . . . My child used to play with the other kids, then [they don’t allow their kids to play with mine] . . . They are so afraid, and don’t understand at all. Not to mention support, just fear. (Married male, age 30; husband of a female PLWHA, age 34)

> We were best friends before. Previously, we often ate together, and drank. Later, they wouldn't call me . . . Anyway, just like people said, they are afraid of you. They want to stay away from you . . . The biggest change [is that] my social circle has become smaller . . . [Now] I seldom go to other places to eat or drink, because other people stay far away from us as if I were ostracized. (Married male, age 31; husband of a PLWHA, age 30)

Social Support Seeking

The family living with HIV/AIDS is not only a target for stigmatization but also an asset that can provide its members with strength to cope with and fight against HIV-related stigma and discrimination. The social support aspect is relatively independent of the concepts of face, shame, and stigma, and is thus examined in a separate section. It turned out that most families participating in our study provided extensive tangible and emotional support for the family members living with HIV/AIDS. One 68-year-old father said the following about his HIV positive son:

> We love him and try to give him better food. We wear simple clothes . . . but for my kid, [for] his health, [we don't spare one penny]. [We] try to make him live one more year, one more month, one more day, even if just one more hour, we will be very happy. (Married male, age 68; father of a single male PLWHA, age 32)

PLWHA reported that they had benefited greatly from family support in order to battle against HIV/AIDS and stigma. Making the family feel proud often becomes the main motivation for many PLWHA toward their living a "normal" and productive life again.

> I think if one day I am needed to stand up, if my family can, they can stand with me, give me strength, and they can also accept the fact [that I'm HIV infected], they can also bear the rumors, can endure all of this, I think it will be good to stand up. People should have the character and the courage. (Single male PLWHA, age 37)

Facing social discrimination and stigma, families used different coping strategies. Some families reported participating in local HIV training programs. Family members used the HIV/AIDS knowledge they acquired to educate other family members and became more comfortable supporting the PLWHA.

> Five families were sitting together in a meeting room. After I came back, I told my husband. We all cried. I said, even the unrelated people were caring about our son, how can we leave him alone? I said to my husband, we will let him live happily everyday . . . I said [to my son]: "you are my son forever." I told him: "I will support you in everything . . . ." (Married female, age 50; mother of a single male PLWHA, age 25)

> Originally, we were still worried about him, and we were afraid of transmission. Later, after he was trained in [the HIV program], we also read those materials. Later, they asked us to listen to the lectures. I listened . . . . So I am not afraid now . . . . We lived together in these years, but we didn't get infected. So we set our hearts at ease after we listened to their lectures . . . . This disease is not a big deal. We just have to treat this disease right. (Married male, age 61; father of a single male PLWHA, age 29)

Participation in these programs also provided family members opportunities to learn about the experiences of other families. Family members became acquainted with others who were facing similar challenges while building a support network.

> Once I told XX and YY's mothers [about my daughter's HIV infection]. I knew them through the training program; we talked about it when we went to the farmer's market together. (Married female, age 67; mother of a divorced female PLWHA, age 39)

> I know some of [the family members of other PLWHA]. I get on okay with some of them [and we became] friends. We are together all the time, chatting and having dinner together . . . I brought my friends there to study, too. Now many of my friends had been brought to the training program . . . . (Married male, age 30; husband of a female PLWHA, age 34)

DISCUSSION

This study represents an early effort to examine the impact of HIV-related stigma on families living with HIV/AIDS in China. Findings are consistent with other studies that have shown that families across Africa and Asia experience stigmatization for simply being associated with HIV/AIDS. Our study explored this issue further by identifying specific dimensions and processes within and outside of families living with HIV/AIDS as related to the impact that HIV-related stigma has on the family. Our findings demonstrate that the stigma associated with HIV/AIDS has a substantial impact on family identity, relations within the family and within broader social networks, and behavior related to coping with and reducing the associated distress. Through specialized HIV/AIDS programs and trainings, many families found that valuable coping strategies include the building of networks with other HIV/AIDS-affected families for support and encouragement, learning more about the disease, and seeking to educate others.

In traditional Chinese culture, individuals are not viewed as independent agents. Individuals are viewed as embedded in a system with the family as the basic unit (Jin, 1994; Wright & Twitchett, 1962). Family identity is often considered equal to or even more important than individual identity. Thus, when an individual is HIV positive, not only is he or she stigmatized, but his or her entire family is stigmatized. The family as a whole also feels shame and blame, and family identity, pride, and status in the community are challenged. This cultural tradition helps explain why HIV-related stigma is a family issue in China.

In Chinese culture, family members are differentiated from other people outside the family, and the family is a domain of privacy and intimacy. Family boundaries provide a safety net for its members (Chan, 2000; Liang, 1987). For the majority of people in China, the family is the center and focus of village and household life. Festivals, rites of passage, economic success, health care, and psychological support are all important components of the family’s function (Saso, 1999). Families living with HIV/AIDS are stigmatized against as one unit and, as such, they band together and fight against the stigma as one unit.

The ability of a family to maintain its integrity and strength is tested whenever a traumatic event occurs. When a family is faced by HIV/AIDS, it is the strength of family relationships and the support system that holds a family together and allows it to endure. In countries with high rates of HIV (i.e., those in Africa and Asia), families and clusters of families become even more interdependent for their survival (Rotheram-Borus et al., 2005). Interdependence is an equally important characteristic of Chinese families. From early childhood, people are socialized for lifelong interdependence with others by developing skills and values that promote harmony (Bond, 1991). As is illustrated in this study, HIV-related stigma affects family relations and social networks, and this directly impacts family well-being and the quality of life of each family member. Yet, although the secrecy caused by shame can tear a family apart, outside pressure can also bring family members together. Through family coping and support, family relations can improve by way of collectively suffering hardship (Shek et al., 2003). As long as family members continue to support each other, they can emerge successfully from their fight against stigma.

A unique feature of this study is that interviews with both PLWHA and their family members were analyzed. The combination of PLWHA and their family members' views on the key issues gives us more comprehensive and complementary perspectives. Inclusion of interviews from parents, spouses, siblings, and other relatives of PLWHA allowed us to identify and explore how concepts of family and caretaking have to be understood in their cultural context. Putting these perspectives together allows for a more meaningful and detailed account of the types of stigma faced by families in China.

Our study illustrates the benefits of designing HIV/AIDS interventions that include family members. We made it unambiguous that HIV/AIDS in China is much more than an individual matter—the well-being of entire families is affected. Although the sample size can be considered adequate for a qualitative study, the study results may be limited by the relatively small numbers of interviews conducted. Given that many of the participants in this study were IDU individuals and some were ethnic minorities, findings of this study may not be applicable to other geographic areas and to PLWHA through other modes of transmission.

Although there is some evidence of change in people's values over time, the traditional values remain strong in China (Ryozo, 2006). To most people in China, HIV/AIDS is often associated with risky sexual behavior and drug abuse, both of which have been considered to represent low moral standards. As a result, the stigma faced by individuals and families will continue to be strong, and effective intervention strategies should be developed that allow family members to deal with HIV-related stigma imposed on them by society, while continuing to support and care for the HIV/AIDS-infected individual in their family. Possible strategies include the strengthening of social support within families and the building of networks with other PLWHA families. In particular, empowerment mobilization may prove useful in helping families to develop better coping strategies so that they are able to provide patients with better care and gain access to more resources. In addition, this research demonstrated that just as the HIV-related stigma extends to families, it may very well extend to communities involved. Fighting the stigma thus needs to be a community effort also.

Acknowledgments

This article was completed with the support of National Institute of Mental Health grant R01MH070931. We thank Haixia Cui, Zhihua Yan, Fan Zhang, Lin Lu, Yong Zhang, Chunqing Lin, and other local investigators and data collection team members. We also thank Alan Semaan and Sonia Johnson for their literature and editorial assistance with this article.

REFERENCES

Alubo O, Zwandor A, Jolayemi T, Omudu E. Acceptance and stigmatization of PLWA in Nigeria. AIDS Care 2002;14(1):117–126. [PubMed: 11798411]

Bond, MH. Beyond the Chinese face. Oxford University Press; Hong Kong: 1991.

Bor R, Miller R, Goldman E. HIV/AIDS and the family: A review of research in the first decade. Journal of Family Therapy 1993;15(2):187–204.

Boyd-Franklin, N.; Steiner, G.; Boland, M. Children, families, and HIV/AIDS: Psychosocial and therapeutic issues. Guilford Press; New York: 1995.

Busza, J. Challenging HIV-related stigma and discrimination in Southeast Asia: Past successes and future priorities (Horizons Literature Review). Population Council; Washington, DC: 1999.

Chan Y. Privacy in the family: Its hierarchical and asymmetric nature. Journal of Comparative Family Studies 2000;31(1):1–17.

Chinese Center for Disease Control and Prevention. HIV/AIDS Surveillance Report. Chinese Center for Disease Control and Prevention; Beijing, China: 2004.

Derlega VJ, Winstead BA, Oldfield EC III, Barbee AP. Close relationships and social support in coping with HIV: A test of sensitive interaction systems theory. AIDS and Behavior 2003;7(2):119–129. [PubMed: 14586197]

Fehr, B. Friendship processes. Sage; Thousand Oaks, CA: 1996.

Gaines SO. Coping with prejudice: Personal relationship partners as sources of socioemotional support for stigmatized individuals. Journal of Social Issues 2001;57(1):113–128.

Harvey JH, Wenzel A. HIV, AIDS, and close relationships. Journal of Social and Personal Relationships 2002;19(1):135–142.

Jin Y. Zhongguo ren dui siy-inquan de lijie [Chinese idea of privacy right]. Ming Pao Monthly February; 1994 :56–62.

Jones DJ, Beach SRH, Forehand R, Foster SE. Self-reported health in HIV-positive African American women: The role of family stress and depressive symptoms. Journal of Behavioral Medicine 2003;26 (6):577–599. [PubMed: 14677213]

Joseph EB, Bhatti RS. Psychological problems and coping patterns of HIV seropositive wives of men with HIV/AIDS. Social Work in Health Care 2004;39(12):29–47. [PubMed: 15774383]

Levinger G. Toward the analysis of close relationships. Journal of Experimental Social Psychology 1980;16(6):510–544.

Li, JH. HIV and AIDS in Yunnan: Socioeconomic impact of HIV-AIDS; Paper presented at the Sino-U.S. Conference on Research and Training in AIDS-related Areas; Beijing, China. 2002, November;

Li L, Sun S, Wu ZY, Wu S, Lin CQ, Yan ZH. Disclosure of HIV status is a family matter: Field notes from China. Journal of Family Psychology 2007;21(2):307–314. [PubMed: 17605553]

Li L, Wu S, Wu ZY, Sun S, Cui HX, Jia MH. Understanding family support for people living with HIV/AIDS in China. AIDS and Behavior 2006;10(5):509–517. [PubMed: 16741672]

Liang, S. Zhongguo wenhua yaoyi [The essence of Chinese culture]. Joint Publishing (HK); Hong Kong: 1987.

Lieber E, Li L, Wu Z, Rotheram-Borus MJ, Guan J, the National Institute of Mental Health (NIMH) Collaborative HIV Prevention Trial Group. HIV/AIDS stigmatization fears as health seeking barriers in China. AIDS and Behavior 2006;10(5):463–471. [PubMed: 16374668]

Ma Y, Li Z, Zhang K. HIV was first discovered among injection drug users in China. Chinese Journal of Epidemiology 1990;11:184–185.

Muhr, T. User's manual for ATLAS.ti 5.0 (version 5). ATLAS.ti Scientific Software Development GmbH; Berlin: 2004.

National Bureau of Statistics of China. China Statistics Yearbook, 2004. 2004. Retrieved November 3, 2005, from http://www.stats.gov.cn/tjsj/ndsj

Pequegnat W, Bauman LJ, Bray JH, Di-Clemente R, DiIorio C, Hoppe SK, et al. Measurement of the role of families in prevention and adaptation to HIV/AIDS. AIDS and Behavior 2001;5(1):1–19.

Pequegnat, W.; Szaponick, J. Working with families in the era of HIV/AIDS. Sage; Thousand Oaks, CA: 2000.

Rawlins, WK. Friendship matters: Communication, dialectics, and the life course. Aldine de Gruyter; Hawthorne, NY: 1992.

Rotheram-Borus MJ, Flannery D, Rice E, Lester P. Families living with HIV. AIDS Care 2005;17(8): 978–987. [PubMed: 16176894]

Rotheram-Borus MJ, Robin L, Reid H, Draimin BH. Parent-adolescent conflict and stress when parents are living with AIDS. Family Process 1998;37(1):83–94. [PubMed: 9589283]

Ryozo Y. A social value survey of China: On the change and stability in the Chinese globalization. Behaviormetrika 2006;33(2):111–130.

Sandelowski M. The problem of rigor in qualitative research. Advances in Nursing Science 1986;8(3): 27–37. [PubMed: 3083765]

Saso, M. Velvet bonds: The Chinese family. New Life Center; Carmel, CA: 1999.

Schuster MA, Kanouse DE, Morton SC, Bozzette SA, Miu A, Scott GB, et al. HIV-infected parents and their children in the United States. American Journal of Public Health 2000;90(7):1074–1081. [PubMed: 10897185]

Semple SJ, Patterson TL, Temoshok LR, McCutchan JA. Identification of psychobiological stressors among HIV-positive women. Women and Health 1993;20(4):15–36.

Shek DTL, Tang V, Lam CM, Lam MC, Tsoi KW, Tsang KM. The relationship between Chinese cultural beliefs about adversity and psychological adjustment in Chinese families with economic disadvantage. American Journal of Family Therapy 2003;31(5):427–443.

Songwathana P, Manderson L. Stigma and rejection: Living with AIDS in villages in southern Thailand. Medical Anthropology 2001;20(1):1–23. [PubMed: 11820765]

Tsui M. Changes in Chinese urban family structure. Journal of Marriage and the Family 1989;51(3):737–747.

UNAIDS. *World AIDS campaign 2002-2003*: Live and let live. 2003. Retrieved November 3, 2005, from http://www.unaids.org/wac/2002/background_en.html

Wright, AF.; Twitchett, D., editors. Confucian personalities. Stanford University Press; Stanford, CA: 1962.

Yunnan Center for Disease Control and Prevention. HIV in Yunnan update to 2005. Yunnan Center for Disease Control and Prevention; Kunming, China: 2006.

Zhang QY, Chen Q. Study and analysis of the psychological state of immediate family members of IDUs. Chinese Journal of Substance Abuse and Prevention 1996;5(2):23–25.

Zhou F, Teng T, Ruan YH, Hao QN, Chen KL, Tai GM, et al. Preliminary study result of factors affecting program follow-up among the IDU population. China HIV/AIDS and STD 2004;10(5):338–340.