

Disclosure of HIV Status Is a Family Matter: Field Notes From China

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This study examines the role that family plays in disclosure of HIV–AIDS in China. In-depth semistructured interviews were conducted with 30 individuals living with HIV–AIDS infected through different routes. The vast majority of participants were between the ages of 20 and 39 years old (93.4%) and about a third (36.7%) were women. Two primary disclosure processes, involuntary and voluntary, are described. In both processes, family members other than the patient are usually the first to know HIV status. Positive impacts of disclosure include strengthening family relations and help with medical care and counseling, whereas negative impacts include fear, isolation, avoidance, and psychological burden. This study illustrates that family is an intricate part of the disclosure process in China and demonstrates the importance of including families in HIV–AIDS interventions.

Keywords: HIV in China, family relations, disclosure, qualitative study

It is generally recognized that HIV status disclosure is a complicated matter that involves many components, including patient HIV status notification, the decision of whether to disclose, and the decision of whom to disclose to (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Kimberly, Serovich, & Greene, 1995; Landau & York, 2004; Larkins, Reback, Shoptaw, & Veniegas, 2005; Paxton, 2002; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005). In the United States, HIV confidentiality guidelines recommend that health professionals should not divulge personal information to others in ways inconsistent with the client's original consent (United States Centers for Disease Control, 1999). Thus, in general, people living with HIV–AIDS (PLWHAs) in the United States have the individual choice of whether to disclose their HIV status and whom to disclose to. However, not all countries have clear policies regarding confidentiality of HIV status notification, and cultural traditions also play an important role.

In many societies and cultures, disclosure is not considered an individual matter. In contrast to individualistic so-

cieties that consider individuals as autonomous independent entities living together under a social contract, individuals in collectivistic cultures are often regarded as part of an organic whole, and family is seen as the basic unit (Schweder & Bourne, 1984). Because of this cultural belief, some health professionals disclose HIV status to the family or notify PLWHAs of their status with their family present as a social buffer and safety net for the PLWHA (Chandra, Deepthivarma, & Manjula, 2003; Li, Wu, Wu, Sun, Cui, & Jia, 2006).

Even within the United States, there are ethnic differences regarding the disclosure process. Hispanics are more likely than African Americans and Caucasians to withhold their diagnosis from parents to prevent upsetting them (Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Simoni et al., 1995). For Asian Americans, disclosing to those within the culture, including members of one's family and ethnic community, appears to be particularly difficult because PLWHAs consider family before disclosing (Chin & Kroesen, 1999). One of the most pronounced factors in Asian culture that influences the decision to disclose is a desire to protect the family from shame (Yoshioka & Schustack, 2001). The major difference between the disclosure processes of ethnic minorities in the United States and the disclosure processes of those in many Asian countries is that involuntary disclosure occurs much less frequently in the United States because of clearer status notification guidelines.

One of the main concerns regarding disclosure of HIV status is stigmatization and discrimination (Black & Miles, 2002; Derlega, Winstead, Greene, Serovich, & Elwood, 2002, 2004; Petrak, Doyle, Smith, Skinner, & Hedge, 2001; Serovich, 2001; Health and Development Networks Moderation Team, 2004). Although stigma is an issue in all

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This article was completed with the support of National Institute of Mental Health Grant R01MH070931. We thank Sonia Johnson and Lynwood Lord for their editorial assistance.

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cultures, it becomes even more powerful in family oriented societies. HIV-related stigma is borne not only by the individual but also by the family and community. A study by Songwathana and Manderson (2001) in Thailand showed that if the status of a PLWHA is disclosed to the community, then the entire family fears losing face. Furthermore, social networks in Thailand often treat an entire family discriminatorily because one of its members is HIV positive. In South India, one of the main reasons cited for nondisclosure is disgrace of self and family, with concerns about the future of family members (Chandra et al., 2003).

Given the potential risk of an HIV-AIDS pandemic in China (United Nations Theme Group on HIV/AIDS in China, 2002) and the important role that families play in the life of PLWHAs, the need to study families living with HIV in China is clear. However, there have been no studies that systematically examine the role that family plays in the process of HIV status disclosure. This study is a first step in describing the process of both voluntary and involuntary HIV disclosure in China and its effects on the family by examining interviews with PLWHAs that led to the development of themes related to disclosure and family. Using deductive qualitative analysis, it was determined that all participants mentioned the role their family played in the disclosure process and the impact disclosure had on the family (Gilgun, 2005).

Method

Setting and Procedure

Qualitative data were collected from three sites in Yunnan, China. The three recruitment sites ranged in population from 500,000 to 45 million. At two of the sites, the Han ethnic group comprised a majority of the residents; the third site was primarily populated by minority ethnic groups (National Bureau of Statistics of China, 2004). The sites were chosen because of their high number of reported HIV infections. The in-depth interview guide for PLWHA participants was designed by the project research team and community advisory board (CAB). The CAB was formed to provide consultation on cultural appropriateness and content applicability of the study design and administration and was composed of officials from the provincial health bureau, health providers from local hospitals, administrators from the local Center for Disease Control and Prevention, family members of PLWHA advocates, and local advocates. Of the several family members and local advocates approached, feedback was gathered only from those who agreed to participate and attended meetings. For the HIV-positive participants to have enough knowledge to answer the interview questions, they were required to know their serostatus for a minimum of 3 months at the time of the interview.

Flyers and informational materials about the study were provided in local clinics and hospitals that treat HIV patients. HIV treatment service providers were also informed of the study, and they notified the potential PLWHAs about the study. If a PLWHA was interested in learning more about the study, he or she was referred to a project staff member. Some local nongovernmental organizations also helped recruit participants using a similar recruitment procedure. All potential participants were told about the study by project staff. Those participants who expressed interest and agreed to participate were given a consent form containing information about the purpose of the study, the interview that they

would voluntarily participate in, the estimated risk and benefit to them, and the contact information for the principal investigators and the Office for Protection of Research Subjects in both China and the United States. Study staff asked participants several questions about the consent to make sure everything was understood, and in cases where participants did not fully understand, the consent form was reviewed again. Participants were also given a copy of the consent form. The overall refusal rate was 10%.

Between March and July of 2004, in-depth interviews were conducted with 30 PLWHAs. Interviews were about 1 to 2 hr long and were held in a private room. Most interviews were conducted in the clinic where the participants went for regular health care. Occasionally, by the participants' request, some interviews were held in the project office privately. Interviews consisted of open-ended questions about personal experiences with HIV-AIDS and health services after diagnosis. The interview guide consisted of specific questions regarding disclosure processes and general questions about the consequences of disclosure. The level of detail in the interview guides was determined by consultation with field specialists and members of the CAB. To allow flexibility and spontaneity as new content was revealed during interviews, interviewers were not required to ask questions in the same order or with the same wording in the interview guide. However, all questions in the interview guide were covered in each interview. Before any fieldwork started, the study protocols and all study materials were approved by the Institutional Review Boards of both the University of California, Los Angeles and the China Center for Disease Control and Prevention, Beijing, China.

Participants

The vast majority of PLWHAs were between the ages of 21 and 39 years old (93.4%), with the ages ranging between 21 and 56 years. The mean age was 31 years, and the median age was 30 years. About one third (36.7%) were women. Most of the PLWHAs had attended junior high school (70%), only one fourth of the participants were married, and 63% of the PLWHAs were unemployed. Seventeen percent of the participants belonged to the Bai or Hui ethnic minority groups. This percentage is higher than the national average (less than 8%) but lower than the provincial average (33%; China Population Information and Research Centre, 2000).

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 and 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. Of the 11 female IDU participants, only 1 mentioned her husband's drug use as the reason for her infection. At the time of the interview, only 3 participants knew their CD4 counts, which were between 180 and 300. About one third (30%) of the participants were in AIDS treatment, and 7% were using Chinese herbs only. Comorbidities included tuberculosis, hepatitis B, and pneumonia.

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

Atlas TI (Version 5.0; Muhr, 1997) was used to analyze the data (Muhr, 1997). All interviews were audiotaped and transcribed by a project staff member and cross-checked for quality control. When local dialect was used, a local project staff member, fluent in the local dialect, transcribed the interview. Transcripts were then translated into English for data analysis. Qualitative data analysis for this article was an iterative process, with interview data analyzed using consensual qualitative research strategies. Interview guidelines and the actual content of a number of interview transcripts were the basis for the first draft of the code list, which consisted of common themes discovered in the transcripts. To reach better intercoder reliability, as well as to refine the code list further, the research team then coded one transcript together (Sandelowski, 1986). After several drafts of the code list and many changes based on the content of the interviews, a total of 63 codes and 18 code "families" (a group of codes with the same theme) were created. The 63 codes then became subthemes under each family code name. This made it easier to analyze by individual family code as well as to visualize the relations among codes in a network. For example, initial reaction is a family code, under which are the codes how long status known, how first discovered, and feeling when first discovered. The initial reaction family code can be searched as a way to view the complete reaction by the participant. At the same time, each individual code can be searched for related specific experience. Analysis was further accomplished by identifying the themes occurring most frequently across transcripts and putting them in the context of other information about participants. When analyzing data for this article, all codes relevant to disclosure were searched and results categories were determined on the basis of common themes across disclosure related codes.

Results

After analyzing the transcripts, two major themes regarding disclosure were identified: (a) the process of disclosure and (b) the impact of disclosure on family. Under the theme of disclosure process are the subthemes of involuntary disclosure to family and voluntary disclosure to family. Within the theme of the impact of disclosure are the subthemes of positive and negative impacts on family.

With disclosure, family is often informed first, either voluntarily or involuntarily. When disclosure to family is involuntary, parents are frequently the first told of the PLWHA's status and PLWHAs are then informed of their status by their parents. This method of disclosure led to mixed reactions from our participants. When PLWHAs have the choice of whether to disclose to family, they consider whether to disclose and to whom to disclose first. If disclosure has been made to the family, disclosure to the community is usually discussed within the family and the decision of whether to disclose is made together as a family.

There are many reports of the positive impacts that disclosure can have on family, including strengthening family relations and bringing family members closer together. It also provides the opportunity for family to offer support to the PLWHA through help with medical care or counseling. PLWHAs are then able to handle the difficulties and complications of their disease. However, disclosure to family can also cause fear, shame, or stress, leading to isolation,

avoidance, and an increase in psychological burden on the entire family.

Theme 1: Disclosure Process

Two primary disclosure processes were identified: involuntary and voluntary disclosure. In some cultures, it is expected that the PLWHA will decide whether to disclose and to whom to disclose first. In other highly family oriented societies, such as China, however, involuntary disclosure to family occurs because it is thought to benefit the PLWHA in dealing with his or her test result.

Process of involuntary disclosure. In China, because of a strong belief in family values, some service providers first inform a family member of the PLWHA's HIV status. Then, it is the family member's responsibility to inform the PLWHA and the rest of the family. Among the participants in our study, 47% experienced involuntary disclosure. Of those PLWHAs, 14% mentioned that they disagreed with the process and 57% said that they appreciated the support from their families when discovering their HIV status.

When disclosure is involuntary, a family member is usually the first to know. In a society where family is typically regarded as the individual unit, secrets are not expected among family members. This expectation, along with the hope that family can be supportive of the PLWHA during and after test result notification, is the service providers' reasoning to adopt the involuntary disclosure procedure. Once one family member is informed of the PLWHA's status, it is his or her responsibility to decide which other family members should be informed. Sometimes disclosure duties are shared, and each informed family member has the task of disclosing to yet another family member. Family members also find that at times they must be the ones to inform the PLWHA. In our study, 17% of the time, parents were the first family members to be disclosed to because they were the heads of the unit and best able to facilitate disclosure to the PLWHA.

My parents knew first. . .Because after the test, my father didn't give me the testing sheet. . .It was my father who accompanied me to take the test. . .The screening test. . .and then, I came here to take the test, also the same result. . .also the same result. . .they handed over the result to my father, but did not hand it over to me. (Single female, age 26, Hui ethnicity)

My family all knew it before I knew. . .Because when the testing result came out, they had already, my family basically all knew. (Divorced male, age 42, Han ethnicity)

PLWHAs had very different reactions to the involuntary disclosure to their families. One participant felt that her family was a good buffer and appreciated the support that her family provided to her when she first learned of her status. She felt that she was better able to accept the test result when it came from her family than if she had been notified by a service provider alone:

The staffs in [local organization] were afraid I couldn't accept it, so they told my father first, and then my father told my husband and they were discussing how to do with it. All my family have discussed it, including my younger brother. . .But

anyway, because my younger brother was worried that I couldn't accept it, he had told me [that he was HIV positive] first, which gave me psychological preparation. Therefore, it was better and wasn't [like they thought that I] couldn't accept anything at all. (Married female, age 34, Han ethnicity)

Some participants completely disagreed with the process of involuntary disclosure and were angered by the lack of confidentiality and respect for the PLWHA's right to choose to disclose. They felt that the PLWHA should be notified of the result first and in privacy, and then the PLWHA could decide whether to disclose to family members.

[When they told me my result, there was] no confidentiality at all. Not only that, I felt like that as if you are some sort of sinner to the world when you got infected. Then I thought [the doctors] didn't care about your privacy, and so forth, at all. I think, under such circumstances, the doctor should talk to me privately and give the test report to me. That so called test report or whatever, so many people were there in the office. (Single male, age 37, Han ethnicity)

I think in [protecting patients' confidentiality], they should. . . hum, anyway, [the doctors] didn't do a good job in this aspect. I think after the results come out, well, they should tell the patient themselves first, they should tell you that you are infected, and then tell him some knowledge, and then provide them with some helpful thing, well, some place or some institution, and then ask him, well, it should be based on [the infected person's] opinion, it's also their right [to decide] whether or not if to tell his family members or not according to his opinion, and tell the others, that is their right to, to tell the others that he had got [HIV]. (Single female, age 21, Han ethnicity)

Process of voluntary disclosure. There are many reasons why participants chose to disclose or not disclose their status to their families, and their decisions were often based on how the PLWHA thought the news would affect family members. Once participants decided to disclose, they tended to be very selective about whom they initially disclosed to, choosing family members that they felt the most comfortable with. Twenty-seven percent of participants chose to disclose to a sibling first, 17% chose a parent, 13% chose a spouse, 27% chose a friend, 10% chose no one, 3% chose multiple persons, and 3% chose "other."

The first step in voluntary disclosure is to decide whether to disclose. One reason that PLWHAs chose not to tell family members about their status was to prevent disappointing or burdening them. Thirty-three percent of the participants felt that parents or children could not handle the news and wanted to protect them from the pressures of knowing.

Especially as I was concerned about my child. . . It seemed I thought once my child would know I had this disease, he would have some thought or some opinion. (Divorced female, age 39, Hui ethnicity)

I'm afraid to hurt my parents [if I tell them about my serostatus]. (Single female, age 28, Han ethnicity)

[Other PLWHAs] also have heavy psychological pressure and dare not tell their families and friends. Once they tell their friends and families, it will hurt their families. And if friends know, they will look down on him, won't they? They will discriminate against him, and will think his behaviors are bad

so that he deserves the disease, doesn't he? (Married female, age 22, Han ethnicity)

Thirteen percent of participants chose to disclose to family out of a sense of responsibility. All of these participants were women, and they disclosed to either a husband or boyfriend. One PLWHA told her husband because she did not want to transmit the disease to him. She felt that he had a right to know:

Because I had sexual contact with [my husband], if I didn't tell him and without any protection, I could have transmitted this disease to him. I thought it was unfair and irresponsible to him. Therefore, I told him. (Married female, age 34, Han ethnicity)

Others chose to disclose to family members to receive necessary support. The pressure of having a fatal disease as well as harboring a big secret can be very taxing on PLWHAs. Participants felt that family members could provide emotional and psychological support to help them during stressful times.

Ah, at that time, my thoughts were very complex as I told you. . . if someone in the family knew my state, they could understand these. My elder sister also worked in a hospital, so I told her. . . because I was infected with this, my pressure was big, psychological pressure was big. So I told [my sister]. I just hope she could give me psychological support. (Separated male, age 29, Han ethnicity)

I really needed some care, especially after I knew I had the disease. So. . . I told [my family] at last, after considering for several days. (Single male, age 25, Han ethnicity)

After the decision to disclose, the next step is to choose whom to disclose to. When deciding whom to disclose to first, many participants chose family members that they trusted the most and those with whom they had strong relationships. Chosen family members varied from parents to aunts to spouses and siblings.

Definitely, I will tell my own parents first. I definitely won't tell my friends and my classmates. First, I will tell my own parents. . . Because if they know my situation, it will be a preparation for their psychology, won't it? And then, they can accept the fact. (Married female, age 22, Han ethnicity)

At the beginning, I first told my aunt because I have been close to my aunt since I was young, because I had lived with her for eight years. (Single male, age 34, Han ethnicity)

I told the persons I relied on most. I first told my husband, and then I told my younger brother. (Married female, age 56, Han ethnicity)

Of the participants who disclosed to a family member first, 65% disclosed their status to a family member of the same generation (i.e., spouse, sister, or brother) first. Siblings are probably less judgmental than parents because they are younger and often know more about HIV than the older generation.

Because. . . my parents were old after all, they didn't know what it was; because I just said I had a serious disease in hospital in those days and they were very worried, I first think to tell [my sister]. Then, after she knew, then. . . because she is a little younger than me, maybe she knew knowledge in this aspect more than me. (Married male, age 32, Han ethnicity)

When the test result was out, [my sister] asked me, and I told her then. At first, I didn't want to tell her, but I thought about it later that, after all, she was my sister, so I told her. (Single male, age 37, Han ethnicity)

On the basis of self reports, it took an average of only 1 day for both female IDU and female non-IDU participants to disclose their status to others, whereas it took 30 days for male IDU participants and 6 months for male non-IDU participants to disclose. Compared with participants who knew their status for a short period, participants who knew their status for a longer period tended to disclose to more people, had more knowledge about HIV, and had more thoughts about their future.

Theme 2: Impact of Disclosure

Disclosure had various impacts on how HIV–AIDS affected families. Some of the positive impacts included that disclosure strengthened family relations, that disclosure allowed family members to help PLWHAs with medical care, and that disclosure provided the opportunity for family to offer counseling to the PLWHAs. Negative impacts of disclosure included feelings of fear, shame, and stress by PLWHAs and their families. Sometimes, these feelings caused family members to isolate and/or avoid PLWHAs, PLWHAs to withdraw from the family and society, and psychological burden for the entire family.

Positive impact of disclosure. Disclosure can often have positive effects on the family. It can strengthen relationships and generate support for PLWHAs. Many participants chose to disclose to family members to receive support, and most families help PLWHAs with medical care and provide counseling; this has a positive impact on the family as a whole, as family members feel useful and needed and PLWHAs get necessary support.

In times of need, many families pull together and family relations are strengthened. One participant said that her husband would go to the hospital to sit with her every day because he was worried she could not handle the news of being HIV positive: "Since my husband knew I was infected with the disease, he watched me every day" (Married female, age 56, Han ethnicity). Other participants felt the same way. After their family members learned of their status, their relationships were strengthened.

They, at that time, when I had the disease to take the blood test, almost all my siblings were close-knit, right? Almost all of them came, came to help me, like this. (Widowed male, age 39, Bai ethnicity)

Disclosing to family members is very helpful to PLWHAs because they can receive help with medical care and they no longer have to hide the fact that they are taking medication. Loved ones can help the PLWHAs comply with a prescribed medication regimen as well as with the cost of medication. It was difficult for participants to afford HIV medication, and PLWHAs often cannot work because of their weakened health. In many cases, family members would help with the expenses of health care and treatment.

I heard from my sister. She said that it seems my mom...knew what happened to me. She said she did not

blame me. But she said that as I was in this situation...she decided to sell the house in order to get treatment for me. (Single male, age 37, Han ethnicity)

Sometimes it was also difficult for participants to get to the hospital or to pick up medications. Without the help of family members, medication compliance would drop. Assistance with medical care increases the chance that PLWHAs are receiving their medications and taking them consistently.

My younger sisters help me resolve the problem of medicine...Sometimes, they go to get the prescriptions [for me]. Sometimes, they get the prescription, and then call me to pick it up (laugh)...Before I ask for help, she has already got the prescription and asks me to pick it up. Always like this. (Divorced male, age 42, Han ethnicity)

Disclosure of HIV status to family members allowed participants to receive the necessary counseling and psychological and emotional support to get through a difficult time. Kind words and reassurance sustained many PLWHAs and allowed them to accept their situations. Knowing that people cared about them regardless of their status gave some participants a reason to live.

[My husband] comforted me. He said, "No matter what disease you have, since we have already been a couple and lived together for a long time, no matter how big a difficulty we meet, I will accompany you to finish all your life." He said so to me. He said, "Don't have other thoughts." That's it. I should live. (Married female, age 56, Han ethnicity)

Negative impact of disclosure. Although disclosure can have many positive consequences, it also has the potential to drive families apart. In one case, a participant got a very negative reaction from his father after disclosing his status and asking for help:

[My father's] attitude was very, very bad. It must be a repulsive attitude. Then, at a time, after I told him [that I'm HIV positive], because I needed money for medication, I asked him for some money. He said lots of harsh words, and then he hung up the phone. I didn't ask him again. (Single male, age 34, Han ethnicity)

Given that HIV is a highly stigmatized disease and many people do not know the facts about it, there is often fear, shame, and stress associated with finding out that a family member is HIV positive. These feelings can cause isolation and avoidance. These behaviors can make PLWHAs feel ostracized and cut off from the family, suggesting that disclosure of HIV status can lead to the weakening of family relations.

When family members did not know much about HIV transmission, they became afraid that they would get infected just from being around PLWHAs. This fear is what led some family members to stop visiting participants, isolating them from the family: "Because even some of my relatives will be afraid of me...because they don't understand, don't understand and so they are scared" (Single male, age 31, Han ethnicity).

In China, families usually eat together and share food dishes. After discovering the participants' status, 17% of the PLWHAs' family members decided to have them use sep-

arate utensils and eat from separate food dishes. This type of isolation can be very difficult for PLWHAs because they are alienated from their families during a time that is typically very family oriented.

... when we are eating, my grandparents are kind of... they seem to be picky, they give me a special bowl, I feel like I can't accept it, so I would not go to their home to have dinner anymore. (Single female, age 21, Han ethnicity)

Prestige, value, or standing in the eyes of others is known as "face" in China. When something shameful is discovered about someone, it causes that person to "lose face." Sometimes when PLWHAs disclose their status to family, the whole family feels shame, causing them to avoid society. To prevent this, some participants would try to distance themselves from their family by avoiding being seen together.

I wouldn't like them to accompany me [to the doctor's], because I know everyone is afraid of it. They are so old that it is inconvenient for them to walk. And that is to say, they work hard for a whole life, that is to say, in society now, if others find out that they come, they will lose face. So I don't ask them to accompany me. (Single male, age 26, Han ethnicity)

Other participants either knew or assumed that their parents were ashamed of them. This often led to avoidance of society.

I think that if I were to tell them, my parents would not be able to accept it... They will think that others are looking at them strangely... I just have this feeling. (Single female, age 26, Hui ethnicity)

Well, I think my parents now, when they are in front of many people, if they talk about me, my parents try not to speak, because they don't want... to talk about their own children like this. They feel ashamed. (Single male, age 25, Han ethnicity)

PLWHAs realize that HIV-related stigma is so great that it can affect the relationships of anyone associated with them. To shield their families from discrimination, PLWHAs often hide their status from the community. This creates a burden of secrecy and can take its toll on family relations.

I worried that after they found out, it would be bad and inconvenient for 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, right? (Married male, age 30, Han ethnicity)

Everything about the process of disclosure can cause stress for PLWHAs and their families. With involuntary disclosure, the lack of choice about whether to disclose can create worry for the PLWHAs. Sometimes, family members are saddled with the responsibility of telling the PLWHA about his or her status, leading to a stressful situation for the entire family. When the family knows the PLWHA's status before the PLWHA knows, the secrecy causes a lot of pressure and psychological burden within the family.

The gravity of AIDS and HIV status prevents some PLWHAs from disclosing to their family. They do not want to cause extra burden and concern for their family members.

Many participants worried about their family members' health and felt that telling their status to their families would cause stress. This negatively affected PLWHAs because they now worried not just about their own health but also about their family members' health.

[My sisters] will be frustrated; they are mainly worrying about my mother. If she knows it, if I let her know it, her eyes, because of diabetes... her blood sugar is high, she has a little cataract, her eyes are like in such a poor situation that she could not stand by herself. To be honest, it was beyond my family's capacity to afford it, so I can't tell them easily. I could only prevent that by keeping it to myself. (Single male, age 28, Han ethnicity)

Discussion

We present the first systematic and in-depth description of HIV disclosure in China. Two types of disclosure are identified: involuntary and voluntary disclosure. With involuntary disclosure, a family member of the PLWHA is usually the first to know and parents are often chosen by a health service provider to bear the responsibility of informing the PLWHA. Participants expressed mixed reactions about this form of disclosure, with some PLWHAs adamantly against it and others finding the process helpful. With voluntary disclosure, the biggest decisions were whether to disclose, whom to disclose to first, and when to disclose. The advantages and disadvantages of disclosure were weighed by PLWHAs in regards to the effect it would have on their families. Once PLWHAs decided to disclose their status to their families, they often told a family member of the same generation (i.e., spouse or sibling) first.

The HIV disclosure process in China is unique, beginning with the notification of test results. Health professionals often inform the PLWHA's family first of the HIV status or inform the PLWHA while a family member is present. As there are no reinforced policies in place for test result notification for HIV or other diseases in China (e.g., cancer, heart disease), health professionals are trusted to use their judgment about the best method for test result notification. Reactions from PLWHAs in our study provide preliminary evidence that there may be a need to reexamine Chinese policies regarding HIV status notification so that there are basic guidelines and procedures for health professionals throughout the country.

China is a family oriented society. Individuals rarely make decisions without first considering their family, and whatever individuals experience, they often share it with their family (Muller & Desmond, 1992). Children are very respectful of their elders and family members are supportive of each other (Lee, Ruan, & Lai, 2005). There is a huge fear of disappointing or causing concern for the family, and this environment may prevent PLWHAs from disclosing their status to family members. Our study has shown that although disclosing to family can have a positive impact on family relations, it can also have its downfalls and, in some cases, may break families apart.

Non-IDU participants and male participants tended to wait longer before disclosing their HIV status. This could be due to the fact that most participants who had non-IDU

transmission routes contracted HIV through sexual contact, and extramarital sex is looked down upon. Women who contracted HIV through sexual contact were most likely infected by their husbands, whereas men who contracted HIV through sexual contact were likely infected through extramarital sex. Although drug use is also shameful, most families were already aware of their family member's drug use.

Other studies have shown that HIV status disclosure can involve family in many areas of the world (Chandra et al., 2003; Landau & York, 2004; Lie & Biswalo, 1996). This study identified the dimensions and process of HIV status disclosure in a family context, illustrating that disclosure can promote open communication but can also create strife for everyone in the family. Disclosure of HIV status can have a huge impact on family relations because chronic disease has many implications for family dynamics. When an adult becomes chronically sick, his or her role in the family changes, which then affects relationships with other family members. In Asian families, the typical role of an adult is to be an independent, productive person who cares for children and aging parents. Chronic illness reverses this culturally prescribed role, requiring the aging parents to care for their adult child (Chin & Kroesen, 1999). In the case of HIV-AIDS, this can significantly strain the relationship between PLWHAs and their parents.

Chronic illness may also affect the relationship between spouses. For example, the added burden a spouse experiences while looking after a PLWHA can lead to depression. It has been shown that the more depressed a spouse is from caretaking demands, the worse off he or she perceives the marriage to be (Lewis, Woods, Hough, & Bensley, 1989). Chronic illness or disabling conditions are powerful forces that often control the structure, actions, and reactions of family members. They can (a) result in sweeping changes in family roles, (b) realign subsystems within the family, and (c) isolate family members from each other and from outside influences. Consequent anger and guilt can change a normally functioning family into a frustrated, rigid, and unhappy group (Hudgens, 1979).

In the collectivistic culture of China, especially in rural areas, dealing with negative aspects of HIV disclosure, such as stigma, becomes a serious issue. PLWHAs and their families already feel the shame of being connected to a disease that others consider immoral and caused by promiscuity or drug use. Living in a society where neighbors and friends know most of what happens in one's home amplifies the shame felt by families and individuals affected by HIV-AIDS. These conditions make it even more difficult for HIV-AIDS-affected families to integrate into society. Further complicating the situation is the fact that most people affected by HIV-AIDS in China come from poor economic backgrounds and either have sold their blood for money or are drug users. The combination of the increased cost of health care for HIV-positive adults and decreased family income because of unemployment can even hinder access to basic goods, such as food, housing, medication, and education for children ("AIDS mothers," 2004). Consequently, families affected by HIV-AIDS frequently face double or

triple stigma. For a family already struggling to make ends meet, having a PLWHA in the family poses a huge challenge.

China is experiencing rapid social change and is increasingly influenced by Western culture, with growing migration to urban areas, smaller family size, and changing material desires. The mentality that everything must be shared within the family is also gradually changing, and individuals are gaining more power over their own decisions. Although health care providers usually have the best interest of their patients in mind, they need to be aware of this shift. In the past, it was logical for family members to be informed first of a PLWHA's status, as they could then share in the benefits and difficulties of disclosure. This standard practice, however, may soon become defunct. Although families are used to providing a buffer for PLWHAs when they are notified of their status, telling family members first may now be more of a violation of privacy and confidentiality.

As a qualitative study, study results are limited by the 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. The study sample may bear more stigma than others because of their different risk factors, and disclosure may be more difficult. The prevalence of HIV in the studied area is also higher than in other areas of the country, but, tempered by the additional stigma associated with transmission route, should be comparable with other parts of China.

This study has several implications for HIV interventions that focus on improving the quality of life for PLWHAs and their families. Because PLWHAs seem to be more comfortable with disclosing to family members of the same generation, more programs targeting siblings and spouses of PLWHAs can be developed. In our previous studies, family members often helped PLWHAs make decisions regarding HIV treatment regimen, and it is not unusual in China to see family members accompanying their HIV-positive relatives to HIV treatment and testing settings. Potentially, family members can act as advocates to encourage PLWHAs to participate in interventions and counseling and to improve treatment adherence. It is important to include family members in some intervention programs, but researchers must be more sensitive to whether PLWHAs want their families involved. Because feelings and opinions regarding disclosure to family vary widely among PLWHAs, interventions must be tailored to account for this diversity and be inclusive of all beliefs.

Recently, the Chinese government launched a "Four Free One Care" national campaign. The four free services offered are (a) free medical assistance to PLWHAs who cannot afford AIDS medications, (b) free and anonymous HIV tests, (c) free education for orphans of HIV-AIDS victims, and (d) free prenatal treatment of infected pregnant women. The one care service is free care for elderly people who have lost children to AIDS (State Council AIDS Working Committee Office and United Nations Theme Group on HIV/AIDS in China, 2004). Regardless of its intentions, the policy will face challenges of participant recruitment and

medication compliance. On the basis of the findings of this study, the government can achieve a higher rate of participation and compliance from PLWHAs by recruiting and educating family members to facilitate the process.

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Received November 8, 2005

Revision received March 14, 2006

Accepted March 20, 2006 ■