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Chinese HIV-Positive Patients and Their Healthcare Providers

Contrasting Confucian Versus Western Notions of Secrecy and Support

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In this qualitative study, 29 HIV-positive, Chinese patients reported highly favorable impressions of their healthcare providers, who were seen as providing important medical-related, financial, and emotional support. Generally, the patient-provider relationship positively impacted the participants and their ability to maintain their health and was especially critical when patients were isolated from familial sources of support due to intense AIDS stigma. Often family members were informed of an HIV diagnosis before the patient, revealing tensions between Confucian principles of collectivism and familial authority and increasingly prevalent Western ideals of individual autonomy and the privileged status of personal health information. **Key words:** *AIDS*, *China*, *Confucianism*, *healthcare provider*, *HIV disclosure*, *privacy*

CHINA is facing an HIV/AIDS crisis in which increasing numbers of HIV-positive individuals are in need of care. Current reports of the AIDS epidemic in China have confirmed more than 141,000 cases of persons with HIV infection and estimate that approximately 650,000 people are infected with HIV; approximately 80% of these individuals do not know they are infected.[1] If the rate of new infections continues unchecked, China's HIV epidemic will quickly escalate.[2]

Healthcare providers (HCPs) play an important role in HIV treatment.[3-7] Chinese patients seek therapy with the expectation that their HCPs have the knowledge and expertise to diagnose and treat illness, and that they will tell them or their family what they need to know. Patients are socialized to accept information and instructions from HCPs without asking many questions, in part because the healthcare system is organized along lines of trust. Patients trust that their HCPs will act in their best interest because HCPs are taught to treat patients as if they were family members.

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The role of the HCPs and medicine itself is to serve the patient in a loving manner, which is a concept that is profoundly influenced by Confucianism.[8]

Confucianism provides a set of moral predicates that are deeply embedded in relationships, responsibility, and appreciation for others.[9] In collectivistic Chinese society, responsibility to others is emphasized over individual rights.[8] Individuals are expected to act in accordance with their place in the social and familial hierarchy to facilitate the orderly and smooth functioning of society. People are taught to look after the interests of the whole family, and the family's needs are regarded as superior to those of any individual member. Benevolence is one of the most important values of Confucianism that guides how Chinese society is organized. The "Three Cardinal Guides" outline the hierarchy of responsibility for maintaining social order: the ruler guides the subject, the father guides the son, and the husband guides the wife.[10]

Confucianism in healthcare dictates that (1) the family, not the individual patient, has the responsibility and authority to communicate on the patient's behalf, including receiving diagnostic information and making treatment decisions; (2) the family is expected to provide all types of support during the patient's illness, including financial assistance; and (3) the timing and determination of when patients are ready to return to their previous roles in society is in part dependent on the needs of the family.[9-12] The influence of these Confucian beliefs is reflected in the laws that govern consent; for example, the central government regulation Article 33 states that the hierarchy of people who can sign a surgical consent form is a family member, the patient, or the employer of the patient (who has authority because of the responsibility for the medical bills).[8-12]

Privacy rights are an important aspect of respect for individual patients. In the United States, patients have the right to receive accurate and easily understood information about their diagnosis, health plan, and treatment management, and personal health information is considered privileged and is not generally shared without the patient's explicit consent.[13] In the Chinese context, individual privacy is understood differently and diagnosis disclosure, for example, is not considered a personal issue. Chinese physicians tend to first weigh the best interests of the family rather than the individual, and thus usually inform the family members first, typically the patient's spouse or parents, rather than the patient.[14] This practice is predicated on the belief that the family is in the best position to judge what is in the best interest of the family unit as well as the individual patient.[8,14] These cultural values and beliefs are central to the practice of disclosing and HIV diagnosis in China, which is a very sensitive issue because of the intense stigma and discrimination that is associated with the disease.[15,16] In disclosing an HIV/AIDS diagnosis, HCPs usually tell family members first to protect patients who may not accept the facts of their illness and also to prevent them from feeling stigmatized or losing hope or the will to fight.[17-19]

The HIV epidemic in China corresponds to 3 primary routes of transmission, including drug use, commercial blood/plasma donation, and sexual contact. When compared with other types of illness, HIV/AIDS is unique in several respects, including potentially stigmatizing routes of transmission, the prevalence of HIV among stigmatized groups, and family members' as well as HCPs' potential perception of vulnerability and self-identification with the disease. While ensuring equitable access to care and attaining high standards of physical and mental health are increasingly defined as essential human rights, many persons with HIV living in China do not have an access to basic healthcare services even though care and treatment prospects are improving. Because of the stigmatized nature of the illness, persons living with HIV are often the targets of discrimination and prejudice in healthcare as well as other settings.

The goal of this article is to further understand HIV care in China with specific attention to the multiple roles of HCPs, diagnosis disclosure patterns, types of support

HCP provide, as well as the impact of the patient-HCP relationship on the patient. We discuss the complex value dilemmas arising in HIV care given the confluence of traditional cultural values, HIV as a stigmatized illness, and the increasing influence of Western perspectives.

METHODS

This study is part of a larger project to examine the feasibility of behavioral interventions to increase antiretroviral therapy (ART) adherence in China (Simoni et al, unpublished data, 2007). We used semistructured interviews with HIV-positive patients to explore their perceptions and experiences with HCPs involved in their HIV care.

Sample characteristics

Eligible participants were at least 18 years old, not cognitively impaired or medically unstable, receiving care at the hospital (either inpatient or outpatient), and either currently undergoing ART or about to initiate treatment. Twenty-nine HIV-positive individuals participated in the study (22 men and 7 women). Twenty-one of the participants had been undergoing ART for longer than 6 months, and the other 8 were to begin ART treatment within 2 weeks. Their mean age was 38 years (SD = 11 years; range 23–72). Most were of Han ethnicity (90%) and lived in the city where the hospital was located (76%). Twenty participants (72%) had at least high-school diplomas. Reported methods of HIV transmission included blood products (n = 8) and sexual contact (n = 10). Other participants did not know (n = 3) or were not willing to report (n = 8) the source of their HIV infection. Thirteen participants currently were married, 4 living with a same-sex partner, 6 were never married (and not living with a partner), 4 were divorced, and 2 were widowed. Participants had known their HIV status for 2 months to 10.8 years (mean = 2.7 years).

Recruitment methods

All participants were recruited from a major hospital in a large, northeastern city in China known for its premium HIV care. Potential participants were approached directly by clinic staff, and those who were interested (97%) were referred to study personnel. After the study personnel explained the nature, risks, and benefits of the study, patients who agreed to participate in the study provided written consent. Participants could choose whether to be audio-recorded; if they declined, detailed notes were taken. All participants received 150 RMB (~$20) as compensation for their participation.

Data collection and analysis

As part of semistructured interviews with HIV-positive patients to explore barriers and facilitators to adherence, we also discussed what they experienced and expected in their encounters with HCPs during HIV-related visits. The interviews were conducted in Mandarin between July and September of 2005. Interviews averaged approximately 1 hour and were conducted in a private office at the hospital or at a private location of the participant's choice. The interviewers included research staff as well as hospital physicians and nurses with whom patients had established relationships in the hopes they would be more likely to discuss sensitive topics. All of the interviewers completed a 2-day training to familiarize themselves with the goals of the study and to practice semistructured interviewing techniques (vs clinical interviewing) and the use of open-ended questions and probes to elicit further information from participants. The interviewers used a guide developed in advance by the research team to assure that the following topics were discussed: testing history; disclosure experiences; medication history; side effects; adherence to ART; adherence access, barriers, self-efficacy and facilitators; and social support. All interviews were transcribed in Mandarin and then translated to English for analytical purposes. To retain meaning, the English text was translated and compared with original translations by bilingual researchers.

Two investigators independently reviewed the transcripts and identified codes to represent concepts in the narratives related to the interview questions and additional topics raised by the participants. The investigators met to review and discuss their coding and resolve any discrepancies in how codes were assigned, the meaning associated with the codes, and general patterns observed in the data. ATLAS.ti (Scientific Software Development, 2005) was used to manage the data coding process and generate reports that included sections of the narrative assigned to the codes for the disclosure of the diagnosis (including the circumstances that triggered the HIV test and where and to whom the diagnosis was disclosed); perceptions of the HCPs (in general and with respect to the disclosure process); and forms of support received from HCPs and the impact of the patient-HCP relationship on HIV/AIDS care. This analysis is based on a content analysis of these reports to explicate and summarize the range of responses and to gain a better understanding of the participants' experiences with their HIV care.[20]

RESULTS

Study findings are reported in 4 major areas: perceptions and roles of HCPs, disclosure patterns related to the HIV diagnosis, types of support HCPs provide, and the impact of the patient-HCP relationship on the patient.

Patient perceptions of HCPs

Faith and trust in HCP skills

Most of the participants revered their HCPs because of their ability literally to give them life, rescuing them from a painful death. A 46-year-old businesswoman regarded her HCP as "God." Another patient similarly expressed total trust in HCPs, stating that, "Even though I don't know what medicine I am taking, I believe that what the doctor gave me will not hurt me" (40-year-old skilled laborer). This absolute faith in the HCP often served as a strong motivator to adhere to antiretroviral medications, even in the face of severe side effects. A 32-year-old skilled laborer complained of allergies, dizziness, nausea, and vomiting because of ART. After her HCP's reassurance, she convinced herself to continue the treatment. She reported, "As long as the doctor told me to keep taking meds, I will do that. I know clearly that the meds can prolong my life, and I want to live. I will obey the doctor's orders." Another participant described how the HCPs asked him to continue the same treatment even though he had severe skin rashes. "The doctor suggested that I take the regimen longer to see whether I can handle it" (40-year-old man, skilled worker). Finally, 1 participant expressed his complete reliance on the HCPs for dealing with side effects, "I know nothing. I can only turn to the doctors to manage my side effects" (46-year-old man, unskilled worker).

Participants also implicitly respected doctors' decisions about the timing of the treatment and the choice of medications. A 25-year-old woman expressed her dependence on her doctor's decisions as follows: "The doctor should decide when I must take the medicine. As long as he tells me, I will do it." Doctors encouraged participants to switch medications for various reasons. For example, a doctor encouraged a participant to buy imported medicine, even though the imported medicine was not covered by the free government policy. "The doctor told me that the domestic medicine doesn't work well. . . . it is better to use the imported medicine" (37-year-old woman, technical worker).

One participant reduced his medicine because he was afraid that he might not have enough medicine to last. He said, "The doctor told me not to, and I obeyed" (34-year-old man, unskilled worker). Another participant had a fever for more than 2 weeks yet he did not take any fever-reducing medicine because "the doctor said it is not good to monitor the change of my body temperature" (30-year-old man, professional). Participants took their doctors at their word, seldom questioning their decisions. A 46-year-old woman said, "I don't know how the medicine works. But the doctor said that I couldn't stop the therapy."

Levels of trust

Participants' trust depended on the sense of their HCPs' expertise with HIV/AIDS. Most of them mentioned that they believed that doctors in the large city hospitals had better training and experience than doctors in provincial settings. A 40-year-old saleswoman believed the local hospitals could only do the tests but do not provide treatment because they lacked sufficient knowledge. She said, "I didn't trust doctors in my town. But I trust doctors here. They have better clinical experience." The patients' trust in their HCP often generalized to the hospital as well: ". . .I don't have any concerns . . . it is useless to worry. This is the best hospital in this area and it should be trustworthy" (30-year-old man, manager).

Authority figures

Physicians have the authority to suggest that patients undergo tests, even when the tests are more expensive than patients can afford. Several participants agreed to test CD4 cell count and viral loads because "the doctor suggested I do so." Participants rationalized the suggestions even though they did not believe the test results would be meaningful. A participant described the following:

> Since my CD4 is so low, I think my viral load must be very high. So there is no need to test it. But the doctor suggested I test it, so I did. . . .the viral load is a good indicator. But it is too expensive for me. (30-year-old male professional)

Respect for the HCP as the ultimate and supreme authority carried over to other life decisions such as pregnancy. Currently, physicians in China prefer HIV-positive female patients not get pregnant or terminate a pregnancy if they should conceive. A 32-year-old, skilled laborer said, "I can't have kids . . . the doc says that I shouldn't have baby because of my status." Respect for authority as a cultural value seemed to lead to patients' implicit trust of their HCPs. If a patient dared to even slightly question the authority of the physician, it was often viewed as a sign of poor self-management of the illness.

> As for patients, they cannot do anything, because they know nothing and they can never be experts. Therefore, patients will have to follow their doctors' advice and must trust doctors. You can't let patients lose faith in doctors' words; otherwise . . . those patients will just muddle along, caring for nothing. Since even doctors do not know the best, then what should a patient should do? (28-year-old man, manager)

Regarding those patients who have their own ideas about treatment, 1 participant viewed such behavior as very foolish:

> My roommate was cheating on himself. When nurse gave him an intravenous injection, he pulled out the needle. He is always against doctors and nurses; he must not want to live. We are here to follow doctors' orders" (72-year-old man, retired unskilled laborer).

Negotiating with HCPs

After having followed doctors' orders and advice for a period of time, some of the experienced participants had their own ideas about their HCPs' advice. There is an old saying in China, "If you are sick for a while, you will become the expert in curing yourself." One of the participants mentioned that doctors might know the mechanism of the medicine, but he knew the feeling of side effects. This first-hand knowledge based on his personal experience empowered him to discuss his needs more openly with his physicians. Others negotiated with their physicians to change their medications or the specific dosage, the quantity of medicine received at any given time to reduce traveling time and expense, requests for in-depth assessment for medicine resistance, obtaining duplicate record for local hospital providers, and even the choice of location for hospitalization.

Nursing ability was also questioned, especially in general hospitals. Participants were asked whether they would be open to having a nurse provide counseling. "I think they don't know HIV. Nurses are not able to provide counseling" (46-year-old female manager).

Diagnosis disclosure patterns

Rationales and expectations for HIV testing

Patients' reactions to the disclosure of any diagnosis are shaped by their expectations and the circumstances that initiated testing. HIV testing is done in China for a variety of reasons, including as part of routine preoperative screening procedures, for civil service, employment, immigration, and marriage certificate examinations, when other diagnostic tests are negative, and when partners test positive, and when patients are symptomatic and have received or donated blood. In all but the last 2 situations, patients are rarely informed that they are being tested for HIV. All these reasons for testing were reported by the participants in this study, thus many of the patients did not know they were infected with HIV until they visited HCPs for other illnesses or persistent symptoms. Only 8 of the 29 participants suspected they might have HIV prior to testing because they had HIV-positive partners or had donated blood and were advised by hospital officials to get tested. Two of the participants found that they were HIV-positive before hemorrhoid surgery; 6 others had fevers and cold-like symptoms for months but their doctor neither discovered the etiology behind these symptoms nor suggested HIV testing. One of the participants learned her diagnosis from premarital testing, and another learned of the diagnosis during the immigration process.

Disclosure to the participants, family members, and others

The testing process in China frequently involves multiple steps and institutions and there are no universal standards or protocols directing which HCP should be responsible for disclosing the diagnosis. Clinicians at general hospitals or provincial clinics will frequently order the first HIV test but then refer patients to the Center for Disease Control & Prevention for confirmatory tests, sometimes without explaining what the tests are for. Because patients are socialized not to ask questions, they will often comply with the referral without knowing why they are getting additional tests. One man who was somewhat knowledgeable about HIV was left to infer the diagnosis himself:

> Nobody told me. I was hospitalized in [the University Hospital]. The doctor asked me a series of questions . . . [such as whether] I had a history of blood transfusions or plasma donations. He also asked me if I had been to those entertainment places [brothels], and if I had casual sex. . . .I felt like it had something to do with HIV. Then they transferred me to [the HIV specialty clinic, where the doctor told me directly]. (31-year-old skilled laborer)

When HCPs did disclose the diagnosis, more than half (59%) of the participants reported that the doctors told them directly, sometimes in the presence of other family members and other times when they were alone because they believed that the patient had the right to know. Eight participants (30%) reported that the HCPs had first told family members or a close friend and later learned their diagnosis from them. One woman's description was typical of this process:

> I was tested in a hospital, but the doctor did not tell me [my test result]. When the doctor knew I had this disease, he called the infectious disease hospital. At the same time, he told my family about my diagnosis. My family told me after I was transferred. I asked, "[Do] you know why I need to be transferred?" Then they told me. (46-year-old manager)

She did not appear to have a problem with this process, but that was not universally the case. A 72-year-old retired, unskilled laborer learned of his diagnosis 3 years after he was tested, when he was admitted to an infectious disease hospital. "My family told me after I got here . . . they knew my diagnosis 3 years ago, but they told me I had hepatitis. They cheated me."

Disclosure also extended to patient's employers, which carried great risks for the participants in terms of possible loss of employment and income as well as potential discrimination from coworkers and supervisors. In the case of one of the participants, who worked in the hospital where he received his diagnosis, the lack of respect for confidentiality made him feel like giving up.

> The doctor in that hospital told my supervisor [about my status]. Because of this, I didn't want to live. I don't want to live not because I am physically ill but because I cannot accept the situation psychologically. My friends who work in that hospital told me there were rumors about me. So I decided I shall live to prove myself. (40-year-old skilled laborer)

Rationales for not disclosing the diagnosis to family members first

A few participants shared that they felt that physicians should not reveal a diagnosis to their family members first. They felt that they, as patients, had a right to be in charge of their own health and that they were truly harmed by others knowing about their condition.

> I should be able to make my own decision, because I know how I want to deal with my own problem. I told him (the doctor) clearly, but he did not respect my decision. I was furious. . . . he should not have told my family and made a scene of it. Now everyone knows. (47-year-old technician)

In addition, some participants wanted to keep their diagnosis private as a way to protect their families from possible harm, either to their health or in the form of public discrimination. Three participants mentioned that they specifically did not tell their elderly parents about their diagnosis because they worried it would adversely affect them, which would increase the burden on the patients. This fear was realized in the case of one 30-year old male professional:

> When I first knew [my diagnosis], I was very depressed. But my parents didn't know. I told them that the doctors were trying to figure out what that was but the condition was not that optimistic, it was hard to say what my illness was, [but] if it was something bad, I might meet the end of my life soon. My father was frightened, and he cried the whole afternoon. And a week later, he was sent to the hospital for pigeon breast. Do you know that? It is the earlier stage of emphysema. . . . spontaneous pigeon breast happens when people are nervous. He stayed in the hospital for 9 days. At that time, I took care of him while [I] myself was seriously ill.

Another protective move was that patients deliberately distanced themselves from their family members as a means to spare them the pain of the illness as well as potential social isolation. A 28-year-old unskilled laborer described how he works to hurt his mother to spare her the future pain of losing him to HIV:

> [My mom] doesn't know. I especially don't want her to care about me. If she is nice to me, then if I die early she would be so sad. So I'd rather she doesn't care about me. . . . my mom is very, very nice to me because I am her only child. . . . she would buy me food that she couldn't afford to eat. It was okay before, but now if she is nice to me, I get mad at her and leave her right away. I just told her "I don't need your care." I just want her to hate me.

Those participants who preferred to get the diagnosis first (and alone) reported that they needed time and privacy to accept and manage their new lives by themselves. Others preferred that HCPs help family members to accept their status by informing them first. In these cases, HCPs became liaisons who explained, advised, and supported family members to keep supporting their loved ones who live with HIV.

Disclosure to others outside the family unit

Aside from whether participants or their families were first informed of an HIV diagnosis, the lack of privacy and confidentiality beyond the family was an issue of concern. The account shared by a 30-year-old male manager reflects the experience of several participants, whose clinicians disclosed their status to staff members in the hospitals where they first received their HIV diagnosis:

> In the hospital, everyone says, "We will keep your status as a secret," . . . but actually it is not the case.

> Take that big hospital, for example . . . my HIV status was publicized like big news throughout the hospital. I really don't trust any institution or any place where they declare that they can keep a patient's identities confidential.

Violations of privacy and confidentiality were also shared with respect to discussing HIV diagnoses in front of other patients. For example, a 47-year-old male technical professional spoke of switching doctors after he was an unwitting witness to such a disclosure:

> The reason why I refused to go back to the doctor after a year is that I really hated him. He made fun of patients. There is a patient who shared a hospital room with me. He and his wife kowtowed in front of the doctor to thank him. But the doctor asked very detailed questions, like how were you infected, and other very private information. He did not even consider that I was also in the room . . . I hated him.

In summary, HCPs varied in their delivery of an HIV diagnosis. Some HCPs informed the participants directly and privately, other times they disclosed the diagnosis to both the participants and their family members simultaneously, while in other cases to only family members without the participants' knowledge. In some cases, disclosure extended beyond the participant and the family, including other hospital employees as well as coworkers and employers. While traditionally diagnoses have often been delivered in these ways, given the highly stigmatized nature of HIV and AIDS, many participants objected to such practices.

Forms of support HCPs provide

Participants reported overwhelmingly positive support from their HCPs. This support was largely related to their health needs and medical care as well as emotional support and the acquisition of resources to ease financial burdens. In addition, HCPs supported their patients by providing information and education about disease prognosis, emphasizing the importance of ongoing adherence to taking the medication and how to respond to side effects.

> The doctor told me that the protease inhibitor and . . . [other drug, forgot the name] have to work together. So I have to take two medicines on time and take the right amount. The doctor told me in detail before I started the medicine (37-year-old woman, technical field).

Emotional and social support

About half (52%) of the participants expressed the difficulties surrounding their inability to disclose their disease to anyone except HCPs in the HIV-specialty clinics. For example, some participants called, left messages, and waited for HCPs at the front door of the hospital just to talk. Participants appreciated HCPs for paying attention to their psychological as well as medical needs. One participant said he appreciated the warm response and emotional support he received from HCPs when they discussed his physical and mental health. He mentioned, "The healthcare providers maintain good relationships with everybody. Both those nurses and physicians are so great" (40-year-old man, skilled laborer).

The encouragement and help participants reported receiving from HCPs was especially critical when they had lost support from family members or isolated themselves because of HIV. Another man mentioned that after he was diagnosed with HIV, he felt very depressed but the support he received from the nurse specialist made a difference:

> It has been a year [since my diagnosis]. Life is very, very hard. However, the nurse manager is nice. She calls me sometimes, just like a sister. I can talk to her as a brother and share my thoughts. What I can't say to my family, I can say to her. (42-year-old man, technical field)

Participants also appreciated when HCPs helped their families understand and accept the disease. One participant appreciated that the HCPs helped his wife to understand HIV and how to deal with it: "In the beginning, of course, she couldn't bear this. Doctors' and nurses' explanations changed her" (46-year-old man, technical field).

Financial support

HIV/AIDS treatment can be expensive for Chinese patients. Although screening tests and ART medications are generally free, patients usually must pay for confirmatory tests and laboratory analyses.[21] Many of the study participants did not have consistent financial assistance and, after they were diagnosed, they looked to HCPs who helped them get access to free medications and laboratory tests, either by referring them to research projects that covered these costs or through their own connections with pharmaceutical companies. A 28-year-old businessman stated that, "The doctor actively looked for medications. I joined a pilot project for free medicine, so I only paid for 2 months out-of-pocket." Another 48-year-old technical worker mentioned that he formerly bought medicine from India or Thailand, but then could no longer afford it. "Stavudine costs 10,000 RMB [$1250] per month. I could never afford it so the doctor helps me to find some free medicine."

In addition to the medication, CD4 cell count and viral load testing fees can increase the participants' financial burden. Costs are especially high when multiple family members are HIV-positive and all have to regularly check their CD4 cell counts and viral loads. Many participants stated that they came to hospital on special days of free testing, as described by this 40-year-old man, skilled worker:

> Every time I come here, I will ask if there are some free CD4 and viral load testing. It costs me more than 1,000 RMB [$125]. I am not working and my wife and I can't afford it. Two of us need more than 2,000 RMB [$250] to do these tests. I won't do the tests unless they are free.

Many participants shared they need financial assistance from HCPs as well as other organizations to provide financial assistance because they feel they are unable to use their health insurance. While some of the participants had workers' insurance they often chose not to use it to cover HIV-related expenses. A 47-year-old unskilled worker explained that, "...although I have health insurance, I dare not use it because of privacy issues."

Impact of the HCP-patient relationship on the patient

Provision of healthcare services

Participants appreciated HCPs providing the medicine and service. They felt that HCPs had saved their lives and without them they would not know what to do. A 25-year-old woman acknowledged, "... the doctors were very nice, and I learned a lot about my illness. I am really grateful." Participants expressed wanting to maintain good relationships with their HCPs, so they could not only remain informed of their medical progress but also to obtain the most up-to-date information on new treatment regimens. A 72-year-old retired unskilled worker believed that he could "... at least get informed of the latest discovery of AIDS, or the newest treatment. I am not going to believe anyone else. The doctors are experts in this, and they won't be wrong."

Other participants talked about how caring relationships with HCPs were the key to maintaining good, long-term adherence to ART. A 46-year-old businesswoman expressed the following:

> First, I care about is the medicine. Then, the ability of the doctors is important. Doctors and nurses' attitude towards patients are also play a key role in adherence. I want to talk to those old, experienced doctors. That can make me feel better. I always hope that doctors can talk to me more often.

Emotional support and guidance

Participants expressed deep appreciation for the "caring" that some HCPs offered. The majority of participants spoke of how, even when their family members knew about their diagnosis, they were very reluctant to share this information with friends or coworkers. This made the support of HCPs even more important because they had few outlets to talk about their illness or share their feelings.

The key point is to provide us mental support.

> . . . currently, there is no one in charge of those psychotherapeutic services in our country. It [mental support] should be provided among patients, doctors, and nurses . . . in the hospital. Doctors and nurses should take care of us. There are so few people in the same situation as we are. After my friend and coworkers know my HIV status, they rarely want to contact me. (42-year-old man, skilled laborer)

Another participant appreciated the encouragement from HCPs. Even though his health condition was not good, as long as the HCPs told him that everything was in control, he felt relieved.

> . . . I think the most important support came from nurses. Smiles on nurses' faces are the medicine. As for doctors, if the doctor in charge told me I am fine, I will feel much more relaxed. I am sick, for sure, and the doctor knew that I am in a difficult condition. If the doctor comes to me and told me that I am fine, I will be very happy and try I best. Even though I am in trouble, it is not necessary to let me know. A doctor shall do first is to encourage the patient and support him/her. (24-year-old man, technical worker)

Another HCP helped the patient to accept the diagnosis and help him disclose to his friends in a way to minimize stigma.

> The doctor from the CDC got an idea for me. He said, "You can tell those who are not that close to you that you got hepatitis C." So, except for my wife and her sister, people all think that I have hepatitis C, including my son (46-year-old man, technical field).

Payback

After making many visits to the same hospital over a period of time, some participants wanted to give back to the HCPs as well as the hospital. For example, a 47-year-old unskilled laborer volunteered to work as a peer counselor for newly diagnosed patients. As a result, HCPs call him frequently to visit new patients who are having difficulty accepting their diagnosis. As a peer counselor, he can share his own experience with patients and guide them through the early rough stages of adjusting to their new status and managing their illness and treatment. Participants also expressed their appreciation by volunteering for medical research. By participating in HIV-related research, participants felt that their contributions would help physicians provide better treatments and benefit future patients.

Negative encounters

Some providers failed to meet the expectations of the patients, while other participants felt stigmatized by their HCPs, particularly those whose providers practiced in general hospital settings or who had less specialized training in HIV/AIDS care. These participants vividly recalled those experiences because they were traumatic. A 42-year-old man in a technical profession described his experience when he was hospitalized as follows:

> I had a fever one night and the nurse just stood at the door. She stood far away from me and brought in an ice bag and threw it to me. Nurses there are much worse than the nurses here. So now I really hate that hospital. I live close to that hospital but whenever I pass that hospital, I feel sick.

Participants were very sensitive to HCPs' attitudes toward them and their disease. One of the participants was very upset because some of his HCPs treated him as an abnormal patient.

> . . . the traditional medicine doctor, who uses gloves when he feels my pulse, I would rather not take the traditional medicine from him. . . . the medical staff should understand that the gloves are not necessary. . . . in other hospital, the [medical] director uses gloves when she touched me. I will never ask to see her. I would rather see the junior doctor, although he is inexperienced, he doesn't use gloves or mask. I feel better with him because he doesn't discriminate me. (47-year-old unskilled worker)

Some of the participants felt that their illness was a deeply private issue and they did not want to discuss matters with their HCP. When discussing the advantages of a peer-counseling program, some of the participants preferred to have peer counselors discuss their day-to-day living issues, even when HCPs were accessible, since they perceived gaps in understanding between HCPs' experiences and their own. They reported that sharing their feelings with an HIV-positive peer was more comforting. One 47-year-old male unskilled laborer said, "There is a time when people just want to share their issues with someone but not with doctors and nurses." Another participant commented:

> When doctors are talking to a patient, they always speak with authority. Patients have no choice but to follow. I do not mean doctors are arrogant. The problem is in patients. They hesitate to ask questions. If they talk to other positive people, there will be no problem at all [talking about their concerns]. (47-year-old male manager)

DISCUSSION

The disclosure practices for HIV in China highlight a dilemma for clinicians, patients, and families created by the intersections of Western and Chinese values. Both cultural systems place a high regard on promoting the patient's best interests, yet they differ on who has the authority to determine those interests. In the West, the focus is on individual patients who are generally believed to be best situated to determine their own interests and whose privacy concerns mean they have the right to control the disclosure process about personal health information. In China's collectivistic-oriented culture, the best interests of an individual are typically determined by family members who are responsible for the well-being of the entire family unit. In this case, maintaining an individual patient's privacy is not the most salient goal.

In China, a person is educated to be responsible to the family and society, not to have rights.[8] Within the Confucian value system with a primary focus on beneficence, it is considered ethical to disclose an HIV diagnosis to family members who are responsible for attending to the best interest of the suffering patient. However, the stigma and discrimination associated with HIV in China disrupts the traditional practice of disclosing diagnostic information to family members. In this context, serving the best interests of the patient and the family may be better achieved by adopting some of the Western norms of respecting individual patients' rights for personal privacy and restricting disclosure of confidential information to those persons named by the patient. Stigma not only increases the patient's desire for privacy but also may increase the need for the family's involvement, thus disclosure practices to the patient first or the family first could both be understood as promoting the best interests of the family unit.

The findings in this study highlight the dynamic nature of relationships between persons living with AIDS and their HCPs in China. The participants in this study reported the importance of their relationships with HCPs as exemplified by their comments about saving lives, holding specific knowledge, and providing various kinds of support and assistance. All 3 of these roles help HCPs gain and maintain patient trust.

In our study, participants tended to prefer that doctors inform them first about their diagnosis because they needed time and privacy to rearrange their lives. The stigma and discrimination associated with HIV creates incentives for individual patients to keep their diagnosis secret, particularly when they have engaged in behaviors (such as homosexual sex or intravenous drug use) that the family is not likely to sanction or view as being in the collective's best interest. The results from our study suggest that even when HCPs disclose an HIV diagnosis to individual patients, this practice may still be achieving the intent of the Confucian value system, as the motivation for keeping this information private is to protect individuals and families from the social harms associated with HIV stigma and discrimination. Maintaining secrecy is in keeping with Confucian values because patients wish to promote the best interests of their family members by protecting them from shame and discrimination by others in the community as well as protecting themselves from ostracism by their families.

For persons infected with HIV in China, HCPs often are a buffer against stigma and discrimination, and sometimes become the only source of support, especially for those individuals who wish to keep their serostatus secret. Therefore, HIV infection presents a challenge to the norms of disclosure to family members as a means to protect patients from harm. The promotion of family well-being was facilitated by HCPs who helped patients and family members accept the HIV diagnosis and inform them about their situation and options for optimizing their health. For most participants in this research project, HCPs were a critical source of all kinds of support, particularly those HCPs with expertise in HIV/AIDS. Patients relied on these HCPs for medical management of their symptoms, education about the disease and prognosis, emotional support, and access to medications and laboratory services. They expressed that they could find comfort from HCPs' reassuring conversations and information. Most HCPs knew their patients very well and could give them the personal advice that they needed. Meeting the emotional needs of HIV-positive patients is important both to those patients and to their HCPs.

Keeping a good relationship can generate positive health outcomes for patients and in turn stimulates a sense of satisfaction for HCPs.[18,22–25] Establishing support for patients and gaining their trust in the proposed treatment plan is important to ensuring that patients follow medical advice.[24] Martini et al[26] reported that patients who have a satisfying relationship with providers have better adherence to their ART regimens.[27] Bakken and her research team reported that patients who have strong rapport with their healthcare providers have better adherence to medication routines and keeping appointments.[3,4,6,7,28] In Chinese society, a physician's authority is highly valued. Therefore, patients usually follow their doctors' orders, and this is especially so when they trust their providers as well. HCPs can greatly assist patients by taking advantage of their authority and rapport to encourage those patients to better adhere to their ART regimens.

HCPs who are taking care of HIV-positive patients can also sometimes feel that they have been stigmatized and discriminated against. Li[17] reported that perceived stigmatization and internalized shame might cause negative consequences when taking care of HIV-positive patients. During interviews for the current study, some participants remembered and described their feelings about HCPs who had mistreated them, for example, by categorizing them as "contagious." This behavior led some patients to refuse to return to the same provider. This type of unkind and disrespectful attitude toward HIV-positive patients might have arisen in some HCPs because they internalized their own sense of shame about providing care for HIV-positive patients. HCPs represent one segment of the general population and, if they discriminate against these patients in their day-to-day lives, they will also likely to show these attitudes in the healthcare setting.

Chinese patients are most likely to obey doctors' order. It is imperative to educate HCPs to provide positive and caring attitudes regarding patients with HIV. Providing updated knowledge is another way to decrease discrimination by HCPs.[13,29] Beginning here, HCPs and their families can gradually change Chinese attitudes about HIV.

When a patient first receives an HIV diagnosis, it is like a "death sentence." For some, HCPs are regarded as heroes who have the capacity to save these patients' lives. Over the time, patients learn how to live with HIV, share their experiences with others, and request more assistance from HCPs and peer counselors. Study participants appreciated HCPs when they provided psychological support, especially for providers who were experienced in HIV/AIDS care. Patients believed that HCPs' experience is the key to wisdom. Nurses who provide care and encourage patients along their treatment are highly valued. However, currently nurses in China are not well-trained in nursing, counseling, and HIV-related care and are instead more focused on clinical techniques.[30]

There are some limitations in this study. First, the study was based on the perspective of participants from a specialty HIV hospital in an urban setting and thus may not be representative of persons living with HIV and their experiences with HCPs in other parts of China. The high response rate (97%) may reflect an overall positive attitude toward HCPs in the particular setting in which the study was conducted. However, participants discussed experiences with HCPs from multiple healthcare settings and reported a variety of encounters, both positive and negative. Second, patients who seek care from this type of specialty hospital tend to be more educated and have better financial resources. Therefore, they might have expected HCPs to provide more than the standard level of care. Third, we asked about perceptions of HCPs without necessarily distinguishing between physicians and nurses, as well as between generalists and HIV specialists. Participants did not always specify the context of who they were referring to or where the HCPs practised when sharing their experiences.

CONCLUSION

Culture shapes the norms and standards by which world citizens evaluate how specific societies respect the human rights of their members. Different interpretations of the practices that appear to promote discrimination must be viewed in context to understand the norms behind the practices and how different circumstances, such as the stigma and discrimination associated with HIV, challenge the accepted norms. Interpretations of human rights "violations" must, therefore, be viewed with some understanding of the cultural norms associated with the practices.

Delivering sensitive information such as an HIV diagnosis is an art and the stigmatized nature of the disease provides reasons to evaluate the traditional practices of disclosing health information to family members first, in the interest of protecting patients from harm. Given that HIV-related discrimination can affect all members of the family, and in some cases may cause discrimination within the family, HCPs must evaluate the circumstances of the particular family unit before determining which disclosure method will serve the family's best interests.

Nurses would do well to take charge in several parts of this effort to improve conditions. For example, they can offer more educational and emotional support to patients with HIV. Furthermore, nurses can play an important role as liaisons among patients, their families, and other healthcare providers/services. The nursing role should be explored in more detail so nurses can provide sophisticated and empathic care to patients. Future programs related to provide nursing training should be developed to include this topic.

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