“If you get AIDS… You have to endure it alone”: Understanding the social constructions of HIV/AIDS in China

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Abstract

Recent AIDS research has documented the widespread discrimination toward people living with HIV/AIDS (PLWHA) in China. General ignorance and misconceptions about this disease have been identified as the two primary reasons for this prejudice. Yet, little attention has been paid to social constructions of HIV/AIDS in the Chinese context and to the processes by which such constructions are experienced, understood, reacted to, and, perhaps, reconstructed through social and interpersonal interactions. Based on a qualitative study of Chinese PLWHA’s illness experiences, this paper explores how HIV/AIDS, as a social construct, is understood by these individuals in the context of their daily encounters. It is discovered that, despite their knowledge of HIV/AIDS, PLWHA’s perceptions about and responses to this disease are greatly influenced by their experiences of interacting with others (e.g., their families, friends, and health workers). The conflicts between individuals’ mastery of knowledge pertaining to, and their overreactions in practice toward, HIV-infected bodies suggest that AIDS education should not be limited to the dissemination of knowledge per se, but that the interpersonal or interactive dimensions of discrimination and efforts to combat it must also be taken into account.

Keywords: HIV/AIDS; Social construction; Stigma; Discrimination; China

Introduction

As of the end of 2005, the estimated number of people currently living with HIV/AIDS in China was 650,000. Only about 20% of this population was reported, which means the majority remains invisible (Ministry of Health (MOH), Joint United Programme on HIV/AIDS (UNAIDS), & World Health Organization (WHO), 2006). Stigma associated with HIV/AIDS and discrimination toward people living with HIV/AIDS (PLWHA) have been identified as key barriers to fighting this epidemic effectively, because the prejudice has not only inhibited PLWHA from accessing HIV testing, disclosing their serostatus to intimate partners, and engaging with health care, but has also made it difficult to intervene in populations that are affected by this disease (Lieber et al., 2006; Liu et al., 2006; Wu et al., 2002; Wu, Rou, & Cui, 2004).

Recent AIDS research has documented the widespread discrimination toward PLWHA in China (e.g., Anderson, Qingsi, Guanglin, Zhijun, & Wei, 2003; Lee et al., 2005; Williams et al., 2006). In their study of 209 market workers in an eastern coastal city, for instance, Lee et al. (2005) found that half of...
the participants believed that punishment was an appropriate response to PLWHA; that over half (56%) were unwilling to be friends with PLWHA; that 73% of participants thought PLWHA should be isolated; and that 85% agreed that PLWHA should not take care of other people’s children. Similar attitudes were found among health workers. In a study of 149 hospital-based healthcare professionals in Guangxi Zhuang Autonomous Region, a sizable proportion presented little desire to care for PLWHA: 23% would not want to care for AIDS patients, and 33% would consider asking to be assigned elsewhere if they were assigned to care for AIDS patients (Anderson et al., 2003).

Ignorance about and misunderstanding of HIV/AIDS have been identified as two of the main reasons for discrimination toward PLWHA in China (Ministry of Health (MOH) and UN Theme Group on HIV/AIDS in China (UNTG), 2003). Some studies have indicated that people’s (including health professionals’) attitudes positively changed after they received education featuring correct AIDS information (e.g., Anderson et al., 2003; Wu et al., 2002). However, studies also suggest that there is a conflict between people’s mastery of AIDS knowledge and their discriminatory attitude toward PLWHA (e.g., Anderson et al., 2003; Treise, Walsh-Childers, Dai, & Swain, 1996; Williams et al., 2006). In their study on the effectiveness of a HIV/AIDS education programme involving 208 nurses from seven provinces, for instance, Williams et al. (2006) discovered that the nurses’ willingness to care for PLWHA did not increase with their mastery of AIDS knowledge, and that their actual experiences of working with PLWHA did not encourage a positive attitude toward PLWHA on their part, either. The nurses’ knowledge about HIV transmission and awareness of their occupational exposure to HIV did not necessarily result in acceptance of PLWHA at an individual level.

Prejudice toward PLWHA has existed worldwide since the first HIV-infected case was identified in the early 1980s. Goffman’s (1963) stigma theory has been widely used to explain AIDS-related stigma and discrimination in various contexts around the world. Specifically, AIDS stigma is viewed as an individual’s deviance (e.g., “immorality”, “promiscuity”, “perversion”, “contagiousness” and “death”) from socially accepted standards of normality. Accordingly, PLWHA and populations affected by this disease (e.g., gay men, drug users, sex workers, and certain minority groups) are largely constructed as the other that is disgracefully different from and threatening to the general public (Bethel, 1995; Feldman, 1990; Worth, 1990). Discrimination toward PLWHA is not solely about HIV/AIDS as a disease, but always intersects with existing social prejudices (e.g., homophobia, sexism, racism, and xenophobia) that may have contributed to the social constructions of HIV/AIDS in a society. As a result, PLWHA’s felt stigma is not only their internalization of the AIDS stigma, but also an effect of their interactions with others or actual experiences with public attitudes through which AIDS-related social standards are manifested (Green, 1995; Herek, 1999; Lawless, Kippax, & Crawford, 1996; Parker & Aggleton, 2003).

Applying Goffman’s theory across sociocultural settings also generates questions around the contextuality of stigma and stigmatization: “stigma arises and stigmatization takes shape in specific contexts of culture and power” (Parker & Aggleton, 2003, p. 17). The roles of sociocultural beliefs, values and morals in structuring stigma and discrimination are gradually taken into account. Based on their study of stigma associated with epilepsy, for instance, Kleinman, Wang, Li, and Cheng (1995) argue that stigma in China should be viewed as family-based (rather than individual-based) responses in that moral blame associated with stigma is applied not to the patient alone, but extends to the entire family. In their study on social discrimination experienced by men who have sex with men (MSM) in Shanghai, Liu and Choi (2006) found that men’s felt stigma was not only influenced by their daily interactions with others, but also structured by their fears that they would fail to meet their social and familial obligations (e.g., getting married and having children) due to their sexual preference. The family-based stigma and family-oriented strategies to avoid stigmatization (e.g., suppressing their same-sex desire for the sake of family interests) were also revealed in Zhou’s (2006) study on illness experiences of HIV-infected MSM in China.

Although social norms (including sexual norms) in China are changing rapidly, most populations (e.g., drug users, sex workers and MSM) that are significantly affected by HIV/AIDS are still highly stigmatized: specifically, both drug use and prostitution are illegal, and homosexuality is largely viewed as “abnormal”, “promiscuous” and “immoral” by the public, despite its being legal (Liu & Choi, 2006). Though there is so far little research on
the impact of Chinese social norms on HIV/AIDS constructions, studies have suggested that the public’s moral judgements permeating current AIDS discourses have had profound effects on the responses of PLWHA and so-called “high-risk groups” to this disease. To avoid stigma associated with “deviant” sexuality (e.g., “promiscuity” and homosexuality), patients with sexually transmitted diseases (STDs) may, for instance, refuse to seek treatment and/or to notify their sex partners (including spouses) about their health status (Liu, Detels, Li, Ma, & Yin, 2002), and MSM may engage in risky sexual behaviours and decide not to use HIV prevention services (Liu & Choi, 2006). Such stigma and discrimination have adversely affected the health and well-being of those individuals. A study found a high rate of major depression and suicidality among PLWHA in China: about two-thirds of study participants still reported significant depressive symptoms more than 2 years after learning of their serostatus (Jin et al., 2006).

At present, biomedical discourses on HIV/AIDS are dominant in China, while the sociocultural meanings of the disease and their impacts on stigma and discrimination are rarely examined. The discrepancies that have emerged between countrywide AIDS education and pervasive discrimination toward PLWHA raise questions around the potential limitations of promoting AIDS knowledge as a primary (if not the sole) approach to battling discrimination and about the non-biomedical dimensions of AIDS constructions that may have contributed to shaping people’s attitudes toward PLWHA. However, most studies of discrimination in China focus on people’s views about HIV/AIDS and hypothetical interactions with PLWHA. Little is known about the actual interactions between PLWHA and non-HIV-infected people. It is not clear yet how HIV/AIDS is understood and responded to at a social or interpersonal level; what the connections are between such social/interpersonal interactions and the non-biomedical dimensions of AIDS discourses in China; and how such interactions intersect with and, perhaps, strengthen prejudices.

To fill these gaps, therefore, this paper, as part of a research project on the illness experiences of Chinese PLWHA, explores the constructions of HIV/AIDS in China from the perspectives of these individuals. A closer look is taken at the ongoing interactive processes in which the meanings of HIV/AIDS are constructed, experienced, understood, and responded to. Based on the main themes emergent in data analysis, this paper represents the findings relating to PLWHA’s understandings of this disease in their daily lives. These findings also provide a context in which to discuss the relevance of AIDS constructions to anti-discrimination practices.

**Methods**

The core purpose of this study is to understand Chinese PLWHA’s experiences of living with this disease from their own perspectives. To this end, a phenomenological approach, informed by a number of authors (e.g., Creswell, 1998; Merleau-Ponty, 2002a, 2002b; Moustakas, 1994; Van Manen, 1997), was adopted. First, the phenomenological approach aims to describe, understand and investigate the meanings of lived experiences. It recognizes that Chinese PLWHA are able to articulate the meanings of their experiences of living with HIV/AIDS within their own contexts, and that it is possible for researchers to capture and understand the meanings of such experiences. Second, the phenomenological approach attempts to understand an empirical matter or phenomenon (e.g., PLWHA’s illness experiences) from the perspectives of those who experience them. Viewing individuals’ experiences and perceptions as positional and intentional, this approach also allows an examination of such experiences in a way that is not constrained by researcher preconceptions. Third, the phenomenological approach recognizes the importance of PLWHA’s reflective descriptions of experiences, through which the researcher is able to gain access to the meanings of their experiences.

The implementation of this research project included two phases: a pilot study in 2003 with 10 Chinese frontline AIDS professionals as key informants, and a formal study in 2004 with 21 Chinese adult PLWHA. The main purpose of the pilot study was to collect a range of information (e.g., PLWHA’s main concerns, networks, and subcultures) that would be helpful in designing later interviews with PLWHA and in developing appropriate strategies to approach and interact with this group. Due to length constraints, this paper presents only the data collected from the interviews with PLWHA.

Beijing was selected as the study site from which PLWHA were recruited. As the capital city of China, Beijing has better health resources (e.g., facilities and
expertise), and thus hosts PLWHA from across the country. Therefore, the researcher was more likely to be able to recruit PLWHA from different social settings (e.g., from both urban and rural areas) in Beijing, and, in turn, to generate information to enrich our understanding of the life experiences of PLWHA of diverse socioeconomic backgrounds. In addition to the ethical review conducted at the University of Toronto (Toronto, Canada), with which the researcher was affiliated, an ethics review also was approved by the Institutional Review Board for Human Subject Research at the Tsinghua University in Beijing, China.

Four of the 21 PLWHA were recruited through Beijing-based social and health networks (e.g., hospitals and AIDS NGOs), one was directly recruited by the researcher from an AIDS-related conference, and the other 16 participants were recruited through snowball sampling based on personal referral of PLWHA interviewed. The researcher asked those PLWHA who agreed to help recruit their peers to forward project materials, including a recruitment flyer and an information sheet, to those who expressed an interest in participating. Some potential participants phoned the researcher for more information before making their final decision. The snowball sampling also facilitated PLWHA developing trust in and rapport with the researcher.

Participants were asked to select a convenient location that provided sufficient privacy for the interviews. Public places, such as a cafe or tea house, were viewed by them as acceptable. Some interviews were conducted in a separate room of the tea house at the participant’s request. Written, informed consent was obtained from the participant before the interview. Before signing the consent form, participants were asked to read an information sheet describing the purpose of the study. They were encouraged to seek clarification and ask questions about the study and the research process. With their permission, interviews with 15 PLWHA were audio taped. With the permission of the other six who did not want their interviews audio taped, the researcher took detailed notes of their narratives and non-verbal responses.

The interview guide included several general prompts to ensure that the interview maintained focus and that major themes of interest were explored. After introducing each participant to the research project, the researcher suggested the participant organize her/his storyline according to her/his rationale (rather than the researcher’s) so as to facilitate a participant-led discussion, though most participants still preferred sharing their experiences according to researcher’s interview questions. Specifically, the researcher asked these PLWHA about their experiences of living with HIV/AIDS, their understanding of such experiences, their self-perceptions, and the strategies they used to facilitate living with HIV/AIDS. The PLWHA were also asked about their understanding of the terms “HIV/AIDS” and “PLWHA” in relation to their illness experiences. Depending on the interview context, the specific phrasing of questions varied slightly across participants, and some other open-ended questions were also generated during the interview process.

Participants were interviewed in Mandarin by the researcher, a native Mandarin speaker. Each interview lasted approximately 3h, including the time needed to obtain informed consent, the interview itself and collection of demographic information. Pseudonyms are assigned to protect participants’ identities.

At the end of each interview, demographic information was collected with a standardized background questionnaire. As elaborated on in Table 1, the research sample presents the diverse backgrounds (e.g., gender, age, relationship status, socioeconomic status, infection mode, and living setting) of Chinese PLWHA. The use of snowball sampling, however, meant that some backgrounds (e.g., male PLWHA and PLWHA infected through same-sex practices) were represented more than others (e.g., female PLWHA and PLWHA infected through commercial blood donation). People infected through injection drug use could not be recruited for this study, in part because this group is relatively small in Beijing, and it is hard for them to “come out”, given their illegal status.

The audio-taped interviews were transcribed verbatim in Chinese. The researcher read through the texts of all transcripts and interview notes as constituting the full descriptions of participants’ experiences, and then assigned tentative category labels (e.g., “beliefs about HIV/AIDS”, “post-diagnosis social interaction”, and “self-perception”) to the unique or discrete statements of participants. Statements with similar category labels were later grouped into clusters using an electronic coding system (i.e., N-Vivo), and careful attention was paid to the diversity of perspectives presented. Themes emerged in the process of coding, presenting the
meanings of the reported experiences. Based on the data analysis, the researcher was able to develop a comprehensive synthesis (i.e., the results presented below) of Chinese PLWHA’s understanding of HIV/AIDS. To avoid the loss of nuances within original narratives, the transcribed data were not translated into English until the stage of report writing.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency/range (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>21–46 years (36.1 years)</td>
</tr>
<tr>
<td><strong>Originally come from</strong></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>15</td>
</tr>
<tr>
<td>Rural area</td>
<td>6</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>Master’s degree</td>
<td>1</td>
</tr>
<tr>
<td>Bachelors’ degree</td>
<td>2</td>
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<tr>
<td>College or equivalent</td>
<td>3</td>
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<tr>
<td>Senior high school</td>
<td>8</td>
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<tr>
<td>Junior middle school</td>
<td>4</td>
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<tr>
<td>Elementary school</td>
<td>3</td>
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<tr>
<td><strong>Current relationship status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7</td>
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<tr>
<td>Living with partner</td>
<td>5</td>
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<tr>
<td>Divorced</td>
<td>3</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
</tr>
<tr>
<td>Single and never married</td>
<td>3</td>
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<tr>
<td><strong>Infection modes</strong></td>
<td></td>
</tr>
<tr>
<td>Heterosexual practice</td>
<td>4</td>
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<tr>
<td>Same-sex practice (MSM)</td>
<td>11</td>
</tr>
<tr>
<td>Commercial blood donation</td>
<td>1</td>
</tr>
<tr>
<td>Blood transfusion or blood product</td>
<td>2</td>
</tr>
<tr>
<td>Not sure</td>
<td>3</td>
</tr>
<tr>
<td><strong>Time of being diagnosed as HIV positive</strong></td>
<td></td>
</tr>
<tr>
<td>Range (mean)</td>
<td>11–115 months (46.6 months)</td>
</tr>
</tbody>
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participants reported that they had known little about this disease before their diagnosis. Many never thought they would be infected with HIV because they considered it a “foreigners’ disease”, a disease of “promiscuous” or “bad” people, and/or a “rich people’s disease” (e.g., “only those who can afford to visit prostitutes get it”). Various misconceptions in China had created a false sense of security among the participants despite their exposure to HIV. In spite of his engagement in unprotected same-sex practices, for instance, Dong had thought that he, as a Chinese, would not get HIV, given that it is “an American’s disease”. The family of Xiu, a housewife from a small township, were also perplexed by her diagnosis because she was not “the kind of person who is supposed to have HIV”. As well, Xiu’s husband once viewed as insulting some doctors’ suggestion that he have a HIV test done when he was experiencing a constant fever. With little expectation or awareness of the potential for infection, most participants felt “shocked” and/or “incredulous” when they first heard the result of their HIV test, which was part of the physical check-up before surgery or blood donation. Such confusion, however, was compounded with the dominant AIDS discourses that had shaped PLWHA’s perceptions about this disease in their post-diagnosis lives.

The earlier “scare” propaganda (e.g., HIV/AIDS as a “lethal or deadly disease” and the popular AIDS images of emaciated bodies and skulls) in China had profound impacts on PLWHA’s initial understanding of this disease. Describing their diagnosis as a “death sentence”, most participants were frightened, especially during the early period of knowing their serostatus, by the disease’s incurable nature and their “impending death”. Dramatic descriptions of the anticipated death were common in their narratives, as elaborated below:

I am happily chatting with you today, but perhaps I will be gone two months from now. It is possible. (Interview with Guoqiang)
You may see me healthy now, but opportunistic infections mean I may soon be gone. (Interview with Ge)
Perhaps I am well now, but how I will be later is very uncertain. ...It [i.e., death] will show up some day, perhaps too unexpectedly to be responded to. (Interview with Yue)

Their fear of death often intersected with their sense of guilt because their “death” would cause
various emotional and financial crises for their families. For instance, Guoqiang, a man in his late 40s, was greatly bothered by the possibility of being unable to fulfil his filial duties to his parents: “They only have me. If I die, they will have nothing.”

In addition to its “lethality”, HIV/AIDS was also perceived as an “indecent” disease by many PLWHA. Upon diagnosis, some participants experienced psychological crises and even tried to commit suicide, in part because they could not face the judgement of people, including their families. All participants, as members of the group carrying the HIV/AIDS label, reported that they felt “awkward”, “faceless”, “ashamed”, and/or “inferior”. Some could not even bear to hear the term “HIV/AIDS” spoken because “the word is like a needle stabbing my heart”.

Guo also claimed that his wife divorced him because the stigma associated with the term was too heavy:

[My wife] didn’t accept these three words [i.e., ai zi bing, HIV/AIDS]. These words sound awful. I never thought I would get this disease, either. ...When [one] hears these words, the first thing that comes to one’s mind is that you must have some immoral relationships outside [your marriage]. You get this disease only because you have promiscuous behaviours. ...Not only she thinks this way, most people think this way. According to the old Beijing saying, this is a dirty disease. One’s reputation is not good if one gets it.

“Innocent” versus “culpable”: the meanings of infection modes

The participants who were infected through blood transfusion, blood products, or commercial blood donation appeared more motivated to talk about their infection modes than those infected through other modes (e.g., “promiscuous” or “deviant” sexual behaviours). Even before the interview had formally started, a couple of PLWHA voluntarily disclosed their infection modes, as did Xiaofen:

Don’t you agree I am completely innocent?! I’m not like those who aren’t married [but had “promiscuous” behaviours]—they got this disease because they deserve it. I got this disease from my husband! I am completely innocent!

Such a claim of “innocence”, in effect, pushes other PLWHA into the opposite category of being the “culpable”, referring to those whose infection “had something to do with themselves”. Feeling silenced by his “culpable” infection, for instance, Guoqiang commented: “I am such a good person, but I did such a bad thing [i.e. same-sex practices]. I have nothing to say.”

Regardless of their willingness or reluctance to talk about it, PLWHA were frequently confronted by the inquiry about their infection mode from their families, friends, health workers, and/or other PLWHA. Their answers to this question largely determined how she/he as an individual would be evaluated and responded to by others. When Xiu’s husband was diagnosed, for instance, he was repeatedly asked by his doctors and his family if he had ever visited prostitutes or done something “bad”. Some participants also reported being interrogated by health workers on this subject more than was necessary, as Linlin complained: “Now I no longer care if they ask [because I’ve got used to it]. But still they made me feel like I did something immoral.”

The moral meanings underlying infection modes created various challenges in PLWHA’s daily lives, especially when their infection modes happened to be “hard to explain”. After his diagnosis, for instance, Wuyi withdrew from his social life and even feared going outside his home, partly because he had not yet figured out how to explain his condition if he bumped into acquaintances. Similarly, Yu was reluctant to see doctors because “it’s just too difficult to explain how I got infected”. Jian, an HIV-infected NGO worker, reported that he was worried every time he was invited to provide AIDS knowledge training to the public, since he was uncertain if the audience would ask him questions about his infection mode. Strikingly, the social stereotypes about infection modes also manifested within the group of PLWHA themselves. In Beijing, male PLWHA are very likely to be recognized as tongzhi (people with same-sex preference) by infected peers, while female PLWHA are often assumed by their male peers to be sex workers. Such prejudice adversely influenced the dynamics among various PLWHA sub-groups, and thus created difficulties for these minority sub-groups (e.g., female PLWHA) in accessing to health and social services.

The meanings of infection modes also structured PLWHA’s perceptions of themselves and of their perceived “responsibility” for their situations. Internalizing the stigma associated with homosexuality
in China, for instance, some participants who engaged in same-sex practices accepted that they should not expect social sympathy or support, and should take full responsibility for any consequences (e.g., isolation, financial difficulty, and discrimination) caused by the infection. They tended to remain silent about their sufferings, and even tried to justify the injustice they experienced because, “simply speaking, you got this disease because of your own fault, so how can you expect anything from others?” In contrast, the “innocent” PLWHA were much more visible in current services and AIDS activism, and were frank about their “sense of privilege”. Despite their confidentiality concerns, for instance, they appeared to have fewer constraints in talking about the disease, in accessing to services, and in speaking up about their needs. The hierarchy of stigmas in relation to infection modes also played an important role in PLWHA’s decision-making, health practices and well-being, as described in the following two quotes:

Though we all are people with HIV/AIDS, I feel I am inferior. ...People infected through blood transfusion are better than me, even those infected through drug use are better than me, and those infected through heterosexual behaviours are better than me. It’s so hard for people infected through same-sex behaviours to come out! (Interview with Guoqiang)

People with HIV like me are different from others. Those famous PLWHA such as __ and __, didn’t dare to speak up in the public, but I can. Why? I am innocent! I was not infected because of drug use, sex, or homosexuality. I am innocent! So why shouldn’t I stand up and speak?! They said our psychological statuses are different: they can only sit in the back row when they want to speak, but I can speak as loudly as I want. (Interview with Minqin)

An untellable disease: living with secrets

The public fear surrounding HIV/AIDS, as well as the moral judgement of PLWHA based on their infection modes, made it difficult for them to come out in the larger society. To protect themselves and their families from discrimination, participants appeared highly cautious in their social and interpersonal interactions. Strictly protecting their secret of HIV infection (i.e., serostatus and/or infection mode) was viewed as an effective strategy for maintaining “normal” life and a mechanism for coping by many of them. To ensure his complete confidentiality, for instance, Yu reported that he never contacted or wanted to contact any other PLWHA: “If I didn’t wrap myself so tightly like this, I would not have survived until today.” Accounts of the tragic consequences of breaching confidentiality often circulated among PLWHA, and increased their fear of unexpected disclosure. After confirming his HIV infection seven years before, for instance, the local health authority informed Jing’s employer, and he was immediately fired. As well, after a group of health workers with white coats, rubber gloves and medical masks showed up in her yard four years before, Yin and her children were isolated by other villagers: “Like when I got on the bus [to the township], all the other people on the bus would get off.” In recent years, disclosure without consent by the health institutions in China has greatly decreased, primarily because it is explicitly prohibited by official regulations. However, unconsenting disclosures by individuals (e.g., friends and doctors) still occur now and then. For instance, Guo’s HIV serostatus was disclosed by a doctor who treated him for tuberculosis, and Qin’s was disclosed by a close friend, who was overwhelmed by the news.

Participants’ decision-making on disclosure to their families was also influenced by their infection modes. “Innocent” PLWHA felt less pressured by such disclosure than their “culpable” peers because they believed their families would understand. Instead of telling his ex-wife about his serostatus and same-sex preference, in contrast, Jian initiated divorce and left his home. Participants’ timely disclosure to their intimate partners could have precluded the latter from the further risk of transmission, but procrastination, which may be related to a delayed HIV test in some cases, often resulted in a delay of their partners becoming aware of their health status and getting medical attention. Xiaofen, for instance, did not know of her husband’s or her own HIV infection until a couple of years after he died. Concern for elderly and minor family members was also a factor influencing PLWHA’s decision on disclosure. Many participants chose not to tell their parents or children about their serostatus because “they are too old or young to understand it” and “no good can come from letting them know about this”.

Participants tended not to disclose their serostatus to people outside their families, such as friends,
co-workers, neighbours, and/or health workers. To reduce the odds of unexpected breach, they gradually withdrew from social activities, which increased their sense of isolation and exclusion. Minqin was one of the few who voluntarily disclosed his serostatus to his previous co-workers and friends. He explained: “We’ve been friends since childhood. They know I have haemophilia, so they know how I got infected.” Yet he did not have the courage to disclose it to his neighbours, because “they would not understand it as my friends do”, and “they are [physically] close enough to make trouble for me”. Fear of discrimination also made participants reluctant to disclose their serostatus to health workers outside AIDS-specific health institutions. For instance, Jing became extremely cautious after hearing of his friend’s experience of being mistreated by a dentist: when the man disclosed his HIV serostatus when he went to have teeth removed, the dentist promptly put down all his instruments and left. Han’s story of being rejected for surgery by a hospital was also well known among PLWHA and increased their nervousness about disclosure.

Alternatively, many participants made a conscious decision to hide their serostatus and live with their secrets. Some strategically claimed that they had such diseases as flu, hepatitis B, tuberculosis and cancer to explain their condition (e.g., fever, weight loss, deteriorated health, and withdrawal from physical contact). Yet hiding their serostatus at the workplace turned out to be difficult and psychologically overwhelming. “Having two faces” and “living a double life” were expressions frequently used in reference to the struggles between their pretension to be a “healthy” person and their secret-keeping initiatives. For instance, inquiries about their health status or physical changes from co-workers were often viewed as a burden or battle, as conveyed by Xiu and Yu:

I controlled myself and did not tell. I would never say these three words [i.e., ai zi bing, HIV/AIDS] at the places where I work and live. I controlled myself, but I still feared that I would say it by accident. ...I have a booth at __ Market. They [i.e., the other vendors] always asked me, “Are you well?” They saw me getting thinner, and I had the rashes on my face. They always asked if I was sick. I said, “It’s nothing.” I cannot tell them. They all said, “You look different than before, what’s wrong?” “Nothing,” I said. I cannot tell them. (Interview with Xiu)

In my previous company, I felt like a half-human and a half-devil. Because of my health status, I was unable to work very hard. My colleagues would wonder: “Why is this person always sick? Why does he always have a cold or fever?” Sometimes they joked with me, saying, “Do you have HIV?” They were joking – which would be okay if I didn’t [have HIV]; but I did. So it was very hard for me to pretend that I didn’t [have it], and to joke back with a laugh. It was very hard! No one could understand that kind of feeling unless she/he had experienced it. (Interview with Yu)

The multiple stigmas associated with HIV/AIDS have made it challenging for participants to talk about it openly or seek help from others. For this reason, many perceived it as “more horrible”, “scarier”, and “more painful” than other incurable diseases (e.g., cancer and diabetes) or infectious diseases (e.g., hepatitis B and tuberculosis). As participants observed, while people with other incurable or infectious diseases are visited by their families when they are hospitalized, it is not always the case for them. “I think only people living with HIV/AIDS can understand such pain.” Guo commented: “If I had cancer, I could tell people about that. But if you get AIDS, you cannot tell anyone about it. You have to endure it alone.”

**Exaggerated contagiousness**

Upon the breach or disclosure of their serostatus, participants often encountered strong reactions to their “contagiousness”. The families of many participants presented tremendous fear of physical contact. Separation of various aspects of the living arrangements of PLWHA from those of the other members of their family, such as sleeping, cooking, eating, using utensils and doing laundry, was commonly reported. Jun’s mother even asked him to move out of the home because his presence was seen as “dangerous” to the others. Jun had to move in with his partner Pin. He soon found, however, that their “contagiousness” was perceived as even more terrifying at Pin’s home. He described:

His mother is more nervous than my mother. Ah, she always wears gloves, even when she just holds the plates. ...When filling our bowls with rice, she must do this for us, and we are not allowed to
touch them. She always uses a paper to separate our bowls from her hand when she holds them. The same with the sofa: we must sit on this side, and we are not allowed to sit on that side where they would sit.

In some cases, the family members who had close contact with PLWHA were also viewed as “contagious” by others. For instance, Jing perceived that his relatives became aloof toward both himself and the rest of his family. As well, Xiaofen’s mother, who was a primary caregiver for her and her HIV-infected daughter, was often reminded by her relatives to “pay more attention to hygiene”, and “don’t go outside or visit others too often”. Though some participants reported reduced fear among their families/relatives after the latter had received correct information about HIV/AIDS, a couple of PLWHA’s families refused to learn more, and the attempt itself was viewed as “embarrassing” or even “shameful”.

Physical avoidance and explicit discrimination against their “contagious” bodies were also observed by participants when they interacted with friends and/or co-workers who knew about their serostatus. For instance, at a dinner right after an AIDS education session, in which Jian was invited to give a talk as a person with HIV, ironically, a trainer suggested him not bring his chopstick directly into contact with the food. After Jing’s diagnosis was disclosed in his previous working unit by the local health authority, he too perceived that many of his colleagues overreacted, including those with whom he had been close:

I had a colleague who used to share an office with me. The second day after he found out my [sero]status, when I saw him, his face looked swollen and his eye circles were very dark. Later I heard that this was because he had used ultraviolet radiation to sterilize himself.

Yet the fear of being contaminated by HIV-infected bodies is not necessarily related to people’s ignorance about HIV/AIDS. Health workers’ overreaction toward PLWHA’s “contagiousness” was also reported. When Han was hospitalized in a hospital for infectious diseases three years before, for instance, he and other PLWHA appeared to be viewed as more contagious than patients with other infectious diseases. He recalled:

When doctors did B-mode ultrasonic scanning for other normal patients, they didn’t have any protection. But when it was my turn, doctors would wear medical masks and gloves. That winter, every patient was given a winter coat, but patients with HIV/AIDS were not.

Han, as well as some other PLWHA, voluntarily used the word “normal (zhengchangde)” when they compared their experiences with those of other patients who were not HIV positive. The perceived discrimination had made many participants interpret HIV/AIDS as much more contagious than it is.

The overreactions of others affected participants’ understanding of their post-diagnosis experiences and themselves. Many said they understood the way people treated them, because that they “might do the exactly same things” in their place, and that “self-protection is a basic instinct of human beings”. Simultaneously, however, they felt hurt by people’s avoidance. For instance, Han reported reduced self-esteem due to his restricted freedom at home; Jun perceived that he was looked down upon by his extended family; and Guoqiang depicted himself as “a poisonous snake”, dangerous and unwanted. As well, many PLWHA presented a strong awareness of their contagious bodies in social and interpersonal interactions. When the researcher first interviewed Jing, for instance, he even gave her a wet anti-virus napkin to clean her hand after she had shaken his. He explained it as a “psychological obstacle”, because he knew that some people would wash their hands. When interacting with his best friends, as well, Minqin kept reminding himself of his “contagiousness” so as to prevent himself from becoming too relaxed to remember the “guard-line” between his body and others’ “healthy” bodies. The tendency to self-discipline and to self-policing is also found in interactions at home. Despite his knowledge about HIV transmission, for instance, Yu had not dared to kiss or hug his daughter since his diagnosis 7 years before, and he still washed his hands so much they looked blanched. Though calling himself squeamish, Yu insisted that all such “protections” for his family were absolutely necessary, because “any tiny accident could have a catastrophic result [i.e., HIV infection]”. To prevent their HIV-infected bodies contaminating others, most married PLWHA retreated from sexual activity after diagnosis, and some single participants reported that they didn’t have the courage to engage in a romantic relationship with “healthy” or “normal” people.
These socially constructed boundaries around HIV-infected bodies are not insurmountable, however. In addition to mastery of correct HIV/AIDS knowledge, understanding, support and care from others (e.g., family, friends, and health workers) can alleviate PLWHA’s fear of themselves. For instance, Han felt better about his health status after “just a smile or a warm eye contact” from others; and Wuyi felt less frightened after being visited by someone from outside his family, since he used to think no one else would dare to come near him. As well, Jing commented that having an experience of sharing a meal with a health professional was “a great comfort” for him with respect to his contagiousness: “They are the experts in this regard: if they can eat with you, this might mean that you are not all that horrible.” This study also found that participants’ understandings of HIV/AIDS were not static during the course of living with this disease. Following the availability and effectiveness of antiretroviral drugs, for instance, some PLWHA felt hopeful about their future lives; thus, HIV/AIDS didn’t appear “as scary as before” or “very different from other diseases”. Given its increasing manageability due to the progress and/or availability of medications, a couple of participants have begun to view HIV/AIDS as a “chronic disease”. Meanwhile, significantly, some participants presented their autonomy in reconstructing AIDS discourses in their daily lives. For instance, Guo invited AIDS volunteers to his home for dinner so as to show his family that it is “safe” for “healthy” people to have contact with him. To deal with her mother’s AIDS-phobia, Xiu often brought AIDS education brochures and videos home: “I wanted her to know more about how other PLWHA live their lives and how they live with their families.”

Discussion

The dominant discourses of HIV/AIDS in China are still morality-centred, and PLWHA are constructed as morally problematic others. The earlier epidemiological discourses on “high-risk groups” (e.g., “promiscuous” people and drug users) that over-emphasized the “causal relationship” between moral degeneration and HIV infection had profound and lasting impacts in the way that this disease was understood and responded to by the public, including PLWHA themselves. Being viewed as an “indecent” disease, HIV/AIDS has severely stigmatized people, families, and communities that are associated with it. The moralized discourses of HIV/AIDS have given the public a false sense of security: people from outside “high-risk groups” tend to be blind to their possible exposure to HIV. The stigma has also inhibited people from seeking relevant information and knowledge, which may explain the contrast between the high visibility of “high-risk groups” in epidemiological discourses and their ignorance of HIV/AIDS. As well, the “importance” of one’s morality fuelled people’s inquiry about one’s infection mode, along which the hierarchy of stigma is constituted and social sympathy/support for certain PLWHA is distributed. The dichotomy between the “innocent” and the “culpable” has adversely affected the development of solidarity among various PLWHA and further stigmatized and marginalized those already stigmatized due to their “deviance” prior to HIV infection.

Chinese PLWHA’s understanding of HIV/AIDS is not merely informed by their knowledge about this disease, but also, and more important, is structured by their experiences of interacting with others who are non-HIV-infected. Despite its biomedical characteristics, the contagiousness of HIV/AIDS was often exaggerated by others (e.g., family members, friends and health workers) when they were interacting with PLWHA, which, in turn, enhanced the latter’s nervousness about their “contagious” bodies. The boundaries delineated around PLWHA in their daily lives also shaped their feeling about themselves and their relationship to “normals” (Goffman, 1963). Parallel with their reduced sense of normality, many PLWHA voluntarily disciplined themselves to refrain from “contaminating” others. The conflicts between people’s (including PLWHA’s) mastery of AIDS knowledge and their response to HIV-infected bodies in practice suggest the importance of understanding the non-biomedical dimensions of HIV/AIDS constructions and their impacts on social and interpersonal interactions. Findings of this study also illustrate that the positive interactions between PLWHA and others were not only helpful for them to constructively understand this disease, but also significant for building a supportive environment for people affected by this disease in the long term.

PLWHA’s understanding of HIV/AIDS is also shaped by family concerns. To protect themselves and their families from stigmas and discrimination, many PLWHA made a conscious decision of non-disclosure. However, living with secrets creates more challenges in PLWHA’s daily lives and, thus,
may further compromise their health and well-being. The silence and invisibility of PLWHA has made this group hard to reach and intervene with, which in turn may create a greater risk of HIV transmission. Therefore, how to construct or reconstruct AIDS discourses that can de-stigmatize HIV/AIDS as a disease and PLWHA as a social group should be integral to anti-discrimination initiatives in China. Otherwise, Chinese PLWHA may remain underground or hesitate to come out to pursue their rights, despite the progress in AIDS education and anti-discrimination legislation. As shown in this study, PLWHA tend to sacrifice their interests for another “more important” concern—“secret-keeping”—as long as HIV/AIDS is still a disease that is too “indecent” to tell.

In conclusion, this paper examines the constructions of HIV/AIDS and their impacts in the Chinese context through the lens of PLWHA’s daily encounters. The actual interactions between PLWHA and others reveal that the sociocultural meanings of this disease are not fixed but are ongoingly co-constructed by the various participants (e.g., PLWHA and their families, friends, and health workers) in such interactions. Despite people’s mastery of knowledge, prejudices toward HIV/AIDS and PLWHA can be generated, spread, and, perhaps, worsened through interpersonal interactions. Social and interpersonal interactions are part of the processes of HIV/AIDS constructions; therefore, AIDS education should not be limited to the dissemination only of biomedical knowledge; the non-biomedical and interactive dimensions of stigma and discrimination must also be considered. In addition to various nationwide HIV prevention programmes, for instance, community-based education projects that target AIDS-related prejudices in those communities should be developed. Having critical conversations with PLWHA’s families, friends, and health workers about discrimination may facilitate such social ties/networks transforming into anti-discrimination forces within communities, which, in turn, will positively shape PLWHA’s self-perception, and gradually bring about changes in the larger society. Yet, the creation of a supportive social environment is also determined by the achievement of social justice for various groups who have been disproportionately affected by HIV/AIDS due to their gender, socio-economic status, sexual preference, and lifestyle.

It is also noted that the results of this study may not be generalizable for Chinese PLWHA as a whole, given its small size sample. Despite that limitation, there is no doubt that this exploratory study will contribute to our understanding of the interactive relationship between HIV/AIDS constructions, stigma and discrimination in China. Such knowledge will also inform the development of more responsive and effective anti-discrimination strategies at local, community and interpersonal levels.

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