Help-seeking in a context of AIDS stigma: understanding the healthcare needs of people with HIV/AIDS in China

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Abstract
Despite the rapid increase of HIV infection cases in China, the majority of this population have not yet accessed AIDS-related healthcare services. Most current research in China focuses on HIV prevention and disease control, and pays inadequate attention to the barriers facing HIV-infected individuals in accessing and adhering with healthcare services. This article, as part of a research project on the illness experiences of people with HIV/AIDS in China, aimed to explore these individuals' healthcare experiences, shedding light on the gaps between their needs and existing healthcare services. Data for this qualitative study were collected through individual in-depth interviews with 21 HIV-infected adults in China. The results of data analysis suggest that these individuals' healthcare experiences were greatly affected by social discrimination and the limitations of healthcare resources. While AIDS stigma has reduced the social resources available for this population, HIV-related health institutions were perceived by them as an indispensable source of social support. It is concluded that healthcare institutions, as one of the few places in which HIV-infected people are willing to disclose their HIV positive status, should incorporate social care into healthcare service development and delivery so as to facilitate this population's accessing healthcare services and to address their unmet needs that go beyond the conventional scope of health care. Improving the visibility of people with HIV/AIDS in health care will also have a long-term impact on their own well-being and on HIV prevention in China.

Keywords: China, health care, HIV/AIDS, qualitative research, social discrimination

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Introduction
As of the end of 2005, the estimated number of accumulated HIV-infected cases in China was 650,000, of which only about 20% were detected (MOH et al. 2006). This means that the majority of this population is still invisible: they have not yet accessed AIDS-related health services, including HIV testing. Most current research in China focuses on HIV prevention and disease control, and pays inadequate attention to HIV-infected individuals' actual healthcare experiences. Lack of knowledge in this regard has inhibited AIDS researchers and professionals in understanding the barriers this population faces in accessing and adhering with healthcare services, and in identifying the gaps between their needs and existing healthcare services.

Current studies suggest that delayed access to HIV testing in China is related to ignorance of and misconceptions about HIV/AIDS. In their survey with 482 men who have sex with men (MSM) in Beijing, for instance, Choi and colleagues found that 82% of them had never tested for HIV, in part because most participants (72%) perceived that they were at a low risk of infection, despite a high rate of reported unsafe sexual practices (Choi et al. 2004, 2006). Multiple stigmas associated with HIV/AIDS, such as ‘immorality’, contagiousness and lethality (Zhou 2007), have also inhibited those most vulnerable to it from accessing AIDS-related services.
such as HIV information, HIV testing and primary health care. Empirical studies have found that their fear of other people learning about their homosexuality is one of the common reasons (47% of 482 participants) MSM have for not seeking HIV testing (Choi et al. 2006), and that negative emotions such as shame, fear and embarrassment have been salient barriers to seeking health care for those who have engaged in stigmatised risky acts (e.g. ‘promiscuous’ sex) (Lieber et al. 2006). It is not unusual that avoiding AIDS-related services was even used as a strategy for HIV-affected people for protecting themselves and their families from stigmatization and social discrimination (Lieber et al. 2006, Liu & Choi 2006). While widespread homophobia in Chinese society has made it difficult for HIV-infected MSM to seek support from their families, social networks and, even, other HIV-infected individuals, public fear of HIV/AIDS has also inhibited their doing so within the gay community (Zhou 2006). In other words, multiple social prejudices towards people with HIV/AIDS have reduced the social support available to them.

Despite the present anti-discrimination policies in China, various forms of discrimination, such as judgmental attitude, avoiding interaction, refusal to provide treatment and involuntary disclosure, against people with HIV/AIDS were also reported in healthcare institutions (Anderson et al. 2003, Chen et al. 2004, Yang et al. 2005, Williams et al. 2006, Li et al. 2007). In their study of hospital-based healthcare professionals in Guangxi Zhuang Autonomous Region, for instance, Anderson et al. (2003) discovered that 23% of 149 participants would not want to care for patients with HIV/AIDS, and 33% would consider asking to be assigned elsewhere if they were assigned to care for HIV-infected patients. Although health workers’ mastery of correct AIDS knowledge is often viewed as helpful in reducing their discriminatory attitudes, some studies have also suggested that health workers’ attitudes in practice are not necessarily consistent with their knowledge, and that they have internalised the AIDS-related stigmas that are present in the larger society (e.g. Williams et al. 2006, Li et al. 2007). Most studies in this regard have, however, been conducted from the perspectives of health workers in hypothetical contexts (i.e. are more about their attitudes or opinions than about their actual practices); we know little about the actual interactions between HIV-infected patients and health workers, and their impacts on the former’s health-seeking practices.

The affordability of medical care has become a salient issue for many people in China since the commencement of healthcare reforms in the 1980s. The collapse of the Cooperative Medical System in rural areas and the introduction of new medical insurance schemes in cities have resulted in the loss of basic healthcare security for hundreds of millions of people, such as rural dwellers, rural migrant workers and unemployed urban residents (Feng et al. 1995, Akin et al. 2005). Meanwhile, the rapid growth of healthcare costs due to the commercialization of the healthcare system has made some basic care services too costly for the poor (Liu 2004). Although in 2003, the Chinese government issued the Four Frees and One Care policy to assist people with HIV/AIDS with financial difficulties in accessing free (domestically produced) anti-retroviral drugs, unaffordability of healthcare services was still a salient concern for HIV-infected individuals and their families, and led them to delay seeking services (Xu et al. 2007).

To fill these gaps, therefore, this article, as part of a research project on the illness experiences of people with HIV/AIDS in China, aimed to explore these individuals’ healthcare experiences from their own perspectives. A closer look is taken at the intersections among their healthcare needs, the healthcare resources available and social discrimination in Chinese society. Given the invisibility of the majority of this population, it is important to understand their actual healthcare practices (e.g. decision-making, service utilization and relationships with health professionals) and, in turn, the barriers facing them in accessing and adhering with healthcare resources. The findings presented also lay a foundation on which to discuss the relevance of incorporating social care into healthcare service delivery in a context of AIDS stigma and social discrimination.

Methods

The core purpose of the larger study, from which the data reported here were drawn, was to understand Chinese people’s experiences of living with HIV/AIDS. Data for this study were collected through individual, face-to-face, in-depth interviews with 21 HIV-infected adults in a metropolitan city in north China in 2004. In addition to the ethical review conducted at the University of Toronto (Canada), with which the researcher was affiliated, an ethics review was also approved by the Institutional Review Board for Human Subject Research at a local university in the study city.

Four of the 21 participants were recruited through local social and health networks (e.g. hospitals and AIDS-related non-governmental organizations), 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 participants interviewed. Written, informed consents were obtained from all participants before the interviews. With their permission, interviews with 15 participants were audiotaped, and with the remaining participants
Delayed HIV diagnosis and need for psychological support

Ignorance about HIV, at both individual and institutional levels, had delayed participants’ HIV diagnosis. Despite their exposure to HIV risks, such as unprotected sex, participants’ awareness of this disease was generally limited. Most participants were unaware of their infection until they underwent opportunistic testing, such as physical examinations prior to surgery or blood donation. As a result, for instance, when they had their first test, two men in this study were immediately diagnosed as in the late stage of AIDS. Physicians’ lack of clinical knowledge of HIV/AIDS also led to misdiagnoses, which inhibited HIV-infected patients from timely accessing appropriate healthcare services. Before receiving the correct diagnosis, some participants were misdiagnosed with lung disease, tuberculosis or sexually transmitted infections at some non-AIDS-specific hospitals. For instance, Mrs Xiu’s husband spent over a year undergoing treatment for lymph-related and respiratory diseases at various hospitals (both in their hometown and in the study city). He died 3 months after his HIV diagnosis, leaving his child and HIV-infected wife behind.

Upon receiving their diagnosis, participants in this study commonly went through a wide range of negative psychological experiences, such as feelings of disbelief, shock, anger, panic, fear, pessimism, depression and suicidal thinking. For the participants who were diagnosed in the 1990s or in non-AIDS-specific hospitals, the lack of institutional post-diagnosis interventions (e.g. psychological counselling and peer support) was salient. Those who were diagnosed more recently at a few hospitals with AIDS-specific healthcare services in the study city reported less psychological pressure after their diagnoses, in part because they received psychological support from health workers and/or other HIV-infected patients. Mr Qin, a man in his early 30s, commented on the psychological counselling he received from nurses and peers right after his diagnosis,

The impression they gave me is that there is nothing to be frightened of.... They made me feel like, okay, if other [HIV-infected people] can carry on with their lives, I can too.

Participants’ desire for psychological support, especially professional support, lasted throughout the process of living with the disease. However, psychological crises may be provoked at any stage by such challenges as social discrimination, deteriorated health, financial difficulty, relationship conflict and impending death. Despite the commonly reported need for mental health care in their post-diagnosis lives, no participant sought professional help, in part because of the lack of services and the lack of information about such services.

Access to health care: affordability, confidentiality concerns and fear of discrimination

The expense of the anti-retroviral drugs had been problematic for participants until the production of domestic drugs a couple of years before the interviews. Some participants diagnosed in the 1990s had rejected medications because of the costs of imported Western drugs. The tremendous drop in price in recent years of those imported drugs had made them more accessible to some participants in this study, although not to others because of their low income or unemployed status.
Some participants reported that they didn’t take the medications on time according to the instructions in order to save some for the future or for their similarly HIV-infected family members, again due to financial concerns. Mr Jian, a migrant worker from a rural area, postponed taking anti-retroviral drugs for years in spite of his opportunistic infections. Relevant medical check-ups, such as tests for CD4 cell count, viral load and liver function, were also reported unaffordable by most participants.

Participating in drug trials, therefore, was often viewed as a ‘lucky’ route to accessing free medications. More than half of the participants (12/21) had taken part in, or were taking part in, various drug trial projects. Ms Lin, a migrant worker, for instance, had participated in trials for Western anti-retroviral drugs, Chinese traditional medicine and domestic anti-retroviral drugs since her diagnosis 4 years before. Those with no such opportunity managed to buy medicine by paying for it themselves or by using money obtained through lawsuit compensation, government assistance or financial assistance from their extended families or, even, from individual foreign donors. For instance, Mr Zhuang, a rural migrant worker, and his four-person family had received financial support for his medical treatment from his four siblings, who were also migrant workers living in poverty.

Confidentiality had been a major concern for those who were eligible to access the limited health resources available. However, perceiving that the present medical reimbursement procedures could threaten their confidentiality, the eight participants who had medical insurance tended to postpone using it unless they had no other choices. As long as they or their families could still afford it, these participants ‘preferred’ paying medical costs out of their own pockets, because they viewed ‘secret-keeping’ as a key strategy for them and/or their families to survive pervasive social discrimination. Although the Four Frees and One Care policy targeting HIV-infected individuals living in poverty has been implemented in many places across the country since 2003, some administrative requirements (e.g. income eligibility and personal identification) have inhibited most participants in the study from accessing free domestic anti-retroviral drugs. For instance, Mrs Xiu, a self-employed migrant worker and a single mother, had finally decided to access free medications at the disease control institution in her hometown. She commented that she had run out of options because of financial difficulty, although taking advantage of free medications might risk her own confidentiality and, thus, expose her family in their hometown to social discrimination.

Fear of social discrimination also dissuaded some participants from accessing primary health care in time. To avoid AIDS stigma, they might, for instance, deliberately avoid using AIDS-specific services or selecting the AIDS-specific hospitals as their contracted hospitals covered by their medical insurance. When her husband came down with AIDS-related opportunistic infections, for example, Mrs Yin first sent him to a regular hospital that turned out to be unable to deal with them. This woman elaborated on this ‘intentional’ delay in accessing appropriate healthcare services:

If I sent him to the AIDS-specific hospital [in the first place], my relatives and others would suspect that he also has this disease [as I do]. If they knew that my husband was [HIV positive], no one would dare to come near us any more. They know how horrible this disease is; they would say, if this disease is not extremely contagious, how come her husband also got it?!

Experiences of medication-taking: side effects and secret-keeping

For many who had taken anti-retroviral drugs (either via drug trials or self-payment), coping with the side effects had been part of their daily struggle. They reported such side effects as body numbness, insomnia, physical changes, reduced appetite, joint pain, memory reduction, damage to vocal cords and/or neuritis. For instance, Mr Han, a 45-year-old man, once considered killing himself because the side effects were intolerable. He described the continuing struggle between the side effects and his desire to live:

When the side effects were at their worst, I couldn’t fall asleep for 2 months because of the pain caused by the nerve damage.... To deal with the pain, I tried all the methods I could think of. ... Now I always wear shoes with extra thick soles. My current sensation in my feet is different from before. For example, when I try to exert my strength, the feet feel no strength at all. If I step on something solid, such as stone, I feel like I’m getting an electric shock.

Although the intensity of the specific side effects varied among individuals and with different drugs, most participants reported that their sensations of their bodies and/or themselves changed somewhat during the process of medical treatment. The salient changes in their physical appearance (e.g. a rash on the face, darkening of the skin, and weight change) could endanger their secret-keeping. Reduced self-esteem resulting from physical changes was also reported by both men and women in this study.

Participants’ secret-keeping initiative had made taking their daily medication a challenge. Specifically, regular medication-taking practices often aroused others’ curiosity about their health, and the labels printed on medication boxes or bottles also had the potential to result in the leaking of their secrets. For instance, one participant’s
HIV positive status was found out because the powdered Chinese traditional medicine he took aroused his family’s suspicion. Therefore, caution, even excessive caution, was often used as a strategy for secret-keeping, as described by Mrs Xiu:

I save all the used medication boxes and bottles, and later I take them to __ Hospital and throw them in the garbage cans there. I don’t dare throw them in the garbage cans in my neighbourhood. Now I realize that some people don’t know what [the English term] ‘HIV/AIDS’ means. In the past, before I threw them away, I soaked them in water and then ripped off the labels. [Chuckle] When I was living in my hometown, I would light a fire to burn all those boxes and bottles.

Interactions with health workers: ‘psychological pillar’ and perceived discrimination

Participants perceived health workers (e.g. doctors and nurses) as among their most important others, and their relationships with health workers as significant for their health, quality of life and well-being. Health workers were seen not only as service providers but, more important, as a key source of social support: in their own words, as a ‘psychological pillar’. Due to widespread discrimination against people with HIV, health workers are often among the few (or even are the only) people who know of their HIV positive status. Therefore, participants tended to have higher expectations of and to be very sensitive towards health workers’ reactions to them, as elaborated on in the following two quotes:

Any gesture or expression from the doctors could affect me greatly. I was highly sensitive and vulnerable.

At the very beginning, I was scared to see doctors: I felt my hair almost stand up. I still feel awkward. I was extremely sensitive to their reactions, and I’ve paid so much attention to how they think about me.

Understanding, acceptance and/or support from health workers were greatly appreciated by participants. Due to the lack thus far of social or professional psychological services for this population in China, participants often viewed health workers as ‘the last lifesaver’ or ‘the last family’ they could count on, and some front-line health workers had voluntarily provided them with such assistance as helping them deal with medical compensation issues, providing counselling, assisting them in contacting their families and satisfying some of their needs (e.g. cooking, knitting sweaters for them and accompanying them) in their daily lives. The social discrimination in the larger society also ‘motivated’ some participants to become psychologically or emotionally attached to the health workers they trusted. Some participants reported that they panicked when the health workers they trusted became ill or transferred to other places. A participant even phoned a doctor when the latter went to Africa because he felt that particular doctor was the only one who could understand him, and he had to contact him to gain peace of mind.

The impacts of perceived discrimination by health workers against HIV-infected patients were often destructive, however. Participants often complained of various prejudicial behaviours of health workers: some experienced explicit discrimination, such as physical avoidance, over-interest in their infection modes and verbal insult; some reported subtle negative attitudes, such as coldness and neglect. Participants who were infected through ‘immoral’ modes (e.g. homosexuality and the sex trade) often observed more explicit discrimination by health workers than was experienced by their peers infected through other, ‘innocent’, modes (e.g. consumption of contaminated blood products). For instance, Mr Liu, a man in his late 40s, felt insulted when a doctor asked unnecessary questions about his same-sex preferences, and laughed in his face.

Health workers’ insensitivity about their patients’ feelings made it even more difficult for some participants to continually use healthcare services. Five years before, for instance, Mr Jing quit the drug trial project in which he had participated, because he couldn’t bear being looked down upon by a project holder, and he had not accessed anti-retroviral drugs since then. The profound effect of health workers’ attitudes on HIV-infected patients’ help-seeking motives was commented on by Mr Guo:

For [health workers], [their reaction] is like a small move; but for us, such a small move makes a big difference. Like when I went to the office of Dr __, I felt so warm: it is like going home. They made me feel like I was his brother. But when I went to other doctors’ offices, I just felt that they avoided me like I had plague.... I felt I would rather die than have them look down on me.

Despite the complaints, some participants reported that health workers’ attitudes towards them had changed for the better in recent years, and that healthcare service delivery had become more humane and sensitive. For instance, when Mr Jian was first hospitalised in 1999, he observed that the doctors and nurses seemed unwilling to work with him, and treated him as an emotionless object. Hospitalised in the same institution 2 years later, however, he felt that some emotional elements had been added to the medical treatment: ‘Sometimes [health workers] chatted with me about things in my life. It seemed that what they provide is not limited to medical treatment any more.’

Discussion

Results of this study suggest that the post-diagnosis healthcare experiences of HIV-infected individuals have
been greatly influenced by AIDS stigma and by the health resources available in China. What they perceived as discrimination against them in healthcare settings and in the larger society further constrained this population’s motivation and capacity to engage with health care in an effective way.

There was, in confirmation of earlier research (e.g. Choi et al. 2006, Lieber et al. 2006, Liu & Choi 2006, Li et al. 2007), a vicious cycle of ignorance about HIV/AIDS; poor awareness of HIV risk; and delayed access to HIV testing, diagnosis and access to healthcare services. The delay in HIV diagnosis not only compromised the health of the infected, but also increased the risk of secondary transmission to their intimate partners and/or family members, however (Choi et al. 2004, Zhou 2006). Strikingly, in some cases, the delay was caused by the misdiagnosis they had received. Ignorance about HIV/AIDS among health professionals generates questions about uneven distribution of health resources (e.g. knowledge, expertise, personnel and facilities) across geographic regions (e.g. rural areas versus cities, and small versus big cities) and AIDS education in a wide range of healthcare settings (MOH et al. 2006, Wu et al. 2007). Poor awareness of HIV also left most participants unprepared for their seropositive result, which may have precipitated their psychological crises immediately after the diagnosis (Molassiotis et al. 2002, Liu et al. 2006). Although post-diagnosis psychological support (mostly non-professional) became available to some degree in some AIDS-specific hospitals, many participants reported that they experienced psychological burnout and mental health problems at other subsequent stages, and could find help nowhere.

Expense had been a salient barrier for them in accessing health care, including medications. Most participants in this study had no medical insurance, and paying for medical treatment themselves had aggravated the poverty experienced by these individuals and their families. The fear of social discrimination also inhibited those who had medical insurance from using it. Therefore, participating in drug trials was often viewed as a ‘lucky’ route to gain free medications. The severe side effects of anti-retroviral drugs made the treatment process itself an ordeal for many participants. The intention to protect their HIV infection ‘secret’ and to avoid stigmatization had held them back from engaging in health practices that would have been in their best interest. Concerns about the medical costs also led to some unhealthy practices, such as postponing necessary treatment and deliberate under-treatment.

Interactions between HIV-infected patients and health workers played an important role in the quality of the former’s post-diagnosis lives. Pervasive discrimination has limited the social support available to this population, and inhibited them from seeking help in the larger society. The isolation experienced by participants also created a great demand for social care from health workers, given that the latter were often among the few who know their ‘secret’ and there were no other institutional care resources available. While participants commonly reported the need for social support and mental health care throughout the process of living with this disease, services in this regard in China have not yet developed to the point of becoming professionalised or institutionalised (MOH & UNTG 2003, MOH et al. 2006). While the positive relationship between HIV-infected patients and health workers proved significant for the former’s well-being, the discrimination they perceived in healthcare settings not only discouraged participants from accessing health care, but also adversely affected their self-perceptions and mental health.

In conclusion, the healthcare experiences of people with HIV/AIDS in China should be understood in the contexts of the pervasive social discrimination against this population and the limitations of the health resources available. The constraints on current health resources are not only reflected by the various challenges faced by participants in accessing basic medical treatment, but also by the lack of social care services (e.g. psychological counselling, mental health care, social assistance or benefits and ancillary services) that may facilitate their accessing HIV primary care and adhering to its regimens (Lo et al. 2002, Messeri et al. 2002). While AIDS stigma has greatly reduced the social resources available for this population, HIV-related health institutions were perceived by them as an indispensable source of social support. Therefore, I argue that healthcare institutions, as one of the few places in which HIV-infected people are willing to disclose their HIV positive status, should take into account the complementary relationship between health care and social care, so as to develop more sensitive services. Incorporating social care into healthcare service development and delivery will help improve the effectiveness of HIV/AIDS services, and address their unmet needs that go beyond the conventional scope of health care. In the context, especially, of the persisting invisibility of the majority of this population in Chinese society, healthcare institutions should also be a key site in which people with HIV/AIDS will be supported, encouraged and empowered to pursue their health in the process of living with this chronic disease. Improving the visibility of this population in health care will have a long-term impact on their own well-being and on HIV prevention in China.

It is also noted that the findings may not be fully transferable to all people with HIV/AIDS in China due to the type of sampling (i.e. non-purposive, opportunistic
sampling) used in this study. Yet, there is little doubt that this study will enrich our understanding of their healthcare experiences, which is still a little known area in current AIDS research. This type of information will also inform the development of more responsive and sensitive health and social policies (e.g. medical insurance and social welfare), programs (e.g. anti-discrimination education among health workers) and services (e.g. holistic care services) for this population.

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