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Xiying Wang
Beijing Normal University

Xiuulan Zhang
Beijing Normal University

Yuebin Xu
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Yurong Zhang
Beijing Normal University

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Health Service Access for Rural People Living with HIV/AIDS in China: A Critical Evaluation

XIYING WANG
XIULAN ZHANG
YUEBIN XU
YURONG ZHANG

School of Social Development & Public Policy
Beijing Normal University

The increasingly serious HIV/AIDS epidemic creates a significant burden for the public health system; however, little attention has been paid to the issue of health service access in rural China. Based on a qualitative study of 34 Chinese rural People Living with HIV/AIDS (PLWHA) and 13 health providers, this study fills a gap by examining health service access from both the demand and supply-side. Utilizing access theory, this study explores the availability, affordability and acceptability of health services in rural China. Moreover, this study focuses on access barriers and institutional obstacles that PLWHA meet during their illness and considers the influence of the current Chinese political philosophy of marketization and privatization of the health care systems.

Key words: HIV/AIDS, access, PLWHA, health care, China

The HIV/AIDS epidemic is a growing social problem in China. As of the end of October 2009, the number of people living with HIV/AIDS (PLWHA) in China was reported to be a total of 319,877 (Chinanews.com, 2009). The estimated population at the end of 2009 was 1.334 billion (Juan, 2011), meaning that 2.396% of the population were reported as living with HIV/AIDS.
with HIV/AIDS. Since it is estimated that only 20% of the total number of PLWHA was reported, the actual number of people affected by HIV is likely to be much greater than indicated in the above statistics (UNAIDS China, 2006). Even if China is able to keep new infection rates to 2-3%, similar to that of Thailand's success during the 1990s, the total size of the infected population would still be around 27.5 million by 2020 (Saich, 2006).

Measures dealing with the HIV/AIDS epidemic rely heavily on the health system for effective prevention and treatment programs, and this creates significant additional burdens for health service provision, health education, monitoring, logistics supply, and manpower specialization (Liu & Kaufman, 2006). Existing studies demonstrate how the marketization and privatization of health reform have weakened the Chinese public health system and have failed to provide high-quality, affordable, and equitable health services for the majority of the rural population (Farmer, 2006; Liu, 2004a, 2004b; Saich, 2006; Wang, 2004). More than 70% of PLWHA live in rural areas. However, there has been little evaluation of the capacity of China's weakened rural public health system to meet the pressing needs to offer an effective medical response to the AIDS epidemic, either in terms of prevention or treatment.

This study attempts to fill a research gap by examining health service access in two provinces in rural China (Anhui and Henan), from both supply- and demand-sides, and describes the challenges and access barriers that are faced by rural public health infrastructures in dealing with HIV/AIDS. The sheer size of the country and the different characteristics of different regions make it impossible to adopt only one strategy to deal with the epidemic in all different areas. This study critically evaluates the drawbacks, ineffectiveness, and unreliability of the existing rural public health system in combating HIV/AIDS under the guidance of "marketization/privatization" and "decentralization" of China's health policy.

Rural Health System in a Chinese Socio-historical Context

China was the first large nation in the world to develop a
nationwide rural health insurance system, in the Maoist Era. The township public health center, together with the Rural Cooperative Medical System (RCMS) and the barefoot doctor, were praised by the World Health Organization (WHO) as the “three magic weapons” in meeting the needs of rural populations, and received much publicity in the West. The RCMS was a community-based rural health financing and provision system which functioned as collective medical insurance in villages. Although schemes varied, families were usually asked to contribute about 2% of their annual income, and this was matched with money from the village’s welfare fund (Liu, 2004b; Zhang & Chen, 1996). ‘Barefoot doctor’ was a term that emerged in the mid-1960s, referring to a paramedical worker with basic medical training who worked in a rural district in China. Under the RCMS, barefoot doctors provided both Western and traditional Chinese medical care and many public health services (Blumenthal & Hsiao, 2005), and were subsidized by the government. By 1980, about 90% of production brigades (comparable to the present-day administrative villages) were implementing RCMS, forming part of a three-tiered (county, township, and village) health services network that combined prevention, treatment, and health maintenance with a formal bottom-up referral process for patients. This health revolution in the Chinese countryside basically realized the goal of “treating minor diseases in the village, and major diseases in the township.” The WHO and the World Bank praised the “Chinese model,” which allowed the greatest health benefits for the smallest inputs (Hillier & Shen, 1996; Liu, 2004a; Wang, 2004).

In 1985, a State Council document set out regulations allowing for “diversity of provision” in health care and licensed private medical practice, and promoted a multiplicity of types of ownership of facilities and methods of payment for health care. In rural areas, when China transformed its system of collective agricultural production to private production in the late 1970s, the RCMS collapsed immediately: vaunted barefoot doctors became unemployed and stopped providing public health services, for which they were no longer compensated. Nine hundred million rural peasants, mostly poor citizens, became, in effect, uninsured overnight. Under this situation,
some of the barefoot doctors became private health care practitioners with licenses, renamed "rural doctors" and "village doctors." Drug prescriptions are their main source of income, and obtaining fee-for-service is their daily practice.

The last twenty years have witnessed remarkable economic growth in China. However, China's performance in the field of public health has been disappointing. Though China's primary health care system was held up as the model in the call for "health for all by the year 2000" at the WHO's Alma Ata conference in 1978, China ranked 188 out of 191 countries in terms of fairness of financial contribution to health in 2000; in 2001, 21.6% of poor rural households fell below the poverty line as a result of medical expenses (Liu & Kaufman, 2006; Saich, 2006). As the financing and operation of hospitals in China has become increasingly privatized and marketized, inequalities in health care and health status have increased between rich and poor, rural and city, and between different regions. Moreover, health care providers have become less interested in public health work, as there is little or no remuneration for preventive service (Liu, 2004a). The three-level network of county-township-village health units for rural people has also been weakened because of twenty years of underinvestment in health in rural China (Saich, 2006), thus public health in rural areas has been neglected. For example, in some poor rural areas infant mortality has recently increased, while it has continued to fall in urban centers, and there has been a resurgence of some infectious diseases such as schistosomiasis, which was nearly brought under control in the past (Blumenthal & Hsiao, 2005).

The outbreak of SARS in the winter/spring of 2002-2003 alerted the Chinese government not only to the relative weakness of its rural medical system, but also to the dangers of epidemic, life-threatening infectious diseases that could undermine economic growth (Kaufman, Kleinman, & Saich, 2006; Saich, 2005; Wang, 2004). In late 2003, the Chinese government officially took a more practical and realistic stance than previously and announced a new national policy, "Four Frees and One Care," which includes the provision of: free antiretroviral (ART) drugs for all rural residents and poor people in cities; free counseling and testing services; free treatment for pregnant women and testing for their babies; free school fees for
children affected by HIV/AIDS; and financial support for affected families (State Council AIDS Working Committee Office & UNAIDS China, 2004). This policy indicated that the government squarely recognized the need for treatment and care, not only for improving the lives of people and the functioning of communities affected by HIV/AIDS, but also for preventing further transmission of the disease.

With the Ministry of Health at the apex of the pyramid for monitoring the health system, accountable to the State Council, two types of health provision institutions are now available for PLWHA and the general public. One of these is the Center for Disease Prevention and Control (CDC), which is mainly responsible for testing and preventive institutions; the other consists of the hospitals, health stations, and private clinics, which are mainly curative and treatment institutions. Shortly after the SARS epidemic in 2003, the establishment of the China CDC was approved by the State Council; later, the former Epidemic Prevention Stations (EPS) all over China were renamed as CDC, although their capacity, staff, facilities, and functions, etc., remained virtually the same as those of the former EPSs. However, the national infrastructure of the public health surveillance and response system has yet to be established, and this comprises CDC at different administrative levels (province, city, and county, with the county as the lowest level). The concrete task of the CDC is to prevent communicable disease, chronic non-communicable disease, and other kinds of harm. AIDS is listed as the most serious communicable disease, with the highest mortality rate, and therefore the CDCs have become the most important institutions of HIV/AIDS prevention and treatment. Besides offering HIV/AIDS testing, CDCs are also in charge of health surveillance, information collecting and reporting, and offering guidance on disease prevention for health units in hospitals and clinics at the same administrative level or lower. Routine testing in health care settings and detention centers was introduced in 2005; behavioral surveillance began in 2004, and there were already 159 sites in 27 provinces by the end of 2006 (Sun et al., 2007).

China’s National Free Antiretroviral Treatment (ART) Program began in 2003 in Henan province and was then
extended to Anhui Province. The care model is designed to be community-based, which involves the provision of ART at the county level with routine follow-up, monitoring, and care at the village or township level. County- and prefecture-level clinicians address serious opportunistic infections (OI), adverse reactions, and other complications, with consultative referral to the provincial and national level as required (Zhang et al., 2007). Later, this article will discuss how the design of the surveillance and referral system is transformed and adapted according to local situations.

Theoretical Framework

Drawing on Donabedian (1973), access is the "degree of fit" between the health system and those it serves—a dynamic process of interaction between health system (supply-side) issues and individual or household (demand-side) issues. Access has a number of dimensions (Gulliford, 2002; Liu & Kaufman, 2006; Penchansky & Thomas, 1981):

*Availability* refers to whether or not the appropriate health services are in the right place and at the right time. For example, availability includes the location of services; hours during which care is provided and the type; range, quantity and quality of service; and each is considered relative to the health needs of the population served (Gilson & Schneider, 2008).

*Affordability* refers to the "degree of fit" between the cost of health care and individuals' ability to pay. *Acceptability* refers to the social and cultural distance between health care systems and their users. The concept of acceptability goes beyond patient-provider interaction, and includes three central elements (Gilson, 2007): (1) the fit between lay and professional health beliefs—covering both patients' perceptions of the effectiveness of treatment and the extent to which their constructions of health and healing match health care providers' understandings on these issues; (2) patient-provider engagement and dialogue—with particular emphasis on the communication practices of providers, the extent to which patients are themselves given opportunities and are able to discuss their own care, and whether or not providers demonstrate
prejudice towards patients, perhaps simply by stereotyping them and their needs rather than listening to each patient; and (3) the ways in which health care organizational arrangements influence patient responses to services—for example, fees for service systems often generate patient concern that the provider is more interested in making money than in addressing their needs fully.

The concept of access is helpful for linking rural PLWHA’s experiences of illness and medical care-seeking behavior within the context of the rural public health system under the influence of marketization and the privatization of health reform in China, with special focus on how the individual's access to health service is shaped by institutional barriers. The concept of access also provides a conceptual perspective from which to measure differences in health care utilization, to assess inequalities in utilization, and to examine the interaction between PLWHA and health providers and the integration of various dimensions of access—namely, availability, affordability, and acceptability—within the Chinese socio-historical context.

Methods

Study Setting and Procedures

This study is part of a larger research project that includes both a large-scale household survey and qualitative interviews aimed at understanding the determinants and impacts of the HIV epidemic on the social and economic conditions of rural households. Because of space constraints, this article presents only the qualitative data collected from the larger project. Ethical approvals were obtained from the research ethics committees at the project implementing university.

For this study, qualitative data were collected from Henan and Anhui provinces of China at sites including two cities, five counties, 10 townships, and 19 villages. The main reasons for having selected these two provinces are that: (1) they are both epidemic-hit areas, where the dominant transmission was through illicit blood and plasma donation in the mid-1990s. The rate of infection among blood/plasma donors has reached an average of 10-20%, with rates as high as 60% in some communities (UNAIDS China, 2003); and (2) both provinces are
involved in the National Free ART program and have community-based state-funded ART Clinics.

The research team included three research professors and 10 postgraduate students. The implementation of this study included two phases. The first round of data collection was carried out between December 2006 and April 2007, when 36 PLWHA from the two provinces were interviewed. After analyzing the first round of data, we felt that we could not understand PLWHAs' illness experience deeply without examining the viewpoints of health providers. Therefore, a second round of data collection was conducted between August and September 2008, during which 13 health service providers from the two provinces were interviewed. After informed consent was obtained, each confidential interview was conducted in a private room on a one-to-one basis and lasted for one to two hours. During these in-depth semi-structured interviews, PLWHA participants were asked open-ended questions about their illness experience and utilization of health services; service providers were asked about their HIV knowledge, attitudes and interactions with PLWHA, and their personal practices, difficulties and challenges at work.

To allow flexibility and spontaneity as new content emerged during interviews, interview questions were not necessarily asked in the same order or wording as in the interview guide, however, all questions in the interview guide were covered during each interview. At the end of each interview, demographic information was collected with a standardized background questionnaire. Audiotaping was avoided in order to ease informants' possible unwillingness to respond and in consideration of the sensitivities of the topic. The researchers took detailed notes during the interviews and made field notes, recording dialogues, observations, and self-reflections in a timely manner, as part of the compilation of data for analysis. In order to protect the participants' privacy, all names remain anonymous and have been replaced by figures. Within the text, "A" and "H" represent Anhui and Henan provinces, respectively.

Study Participants

As shown in Table 1, the thirteen health service provider participants included 11 males and 2 females. Their ages
ranged from 20 to 61, with an average age of 37.9. In terms of educational background, only three had graduated from university; the others had graduated from college (n = 1), senior high school (n = 1), vocational nursing school (n = 7), or junior high school (n = 1). Eleven of them were doctors and two were nurses. All provided HIV/AIDS related services. They served in different types of medical institutions, including village clinics (n = 5), township hospitals (n = 5), and county hospitals (n = 3). Ten of the 13 had received some HIV-related training; the other 3 had received none.

Table 1. Demographic Characteristics of Provider Participants (n=13)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency/range (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Range (mean)</td>
<td>20 - 61 years (37.9)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Junior high school</td>
<td>1</td>
</tr>
<tr>
<td>Vocational nursing school</td>
<td>7</td>
</tr>
<tr>
<td>Senior high school</td>
<td>1</td>
</tr>
<tr>
<td>College</td>
<td>1</td>
</tr>
<tr>
<td>University</td>
<td>3</td>
</tr>
<tr>
<td>Level of care</td>
<td></td>
</tr>
<tr>
<td>ART clinic</td>
<td>5</td>
</tr>
<tr>
<td>Township hospital</td>
<td>5</td>
</tr>
<tr>
<td>County hospital</td>
<td>3</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>11</td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Contact with PLWHA</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>HIV training</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
</tbody>
</table>

As shown in Table 2, the thirty-six PLWHA participants included 17 males and 19 females. Their ages ranged from 23 to 67, with an average age of 42.8 years. Their educational background was generally low: 16 participants were illiterate, and others were junior high school (n = 9) or primary school (n = 11) graduates. At the time of the interviews, the length of their HIV diagnosis averaged 4.6 years. Twenty-five participants were married, 10 were widowed through the death of their HIV-infected spouses, and 1 was currently single,
never having been married. Their infection modes are divided between "commercial blood donation" (n = 34) and "heterosexual behavior" (n = 2).

Table 2. Demographic Characteristics of Chinese PLWHA (n = 36)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency/range(mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Range (mean)</td>
<td>23 - 67 years (42.8)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Junior high school</td>
<td>9</td>
</tr>
<tr>
<td>Primary school</td>
<td>11</td>
</tr>
<tr>
<td>Illiterate</td>
<td>16</td>
</tr>
<tr>
<td>Current relationship status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>25</td>
</tr>
<tr>
<td>Widowed</td>
<td>10</td>
</tr>
<tr>
<td>Single and never married</td>
<td>1</td>
</tr>
<tr>
<td>Infection modes</td>
<td></td>
</tr>
<tr>
<td>Commercial blood donation</td>
<td>34</td>
</tr>
<tr>
<td>Heterosexual practice</td>
<td>2</td>
</tr>
<tr>
<td>Time of being diagnosed as HIV positive (mean)</td>
<td>(1 - 9)/4.6 year</td>
</tr>
</tbody>
</table>

Data Analysis

The data analysis process included three main phases: identifying significant statement for coding; categorization; and theming. In order to attain better inter-coder reliability, the four authors read through the texts of all transcripts and field notes, brought tentative coding into team meetings and discussions, and then assigned category labels (e.g., "location of service," "quantity and quality of service," "individual's ability to pay," and "prejudice towards patients"). Statements with similar category labels were later grouped into clusters, which allowed easier examination of consistency of experience and the diversity of perspectives. Based on data analysis, we were able to develop a comprehensive synthesis of HIV/AIDS health service access in rural China. To avoid the loss of nuance within original narratives, the data were not translated into English until the stage of writing-up the research.

Results

Availability: Can PLWHA receive health service in the right place and at the right time? In Henan and Anhui,
community-based, state-funded ART Clinics have been established, to which health care workers are assigned. They are paid by the local government. The ART Clinics not only distribute antiviral drugs free of charge, but also provide some amount of free medicine to cure opportunistic infections. Usually, these ART clinics were located where infected groups and communities were highly concentrated. For example, one ART Clinic we visited was established in May 2007 in Anhui Province in A village, which had 155 PLWHA; also close to B village (three miles away), which had 117 PLWHA; and to C village (two miles away), which had 40 PLWHA.

An AIDS patient from B village told us how the establishment of the ART Clinic within the community had brought convenience to her life.

In the past, I had to pick up the medicine from County CDC, which is 20 miles away. Since last May, I came to A village to pick up the medicine, which is much closer to my home, as it only took 20 minutes by bicycle. (A3, F, 55)

In general, physical access was not a big issue for PLWHAs in these communities in both Henan and Anhui. Some villages of Henan even had a special distribution arrangement plan that used the services of PLWHA.

Here County CDC distributes ART drugs to the clinic. We selected one from every ten PLWHA to be in charge of distributing free ART drugs, [and this person] got 60 RMB from the government as monthly stipend. Most AIDS patients here can receive medicine without leaving home. (ART Clinic doctor)

For some patients not living in high-rate communities, however, physical access to health service remains a huge problem. We interviewed one AIDS patient who lived more than 30 kilometers away from an ART Clinic. However, instead of complaining about the long distance, A2 thinks that it was good for her to keep the her illness secret from other villagers, since she was the only HIV-infected person in the village and she was afraid of isolation and discrimination associated with HIV stigma.
At the time of the interviews, we also noticed a phenomenon wherein migrant workers only returned to their hometown villages to seek health care after having been diagnosed as HIV positive, since rural PLWHA can usually obtain free (or reimbursable) medical services at the particular ART Clinics at the location of their Hukou registration. If they do not go to ART Clinic where their Hukou registered, they cannot get any medical assistance at all. On the one hand, this policy improves availability of health service for PLWHA within their community of origin; on the other hand, it limits PLWHAs' mobility and flexibility of health care seeking in order to control the spread of the HIV/AIDS epidemic.

Every resident of China was classified as either a rural or urban household (sic) through a household registration certificate (hukou). Although analysts differ on the motivating factors that led to these decisions, the effect was to create a “caste-like system of social stratification” (Potter & Potter, 1990) between urban dwellers and the rural peasantry. As Solinger (1999) describes in great detail, a Chinese person’s classification as a rural or urban hukou-holder not only determined place of residence, but also the benefits she or he would receive from the state (as cited in Woronov, 2004, p. 291).

According to the original design of the health system, ART clinics can only provide simple ART treatment; as for OI treatment, patients can be transferred to township and county hospitals. However, the research confirmed that the health system adopts different strategies in order to keep the PLWHA’s treatment within the ART clinics. In one county, if a patient was transferred from an ART clinic to a higher level hospital, he or she needed to pay 15% more than the cost of treatment at the ART clinic from his or her own pockets. This decreases PLWHAs’ incentives to seek health care at a higher level hospital. In another county, the county hospital had been sending doctors to clinics since June 2008, so that, as the director of the ART clinic put it, “the ART clinic provides ‘one station for all’ service.”

Our patients can receive as high-quality treatment here as in the county hospital, since their doctors were sent here. The ART clinic can provide the highest quality
of treatment in the county, and there is no need of transfer. If we cannot cure here, nowhere can. (ART clinic director)

This story sounds encouraging and promising—PLWHA can receive high-quality care in their own communities. However, we heard another side of the story from the doctor sent to the ART clinic by the county hospital, which shows that the arrangement per se has the function of excluding PLWHA from obtaining proper and better treatment.

I did not receive any kind of HIV-related training. Sometimes I think that I cannot make any difference, since I treat their OI just as [I treat] ordinary patients, and the only difference is that I prescribe them bigger doses of medication. I am here just because my boss did not like me. The other reason is that the county hospital does not like PLWHA going there and scaring other patients off. (Doctor sent by the county hospital)

Moreover, the arrangement makes it difficult for PLWHA to be transferred to higher-level hospitals. It is very complicated to get the paperwork done and to go through all the official procedures. Sometimes, in Anhui, one PLWHA needs to get the county CDC and county bureau of health approvals to move to a higher-level hospital. The so-called convenient availability within a community thus actually deprives PLWHA’s freedom and rights to pursue high-quality medical care.

We found that it was always difficult for people to decide whether to take an HIV test or not. At the time of the interviews, many PLWHA told us that their spouses and children have not been examined. For example, A9 and her husband both are HIV infectors, but they did not send their children for examination. “I am afraid of the influence on the children if they are diagnosed as AIDS-infected. They are so young. My husband and I would not be able to bear it if we found out they are infected” (A9, F, 33).

In the long term, persuading people at risk of HIV to be examined as early as possible is beneficial for the people, their families, and their communities, but as can be seen from the above quotes, people were resistant to this. It was apparent
that the ART clinics need to pay more attention to HIV/AIDS surveillance and education. According to government regulations, PLWHAs need to have their CD4\textsuperscript{1} tested twice per year in order to track the effect of their treatments. However, CD4 testing even once a year for PLWHAs could not be guaranteed, since the county CDC lacked the equipment necessary to perform the test.

**Affordability: Can PLWA afford to be sick?** The Chinese national policy of “Four Free and One Care” has reduced AIDS patients’ financial burden, but it remains an obstacle, since PLWA still need to pay something for OI treatment, despite the fact that medical assistance is subsidized by the local government. For example, in Henan province, only 129 prescribed drugs for OI treatment are free. For rural poor PLWA, even though they may get free treatment, small payments may become a huge burden.

When I was hospitalized, I needed to pay the daily expenditures. Every day I needed more than 10 RMB (1.3 USD) for meals, and I was still hungry. When I was seriously sick, my wife and son took turns taking care of me. When I got a little better, I asked them not to come, to save the money for [my] meals. (H7, M, 41)

Impoverishment due to medical expenses has become a serious problem in rural China (Jin, Tang, Zhao, & Lu, 2004; Li & Tang, 2005; Liu & Kaufman, 2006; Saich, 2006). Lacking adequate income to purchase basic health care when needed was a common complaint among the informants. For rural PLWA, “not seeking care” often is the choice that they make when they are sick but have no money to pay because of their economic difficulties. As H2 stated, “The biggest worry I face now is how to pay my medical fees. I try not to go for treatment for minor problems” (H2, F, 52).

In Henan province, there were different types of medical assistance for PLWA with different levels of CD4. According to a health care worker from an ART Clinic in Henan Province, the practice works like this:

Our clinic’s standard is: if the CD4 is below 200, each patient can get free medication worth 1,200 RMB per
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year; if it is higher than 200, each patient gets 800 RMB per year. If someone takes very little of the free medication, he will be reimbursed. (ART clinic doctor)

Such a policy may sound good, but in practice there are some problems, as H9, a patient from the ART Clinic, said in his interview.

I think that the existing policies are good, but two problems remain. First, the types of drugs in ART Clinics are limited—lacking in many drugs. When I and many other villagers got sick and the ART Clinics could not meet our needs, we had to go to private clinics, at our own expense. Second, the reimbursement policies from village hospitals were unclear, and it seems that the ART Clinic never told us clearly how much we had spent. (H9, F, 33)

As H9 has stated, when ART Clinic could not offer necessary medication, PLWHA may seek treatment from private clinics, if they can afford it. H10 made a similar compliant:

I started to take ART drugs in January 2004. Sometimes I felt that the drugs of the ART Clinics did not work well, so I had to buy medicine from private clinics, which is cheaper and has better effects, but they still cost me 30 to 50 RMB (4 to 7 USD) every time. I had a canker sore on my mouth, and the ART Clinic could not treat it; I had to see a doctor in a private clinic. Last year, I spent 3000 RMB (450 USD) on medical care, and most of it was spent in a private clinic. (H10, M, 42)

Both H9 and H10 stated that the 129 free drugs of the ART clinics are not good enough for OI treatment. Some local doctors confirmed this.

Among the 129 types of free drugs, more than 10 types needed to be changed—of course further clinical research is required. Since purchasing drugs invites public bidding, usually cheaper drugs are easier to get, but the treatment effect is not that good. Patients always need to pay for better drugs. Moreover, the government needs to provide second-line medicine,
because the current drugs are no longer effective for some patients who have taken them for a long term. (ART clinic doctor)

Another doctor also suggested that "Experts should update the list of prescribed drugs according to changing disease conditions more frequently, in order to improve the quality of treatment" (ART clinic doctor).

Right now, many PLWHA in Henan and Anhui have entered the peak outbreak period of opportunistic infection, which occurs after more than ten years of illness. This means that their demand for medical care and assistance is becoming greater. However, the conditions of insufficient drugs and fees for OI treatment remain heavy burdens for these poor rural PLWHA.

Acceptability: Can PLWHA be accepted as ordinary patients? On a more hopeful note, relationships between provider and patient were quite good at the ART clinics we visited. As a nurse put it, "[I] put myself in their position: you treat them well, and then they treat you well. Sometimes with patient explanations, they will all be reasonable" (ART clinic nurse).

However, sometimes the good provider-patient relationship may jeopardize the universal precautions that the health providers need to take.

There is no need for protection, we just need to be more careful. We are required to wear masks and gloves, but now it is so hot and inconvenient. Besides, wearing those is not good for the patients—they will say, 'I see, you are scared.' The potential risk does exist, because we need to give them injections. The other day, one nurse was pricked by the needle accidentally. Now he went back home to have a rest and wait for the test result. (ART clinic nurse)

We found that such accidents happened in almost every ART clinic, and most health-provider participants in this study had experienced being pricked by an infected needle. Universal precautions should thus be made an urgent priority.

There are also other issues in ART clinics that need to be addressed. In most ART clinics, workloads are heavier and the pay is less than elsewhere.
Sometimes I really want to quit. Not because of fear of HIV/AIDS—mainly because I am too tired. Sometimes in one morning nearly 20 persons come here for intravenous drips. Everyone had three bottles. I just could not handle it. After the work, I was too tired to move. (ART clinic nurse)

As an ART clinic nurse, this woman's monthly salary was 800 RMB (around 120 USD) plus a 400 RMB (around 60 USD) stipend. This is lower than incomes at ordinary clinics and hospitals of the same level. In addition, at the time of interview, neither she nor her colleagues had received payment for three months. Even patients protested the unfair situations of the providers, and some of them even asked us to report the situation to upper-level government in order to remedy their providers' low salaries and delayed payments. They put it very simply: "Who is going to treat us if they leave?"

As mentioned, patient-provider engagement and communication is quite good within the ART clinics: patients trust their providers, express their gratitude for their providers' stressful work, and are willing to discuss their illness and life obstacles with them. Most providers can lose their initial feelings of fear and can treat PLWHAs without prejudice. A director of one ART clinic concluded that the good relationship between providers and patients stemmed from doctors' professional ethics and sense of responsibility, and said that the ART clinics have been assigned a mission from the government to comfort patients and prevent them from causing troubles in the society. These providers play important roles, both in preventing the spread of HIV/AIDS in families and communities with infected individuals and in helping to improve the quality of life of those who are infected by providing consultations, treatment, and social support.

ART clinics thus manage to create a small comfortable atmosphere within the community for the PLWHA. However, the external medical institutions are less welcoming. We found that many informants reported their experience of being rejected by ordinary hospitals just because of HIV-related stigma and discrimination. Even doctors interviewed from county hospitals thought that the existing medical system
discriminates and excludes PLWHA in certain ways.

Now the existing medical system just barely satisfies PLWA’s needs. If they need to have a small surgery, such as an abortion or a tooth extraction, their medical needs are often denied, because it may cause the pollution of medical instruments. In many cases, PLWHA are put into a double-bind: if they tell they are PLWHA, the hospital may not provide the service; if they do not tell, they may cause the infection of health providers and the pollution of medical instruments. Sometimes a small operation needs to be coordinated by the CDC and the Bureau of Health. (county hospital doctor)

Most county hospitals try to exclude PLWHA in the name of considering other patients’ well-being. Sometimes this exclusion by the county hospital turns the CDC into an OI treatment department for PLWHA. However, compared to county hospitals, especially those set up for communicable diseases, the CDCs lack the advanced technology, facilities and professionals to provide PLWHA with proper treatment.

However, certain hospitals especially welcome PLWHA because the fees-for-service system brings them more money. Such providers are more interested in making money than in addressing PLWHA’s needs fully. For example, expensive drugs may be prescribed unnecessarily. In this situation, the PLWHA is often left with no other options, because the hospital may be the highest-level government-assigned hospital for treating HIV/AIDS within the county, and the only one in which they can enjoy certain preferential policies.

Discussion

This article has evaluated health service access in rural Henan and Anhui provinces in an integrative way, through the examination of availability, affordability, and acceptability of treatment for PLWHAs. We find that ART clinic medical care does benefit PLWHA, however, issues like poverty, stigma and discrimination, and the "fee for service" health care system prevent PLWHA from accessing the most effective
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care. Moreover, PLWHAs encounter institutional obstacles as a result of the philosophy of marketization and privatization of the health care system.

Inadequate Funding of CDCs

At present, government allocations to county-level preventive health services cover only approximately one-third of their expenses; the rest of their funding derives from income from professional services. The CDCs do not get sufficient government allocations, and are thus unable to get new equipment or sufficient reagents and staff for disease surveillance. From 1949 to the mid 1980s, the government’s emphasis in its health work was on the prevention and eradication of infectious diseases and similar basic public health services (Wang, 2004). The slogan then was “Prevention First,” and the work of local CDCs was highly emphasized. However, in the wake of the government’s move towards a market-driven economy, the role of the government in financing, organizing, and delivering public services has been weakened, leading to an underfunded and fragmented public health care system (Liu, 2004a). In central and western China, many CDCs at the county level have not upgraded their laboratory instruments in many years; some are barely able to pay salaries to their workers. In order to ensure their survival, many CDCs are forced to expand profitable services, especially when PLWHAs are turned down by other ordinary hospitals. CDCs, in the name of “health inspection,” may charge a variety of fees in order to survive (Liu, 2004a). This survival strategy has deeply changed their working emphasis and has drastically lowered their ability to prevent and control large-scale epidemics such as HIV/AIDS. These conditions are a signal that China’s preventive health safety net has been damaged.

Weakness of Referral System

According to the original design, a three-level network of county-township-village health units would exist as a structural foundation, as well as a formal bottom-up referral system for HIV/AIDS prevention, control, and treatment in rural China. However, the structure has become split and the foundation is not reliable anymore. One reason for this is that the existing
health care system attempts to restrict the mobility of PLWHA to the ART clinics only; another reason is that the functions of township public health centers are limited, due to a lack of staff and facilities. In terms of the care provided, township hospitals may offer little more than the village clinics: for minor OI treatment, the clinics can take care of them, but serious OI treatment is a tough job for them. Usually, rural PLWHA just skip the township hospital and seek help at county hospitals when they encounter serious OI problems.

Lack of Training of Health Providers
Among the interviewed 13 health providers, 3 had not received any kind of HIV/AIDS related training, although one of these had been sent by the county hospital to an ART clinic as an 'expert' in HIV/AIDS care. Even those who had received trainings complained that most of the trainings are not that useful for their daily work, "because training organizers only want to spend the training money." Universal precautions for health providers remain a big problem, and many health providers are at risk of contracting illness because of the lack of proper protection.

Regional Inequality and Inconsistent Medical Assistance
With the decentralization of health care units, the financial allocation from central government remains low, so that individual contributions for treatment are overly high. Thus the inequality of economic growth brings out health inequalities between different provinces, between city and rural areas, and between the rich and the poor. As investment and spending decisions have been decentralized to provincial, county and township governments (Liu, 2004a), it is no wonder that rural PLWHA receive different medical assistance in different provinces, and even counties, townships, and villages have different policies for medical assistance. We also noticed that ART Clinics in two nearby counties in the same province had different policies for reimbursement and medical assistance during our field work.
Conclusion

Based on our examination of the interaction between rural PLWHAs' health service access experience and institutional obstacles in this paper, we argue that there is an urgent need to reconstruct a sustainable and effective public health system in China to cope with HIV/AIDS and other epidemics and diseases. The government has to pay serious attention to the work of disease prevention, and to put "prevention first" as the priority of the Chinese public health system. Such prevention work needs not only focus on the issue of HIV/AIDS, but should be extended to an emphasis on other diseases and health issues, including sexually transmitted diseases, such as gonorrhea and syphilis, women's reproductive health, and drug abuse etc. If the CDC system is guaranteed reliable government funding, it can focus effectively on its mission. However, only by strengthening the three-level referral system in rural China, getting rid of the institutional discrimination and stigma of PLWHA, and increasing the training of providers, will PLWHA be able to utilize health service more consistently and equally. The government should take responsibility for revising the unequal distribution of benefits caused by the household registration system and provide similar basic public services, including health, for all of its citizens, regardless of where within the country they live. On the one hand, there should be health equality between urban and rural areas. As well as this, health fairness between east coastal, central, and western areas through tax-sharing and public funding needs to be promoted. Furthermore, China should invest in public education regarding HIV/AIDS knowledge, safe sex practices, personal hygiene, and other public health practices, that might prevent future epidemics.

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References


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Endnotes:

1. A CD4 count is the measured level of a certain type of protein, which is often present in certain types of white blood cells. CD4 stands for “cluster of differentiation four,” and is an important component of the body’s ability to produce an immune response to a would-be infection. A CD4 count can also refer to the specific lab work that is done to determine its level, as a routine part of
treatment for someone with the human immunodeficiency virus (HIV), which can lead to acquired immune deficiency syndrome (AIDS) (www.wisegeek.com).