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BARRIERS TO ADHERENCE TO ANTIRETROVIRAL MEDICATIONS AMONG PATIENTS LIVING WITH HIV IN SOUTHERN CHINA: A QUALITATIVE STUDY

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Abstract

Although China's government is rapidly expanding access to antiretroviral therapy, little is known about barriers to adherence among Chinese HIV-infected patients, particularly among injection drug users (IDUs). To better understand barriers to antiretroviral treatment adherence, we conducted a qualitative research study, using both focus group and key informant methods, among 36 HIV-positive men and women in Dali, in southwestern China. All interviews utilized semi-structured question guides and were conducted in Mandarin, audio-recorded, and translated into English for analysis. The most commonly cited adherence challenges were stigma, including secondary stigma experienced by family members; mental health issues; and economic concerns, particularly related to finding and maintaining employment. Distinctive gender differences emerged, partly due to previous heroin use among male respondents. Optimizing adherence may require that antiretroviral therapy programs be linked to other services, including drug addiction treatment, mental health services, and vocational treatment and support. HIV care and service providers, and policy makers in China responsible for HIV treatment, should be aware of these important barriers to adherence.

Keywords

HIV; AIDS; antiretroviral therapy; adherence; injection drug users; qualitative research; China; mental health; stigma; vocational support

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Introduction

The increased availability of antiretroviral therapy (ART) offers real hope of long-term survival to millions of HIV-infected individuals (World Health Organization, 2006). However, in addition to access, strict adherence to ART regimes is critical for successful treatment (Bangsberg et al., 2000; Paterson et al., 2000). Optimizing ART requires a deep understanding of the factors that impact patients' adherence, which can be highly contextual (Kumarasamy et al., 2005; Lewis et al., 2006; Malcolm et al., 2003; Malta et al., 2005; Powell-Cope et al., 2003; Sankar et al., 2006; Vervoort et al., 2006).

China is experiencing one of Asia's most serious HIV/AIDS epidemics (World Health Organization, 2006). The Chinese government has made provision of free ART to qualifying patients a cornerstone of its HIV/AIDS policy (Qiang, 2003; F. Zhang et al., 2004), successfully providing ART to 18,000–20,000 patients by the end of 2006 (World Health Organization, 2007). Currently, efforts focus on expanding ART in border areas such as Yunnan, where the HIV epidemic remains concentrated among injection drug users (IDUs) (Yunnan Center for Disease Control, 2005). Little is known about what factors influence ART adherence in China. To better understand adherence barriers faced by this population, we conducted a qualitative research among Chinese patients, most of whom were former IDUs.

Methods

The study was conducted at the Dali Second People's Hospital (DSPH) in Old Dali, Yunnan province (40,000 population), situated along a major heroin transit route from Vietnam and Myanmar. Respondents were sampled from among HIV-positive patients attending the DSPH Dermatology and Sexually Transmitted Diseases Clinic, which was selected in mid-2005 as a free ART site. Patients were eligible for participation if they were: (1) willing to provide informed consent; and (2) aged 18 years or above. Respondents participated in an in-depth interview (IDI), a focus group discussion (FGD), or both.

Procedures

A team of local researchers with experience conducting qualitative research in China, who were provided additional training on HIV/AIDS, ART adherence, and research ethics by the Boston-based and Beijing collaborators, collected data in Dali. The team identified potential respondents with assistance from DSPH clinicians. Two interviewers conducted each IDI/FGD, one facilitating the IDI/FGD, and the other taking notes. All IDIs/FGDs took place in a location agreed upon by the respondent(s) and were conducted in Mandarin Chinese using semi-structured interview guides. We audio-recorded each IDI/FGD, a practice acceptable in China; these recordings did not appear to inhibit recruitment or in-depth discussion. Respondents were given a small stipend. The study was approved by ethical review boards at Boston University and Ditan Hospital, Beijing.

Questions addressed knowledge of HIV/AIDS and ART, barriers to medication-taking, and circumstances related to episodes of non-adherence. Specific queries included: (1) How do you take your medications?; (2) Do you have any problems taking your medications and, if so, what are they?; and (3) What things might make it difficult for you to take your doses on time?

Data analysis

Recordings were transcribed and translated into English, and supplemented by the note-taker's written observations. We coded and analyzed the English language transcripts using NVivo7™. Responses were prioritized by the frequency with which they were mentioned;

the extent and nature of divergent views were also explored. Reports of specific challenges were included in the frequency analysis if a respondent mentioned the challenge as: (1) related to previous adherence experiences; (2) related to his/her HIV status or medication-taking behavior; or (3) a potential adherence issue for ART patients generally.

Results

Data were collected between December 2005 and March 2006. We conducted 4 focus groups (2 with men, 2 with women) and 18 in-depth interviews (11 with men, 7 with women), with a total of 36 individual respondents (Table 1). Just over three-quarters of respondents had begun ART (n=28), although the majority had only been on therapy for three to six months. All ART patients were on twice daily regimens of nevirapine/efavirenz, lamivudine, and stavudine/zidovudine. Patients obtained their medications on a monthly basis, and were provided quarterly CD4 and viral load testing, free of charge. All of the men (19/19), but a minority of the women (2/17), had contracted HIV through IDU. Aged 23 to 55 years, most respondents had a middle school education (nine years of schooling), typical of a semi-urban area in China, and lived with one or more family members, often parents or parents-in-law. About one-third were unemployed or retired.

Three dominant themes relating to potential adherence barriers emerged: stigma, mental health issues, and financial concerns. Other less frequently mentioned barriers included forgetfulness, regimen-related problems, and substance abuse. Table 2 summarizes the frequency of specific themes and sub-themes by gender. The major themes are discussed below, with supplemental statements by respondents provided in Table 3.

Stigma

Stigma related to HIV/AIDS was by far the most commonly cited adherence challenge. Respondents expressed three sources of anxiety: (1) fear of disclosure of HIV status; (2) fear of work-related stigma; (3) and fear of stigma directed at family members.

Almost every respondent (32/36) conveyed intense fear of disclosure related to medication use. Dali, like most places in China, is densely populated. Respondents lived and worked in crowded conditions, making it difficult to ensure privacy at dose-taking times. Most had revealed their status only to close family members and friends, although some reported disclosure by doctors to family members without their permission. This did not accord with China's national laws governing AIDS prevention and treatment (Chinese Center for Disease Control and Prevention, 2006; State Council Legislative Affairs Bureau, 1988), which prohibits disclosure of an individual's HIV status, but was not unusual in China's family-oriented culture. A few patients described keeping their status secret from family members to avoid worrying them or being "blamed." To prevent unwanted disclosure, respondents reported hiding their medications, disguising them, lying about them, and delaying taking them. A 31 year-old married man explained, "I fear other people will see me when I take medicine, and that wouldn't be good."

Male respondents frequently mentioned stigma related to both IDU and HIV/AIDS. A 40 year-old married man made this typical statement: "Drug users, it's a group that right now everyone in society hates. Including myself, I hate myself. But the problem is [that] there is nothing I can do." Several described using heroin again due to feelings of social isolation. In a male FGD, the group reflected on the difficulties "drug users like us" face in rejoining mainstream society as ART patients. A 36 year-old married man, apparently referring to official files held by local authorities on Chinese citizens that include records of imprisonment, labor reeducation, and drug detoxification, explained: "We have the capabilities. We have the expertise. But locally we had some black marks in our records."

Workplace stigma emerged as a major concern, both for men and women, and for several unemployed respondents who anticipated working. Some had already felt humiliated by employers or co-workers. A single 43 year-old woman reported open discussion by supervisors about her infection and described having to leave her job and turn to commercial sex work to support her child.

Most respondents sought to evade suspicion by concealing or disguising their pills at work. Given generally crowded circumstances, as well as China's traditional emphasis on collective welfare over individual privacy, many respondents found it difficult to keep their medication-taking secret at work. Respondents typically took their medications between 8:00–10:00 am/pm, when on route to work or already on the job. Many insisted that it was best to avoid appearing sick at all. In one female FGD, the group agreed that wrapping the medications in paper was a good way to hide them at work. One man who worked in construction explained that he would delay taking his dose on some sites due to lack of privacy.

A number of respondents (9/36) worried that their HIV status would cause members of their families, usually children or parents, to be stigmatized. For example, a 31 year-old man explained that he had disguised his medication bottles to protect his child. Others voiced concern about stigma directed toward their entire families. One 34 year-old married woman claimed, "If they look down on me then they'll look down on my family. These damn farming communities are just like this."

Mental health issues

Several mental health issues emerged as significant potential barriers to adherence. Three-quarters of respondents (27/36) described powerful feelings of sorrow, pain, and/or pressure related to being HIV-positive. The most common words used to convey these emotions were: "sad," "depressed," "gloomy," "unhappy," "in pain," and "psychological pressure." Many women spoke of weeping for long periods and having trouble sleeping after learning of their status. A 27 year-old woman whose husband and daughter were also HIV-positive described her fears of death: "I'll start crying. My child will give me some tissues to wipe my tears."

One-third of respondents (12/36), 7 men and 5 women, described feeling isolated. These feelings usually stemmed from self-imposed separation motivated by wishing to spare others HIV-related difficulties or shame. Many had kept secret their HIV status from loved ones, especially parents. Some had specifically asked Dali clinicians not to divulge this information to anyone. Others appeared to be socially isolated by the attitudes of family and friends. One respondent, a single 31 year-old man not yet on ART, explained: "I feel like a wall appeared between my family and me when they found out about my illness…. I feel abandoned."

Both men and women, but especially men, conveyed anxiety about not "being normal." One 32 year-old single man was worried about finding a wife, while many men equated being unable to find employment with being a social outsider. Women focused more on the isolating effects of ART. Several female respondents maintained that ART medications themselves made patients feel "different," "disgusting," or "depressed."

The men often articulated feelings of despair and guilt related to the previous needle-sharing that was responsible for their infections. Their remorse focused on the shame, financial hardship, and risk of, or actual, infection they had inflicted on family members. They described disappointing their parents, who traditionally in China gain social status and financial security through their son(s)' accomplishments, as well as their failure to

adequately support their wives and children. A 46 year-old married man seemed to express the views of an entire FGD: “Because we are all drug users, the harm to the family is pretty great….This is a long-term guilt, when I think that it was my own mistake….I can’t speak of any contribution to my family. …I think about it a lot.”

When asked whether such feelings would affect their adherence, some said they would persevere with the medications regardless of their pain. They tended to describe their distress as a “problem” with therapy and implied, rather than stated directly, that the psychological ‘burden” of lifelong ART would discourage them from continuing their regimens. Some respondents, however, acknowledged that depression might hinder their adherence. One woman explained, “If I’m happy today, I’ll take the medicines. And tomorrow I won’t take them. People like us…(broke down in tears)”.

Seven respondents, four women and three men, described recent thoughts of or attempts at suicide. Among the men, these admissions were accompanied by remorse at having disappointed or hurt family members. A single 37 year-old man explained: “I just wanted to disentangle and did not really want to go on. I just wanted to die. I was a burden for my family…. I almost committed suicide.” The women were particularly expressive in recounting grief, hopelessness, and pain. A single 28 year-old woman told of feeling “life is meaningless.” One 34 year-old woman with children disclosed: “Sometimes I don’t want to see anyone. I just think if I die I can end it all.”

Economic issues

Most respondents reported economic worries related to their current medication-taking. Financial reliance on others was common, so lack of money was frequently raised as a major concern, particularly by unemployed female respondents. However, even employed respondents discussed money pressures.

Nearly two-thirds of respondents (23/36), 10/19 men and 13/17 women, identified the cost of ART medications as a significant issue. Although all respondents received ART free of charge, many stated that having to pay for ART would pose a critical adherence barrier. Most respondents reported constant “worry” or “fear” about possible future charges for the medications, which they equated with a virtual death sentence. A number of respondents recalled having to wait to begin therapy until the medications were freely provided; several had expected to pass away before that occurred. An entire female FGD group agreed on the “big pressure” they associated with paying for medications.

Although ART itself was free, other aspects of care remained costly. The most common charges discussed were for medical tests, treatment for side effects, and transportation to the clinic. Although public bus fares only appeared to be a problem for patients with no or few independent resources, tests and non-ART medications could be expensive (several hundred yuan, or more than $40) and represent a significant challenge even for working patients. A 36 year-old farmer explained, “Sometimes I don’t even have enough money to pay for the blood tests. I have to go home and ask my 60–70 year-old parents for money. It’s a pretty bad feeling.”

Nearly all participants emphasized the importance of employment. About one-half of respondents (17/36, 14/19 men and 3/17 women), including most unemployed respondents and some part-time workers, revealed a powerful yearning for a job. Financial security, supporting themselves and their families, and a desire to be a “normal” member of society were the main reasons cited for wanting work. The men, in particular, agonized over the need for a secure income, while admitting that previous heroin use made finding employment difficult. Several respondents asserted that reliable employment was even more

critical than ART medications. In a male FGD, the group agreed that it was vital to help everyone "return to work in mainstream society," because, as a 46 year-old married man concluded, compared with ART medications, "Finding a job is more important."

Discussion

The main barriers to adherence that we identified were stigma; mental health difficulties, including depression, anxiety, and isolation; and economic worries. In addition, we found some salient gender differences in the experience of being HIV-positive and on ART.

Given previous studies in Africa and Asia that identified stigma as affecting ART patients (Kumarasamy et al., 2005; Weiser et al., 2003), we were not surprised to find stigma identified as a major issue in China. More remarkable was the multifaceted way that stigma was manifested, and how intertwined it was with other factors influencing adherence. Patients were stigmatized by society at large, at work, and by family members. Yet, fear of personal stigma was sometimes overshadowed by stigma directed at family members—i.e. secondary stigma. Moreover, worries about stigma were linked with patients' psychological distress and financial problems, including difficulties finding employment. Much of this stemmed from fear of detection created by the need to store and take pills regularly, whether at home, on the bus, at work, or while socializing. Notably, before patients began ART, their HIV status was relatively easy to keep secret. Afterward, dose-taking could threaten exposure and personal or family humiliation. One consequence was that some patients opted to delay or skip doses to avoid disclosing their infections, preferring 'saving face' over actions that might extend their lives.

Similarly striking was the way in which HIV stigma overlapped with and magnified the shame associated with heroin use. Particularly among men, this dual stigma exacerbated difficulties in finding employment close to home and the Dali clinic, creating additional barriers to treatment. This suggests that in communities where HIV and IDU coexist, programs aimed at mitigating HIV-related stigma will be only marginally effective at supporting adherence unless they address IDU-related stigma. Coupling HIV management with heroin rehabilitation or methadone treatment may substantially improve treatment for patients with a history of heroin use. In addition, official sanction, even encouragement, of employing workers with a history of heroin detoxification might help address one of the key challenges former users face in reintegrating into society as ART patients.

There were important similarities observed among female respondents, few of whom were IDUs. In contrast with the men, whose previous–and perhaps continued–heroin use and HIV status complicated efforts to find work, the women were more worried about losing current jobs from disclosure of their HIV status. This is understandable given that in urban and semi-urban areas like Dali, where the economy is relatively developed and families are small due to China's 'one child' policy, women typically work full-time in formal establishments—factories, offices, and stores—rather than in informal businesses or farming. Their livelihoods and social roles, as well as their families' financial well-being, usually depend on their employment. Here, the need to conceal one's HIV status was just as significant an adherence barrier for women as for men. For both men and women, fear of work-based stigma sometimes superseded the need to take their HIV medications.

While not specifically defined as such, secondary stigma has been noted elsewhere as a potential barrier to adherence (Kumarasamy et al., 2005). Our findings here are significant because they extend this issue to the China context and suggest a poignant irony. For male respondents, emotions expressed regarding family-related stigma were closely linked to feelings of guilt related to past, and perhaps continued heroin use, and a strong desire to

provide for their families. Yet, in trying to protect their families' social standing by concealing their HIV status, these men may skip ART doses, potentially compromising their treatment and, ultimately, their ability to stay alive and provide for their families.

We observed a high frequency of mental health issues, although we did not conduct formal depression assessments. These issues have been described in the literature from the developed world (Abel & Painter, 2003; Hill et al., 2003; Remien et al., 2003; Westerfelt, 2004; Wood et al., 2004), including among IDUs (Witteveen & van Ameijden, 2002), but little has been published from developing countries. However, several studies have reported on the connection between depression and HIV status in African and Asian populations (Kaharuza et al., 2006; Mills et al., 2006; Ross et al., 2007; Sahay et al., 2007; Simbayi et al., 2007) as well as in China (Jin et al., 2006). Our results extend this connection among developing country populations and add to the growing recognition of the importance and prevalence of mental health issues among HIV-positive Chinese individuals. The frequent mention of suicide as a potential recourse is notable, though perhaps not surprising given China's generally high rate of suicide (Phillips et al., 2002; J. Zhang et al., 2004). If such anxieties are widespread, we would argue for incorporating mental health screening into routine HIV care and treatment in China, and evaluating the effectiveness of such interventions as support groups, which have proven useful elsewhere (Lyttleton et al., 2007; Maher et al., 2007) but have not been widely adopted in China.

Other researchers have established a strong link between ART costs and adherence in developing countries (Crane et al., 2006; Kumarasamy et al., 2005; Weiser et al., 2003). Given that our respondents were receiving ART free of charge, we were surprised at their frequently expressed worries about treatment costs. Most fears focused on a possible policy change regarding free ART, which would leave them without a source of medications. Additional concerns related to the many uncovered facets of care that patients bore themselves, including test costs, lost work time, and travel costs, which for patients with limited independent resources represented a significant challenge. In this, they are like so many ART patients in other developing countries who need financial interventions to sustain ART over the long run.

Conclusions

In a population of Chinese HIV-positive patients with a high rate of IDU, primary and secondary stigma, mental health issues, and financial concerns all emerged as key challenges to ART adherence. These factors were often interrelated and reinforced each other in complex ways. Optimizing adherence may require that ART programs be linked to other services, including drug addiction treatment, mental health services, and vocational support. HIV care providers, and policy makers in China, should be aware of these important barriers to adherence. While provision of "wrap around" services involves cost and administrative effort, the long term socio-economic costs of increased HIV transmission and viral resistance that can result from suboptimal ART adherence may be far greater.

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References

Abel E, Painter L. Factors that influence adherence to HIV medications: perceptions of women and health care providers. Journal of the Association of Nurses in AIDS Care. 2003; 14(4):61–69. [PubMed: 12953613]

Bangsberg DR, Hecht FM, Charlebois ED, Zolopa AR, Holodniy M, Sheiner L, Bamberger JD, Chesney MA, Moss A. Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. Aids. 2000; 14(4):357–366. [PubMed: 10770537]

Chinese Center for Disease Control and Prevention. Aizibing fangzhi tiaoli ("Regulations on AIDS Prevention and Treatment"). Chinese Center for Disease Control and Prevention; 2006.

Crane JT, Kawuma A, Oyugi JH, Byakika JT, Moss A, Bourgois P, Bangsberg DR. The price of adherence: qualitative findings from HIV positive individuals purchasing fixed-dose combination generic HIV antiretroviral therapy in Kampala, Uganda. AIDS and Behavior. 2006; 10(4):437–442. [PubMed: 16636892]

Hill Z, Kendall C, Fernandez M. Patterns of adherence to antiretrovirals: why adherence has no simple measure. AIDS Patient Care and STDs. 2003; 17(10):519–525. [PubMed: 14588092]

Jin H, Hampton Atkinson J, Yu X, Heaton RK, Shi C, Marcotte TP, Young C, Sadek J, Wu Z, Grant I. Depression and suicidality in HIV/AIDS in China. Journal of Affective Disorders. 2006; 94(1–3): 269–275. [PubMed: 16764941]

Kaharuza FM, Bunnell R, Moss S, Purcell DW, Bikaako-Kajura W, Wamai N, Downing R, Solberg P, Coutinho A, Mermin J. Depression and CD4 cell count among persons with HIV infection in Uganda. AIDS and Behavior. 2006; 10(4 Suppl):S105–111. [PubMed: 16802195]

Kumarasamy N, Safren SA, Raminani SR, Pickard R, James R, Krishnan AKS, Solomon S, Mayer KH. Barriers and facilitators to antiretroviral medication among patients with HIV in Chennai, India: A qualitative study. AIDS Patient Care and STDs. 2005; 19(8):526–537. [PubMed: 16124847]

Lewis MP, Colbert A, Erlen A, Meyers M. A qualitative study of persons who are 100% adherent to antiretroviral therapy. AIDS Care. 2006; 18(2):140–148. [PubMed: 16338772]

Lyttleton C, Beesey A, Sitthikriengkrai M. Expanding community through ARV provision in Thailand. AIDS Care. 2007; 19(Suppl 1):S44–53. [PubMed: 17364387]

Maher L, Coupland H, Musson R. Scaling up HIV treatment, care and support for injecting drug users in Vietnam. Int J Drug Policy. 2007; 18(4):296–305. [PubMed: 17689378]

Malcolm SE, Ng JJ, Rosen RK, Stone VE. An examination of HIV/AIDS patients who have excellent adherence to HAART. AIDS Care. 2003; 15(2):251–261. [PubMed: 12856346]

Malta M, Petersen ML, Clair S, Freitas F, Bastos FI. Adherence to antiretroviral therapy: a qualitative study with physicians from Rio de Janeiro, Brazil. Cad Saude Publica. 2005; 21(5):1424–1432. [PubMed: 16158148]

Mills EJ, Nachega JB, Bangsberg DR, Singh S, Rachlis B, Wu P, Wilson K, Buchan I, Gill CJ, Cooper C. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. PLoS Medicine. 2006; 3(11):e438. [PubMed: 17121449]

Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, Wagener MM, Singh N. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. Annals of Internal Medicine. 2000; 133(1):21–30. [PubMed: 10877736]

Phillips MR, Li X, Zhang Y. Suicide rates in China, 1995–99. Lancet. 2002; 359(9309):835–840. [PubMed: 11897283]

Powell-Cope GM, White J, Henkelman EJ, Turner BJ. Qualitative and quantitative assessments of HAART adherence of substance-abusing women. AIDS Care. 2003; 15(2):239–249. [PubMed: 12856345]

Qiang, G. Speech by Executive Vice Minister of Health, Mr. Gao Qiang, at the HIV/AIDS High-level Meeting of the UN General Assembly, 2003. 2003. from http://www.china-un.org/eng/smhwj/2003/t29413.htm

Remien RH, Hirky AE, Johnson MO, Weinhardt LS, Whittier D, Le GM. Adherence to medication treatment: a qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities. AIDS and Behavior. 2003; 7(1):61–72. [PubMed: 14534391]

Ross R, Sawatphanit W, Suwansujarid T, Draucker CB. Life story of and depression in an HIV-positive pregnant Thai woman who was a former sex worker: case study. Archives of Psychiatric Nursing. 2007; 21(1):32–39. [PubMed: 17258107]

Sahay S, Phadke M, Brahme R, Paralikar V, Joshi V, Sane S, Risbud A, Mate S, Mehendale S. Correlates of anxiety and depression among HIV test-seekers at a Voluntary Counseling and Testing facility in Pune, India. Quality of Life Research. 2007; 16(1):41–52. [PubMed: 17091367]

Sankar A, Golin C, Simoni JM, Luborsky M, Pearson C. How Qualitative Methods Contribute to Understanding Combination Antiretroviral Therapy Adherence. Journal of Acquired Immune Deficiency Syndromes. 2006; 43:S54–S68. [PubMed: 17133205]

Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Social Sciences and Medicine. 2007; 64(9):1823–1831.

State Council Legislative Affairs Bureau. S. C. L. A. Bureau. Zhongguo renmin gongheguo fagui huibian (Collected Laws and Regulations of the PRC: January-December, 1987). Beijing: Legal Publishing House; 1988. Aizibing jiance guanli de ruogan guiding: 1987 nian 1 yue -12 yue (Some measures on the detection and control of AIDS); p. 953-958.

Vervoort S, Borleffs J, Hoepelman A, Grypdonck M. Adherence in Antiretroviral Therapy for HIV: a Review of Qualitative Studies. Aids. 2006; 21(3):271–281. [PubMed: 17255734]

Weiser S, Wolfe W, Bangsberg D, Thior I, Gilbert P, Makhema J, Kebaabetswe P, Dickenson D, Mompati K, Essex M, Marlink R. Barriers to Antiretroviral Adherence for Patients Living with HIV Infection and AIDS in Botswana. Journal of Acquired Immune Deficiency Syndromes. 2003; 34(3):281–288. [PubMed: 14600572]

Westerfelt A. A qualitative investigation of adherence issues for men who are HIV positive. Social Work. 2004; 49(2):231–239. [PubMed: 15124963]

Witteveen E, van Ameijden EJ. Drug users and HIV-combination therapy (HAART): factors which impede or facilitate adherence. Substance Use and Misuse. 2002; 37(14):1905–1925. [PubMed: 12511058]

Wood SA, Tobias C, McCree J. Medication adherence for HIV positive women caring for children: in their own words. AIDS Care. 2004; 16(7):909–913. [PubMed: 15385246]

World Health Organization. The World Health Report - Working Together for Health. Geneva: World Health Organization; 2006.

World Health Organization. Progress Report. World Health Organization; 2007. Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector.

Yunnan Center for Disease Control. The Yunnan HIV/AIDS Epidemic. Kunming; Yunnan Province, China: 2005.

Zhang, F.; Hsu, M.; Yu, L.; Wen, Y.; Two, JRZ. Initiation of the National ARV Therapy Program in Rural China. 2004.

Zhang J, Conwell Y, Zhou L, Jiang C. Culture, risk factors and suicide in rural China: a psychological autopsy case control study. Acta Psychiatrica Scandinavica. 2004; 110(6):430–437. [PubMed: 15521827]

Table 1

Characteristics of Respondents

Characteristic	In-depth interviews (IDIs) only (n=13)	Focus group discussions (FGDs) only (4 FGDs; n=18 respondents)	Both IDIs and FGDs (n=5)
Gender			
Male (n=19)	7	8	4
Female (n=17)	6	10	1

Sample characteristics of all respondents	Male (n=19)	Female (n=17)
	n	n
Mode of HIV transmission		
Injection drug use	19	2
Heterosexual sex	0	12
Unknown	0	3
ART initiation		
On ART	16	12
Not yet on ART	3	5
Age		
25 or below	1	5
26 to 30	5	6
31 to 35	5	3
36 to 40	5	1
41 or above	3	2
Education		
Elementary school (6 years)	7	4
Lower middle school (9 years)	10	12
Upper middle/technical school (10–12 years)	2	1
Occupation		
Unemployed	7	5
Farming	2	3
Unskilled/semi-skilled work[a]	6	5
Professional/managerial	1	2
Business owner	0	1
Retired	0	1
Volunteer	3	0
Monthly income		
0	10	7
1 to 500 yuan (up to $62.5)	3	5
501 to 1,000 yuan ($62.5–$125)	4	3
Over 1,000 yuan (Over $125)	1	1
N/A or variable	1	1

[a] Driver, tailor, construction worker, etc.

Table 2

Reported Challenges to Adherence

	All respondents (n=36)	Men (n=19)	Women (n=17)
Issues identified by respondents	**# who mentioned**	**# who mentioned**	**# who mentioned**
Stigma issues			
Fear of disclosure of HIV status	32	17	15
Fear of work-related stigma	18	9	9
Fear of stigma toward family	9	6	3
Psychological issues			
Anxiety or depression	27	12	15
Isolation, loneliness, feeling “not normal”	12	7	5
Thoughts of/attempts at suicide	7	3	4
Financial concerns			
ART-related worries	23	10	13
General lack of money	20	8	12
Need for a job	17	14	3
Forgetfulness			
Worries about forgetting	22	11	11
Being busy – it’s easy to forget	14	6	8
Regimen issues			
Strict timing and work demands	20	10	10
General requirements – timing, liquids, carrying pills around	17	9	8
Pill taste, size	8	3	5
Number of pills/different medications	5	2	
Side effects			
Worries about side effects	17	5	12
Has side effects now	7	4	3
Worries about looking bad from side effects	3	2	1
Drug or alcohol abuse			
Drinks/takes drugs or claims they affect adherence	7	6	1

Table 3

Typical Statements by Respondents By Theme

Stigma	Mental Health Issues	Financial Concerns
Fear of disclosure of HIV status: *I am worried that people will discriminate against me if they know about my illness. It would cause me a lot of pain and hurt.* – 36 year-old single man *Others look down on people who have AIDS….It's better not to be seen by anyone when I leave [the clinic] with the medications.* – 33 year-old divorced woman *If there's someone next to me sometimes I'm afraid to take the medication.* – 36 year-old married woman IDU-related stigma *From when I started taking the medicines until now…the people who know that I have this disease are people from this circle. Mainly they are drug users. They are people that I used to be good friends with. …they'll know that we have our own little family.* – 40 year-old married man *I was looking for a job and I felt extremely depressed because I was looked down upon at my job. …I can never understand society's attitude towards us.* – 36 year-old single man, on how he used heroin, after quitting, because of IDU-related stigma *For us (drug users), it is really difficult to find jobs locally. We have to go elsewhere. …But you have to return to be examined. Sometimes, the job requires you to be there and you can't come back. And you run out of the medication. This is really difficult. This is the biggest burden now.* – 36 year-old married man Work related stigma *I got sick and I made it public, and so now I'm discriminated against. It's impossible to work any longer.* – 43 year-old single woman, regarding why she left her job *I'm just saying this. I'll hide when I take the medications.* – 40 year-old married man, on taking ART at work Stigma directed at family members *She [respondent's 5 year-old daughter] asked, "what's HIV/AIDS?" Why don't the other children want to play with her? …We all said we don't know. We can only say she's just not very fortunate.* – 27 year-old married woman *I worry. I don't want anyone to know what medicines I'm taking. I even changed the bottles. …I still have a child. He's young. He still has to go to school. My biggest fear is doing something that would have a negative impact on my child's future.* – 31 year-old married man	Anxiety related to HIV status and ART *Sometimes I can't help thinking that I'm so unfortunate to have gotten this disease. I lost confidence and felt quite depressed.* – 34 year-old single woman *Initially, I couldn't accept it. I felt resistant. It felt like something was weighing down my heart. It was like the sky was dark.* – 36 year-old married man *Taking medications – just thinking about it is scary. Have to take it the rest of my life. I'm afraid to even imagine it.* – 28 year-old married woman. *Medicines make them [patients] feel disgusting. Having to take medicine constantly makes one feel depressed.* – 43 year-old single woman Social isolation *My father died and my mother is over 80 years old —she wouldn't be able to endure this shock! My brother and sister have their own burdens. …I have to endure this myself.* – 37 year-old single man *I just feel different from other normal people…. I have to take medicines everyday. Other people only have to take medicines when they're sick. I just feel that I'm a patient everyday.* – 23 year-old single woman *To be honest, all together about ten times [that I used heroin recently]. …I just wanted to get rid of this pain. …I would feel emotionally frustrated at times, when my family and friends did not understand me. I would feel very gloomy.* – 31 year-old single man Guilt related to previous IDU *I completely despaired. …I was disobedient previously, bringing too much trouble to my family. My family hated me. To be honest, I haven't made any contribution to my family. …Only made them worry. I also felt guilty. I was really scared at that time.* – 29 year-old single man *When I see similar situations I feel like crying. I feel pained inside. I gave it to my wife.* – 30 year-old married man, on seeing his wife weeping as she discussed her HIV infection Thoughts of suicide *I just think about that I am thirty years old, penniless, and still a heavy burden on my family. … I just thought it might be just better to die and save my family the trouble and burden.* – 29 year-old single man *I thought, "I don't want to live. Life has no meaning."* – 33 year-old divorced woman, on learning she was HIV-positive *…I'll be honest with you. At the time when I found out, I wanted to just die, so I used heroine again.* – 40 year-old married man	ART-related financial concerns *My family is poor. If it costs money and I can't afford it, then I'll have to stop getting the treatment.* – 36 year-old single man *Initially, when I found out I had the disease I was told I had to pay. I had no money. I could only wait to die.* – 30 year-old married man General lack of money/financial issues *They (ART medications) cause side effects. If I get side effects I have to spend my own money to go to the doctor. …My biggest problem now is that my parents are both in their sixties and seventies. …Their retirement wages together only add up to 500RMB [about $65] a month. It's used for 4 people.* – 42 year-old divorced man *We don't have much savings either. Before, whatever we had he used on drugs. Now that I'm sick life seems without hope.* – 34 year-old married woman *Patients like with us, our kids are still young. We have duties. First, we have to take care of the old. Second, we have to bring up the young. We have to earn money for our family. We have to take care of our household.* – 29 year-old single man Importance of employment *Only with a job can you survive in society and feed your family. We wish that we could live like everyone else–work, live life. We don't want anyone to arrange any special jobs for us.* – 32 year-old single man *If I could be healthier, my family won't have to worry about me so much, and maybe I can go out to do some work later.* – 34 year-old single woman *I would just like to get out of this difficult position step by step—to have some financial security. …I want to work…. I've thought about nothing else.* – 34 year-old married woman *We need to have jobs and an income or at least something to do on a daily basis. As long as we are busy, and our minds are occupied, there is no need for us to think about taking drugs.* – 36 year-old single man *…if you say that you used to use drugs… they'll reject you. They don't understand at all how much these drug users need the job. …it doesn't matter how much the compensation is, at the very least you'll be able to live. This is the most serious thing. You first have to have some security.* – 40 year-old married man

Stigma	Mental Health Issues	Financial Concerns
I'm afraid of being seen by acquaintances. I don't really mind for myself, I just don't want my parents to be embarrassed by me… – 29 year-old single man		