

# A Qualitative Study of HIV/AIDS Social Policy Implementation in Rural Central China: Recipient Perspectives

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## Abstract

Social assistance policy initiatives are crucial to improve the socio-economic conditions of people living with HIV/AIDS (PLWHA). Little is known about the implementation of HIV/AIDS social assistance policies in China, as well as the effects on recipients of the subsidies associated with these policies. This qualitative study examined HIV/AIDS social assistance policy implementation in rural Central China, a region heavily affected by HIV/AIDS. Using thematic analysis, we analyzed data from 15 interviews with PLWHA in Fuyang City, Anhui. The findings reveal the predominant role that social assistance policies played in mitigating the deleterious impacts of HIV/AIDS on PLWHA. These policies provided living subsidies and greatly reduced the economic burdens through medical and educational assistance plans. Our findings also highlight challenges with implementation of the policy, including access and coverage issues, inadequate subsidies, stigma, and issues related to recipients' privacy. This study provides recommendations to improve social assistance policies that mitigate the negative impacts of HIV/AIDS on vulnerable households.

**Keywords:** HIV/AIDS, social assistance policy, rural Central China, poverty, former commercial plasma donors

## 1. Introduction

According to the latest national data, by the end of September 2018, approximately 850,000 people were living with HIV, and 262,000 deaths due to AIDS had been reported in China (National Health Commission of China [NHC], 2018a). About 1.25 million people living with HIV were estimated by the end of 2018 (NHC, 2018a). This study examines the impacts of HIV/AIDS social assistance policies (medical and education assistance, as well as living subsidies implemented by government for people living with HIV/AIDS [PLWHA] and their family members) on the population of PLWHA who acquired HIV through former commercial plasma donations in rural Central China. According to Kaufman and Jing (2002), the early 1990s was the time when the HIV epidemic among former commercial plasma donors (FCPD) in China became exacerbated. At that time in China, the demand for blood and plasma products (which were used by pharmaceutical companies) coincided with its integration into the world economy (Chen, 2014). Poor farm workers were offered opportunities to make money by donating their blood and plasma at unsanitary paid blood and plasma donation centers across central rural China (Gittings, 2001; He, 2000; Kaufman & Jing, 2002; Volkow & del Rio, 2005). The problem occurred during the reinfusion process when donor's blood and plasma products came in contact with HIV (Gittings, 2001; Kaufman & Jing, 2002; Sullivan et al., 2010; Wu, Rou, & Detels, 2001). To speed up the process, donors were given blood from other donors with the same blood type and sent away without realization that the blood they were given was infected with HIV during the process (Chen, 2014). This scandal became widely known in 1990s, but no action was taken by the Chinese government until 2004, when the impacts of HIV and AIDS among this marginalized group could no longer be ignored (Copeman, 2009; Kaufman & Jing, 2002; Rosenthal, 2001).

### 1.1 HIV/AIDS Policy Developments in China

Over the past 30 years, China's HIV/AIDS policy has gone through different stages (Huang, 2006; Knutsen, 2012; Wu, Sullivan, Wang, Rotheram-Borus, & Detels, 2007; Xia, 2006; Xue, 2005; Heather, 2004). Knutsen (2012) highlights that between 2002 and 2003 the Chinese government had a radical policy shift by undertaking more proactive initiatives to address HIV/AIDS in the country. At the same time, governmental rhetoric surrounding

HIV/AIDS issues shifted from a disease-centered to a human-centered discourse (Xia, 2006). As a result, the government's policy focus on prevention and treatment was expanded to include aspects related to mitigation of socio-economic impacts of HIV/AIDS. An example of that is the "Four Frees and One Care" policy issued in 2003 by the State Council, which encompassed free treatment and voluntary counselling and testing, free treatment of HIV in the context of mother-to-child transmission, and free schooling for orphans whose parents died of AIDS. The policy included free antiretroviral medications for rural residents and economically marginalized urban residents, medication to HIV-positive pregnant women, HIV testing, and education for orphans of PLWHA, as well as financial care/support for households affected by HIV/AIDS.

According to existing research (Huang, 2006; Knutsen, 2012; Heather, 2004), there has been a fundamental change in China's HIV/AIDS policy since 2003. This shift in policy was partially facilitated by the SARS outbreak as well as a change in national leadership, which focused on addressing the needs of economically vulnerable PLWHA. Existing public health approaches were replaced by governmental approaches that focused on care, assistance, and support of PLWHA (Knutsen, 2012). The "Four Frees and One Care" symbolized this shift in the government's policy towards socio-economic issues of assistance and care.

Following these developments, in 2004, the State Council issued the Announcement on Strengthening the Work on AIDS Prevention and Control. The same year, the Ministry of Civil Affairs (MCA, a national department in charge of social assistance) issued the Announcement on the Provision of Social Assistance for PLWHA, their Family Members, and Orphans. Both announcements pointed out the significance of social assistance for PLWHA. The State Council's announcement highlighted that local jurisdictions had to: 1) incorporate PLWHA and their families with financial difficulties into social assistance programs, 2) provide free and compulsory education for orphans and children from poor households affected by HIV/AIDS (as well as tuition waivers, and fee waivers for preschool and high school education), and 3) provide employment supports for PLWHA. MCA's announcement required the local government to include HIV/AIDS-affected households with financial difficulties into the Minimum Living Standard Scheme (MLSS) and Assistance for Extremely Poor Households, and provide the medical assistance for poor PLWHA. Finally, in 2006, Regulations on AIDS Prevention and Control reframed the "Four Frees and One Care" policy in the form of law (Article 44 and Article 46).

### *1.2 HIV/AIDS Social Assistance Policies: Global Context*

Research conducted in Cambodia, India, Ethiopia and Kenya indicated how cash transfers allowed HIV/AIDS-affected families to secure basic subsistence, reduced food insecurity, enhanced social capital, as well as contributed to PLWHA's income-generating activities (Adato & Bassett, 2008; Farrington, Slater, & Holmes, 2004; Skovdal, Mwasijaji, Morrison, & Tomkins, 2008). Scholarship from South Africa showed the positive effects of social grants (particularly old age pensions and disability grants) in mitigating the economic impacts of HIV/AIDS and improving income distribution in households affected by the disease (Booyesen & Berg, 2005). In addition, cash transfers had a positive effect on human capital, in particular increasing enrollment and school attendance among children from HIV/AIDS-affected households in Sub-Saharan Africa (Adato & Bassett, 2008; Taaffe, Longosz, & Wilson, 2017). Research from Uganda and Kenya demonstrated how cash transfers can increase HIV testing and HIV service utilization (Emenyonu et al., 2010; Rebecca, 2008; Taaffe et al., 2017). Other research from South Africa also highlighted the positive effects of micro-finance programmes to help PLWHA cope with the effects of HIV/AIDS (Rural AIDS Development Action Research Program, 2002).

### *1.3 HIV/AIDS Social Assistance Policy Implementation in Rural China*

Provinces in rural Central China with high prevalence of FCPD (Henan, Anhui, Shanxi and Hubei) showed significant interest in HIV/AIDS policy initiatives. In order to actually implement the government's HIV/AIDS assistance social policy, these provinces in China issued their own regional protocols for the implementation of HIV/AIDS social policies, and provided additional assistance for PLWHA and households affected by the virus. Some provinces (Henan, Anhui, Hubei) implemented a series of measures, including providing free drugs for opportunistic infections (OI) and subsidizing a fixed percentage of hospitalization costs per year to mitigate the impact of HIV/AIDS on affected households (Moon et al., 2008).

Through HIV/AIDS social assistance policy implementation in China, rural PLWHA and their family members received targeted assistance through health departments (for issues related to treatment), and civil affairs department (for economic assistance, living subsidies, and education waivers). However, although HIV/AIDS social assistance policies have been implemented in these provinces, the quality and standards of these assistance programs varied significantly due to differential level of economic development and financial resources of local governments.

Importantly, although the focus of government shifted away from policies related to prevention and treatment towards policies that mitigate the socio-economic impacts associated with HIV/AIDS, policy research has not reflected this change. The policy research arena is primarily dominated by studies (Shen & Yu, 2005; Sun et al., 2010; Wang, 2007; Wu et al., 2007; Wu, Wang, Detels, & Rotheram-Borus, 2010; Xue, 2005) that analyze public health policies of the prevention and treatment of HIV/AIDS in China. Research has already documented the economic hardships that PLWHA in rural Central China face, which need to be addressed (Zhang & Souleymanov, 2017; Souleymanov & Zhang, 2018). Yet, scholars have neglected the importance of analyzing the impacts of social assistance policies that mitigate the deleterious socio-economic impacts of HIV/AIDS on vulnerable and marginalized communities. In addition, existing studies (Hao et al., 2014; Kaufman, Kleinman, & Saich, 2006; Pisani & Wu, 2016; Liang et al., 2005) did not examine the impacts of these policies from the recipients' perspectives.

To address this gap in knowledge, the current study tried to answer the following questions: 1) What are the effects of the implementation of HIV/AIDS social assistance policies on PLWHA in Central China? 2) What are the perspectives of PLWHA who are being targeted by these policies? 3) What challenges exist with implementing these policies? 4) How can these policies be improved? Answering these questions has the potential to strengthen the existing governmental responses to HIV/AIDS in China and to improve service and program delivery to marginalized communities.

## **2. Methodology**

### *2.1 Research Study Location and Context*

This project took place within the Jingjiu health station. Study participants were recruited from a community health center located in Fuyang Economic and Technological Development Zone (FETDZ) in Fuyang City, Anhui Province (Central China). The center provides health services to PLWHA, and FETDZ area has a high proportion of FCPD.

In 2004, there were 350 PLWHA and 150 deaths due to AIDS that were registered in FETDZ. The first case of HIV transmission in the area was traced back to FCPD population (Wu, Liu, & Detels, 1995). Anhui province was one of four provinces (besides Henan, Hubei and Shanxi) where over 90% of PLWHA were infected with HIV through FCPD transmission (Joint United Nations Programme on HIV/AIDS [UNAIDS] & World Health Organization [WHO], 2011).

Fuyang city was the first area in Anhui that implemented policies for medical and basic living assistance for PLWHA in March 2004. The main content of these policies includes financial assistance for living and educational subsidies for HIV treatments. Urban residents with financial difficulties and all rural PLWHA (and their family members) were the recipients of these subsidies. Specifically, the target population of these policies receive the following assistance and services: 1) a basic living subsidy from local assistance programs and the MLSS subsidy, 2) free compulsory education and tuition waivers for children affected by HIV/AIDS, 3) free antiretroviral (ARV) treatments, 4) 300 yuan medical subsidy for outpatient services per person each month, and 5) reimbursements for hospitalization expenses (which in 2004 was at 85%, and then increased to 95% in 2008).

### *2.2 Procedure*

Interviews took place between December 2013 and January 2014. Health center staff provided information about the study to all PLWHA at the center. The findings that were used for this analysis come from a larger study examining social and economic hardships of FCPD in China. Those PLWHA who expressed interest were invited by the research staff to take part in the project. In the end, 15 PLWHA were recruited to participate in the interviews. Informed consent was obtained from all respondents. Participants were allowed to withdraw from the study at any point without any penalty. The interview questionnaire included demographics, and questions related to HIV/AIDS social assistance policy impacts, and implementation challenges.

The face-to-face interviews lasted approximately one hour and participants were compensated 50 yuan for their time (equivalent to US\$8, an average day's salary for a worker in these regions). This study was approved by the Review Board of the School of Social Development and Public Policy, Beijing Normal University.

### *2.3 Study Participants*

Fifteen individuals were interviewed in this study. The detailed information about study participants is presented in Table 1 and Table 2.

Table 1. Characteristics of participants (n=15)

	N	%
<b>Gender</b>		
Male	9	60.0
Female	6	40.0
<b>Age</b>		
30-39	8	53.3
40-49	3	20.0
50-59	4	26.7
<b>Education Level</b>		
Illiterate	5	33.3
Primary school	4	26.7
Middle school	6	40.0
<b>Marital status</b>		
Married	14	93.3
Widowed	1	6.7
<b>Diagnosis status of spouse</b>		
HIV/AIDS	4	28.6
No HIV/AIDS	10	71.4
<b>Year of diagnosis</b>		
1995-2000	3	20.0
2001-2005	12	80.0
<b>Are you taking Antiretroviral (ART)?</b>		
Yes	12	80.0
No	3	20.0
<b>Year of received ART</b>		
1995-2000	2	16.7
2001-2005	8	66.7
2006-2010	2	16.7
<b>Labor impairment status</b>		
Fully loss	1	6.7
Partially loss	13	86.7
No effect	1	6.7

Table 2. Characteristics of study household with HIV/AIDS (n=15)

	N	%
<b>Family size</b>		
3	5	33.3
4	7	46.7
5	1	6.7
6	2	13.3
<b>Family structure</b>		
Parents(both HIV positive)+children	3	20.0
Father(HIV positive)+children	5	33.3
Mother(HIV positive)+children	5	33.3
Grandparent(both HIV positive)/ Grandpa(HIV positive)+children+ grandchildren	2	13.3
<b>Number of PLWHA in household</b>		
1	12	80.0
2	3	20.0
<b>Number of children (&lt;18) in household</b>		
1	6	50.0
2	6	50.0

#### 2.4 Data Analysis

The interviews were recorded, transcribed and then translated into Mandarin. Thematic analysis methodology (Braun & Clarke, 2019; Guest, MacQueen, & Namey, 2012) was used to analyze the data. In line with inductive analysis, the first step centered on drawing inferences and ideas from the data. This approach was grounded in the study's objective to examine the HIV/AIDS social assistance policy, how the policy was implemented, and the challenges associated with policy implementation from policy recipients' perspective. The second step included a comparative method where all data were grouped along similar concepts, and then these concepts were differentiated from one another. The third step included generating themes to describe and summarize the data in each category. To support data trustworthiness, validity and reliability, two coders who are native Chinese speakers read through all transcripts and notes. The coders met regularly to resolve coding discrepancies. As recommended by scholars, the interviews were not translated until the authors started drafting this manuscript (Larkin, Dierckx de Casterlé, & Schotsmans, 2007).

### 3. Results

#### 3.1 Description of Subsidy Allowance, Access, and Coverage

This section presents a general overview of the two subsidies received by PLWHA in Fuyang city as part of the national and local HIV/AIDS social assistance policies: the local living allowance and the MLSS subsidy. The two forms of basic living assistance originated from different jurisdictions, and came with different allowances and requirements that had to be satisfied in order to receive the subsidies. First, the local living allowance was provided through the local jurisdiction (FETDZ), and was 200 yuan per person per month. The eligibility for receiving this living allowance was: a) being a PLWHA, and b) having a local household registration (hukou). The local government continuously adjusted the subsidy amount. In the beginning, the allowance was 50 yuan per month for PLWHA who were not taking their HIV medications, and 100 yuan for PLWHA who took their medications. At the time of the interviews, the amount was 200 yuan for all PLWHA (without the distinction between those who did or did not take their medicines).

Secondly, the MLSS subsidy was implemented by the MCA and was delivered as part of the Rural Minimum Living Standard Scheme (RMLSS). The RMLSS is a mechanism through which a minimum income is guaranteed for economically destitute rural residents. While in theory the MLSS subsidy is based on financial eligibility, PLWHA are automatically incorporated into RMLSS without any tests of financial eligibility. Thus, the only eligibility requirement to receive this subsidy is being a PLWHA. The following quote exemplifies a common

response from study participants, and provides the needed context to understand the HIV/AIDS social assistance policy in China:

*The local living allowance is now 200 yuan per person per month, whether or not you are taking medications. Previously, people who didn't take their medications received 50 yuan per month, and those who took their medications and were receiving treatment were given 100 yuan per month. This allowance was provided every three months, and it was enough to cover basic living expenses. In addition, as long as you were infected with HIV, you could also receive 40 yuan as part of the MLSS subsidy per person per month (Kefu, male, 58).*

From respondent's description, we can see the significant change in policy implementation. The criterion (of taking the medicine) was removed, and the level of local living allowance also increased by 100%. Due to this change, the recipients were satisfied with the allowance and thought that it provided necessary financial support to sustain basic needs.

### 3.2 Challenges with the Amount, Access, Implementation, and Flexibility of Subsidies

Our findings indicated that while the policy allowed a large number of PLWHA to be enrolled into RMLSS, there were significant issues with the amount of the allowance, as well as access and implementation issues. For many respondents the amount provided by the subsidies was too low to improve their living conditions in a meaningful way, and they had to cope with this by resorting to other forms of employment. One respondent commented:

*My wife and I are both infected with HIV and we receive a subsidy of 480 yuan every month, which includes a 400-yuan basic living subsidy and 80 yuan RMLSS subsidy... The 40-yuan allowance is too low. Basically, you can't buy anything (Guofu, male, 38).*

Similarly another respondent highlighted:

*We (the interviewee and his wife) received the local living allowance and RMLSS subsidy. The RMLSS subsidy is too low. Previously, I was a bricklayer. I could not continue my previous work after my diagnosis, and began to raise pigs. The annual income I had through selling pigs was 4000-5000 yuan (Shoujun, male, 42).*

A common issue was brought up by another respondent who talked about differential access to RMLSS subsidies:

*Our son was not covered by the RMLSS. However, in some other places the children from HIV/AIDS affected households are receiving the RMLSS subsidy (Guofu, male, 38).*

The following quote exemplifies a common response from study participants in relation to subsidy access:

*The basic living subsidy was just increased from 100 yuan to 200 yuan last year. The local government released the subsidy promptly. The allowance of RMLSS subsidy was too low. It is only 40 yuan. Often it is not released on time (Huaqin, female, 39).*

In summary, some respondents spoke about how not all children were receiving the RMLSS subsidy in Anhui. Children affected by HIV/AIDS in different places across China had different access to the basic living subsidy. Different locations across China have adopted different policies and this affected the characteristics of the policy. Beyond pointing out the issues with the amount of the allowance and access issues, participants also brought up implementation issues. For example, the RMLSS subsidy was often not released to them on time, which consequently had an impact on the lives of marginalized PLWHA.

### 3.3 Benefits and Challenges of Receiving Medical Assistance

Medical assistance for PLWHA includes free ARV treatment and reimbursement for the treatment of OI. Participants' descriptions below highlight multiple positive effects of free antiretroviral (ARV) medication that they gained access to through their medical assistance package:

*Free medication works well. Without the medication, I would have died long ago. Now I am taking the medicine and I don't need to go to the hospital as much anymore (Lijun, male, 36).*

Another participant commented:

*ARV treatment is free and you don't have to pay. I usually came to the health station to take my medications every month. My level of CD4 (immunity cells) increased from 9 to 17 after taking the medication for two years. After that, I continued to take this medication and my CD4 level is now above 100. I am now taking the second-line medication (Yongzhen, female, 31).*

As recipients of the "Four Frees and One Care", respondents highlighted that they can now access free medication. The free ARV reduced the financial burden of medical expenses. In addition, poor PLWHA in China are also provided free access to second-line/alternative medication therapies in cases of drug resistance, or when first-line

medications caused side effects. The free medication played an important role in improving the quality of life of rural PLWHA.

Another important element of medical assistance for PLWHA is the reimbursement for OI treatments. Medical expenditures for OI treatments are a significant economic burden for PLWHA. The experiences of study participants show the important role that reimbursement policy has played in reducing the economic burden for households affected by HIV/AIDS. The following quote exemplifies a common response from study participants:

*My wife stayed in hospital for 15 days because of inflammation and we only paid about 200 yuan and 95% of the cost has been reimbursed. The previous reimbursement proportion was at 75%. (Shoujun male 42)*

One respondent commented:

*We have no ability to earn money, so without this policy (of free ARV and reimbursement of OI treatments), we would have no money to see a doctor or pay the hospital bill. The only thing you can do is to wait for death (Huqin, female, 39).*

Compared with the cost of ARV, the expenditure of OI treatment is a huge economic burden, especially for poor rural PLWHA at AIDS clinical stage. In particular, if a farmer is sick they cannot generate income. Under such circumstances, the role of the reimbursement policy is more significant in reducing the economic burden for such vulnerable PLWHA. Due to the reimbursement policy, as indicated by some respondents, they only needed to pay 5% (200 yuan) of hospitalization expenses. Without the reimbursement, they would have had to pay approximately 4000 yuan. In addition, the rate of reimbursement is constantly increasing. The description provided by the last respondent in this section further demonstrates the importance of this policy for households with limited incomes. Medical assistance in the form of reimbursements also increased PLWHA's access to basic healthcare, which consequently had a positive impact on their wellbeing and fundamentally improved their quality of life. Finally, delivery of medical assistance is one of the salient issues identified by PLWHA. According to "Four Freed and One Care" policy, PLWHA can only receive medical assistance at the locally designated hospitals, clinics, or community health stations. PLWHA must pay out of pocket if they chose to receive services elsewhere. The Jingjiu health station was designed for PLWHA in this study. The function of the health station includes providing free ARV treatment and other basic health services that meet the needs of PLWHA. However, receiving medical assistance services at designated health stations had unintended consequences – stigma, and lack of privacy:

*I go to the health station only when I need to get the free ARV medications. Sometimes when I was sick I didn't see the doctor at the health station. I just bought some medicine at the drugstore. I was afraid that other people would find out that I was infected with HIV. Only PLWHA receive services there (at the health centre). The more frequent you came here, the more people will see you here. My husband told me to hide when you see an acquaintance around. When my husband took the HIV test last time, he chose to come to the station at noon because most people had lunch at that time, so he could avoid others seeing him there (Yongzhen, female, 31).*

In order to ensure timely and effective health services for PLWHA, government designated specific hospitals, clinics, or community health stations. Faced with the environments characterized by social exclusion, this policy arrangement has produced an unintended effect on PLWHA. From the last respondent's description, we can see that she and her husband adopted coping strategies to deal with the stigma, privacy, and HIV disclosure because of this policy arrangement. The coping strategies included out-of-pocket payments for medicines and choosing a special time to receive health services at the health station.

### *3.4 Educational Assistance: Privacy Issues and the Role of Non-Governmental Organizations*

Beyond PLWHA themselves, recipients of HIV/AIDS social policies are also their family members, in particular their children. Reducing education expenditures for children from households affected by HIV/AIDS is at the core of the education assistance policy, which consists of free compulsory education, and an education waiver policy for higher education.

*I really can't afford the cost without this tuition assistance (Hongfang, female, 52).*

*We didn't need to pay the tuition fee. Education is free for children affected by HIV/AIDS. The only expense we had was paying for some school supplies (Wentao, male, 35).*

*It doesn't cost much to go to school. We just need to pay less than 100 yuan for my two grandchildren for school (Hongfang, female, 52).*

As the quotes suggest, many participants relied on the tuition assistance and the waivers. Education assistance reduced the economic burden of households affected by HIV/AIDS. As tuition for compulsory education is free, the only expense incurred by the households affected by HIV/AIDS were costs related to school supplies, which

are somewhat affordable to these households. More importantly, the implementation of this policy guarantees the right to education for children affected by AIDS, which significantly reduced a series of negative effects caused by the inability to receive education long term. In addition, it should be noted it was not only children of PLWHA who could enjoy the education assistance, but also the grandchildren of PLWHA were covered by this policy. The wide coverage of the education policy alleviated the economic burden of vulnerable grandparents raising grandchildren. One of the major implementation and access issues of education assistance waivers is the protection of privacy for potential waiver recipients, particularly during the waiver application process. Due to HIV/AIDS-related stigma, discrimination and exclusion, the protection of applicants' privacy is a significant concern. The following quote exemplifies this issue:

*When my daughter attended college, she wouldn't dare to apply for the tuition waiver because she was afraid that her teachers or classmates would find out that her mother was HIV-positive, and that she was from a family where people have HIV. In order to make some money while at college, she picked up a part-time job as an appliance salesperson (Huazhen, female, 49).*

Furthermore, another challenge in the implementation of the education assistance policy is how the issue of privacy was exacerbated due to the bureaucratic application process:

*First, the tuition waiver application for my son included the village committee providing me the evidence of my own illness. Then, I had to send this evidence to the Bureau of Education. The Bureau would then provide us with a note that we didn't need to pay the tuition due to family difficulty. The information about my illness was deliberately hidden from all communication to protect my privacy. I then gave the note to the teacher at the school, and eventually the tuition was free. Although the teacher at that school knew that I was infected with HIV, I didn't tell anyone about my status. However, somehow my son's classmates learned that I was infected with HIV (Xueqin, female, 34).*

Besides the education assistance policies implemented by the government, non-governmental organizations play an important role in alleviating the education expenditures of marginalized households affected by HIV. For example, the Chi Heng Foundation (one of the oldest running non-governmental organization that helps children from households impacted by HIV and AIDS in China) offers some financial help to children with at least one parent who is living with HIV or has died due to AIDS. At times this non-governmental organization filled in the coverage gaps in governmental policies. The following quote exemplifies this:

*The Foundation gave grants to children affected by HIV/AIDS. 100 yuan each semester for primary school, 200 yuan for middle school. The high school education is not included in the government's education assistance policy. The Foundation subsidized the tuition, especially non-compulsory education. The tuition of my son's high school education is 1400 yuan one year. The Foundation subsidized 1000 yuan and this helped me a lot (Huazhen, female, 49).*

Similarly, another participant commented:

*The Foundation partially covered the nursing school tuition of my eldest daughter. The Foundation reimbursed 50% of the tuition, which greatly reduced the economic burden on my household (Lijun, male, 36).*

#### **4. Discussion**

The study identified the impacts of three HIV/AIDS social policies implemented by central and local governments in China. These included basic living supports (the local living allowance and the MLSS subsidy), medical assistance (free medications and hospital treatment reimbursements), and education assistance for children of PLWHA. These assistance policies played an important role in reducing some of the economic burdens that were experienced by PLWHA and their families.

Although the impacts of these policies were positive, there were multiple challenges associated with the implementation of, access to, and coverage by these policies. First, our findings highlighted that while these policies allowed a large number of PLWHA to be enrolled into existing social assistance like RMLSS, there were significant issues with how much money was offered as part of the social assistance. Participants often spoke about the low allowance amount they received through the RMLSS, as well as how subsidies were withheld, or not released on time. The RMLSS is related to the level of local economic development of the area where the subsidy is provided, and varies considerably across China. Anhui (where this study was conducted) is a province in Central China, where economic development levels are low compared to other areas, like Eastern China. Therefore, the RMLSS allowance is only one fifth of the local living allowance. According to the Anhui Provincial People's Government (2014) data, in 2013 the per capita annual net income of farmers in Fuyang was 6,965 yuan, and the per capita annual consumption expenditure was 3,795 yuan. Hence, improvement in HIV/AIDS social assistance



policy has to be accompanied by structural socio-economic interventions.

In addition, our study indicated that not all children who come from households affected by HIV/AIDS in Anhui had access to the RMLSS subsidy. Interestingly, in neighboring province of Henan (another province with high number of FCPD) all members from households affected by HIV can qualify and receive the RMLSS subsidy, regardless of their HIV status (Research Group of Policy Analysis of China HIV/AIDS Prevention and Treatment, 2010). Policy makers must resolve this issue of differential access to subsidies in China by adopting a more streamlined subsidy process for PLWHA and their family members. The economic wellbeing of household affected by HIV also depends on the wellbeing of children, and policy makers should pay particular attention to this marginalized population.

Furthermore, as HIV is becoming a chronic and episodic condition (Deeks, Lewin, & Havlir, 2013; Mahungu, Rodger, & Johnson, 2009; McGrath et al., 2014), social assistance policies should reflect this shift by making the delivery and access to social assistance more flexible. Our findings indicated that because allowances and subsidies were extremely low, PLWHA had to undertake other forms of employment. This highlights the importance of creating more flexible employment support policies, programs, and other forms of employment accommodations for PLWHA with deteriorating health, so that they can ameliorate their own economic conditions by engaging in forms of employment that require less intense labour.

Our findings also indicated that medical assistance for PLWHA (in the form of free ARV treatments and hospital reimbursements) had positive impacts on their physical and mental well-being. The findings also showed that as recipients of the “Four Frees and One Care” poor PLWHA in China had access to second-line/alternative medication therapies in cases of drug resistance (or when first-line medications caused side effects). However, it is important to mention that not all PLWHA qualified for free ARV or OI treatment in China. According to the “Four Frees and One Care” policy, only rural or poor urban PLWHA without medical insurance qualified for free ARV and OI treatments. In addition, at the time of the interviews, there was another eligibility criterion for receiving free ARV, which included having CD4 cell count below 250. In 2016, as per WHO recommendations, National Health and Family Planning Commission of China (NHFPCC) (2016) finally removed the eligibility criterion of having a low CD4 cell count in order to receive free ARV.

Another important issue related to free ARV and OI treatments is that only PLWHA with local hukou could access medical assistance. This is a significant challenge for HIV/AIDS social assistance policy implementation, especially given that China has 244 million people that are characterized as a “floating population” (NHC, 2018b). Although this policy was carried out nation-wide, the criteria of hukou also made it impossible for PLWHA in a good physical state to get free medications while working outside their hometowns. A large number of migrants are also excluded from the HIV/AIDS medical assistance policy due to the hukou condition (Moon et al., 2008; Research Group of Policy Analysis of China HIV/AIDS Prevention and Treatment, 2010). The elimination of hukou restrictions for accessing free ARV and OI treatments is an essential step in HIV/AIDS prevention and care (UNAIDS and WHO, 2011).

Importantly, the study uncovered a significant issue in HIV/AIDS assistance policy implementation that had to do with privacy issues and HIV stigma. Participants in this study spoke about a lack of choice where they receive their medical care. According to “Four Frees and One Care” policy, PLWHA can only receive medical assistance at locally designated hospitals, clinics, or community health stations, and significant privacy issues are faced by PLWHA in small rural areas. Due to stigma and discrimination, some PLWHA may hesitate to go to these health stations to receive lifesaving treatments. A similar problem also happens when PLWHA need hospitalization and have to go to the locally designated hospital for PLWHA (i.e., 2nd People’s Hospital of Fuyang). The economic destitution of this population coupled with the fact that medical assistance can only be delivered at designated health stations, leaves PLWHA no choice but to engage with the available services. Policy makers should take these issues into account and consider designing and implementing privacy protection measures and protocols, as well as remove various types of discrimination that block PLWHA from the employment sector.

Findings also showed that children had to conceal their parents’ HIV status from others in education contexts due to stigma, discrimination and social exclusion. Some college students would not apply for the tuition waivers because they were afraid that their teachers or classmates would find out that their parents were HIV-positive. These findings highlight the deleterious effects of stigma and social exclusion towards children and family members from HIV-affected households in China (Sullivan et al., 2010; Wan, Hu, Guo & Arnade, 2009). Findings also showed that assistance policies significantly reduced education-related expenditures for children from households affected by HIV/AIDS. The typical practice for economically destitute households affected by HIV/AIDS is to withdraw their child from school (or let them drop out of school) in order to reduce education

expenditures. The education assistance that is currently being provided to PLWHA can prevent this from occurring, therefore mitigating the negative impacts of poverty on these communities. Similar to medical assistance, privacy issues exist when one applies for education assistance. These findings are consistent with the existing research (West & Wedgwood, 2006).

The findings from this study also underscore the need for HIV/AIDS social assistance policy initiatives that address the intersecting social and economic impacts of HIV/AIDS, such as stigma, poverty, unemployment and economic development. Thus, policy responses in China need to focus on initiatives that include continuing financial assistance to PLWHA, poor farming communities, and organizations that support these marginalized groups.

Although the implementation of HIV/AIDS social assistance policy has greatly reduced the economic burden of PLWHA, the policy still has a lot of room for improvement. These improvements must include: expanding policy coverage to enable more people in urgent need of medical services to enter the medical assistance; raising assistance subsidy levels to further improve the living standards of PLWHA; cancelling hukou restrictions, which will allow marginalized communities (i.e., migrants) to obtain free OI drugs at their place of residence; adhering to privacy measures as part of the policy implementation process (especially in the context of service delivery and assistance application procedures); and establishing partnerships between government and NGOs.

The findings from our study show the positive impacts of three HIV/AIDS social policies implemented by central and local governments in China. These findings also contribute to the wealth of knowledge on the effects of social assistance policy initiatives designed to improve the socio-economic conditions of PLWHA from countries other than China (Booyesen & Berg, 2005; Farrington et al., 2004; Skovdal, 2008).

This study has to be contextualized within its limitations. First, our recruitment was focused only on those PLWHA who were already linked to health services, and PLWHA who were not receiving services at the health center were therefore not included in this analysis. Second, this analysis included a relatively small sample size, thus results cannot be generalized to all rural PLWHA infected through FCPD. The findings from the interviews are primarily used to contextualize the policy environment, and provide the necessary nuance to this study of HIV/AIDS social assistance policy.

Despite limitations, this research builds on several strengths and provides the needed context of the impact of HIV/AIDS social policies on China's rural PLWHA infected through FCPD. The findings from this study may serve as a foundation for HIV/AIDS social policy initiatives focused on the improvement of the wellbeing of PLWHA in China.

## 5. Conclusion

This study demonstrated how HIV/AIDS social assistance policies played an important role in reducing the socio-economic burdens that were experienced by PLWHA and their families, as well as challenges associated with the implementation of these policies. The Government of China should take on a leadership role and engage national, provincial, and local governments in a process directed at a significant reform of HIV/AIDS-related social assistance policies and programs that deal with income support and benefits for PLWHA, as well as larger structural issues related to poverty, unemployment, and social stigma in rural Central China.

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## Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

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