

## Older Adults with HIV/AIDS in Rural China

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**Abstract:** Although the number of older people living with HIV/AIDS (PLWHA) has increased substantially, few studies have focused on older PLWHA in developing countries. Based on a sample of 866 rural PLWHA in Henan, Anhui and Yunnan provinces in China, this study compares the characteristics of PLWHA aged 50 or older (n=185) with younger PLWHA (n=681). Most of the older PLWHA were female (n=112), illiterate, married and at the clinical stage of HIV. Over 90% of older people with HIV/AIDS lived in Henan and Anhui provinces. The severe epidemic in Henan and Anhui provinces was caused by commercial blood and plasma donation. Older PLWHA were less educated, received less social support and were more likely to live alone than younger PLWHA. The results underline the importance of developing programs and policy initiatives targeted at older people infected with HIV/AIDS. The policy and program recommendations include using a gender sensitive strategy, designing specific AIDS education and prevention programs suitable for low-literacy older adults and social support interventions for older PLWHA.

**Keywords:** Asia, HIV/AIDS, human immunodeficiency virus infection/acquired immunodeficiency syndrome, older adults, older people, rural China.

### INTRODUCTION

It is commonly assumed that older adults are not a high risk group for HIV infection [1]. However, the prevalence and incidence of HIV among people age 50 and over are increasing [2]. There is a growing body of literature pertaining to HIV/AIDS among older adults in the United States and Europe but less is known about HIV/AIDS among older adults in the developing world. In this introduction, we examine HIV/AIDS among older adults. A review of the literature was conducted for two main purposes; 1) To identify some of the factors that contribute to the growing HIV/AIDS prevalence and incidence rates among older adults in general, drawing heavily from the U.S. and European literature, and 2) To summarize the limited literature focused on HIV/AIDS in China, with particular attention to what is known about older Chinese PLWHA.

### HIV AMONG OLDER ADULTS IN THE UNITED STATES AND EUROPE

In the United States approximately one-quarter of persons living with HIV/AIDS in 2005 were 50 years of age and older [3]. By 2012, one-third of those living with HIV in North America, Western and Central Europe were aged 50 or older [4]. Worldwide, there are an estimated 3.6 million older adults living with HIV [4]. The increasing prevalence of HIV/AIDS among older adults is largely due to the effectiveness and availability of Highly Active Antiretroviral Treatment (HAART) that has allowed for a

significant increase in the lifespan of individuals living with HIV/AIDS [5-7], and a lowering in the incidence of HIV among younger adults in Europe and North America [4].

In addition, there are also persistently high rates of *new* HIV infections in older adults [7]. Of particular concern, a recent British study indicates that older adults seek initial treatment later in the disease progression (as measured by CD4 cell counts below 350 cells/mm<sup>3</sup>) and have almost a threefold risk of mortality in comparison to younger adults with HIV [8]. A number of explanations both social and physiological have been posited for the increase in incidence in HIV infection among older adults. Research indicates that older persons have limited knowledge about HIV/AIDS [9], yet they are less likely to receive prevention education [10-12]. Older adults are engaging in more sexual activities than previous cohorts of older adults due to the availability of erectile-dysfunction drugs like Sildenafil and Tadalafil (brand names Viagra and Cialis) [13, 14]. However, condom use to prevent the transmission of HIV has been found to be low among older adults [14, 15]. Older women are thought to be especially vulnerable to HIV infections, due to specific physical changes associated with normal aging processes which increase susceptibility to the virus [12]. Research also indicates that intravenous drug use has become a pathway to new HIV infection among older adults [16].

Many older adults do not believe they are at high risk for contracting HIV [13] or AIDS [14], especially older women [17]. Symptoms of HIV/AIDS are often mistaken for age-related disorders [8, 16]. Consequently, often older adults are not screened for HIV/AIDS by their health care practitioners [8, 15] and do not seek out HIV testing [8, 18]. These factors may lead to an HIV diagnosis at a later stage in the disease course [8, 19].

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Among older adults with HIV/AIDS, there have been particularly large increases in the number of women, minorities and lower income groups infected [20]. Older adults with HIV/AIDS confront unique health challenges [21]. The combined effect of HIV/AIDS and the aging process may cause older adults to process and respond to antiretroviral drugs differently than younger adults with HIV/AIDS and may increase vulnerability to opportunistic infections and other diseases [2].

Research indicates that many older adults living with HIV/AIDS receive inadequate social support [7, 22], partially due to the double stigma of aging and living with HIV/AIDS [7].

Unfortunately, the research on HIV/AIDS among Chinese Americans, in general, and older Chinese Americans, in particular, is extremely limited. This lack of research may be due to the relative rarity of HIV/AIDS among this population. In 2009, only 1.1% of all persons living with HIV infection in the United States were of Asian origin (which includes Chinese, Japanese, Filipino, Korean, Vietnamese and several other ethnicities) [23].

### **HIV/AIDS IN CHINA**

The estimated prevalence of HIV/AIDS in the population is 0.06% [24]. In 2009, the number of HIV positive Chinese citizens and new infections was approximately 740,000 and 48,000 respectively [24].

Research shows that among adults in China, intravenous drug use and heterosexual sexual contact are the primary modes of infection [25]. Female sex workers, men who have sex with men and intravenous drug users are particularly vulnerable to infection [25]. Condom use has been found to be infrequent among some high risk populations such as clients of female sex workers [26]. Research shows that among adults in China, there is limited participation in voluntary HIV testing, particularly among adult women [27].

Due to the increasing availability of Highly Active Antiretroviral Treatment (HAART) in China, many younger and middle aged adults with HIV/AIDS live to age 50 and beyond. HIV/AIDS has shifted from an acute illness to a chronic disease. Among older adults in China the reported cases of HIV/AIDS have substantially increased. In 2006, older adults aged 50-64 represented 6.1% of all reported cases of HIV/AIDS, however, by 2009 this percentage almost doubled to 10.6% [24].

Despite the large increase in the number of older adults with HIV/AIDS in China, researchers have not paid enough attention to this population. The limited research on older people living with HIV/AIDS (PLWHA) has shown that plasma and blood donations during the 1990s were the main mode of infection of older adults in China. The commercial blood and plasma donations were disproportionately situated in rural areas, and the vast majority of older adults in China live in rural areas. Despite the significance of this group, little is known about the demographic profile and needs of rural elders with HIV/AIDS.

To enhance outreach, education and screening efforts, it is important to develop an understanding of the characteristics of older adults with HIV/AIDS in rural China. Using data from a large study conducted by the first and last

author in three provinces in 2006-2007, we develop a profile of older populations infected with HIV/AIDS in rural China. We also compared this group with younger HIV-positive rural Chinese.

## **METHODS**

### **Survey**

The data presented in this study are from a cross-sectional survey conducted in rural areas of three provinces (Yunnan, Henan and Anhui) from November 2006 to February 2007. These provinces have a high prevalence of HIV/AIDS. People Living with HIV/AIDS (PLWHA) who were over 18 years of age were eligible to participate in the study. Only one PLWHA was interviewed per household. The Institutional Review Board of Beijing Normal University approved the study protocol. More details about the survey are available elsewhere [28, 29].

The local Civil Affairs Department provides ongoing financial assistance to PLWHA. Individuals receiving Civil Affairs Funding for PLWHA were notified through the local Civil Affairs Department about the possibility of volunteering for this study. PLWHA who were interested in being interviewed were provided with information on how to directly contact study staff. Each interview took approximately one and a half hours and the respondents received RMB 20 (\$3 U.S.) in compensation for their participation.

Once PLWHA who were interested in being interviewed had contacted a member of the survey team, they were asked their preference for the time and location of the interview. The interviews were conducted in the location selected by the participant. Before starting the survey, informed consent was obtained from PLWHA who agreed to take part in the survey. Each participant was assured of confidentiality. Participants were aware they could withdraw from the survey at any time without penalty.

There were 185 PLWHA aged 50 or older and 681 younger PLWHA.

### **Statistical Analysis and Measures**

This study examined differences between younger (<50 years) and older (≥50 years) respondents with HIV/AIDS. Chi-square analysis was used to compare the two groups with respect to demographic, socio-demographic and health characteristics, social support and perception of the impact of HIV on their lives. The analysis was conducted using SPSS 11.5 software.

The following demographic variables were investigated: regional distribution (Henan, Anhui and Yunnan provinces), gender, education level (illiterate, completed primary school, middle school, and above middle school), marital status (married, widowed, and unmarried), the year of diagnosis and the extent to which social support was received from each of the following sources: parents, children and siblings. PLWHA were also categorized by clinical stage of the disease (respondents taking HAART were considered to have AIDS; otherwise respondents were considered to have HIV). HAART is available free of charge to all individuals with full-blown AIDS. Variables investigated included whether the PLWHA could take care of themselves

independently, employment status (currently employed versus not), whether medical care was received since diagnosis, respondent's perception that medical care has eased family burden (yes, partially, no) and that there has been a big impact of HIV/AIDS on household income and on children's schooling (none, a little, medium, a lot, huge).

## RESULTS

Of the 866 respondents, one fifth (21%,  $n=185$ ) were 50 years of age and over (See Table 1). Most of the older PLWHA were female ( $n=112$ ), illiterate, married and at the clinical stage of HIV.

There were regional differences by age group ( $p<0.001$ ). The majority of older respondents came from Henan. Only 7% came from Yunnan Province. In contrast, the population aged 49 and younger were evenly divided between the 3 provinces. Women make up a disproportionately high percentage (60%) of the older PLWHA. Among respondents aged 49 and younger, each gender was equally represented. There was a significant difference between older and younger populations with HIV/AIDS with regard to their education and marital status ( $p<0.001$  respectively). Older PLWHA had completed fewer years of school and were more likely to be widowed. Over half of older PLWHA were illiterate and one-quarter were widowed. For both younger and older people, the main reason for being widowed was that their spouse had died of AIDS. Older PLWHA are less likely to be in the labor force than younger people with HIV/AIDS ( $p<0.001$ ).

Over half of older adults infected with HIV/AIDS were diagnosed approximately four years before the 2006-2007 interview (i.e. in 2002- 2003) in comparison to one-third of the younger PLWHA. Older adults with HIV/AIDS were more likely to be in the AIDS stage of the disease ( $p<0.05$ ) and were more likely than younger people to need the assistance of others in their personal care ( $p<0.001$ ). There were significant differences in receiving medical treatment and medical care between the two groups ( $p<0.001$ ). The older population was more likely to receive treatment and to think the effects of medical care were more helpful.

As was shown in Table 2, younger PLWHA were more likely than older adults to receive support from their parents ( $p<0.001$ ) and siblings ( $p<0.05$ ). In contrast, the main source of social support for the older population infected with HIV/AIDS was their children ( $p<0.001$ ). Compared to younger PLWHA, a higher percentage of the older population reported that they had few close friends ( $p<0.05$ ), and/or were isolated from their family and were living alone ( $p<0.01$ ). Older PLWHA were also less likely than younger PLWHA to participate in any activities provided by organizations including religious organizations, non-governmental organizations or self-help groups (15% versus 28%;  $p<0.01$ ). Older respondents were less likely than younger PLWHA to report that the impact of HIV/AIDS on their household income ( $p<0.01$ ) or their children's schooling ( $p<0.01$ ) was huge.

## DISCUSSION

The majority of older PLWHA in our sample were infected through commercial blood and plasma donations.

Over half of older respondents were female and were illiterate. Our analysis shows that older PLWHA were more likely than younger PLWHA to live alone, to be isolated and to have few sources of social support.

In this study, most of the older PLWHA (over 90%) were living in Henan and Anhui provinces, while the percentage of older PLWHA in Yunnan province accounted for less than 10%. The uneven distribution of older adults with HIV/AIDS among the different provinces is closely related to the main transmission modes in each province (commercial blood and plasma donation in the former two provinces and injection drug use in Yunnan).

Generally, older people had few chances to receive formal education, especially in rural China. Four-fifth of the older PLWHA had less than a middle school education and half were illiterate. Our analysis shows that younger people were less likely to receive treatment and less likely to report that medical care greatly decreased the burden on their family. Research has shown older PLWHA to be more compliant with medication regimes than younger PLWHA [30]. This may reflect the fact that older adults were more likely to have full-blown AIDS than younger PLWHA (33% versus 24%). The impact of HIV/AIDS on household income and children's schooling among the younger age group was more pronounced than it was among older adults. Younger respondents are more likely to be in their prime earning years and to be the main wage earner in the household. PLWHA under the age of 50 are also more likely to have under-age dependents than older respondents. Thus, it is not surprising that the younger PLWHA were more likely to report a huge economic impact in comparison to the older cohort.

All respondents, both young and old, relied heavily on family members for social support. This result is similar to previous findings that older adults living with HIV/AIDS rely heavily on friends and family members to provide social support [7]. Younger people mainly received social support from their parents and siblings, while older people were more likely to be supported by their children. This pattern of intergenerational exchange is common in developing countries without well-established pension and social security programs. This tradition is deeply rooted in China's culture of filial piety [31]. HIV/AIDS undermines the traditional context of caregiving. The younger people who would normally be the main financial supporters of households have become the most affected group of PLWHA. Thus, the normal direction of intergenerational exchange support has been reversed. Facing the devastating impact of HIV/AIDS on younger people, many older parents have had to provide shelter and financial support to their adult children with HIV/AIDS and to their grandchildren.

Older people with HIV/AIDS had fewer friends than younger PLWHA. In addition, older people were more likely to live alone than younger people due to the death of spouses and other loved ones. Compared to younger people with HIV/AIDS, older people were less likely to be involved in organized activities. Previous North American research suggests older persons with HIV/AIDS are more likely than younger PLWHA to become socially isolated themselves [32]. We found, congruent with existing U.S. research, that

**Table 1. Demographic and Health Characteristics. Older ( $\geq 50$  years) and Younger ( $< 50$  Years) People Living with HIV/AIDS in Rural China**

	Below 50 (%) (n=681)	50 and Older (%) (n=185)	p Value
Gender			<0.01
Male	50.2	39.5	
Female	49.8	60.5	
Education Level			<0.001
Illiterate	27.4	54.1	
Primary school	53.1	27.0	
Middle school	18.1	16.2	
Above middle school	1.5	2.7	
Marital status			<0.001
Married	70.8	73.5	
Widowed	17.6	24.9	
Unmarried	11.6	1.6	
Reason of being widowed			0.23
Died of AIDS	84.2	76.1	
Other	15.8	23.9	
Current Employment Status			<0.001
Working	80.0	61.6	
Not working	20.0	38.4	
Living arrangement in the last year			<0.01
Living with the family	97.7	95.6	
Living alone, isolated from the family	0.9	4.4	
Living with classmates, colleagues and friends	0.9	0.0	
Moving a lot, living with strangers most of the time	0.5	0.0	
Province			<0.001
Yunnan	34.5%	7.6%	
Henan	34.4%	53.5%	
Anhui	31.1%	38.9%	
Year of diagnosis			<0.001
Before 1994	2.3	0.0	
1994-1999	10.6	7.0	
2000-2001	8.0	13.1	
2002-2003	34.8	53.3	
2004-2006	44.2	26.6	
Clinical stage of disease			<0.05
HIV	75.6	67.0	
AIDS	24.4	33.0	
Can you take care of yourself?			<0.001
Can't	0.3	0.5	
Partially can	1.3	7.6	
Fully can	98.4	91.9	
Have you received any treatment after diagnosis?			<0.001
Yes	65.7	83.2	
No	34.3	16.8	
After receiving medical care, do you feel the family's burden have been eased?			<0.001
No	2.3	1.6	
Yes, to some degree	23.0	21.7	
Yes, greatly	43.4	67.4	

**Table 2. Social Support and Perception of HIV Impact Comparing Older ( $\geq 50$  Years) and Younger ( $< 50$  Years) People Living with HIV/AIDS in Rural China**

	Below 50 (%) (n=681)	50 and older (%) (n=185)	p Value
Support from parents			<0.001
None	13.1	25.8	
Little	13.1	31.8	
Average	10.4	16.7	
Fully	63.6	25.8	
Support from children			<0.001
None	16.8	3.9	
Little	18.5	7.9	
Average	11.3	24.7	
Fully	53.4	63.5	
Support from siblings			<0.05
None	5.2	8.4	
Little	13.5	19.3	
Average	19.6	22.9	
Fully	61.7	49.4	
How many close friends do you have?			<0.05
None	42.9	54.9	
1-2	16.5	13.0	
3-5	22.7	19.0	
6 or more than 6	17.9	13.0	
How often do you join activities organized by organizations (such as religious organization, NGO, self-help group)?			<0.01
Never	71.6	84.8	
Occasionally	10.1	3.8	
Often	15.6	9.8	
Frequently and with great enthusiasm	2.8	1.6	
The level of impact of HIV/AIDS on household income			<0.01
None	9.0	5.9	
A little	11.5	17.8	
Medium	6.0	9.7	
A lot	41.0	43.8	
Huge	32.4	22.7	
The level of impact of HIV/AIDS on children's schooling			<0.001
None	63.1	89.3	
A little	11.0	2.7	
Medium	2.7	1.8	
A lot	19.5	6.3	
Huge	3.7	0.0	

older people with HIV/AIDS tend to receive less social support than younger PLWHA [33]. They are also more likely to be isolated by AIDS stigma and ageism [7]. Thus, the older population with HIV/AIDS is more likely than younger PLWHA to become socially withdrawn due to a lack of strong networks. Furthermore, older adults may also need to cope with life transitions, such as the death of a spouse [34].

Three-fifth of older people with HIV/AIDS in this study were female. Disproportionate representation of older women among older persons with HIV/AIDS also has been noted elsewhere [12]. The sex ratio in our Chinese sample may result from two reasons: greater female longevity and gender differences in rural to urban migration. Women are more likely to survive into old age than men. Among those aged 65 and older in China, the ratio of men to women is

0.92 [35]. However, the ratio of older men to women in our study represents an even larger discrepancy. It has been common for the past two decades for rural men to move to the cities in search of work, leaving the women and children in their rural communities. For example, a 1999 study of Anhui and Sichuan province showed that rural to urban migrants were 67% male [36]. The commercial blood contamination occurred in the rural villages, which were probably disproportionately female.

### IMPLICATIONS FOR PRACTICE AND POLICY

This study has important implications for social service program development and policy initiatives targeted at older PLWHA in rural China. The fact that one in five of those with HIV/AIDS in this study was aged 50 and over underlines the magnitude of this “hidden population” [37] and the importance of HIV/AIDS health professionals and service providers tailoring programs to serve this cohort. Furthermore, with women representing the majority of older PLWHA in our analysis, there is a need to incorporate a gender sensitive strategy into rural AIDS programs and policy initiatives. The variation across provinces in the age distribution of PLWHA highlights the inappropriateness of a centralized “one size fits all” program to provide services to the HIV infected population and to prevent further spread of HIV prevention.

In several of our survey locations, non-governmental organizations (NGOs) had organized self-help groups with the aim of providing AIDS information and assistance for people infected with HIV/AIDS. Our findings suggest that 85% of older adults do not participate in any activities established by organizations such as religious groups, NGO, and/or self-help group, making it clear that this strategy for disseminating information is not sufficient for the older age cohort. With such low rates of group attendance among older adults, other one-on-one forms of service provision and information sharing are preferable.

Low literacy levels may contribute to a lack of knowledge on how to prevent HIV/AIDS infection. Flyers using clear visual images rather than words to explain ways to minimize the spread of HIV have been created for illiterate populations in other countries [38]. It is possible that flyers could be developed to inform illiterate rural individuals in China, whether or not they are infected with HIV/AIDS.

The combination of low literacy rates and extensive use of Highly Active Antiretroviral Treatment (HAART) in both younger and older rural Chinese PLWHA presents important issues for health care providers. The most effective use of HAART requires greater than 95% compliance with the complex and demanding drug regime. Traditional word-based patient information leaflets are of minimal assistance to individuals with low literacy. Chinese health care providers may benefit from the lessons learned from South African programs using creative pictograph-based leaflets to better inform illiterate patients of negative side effects of HAART such as vomiting, peripheral neuropathy, fever and dizziness and to clarify information on medication usage (frequency of use, storage of medicine out of the sun, etc.) [39]. Within China, similar pictograms refined through

cultural consultation could potentially help to improve comprehension and improve recall of important medication related information among HAART patients.

Social isolation was a substantial problem for many of the older PLWHA. Health professionals and social service workers should routinely ask clients with HIV/AIDS about the social support they are receiving and isolation issues they face [40]. For isolated seniors, referrals to resources in the community including recreational older adult groups as well as HIV-specific older adult support groups may be helpful. Home based health care organizations can provide assistance through volunteers or trained health professionals. When individual providers consistently serve particular patients, the opportunity arises for the development of an ongoing supportive relationship which can decrease the social isolation of the client.

### CONCLUSIONS

This study is a preliminary exploration of the difference between older and younger populations with HIV/AIDS in rural China. In order to develop a complete picture of older PLWHA in China, more research attention should be directed to urban older adults infected with HIV/AIDS due to the large differences between urban and rural areas in China. In addition, gender perspectives should also be incorporated into future research due to the disproportionately high percentage of older women who have HIV/AIDS.

There are several limitations in this study. First, in order to get enough respondents, our sample was drawn from villages with high HIV/AIDS prevalence rates. Second, there was a self-selection effect such that only those interested in participating contacted the interviewers in order to be in the study. Therefore, results of this study cannot be generalized. Thirdly, our data set is cross-sectional. Longitudinal data could profile how people’s situations changes as they age with HIV/AIDS and if the needs of those who acquire HIV/AIDS later in life differ from their peers who acquire the disease at a younger age.

Despite these limitations, our study provides the largest investigation, to date, examining the characteristics of older PLWHA in rural China. The findings lay a solid foundation for designing effective programs to service the older PLWHA population in rural China.

### CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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