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A Comparative Study of the Barriers to HIV Self-Management Among Myanmar Migrant and Han Chinese Women in Yunnan, China

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**A Comparative Study of the Barriers to HIV Self-Management
Among Myanmar Migrant and Han Chinese Women in Yunnan, China**

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ABSTRACT

HIV has transitioned from high-risk populations to the general population through sexual transmission – now the primary mode of transmission in China – and is currently the biggest public health crisis in China. Those who are not directly involved with commercial sex work (CSW) or intravenous drug use (IDU) are now vulnerable to contraction. Han Chinese women, especially young women, are generally more vulnerable to transmission than their male counterparts, both physically and socially, and the virus affects their lives more deeply. Myanmar migrant women are even more vulnerable, as their migrant status leaves them without support structures or protections for their human rights in both their native countries and in China. The aim of this study was to examine the barriers to HIV self-management for these two populations of women living with HIV (WLHIV) in Yunnan and analyze the trends that hinder their ability to manage their disease. The term ‘barriers to health care’ refers to the political socio-economic factors that prevent one to access suitable health care. Likewise, according to the US Centers for Disease Control and Prevention Website, ‘self-management’ can be defined as the management of a chronic condition in order to live life to the fullest. To achieve this aim, fifteen WLHIV (eight Myanmar migrant and seven Han Chinese women) and three healthcare providers were participated in semi structured in-depth interviews in three cities in Yunnan province about the lives of WLHIV, how WLHIV access care, and the HIV/AIDS epidemic in general. Facilitators of HIV self-management include permanent resident status, family support after disclosure, learning to live with HIV, and antiretroviral therapy adherence. Barriers to HIV self-management include lack of family support system, stigma, discriminatory hiring policy and practices, physical fatigue, and financial difficulty.

Key words: HIV/AIDS Demography; Global Health; Gender Studies

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Figures and Tables

Table 1. Demographic characteristics WLHIV participants

Abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
CSW	Commercial sex worker
HIV	Human immunodeficiency virus
IDU	Intravenous drug use/user
MSM	Men who have sex with men
NGO	Non-governmental organization
NHFPC	National Institute and Family Planning Commission of the People's Republic of China
PLHIV	People living with HIV
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary counseling and testing
WLHIV	Women living with HIV

Introduction

Global Overview of HIV/AIDS

Human immunodeficiency virus (HIV), the virus that causes acquired immunodeficiency syndrome (AIDS), is currently one of the world's most pressing health and developmental concerns (M.-B. Huang et al., 2016). Since the first cases of HIV were reported in 1981, the epidemic has grown to affect approximately 36.7 million people today – accounting for 0.8% of the world's population – and has taken tens of millions of lives. One of the reasons why the epidemic was able to grow to such proportions is because of globalization and urbanization (Sutherland, 2011). Another contributing factor to its rapid global spread of roughly 5000 new infections per day (UNAIDS, 2016) is because that people who are affected by or at risk of contracting HIV often face difficulties in accessing prevention, care, and treatment (Henry J. Kaiser Family Foundation, 2017).

HIV/AIDS in China

Recent estimates show that there are approximately 660,000 people living with HIV, and 490,000 people living with HIV on treatment (UNAIDS, 2017). Though the national prevalence is 0.037% (National Health and Family Planning Commission of the People's Republic of China, 2015) – relatively low when compared to the worldwide prevalence of 0.8% (UNAIDS, 2016) – there are regions and particular high-risk groups where the HIV incidence rates are higher. The epidemic is especially severe in twelve regions in China – including Yunnan, Guangxi, Sichuan, Henan, and Guangdong – which altogether represent 84.3% of the nation's total cases (M.-B. Huang et al., 2016). Yunnan was the first province to report an HIV outbreak and has one of the HIV highest incidence rates in mainland China (Xiao, Kristensen, Sun, Lu, & Vermund, 2007). Commercial sex workers (CSW), men who have sex with men (MSM), and intravenous drug users (IDU) constitute the China's high-risk

populations with an HIV prevalence of 0.22%, 7.7%, and 6%, respectively (National Health and Family Planning Commission of the People's Republic of China, 2015). Other at-risk groups include migrant workers, plasma donors, and the low-risk sex partners of aforementioned groups (Jia et al., 2010). Active testing and targeted prevention strategies are key approaches being used to slow the transmission rate among high-risk groups, however high levels of stigma and discrimination in Chinese society must continue to be addressed in order to truly address the epidemic in its entirety.

History of HIV/AIDS in China

China has had a complicated and controversial relationship with HIV/AIDS since a tourist died in Beijing of AIDS-related complications in 1985. At the time, HIV was dismissed as a foreign disease that could be halted if China only monitored its entry from abroad. Since 1985, however, the HIV/AIDS epidemic has grown to touch hundreds of thousands of people across 31 provinces, autonomous regions, and municipalities.

The first phase of the HIV epidemic in China was roughly from 1989 to mid-1990s, primarily affecting Jingpo and Dai minority IDUs in the Yunnan Province by the Myanmar border (Xiao et al., 2007). The 1979 “Reform and Opening” policy helped to open China’s formerly tightly controlled borders to trade with neighboring countries. Among the products traded across the southern border were opiates and methamphetamines, which entered Yunnan through the “Golden Triangle” drug trafficking routes. The “Golden Triangle”, which borders Yunnan and includes Myanmar, Laos, and Vietnam, is one of the largest drug production and distribution centers in the world (Qian, H Qian, Vermund, & Wang, 2006). Close proximity to the “Golden Triangle” in conjunction with an increase in disposable income and lack of education on the risks of drug use resulted in a rise in IDU. Opium smoking had been a practice of certain minority cultures in Yunnan through history, however

when refined heroin became introduced in Yunnan, IDU became part of the culture. The sharing of syringes, or ‘sharing the happy’ became a demonstration of friendship, especially within minority groups (Duo, 2017; Pisani & Zhang, 2017). As HIV can be transmitted through the sharing of syringes, rinse water, or other objects used to prepare drugs for injection (US Centers for Disease Control and Prevention (CDC), 2017). HIV spread rapidly throughout Yunnan, to neighboring regions such as Guangxi and beyond.

The second major phase of the epidemic was focused in eastern and central China in the mid-1990s among blood and plasma donors and recipients. Following the national ban on imported blood products enacted in the fall of 1985, thousands of plasma collection sites were established across the country to fill the demand. Many of the sites were illegal and were located in impoverished and rural areas with limited law enforcement, where people were eager to sell their plasma to supplement their modest incomes. Collection practices were often unsafe, and this widespread negligence resulted in the transmission of HIV unbeknownst to thousands of donors and recipients (UN Theme Group on HIV/AIDS in China, 2002). The China Ministry of Health estimated in 2006 that former commercial plasma donors and recipients accounted for approximately 10% of infections in 2005, which led to a striking increase in the spread of HIV in the years following the crisis (China Ministry of Health, People's Republic of China, Joint United Nations Programme on HIV/AIDS, & World Health Organization, 2006). The Chinese government attempted to conceal its complicity in the plasma trade and limit speech by barring charity groups from Henan province (where unsafe plasma collection and transfusion practices were particularly dire), firing journalists who had reported on the epidemic there, and suing health officials investigating the issue (Volodzko, 2016).

The third phase is currently in motion across all provinces in China, where the dominant route for HIV infection is sexual transmission, affecting young people and MSM

especially forcefully. According to the 2015 China AIDS response progress report by the NHFPC, the percentage of sexually transmitted cases among the total number HIV cases reported increased from 33.1% in 2006 to 92.2% in 2014, indicating a greater need to increase outreach and services to the general population. Additionally, in recent years, the rate of new HIV infections among young people aged 15 to 24 has grown approximately 35% per year such that in 2015, people in this age group represented 14.7% of new reported HIV infections. This growth can be explained in part by the increasingly liberal attitudes toward sex and the lack of sexual health education (Griffiths, Fang, & Wang, 2016). Today, more and more young people are engaging in premarital sex, with 60% of Chinese individuals having had sex between the ages of 19 and 25 years old. Moreover, sexual education isn't taught in most schools, and students must rely on other sources, such as foreign porn films to learn (often misleading information) about sex, as the details of sex are not discussed with family members (Abkowitz & Xin, 2015). Another cause for concern has been the recent rise in sexual transmission between MSM, from a rate of 2.5% in 2006 to 25.8% in 2014, according to the NHFPC (2015). Though homosexuality was legalized in 1997, being gay is a stigmatized identity and men are still expected to marry and have a family. Most gay men comply to save face, but also often conduct homosexual relationships on the side. As is the case in other countries, social stigma surrounding homosexuality in China has prevented many closeted MSM from seeking HIV and STD testing services and ART for fear of being exposed (Volodzko, 2016). This stigma also puts their wives and other sexual partners who would ordinarily be low-risk in a more vulnerable position for contracting HIV.

Current Healthcare Policy in China

After the establishment of the People's Republic, healthcare became universal for all Chinese citizens. The over 90% of rural residents in China who had previously been lacking in healthcare compared to their urban counterparts finally became covered with the 'barefoot

doctor' system. However, this coverage ended at the end of the Cultural Revolution, and though there continued to be universal healthcare where typical Chinese resident health insurance subsidizes 70% of medical costs, but can cover up to 90% of medical costs if the resident falls below the poverty line (M.D. C, 2017), disparities in health care between citizens in urban and rural areas have emerged once more.

Finally income is a large predictor of health quality. In the past 15 years, there have been inequalities of urban incomes of up to 3.21 times that of rural incomes. This figure is especially concerning, as also income inequalities in China today have legitimate implications for healthcare resource availability of the HIV/AIDS epidemic and public health (Sutherland, 2011).

HIV/AIDS Policy and Prevention Efforts

In the past decade, the Chinese central government has made a commitment to this public health issue, dedicating its efforts to the creation and implementation of evidence-based HIV/AIDS policies. 2003 was a landmark year in HIV/AIDS healthcare policy, where President Hu Jintao's administration presented multiple initiatives to curb the rate of transmission and assist PLHIV. One initiative was the China Comprehensive AIDS response (China CARES) plan with the goal of providing care and support for PLHIV in 127 high-prevalence counties across the country. Another substantial initiative was the "Four Free and One Care" policy that provided free ART to AIDS patients who were rural residents or people without insurance living in urban area, free voluntary counseling and testing, free ART to HIV-infected pregnant women to prevent mother-to-child transmission, and HIV testing of newborn babies, free schooling to children orphaned by AIDS, and care and economic assistance to the households of PLHIV. The third important initiative introduced by the Hu administration was the formation of the State Council AIDS Working Committee, which was responsible for the development of a comprehensive policy framework, and the

creation of new policies supported by expanded budgets (National Health and Family Planning Commission of the People's Republic of China, 2015).

According to the 2015 AIDS Response Progress Report by the NHFPC, there are four main prevention intervention goals being undertaken to reduce the transmission of HIV: preventing sexual transmission, preventing transmission through drug abuse, preventing mother-to-child transmission (PMTCT), and preventing infection through blood transfusion. Preventing sexual transmission is key to slowing the spread of HIV in the general population, and is being undertaken with relative success through the widespread promotion of condom use, AIDS testing and counseling, STD services, and peer education and outreach intervention for CSW. For example, efforts to reduce transmission with ART for the infected spouse, condom promotion, and regular testing of the uninfected spouse within serodiscordant couples has reduced the rate of new infection by 76% from 2009 to 2014. Secondly, the resolution to prevent transmission through drug abuse has been undertaken with relative success through the establishment of 814 needle exchange sites and 767 methadone maintenance clinics across the country, serving 56,000 IDUs across 14 provinces and 184,000 IDUs across 28 provinces, respectively, in 2014. Thirdly, PMTCT is being tackled through a 2015 increase in funding of 440 million RMB to total 1.41 billion RMB towards the full coverage of PMTCT of AIDS, syphilis, and hepatitis B through scaling up of services, availability of ART, and antenatal service awareness-raising, as work in this area has proved to be successful with a demonstrated drop in child HIV infections from 6.7% in 2013 to 6.1% in 2014. Lastly, the push to prevent infection through blood transfusion has been appropriated 1 billion RMB by the national treasury to upgrade the nucleic acid test for more thorough testing of blood products at collection stations (National Health and Family Planning Commission of the People's Republic of China, 2015).

In an attempt to combat the rise of HIV cases reported among individuals between the ages of 15 and 24, the central government has also made sexual education of the younger generation a priority. In late 2015, the National Health and Family Planning Commission and the Ministry of Education announced in a circular that middle school and high school student would henceforth be required to attend six and four hours of HIV/AIDS prevention classes, respectively, and that “provinces should combine health education on HIV/AIDS prevention with sex health education...with focuses on sexual morality and responsibility, prevention, and rejecting unsafe sex”. Furthermore, the circular recognizes that “health education on preventing HIV/AIDS is insufficient in some schools; students are not fully aware of self-protection”, so schools should take it upon themselves to provide information to students about HIV counseling and testing sites (Abkowitz & Xin, 2015).

Some of the major professional and research institutions that are currently actively involved in the AIDS response are the China Preventative Medicine Association (CPMA), the China Association of STD and AIDS Prevention and Control, the Chinese Foundation for Prevention of STD and AIDS and China Red Ribbon Foundation (NHFPC, 2015). In addition to government-led programs, healthcare NGOS are on the ground working on HIV/AIDS response work specifically in Yunnan. In 2014, the Yunnan government designated 5 million RMB to fund 77 different social and community organizations in their HIV/AIDS response work (NHFPC, 2015). These organizations have tailored to support different groups of PLHIV in managing various aspects of their conditions from symptom management to social stigma. For example, the Sunshine Homeland Project peer group serves IDUs and CSWs, the Rainbow Sky Work Team peer group supports MSM, and Burma Women’s Union aids migrant women CSW from Myanmar.

Barriers to HIV/AIDS Prevention Efforts

HIV/AIDS prevention policy has been sweeping and relatively successful. For instance, the high cost of testing and ART were addressed in 2003 when HIV testing become available and free for the lower-income individuals, and later ART become free under the “Four Free and One Care” policy. Unfortunately, efforts to prevent the growth of the epidemic are continually undermined by barriers which include stigma at various levels and inconsistent application of policy.

Though voluntary counseling and testing is available through the “Four Free and One Care” policy, individuals can be reluctant to seek HIV testing due to “cost, inaccessibility of services, absence of any treatment, scant publicity or advocacy for testing, low or no perceived risk, and stigma associated with the use of testing services” (Wu, Sullivan, Wang, Rotheram-Borus, & Detels, 2007). Of these barriers, stigma is perhaps the most persistent and daunting to overcome.

Since the beginnings of the epidemic, HIV has been widely feared and misunderstood, and thus stigmatized. Stigma surrounds high-risk occupations and behaviors commonly associated with HIV such as CSW, homosexual sex, and IDU. Though discrimination of PLHIV is illegal in China, discriminatory attitudes towards this group inevitably cause them to face inequity in employment, healthcare, housing, and education. As the stakes are so high, fear of discrimination can drive PLHIV to not seek testing and treatment. So long as stigma surrounding HIV/AIDS is permitted to exist, efforts to prevent the spread of HIV will continually be undermined. Stigma also exists at the institutional level, and serves as yet another barrier to healthcare for some populations. Significant effort has been made in China to reach high-risk populations for testing and reducing AIDS-related deaths with ART. Unfortunately, there are disparities in Chinese policy where PLHIV are simultaneously

protected and criminalized. The protections set in place for PLHIV guarantees that a healthcare provider cannot refuse them care. In contrast, sex work and drug usage –typically the reasons why PLHIV are seeking care in the first place – are criminalized under the “Anti-Drug” law (National Health and Family Planning Commission of the People's Republic of China, 2015) and discourages people from accessing the existing resources.

Another barrier to the central government’s prevention efforts has been delayed recognition of the HIV/AIDS epidemic, as well as the delayed creation and inconsistent application of HIV policy. As with the SARS crisis in 2002, there was also a deadly hesitation by the central government to undertake the HIV/AIDS epidemic (Y. Huang, 2004). This was primarily due to the initial denial of the existence of the scale of the HIV epidemic which led to thousands of deaths as of 2014 (National Health and Family Planning Commission of the People's Republic of China, 2015) Once the Another of China’s biggest challenges is implementing strong policy measures at the local and provincial levels (Parry, 2006). This is especially important because programs such as PMTCT only effective if there is enough ART available (AVERT, 2016). HIV prevention efforts have been robust and effective in some areas, but necessitate more targeted strategies to not only prevent transmission through known high-risk populations but also through less obvious populations. This would entail the specific needs of populations that are vulnerable to infection and to “combine these tools into combination HIV prevention packages that address the specific needs of populations that are being left behind, and to establish enabling environments that allow these populations to access HIV, health and social services without fear of violence, arrest or persecution”, according to UNAIDS (2017).

Return of Gender Disparities in China and Feminization of HIV/AIDS

Until the modern age, Confucianism dictated the way to peaceful society and government in China through a series of hierarchical interconnected relationships, where

women were beneath men in status. Legal and social equality was struck between the genders at the establishment of the People's Republic of China in 1949, when Mao Zedong famously announced that 'women hold up half the sky' (Hong Fincher, 2014). However, in the current post-socialist era, gender inequalities are reappearing (Sutherland, 2011). Though women today are fewer (as a result of the One Child policy and traditional preference for boys) and overall more educated than their male counterparts, they still face pressure from society to marry young – even if that means settling for someone less educated – to resist being a 'leftover woman' (Hong Fincher, 2014). Furthermore, 60% of women in China in the workforce are often locked a double bind, forced to choose between being caring mother or a professional woman. When they choose their work, they are more likely to be discriminated against in job opportunities, paid less than their male counterparts, and laid off (Shen, Yin, & Zhou, 2017).

Patriarchal tradition and current socioeconomic conditions contributed to the emergence of this trend of growing gender and income inequalities in China today – which has serious implications for the HIV/AIDS epidemic and public health, as Sutherland argues in "Reform, Openness and Public Health" (Sutherland, 2011).

Migration and Health of Myanmar Migrant Women

The political repression and worsening economic climate of Myanmar and the rapid development in China in recent years has resulted in the massive migration from Myanmar into southern China (Burmese Women's Union, 2012). These push and pull factors have resulted in over 100,000 migrants coming to the border town of Ruili in the Yunnan province in search of a peaceful place to live and work. The majority of these migrants are women, as they generally shoulder the gendered expectation to provide for their parents, siblings, and children, which results in them often being the ones to move to China in search of better work opportunities (Burmese Women's Union, 2012). Often with little or none work skills

training, these women fill the need for cheap labor in the service, retail, and manufacturing industries. A 2012 study conducted by the Burmese Women's Union on 32 migrant women working in diverse work sectors revealed that work exploitation, unsafe and unhealthy working conditions, and mistreatment by employers was exceedingly common.

Higher wages and better working conditions pull migrant women to higher-paying CSW. Health and safety risks are heightened for migrant women in this industry, who are more vulnerable to physical danger, violence, and infection, especially from clients who use drugs (Sutherland, 2011). Migrant workers have no way to seek justice for the violation of their rights, form workers' unions, or use Chinese resident health insurance resources. Furthermore, political, financial, and personal reasons leave them little option to return to Myanmar. The Myanmar military holds the political power and a large part of the national budget, leaving little to fund health and education services. If they wished to seek health services in Myanmar, they would be expected to pay nearly 90% of their bills, as health insurance in Myanmar covers only 10% of medical costs (M.D. C, 2017). For these reasons, Myanmar migrant women are essentially one of the most vulnerable populations in Yunnan and for which targeted prevention and assistance programs should be focused on in the future.

Methods

Justification for Research

In order to examine the barriers to HIV self-management among women of two different populations in Yunnan, China, a qualitative study was conducted. Although plenty of research has been conducted in China on various aspects of the current HIV epidemic, little has been done on the barriers to HIV self-management for women, particularly with respect to transnational migrant worker populations. The aim of the study was to reveal the disparities between Myanmar migrant and Han Chinese women's experiences in managing

their disease and to analyze the trends that hinder their access to health care. A qualitative rather than a quantitative model was chosen for this study due to its ability to provide rich personal history and to the research constraints of this particular study.

Research Sites

Research was conducted in Yunnan, China. Yunnan is not only known for its geographical, biological, and cultural diversity, but also for its position at the heart of Southeast Asia's "Golden Triangle", the world's second-largest drug production and distribution center that also includes Myanmar, Laos, and Vietnam along Yunnan's southern border. The prevalence of drug trafficking as well as changing social norms and increased transnational migration in Yunnan has all contributed to the high incidence of intravenous drug use especially among those with limited educational and employment opportunities.

Multiple research sites were chosen in order to best reach the populations that I sought to interview: Myanmar migrant and Han Chinese women. Part of the research was conducted in the cities of Ruili and Mangshi in Dehong Dai and Jingpo and Autonomous Prefecture in Yunnan, which is the home to a large Myanmar migrant population. Two of Ruili's five counties are among top ten counties in China with the highest number of HIV-positive individuals. The remainder of the research was conducted in Kunming, the capital city of Yunnan, whose rapid development in the past 30 years and opportunity has attracted many (including the Han Chinese women I sought to interview) from all over the province.

Data Collection and Analysis

Fifteen HIV-positive Myanmar migrant and Han Chinese women and 3 healthcare providers participated in semi structured in-depth interviews in November 2017.

Interviews were set up with the indispensable assistance of my advisor Dr. Duo Lin, Luo Xiaolei, and Zhao Jie. Dr. Duo secured interviews with seven Myanmar migrant women in Ruili at a public hospital, four Han Chinese women in Kunming at another public hospital, and one healthcare provider in Kunming at a specialty hospital. Luo Xiaolei provided me with contacts which allowed me to secure interviews with one Myanmar migrant woman, three Han Chinese women, and one HIV/AIDS healthcare provider in Mangshi at a public hospital. Zhao Jie arranged and translated at interview with one obstetrician/gynecologist healthcare provider in Kunming at a public hospital.

Interviews were held in private rooms on a 1-on-1 or 1-on-2 basis for 20-40 minutes. Potential participants were explained the nature of the study, and those who agreed to participate gave oral consent to be interviewed and have their information included anonymously in the study. Before the interviews, participants were told that their participation in the study was voluntary and that they were free to withdraw at any time. Additionally, participants were given the option to have their interviews tape recorded. During the interviews, HIV-positive women were asked open-ended questions about their life, families, work, move to China (if applicable), HIV diagnosis and treatment, and access to health resources. Health service providers were asked open-ended questions about their work, the HIV/AIDS crisis in Yunnan, and HIV diagnosis and treatment procedures, and women's access to health resources. Interview questions were not required to be asked in the order listed in appendices A and B to allow for spontaneity and flexibility as new content was revealed. Detailed notes were taken in a notebook rather than a computer to increase the participants' comfort in the interview setting, and all interviews (save one) were tape recorded so they could be reviewed in detail at a later date. All participants were offered 50 RMB as compensation for their participation in the study.

Limitations and Shortcomings

This project faced several research constraints, primarily due to a shortage of human, financial, time, and linguistic resources. As PLHIV is a marginalized group in Chinese society and worldwide, it was difficult to find participants willing to be interviewed for the study due to the sensitivity of the topic. For that reason, monetary compensation was granted to each WLHIV participant, which also served to limit the number of participants that could be interviewed. Furthermore, travel costs to go to Ruili and Mangshi for interviews also restricted the number of participants that could participate in the study.

The study was conducted over a period of one month. This short time period resulted in the interviewing of fewer participants, as interviewing and processing the collected data requires a great deal of effort and attention. It was also relatively difficult to find health service providers willing to take time out of their days for interviews. The time limit also resulted in the potential collection of less and/or less detailed data that could otherwise have been collected in a longer period of time, as one month was too short to establish a trusting relationship with the participants.

Lastly, because the interviews with exception of those conducted two healthcare providers were conducted in Chinese, which is not my first language, information gathered in the interviews may be less detailed, and its interpretation less nuanced than if it had been conveyed to a native speaker. To minimize the effect of this limitation, I routinely repeated participants' answers back to them to confirm, correct, and/or add upon the information gathered. Post interview, I reviewed the corresponding tape recording to ensure that all the information shared was entered in my notes. Though much data was gathered in this period, it was generally insufficient in quantity and quality for a qualitative study.

Results and Discussion

Participant Demographics

A total of fifteen HIV-positive patients – seven Myanmar migrant women and eight Han Chinese women – and three healthcare providers were interviewed. The average age of the participants was 36.7.3̄ years old and twelve of the fifteen participants were over 30 years of age. Eight of the participants were originally from Myanmar, ranging from 24 to 52 years old and averaging 34.5 years of age. The remainder of the participants were Chinese citizens of the Han majority, ranging from 36 to 43 years old and averaging 39.3 years of age. All of the participants but one was diagnosed in the past twelve years after the enactment of the “Four Free and One Care” policy. All of the Myanmar migrant participants discovered their status at a health checkup when they moved to China.

All but one participant had been married at least once, and one-third of the participants have been divorced and remarried. Eleven of the participants had one or more children, with one participant’s child having contracted HIV via mother-to-child transmission. Five of the eleven participants who had children found out their status through an HIV test at a prenatal checkup.

Seven of the participants were employed outside of the home (three doing manual work, and four working in their own businesses), four participants were housewives, and four participants were wholly unemployed. All but two participants were employed before their diagnosis. They had worked in low-paying jobs in the agriculture, hospitality, and public service industries. Following their diagnosis, seven of the participants continued to work in their current jobs, while four became housewives and another four became unemployed.

A notable trend found during the interviews with WLHIV was that of the five Myanmar migrant participants that were currently in relationships (either married or

remarried) were married to Chinese men. This would make sense given the fact that the majority of Myanmar migrants coming to Dehong prefecture are women in various relationship statuses coming alone looking for work. It was surprising, however, to hear that when asked how they met their Chinese husbands, they explained that their families had actually introduced them. This finding could be due to misunderstanding between the participant and the interviewer when discussing this matter.

In addition to WLHIV, three healthcare workers were interviewed. In order to protect their anonymity and privacy, this paper will henceforth refer to these interviewees as Doctor. A, Doctor. B, and Doctor. C. Doctor A. has treated HIV/AIDS patients for twelve years and serves as the vice president of a public hospital in Mangshi, Dehong prefecture. Doctor B has worked for twenty years as an obstetrician and gynecologist at a public hospital in Kunming and has treated several HIV/AIDS patients in her time. Doctor C has been working for the HIV/AIDS regional project in Yunnan for a foreign government agency, which provides technical support for healthcare NGOs in China. All three healthcare workers interviewed were of Han Chinese background, who had lived in Yunnan all of their lives. Their background undoubtedly influenced their commentary on the subject.

Demographic characteristics of WLHIV interviewed

Table 1. Demographic characteristics of WLHIV interviewed ($n=15$)

Characteristics	Number	Percentage
Age (years)		
20-24	1	6.̄6%
25-30	2	13.̄3%
31-35	4	26.̄6%
36-40	3	20%
>40	5	33.̄3%
Nationality		
Burmese (Myanmar)	8	53.̄3%
Chinese	7	26.̄6%
Marital status		
Never married	1	6.̄6%
Married	6	40%
Divorced	3	20%
Remarried	5	33.̄3%
Mother to one or more children	11	73.̄3%
Current Occupation		
Manual labor	3	20%
Self-employed	4	26.̄6%
Housewife	4	26.̄6%
Unemployed	4	26.̄6%

Facilitators of HIV Self-Management Among WLHIV Interviewed

Permanent Resident Status

Having a *hukou* or household registration or being married to a Chinese citizen greatly affects one's access to HIV health resources. Under the "Four Free and One Care" policy – referenced in the introduction – rural and uninsured urban Chinese residents could receive a multitude of free and subsidized HIV/AIDS resources. Along the Chinese-Myanmar border where HIV prevalence is especially high, local policy states that a Myanmar migrant can informally receive HIV healthcare services if they have been a permanent resident in China for over a year or are married to and/or a parent of Chinese citizen. This is a likely explanation as to why women in Ruili and Mangshi – relatively smaller cities – are able to easily access HIV healthcare services. All participants reported that they had received some form of VCT and most shared that they were undergoing ART and routinely picked up

medicine every three months and underwent CD4 testing every six months. The healthcare providers interviewed agreed that this policy was impressive in its coverage of all Chinese citizens, including those in poverty.

Access to healthcare services is theoretically universal since the establishment of the People's Republic, but rather is more dependent on where one lives in China, or Yunnan. In recent years, China has been praised for its strong national HIV policy, however it has been criticized for its inconsistent implementation of policy at the regional and local levels. Larger cities are more likely to have the infrastructure to carry out these policies to their full capacity.

Family Support after Disclosure

Family knowledge of status is influential in the WLWHA seeking medical care. Only five participants chose to notify their parents of their condition after their diagnosis with HIV. They received mixed reactions from sadness to disbelief to assurances of love and support. Those who received support were more likely to access healthcare services. One 43-year old Han Chinese participant from Kunming disclosed that when she told her parents, her mother cried and the rest of her family were fine with the news, and accepted her. She said that although they didn't understand the disease, they knew that there was free medicine available for her problem, and encouraged her to seek treatment, which she did. Overall, there was no obvious link between nationality and parent knowledge of their daughter's HIV status, nor was there a link between nationality and level of family support.

Learning to Live with HIV

All WLWHA participants reported receiving voluntary counseling and testing (VCT) services by healthcare providers at public hospitals in the past ten years. This

reflects the efforts to scale up coverage of HIV testing and counseling in order to close the gap between the number of diagnosed PLHIV and total PLHIV. According to the 2015 China AIDS Response Progress Report, 2010 saw an increase in 11,516 medical and health facilities established, 70 million antibody tests conducted, and 39,393 new HIV cases discovered. Many participants emphasized that in their initial meetings following their diagnosis, the healthcare providers very clearly explained the nature of their disease, their medication schedule, and how often to come in to collect their medication and take a CD4 count test. From these responses, it became clear that patient-provider communication is integral to these women managing their condition at a fundamental level.

Only two participants, both 43-year-old Han Chinese women from Kunming, reported being part of a coeducational peer education group at the hospital that meets twice a week meetings and educational activities. Previous studies in Yunnan have revealed that HIV peer education groups are critical in the dissemination of information about HIV management. They also helped group members to ease initial depression and meet others in a similar situation. Doctor C agreed with these findings, explaining that though doctors are trained to treat HIV/AIDS patients, they can't relate to and don't necessarily know how to counsel their patients on symptom and stigma management. For example, peer group members can share their solutions to symptoms such as fat relocation and sensitivity to spicy food, solutions to daily problems, and ideas for low-cost leisure activities and can compare certain HIV/AIDS healthcare providers with other patients.

ART Adherence

ART adherence was another aspect key to HIV self-management among the WLWHA interviewed, helping them to feel like they were taking an active role in their health. Though some commented on the initial side effects of the medication such as hair thinning and hair loss, all participants reported no major lingering side effects.

For the five women who had contracted HIV before having children, ART helped to somewhat ease their anxiety about inadvertently transmitting the virus to their children. ART also gave them the option to have children, and establish ‘roots’ – or a legacy on earth (M.D. C, 2017).

Life Purpose

Having a job or life purpose facilitated self-management among WLWHA. A peer group leader from Kunming’s Wuhua District “New Start” support group – who had spoken at the HIV Gender and Minority culture lecture given by Dr. Duo Lin at Yunnan Minzu University in Kunming in September 2017 – shared that she found much satisfaction in leading peer groups, educating PLHIV about HIV/AIDS, and helping them to manage their disease. In an interview, the 36-year-old Han Chinese WLHIV from Kunming – who earlier in her interview expressed that when she was first diagnosed with HIV didn’t have the courage to live afterward – proudly mentioned that she worked a very strenuous job as a public sanitation worker which required her to get up as early as four or five o’clock in the morning. Having a role to fill helped gives participants a sense of productivity and helped to normalize their lives.

The eleven WLWHA interviewed who were mothers of one or more children expressed their sense of duty to care for their family. Even a 32-year-old Myanmar woman from Ruili whose son had been kidnapped and brought to Shanxi province ten years ago and whose current location is unknown to her said in an interview that takes care of her health to have the strength to find him someday .

Barriers to HIV Self-Management Among WLHIV Interviewed

Lack of Family Support System

Upon receiving their diagnosis, ten of the fifteen participants (five Myanmar migrant and five Han Chinese) declined to notify their parents of their condition as they were elderly, lived elsewhere and/or did not wish to trouble them with this information. Given the fact that all Myanmar migrant participants' parents lived back in Myanmar and they did not see them often, Myanmar migrant workers shared that there was little reason to concern their parents with their illness, as they could manage their illness themselves. Two Han Chinese participants who were sisters (43 and 39 years old) from Kunming explained that there was simply no way to tell their parents, even if they both were to die from AIDS-related causes. As Myanmar and Chinese societies are largely collectivist that place great importance on strong family connections, WLWHA who did not notify their parents found it very difficult to face their families when they reunited with them on occasion.

Stigma

Stigma at the individual, community and societal levels constitutes one of the greatest barriers to HIV self-management. STIGMA INDEX STUDY

A 29-year-old Myanmar migrant participant from Ruili disclosed that even though she had the support of her older sister and brother-in-law in seeking care, she still felt ashamed and sorry for them to have to care for her, and embarrassed to face them. Another participant – a 36-year-old Han Chinese woman from Mangshi – recounted that when discovered her HIV status, she didn't have the courage to live anymore, especially because she felt guilty about having transmitted the infection to her daughter, and considered not seeking care.

At the community level, stigma was the cause of distress and sadness among WLWHA interviewed that greatly reduced their support systems in managing their disease. A 35-year old-Han Chinese participant from Mangshi disclosed that when her second husband heard that she was infected at her first pregnancy checkup, he accepted her and remained with her, however when their close friends heard of her status, they advised him to ask his wife to get an abortion and divorce her immediately. They stayed together but ultimately lost several friends. One 32-year-old Myanmar migrant participant from Ruili shared that after her diagnosis, many of her friends that she cared for didn't come in contact with her, which produced feelings of loneliness. This is most likely the reason why the majority of participants did not disclose their status outside of their families (if they told their families at all). One 43-year-old Han Chinese participant from Kunming avoided telling close friends until she felt the economic stress from having the small welfare subsidy as her only source of income, and then could not hide her status anymore.

Stigma at the societal level was found to be the most pervasive form of stigma, affecting all WLWHA interviewed, regardless of nationality. According to Doctor C, there is a simultaneous disgust with and sympathy for WLWHA. Because CSW and IDU are immoral and illegal activities in China, society tends to hold deep contempt

for these women. In contrast, because they are women, society is generally more sympathetic to their situation.

When asked about her challenges faced in accessing suitable health care, a 43-year old Han Chinese participant and former IDU from Kunming expressed her belief that care is better for people who don't hadn't been IDUs in the past. Doctor B echoed this perception, stating that though healthcare providers are expected treat PLHIV as normal patients with an equal chance of transmitting a contagious disease, and without judgement, but the fear of HIV infectors is very obvious. HIV patients are treated in different wards in her obstetrics and gynecology department, separated from non-HIV patients. Doctor C believes that this fear by healthcare providers is hidden under the cover of professionalism, but still effects care delivery. Societal stigma influenced healthcare for Myanmar migrant women as well. It resulted in one Myanmar migrant participant's physician from personally notifying her that she was infected with HIV. When the participant wasn't feeling well a few years after her fourth child was born, she went in to get tested, and the physician reported her results directly to her Chinese husband instead of her. She believed this to be due to the sensitivity of the subject, but there could be other factors influencing this common phenomenon, including discriminatory attitudes against women and migrant workers. Another interesting factor that was brought up in my interview with Doctor C was that there even exists stigma within peer support groups, where those who contracted HIV through stigmatized high-risk activities are discriminated against and judged more than their counterparts who did not contract the virus through those modes of transmission.

Discriminatory Hiring Practices

Nine of the fifteen WLHIV interviewed reported that they had experienced difficulties in finding employment because of their HIV status. Although it is technically illegal to discriminate against those with and HIV status in China discrimination exists nonetheless, widely unchecked, through illegal mandatory pre-employment health checks by employers (Ren, 2013). The central government's nonaction on this issue coupled with its barring of PLHIV from civil service qualification demonstrates that if the central government wishes to support the holistic well-being of its HIV-positive residents, it must be persistent in its enforcement of preexisting laws and revise those that do not serve that population well.

Physical Fatigue

Physical fatigue was one of the most commonly reported symptoms by both Myanmar migrant and Han Chinese participants. Fatigue render them unable to work, and made completing everyday tasks extremely difficult. This was incredibly burdensome for Myanmar migrant women. When asked about her symptoms of HIV and whether or not they affected her life, a 32-year-old Myanmar migrant woman from Ruili explained that her fatigue leaves her incapable of working or staying up all night. She continued, asserting that Myanmar migrant PLHIV are especially vulnerable to this barrier as they are unable to do heavy work, be overworked, or stay up all night, which closes them out of the low-wage sectors where Myanmar migrants usually work. Their condition ultimately removes a possible facilitator of managing their disease – a purpose, but also a source of income.

Financial Difficulty

Though their care is covered by local policy in the Dehong prefecture, Myanmar migrant women had financial difficulties stemming from the associated travel costs in accessing HIV healthcare resources and the lack of welfare subsidy that Chinese citizens are entitled to under the “Four Free and One Care” policy. Even with the welfare subsidy provided, which is the lowest civil affairs stipend available at approximately 370 RMB per month (M.D. C, 2017), Han Chinese WLWHA reported experiencing financial difficulties, but declined to specify what difficulties they faced.

Additional Findings

There were several less expected phenomena that were brought to light in the interviews that do not necessarily fit into the ‘facilitators of’ and ‘barriers to’ categories that deserve mention.

The first is the fact that both populations of WLHIV interviewed were much older than was expected, with the average age of the Myanmar migrant WLHIV interviewed being 34.5 years old, and the average age of the Han Chinese WLHIV interviewed being 39.3 years old, and had been managing their disease for an average of 5.5 years and 9.3 years, respectively. Going into this study, a younger population that had been more recently diagnosed was expected. A possible explanation for an older population could be that the growth rate is slowing to a point and that the population is aging.

Another unexpected finding was that there was a lack of clarity among the majority of the WLHIV interviewed as to how they had contracted the virus. A 32-year-old Myanmar migrant woman shared that she was fairly certain that she contracted HIV when she cut her foot while doing manual labor in a depression in the ground. Although six WLHIV said that they could have contracted HIV through their (former) IDU spouse or sexual partner, the remainder of the WLHIV interviewed could not say how they had contracted the disease.

Upon reflection, this could be two or more reasons for this phenomenon – that the counseling part of VCT does not encompass enough infectious disease education for WLHIV to understand the causes of their infection, or that the WLHIV were ashamed of their mode of contraction.

Lastly divorce was common overall in both populations of WLHIV interviewed. Eight of the fifteen WLHIV interviewed had been divorced. Furthermore, of the five Myanmar migrant WLHIV that were currently married (either married or remarried), were married to Chinese men. Divorce was not as surprising given the fact that HIV/AIDS is a sensitive topic and would undoubtedly put a strain on a relationship. What was the trend of all of the married Myanmar migrant women being exclusively married to Chinese husbands. The logical explanation is that there is a shortage of Chinese women of marriageable age in China due to the One Child Policy and the traditional preference for boys, and there are many women from Myanmar settled in China to work, however given the privileges of being a Chinese man and the lack thereof of being a transnational migrant worker without the support of family nearby, one is slightly suspicious of the additional power dynamic that is added to the traditionally uneven heterosexual relationship.

Conclusion

A society can be judged by how well it takes care of its most vulnerable populations. Though it took nearly two decades to begin to address the crisis and the needs of PLHIV, it now has in place tangible, evidence-based policies to slow the growth of the epidemic and to support its citizens. The literature and this project has shown both how far China has come in handling the crisis, and how much more must to be done to support newer, even more vulnerable populations being affected by HIV, such as handling stigma surrounding the disease, eliminating nearly worldwide traditional gender imbalance which makes women

inferior to men, and allowing smaller, non-governmental organizations assist in the effort to end the epidemic.

Stigma – one of the biggest barriers to disease management as demonstrated in this study – discourages WLHIV to seek care, access resources, and lead more fulfilling lives. Furthermore, stigma surrounding the HIV and gender disparities encourage ignorance surrounding the disease and contributes to its transmission. Stigma coming from WLHIV themselves, their communities, and society all serve to prevent WLHIV from taking care of their physical health, coming to terms with their status, and ultimately living healthier and happier lives. So long as stigma surrounding HIV/AIDS is permitted to exist, efforts to prevent the transmission of HIV will continually be undermined. Finally, the literature and the findings of this study support the notion that social support, including that from the family and that from peer education groups, is an effective way of HIV management. Until the more accepting and open attitudes towards those who suffer from the disease are obtained by the general public, small efforts must be supported by those leading the charge.

The semi structured in-depth interview model used for this research was extremely useful in uncovering the various intersections and trends among and between the lives of the WLHIV interviewed, and has revealed to me multiple suggestions for further research that can be done including, but not limited to: the facilitators of and barriers to HIV self-management for ethnic minority PLHIV or WLHIV, the facilitators of and barriers to HIV self-management for children infected via mother-to-child transmission, the effect WLHIV peer groups on HIV self-management, and a study of WLHIV experience of pregnancy and their relative access to medical, social, and educational resources.

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Appendices

Appendix A: Interview Questions for WLHIV

1. Introduction – age, job, marital status, family, ethnicity/nationality, etc.
2. When did you move to China? After you moved to China, how did your life change? (Myanmar migrant women only)
3. Did you have sexual education? If so, what topics did it consist of?
4. When and how did you contract HIV?
5. How did you realize you needed to be tested?
6. Since contracting HIV, how has your life changed?
7. Does your family know your status? If so, which members? If not, why not?
8. How did you and/or your family react when you realized your status?
9. How do you think society views HIV-positive people? HIV-positive women/mothers?
10. Have you had children? If so, when?
11. Does your husband (or husbands) and children have HIV?
12. After your diagnosis, what advice did you receive from your doctor and family (if applicable)?
13. What did you think about the quality of health care you received after being diagnosed with HIV?
14. Aside from free HIV medical counseling and medication, what medical, social, and educational resources are available to HIV-positive women?
15. Are you able to access these resources? If so, why and which ones?
16. What challenges do you face in accessing suitable health care?
17. What is HIV medication plan like? Does it impact your life, and how?
18. Do you come to [clinic where interview is held] to pick up your medications? How often and how far do you travel to come to [clinic]?
19. Have you been diagnosed with other illnesses? If so, what is the treatment like, and what are the associated costs?
20. Do you know other women of similar condition? If so, do you discuss your illness together?
21. Is there anything else that you would like to let me know regarding your condition? Is there anything that you would like to ask me regarding my research?

Appendix B: Interview Questions for Healthcare Professionals

1. Introduction – organization, position at organization, responsibilities associated with position, how initially got involved in HIV health services etc.
2. What is the demographic for HIV-positive women today?
3. What is sexual education like in China? What sources do people typically get their information from? Which topics do people usually learn?
4. Do women typically know about the virus and how it is spread before they contract it?
5. Do you think that HIV awareness/prevention campaigns are effective in conveying information?
6. How do healthcare professionals, society, and the Chinese government view HIV-positive people? HIV-positive women/mothers?
7. Is the family of HIV-positive women typically involved in the healthcare access and decisions of their family member? In what ways?
8. When an HIV+ woman comes to a hospital or clinic seeking care, what is the typical process she goes through? What requirements must she fulfill to undergo treatment?
9. What medical, social, and educational resources are available to HIV-positive women? Which ones are subsidized? Are they provided across all hospitals in China?
10. How do you advise HIV-positive women of childbearing age on family planning and health maintenance?
11. Does hospital staff receive training on how to care for HIV+ women? If so, is it the case in every hospital?
12. How do you perceive the quality of health care that HIV-positive women receive? Is it consistent in every hospital?
13. What challenges do HIV-positive women face in accessing/receiving suitable healthcare services? Do they have jobs/practices/conditions/living situations that prevent them from seeking care?
14. What do you perceive to be the differences and similarities between the experiences of HIV-positive men and women/HIV-positive ethnic minority and Han Chinese women/HIV-positive Myanmar migrant and Han Chinese women?
15. What have been some successful past public health initiatives, in your opinion? What future public health initiatives do you recommend?
16. What other medical, social, or educational resources do you think would improve the lives of HIV-positive women?
17. What is the biggest barrier to healthcare for HIV-positive women, in your opinion?
18. What do you recommend to help reduce the social stigma surrounding this condition?
19. How does your organization support HIV-positive women?
20. Is there anything else that you would like to let me know regarding this subject? Is there anything that you would like to ask me regarding my research?

Appendix C: Log of Fieldwork Hours

Date	Activity	Hours
11/7	Interviews in Ruili	3
11/8	Tape processing	5
11/9	Trip to Ruili/Muse border with Dr Duo and Libby	6
11/10	Interviews in Ruili	3
11/11	Tape processing Interview preparation	5
11/12	Interviews in Mangshi	4
11/13	Return to Kunming	0
11/14	Tape processing	5
11/15	Tape processing	5
11/16	Interview preparation	2
11/17	Interviews	3
11/18	Tape processing	5
11/19	Tape processing	5
11/20	Research	5
11/21	Research	5
11/22	Research	5
11/23	Interview preparation	2
11/24	Interview in Kunming	1
11/25	Research	5
11/26	Interview preparation	2
11/27	Interview in Kunming	2
11/28	Research	5
11/29	Research	5
11/30	Research	5
12/1	Writing	5
12/2	Writing	5
12/3	Writing	5
12/4	Writing	5
12/5	Writing	5
12/6	Writing	5
12/7	Writing	5
12/8	Writing	5
12/9	Writing	5
Total Hours		133