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**A COMPARATIVE STUDY OF HOW TO AVOID  
STIGMA IN UNCOMPETITIVE POLITICAL SYSTEMS:  
HIV SELF-TESTING IN CHINA AND SOUTH AFRICA**

by

**SIYAN MENG**

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Approved by

First Reader

---

John Stone, Ph.D.  
Professor of Sociology

Second Reader

---

Joseph Harris, Ph.D.  
Assistant Professor of Sociology

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**ABSTRACT**

HIV/AIDS has been the subject of much debate since the 1980s in the fields of medicine, public health and sociology. These discussions have involved medical practitioners, social campaigns, and NGOs in the U.S. and European countries. However, in China and South Africa, because of their political systems, religion, gender, and traditional cultures, HIV/AIDS policy was established by uncompetitive governmental policies, indigenous culture, and social structure that led to outbreaks of the disease and consequent public crises. As a contagious, global disease without a cure, HIV/AIDS is often related to marginal groups, which are easily stigmatized by mainstream society. In China, men who have sex with men (MSM) is a high HIV/AIDS-infected group, which is often excluded by mainstream society because homosexual marriage is illegal. To weaken stigmatization of HIV/AIDS and people living with it and decrease the rate of infection, the Chinese government has been working with community-based organizations (CBOs) to promote HIV self-testing among MSMs to encourage them to take HIV/AIDS tests at home in a private and more comfortable setting than facility-based testing places. The process of self-testing allows people to control the time and place to take the test by themselves, meanwhile de-

medicalizing the HIV/AIDS testing and empowering MSMs.

**Key Words:** HIV/AIDS, China, South Africa, MSM, CBO, HIV Self-testing, Discrimination, Stigmatization, Empowerment.

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## HIV/AIDS in China

China's first HIV case was identified in 1985. Since then, Avert data show there are five hundred thousand people living with HIV/AIDS in 2015. According to the 2015 China AIDS Response Progress Report, two key developments are- first, the number of people living with HIV/AIDS is still increasing. For example, from the end of 2013 to the end of 2014, the reported number increased from 437,000 to 501,000, and there also remained undiagnosed cases. Second, the prevalence of HIV/AIDS has been rising among certain group via sexual transmission, especially among men who have sex with men (MSM). From 2003 to 2014, the rate of HIV/AIDS prevalence among MSMs has increased from 1% to 8%.<sup>1</sup>

Back in the 1990s, the HIV/AIDS health care system was limited in China, and resulted in HIV/AIDS spreading rapidly. In 1995, Hsiao estimated that only 10 percent of China's rural population was covered by health care insurance (Hsiao 1995). The health care reforms, which were launched in 1992, privatized public hospitals to make them more profitable. That made China's health care costs increase rapidly from 1990 to 1997, which resulted in poor urban people being unable to afford health care (Grusky, Liu and Johnson 2002). Making matters worse, HIV/AIDS exploded in rural districts because of illegal commercial blood-selling. Most blood-selling sites were established in rural poor communities



(Erwin 2006). To save costs and improve donation frequency, donors were injected multiple times with the same needles and other unhygienic equipment (Wu *et al.* 1995). The prevalence of HIV/AIDS among blood donors was first reported around 1995 (Wu, Liu and Detels 1995). Since then, HIV/AIDS infection climbed from 0.2% to 56.1% among donors in the rural areas, including Henan, Anhui, Shandong, Hebei and Shanxi provinces (Wang *et al.* 1994; Zheng *et al.* 2000; Wu *et al.* 2001; Zhang 2001).

The Chinese government reported that at least 100,000 people were infected nationwide because of blood-selling (Eckholm 1998), and this number is believed to be an underestimate. As Erwin states, “The Henan Health Department estimates the number of infections in that province to be 370,000” (Erwin 2006, 140). Commercial blood selling centers were active between 1992 and 1995. This phenomenon was “not a secret” (Erwin 2006, 147) to the government. Due to the health care reforms, public hospitals and clinics needed to make incomes on their own, rather than relying on state funding as they used to do. The state shifted the money from the health system to city infrastructure (Erwin 2006) that has been exacerbating the economic disparity between urban and rural areas. Because of poverty, lack of knowledge about hygiene, and the existence of commercial blood banks from government support, HIV/AIDS broke out among Chinese rural

communities- the so-called “AIDS villages” (Rosenthal 2000).

In 1996, the Chinese government “quietly closed” (Erwin 2006, 140) state-run commercial blood banks, and in 1998, declared for-profit blood centers illegal. From 2002, the government struggled to shut down private commercial blood centers and establish a more thorough system to screen blood donors (Erwin 2006). To deal with HIV/AIDS, the Chinese government established a national sentinel surveillance system: condom promotion and blood supply screening starting in 1995 (Grusky, Liu and Johnson 2002). In 2014, the State Council established an assistance system aiming at providing financial support for urban and rural people living with AIDS in case they encountered life-threatening emergencies (UNAIDS 2015).

With the interventions from the 1990s to the early 2000s, people rapidly came to understand HIV/AIDS as a lethal, contagious disease. Herek’s survey taken in the U.S. shows that the public clearly understands well how HIV/AIDS is transmitted, but they lack knowledge about how HIV/AIDS is not transmitted (Herek 2002). This result is also applicable in China. A study in 2003 among 2062 high school students in Beijing reveals their knowledge of HIV/AIDS. Eighty percent of the students acknowledged that HIV/AIDS could be transmitted through blood and sexual intercourse; only 34.9 percent of them knew that

HIV/AIDS cannot be transmitted through mosquito or other insects (Chen, Li and Wang 2003). The HIV/AIDS education among elementary school and middle school students focuses on the major three ways it is transmitted, but the education lacks information that except for blood and semen, saliva and skin contact (e.g. handshaking or hugging a HIV-positive person), cannot transmit HIV/AIDS.

However, the effects of state-run media and education as scare tactics led people to label HIV/AIDS as lethal and more easily transmitted than the disease actually is. Influenced by the scare tactics, over 65,000 registered active accounts on a social network discussion website called “HIV/AIDS Phobia”<sup>ii</sup> continues to build upon fear. In our interviews conducted on 42 MSMs, 10 out of 42 declare that they had or still have HIV/AIDS phobia. The public knowledge about HIV/AIDS based on fear of it, which leads to a misunderstanding not only about HIV/AIDS, but also about people who are HIV-positive. Illnesses are easily stigmatized when they cannot be cured and are believed to be contagious (Conrad 1986). Thus, people will isolate the HIV-positive in order to isolate themselves from a lethal illness. This discrimination is labeled as “instrumental stigma”, which “reflects the apprehension likely to be associated with any transmissible and deadly illness” (Herek 2002).

Unfortunately, discrimination against the HIV-positive has not decreased. The government stresses the danger of HIV/AIDS as a menacing way to reduce the numbers of drug users, sex workers, and MSMs. At first, the Chinese government tried to use scare tactics to change people's behavior because HIV/AIDS was related to marginal groups. "... portraying AIDS as a 'death sentence' and associating it with particular symptoms made the disease visible and avoidable" (McDonnell 2016, 148). In 1993, a study about HIV/AIDS among Chinese medical students showed that two-thirds of the participants thought that the HIV/AIDS-positive deserved to be diagnosed with the illness (Li *et al.* 1993). At present, this misunderstanding towards people who live with HIV/AIDS is still held by many people.

On social networks, discussions about HIV/AIDS are mostly from two perspectives. One expresses anger towards MSMs, blaming the illness on promiscuousness, saying they should be responsible for taking care of themselves. The other expresses sympathy because the HIV-positive, from now on, face a future in which their lives have been destroyed--- they cannot have relationships; they cannot have children; they may even lose their jobs, etc. These concerns reveal how ignorant people are towards HIV/AIDS. For at least a decade, the Chinese government did not try to correct people's

misunderstandings because they thought that this scare strategy was an effective way to suppress the rates of HIV/AIDS infection.

However, the scare strategy was abandoned by the Chinese government when data showed HIV/AIDS infection among those aged between 15 and 24 increased 13 percent per year from 2011 to 2015 among the total Chinese population<sup>iii</sup>, the infection from HIV/AIDS among adolescents who are not a deviant group, drew the Chinese Center for Disease Control and Prevention's (CDC) attention. Hence, the CDC has been promoting free medication and effective treatment for the HIV-positive via social networks that encourage receipt of immediate treatment because it is a controllable disease. From 2013 to 2014, the number of people living with HIV/AIDS receiving antiretroviral therapy (ART) increased from 227,489 to 295,358 (UNAIDS 2015).

On social networks, official statements about HIV/AIDS have changed. Although not held by the public, government controlled media portrays the changing attitude towards HIV/AIDS and people living with it, from scare tactics to control tactics; which converts the idea that HIV/AIDS is a manageable disease and seeks ways to eliminate the discrimination. A lot of celebrities, such as actors and actresses, pop idols, and entrepreneurs, have joined the "No More Discrimination Campaign". The government also established "a free compulsory

education and subsidy system” (UNAIDS 2015) to make sure all children of school age, including children who are living with HIV/AIDS, can receive free compulsory education (ibid).

Ironically, despite all these efforts, institutional discrimination has not stopped in non-compulsory high school education. In 2015, a HIV/AIDS-positive girl was refused public high school admission in the Hebei province.<sup>iv</sup> According to the report, she was raised in a small village where she grew up being afraid of mentioning her parents’ names because other villagers might look down upon her parents who unfortunately became HIV-positive victims through blood selling. The changing attitude and strategy towards HIV/AIDS is the first step to reduce discrimination. The next step should reflect changes in governmental policy.

The history of Chinese HIV/AIDS development has been heavily influenced by the state dependent. A patriarchal regime makes the state government play a “big-brother” role in every aspect of society, especially stressing control over the media. In the 1990s and early 2000s, the media was not allowed to cover and comment on the “AIDS villages” issue. Another tragedy of media control happened in early 2003 with the outbreak of Severe Acute Respiratory Syndrome (SARS). This disease can be contagious through saliva, and its symptoms are like the flu. The government was afraid of cultivating mass hysteria, so it censored the

information about SARS. In 2003, the main vehicle that people obtained news was from official state-run media through TV, radio, online news and newspapers, instead of from “We Media”(citizen journalism) as in the present day. The government had decision-making power on selecting information that could be passed on to the public. This limited freedom of news contributed to 159 deaths from March to late April 2003, and by the end of July, the total number of deaths increased to 349<sup>v</sup> out of 735 globally across 32 countries.<sup>vi</sup>

### **Comparison between China and South Africa**

In a similar manner to China’s uncompetitive government’s influence on public health problems, the African National Congress (ANC) in South Africa dominated the policy on HIV/AIDS, and constructed the language of hegemonic belief from 1994 to 2009. The ANC’s intervention resulted in a disastrous outcome over HIV/AIDS in South Africa. South Africa’s health system was influenced by its political situation during three phases: “colonial subjugation”, “apartheid dispossession”, and the “post-apartheid” era (Coovadia *et al.* 2009, 817). The first democratic election took place in 1994, which marks South Africa’s start of the post-apartheid period. During the later years of the apartheid era, in the 1980s, South Africa also had significant health care reforms.

Like the Chinese health changes in 1990s, the South African government also encouraged the privatization of the health system. The numbers of private (for-profit) hospitals expanded by nearly double between 1988 and 1993 (McIntyre *et al.* 1995). However, less than 15 percent of the population could afford private hospital services, leaving 64 percent still needing to rely on the public health sector (Coovadia *et al.* 2009). From 1994, the health system was affected by a mal-distribution of human and medical resources with the increase of Sexually Transmitted Infections (STI), tuberculosis, and child, maternal and mental health needs (Wood and Jewkes 2006). What was worse, a direct consequence of governmental control of public health was the denial of HIV/AIDS during Mbeki's presidency. The major reasons for denial were to protect South Africa's cultural identity and his regime, by rejecting Western methods of treatment and supporting indigenous healing. Similar to the Chinese media control over "AIDS villages", this denial was a major reason for the breakout of HIV/AIDS in the early 2000s.

In addition, another similarity between South Africa and China is the acceptance and prevalence of indigenous healing (or traditional healing). Both Chinese and South African indigenous healing methods are not supported by clinical trials, and traditional medicine (herbal medicine) is not approved by the



U.S Food and Drug Administration (FDA), which is often used as the scientific standard of measurement in China.

South African indigenous healing necessitates a healer as a medium “between the natural and the social, between the living and the dead, between the individual and the community” (Decoteau 2013, 215), that makes indigenous healing like a religious ritual. One reason that people seek indigenous healing is driven by poverty. Although some clinics provide free ART for people living with HIV/AIDS, the travelling expense is a burden for the poor rural people. Public transportation is not frequent and convenient enough; for instance, a bus from a village to a city runs twice a day. Public clinics are always crowded so a person even after travelling, may not be seen by a doctor (Decoteau 2013).

However, some people who can receive ART still seek indigenous healing. The reason for this phenomenon is “people... are too confused and scared of being stigmatized to find out about their HIV status and get treatment” (Boseley 2005). Many South Africans have doubts about ART, a Western medicine, because of Mbeki’s statements on the subject and other denialists that spread false information about HIV/AIDS treatment. It is suggested that ART is toxic; instead, Vitamin C, lemon, and garlic can cure the disease (ibid). Decoteau argues that the prevalence and acceptance of indigenous healing reflects a key

strategy for Mbeki's government to "paint biomedicine as anti-African and to pit it against more indigenous beliefs about healing" (Decoteau 2013, 123).

Indigenous healing in China is called traditional Chinese medicine/healing, including herbal medicine and physical medicine such as acupuncture. Different from the South African government's approach under Mbeki, the Chinese government argues that the only effective way to treat HIV/AIDS is by ART, which has been free in specified public hospitals and the Centers for Disease Control and Prevention (CDCs) since 2004, and other ways to treat HIV/AIDS are full with fraud. However, people still pay a lot of money for traditional Chinese medicine, not only for HIV/AIDS, but also for other illness: for example, colds, arthritis, migraines, and even cancer. Less or even no side effects compared to Western medicine is one of the biggest assets of traditional healing. The main theory behind traditional healing is that every medicine is toxic, which expresses itself as a side effect. Traditional healing promotes the human body as an organism, in which parts, such as the heart, kidneys, the stomach etc., cannot be treated separately, as they are treated in Western medicine. If something is wrong with your kidney, for example, there must be some other problems with your other organs.

Similar to South African indigenous healing, Chinese traditional medicine also

emphasizes the importance of diet, and advocates food as a natural medicine that can be helpful in curing diseases. Another important reason that people support these beliefs is the view of ancient Chinese history where traditional healing seemed to be cured Chinese people for thousands of years before Western medicine appeared. The vague claims about traditional healing and its own history make it seem persuasive. In February 2017, the State Council released the HIV/AIDS Intervention Plan for the next five years, claiming to gradually expand the treatment of traditional medicine<sup>vii</sup>.

This claim can mislead public knowledge about HIV/AIDS treatment suggesting that traditional medicine can be an alternative to ART, and resulting in the possibility of decreasing the use of ART. Both in China and in South Africa, indigenous/traditional healing for some people is like a religion that should be a supplemental or comfort treatment, but it also leads to distrust in Western medicine. It seems to them that indigenous/traditional healing and Western medicine are opposed to each other and they have to choose between them. In this circumstance, promoting ART by proving indigenous/traditional healing is not scientific is meaningless (Decoteau 2013). What the two countries need is biomedical education.

Biomedical education is urgently and widely needed because the Chinese

population living with HIV/AIDS has been changing to younger groups and MSMs. According to UNAIDS, “The percentage of people living with HIV of men who have sex with men shows a marked uptrend” (UNAIDS 2015, 8). The rate of HIV testing is low among MSMs and male sex workers in rural areas.<sup>viii</sup> The infection rate in youth, between ages 15 and 24, which is another target population, has been increasing fast, and 65 percent of infection happened in college between ages 18 and 22<sup>ix</sup>.

Unlike the Chinese HIV/AIDS situation, South Africa needs not only biomedical education, but also changes towards greater gender equality. “The history of war and violence has shaped dominant forms of South Africa’s racially defined masculinities, in that they all valorise the martial attributes of physical strength, courage and an acceptance of hierarchical authority” (Coovadia *et al.* 2009, 819). This type of masculinity leads to gender hierarchy. “Contemporary research has shown that the control of women is a central part of present day constructions of South African masculinity” (ibid, 821). The control of women involves physical and sexual abuse, when women are held against their will. Rape and violence against women increase the rates of HIV/AIDS infection, because women are physically vulnerable, even in marriage (Wood, Maforah and Jewkes 1998).

There are two contradictory perspectives on sexuality in postcolonial history. One is related to Christianity, which advocates that sex is for procreation within marriage, and cannot be discussed among young people in South African culture (Coovadia *et al* 2009). The other is rooted in traditional African culture that regards sex as normal and healthy, that it can be talked about in daily life (Delius and Glaser 2002; Jewkes, Penn-Kekana and Rose-Junius 2005). This perspective, after urbanization, is prevalent among black African working class youth that results in casual sex without resistance and supervision from adults (Delius and Glaser 2002). “Premarital, and often teenage, pregnancy has become normal for black women, until recently, unsafe abortion was a major cause of reproductive morbidity and mortality” (Coovadia *et al.* 2009, 822). These competing perspectives towards sexuality lead to “extreme structural inequality” (Decoteau 2013, 174). South African’s present president Jacob Zuma, has been trying to promote tradition by focusing on gender rules and Zulus’ traditional sexuality, which stresses hegemonic masculinity (Decoteau 2013). According to the South African Police Minister, the state spent 8.6m (\$550,000) on Zuma’s new cars and four wives in the past three years (Nkosi 2016). For women, especially poor women, marriage is a way to change their quality of life. Hence, sex becomes a tool for exchanging, which is often referred to as “transactional sex”

(Decoteau 2013, 175). Although it does not mean legitimation of prostitution (Hunter 2002; Epstein 2007), for unemployed and poor women, they “are often forced to engaged in more than one ‘transactional’ relationship” (Decoteau 2013, 175).

Marriage/sex relationships for men are a symbol of prestige and power. The unequal gender relationship forces women by exposing them to the danger of getting infected by STI, and cannot get immediate and adequate treatment. Scholars assert: “transactional sex is one of the primary mechanisms of HIV transmission” (ibid, 179). This inequality also harms poor men’s living conditions. Such twisted masculinity leads to a misunderstanding that “real men don’t get sick” (ibid, 176). HIV/AIDS is a symbol of disability and a “loss of dignity” (ibid). Thus inequality in the gender structure in South Africa exacerbates HIV/AIDS prevention and treatment.

### **HIV/AIDS in South Africa**

Both China and South Africa have large populations who live with HIV/AIDS. According to data 2015 UNAIDS, there were around 7 million people living with HIV/AIDS; the prevalence rate among ages between 15 and 49 is 19.2% in South Africa. The first known case of HIV/AIDS in South Africa was in 1982, and the first

recorded death from HIV/AIDS was in 1985.<sup>x</sup> In 1988, the South African government established a group called AIDS Unite and National Advisory Group to broadcast the awareness of HIV/AIDS. In early 1991, the National Advisory Group provided comprehensive advice and details about HIV/AIDS intervention. In 1994, President Mandela's new government proposed three structures focusing on HIV/AIDS policy in civil society: "1, an HIV/AIDS and STD Advisory Group; 2, a committee on NGO funding; 3, a committee on HIV/AIDS and STD research".<sup>xi</sup>

However, they did not produce effective results. The reasons include: first, the lack of clinics, even in the cities; second, HIV/AIDS is highly stigmatized as a "gay disease" in South Africa, people are reluctant to get tested and undergo treatment; third, HIV/AIDS is also spiritually stigmatized as a sin or punishment from God; fourth, indigenous healing is prevalent and popular in South Africa. People also lack medical knowledge and do not believe in Western medicine (Decoteau, 2013). What was worse, in 1999, Thabo Mbeki became the second post-apartheid President. After that, an era of HIV/AIDS denial arrived.

In 1999, the Treatment Action Campaign (TAC) promoted the effectiveness of antiretroviral therapy (ART) and encouraged pregnant women to get antenatal testing (Heywood 2004). Mbeki directly responded to this campaign claiming that

ART was “toxic” and urged the health minister to discover the truth (Mbeki 1999). In 2000, Mbeki held a Presidential Advisory Panel on HIV/AIDS that included AIDS deniers, such as Peter Duesberg, a well-known scientist who emphasized that the HIV virus does not cause AIDS, was just a “passenger” (Specter 2007). HIV deniers argue that other factors may also influence the disease; for example, life style, toxins, and the environment (Thornton 2008). Mbeki “identified as a denier” by stating that “poverty rather than HIV is the cause of AIDS” (Decoteau 2013, 80) at the International AIDS Conference in late 2000. Mbeki also rejected the idea that individual sexual behavior was the causal factor for transmission because he did not admit Africans have more unprotected sex than Westerners (Decoteau 2013). Therefore, he reframed the argument by claiming that HIV/AIDS was not caused by individual decisions, but was the result of collective and structural social forces.

There are other fundamental issues making him as a denialist. First, HIV/AIDS, a powerful and contagious disease, was a threat to the post-apartheid government. HIV/AIDS “emerged as a kind of everlasting affliction precisely at the point when the end of apartheid should have brought a better life for all” (Schneider and Fassin 2002, 46). Denial was a way to avoid the question of the government’s inability to solve the problem. Mbeki’s denial position was related to



colonization, and he tried to invoke African nationalism in South Africa. “He urges South Africans to remember the scientific racism inherent in the eugenics movement” (Decoteau 2013, 88). In fact, South Africa is a racially stratified society and one of the most unequal countries in the world (World Bank 2001; Johnson and Budlender 2002).

In addition, the government treated Western medicine as a new manifestation of colonization. The denial was a statement and rejection of colonialism. The sensitivity concerning Western intervention stems from the South African history. For some 400 hundred years, South Africa was colonized and then ruled by European settlers and their descendants<sup>xii</sup>. During the colonial period and under Afrikaner nationalism, native South Africans were forced by violence and warfare to leave farms and become low-waged laborers in the cities to support mining and industry (Coovadia *et al.* 2009). In 1912, saw the foundation of the Native National Congress, later renamed the African National Congress, which was an organization of oppressed black Africans, and after the end of apartheid, it was converted into a democratic political party.<sup>xiii</sup> Rejecting Western medicine was for some of its leaders like Mbeki, a way to stress South African indigenous self-identity.

The national chairman of the Treatment Information Group, Anthony Brink,

suggested that “AIDS in South Africa was constructed and turned into a ‘mass epidemic hysteria’ by ‘white liberals’ who needed to find a sense of belonging after the fall of apartheid” (Decoteau 2013, 97). The conspiracy theory about Western medicine was a way to encourage indigenous healing “as an ideological weapon in the symbolic struggle over HIV/AIDS” (ibid 93). However, indigenous healing is merely an informal and alternative choice for poor African communities because the government is “failing to provide funding for prevention” and “refusing emergency medical care to activists” (ibid, 88). In this sense, denialism became an excuse for the government to avoid providing medical support to the public.

Denialism influenced South African health care policy from at least 1999 to 2007, and resulted in the deaths of 365,000 people who died directly because of it (ibid). During the denial era, Mbeki faced a lot of condemnation and political risks, but he could still question the science (Schneider and Fassin 2002) and made a series of policies to support his illusion. One of the vital reasons that denial had such long-term effects on South Africa’s public health policy was because the health system “was fully centralized in the early years of democracy, as opposed to incorporating civil society participation” (Thornton 2008, 161).

Under uncompetitive systems, both China and South Africa established knowledge by political power. Such systems can easily turn every issue into

politics. However, public health is not only a medical issue but also a political issue. It cannot be overlooked among societal perspectives, dealing with race, gender and marginal groups. In this situation, when the country faces a crisis, the purpose is not to solve the problem, but to protect the regime. Take HIV/AIDS as an example. In China, it is related to LGBT groups, drug users, and sex workers. These marginal groups are also related to the issue of the migrants who are moving from the countryside to big cities. HIV/AIDS as a social phenomenon was discussed at length in the U.S, especially from the mid-1980s to the mid-1990s. Science, the media, government views and LGBT NGOs collectively constructed HIV/AIDS knowledge (Epstein 1996). The multi-aspect discussion can give the public a wider understanding of HIV/AIDS that benefits prevention and intervention. In China, intervention, apart from compulsory education in schools and information about testing in the media, now has another new strategy in HIV self-testing, which can be particularly valuable for marginal groups.

Both in China and South Africa, HIV/AIDS, and MSMs are stigmatized and this can be a barrier to accessing HIV/AIDS testing, which is the first step for prevention. One of the ways for HIV/AIDS testing, HIV self-testing, acts as a shelter for people who want and need to be tested. The discrimination against MSMs and HIV/AIDS is a vital factor for MSMs to choose HIV self-testing. As

Goffman defines it, stigma is a “relationship between attribute and stereotype”(Goffman1963, 3). Link and Phelan point out that there are varied definitions of stigma (Link & Phelan 2001). Based on different definitions, they conceive stigma as a process of “labeling, stereotyping, separation, status loss, and discrimination” (ibid, 367). Regardless of the specific definition, there is a great similarity in the general way that stigma stems from labeling, which categorizes people as an “outsider”. But how do we label people? How does society create standards of evaluation? Being a MSM is a physical and social individual “defect” (Goffman 1963), which is excluded by mainstream culture in China. Society labels being a MSM as an illness that shapes the stereotypes of MSMs; people separate themselves from MSMs, who are seen as a minority and defective group, and MSMs lose their social status and get stigmatized.

In this circumstance, HIV self-testing is an effective way to protect MSMs and increase the rate of HIV testing. A study shows that South African stake holders, including governmental officials, NGO organizers, and academic researchers, claim that HIV self-testing can scale-up testing rates and has far-reaching positive effects, especially in marginal groups such as MSMs and sexual workers (Makusha *et al.* 2015). From my interviews, a STI physician and the CDC director in Guangzhou also state that HIV self-testing can meet the gap of facility-based

testing and encourage MSMs to get tested. Easy access and private testing make HIV self-testing a new form for intervention which will now be discussed in greater detail.

### **A New Form for Intervention: HIV Self-testing**

HIV self-testing is a tool to know HIV status privately (UNAIDS 2013). On July 3, 2012, the U.S FDA approved in-home HIV testing, which includes the processes of collecting a specimen, performing a test, and interpreting the test results in 20 to 40 minutes.<sup>xiv</sup> There are two types of HIV self-testing: oral and blood testing. The blood testing kit provided in Guangzhou, China, named Lingnanzhun, includes HIV/AIDS and syphilis testing, provided by the Guangzhou Tong Zhi (GZTZ), a MSM Community-Based Organization (CBO).

This research involves 42 MSMs interviewed by researchers from Social Entrepreneurship for Sexual Health (SESH) program to evaluate the effects of HIV self-testing kits among MSMs. This research also includes interviews of six stakeholders: two physicians from Sexually Transmitted Infection (STI) department in Guangdong Provincial Dermatology Hospital, two directors from the Guangdong Centers for Disease Control and Prevention (CDC), and two officers from Guangzhou Tong Zhi (GZTZ), the CBO for MSMs.

According to various studies, HIV self-testing is highly accurate whether administered by oral or blood testing methods (Choko *et al.* 2011; Ng *et al.* 2012). Accuracy of 4<sup>th</sup> generation HIV self-testing can reach 95 percent of infections in 28 days after exposure, although the accuracy needs to be considered within the window period<sup>xv</sup>, which is a time between potential exposure to HIV/AIDS infection and the point when the test will give an accurate result. Xiao Tang, a physician at GZTZ, also confirmed the accuracy of HIV self-testing: “If the process of using HIV self-testing is accurate, following the manual in the kit, then the result is accurate”.<sup>xvi</sup>

The reasons that MSMs choose HIV self-testing are the advantages of privacy and convenience. With HIV self-testing, one can decide when and where to conduct the test. Compared to facility-based testing (including hospital based testing and CBO based testing), self-testing empowers MSMs to actively take control of the process of testing; he does not need to worry about others finding out whether he is HIV positive or if he is gay. The sensitivity about exposure of identity is mentioned by a MSM: “Self-testing is very convenient. You don’t need to worry whether your personal information is going to be leaked. You don’t need to deal with the embarrassment that arises when you test in a hospital or a CBO or CDC.”<sup>xvii</sup> Empowerment is important to MSMs because they live in the shadow

of the mainstream society, in which homosexual marriage is not legal, and the idea of homosexuality is not socially accepted by the majority of the public.

Most of the MSMs we interviewed are not accepted by their family or in their workplaces, so they have to hide their identity. In our interviews, only 3 out of 42 participants had come out to their family; 14 out of 42 do not disclose their sexual orientation to anyone; others come out to their friends or gay friends. As one MSM describes it: “I thought about coming out to my parents and friends, but I decided not to because right now, there is no significance in coming out. I thought about coming out to a close friend, but what’s the point? It’s meaningless because we get along right now. I’ll never come out to my parents. They can’t accept this gay idea. They don’t even understand it.”<sup>xviii</sup> These MSMs prefer not to tell their friends who they are because they are afraid of being rejected, and get themselves into unnecessary trouble. When they test for HIV/AIDS in a hospital, they worry about being judged by the doctors, the nurses and other patients. As an unaccepted group, MSMs gradually silence their voice at work, in the family, and among friends, becoming passive.

Research conducted by Rose Weitz in 1991, argued that the “disclosure of homosexuality seems to result in a release of deep-seated repugnance, fear, and anger that, even in this age of ‘zero tolerance,’ disclosure of drug use does not”

(Weitz 1991,127). Additionally, the most difficult part of being infected with HIV/AIDS is that they know the disease cannot be controlled (Weitz 1991). With the exacerbation of HIV/AIDS, they cannot even control their lives; such as they cannot drink whenever they want, they cannot eat whatever they want, and they cannot hang out with friends as they used to do (ibid). However, by conducting HIV self-testing, MSMs can at least take control of the process of testing that matters to them and gives them confidence, dignity, and empowerment. Robins argues “what is need for AIDS treatment... is a well-resourced and responsible public health system and empowered, knowledgeable and ‘responsibilized’ client-citizens. They are calling for an effective health system together with new forms of community participation and citizenship, or ... ‘government from below’” (Robins 2008, 142). “Government from below” means to give power back to people (including people living with HIV/AIDS, MSMs, and other people), and let them decide ways of testing and treatment. The Chinese government is high centralized and good at playing an active role as educator, or parent, rather than as a servant, to citizens. Let professional health practitioners lead and educate people about HIV/AIDS knowledge, and let people learn to protect and save themselves in the right way are the keys to cultivate responsible client-citizens. HIV self-testing gives this strategy a chance.



Another advantage of HIV self-testing is that it can de-medicalize the process of HIV-testing. According to Conrad, “de-medicalization occurs when a problem is no longer defined as medical, and medical treatments are no longer deemed appropriate” (Conrad 2007, 120). One MSM mentioned that, “when I got tested in a hospital, the most torturing moment is when a doctor is writing the testing prescription. He has a nuanced expression on his face.”<sup>xix</sup> From the MSM’s perspective, going to a hospital for HIV-testing is like admitting you are already a HIV-positive “patient”. The relation between the physician and an individual in a hospital tends to be defined as an unequal physician-patient relationship, which makes MSMs feel more nervousness and panic than in a more personal, controllable environment.

According to symbolic interactionism theory, interaction, which is a process rather than a product of human conduct, is based on “rooted images” (Blumer 1969). A person reacts to others’ language, gestures, or facial expressions every second, even though their relationship is fixed. In a hospital, a rooted image between medical professionals and customers refers to physician/nurse and patient interaction. As physicians have professional knowledge, they hold authority in a physician-patient relationship. The interaction between physicians and people, who are yet to be categorized as patients, makes MSMs

uncomfortable.

Because the hospital environment causes stress for MSMs, they tend to avoid facility-based testing. “When I accompanied my friend getting tested for HIV/AIDS in a hospital, I saw [HIV-positive] patients there waiting for drugs or further examination. The atmosphere was so oppressive and desperate. I saw some patients with masks but there were bruises, the side effects, on their arms. They looked so depressed. I couldn’t stay there for a minute.”<sup>xx</sup> Peter Conrad also emphasizes that illness will result in more stigma if it creates visible and disfiguring changes that seem to transfer a person into something beastly (Conrad 1986). The hospital atmosphere increases fear of HIV/AIDS. Some MSMs decide not to get tested because they do not engage in high-risk sexual behaviors (without condoms or with settled sexual partners), the CBO is far from their homes, and they do not like the pressure in hospitals, even though they know it is necessary to get routine testing. Self-testing becomes their back-up choice and even the first-time testing method for some MSMs. This fear discourages the rates of HIV-testing in hospitals, which is not beneficial for MSMs and the prevention of HIV/AIDS because testing is one of the best ways to achieve successful intervention.

If a man goes to a hospital to be tested for HIV, he will be asked: why he

wants to be tested, whether or not he has had high-risk sexual behaviors, and when he was tested for HIV the last time. If he has been tested within three months, then he cannot make a new appointment. When he enters a hospital to be tested for HIV/AIDS, he is afraid of being recognized, and is worried about being judged by other people. Eight out of 42 interviewed MSMs mention that “if you go to a hospital and tell the nurse that you want to get HIV testing, people will judge you, even nurses and doctors will look at you a couple of times more than others.”<sup>xxi</sup> Although getting tested for HIV/AIDS in Guangzhou is convenient because every district has a free clinic for HIV-testing, MSMs refuse to go because they are afraid of being treated as a gay person or a HIV carrier. MSMs experience enormous pressure about being gay and being HIV positive.

The reason their fear, or the social exclusion of MSMs, is that homosexuality is not beneficial for producing population. Foucault points out the relationship between population and capitalism: the right to decide life and death is controlled by the monarchy, in which bodies are inserted as machinery of production in an economic process (Rabinow ed 1984). This right is biopower, which “the productive power to discipline and regulate both individuals and populations in order to cultivate a strong, healthy society” (Decoteau 2013, 104). Human bodies are an essential link in economic production.

Chinese society relied on agriculture for thousands of years. Before the industrial era, increasing the number of people who produced more agricultural output was important. In the past four decades, the Chinese economy has been based on manufacturing, which also needs a large population of workers. In this sense, homosexuality and its effect on reproduction have always been seen as a factor reducing economic growth. The government uses biopower to control population and economic growth and this is not only happening in China. The South African government once preferred not to pay attention to people with HIV/AIDS because this surplus population was viewed as an obstacle to economic development (Decoteau 2013).

Another critical reason is that the traditional family structure is made up of a woman and a man. However, family structure is influenced by political power aimed to promote economic growth; government regimes constructed the conception of the family to support a prosperous economy. Foucault points out the economy-driven logic in *Madness and Civilization (1961)*, which argues that the reason hospitals were established in the first place was not for treating patients, but for controlling surplus people as well as the general population while maintaining governmental power. A hospital constituted as a source of confinement was due to an economic crisis in seventeenth century France. From

Foucault's perspective, the purpose of a hospital was due to surplus population from an economic crisis. The French government did not know how to cope with these people and was afraid of protests, which posed as a threat to the regime.

Just as the establishment of the French hospital sustained the regime and its stable economy, the Chinese family composition follows the same logic. Before the nineteenth century agricultural age in China, there was a clear division of work between men and women based on their physical abilities. For example, men were seen as better at plowing, which required a robust body. In contrast, women were good at silk-reeling or clothes-making. Women and men were complementary to each other in daily life. In much the same way as the origin of the hospital, the reason for family structure is not because of romance, but because of survival and reproduction. As the family structure became a basis of the economy, political leaders have been stressing the importance of the family, from ancient China to the present. Because of the emphasis, people have gradually shaped a conception of that family as necessary. The idea of a family, comprising a woman and a man, is rooted in tradition, despite the different regimes prevailing over thousands of years. People who are not married are treated as abnormal, unpopular "outsiders", not to mention gay couples.

One of my sample struggles with his sexual identity, defining himself neither

heterosexual, homosexual, nor bisexual: “I’m not sure whether I’m gay or not. I dated a woman before. I like women a lot. I think I’m going to be a good husband and father. A family should be a man and a woman. My parents have a great relationship. It’s so weird that two men live together or even have a kid. People will judge them.”<sup>xxii</sup> The traditional family structure and related social pressures have brainwashed this MSM to feel pain and loss. Under these circumstances, it is easy to imagine how difficult it must be for MSMs to survive in a narrow-minded society. The exclusion of MSMs makes them outsiders with a discredited reputation in Chinese society, and the exclusion leads to segregation and stigma. Peter Conrad argued that discrimination reach its greatest point when illnesses are connected to already stigmatized groups (1986).

Rose Weitz explained that the unique HIV/AIDS stigma is “because HIV disease is contagious, deforming, fatal, imperfectly understood, and associated with groups that already experience stigma, no other contemporary physical illness carries such severe stigma” (Weitz 1991, 126). Stigma over HIV/AIDS branches into two areas: medical and moral. Stigma from the medial area refers to the contagious and lethal nature of HIV/AIDS as a disease. “Illnesses are also likely to be especially stigmatized if no vaccine is available, accurately or inaccurately, they are believed to be contagious” (Weitz 1991, 47).

From a moral perspective, HIV/AIDS is easily associated with marginal and discreditable groups in mainstream culture. This kind of discrimination refers to “symbolic stigma”, which uses HIV/AIDS as a vehicle for expressing hatred towards stigmatized groups (Herek 2002). The reflection on symbolic stigma also distinguishes “them” versus “us”, acting as a declaration of one’s identity in society. Trying to maintain positive social identities is an incentive to stigmatize HIV/AIDS (Devine, Plant and Harrison 1999). In the U.S, MSMs might be viewed as “morally weak and irreverent to religious codes of behavior” (ibid). In China, people value one’s morality in a narrow way. The standard of judging a person is based on whether he or she lives a similar life as the majority does. Mainstream media and the public despise sex workers and assume they are promiscuous and shameless. A study among middle-class urban Chinese shows that half of the participants believe punishment is an appropriate response toward the people living with HIV/AIDS due to their evil behavior (Lee *et al.* 2005).

What is worse, the discrimination against the HIV-positive and MSMs are also from health professionals. In a study, health professionals are less willing to interact with HIV/AIDS patients, compared to hepatitis B patients, in Yunan Province, China (Li *et al.* 2007). Health practitioners consider HIV- infected people are less competent and morally worthy than persons with cancers, diabetes or,

heart disease (Katz *et al.* 1987). A MSM in our sample indicates discrimination from a nurse who drew his blood: “I don’t know why they [health professionals] are so sensitive to the HIV-positive even though they need to face different kinds of contagious patients. It was my first time that a nurse asked me to lift my hand so that the cushion couldn’t physically contact my hand when she was drawing my blood. And I replied directly: your cushion is dirtier than my hand!”<sup>xxiii</sup>

Another MSM reveals his testing experience in Fuyang, Anhui Province, which is a small city in China. “I went to the Fuyang CDC for HIV/AIDS testing. ‘No homosexuality, no HIV/AIDS’ was a sign on the reception desk!”<sup>xxiv</sup> The conception of homosexuality is easily associated with HIV/AIDS. The discrimination from medical professionals is because of the lethal contagious quality of HIV/AIDS and the rejection of homosexuality. A STI physician says:

A lot of hospitals discriminate against HIV/AIDS patients, and they are transferred to our hospital. [Discrimination] is a pervasive phenomenon in the medical profession, even in our hospital. If other departments find out that a patient is HIV-positive through the assay, the first thing they do is to transfer them to the STI department. Therefore, patients might have an awful experience, and refuse to come to the hospital. The reasons for the discrimination, on the one hand, it is that hospital staff do not know how to deal with HIV/AIDS; and most of the doctors have no experience or training for HIV/AIDS. On the other hand, they do not know how to treat people with HIV/AIDS. They think they need to wear protecting clothing. In fact, it is unnecessary to treat the HIV-positive patients differently to other people.”<sup>xxv</sup>



A study taken in Yunan Province, China, reveals that healthcare professionals have a low level of understanding about how the HIV virus is transmitted (Anderson *et al.* 2003). The lack of medical knowledge on HIV/AIDS leads to the fear of it.

However, facility-based testing also has its attractive advantage - accuracy. Facility-based HIV testing can not only test whether you have HIV/AIDS, but also gives you the CD4 count, which is “like a snapshot of how well your immune system is functioning.”<sup>xxvi</sup> Accuracy is the most advantageous factor, which also leads to the question about HIV self-testing: is it accurate enough?

While some MSMs have doubts on this question, a lot of them in Guangzhou are willing to try HIV self-testing because of their trust in Guang Zhou Tong Zhi (GZTZ), which is a MSM CBO focusing on HIV/AIDS testing and bridging homosexual culture to the public knowledge specifically targeting college students. Around 43 percent of interviewees (18 out of 42) directly knew about HIV self-testing via GZTZ (CBO), from its official website and its social network accounts. In comparison, 26 percent of the interviewees were informed about HIV self-testing by other means, such as from friends or other websites, to learn about HIV self-testing. Among these 11 participants, only 4 of them were aware of HIV self-testing kits, which were not the GZTZ’s kit. GZTZ is a vital vehicle that lets

more than half of the interviewed MSMs be familiar with HIV self-testing. “I saw its (GZTZ) website had free-promotion of HIV self-testing. I had never heard of it, and thought to give it a try”; “A friend sent me a link via Wechat [a social networking Application]. GZTZ has a great reputation. So I applied”; “My friend recommended it to me [the self-testing kit]. I looked it up to find out that it’s from GZTZ, which is a proof of quality in the gay group. So I bought it without hesitation”, etc.

They know Guangzhou Tong Zhi (GZTZ), the CBO, has been working with the CDC, who provides HIV self-testing kits for MSM. So they prefer HIV self-testing kits from GZTZ rather than from other online sources. In our interviews, half of the MSMs (22 out of 42) already recommended HIV self-testing kits to their friends. Since September 2014 GZTZ started promoting its kits (Lingnanzhun). Until July 2016, 36 percent of interviewees have used the kit more than three times (15 out of 42). Among these 15 MSMs, 7 of them have no testing experience in hospitals or the CDC. 19 out of 42 participants (45.2 percentage) have neither been tested in hospitals, nor in the CDC. With the convenience from privacy and accuracy, HIV self-testing is their only viable way to get tested. The physician at GZTZ says sales volume of the kit is around 2000 packs last year (2015), and it has been increasing this year (2016), even though the kit is no longer free. The rate of repurchase is also increasing steadily.

HIV self-testing alleviates HIV/AIDS phobia and shortens the process of HIV-testing. Therefore, HIV self-testing carries the potential to increase the rates of testing. More than one MSM stresses:

If there wasn't HIV self-testing, the rates of my HIV testing would probably be not that high. Because of high testing rates, HIV self-testing is like an alarm, which reminds me of HIV and testing. Otherwise, I might think HIV is unrelated to me. It is a change of attitude.<sup>xxvii</sup>

I never go to CDC or a hospital because I don't like it there and I always have condoms. But sometimes I still have worries, especially when my stomach is not feeling well or I have a cold. At these times, I know I really need to be tested. I knew about self-testing online, and thought why not give it a try. And now, HIV-testing becomes a routine matter.<sup>xxviii</sup>

Two MSMs mention using HIV-self testing kits as an emergency back-up plan at first. Then they found HIV self-testing kits are easy to buy and to use, gradually their use becomes a habit and increases their awareness about safety:

I hooked up with a guy via Blued [a social networking APP for homosexual and bisexual men], before we had sex, I gave him a self-testing kit, and we both did the test. I know HIV/AIDS has a window period, but before casual sex, self-testing can screen for the possibility of results which give me comfort. After my first time using the kit, I looked it up and found out it's accurate and easy to buy. Now I've used it more than five times, and I get tested at least every six months.<sup>xxix</sup>

## The GZTZ Model: Government Purchase Service

Interviewees show great trust in Guangzhou Tong Zhi (GZTZ), which is one of the oldest well-known homosexual CBOs in Guangzhou. It has been providing HIV/AIDS and syphilis tests, and linkage to care for more than 10 years. Unlike other NGOs, GZTZ is a government-support organization. Yongheng, the Program Director of GZTZ, says: “GZTZ’s funding is all from public [governmental] organizations”<sup>xxx</sup>. Mr. Cheng, a Guangzhou CDC Director, illustrates why the CDC has been working with GZTZ for more than 10 years, and how they build a good reputation together:

The CDC has a long-time history of cooperation with GZTZ, since 2002. It is dedicated to building homosexual and bisexual cultural circles, which establishes a platform for gay men to communicate. HIV/AIDS is an inevitable topic, at first, we [CDC] gave them money and asked them to promote HIV/AIDS intervention on their website. Even though, they didn’t want to work with us because they were afraid to build their website like a HIV/AIDS website. They have their concerns, I understand. We have been cautious about the HIV/AIDS topic all the time. In the first couple of years, we cooperated with interventions. After intervention, HIV testing was naturally seemed to be necessary. Until 2008, MSM were still very sensitive about HIV/AIDS testing. GZTZ suggested that only an MSM-friendly environment could attract more MSMs. So we sent professional physicians and nurses to GZTZ for instruction and HIV testing. Also, we provide places for them.<sup>xxxi</sup>

With CDC-supported tests, GZTZ has accumulated a lot of faithful MSM clients. When Yongheng first proposed that GZTZ wants to promote HIV self-testing in March 2014, the CDC immediately approved: “We’ve been doing

STD intervention for more than 15 years, so we know about all different kinds of tests. When they [GZTZ] first suggested this [HIV self-testing] idea, we thought, why not? We provide testing kits, and GZTZ is responsible for promotion, as we always do”.<sup>xxxii</sup> The relationship between GZTZ and CDC works on a model known as Government Purchase Service, which is a way to provide social services (Lipsky and Smith 1989).

The best feature of the Government Purchase Service is that it can connect professional support to marginal groups. HIV self-testing kits provided by Guangzhou Tong Zhi (GZTZ) were initially free when MSMs uploaded their test results on the GZTZ’s website until last year. Currently, the reimbursement process enables MSMs to purchase HIV self-testing kits for 145RMB (21 dollars) firstly; after they upload their testing results on the website, they will receive 100RMB (14.5 dollars) refund. Otherwise, MSMs will not receive a refund. This method of self-uploading encourages MSM involvement to promote HIV self-testing. One MSM remarks, “If the [self-testing kit] is free or only 45 [6.6 dollars], I would use self-testing forever!”<sup>xxxiii</sup> The purpose to have MSMs upload testing results is that it is easy for the GZTZ to provide linkage to care. “There are a lot of online shops selling different kinds of HIV self-testing kits, but they lack services: such as instructions before tests, tracing after tests, and information

about how to transfer the HIV-positive cases for medical treatment, etc.”<sup>xxxiv</sup> says Mr. Cheng. The CDC needs to follow up with the HIV-positive cases to assure that they get professional care in the form of tests and medication. HIV self-testing for GZTZ and CDC is a means of service rather than a product.

For HIV self-testing, the GZTZ-CDC model is a way to “legalize” self-testing kits. HIV self-testing is on the edge of the discussion for approval in policy circles. Mr. Cheng explains: “There is no official policy that says HIV self-testing is legal. This type of testing is in a grey area. When our department first mentioned that we’re going to promote HIV self-testing, some leaders worried that we’ll break rules. So we work with GZTZ as an experimental program, and treat HIV-self testing as a service.”<sup>xxxv</sup> Adopted by CBOs or NGOs in Yunnan, Beijing and Shandong<sup>xxxvi</sup>, the model is also a disguise to introduce HIV self-testing to MSMs.

As the CDC’s Director and Guangzhou Tong Zhi’s (GZTZ) Program Director mentioned, HIV self-testing is a service for MSMs, which is another advantage of facility-based testing, especially for CBOs and NGOs. Facility-based testing is performed at a hospital, CDC, and CBO. GZTZ has been providing free HIV-testing for more than 10 years. A lot of MSMs prefer GZTZ because it is a MSM organization, in which they do not need to worry about exposing their identity. Also GZTZ is good at providing linkage to care, which means that the

volunteers give MSM HIV/AIDS related information after the test, and if a MSM is HIV positive, they can immediately give him instructions on how to deal with HIV/AIDS. Linkage to care is crucial to HIV-positive MSMs.

Nowadays in China, people still have phobias and misunderstandings about HIV/AIDS. Wang Ke (alias) who was at the top of Civil Servant Exam in December 2015, was rejected by the Shangrao government, Jiangxi Province, when the supervisor found out that he was HIV positive.<sup>xxxvii</sup> Government discrimination influences public attitudes toward HIV/AIDS. The arbitrary discrimination in the forms of refusal to offer treatment can lead to common cross discrimination (Yang, Zhang, Chan, and Reidpath 2005). A lot of people do not know that HIV/AIDS can be controlled with treatment, which is free and provided by the government. In other words, a lot of people do not know that HIV/AIDS is like a chronic disease, such as diabetes, arthritis, and heart disease. Even if you are HIV-positive, you will not die as long as you take the appropriate medication. Because of this misunderstanding about HIV/AIDS, people may take irrational actions after they find out that they are HIV-positive. However, a HIV-positive participant says:

I found out I'm HIV positive through self-testing at home. I think it's better to find out at home than at GZTZ or hospitals, because at CBO and hospitals, if you are HIV positive, you will be asked to finish a questionnaire. There are a bunch of questions! Such as whether or not you had high-risk sexual behaviors, if you did, when did it happen, and

what is your last time to get HIV testing. These questions make me embarrassed and frustrated. HIV self-testing gave me time to calm down. And I don't believe people will commit suicide if they find out they are HIV positive. Of course we are depressed, but after all we will go to hospitals.<sup>xxxviii</sup>

We take for granted that people need care and encouragement when they find themselves HIV-positive. Expressed as questions and instructions that are also a confirmation which assures the HIV-positive individual will get appropriate treatment and will not take irrational actions. Our institutional and emotional care can bring embarrassment and a burden to such people. In this case, we need to find out another way to make sure that they are encouraged to take rational action. A HIV-positive MSM says: "in this [MSM] community, most of us have HIV-phobia because we are a high-risk group to get it, and I saw a friend of mine died because of HIV/AIDS. He was only in his early thirties. Because we are afraid of it, most of us know about HIV/AIDS and how to deal with it. I was calm when I found I'm positive."<sup>xxxix</sup> As this MSM said, they are afraid of HIV/AIDS more than other people, so they collect information and ways of treatment for the disease. The knowledge supports them to be rational when they get a positive result. It is safe to assume linkage to care is not as critical as people think.

Besides, HIV self-testing can play the role of linkage-to-care to some degree.

The kit can be bought at any time MSMs want to be tested. They are not limited to



the three-month rule (the latest HIV/AIDS test should be three-month after the last test) by facility-based test. HIV self-testing is not only a novel medical way for the testing, but also a placebo for MSMs. One MSM states: “I used to be so afraid of HIV/AIDS that I tested it for four or five times a month with the kit. The hospital or the CDC will not give you the testing unless the testing interval is longer than three months.”<sup>xi</sup> However, using HIV self-testing as a comfort is a concern for the GZTZ and the CDC because it is a way to waste resources. “If MSMs apply as much kits as they want at this cheap price, it is an adverse outcome because it does not benefit them, but also is a way of wasting resources. However, we have no solution for this situation, maybe we need to strengthen HIV/AIDS knowledge to decrease their fear,”<sup>xii</sup> said Yongheng, the Program Director of GZTZ.

Mainstream Chinese society displays a lot of ignorance and hostility towards people living with HIV/AIDS. For these individuals, fears of stigmatization become obstacles to seeking health care (Gostin, Ward and Baker 1997; Chesney and Smith 1999). A study in China shows that fear is the most relevant factor preventing people living with HIV/AIDS from seeking health-care (Leiber *et al.* 2006). Because of the advantages of HIV self-testing, it can encourage MSMs to test their HIV/AIDS status regularly, which can help to reduce their fear of the disease, and treat it in a rational way. As studies have shown, when MSMs treat

HIV self-testing as a placebo, it is the beginning and effective way to decrease the fear of HIV/AIDS.

## **Conclusion**

HIV/AIDS is a worldwide disease has been stigmatized because of its contagious and incurable nature. Weitz's study in 1991 reveals the struggle for people who live with HIV/AIDS- the sense of desperation from social discrimination and the loss of control of both the disease and their own life. At present, stigmatization on HIV/AIDS and its people still exist, especially in countries that lack biomedical education and adequate treatment (ART).

This study compares two developing countries that had HIV/AIDS breakouts, China and South Africa to discuss each country's political system, indigenous treatment, race, gender, and family culture cultivating the knowledge of HIV/AIDS, as well as how the respective countries deal with the illness and its afflicted people. Both of these countries had hegemonic systems that influenced policies on HIV/AIDS to protect regimes. However, HIV/AIDS, as a social problem, is not only related to politics, but also connected to societal structure and culture.

Sexual transmission is a key vehicle for HIV/AIDS, which easily results in

stigmatization for the disease and people who live with it. In South Africa, gender inequality makes women use marriage or sexual relationships as a way for survival; and religion leads to the rejection of condoms; furthermore, indigenous treatment becomes a barrier for people to seek antiretroviral therapy (ART). Similarly, in China, a significant phenomenon is highly prevalent among MSMs, who are under double stigmatization for being homosexual, and being easily connected to HIV/AIDS. This study reveals the stigmatization of HIV/AIDS and on MSMs by interviews with 42 MSMs in Guangzhou, China.

To increase testing rates and decrease stigmatization, Chinese CDC and CBOs use HIV self-testing as a tool for prevention. We find out that, with the CBO as a trustworthy platform, MSMs tend to use HIV self-testing rather than going to facility-based testing sites, because of its confidentiality and accuracy, which are important for marginal groups. Interviews with MSMs give us an opportunity to examine to what degree HIV self-testing can be accepted and how HIV self-testing encourages them to build a habit of testing. South African's scholars and stakeholders also confirm that HIV self-testing has far-reaching effects. In 2016, the HIV self-testing kit has been approved by the South African Pharmacy Council, and is available in retail pharmacies (SA News). The fact that MSMs, as a marginal group in both China and South Africa, are willing to use HIV

self-testing reveals that HIV self-testing holds a potential market for MSMs and other marginal groups. It also can close the gap of a lack of clinics in rural regions of South Africa. This study seeks to advance HIV self-testing for development in the future.

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## Curriculum Vitae

### Siyan Meng

Department of Sociology, Boston University  
617-902-8857 • siyanm@bu.edu

## Education

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### Master of Arts, Sociology, Boston University

*Boston, MA, 2017*

### Bachelor of Law, Sociology, Sun Yat-Sen University

*Guangzhou, China, 2011-2015*

Thesis completed on: "The Influence of Multiple Workplaces on Physician-Patient Relationship"

## Research Experience

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### Research Assistant, SESH: Social Entrepreneurship for Sexual Health, China

*June 2016-August 2016*

- Conducted in-depth interviews with men who have sex with men (MSM) about HIV self-testing.
- Analysed qualitative data with Nvivo.

### Research Assistant, Department of Sociology, Sun Yat-Sen University, China

*2012-2014*

- Conducted interviews and surveys on China Religion Survey, CRS & China Longitudinal Aging Social Survey, CLASS.
- Won third prize in *Sociologist Focus*, a competition that competes for the best social science research in Sun Yat-Sen University.
- Conducted questionnaires, interviews, and data analysis on research: "The Occupational Ambition Survey about City Town Elementary Students."

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## Internship

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### **Program Coordinator, SESH: Social Entrepreneurship for Sexual Health, China**

*May 2015-July 2015*

- Organized events and promoted Video Competition for safe sex with social media.

### **Intern, CCTV (China Central Television), China**

*July 2015 - September 2015*

- Intern for Quality Report Weekly program, Department of Social News.
- Conducted interviews with officers in SAIC (State Administration for Industry and Commerce).

### **Volunteer, Rural Women Development Foundation Guangdong, China**

*2013-2015*

- Taught 20 10-year-old students English and handicraft once a week.

## Skills & Language

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Proficient with Nvivo, Stata, R, and Microsoft suite: Excel, Powerpoint, and Word.  
Fluent in Mandarin and English.