Title
HIV-Related Stigma, Social Support, and Access to Care among People Living with HIV in Rural Anhui Province, China

Author
Lan, Chiao-Wen

Publication Date
2018

UNIVERSITY OF CALIFORNIA

Los Angeles

HIV-Related Stigma, Social Support, and Access to Care among People Living with HIV in Rural Anhui Province, China

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Community Health Sciences

by

Chiao-Wen Lan

2018

ABSTRACT OF THE DISSERTATION

HIV-Related Stigma, Social Support, and Access to Care among People Living with HIV in Rural Anhui Province, China

by

Chiao-Wen Lan

Doctor of Philosophy in Community Health Sciences

University of California, Los Angeles, 2018

Professor Chandra L. Ford, Chair

Background

People living with HIV/AIDS (PLWHA) in rural Anhui Province, China, face tremendous challenges, including HIV-related stigma and lack of social support; but it is unclear exactly how these two factors influence access to healthcare. The purpose of this dissertation is to explain the association between HIV-related stigma and social support relative to access to care in a sample of HIV-infected men and women in rural Anhui Province, China. This study has two distinct parts. The first part is a quantitative study. It examines (a) whether the two dimensions of HIV-related stigma —perceived stigma and internalized shame —are associated with access to care among HIV-positive men and women in rural Anhui Province, China, and (b) whether the three dimensions of social support (i.e., emotional support, tangible support, and affectionate support) are associated with access to care among the same population. The second part of the dissertation

is a critical performance based on ethnodrama strategies as applied to the issue of HIV-related stigma in this region.

Conceptual Model

This study is guided by Andersen's Behavioral Model of Health Services Use with concepts of stigma borrowed from Bruce Link and Jo Phelan as well as Gregory Herek.

Sample

This study used the baseline data of a randomized controlled intervention trial for HIV-affected families in four rural counties in Anhui Province, China. The 32 villages included in Anhui Province were all rural and poor; the residents were primarily farmers. A total of 522 PLWHA aged 30 to 73 years were included. Most of the PLWHA acquired HIV infection through commercial plasma donation in the 1990s.

Data Collection

The data were from Together for Empowerment Activities (parent study). The baseline data were collected between October 2011 and March 2013. All of the data were obtained via computer-assisted personal interviewing (CAPI), which was administered by the trained research staff. The trained research staff asked the respondents questions and entered the data directly into a computer database.

Measures

The main outcome of the quantitative study was access to care. The primary predictor variables were HIV-related stigma and social support: the two dimensions of HIV-related stigma (perceived stigma and internalized shame) and the three dimensions of social support (emotional, tangible, and affectionate support). In addition to demographic variables (age, gender, marital status, educational level), family characteristics (e.g., family annual income) were also included.

Analysis

This was a cross-sectional secondary analysis. Univariate analyses were performed to examine the variables. Descriptive statistics and frequencies were calculated to explore bivariate associations and the sample demographics. The main analyses involved mixed-effects linear regression models to identify predictors of access to care, controlling for demographic characteristics. The descriptive analyses were carried out to explore variable characteristics and bivariate associations. To account for the clustering structure, mixed-effect models with village-level random effects were used to account for the clustering effects within a village. Mixed-effects models were employed to ascertain the extent to which the two dimensions of HIV-related stigma and the three dimensions of social support were associated with access to care, while simultaneously controlling for confounders.

Performance Methods

Based on Conquergood’s five areas of performance studies as well as ethnodrama’s strategies, six elements were included in the program: movement, original text, quotes from people living with HIV/AIDS, and spectacle such as photographs, set, and props.

Results

Quantitative study. Levels of perceived stigma and tangible and affectionate support were associated with access to care. In the main analyses, higher levels of perceived stigma were significantly associated with lower levels of access to care (estimated difference = – 0.08, $p = 0.015$). Conversely, internalized shame was not associated with access to care (estimated difference = –0.01, $p = 0.691$). Higher levels of affectionate support were associated with higher levels of access to care (estimated difference = 0.43, $p < 0.0001$). Conversely, tangible support was negatively associated with access to care (estimated difference = – 0.17, $p = 0.003$). However, emotional support was not associated with access to care (estimated difference = 0.03, $p = 0.373$). Depressive symptoms remained negatively associated with access to care while controlling for demographic variables (estimated difference = – 0.10, $p < 0.001$).

Performance. The performance took place on January 26, 2018, at Kaufman Hall at the University of California, Los Angeles. The performance lasted 25 minutes, followed by questions and discussion for 10 minutes, and a dessert reception afterward.

Discussion

Quantitative study. This study underscores the complexity of HIV-related stigma and social support relative to access to care in rural Anhui Province, China. The findings from the research offer guidance about the dimensions of HIV-related stigma and social support to target in future intervention research.

Performance. In addition to the quantitative analysis, the performance shows that it has the capacity to convey information about these issues in ways that tap into affects and emotions.

Future research should explore ways to build on performance in generating awareness about these issues that warrant further exploration.

Conclusions

Levels of perceived stigma may impact access to care among PLWHA in rural Anhui Province, China. Future study should explore how programs incorporating social support and psychosocial components may defer the adverse effects of the disease for PLWHA in this region. By elucidating the complex relations between HIV-related stigma, social support, and access to care among PLWHA in rural Anhui Province, China, this dissertation highlights implications for HIV-related stigma and social support. Using performance as a method of communicating research provided opportunities to innovate in non-traditional research dissemination, and it could have implications for fostering dialogue between the researchers and the community.

The dissertation of Chiao-Wen Lan is approved.

David H. Gere

Jessica D. Gipson

Li Li

Donald E. Morisky

Chandra L. Ford, Committee Chair

University of California, Los Angeles

2018

TABLE OF CONTENTS

CHPATER ONE INTRODUCTION TO THE DISSERTATION

CHPATER TWO LITERATURE REVIEW

CHAPTER THREE THEORETICAL FRAMEWORK & SPECIFIC AIMS

Quantitative Analysis

Critical Performance

CHPATER FOUR METHODOLOGY

Quantitative Analysis

Critical Performance

CHPATER FIVE RESULTS

Quantitative Analysis

Critical Performance

CHPATER SIX DISCUSSION

Quantitative Analysis

Critical Performance

LIST OF FIGURES

Chapter Two

Chapter Three

Chapter Four

Chapter Five

LIST OF TABLES

Chapter Four

Chapter Five

Appendix

LIST OF ACRONYMS

ART	Antiretroviral therapy
FSW	Female sex workers
MSM	Men who have sex with men
PAR	Participatory Action Research
PLWHA	People Living with HIV/AIDS
PEPFAR	The U.S. President’s Emergency Plan for AIDS Relief

ACKNOWLEDGEMENTS

This research used data from the project conducted by Principal Investigator Dr. Li Li at the University of California, Los Angeles, and the randomized controlled intervention trial was funded by grant number R01HD068165 from the National Institute of Health. This research was supported by the UCLA Fielding School of Public Health Department of Community Health Sciences and the UCLA Graduate Division.

Numerous individuals have contributed to my growth as a public health scholar and have made this work possible. I want to thank each of my committee members for their support. Thank you, Dr. Chandra Ford, for your continued encouragement and guidance throughout this process. Without your support, I would not be where I am today and I am appreciative of your encouragement and inspiration. I also want to thank my minor field advisor, Dr. David Gere, for guiding me as I explore the connections between the arts and health and for always trusting and believing in me. I also would like to thank my committee members:Dr. Donald Morisky for always making himself available to answer my questions and providing timely feedback and Dr. Jessica Gipson for being very supportive during this process and for valuable guidance. Thank you, Dr. Li Li, for your assistance and mentorship throughout my doctoral program. Without your help and guidance, I would not have been where I am today.

Many thanks to the UCLA Semel Institute for Neuroscience and Human Behavior, Center for Community Health. My colleagues at the Center and on Dr. Li Li's team have been my source of support throughout the research process and have contributed tremendously to my growth as a researcher. There will always be a special place in my heart for my time spent at the Center for HIV Identification, Prevention, and Treatment Services. Special thanks to UCLA Arts

and Global Health Center for always being my source of inspiration. I also would like to give heartfelt thanks to the UCLA Department of World Arts and Cultures/Dance for nurturing my passion for the arts and for providing the space for the performance and making it a reality. I would also like to thank my family and friends who have supported me throughout this journey. Thank you for all your continued love.

VITA

Education

2012 – 2014 Master of Public Health, Brown University

2009 – 2012 Bachelor of Sciences, Molecular Environmental Biology

Bachelor of Arts, Comparative Literature, University of California, Berkeley

Professional Experience

2015 – 2018 Graduate Student Researcher, University of California, Los Angeles

2014 – 2015 Teaching Assistant, University of California, Los Angeles

2013 – 2014 Research Assistant, Brown University

Honors and Awards

2017 UCLA Dissertation Year Fellowship

2015 UCLA Graduate Summer Research Mentorship

2013 Brown University Executive Scholars

Selected Peer-Reviewed Publications

1. Li, L., Hien, N., Liang, L-J., Lin, C., **Lan, C-W.**, Lee, S-J., Tuan, N. A., Tuan, L. A., Thanh, D. C., Ha, N. T. T. (2018). Efficacy of communication training of community health workers on service delivery to people who inject drugs in Vietnam: A clustered randomized trial. *American Journal of Public Health*, *108*(6), 791–798.

2. Lin, C., **Lan, C-W**., Li, L, Rou, K. Service providers' adherence to methadone maintenance treatment protocol in China. *International Journal of Drug Policy, 56*: 1.

3. Asanad, K., Zheng, J., Chan-Golston, A., Tam, E., Bhetraratana, M., **Lan, C-W**., Zhao, M., Abdi, R., Abdi, F., Vasti, E., Prelip, M. (2017). Assessing quality of care through client satisfaction at an interprofessional student-run free clinic. *Journal of Interprofessional Care*, *32*(2), 203–210.

4. **Lan, C-W**., Lin, C., Thanh, D., Li, L. (2017). Drug-related stigma and access to care among people who inject drugs in Vietnam. *Drug and Alcohol Review*, *37*(3), 333–339.

5. Li, L, Ji, G., Liang, L-J., Lin, C., **Lan, C-W**., Ji, G., Xiao, Y. (2017). Changes in behavioral outcomes among children affected by HIV/AIDS: Results of a randomized

controlled trial in China. *Journal of Health Psychology.* doi: 10.1177/1359105317746479.

6. Li, L., Comulada, W. S., **Lan, C-W**., Lin, C., Xiao, Y., J, G. (2017). Behavioral problems reported by adolescents and parents from HIV affected families in China. *Journal of Child and Family Studies*, *27*, 365–373.

7. Li, L., Luo, S., **Lan, C-W**., Lin, C., Tuan, L. A., Feng, N., Tuan, A. N. (2017). Alcohol use, HIV treatment adherence, and sexual risk among people with a history of injecting drug use in Vietnam. *AIDS and Behavior, 21*(2), 167–173.

8. Li, L., Ji, G., Liang, L-J., Lin, C., Hsieh, J., **Lan, C-W**., Xiao, Y. (2017). Efficacy of a multilevel intervention on the mental health of people living with HIV and their family members in rural China. *Health Psychology*, *36*(9): 863.

9. **Lan, C-W**., Tavrow, P. (2017). Composite measures of women's empowerment and their association with maternal mortality in low-income countries. *BMC Pregnancy and Childbirth*, *17*(2):337.

10. **Lan, C-W**., Scott-Sheldon, L. A. J., Carey, K. B., Johnson, B.T., & Carey, M. P. (2017). Prevalence of alcohol use, sexual risk behavior, and HIV among Russians in high-risk settings: A systematic review and meta-analysis. Manuscript submitted to *International Journal of Behavioral Medicine*, *24*(2), 180–190.

11. Li, L., Comulada, W.S., Lin, C., **Lan, C-W**., Cao, X., Wu, Z. (2016). Report on provider-client interaction from 68 methadone maintenance clinics in China. *Health Communication*, *11*(32), 1368–1384.

12. Li, L., Ji, G., Lin, C., Liang, L-J., **Lan, C-W.** (2016). Antiretroviral therapy initiation following policy changes: Observations from China. *Asian Pacific Journal of Public Health*, *28*(5), 416-422.

13. **Lan, C-W**., Li, L., Lin, C., Feng, N. (2016). Community disclosure by people living with HIV in rural China. *AIDS Education and Prevention*, *28*(4), 287–298.

14. **Lan, C-W,** Fiellin, D.A., Barry, D.T., Bryant K.J, Gordan, A.J., Edelman, E. J., Gaither, J. R., Maisto, S.A., Marshall, B.D.L. (2016). The epidemiology of substance use disorders in US veterans: A systematic review and analysis of assessment methods. *The American Journal on Addictions*, *25*(1), 7–24.

15. **Lan, C-W**, Scott-Sheldon, L. A. J., Carey, K. B., Johnson, B.T., & Carey, M. P. (2014) Alcohol and sexual risk reduction interventions among people living in Russia: A systematic review and meta-analysis. *AIDS and Behavior*, *18*(10), 1835–1846.

CHAPTER ONE

INTRODUCTION TO THE DISSERTATION

1.1 Purpose

This study proposes to explore the ways in which HIV-related stigma and social support may affect the patterns of care access among people living with HIV/AIDS (PLWHA) in rural Anhui Province, China. This study has two distinct parts. The first part is a quantitative study. The aims of the quantitative study are two-folds: (a) to examine whether the two dimensions of HIV-related stigma are associated with access to care among PLWHA in rural Anhui Province, China, and (b) to examine how the three dimensions of social support are specifically associated with access to care among PLWHA in rural Anhui Province, China.

The second part of the dissertation is a critical performance based on ethnodrama. The performance, drawn from the quantitative analysis of the dissertation, aims to go beyond the empirical data and incorporates minor field studies offered in the Department of World Arts and Cultures/Dance. The findings provide a deeper understanding of the challenges faced by PLWHA in rural Anhui Province, China, and provide a foundation for the future development of targeted interventions.

1.2 Statement of Problem

In recent years, increased rates of survival and improved health status have been attributed to the use of antiretroviral medication, thus transforming HIV infection from a fatal diagnosis into a manageable chronic illness (Deeks, Lewin, & Havlir, 2013). Yet, many countries continue to face challenges in increasing access to care for PLWHA (Mugglin et al., 2012). China, in particular, is especially burdened by persistent disparities in care access and widespread HIV-related stigma (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). By the end of 2015, there were approximately 577,000 PLWHA in rural China (China CDC, 2016). Stigma and discrimination are among the foremost barriers to HIV prevention, treatment, care, and support (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014). There is an urgent need to improve access to healthcare for PLWHA (UNAIDS, 2015). In response to the HIV epidemic in rural China, in 2003, the government expanded what had initially been a community-based free HIV treatment, care, and prevention program to the entire nation (Zhang et al., 2007). While local governments are mandated to support medical care for HIV/AIDS patients, challenges remain to link HIV-positive individuals to recommended care and treatment, especially in rural areas where resources are limited (Zhang et al., 2007).

1.3 Specific Aims

The goal of the research is to identify and understand the relationship between HIV-related stigma and access to care and between social support and access to care among HIV-positive men and women in rural Anhui Province, China. This research is guided by a multilevel conceptual framework that examines the effects of individual, interpersonal, and family factors on healthcare access. The Specific Aims of the study are as follows:

Aim 1: To determine whether the two dimensions of HIV/AIDS-related stigma, (a) perceived stigma and (b) internalized shame, are associated with access to care among HIV-positive men and women in rural Anhui Province, China.

Aim 2: To determine whether the three dimensions of social support—(a) emotional support, (b) tangible support, and (c) affectionate support—are associated with access to care among HIV-positive men and women in rural Anhui Province, China.

1.4 Significance

1.4.1 HIV Epidemic in Rural China

The epidemic of HIV/AIDS has spread dramatically in China since the first AIDS case was identified in the mid-1980s (Wu, Rou, & Cui, 2004). Previously, HIV infection had largely been confined to certain high-risk populations such as people who inject drugs and former blood and plasma donors (Wu, Sullivan, Wang, Rotheram-Borus, & Detels, 2007). However, recent surveillance has found that HIV prevalence has increased rapidly in other populations, including commercial female sex workers and men who have sex with men (Gill, Huang, & Lu, 2007). China’s public health surveillance system for HIV, which was established in the late 1980s and used a computerized system to monitor the HIV epidemic at various levels in the country (Zhang, Chow, Zhang, Jing, & Wilson, 2012). UNAIDS (2013) reported 28,000 AIDS-related deaths in China in the year 2011 alone (UNAIDS, 2013). By 2015, approximately 577,000 people living in China were reported as having HIV/AIDS, and there were 159,000 HIV/AIDS-related deaths (National Health and Family Planning Commission [NHFPC], 2015). Also problematic, there were an estimated 322,000 undiagnosed HIV infections in the same year (NHFPC, 2015). Treatment, care, and support challenges still prevail in the country.

1.4.2 The Effect of Stigma on Access to Care

Stigma is defined as the dehumanization of the individual based on their social identity or participation in a negative or undesirable social category (Goffman, 1963). The link between stigma and decreased access to healthcare and negative health outcomes is well documented in the literature. For instance, Hatzenbuehler and colleagues (2013) found that stigma continues to impact health and potentially contribute to health disparities. Other researchers have also found that in many communities, stigma deters individuals from seeking out preventive care services, including talking to primary care providers and attending drug treatment programs (Calsyn et al., 2004; Ojeda & McGuire, 2006; Riley et al., 2002). The significant stigma associated with HIV/AIDS also discourages HIV-infected people from seeking help and the healthcare services they need (Schuster et al., 2005). Furthermore, stigma may also prevent individuals from disclosing their drug use problems to their healthcare providers, the very issue leading to their need for care, thereby endangering their health (Kurtz et al., 2005; Ross, Timpson, Williams, Amos, & Bowen, 2007).

Specifically, stigma has been found to be associated with diminished access to treatment and care, lower rates of medication adherence, and poorer mental health (Sayles et al., 2009; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Young, Stuber, Ahern, & Galea, 2005). In a qualitative study conducted in South Carolina, researchers (Vyavaharkar, Moneyham, & Corwin, 2008) found that rural African American women reported perceived stigma and discrimination among their HIV healthcare providers and were more likely to report poorer health, being less satisfied with care, and having more depressive symptoms. Poor health outcomes influenced by HIV-related stigma underscore the need for culturally competent HIV/AIDS medical services. As a result, HIV-related stigma remains a barrier to care by impeding entry into the healthcare system, reducing treatment adherence, and delaying initiation of treatment (Ahern, Stuber, & Galea, 2007).

1.4.3 Challenges Associated with Access to Care among PLWHA in Rural China

China’s government sought to implement healthcare reforms, and since their implementation in 2009, these reforms have shown significant effects in increasing the number of insured Chinese (Yip et al., 2012). However, tremendous health inequalities persist between rural and urban areas of China (Li, Ji, Lin, Liang, & Lan, 2016). Whereas Chinese people living in urban cities have access to state-of-the-art care, about half of all Chinese people live in rural areas and generally have lower socio-economic status than their urban counterparts (Li et al., 2016). As a result, people in rural areas encounter more difficulties in accessing health services (Meng & Xu, 2014).

With the advances in HIV therapy and care, including expanded access to antiretroviral drugs, linking HIV-infected individuals to appropriate care and treatment has become a critical issue, particularly in low-resource settings. The standard of care for PLWHA in rural China includes a regular follow-up twice a year with a physical check-up and CD4 test (China CDC, 2016). Patients with AIDS are followed-up six times the first year and twice thereafter (China CDC, 2016). Antiretroviral treatment (ART) is provided for free (China CDC, 2016). Incorporating the theoretical framework of stigma will assist in gaining a better understanding of the complex relationships between HIV-related stigma, social support, and healthcare access disparities.

1.5 Overview of Dissertation

This dissertation has two parts. Part I is a quantitative secondary data analysis and Part II is a critical performance as well as analysis. The dissertation is composed of six chapters. Chapter 2, the Literature Review, discusses the literature on HIV-related stigma and known factors that influence access to care. Chapter 3 presents the study's conceptual model, which guides the conceptualization of the hypothesized relationships and analyses of the study. The model integrates Andersen's Behavioral Model of Health Services Use and the constructs of stigma offered by Link and Phelan. The chapter also includes the literature on critical performance theory. Chapter 4, Methodology, describes the study's data sources, measures, samples, and analysis plan. The process of creating the performance is also described. Chapter 5, Results, presents the findings of the quantitative analyses as well as the critical performance.

Lastly, Chapter 6, Discussion, interprets the findings from the quantitative study and includes implications for research and practice as well as strengths and limitations. It also integrates the critical performance discussion taking place at the event along with performance reflection and critical performance analysis and offers suggestions about the incorporation of performance into HIV prevention research. The chapter closes with a conclusion based on the entire dissertation project.

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview

This chapter is composed of eight sections in which the literature is reviewed. Also, gaps and limitations are identified in the field to which this study responds. Section 2.2 is a brief summary of the history of the HIV epidemic in China and the historical HIV epidemic in rural Anhui Province, China. Section 2.3 is an overview of HIV-related stigma, its impact, and the factors related to it as documented in the literature. Section 2.4 is an examination of the extant research on social support among HIV-positive individuals. Section 2.5 is an examination of the access to care in rural Anhui Province, China. Section 2.6 is a summary of how performance has been integrated into the field of public health. Section 2.7 shows the gaps in the literature. The chapter closes with Section 2.8, a brief summary.

2.2. Brief Summary of the History of the HIV Epidemic in China

The HIV epidemic has spread dramatically in China since the first case of AIDS was identified in 1985 in a dying tourist (Wu et al., 2004). In 1989, the first indigenous HIV/AIDS cases were reported in people who used heroin in Yunnan Province, on the southwest border of the country (Ma et al., 1990). In the following years, HIV spread from Yunnan Province to neighboring areas, from people who injected drugs to their sexual partners and children (Wu et al., 2007). The second outbreak of the HIV epidemic occurred in commercial plasma donors in the east-central provinces in the mid-1990’s, such as Anhui, Henan, Hubei, and Shanxi (Wu, Rou, & Detels, 2001). By 1998, HIV had reached all 31 provinces in the country (China Ministry of Health, 2004).

Between 1995 and 2000, there was a 30% annual increase in HIV and AIDS cases reported in the country (Li, Wang, Williams, & He, 2009). In 2008, AIDS also became the first leading deadly infectious disease in China (Ministry of Health of the People's Republic of China, 2010). At first, the epidemic was concentrated among high-risk populations, namely injection drug users and female sex workers (FSW; Liu, Dumenci, Morisky, Xu, Li, Jiang, 2016; Liu, Morisky, Lin, Ma, Jiang, & Yin, 2016). However, by the end of 2014, the epidemic was no longer contained in certain high-risk populations. For instance, the country had an increase of older PLWHA with heterosexual contact as a dominant transmission mode (Liu, Lin, Xu, Chen, Shi, & Morisky, 2012). By 2015, there were approximately 501,000 reported cases of PLWHA across the country (National Health and Family Planning Commission of the People's Republic of China, 2015).

2.2.1 Historical HIV Epidemic in Rural China

The spread of HIV infection across the general population in the rural east-central provinces in China in the mid-1990s is largely attributed to commercial plasma donations and blood transfusion (Ji, Detels, Wu, & Yin, 2006). During the late 1980s and early 1990s, thousands of illegal commercial plasma collection centers were established in rural areas (Wu et al., 2001). During the late 1980s, commercial blood and plasma donation was a simple and quick opportunity for the rural poor to alleviate their financial predicament (Xu et al., 2007). Most of the commercial plasma donors were rural farmers who participated in this practice in order to augment their income. They were paid 50 yuan (equivalent to about USD 7) for their plasma and 200 yuan (equivalent to about USD 30) for their blood (Xu et al., 2007). Plasma donation was more popular since it could be done more frequently than blood donation. The plasma collection centers paid plasma donors to donate blood (usually 800 ml), removed their plasma, then re-infused the red blood cells back to the donors to prevent anemia that can occur from repeated donations (Wu et al., 2001). The unsafe practice of pooling blood and re-infusing red blood cells into donors of the same blood types caused a rapid spread of blood-borne diseases, including hepatitis B and C, and HIV since HIV-1 antibody testing was not required prior to 1995 (He & Detels, 2005).

When the government realized the process had become the major driver of the HIV epidemic, the collection centers were shut down, and new laws were introduced to regulate the blood donation industry (Wu et al., 2001). Unfortunately, however, it has been estimated that about 55,000 former plasma donors had already contracted HIV, accounting for 8.5% of HIV cases at the end of 2005 (Ministry of Health of China, 2005). Although these practices ended more than two decades ago, the history of this HIV outbreak continues to impact many rural areas in the country. In particular, the areas that were most impacted were Anhui, Henan, Shanxi, Hebei, and Hubei Provinces (State Council AIDS Working Committee Office, UN Theme Group on HIV/AIDS in China, 2004).

2.2.2. HIV Epidemic in Anhui Province, China

Anhui Province is located in the northwest corner of Eastern China (Figure 2.1). It has a population of over 61 million in 56 counties, of which many are rural and poor. Anhui is one of the 10 provinces with the highest rates of HIV in China. In 2005, it was estimated that there were approximately 50,000 PLWHA living in this region (Lu et al., 2006). As previously mentioned, most existing infections (over two-thirds) were caused by paid plasma donation in rural areas in the 1990s (Wu, Liu, & Detels, 1995; Wu, Rou, & Detels, 2001). Moreover, it has also been found that infection rates for former plasma donors in this region range from 15.2% to 25.9% (Ji et al., 2006; Yan et al., 1999; Zheng et al., 2000).

Figure 2.1. Map of Anhui's location in China

2.3. HIV-Related Stigma: Overview of the Literature

Following the devastating HIV epidemic were the impacts of HIV-related stigma experienced by individuals and their family members. Globally, stigma related to HIV is the foremost barrier to HIV prevention, treatment, care, and support (UNAIDS, 2014). In particular, fear of stigma is linked to infected individuals not disclosing their HIV-positive serostatus, which undermines their ability and willingness to access and adhere to treatment. Consequently, this discourages individuals, families, and communities to address the disease effectively.

2.3.1. Stigma

Stigmatization is a complex process that contains cognitive, emotional, and behavioral aspects (Bos, Schaalma, & Pryor, 2008). The term *stigma* dates back to the Greeks, who cut or burned marks into the skin of criminals, slaves, or traitors, a process that was “designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1963, p. 1). Yet, the term today does not merely reflect a physical mark but rather an attribute that results in social disapproval (Bos et al., 2013). One of the earliest writings on the concept of stigma came from Erving Goffman (1963), who defined stigma as the dehumanization of the individual based on the person’s social identity or participation in a negative or an undesirable social category. Goffman described the occurrence of stigma as when an attribute creates a deeply discrediting gap between who we think we are (“our actual social identity”) and how we are seen by others (our “virtual social identity”). Thus, “spoiled identity” is created that cuts the stigmatized person “off from the society and from himself, so that he stands as a discredited person facing an unaccepting world” (Goffman, 1963, p. 19). Goffman focuses on the socially constructed meaning of the mark and describes stigma as possessing an attribute that marks the person as different from the rest of the community or its understanding of “normalcy.” Link and Phelan (2001) later proposed a sociological definition of stigma as a broad umbrella concept that links interrelated components.

Researchers lack consensus regarding the definition, construct, and types of stigma (Link & Phelan, 2001; Livingston & Boyd, 2010; Livingston, Miline, Fang, & Amari, 2011). Recently, researchers have posited several types of stigma, including perceived, public, enacted, and internalized stigma (Kulesza, Larimer, & Rao, 2013). *Perceived stigma* refers to a process whereby stigmatized individuals think that most people believe common negative stereotypes about individuals belonging to the same category as they do (e.g., people think PLWHA should leave their villages; Livingston & Boyd, 2010), whereas *internalized stigma* has been defined as negative thoughts, feelings, and diminished self-image that emerge from identification with a stigmatized group and their resulting behavioral impact (e.g., avoidance of treatment, failure to seek employment; Corrigan, Watson, & Barr, 2006; Herek, 2007; Luoma et al., 2007). For the person being stigmatized, internalized stigma may occur when individuals begin to expect the application of the stereotype and fear of rejection.

2.3.2. HIV-Related Stigma

People infected with HIV experience complex forms of related stigma (Churcher, 2013; Li et al., 2009). Stigma related to HIV/AIDS can be defined as “prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS” (Herek, 1999, p. 122). Fear, ignorance, lack of knowledge, and denial about HIV/AIDS have led to reactions that have had tragic effects on individuals, families, and communities (Malcolm et al., 1998). First, HIV/AIDS was called the “gay plague.” Then, Haitians were stigmatized as “AIDS carriers.” Then, there was a discursive construction of “African AIDS” in the media (Barnett, Whiteside, & Whiteside, 2002). One of the key factors contributing to HIV-related stigma is that HIV/AIDS is associated with behaviors that are already stigmatized (Hatzenbuehler, Nolen-Hoeksema, & Erickson, 2008). For instance, drug abuse was associated with HIV about five years after the initial diagnosis of AIDS; then, the disease was stigmatized as being associated with sexual promiscuity (Hatzenbuehler et al., 2008).

2.3.3. Factors Contributing to HIV-Relate Stigma

Previous studies have identified several factors related to the stigmatization of PLWHA. First, the perceived contagiousness of HIV is related to fear and stigmatization (Malcolm et al., 1998). Many people respond with fear and social rejection despite the fact that the disease is not contagious in everyday contact. Second, people tend to respond negatively to PLWHA because the disease was once thought of as a death sentence. Next, perceptions of responsibility are related to stigmatization. For example, people tend to stigmatize PLWHA for being personally responsible for the onset of the disease as a result of immoral behaviors (e.g., unsafe sexual behaviors and injecting drug use; Hatzenbuehler et al., 2008). Empirical studies have shown that HIV-related stigma is associated with negative feelings, beliefs, and attitudes toward people with HIV/AIDS (Herek, 1999). In a study conducted in China, researchers (Li, Lin, & Ji, 2016) also found that HIV-infected females reported significantly higher internalized shame than males.

2.3.4. HIV-Related Stigma and Routes of Infection

The routes of HIV infection may also impact HIV-related stigma (Cao et al., 2006; Valdiserri, 2002; Wong, Holroyd, & Bingham, 2011; Wong & Syuhada, 2011). Reporting results of their qualitative study conducted in Malaysia, Wong & Syuhada (2011) found that HIV infection by drug injection or sexual promiscuity, such as commercial sex work, was deemed as a punishment on the individuals for their immoral lifestyles, whereas PLWHA who were infected by medical accidents (e.g., blood transfusion) were considered as “innocent” or “blameless” victims.

Historically in China, HIV/AIDS largely has been concentrated in three populations: (a) injecting drug users, (b) commercial sex workers; and (c) former plasma donors (State Council AIDS Working Committee Office & UN Theme Group on HIV/AIDS in China, 2004). For the first two groups, HIV-related stigma is linked to their engagement in illegal behaviors. A previous study (Zhang et al., 2016) conducted in southwest China showed that PLWHA who were infected with HIV via drug injection had higher HIV-related stigma than their peers who were infected via some other routes (e.g., sex with stable partners), whereas sex with commercial sex workers increased the HIV-related perceived and internalized stigma.

In contrast, former plasma donors sold their blood or plasma (or both) as a way to augment their income and support their families (Wu et al., 2001), a practice that is considered socially undesirable but not as unacceptable as commercial sex work or drug use (Cao et al., 2006). A previous study (Gao et al., 2004) conducted in China also showed that many people sympathize with former plasma donors and do not view their behavior as immoral. Furthermore, former plasma donors are even seen as the “innocent” or “blameless” group that was affected by HIV/AIDS, similarly to transfusion patients who are generally judged less harshly (Alonzo & Reynolds, 1995). However, despite the notion that former plasma donors may not be seen as “immoral” as those who engage in commercial sex work or drug use, HIV-related stigma still persists even in areas where plasma donation was the primary route of HIV infection (Cao et al., 2006). In a study conducted in rural China where HIV infection among plasma donors had been reported, Qian et al. (2007) documented that although most residents in the community were familiar with the main routes of HIV infection being plasma donation, substantial misconceptions still existed about the risk of HIV transmission through casual social contacts, thus contributing to the persistence of HIV-related stigma ().

2.3.5. The Impacts of HIV-Related Stigma

Although treatment advances have turned HIV into a chronic and manageable condition, HIV-related stigma persists (Bond, Chase, & Aggleton, 2002). The HIV-related stigma continues to be a major barrier to the effectiveness of HIV prevention, care, and treatment programs and may negatively affect healthcare in a variety of ways (Bond et al., 2002; Kalichman & Simbayi, 2003; Kinsler et al., 2007). Stigma inhibits voluntary HIV testing and counseling (Kalichman & Simbayi, 2003), as well as prevents PLWHA from disclosing their seropositive status to sexual partners, family, and friends (Liu et al., 2006). It has tremendously negative effects on social relationships, access to resources, social support, as well as the psychological well-being of PLWHA (Nyblade et al., 2003; Ogden & Nyvlade, 2005). Herek, Saha, and Burack (2013) highlight the importance of recognizing the potentially negative consequences of self-stigma on the psychological well-being of PLWHA. For instance, self-stigma is correlated with low self-esteem and, thereby, leads to depression, anxiety, and other forms of psychological distress (Herek, 2009; Link, Castille, & Stuber, 2008).

The stigma associated with HIV may severely affect both physical and mental health of PLWHA (Li et al., 2009), and may negatively impact PLWHA's access to healthcare, as well as medication adherence (Li, He, & Wang, 2007). PLWHA may avoid AIDS-related services to protect themselves and their families from stigmatization and social discrimination (Liu & Choi, 2006). The impact of HIV is not only on individuals, but also extends to their family members and children (Murphy, Austin, & Greenwell, 2007). Literature shows that children who have lost one or both caregivers to HIV, or children living with HIV-positive caregivers, are at high risk for mental health problems and poor developmental outcomes (Cluver, Orkin, Gardner, & Boyes, 2012; Doku, 2009; Forehand et al., 2002).

2.3.6. Efforts to Reduce HIV-Related Stigma

In response to the impacts of HIV-related stigma, stigma reduction became a key priority in the U.S. President’s Emergency Plan for AIDS Relief’s (PEPFAR; 2012) blueprint for achieving an AIDS-free generation and in UNAIDS’ HIV investment framework (PEPFAR, 2012; Schwartländer et al., 2011). The first global review of interventions to reduce HIV-related stigma showed that most studies attempted to increase the general public’s tolerance or health providers’ willingness to treat PLWHA (Brown, Macintyre, & Trujillo, 2003). Various forms of stigma interventions have continued to be developed and implemented in the field worldwide (Li et al., 2013; Nyblade et al., 2008; Uys et al., 2009). For example, in a study conducted in Uganda, researchers (Mburu et al., 2013) found that groups of PLWHA working collectively to reduce stigma in their communities bolstered confidence among members, reduced self-stigma, and improved group members’ ability to deal with external HIV stigma when encountered. Additionally, there have also been efforts to reduce HIV-related stigma in China over the years. For example, an intervention conducted in 40 county-level hospitals in two provinces of China resulted in significant improvement in reducing service providers’ stigmatizing attitudes and behaviors toward PLWHA (Li et al., 2013). The considerable progress made in the stigma-reduction field was documented in a systematic review of HIV-related stigma interventions from 2002 to 2013, yet the review also showed the critical challenges and remaining gaps that impede identification of effective stigma-reduction strategies that can be implemented by a national government on a larger scale (Stangl, Lloyd, Brady, Holland, & Baral, 2013).

2.3.7. HIV-Related Stigma Measurements

Alongside a lack of consensus among researchers regarding the definition and various types of stigma mentioned previously, the researchers also lack agreement about how to measure the various domains of HIV-related stigma (Grossman & Stangl, 2013). This is evidenced by how HIV-related stigma is conceptualized and measured in a wide range of studies (Berger, Ferrans, & Lashley, 2001; Holzemer et al., 2007; Kalichman et al., 2009). For example, Berger's HIV Stigma Scale uses a measure of stigma as perceived by PLWHA that consists of 40 items with four subscale: including personalized stigma, disclosure concerns, negative self-image, and public attitudes (Berger et al., 2001). Similar to Berger's HIV Stigma Scale, several studies have focused on measuring the perceptions of PLWHA about HIV-related stigma (Clark, Linder, Armistead, & Austin, 2003; Derlegaa, Winstead, Greene, Serovich, & Elwood, 2002; Preston et al., 2004; Swendamen, Rotherma-Borus, Comulada, Weiss, & Ramos, 2006). In a few studies, researchers (Berger et al., 2001; Fife & Wright, 2000; Swendeman et al., 2006) measured *enacted stigma*, the actual stigma experienced among PLWHA. Items used to assess HIV-related *perceived stigma* can be divided into two categories: (a) fears of what would happen if others knew about their status and (b) expectations of what "others" would think or how they would behave. *Internalization of stigma* was also measured in several aforementioned studies (Berger et al., 2001; Fife & Wright, 2000; Lee, Kochman, & Sikkema, 2002; Swendeman et al., 2006). The existing literature provides a good basis on which to build and test measures of HIV-related stigma, although studies are needed in a wider variety of contexts as well as on a larger scale (Nyblade, 2006).

2.3.8. HIV-Related Stigma in China

HIV-related stigma is widespread in China (Yang, Zhang, Chan, & Reidpath, 2005). Even worse, negative attitudes toward PLWHA continue to hamper prevention and control efforts made by the Chinese government (Hesketh, Zhu, & Duo, 2002). PLWHA in the urban areas lose jobs or are unable to continue their education as a result of their HIV status disclosure (Ding & Han, 2006). Exclusion and isolation are the primary manifestations of HIV-related stigma in rural areas in China (Cao, Sullivan, Xu, & Wu, 2006), where most people would decline the opportunity to talk or eat with an HIV-infected individual (Gao et al., 2004). Although the Chinese government has already established anti-discrimination policies in the country, various forms of HIV-related stigma are still being reported. For instance, a study surveying 780 health professionals in Yunnan Province, a Province that accounts for 40% of all official HIV/AIDS reports, showed that 23% of the participants thought of HIV as a disease of "low-class and illegal" people, 48% thought that PLWHA should not be allowed to get married, and 30% of the participating providers were unwilling to treat an HIV-infected individual (Hesketh, Duo, Li, & Tomkins, 2005). Moreover, a HIV-positive teacher was turned down for a job in 2010 because the civil service's recruitment policy states that applicants with HIV cannot be hired, which violates the employment promotion law in the country (Wines, 2010).

2.4. Social Support among HIV-Positive Individuals

Social support can be subdivided into structural and functional aspects of support (Uchino, 2004). Structural support includes the size, type, contact, and density of social networks, whereas functional support consists of the capacity of relationships to fulfill particular functions, including providing affection, a sense of belonging, or material aid (Uchino, 2004). Social support consists of various dimensions, including emotional support, tangible support, and affectionate support (Langford, Bowsher, Maloney, & Lillis, 1997). Emotional support refers to when one receives warmth and comfort in a social context (Heaney & Israel, 2008). Tangible support occurs when needed services or goods are offered (Kelly, Hartman, Graham, Kallen, & Giordano, 2014). Social support can mitigate the negative impacts of stress and hardships on PLWHA (Li et al., 2006).

Research has showned that social support can influence health service utilization and other health-related behavior (Berkman, Glass, Brissette, & Seeman, 2000). Social support is one of the factors impacting patients' access to care (McCoy et al., 2009). Previous studies have shown that social support plays a positive role in promoting people's health condition, both physically and psychologically (Broadhead et al., 2002; Carrieri et al., 2003). Studies have indicated that among PLWHA, as with other chronically ill populations, social support is associated with medical service utilization, adherence to ART, risk and other health-related behaviors (Broadhead et al., 2002; Carrieri et al., 2003; Knowlton et al., 2007). Additionally, past research in the United States has shown that higher social support is inversely associated with lower levels of perceived HIV-related stigma reported by HIV-positive individuals (Galvan, Maxwell, Davis, Banks, & Bing, 2008). However, little is known about this relationship in non-Western contexts.

Furthermore, lack of social support is associated with lower adherence to ART (Atkinson, Schönnesson, Williams, & Timpson, 2008; Krousel-Wood et al., 2010). Evidence also exists that tangible support (e.g., someone who assists with medication refills) is linked to adherence to ART (Ulett et al., 2009; Vyavaharkar et al., 2007). Additionally, some evidence exists on how social support can impact linkage to HIV care after diagnosis (Anthony et al., 2007). For instance, in a study conducted in North Carolina, researchers (McCoy et al., 2009) found that limited social interactions (e.g., not having someone to enjoy life with) were associated with delays in HIV care. However, the relationship between social support and linkage to care has been mixed. A randomized controlled trial conducted in four major cities in the United States showed that participants who reported having someone helping them to get into care were significantly more likely to see a healthcare provider (Gardner et al., 2005). However, social support among PLWHA who use drugs was not associated with linkage to care (Bell et al., 2010). Inconsistencies in previuos intervention outcomes suggest the need for distinguishing correlates of optimal and sub-optimal medical service utilization (Knowlton, Hua, & Latkin, 2005).

Given that China is a family-oriented society (Cao, Chen, & Fan, 2011), social support can play a major role in determining access to care among HIV-positive individuals. Literature also shows that social support is found to be an important coping resource in Chinese patients with chronic illness (Molassiotis, Chan, Yam, & Chan, 2000; Pang, Ip, & Chang, 2001). A previous qualitative study conducted in rural Anhui, China showed that families can provide psychological support and financial assistance to their infected family members (Li et al., 2006).

2.5. Access to Healthcare in Rural Anhui, China

The lack of access to and low utilization of HIV treatment are detrimental to individuals infected with the virus as well as to the communities in which they live (Lima et al., 2008). In rural China, many of the former plasma donors have been infected for more than 10 years, and many have advanced to AIDSs and are in need of frequent treatment (Zhang et al., 2007).

China’s responses to the HIV epidemic have been evolving since the start of the epidemic. In particular, treatment policies in the country have changed over time (Li et al., 2016).

First, in 2002, the Chinese government initiated a pilot program for free HIV treatment, care, and prevention called China CARES, which was later expanded to the entire country in 2003 and became the current National Free Antiretroviral Treatment Program (Zhang et al., 2007). Later in 2003, the Chinese government implemented a national HIV policy called “Four Frees and One Care” to provide free antiretroviral drugs (domestically produced) for PLWHA with financial difficulties, including those who are rural residents or uninsured urban residents (Wu et al., 2007; Wu, Wang, Detels, & Rotheram-Borus, 2010). The “Four Free and One Care” policy includes the following: (a) free antiretroviral treatment for AIDS patients who are rural residents or people with financial difficulties who reside in urban areas, (b) free voluntary counseling and testing, (c) free services to provide newborns testing and to prevent mother-to-child transmission, (d) free schooling for AIDS orphans or children of PLWHA, and (e) care and economic assistance to the household of people living with HIV/AIDS (State Council AIDS Working Committee Office, 2004). Specifically, the local government provides financial support for HIV-positive residents, in the form of 50 to 80 yuan per month for all patients infected with HIV, and an additional 100 to 150 yuan per month for those patients on ART. Antiretroviral drugs are freely available to patients with AIDS through the local China Center for Disease Control and Prevention (CDC).

Although providing ART free of charge is an important step, other factors such as HIV-related stigma and cost of the components of care continue to create barriers to access appropriate care (Zhang et al., 2007). This could lead to undesirable outcomes, including impoverishment of AIDS-affected families, higher drug-resistant rates (Sungkanuparph et al., 2007), and the need for more complex, second-line antiretroviral treatment (fixed doses co-formulated combination of AZT/3TC/ABC and lopinavir/ritonavir [LAP/r] are the second-line medicines available for use in China; Wang et al., 2015; Zhao et al., 2011;).

HIV care has not been integrated into the healthcare system in rural China and the Chinese Center for Disease Control and Prevention (CDC) continues to manage the care for PLWHA. The local CDC arranged their health workers to distribute, manage, and supervise ART (Xu et al., 2007), and PLWHA living in rural areas usually pick up their ART medication at the village clinics. In 2003, the Chinese government launched a screening campaign among former plasma donors to identify those who had been infected with HIV and to link them to care and treatment services provided under the Four Free and One Care policy (Wu et al., 2007). The Four Free and One Care program significantly expanded access to ART in the country, resulting in an increased number of PLWHA enrolled in the program (Han et al., 2010; Zhang et al., 2007). However, challenges remain as counties with a severe epidemic receive assistance from the central government of China, but the local governments had to fund the remaining costs themselves to make the Four Free and One Care service available (Xu et al., 2007).

2.5.1. Current Standard of Care

The current standard care for HIV-positive patients includes a regular follow-up twice a year with a physical checkup and CD4 tests (UNAIDS, 2014). Patients with AIDS or advanced HIV disease are followed up six times in the first year and twice thereafter. Under the Four Free and One Care program, antiretroviral drugs are provided free of charge by the government. Additionally, treatment of opportunistic infection is also free to patients in rural areas in China (China CDC, 2016).

2.5.2. Challenges of Rural Healthcare in Anhui Province, China

The healthcare system in rural China has undergone remarkable changes over the past few decades (Tian et al., 2013). Since the collapse of China's Cooperative Medical Systems in the rural areas — which were the pillars for prevention and healthcare delivery in the pre-market-reform era — limited effort has been devoted to rebuilding community-based health schemes (Yip et al., 2007). After the start of the healthcare reforms in the 1980s, the rapid growth of healthcare costs due to the commercialization of the healthcare system has made some basic care too costly for the poor (Zhou, 2009). After the reform, the central government was no longer the financier of healthcare and local governments would have to source some of their funding themselves (Xu et al., 2007). Furthermore, providers were permitted to charge for services and were encouraged to profit from the sale of medications, tests, or treatment. This has created a healthcare system that is inaccessible to much of the population (Xu et al., 2007). The introduction of new medical insurance schemes in urban cities led to the loss of basic healthcare security for millions of people, including rural migrant works, unemployed urban residents, and others. (Akin, Dow, Lance, & Loh, 2005).

The reforms of the 1980s have particularly affected the rural poor who account for nearly 60% of China's 1.3 billion (National Population and Family Planning Commission of China, 2017), and significant rural-urban differences exist in China. In order to eliminate the rural-urban disparities in healthcare, the Chinese government made strides to reform the healthcare system between 2009 and 2012 with funding of RMB 850 billion (equivalent to USD 130 billion; Yip et al., 2012). Although the gap between regions has narrowed in the past few years, research continues to document the existence of rural-urban inequalities in healthcare (Li et al., 2016). Despite the Four Frees and One Care policy, unaffordability of healthcare remains a critical concern for PLWHA and their families (Xu et al., 2007).

2.6. Performance in Public Health

This dissertation also involves a performance (Part II) drawn from the quantitative analyses (Part I) of the dissertation. Performance, theater production, in particular, has been explored globally as an educational and behavioral change strategy on public health–related issues for several decades (Cueva, Kuhnley, Lanier, & Dignan, 2005; Noone, Castillo, Allen, & Esqueda, 2015). The theater is an effective pedagogical tool that has been found useful in approaching a diversity of health-related subjects (Buitrago et al., 2013). It allows for the acquisition of knowledge and skills as well as opportunities to practice, apply, and enhance learned information (Helmeke & Prouty, 2001; Kevelighan, Duffy, & Walker, 1998). Studies have consistently shown that well-designed and executed live theater performances can engage audiences, influence the knowledge, attitudes, and behaviors of audience members, and positively impact peer, social, and cultural norms (Conquergood, 1988; Kincaid, Yun, Piotrow, & Yasar, 1993; Piotrow, Kincaid, Rimon, Rinehart, & Samson, 1997; Singhal & Rogers, 2012).

Additionally, theater-based interventions have been utilized in public health to promote functional learning through scenarios and vignettes that seek to explain, demonstrate, and compare the consequences of different life choices (Glik, Nowak, Valente, Sapsis, & Martin, 2002). For instance, theater-based programs have been used to reduce weight-related teasing among children (Haines, Neumark-Sztainer, Perry, Hannan, & Levine, 2006), to promote healthy relationships among adolescents (Fredland, 2010), and to reduce substance abuse among adolescents (Guttman, Gesser-Edelsburg, & Israelashville, 2008). Besides the use of theater-based techniques in health promotion, theater-based peer-education strategies have also been used to engage adolescents in HIV prevention for over a decade (Daykin et al., 2008; Jackson, 2002; Lieberman, Berlin, Palen, & Ashley, 2012; McEwan, Bhopal, & Patton, 1991).

Besides the theater being used as a method of intervention, the theater also has been used as an innovative way to disseminate research findings. Mienczakowski, Smith, and Morgan (2002) and Rolfe, Mienczakowski, and Morgan (1995) created two plays: One depicted the struggles of people living with schizophrenia (*Synching Out Loud*), and another captured the experiences of alcoholics who have undergone detoxification within an institution (*Busting*). Both plays were based on ethnographic studies and were performed by student actors and student nurses for an audience composed of research informants, students, and healthcare professionals (Mienczakowski, 1999; Rolfe et al., 1995). Another group, Durham Focus Group Project, used ethnodrama/ethnotheater, a live performance based on study findings, to communicate their study findings of exploring African-American men's health-seeking behaviors and experiences with health and healthcare services in Durham, North Carolina (Taylor, Namey, Carrington Johnson, & Guest, 2017). The program pointed to the success of the performance in both entertaining and educating the audience (Taylor et al., 2017).

Ethnodrama is a scripted dramatization of research data performed for an audience (Saldaña, 2011). The term, coined by Turner (1982) and used by health researchers, refers to a research-based theater that aims to "remain true to the informants who contribute to our research" (Mienczakowski, Smith, & Morgan, 2002, p. 34). Ethnodrama aims to communicate research findings and to remain faithful to primary research subjects and the veracity of the data (Rossiter et al., 2008). Although it has been an effective knowledge transfer tool among populations that traditionally employ storytelling to influence behaviors (Hinyard & Kreuter, 2007), it has rarely been employed to communicate research findings (Taylor et al., 2017).

2.7. Gaps in the Literature

Quantitative Study. Although considerable research has been devoted to reducing HIV-related stigma, rather less attention has been paid to HIV-related stigma in China. A need exists for a better understanding of the barriers that PLWHA face in accessing healthcare services in rural Anhui Province, China, a region impacted by the history of HIV outbreak among former plasma donors (Zhou, 2009). To date, 5 systematic reviews have been carried out to synthesize the findings on the effectiveness of interventions for HIV-related stigma reduction (Brown et al., 2003; Loutfy et al., 2015; Mak et al., 2017; Sengupta et al., 2011; Stangl et al., 2013). Brown and colleagues (2013) reviewed 22 studies and found that most of the studies aiming to increase tolerance of PLWHA in various populations (e.g., healthcare workers, primary and secondary students) achieved mixed success. The results suggest that some stigma reduction interventions appear to work on a small scale and in the short term; however, none of the interventions included in this review were conducted in China. Sengupta et al. (2011) conducted a systematic review of 19 interventions in reducing HIV-related stigma and reported that most of the studies were effective in reducing stigma among providers and students in elementary and high school as well as college. Of those 19 studies, one was conducted in China and only one study was conducted among PLWHA in the United States (Rounds, Galinsky, & Despard, 1995; Yang & Zhang, 2004).

So far, investigations have been confined to HIV-related stigma reduction among healthcare providers and students, and little is known about HIV-related stigma among PLWHA in China. In a recently published systematic review of 48 studies conducted between 2002 and 2013, Stangl et al (2013) assessed the effectiveness of interventions to reduce HIV stigma and discrimination. Among the 48 studies, six were conducted in China; of those, five were among service providers, and one was among high school students. The review revealed that a majority (82%) of the 48 interventions were effective at reducing some aspects of the HIV-related stigma they measured (18 studies reported that their HIV-related stigma measures were validated). Most studies in the review targeted a single domain of HIV-related stigma, such as driver, facilitator, or manifestation. None of the studies in this systematic review assessed the influence of HIV-related stigma or HIV-related discrimination on HIV-related health outcomes (Stangl et al., 2013). The most common target populations of the HIV-related stigma reduction interventions in the systematic review were students, healthcare workers, and community members (Stangl et al., 2013).

Few studies attempt to address multiple dimensions of HIV-related stigma. In a systematic review by Loutfy and colleagues (2015) investigated the effectiveness of HIV-related stigma-reducing interventions for African/Black diasporic women. Five studies were included in the review, and four demonstrated effectiveness of the interventions in reducing HIV-related stigma, yet only two of the five studies were designed for HIV-positive African/Black diasporic women (Loutfy et al., 2015). Few interventions are designed to address multiple forms of HIV-related stigma, including gender and racial discrimination experienced by PLWHA in other racial groups (Loutfy et al., 2015).

Although many efforts to reduce HIV-related stigma have been undertaken over the years, most of the work has been done among the general populations or healthcare providers while limited attention has been paid to PLWHA. Among the five systematic reviews (Brown et al., 2003; Loutfy et al., 2015; Mak et al., 2017; Sengupta et al., 2011; Stangl et al., 2013) that have been conducted to examine the effectiveness of interventions aimed at reducing HIV-related stigma, none was designed for PLWHA specifically. There is a need to investigate the different forms and dimensions of HIV-related stigma among PLWHA, especially in rural China, to better inform future efforts in HIV-related stigma reduction among PLWHA.

Compared to HIV-related stigma, social support has had less attention devoted to it. In particular, an examination is needed of its multidimensional construct (i.e., tangible, emotional, and affectionate support) among HIV-positive individuals and how it affects access to HIV care (Lin, Li, Ji, & Jie, 2015). Although there is a long history of research on social support and evidence indicating its ability to buffer against adverse physical effects of stress, less attention has been paid to the specific aspects of social support that are useful for specific cultural groups (e.g., PLWHA in rural China). A study conducted among PLWHA aged above 50 in Anhui Province, China, showed that higher levels of tangible support were reported by PLWHA who were married or living with a partner; having access to healthcare was associated with levels of emotional support but not tangible support (Lin et al., 2015). Gaps remain and impede the process of identifying the impacts of the multidimensional social support on access to care among PLWHA and the specific needs of the population.

Performance. Performance has a rich history of imparting information and encouraging reflection; yet formal ties between performance and research, particularly in terms of the translation of research results, have only developed recently (Gray & Sinding, 2002; Rossiter et al., 2008). Although performance-based interventions have received increased attention in scholarly work, there is a paucity of literature on applying performance as a method of analysis and not as a medium for health education (Roositer et al., 2008). There is an opportunity to utilize performance as a means of interpreting, enlivening, and enriching the research findings.

2.8. Summary

A substantial body of literature has documented the importance of addressing HIV-related stigma. However, there is a scarcity of evidence on how HIV-related stigma and social support may affect access to care among PLWHA in China. The relationship between the different dimensions of HIV-related stigma, social support, and access to care has not yet been clarified. For the purpose of a better understanding of how HIV-related stigma and social support may impede the care assessed by PLWHA in rural Anhui Province, China, this study included the consideration of the impacts of individual and contextual factors on the relationship between HIV-related stigma, social support, and care access. Therefore, the goals of this study were to understand whether the different dimensions of HIV-related stigma and social support were associated with access to care among PLWHA in order to inform future programming efforts in improving the health of PLWHA in rural Anhui, China.

In addition to Part I quantitative analysis, this dissertation also includes Part II, which is a performance drawn from the quantitative analysis of the dissertation and aimed to extend the information of the empirical data as well as incorporate the minor field studies offered in the Department of World Arts and Cultures/Dance.

CHAPTER THREE

THEORETICAL FRAMEWORK & SPECIFIC AIMS

3.1. Overview

This present chapter describes the development of a conceptual framework used to guide all dissertation study aims and research hypotheses. It is a framework that integrates two theoretical elements: the constructs of stigma and Andersen's Behavioral Model of Health Services Use.

Section 3.2 introduces the constructs of stigma. Section 3.3 describes Andersen's Behavioral Model of Health Service Use on which the study's conceptual foundation was based. Section 3.4 presents the conceptual model of the current study. Section 3.5 presents the three aims of the study and their corresponding hypotheses. Finally, Section 3.6 describes the theories in critical performance analysis.

Part I. Quantitative Study

3.2. Constructs of Stigma

Goffman's (1963) seminal publication entitled *Stigma: Notes on the Management of Spoiled Identity* defines stigma as "an attribute that is deeply discrediting" and "an undesired differentness," and proposes that the stigmatized person is reduced "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). However, the construct of stigma is complex (Link & Phelan, 2001). In recent decades, numerous empirical and multidisciplinary perspectives have emerged (Bos, Pryor, Reeder, & Stutterheim, 2013).

Stigma is an umbrella concept with several interrelated components: labeling, stereotyping, cognitive separation, emotional reactions, and status loss and discrimination (Link & Phelan, 2001). Link and Phelan define stigma regarding presence and convergence of the interrelated components and identify the social processes that occur within the sociocultural environment whose effects can be observed within the individual (Link, Yang, Phelan, & Collins, 2004). In the first component, labeling, people distinguish and label others based upon perceived differences. In the second, stereotyping, dominant cultural beliefs link marked individuals to undesirable characteristics—negative stereotypes. In the third, cognitive separation, tagged individuals are placed in distinct categories to accomplish some degree of separation of "us" from "them." In the fourth, emotional reactions, including emotions of embarrassment, shame, fear, alienation, or anger, can be experienced by the person who is stigmatized, In the fifth, status loss and discrimination, labeled individuals experience a loss of status and discrimination that lead to unequal outcomes. Link and Phelan also emphasized that stigma exists when the aforementioned interrelated elements occur together in a power situation that allows them and when the components do not live in some independent existential way (Link et al., 2001). Additionally, Link and Phelan's conceptualization of stigma also concludes that it exists as a matter of degree, such as the strength of the connection between labels and undesirable attributes can be either strong or weak (Link & Phelan, 2001).

Figure 3.1 describes the components included in Link and colleagues' definition (Link, et al., 2004). Additionally, stigma operates at the macro and micro levels of social life, and that stigmatization is contingent on access to social, economic, and political power (Link & Phelan, 2001).

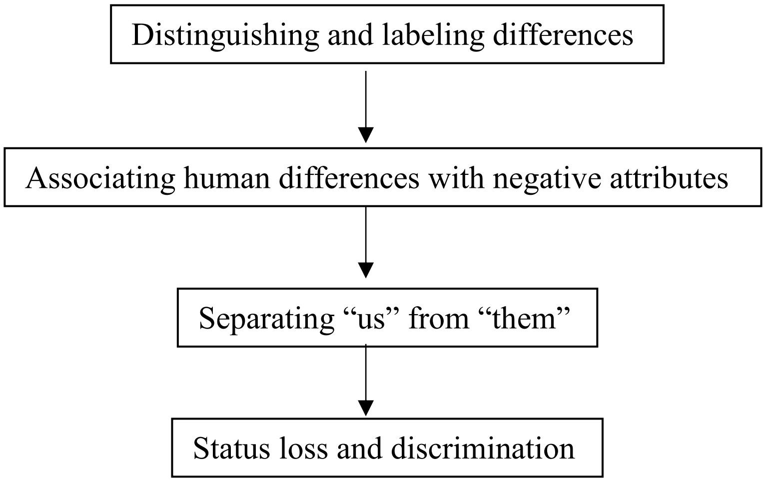


Figure 3.1. Components of stigma (Link & Phelan, 2001).

Pryor and Reeder (2011) articulated four dynamically interrelated manifestations of stigma: public stigma, self-stigma, stigma by association, and structural stigma (Figure 3.2). Public stigma represents people’s social reactions to someone they stigmatize. Self-stigma pertains to the social and psychological effect of possessing a stigmatizing attribute, including internalization of the negative beliefs and feelings associated with the stigmatized condition. Stigma by association refers to the social and psychological impact on people related to stigmatized individuals, such as family and friends. Finally, structural stigma refers to the perpetuation of a stigmatized status by society’s institutions (Pryor & Reeder, 2011).

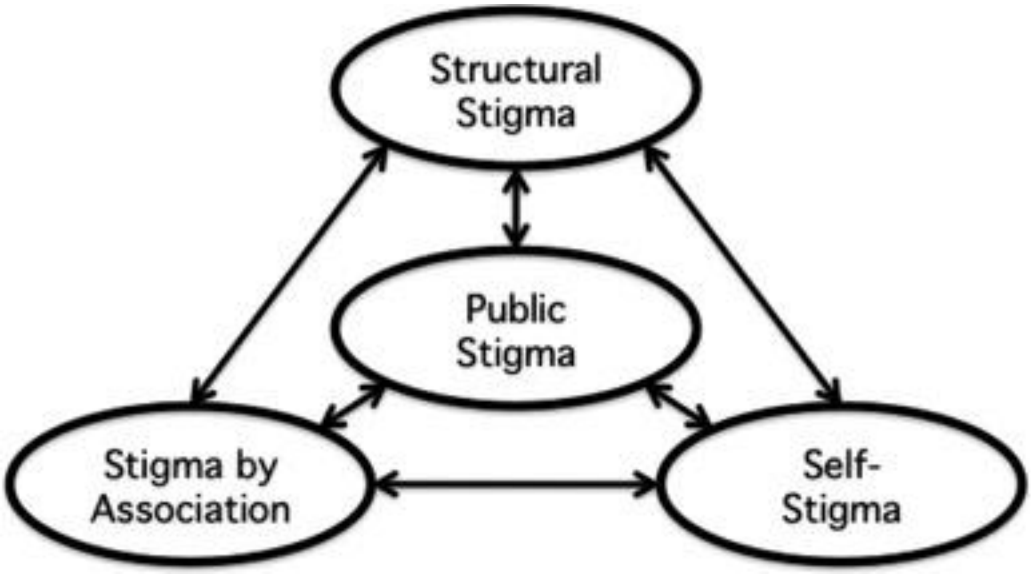


Figure 3.2. Four types of stigma (created by Pryor & Reeder, 2011).

A substantial amount of literature has documented the detrimental consequences of stigmatization on individuals (Meyer, 2003; Sutterheim et al., 2009). Self-stigma can be divided in three ways: (a) enacted stigma, the adverse treatment of a stigmatized person; (b) perceived stigma, the experience or anticipation of stigmatization on the part of the stigmatized person; and (c) internalized stigma, the reduction of self-worth and accompanying psychological distress (Herek, 2007, 2009).

3.2.1 Types of Stigma

Perceived Stigma. *Perceived stigma*, also labeled as *felt stigma*, refers to an individual's expectations about the probability that stigma will be enacted in different situations (Herek, 2009). It relates to the expectations that stigma will occur during social interactions within the community (Churcher, 2013). It is based on an awareness of the existence of stigma and beliefs about how and when society condones its enactment (Herek, 2009). Perceived stigma motivates stigmatized individuals to avoid situations in which stigma enactments are possible (Nelson, 2009).

Internalized Shame. Internalized shame is the process by which individuals adopt a social value or belief for conduct as their own and experience it as part of themselves (Kelman, 1961; Ryan & Connell, 1989). Internalized shame refers to an individual's acceptance or endorsement (or both) of stigmatizing beliefs like his or her self-concept (Herek, 2009; Kalichman et al., 2009). HIV-positive individuals may devalue themselves because "they now belong to a category that they believe most people view negatively" (Link, 1987, p. 105). Internalized shame differs from perceived stigma in that the latter one is about one's awareness of social norms and expectations that stigma will be enacted, but one who has internalized shame believes that the shame is justified. Earnshaw and Chaudoir (2009), in their review, identified seven scales used to measure HIV-related stigma from the perspective of HIV infected people. All of the scales include items measuring internalized stigma, whereas five scales measure perceived stigma.

3.2.2. Direct and Indirect Effects of HIV-Related Stigma

There is growing evidence that HIV-related stigma has direct and indirect effects on HIV outcomes. A few authors (Herek & Capitanio, 1999; Polednak, 1997) have hypothesized that HIV-related stigma has an indirect impact on health outcomes. In empirical studies, Herek and Capitanio found that HIV-related stigma is associated with negative feelings, beliefs, and attitudes toward people with HIV/AIDS (Herek & Capitanio, 1999). Polednak suggests that stigma operates through other factors (i.e., the concentration of poverty and quality of life) that act as "mediators" between stigma and mortality among people living with HIV (Polednak, 1997). In the case of an infectious disease such as HIV/AIDS, both indirect and direct mechanisms operate. For one thing, stigma may have an indirect effect on the transmission of contagious disease through the quality of neighborhood environment (e.g., concentrated risk factors for HIV and limited access to adequate healthcare in the communities). Additionally, stigma may play a direct role, such as influencing the probability of contact across and within stigmatized groups. Internalized shame may lead to serious responses, including secrecy, withdrawal, and isolation (e.g., nondisclosure of HIV status; Tsai et al., 2013), leading to increased HIV risk behaviors (Simbayi et al., 2007) and hindrance of ART adherence (Katz et al., 2013). Not only does internalized shame have adverse effects on PLWHA (e.g., virological failure [Gross et al., 2006], increased mortality [Lima et al., 2009]), it also could increase HIV transmission (Loutfy et al., 2013).

3.2.3. HIV-Related Stigma and Othering

Othering. The process of negative othering creates an illusion of control by attributing the risky behavior related to HIV infection to the other and by blaming other groups for being at risk (Nelkin & Gilman, 1988). Besides, negative othering involves the exploitation of power imbalances, resulting in one's gain at the expense of others (Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006). The otherness can also be used to stigmatize specific groups that are determined as "high risk" for obtaining the disease, including sex workers and gay men. This is a product of stigmatization and othering. As a result, a society creates "other spaces" for those who do not fit within society's norm (Foucault & Miskowiec, 1986).

The concept of othering is also closely linked with Said's (1978) Orientalism. Scholars have critiqued forms of societal others inscribed in Said's Orientalism. According to Said, the colonial systems of domination continued and became entrenched in the postcolonial and globalization era, as the former colonizer continued to economically, culturally, and financially dominate what constitutes the so-called developing world (i.e., the third world, the formerly colonized nations; Said, 1993). Because of the agenda and research method set by the Western institutions, many cultures were not allowed to name HIV/AIDS from their cultural perspectives and languages (Chakrabarty, 2000). The language and topics of research on HIV/AIDS have continued to be based on Western perceptions of reality and to marginalize the third world's own perception of reality and what counts as knowledge in combating the HIV/AIDS pandemic. That is to say, the research on HIV/AIDS works within the established colonial framework of homogeneity in the search for solutions to the HIV/AIDS pandemic, thus leaving out the voices of the researched colonized other (Nelkin & Gilman, 1988). This idea coincides with Chakrabarty's (2000) argument that Western theories are inadequate in their basis of historicism.

Subalternity and HIV. The term *subaltern* pertains to being of inferior rank (Guha & Spivak, 1988). This term has historically been used to refer to the disadvantaged groups of South Asian societies, characterizing the position of subordination expressed in class, caste, age, gender, office or in any other way (Guha & Spivak, 1988). Others have conceptualized subalternity as the condition of "being erased" and "being under" the mainstream platforms of civil society, of "being hidden" from history and the knowledge production process (Beverly, 2004). Subalterns are those whose voices have historically been absent and erased from structures and mechanisms of knowledge production. For example, what accentuates sex workers' condition of subalternity is their being subject to surveillance and discrimination because of the high incidence of HIV/AIDS among them. Not only that, in many parts of the world, female sex workers still have no bargaining power to turn down a client refusing to wear a condom (Faleiro, 2006).

Moreover, in certain areas around the world, such as South Africa, HIV-related stigma is more strongly expressed against women than against men (Petros et al., 2006). This phenomenon aligns with Williams and Chrisman's idea that the dynamics of gender and sexuality are "central issues for both post-colonial and colonial discourse theory" (Williams & Chrisman, 1994, p. 17). This also exemplifies Spivak's argument that within the postcolonial context, the subaltern as female is even more deeply shadowed than muted (Spivak, 1988). The subjugation of the other in their knowledge formation is even more entrenched along the lines of age, gender, race, and ethnicity.

3.3. Andersen's Behavioral Model of Health Service Use

This section presents the Andersen Behavioral Model of Health Service Use. It is one that emphasizes individual as well as contextual determinants of access to care. Dimensions of access are defined according to components of the framework.

3.3.1 Andersen Model Overview

Andersen's Behavioral Model of Health Service Use has been applied to various health services research in recent decades (Andersen, 1995). The model posits that an individual's access to and use of health services is considered to be a function of three sets of individual characteristics: predisposing factors, enabling factors, and need factors. The initial model was developed in the 1960's to assist in the understanding of why families use health services

(Andersen, 1995). Since the original conceptualization, the unit of analysis in Andersen's Behavioral Model has shifted to the individual.

Andersen's original Behavioral Model conceptualization is depicted in Figure 3.3. It suggests that people's use of health services is a function of their predisposition to use services, those that enable or impede individuals' use and need for care (Andersen, 1995). Andersen proposed several predisposing characteristics, including demographic factors (e.g., age and gender) and social structures that have traditionally been measured using the indicators of education and occupation status. Another predisposing characteristic is health beliefs —– i.e., attitude, values, and knowledge that people have about health that might influence their subsequent perception of need and use of health services (Andersen, 1995). The initial model aimed at assisting to define and measure multiple dimensions of access to care (Andersen, 1995).

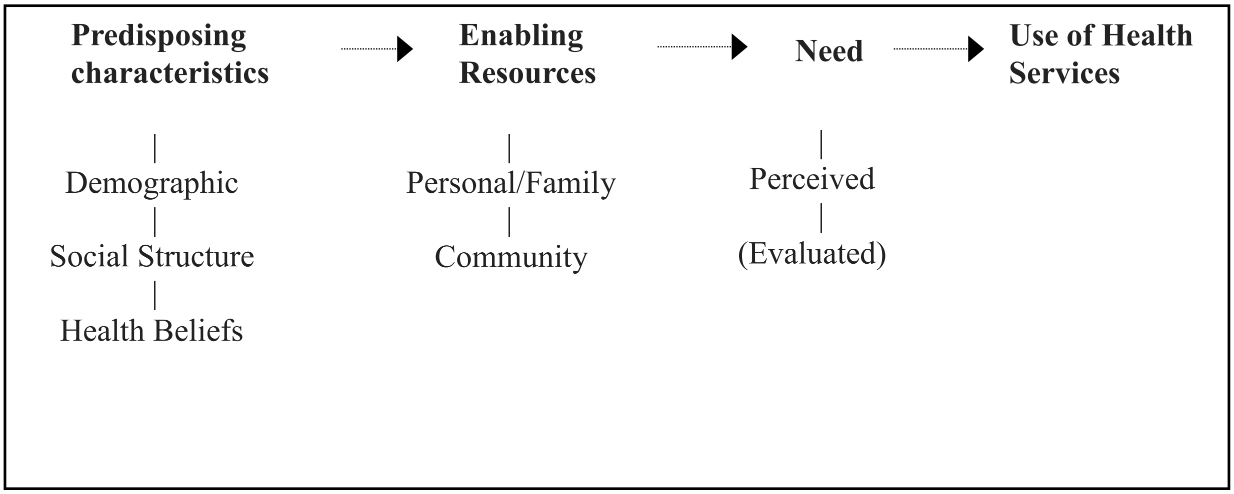


Figure 3.3. The Initial Behavioral Model (1960s).

The Andersen Behavioral Model of Health Service Use has evolved since it was conceived. As elaborated over time, the model has differentiated potential and realized access (Figure 3.4). Figure 3.4 depicts the last phase of the model (phase five), which includes most of the fundamental model components of the previous phases of the model (Andersen, 2008). Realized access reflects utilization and satisfaction, whereas potential access is influenced both by predisposing (need, health beliefs, social structure) and enabling processes (availability of services; Andersen, 2008). This model emphasizes that understanding the usage of health services is best accomplished by focusing on individual and contextual determinants (Andersen, Davidson, & Baumeister, 2007). Contextual characteristics are measured at some aggregate instead of individual-level factors, such as provider-related indicators and community characteristics.

In 2008, the model added feedback loops to acknowledge the interactive and recursive relationship between the factors (Andersen, 2008). For instance, the arrow at the bottom of Figure 3.4 that points from left to right connotes that predisposing factors influence perceived health and evaluated health status. A feedback loop is conveyed by the arrow above that points from right to left. It indicates that perceived health and evaluated health status could affect not only health behaviors but also predisposing factors as well as a perceived need for services. This model reflects the interaction between providers and patients in the delivery of medical care, including but not limited to providers’ behaviors and attitudes toward patients (Andersen, 2008). These arrows indicate the complex relations and the interconnectedness between the predisposing, enabling, and need factors at the contextual and individual level, health behaviors, and outcomes. Figure 3.4 shows that improving access to care is best accomplished by focusing on contextual as well as individual determinants (Andersen, 1995, 2008).

In the 2008 model, contextual factors are divided in the same way that individual characteristics have traditionally been divided—predisposition, enabling, and need. Contextual characteristics include demographic characteristics of a community (e.g., age, gender, marital status composition; Andersen, 2008); social characteristics at the contextual level describe how supportive or detrimental the communities where people live and work might be to their health and access to care (Andersen, 2008), including relevant measures as educational level, measures of spatial segregation, and employment levels (White, Hass, & Williams, 2012). The model depicted in Figure 3.4 also reflects the recursive nature between the factors; however, these interactions were not the focus of this dissertation and were not examined.

This model has been used to examine a wide range of outcomes, including HIV prevention and intervention outcomes. Predisposing factors are the characteristics that influence people to use or not use services (Andersen, 2008), including sociodemographic characteristics such as age, gender, exposure to HIV, education, income, beliefs about HIV/AIDS, substance use, and other comorbidity-related healthcare services. Enabling factors are the characteristics that facilitate or impede use of services (Andersen, 2008), such as provider-patient relationship and perceived social support. Depending on the provider-patient relationship, it could serve as a facilitator or inhibitor. Need factors are the characteristics that laypeople or professionals recognize as requiring medical treatment (Andersen, 2008), including both perceived needs for healthcare services and actual needs such as current health status, CD4+ count, viral load, and co-morbid conditions. Literature has long documented that PLWHA have not only medical needs but also other social demands related to subsistence needs, including the need for food, clothing, and housing, resulting in postponing care and the inability to seek medical services (Cunningham et al., 1999; Katz et al., 2000; Reif, Whetten, Lowe, & Ostermann, 2006).

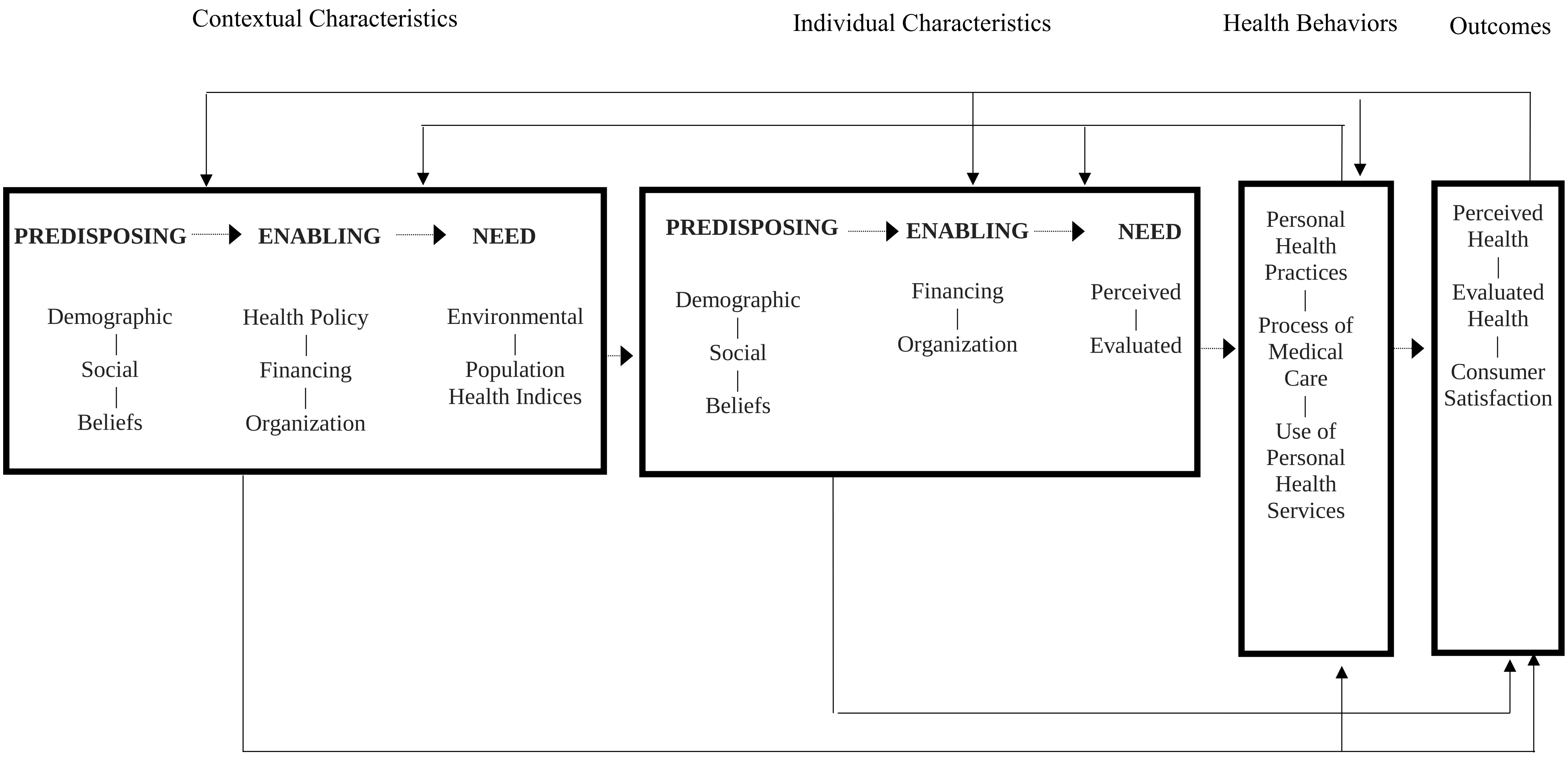


Figure 3.4. Phase 5: A behavioral model of health services use including contextual and individual characteristics.

3.4. Conceptual Model

The conceptual model used to guide study analyses in this present dissertation is depicted in Figure 3.5. It is informed by Andersen's Behavioral Model of Access to Care and the constructs of stigma (Andersen, 2008; Link & Phelan, 2001), as well as the literature presented in Chapter 2. The conceptual model can be used to gain a better understanding of the relationship between HIV-related stigma and access to HIV treatment among PLWHA in rural Anhui Province, China. An ecological perspective implies that the health behavior results from the interaction of both individual and environmental determinants (McLeroy et al., 1988), including psychological, social, cultural, and structural factors.

The conceptual model draws from the categories of individual and contextual factors in the Andersen model: predisposing, enabling, and need factors (Andersen et al., 2000). First, individual predisposing factors include demographic variables such as age, gender, marital status, and education, as well as contextual predisposing factors such as China's healthcare policy. All rural residents were eligible to receive free healthcare and ART under the current "Four Frees and One Care" policy in China (Wu et al., 2007). This factor was not examined in this dissertation as the information was not collected.

Next, enabling factors include variables that may facilitate or deter the use of medical services, including both individual and contextual factors. Individual enabling factors include social support; family characteristics include annual family income, family functioning, caregiver burden, and family members' HIV knowledge. As in Andersen's 2008 model, beliefs about the disease are included as one of the individual predisposing factors; HIV-related stigma is also an individual predisposing factor in the conceptual model of this study. The broader contextual enabling factors include HIV-related stigma in the community, community members' HIV-prevention knowledge, and perceived HIV-risk and susceptibility among uninfected individuals in the society.

Need factors include the objective and subjective need for health services, such as clinically evaluated health conditions (e.g., CD4+ count, viral load, self-rated current health status). Additionally, "vulnerable predisposing factors" are also included in the conceptual model, such as psychosocial, attitudinal (e.g., HIV-related stigma and knowledge about HIV), and behavioral variables (e.g., drug use, risky sexual practices) that may be associated with increased or decreased likelihood of using healthcare services. Two dimensions were used in the current study to measure HIV-related stigma: perceived stigma and internalized shame. Stigmatized persons may internalize perceived prejudices and develop negative feelings about themselves (Latalova, Kamaradova, & Prasko, 2014).

Andersen's model has been used to examine healthcare and treatment utilization among PLWHA for over a decade (Andersen et al., 2000; Kilbourne et al., 2002; Saint-Jean et al., 2011; Smith & Kirking, 1999; Ulett et al., 2009). The model has also been used to investigate the factors associated with accessing healthcare in five studies conducted in China (Gong, Kendig, & He, 2016; Li, Nong, Wei, Feng, & Luo, 2016; Liu et al., 2017; Wang et al., 2009). Even though PLWHA are eligible to receive free ART in rural China, individual and contextual factors continue to influence PLWHA's access and utilization of healthcare. Under Andersen's (2008) model, individual beliefs also constitute a critical factor in accessing healthcare (Figure 3.4). HIV-related stigma is one of the factors relating to health beliefs as described in Andersen's 2008 model, in addition to attitudes, values, and knowledge related to health services. Also, the healthcare reforms in China in both the 1980s and 2009 were modeled after the Western healthcare practices (Yip et al., 2012). Thus, the application of Andersen's Behavioral Model of Health Service Use, a widely used Andersen healthcare model, to PLWHA in rural Anhui, China will contribute to the literature. However, it should be noted that Andersen's healthcare model was developed in the United States and that any interpretations should take the cultural context of China into consideration. For instance, the culture perspectives include cultural practices as well as values and norms.

3.5. Specific Aims and Hypotheses

This section provides a detailed description of the three research aims and their corresponding hypotheses. Figures 3.6, 3.7, and 3.8 convey the relationship under consideration for Aim 1, Aim, 2, and Aim 3, respectively. Each figure fits within the conceptual framework presented in Figure 3.5.

> **Aim 1:** To determine whether the two dimensions of HIV-related stigma (i.e., perceived stigma and internalized shame) are associated with access to care among HIV-positive men and women in rural Anhui Province, China.

This study assesses stigma not as a risk factor, but as a lens to identify how PLWHA in rural Anhui Province, China, are at risk for lower access to care. It is unclear which dimension of stigma is most pertinent to the health of PLWHA. This research aim evaluates the extent to which different dimensions of HIV-related stigma, perceived stigma and internalized shame, influence access to care.

Hypothesis 1: HIV-related stigma reported by PLWHA will be negatively associated with access to care.

The study hypothesizes that both dimensions of stigma, perceived stigma and internalized shame, will be negatively associated with access to care among PLWHA in rural Anhui, China.

Aim 2: To determine whether the three dimensions of social support—(a) emotional support, (b) tangible support, and (c) affectionate support—are associated with access to care among HIV-positive men and women in rural Anhui Province, China.

Hypothesis 2: Given the importance of the process of HIV care and the evidence supporting social support's impact on some process, the study hypothesizes that levels of social support reported by PLWHA will be positively associated with access to care.

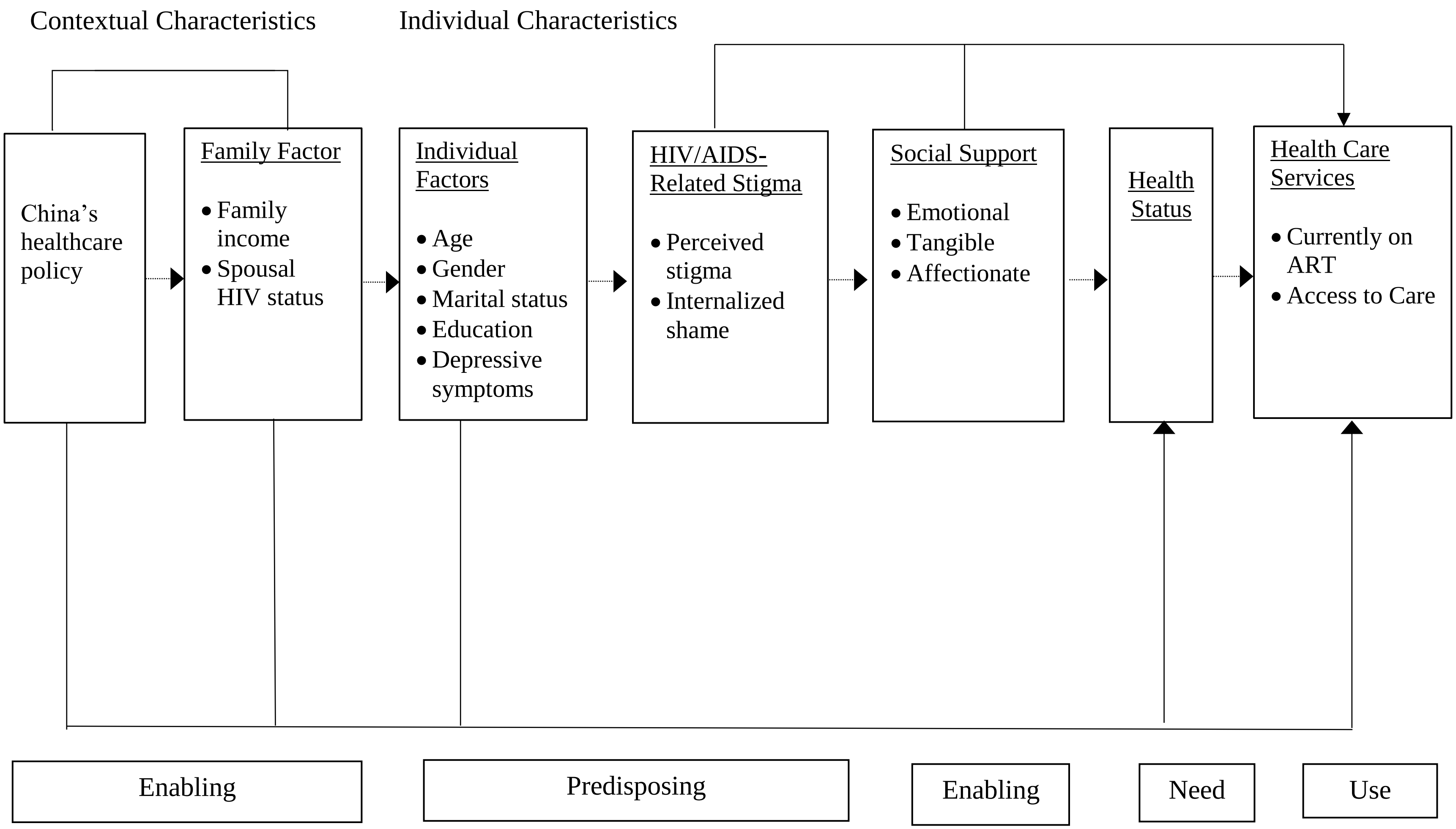


Figure 3.5. Diagram of the Conceptual Model

Part II. Critical Performance

3.6. Performance Theories

Overview. To explain the decision to create a critical performance based on the quantitative part of this dissertation, this section will describe the theories and ideas from the field of performance studies that have informed the creative process of the performance. As the concepts of "performance" have achieved broad resonance in contemporary theory, art, and studies of social behavior, this section presents some fundamental theories of performance. Further, this section describes the interdisciplinary nature of performance, including the allied areas of performativity, embodiment, construction of identity and differences, as well as inter-culturalism. In addition, this section includes an exploration of how performance acts as a repository of history and meaning in a range of cultural contexts.

3.6.1. Definition of Performance

Scholars have described the function of *performanc*e as "vital acts of transfer, transmitting social knowledge, memory, and a sense of identity through reiterated, or what Richard Schechner has called "twice-behaved behavior" (Schechner, 1990, p. 100). On one level, "performance" constitutes the process of analysis in performance studies, including many practices and events (e.g., dance, theater, rituals, etc.). For instance, a particular speech act or dance has a beginning and an end; thus, performance amounts to an ontological affirmation, a thoroughly localized one (Taylor, 2003). However, one can also analyze events *as* performance, such as gender, ethnicity, or sexual identity, as these are rehearsed and performed daily in the public sphere (Schechner, 2017; Taylor, 2003). Thus, performance can also function as epistemology. It is acknowledged that in performance studies, the notions and definitions of performance vary widely (Taylor, 2003). Diane Taylor (2003) states that performance is always in situ, “intelligible in the framework of the immediate environment and the issues surrounding them.” Victor Turner (1982) based his understanding of performance on the French etymological root, *parfournir,* which means “to furnish forth,“ “to complete,” or “carry out thoroughly” For Turner (1982), performances reveal a culture’s deepest, truest, and most individual character, and he believed that populations could grow to understand each other through their performances.

3.6.2. Performative and Performativity

Philosophy and rhetoric scholars J. L. Austin (1975) and Judith Butler (1997) have used the terms *performative* and *performativity* in a distinctive way. Austin states that performative cases are those in which “the issuing of the utterance is the performing of an action,” for example when the justice of the peace says the words, “I now pronounce you husband and wife,” thereby sealing the marriage bond (Austin, 1975). Working primarily in the terrain of linguistic analysis, Austin attempted to pry apart “constative” and “performative” utterances, with the former being defined as a statement that “describes” or “reports” and the latter as an utterance that “[performs] an action’; Austin stated, “It is not normally thought of as just saying something” (Austin, 1975, p. 5). Austin insists that we investigate any speech act as a “force” in the context of its discursive situation (Austin, 1975, p. 147). In *How to Do Things with Words*, he considers not just what a speech act might mean, but “in what precise way” we use a locution “on this occasion” (Austin, 1955).

Building on Austin’s work and applying it to a broad swath of everyday life, Butler (1977) framed the use of performativity as the process of socialization whereby gender and sexuality (for example) are produced through regulating and citational practices. For instance, the boy who stands with his legs wide apart and his fist on his waist is citing a gender trope. Taylor (2003) has summarized that this "multi-layeredness indicates the deep interconnections of … systems of intelligibility and the productive frictions among them" (p. 6). The complexity of the nature and notion of performance does not hide the fact that performance carries within itself the possibility of challenge, even a self-challenge (Taylor, 2003). In Peggy Phelan's (1993) seminal work, *Unmarked: The Politics of Performance*, she refers to performances as "representation without reproduction." As a result, scholars have viewed performance as a temporal condition.

3.6.3. Five Areas in Performance Studies

In *Rethinking Ethnography* (1991), Dwight Conquergood (1991) identified five areas of performance studies, which became the basis of the critical performance analysis for this study: (a) performance and cultural processes, with the cultural element functioning as an unfolding performative invention; (b) performance and ethnographic praxis, which provide the methodological implications of thinking about fieldwork as the collaborative performance of an enabling fiction between observer and observed; (c) performance and hermeneutics, which are used to indicate the kinds of knowledge that are privileged when performed experience becomes a way of knowing; (d) performance and scholarly representation, which potentially offer an alternative form of "publishing" research; and (e) the politics of performance, which queries the relationship between performance and power (Conquergood, 1991).

Similar to Conquergood's (1991) notion of scholarly representation, the critical performance being created in tandem with my dissertation here became the mechanism with which quantitative research findings were combined with performative elements and were "published" in front of a group of people, also known as an "audience." This method of dissemination was different from the traditional way of knowledge dissemination—that is, through peer-reviewed journals, reports, or conference presentations (Gagnon, 2009). Although disseminating public health research activities typically targets the academic research community within the field of public health, this performance explored innovative dissemination techniques to reach broader audiences, including public health researchers as well as scholars from other fields and members of the public.

3.6.4 Theory-Based Performance

Interactive theater interventions to promote behavioral change are often informed by the Health Belief Model and Social Cognitive Theory (Bandura, 1989; Rosenstock, 1974), in addition to the concept of drama for social change (Boal, 1985). The theories suggest that modeling behaviors and providing activities can strengthen self-efficacy and increase awareness of an individual's susceptibility to disease, thus changing behavioral intentions (Bandura, 1989; Rosenstock, 1974). Using Augusto Boal's (1985) seminal work, *Theatre of the Oppressed*, as a foundation, interactive theater can transform the audience members into active participants, and by doing so, consciousness about their agency in facilitating real-life actions can be raised (Christensen, 2013; Schaedler, 2010). The mechanisms for behavioral change in theatrical approaches have included a heightened sense of vulnerability and enhanced identification with the character in the narrative (Moyer- Gusé & Nabi, 2010). Dramatic approaches offer the opportunity to observe human behaviors, peel back the layers of fear and defensiveness, and create a space in which new action can be imagined (Dill-Shackleford, Green, Scharrer, Wetterer, & Shackleford, 2015; Hughes et al., 2016).

According to drama theory and drama research, live performance can structure the social environment through its powerful functions—for instance, by making an emotional appeal to multiple senses (Capo, 1983). Transportation theory further explains why people are persuaded by information in the narratives presented through theatrical approaches; when a story transports us, we are persuaded because transportation decreases counter arguing and increases connections with the characters (Green & Brock, 2000). Engaging with a theatrical story allows audience members to suspend disbelief, thus facilitating persuasion toward viewpoints embedded in the story.

CHAPTER FOUR

METHODOLOGY

4.1. Overview

This chapter has two parts. Part I (Sections 4.2 to 4.5) describes the methods used to conduct the quantitative secondary data analysis. Part II describes the methods of the performance portion of the dissertation project (Section 4.6). Secondary analysis of data from a randomized controlled intervention trial named TEA (Together for Empowerment Activities, TEA) was used to examine the influence of HIV-related stigma and social support on access to care. Section 4.2 provides details of the parent study, the data source on which the quantitative data analyses were based. Section 4.3 provides details of the study design, measurements, and operationalization of the key constructs assessed in this dissertation. Analysis of Aim 1 and 2 are described in Sections 4.4 and 4.5. Section 4.6 details the methods used to create the critical performance program. The chapter closes with the summary provided in Section 4.7.

Part I. Quantitative Study

4.2. The Parent Study

The TEA randomized controlled trial assessed the efficacy of the family intervention for HIV-affected families, including parents living with HIV and adult family members to improve their long-term health, mental health, and behavioral adjustment of their children. The TEA Study recruited a total of 522 PLWHA from 32 villages in rural Anhui Province, China. Most of the PLWHA in this region contracted HIV due to commercial plasma donation in the 1990s. The government provided free antiretroviral therapy for PLWHA. This trial was registered in the

ClinicalTrials.gov protocol registration system (NCT01762553). A detailed description of the intervention pilot has been previously reported (Li et al., 2011).

4.2.1. Study Sites of the Parent Study

Anhui Province is located in the northwest corner of Eastern China (Figure 4.1). It has a population of over 61 million in 56 counties. Anhui Province is one of the 10 provinces in China with the highest rates of HIV (Xu et al., 2007). Paid plasma donations caused most of the existing HIV infections in Anhui Province in the 20th century (Ji et al., 2006; Wu et al., 2001). As previously noted in Chapter 2, commercial plasma donation was a popular way to supplement income in central China during the early to mid-1990s (Wu et al., 2001). Some plasma collection stations collected the whole blood, removed the plasma, and injected the pooled red blood cells intravenously to the donors so that donors could donate more often without developing anemia (Wu et al., 2001). The HIV-1 antibody test was not required in the country before 1995; thus, it was not performed at any local plasma collection center (Wu et al., 2001). As a result, reuse of tubing and mixing during collection and reinfusion led to an HIV outbreak among former plasma donors until the practice was stopped in 1996 (Wu et al., 2001).

Figure 4.1. Map of Anhui Province’s location in China

Gaps in the Parent Study. The Parent Study focused on the impacts of HIV on families, in particular, on children living with HIV-infected parents in rural Anhui Province, China. The quality of life for PLWHA, their family members, and children, depends on how the family can cope with stress, health-seeking behaviors, and stigma associated with HIV (Li et al., 2011). Unknown, however, isthe extent to which HIV-related stigma and social support are associated with access to care among PLWHA in the parent study. The dissertation seeks to fill this gap in the parent study by examining how the dimensions of HIV-related stigma and social support were associated with access to care among PLWHA in rural Anhui, China. This dissertation provides a unique contribution to the understanding of HIV-related stigma by advancing our knowledge of the dimensions of HIV-related stigma and social support among PLWHA in rural Anhui, China.

4.2.2 Data Collection of the Parent Study

The institutional review boards (IRB) of the University of California, Los Angeles, and the Anhui Provincial Center for Disease Control and Prevention approved the parent study. Because each administrative village has a health clinic, the recruitment process began at village clinics, a nonstigmatized setting to approach potential participants since the village clinic represents a primary source of care for PLWHA and also a common place where families in the community visit (Li et al., 2017a). Village health workers verbally communicated with community members about the study and distributed printed flyers to potential participants. Potential participants who demonstrated an interest in the study were referred to a study recruiter who met with them individually to assess their eligibility for the study. The intervention study was referred to as “Children and Family Health Study” at all times. The focus of the recruitment was based on confidentiality and respect for the communities.

Inclusion criteria for PLWHA were the following: (a) participants must be aged 18 or more, (b) participants must be residents of one of the 32 selected villages, (c) participants must have a sero-negative family member and children in the family who were willing to participate in the study, and (d) participants must be able to provide informed consent. The project recruiters followed a standardized script to introduce the study’s purpose and procedures, confidentiality issues, and potential risks and benefits. Participants were assured that their participation in the study was entirely voluntary and that their decision to be involved in the research would not affect the services they obtained at the village clinics. The refusal rate was approximately 5% of those eligible. Written informed consent was obtained from all participants before data collection.

In the parent study, the data were collected from October 2011 to March 2013. Trained local interviewers conducted in-person interviews with PLWHA at the location they preferred (e.g., in private offices in village clinics, in classrooms at local schools, or at other locations preferred by PLWHA). If participants were more comfortable completing the interview at home, the interviewers were available to make home visits. At baseline and each of the follow-up points, the assessment was conducted using the computer-assisted personal interviewing (CAPI) method as an interviewer asked the participants questions that were displayed on a screen and input the responses directly into a laptop computer database. Participants were individually interviewed. All interviews were conducted in Mandarin Chinese, the same language as the participants' native tongue. Each assessment lasted approximately 45 to 60 minutes. The participants received 50 yuan (equivalent to USD 8.30) for their time and participation.

4.3. The Quantitative Dissertation Analysis

The following section describes Part I of the dissertation, quantitative analysis. The section will include the design of the study that is the subject of this dissertation, the included measures, as well as the analysis plan.

4.3.1. Study Design

A cross-sectional study design was used for this dissertation to examine the baseline data of the aforementioned TEA study. The TEA study is an intervention trial for HIV-affected families and contains a wealth of information relevant to understanding the complex issues of HIV-related stigma and social support that affect PLWHA's access to care. Specifically, the TEA study collected data about the different dimensions of HIV-related stigma and social support among respondents. Thus, the parent study contains measures of the key constructs included in the conceptual model for this dissertation. This dissertation will focus on the adults living with HIV/AIDS.

4.3.2 Measures

Overview. This section describes the measures used to operationalize the constructs in the conceptual model (Figure 3.5). All of the measures included in this dissertation were the same as those originally used in the parent study. Section 4.3.2a describes the dependent variable. Section 4.3.2b describes the independent variables. Lastly, section 4.3.2c explains the control variables: participants' demographic information, such as age, gender, and other background characteristics, including marital status, years of education, and annual family income.

Focal relationship. The focal dependent variable is access to care. Because the underlying goal of this dissertation is to explain the impacts of HIV-related stigma and social support on care access, these two variables are the focal independent variables. All analyses controlled for demographic characteristics (e.g., age, gender, marital status) and social economic status (e.g., education attainment, family income).

4.3.2.a Focal Dependent Variable

Access to care. Access to care is the ability to receive care and the ability to actually use the healthcare system (Andersen, 1995). To capture a measure of access, this study used a self-reported measure. This continuous variable indicates whether an individual had the ability to access care. It was measured using an eight-item, self-reported instrument. The instrument was pilot tested among PLWHA in Anhui, China (Li et al., 2011). The scale included indicators that measure realized access, which is the actual use of services (Andersen et al., 2011). *Access* is defined as a way of approaching, as an opportunity to reach, use, or visit (*Merriam-Wesbter*, n.d.). Access to care is a product of multiple factors, including the availability of services, the attitude, the skills, and the self-care practices (Andersen et al., 1995).

In the instrument used in the study, PLWHA were asked whether they believed the following eight statements applied to them:

1. I have regular visits to my doctors or medical providers.
2. If I get sick, I know where to go to get treatment.
3. If I need more information about my illness, I know where to get it.
4. I know when to go for my regular check-up when I am not sick.
5. I know how to protect myself from getting sick (e.g., opportunistic infections).
6. I know how to eat right to get proper nutrition to stay healthy.
7. I know how to exercise and stay healthy.
8. I can talk freely to my doctor and other medical providers about my illness.

Response ranged from 1 “totally untrue” to 4 “totally true.” A composite score was derived by summing across the response categories (1 = “totally untrue,” 2 = “basically untrue,” 3 = “basically true,” and 4 = “totally true”) for each of the potential recipients (score range = 8 to 32), with a higher score indicating higher level of access to care. The scale had a Cronbach’s alpha of 0.84 in this study, which is a measure of internal consistency obtained by analyzing how closely related a set of items are as a group, written as a function of the number of test items and the average inter-correlation among the items. The coefficient reliability of 0.84 is good considering that 0.70 is the cutoff value for being acceptable (Santos, 1999). The following formula was used for the standardized Cronbach’s alpha:

$$\alpha = \frac{N \cdot \bar{c}}{\bar{v} + (N-1) \cdot \bar{c}}$$

The N is equal to the number of items, c-bar is the average inter-item covariance among the items, and v-bar equals the average variance.

4.3.2.b Focal Independent Variables

Overview. This dissertation included two independent variables: HIV-related stigma and social support. HIV-related stigma in this study was measured via a 17-item instrument, which included two dimensions of HIV-related stigma—perceived stigma (eight items) and internalized shame (nine items). Social support was measured using a 15-item instrument that included three dimensions of social support—emotional support (eight items), tangible support (four items), and affectionate support (three items). Details of the independent variables are described below.

HIV-related stigma. Perceived stigma and internalized shame, the two dimensions of HIV-related stigma measured in this study, are described in this section.

Perceived Stigma. HIV-related stigma can be seen as an element in the social environment. Perceived stigma is the extent to which individuals are aware of that element. Perceived stigma was measured using an 8-item subscale adapted from the work of Herek and Capitanio (1993). The subscale was first validated among PLWHA in Thailand (Cronbach's alpha in the Thailand study = 0.75; Li, Lee, Thammawijaya, Jiraphogsa, & Rotheram-Borus, 2009) and among PLWHA in Anhui Province, China (Cronbach's alpha in the China study = 0.72; Li et al., 2011). The scale consists of eight items that measure stigmatizing attitudes or behaviors (or both) against PLWHA that have been felt or experienced by the respondent. Participants were asked to evaluate the degree to which they agreed or disagreed with the statements. The response was rated on a 5-point Likert scale that ranged from 1 "strongly disagree," 2 "disagree," 3 "undecided," 4 "agree," to 5 "strongly agree." Scale scores were created to represent the sum total of endorsed items, ranging from 8 to 40, with higher score implying a higher degree of perceived stigma (Cronbach's alpha of the scale in this study = 0.78).

Internalized Shame. The second dimension of HIV-related stigma, internalized shame, was assessed using a nine-item subscale adapted from the work of Herek and Capitanio (1993). The subscale has been validated previously among PLWHA in Thailand (Cronbach's alpha in the previous Thailand study = 0.81; Li et al., 2009) and among PLWHA in Anhui Province, China (Cronbach's alpha in the last China study = 0.77; Li et al., 2011). Participants were asked to evaluate the degree to which they agreed or disagreed with the 9 statements in the instrument. The nine items were answered on a 5-point Likert scale ranging from 1 "strongly disagree," 2 "disagree," 3 "undecided," 4 "agree," to 5 "strongly agree." Scale scores were created to represent the sum total of endorsed items, ranging from 9 to 45, with a higher score implying a higher degree of internalized shame. This measure showed high internal consistency in the present study (Cronbach's alpha of the scale in this study = 0.83).

Social Support. Perceived social support is a coping resource that manifests as an individual's perceptions or beliefs about being loved, cared for, understood, or valued by significant others, including family members or friends (Thoits, 1995). In this dissertation, social support is conceptualized as a focal independent variable and operationalized as a continuous variable. Respondents were asked the extent to which they experience each dimension of social support.

Social Support Instrument. In the Parent Study, participants reported their social support using items from the MOS Social Support Survey (MOS-SSS), a well-established psychological scale by Sherbourne and Stewart (1991). The original MOS-SSS consists of four subscales in an 18-item questionnaire that measures the self-perceived adequacy of functional social support of patients with chronic illness (Sherbourne & Stewart, 1991): emotional-informational support (8 items), tangible support (4 items), affectionate support (3 items), and support through positive social interaction (3 items). Emotional-informational support refers to the expression of positive affect, empathetic understanding, and the encouragement of expression of feelings. Tangible support is the provision of material aid, behavioral assistance, or assistance in completing tasks; affectionate support involves a direct expression of love and affection (Sherbourne & Stewart, 1991). High internal consistency was reported in the original MOS-SSS scale with a Cronbach's alpha of 0.97. The Chinese version MOS-SSS (MOS-SSS-C) was developed based on Brislin's (1986)'s model of translation (Yu, Lee, & Woo, 2004a) and validated among Chinese patients with chronic illness (Mak et al., 2007; Yu, Lee, & Woo, 2004b).

This dissertation included the MOS-SSS-C instrument in the same form as used in the Parent Study. In the present study, only three subscales were used—emotional support (8 items), tangible support (4 items), and affectionate support (3 items) —because they were most relevant to the research topics. The numbers of items in the three subscales were the same as in the original MOS-SSS instrument. This dissertation relied on the Parent Study's psychometric properties of the scales, as they have been pilot tested in similar populations in China.

The following instruction was given to the participants before answering the questions: "People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?" Cronbach's alpha for the affectionate social support scale in this study was 0.79. Affectionate support differs from emotional support in that it refers to "manifestation of love," such as hugs, the direct expressions of love and affection to a receiver (Sherbourne & Stewart, 1991). Responses for the three subscales ranged from 1 to 5, with 1 "none of the time," 2 "a little of the time," 3 "some of the time," 4 "most of the time," and 5 "all of the time." The responses to the statements were summed, with higher scores indicating higher levels of social support.

Tables 4.1–4.3 summarize the scales used in this study.

Table 4.1

Questions Comprising Access to Care Scale

Access to Care (α = 0.84)

1. I have regular visits to my doctors or medical providers.
2. If I get sick, I know where to go to get treatment.
3. If I need more information about my illness, I know where to get it.
4. I know when to go for my regular check-up when I am not sick.
5. I know how to protect myself from getting sick.
6. I know how to eat right to get proper nutrition to stay healthy.
7. I know how to exercise and stay healthy.
8. I can talk freely to my doctor and other medical providers about my illness.

Table 4.2

Questions Comprising HIV-Related Stigma Scale

HIV-Related Stigma

Perceived Stigma (α = 0.78)

1. I am accused by others of spreading AIDS in the community.
2. People gossip about my HIV status.
3. People look down on me.
4. The society isolates me.
5. I feel discriminated against by health workers.
6. I feel my life in this society is lonely.
7. I worry about how other kids treat my children in school as a result of my HIV.
8. I worry about how others will treat my family members as a result of my HIV.

Internalized Shame (α = 0.83)

1. I am punished by evil.
2. My life is tainted.
3. I am angry with myself for getting HIV.
4. I am a disgrace to the society.
5. My life is filled with shame.
6. I feel guilty for being the source of disruption in the family.
7. I feel my life is worthless.
8. I feel my reputation is lost.
9. If possible, I want to conceal my HIV status for life.

Table 4.3

Questions Comprising Social Support Scale

Social Support

Emotional Support (α = 0.86)

1. Someone you can count on to listen to when you need to talk.
2. Someone to give you information to help you understand a situation.
3. Someone to give you good advice about a crisis.
4. Someone to confide in or talk to about yourself or your problems.
5. Someone whose advice you really want.
6. Someone to share your most private worries and fears with.
7. Someone to turn to for suggestions about how to deal with a personal problem.
8. Someone who understands your problems.

Tangible Support (α =0.88)

1. Someone to help you if you were confined to bed.
2. Someone to take you to the doctor if you needed it.
3. Someone to prepare your meals if you were unable to do it yourself.
4. Someone to help with daily chores if you were sick.

Affectionate Support (α = 0.79)

1. Someone who shows you love and affection.

2. Someone to love you and make you feel wanted.
3. Someone who hugs you.

4.3.2.c. Co-variates

Individual Characteristics. Demographic information was collected from each participant: gender, age, years of schooling, and marital status. In addition, two other background characteristics were included: depressive symptoms and whether the participant contracted HIV through commercial plasma donation. Age was obtained by asking each respondent the question "How old are you?" For this analysis, age was measured in years and coded as a continuous variable. Education was measured in years as a continuous variable. The level of education was assessed by asking the participants how many years of school they had completed. A new categorical variable for educational level was generated by dividing respondents to three categories: "illiterate" (zero years of schooling), "educated 1–6 years," and "more than six years of schooling." For current marital status, there are three categories: married/partnered, separated/divorced/widowed, and never married. For this analysis, marital status was measured as a categorical variable by asking the participants the following question: "What is the current status of your marriage?" The response items included (a) "married/living as married," (b) "separated/divorced/widowed," and (c) "never married." Only three participants had never been married; therefore, marital status was dichotomized into two categories—currently "married/living as married" and "not married" (which included /separated/divorced/widowed/never married)—for the statistical analyses of this dissertation.

Spouse HIV status. The HIV-related clinical information obtained from the participants included their partner's HIV status. A single question asking the participants "What is your spouse's illness?" was used to obtain the spouse's HIV status. The response categories included (a) HIV/AIDS and (b) other.

HIV transmission routes. Data on how the participants thought they had acquired the HIV infection were based on the following question: "In your opinion, how did you get HIV infection?" The response categories included (a) "heterosexual intercourse," (b) "homosexual intercourse," (c) "drug injection/needle sharing," (d) "selling/donating blood," (e) "blood transfusion," (f) "mother-to-child transmission," and (g) "other." In this study, this variable was dichotomized so that respondents were grouped into those who contracted HIV through commercial plasma donation and those who contracted it through other mechanisms.

Depressive symptoms. Having depressive symptoms is a measure of psychological distress. It refers to emotions and behaviors associated with an effective state of extreme sadness (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). Depressive symptoms were measured using the shortened version of the Zung Self-Rating Depression Scale (Zung, 1965). The Zung Self-Rating Depression Scale is widely used in research as a tool to measure the level of depressive symptoms (World Health Organization, 2015). A short version (9-item) of the Zung Self-Rating Depression Scale was developed previously by experts in the field based on cultural relevance and appropriateness (Li, Liang, Ding, & Ji, 2011). The scale was validated in a previous pilot intervention study among PLWHA and their family members in Anhui, China, and had a Cronbach alpha value of 0.76 (Li et al., 2011). The shortened Zung Self-Rating Depression scale consists of six negatively worded items:

1. I feel down-hearted and blue.
2. I have trouble sleeping at night.
3. I notice that I am losing weight.
4. I get tired for no reason.
5. I am restless and can't keep still.

6. I am more irritable than usual.

The shortened scale also has three positively worded items:

7. I eat as much as I used to.
8. My mind is as clear as it used to be.
9. I feel hopeful about the future.

Participants were asked how often they thought about each of the nine items. Response categories ranged from 1 “a little of the time,” 2 “some of the time,” 3 “good part of the time,” to 4 “most of the time.” The overall score was a continuous variable constructed by summing the nine items with the three positively worded items reverse coded (possible range 9–36). A higher overall score indicated a higher level of depressive symptoms (Cronbach’s alpha in this study = 0.82).

Family Characteristics. One family characteristic was included in this dissertation—**annual family income**. It was obtained by asking, “What is your total yearly family income?” Instead of pre-determined categories being used for annual family income, the question was open ended; it was treated as a continuous variable in the collection.

4.3.3 Analysis Plan

Overview. All analyses were conducted using SAS for Windows (Version 9.4; SAS Institute, Cary, NC). The goal of the overall analysis was to estimate the association among salient dimensions of HIV-related stigma, social support, and access to care. This section presents the statistical procedures that were used to address the specific aims and hypotheses. As all variables examined here were from the parent study, this secondary data analysis was based on the particular configuration of the variables from the Parent Study. The strategies used to address the specific aims were guided by the elaboration model (Rosenberg, 1968) as put forth by Aneshensel (2013). The elaboration model outlines a systematic approach to inferential analysis when using observational data.

Descriptive statistics, bivariate analysis, and regression models were carried out for each specific aim. Univariate analysis was conducted for each variable to examine data normality and missing data. The contribution of the set of variables to explaining the associations between HIV-related stigma, social support, and access to care was assessed. Although the primary focus of this dissertation was the impacts of HIV-related stigma and social support on access to care, the effect of other variables in the model was of substantive interest, too.

Clustered data. A critical consequence of clustering is that measurements on units within a cluster are more similar than measurements on units in different clusters (Goldstein, 2011). Because the 522 participating PLWHA were recruited from 32 villages in four counties in rural Anhui, China, participants within a particular village might have been more similar to each other than to participants randomly selected from different villages. Thus, I sought to choose an appropriate method to address the data. Several methods that can account for the dependence among observations have been developed in the statistical literature to address data that come from a nested structure (McNeish & Stapleton, 2016).

Mixed-effects modeling. One such method is called *mixed-effects modeling* (Raudenbush & Bryk, 2002). A few guidelines have been suggested to ensure unbiased estimates while using mixed-effects modeling. First, it is suggested that having a minimum of 20 clusters is required to carry out an accurate estimate (Snijders & Bosker, 2012). Researchers have also advised against using this method if the number of a cluster is below 10 (Snijders & Bosker, 1993). Second, minimum cluster size (sample size within each cluster) recommended for an accurate estimate using mixed-effects modeling is five for a continuous outcome (McNeish & Stapleton, 2016).

The total number of clusters in this study (total number of village) is 32, and the smallest cluster size is five. The number of participants in each village ranged from five to 50 (median = 16, mode = 16, standard deviation [SD] = 10). Therefore, this clustered sample met the minimum requirements for carrying out mixed-effects modeling for accurate estimation. Additionally, previous studies utilizing the sample from the Parent Study had confirmed the appropriateness of carrying out mixed-effects models with village-level random effects (Li, Liang, Lin, Ji, & Xiao, 2017; Li et al., 2017a; Lin et al., 2015).

Mixed-effects modeling is conceptually similar to multiple regression in that outcome variable is linearly predicted from various independent variables (covariates or predictors; McNeish & Stapleton, 2016). Mixed-effects modeling was chosen for the following reasons: (a) mixed-effects model can treat clustered data adequately and assume two sources of variation, within a cluster and between clusters; (b) the mixed-effects model copes with parameter multidimensionality (McNeish & Stapleton, 2018). Introduction of random effects is an approach for modeling clustered data that will accommodate nested structure in the analysis (Laird & Ware, 1982; Stiratelli, Laird, & Ware, 1984).

Different types of parameters are present within mixed-effects modeling, including fixed effects at each level, random effects, their variance, possible covariance components, and the standard error estimate of each parameter (McNeish & Stapleton, 2016).

Fixed effects. Linear mixed-effects regression models were used to address both Aim 1 and Aim 2. The mixed-effects regression model included both fixed and random effects to assess the effect of HIV-related stigma and social support on access to care. Fixed effects are estimated to represent relations between predictors and the outcome irrespective of which cluster observations belong, similar to a standard single-level multiple linear regression model (Raudenbush & Bryk, 2002). The fixed effects (covariates) included individual demographic characteristics (age, gender, marital status, education) and family background (family income). The fixed factors were chosen to control for differences in these covariates.

Random effects. Unlike fixed effects, random factors capture how much the relationship between the predictor and the outcome differs from the fixed effect estimate for a specific cluster, thus essentially capturing the unique effect of the predictor in the cluster of interest (McNeish & Kelley, 2018). Random effects assume that data within clusters are dependent to some degree. Random factors should be chosen when a researcher is interested in quantifying how much of the overall variation is attributed to this factor and when a researcher wants to account for variation in this factor. Thus, to account for the clustering structure in this study, I selected the mixed-effect model with village-level random effects to account for the clustering effects within villages. One level of random effects, village-level random effects, were included in the model to account for the dependence within the villages. Random effects only included the village level and not the county level for the following two reasons: (a) because the 32 villages were nested within the four counties, the inclusion of village-level random effects would be a more appropriate proximate to adjust for the clustering effects; (b) the number of counties in this study did not meet the aforementioned criteria for carrying out a mixed-effects modeling (i.e., any cluster number below 10 can lead to bias estimates). The models fit each participant's measure for access to care, adjusting for the following covariates: age, gender (male versus female), marital status (married/partnered versus single/separated/divorced/widowed), family annual income, educational level, and depressive symptoms.

Modeling procedures. Both full maximum likelihood (FML) and restricted maximum likelihood (REML) produce similar estimates with large numbers of cluster, but REML can provide less biased estimates of variance components (McNeish & Stapleton, 2016). REML estimates the fixed effects and the variance components separately such that the estimation of the fixed effects does not interfere with variance component estimation (Raudenbush & Bryk, 2002). Thus, the SAS PROC MIXED procedures with the REML method that accommodated data that were missing at random were used to estimate fixed- and random-effects parameters (Little, 1995; Rubin, 1976). The mixed model approach used in PROC MIXED is more flexible and fits the broader class of random- and mixed-effect linear models than either the univariate or multivariate approaches (SAS, 2017). The RANDOM statement was used to indicate that the outcome—access to care—was modeled by a random intercept clustered by villages.

4.4 Analysis of Aim 1

Aim 1: To determine whether the selected two dimensions of HIV-related stigma (i.e., perceived stigma and internalized shame) are associated with access to care among HIV-positive men and women in rural Anhui, China.

4.4.1 Descriptive Statistics of Aim 1

Univariate Analyses. First, univariate analyses were conducted to examine each variable in this study (e.g., age, gender, annual family income) to obtain descriptive statistics (e.g., means, standard deviations, and proportions). For each variable, it was useful to inspect them using a histogram that showed the information about the shape of the variable better than simple numeric statistics. For continuous variables, range, variance, maximum, minimum, as well as mean and standard deviation were calculated. For categorical variables (e.g., marital status), frequency distribution was reported. Descriptive statistics were used to explore the nature of missing data and data normality. All of the variables were examined for outliers.

4.4.2. Validity and Reliability of Scales

This section describes the psychometric properties of the scales used in this study, including reliability (internal consistency) and validity. Validity, verification that the tool measures the concept that it is presumed to measure, includes four areas: face validity, content validity, criterion validity, and construct validity. Within each category, there are sub-categories. The psychometric properties of the multi-item scales used in this study were previously examined in the parent study (Li et al., 2011; Li et al., 2014; Li et al., 2017; Li et al., 2018).

Construct Validity. Construct validity includes three aspects: convergent validity, divergent validity, and discriminant validity. Campbell and Fiske (1959) developed the matrix to assess the construct validity of a set of measures in a study and stressed the importance of using both item-convergent and item-discriminate validation techniques when evaluating new tests. To establish construct validity, a researcher has to demonstrate both convergence and discrimination. Item-convergent validity and item-discriminant validity are subtypes of construct validity (Campbell & Fiske, 1959).

Convergent Validity. Convergent validity can be established if two similar constructs correspond with one another. The correlation with similar (convergent) validity was tested using bivariate analysis (Pearson correlation coefficient; Nunnally & Berstein, 1994). Measures of depressive symptoms were used to assess construct validity. To examine the correlations among the depressive symptom measure, the HIV-related stigma scale, social support scale, and their respective subscales were examined. Relationships among these related measures matched with the predictions: higher levels of depressive symptoms were associated with higher levels of overall HIV-related stigma, as well as higher levels for each of the subscales (i.e., perceived stigma and internalized shame). Similarly, higher levels of depressive symptoms were associated with lower levels of overall social support, as well as lower levels for each of the subscales (i.e., emotional, tangible, and affectionate support).

Discriminate Validity. Discriminate validity can be applied to two unique constructs that can be easily differentiated. The correlation with different scales (discriminant validity) was also measured using bivariate analysis by Pearson correlation coefficient. For discriminant validity, a weak correlation ($r < 0.4$) was expected. In this study, convergent validity and item-discriminate validity were assessed, and the results showed that items had higher correlations within their own scale as compared with the other scales. The multiple-item scales of HIV-related stigma and social support reached the established standard for internal consistency reliability for group-level comparisons (Cronbach’s alpha = 0.70).

Criterion Validity. Criterion validity includes two sub-types: Concurrent validity and predictive validity. This is examined when a construct is evaluated by the scale being tested and by a reference criterion (gold standard). In order to accomplish this, a sufficient number of subjects need to be evaluated independently using the two tools, and the correlation coefficient is evaluated. This could not be carried out in this study, as no two measures were available to test the criterion validity of the scales, nor was a biological outcome available to test the scale against a gold standard.

Internal Consistency. Cronbach’s alpha is used to measure the internal consistency of a group of items relating to a single domain—in other words, to examine how the items correlate with each other. The internal consistency was tested during the development of the scale by the researcher in the parent study (Li et al., 2011). Cronbach’s alphas were calculated for the total HIV-related stigma scale and the two subscales, as well as the social support scale and its three subscales. The obtained value of the alphas provided evidence of internal consistency reliability.

4.4.3. Bivariate Analysis of Aim 1

Bivariate Analyses. Bivariate analyses were carried out to obtain bivariate associations (e.g., correlations, chi-square statistics) among study variables. Pearson correlation coefficients (or independent *t*-tests when one variable was dichotomous; chi-square tests when both variables were dichotomous) were computed to examine whether there were any significant associations between perceived stigma and access to care, as well as the control factors, including the demographic variables such as age, gender, annual family income, and education. Scatterplots of all the bivariate correlations were generated and examined. Scatterplots with fitted predictor lines (for continuous independent variables) and connected line graphs (for plotting group means of categorical variables) were used to visually represent the relationship between focal independent variables and the focal dependent variable. Next, two simple linear regression analyses were carried out to test the two dimensions of HIV-related stigma. First, I examined the relationship between perceived stigma and access to care to see whether levels of stigma were related to care access. Next, I conducted a similar regression analysis for internalized shame and access to care.

4.4.4. Mixed-Effects Linear Regression Models for Aim 1

The first aim of this dissertation is to determine the extent to which levels of access to care differ by dimensions of HIV-related stigma. The significant association from the focal bivariate analyses was further investigated through mixed-effect linear regression analyses in which control variables that are correlated to the focal variables and also had a biological, sociological, or other justifiable basis for inclusion were added to the significant association between HIV-related stigma (i.e., perceived stigma, internalized shame) and access to care in order to further elaborate on this association. Mixed-effect linear multiple regressions were suitable for this investigation ,as the technique is used to explain the relationship between one continuous dependent variable and two or more independent variables. In this study, the dependent variable—access to care—is a continuous variable; thus, linear regression was chosen to investigate the focal relationship of interest further.

The potential confounding factor must be related to both independent and dependent variables to be able to advance understanding of the focal relationship. If the possible confounding factor was related to only the dependent variable, it helped in models that seek to further account for the occurrence of the dependent variable without altering the focal relationship (Aneshensel, 2013). If, for instance, the potential confounding factor(s) was associated with both the variables in the association (e.g., perceived stigma and access to care), then mixed-effects linear regression modeling would be employed to see whether the association persisted when controlling for the potential confounding factor(s). See the following illustration of the equation for a linear mixed-effects model (Raudenbush & Bryk, 2002):

$$Y_{ij} = \beta_{0j} + \beta_{1j}X_{1ij} + r_{ij}$$

$$\beta_{0j} = \gamma_{00} + \gamma\gamma_{01}W_{1j} + u_{0j}$$

$$\beta_{0j} = \gamma_{10} + \gamma\gamma_{11}W_{1j} + u_{1j}$$

Y_{ij} is the continuous outcome variable for the *i*th observation in the *j*th cluster, X_{1ij} is the value of the level-1 predictor for the *i*th observation in the *j*th cluster, and r_{ij} is the level-1 residual for the *i*th observation in the *j*th cluster. γ are the d estimates, W_{1j} is the value of the level-2 predictor for the *j*th cluster, and u_{0j} and u_{1j} are the random effects whose variance and covariance are housed in the τ matrix.

Univariate analysis of the two variables family annual income and educational level indicated that it wouldn’t be most suitable to include them as continuous variables in the regression analysis. Thus, both of the variables were included as categorical variables in the regression analyses for both Aim 1 and Aim 2. On the basis of the univariate analysis, family annual income was categorized as (a) below 9,000 yuan (USD$1,421), (b) between 9,000 yuan and 18,000 yuan (USD$1,421 – USD$2,843), and (c) above 18,000 yuan (USD$2,843 or higher). Under the SAS CLASS statement, the categorical independent variables (e.g., education and family annual income) were listed. SAS created dummy coded variables for any variables in the CLASS statement.

I, then, carried out linear mixed-effects regression models to examine whether perceived stigma was associated with access to care. The elaboration model (Rosenberg, 1968) was used to develop the models for analysis using linear regression. Of interest within the elaboration model were questions such as whether age, marital status, gender, educational level, depressive symptoms, and family annual income were extraneous variables that, when controlled for, would modify or negate the focal relationship in question; or did these variables have a conjoint influence alongside stigma factors on access to care? If the aforementioned “confounding” variables had an independent association on the dependent variable, then did these variables or the stigma factor have the stronger association with care access? The relative effects of each was ascertained by controlling for one or the other in multiple linear regression analysis. Regression coefficients estimates and their significance levels were reported. An alpha level of 0.05 was used for all analyses.

In line with the steps of the elaboration model (Aneshensel, 2013), the parameter estimates (e.g., regression coefficient) of three-variable regression models were compared to the estimate of the focal relationship. The interpretation of the change in the size of the regression coefficient depends upon the role of the third variable as stated in the analytical models. For instance, if a statistically significant bivariate association between HIV-related stigma and access to care was no longer significant when a control variable was added, then the focal relationship was considered a spurious one that is confounded by the controlled variable. If the third variable added is an alternative independent variable, then the loss of a significant focal relationship suggests that the effect of HIV-related stigma on access to care is not separate and distinct from the effect of the third variable. That is, there is a redundancy in the model because both independent variables, unlike spuriousness, are associated with access to care and each other, although no causal association is attributed to the latter. Moreover, a reduced coefficient that remains statistically significant would point to different conclusions—spuriousness with a controlled variable, redundancy with a rival independent variable, and partial mediation with an intervening variable (Aneshensel, 2013). If the magnitude of the focal independent variable remains the same when a third variable was added, it would indicate that the third variable did not explain the focal relationship; if, however, the magnitude of the regression coefficient for the focal relationship increased, it would indicate suppression. When adding a third variable that was operationalized as multiple dummy variables, a Wald test was used to determine whether the addition of the set of variables to the bivariate model would produce a significant increase in R^2, which would be equivalent to testing the null hypothesis that the added coefficients all equal zero. If the null hypothesis was rejected (at the 0.05 significance level), then the statistical significance of the singular dummy variables was examined.

Table 4.4 presents the equations pertaining to Aim 1. To test Hypothesis 1, I regressed access to care on perceived stigma (Model A1), which is operationalized by a continuous variable. To test for moderation effects such as gender, I first regressed access to care on gender (Model 1B), and then regressed access to care on perceived stigma, gender, and the interaction term of perceived stigma and gender (Model 1C). Then, I added other individual characteristics such as age to the model (Model 1D).

Table 4.4

Steps in the Analysis of Perceived Stigma, Internalized Shame, and Access to Care

Step	Description of Statistical Procedure	Label	Regression Equation
1	Association between perceived stigma and access to care	Model 1A	$Y = \alpha + \beta 1X + \varepsilon$
2	Association between gender and access to care	Model 1B	$Y = \alpha + \beta 2Z + \varepsilon$
3	Conditional effect of perceived stigma on access to care by gender	Model 1C	$Y = \alpha + \beta 1X + \beta 2Z + \beta 12\,(X*Z) + \varepsilon$
4	Adjustment for individual and family characteristics	Model 1D	$Y = \alpha + \beta 1X + \beta 2Z + \beta 3C + \varepsilon$
5	Association between internalized shame and access to care	Model 1E	$Y = \alpha + \beta 4I + \varepsilon$
6	Conditional effect of internalized shame on access to care by gender	Model 1F	$Y = \alpha + \beta 4I + \beta 2Z + \beta 24\,(I*Z) + \varepsilon$
7	Adjustment for individual and family characteristics	Model 1G	$Y = \alpha + \beta 4I + \beta 2Z + \beta 3C + \varepsilon$

Note. Y = access to care, X = perceived stigma, Z = gender, I = internalized shame, C = individual and family characteristics.

Additionally, regression diagnostics were carried out to examine for potential problems such as multicollinearity and outliers in each model. For instance, variation inflation factors (VIF) were examined to gauge the effects of the presence of collinearity among the independent variables upon the regression equation. A variance inflation factor that exceeded the value of 4 was indicative of serious multicollinearity problems (Neter, Wasserman, & Kutner, 1989). The normal probability plots of the standardized residuals were plotted and examined to see whether they revealed any uncommon patterns.

4.4.5. Subanalyses of Aim 1

A subanalyses was performed to compare and contrast whether the relationship between the two dimensions of HIV-related stigma and access to care differ across HIV concordant and discordant couples; moreover, regression analyses performed in the entire sample were controlled for whether the PLWHA had a HIV-positive partner. An additional subanalysis was performed to compare and contrast results from the former plasma donors versus those who were not plasma donors. For each sub-analysis, procedures were carried out for the bivariate analysis and mixed-effects linear regressions. The subanalyses helped to gain a better understanding of whether HIV-related stigma impacts access to care differently in the sub-populations.

4.5. Analysis of Aim 2

Aim 2: To determine whether the three dimensions of social support—(a) emotional support, (b) tangible support, and (c) affectionate support—are associated with access to care among HIV-positive men and women in rural Anhui, China.

4.5.1. Descriptive Statistics of Aim 2

Univariate Analyses. First, univariate analyses were conducted to examine the second dependent variable, social support, to obtain descriptive statistics (e.g., means, standard deviations, and proportions). Similarly to the univariate analyses procedures that I followed in Aim 1, I inspected the variable using a histogram that showed the information about the shape of the variables. Since the three dimensions of social support were measured as continuous variables, the range, variance, maximum, minimum, as well as mean and standard deviation were calculated and reported. Examination of outliers was also performed for each variable.

In order to assess the psychometric properties of the multi-item social support scale used in this study (Eisinga, te Grotenhuis, & Pelzer, 2013), correlations within the multi-item scale were also examined for social support (three dimensions of emotional, tangible, and affectionate support). The results are summarized in Appendix A.

4.5.2. Bivariate Analysis of Aim 2

Bivariate Analyses. Second, bivariate analyses were carried out to obtain bivariate associations (e.g., correlations) between social support and access to care. Pearson correlation coefficients were computed to examine whether there was any significant association between social support and access to care, as well as the control factors, including the demographic variables such as age, gender, annual family income, and education. Scatterplots of all the bivariate correlations were generated and examined. Similarly to the procedures for analysis of Aim 1, scatterplots with fitted predictor lines (for continuous independent variables) and connected line graphs (for plotting group means of categorical variables) were used to visually represent the relationship between focal independent variables (i.e., three dimensions of social support) and the focal dependent variable (i.e., access to care).

As outlined in the analytical procedures for Aim 1, if there were missing data within the analytical sample, as, for example, with social support among the PLWHA in all 32 villages, the statistical significance of mean differences between those that did and did not have the data would be assessed using independent sample *t*-tests, including the Levene test for homogeneity of variance (Levene, 1960). The Levene test assesses the assumption that variance of the populations from which different samples are drawn are equal. If the resulting *p*-value of the Levene test is less than the significant level (0.05), the obtained differences in sample variances are unlikely to have occurred based on random sampling from a population with equal variance. Next, linear regression analyses were used to test whether (a) emotional support, (b) tangible support, and (c) affectionate support were independent predictors of access to care.

4.5.3. Mixed-Effects Linear Regression Models for Aim 2

Mixed-effects linear regression models were carried out following the general outline presented in section 4.4.4 in Aim 1 to further elaborate upon the association between the three dimensions of social support and access to care. The elaboration model (Rosenberg, 1968) was also used, as described previously, to develop the models. Finally, regression diagnostic tests, as describe previuosly, were applied to each analysis. Regression coefficients estimation and their significance levels were reported. An alpha level of 0.05 was used for all analyses.

Table 4.5

Steps in the Analysis of Emotional Support, Tangible Support, Affectionate Support, and Access to Care

Step	Description of Statistical Procedure	Label	Regression Equation
1	Association between emotional support and access to care	Model 1A	$Y = \alpha + \beta 1E + \varepsilon$
2	Association between gender and access to care	Model 1B	$Y = \alpha + \beta 2Z + \varepsilon$
3	Conditional effect of emotional support on access to care by gender	Model 1C	$\mathrm{Y} = \alpha + \beta 1E + \beta 2Z + \beta 12\ (\mathrm{E*Z}) + \varepsilon$
4	Adjustment for individual and family characteristics	Model 1D	$\mathrm{Y} = \alpha + \beta 1E + \beta 2Z + \beta 3\mathrm{C} + \varepsilon$
5	Association between tangible support and access	Model 1E	$Y = \alpha + \beta 4T + \varepsilon$

	to care		
7	Conditional effect of tangible support on access to care by gender	Model 1F	$Y = \alpha + \beta 4T + \beta 2Z + \beta 24 (T*Z) + \varepsilon$
8	Adjustment for individual and family characteristics	Model 1G	$Y = \alpha + \beta 4T + \beta 2Z + \beta 3C + \varepsilon$
9	Association between affectionate support and access to care	Model 1E	$Y = \alpha + \beta 5A + \varepsilon$
10	Association between gender and access to care	Model 1B	$Y = \alpha + \beta 2Z + \varepsilon$
11	Conditional effect of affectionate support on access to care by gender	Model 1F	$Y = \alpha + \beta 5A + \beta 2Z + \beta 25 (A*Z) + \varepsilon$
12	Adjustment for individual and family characteristics	Model 1G	$Y = \alpha + \beta 5A + \beta 2Z + \beta 3C + \varepsilon$

Note. Y = access to care, E = emotional support, T = tangible support, A = affectionate Support, Z = gender, C = individual and family characteristics.

4.5.4. Subanalyses of Aim 2

In a way similar to 4.4.5, subanalysis was carried out for Aim 2 to (a) compare and contrast whether the relationship between the three dimensions of social support and access to care differ across HIV concordant and discordant couples and to (b) compare and contrast the results for those who were infected via commercial plasma donation and those who were not plasma donors. For each subanalysis, similar procedures were carried out as in 4.4.5.

4.5.5. Calculation of Indirect Effects: Mediation Analysis

As a secondary goal of the study, I examined whether social support mediated the relationship between HIV-related stigma and access to care (Baron & Kenny, 1986). The general model was described regarding mediated effects. The mediator has been called an intervening or process variable. Complete mediation is the case in which independent variable X no longer affects dependent variable Y after Mediator M has been controlled, making path c' zero (Figures 4.6 and 4.7). Multivariate normal distribution and normally distributed error terms were examined to meet the assumption for this model. The effect of adding a third variable could be calculated in based on the differences between the two regression parameters (c - c') (indirect effect). The following three regression equations were estimated for the aforementioned method.

Model 1: $Y = i_1 + cX + \varepsilon_1$

Model 2: $Y= i_2 + c'X + \beta M + \varepsilon_2$

Model 3: $M= i_3 + \alpha X + \varepsilon_3$

Where Y is the outcome variable (access to care in this current study), X is the independent variable (HIV-related stigma), M is the mediator (social support), c (total effect) codes the relationship between the independent variable (HIV-related stigma) to the outcome variable (access to care) in the first equation. Whereas c', direct effect, is the coefficient relating the independent to the outcome adjusted for the effects of the mediator, ε_1 and ε_2 code for the unexplained variability, and the intercepts are a_1 and a_2.

Path c in Figure 4.6 is called the *total effect*. The effect of HIV-related stigma may be mediated by a process or mediating variable M (social support) as shown in Figure 4.7.

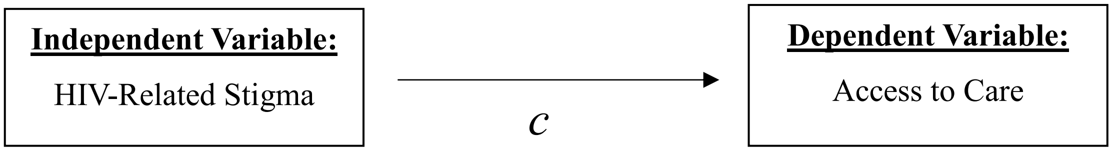


Figure 4.2. Total effect (c) of HIV-related stigma and access to care

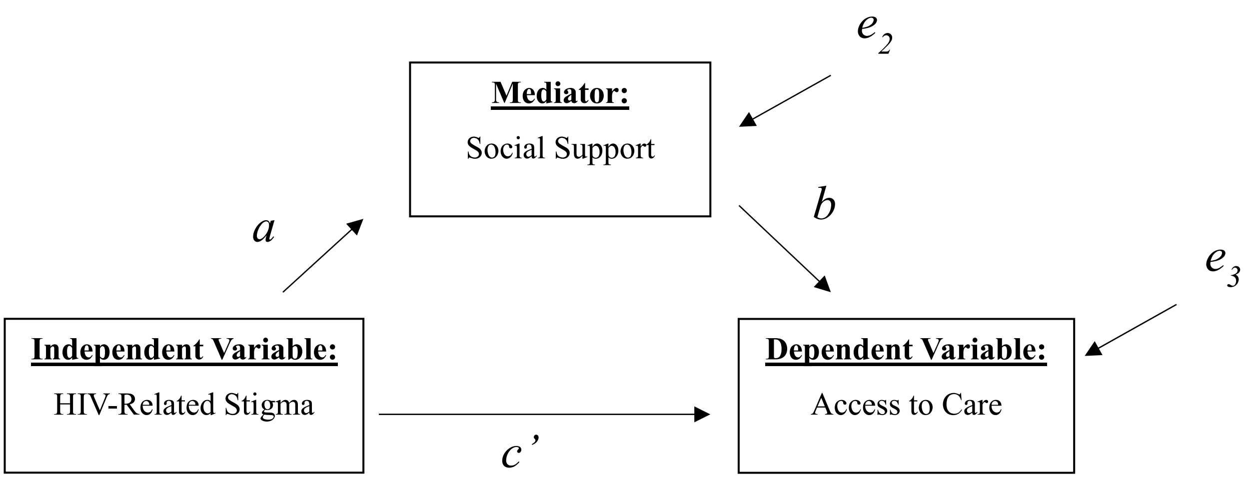


Figure 4.3. Mediation analysis (c') of HIV-related stigma and access to care mediated by social support

Barron and Kenny's four steps of mediation analysis. Based on Barron and Kenny's method of testing mediation (Barron & Kenny, 1986), the four steps in establishing mediation are summarized in Table 4.6.

Table 4.6
Steps of Mediation Analysis – HIV-Related Stigma and Access to Care Mediated by Social Support

Step	Description	Label
1	Show that the initial variable is correlated with the outcome	Model Y = X
2	Show that the initial variable is correlated with the mediator	Model M = X
3	Show that the mediator affects the outcome variable	Model Y= M X
4	To establish that M completely mediates the X-Y relationship, the effect of X on Y controlling for M (path c') should be zero	Model Y = X M

First, show that the independent variable is correlated with the dependent variable. Use Y as the criterion variable in the regression equation and X as a predictor (estimate the test path c in Figure 4.6). Second, show that the independent variable is correlated with the mediator. Use M as the criterion variable in the regression equation and X as the predictor (estimate and test path as shown in Figure 4.7). This step essentially involves treating the mediator as if it were an outcome variable. Third, show that the mediator affects the dependent variable. Use Y as the criterion variable in the regression equation and X and M as predictors (estimate and test path b). It is not sufficient just to correlate the mediator with the dependent (outcome) variable because the mediator and the outcome may be correlated because they are both affected by the dependent variable X. Thus, the X variable must be controlled in establishing the effect of the mediator on the outcome. Fourth, to establish that M completely mediates the X-Y relationship, the effect of X on Y controlling for M (path c') should be zero. The effects in both Step 3 and 4 are estimated in the same equation. The paths of c, a, b, and c' (as shown in Figure 4.7) can be estimated by multiple regression.

Following Barron and Kenny's method, I used the results generated for Aim 1 as Step 1 (I examined the association between HIV-related stigma and social support [Step 2], as well as social support and access to care as part of Aim 2 [Step 3]). If the first two associations were significant, then the possibility of a mediation relationship would be heightened. According to the standard criteria for assessing mediation, I examined the association between HIV-related stigma and access to care as part of Aim 1. In the final step, I examined the extent to which the association between HIV-related stigma and access to care was attenuated by adding social support to the model.

Part II. Critical Performance

4.6. Methods

Overview. This section describes the development and implementation of the performance and how materials were selected and included in the program. The following sections describe the process of planning and producing the event. The process included a selection of performative elements suitable for the program, refining the content of the program, as well as discussion with my committee chair and minor field advisor regarding the content. The following paragraphs detail the process of generating movements and text, as well as organizing the structure and production elements of the program.

4.6.1. Methods of Creating Performance

I selected choreography and theatrical performance as the media that would appropriately reflect the data, audience, and purpose of dissemination (Gognan, 2009). In the process of creating a text-based performance that conveys the messages from the dissertation while incorporating performative elements, I sought to answer two questions: “What do stigma and support feel like in the body?” and “What happens when one experiences stigma and support?” The two questions were critical for me as they helped me “embody” the dissertation’s specific aims that sought to ascertain the relationship between HIV-related stigma, social support, and access to care. Through the movements, I aimed to explore body-related experiences in men and women living with HIV/AIDS in rural Anhui, China. When I asked the question, “What does stigma feel like in [my] body?” the question was intended to generate movements that would eventually resonate with the audience viewing the movements.

The work began as a response to the dissertation work and grew out of the oral qualifying exam, while seeking to expand it into a different dimension, beyond the linear, quantitative arguments presented on the paper. The project sought to incorporate multimedia, spoken word, narrative, and movement in an exploration of relationship, identity, and meaning. I embarked on a transdisciplinary choreographic process, one that combined movement-based and theoretical research across the disciplines of public health, dance, theater, literature, and music. Through the orchestration of dance, music, props, acting, video, and spoken word, these production elements were synthesized into a transformative theatrical experience for the audience. In the following sections, I explain the inspirations behind the piece, how I arrived at the selected elements, and what the practice looked and felt like in progress. I also describe the performance that resulted from this creative process. On the basis of Conquergood's five areas of performance studies as well as ethnodrama's strategies (Conquergood, 1991; Saldaña, 1999), I decided that the emphasis of the project would on six elements: movement, original text, quotes from people living with HIV/AIDS, and spectacle such as photographs, set, and props. Through movement, I tried to dialogue with my own writing as well as with the quotes from individuals living with the disease.

Video

I sought to include a short film clip in this performance because of the long tradition of film and video media in health promotion and education (Bhugra, 2003; Gabbard & Gabbard, 1999; Jones, 2014). Besides, video media have been efficacious in creating an emotional response and enhancing empathy in audience, while providing information to viewers (Strasburger, Wilson, & Jordon, 2009).

Photographs

Caroline Wang (1999) coined the term *photovoice* for participatory photography. Photo-voice puts cameras in the hands of community residents so they can take photographs of their community, promoting dialogue and deeper understanding of the issues that govern their lives. Photo-voice can be used as a tool to empower disenfranchised people to act as catalysts for community change (Wang, 1999). Photo-voice is a qualitative and exploratory research methodology founded on the principles of constructivism, feminist theory, and documentary photography (Rhodes, Hergenrather, Wilkin, & Jolly, 2008). Constructivists typically emphasize the importance of the active construction of knowledge and that real understanding can only occur when individuals participate fully in their own learning (Harris & Graham, 1994). As a result, it can lead to deeper understanding and use of knowledge, thus promoting access to and application of the lessons learned (Pressley, Harris, & Marks, 1992). Gender theorist Judith Butler (1988) states that feminist theory seeks to understand the way in which "systematic or pervasive political and cultural structure are enacted and reproduced through individual acts and practices, and how the analysis of ostensibly personal situations is clarified through situating the issues in a broader and shared cultural context" (p. 522). Documentary photography has been tied to exploration and social reform (Becker, 1995), and it refers to a form of photography used to chronicle events or environments both significant and relevant to history, historical events, and everyday life (Rosler, 1989).

I intended to use photovoice to represent the PLWHA in ways that matched their self-perception (Wang, 1999). Therefore, photos taken by the PLWHA in the TEA intervention trial were included in this performance. Instead of displaying photographs *of* HIV-positive individuals, I intended to showcase the photographs taken *by* HIV-positive individuals. In this way, the individual shifts from the role of being the subject and observed to being the one in charge, allowing and inviting the viewers to see what he orshe provides. This also exemplifies how technology, the camera, mediates and produces subjectivities in the world. This process challenges the established politics of representation by shifting the means of documenting lives from the powerful to the powerless, the expert to the layperson, the observer to the observed (Booth & Booth, 2003). Research has shown that photo-voice empowers participants via a process called Empowerment Education (Freire, 1970). The photograph taken by HIV-positive individuals allows the viewer to gain a better understanding of the cultural meaning that shapes or constructs the PLWHA's experiences in their social and cultural context. The ethnographically grounded descriptive and analytic research on the social and cultural construction of HIV meanings behind the narrative provides important insights to the representations shaping HIV-related experiences in rural Anhui Province, China.

The use of photographs also exemplified Austin's (1975) ideas about words as active agents. In the context of this performance, photographs were not merely images but could be seen as speech acts, emphasizing photography's contexts of reception and the intersubjective relations that initiate the photograph's performative force and meaning. Austin's argument about linguistic performatives being contractual ("I bet") or declaratory ("I declare war") utterances (Austin, 1975) can be applied in the analysis of photographs in which it exceeds the status of testimony or evidence by calling for action on the part of the viewer. Austin's ideas could be drawn upon to explore how photographs work performatively to solicit affective responses to human conditions. Surely photographs could operate in the way that Austin describes, but it was also important to recognize what Austin noted, that performative acts only accrue force if they succeed in the "securing of uptake" (Austin, 1955).

I envisioned that the photographic works and storytelling embedded in the performance would allow the audience to observe and to participate in this exploration of the impact of HIV/AIDS, as expressed through the movements and narratives, and to see how it can and does relate to their own lives. The photos and stories were used to call for raising awareness of HIV, public policy change, advocating for human rights, and addressing HIV-related stigma. My goals for the piece were to invite the audience to experience the emotions of PLWHA, to see the society's attitudes of and towards PLWHA, and to reflect on the connections to their own lives. The audience would be asked through the delivery of the content of the piece to make investigations and connections.

4.6.2. Methods of Creating Movement Phrases

Creating movement is a process of becoming aware of one's body and allowing oneself to be a vessel. As all choreographers, I intended to utilize the elements of space, time, and energy to enhance the quality of the dance. The following elements were used during the creation process of the piece: space; shape/line; level; direction; focus; points on the stage; floor patterns; depth and width; phrases; transitions; time—speed/tempo, pulse/underlying beat, rhythmic pattern, time signature/meter, no counts at all, breath/emotional phrasing, stillness; words/text/sounds/silence; and energy—dynamics, quality.

It was my intention to push myself as a solo artist, as I thought it would be appropriate to create a dance around myself as a central character. I started by choreographing a solo section for myself, consisting of dance and monologue. The first draft of the solo was created and revised to distill the most interesting movement aspects and to think about how and when text would be introduced into the work. The creative process included reading the texts and journaling. Several journal entries were generated as a response to the prompts I set out for myself, including looking at self-worth, support that I lean on, and examining how and why I form certain perceptions about others. An example of the prompt would be:

1. Write in the first-person present tense.
2. Write something about the movement itself and describe it.
3. Complete the following sentences, “I feel ____” and “I imagine ____.”

The goal was to consider how I relate to others, to the space, to the light, the darkness, the movement, the issues and muscle groups in my body and emotions. Some exercises were used to create movement phrases. For example, I picked two words to create a movement around, including (a) a word describing texture (e.g., smooth) and (b) an image (e.g., open field). Instead of choreographing from the beginning, I began working on several movement phrases to see where they would take me.

The process of choreography is about relating to my body and mind while exploring the interface between the two. I performed a number of improvisations on these themes and turned my favorite moments into a short phrase. While creating the phrases, I imagined that I was dancing with someone whom I received support from as I performed these movement phrases. What would my movements say to this person? What would the connection between the phrases be? When do I lean physically on them, when do I pull away? What is the physical quality of the action? This exercise changed the performance of the movement phrase notably. Improvisation was used very often as an impetus for movement. I videotaped improvisations and examined the pieces later to incorporate them into the piece.

The movements were then joined with the voice recording. The recording consisted of reading the definitions of stigma as well as social support. For instance, one of the definitions of stigma was drawn from Goffman's (1963) seminal work on stigma. Instead of choosing one definition of stigma, different definitions were used and recorded to convey the variety of stigma definitions; the definitions were recorded in chronological order based on the publication date. I wanted to include text, both spoken and projected, in the piece. I looked through a variety of sources, including published peer-reviewed qualitative studies conducted in China, for quotes from PLWHA on experiencing stigma and their sense of social support.

4.6.3. Methods for Creating Narratives

I employed the method of ethnodrama to convey the stories behind the HIV epidemic in rural Anhui Province, China. Ethnodrama was an appropriate medium because it would "credibly, vividly, and persuasively" convey stories to an audience (Saldaña, 2005, p. 61). The basic requirements of ethnodrama include characters, plot, and scene. I selected a few quotes published in peer-review journals to share with the audience (Chen et al., 2011; Xie et al., 2017). Three narratives were created for HIV-related stigma, and four narratives were selected for social support. On stage, I became the protagonist in each of the narratives, delivering the first-person narrative. I used a prop for each character to distinguish narratives from one another. As I choreographed the piece, I sought feedback from peers as well as my professors.

According to the narrative engagement framework, messages communicated in "narrative form," like through an ethnodrama, must be simplified and refined, and thus are capable of demystifying complex research findings (Miller-Day & Hecht, 2013). Since there were many quotes from published qualitative studies, I selected the quotes and then simplified them into seven narratives. All the quotes were drawn from published peer-reviewed qualitative studies conducted in China.

4.6.4. Performance Program Structure

Once the movement phrases and texts were created, I arranged the pieces into larger movement phrases based on Conquergood's (1991) five areas of performance studies as well as ethnodrama strategies. Different orders have been tried; some movements were layered in contrasting movement or fragmented. Since I first choreographed without music, I then searched for a piece of music that I thought would be good for the piece. Then, I chose music and sound to add to specific parts of the movement piece. I then answered the following questions: "Where did I see this music fitting into the piece?" and "Why did I pick it?" The piece also incorporated post-modern dance techniques, which used pedestrian movements such as walking and everyday gestures while incorporating spoken word, video projection, and other multimedia elements.

4.6.5. Performance Production Elements

The performance elements included props, lighting, costume, sound, set, and choreography. After putting the texts, sound, and the movement phrases together, I explored different costumes and props to enhance the piece. For example, I used an apron as a prop in the first narrative stigma story, and a bowl was added to the narrative of a social support story. These props emphasized the protagonists' characters. Seven props in all were selected based on the characters: a bamboo basket, an apron, a wide black scarf, a bowl with chopsticks, a large straw bamboo sun hat, a blue cotton bag, and a ring. Additionally, I also designed the lighting to accent the piece by dimming lights for some parts of the movements.

4.6.6. Production Materials, Marketing, and Promotion

Production materials for the performance included a performance flyer and program pamphlet. Since the most well-known HIV awareness ribbons are the red ribbon in support of those who acquired AIDS, the red ribbon was included in the flyer design as well as the program. The flyer draft was prepared and sent to both Dr. Ford, my dissertation committee chairperson, and Dr. Gere, my minor field advisor, for review and feedback. I completed the graphic design for both the flyer and the program. The flyer and program are included in Appendix B.

A simple marketing plan was developed for this event: direct outreach, listservs, and web-based promotion. The flyer was sent to listservs on the UCLA campus and to departments to spread the word of the event. I personally sent an invitation to contacts through text messaging, word of mouth, and emails. The flyer was sent to the student affairs officers of my major and minor departments, as well as the Fielding School of Public Health listservs. Finally, the Center of HIV, Identification, Prevention, and Treatment Services (CHIPTS) listed the event online as a featured event, marketing on both the CHIPTS website as well as social media platforms (CHIPTS Facebook page as well as CHIPTS Twitter account). Hard copies of flyers were placed in the stairways of the Fielding School of Public Health and the bulletin board of the Department of Community Health Sciences. Two posters were placed in the Department of World Arts and Cultures/Dance—one at the bulletin board of the Rainbow Lounge where students often sit in between classes and one on a poster stand and placed outside of the Kaufman Hall building to advertise the event.

4.6.7. Performance Location and Rehearsals

The venue of the performance was decided to be at the Department of World Arts and Cultures/Dance because the department could provide a theatrical space for the event, while allowing it to be free of charge and open to the public. Given the planned structure of the performance (i.e., solo performer, multiple characters), the setting of the stage was simple: one bench on stage right with a podium on stage left, while the river of time came through in the middle. The bench was covered with a red tablecloth and black tulle on top. The choice of the fabrics and colors was tied to the core elements of the program. Red symbolized blood, and black symbolized darkness and HIV-related stigma. The bench also made it easy to store all props behind it and allowed me to change props on stage while "transitioning" from character to character between the seven narratives. To make character transition recognizable to the audience, a different background was shown for each of the characters, along with a pseudonym of the character on the projected screen. Additionally, I also said the pseudonym of the character before beginning the first-person narrative (e.g., "Xiao Liu's story"). The date for the event was selected and reserved based on the theater's available dates and time, as well as the committee members' availability. Once the venue was selected, I worked with my minor field advisor Professor David Gere and the Department of World Arts and Cultures/Dance to finalize logistics such as refreshments, marketing materials, and performance day needs.

Four full rehearsals took place at the location where the event occurred. The first full rehearsal was scheduled for December 14, 2017, after the initial program design was completed. Besides me, both Dr. Ford and Dr. Gere attended the first full rehearsal and provided feedback on the program content. During the debriefing after the full rehearsal, prop placement was rearranged and the schedule for the day was confirmed. One rehearsal was conducted on January 8, 2018, at the Center for Community Health (UCLA Wilshire Center). It was organized by the committee member Dr. Li Li, who is the principal I=investigator of the TEA study. Five colleagues who are experts in HIV in China, also attended the rehearsal and provided feedback on the flow of the program and usage of props. I had two additional full rehearsal times at the event location, one of which was a solo rehearsal during which I practiced the movement in the space. The fourth rehearsal was attended by Professor Gere, two graduate students interested in the connection between the arts and health, and one public health researcher. The fourth rehearsal was also a technical, full-dress rehearsal to ensure that the video, slides, lighting, and sound were set for audibility. The program content evolved after each rehearsal as I tried to incorporate all the feedback I received during run-throughs.

4.7. Summary

To summarize, the methods for this dissertation build on the conceptual model to estimate the association between HIV-related stigma, social support, and access to care using quantitative analyses (Part I) and to develop and deliver a theory-based performance (Part II). Part I used descriptive statistics and regression analyses to ascertain the extent to which dimensions of HIV-related stigma and social support influence access to care. Part II incorporated photographs, film, and dance movements to extend the dissertation beyond the quantitative analyses.

CHAPTER FIVE

RESULTS

5.1. Overview

This chapter presents the results for both parts of the dissertation. To review, Aim 1 examined whether the two dimensions of HIV-related stigma, (a) perceived stigma and (b) internalized shame, were associated with obtaining care among HIV-positive men and women in rural Anhui, China. Aim 2 analyzed whether the three dimensions of social support, (a) emotional support, (b) tangible support, and (c) affectionate support, were associated with access to care among HIV-positive men and women in rural Anhui, China.

The chapter has five sections. Sections 5.2 to 5.4 present the results of Part I, the quantitative study of the dissertation. Section 5.2 presents the results of the descriptive analyses including the univariate statistics, bivariate statistics, and sample characteristics. Sections 5.3 and 5.4 summarize the key findings for Aim 1 and Aim 2, respectively. Section 5.5 presents the result of Part II, the critical performance of the dissertation, and it provides a descriptive and reflexive summary of the performance held on January 26, 2018.

Part I. Quantitative Study

5.2. Descriptive Analyses

Before the investigation of Aim 1 and Aim 2 of the dissertation, preliminary analyses were conducted to describe the population and to examine bivariate associations among the study variables. The demographic, socioeconomic characteristics of the sample are summarized in section 5.2.1.

Table 5.1 presents the sample statistics of the key variables of the dissertation—that is, the focal dependent variable and the focal independent variables. Access to care is the focal dependent variable. In this sample, the average mean of access to care was 26.4 (SD = 3.9). The focal dependent variables are HIV-related stigma and social support. For HIV-related stigma, the average scores for perceived stigma and internalized shame were 24.9 (SD = 6.4) and 31.5 (SD = 7.0), respectively. For social support, the average scores for emotion, tangible, and affectionate support were 16.8 (SD = 5.9), 13.0 (SD = 3.7), and 8.7 (SD = 2.8), respectively.

Table 5.1

Summary of Univariate Analyses of Independent and Dependent Variables in Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

Study Variables	Score Range	Mean	SD	Skewness
Independent Variable				
Access to care	8 – 32	26.4	3.9	– 0.06
Dependent Variables				
HIV-related stigma				
Perceived stigma	8 – 40	24.9	6.4	– 0.31
Internalized shame	9 – 45	31.5	7.0	– 0.52
Social support				
Emotional support	8 – 40	16.8	5.9	0.51
Tangible support	4 – 20	13.0	3.7	– 0.38
Affectionate support	3 – 15	8.7	2.8	– 0.32

Note. SD, standard deviation.

5.2.1 Sample Characteristics

A total of 522 PLWHA were included in the study. Table 5.2 contains demographic and background characteristics for the PLWHA. There was an approximately equal number of male and female PLWHA in the sample (44.8%, n = 234, male vs. 55.2%, n = 288, female). On average, the PLWHA were 48.5 years old (SD = 8.8). The majority (81.4%) of the PLWHA were married or living with a partner, and about one fifth (18.6%) of the sample was single, separated, divorced, or widowed. The most common occupation was the full-time farmer (42.0%). The average number of years of completed school was 2.8 (SD = 2.9), with 40.2% of the PLWHA having no formal education. The median annual family income was 10,000 yuan (equivalent to USD$1,580). About one-third (n = 141, 27.0%) of the participants had an HIV-positive partner. Most of the PLWHA were on ART (n = 482, 92.3%).

Table 5.2

Sample Characteristics of Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

Characteristics	Total Sample (N = 522)		PLWHA with HIV Positive Spouses (n = 141)		PLWHA with HIV Negative Spouses (n = 381)	
	N	%	N	%	N	%
Individual Characteristics						
Gender						
Male	234	44.8	57	40.4	177	46.5
Female	288	55.2	84	59.6	204	53.5
Age, years						
M ± SD	48.5	8.8	47.1	7.4	49.1	9.3
20 – 40	104	19.9	27	19.2	77	20.2
41 – 50	222	42.5	75	53.2	147	38.6
51 – 60	144	27.6	32	22.7	112	29.4
61 or older	52	10.0	7	5.0	45	11.8
Marital status						
Married or partnered	425	81.4	137	97.2	288	75.6
Not married	97	18.6	4	2.9	93	24.4
Education, years						
M ± SD	2.8	2.9	2.4	2.8	2.9	3.0
None	210	40.2	64	45.4	146	38.3
1 – 6	241	46.2	62	44.0	179	47.0
More than 6	71	13.6	15	10.6	56	14.7
Currently on ART	482	92.3	129	92.1	353	92.9
Family Characteristics						
Family annual income, yuan§						
M ± SD	14897	13594	12571	10873	15343	14409
Less than 9,000	191	36.7	65	46.4	126	33.2
9,000 to 18,000	176	33.9	42	30.0	134	35.3
> 18,000	153	29.4	33	23.6	120	31.5

Note. M = mean; § Forty-seven participants did not report their annual household income; SD = standard deviation.

5.2.2 Bivariate Sub-analyses on the Key Variables

Overview. The results from the sub-analyses on HIV-related stigma and social support examined whether HIV-related stigma or social support differed by spouse HIV status or transmission route. Each sub-analysis was based on a bivariate model. The results of the three bivariate sub-analyses are summarized in Tables 5.3 and 5.4.

Spouse HIV Status. Levels of access to care were higher among PLWHA with HIV-positive spouses than those with a HIV-negative spouses (26.48 vs. 25.65, $p = 0.009$). There was no difference by spouse HIV status among PLWHA for both dimensions of HIV-related stigma (p-values > 0.05). Even though PLWHA with HIV-positive spouses had slightly higher levels of perceived stigma and internalized shame than those with HIV-negative spouses (25.57 vs. 24.68; 32.16 vs. 31.29, respectively), those differences did not appear to reach statistical significance based on a significant level of 0.05. Additionally, the analysis showed that the three dimensions of social support did not differ by PLWHA's spouse HIV status, either. Even though PLWHA with HIV-negative spouses had slightly higher levels of social support in all three dimensions compared to those with HIV-positive spouses (emotional support, 16.95 vs. 16.36; tangible support 13.18 vs. 12.62; affectionate support 8.81 vs. 8.48), the differences were not statistically significant. Table 5.3 summarizes the sub-analyses for the key variables by spouse HIV status.

Table 5.3

Key Variables among Adults Living with HIV/AIDS by Spouse HIV Status in Rural Anhui, China, N = 522

	PLWHA with HIV-Positive Spouses n = 141 (27.0%)		PLWHA with HIV-Negative Spouses n = 381 (73.0%)		*p*
	Mean	SE	Mean	SE	
<u>Dependent Variable</u>					
Access to care	26.48	0.18	25.65	0.48	0.0090
<u>Independent Variables</u>					
HIV-related stigma					
Perceived stigma	25.57	0.50	24.68	0.34	0.1269
Internalized shame	32.16	0.54	31.29	0.37	0.0885
Social support					
Emotional support	16.36	0.49	16.95	0.31	0.7490
Tangible support	12.62	0.32	13.18	0.19	0.6896
Affectionate support	8.48	0.24	8.81	0.14	0.7159

Note. SE = standard error; Mean = estimated mean.

Transmission Routes. Former plasma donors and respondents without plasma donation transmission of HIV did not have a detectable statistical significance in the two dimensions of HIV-related stigma. However, former plasma donors had significantly higher access to care (26.48 vs. 25.65, $p = 0.009$; Table 5.4). Furthermore, the results show that those who were infected via commercial plasma donation had higher social support in all three dimensions, emotional, tangible, and affectionate (17.11 vs. 14.76; 13.19 vs. 11.99; 8.81 vs. 8.17, respectively, all $p < 0.05$). Table 5.4 summarizes the subanalyses for the key variables by transmission routes.

Table 5.4

Key Variables among Key Variables among Adults Living with HIV/AIDS by Transmission Routes in Rural Anhui, China, N = 522

	Adults with Plasma Donation Transmission n = 451 (86.4%)		Adults without Plasma Donation Transmission n = 71 (13.6%)		*p*
Variable	Mean	SE	Mean	SE	
Dependent Variable					
Access to care	26.48	0.18	25.65	0.48	0.0090
Independent Variables					
HIV-related stigma					
Perceived stigma	24.82	0.31	25.56	0.71	0.366
Internalized shame	31.68	0.33	30.67	0.79	0.276
Social support					
Emotional support	17.11	0.28	14.76	0.64	0.0018
Tangible support	13.19	0.17	11.99	0.44	0.0105
Affectionate support	8.81	0.13	8.17	0.34	0.0730

Note. SE, standard error; Mean, estimated mean.

5.3. Summary of Key Findings for Aim 1

To review, the goal of Aim 1 was to determine whether the two dimensions of HIV-related stigma, (a) perceived stigma and (b) internalized shame, were associated with access to care among HIV-positive men and women in four rural counties in Anhui Province, China.

Hypothesis 1: HIV-related stigma reported by PLWHA will be negatively associated with access to care.

5.3.1 Correlational Matrix of Aim 1

This section presents the bivariate association of access to care with the demographic variables as well as the independent variable for Specific Aim 1. In order to show the measurement of the general strength and direction of relationships among variables, Table 5.5 presents a correlation matrix of the study variables, showing the associations between access to care and the other study variables.

Significant negative correlations were observed between access to care and perceived stigma (r = – 0.22), internalized shame (r = – 0.16), family income (r = – 0.10), and depressive symptoms (r = – 0.21). Being female was positively correlated with internalized shame (r = 0.19) and depressive symptoms (r = 0.21), whereas females were negatively correlated with education level (r = – 0.46). Annual family income was negatively correlated with depressive symptoms, perceived stigma, and internalized shame (r = – 0.18; r = – 0.17, r = – 0.12, respectively). Levels of depressive symptoms were positively correlated with perceived stigma (r = 0.39) and internalized shame (r = 0.42). Internalized shame was negatively correlated with education, family income, and depressive symptoms (r = – 0.21; r = – 0.12, r = – 0.42, respectively). Not surprisingly, perceived stigma was positively correlated with internalized shame (r = 0.55). The results were in line with the expectations that perceived stigma and internalized shame inversely correlated with access to care.

Table 5.5

Correlation Matrix of Access to Care, HIV-Related Stigma, and Demographic Variables among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

Variable	1	2	3	4	5	6	7	8
1. Access to care								
2. Age	0.04							
3. Female	– 0.07	0.02						
4. Married	– 0.07	0.27^{***}	0.08					
5. Education	0.03	$– 0.14^{**}$	$– 0.46^{***}$	– 0.06				
6. Family income	$– 0.10^{*}$	0.02	– 0.02	– 0.04	0.04			
7. Depressive symptoms	$– 0.21^{***}$	0.14^{**}	0.21^{***}	0.06	$– 0.20^{***}$	$– 0.18^{***}$		
8. Perceived stigma	$– 0.22^{***}$	– 0.07	0.06	– 0.04	0.01	$– 0.17^{**}$	0.39^{***}	
9. Internalized shame	$– 0.16^{**}$	0.02	0.19^{***}	0.06	$– 0.21^{***}$	$– 0.12^{**}$	0.42^{***}	0.55^{***}

Note. ${}^{*}p < 0.05$; ${}^{**}p < 0.01$; ${}^{***}p < 0.0001$.

5.3.2 Main Analyses: Mixed-Effects Linear Regression Models on HIV-Related Stigma

Table 5.6 shows the mixed-effects models examining the association between perceived stigma, internalized shame, and access to care. Controlling for demographic variables (age, gender, marital status, and income), higher levels of perceived stigma were significantly associated with lower levels of access to care (estimated difference = –0.080, SE = 0.032, p = 0.015). Conversely, internalized shame was not significantly associated with access to care (p = 0.691), while simultaneously controlling for other factors in the model. The finding supported the hypothesis that HIV-related stigma was negatively associated with access to care. However, only one dimension of HIV-related stigma, that is, perceived stigma and not internalized shame, was negatively associated with access to care among PLWHA in rural Anhui, China. Further, levels of depressive symptoms were negatively associated with access to care (estimated difference = –0.102, SE = 0.038, p = 0.008).

Table 5.6

Mixed-Effects Models for Access to Care and HIV-Related Stigma among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

	Access to Care		
Variable	Estimate	SE	*p*
Age	0.034	0.021	0.102
Female	– 0.327	0.386	0.398
Married	0.812	0.449	0.071
Education (REF: None)			
1 – 6 years	0.054	0.407	0.895
More than 6 years	– 0.321	0.578	0.579
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.247	0.399	0.537
More than 18,000	0.687	0.428	0.109
Depressive symptoms	– 0.102	0.038	0.008
Perceived stigma	– 0.080	0.032	0.015
Internalized shame	– 0.012	0.030	0.691

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

The following two analyses were carried out to examine whether spouse HIV status or transmission route influence the relationship between HIV-related stigma and access to care. In sum, after considering spouse HIV status and transmission routes in PLWHA, the results from the mixed models remained similar to the findings shown in Table 5.6.

Spouse HIV status. Multiple regressions were performed in the entire sample while simultaneously controlled for whether the PLWHA had a HIV-positive partner or not. After controlling for spouse's HIV status, the results from the multiple regression analysis remained the same, as perceived stigma and depressive symptoms were the only variables that were negatively associated with access to care (estimated difference = –0.079, SE = 0.032, $p = 0.016$; estimated difference = –0.105, SE = 0.038, $p = 0.006$, respectively). The results from the regression analysis are summarized in Table 5.7.

Table 5.7

Mixed-Effects Models for Access to Care and HIV-Related Stigma Controlling for Spouse HIV Status among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

	Access to Care		
Variable	Estimate	SE	*p*
Age	0.035	0.021	0.087
Female	– 0.342	0.386	0.376
Married	0.678	0.462	0.143
Education (REF: None)			
1 – 6 years	0.081	0.407	0.842
More than 6 years	– 0.283	0.578	0.625
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.289	0.407	0.471
More than 18,000	0.745	0.431	0.084
Spouse HIV positive	0.485	0.398	0.223
Depressive symptoms	– 0.105	0.038	0.006
Perceived stigma	– 0.079	0.032	0.016
Internalized shame	– 0.013	0.030	0.672

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

Transmission Routes. In addition, an analysis was carried out to see whether the transmission route impacts the relationship between HIV-related stigma and access to care. After controlling for whether the PLWHA contracted HIV through plasma donation, the results from the mixed-effects models were similar to that of the previous two models presented in Table 5.6

and Table 5.7. Perceived stigma and depressive symptoms remained negatively associated with access to care (estimated difference = –0.077, SE = 0.032, p = 0.018; estimated difference = –0.104, SE = 0.038, p = 0.007, respectively). The results from the regression analysis are summarized in Table 5.8.

Table 5.8

Mixed-Effects Models for Access to Care and HIV-Related Stigma Controlling for Transmission Routes among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

	Access to Care		
	Estimate	SE	*p*
Age	0.029	0.021	0.171
Female	– 0.289	0.386	0.455
Married	0.770	0.451	0.088
Education (REF: None)			
1 – 6 years	0.064	0.406	0.875
More than 6 years	– 0.280	0.578	0.628
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.232	0.399	0.560
More than 18,000	0.669	0.427	0.118
Former plasma donors	0.688	0.501	0.170
Depressive symptoms	– 0.104	0.038	0.007
Perceived stigma	– 0.077	0.032	0.018
Internalized shame	– 0.014	0.030	0.631

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

5.4. Summary of Key Findings for Aim 2

To review, the goal of Aim 2 was to determine whether the three dimensions of social support, (a) emotional support, (b) tangible support, and (c) affectionate support), were associated with access to care among HIV-positive men and women in four rural counties in Anhui Province, China.

Hypothesis 2: With greater levels of social support, there will be an increase in access to care for PLWHA.

5.4.1. Correlational Matrix of Aim 2

This section presents the bivariate association of access to care with the demographic variables as well as the independent variable for Aim 2. In order to show the measurement of the general strength and direction of relationships among variables, Table 5.9 presents a correlation matrix of the three dimensions of social support and study variables.

Significant positive correlations were observed between access to care and emotional support (($r = 0.21$), affectionate support ($r = 0.28$), and family income ($r = 0.10$). Access to care was negatively correlated to depressive symptoms ($r = –0.21$). Female status was negatively correlated with all three dimensions of social support (emotional, $r = –0.17$; tangible, $r = –0.09$; affectionate, $r = –0.11$). A positive correlation was found between emotional support and income ($r = 0.14$), as those with higher family annual income were more likely to have higher levels of emotional support. Not surprising, levels of emotional support were moderately correlated with tangible support ($r = 0.32$) and affectionate support ($r = 0.55$), and tangible support was moderately correlated with affectionate support ($r = 0.59$).

Table 5.9

Correlation Matrix of Access to Care, Social Support, and Demographic Variables among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

Variable	1	2	3	4	5	6	7	8	9
1. Access to care									
2. Age	0.04								
3. Female	– 0.07	0.02							
4. Married	– 0.07	0.27***	0.08						
5. Education	0.03	– 0.14**	– 0.50***	– 0.06					
6. Family income	0.10*	0.02	– 0.02	– 0.04	0.04				
7. Depressive symptoms	– 0.21***	0.13	0.21***	0.06	– 0.20***	– 0.18***			
8. Emotional support	0.21***	– 0.03	– 0.17**	– 0.04	0.22***	0.15**	– 0.31***		
9. Tangible support	0.07	0.07	– 0.09*	– 0.08	0.07	0.12**	– 0.12**	0.32***	
10. Affectionate support	0.28***	0.06	– 0.11*	– 0.01	0.11**	0.15**	– 0.22***	0.55***	0.59***

Note. $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.0001$

5.4.2 Main Analyses: Mixed-Effects Linear Regression Models on Social Support

Table 5.10 shows the results of using mixed-effects linear regression models to examine the association between emotional, tangible, affectionate support, and access to care. Controlling for demographic variables (age, gender, marital status, education, and income), higher levels of affectionate support were positively associated with levels of access to care (estimated difference = 0.430, $p < 0.0001$). Conversely, tangible support was negatively associated with access to care (estimated difference = – 0.165, $p = 0.003$). Depressive symptoms were negatively associated with access to care while simultaneously controlling for other characteristics (estimated difference = – 0.103, $p = 0.003$).

Table 5.10

Mixed-Effects Models for Access to Care and Social Support among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

	Access to Care		
Variable	Estimate	SE	*p*
Age	0.036	0.020	0.074
Female	– 0.229	0.376	0.542
Married	0.862	0.438	0.050
Education (REF: None)			
1-6	0.009	0.396	0.981
More than 6	– 0.527	0.558	0.345
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.190	0.393	0.630
More than 18,000	0.709	0.417	0.089
Depressive symptoms	– 0.103	0.034	0.003
Emotional support	0.030	0.034	0.373
Tangible support	– 0.165	0.055	0.003
Affectionate support	0.430	0.081	<0.0001

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

Spouse HIV Status. After controlling for spouse's HIV status and other demographic variables, the results from the mixed-effects regression analysis remain similar to the original model. That is, the results still showed that higher levels of affectionate support were positively associated with access to care (estimated difference = 0.429, $p < 0.0001$), whereas tangible support and depressive symptoms were still negatively associated with access to care (estimated difference = –0.160, $p = 0.004$, estimated difference = –0.106, $p = 0.002$). Table 5.11 shows the results of the use of mixed-effects models to examine the association between emotional, tangible, and affectionate support, and access to care while controlling for demographic characteristics as well as spouse HIV status.

Table 5.11

Mixed-Effects Models for Access to Care and Social Support Controlling for Spouse HIV Status among Adults Living with HIV/AIDS in Rural Anhui, China, N= 522

	Access to care		
Variable	Estimate	SE	*p*
Age	0.037	0.020	0.063
Female	– 0.243	0.376	0.519
Married	0.734	0.451	0.104
Education (REF: None)			
1-6	0.039	0.396	0.922
More than 6	– 0.490	0.558	0.381
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.224	0.394	0.570
More than 18,000	0.759	0.419	0.070
Spouse HIV positive	0.456	0.387	0.239
Depressive symptoms	– 0.106	0.034	0.002
Emotional support	0.030	0.034	0.375
Tangible support	– 0.160	0.055	0.004
Affectionate support	0.429	0.081	< 0.0001

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

Transmission Routes. The results were similar to the original model and showed that higher levels of affectionate support were positively associated with access to care (estimated difference = 0.436, $p < 0.0001$), whereas tangible support and depressive symptoms were still negatively associated with access to care (estimated difference = –0.170, $p = 0.002$, estimated difference = –0.106, $p = 0.002$). Table 5.12 shows the results of using mix-effects multiple linear regression models to examine the association between emotional, tangible, and affectionate support, and access to care while controlling for transmission routes.

Table 5.12

Mixed-Effects Models for Access to Care and Social Support Controlling for Transmission Routes among Adults Living with HIV/AIDS in Rural Anhui, China, N = 522

	Access to care		
Variable	Estimate	SE	*p*
Age	0.031	0.020	0.123
Female	– 0.211	0.375	0.575
Married	0.832	0.439	0.058
Education (REF: None)			
1-6	0.019	0.396	0.961
More than 6	– 0.474	0.560	0.397
Family annual income (REF: < 9,000)			
9,000 – 18,000	0.191	0.393	0.627
More than 18,000	0.704	0.416	0.091
Former plasma donors	0.596	0.494	0.228
Depressive symptoms	– 0.106	0.034	0.002
Emotional support	0.024	0.034	0.480
Tangible support	– 0.170	0.055	0.002
Affectionate support	0.436	0.081	<0.0001

Note. REF = reference; SE = standard error. The model also included village-level random effects to account for dependence within villages.

5.4.3. Social Support as a Mediator of the Relationship between HIV-Related Stigma and Access to Care

To examine social support as a potential mediator of the relationship between HIV-related stigma and access to care, the mediation model was tested as presented in Figure 5.1. To test for mediation (Baron & Kenny method), three regressions were run for each purpose. First, the outcome (access to care) was regressed on the predictor variable (HIV-related stigma). This relationship was statistically significant (c = – 0.07, p <0.0001); HIV-related stigma was negatively associated with access to care. Next, in the second equation, the mediator (social support) was regressed on the predictor variable (HIV-related stigma). The result indicated that there was a significant relationship between the mediator and predictor variable; that is, HIV-related stigma was negatively associated with social support (α = –0.35, p <0.0001). The third equation involved regression of the outcome variable (access to care) simultaneously on the predictor (HIV-related stigma) and mediator variable (social support). The finding implied that the previously significant relationship between predictor (HIV-related stigma) and the outcome (access to care) remained significant (c' = – 0.06, p = 0.001). Full mediation relationship could not be established. The effect of HIV-related stigma on access to care still exists but in a slightly smaller magnitude. However, the reduction in variance explained by HIV-related stigma was not statistically significant as determined by the Sobel test (Sobel, 1982). Thus, a mediation effect of social support on HIV-related stigma and access to care was not established.

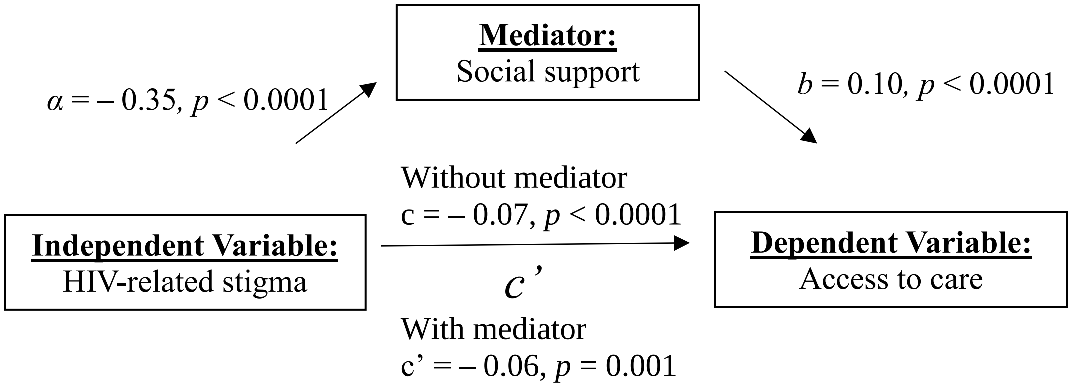


Figure 5.1. Standardized regression coefficients for the relationship between HIV-related stigma and access to care as mediated by social support

Part II. Critical Performance

5.5. Critical Performance

The title of the program, “STOP STIGMA,” seeks to bring in innovative ways of delivering public health research findings by combining films, photography, and movements into a 20-minute program.

Below is the program outline, followed by a detailed description in the paragraphs.

- Welcome & Introduction, Professor Chandra Ford & Professor David Gere (2 minutes each)
- Prologue (3 minutes)
- Stigma (7 minutes)
- Social Support (7 minutes)
- Epilogue (3 minutes)
- Q&A Discussion (10 minutes)

On January 26, 2018, more than 40 individuals from the School of Public Health and the Department of World Arts and Cultures/Dance attended the performance. Attendees comprised different targeted audiences, including master’s and doctoral students from five academic departments at the Fielding School of Public Health—Biostatistics, Community Health Sciences, Environmental Health Sciences, Epidemiology, and Health Policy and Management; faculty from the School of Public Health; undergraduate students from the Department of Anthropology; staff and faculty from the Fielding School of Public Health; staff and researchers from CHIPTS; and graduate students from the Department of World Arts and Culture/Dance, and others. As the audience members walked in, the screen projected a slide that read “75,000 children in rural Anhui, China have been orphaned by HIV” (UNICEF, 2014).

5.5.1 Opening of Program

The opening of the program consisted of welcome addresses by Professor Chandra Ford, the chair of the my doctoral committee, followed by Professor David Gere, the Director of UCLA Arts and Global Health Center, who is also my minor field advisor.

5.5.2 Prologue

“Would you dance with me if I were HIV-positive?” I danced to the center of the stage from the side with a red scarf motif in hand and asked the audience this question. Shortly following the opening dance, a two-minute trailer of the documentary film, “The Blood of Yingzhou District,” was played to provide cultural context to the audience. This 40-minute documentary was released in 2006 and tells a year in the life of children in the remote villages of Yingzhou district in rural Anhui Province, China, who have lost their parents to AIDS. The film was chosen as a way to introduce the context and background of the study to the audience. The film was shot in the same province where the participants of the quantitative part of the dissertation were from. Through the documentary, the audience came to know a handful of children who were affected by the disease. The suffering of these AIDS orphans was compounded by the stigma associated with the disease. This documentary film brought the audience to a previous century—a time when the disease had the power to strike incomprehensible terror into the lives of farming families in rural Anhui Province, China. The film followed the three AIDS orphan to their family homes, filled with empty medicine bottles and old toys. Despite such a fierce will to live among these orphans, they were shunned by their relatives, neighbors, and classmates for fear of HIV infection. Stigma and fears surrounded the children orphaned by AIDS.

The two-minute film trailer was followed by me raising a question. The following paragraph summarized the script of the opening speech:

"Would you play with me if my parents died from AIDS? How would you respond to this question to a five-year-old child? Although HIV has been around for 30 years, stigma continues to affect the disease profile and mortality."

I walked along the river of time with signs of every year since 1981 displayed on the floor to provide the chronological events of HIV history in rural Anhui, China. Key years along this timeline (indicated after this paragraph) were featured during this phase of the performance with the script (as well as printed in red as opposed to black colors for other year signs). During this time, the screen projected the same year as my narration goes, such as "1981," when I talked about the year when AIDS was discovered, as I narrated the history of HIV in rural Anhui, China:

1981 – AIDS was discovered.

1984 – First case of HIV infection in rural Anhui, China was identified.

1985 – First death of AIDS patient in rural Anhui, China, was recorded.

1991 - I want you to take a trip with me. Picture yourself walking down a small road in rural Anhui Province, China. As you walk along, you look off to the side, you see a small building with many people lining up, almost pushing each other and brushing their shoulders together. You wonder, “What’s going on here?” (Photograph projected on screen showed people walking in rural Anhui Province, China). People tell you, that it is the line for blood donation (Photograph projected on the screen showed people in line for blood donation in rural China). The plasma collection centers removed donor’s plasma, then re-infused the red blood cells back to the donors so they would soon be ready to make their next donation (Photograph projected on the screen showed a woman who was getting blood drawn for plasma donation at a collection center in China). They were mostly rural farmers and got paid 50 yuan, which is equivalent to about USD $7 for each plasma donation. Just as the little girl’s parents in the video, many people in rural Anhui Province, China, got infected with HIV because of paid plasma donation (Photograph projected on the screen showed a right arm marked with the blood donation stamp).

1995 – When the Chinese government realized the process had become the primary driver of the HIV epidemic in the country, China shut down all blood collection centers. However, hundreds of thousands of former plasma donors were already infected with HIV.

1998 – HIV was found in all 31 Provinces in rural Anhui, China. The same year, the law required health authorities to standardize blood collection. Illegal blood collection for commercial purpose was banned.

2003 – China initiated a program known as “Four Free and One Care.” The four frees are: free antiretroviral drugs, free prevention of mother-to-child transmission, free voluntary counseling and testing, and free schooling for children orphaned by AIDS, and one care is for people living with HIV/AIDS. Although these practices ended more than two decades ago, the history of this HIV outbreak continues to impact many rural areas in rural Anhui, China. Despite the treatment advances that have turned HIV into a chronic and manageable condition, the HIV-related stigma persists, and it continues to be a major barrier to the effectiveness of HIV care and treatment programs (Photograph projected on the screen showed an elderly person in rural China grieving for the loss of his son who died from AIDS).

5.5.3 HIV-Related Stigma

This part of the program began with dance movements to the recorded definition of HIV. The screen projected a collage of words related to stigma, such as “shame,” “tainted,” “disgrace,” “guilty,” and “worthless.” At the same time, the recording about HIV-related stigma was played through the audio system, providing the definition of stigma as well as measures of HIV-related stigma. The voice recording was made possible by a staff member at CHIPTS. While the recording was playing, I danced across the stage to portray how HIV-related stigma could be embodied, felt, and experienced. Black tulle was used during the movement to symbolize HIV-related stigma. At one point during the movements, I was covered in the entangled black tulle, indicating the HIV-related stigma suppressing the individual infected with the disease.

Afterward, three first-person narratives of HIV-infected individuals describing the experience of HIV-related stigma were performed. For each character, a photograph was displayed on the screen as a background to provide contextual information. I first picked up a prop symbolizing this character and then said the pseudonym of the character before delivering the first-person narrative. The following paragraphs are the text of words that I spoke to represent the three narratives included in the HIV-related stigma section of the program.

Xiao Zhang's story. *My wife did not accept the word HIV. I never thought I would get this disease either. When someone hears the word, the first thing that comes to one's mind is that you must have some immoral relationships outside your marriage. You get this disease only because you have promiscuous behaviors. . . . Not only does my wife think this way, most people think this way. According to the old saying, this is a dirty disease. Now I have the disease, I'm causing my wife and child shame, you know. . . . they will think that they are less than other people, less than an average person. I asked other villagers to build a house for me. They did not eat my food, did not drink my tea, and asked me for more money. They are afraid of being infected by me.* (Prop: bamboo basket)

Xiao Huang's story. *I controlled myself and did not tell. I would never say the word, the word HIV [i.e., ai zi bing, HIV/AIDS]. I controlled myself, but I still feared that I would say it by accident . . . . I have a booth at the Market. The other vendors always asked me, "Are you well?' They saw I am getting thinner, and I had the rashes on my face. They always asked if I was sick. I said, it's nothing. I cannot tell them. They all said, "You look different than before, what's wrong?" Nothing, I said. I cannot tell them. Some people transferred their children to a different school because they don't want their children to study together with children from HIV/AIDS families. I avoided going to see the doctor for AIDS at the beginning because I don't want my child's life to be affected. People ask their children to stay away from the children of HIV/AIDS families. Several months ago, during a villager's wedding, I sat at a table. People at the same table immediately got up and changed to another table. Only the children did not move because they did not know what AIDS was.* (Prop: apron)

Xiao Yang's story. *Like us who have this disease, [we] feel like we are beneath other people, feel like we are unable to be a human being in front of other people. If I could choose between cancer and HIV, I would choose cancer. Even if I could survive only for one month with cancer but another decade with HIV, I would definitely choose cancer, and would definitely choose to die within a month. I would never want to live with this disease for 10 years. The shame brought by this disease is even beyond my words. It is like the "dirty disease". I feel trapped, lost and hopeless, like I am sentenced to death. Many other people just gave up and asked for death.* (Prop: black scarf)

5.5.4 Social Support

Silence remained on stage after I delivered the third narrative for HIV-related stigma. The screen projected "Social Support," and the next slide of a collage of social support-related words was shown on the screen. At the same time, the recorded words were played, which provided the definition of social support and measures of social support items utilized in the quantitative part of the dissertation study. While the recording was playing, I danced on stage to portray how social support could be embodied, felt, and experienced. A red scarf was used as a motif during this part of the dance. This part of the program was followed by four first-person narratives from HIV-infected individuals describing the experience of receiving social support. For each character, a photograph was displayed, and I began telling the story in the first-person narrative. The following paragraphs summarize the four narratives included in the social support section of the program:

Xiao Liu's story. *In the beginning, my husband was very scared. He did not eat what I cooked. He said my food would infect others. He and our child bought food for themselves and* *wanted to eat separately from me. The government started providing subsidies like flour and money, but like many other infected villagers, I pick up my subsidies in secret at night instead of the daytime because I don't want others to find out about my status.* (Prop: bowl and chopsticks)

Xiao Wang's story. *My husband has died of AIDS. This summer, no one came to help me to dry my corn. I harvested about 3,000 kilograms of corn and no one came to help me. If other villagers. . . asked someone to help, things would be different.* (Prop: bamboo farmer hat)

Xiao Guo's story. *I knew that disclosing was a gamble, but I really needed to know whether they would still support me. If they rejected me, I had already decided that I would move to a faraway place where no one could find me; I would restart my life somewhere else. I am glad that they accepted me right away. My sister said, "How come life is so hard on you? You really need to treat yourself better!" I am closest to my sister and never contact any other family members besides her. I am thankful that she's been by my side for all these years, not abandoning me, and supporting me financially.* (Prop: navy blue cotton cross-body bag)

Xiao Lin's story. When [my husband's] diagnosis came out negative, I said to him that we should file for divorce. He asked me why. I asked him, "I don't want to be a burden to you . . ." and he said, "No, you're not a burden to me". (Prop: ring)

5.5.5 Epilogue

This part of the program displayed photographs taken by HIV-affected families who participated in the TEA study from which the data for the dissertation were drawn. The following paragraph summarize the script for this section of the program:

> When these HIV-affected families took cameras to take pictures of their surroundings and their lives, we see that there's so much more than the illness. We see families supporting each other, we see people eating together, and we see smiles on children's face. Even though the children are affected by HIV, but that doesn't mean they are victims of the disease. They, too, are exhibiting resilience." (Photographs projected on the screen showed four photographs taken by HIV-affected families).

I picked up the sign that read "2013" and walked to the podium on stage left. At the podium, I put on the blazer and began the "podium speech" for this part of the program. The following paragraph provided the script of the speech:

> The data from my dissertation were collected in 2013. My dissertation used the baseline data of a randomized controlled intervention trial for HIV-affected families in rural Anhui Province, China. The intervention study is called the China TEA study. TEA stands for Together for Empowerment Activities. Professor Li Li received a grant from the National Institute of Health to conduct this intervention. The intervention aimed to address the challenges that HIV-affected families face, build families' skills, and form supportive local community networks. The intervention activities included three levels: the individual level where there were small group sessions for people living with HIV/AIDS and family member, the family-level where they could bring home-based family activities back home to do with their children, and the community-level where community events were held to build social integration.
>
> The map here shows where the Anhui Province is located. In this region, most HIV infections were caused by commercial plasma donations in the 1990s, just as in the

> pictures shown earlier. A total of 522 people living with HIV/AIDS were included in the study.
>
> Because of the component of building social support and addressing stigma in this intervention, it allowed me to explore that complex relationship between HIV-related stigma and access to care in people living with HIV in rural Anhui Province, China, in hopes to utilize the findings to inform future efforts of programming and intervention development.

After delivering the "podium talk," I walked away from the podium and picked up the sign that read "2018" and stood in front of the audience at the center stage and gave the following address:

> You have heard many stories today, but the story does not have to end here. We have the tool to make changes. This program is designed with the intention that, we could bring artistic approaches to design and disseminate public health information. We could bring in dance and movement, arts-based approaches to enhance communication, building connections, promoting positive emotions, fostering engagement, and managing the impacts of stigma. The possibilities are endless. We do not have to have all the answers to call for change. We just need courage. We need a transformation, and transformation can only happen when we come together, as scientists, providers, activists. We just need courage. The health of us all (pause), depends on it.

After a few seconds of pause, I walked to the side of the stage and picked up the red scarf motif again and danced to the middle of the stage, saying the same line to the audience "would you dance with me, if I were HIV-positive?” (This time, the “positive” was emphasized and given an uplifting tone).

End of program.

5.5.6 Q&A Discussion Following the Program

After the solo performance ended, the dissertation committee chair, Professor Chandra Ford, walked to the podium and invited me to give a few remarks. I shared with the audience how the idea of the program came about. I also mentioned that because I can relate to and remember the stories much better than with numbers, the program included many narratives drawn from original quotes from the HIV-infected individuals in rural Anhui Province, China.

One of the aims of creating a performance drawn from the quantitative part of the dissertation was to engage the audience and generate discussion. After the planned program ended, Professors Ford invited the audience for questions and discussion on the topic. One audience member asked whether the performance would be shown in the region where the participants were from. Another audience member asked whether the use of “xiao” for the pseudonyms was playing with the word “small” in Chinese, and I clarified that it was meant to indicate familiarity instead of belittling. One audience member asked about what “courage” means in this context, to which I answered that it was the courage to pull out our individual toolbox and be willing to lay it out on the table to be used for social change. Following the program, there was a reception at the Rainbow Lounge on the first floor of Kaufman Hall to further foster a space of discussion among the attendees. I was approached by many audience members and was able to engage in a discussion about the intersection of the arts and public health; I also made new connections.

The critical performance flyer is attached in Appendix B, along with the performance program. The performance was video-recorded. The videographer was a staff member at the Department of World Arts and Cultures/Dance who recorded, edited, and formatted the recording of the performance.

CHAPTER SIX

DISCUSSION

6.1. Overview

The dissertation has two parts, a quantitative analysis and a critical performance. The goal of the quantitative study was to improve understanding of the relationship between dimensions of HIV-related stigma, social support, and access to care among PLWHA in rural Anhui Province, China. The study had two aims: (1) to determine whether the two dimensions of HIV-related stigma, (a) perceived stigma and (b) internalized shame, were associated with access to care among HIV-positive men and women in rural Anhui Province, China; and (2) to determine whether the three dimensions of social support, (a) emotional support, (b) tangible support, and (c) affectionate support, were associated with access to care among HIV-positive men and women in this location. The study's conceptual model integrated Andersen's Model of healthcare utilization, which though developed in the United States has been used in a number of studies in China (Bao, Wang, Yang, & Mao, 2015; Liu et al., 2017; Liu, Hao, & Zhang, 2016), and the constructs of stigma (Link & Phelan, 2001; Herek, 1999). The quantitative study was completed via a secondary data analysis using the baseline data of a randomized controlled trial in rural Anhui Province, China. The second part of the dissertation was a critical performance written and performed by the investigator, was based complemented findings drawn from the quantitative analysis.

This final chapter of the dissertation has nine sections. Sections 6.2 and 6.3 present the discussion of Aim 1 and Aim 2, respectively, relative to the existing literature. Section 6.4

discusses the representativeness of the study, followed by Section 6.5, which describes the limitations of the study. Section 6.6 addresses the strengths of the study, and Section 6.7 identifies implications for research and practice. Following the discussion of the Part I quantitative analysis of the dissertation, Section 6.8 provides the discussion for Part II, the critical performance of the dissertation. This chapter ends with a conclusion for the overall dissertation. Section 6.9 provides the conclusion of the dissertation.

Part I. Quantitative Study

6.2 Aim 1: HIV-Related Stigma and Access to Care

The findings of this study suggest that HIV-related perceived stigma experienced by PLWHA could result in lower access to care, leading to public health concerns. While the study showed an association between HIV-related perceived stigma and access to care, research on stigma has suggested that there could be other negative consequences, including lack of compliance with medication, lower access to social welfare systems, and engagement in sexual risk behaviors (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007).

The findings from this study indicated that while perceived stigma was associated with access to care, internalized shame was not. This could be explained by the fact that the participating PLWHA were from rural China, where others' opinions and perceptions matter more than one's own self-perception. The impact of perceived stigma may be greater than that of internalized shame in the Chinese culture, as it is more collectivist and less individualistic compared to the Western cultures (Zang, Guida, Sun, & Liu, 2014). The collectivist Chinese culture emphasizes the interdependent group values more than individualistic autonomy (Kim, Triandis, Kâğitçibaşi, Choi, & Yoon, 1994; Zang et al., 2014). As a result, how others perceive onecarries more weight and influence on an individual's behavior, such as seeking or accessing healthcare services.

Previous literature has suggested that HIV-related stigma impedes access to and retention in HIV care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Rajabium et al., 2007; Reif, Golin, & Smith, 2005). In a study conducted in Los Angeles, researchers (Kinsler et al., 2007) found that perceived stigma was associated with low access to care both at baseline and at six-month follow-up, even after controlling for socio-demographic characteristics as well as recent CD4 count. The findings from this dissertation concur with those US-based patterns, which suggest perceived stigma could impede access to care among PLHWA in diverse cultural contexts.

Consistent with the prior literature, in the current study, bivariate analyses showed that among the participants, being female was positively associated with internalized shame. Although the pattern did not hold in the multivariable analysis, this finding together with the existing literature suggests gender dynamics require further attention. A previous study conducted in rural Anhui Province, China, showed that women were more sensitive to rejection, criticism, and separation (He et al., 2015). Additionally, according to the theory of gender and power (Connell, 1987), women are often segregated in unpaid work, have less education and greater financial reliance on men, thus limiting women's control over healthy behaviors (Connell, 1987). Furthermore, the theory of gender and power also states that social norms attach women's HIV infection to impurity and immorality (Connell, 1987; Wingood & DiClemente, 2000). Further, gender norms and attitudes toward healthcare services may inform how women uptake services (Gipson et al., 2010).

Since the participants in this study were rural residents with almost half of the sample lacking formal education, they may hold traditional gender values in the society. Traditional rural values are more likely to be consistent with stereotyped assumptions about women with HIV/AIDS (Mo & Ng, 2017)—for example, that they are prostitutes, illegal drug users, or promiscuous (or a combination of these). As a result, women in rural Anhui Province, China, may already hold more stigmatizing attitudes toward PLWHA, thus leading to higher internalized shame among women living with HIV (Xie et al., 2017). For instance, a study examined how factors associated with HIV-related stigma differed by gender in a nationally representative sample of women aged 15 to 49 years and men aged 15 to 54 years in Kenya and found that women had higher stigmatizing attitudes toward PLWHA than men (Mugoya & Ernst, 2014). Additionally, several factors were associated with these differences, including HIV knowledge, education, psychosocial practices, and socio-economic standing (Mugoya & Ernst, 2014).

In the current study, women and men living with HIV/AIDS did not differ in their levels of perceived stigma. A study conducted in the United States identified the constructs within Goffman's (1963) stigma model and examined the relationships between gender, social support, and HIV-related stigma (Colbert et al., 2010). In Colbert's study, women reported significantly higher levels of HIV-related stigma than men did (Colbert et al., 2010), highlighting the unique needs of women living with HIV/AIDS (Wingood et al., 2007). A study conducted in rural China found that HIV-positive women reported a significantly higher level of depressive symptoms than their partners/spouses (Li et al., 2017); further, HIV-positive women with HIV-positive partners had higher depressive symptoms than those with HIV-negative partners, whereas HIV-positive men reported similar levels of depressive symptoms regardless of their partner's serostatus (Li et al., 2017).

HIV-related stigma may be manifested very differently among PLWHA across Asian countries. Compared to a study conducted among PLWHA in Thailand using the same measure for HIV-related stigma (Li et al., 2009), PLWHA in this current study reported higher levels of HIV-related stigma, including more perceived stigma and internalized shame than their counterparts in Thailand.

Spouses were the most important source of support for PLWHA in rural Anhui, China (Li et al., 2006). The literature showed that HIV-positive concordant couples might face doubled stigma as well as added disease burden (Bhagwanjee et al., 2013; Gordon-Garofalo & Rubin, 2004; Talley & Ann Bettencourt, 2010). Contrary to the literature, findings from the current study suggested that HIV-related stigma did not differ by spousal HIV status; those PLWHA with a HIV-positive spouse did not report a significantly higher level of HIV-related stigma than PLWHA with a HIV-negative partner. One possible explanation could be that the majority of the participants were infected via commercial plasma donation rather than, for instance, high risk sexual behaviors; thus, the HIV-positive concordant couples may not face additional stigma tied to how HIV was acquired.

HIV-related stigma may also be associated with transmission routes. That is, those PLWHA who contracted HIV accidentally (e.g., commercial plasma donation, or spouses who contracted HIV through their spouses who were former plasma donors) may experience less stigmatization than those who contracted it through culturally unacceptable behaviors (e.g., commercial sex and drug use). In this study, the majority of the PLWHA reported that they contracted HIV due to plasma donation. There was no statistically significant difference in the two dimensions of HIV-related stigma in former plasma donors and their counterparts. It is possible that the high prevalence of HIV infection in Anhui due to commercial plasma donation as a mode of transmission could increase community's tolerance of PLWHA and, hence, place less stigma on these individuals and on the children in their families, as compared with persons acquiring HIV through sex or intravenous drug use. One possible explanation for this could be that because the HIV epidemic was driven by commercial plasma donation in the 1980s severely affecting rural Anhui, China, people in this area did not generally differentiate HIV-infected individuals based on whether they were former plasma donors were not. This aligns with the phenomenon illustrated in the documentary film, *The Blood of Yingzhou District*, where there is prevalent social stigma towards poverty.

This result is consistent with the literature stating that people infected with HIV through commercial plasma donations were thought to be the "blameless" population or "innocent victims" (Cao et al., 2006). Therefore, PLWHA who got infected through plasma donations did not internalize HIV-related stigma toward themselves and were less sensitive to it, whereas commercial sex workers and their clients, injecting drug users and men who have sex with men (MSM) who acquired HIV infection were perceived as "guilty" (Chan, Yang, Li, Stoove, & Reidpath, 2009). Additionally, those who were infected via other transmission routes may be more inclined to feel "guilty" and to self-blame for their infection (Wong et al., 2011). A study conducted among MSM in southern China showed that gay-related stigma was identified as a major barrier to HIV testing among Chinese MSM (Wei et al., 2014). Future research should explore the differences in magnitudes and directionality of the dimensions of HIV-related stigma that may be associated with different transmission routes among subgroups of PLWHA in China.

The findings from the current study suggested that higher levels of income were associated with decreased internalized shame, but not with decreased perceived stigma. One possible explanation for this could be that when individuals were fulfilling the role of being financial contributors to the family as in the collectivist society in rural Anhui, China (Zang et al., 2014), one could feel less ashamed of other disease conditions. A previous qualitative study conducted in Anhui, China, showed that residents in the province used to sell their blood frequently to make money, sometimes even five to six times a week (Xu et al., 2007). Xu and colleagues also found that economic barriers to healthcare were one of the most significant factors reported by PLWHA in rural Anhui (Xu et al., 2007).

6.3. Aim 2: Social Support and Access to Care

Overview. This section details the findings for Aim 2 on the association between social support (i.e. affectionate support, tangible support, and emotional support) and access to care among PLWHA. Because the relationship to access to care differed between the dimensions of social support, there are separate discussions for each dimension of social support. First, Section 6.3.1 discusses the association between affectionate support and access to care. Sections 6.3.2 and 6.3.3 explain why the results on tangible support and emotional support and access to care were contradictory to the study hypothesis. Sections 6.3.4 discusses the findings of the subanalyses by HIV spousal status and transmission route in this sample. Finally, section 6.3.5 engages the literature for discussion about social support in general and access to care for PLWHA in China.

6.3.1. Affectionate Support and Access to Care in Rural Anhui, China

Consistent with the study hypotheses, affectionate social support was associated with a greater level of access to care. This may be explained in that supportive people may influence each other through formation and reinforcement of positive social norms—for instance, modeling or social comparison of supportive others' service-seeking behaviors (Latkin, 1993). Tangible support aims to help the individual's overt performance directly, whereas affectionate support may change an individual's mood, attitudes, or even cognitive process (Veiel, 1985).

Cultural beliefs can have significant impacts on individuals' attitudes toward social support (Wong & Lu, 2017). In China, affections are believed to be contained and controlled (Tsai & Levenson, 1997). Compared with Western cultures, Asians tend to prioritize maintaining interpersonal harmony over gaining emotional support and are reluctant to seek social support even when under extreme stressors such as cancer diagnosis (Kagawa-Singer & Wellisch, 2003). This is exemplified in the results showing that levels of emotional support were the highest of the social support among the PLWHA in rural Anhui, China, followed by tangible support, and affectionate support. These findings were different from those of a previous study conducted among PLWHA at a large HIV outpatient clinic in North Carolina, in the United States, where levels of affectionate support were highest, followed by tangible support, and emotional support (McCoy et al., 2009). These differences could be explained by how social support is manifested in the Chinese culture.

In China, PLWHA may tend to keep their psychological issues to themselves in order to avoid upsetting others or causing an emotional burden to their partners or family members (Liu et al., 2012), and they often don't receive social support in an affectionate form. In contrast to the

Western view of self (a person possesses a set of self-defining attributes), collectivistic cultures like China hold the interdependent view that the self is primarily a relational entity interdependent with others (Kitayama & Markus, 1994). Furthermore, explicit and open affectionate communication are often considered too embarrassing or uncomfortable, as family members are assumed to know each other's feelings without direct expression (Lam et al., 2007). Affectionate support could be an implicit form of social support that one can receive without disclosing specifics of stress or discussing problems (Kim, Sherman, & Taylor, 2008). The benefit of affectionate support for PLWHA may create a sense of acceptance, which is crucial to help patients sustain their therapeutic efforts (Reblin et al., 2015). The significant relationship between affectionate support and access to care suggests that, when delivering care for PLWHA in rural Anhui, China, expressing affection and care for them would potentially have a more profound impact.

6.3.2. Tangible Support and Access to Care in Rural Anhui, China

In contrast to the findings on affectionate support, tangible support was negatively associated with accessing care. This finding is contrary to the hypothesis and it contradicted the findings from a study conducted among PLWHA aged 50 or older in rural Anhui, China, where access to care was not significantly associated with tangible support (Lin et al., 2015). This could be explained by the differences in age-specific health needs between the populations. It may also be that because the need for care is greater among older adults, they are more likely to access are regardless of their levels of affectionate support. However, the finding from the current study does not imply that practical assistance and care for PLWHA in rural Anhui, China, are unnecessary. The findings also differ from those of another study (Han et al., 2014), which found that tangible support appears to reduce nonpsychological burdens and improve one’s ease of access and utilization of service among people with chronic illness such as dementia (Han et al., 2014). The contradiction between this study’s finding and that of Han’s study conducted in South Korea could be attributed to the differences in the study populations, particularly their health status and health needs (people with dementia versus PLWHA).

The cultural context of China should be taken into account when interpreting these findings. In China, family provides the most critical source of tangible support, including financial support and daily care assistance (Li & Wang, 2012). This is especially true for our participants in the study as they were mostly rural farmers who were living with their families. The negative association found between tangible support and access to care may be due to the high levels of tangible support that were already available to the study participants. The average tangible support score in the study participants was 13.0 out of a total possible score of 20, indicating a moderate tangible support score. This score was comparable to prior studies conducted in China, including among PLWHA (score 12.1; Wu et al., 2015) as well as those patients with a documented diagnosis of heart failure (score 12.8; Yu et al., 2004). In Chinese culture, support for close family members or even a spouse or partner is usually confined to providing tangible support (Li, Ji, & Chen, 2014). The existing high levels of tangible support may have masked the true effect of tangible support on access to care.

The distinctive relationship between tangible and affectionate support is likely a result of the cultural differences in how people seek and receive social support in China’s collectivist culture. Explicitly seeking and receiving tangible forms of support involve active disclosure and discussion of problems, as well as a request for assistance from others. Yet, this is not a practice encouraged in Chinese culture, where one should try not to be a burden to one's family or community. Researchers have theorized that for cultures valuing interdependent harmony (Kim, Sherman, Ko, & Taylor, 2006; Taylor, Welch, Kim, & Sherman, 2007; Wang, Shih, Hu, Louie, & Lau, 2010), such as in China, soliciting or receiving social support in tangible forms may be perceived as disrupting social networks and has the potential to negatively affect relationships (Yang et al., 2015). The desire to maintain group harmony exacerbates the concern that sharing problems would result in poor evaluation by other people (Taylor et al., 2004). Thus, PLWHA may be reluctant to disclose, recruit, or receive any tangible social support or needs due to interdependent relationship concerns (Kim et al., 2008), including fear of being seen as a burden to others or disrupting relationships.

Tangible support may not be the most culturally appropriate or acceptable form of social support in a collectivistic culture like China. A prior study also showed that Asians would be buffered against psychological and biological responses to stress more by implicit social support than by explicit social support, and that explicit social support might actually exacerbate their stress (Taylor et al., 2007). Certain forms of social support may be deemed as "inappropriate" in a particular culture. That is, receiving tangible support may actually exacerbate stress for Asians. In Chinese collectivist culture where relationships involve social obligations, relationships are based on the assumptions that they are less voluntary and more "given," conveying a sense of mutual obligation (Miller, Bersoff, & Harwood, 1990). In this relationship context, a person is expected to avoid bringing his or her personal problems to the attention of others to avoid enlisting their help because such an act could undermine harmony or even been seen as making inappropriate demands on the social group (Kim et al., 2006).

6.3.3. Emotional Support and Access to Care in Rural Anhui, China

In contrast to the findings on affectionate and tangible support, emotional support was not associated with accessing care. This finding is contrary to the hypothesis and it contradicts findings from a study conducted among PLWHA aged 50 or older in rural Anhui, China, where levels of emotional support were significantly associated with access to care (Lin et al., 2015). Emotional support can be expressed in the form of conveying empathy, reassurance, and encouragement (Heaney & Israel, 2008). However, receiving encouragement and having someone to confide in or talk to about his or her problems may not be a desirable option for PLWHA in rural Anhui, China. In a collectivistic culture like China, PLWHA may be very reluctant to share the information about their disease with their family members or friends for fear of becoming a burden to others or breaking the harmony of their existing relationships. Prior study has reported that some PLWHA in China felt that their illness was a deeply private issue and they did not want to discuss matters with others (Chen et al., 2007), thus lowering the likelihood of wanting or receiving emotional support as a result of their HIV status.

Furthermore, disclosure of HIV status is a difficult emotional task that could hinder PLWHA in rural Anhui, China to seek or receive emotional support. The collectivist cultural values imbedded in Asian countries like China emphasize harmony and avoidance of conflict (Yoshioka & Schustack, 2001), thus affecting the disclosure experiences of PLWHA in the region. PLWHA in rural Anhui, China may not seek emotional support in order to protect their families from obligations to help or to avoid communication regarding highly personal information. A study conducted among Chinese gay men living with HIV/AIDS and their use of social media to exchange social support found that emotional support-seeking messages were most common (Chen, Guo, & Shi, 2018), which revealed the perceived threat of seeking emotional support in person for PLWHA in China. The desire to maintain harmony exacerbates the concern that sharing problems would result in poor evaluation by other people (Taylor et al., 2004). Since the participating PLWHA in this dissertation were mostly rural farmers in Anhui, China, it was less likely for them to seek emotional support to avoid disclosure of their HIV status or any possible disruption of harmony.

The findings from the present dissertation contribute to the literature and suggest that how people gain the psychological and biological benefits of social support in a given cultural context may depend on the cultural emphasis on relationship goals (Taylor et al., 2007). In China, maintaining harmonious social relationships is emphasized. Thus, not bringing relational "risks" may be more beneficial and more commonly used (Kitayam & Markus, 1994).

6.3.4. Sub-analyses of Specific Aim 2

Subanalysis by HIV status of spouses was conducted since a portion of the PLWHA who participated in the study had a spouse who was also HIV infected, whereas the rest had a HIV-negative spouse. For PLWHA with an HIV-negative spouse, access to care was associated with all three dimensions of social support. For PLWHA with an HIV-positive spouse (HIV-concordant couples), access to care was strongly associated with tangible and affectionate support, but not with emotional support. One possible explanation for this phenomenon is that PLWHA with a seronegative partner—that is, HIV discordant couples—may face different challenges, thus requiring different aspects of social support (in this case, all dimensions of social support) to cope with accessing healthcare compared to those HIV concordant couples. In HIV sero-discordant relationships, where one partner is infected and the other is not, managing emotional and sexual intimacy can be challenging because of transmission concerns and the health status of the infected partner (Van Der Straten, Vernon, Knight, Gomez, & Padian, 1998). As a result, HIV discordant couples' care access may be more sensitive to all three dimensions of social support than their counterparts.

Emotional and tangible support were significantly higher among former commercial plasma donors, but not affectionate support. One possible explanation for this could be that former plasma donors were seen as the "victim" of the disease since their HIV infection was a result of their desire to increase their income for the family. Therefore, former plasma donors may receive more emotional and tangible support from their family and social network compared to their counterparts.

6.3.5. Compare and Contrast the Present Study's Findings with the Results Reported in the Literature

The results reported in previous studies that examined the association between social support and accessing healthcare services have been mixed. Although there is a growing number of existing studies in the body of literature that document the correlation between social support and access to care, most studies have been conducted in Western countries. Only a few of the studies in the current body of literature have investigated this relationship in China (Lin et al., 2015; Li et al., 2018). A study conducted among older PLWHA in Anhui, China, showed that emotional support was significantly associated with access to healthcare (Lin et al., 2015). Lin et al. (2015) also found that it is important to provide emotional support for older PLWHA in order to engage them in treatment and care. It was found that a social support intervention program significantly improved the PLWHA's adherence to antiretroviral therapy in Beijing, China, as well as their total score and subjective social support score, which is defined as emotional experience whenever he or she is respected, supported, and understood in social interactions (Li et al., 2018). Although measurements of social support varied across the studies conducted in China, these two studies (Lin et al., 2015; Li et al., 2018) and this dissertation underscore the importance of understanding different dimensions of social support and their distinct relationships with access to care.

Despite the scarcity of evidence for social support and access to care among PLWHA in China, two studies conducted in urban areas in China suggested that decreased social support was associated with HIV-related stigma (Du et al., 2018; Rao et al., 2012). One study conducted in Beijing, China among PLWHA who received care at a facility specializing in infectious disease reported that higher levels of social support were associated with a decrease in HIV-related stigma (Rao et al., 2012). Another study conducted among HIV-positive MSM showed that reduced social support was a mediator between HIV-related stigma and condom use intention (Du et al., 2018). Since these studies used different HIV-related stigma scales and did not report different dimensions of stigma, it was not possible to compare the HIV-related stigma scales used in these studies and the scale used in this dissertation. However, a number of authors have recognized the critical role that social support may play in mitigating the psychosocial consequences of depression among PLWHA in China. The literature shows that increasing social support for PLWHA living in China may generate other benefits. Prior research suggests that social support has a positive effect on medication adherence in patients with diabetes in China (Gu et al., 2017). Thus, the positive relationship between social support and medication adherence could also manifest among PLWHA in China. Dae et al. (2018) reported that social support was associated with health-promoting behaviors following HIV diagnosis. In a large cohort study conducted among PLHWA in Guangxi Province, China, Xu et al. (2017) found that the patients' overall quality of life scores were positively associated with having received family support and not feeling discriminated against by their families, including never experiencing the fear of being abandoned by family members. Xu et al. (2017) showed that family support contributes to the quality of life among PLWHA. Future research should explore how social support among PLWHA living in China could affect other aspects of their health, including medication adherence, quality of life, and other health-promoting behaviors, especially in rural areas where resources are limited.

Although the results from this study may be similar or contradictory to the findings reported in previous studies, including the element of culture in the discussion is essential. Many researchers have documented that cultural differences have an impact on social-support-seeking behavior (Yang et al., 2015). Because culture plays a substantial role in determining the health of individuals, families, and the community (Airhihenbuwa & Webster, 2004), cultural influence is vital in a family-oriented society like China (Muller & Desmond, 1992). Therefore, it is crucial to consider the vital role of culture when comparing this study's findings with the findings reported in previous studies conducted in Asian or non-Asian countries. Although several scholars have already provided the framework within which to recognize the limitations of Western models (Fanon, 1986; Oyewumi, 1997; Mudimbe, 1988), limited attention has been paid to determining the appropriate cultural model for understanding China and its people, especially when the country is longing for speedy development of its society and is seeking to embrace Western ways. This finding provides support for cultural differences in the utility of various forms of social support, and it suggests that culturally specific matching of implicit support (i.e., affectionate support) may lead to improved outcomes for PLWHA in China.

In addition, one study conducted on a sample of PLWHA in New York City showed that social support was associated with ART use (Waddell &Messeri, 2006), but only among those who had disclosed their HIV status. Furthermore, results from a study of African American PLWHA who injected drugs also showed that access to a medical provider was associated with greater emotional support (Knowlton et al., 2005). However, McCoy et al. (2009) and colleagues conducted a study in North Carolina and documented that affectionate, tangible, and emotional support were not associated with the time between HIV diagnosis and engagement in care. Moreover, another study conducted among Latino and African American MSM and women found that social support was not associated with retention in care (Wohl et al., 2011). One possible explanation for the contrast between this dissertation's findings and the findings reported in previous studies is that the participants enrolled in McCoy et al.'s (2009) study were persons newly diagnosed with HIV, whereas the study participants documented in this dissertation were diagnosed with HIV infection more than a decade ago. Additionally, the differences in the findings may be attributed to the differences in the study populations and the cultural contexts within which the studies were conducted (the United States versus rural China).

6.4. Quantitative Study Summary

Representativeness of the Study Sample. In general, the demographic characteristics of this study's sample were similar to those of other HIV-positive populations in rural Anhui, China reported in the literature (Ji et al., 2006; Ji, Qi, Wang, Feng, & Leng, 2010; Mao et al., 2010; Sun et al., 2009; Tian et al., 2012)). For instance, Ji et al. (2006) conducted a study among former plasma donors in rural northern Anhui, China. The authors found that among the HIV-positive former plasma donors, there was an approximately equal number of male and female PLWHA.

In that study, the majority of the PLWHA in the sample were married (92.6%) and about one-third (35.8%) of the HIV-positive individuals did not have any formal education. Sun et al. (2009) recruited PLWHA from 10 villages in Anhui, China also reported demographic characteristics that are comparable to the PLWHA in this dissertation. In the study by Sun et al. (2009), the sample consisted of about an equal number of male and female PLWHA (48.4%); most of the sample had no formal education (51.1%) and most of the sample were married (81.7%). Similar to the PLWHA included in this dissertation, the sample from a study conducted in northern Anhui, China, reported that the main route of HIV infection was through commercial blood donation process (Mao et al., 2010).

Nonetheless, it should be noted that the characteristics of PLWHA vary across different regions of China and they may be different from those of the participating PLWHA in this dissertation. For example, a study examining the demographic features of HIV/AIDS infection in 12 provinces in the west of China documented that the adult male-to-female ratio in the HIV population was 4:1, and 50% of PLWHA were young adults aged 20 to 29 years (Hu, Qin, Zhu, Yang, & Zhang, 2006). Hu and colleagues also reported that because this area is largely economically under-developed, a large number of rural residents are pouring into cities, thus driving the spread of HIV in the region (Hu et al., 2006). Another study conducted among PLWHA in rural Guangxi province, China reported different demographic characteristics from this dissertation sample. About half of the participants were married (55.9%), 61.7% were of Han ethnicity, and 64.2% were farmers (Zhang et al., 2015).

In summary, perceived HIV-related stigma remained associated with access to healthcare. In Aim 1, perceived stigma was a key dimension associated with access to care. In Aim 2, only higher levels of affectionate support, one dimension of social support, were positively associated with access to healthcare. The findings suggest that there is something unique about the dimensions of HIV-related stigma and social support that influence access to care in rural Anhui Province, China. These findings provide an impetus to investigate the specificity of the efficacy of social support and HIV-related stigma reduction for PLWHA.

6.5. Limitations of the Quantitative Study

The study findings must be understood in light of their limitations. First, this study used a cross-sectional design, and causality could not be established. A longitudinal study in the future should be conducted to explore the causal relationship between HIV-related stigma, social support, and access to care. Second, the data were based on self-reports, which were vulnerable to social desirability bias. Literature has documented that individuals tend to avoid negative evaluations of themselves by providing self-reports that are socially desirable (Latkin, 1993; Loo & Thorpe, 2000). Because of social desirability bias, PLWHA may underreport their engagement in illegal behaviors (such as commercial sex work or injecting drug use). The accuracy of routes of HIV infection could not be verified with documentation and may be subject to misclassification. However, a previous study reported that up to 90% of the PLWHA in rural Anhui, China contracted HIV virus through plasma donation (Wu et al., 2001). Therefore, future research should consider checking for a potential presence of self-presentation bias, such as using the Marlowe-Crowne Social Desirability Scale (MCSDS) to examine the validity of self-reported data since individuals who score high on MCSDC will provide an approval-seeking response (Greenwald & Satow, 1970; Loo & Thorpe, 2000). A previous study conducted among female sex workers in the Philippines used the short version of the MCSDC and showed that no social desirability bias existed with the self-report condom use scale among commercial sex workers in the Philippines (Morisky, Ang, & Sneed, 2002). In future longitudinal studies, researchers should pay attention to the impact of how social desirability bias may influence self-report measures of retention in care and consider collection information from medical records as well (Higa et al., 2012).

Generalizability. The study was conducted in rural Anhui Province, China, which may limit the generalizability of the results documented here. PLWHA may not be as homogeneous as assumed. It should be taken into consideration that the sample consisted of individuals who had disclosed their HIV serostatus to at least one family member. The current study only analyzed the HIV-related stigma among adults living with HIV/AIDS. The results might not be generalizable to children or adolescents living with HIV in the region. In addition, a potential threat to the validity of the study findings includes selection bias. Whether those who volunteered for the larger randomized controlled trial in the parent study represent the broader HIV-positive men and women living in rural Anhui, China, was not known. Further, most of the study population was infected with HIV in the 1980s via commercial plasma donation. PLWHA who were infected through other transmission routes (e.g., injecting drug use or commercial sex work) were underrepresented, therefore, these findings should not be generalized to such populations. Moreover, this study was conducted in an area where ART was provided for free; thus, the level of access to care and its relationship with HIV-related stigma and social support may be different in other areas where resource availability is different from the one examined here.

Measurement Limitations. This study analyzed the baseline data of the Parent Study, which limited its ability to evaluate the different aspects of accessing care, such as the acceptability of services and quality of services. Additionally, the Parent Study included only one instrument on accessing ART, thus limiting the ability to examine the patterns of ART among the participating PLWHA. For measuring access to care, there was no measurement for accessing healthcare system over time, or the unmet need of PLWHA (e.g., main program that causes delay or not receiving necessary healthcare). These indicators can track changes in access over time (e.g., direction and speed of change) and differences across sub-groups of PLWHA (WHO, 1981). In sum, future research should consider measuring other dimensions of access to care, such as indicators of patient-provider communication and relationship (e.g., satisfaction with care), to have a holistic view of the utilization of care and quality of care received.

Future studies should also consider investigating the impacts of HIV-related stigma and perceived social support in persons newly diagnosed with HIV to inform the development both of culturally appropriate measures of these constructs and sustainable interventions. The measures used for HIV-related stigma in this current study were not specific to the healthcare setting, thus limiting the ability to distinguish the effects of HIV-related stigma in healthcare settings on access to care. Only data collected in the parent study were analyzed, thus limiting the ability to explore the complexity of HIV-related stigma and its wide range of dimensions, such as HIV-related stigma in the family and community.

Further, while MOS-SSS has been well-validated in China among PLWHAand patients with a documented diagnosis of heart failure (Thompson, Ski, Watson, & Wang, 2014; Yu et al., 2015; Yu et al., 2004a), it measured perceived social support, which may not reflect actual functional support. Furthermore, there are no standardized cut-points for analyzing MOS-SSS data, thus limiting the ability for cross-study comparisons (Kelly et al., 2014). The perceived social supports measured in this study were part of functional support (tangible, affectionate, emotional). Future study can consider capturing structural support such as measuring network size.

MOS-SSS is a well-known and validated measure developed in the United States. Even though the use of MOS-SSS-C has been validated in China among patients with chronic illness, previous literature also noted the difficulties in translation related to differences in cultural experience and linguistic variations with a concept (Yu et al., 2004a). Culture plays a central role in shaping emotional experience and providing the language people use to describe their experiences (Weiss & Kleinman, 1988). The Chinese translation of MOS-SSS may not have captured the nuanced meaning of social support in the context of China. The terms for emotional state can vary across cultures, and it may be difficult to translate them into non-Western languages (Wierzbicka, 1994). Direct translation of some emic terms originated in the Western culture. For instance, in the original MOS-SSS version, the item reads as “someone who hugs you,” the back-translated version became “someone who gives you loving care.” Also, whereas “hugging” is a commonly used body language in the Western culture, this is less likely to be done in the same manner by more conservative Chinese (Yu et al., 2004a), especially in rural regions of China where culture remains conservative.

The different directions of the findings on social support could also be a result of measurement error, that is, the difference between a measured quantity (i.e., emotional, tangible, and affectionate support) and their true value, especially in this understudied rural Chinese population. The magnitude of relevant cultural differences with respect to social support between rural China, where the research occurred, and the United States, where the measures were developed and where they have been used extensively, underscore the possibility that measurement error helps explain this pattern in the data. Although the literature has documented good levels of accuracy and reliability of the MOS-SSS instrument in varying lengths among different populations (Gómez-Campelo et al., 2014; Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012; Yu et al., 2004b), there is diversity in its factorial structure in different sample groups (i.e., factorial structure of four versus three factors; Griep, Chor, Faerstein, Werneck, & Lopes, 2005; Wang et al., 2013). The present dissertation utilized the Parent Study's instrument for social support. It is unknown how the factorial structure of the instrument might differ from its original form when assessing PLWHA in rural China. The instrument developed in the United States to assess primarily explicit efforts to extract emotional or tangible support may be inappropriate for cultural groups that derive their social support largely through implicit means (Taylor et al., 2007). The perception of social support may not always reflect the actual available support, and sometimes even the actual social support might not be perceived (Gómez-Campelo et al., 2014). The observed values of social support may be lower than their actual values, thus underestimating the relationship between social support and access to care. Thus, applying the same factorial structure or categorization of social support (i.e., emotional, tangible, and affectionate) may not be suitable. Further study is needed to provide new evidence of validity based on the internal structure and reliability of MOS-SSS-C. Additionally, there is a need to explore the use of other measures of social support developed in the same context they are going to be used (e.g., social support instrument developed in China or one especially for PLHWA).

Besides, future research should consider using multiple measures for the same construct to reduce possible measurement error.

Future study could benefit from considering other confounders, such as PLWHA's knowledge and perceived benefits of care, which was not included in this study. This dissertation did not include measurements from either family member of PLWHA or healthcare provider. As a result, it was not possible to examine how their perspectives would have an impact on PLWHA's access to care. Specifically, further study should examine how social support and HIV-related stigma perceived by family members of PLWHA and their providers could affect PLWHA's access to care.

There was no question asking the participating PLWHA's ethnicity; therefore, the study could not examine how ethnicity may affect PLWHA's care access. However, a previous study conducted among PLWHA in one county in Anhui, China, reported that most of the sample (99.3%) was of Han ethnicity and only a small portion (0.7%) reported other ethnicities (Tian et al., 2012). Therefore, there may be limited ethnic diversity within this region of rural Anhui Province.

6.6. Strengths of the Quantitative Study

The first strength is that this dissertation analyzes data from a large randomized controlled intervention trial in rural Anhui, China. It is rare to be able to evaluate HIV-related stigma and social support in a population that was mostly infected through commercial plasma donation through a large sample size. The second strength is that this dissertation is grounded in theories. Utilizing the Andersen's Model and constructs of stigma, this dissertation provides results in line with well-established and well-known theory in public health. Adapting this theory and the concepts ensures this dissertation embraces the social, behavioral, and contextual determinants of access to care. Although the original form of HIV transmission in Anhui Province was due to commercial plasma donation, the demographics of the population most greatly affected were similar to PLWHA in other rural areas in rural Anhui, China (Xu et al., 2007). Thus, the findings from this study could have implications to rural families across the Anhui Province.

6.7. Public Health Implications

This section describes the study's implications for public health research and practice.

6.7.1 Research Implications

6.7.1.a. HIV-Related Stigma among PLWHA in Rural Anhui, China

This study underscores the complexity of HIV-related stigma and its relationship with access to care. Our understanding of HIV-related stigma is contingent upon the dimension we choose to focus on. As a result, the concept of HIV-related stigma needs to be considered in relationship to the cultural context to capture the concepts in various settings fully. The findings from this study imply that future study should consider developing a culturally grounded definition of HIV-related stigma, while taking into consideration, not just the cultural aspects such as the family-oriented society (Cao et al., 2011), but also the history of HIV transmission in the area (e.g., commercial plasma donation; Wu et al., 2001). Additionally, it may be beneficial in identifying context-specific characteristics of HIV-related stigma, such as how HIV-positive patients experience stigma in healthcare settings. A previous study conducted in the United

States showed that perceived stigma from a healthcare provider was associated with low access to care, even after controlling for socio-demographic characteristics and most recent CD4 count (Kinsler et al., 2007).

Layered Stigma. In addition to considering context-specific HIV-related stigma, future research should also take into account the layering effects of stigma related to HIV. It is important to note that HIV-related stigma is not a singular entity (Chan Stoové, Sringernyuang, & Reidpath, 2008; Reidpath & Chan, 2005). These co-occurrences of multiple stigmatizing attributes have been conceptualized as *double stigma* (Grossman, 1991), *layers of stigma* (Herek, 1999), or *layered stigma* (Reidpath & Chan, 2005). Instead, HIV-related stigma represents an additional layer of stigma, reinforcing the ways in which certain oppressed groups that are multiply stigmatized (Ford, Konrad, Godette, & Corbie-Smith, 2008; Reidpath & Chan, 2005). PLWHA are stigmatized by not only their HIV serostatus, but also risk factors associated with the routes of transmission (e.g., commercial sex work, injecting drug use, etc.) and other individual characteristics (economic status, sexuality, gender, disability, etc.; Fassin, 2001; Demleitner, 2001; Lane, Mogale, Struthers, Mclntyre, & Kegeles, 2008).

A previous study conducted by McBride and colleague (1998) to examine whether HIV-related stigma would differ by the mode of viral transmission (blood transfusion, unsafe sex, and injecting drug use). McBride (1998) reported that where an HIV infection was associated with a "blameless" transmission such as blood transfusion, the stigma associated with it was significantly less. It is unclear in the current study how the layering of HIV-related stigma contributes to the differences in accessing care among PLWHA. Future research on HIV-related stigma may consider the layering effect of stigma. Understanding the layering of HIV-related stigma could potentially be critical for the development of interventions that will address the entire experience of HIV-related stigma (Reidpath & Chan, 2005).

When considering cultural context in research, one should be mindful not to emphasize the deficits of a group when referencing culture (Airhihenbuwa, Ford, & Iwelunmor, 2014). Ford, Whetten, Hall, Kaufman, and Thrasher (2007) observed that conventional social psychological discourse led to a singular view of “the Down-Low” (the DL) as a self-destructive, African American cultural production linked to the spread of HIV. The DL stigma not only reflects stigmatization of black sexuality but also exacerbates the stigmatization of blacks in general (Ford et al., 2007). A large proportion of PLWHA in the current study were infected by commercial plasma donation. Therefore, how HIV-related stigma manifested in villages heavily impacted by the disease compared to those who were not should be taken into consideration. What are the layers of stigma added on top of existing HIV-related stigma associated with “HIV-affected villages”? Future research should explore how the social context influences the occurrence of HIV-related stigma in communities affected by the history of HIV outbreak among former plasma donors and how social inequalities exacerbate the impact of the disease in these rural regions.

Courtesy Stigma. HIV-related stigma does not only exist in PLWHA, but their family members, and even communities with which they are affiliated (Herek, 1999). According to Goffman (1963), perceived or experienced stigma could be passed on to family members of those with stigmatizing attributes, and Goffman has coined it as “courtesy stigma.” Courtesy stigma has not received the same attention as other types of stigma (Bogart et al., 2007). It refers to prejudice and discrimination against individuals who are associated with stigmatized others (Goffman, 1963).

The cultural context of the family-oriented society in rural China would require further study to examine HIV-related stigma experienced by family members of PLWHA. Researchers have emphasized that understanding HIV/AIDS requires enhanced cultural knowledge (Airhihenbuwa et al., 2014). China is a robust family-oriented society (Muller & Desmond, 1992). Thus, the strong collectivism or familism in China could exacerbate the HIV-related stigma experienced by family members of PLWHA (Yu, Li, Qiao, & Zhou, 2016). Families of PLWHA in a family-oriented country such as China often need to share the HIV-related stigma (Li et al., 2009). A previous social network study conducted among PLWHA in China documented that HIV-related stigma may mediate the relationship between collectivist culture and social network support, thus providing an empirical basis for incorporating aspects of culture into future HIV intervention strategies (Zang, Guida, Sun, & Liu, 2014). Future research should examine the complexity of HIV-related stigma experienced by family members (i.e., stigma by association) to gain a better understanding of the impacts of HIV-related stigma on families in the longterm.

Although the researchers have documented the burden faced by uninfected caregivers, most HIV-related stigma scales have been developed for PLWHA, and very few have examined HIV-related stigma or courtesy stigma for their uninfected family members, including PLWHA’s spouse or children (Liu, Xu, Sun, & Dumenci, 2014). A previous study showed that community-level, HIV-related stigma was the most prevalent barrier to healthcare reported by women living with HIV across 27 countries (Johnson et al., 2015). One should note that in Johnson et al.’s study, China had a higher score of community-level HIV-related stigma compared to other regions (Johnson et al., 2015). Future research on HIV-related stigma should also look into courtesy stigma related to understanding the dynamics of PLWHA and their families better.

In addition to family members and friends of HIV-infected individuals, the negative consequences of courtesy stigma may even extend to those who are merely seen in the presences of PLWHA (Bogart et al., 2007). Therefore, in addition to including courtesy stigma experienced by affected family members of PLWHA, future research in HIV-related stigma should also consider measuring community-level courtesy stigma. Prospective studies could also help examine the directionality of the association between HIV-related stigma and access to care (Sayles et al., 2009); additionally, such studies could also help investigate changes in HIV-related stigma and its contribution to healthcare and health outcomes through the disease trajectory of PLWHA.

Healthcare providers are among the most knowledgeable about HIV disease, yet they may not be free from stigmatization in the society at large (Turan, Miller, Bukusi, Sande, & Cohen, 2008). Previous studies have also reported negative attitudes and behaviors toward PLWHA among healthcare professionals (Campbell, Nair, Maimane, & Nicholson, 2007; Dlamini et al., 2007; Mitchell, Kelly, Potgieter, & Moon, 2007; Turan et al., 2008). HIV-related stigma should also be examined among the providers to assess whether programs could provide better support for providers and reduce their negative attitudes toward PLWHA, thus increasing the quality of care for the population.

6.7.1.b. Social Support among PLWHA

Future research should consider the further characterization of social support—that is, including the distinction between general support and HIV disease-specific support. For example, HIV-specific support that is related to the management of the illness could include assistance in sustaining adherence to complex ART regimens (Wohl et al., 2011). Moreover, future studies should consider the use of social support measures that will capture social network among PLWHA. For instance, a study conducted among Latino and African American MSM and women in Los Angeles measured social support based on the social resource and social support questionnaire, and researchers adapted it for use with PLWHA (Myers, 1996; Wohl et al., 2011). Longitudinal research is needed to examine social support as the illness progresses in PLWHA to better understand the causal pathway through which support networks affect medical service use in this population.

This study contributes to the literature and highlights the importance of increasing social support among HIV-affected couples in rural China to increase PLWHA's access to care. Limited attention has been paid to social support among HIV-affected couples (sero-discordant and sero-concordant; Chadwick et al., 2011). An intervention conducted in a resource-limited setting, Peru, showed that a psychosocial support group tailored according to individuals' need was associated with higher rates of viral suppression (Muñoz et al., 2011). There is a need to explore the benefits of adopting similar strategies and pilot testing the invention in rural China and other resource-limited settings.

Just as HIV-related stigma could not be fully examined outside the cultural contexts that give it meaning (Airhihenbuwa & Webster, 2004), culture also plays an important role in social support, including how it is expressed and received. Literature has already documented how culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying (Kagawa-Singer & Blackhall, 2001). Culture is not only the building blocks of society's shared normative values, but it also shapes how personal understandings of health and illness are constructed and normalized (Airhihenbuwa et al., 2014). Previous research on chronically ill patients' perception of their husband's support in a cross-cultural context found that Asian American women were expected to be self-sacrificing and nurturing of their husband and family, as compared to Euro-American women (Kagawa-Singer & Wellisch, 2003). Scholars have emphasized the necessity to foreground local cultural contexts and meaning surrounding the construction of HIV/AIDS (Airhihenbuwa, 1995; Dutta, 2008). As rural China, like Anhui remains conservative, implicit forms of social support would be more commonly performed than other explicit forms of support. Therefore, future research should consider comparing dimensions of social support among different ethnic groups, such as rural China, to gain a better understanding of the support needed by PLWHA in cross-cultural settings. Even though this study may not have captured the gender differences in social support, it is crucial to include this element in future study to examine how cultural dynamics and gender roles affect forms of social support in China. Moreover, a culture-centered approach to designing care and support for PLWHA is a critical strategy (Airhihenbuwa & Webster, 2004).

6.7.1.c. Access to Care among PLWHA

Access is a complex concept and consists of several aspects. The process of access is subject to social and cultural influences, as well as environmental constraints (Gulliford et al., 2002). Since this study's measures were part of the larger Parent Study, it was limited in its ability to evaluate the different aspects of accessing care. Thus, in future studies, researchers may be able to address the complex issue of measuring access to healthcare more in-depth by including measurement's domains in the "effectiveness" and "values of services received" (Gold, 1998). Given the importance to consider HIV care continuum, it may be worthwhile to include care retention besides accessing care among PLWHA.

Controlling for sociodemographic variables, the findings report that PLWHA in rural Anhui, China, with higher levels of depressive symptoms have less access to care. This could have other public health implications. Previous research has shown that patients with depressive symptoms have worse health outcomes (Mallik et al., 2005). A growing body of literature has linked psychosocial factors to immune suppression and has suggested that depression or stress may accelerate HIV disease progression (Avagianou, Piperakis, & Zafiropoulou, 2006; Kopnisky, Stoff, & Rausch, 2004; Leserman, 2003). For instance, a study conducted among HIV-positive women in sub-Saharan Africa showed that depression was associated with increased risk of HIV disease progression and mortality (Antelman et al., 2007). Additionally, literature has suggested that depressive symptoms may be linked to patients' non-adherence to medical recommendation (Krousel-Wood et al., 2010), thus they negatively affect the disease mortality (Ammassari et al., 2002; Ickovics & Meade, 2002; Lima et al., 2007). Because depressive symptoms might be an additional barrier to accessing care and care retention, future research should explore the potential benefits of depression screening in adjunct to providing care to PLWHA. The findings underscore the need for increased attention to the psychological well-being of this population to minimize the impact of depressive symptoms on aspects of access to care (Simoni et al., 2011).

Although the current dissertation did not examine HIV disclosure, the literature has documented the role of disclosure plays in HIV-related stigma (Ding, Li, & Ji, 2011). Authors (Ding et al., 2011) of a study conducted in rural China reported that PLWHA who had higher levels of disclosure to members within the community reported an increased level of access to care and the use of ART. Another study conducted among PLWHA in Anhui, China, showed higher levels of HIV serostatus disclosure to community members (e.g., neighbor, village leaders, people in the village, and co-workers) among older age groups of PLWHA, whereas PLWHA with less family income tend to disclose more to community members than those with higher family income (Lan, Li, Lin, Feng, & Ji, 2016). However, a meta-analysis reported a negative correlation between HIV-related stigma and serostatus disclosure (Smith, Rossetto, & Peterson, 2008). In future studies, investigators should consider examining the complex relationship between HIV-related stigma, disclosure, and access to care, to better understand how disclosure plays a role in access to care in China.

Although this dissertation included only one instrument on access to care as available in the parent study, there are multiple ways of measuring access to care that might be considered in the future. For instance, measuring the utilization of healthcare services or specifying HIV-related services will be informative. Previous studies have used a variety of items to measure healthcare utilization, including emergency room visits and inpatient hospital stays (Hughes et al., 2018; Zhou et al., 2008), number of visits to physicians in the past 12 months (Yu, Mols, Stewart, & Zhang, 2017), outpatient face-to-face consultations and home visits, yearly hospitalizations (including length of stay; Zhou et al., 2008), and dental visits among adults (Wang, Li, Chen, & Si, 2018).

Given the importance of healthcare utilization and especially care retention for PLWHA, it would be important for future research to separately measure “realized access” (which was the measure included in this study), “healthcare utilization,” and “retention in care” to better inform future programming efforts for PLWHA care continuum. Another study conducted among 30 counties in Sichuan Province, China, defined the level of healthcare utilization as “the type of facilities visited by household members who had used healthcare services during the past 30 days” (Flatø & Zhang, 2016). Additionally, it would be useful for future studies to not only include the self-reported utilization of care, but also obtain the information from medical records to assess the validity of such information (Roberts, Bergstralh, Schmidt, & Jacobsen, 1996).

Although this dissertation applied the Andersen’s Model, other theories and models could also provide useful insights for the understanding of HIV-related stigma, social support, and access to care among PLWHA. For instance, the widely used PRECEDE-PROCEED model (Green & Kreuter, 1999, 2005) provides a structure for applying theories and concepts systematically for planning and evaluating health behavior change programs (Gielen, McDonald, Gary, & Bone, 2008). The PRECEDE-PROCEED model, stands for Predisposing, Reinforcing, and Enabling Construct in Educational/Environmental Diagnosis and Evaluation, (Green & Kreuter, 1999).

Similar to the Andersen’s model, the PRECEDE-PROCEED model identifies the predisposing and enabling factors. Predisposing factors include knowledge, attitudes, beliefs, perception, values, existing skills, self-efficacy, and culture. This includes the perspectives from the patient (e.g., PLWHA), provider, and family members. Even in instances where ART is freely available to PLWHA, such as in China, fear of taking medication could dissuade PLWHA from taking their treatment (Unge et al., 2008). Also, high self-efficacy for care enables families and providers to care for PLWHA, while low self-efficacy caused by HIV-related stigma can make it difficult for PLWHA to accept care or impede their motivation to reduce risk by seeking appropriate care (Mbonu, Van den Borne, & De Vries, 2009).

The PRECEDE-PROCEED model conceptualizes access to care not just as a single behavior (e.g., a single visit to the provider) but as a perpetual behavior that requires retention and reinforcement. The model suggests that access to care should be examined over time and that health behaviors must be reinforced as well as enabled (Green & Kreuter, 2005). As for health behavior, such as service seeking, needs to be sustained over long periods to achieve the desired health benefits (Green & Kreuter, 2005), just as PLWHA are required to adhere to an ART regimen. The PRECEDE-PROCEED model includes a unique factor, the reinforcing factor. The reinforcing factors include elements that reward or reinforce the desired behavior change, such as social support.

In the PRECEDE-PROCEED model, social support can also be conceptualized as a reinforcing factor, an element that can help not only achieve but also reinforce care access for PLWHA. For example, social support from family and healthcare providers can reinforce care access for PLWHA by providing reminders, assistance, as well as confidential and compassionate care at non-discriminatory facilities. Other provider- or clinical-level factors may reinforce patient's access to care, including provider-patient interaction and institutional support for providers (Li, Liang, Lin, & Wu, 2015). Furthermore, the PRECEDE-PROCEED model could provide alternative explanation for the distinctive directions between tangible support, affectionate support, and access to care. In the model's application, affectionate support becomes the key domain of support that can reinforce access to care while tangible support does not reinforce care access. Once the care is established, it is critical for PLWHA in rural China to experience affectionate support.

In addition to the concept of continuation for access to care suggested in the PRECEDE-PROCEED model, the model also recommends using wider sources of data. The model is based on the premise that the determinants of health are multifactorial, and multisectoral efforts are required to effect behavioral, environmental, and social change (Green & Kreuter, 1999). According to the model, researchers would synthesize disparate sources of data to minimize the risk of subjectivity (Phillips, Rolley, & Davidson, 2012). That is, researchers would also collect HIV-related stigma and social support experienced by family members of PLWHA, their providers, as well as the community members (e.g., the social norms) to ascertain how these factors also influence PLWHA’s access to care.

Application of the PRECEDE-PROCEED model provides a social structure that pays attention to culture and social interaction, and it points out several modifying variables, including poverty, religion, and policy (Mbonu et al., 2009). Moreover, the PRECEDE-PROCEED model can also assist in analyzing people’s coping strategies for dealing with HIV-related stigma problems (Mbonu et al., 2009). In sum, consider applying other theoretical models such as the PRECEDE-PROCEED model in this context to assist in our understanding of the complicated care access of PLWHA. Although these additional data were not available in the current dissertation, other models like the PRECEDE-PROCEED could provide auxiliary insight to examine care access.

By understanding the complex relationship between perceived stigma and access to care among this population in rural Anhui, program developers can better tailor future programs to the needs of the population. Furthermore, although the sociodemographics of the study participants were comparable to those of a PLWHA population assessed by a household survey conducted in three provinces in rural Anhui, China (Zhang, Fuller-Thomson, Mitchell, & Zhang, 2013), future study should compare whether the association between HIV-related stigma, social support, and access to care differ across various regions in China, especially comparing the HIV-related stigma experienced by PLWHA in communities impacted by commercial plasma donation and those who did not reside in these communities.

Although Han Chinese make up the vast majority of the population in Anhui Province, Anhui Province consists of 55 ethnic groups, including the two largest minority groups, She and Hui nationalities (China CDC, 2016). Literature has shown that, for minority patients, racial concordance between provider and patient is associated with higher health service utilization and increased uptake of preventive tests (Ford, Konrad, Godette, & Corbie-Smith, 2008; LaVeist, Nuru-Jeter, & Jones, 2003). The current study could not be used to examine how ethnicity may have an impact on accessing care since this information was not collected. Future research should also consider ethnicity when addressing access to care in rural regions of China where diverse minority groups reside.

Previous literature has pointed out that the Chinese government has prioritized economic growth over other considerations and health system for many years, which led to serious problems (Eggleston et al., 2008; Meesen & Bloom, 2007). However, China began its healthcare reform in 2009, and it is still in the first phase towards achieving comprehensive universal health coverage by 2020 (Yip et al., 2012). The impact of this healthcare reform on PLWHA's access to care has not been fully understood. In future studies, investigators should consider the implications of access to care among PLWHA under the new healthcare system in rural China, and how its relationship with HIV-related stigma and social support may be altered because of structural changes.

The structural changes occurring in the healthcare system could have implications for access measurement (Gold, 1998). As such, future studies on accessing healthcare could consider including measures that capture the contextual-level characteristics (Andersen, 2008), such as resources potentially available for people, including community per capita income and wealth and ratios of providers to population. As the characteristics of the Chinese healthcare system continue to undergo a transformation in rural Anhui China, future research in access to healthcare should also consider effectiveness and efficiency of access, such as quality of providers, patient adherence outcomes, or other HIV-related comorbidities. However, it has been reported that individuals in rural Anhui, China, may distrust the government (Li, 2011). The impact of government mistrust would be greatest for people who rely on the government for public services or healthcare (Ford, Wallace, Newman, Lee, & Cunningham, 2013). Given the history of the HIV epidemic in rural Anhui Province, China, it is critical to investigate beliefs held by PLWHA, including mistrust of government and belief about the disease among others, to gain a better understanding of the factors influencing PLWHA's access to care in rural areas in rural Anhui, China.

6.7.2. Implications for Practice

The results suggest there may be potential benefits to addressing HIV-related perceived stigma in enhancing care access among PLWHA and deterring the detrimental influence of stigmatization on mental and physical health stemming from exposure to chronic stress. The findings suggest the importance of targeting HIV-related perceived stigma in interventions to mitigate their potential aversive influence on healthcare service use. Additionally, the results also suggest that programs should consider incorporating social and psychological components to increase affectionate support among PLWHA and the significant persons in their lives to improve PLWHA care access.

6.7.2.a. Strategies to Reduce HIV-Related Stigma

The findings from this study imply that it may be beneficial for program developers to consider adopting previously successful HIV-related stigma reduction interventions to enhance PLWHA's access to care. A recent systematic review of studies that assessed the effectiveness of interventions around the world to reduce HIV-related stigma showed that most of the studies were effective at reducing the aspects of HIV-related stigma they measured; however, most interventions targeted a single socioecological level and a single domain of HIV-related stigma (Stangl et al., 2013). Different strategies were used to decrease HIV-related stigma in various countries. For example, a radio- and theater-based educational program was conducted among PLWHA in an HIV-related clinical setting in India and reported that the program exposure was associated with reduced HIV-related enacted stigma in PLWHA (Nambiar et al., 2011). Another community participation intervention conducted in one village in the northeastern region of Thailand over a period of eight months showed a significant effect on HIV-related stigma score reduction (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007). In particular, the intervention improved the levels of accurate HIV/AIDS knowledge and reduced the level of community stigma in the intervention village compared to that of the control village (Apinundecha et al., 2007). Another study conducted in a resource-constrained HIV treatment setting in South India showed that a radio- and a theater-based educational program was effective in increasing HIV-related knowledge and lowering levels of HIV-related stigma among PLWHA (Nambiar et al., 2011).

It should be noted that given the family-oriented culture of China and the important role culture plays in the understanding of behaviors (Airhihenbuwa et al., 2014), an individualistic approach to stigma would not be adequate, as they belong to families or communities and cannot be isolated entities from the larger entity (Smith & Mbakwem, 2010). Accounting for the strong bonds that exist between families and communities (Li, Liang, Lin, Wu, & Rotheram-Borus, 2010), similar to Apinundecha and colleagues' intervention strategies implemented in a village in northern Thailand, future studies should consider exploring the benefits of adopting similar approaches to reduce HIV-related stigma in the rural counties in Anhui Province.

6.7.2.b. Strategies to Increase Social Support among PLWHA

This finding has critical implications for programming efforts for PLWHA in rural Anhui Province, China. The study results suggest the importance of examining dimensions of social support in health service research and their potential benefits for informing the development of interventions. The results suggest that intervention that promotes affectionate support may help optimize healthcare service use among PLWHA in rural Anhui, China. For instance, family members could openly express their care and affections beyond offering basic assistance with PLWHA's daily chores (Slomka, Lim, Gripshover, & Daly, 2013). Additionally, aside from providing concrete assistance when delivering care services for PLWHA, conveying affection and care would potentially have a more profound impact. Programs that educate healthcare providers and enhance their skills related to providing affectionate support to PLWHA (e.g., empathic expression or empowering statements) may promote access to care (Slomka et al., 2013).

In addition to the family-based intervention, a previous study reported that PLWHA serostatus discordant couples suggested that including individual as well as couple counseling and support groups could have a positive impact on their lives (Bunnell et al., 2005). The findings from this study could provide useful information for the interventionist to consider exploring programs that address specific dimensions of social support. Just as HIV-related stigma and social support could not be thoroughly examined outside the culture contexts that give it meaning (Airhihenbuwa & Webster, 2004), future programming efforts to enhance social support for PLWHA should also focus on the cultural contexts that nurture the adoption of specific behaviors (Airhihenbuwa et al., 2014).

Part II. Critical Performance

6.8. Critical Performance

This portion of the dissertation involved the use performative elements to interpret some of the understandings I have been developing about the concepts of HIV-related stigma and social support in the regions of China where the data for the dissertation research were drawn. Although the quantitative analyses of the study examined only the adult PLWHA in rural Anhui, China, the critical performance highlighted HIV-affected children while including narratives from HIV-infected individuals in the same region, rural Anhui, China. The film clip was shown at the beginning of the performance. *The Blood of Yingzhou District* was filmed in Yingzhou county, located in the same province, Anhui Province, where the participating PLWHA were from. In the performance, the experiences of the HIV-affected children became a natural way to bridge the two parts of the quantitative and performative parts of the study, especially given the strong family-oriented culture of Chinese society.

The critical performance also raised the question of what it means for the work to be "performed" and "staged" in English, and be presented in the "West." As culture is a central element in the understanding of the quantitative analyses, it also plays a vital role in understanding the implications of the performance in a cultural context. As a researcher in training, I wish to reflect on the lessons I have learned as a "Western-educated" intellectual about the dominant first-world epistemologies on HIV/AIDS, the naming and description of the *Other*. The terms *Western*, *first-world*, *third-world* used here are not meant to further the division among people, place, or space, but to aid in my examination of this issue. The language and topics I have been trained on in the field of public health mostly include data-gathering instruments such as the questionnaire survey that makes the Eurocentric perception on HIV/AIDS inescapable. Therefore, the question at hand is how the colonizer/colonized dichotomies work to subjugate other knowledge systems in HIV/AIDS research.

Subaltern voices point toward alternative ways of approaching the HIV/AIDS pandemic in developing countries beyond the narrow realm of problems defined by the Western researchers. The concepts from subaltern studies offer a different, but much needed, approach to writing history, from below, documenting the narratives of women and other marginalized groups, while challenging the elitist approach to constructing knowledge (Guha & Spivak, 1988). The performance was an attempt to bring subaltern voices into the representation of PLWHA by speaking the words of PLWHA during the seven narratives. The performance seeks to move away from the dominant perspective to that of the marginalized and to locate the agency of the marginalized subject within the discursive space (Dutta, 2006).

Although Spivak and Said's concepts provide methods for critically analyzing the approaches used in HIV/AIDS research, Spivak (1988) and Said's (1993) concepts do not include the range of coping responses from marginalized individuals, including the discussion of *resilience*. As shown in the photographs included in the last part of the performance, children in HIV-affected families have shown resilience in facing this disease. Although HIV has made an undeniable impact on these families, individuals in the photographs exemplified their response to the disease or resistance to it, including women, PLWHA, and children affected by HIV. It should be noted that photographs get meaning from their contexts like all cultural objects do (Becker, 1995). When one views the photographs, one should consider the environment, the society, the culture, and the ability to be “photographed” as well as the agency of “taking photographs.”

As a performance, the performance is simultaneously “real” and “constructed,” as different narratives, photographs, a film clip, and dance moves brought together what historically has been kept separate as discrete, supposedly free-standing discourses. The audience at the performance was invited to see and to understand what HIV-related stigma manifested through photographs, words, and movements. It is critical to remember that “the power to narrate,” or to block other narratives from forming and emerging, is very important to culture and imperialism, and constitutes one of the main connections between them (Said, 1993). Together, these pieces in the program formed a constructed narrative about HIV in rural Anhui Province, China.

The exploratory critique of the performance, integrations of the concepts of subaltern as well as othering highlight out that the discourse that materializes individuals from the margins should be located at the core of the researcher’s understanding and configuration of HIV/AIDS. Just as several audience members commented that there’s a great need for bringing arts-based approaches and public health together, this performance pioneered the way to bridge these two fields in this experimental performance. The performance raised the question of agency as applicable to the PLWHA. Future areas of exploration include the use of performance practice as tools to increase agency among PLWHA, so that they can engage with structures that encompass their lives, to make meaning through this engagement, and to create discursive openings to transform these structures (Dutta, 2008). Dwight Conquergood (2002) argues that performance is at once a radically multidisciplinary and it embodies approach to examining an object of inquiry.

6.8.1. Implications for Performance Practice in Public Health

Performance, or theater-based techniques, are effective in creating emotional experiences for viewers that can affect attitudes at a deeper level than traditional didactic teaching methods (; Joronen, Rankin, & Astedt-Kurki, 2008; Lieberman, Berlin, Palen, & Ashley, 2012). The photovoice included in the performance provided an emic perspective from PLWHA on their experiences living with the disease that might not have been available using other quantitative methods. The performance offered an opportunity to deliver individual and collective stories that represent how they experienced living with HIV/AIDS in rural Anhui Province, China, and that played an integral part in the formulation of actions to effect change. It should be noted that the content of the performance did not intend to generalize to all PLWHA in rural Anhui China; instead, the content permitted the expression and interpretation for me to go beyond the empirical data. Additionally, the performance was not designed to be a public health intervention; rather, it was an experimental performance aimed at drawing from the student's quantitative analysis of the dissertation and the minor field in the Department of World Arts and Cultures/Dance.

This method of communicating research findings to the audience could have implications for fostering dialogue between the researchers, the community, and the practitioners who work within these communities. Although arts-based approaches are not new to the scientific community, the integration of dance, video, ethnodrama, and sciences provided opportunities to innovate in non-traditional research dissemination and communication. As I am the first one in the Department of Community Health Sciences to minor in the Department of Worlds Arts and Cultures/Dance, the hope is that the experiences of producing a performance for the dissertation can both inform and inspire others to attempt similar strategies. This mission of the performance also aligns with the participatory research movements that foster more profound levels of engagement with and uptake of research findings (Gagnon, 2009; Keen & Todres, 2007). In Conquergood's (1995) words, performance is boundary breaking and has the potential to help produce an understanding of social problems in more nuanced ways. The lesson learned from this performance could encourage other public health researchers to consider non-traditional approaches to knowledge transfer and research dissemination. It may be beneficial for future practices to explore how photo-voice could be utilized as a strategy to facilitate participant empowerment by creating a space for participation and building the capacity of PLWHA to mobilize to explore, describe, and analyze challenges and assets and problem solve.

6.8.2. Performance as Translational Tool

Performance has a unique potential to interpret, translate, and disseminate research findings (Rossiter et al., 2008). The process of translating the quantitative analyses into a performance was also inspired by participatory action research's (PAR) goal of initiating action. It has been said that PAR's dual emphases are generating new scientific knowledge and initiating action (Delgado, 2015; Park, 1993; Selener, 1997). PAR methods have been applied to HIV work via the use of photo-voice (Wang, 1999). The photovoice PAR technique enables people to record and reflect their community's strength and concerns and to promote critical dialogue and knowledge about personal and community issues through discussion of the photographs (Wang, 1999). There is a long history of the use of live theater as a means to foster social change, and this performance served not as an intervention but as an experiment to further bridge scientific findings and artistic communication. There was no formal discussion with the audience at the performance; however, it may be worthwhile for future research to explore the possibilities of adopting photovoice and PAR methods in HIV work. With the principles of PAR in mind, it may be appropriate and beneficial to find new methods for engaging marginalized communities in the process of conducting research (e.g., assessing the needs and evaluation of healthcare among PLWHA) and for empowering the individuals to create positive changes within their immediate environment (Delgado, 2015).

6.8.3. Performance as Analysis Tool

The critical performance included dramatized reading of the interview transcripts from published qualitative studies that, through the performance, were transformed into monologues. This part of the performance was dependent upon the text. Because the performance was drawn from qualitative research data, the realism and empirical fact were additions to the emotional truth and dramatic style and flow. Nonetheless, the performance represented a step in moving away from a completely textual interpretation of data towards a theatrical style that begins to privileged “an embodied, theatrical representation of data” (Rossiter et al., 2008, p. 135). Within the performance, the placement of text is important as a tool for analysis and knowledge transfer, just as sections of narratives may reflect, contrast, and even “speak” to one another (Rossiter et al., 2008). For instance, one narrative conveyed the HIV-stigma that one PLWHA experienced from her husband, while another narrative highlighted the support a PLWHA received from her sister. This interplay between performed pieces of text provided a comment on, or interpretation of, the qualitative data. Although these texts were drawn directly from interview transcripts, they were not staged scenes that create a story between or about the research findings. Toward the end of the performance, I broke away from the narratives and spoke from a podium. The benefit of such an arrangement was in its ability to make transparent the process of analysis. It showed the audience what I was doing and how I was constructing interpretation.

This method is similar to what Rosenbaum, Ferguson, and Herwaldt (2005) did in their performance text, *In Their Own Words*, which was created from a series of interviews conducted with patients facing a range of diagnoses. In Rosenbaum et al.'s (2005) work, the interviews focused on the interactions between patients and healthcare providers, both negative and positive. Rosenbaum and colleagues (2005) selected pieces from the interviews and arranged them into poem-like stories. This method allows the researcher to utilize pieces of data from the script itself and not "abstracting" or moving away from the data through the process of dramatic interpretation.

The movements choreographed for HIV-related stigma used a black tulle that covered parts of the body while creating an image of entanglement. While this scene was not intended as an actual portrayal of the lived reality of PLWHA, it provided a more "direct pathway to the lived truth of their experiences than a compilation of verbal statements ever could have" (Gray et al., 2000, p. 140).

6.8.4. Performative Elements and Theory in Public Health

Several performative elements could be translated into theory in public health to inform future applications and programming efforts. The approaches in the performance aimed to raise awareness and increase knowledge that is in parallel with the concepts from the social cognitive theory (Bandura, 1986). For instance, the narratives included in the critical performance attempted to raise awareness of HIV-related stigma faced by PLWHA in rural Anhui Province, China. Additionally, the delivery of the background and history of the HIV epidemic in China intended to increase the knowledge of the HIV epidemic in the country, especially the circumstances of the former commercial plasma donors. The social cognitive theory emphasizes that an individual’s knowledge acquisition occurs in a social context with a dynamic and reciprocal interaction between the person, environment, and behavior (Bandura, 1986). By portraying the interactions that PLWHA would have in their communities, the performance introduced how HIV-related stigma was manifested in rural Anhui Province, China. At the same time, the narratives also illustrated how an individual’s behaviors are shaped by the information derived from various personal experiences. The social cognitive theory also emphasizes the mechanisms through which social factors exert their influence on cognitive functioning. Take one of the narratives as an example, one person was afraid of going to the doctor for fear of her HIV-serostatus being known to other villagers. Although this performance was not designed as an intervention, previous research has shown that interventions that involve theatrical performances are an innovative strategy that could raise adolescents’ awareness and knowledge of HIV and health-risk behaviors and could change their HIV-related attitudes, behavioral intentions, and risk behaviors (Glik et al., 2002; Noar, Palmgreen Chabot, Dobransky, & Zimmerman, 2009). Theatrical traditions hold the potential to impact audience members both at the affective and cognitive levels and to foster insight and deepened understanding (Michalak et al., 2014). The translation of performative elements into public health theory could assist the development of future public health interventions.

6.8.5. Limitation of the Critical Performance

As with any live performance, the critical performance was constrained by time and location. Future practice in the area should consider exploring the use of video that can reach a broader audience. Because of the focus on spoken text, the creative potential of the body in the performance was not fully exercised (e.g., the monologues had limited use of props and costumes). In addition, because I am not a professional actress, expressive techniques such as subtlety of voice, intonation, and physicality might not be as effective as they could have been otherwise.

6.8.6. Lesson Learned

There are several lessons learned from this experience of creating a critical performance. If I could do this performance again, I would like to implement several changes. First, this performance only consisted of me as the solo performer. It was an attempt of “embodying” and “examining” HIV-related stigma in rural areas in Anhui, China. It would be beneficial to explore other types of performance for the given context. I would like to recruit multiple performers to have an ensemble cast, including amateur actors, researchers, and PLWHA if possible. By doing so, it may add layers to the narrative by showing how HIV-related stigma could be experienced in a social context and through a variety of in-person interactions. Similarly, I would choreograph movements around social support with multiple performers to exemplify how social support can be manifested through social interactions. In addition, the performance would feature a variety of characters that engage the audience and each other through monologues and dialogues, and scenes that contain elements of dramatic tension (e.g., conflict).

Second, I would also like to conduct focus groups with the participating PLWHA so that their experiences could inform and be integrated into the development of the program. By including the participating PLWHA’s voices, it may be possible for some of the movements to be inspired by the lived experiences of the participating PLWHA to represent them and their stories better. The narratives in this critical performance were drawn from published qualitative studies among PLWHA in rural China. It would strengthen the performance by adding the voices from the participating PLWHA in the quantitative study. In other words, informants themselves would be actively engaged, and thus could correct, add, alter, and reaffirm research findings through theatrical intervention (Rossiter et al., 2008). The cast would review and rework the script in order to more powerfully convey the emotion of the experiences of PLWHA.

Third, although the performance took place in the United States, I believe it might better represent the people if the voice recording for the movement could contain some phrases in dialects spoken by the participating PLWHA. Given the proximity of these scenes to "real life" scenarios, the performance could be more open to interactivity and in-the-moment modification of the performance by both the audience members and performers (Mienczakowskio, 1999). This interactive work draws explicitly from the work of theater practitioner Boal's (1985) methodology, Forum Theatre, or *Theatre of the Oppressed*. This theatrical form will use role-play and scripted texts as a basis of improvisations to aid marginalized people in transforming and transcending social oppression (Boal, 1985).

Finally, yet importantly, I would like to carry out a performance evaluation where I would ask participants a range of questions pertaining to their perceptions of the event, such as whether they learned something new during the performance, whether the performance had an emotional impact on them, and their overall comments for the event. In evaluating the impact of the performance, I would like to use both opened-ended questions as well as structured quantitative surveys. The evaluation will concentrate on two major areas: whether the audience members enjoy the production, and did they learn about the presented topic and change their attitude as a result of attending the performance. Although the performance was not designed as an intervention initially, I would like to evaluate its effectiveness in changing audience members' attitudes toward HIV/AIDS and PLWHA.

6.9. Conclusions

This dissertation addresses the critical yet complex issue of HIV-related stigma and social support that affect PLWHA in rural Anhui, China. More than two decades into the history of HIV outbreak in this region, HIV-related stigma continues to hamper HIV treatment and care efforts. The results support the need to unravel the nexus of HIV-related stigma and social support to identify approaches to improve care for this vulnerable population. The findings from this dissertation shed light on HIV-related stigma among PLWHA in rural Anhui, China. A better understanding of the association between different dimensions of HIV-related stigma and social support, as well as their relationship to access to care will assist health professionals and policy makers to develop tailored strategies for PLWHA to improve their care.

Much of the process of developing a performance drawn from the dissertation was iteratively and experientially created. As a public health professional trained in performance studies, I successfully delivered information from the quantitative part of the dissertation and accomplished it in an engaging way that gave stories behind the empirical numbers and evoked responses. Performance has the potential to enhance our understanding of the complex emotional, interpersonal, and psychological dynamics that often arise in healthcare practices, many of which may be difficult to fully convey in more traditional forms of research dissemination (e.g., scientific articles; Rossiter et al., 2008). The power of arts-based approaches may have the potential to reach and speak to an audience that may not be responsive to conventional methods for addressing HIV-related stigma and may represent a yet-to-be fully tapped mechanism for communicating important message related to HIV/AIDS.

Study Contribution to the Field. The study was a unique opportunity to advance the field in several ways. A significant contribution of this study to the field is improving the understanding of HIV-related stigma among PLWHA in rural China, in particular, in regions where historical HIV outbreak occurred with commercial plasma donations. In addition, the study also contributes to the field in identifying the specific dimensions of HIV-related stigma and social support that are sensitive to access to care among PLWHA in rural Anhui, China. The findings underscore the importance to investigate culturally appropriate forms of support. The performance part of the study demonstrates that performance can communicate research significance and findings in an emotive and embodied manner, and that theater has the potential for health research that engages complex questions of the human condition.

Implications for Future Research. Findings from this study suggested that there were significant associations between HIV-related perceived stigma, affectionate support, and access to care among PLWHA in rural Anhui, China. Identifying the dimensions of HIV-related stigma and social support that may be more sensitive to intervention highlights the opportunities for HIV-related stigma reduction interventions and programs aimed at increasing social support for PLWHA. Furthermore, program developers of HIV-related stigma reduction interventions should pay close attention to the different dimensions of HIV-related stigma, especially perceived stigma, in order to achieve desired program outcomes.

The findings suggest that future research should consider using a longitudinal study design to examine HIV-related stigma and social support as the illness progresses in PLWHA to gain a better understanding of the causal pathway through which dimensions of HIV-related stigma and social support may influence retention in HIV care. Furthermore, more research on the unique and complex interface of depressive symptoms and access to care is needed to inform the development of future intervention that may promote care access, thereby improving the quality of life for PLWHA.

APPENDIX A

Correlations within Multi-Item Scale for HIV-Related Stigma and Social Support

Table A1

Correlation Matrix for Access to Care Items

	Correlations						
Variable	1	2	3	4	5	6	7
1 I have regular visits to my doctors or medical providers.							
2 If I get sick, I know where to go to get treatment.	0.22						
3 If I need more information about my illness, I know where to get it.	0.30	0.51					
4 I know when to go for my regular check-up when I am not sick.	0.19	0.64	0.48				
5 I know how to protect myself from getting sick.	0.34	0.40	0.50	0.48			
6 I know how to eat right to get proper nutrition to stay healthy.	0.38	0.35	0.47	0.36	0.68		
7 I know how to exercise and stay healthy.	0.37	0.30	0.43	0.33	0.61	0.70	
8 I can talk freely to my doctor and other medical providers about my illness.	0.27	0.40	0.30	0.36	0.26	0.27	0.30

Note. N = 522

Table A2

Correlation Matrix for Perceived Stigma Items

	Correlations						
Variable	1	2	3	4	5	6	7
1 I am accused by others of spreading AIDS in the community.							

2 People gossip about my HIV status.	0.45						
3 People look down on me.	0.33	0.52					
4 The society isolates me.	0.27	0.33	0.46				
5 I feel discriminated against by health workers.	0.22	0.06	0.17	0.20			
6 I feel my life in this society is lonely.	0.29	0.25	0.40	0.48	0.34		
7 I worry about how other kids treat my children in school as a result of my HIV.	0.19	0.25	0.25	0.25	0.15	0.32	
8 I worry about how others will treat my family members as a result of my HIV.	0.24	0.27	0.27	0.29	0.16	0.35	0.83

Note. N = 522

Table A3

Correlation Matrix for Internalized Shame Items

	Correlations							
Variable	1	2	3	4	5	6	7	8
1 I am punished by evil.								
2 My life is tainted.	0.41							
3 I am angry with myself for getting HIV.	0.25	0.48						
4 I am a disgrace to the society.	0.26	0.45	0.24					
5 My life is filled with shame.	0.30	0.55	0.30	0.74				
6 I feel guilty for being the source of disruption in the family.	0.22	0.40	0.34	0.34	0.42			
7 I feel my life is worthless.	0.31	0.45	0.35	0.42	0.45	0.42		
8 I feel my reputation is lost.	0.23	0.48	0.51	0.31	0.39	0.46	0.46	
9 If possible I want to conceal my HIV status for life.	0.07	0.15	0.22	0.25	0.22	0.15	0.22	0.22

Note. N = 522

Table A4

Correlation Matrix for Emotional Support Items

	Correlations						
Variable	1	2	3	4	5	6	7
1 Someone you can count on to listen to when you need to talk.							
2 Someone to give you information to help you understand a situation.	0.44						
3 Someone to give you good advice about a crisis.	0.48	0.49					
4 Someone to confide in or talk to about yourself or your problems.	0.45	0.45	0.51				
5 Someone whose advice you really want.	0.39	0.43	0.50	0.41			
6 Someone to share your most private worries and fears with.	0.33	0.36	0.35	0.37	0.50		
7 Someone to turn to for suggestions about how to deal with a personal problem.	0.34	0.49	0.43	0.42	0.48	0.52	
8 Someone who understands your problems.	0.47	0.41	0.47	0.40	0.51	0.48	0.49

Note. N = 522

Table A5

Correlation Matrix for Tangible Support Items

	Correlations		
Variable	1	2	3
1 Someone to help you if you were confined to bed.			
2 Someone to take you to the doctor if you needed it.	0.65		
3 Someone to prepare your meals if you were unable to do it yourself.	0.62	0.60	
4 Someone to help with daily chores if you were sick.	0.63	0.57	0.75

Note. N = 522

Table A6

Correlation Matrix for Affectionate Support Items

	Correlations	
Variable	1	2
1 Someone who shows you love and affection.		
2 Someone to love you and make you feel wanted.	0.69	
3 Someone who hugs you.	0.45	0.52

Note. N = 522

Correlation Matrix for Aim 1

Table A7

Correlation Matrix of HIV-Related Stigma and Demographic Variables among Adults Living with HIV/AIDS with HIV-Positive Spouses in Rural Anhui, China (n = 141)

	1	2	3	4	5	6
1. Access to care						
2. Age	0.05					
3. Gender	– 0.04	– 0.14				
4. Married	– 0.002	0.12	0.05			
5. Income	– 0.16	– 0.14	– 0.26**	– 0.02		
6. Perceived stigma	– 0.26**	– 0.10	0.09	0.08	0.001	

7. Internalized shame	– 0.09	– 0.02	0.39***	0.08	– 0.14	0.39***

Note. *$p < 0.05$; **$p < 0.01$; ***p < 0.0001.

Table A8

Correlation Matrix of HIV-Related Stigma and Demographic Variables among Adults Living with HIV/AIDS with HIV-Negative Spouses in Rural Anhui, China (n = 381)

	1	2	3	4	5	6
1. Access to care						
2. Age	0.04					
3. Gender	– 0.08	0.07				
4. Married	– 0.08	0.28***	0.11*			
5. Income	– 0.03	– 0.20***	– 0.29***	– 0.13*		
6. Perceived stigma	– 0.21***	– 0.05	0.04	– 0.04	– 0.09	
7. Internalized shame	– 0.19**	– 0.04	0.12*	– 0.08	– 0.21***	0.59***

Note. *$p < 0.05$; **$p < 0.01$; ***p < 0.0001.

Table A9

Correlation Matrix of HIV-Related Stigma and Demographic Variables among Adults Living with HIV/AIDS Former Plasma Donors in Rural Anhui, China (n = 451)

	1	2	3	4	5	6
1. Access to care						
2. Age	0.08					

3. Gender	– 0.09	0.08				
4. Married	– 0.05	0.28***	0.09			
5. Income	0.01	– 0.15**	– 0.29***	– 0.10*		
6. Perceived stigma	– 0.22***	– 0.04	0.06	– 0.01	– 0.09	
7. Internalized shame	– 0.14**	– 0.04	0.20***	– 0.08	– 0.21***	0.54***

Note. *p < 0.05; **p < 0.01; ***p < 0.0001.

Table A10

Correlation Matrix of HIV-Related Stigma and Demographic Variables among Adults living with HIV/AIDS Non-plasma Donors in Rural Anhui, China (n = 71)

	1	2	3	4	5	6
1. Access to care						
2. Age	– 0.23					
3. Gender	0.05	– 0.26*				
4. Married	– 0.18	0.31**	0.04			
5. Income	– 0.08	– 0.24*	– 0.18	– 0.14		
6. Perceived stigma	– 0.17	– 0.18	0.02	– 0.25*	– 0.08	
7. Internalized shame	– 0.36*	– 0.11	0.11	– 0.02	– 0.10	0.58***

Note. *p < 0.05; **p < 0.01; ***p < 0.0001.

Correlation Matrix for Aim 2

Table A11

Correlation Matrix of Social Support and Demographic Variables among Adults Living with HIV/AIDS with HIV-Positive Spouses in Rural Anhui, China (n = 141)

	1	2	3	4	5	6	7
1. Access to care							
2. Age	0.05						
3. Gender	– 0.04	– 0.14					
4. Married	– 0.002	0.12	0.05				
5. Income	0.16	– 0.14	– 0.26**	– 0.02			
6. Emotional support	0.20*	0.03	– 0.28**	– 0.07	0.09		
7. Tangible support	0.08	0.20*	– 0.16	– 0.16	– 0.02	0.43***	
8. Affectionate support	0.36***	0.16	– 0.21*	– 0.07	0.04	0.58***	0.61***

Note. **p* < 0.05; ***p* < 0.01; ****p* < 0.0001

Table A12

Correlation Matrix of Social Support and Demographic Variables among Adults Living with HIV/AIDS with HIV-Negative Spouses in Rural Anhui, China (n = 381)

	1	2	3	4	5	6	7
1. Access to care							
2. Age	0.04						
3. Gender	– 0.08	0.07					

4. Married	– 0.08	0.28***	0.11*				
5. Income	– 0.03	– 0.20***	– 0.28***	– 0.13*			
6. Emotional support	0.22***	– 0.06	– 0.12*	– 0.06	0.15**		
7. Tangible support	0.07	0.02	– 0.06	– 0.09	0.04	0.28***	
8. Affectionate support	0.25**	0.02	– 0.07	– 0.02	0.06	0.53***	0.58***

Note. *p < 0.05; **p < 0.01; ***p < 0.0001

Table A13

Correlation Matrix of Social Support and Demographic Variables among Adults Living with HIV/AIDS Former Plasma Donors in Rural Anhui, China (n = 451)

	1	2	3	4	5	6	7
1. Access to care							
2. Age	0.08						
3. Gender	– 0.09	0.08					
4. Married	– 0.05	0.28***	0.09				
5. Income	0.01	– 0.15**	– 0.29***	– 0.10*			
6. Emotional support	0.20***	– 0.02	– 0.18***	– 0.03	0.13**		
7. Tangible support	0.07	0.06	– 0.08	– 0.05	0.03	0.31***	
8. Affectionate support	0.26***	0.07	– 0.11*	0.02	0.04	0.55***	0.61***

Note. *p < 0.05; **p < 0.01; ***p < 0.0001

Table A14

Correlation Matrix of Social Support and Demographic Variables among Adults Living with HIV/AIDS Non-Plasma Donors in Rural Anhui, China (n = 71)

	1	2	3	4	5	6	7
1. Access to care							
2. Age	0.05						
3. Gender	– 0.04	– 0.14					
4. Married	– 0.002	0.12	0.05				
5. Income	0.16	– 0.14	– 0.26**	– 0.02			
6. Emotional support	0.20*	0.03	– 0.28**	– 0.07	0.09		
7. Tangible support	0.08	0.20*	– 0.16	– 0.16	– 0.02	0.43***	
8. Affectionate support	0.36***	0.16	– 0.21*	– 0.07	0.04	0.58***	0.61***

Note. *$p < 0.05$; **$p < 0.01$; ***$p < 0.0001$

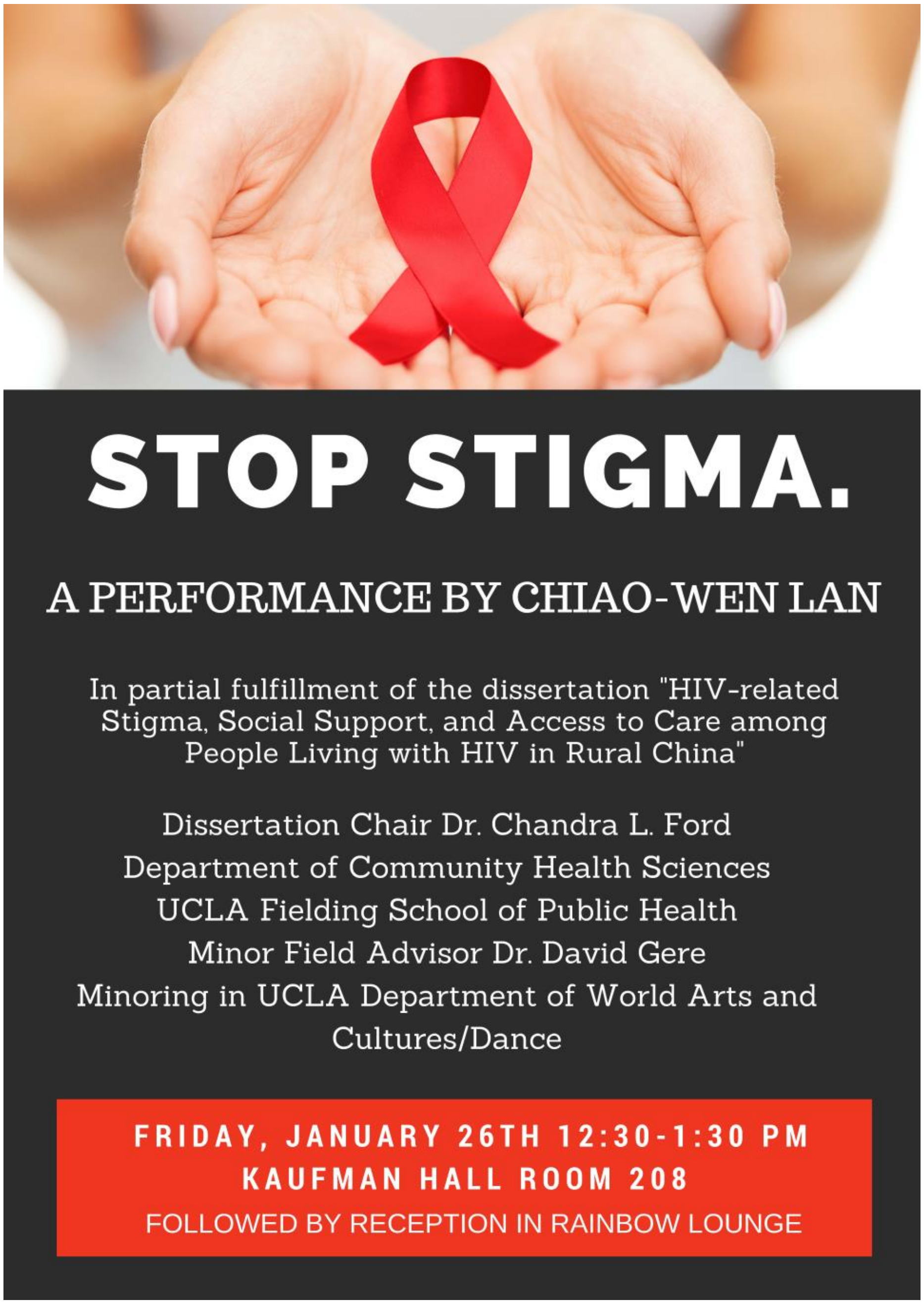
APPENDIX B

List of materials included in APPENDIX B

B1 Performance Flyer

B2 Performance Program

B1 Performance Flyer



STOP STIGMA.

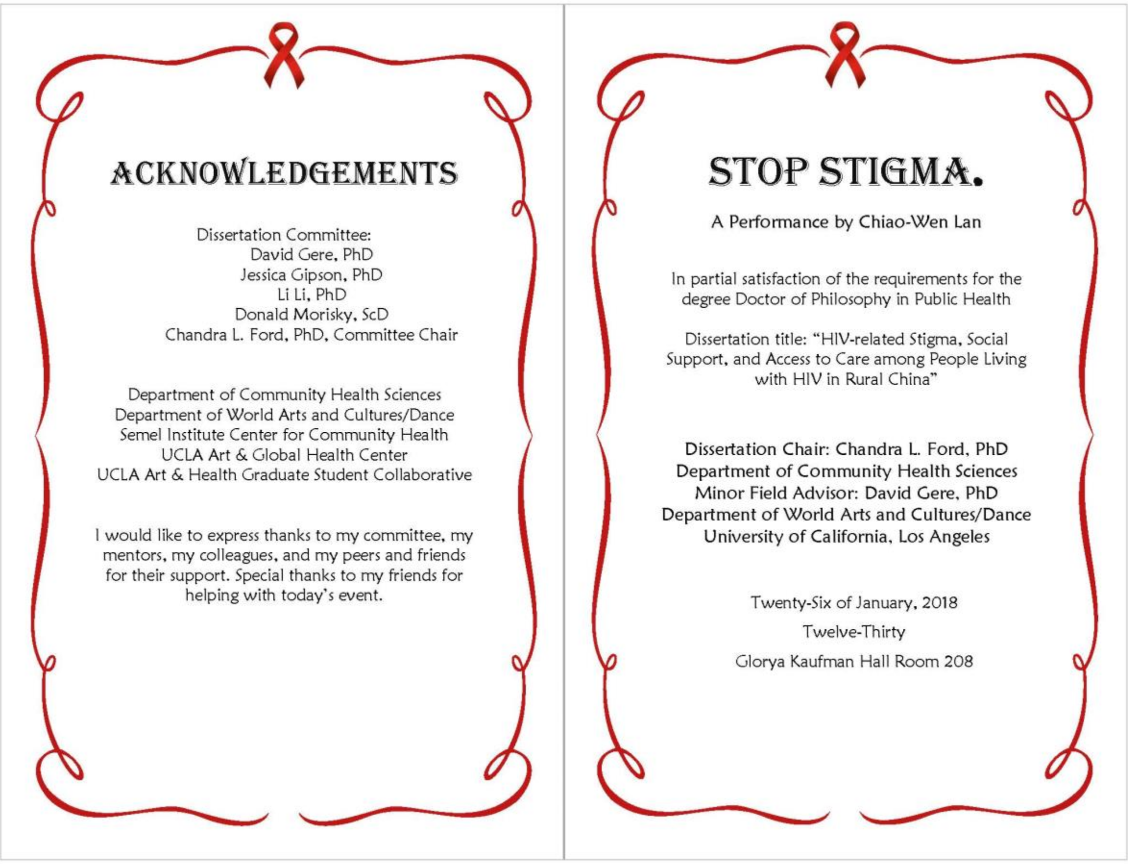
A PERFORMANCE BY CHIAO-WEN LAN

In partial fulfillment of the dissertation "HIV-related Stigma, Social Support, and Access to Care among People Living with HIV in Rural China"

Dissertation Chair Dr. Chandra L. Ford
Department of Community Health Sciences
UCLA Fielding School of Public Health
Minor Field Advisor Dr. David Gere
Minoring in UCLA Department of World Arts and Cultures/Dance

FRIDAY, JANUARY 26TH 12:30-1:30 PM
KAUFMAN HALL ROOM 208
FOLLOWED BY RECEPTION IN RAINBOW LOUNGE

B2 Performance Program



ACKNOWLEDGEMENTS

Dissertation Committee:
David Gere, PhD
Jessica Gipson, PhD
Li Li, PhD
Donald Morisky, ScD
Chandra L. Ford, PhD, Committee Chair

Department of Community Health Sciences
Department of World Arts and Cultures/Dance
Semel Institute Center for Community Health
UCLA Art & Global Health Center
UCLA Art & Health Graduate Student Collaborative

I would like to express thanks to my committee, my mentors, my colleagues, and my peers and friends for their support. Special thanks to my friends for helping with today's event.

STOP STIGMA.

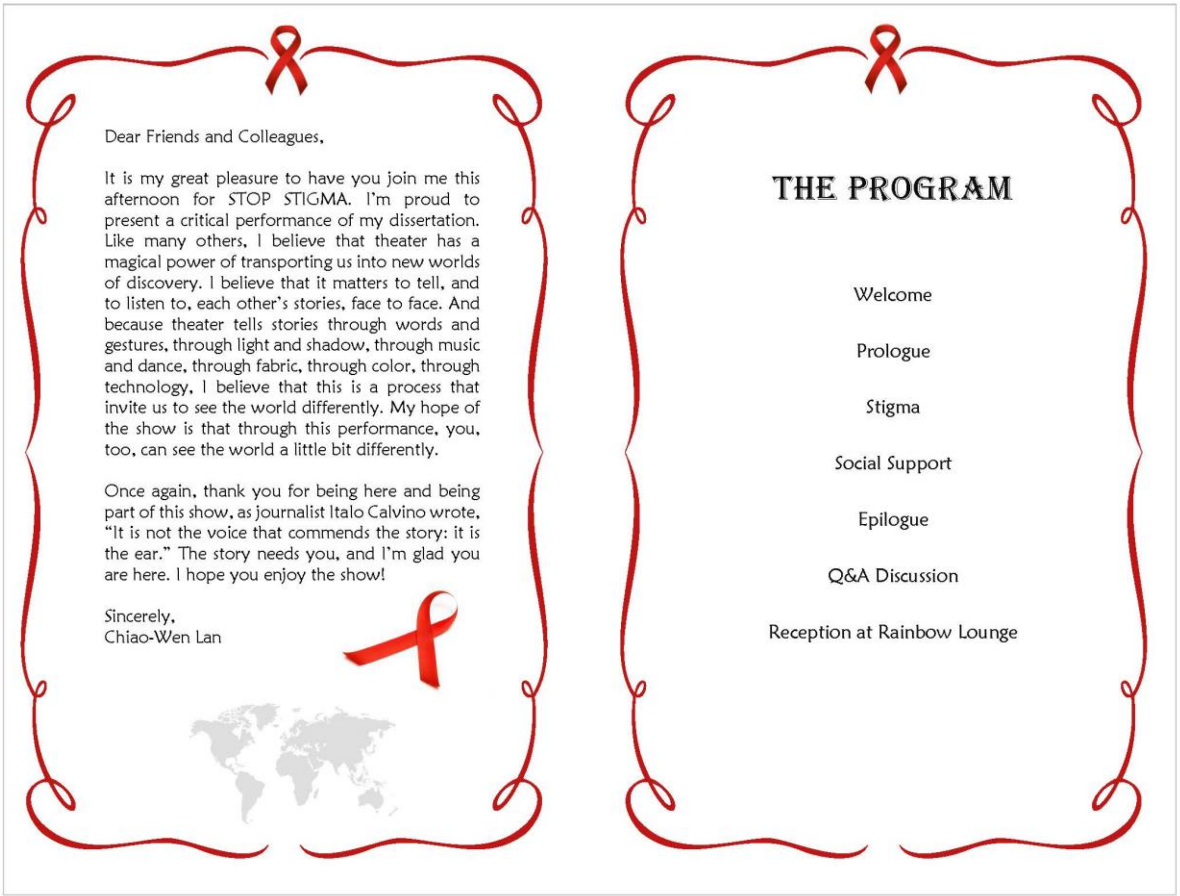
A Performance by Chiao-Wen Lan

In partial satisfaction of the requirements for the degree Doctor of Philosophy in Public Health

Dissertation title: "HIV-related Stigma, Social Support, and Access to Care among People Living with HIV in Rural China"

Dissertation Chair: Chandra L. Ford, PhD
Department of Community Health Sciences
Minor Field Advisor: David Gere, PhD
Department of World Arts and Cultures/Dance
University of California, Los Angeles

Twenty-Six of January, 2018
Twelve-Thirty
Glorya Kaufman Hall Room 208



Dear Friends and Colleagues,

It is my great pleasure to have you join me this afternoon for STOP STIGMA. I'm proud to present a critical performance of my dissertation. Like many others, I believe that theater has a magical power of transporting us into new worlds of discovery. I believe that it matters to tell, and to listen to, each other's stories, face to face. And because theater tells stories through words and gestures, through light and shadow, through music and dance, through fabric, through color, through technology, I believe that this is a process that invite us to see the world differently. My hope of the show is that through this performance, you, too, can see the world a little bit differently.

Once again, thank you for being here and being part of this show, as journalist Italo Calvino wrote, "It is not the voice that commends the story: it is the ear." The story needs you, and I'm glad you are here. I hope you enjoy the show!

Sincerely,
Chiao-Wen Lan

THE PROGRAM

Welcome

Prologue

Stigma

Social Support

Epilogue

Q&A Discussion

Reception at Rainbow Lounge

REFERNECES

Access. (n.d.). In Merriam-Webster's online dictionary (11th ed.). Retrieved from https://www.merriam-webster.com/dictionary/access

Ahern, J., Stuber, J., & Galea, S. (2007). Stigma, discrimination and the health of illicit drug users. *Drug and Alcohol Dependence*, *88*(2–3), 188–196.

Airhihenbuwa, C. O. (1995). *Health and culture: Beyond the Western paradigm*. Thousand Oaks, CA: SAGE Publications.

Airhihenbuwa, C. O., Ford, C. L., & Iwelunmor, J. I. (2014). Why culture matters in health interventions: Lessons from HIV/AIDS stigma and NCDs. *Health Education & Behavior, 41*(1), 78–84.

Airhihenbuwa, C. O., & Webster, J. D. (2004). Culture and African contexts of HIV/AIDS prevention, care and support. *Journal of Social Aspects of HIV/AIDS Research Alliance*, *1*(1), 4–13.

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine*, *41*(3), 303–315.

Akin, J. S., Dow, W. H., Lance, P. M., & Loh, C. A. (2005). Changes in access to health care in China, 1989-97. *Health Policy and Planning*, *20*, 80–89.

Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., . . . Antinori, A. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy:

Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes, 31*(3), 123–127.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10.

Andersen, R., Bozzette, S., Shapiro, M., St Clair, P., Morton, S., Crystal, S., . . . Asch, S. (2000). Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. *Health Services Research*, *35*(2), 389–416.

Andersen, R. M., Davidson, P. L., & Baumeister, S. E. (2007). Improving access to care in America. In R. M. Andersen, T. H. Rice, & G. F. Kominski (Eds.), *Changing the U.S. health care system: Key issues in health services policy and management* (3rd ed., pp. 33–69). San Francisco, CA: Jossey-Bass.

Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. *Medical Care, 46*(7), 647–653.

Aneshensel, C. S. (2013). *Theory-based data analysis for the social sciences* (2nd ed.). Thousand Oaks, CA: SAGE Publications.

Antelman, G., Kaaya, S., Wei, R., Mbwambo, J., Msamanga, G. I., Fawzi, W. W., & Fawzi, M. C. S. (2007). Depressive symptoms increase risk of HIV disease progression and mortality among women in Tanzania. *Journal of Acquired Immune Deficiency Syndromes*, *44*(4), 470–477.

Anthony, M. N., Gardner, L., Marks, G., Anderson-Mahoney, P., Metsch, L. R., & Valverde, E. E. (2007). Factors associated with use of HIV primary care among persons recently diagnosed with HIV: Examination of variables from the behavioural model of health-care utilization. *AIDS Care, 19*(2), 195–202.

Apinundecha, C., Laohasiriwong, W., Cameron, M. P., & Lim, S. (2007). A community participation intervention to reduce HIV/AIDS stigma, Nakhon Ratchasima province, northeast Thailand. *AIDS Care, 19*(9), 1157–1165.

Atkinson, J. S., Nilsson Schönnesson, L., Williams, M. L., & Timpson, S. C. (2008). Associations among correlates of schedule adherence to antiretroviral therapy (ART): A path analysis of a sample of crack cocaine using sexually active African Americans with HIV infection. *AIDS Care*, *20*(2), 253–262.

Austin, J. L. (1975). *How to do things with words*. J. O. Urmson & M. Sbisa (Eds.). New York, NY: Oxford University Press.

Avagianou, P. A., Piperakis, S. M., & Zafiropoulou, M. (2006). Stress and the progression of HIV disease. *Review of Clinical Pharmacology and Pharmacokinetics-International Edition*, *20*(1), 38–42.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, *44*(9), 1175–1184.

Bao, J., Wang, X. J., Yang, Y., Dong, R. Q., & Mao, Z. F. (2015). Can the medical-nursing combined care promote the accessibility of health services for the elderly in nursing home? A study protocol of analysis of the effectiveness regarding health service utilization, health status and satisfaction with care. *The West Indian Medical Journal*, *64*(5), 514–520.

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*(6), 1173–1182.

Becker, H. S. (1995). Visual sociology, documentary photography, and photojournalism: It’s (almost) all a matter of context. *Visual Studies*, *10*(1–2), 5–14.

Bell, C., Metsch, L. R., Vogenthaler, N., Cardenas, G., Rodriguez, A., Locascio, V., . . . Del Rio, C. (2010). Never in care: Characteristics of HIV-infected crack cocaine users in two US cities who have never been to outpatient HIV care. *Journal of Acquired Immune Deficiency Syndromes*, *54*(4), 376–380.

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, *24*(6), 518–529.

Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843–857.

Beverley, J. (2004). T*estimonio: On the politics of truth*. Minneapolis, MN: Universityof Minnesota Press.

Bhagwanjee, A., Govender, K., Reardon, C., Johnstone, L., George, G., & Gordon, S. (2013). Gendered constructions of the impact of HIV and AIDS in the context of the HIV-positive seroconcordant heterosexual relationship. *Journal of the International AIDS Society*, *16*(1), 18021.

Bhugra, D. (2003). Teaching psychiatry through cinema. *The Psychiatrist*, *27*(11), 429–430.

Boal, A. (1985). *Theatre of the oppressed*. New York, NY: Theatre Communications Group.

Bogart, L. M., Cowgill, B. O., Kennedy, D., Ryan, G., Murphy, D. A., Elijah, J., & Schuster, M. A. (2007). HIV-related stigma among people with HIV and their families: A qualitative analysis. *AIDS and Behavior*, *12*(2), 244–254.

Bond, V., Chase, E., & Aggleton, P. (2002). Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. *Evaluation and Program Planning*, *25*(4), 347–356.

Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society*, *18*(4), 431–442.

Bos, A. E., Schaalma, H. P., & Pryor, J. B. (2008). Reducing AIDS-related stigma in developing countries: The importance of theory-and evidence-based interventions. *Psychology, Health & Medicine*, *13*(4), 450–460.

Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology*, *1*(3), 185–216.

Broadhead, R. S., Heckathorn, D. D., Altice, F. L., van Hulst, Y., Carbone, M., Friedland, G. H., . . . Selwyn, P. A. (2002). Increasing drug users' adherence to HIV treatment: Results of a peer-driven intervention feasibility study. *Social Science & Medicine*, *55*(2), 235–246.

Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*, *15*(1), 49–69.

Buitrago, J., Gómez, S., Guerra, A., Lucumí, L., Romero, C., & Sánchez, J. (2013). Evaluation of an educational, theater-based intervention on attitudes toward organ donation in Risaralda, Colombia. *Colombia Médica*, *44*(1), 37–41.

Bunnell, R. E., Nassozi, J., Marum, E., Mubangizi, J., Malamba, S., Dillon, B., . . . Mermin, J. H. (2005). Living with discordance: Knowledge, challenges, and prevention strategies of HIV-discordant couples in Uganda. *AIDS Care*, *17*(8), 999–1012.

Butler, J. (1988). Performative acts and gender constitution: An essay in phenomenology and feminist theory. *Theatre Journal*, *40*(4), 519–531.

Butler, J. (1997). *Excitable speech: A politics of the performative*. Routledge, NY: Psychology Press.

Calsyn, R. J., Klinkenberg, W. D., Morse, G. A., Miller, J., Cruthis, R., & for the Hiv/aids Treatment Adherence, Health Outcomes and Cost Study Group. (2004). Recruitment, engagement, and retention of people living with HIV and co-occurring mental health and substance use disorders. *AIDS Care*, *16*(Suppl. 1), 56–70.

Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin*, *56*(2), 81–105.

Campbell, C., Nair, Y., Maimane, S. & Nicholson, J. (2007). Dying twice: A multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology*, *12*(3), 403–416.

Cao, Y., Chen, X., & Fan, R. (2011). Toward a Confucian family-oriented health care system for the future of China. *Journal of Medicine and Philosophy*, *36*(5), 452–465.

Cao, X., Sullivan, S. G., Xu, J., & Wu, Z. (2006). Understanding HIV-related stigma and discrimination in a 'blameless' population. *AIDS Education and Prevention*, *18*, 518–528.

Capo, K. E. (1983). Performance of literature as social dialectic. *Literature in Performance*, *4*(1), 31–36.

Carrieri, M. P., Chesney, M. A., Spire, B., Loundou, A., Sobel, A., Lepeu, G., & Moatti, J. P. (2003). Failure to maintain adherence to HAART in a cohort of French HIV-positive injecting drug users. *International Journal of Behavioral Medicine*, *10*(1), 1–14.

Chadwick, R. J., Mantell, J. E., Moodley, J., Harries, J., Zweigenthal, V., & Cooper, D. (2011). Safer conception interventions for HIV-affected couples: Implications for resource-constrained settings. *Topics in Antiviral Medicine*, *19*(4), 148–55.

Chakrabarty, D. (2000). *Provincializing Europe: Postcolonial thought and historical difference*. Princeton, NJ: Princeton University Press.

Chan, K. Y., Stoové, M. A., Sringernyuang, L., & Reidpath, D. D. (2008). Stigmatization of AIDS patients: Disentangling Thai nursing students' attitudes towards HIV/AIDS, drug use, and commercial sex. *AIDS and Behavior, 12*(1), 146–157.

Chen, L., Guo, Y., & Shi, J. (2018). Social support seeking on social media among Chinese gay men living with HIV/AIDS: The role of perceived threat. *Telemedicine and e-Health, 1*.

Chen, W. T., Shiu, C. S., Simoni, J. M., Zhao, H., Bao, M. J., & Lu, H. (2011). In sickness and in health: A qualitative study of how Chinese women with HIV navigate stigma and negotiate disclosure within their marriages/partnerships. *AIDS Care*, *23*(Suppl. 1), 120–125.

Chen, W. T., Starks, H., Shiu, C. S., Fredriksen-Goldsen, K., Simoni, J., Zhang, F., . . . Zhao, H. (2007). Chinese HIV-positive patients and their healthcare providers: Contrasting Confucian versus Western notions of secrecy and support. *Advances in Nursing Science*, *30*(4), 329–342.

China Ministry of Health. (2004). *A joint assessment of HIV/AIDS prevention, treatment and care in China*. Retrieved from http://data.unaids.org/UNA-docs/china_joint_assessment_2003_en.pdf

Christensen, M. C. (2013). Using theater of the oppressed to prevent sexual violence on college campuses. *Trauma, Violence, & Abuse*, *14*(4), 282–294.

Churcher, S. (2013). Stigma related to HIV and AIDS as a barrier to accessing health care in Thailand: A review of recent literature. *WHO South-East Asia Journal of Public Health*, *2*(1), 12–22.

Clark, H. J., Lindner, G., Armistead, L., & Austin, B. J. (2004). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women & Health*, *38*(4), 57–71.

Cluver, L. D., Orkin, M., Gardner, F., & Boyes, M. E. (2012). Persisting mental health problems among AIDS-orphaned children in South Africa. *Journal of Child Psychology and Psychiatry*, *53*(4), 363–370.

Colbert, A. M., Kim, K. H., Sereika, S. M., & Erlen, J. A. (2010). An examination of the relationships among gender, health status, social support, and HIV-related stigma. *Journal of the Association of Nurses in AIDS Care*, *21*(4), 302–313.

Connell, R. W. (1987). *Gender and power: Society, the person, and sexual politics*. Palo Alto, CA: Stanford University Press.

Conquergood, D. (1988). Health theatre in a Hmong refugee camp: Performance, communication, and culture. *The Drama Review*, *32*(3), 174–208.

Conquergood, D. (1991). Rethinking ethnography: Towards a critical cultural politics. *Communications Monographs*, *58*(2), 179–194.

Conquergood, D. (1995). Of caravans and carnivals: Performance studies in motion. *The Drama Review*, *39*(4), 137–141.

Conquergood, D. (2002). Performance studies: interventions and radical research. *The Drama Review*, *46*(2), 145–156.

Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self–stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, *25*(8), 875–884.

Cueva, M., Kuhnley, R., Lanier, A., & Dignan, M. (2005). Using theater to promote cancer education in Alaska. *Journal of Cancer Education*, *20*(1), 45–48.

Cunningham, W. E., Andersen, R. M., Katz, M. H., Stein, M. D., Turner, B. J., Crystal, S., . . . Bozzette, S. A. (1999). The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States. *Medical Care, 37*(12), 1270–1281.

Daykin, N., Orme, J., Evans, D., Salmon, D., McEachran, M., & Brain, S. (2008). The impact of participation in performing arts on adolescent and health behavior: A systematic review of the literature. *Journal of Health Psychology*, *13*(2), 251–264.

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*, *382*(9903), 1525–1533.

Delgado, M. (2015). *Urban youth and photovoice: Visual ethnography in action*. New York, NY: Oxford University Press.

Demleitner, N. V. (2001). The law at a crossroads: The construction of migrant women trafficked into prostitution. In D. Kyle, & R. Koslowski (Eds.), *Global human smuggling:*

Comparative perspectives (pp. 257-293). Baltimore, MD: Johns Hopkins University Press.

Derlega, V. J., Winstead, B. A., Greene, K., Serovich, J., & Elwood, W. N. (2002). Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology*, *7*(4), 415–432.

Dill-Shackleford, K. E., Green, M. C., Scharrer, E., Wetterer, C., & Shackleford, L. E. (2015). Setting the stage for social change: Using live theater to dispel myths about intimate partner violence. *Journal of Health Communication*, *20*(8), 969–976.

Ding, X., & Han, M. (2006). Living status and requirement of people living with HIV and AIDS. *Modern Preventive Medicine*, *33*, 930–933.

Ding, Y., Li, L., & Ji, G. (2011). HIV disclosure in rural China: Predictors and relationship to access to care. *AIDS Care*, *23*(9), 1059–1066.

Dlamini, P.S., Kohi, T.W., Uys, L.R., Phetlhu, R.D., Chirwa, M.L., Naidoo, J.R., . . . Makoae, L.N. (2007). Verbal and physical abuse and neglect as manifestations of HIV/ AIDS stigma in five African countries. *Public Health Nursing*, *24*(5), 389–399.

Doku, P. N. (2009). Parental HIV/AIDS status and death, and children's psychological wellbeing. *International Journal of Mental Health Systems*, *3*(1), 26.

Du, M., Zhao, J., Zhang, J., Lau, J. T., Mo, P. K., & Li, J. (2018). Depression and social support mediate the effect of HIV self-stigma on condom use intentions among Chinese HIV-infected men who have sex with men. *AIDS Care*, 30(9), 1197–1206.

Dutta, M. J. (2006). Theoretical approaches to entertainment education campaigns: A subaltern critique. *Health Communication*, *20*(3), 221–231.

Dutta, M. (2007). Communicating about culture and health: Theorizing culture-centered and cultural sensitivity approaches. *Communication Theory, 17*, 304–328.

Dutta, M. (2008). *Communicating health: A culture-centered approach*. Cambridge, England: Polity Press.

Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*, *13*(6), 1160–1177.

Eggleston, K., Ling, L., Qingyue, M., Lindelow, M., & Wagstaff, A. (2008). Health service delivery in China: A literature review. *Health Economics*, *17*(2), 149–165.

Eisinga, R., Te Grotenhuis, M., & Pelzer, B. (2013). The reliability of a two-item scale: Pearson, Cronbach, or Spearman-Brown? *International Journal of Public Health*, *58*(4), 637–642.

Faleiro, S. (2006). Daily round of Russian roulette. Retrieved from http://tehelka.com/story_main24.asp?filename=Sp122306Daily_round_p28-29.asp

Fanon, F. (1986). *Black skin, white masks*. London, England: Pluto Press.

Fassin, D. (2001). A double pain: The social condition of AIDS-infected immigrants. *L'Homme*, *160*, 137–162.

Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 50–67.

Flatø, H., & Zhang, H. (2016). Inequity in level of healthcare utilization before and after universal health coverage reforms in China: Evidence from household surveys in Sichuan Province. *International Journal for Equity in Health*, *15*(1), 96.

Ford, C. L., Konrad, T. R., Godette, D. C., & Corbie-Smith, G. (2008). Acceptance of routine ELISA testing among black women STD patients: Relationship to patient-provider racial concordance. *Sexually Transmitted Diseases*, *35*(3), 211–213.

Ford, C. L., Wallace, S. P., Newman, P. A., Lee, S. J., & Cunningham, W. E. (2013). Belief in AIDS-related conspiracy theories and mistrust in the government: Relationship with HIV testing among at-risk older adults. *The Gerontologist*, *53*(6), 973–984.

Ford, C. L., Whetten, K. D., Hall, S. A., Kaufman, J. S., & Thrasher, A. D. (2007). Black sexuality, social construction, and research targeting 'The Down Low' ('The DL'). *Annals of Epidemiology*, *17*(3), 209–216.

Forehand, R., Jones, D. J., Kotchick, B. A., Armistead, L., Morse, E., Morse, P. S., & Stock, M. (2002). Noninfected children of HIV-infected mothers: A 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy*, *33*(4), 579–600.

Foucault, M., & Miskowiec, J. (1986). Of other spaces. *Diacritics*, *16*(1), 22–27.

Fredland, N. M. (2010). Nurturing healthy relationships through a community-based interactive theater program. *Journal of Community Health Nursing*, *27*(2), 107–118.

Freire, P. (2012). *Pedagogy of the oppressed*. (M. B. Ramos, Trans.). New York, NY: Bloomsbury Academic. (Original work published in 1970)

Gabbard, G. O., & Gabbard, K. (1999). *Psychiatry and the cinema*. Washington, DC: American Psychiatric Press.

Gagnon, M. (2009). Knowledge dissemination and exchange of knowledge. In S. Straus, J. Tetroe, & I. D. Graham (Eds.), *Knowledge translation in health care: Moving from evidence to practice* (pp. 235–248). Chichester, England: Blackwell.

Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS Patient Care and STDs*, *22*(5), 423–436.

Gao, J. H., Zheng, X. W., Shi, X. M., Yang, Z., Jia, W., & Zhang, Y. (2004). Survey on HIV/AIDS-related stigma and discrimination among residents in rural community with a past history of paid blood donation. Chinese *Journal of China STD/AIDS Prevention and Control*, *10*(3), 175–177.

Gardner, L. I., Metsch, L. R., Anderson-Mahoney, P., Loughlin, A. M., Del Rio, C., Strathdee, S., . . . Holmberg, S. D. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*, *19*(4), 423–431.

Gielen, A. C., McDonald, E. M., Gary, T. L., & Bone, L. R. (2008). Using the precede-proceed model to apply health behavior theories. *Health Behavior and Health Education: Theory, Research, and Practice*, *4*, 407–429.

Gipson, J. D., Muntifering, C. J., Tsui, A. O., Hindin, M. J., Chauwa, F. K., & Taulo, F. (2010). Assessing the importance of gender roles in couples' home-based sexual health services in Malawi. *African Journal of Reproductive Health*, *14*(4), 63–73.

Gill, B., Huang, Y., & Lu, X. (2007). Demography of HIV/AIDS in China: A report of the Task Force on HIV/AIDS Center for Strategic and International Studies. *The Center for Strategic and International Studies*. Retrieved from https://csis-prod.s3.amazonaws.com/s3fs-public/legacy_files/files/media/csis/pubs/070724_china_hiv_demography.pdf

Glik, D., Nowak, G., Valente, T., Sapsis, K., & Martin, C. (2002). Youth performing arts entertainment-education for HIV/AIDS prevention and health promotion: Practice and research. *Journal of Health Communication*, *7,* 39–57.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.

Gold, M. (1998). Beyond coverage and supply: Measuring access to healthcare in today's market. *Health Services Research*, *33*(3), 625–652.

Goldstein, H. (2011). *Multilevel statistical models* (Vol. 922). Hoboken, NJ: John Wiley & Sons.

Gómez-Campelo, P., Pérez-Moreno, E. M., de Burgos-Lunar, C., Bragado-Álvarez, C., Jiménez-García, R., & Salinero-Fort, M. Á. (2014). Psychometric properties of the eight-item modified Medical Outcomes Study Social Support Survey based on Spanish outpatients. *Quality of Life Research*, *23*(7), 2073–2078.

Gong, C. H., Kendig, H., & He, X. (2016). Factors predicting health services use among older people in China: An analysis of the China Health and Retirement Longitudinal Study 2013. *BMC Health Services Research*, *16*(1), 63.

Gordon-Garofalo, V. L., & Rubin, A. (2004). Evaluation of a psychoeducational group for seronegative partners and spouses of persons with HIV/AIDS. *Research on Social Work Practice*, *14*(1), 14–26.

Gray, R. E., & Sinding, C. (2002). *Standing ovation: Performing social science research about cancer*. Walnut Creek, CA: Altamira Press.

Gray, R., Sinding, C., Ivonoffski, V., Fitch, M., Hampson, A., & Greenberg, M. (2000). The use of research-based theatre in a project related to metastatic breast cancer. *Health Expectations*, *3*(2), 137–144.

Green, L.W. & Kreuter, M.W. (1999) *Health-promotion planning: An educational and ecological approach*. Mountain View, CA: Mayfield Publishing Company.

Green, L. W., & Kreuter, M. W. (2005). *Health program planning: An educational and ecological approach*. New York, NY: McGraw-Hill.

Green, M. C., & Brock, T. C. (2000). The role of transportation in the persuasiveness of public narratives. *Journal of Personality and Social Psychology*, *79*(5), 70–721.

Greenwald, H. J. & Satow, Y. (1970). A short social desirability scale. *Psychological Reports*, *27*, 131–135.

Griep, R. H., Chor, D., Faerstein, E., Werneck, G. L., & Lopes, C. S. (2005). Validity of the construct of the Medical Outcomes Social Support Study adapted to Portuguese in the Pro-Saude Study. *Cadernos de Saúde Pública*, *21*, 703–714.

Gross, R., Yip, B., Lo, V., Iii, R., Wood, E., Alexander, C. S., . . . Hogg, R. S. (2006). A simple, dynamic measure of antiretroviral therapy adherence predicts failure to maintain HIV-1 suppression. *The Journal of Infectious Diseases*, *6021*, 1108–1114.

Grossman, A. H. (1991). Gay men and HIV/AIDS: Understanding the double stigma. *Journal of the Association of Nurses in AIDS Care*, *2*(4), 28–32.

Grossman, C. I., & Stangl, A. L. (2013). Global action to reduce HIV stigma and discrimination. *Journal of the International AIDS Society*, *16*(2):18881.

Gu, L., Wu, S., Zhao, S., Zhou, H., Zhang, S., Gao, M., . . . Tian, D. (2017). Association of social support and medication adherence in Chinese patients with type 2 diabetes mellitus. *International Journal of Environmental Research and Public Health*, *14*(12), 1522.

Guha, R., & Spivak, G. (Eds.). (1988). *Selected subaltern studies.* New Delhi, India: Oxford University Press.

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., & Hudson, M. (2002). What does ‘access to health care’ mean? *Journal of Health Services Research & Policy*, *7*(3), 186–188.

Guttman, N., Gesser-Edelsburg, A., & Israelashvili, M. (2008). The paradox of realism and “authenticity” in entertainment-education: A study of adolescents’ views about anti-drug abuse dramas. *Health Communication, 23*, 128–141.

Haines, J., Neumark-Sztainer, D., Perry, C. L., Hannan, P. J., & Levine, M. P. (2006). VIK (Very Important Kids): A school-based program designed to reduce teasing and unhealthy weight-control behaviors. *Health Education Research, 21*(6), 884–895.

Han, M., Chen, Q., Hao, Y., Hu, Y., Wang, D., Gao, Y., & Bulterys, M. (2010). Design and implementation of a China comprehensive AIDS response programme (China CARES), 2003-08. *International Journal of Epidemiology*, *39*(2), 47–55.

Han, J. W., Jeong, H., Park, J. Y., Kim, T. H., Lee, D. Y., Lee, D. W., . . . Kim, J. L. (2014). Effects of social supports on burden in caregivers of people with dementia. *International Psychogeriatrics*, *26*(10), 1639–1648.

Harris, K. R., & Graham, S. (1994). Constructivism: Principles, paradigms, and integration. *The Journal of Special Education*, *28*(3), 233–247.

Hatzenbuehler, M. L., Nolen-Hoeksema, S., & Erickson, S. J. (2008). Minority stress predictors of HIV risk behavior, substance use, and depressive symptoms: Results from a prospective study of bereaved gay men. *Health Psychology*, *27*(4), 455–462.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, *103*(5), 813–821.

He, N., & Detels, R. (2005). The HIV epidemic in China: History, response, and challenge. *Cell Research*, *15*(11), 825–832.

Heaney, C. A., Israel, B. A. (2008). Social network s and social support. In Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 189-207). San Francisco, CA: Jossey-Bass.

Helmeke, K. B., & Prouty, A. M. (2001). Do we really understand? An experiential exercise for training family therapists. *Journal of Marital and Family Therapy*, *27*(4), 535–544.

Herek, G. M. (2007). Confronting sexual stigma and prejudice: Theory and practice. *Journal of Social Issues, 63,* 905–925.

Herek, G. M. (2009). Sexual stigma and sexual prejudice in the United States: A conceptual framework. In D.A. Hope, *Contemporary perspectives on lesbian, gay, and bisexual identities* (pp. 65-111). New York, NY: Springer.

Herek, G. M., & Capitanio, J. P. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist*, *42*(7), 1130–1147.

Herek, G. M., Saha, S., & Burack, J. (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology, 35*(1), 41–54.

Hesketh, T., Duo, L., Li, H., & Tomkins, A. M. (2005). Attitudes to HIV and HIV testing in high prevalence areas of China: Informing the introduction of voluntary counseling and testing programmes. *Sexually Transmitted Infections, 81*, 108–112.

Hesketh, T., Zhu, W. X., & Duo, L. (2002). Editorial on epidemiology of HIV in China was misleading. *British Medical Journal*, *325*, 493.

Higa, D. H., Marks, G., Crepaz, N., Liau, A., & Lyles, C. M. (2012). Interventions to improve retention in HIV primary care: A systematic review of US studies. *Current HIV/AIDS Reports*, *9*(4), 313–325.

Hinyard, L. J., & Kreuter, M. W. (2007). Using narrative communication as a tool for health behavior change: A conceptual, theoretical, and empirical overview. *Health Education & Behavior*, *34*(5), 777–792.

Holzemer, W. L., Uys, L. R., Chirwa, M. L., Greeff, M., Makoae, L. N., Kohi, T. W., . . . Wantland, D. (2007). Validation of the HIV/AIDS Stigma Instrument-PLWA (HASI-P). *AIDS Care*, *19*(8), 1002–1012.

Hu, Z., Qin, X., Zhu, M. Z., Yang, S., & Zhang, X. J. (2006). Epidemiological characteristics of HIV/AIDS in west China. *International Journal of STD & AIDS*, *17*(5), 324–328.

Hughes, A. K., Luz, C., Hall, D., Gardner, P., Hennessey, C. W., & Lammers, L. (2016). Transformative theatre: A promising educational tool for improving health encounters with LGBT older adults. *Gerontology & Geriatrics Education, 37*, 292–306.

Hughes, T. M., Merath, K., Chen, Q., Sun, S., Palmer, E., Idrees, J., . . . Pawlik, T. M. (2018). Association of shared decision-making on patient-reported health outcomes and healthcare utilization. *The American Journal of Surgery, 216,* 7-12.

Ickovics, J. R., & Meade, C. S. (2002). Adherence to antiretroviral therapy among patients with HIV: A critical link between behavioral and biomedical sciences. *Journal of Acquired Immune Deficiency Syndromes (1999), 31*, 98–102.

Jackson, A. (Ed.). (2002). *Learning through theatre: New perspectives on theatre in education* (2nd ed.). New York, NY: Routledge.

Ji, G., Detels, R., Wu, Z., & Yin, Y. (2006). Correlates of HIV infection among former blood/plasma donors in rural China. *AIDS*, *20*(4), 585–591.

Ji, G., Qi, R., Wang, H., Feng, C., & Leng, J. (2010). A “planting and eating soybean” project for people living with HIV/AIDS in rural Anhui: A pilot study in China. *AIDS Care*, *22*(1), 126–132.

Johnson, M., Samarina, A., Xi, H., Valdez Ramalho Madruga, J., Hocqueloux, L., Loutfy, M., . . . Martinez, M. (2015). Barriers to access to care reported by women living with HIV across 27 countries. *AIDS Care*, *27*(10), 1220–1230.

Jones, E. (2014). Neuro psychiatry 1943: The role of documentary film in the dissemination of medical knowledge and promotion of the UK psychiatric profession. *Journal of the History of Medicine and Allied Sciences*, *69*(2), 294–324.

Joronen, K., Rankin, S., & Astedt-Kurki, P. (2008). School-based drama intervention in health promotion for children and adolescents: Systematic review. *Journal of Advanced Nursing*, *63*(2), 116–131.

Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: You got to go where he lives. *Journal of the American Medical Association*, *286*(23), 2993–3001.

Kagawa-Singer, M., & Wellisch, D. K. (2003). Breast cancer patients' perceptions of their husbands' support in a cross-cultural context. *Psycho*‐*Oncology*, *12*(1), 24–37

Kalichman, S. C., & Simbayi, L. C. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, *79*, 442–447.

Kalichman, S. C., Simbayi, L. C., Cloete, A., Mthembu, P. P., Mkhonta, R. N., & Ginindza, T. (2009). Measuring AIDS stigmas in people living with HIV/AIDS: The Internalized AIDS-Related Stigma Scale. *AIDS Care*, *21*(1), 87–93.

Katz, M. H., Cunningham, W. E., Mor, V., Andersen, R. M., Kellogg, T., Zierler, S., . . . Shapiro, M. F. (2000). Prevalence and predictors of unmet need for supportive services among HIV-infected persons: Impact of case management. *Medical Care*, *38*(1), 58–69.

Katz, I. T., Ryu, A. E., Onuegbu, A. G., Psaros, C., Weiser, S. D., Bangsberg, D. R., & Tsai, A. C.(2013). Impact of HIV-related stigma on treatment adherence: Systematic review and meta-synthesis. *Journal of the International AIDS Society*, *16*(2), 18640.

Keen, S., & Todres, L. (2007). Strategies for disseminating qualitative research findings: Three exemplars. *Forum: Qualitative Social Research*, *8*(3), 17.

Kelly, J. D., Hartman, C., Graham, J., Kallen, M. A., & Giordano, T. P. (2014). Social support as a predictor of early diagnosis, linkage, retention, and adherence to HIV care: Results from the steps study. *Journal of the Association of Nurses in AIDS Care, 25*(5), 405–413.

Kelman, H. C. (1961). Processes of opinion change. *Public Opinion Quarterly*, *25*, 57–78.

Kevelighan, E. H., Duffy, S., & Walker, J. J. (1998). Innovations in teaching obstetrics and gynaecology-the Theme Afternoon. *Medical, 32*, 517–521.

Kilbourne, A. M., Andersen, R. M., Asch, S., Nakazono, T., Crystal, S., Stein, M., . . . Cunningham, W. E. (2002). Response to symptoms among a U.S. national probability sample of adults infected with human immunodeficiency virus. *Medical Care Research and Review*, *59*(1), 36–58.

Kim, H. S., Sherman, D. K., Ko, D., & Taylor, S. E. (2006). Pursuit of comfort and pursuit of harmony: Culture, relationships, and social support seeking. *Personality and Social Psychology Bulletin*, *32*(12), 1595–1607.

Kim, H. S., Sherman, D. K., & Taylor, S. E. (2008). Culture and social support. *American Psychologist*, *63*(6), 518–526.

Kim, U. E., Triandis, H. C., Kâğitçibaşi, Ç. E., Choi, S. C. E., & Yoon, G. E. (1994). *Individualism and collectivism: Theory, method, and applications*. Thousand Oaks, CA: Sage Publications.

Kincaid, D. L., Yun, S. H., Piotrow, P. T., & Yaser, Y. (1993). Turkeys mass media family planning campaign. In T. E. Backer & E. M. Rogers (Eds.), *Organizational aspects of health communication campaigns: What works?* (pp. 68-92). Thousand Oaks, CA: Sage Publications, Inc.

Kinsler, J. J., Wong, M. D., Sayles, J. N., Davis, C., & Cunningham, W. E. (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care and STDs*, *21*(8), 584–592.

Kitayama, S., & Markus, H. R. (1994). *Emotion and culture: Empirical studies of mutual influence*. Washington, DC: American Psychological Association.

Knowlton, A. R., Arnsten, J. H., Gourevitch, M. N., Eldred, L., Wilkinson, J. D., Rose, C. D., . . . INSPIRE Study Team. (2007). Microsocial environmental influences on highly active antiretroviral therapy outcomes among active injection drug users: The role of informal caregiving and household factors. *Journal of Acquired Immune Deficiency Syndromes*, *46*, 110–119.

Knowlton, A. R., Hua, W., & Latkin, C. (2005). Social support networks and medical service use among HIV-positive injection drug users: Implications to intervention. *AIDS Care*, *17*(4), 479–492.

Kopnisky, K. L., Stoff, D. M., & Rausch, D. M. (2004). Workshop report: The effects of psychological variables on the progression of HIV-1 disease. *Brain, Behavior, and Immunity*, *18*(3), 246–261.

Krousel-Wood, M., Islam, T., Muntner, P., Holt, E., Joyce, C., Morisky, D. E., . . . Frohlich, E. D. (2010). Association of depression with antihypertensive medication adherence in older adults: Cross-sectional and longitudinal findings from CoSMO. *Annals of Behavioral Medicine*, *40*(3), 248–257.

Kulesza, M., Larimer, M. E., & Rao, D. (2013). Substance use related stigma: What we know and the way forward. *Journal of Addictive Behaviors, Therapy & Rehabilitation*, *2*(2), 782.

Kurtz, S. P., Surratt, H. L., Kiley, M. C., & Inciardi, J. A. (2005). Barriers to health and social services for street-based sex workers. *Journal of Health Care for the Poor and Underserved*, *16*(2), 345–361.

Laird, N. M., & Ware, J. H. (1982). Random-effects models for longitudinal data. *Biometrics*, *38*(4), 963–974.

Lam, P. K., Naar-King, S., & Wright, K. (2007). Social support and disclosure as predictors of mental health in HIV-positive youth. *AIDS Patient Care and STDs*, *21*(1), 20–29.

Lan, C. W., Li, L., Lin, C., Feng, N., & Ji, G. (2016). Community disclosure by people living with HIV in rural China. *AIDS Education and Prevention*, *28*(4), 287–298.

Lane, T., Mogale, T., Struthers, H., McIntyre, J., & Kegeles, S. M. (2008). “They see you as a different thing”: The experiences of men who have sex with men with healthcare workers in South African township communities. *Sexually Transmitted Infections*, *84*(6), 430–433.

Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: A conceptual analysis. *Journal of Advanced Nursing*, *25*(1), 95–100.

Latalova, K., Kamaradova, D., & Prasko, J. (2014). Perspectives on perceived stigma and self-stigma in adult male patients with depression. *Neuropsychiatric Disease and Treatment*, *10*, 1399–1405.

Latkin, C. A., Vlahov, D. & Anthony, J. C. (1993). Socially desirable responding and self-reported HIV infection risk behaviors among intravenous drug users. *Addiction*, *88*, 517–526.

LaVeist, T. A., Nuru-Jeter, A., & Jones, K. E. (2003). The association of doctor-patient race concordance with health services utilization. *Journal of Public Health Policy*, *24*(3–4), 312–323.

Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior*, *6*(4), 309–319.

Leserman, J. (2003). HIV disease progression: Depression, stress, and possible mechanisms. *Biological Psychiatry*, *54*(3), 295–306.

Levene, H. (1960). Robust tests for equality of variances. *Contributions to Probability and Statistics*, *1*, 278–292.

Li, H., Ji, Y., & Chen, T. (2014). The roles of different sources of social support on emotional well-being among Chinese elderly. *PloS one*, *9*(3), e90051.

Li, L., Ji, G., Lin, C., Liang, L. J., & Lan, C. W. (2016). Antiretroviral therapy initiation following policy changes: Observations from China. *Asia Pacific Journal of Public Health*, *28*(5), 416–422.

Li, L., Ji, G., Liang, L. J., Lin, C., Hsieh, J., Lan, C. W., & Xiao, Y. (2017a). Efficacy of a multilevel intervention on the mental health of people living with HIV and their family members in rural China. *Health Psychology*, *36*(9), 863.

Li, L., Liang, L. J., Lin, C., Lan, C. W., Ji, G., & Xiao, Y. (2017b). Changes in behavioral outcomes among children affected by HIV: Results of a randomized controlled trial in China. *Journal of Health Psychology*.

Li, L., Wu, S., Wu, Z., Sun, S., Cui, H., & Jia, M. (2006). Understanding family support for people living with HIV/AIDS in Yunnan, China. *AIDS and Behavior*, *10*(5), 509–517.

Li, L., Wu, Z., Liang, L. J., Lin, C., Guan, J., Jia, M., . . . Yan, Z. (2013). Reducing HIV-related stigma in health care settings: A randomized controlled trial in China. *American Journal of Public Health*, *103*(2), 286–292.

Li, L., Lee, S. J., Thammawijaya, P., Jiraphongsa, C., & Rotheram-Borus, M. J. (2009). Stigma, social support, and depression among people living with HIV in Thailand. *AIDS Care*, *21*(8), 1007–1013.

Li, L., Liang, L. J., Lin, C., Wu, Z., Rotheram-Borus, M. J., & NIMH Collaborative HIV/STD Prevention Trial Group. (2010). HIV prevention intervention to reduce HIV-related stigma: Evidence from China. *AIDS*, *24*(1), 115–122.

Li, L., Lin, C., & Ji, G. (2016). Gendered aspects of perceived and internalized HIV-related stigma in China. *Women & Health*, 1–13.

Li, L., Liang, L. J., Lin, C., Ji, G., & Xiao, Y. (2017). Gender differences in depressive symptoms among HIV-positive concordant and discordant heterosexual couples in China. *Psychology of Women Quarterly*, *41*(1), 89–99.

Li, L., Liang, L. J., Lin, C., & Wu, Z. (2015). Addressing HIV stigma in protected medical settings. *AIDS Care*, *27*(12), 1439–1442.

Li, J., & Wang, J. (2012). Individuals are inadequate: Recognizing the family-centeredness of Chinese bioethics and Chinese health system. *Journal of Medicine and Philosophy*, *37*(6), 568–582.

Li, X., He, G., & Wang, H. (2007). Study of stigma and discrimination related to HIV and AIDS. *Chinese Journal of Nursing*, *42*, 78–80.

Li, X. M., Yuan, X. Q., Rasooly, A., Bussell, S., Wang, J. J., & Zhang, W. Y. (2018). An evaluation of impact of social support and caregiving on medication adherence of people living with HIV/AIDS: A non-randomized community intervention study. *Medicine*, *97*, 28.

Li, X., Wang, H., Williams, A., & He, G. (2009). Stigma reported by people living with HIV in south central China. *Journal of the Association of Nurses in AIDS Care*, *20*(1), 22–30.

Li, Y. N., Nong, D. X., Wei, B., Feng, Q. M., & Luo, H. Y. (2016). The impact of predisposing, enabling, and need factors in utilization of health services among rural residents in Guangxi, China. *BMC Health Services Research, 16*(1), 592.

Lieberman, L. D., Berlin, C., Palen, L. A., & Ashley, O. S. (2012). A theater-based approach to primary prevention of sexual behavior for early adolescents. *The Journal of Early Adolescence*, *32*(5), 730–753.

Lima, V. D., Johnston, K., Hogg, R. S., Levy, A. R., Harrigan, P. R., Anema, A., & Montaner, J. S. (2008). Expanded access to highly active antiretroviral therapy: A potentially powerful strategy to curb the growth of the HIV epidemic. *The Journal of Infectious Diseases*, *198*(1), 59–67.

Lima, V. D., Harrigan, R., Bangsberg, D. R., Hogg, R. S., Gross, R., Yip, B., & Montaner, J. S. G. (2009). The combined effect of modern highly active antiretroviral therapy regimens and adherence on mortality over time. *Journal of Acquired Immune Deficiency Syndrome*, *50*, 529–536.

Lima, V. D., Geller, J., Bangsberg, D. R., Patterson, T. L., Daniel, M., Kerr, T., . . . Hogg, R. S. (2007). The effect of adherence on the association between depressive symptoms and mortality among HIV-infected individuals first initiating HAART. *AIDS*, *21*(9), 1175–1183.

Lin, C., Li, L., Ji, G., & Jie, W. (2015). Emotional social support and access to care among older people living with HIV in rural China. *International Journal of Geriatric Psychiatry*, *30*(10), 1041–1047.

Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, *52*(1), 96–112.

Link, B., Castille, D. M., & Stuber, J. (2008). Stigma and coercion in the context of outpatient treatment for people with mental illnesses. *Social Science & Medicine*, *67*(3), 409–419.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*(1), 363–385.

Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, *30*(3), 511–541.

Little, R. J. (1995). Modeling the dropout mechanism in repeated-measures studies. *Journal of the American Statistical Association*, *90*(431), 1112–1121.

Liu, J. X., & Choi, K. (2006). Experiences of social discrimination among men who have sex with men in Shanghai, China. *AIDS and Behavior*, *10*, 25–33.

Liu, H., Dumenci, L., Morisky, D. E., Xu, Y., Li, X., & Jiang, B. (2016). Syphilis among middle-aged female sex workers in China: A three-site cross-sectional study. *BMJ open*, *6*, 5.

Liu, T., Hao, X., & Zhang, Z. (2016). Identifying community healthcare supports for the elderly and the factors affecting their aging care model preference: Evidence from three districts of Beijing. *BMC Health Services Research*, *16*(7), 626.

Liu, H., Hu, Z., Li, X., Stanton, B., Naar-King, S., & Yang, H. (2006). Understanding interrelationships among HIV-related stigma, concern about HIV infection, and intent to disclose HIV serostatus: A pretest-posttest study in a rural area of eastern China. *AIDS Patient Care & STDs, 20*(2), 133–142.

Liu, H., Lin, X., Xu, Y., Chen, S., Shi, J., & Morisky, D. (2012). Emerging HIV epidemic among older adults in Nanning, China. *AIDS Patient Care and STDs, 26*(10), 565–567.

Liu, D., Meng, H., Dobbs, D., Conner, K. O., Hyer, K., Li, N., . . . Gao, B. (2017). Cross-sectional study of factors associated with community health centre use in a recently urbanised community in Chengdu, China. *BMJ Open*, *7*(6), 1.

Liu, H., Xu, Y., Sun, Y., & Dumenci, L. (2014). Measuring HIV stigma at the family level: Psychometric assessment of the Chinese Courtesy Stigma Scales (CCSSs). *PloS One*, *9*:3.

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, *71*(12), 2150–2161.

Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: A systematic review. *Addiction*, *107*(1), 39–50.

Loo, R., & Thorpe, K. (2000). Confirmatory factor analyses of the full and short versions of the Marlowe-Crowne social desirability scale. *Journal of Social Psychology*, *140*(5), 628–635.

Loutfy, M., Tharao, W., Logie, C., Aden, M. A., Chambers, L. A., Wu, W., . . . Calzavara, L. (2015). Systematic review of stigma reducing interventions for African/Black diasporic women. *Journal of the International AIDS Society*, *18*, 1.

Loutfy, M. R., Wu, W., Letchumanan, M., Bondy, L., Antoniou, T., Margolese, S., . . . Rochon, P. A. (2013). Systematic review of HIV transmission between heterosexual serodiscordant couples where the HIV-positive partner is fully suppressed on antiretroviral therapy. *PloS One*, *8*, 2.

Lu, F., Wang, N., Wu, Z., Sun, X., Rehnstrom, J., Poundstone, K., . . . Pisani, E. (2006). Estimating the number of people at risk for and living with HIV in China in 2005: Methods and results. *Sexually Transmitted Infections*, *82*(Suppl. 3), 87–91.

Luoma, J. B., Twohig, M. P., Waltz, T., Hayes, S. C., Roget, N., Padilla, M., & Fisher, G. (2007). An investigation of stigma in individuals receiving treatment for substance abuse. *Addictive Behaviors*, *32*(7), 1331–1346.

Ma, Y., Li, Z. Z., Zhang, K. X., Yang, W. Q., Ren, X. H., Yang, Y. F., . . . Liu, S. Q. (1990). Identification of HIV infection among drug users in China. *Zhonghua Liu Xing Bing Xue Za Zhi*, *11*(184), 5.

Mak, W. W., Cheung, R. Y., Law, R. W., Woo, J., Li, P. C., & Chung, R. W. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV/AIDS. *Social Science & Medicine*, *64*(8), 1549–1559.

Mak, W. W., Mo, P. K., Ma, G. Y., & Lam, M. Y. (2017). Meta-analysis and systematic review of studies on the effectiveness of HIV stigma reduction programs. *Social Science & Medicine*, *188*, 30–40.

Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P., & Verrall, J. (1998). HIV-related stigmatization and discrimination: Its forms and contexts. *Critical Public Health*, *8*(4), 347–370.

Mallik, S., Krumholz, H. M., Lin, Z. Q., Kasl, S. V., Mattera, J. A., Roumains, S. A., & Vaccarino, V. (2005). Patients with depressive symptoms have lower health status benefits after coronary artery bypass surgery. *Circulation*, *111*(3), 271–277.

Mao, Y., Wu, Z., Poundstone, K., Wang, C., Qin, Q., Ma, Y., & Ma, W. (2010). Development of a unified web-based national HIV/AIDS information system in China. *International Journal of Epidemiology*, *39*(Suppl. 2), 79–89.

Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, *98*(2), 224–253.

Mbonu, N. C., Van den Borne, B., & De Vries, N. K. (2009). A model for understanding the relationship between stigma and healthcare-seeking behaviour among people living with HIV/AIDS in sub-Saharan Africa. *African Journal of AIDS Research*, *8*(2), 201–212.

Mburu, G., Ram, M., Skovdal, M., Bitira, D., Hodgson, I., Mwai, G. W., . . . Seeley, J. (2013). Resisting and challenging stigma in Uganda: The role of support groups of people living with HIV. *Journal of the International AIDS Society*, *16*(3), 18636.

McBride, C. A. (1998). The discounting principle and attitudes toward victims of HIV Infection. *Journal of Applied Social Psychology*, *28*(7), 595–608.

McCoy, S. I., Strauss, R. P., MacDonald, P. D., Leone, P. A., Eron, J. J., & Miller, W. C. (2009). Social support and delays seeking care after HIV diagnosis, North Carolina, 2000–2006. *AIDS Care*, *21*(9), 1148–1156.

McEwan, R., Bhopal, R., & Patton, W. (1991). Drama on HIV and AIDS: An evaluation of a theatre-in-education programme. *Health Education Journal*, *50*, 155–160.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, *15*(4), 351–377.

McNeish, D., & Kelley, K. (2018). Fixed effects models versus mixed effects models for clustered data: Reviewing the approaches, disentangling the differences, and making recommendations. *Psychological Methods*.

McNeish, D. M., & Stapleton, L. M. (2016). The effect of small sample size on two-level model estimates: A review and illustration. *Educational Psychology Review*, *28*(2), 295–314.

Meessen, B., & Bloom, G. (2007). Economic transition, institutional changes and the health system: Some lessons from rural China. *Journal of Economic Policy Reform*, *10*(3), 209–231.

Meng, Q., & Xu, K. (2014). Progress and challenges of the rural cooperative medical scheme in China. *Bulletin of the World Health Organization*, *92*(6), 447–451.

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, *129*, 674–697.

Michalak, E. E., Livingston, J. D., Maxwell, V., Hole, R., Hawke, L. D., & Parikh, S. V. (2014). Using theatre to address mental illness stigma: a knowledge translation study in bipolar disorder. *International Journal of Bipolar Disorders*, *2*(1), 1.

Mienczakowski, J. (1999). Ethnography in the hands of participants: Tools of dramatic discovery. In G. Walford & A. Massey (Eds.), *Explorations in methodology* (pp. 145–161). Bingley, England: Emerald Group Publishing Limited.

Mienczakowski, J., Smith, L., & Morgan, S. (2002). Seeing words-Hearing feelings: Ethnodrama and the performance of data. In C. Bagley & B. Cancienne (Eds.), *Dancing the data* (pp. 34–52). New York, NY: Peter Lang.

Miller, J. G., Bersoff, D. M., & Harwood, R. L. (1990). Perceptions of social responsibilities in India and in the United States: Moral imperatives or personal decisions? *Journal of Personality and Social Psychology*, *58*(1), 33–47.

Miller-Day, M., & Hecht, M. L. (2013). Narrative means to preventative ends: A narrative engagement framework for designing prevention interventions. *Health Communication*, *28*(7), 657–670.

Ministry of Health, People's Republic of China. (2006). 2005 Update on the HIV/AIDS epidemic and response in China. Retrieved from http://data.unaids.org/publications/external-documents/rp_2005chinaestimation_25jan06_en.pdf

Ministry of Health, People’s Republic of China. (2010). China 2010 UNGASS country progress report (2008–2009). Retrieved from http://www.unaids.org/en/KnowledgeCentre/HIVData/CountryProgress/2010CountryProgressAllCountries.asp

Mitchell, S.K., Kelly, K.J.M., Potgieter, F.E. & Moon, M.W. (2007). Assessing social preparedness for antiretroviral therapy in a generalised AIDS epidemic: A diffusion of innovation approach. *AIDS Behavior*, *13*(1), 76–84.

Mo, P. K., & Ng, C. T. (2017). Stigmatization among people living with HIV in Hong Kong: A qualitative study. *Health Expectations*, *20*(5), 943–951.

Molassiotis, A., Chan, C. W. H., Yam, B. M. C., & Chan, S. J. (2000). Quality of life in Chinese women with gynaecological cancers. *Supportive Care in Cancer*, *8*(5), 414–422.

Morisky, D. E., Ang, A., & Sneed, C. D. (2002). Validating the effects of social desirability on self-reported condom use behavior among commercial sex workers. *AIDS Education and Prevention*, *14*(5), 351–360.

Moser, A., Stuck, A. E., Silliman, R. A., Ganz, P. A., & Clough-Gorr, K. M. (2012). The eight-item modified Medical Outcomes Study Social Support Survey: Psychometric evaluation showed excellent performance. *Journal of Clinical Epidemiology*, *65*(10), 1107–1116.

Moyer-Gusé, E., & Nabi, R. L. (2010). Explaining the effects of narrative in an entertainment television program: Overcoming resistance to persuasion. *Human Communication Research*, *36*(1), 26–52.

Mudimbe, V. Y. (1988). *The invention if Africa: Gnosis, philosophy, and the order of knowledge*. Bloomington, IN: Indiana University Press.

Mugglin, C., Estill, J., Wandeler, G., Bender, N., Egger, M., Gsponer, T., & Keiser, O. (2012). Loss to programme between HIV diagnosis and initiation of antiretroviral therapy in sub-Saharan Africa: Systematic review and meta-analysis. *Tropical Medicine & International Health*, *17*(12), 1509–1520.

Mugoya, G. C., & Ernst, K. (2014). Gender differences in HIV-related stigma in Kenya. *AIDS Care, 26*(2), 206–213.

Muller, J. H., & Desmond, B. (1992). Ethical dilemmas in a cross-cultural context: A Chinese example. *Western Journal of Medicine*, *157*(3), 323–327.

Muñoz, M., Bayona, J., Sanchez, E., Arevalo, J., Sebastian, J. L., Arteaga, F., . . . Caldas, A. (2011). Matching social support to individual needs: A community-based intervention to improve HIV treatment adherence in a resource-poor setting. *AIDS and Behavior, 15*(7), 1454–1464.

Murphy, D. A., Austin, E. L., & Greenwell, L. (2007). Correlates of HIV-related stigma among HIV-positive mothers and their uninfected adolescent children. *Women & Health*, *44*(3), 19–42.

Myers, H. F. (1996). The social resources and social supports questionnaire: A multidimensional inventory. *Handbook of Tests and Measures for Black Populations*, *2*, 427–441.

Nambiar, D., Ramakrishnan, V., Kumar, P., Varma, R., Balaji, N., Rajendran, J., . . . Gere, D. (2011). Knowledge, stigma, and behavioral outcomes among antiretroviral therapy patients exposed to Nalamdana's radio and theater program in Tamil Nadu, India. *AIDS Education and Prevention*, *23*(4), 351–366.

National Health and Family Planning Commission of the People's Republic of China. (2015). 2015 China AIDS response progress report. Retrieved from http://www.unaids.org/sites/default/files/country/documents/CHN_narrative_report_2015.pdf

National Population and Family Planning Commission of China. Vital Statistics. (2017). Retrieved from http://en.nhfpc.gov.cn/

Nelkin, D., & Gilman, S. L. (1988). Placing blame for devastating disease. *Social Research*, *55*(3), 361–378.

Nelson, T. D. (Ed.). (2009). *Handbook of prejudice, stereotyping, and discrimination*. Routledge, NY: Psychology Press.

Neter, J., Wasserman, W., & Kutner, M. H. (1989). *Applied linear regression models*. New York, NY: McGraw-Hill Education.

Noar, S.M., Palmgreen, P., Chabot, M., Dobransky, N. & Zimmerman, R.S. (2009). A 10-year systematic review of HIV/AIDS mass communication campaigns: Have we made progress? *Journal of Health Communication, 14*, 15–42.

Noone, J., Castillo, N., Allen, T. L., & Esqueda, T. (2015). Latino teen theater: A theater intervention to promote Latino parent-adolescent sexual communication. *Hispanic Health Care International*, *13*(4), 209–216.

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.

Nyblade, L. C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health & Medicine, 11*(3), 335–345.

Nyblade, L., Hong, K. T., Anh, N. V., Ogden, J., Jain, A., Stangl, A., . . . Ashburn, K. (2008). Communities confront HIV stigma in Viet Nam: Participatory interventions reduce HIV stigma in two provinces. Washington, DC: International Center for Research on Women.

Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H. (2003). *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*, Washington, DC: International Center for Research on Women.

Ogden, J. and Nyblade, L. (2005). *Common at its core: HIV-related stigma across contexts*. Washington, DC: International Center for Research on Women.

Ojeda, V. D., & McGuire, T. G. (2006). Gender and racial/ethnic differences in use of outpatient mental health and substance use services by depressed adults. *Psychiatric Quarterly*, *77*(3), 211–222.

Oyewumi, O. (1997*). The invention of women: Making an African sense of western gender discourse.* Minneapolis, MN: University of Minnesota Press.

Pang, S. K., Ip, W. Y., & Chang, A. M. (2001). Psychosocial correlates of fluid compliance among Chinese haemodialysis patients. *Journal of Advanced Nursing*, *35*(5), 691–698.

Park, P. (Ed.). (1993). *Voices of change: Participatory research in the United States and Canada*. Santa Barbara, CA: Praeger.

PEPFAR. (2012). *PEPFAR blueprint: Creating an AIDS-Free generation*. Washington, DC: The Office of the Global AIDS Coordinator. Retrieved from https://www.pepfar.gov/documents/organization/201386.pdf

Petros, G., Airhihenbuwa, C. O., Simbayi, L., Ramlagan, S., & Brown, B. (2006). HIV/AIDS and 'othering' in South Africa: The blame goes on. *Culture, Health & Sexuality*, *8*(1), 67–77.

Phelan, P. (1993). *Unmarked: The politics of performance*. New York, NY: Routledge.

Phillips, J. L., Rolley, J. X., & Davidson, P. M. (2012). Developing targeted health service interventions using the PRECEDE-PROCEED model: Two Australian case studies. *Nursing Research and Practice*, *2012*, 2179431.

Piotrow, P. T., Kincaid, D. L., Rimon, J. G., Rinehart, W., & Samson, K. (1997). *Health communication: Lessons from family planning and reproductive health*. Westport, CT: Praeger.

Polednak, A. P. (1997). *Segregation, poverty, and mortality in urban African Americans*. New York, NY: Oxford University Press.

Pressley, M., Harris, K. R., & Marks, M. B. (1992). But good strategy instructors are constructivists! *Educational Psychology Review*, *4*(1), 3–31.

Preston, D. B., D'Augelli, A. R., Kassab, C. D., Cain, R. E., Schulze, F. W., & Starks, M. T. (2004). The influence of stigma on the sexual risk behavior of rural men who have sex with men. *AIDS Education and Prevention*, *16*(4), 291-303.

Pryor, J. B., & Reeder, G. D. (2011). HIV-related stigma. In J. C. Hall, B. J. Hall, & C. J. Cockerell (Eds.), *HIV/AIDS in the post-HAART era: Manifestations, treatment, and epidemiology* (pp. 790–806). Shelton, CT: People’s Medical Publishing House.

Qian, H. Z., Wang, N., Dong, S., Chen, H., Zhang, Y., Chamot, E., . . . Shao, Y. (2007). Association of misconceptions about HIV transmission and discriminatory attitudes in rural China. *AIDS Care, 19*(10), 1283–1287.

Rajabiun, S., Mallinson, R. K., McCoy, K., Coleman, S., Drainoni, M. L., Rebholz, C., & Holbert, T. (2007). “Getting me back on track”: The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. *AIDS Patient Care and STDs*, *21*(Suppl. 1), S-20.

Rao, D., Chen, W. T., Pearson, C. R., Simoni, J. M., Fredriksen-Goldsen, K., Nelson, K., . . . Zhang, F. (2012). Social support mediates the relationship between HIV stigma and depression/quality of life among people living with HIV in Beijing, China. *International Journal of STD & AIDS*, *23*(7), 481–484.

Rao, D., Kekwaletswe, T. C., Hosek, S., Martinez, J., & Rodriguez, F. (2007). Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*, *19*(1), 28–33.

Raudenbush, S. W., & Bryk, A. S. (2002). *Hierarchical linear models: Applications and data analysis methods* (Vol. 1). Thousand Oaks, CA: SAGE Publications.

Reblin, M., Cloyes, K. G., Carpenter, J., Berry, P. H., Clayton, M. F., & Ellington, L. (2015). Social support needs: Discordance between home hospice nurses and former family caregivers. *Palliative & Supportive Care*, *13*(3), 465–472.

Reidpath, D. D., & Chan, K. Y. (2005). A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, *17*(4), 425–432.

Reif, S., Golin, C. E., & Smith, S. R. (2005). Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care*, *17*(5), 558–565.

Reif, S., Whetten, K., Lowe, K., & Ostermann, J. (2006). Association of unmet needs for support services with medication use and adherence among HIV-infected individuals in the southeastern United States. *AIDS Care*, *18*(4), 277–283.

Rhodes, S. D., Hergenrather, K. C., Wilkin, A. M., & Jolly, C. (2008). Visions and voices: Indigent persons living with HIV in the southern United States use photovoice to create knowledge, develop partnerships, and take action. *Health Promotion Practice*, *9*(2), 159–169.

Riley, E. D., Wu, A. W., Junge, B., Marx, M., Strathdee, S. A., & Vlahov, D. (2002). Health services utilization by injection drug users participating in a needle exchange program. *The American Journal of Drug and Alcohol Abuse*, *28*(3), 497–511.

Rintamaki, L. S., Davis, T. C., Skripkauskas, S., Bennett, C. L., & Wolf, M. S. (2006). Social stigma concerns and HIV medication adherence. *AIDS Patient Care & STDs*, *20*(5), 359–368.

Roberts, R. O., Bergstralh, E. J., Schmidt, L., & Jacobsen, S. J. (1996). Comparison of self-reported and medical record health care utilization measures. *Journal of Clinical Epidemiology*, *49*(9), 989–995.

Rolfe, A., Mienczakowski, J., & Morgan, S. (1995). A dramatic experience in mental health nursing education. *Nurse Education Today*, *15*(3), 224–227.

Rosenbaum, M. E., Ferguson, K. J., & Herwaldt, L. A. (2005). In their own words: Presenting the patients’ perspective using research-based theatre. *Medical Education*, *39*(6), 622–631.

Rosenberg, M. (1968). *The logic of survey analysis*. New York, NY: Basic Books.

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs*, *2*(4), 328–335.

Rosler, M. (1989). In, around, and afterthoughts (on documentary photography). In R. Bolton (Ed.), *The context of meaning: Critical histories of photography* (pp. 303–341). Cambridge, MA: The MIT Press.

Ross, M. W., Timpson, S. C., Williams, M. L., Amos, C., McCurdy, S., Bowen, A. M., & Kilonzo, G. P. (2007). Responsibility as a dimension of HIV prevention normative beliefs: Measurement in three drug-using samples. *AIDS care*, *19*(3), 403–409.

Rossiter, K., Kontos, P., Colantonio, A., Gilbert, J., Gray, J., & Keightley, M. (2008). Staging data: Theatre as a tool for analysis and knowledge transfer in health research. *Social Science & Medicine*, *66*(1), 130–146.

Rounds, K. A., Galinsky, M. J., & Despard, M. R. (1995). Evaluation of telephone support groups for persons with HIV disease. *Research on Social Work Practice*, *5*(4), 442–459.

Rubin, D. B. (1976). Inference and missing data. *Biometrika*, *63*(3), 581–592.

Ryan, R. M., & Connell, J. P. (1989). Perceived locus of causality and internalization: Examining reasons for acting in two domains. *Journal of Personality and Social Psychology*, *57*, 749–761.

Said, E. W. (1978). *Orientalism: Western representations of the Orient*. New York, NY: Pantheon. Said, E. W. (1993). Overlapping territories, intertwined Histories. *Culture and Imperialism.* London, England: Vintage.

Saint-Jean, G., Metsch, L., Gomez-Marin, O., Pierre, C., Jeanty, Y., Rodriguez, A., & Malow, R. (2011). Use of HIV primary care by HIV-positive Haitian immigrants in Miami, Florida. *AIDS Care*, *23*, 486–493.

Saldaña, J. (1999). Playwriting with data: Ethnographic performance texts. *Youth Theatre Journal*, *13*(1), 60–71.

Saldaña (2005). *Ethnodrama: An anthology of reality theatre*. Walnut Creek: AltaMira Press.

Saldaña, J. (2011). *Ethnotheatre: Research from page to stage*. Walnut Creek, CA: Left Coast Press.

Santos, J. R. A. (1999). Cronbach's alpha: A tool for assessing the reliability of scales. *Journal of Extension*, *37*(2), 1–5.

SAS Institute. (2017). *Base SAS 9.4 Procedures Guide* (7th ed.). Cary, NC: SAS Institute Inc.

Sayles, J. N., Wong, M. D., Kinsler, J. J., Martins, D., & Cunningham, W. E. (2009). The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *Journal of General Internal Medicine*, *24*(10), 1101–1108.

Schaedler, M. T. (2010). Boal's *Theater of the Oppressed* and how to derail real-life tragedies with imagination. *New Directions for Youth Development*, *125*, 141–151.

Schechner, R. (1990). Behavior, performance, and performance space. *Perspecta*, *26*, 97–102.

Schechner, R. (2017). *Performance studies: An introduction*. Abingdon, England: Routledge.

Schuster, M. A., Collins, R., Cunningham, W. E., Morton, S. C., Zierler, S., Wong, M., . . . Kanouse, D. E. (2005). Perceived discrimination in clinical care in a nationally representative sample of HIV-infected adults receiving health care. *Journal of General Internal Medicine*, *20*(9), 807–813.

Schwartländer, B., Stover, J., Hallett, T., Atun, R., Avila, C., Gouws, E., . . . Alsallaq, R. (2011). Towards an improved investment approach for an effective response to HIV/AIDS. *The Lancet*, *377*(9782), 2031–2041.

Selener, D. (1997). Participatory action research and social change. *The Cornell Participatory Action Research Network*. Ithaca, NY: Cornell University Press.

Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior*, *15*(6), 1075–1087.

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, *32*(6), 705–714.

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

Simoni, J. M., Safren, S. A., Manhart, L. E., Lyda, K., Grossman, C. I., Rao, D., . . . DiClemente, R. (2011). Challenges in addressing depression in HIV research: Assessment, cultural context, and methods. *AIDS and Behavior*, *15*(2), 376–388.

Singhal, A., & Rogers, E. (2012). *Entertainment-education: A communication strategy for social change*. Abingdon, England: Routledge.

Slomka, J., Lim, J. W., Gripshover, B., & Daly, B. (2013). How have long-term survivors coped with living with HIV? *Journal of the Association of Nurses in AIDS Care*, *24*(5), 449–459.

Smith, S. R., & Kirking, D. M. (1999). Access and use of medications in HIV disease. *Health Services Research*, *34*(1), 123–144.

Smith, D. J., & Mbakwem, B. C. (2010). Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria. *Social Science & Medicine*, *71*, 345–352.

Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care*, *20*(10), 1266–1275.

Snijders, T. A., & Bosker, R. J. (1993). Standard errors and sample sizes for two-level research. *Journal of Educational Statistics*, *18*(3), 237–259.

Snijders, T. A., & Bosker, R. J. (2012). *Multilevel analysis: An introduction to basic and advanced multilevel modeling* (2nd ed.). London, England: SAGE Publications.

Sobel, M. E. (1982). Aysmptotic confidence intervals for indirect effects in structural equation models. In S. Leinhardt (Ed.), *Sociological Methodology* (pp. 290–212). San Francisco, CA: Jossey-Boss.

Spivak, G. (1988). Can the subaltern speak? In C. Nelson & L. Grossberg (Eds.), *Marxism and the interpretation of culture* (pp. 272–285). Urbana, IL: University of Illinois Press.

Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society*, *16*(2), 18734.

Strasburger, V. C., Wilson, B. J., & Jordan, A. B. (2009). *Children, adolescents, and the media*. Thousand Oaks, CA: SAGE Publications.

State Council AIDS Working Committee Office, UN Theme Group on HIV/AIDS in China. (2003). A joint assessment of HIV/AIDS prevention, treatment, and care in China. Retrieved from http://data.unaids.org/una-docs/china_joint_assessment_2003_en.pdf

Stiratelli, R., Laird, N., & Ware, J. H. (1984). Random-effects models for serial observations with binary response. *Biometrics*, *40*(4), 961–971.

Stutterheim, S. E., Pryor, J. B., Bos, A. E., Hoogendijk, R., Muris, P., & Schaalma, H. P. (2009). HIV-related stigma and psychological distress: The harmful effects of specific stigma manifestations in various social settings. *AIDS*, *23*(17), 2353-2357.

Sun, Y. H., Sun, L., Wu, H. Y., Zhang, Z. K., Wang, B., Yu, C., & Cao, H. Y. (2009). Loneliness, social support and family function of people living with HIV/AIDS in Anhui rural area, China. *International Journal of STD & AIDS*, *20*(4), 255–258.

Sungkanuparph, S., Manosuth, W., Kiertiburanakul, S., Piyavong, B., Chumpathat, N., & Chantratita, W. (2007). Options for a second-line antiretroviral regimen for HIV type 1-

infected patients whose initial regimen of a fixed-dose combination of stavudine, lamivudine, and nevirapine fails. *Clinical Infectious Diseases*, *44*(3), 447–452.

Swendeman, D., Rotheram-Borus, M. J., Comulada, S., Weiss, R., & Ramos, M. E. (2006). Predictors of HIV-related stigma among young people living with HIV. *Health Psychology*, *25*(4), 501–509.

Talley, A. E., & Bettencourt, B. A. (2010). A relationship-oriented model of HIV-related stigma derived from a review of the HIV-affected couples literature. *AIDS and Behavior*, *14*(1), 72–86.

Taylor, D. (2003). Acts of transfer. *The Archive and the Repertoire: Performing cultural memory in the Americas*. Durham, NC: Duke University Press.

Taylor, J., Namey, E., Carrington Johnson, A., & Guest, G. (2017). Beyond the page: A process review of using ethnodrama to disseminate research findings. *Journal of Health Communication*, *22*(6), 532–544.

Taylor, S. E., Sherman, D. K., Kim, H. S., Jarcho, J., Takagi, K., & Dunagan, M. S. (2004). Culture and social support: Who seeks it and why? *Journal of Personality and Social Psychology*, *87*(3), 354–362.

Taylor, S. E., Welch, W. T., Kim, H. S., & Sherman, D. K. (2007). Cultural differences in the impact of social support on psychological and biological stress responses. *Psychological Science*, *18*(9), 831–837.

Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, 53–79.

Thompson, D. R., Ski, C. F., Watson, R., & Wang, W. (2014). Mokken scaling of the Chinese version of the medical outcomes study social support survey. *Quality of Life Research*, *23*(2), 581-584.

Tian, L. G., Chen, J. X., Wang, T. P., Cheng, G. J., Steinmann, P., Wang, F. F., . . . Zhou, X. N. (2012). Co-infection of HIV and intestinal parasites in rural area of China. *Parasites & Vectors*, *5*(1), 36.

Tian, M., Feng, D., Chen, X., Chen, Y., Sun, X., Xiang, Y., . . . Feng, Z. (2013). China’s rural public health system performance: A cross-sectional study. *PloS One*, *8*, 12.

Tsai, J. L., & Levenson, R. W. (1997). Cultural influences on emotional responding: Chinese American and European American dating couples during interpersonal conflict. *Journal of Cross-Cultural Psychology*, *28*(5), 600–625.

Tsai, A. C., Bangsberg, D. R., Kegeles, S. M., Katz, I. T., Haberer, J. E., Muzoora, C., . . . Weiser, S. D. (2013). Internalized stigma, social distance, and disclosure of HIV seropositivity in rural Uganda. *Annals of Behavioral Medicine*, *46*(3), 285–294.

Turan, J.M., Miller, S., Bukusi, E.A., Sande, J. & Cohen, C.R. (2008). HIV/AIDS and maternity care in Kenya: How fears of stigma and discrimination affect uptake and provision of labour and delivery services. *AIDS Care*, *20*(8), 938–945.

Turner, V. W. (1982). *From ritual to theatre: The human seriousness of play*. Cambridge, MA: Performing Arts Journal Publications.

Uchino, B. N. (2004). *Social support and physical health: Understanding the health consequences of relationships*. New Haven, CT: Yale University Press.

Ulett, K. B., Willig, J. H., Lin, H. Y., Routman, J. S., Abroms, S., Allison, J., . . . Mugavero, M. J. (2009). The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care and STDs*, *23*(1), 41–49.

Unge, C., Johansson, A., Zachariah, R., Some, D., Van Engelgem, I. A. M. E., & Ekstrom, A. M. (2008). Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya. *AIDS Care*, *20*(2), 146–149.

United Nations Program on HIV/AIDS. (2013). HIV in Asia and the Pacific. Retrieved from http://www.unaids.org/sites/default/files/media_asset/2013_HIV-Asia-Pacific_en_0.pdf

United Nations Program on HIV/AIDS. (2014). Reduction of HIV-related stigma and discrimination. Retrieved from http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf

United Nations Program on HIV/AIDS. (2015). Global AIDS response progress reporting 2015. Retrieved from http://www.unaids.org/sites/default/files/media_asset/JC2702_GARPR2015guidelines_en.pdf

United Nations Children’s Fund. (2014). HIV/AIDS and children. Retrieved from https://www.unicef.org/publicpartnerships/files/HIVAIDS_and_Children_2013_Thematic_Report.pdf

Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoae, L., . . . Holzemer, W. L. (2009). Evaluation of a health setting-based stigma intervention in five African countries. *AIDS Patient Care and STDs*, *23*(12), 1059–1066.

Valdiserri, R. O. (2002). HIV/AIDS stigma: An impediment to public health. *American Journal of Public Health*, *92*(3), 341–342.

Van Der Straten, A., Vernon, K. A., Knight, K. R., Gomez, C. A., & Padian, N. S. (1998). Managing HIV among serodiscordant heterosexual couples: Serostatus, stigma and sex. *AIDS Care*, *10*(5), 533–548.

Veiel, H. O. (1985). Dimensions of social support: A conceptual framework for research. *Social Psychiatry*, *20*(4), 156–162.

Vyavaharkar, M. V., Moneyham, L., & Corwin, S. (2008). Health care utilization: The experiences of rural HIV-positive African American women. *Journal of Health Care for the Poor and Underserved*, *19*(1), 294–306.

Vyavaharkar, M., Moneyham, L., Tavakoli, A., Phillips, K. D., Murdaugh, C., Jackson, K., & Meding, G. (2007). Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the southeastern United States. *AIDS Patient Care and STDs*, *21*(9), 667–680.

Waddell, E. N., & Messeri, P. A. (2006). Social support, disclosure, and use of antiretroviral therapy. *AIDS and Behavior*, *10*(3), 263–272.

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, *8*(2), 185–192.

Wang, L., Wang, N., Wang, L., Li, D., Jia, M., Gao, X., & Smith, K. (2009). The 2007 estimates for people at risk for and living with HIV in China: Progress and challenges. *Journal of Acquired Immune Deficiency Syndromes*, *50*, 414–418.

Wang, J., Wang, Z., Liu, J., Yue, Y., Yang, S., Huang, H., . . . Shao, Y. (2015). Efficacy and HIV drug resistance profile of second-line ART among patients having received long-term first-line regimens in rural China. *Scientific Reports*, *5*, 14823.

Wang, J., Wu, Y., Zhou, B., Zhang, S., Zheng, W., & Chen, K. (2009). Factors associated with non-use of inpatient hospital care service by elderly people in China. *Health & Social Care in the Community*, *17*(5), 476–484.

Wang, S. W., Shih, J. H., Hu, A. W., Louie, J. Y., & Lau, A. S. (2010). Cultural differences in daily support experiences. *Cultural Diversity and Ethnic Minority Psychology*, *16*(3), 413–420.

Wang, Z., Li, X., Chen, M., & Si, L. (2018). Social health insurance, healthcare utilization, and costs in middle-aged and elderly community-dwelling adults in China. *International Journal for Equity in Health*, *17*, 17.

Wei, C., Yan, H., Yang, C., Raymond, H. F., Li, J., Yang, H., . . . Stall, R. (2014). Accessing HIV testing and treatment among men who have sex with men in China: A qualitative study. *AIDS Care*, *26*(3), 372–378.

Weiss, M. G., & Kleinman, A. (1988). Depression in cross-cultural perspective: Developing a culturally informed model. In P. R. Dasen, J. W. Berry, & N. Sartorius (Eds.), *Cross-cultural research and methodology series* (Vol. 10). *Health and cross-cultural psychology: Toward applications* (pp. 179–206). Thousand Oaks, CA: SAGE Publications.

Weissman, M. M., Sholomskas, D., Pottenger, M., Prusoff, B. A., & Locke, B. Z. (1977). Assessing depressive symptoms in five psychiatric populations: A validation study. *American Journal of Epidemiology*, *106*(3), 203–214.

White, K., Haas, J. S., & Williams, D. R. (2012). Elucidating the role of place in health care disparities: The example of racial/ethnic residential segregation. *Health Services Research*, *47*, 1278–1299.

Williams, P. & Chrisman, L. (1994). Colonial discourse and post-colonial theory: An Introduction. In P. Williams & L. Chrisman (Eds.), *Colonial Discourse and Post-Colonial Theory: A Reader* (pp. 1–19). New York, NY: Columbia University Press.

Wines, Michael. (2010, August 31). In race move, China court to hear HIV case. *The New York Times.* Retrieved from https://www.nytimes.com/2010/09/01/world/asia/01china.html

Wingood, G. M., & DiClemente, R. J. (2000). Application of the theory of gender and power to examine HIV-related exposures, risk factors, and effective interventions for women. *Health Education & Behavior*, *27*(5), 539–565.

Wingood, G. M., DiClemente, R. J., Mikhail, I., McCree, D. H., Davies, S. L., Hardin, J. W., . . . & Saag, M. (2007). HIV discrimination and the health of women living with HIV. *Women & Health*, *46*(2–3), 99–112.

Wohl, A. R., Galvan, F. H., Myers, H. F., Garland, W., George, S., Witt, M., . . . Lee, M. L. (2011). Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? *AIDS and Behavior*, *15*(6), 1098–1110.

Wong, C. C., & Lu, Q. (2017). Match between culture and social support: Acculturation moderates the relationship between social support and well-being of Chinese American breast cancer survivors. *Quality of Life Research*, *26*(1), 73–84

Wong, W. C., Holroyd, E., & Bingham, A. (2011). Stigma and sex work from the perspective of female sex workers in Hong Kong. *Sociology of Health & Illness*, *33*(1), 50–65.

Wong, L. P., & Syuhada, A. N. (2011). Stigmatization and discrimination towards people living with or affected by HIV/AIDS by the general public in Malaysia. *Southeast Asian Journal of Tropical Medicine and Public Health*, *42*(5), 1119–1129.

World Health Organization. (2015). The Zung self-rating depression scale. Retrieved from http://www.who.int/substance_abuse/research_tools/zungdepressionscale/en/

World Health Organization. (1981). Development of indicators for monitoring progress towards health for all by the year 2000. Retrieved from http://apps.who.int/iris/bitstream/handle/10665/40672/9241800046.pdf?sequence=1&isAllowed=y

Wu, X., Chen, J., Huang, H., Liu, Z., Li, X., & Wang, H. (2015). Perceived stigma, medical social support and quality of life among people living with HIV/AIDS in Hunan, China. *Applied Nursing Research*, *28*(2), 169–174.

Wu, Z., Liu, Z., & Detels, R. (1995). HIV-1 infection in commercial plasma donors in China. *Lancet*, *346*(8966), 61–62.

Wu, Z., Rou, K., & Detels, R. (2001). Prevalence of HIV infection among former commercial plasma donors in rural eastern China. *Health Policy and Planning*, *16*(1), 41–46.

Wu, Z., Rou, K., & Cui, H. (2004). The HIV/AIDS epidemic in China: History, current strategies and future challenges. *AIDS Education and Prevention*, *16*(Suppl. A), 7–17.

Wu, Z., Sullivan, S. G., Wang, Y., Rotheram-Borus, M. J., & Detels, R. (2007). Evolution of China's response to HIV/AIDS. *The Lancet*, *369*(9562), 679–690.

Wu, Z., Wang, Y., Detels, R., & Rotheram-Borus, M. J. (2010). China AIDS policy implementation: Reversing the HIV/AIDS epidemic by 2015. *International Journal of Epidemiology, 39*(Suppl. 2), 1–3.

Xie, T., Yang, J. P., Simoni, J. M., Shiu, C. S., Chen, W. T., Zhao, H., & Lu, H. (2017). Unable to be a human being in front of other people: A qualitative study of self-isolation among people living with HIV/AIDS in China. *Journal of Clinical Psychology in Medical Settings*, *24*(3–4), 211–222.

Xu, J., Sullivan S.G., Dou Z., & Wu Z. (2007). Economic stress and HIV-associated health care utilization in a rural region of China: A qualitative study. *AIDS Patient Care and STDs, 21*, 787–798.

Xu, J. F., Ming, Z. Q., Zhang, Y. Q., Wang, P. C., Jing, J., & Cheng, F. (2017). Family support, discrimination, and quality of life among ART-treated HIV-infected patients: A two-year study in China. *Infectious Diseases of Poverty*, *6*(1), 152.

Yang, J. P., Leu, J., Simoni, J. M., Chen, W. T., Shiu, C. S., & Zhao, H. (2015). "Please don't make me ask for help": Implicit social support and mental health in Chinese individuals living with HIV. *AIDS and Behavior*, *19*(8), 1501–1509.

Yang, Y., Zhang, K. L., Chan, K. Y., & Reidpath, D. D. (2005). Institutional and structural forms of HIV-related discrimination in health care: A study set in Beijing. *AIDS Care*, *17*(2), 129–140.

Yang, Y., & Zhang, K. L. (2004). HIV/AIDS-related discrimination in Shanxi rural areas of China. *Biomedical and Environmental Science*, *17*(4), 410–417.

Yip, W., Subramanian, S. V., Mitchell, A. D., Lee, D. T., Wang, J., & Kawachi, I. (2007). Does social capital enhance health and well-being? Evidence from rural China. *Social Science & Medicine*, *64*(1), 35–49.

Yip, W. C. M., Hsiao, W. C., Chen, W., Hu, S., Ma, J., & Maynard, A. (2012). Early appraisal of China's huge and complex health-care reforms. *The Lancet*, *379*(9818), 833–842.

Yoshioka, M. R., & Schustack, A. (2001). Disclosure of HIV status: Cultural issues of Asian patients. *AIDS Patient Care and STDs*, *15*(2), 77–82.

Young, M., Stuber, J., Ahern, J., & Galea, S. (2005). Interpersonal discrimination and the health of illicit drug users. *The American Journal of Drug and Alcohol Abuse*, *31*(3), 371–391.

Yu, D. S., Lee, D. T., & Woo, J. (2004a). Issues and challenges of instrument translation. *Western Journal of Nursing Research*, *26*(3), 307–320.

Yu, D. S., Lee, D. T., & Woo, J. (2004b). Psychometric testing of the Chinese version of the medical outcomes study social support survey (MOS-SSS-C). *Research in Nursing & Health*, *27*(2), 135–143.

Yu, Y. J., Li, X., Qiao, S., & Zhou, Y. (2016). Family relations in the context of HIV/AIDS in Southwest China. *AIDS Care*, *28*(10), 1261–1268.

Yu, Y., Yang, J. P., Shiu, C. S., Simoni, J. M., Xiao, S., Chen, W. T., . . . Wang, M. (2015). Psychometric testing of the Chinese version of the Medical Outcomes Study Social Support Survey among people living with HIV/AIDS in China. *Applied Nursing Research*, *28*(4), 328–333.

Zang, C., Guida, J., Sun, Y., & Liu, H. (2014). Collectivism culture, HIV stigma and social network support in Anhui, China: A path analytic model. *AIDS Patient Care and STDs*, *28*(8), 452–458.

Zeng, J., Pang, X., Zhang, L., Medina, A., & Rozelle, S. (2014). Gender inequality in education in China: A meta-regression analysis. *Contemporary Economic Policy*, *32*(2), 474–491.

Zhang, C., Li, X., Liu, Y., Qiao, S., Zhang, L., Zhou, Y., . . . Chen, Y. (2016). Stigma against people living with HIV/AIDS in China: Does the route of infection matter? *PloS One*, *11,* 3.

Zhang, L., Chow, E. P. F., Zhang, J., Jing, J., & Wilson, D. P. (2012). Describing the Chinese HIV surveillance system and the influences of political structures and social stigma. *The Open AIDS Journal*, *6*, 163–168.

Zhang, F., Haberer, J. E., Wang, Y., Zhao, Y., Ma, Y., Zhao, D., . . . Goosby, E. P. (2007). The Chinese free antiretroviral treatment program: Challenges and responses. *AIDS*, *21,* 143–148.

Zhang, Y., Fuller-Thomson, E., Mitchell, C. A., & Zhang, X. (2013). Older adults with HIV/AIDS in rural China. *The Open AIDS Journal*, *7*, 51–57.

Zhang, Y. J., Fan, Y. G., Dai, S. Y., Li, B. Z., Xu, W. D., Hu, L. F., . . . Ye, D. Q. (2015). HIV/AIDS stigma among older PLWHA in south rural China. *International Journal of Nursing Practice*, *21*(3), 221–228.

Zhao, Y., Mu, W., Harwell, J., Zhou, H., Sun, X., Cheng, Y., . . . Zhang, F. (2011). Drug resistance profiles among HIV-1–infected children experiencing delayed switch and 12-month efficacy after using second-line antiretroviral therapy: An observational cohort study in rural China. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *58*(1), 47–53.

Zheng, X., Wang, Z., Xu, J., Huang, S., Wang, C., Li, Z., . . . Qu, S. (2000). The epidemiological study of HIV infection among paid blood donors in one county of China. *Zhonghua liu xing bing xue za zhi Zhonghua Liuxingbingxue Zazhi*, *21*(4), 253–255.

Zhou, F., Shefer, A., Kong, Y., & Nuorti, J. P. (2008). Trends in acute otitis media-related health care utilization by privately insured young children in the United States, 1997–2004. *Pediatrics*, *121*(2), 253–260.

Zhou, Y. R. (2009). Help-seeking in a context of AIDS stigma: Understanding the healthcare needs of people with HIV/AIDS in China. *Health & Social Care in the Community*, *17*(2), 202–208.

Zung, W. W. (1965). A self-rating depression scale. *Archives of General Psychiatry*, *12*(1), 63–70.