Title
HIV-related Stigma in Health Care Settings: Concept, Context, and Response

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Publication Date
2018

UNIVERSITY OF CALIFORNIA,
IRVINE

HIV-related Stigma in Health Care Settings: Concept, Context, and Response

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Public Health

by

Mariam Davtyan

Dissertation Committee:
Associate Professor Cynthia M. Lakon, Chair
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Professor Ellen F. Olshansky

2018

DEDICATION

To

my family, friends, and colleagues near and far

in recognition of their unconditional love, care, and support

Just like moons and like suns,
With the certainty of tides,
Just like hopes springing high,
Still I'll rise.

Maya Angelou
"Still I Rise"

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ACKNOWLEDGMENTS

I am forever indebted to four extraordinary women (JD, SD, BG, and GP), without whom this work would not be possible. Everything that I have learned about HIV-associated stigma has come from your valor.

I honor the global HIV community for its strength, perseverance, and resilience. I stand with you and beside you as an advocate, a friend, and an ally.

I express my deepest and most heartfelt gratitude to the Chair of my Dissertation Committee, Dr. Cynthia M. Lakon, for her exemplary mentorship, unconditional support, unrelenting encouragement, and faith in my abilities. I also gratefully acknowledge Dissertation Committee Members Dr. Scott M. Bartell and Dr. Ellen F. Olshansky for their invaluable expert guidance and dedication to my success.

I thank Dr. Brandon J. Brown immensely for believing in my work, for supporting my unconventional ideas, and for his continued commitment to my professional growth.

I am enormously thankful to Dr. Toni Frederick, Dr. David Timberlake, Dr. Mojgan Sami, and Dr. Shu Farmer for their advice, feedback, and reassurance. Dr. Frederick will forever hold a special place in my heart for inspiring me to pursue a Ph.D.

I thank the Founding Chair of the Program in Public Health at UC Irvine, Dr. Dele Ogunseitan, for the opportunity to pursue higher education with the best and the brightest minds in the field.

To my students: thank you from the depths of my soul for transforming me into a better instructor and a more socially conscious scientist.

I thank Elsevier and Journal of the Association of Nurses in AIDS Care for publishing Chapters Two and Three of my dissertation.

Funding for this research was provided by the University of California Global Health Institute and the UC Irvine Newkirk Center for Science and Society.

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Clinical Project Manager: Pediatric HIV/AIDS Cohort Study-Surveillance Monitoring of ART Toxicities (PHACS SMARTT), Los Angeles County + USC Maternal Child and Adolescent/Adult Center for Infectious Diseases and Virology, Los Angeles, CA

Job Responsibilities:

- Protocol implementation
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- New Protocol Development
    - Helped develop a protocol to assess the effects of Tenofovir on bone mineral density among HIV-exposed infants
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    - Developed protocol to assess the prevalence of internalized stigma and its association with clinical outcomes
- Participation in committees and working groups organized by PHACS
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Project Specialist: Longitudinal Epidemiologic Study to Gain Insight into HIV and AIDS in Children and Youth (LEGACY) Los Angeles County USC Maternal Child and Adolescent/Adult Center for Infectious Diseases and Virology, Los Angeles, CA.

Job Responsibilities:

- Regulatory Compliance
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Research and Evaluation Intern:
AIDS Project Los Angeles (APLA), Research and Evaluation Core (REC), Los Angeles, CA

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- Study enrollment
- Data management & analysis

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Group Founder/Facilitator:
LAC+USC Maternal, Child & Adolescent Clinic (MCA) English-Speaking Community Advisory Board (E-CAB). The E-CAB consists of African American and Hispanic/Latina women living with HIV/AIDS. They provide extensive feedback on clinical services to the clinic's Governing Board, and work to make certain that these services are culturally sensitive and inclusive, as well as congruent with the HIV/AIDS community's needs.

Responsibilities:

- Organizing quarterly CAB meetings
- Developing meeting agendas with CAB members
- Revising, developing, and implementing programs and services at MCA clinic based on CAB's feedback
- Representing the CAB at monthly meetings with MCA's governing body
- CAB's Projects:
    - Hosting health fairs
    - Vetting organizations that provide services to patients living with HIV/AIDS
    - Administered HIV-stigma training to health care workers at LAC+USC Medical Center
    - Developed newsletters for MCA Clinic's patients
    - Developed a PrEP & PEP Infographic
    - Provided feedback on stigma and disclosure questionnaires for PHACS SMARTT study
    - Represented MCA at PHACS and IMPAACT network meetings
    - Developed protocol for patient advocacy
    - Community presentations

09/2012-09/2013
UCLA Center for HIV Identification, Prevention and Treatment Services (CHIPTS)
Community Advisory Board Member:

Responsibilities:

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06/2001-08/2012
Private Tutor:
Subjects: Biology, Chemistry, and Mathematics

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Advisory Board Member/Publicity Coordinator
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Poster Presentation: “Perspectives on Social Media and Technology Use for HIV Research among Young Adults in the Pediatric HIV/AIDS Cohort Study.”
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The International AIDS Conference, Durban, South Africa, July 2016
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Presenter: **Mariam Davtyan**

Breakout Session: “Addressing Ebola-related Stigma: Lessons Learned from HIV/AIDS”
Presenters: **Mariam Davtyan** and Brandon Brown

2014

2014 Pediatric HIV/AIDS Cohort Study Network Meeting, Hyatt Regency, Bethesda, MD, November 2014
Oral Presentation: “HIV/AIDS-related Stigma in Healthcare Settings”
Presenter: **Mariam Davtyan**

2014 International AIDS Conference, Melbourne, Australia July 2014
Poster Presentation: “Addressing HIV/AIDS-related Stigma through PhotoVoice: A Qualitative Approach”
Authors: **Mariam Davtyan**, Brandon Brown, LaShonda Spencer, Toni Frederick, and Andrea Kovacs

2014 UC Global Health Day Conference, University of California Davis, Davis, CA, April 2014
Breakout Session: “Reducing HIV/AIDS-related Stigma through PhotoVoice: A Road to Policy Change”
Presenter: **Mariam Davtyan**

2013

4th International Conference on HIV Stigma, Howard University, Washington DC, November 2013
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Pediatric HIV/AIDS Cohort Study Network Meeting, Hyatt Regency on the Inner Harbor, Baltimore, MD, October 2013
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Authors: **Mariam Davtyan**, LaShonda Spencer, and Brandon Brown

Oral Presentation: “Reducing HIV stigma through PhotoVoice: A Community-based Participatory Research Approach (CBPR)”
Presenter: **Mariam Davtyan**

2013 Community Engagement Awards & Poster Session, University of California Irvine, Irvine, CA, May 2013
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Authors: **Mariam Davtyan**, LaShonda Spencer, and Brandon Brown

UC Global Health Day Conference, University of California Riverside, Riverside, CA, February 2013
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Authors: **Mariam Davtyan**, LaShonda Spencer, and Brandon Brown

Poster Presentation: “Transactional Sex: A Client’s Perspective from Peru”
Authors: **Mariam Davtyan**, Karen Munoz, Lianne Urada, and Brandon Brown

Breakout Session: “Understanding Empowerment across Contexts and Disciplines: A Panel of Graduate Students’ Research on Women’s Health and Empowerment”
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2012

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PUBLISHED MANUSCRIPTS

HIV-related Stigma

Davtyan, M., Olshansky, E. F., & Lakon, C. (2018). Addressing HIV Stigma in Health Care. *The American Journal of Nursing, 118*(3), 11-11.

Davtyan, M., Olshansky, E. F., Brown, B., & Lakon, C. (2017). A Grounded Theory Study of HIV-Related Stigma in U.S.-based Health Care Settings. *Journal of the Association of Nurses in AIDS Care, 28*(6), 907-922.

Davtyan, M., Farmer, S., Brown, B., Sami, M., & Frederick, T. (2016). Women of Color Reflect on HIV-Related Stigma through PhotoVoice. *Journal of the Association of Nurses in AIDS Care*, *27*(4), 404-418.

HIV & Ebola:

Davtyan, M., Brown, B., & Folayan, M. O. (2014). Addressing Ebola-related Stigma: Lessons Learned from HIV/AIDS. *Global health action*, *7*(1), 26058.

Antiretroviral medication-related outcomes:

Siberry, GK., Jacobson, DL., Kalkwarf, HJ., Wu, JW., Dimeglio, LA., Yogev, R., Knapp, KM., Wheeler, JJ., Butler, L., Hazra, R., Miller, TL., Seage, GR., Van Dyke, RB., Barr, E., **Davtyan, M**., Moffenson, LM., Rich, KC. (2015). Lower Newborn Bone Mineral Content Associated with Maternal Use of Tenofovir Disoproxil Fumarate During Pregnancy. *Clinical Infectious Diseases, 61*(6), 996-1003.

Ethics:

Brown, B, **Davtyan, M**, & Fisher, C. B. (2014). Peruvian Female Sex Workers’ Ethical Perspectives on Their Participation in an HPV Vaccine Clinical Trial. *Ethics & Behavior*, *25*(2), 115–128.

Heidari, O, Ghuman, P, Soohoo, M, **Davtyan, M,** Folayan, MO, Brown, B (2014). Using Financial Incentives for HIV Prevention Studies in Diverse Global Contexts: A Review of the Literature. *Nigerian Journal of Health Sciences*,14, 39-51.

<u>HPV:</u>

Brown, B., **Davtyan, M**., Leon, S. R., Sanchez, H., Calvo, G., Klausner, J. D., & Galea, J. (2014). A Prospective Cohort Study Characterizing the Role of Anogenital warts in HIV Acquisition among Men who have Sex with Men: A Study Protocol. *BMJ open*, *4*(9), e005687.

Brown, B., **Davtyan, M**., Galea, J., Chow, E., Leon, S., & Klausner, J. D. (2012). The Role of Human Papillomavirus in Human Immunodeficiency Virus Acquisition in Men who have Sex with Men: A Review of the Literature. *Viruses*, *4*(12), 3851-3858.

<u>Other Publications:</u>

Davtyan, M., Munoz, K., Urada, L., & Brown, B. (2013). Transactional Sex: A Client's Perspective from Peru. *Electronic Journal of Human Sexuality*, *16*.

Munoz, K., **Davtyan, M**., & Brown, B. (2014). Revisiting the Condom Riddle: Solutions and Implications. *Electronic Journal of Human Sexuality*, *17*.

<u>Pre-Doctoral Publications:</u>

Setse R, Siberry GK, Moss WJ, Gravitt P, Wheeling T, Bohannon B, Dominguez K, and **the LEGACY Consortium**. (2012) Cervical Pap Screening Cytological Abnormalities among HIV-infected Adolescents in the LEGACY Cohort. *Journal of Pediatric and Adolescent Gynecology*, *25*(1), 27-34.

Setse R, Siberry G, Gravitt PE, Moss WJ, Agwu A, Wheeling J, Bohannon B, Dominguez K and **the LEGACY Consortium**. (2011). Correlates of Sexual Activity and Sexually Transmitted Infections among Human Immunodeficiency Virus -Infected Youth in the LEGACY Cohort, United States, 2006. *Pediatric Infectious Disease Journal*, *30*(11), 967-973.

Kapetanovic S, Wiegand RE, Dominguez K, Blumberg D, Bohannon B, Wheeling J, Rutstein R, and **the LEGACY Consortium**. (2011). Associations of Medically Documented Psychiatric Diagnoses and Risky Health Behaviors in HAART-Experienced Perinatally HIV-Infected Youth. *AIDS Patient Care and STDs, 25*(8), 493-501.

PEER REVIEW OF MANUSCRIPTS

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- AIDS and Behavior. Review submitted, December 2017.
- AIDS and Behavior. Review submitted, January 2016.

- AIDS and Behavior. Review submitted, January 2016.
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- International Journal of Tropical Diseases & Health. Review submitted, June 2014.
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- “HIV & Stigma”, Diversity in Medicine Course, UC Irvine, Dr. Mojgan Sami, February 28th, 2018

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- “Human Subjects Research & Regulatory Compliance”, UC Irvine, Dr. Miryha Runnerstrom, November 2014-present
- “HIV/AIDS & Stigma”, AIDS & Society Course, USC, Dr. Roksana Karim, October 17th, 2017
- “Epidemiology of HIV/AIDS & Stigma”, Introduction to Epidemiology Course, UC Irvine, Dr. Elani Streja, April 14th, 2017
- “Preparing IRB Applications”, Graduate Seminar in Ethics Course, UC Irvine, Dr. Ted Gideonse, March 14th, 2017
- “HIV and Stigma”, Diversity in Medicine Course, UC Irvine, Dr. Mojgan Sami, February 22nd, 2017

2014

- “HIV-Stigma in Healthcare Settings”, Keck Medicine of USC, MPH Course, Dr. Deborah Mindry, November 2014

2013

- “Reducing HIV- stigma through PhotoVoice: A Community-based Participatory Research Approach (CBPR)”, Pediatric HIV/AIDS Cohort Study Network Meeting, Baltimore, MD, Health Education and Communication Committee, October 3rd, 2013
- “Community-Based Participatory Research & PhotoVoice”, UC Irvine, Dr. Brandon Brown, Public Health Ethics Course, February 20th, 2013

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- “HIV/AIDS-related Stigma”, LAC+USC Maternal Child & Adolescent/Adult Center for Infectious Diseases, Keck Medicine of USC, December 11th, 2012

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English, Armenian

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ABSTRACT OF THE DISSERTATION

HIV-related Stigma in Health Care Settings: Concept, Context, and Response

By

Mariam Davtyan

Doctor of Philosophy in Public Health

University of California, Irvine, 2018

Associate Professor Cynthia M. Lakon, Chair

HIV-related stigma is a catalytic and divisive social phenomenon. It refers to undesirable attitudes and behaviors directed towards people living with HIV (PLWH). Stigma intensifies socially devalued identities and serves as a lingering impediment to effective disease response. HIV stigma is prominent across multiple contexts, including in health insurance, employment, housing, religious environments, and health care. Stigma is entrenched in poor knowledge, value-laden judgments, and insufficient contact with PLWH. Examples of stigma include unnecessary preventive measures, care denial, and indiscretion with HIV status. Ethnic, gender, and sexual minorities are subjected to significant HIV-related stigmatization and these experiences have been linked to reduced testing and access, care interruptions, and mental health conditions. Women of color in the United States (US) are particularly impacted by HIV stigma, yet studies that examine personal accounts of stigma among this group are infrequent. Additionally, while the existing evidence suggests stigmatizing attitudes and behaviors among US-based health care workers and in health care settings, less work has focused on addressing these trends. The present dissertation conceptualized HIV stigma experienced by African American and Hispanic/Latina women using Interpretative Phenomenological Analysis, delineated the critical features of HIV stigma in US-based health care settings using Grounded Theory, and appraised the efficacy of a PhotoVoice-informed HIV stigma training program targeting health care workers in Southern California. The major findings of these studies were that stigma is rooted in historical mischaracterizations, amplified by patient-provider power inequalities, and triggered by fear, inadequate clinical training, inadvertent behaviors, and reduced contact with HIV patients due to overspecialization of HIV treatment. HIV-related stigma was perceived as having a destructive influence, thereby worsening self-esteem, hindering disclosure of sero-status, obstructing interpersonal and intrapersonal relationships, diminishing psychological well-being, and thwarting medical engagement. The PhotoVoice-informed intervention increased knowledge of HIV/AIDS, improved attitudes towards PLWH, and decreased observations of enacted HIV stigma in health care settings. Improving access and uptake of social support and mental health resources among PLWH, mobilizing faith-based organizations, training health care personnel, developing robust stigma reduction programs, and implementing evidence-based anti-HIV stigma policies may help reduce stigma and ameliorate health outcomes across the HIV care continuum.

CHAPTER 1

Introduction

On June 5th, 1981, the Centers for Disease Control and Prevention (CDC) released a Morbidity and Mortality Weekly Report (MMWR) describing a cluster of *Pneumocystis carinii* pneumonia among five young and otherwise healthy men who had sex with men (MSM) living in Los Angeles (Gottlieb et al., 1981). The underlying cause of this infection would later be described as Acquired Immunodeficiency Syndrome (AIDS) related to the progression of the Human Immunodeficiency Virus (HIV). As of 2017, more than 1.1 million people are living with HIV/AIDS in the United States (US) ("HIV in the United States: At A Glance," 2017) and approximately 700,000 people have died of AIDS since the inception of the epidemic ("The HIV/AIDS Epidemic in the United States: The Basics," 2017).

Racial and ethnic minorities, MSM, and bisexual men continue to be overrepresented in the domestic HIV epidemic ("The HIV/AIDS Epidemic in the United States: The Basics," 2017). For instance, African Americans represent 12% of the US population, but account for 45% of HIV diagnoses ("HIV in the United States: At A Glance," 2017). Similarly, Hispanics/Latinos represent 18% of the US population, but account for 24% of HIV diagnoses ("HIV in the United States: At A Glance," 2017). MSM and bisexual men account for 82% of HIV diagnoses among males and 67% of all diagnoses ("HIV in the United States: At A Glance," 2017). African American MSM and bisexual men, specifically, account for the largest number of HIV diagnoses in the US ("HIV in the United States: At A Glance," 2017). African American women account for more than 60% of HIV diagnoses among women ("HIV in the United States: At A

Glance," 2017). In terms of age distribution, more than 60% of HIV diagnoses occur in persons aged between 20 and 39 years of age ("HIV in the United States: At A Glance," 2017). Though HIV has been reported in all 50 states, more than half of HIV diagnoses occur in the Southern parts of the US, with 7 out of 10 top states located in the South ("The HIV/AIDS Epidemic in the United States: The Basics," 2017).

Between 2005 and 2014, the incidence of HIV in the US decreased by nearly 20% and this may have been due to increased testing and targeted HIV prevention efforts ("HIV in the United States: At A Glance," 2017). Additionally, there has been greater global investment and expanded access to antiretroviral medications (ARVs) which have significantly reduced mortality and morbidity, and have improved long-term outcomes among people living with HIV (PLWH). A 2016 longitudinal study of the 50 US states found that states who spent more on social services and public health significantly lowered HIV and AIDS case rates and AIDS deaths (Talbert-Slagle, Canavan, Rogan, Curry, & Bradley, 2016). A study of approximately 25,000 patients living with HIV conducted by Kaiser Permanente California during 1996-2011, found that life expectancy at age 20 increased from 19.1 years in 1996–1997 to 53.1 years in 2011 (Marcus et al., 2016) and these trends were attributed to increased ARV use. Despite significant advancements in HIV care over the last three decades, stigmatization of PLWH has remained persistent. In fact, there is global recognition and consensus that HIV-related stigmatization is a "parallel" epidemic which has wreaked havoc on disease prevention and treatment efforts (Kitara & Aloyo, 2012).

PLWH endure intense social stigma associated with their disease status (Yi et al., 2015) and stigma continues to be a long-standing and tenacious barrier to effective disease management (Shacham, Rosenburg, Önen, Donovan, & Turner Overton, 2015), influencing health-seeking behaviors such access to health and social services, and optimal medical compliance (Rueda et al., 2016). Stigma reinforces existing inequities based on race, gender, sexual orientation and socioeconomic status, displacing historically marginalized and high-risk groups (i.e., MSM, injection drug users, transgender people, sex workers) further downward in the status hierarchy (Dizon, 2017). A multitude of adverse outcomes, including virologic failure (Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), reduction and loss of social support (Galvan, Davis, Banks, & Bing, 2008), and diagnosis with a mental health condition (Rueda et al., 2016; Tesfaw et al., 2016; Logie et al., 2018) have been linked to HIV-related stigmatization. Overall, stigma has profoundly impacted the social world in which PLWH live, the attitudes and behaviors of people with whom PLWH engage, and the care that PLWH receive.

This chapter of the present dissertation will introduce the social phenomenon of HIV-related stigma. It will begin with several widely accepted definitions of stigma, contributed by some of the most prominent and prolific scholars in the field. Additionally, the chapter will focus on the types of stigma that PLWH experience, common social spheres in which stigma occurs, manifestations of stigmatization faced by PLWH, gender and racial disparities in stigma experiences, the impact of stigma on affected populations, and stigma reduction efforts that have shown efficacy. The chapter will conclude with the conceptual frameworks that guided the current research and a discussion on how the succeeding three research studies, “Women of Color Reflect on HIV-related Stigma through PhotoVoice,” “A Grounded Theory Study of HIV-related

Stigma in US-based Health Care Settings," and "Assessing the Efficacy of a PhotoVoice-informed HIV Stigma Training for Health Care Workers in Southern California," contribute to the current body of knowledge on HIV-related stigma.

Conceptualizing HIV-related Stigma

Many scholars have theorized about and conceptualized the social construct of stigma. One of the most popular theorists of stigma, Erving Goffman, described it in his groundbreaking work "Notes on the Management of Spoiled Identity," as an "attribute possessed by an individual that is deeply discrediting," and one that thwarts normal social interaction, acceptance, and participation (Goffman, 1963). Goffman argued that others see the stigmatized individual as occupying an undesirable "difference" and this difference is apportioned by society through rules and sanctions, leading to a spoiled identity. Stafford & Scott (1986) referred to stigma as a characteristic that is contrary to a "social unit" norm, where norm is a communal belief that an individual should behave in a certain way at a particular time. Crocker, Major, & Steel (1998) defined stigma as an attribute/characteristic that conveys a lessened social identity with negative stereotypes and politics attached to this identity.

Over time, HIV scholars expanded, contextualized, and refined the construct of stigma. Link & Phelan (2001) emphasized the socially devaluative properties of stigma, as well as the behaviors of individuals without the attribute towards those possessing the attribute. They described stigma related to HIV as an act of labeling, stereotyping, separating, status loss, and discrimination. Parker & Aggleton's (2003) conceptualization of HIV-related stigma departed from existing paradigms and focused on macro-level determinants of stigma. They stated that individual behaviors that contribute to stigma might be logical in some settings where people are considered free agents. However, in other settings, particularly in resource-constrained parts of the world, the individual-level paradigm is not contextually appropriate because stigma is a byproduct of social and cultural phenomena that influence group actions. Additionally, they highlighted that stigma and discrimination of PLWH are intimately linked and influenced by culture, power dynamics, inequality, and difference. Similarly, Castro & Farmer (2005) maintained that a focus on individual attitudes and behaviors in different situations is a de-socialized and de-contextualized approach, in that structural factors (i.e., poverty, racism, classism) that may amplify a group's risk of stigmatization are not fully considered.

Classifying HIV-related Stigma

PLWH experience different mechanisms of stigmatization, including perceived, internalized, anticipated, intersectional, and enacted stigma. Perceived stigma refers to the awareness that PLWH have of societal attitudes and discriminatory actions toward them (Phillips, Moneyham, & Tavakoli, 2011). Internalized stigma refers to the extent to which negative feelings about self are incorporated into the self-concept (Hasan et al., 2012). Anticipated stigma is the expectation of differential treatment in the event of HIV sero-conversion and/or status disclosure (Golub & Gamarel, 2013). Intersectional stigma refers to stigma that occurs across multiple contexts, including interpersonal, community, and structural (Sangaramoorthy, Jamison, & Dyer, 2017). Enacted stigma refers to episodes of discrimination, stereotyping, and prejudice directed towards those who possess a stigmatized attribute or characteristic (Lekas, Siegel, & Leider, 2011).

In a study of PLWH and caregiver dyads, perceived stigma was 2.5 times higher in PLWH and was associated with poor quality of life in the context of physical health (i.e., energy, sleep, mobility), reduced psychological function (i.e., self-esteem, body image, spirituality), social relationships (i.e., social support, sexual activities), and environmental aspects (i.e., security, transport) (Liu et al., 2013). Internalized stigma has been linked to reduced disclosure of HIV status to primary sexual partners and clinically significant depression (Okello et al., 2015). Anticipated HIV stigma is associated with lower risk perceptions and a decrease in the odds of HIV testing (Golub & Gamarel, 2013). Studies have also linked anticipated stigma to poor ARV adherence (Turan et al., 2016).

In a study of midlife and older Black women living in Prince George's County, Maryland, experiences of HIV stigma intersected with and were intensified by ageism, sexism, and racism, and occurred at many levels including interpersonal, community, and institutional/structural (Sangaramoorthy et al., 2017). In the same study, intersectional stigma was associated with reinforcement of stereotypes about Black women (i.e., hypersexual, drug-dependent, partners of incarcerated men), feelings of dependency and helplessness, rejection and indifference from family members, blaming, gender-based violence, and biased medical treatment. In a study of social determinants of health and intersectionality among African American mothers living with HIV, it was found that gender-based inequality, racism, classism, as well as HIV stigma were all linked to poorer mental and physical health outcomes (Caiola, Docherty, Relf, & Barroso, 2014).

A study of enacted stigma among HIV and Hepatitis C Virus (HCV) co-infected adults revealed that episodes of discrimination based on HIV infection resulted in perceptions of HIV as far more pervasive and detrimental compared to HCV, social isolation, self-loathing, and self-perception as a member of a despised social group (Lekas et al., 2011). Furthermore, enacted HIV stigma is associated with physical indicators of health and well-being such as diagnosis with a chronic illness and or a decrease in CD4 cells (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013). Takada et al. (2014) found that higher levels of enacted HIV stigma were associated with lower levels of emotional and instrumental social support from friends and family. Whetten et al. (2009) found that enacted stigma may directly increase the likelihood of psychological distress among PLWH as well as their family members. Chi, Li, Zhao, & Zhao (2014) reported that enacted stigma predicts later depressive symptoms, which in turn exacerbate the deleterious effect of perceived stigma on depressive symptoms. Similarly, PLWH who experience higher levels of enacted stigma also experience greater internalized stigma (Berger, Ferrans, & Lashley, 2001; Earnshaw & Quinn, 2012).

Contextualizing HIV-related Stigma

While overt prejudice towards PLWH in the US has declined in the last three decades, PLWH continue to experience a variety of stigmatizing and discriminatory attitudes and behaviors (Herek, 2002). These include discrimination in health insurance, employment, housing, religious environments, and health care. In a study of cost-sharing tiers under the Affordable Care Act, researchers found that insurers categorized nucleoside reverse-transcriptase inhibitors (NRTIs), a commonly prescribed class of HIV medications, as high cost-sharing medications (coinsurance or copayment of at least 30%) and this may have deterred patients living with HIV from choosing certain insurance plans (Jacobs & Sommers, 2015).

Using data from the Equal Employment Opportunity Commission's (EEOC) Integrated Mission System database, Conyers, Boomer, & McMahon (2005) found that HIV/AIDS had a significantly higher proportion of employment discrimination allegations found to have merit compared to other conditions. In the same study, PLWH reported discrimination based on employment benefits, job-related training, demotions, job assignments, working conditions and job environment, and discipline. In a study of HIV-related stigma and social isolation among people living with HIV in Tennessee conducted by Audet, McGowan, Wallston, & Kipp (2013), respondents revealed employment termination and being forced to quit their employment once their HIV status was disclosed. A report by Lambda Legal (2010) reported incidents of housing discrimination towards PLWH in the form of rejections from assisted living facilities. In religious settings, stigma manifests as beliefs that HIV/AIDS is a byproduct of sexual deviance, degradation of traditional cultural practices, and erosion of the family unit (Genrich, & Brathwaite, 2005).

Perhaps the most alarming setting where PLWH experience stigma and discrimination is in health care. The existing evidence clearly and unequivocally implicates the health care sector as a critical source of HIV-related prejudice (Feyissa, Abebe, Girma, & Woldie, 2012; Turan et al., 2017). Furthermore, stigma directed towards PLWH from health workers has been linked to poor care continuity and immunological decline (Magnus et al., 2013; Earnshaw et al., 2013). Examples of such stigma include negative attitudes towards patients with HIV, unwillingness to perform medical services for patients with HIV, and excessive precautionary measures (Audet et al., 2013). Stringer et al. (2016) assessed HIV-related stigma among health care workers in the Deep South and found that 93% of social and community workers, 89% of clinical staff, and 90% of all other staff endorsed at least one stigmatizing attitude towards PLWH. Stigmatizing attitudes and discriminatory dispositions included subscribing to the opinion that PLWH could have prevented HIV acquisition if they wanted to, that HIV is punishment for irresponsible behaviors, and that PLWH have had many sexual partners. In a study of HIV-related stigma in health care services in Los Angeles County, Sears (2008) found that 56% of nursing facilities, 26% of cosmetic surgeons, and 47% of obstetricians refused to accept patients with HIV for any type of services even if patients were asymptomatic. This refusal was attributed to lack of expertise and equipment, no previous contact with HIV positive patients, and inadequate clinical training. In a study of health care workers employed at a tertiary government teaching hospital, Lopez, Ramiro, and Loxas (2017) reported differential infection control procedures for patients with HIV compared to those without HIV, wearing multiple pairs of gloves, using gloves for all aspects of care involving HIV patients, and implementing additional infection control action plans during labor and delivery of HIV positive pregnant women.

Gender and Racial Disparities in HIV Stigma

The US HIV/AIDS epidemic is prominent in socially marginalized communities (Pellowski, Kalichman, Matthews, & Adler, 2013). HIV-related stigma may be of special concern to women as they experience higher levels compared to men (Geary et al., 2014; Sandelowski, Lambe, & Barroso, 2004). In the US, specific groups of women, including sex workers, migrants, and pregnant women, have been targeted as “vectors” of HIV disease and are therefore susceptible to higher levels of stigma (Higgins, Hoffman, & Dworkin, 2010). Studies indicate that women living with HIV (WLWH) continue to experience severe and multilevel stigmatization and as a result, are more likely to experience social rejection and shame compared to men (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006; Sandelowski et al., 2004; Enriquez et al., 2010). In one study of African American WLWH in the South, stigma was experienced at the interpersonal, community, and institutional level. Study participants reported being disowned by family members, rejected by their church, and their disease status involuntarily disclosed to social networks (Fletcher et al., 2016). Additionally, internalized HIV-related stigma is higher among women compared to men (Yakhmi, Sidhu, Kaur, & Dalla, 2014) and this leads to feelings of uncertainty and loss, low self-esteem, anxiety, depression and suicidal ideation, as well as poor treatment compliance (Paudel & Baral, 2015; Turan et al., 2016).

Men living with HIV also face stigma, but the manifestations are different in that they involve social constructions of masculinity, discretion, and concerns with public attitudes. Lichtenstein (2004) reported that men anticipate HIV-related stigma in the context of reputation loss and lack of privacy. The same study also conveyed that men also fear stigmatization associated with HIV because of the threat it poses to their identity as a “non-deviant entity,” its association with homosexuality, and its ability to influence their actual or potential relationships with women. In a study of Spanish-speaking Latinos in the US, Grieb, Shah, Flores-Miller, Zelaya, & Page (2017), found that men anticipated HIV-related community stigma and were more hesitant than women to test for HIV due to fear of people's reaction if the test was positive.

MSM, who are excessively impacted by HIV in the US, are also exceptionally vulnerable to stigma ("HIV in the United States: At A Glance," 2017). MSM report perceived and anticipated stigma such as changes in others' attitudes, speech, and behaviors when their serologic status is revealed, and the belief that others will inevitably view them with contempt if their serological status becomes known (Jeffries et al., 2015). Additionally, stigma experienced by MSM is directed from non-infected persons and non-MSM, as well as from the MSM community (Goldenberg, Vansia, & Stephenson, 2016). Stigma among men is associated with self-isolation, shame, embarrassment, loss of social status, unwillingness to disclose HIV status, and unwillingness to discuss HIV status with sero-discordant partners (Jeffries et al., 2015).

HIV-related stigma is also persistent in the transgender community. A 2013 CDC report indicated that the estimated percentage of transgender WLWH in the US is 22% (Baral et al., 2013). Additionally, among the 3.3 million HIV testing events reported to the CDC in 2013, the percentage of transgender people who received a new HIV diagnosis was more than 3 times the national average ("HIV Among Transgender People," 2017). These factors dramatically amplify the vulnerability of transgender people to HIV-related stigmatization. In a study of barriers and facilitators to engagement and retention in care among transgender people living with HIV, participants reported unwillingness to access HIV care due to fear of being seen entering or leaving a facility that offers services to the transgender community. In the same study, many participants reported that prior to their HIV diagnosis, they avoided

HIV testing due to confidentiality concerns and stigma, and this resulted into delays in diagnosis (Sevelius, Patouhas, Keatley, & Johnson, 2014). Similarly, a study of HIV-positive LGBQT women revealed multiple barriers to HIV services and support, including pervasive HIV stigma, heteronormative assumptions about services, and discriminatory treatment by health care workers (Logie, James, Tharao, & Loutfy, 2011).

Racial and ethnic minority populations not only experience significant disparities in rates of HIV infection, but also stigma related to their disease status. A national prevalence study of internalized HIV stigma in the US conducted by Baugher et al. (2017) indicated higher rates of stigma among Hispanic/Latino and other/multiracial males compared to their White counterparts. In the same study, Hispanic/Latinas experienced the highest rates of stigma compared to other women. Transgender persons identifying as other/multiracial individuals reported highest stigma compared to all other groups.

Wohl et al. (2013) indicated that Hispanic/Latino MSM experienced more HIV-related stigma than African American MSM, but less stigma than mixed race/gender/sexual orientation study groups. The pervasiveness of HIV-related stigmatization among people of color is related to the innate intersectionality of stigma. Specifically, people of color are devalued for multiple social identities including HIV sero-positivity, sexual minority orientation, transgender identity/expression, illicit drug use, commercial sex work, incarceration, and immigration status (Earnshaw, Bogart, Dovidio, & Williams, 2013).

The Impact of HIV Stigma

The consequences of HIV-related stigma are well documented in the literature. PLWH who are subjected to stigma often endure serious mental health outcomes, including depression, anxiety, and suicidal ideation. Stigma related to HIV has also been linked to reduced social support, lack of disclosure of HIV status to intimate partners, immunological failure, and poor treatment compliance.

Kamen et al. (2015) found that women who had greater worries about being infected with HIV and experienced HIV-related stigma were significantly more likely to report greater symptoms of anxiety and depression. In a study of suicide among gay and bisexual men living with HIV, Ferlatte, Salway, Oliffe, & Trussler (2017) found that suicidal ideation was significantly associated with experiences of stigma measured as social exclusion due to HIV status, sexual rejection, and verbal and physical abuse. Takada et al. (2014) found that enacted HIV-related stigma may jeopardize the ability to access both emotional (i.e., care, empathy) and instrumental social support (i.e., financial assistance, help with tasks) from friends and family members. In the same study internalization of HIV-related stigma impacted one’s ability to access emotional support.

A study of WLWH by Ojikutu et al. (2016) found that anticipated and perceived community stigma (based on beliefs that HIV infection in women was due to sex work and multiple sexual partners) was associated with reduced disclosure of HIV status to current sexual partners. In a study of patients with HIV on the first line treatment with ARVs, Kapesa et al. (2014) found a significant association between HIV-related stigma, measured as disclosure concerning factors and perception on public attitude about

PLWH, and subsequent immunological failure. Immunological failure was measured as a 50% drop in CD4 cell counts from the peak value in six months or return to the baseline CD4 cell counts, and was attributed to poor ARV adherence. Mhode & Nyamhanga (2016) found that stigma compromises ARV adherence by reinforcing concealment of HIV status and discouraging social support.

HIV Stigma Reduction Programs

The global consensus that HIV-related stigma is deleterious to social, physical, and psychological outcomes has led to the development of myriad stigma reduction programs. These programs have spanned large geographical areas (i.e., North and South America, the Middle East, Asia) and have engaged a wide array of groups (i.e., health care workers, students, historically high-risk groups) (Norr et al., 2012; Shah, Heylen, Srinivasan, Perumpil, & Ekstrand (2014); Adam et al., 2011; Li, Guan, Liang, Lin, & Wu, 2013). Program contents have included education, environmental modifications, increased contact with PLWH, counseling/support, and technology-based learning tools (Stangl, Lloyd, Brady, Holland, & Baral, 2013; Radhakrishna et al., 2017).

A study conducted by Li et al. (2013) utilized popular opinion leaders, group discussions, games, and role-plays to engage medical institutions and health care workers to reduce prejudicial treatment of patients with HIV. The study was successful in reducing prejudicial attitudes and avoidance intent. A study conducted by Shah et al (2014) employed knowledge-building and testimonials from PLWH to reduce stigma among nursing students. The brief intervention was successful in reducing blame, endorsement of coercive policies and intent to discriminate, while increasing HIV-related knowledge and program endorsement.

Denison et al. (2011) found that a program facilitated by trained volunteer peer educators aged 18-25 years was successful in increasing HIV- and reproductive health-knowledge and self-efficacy, and reducing levels of stigma and sexual risk-taking behaviors among eighth and ninth graders. Norr et al. (2012) implemented a professionally assisted peer group intervention program to influence HIV/AIDS-related knowledge, attitudes, and behaviors among health care workers. The study resulted in less stigmatizing attitudes toward general contact with PLWH and patient contact in the clinic. A blog- and discussion-based HIV stigma reduction intervention targeting the MSM community conducted by Adam et al. (2011) led to greater recognition that HIV positive MSM face stigma in the gay community and that stigmatization reduces the likelihood of HIV disclosure.

Bridging Gaps in Research

The current literature indicates that women of color are disproportionately impacted by HIV-related stigmatization. Studies of gender-dimensions of HIV stigma indicate that women of color experience more stigma compared to men, and are more likely to internalize their experienced stigma. While many studies have assessed the intensity and consequent aftermath of stigma among women, fewer studies have examined personal experiences and accounts of HIV-related stigmatization among this segment of the population. The first study of this dissertation entitled “Women of Color Reflect on HIV-related Stigma through PhotoVoice,” employed Interpretative Phenomenological Analysis and a Community-based Participatory Action Research methodology called PhotoVoice to bridge this gap. Interpretative Phenomenological Analysis and PhotoVoice were utilized to understand how women of color living with

HIV defined, described and made sense of their lived experiences with stigma, and how they discussed their experiences using PhotoVoice. The research questions examined in this study were:

1. How do African American and Hispanic/Latina women living with HIV make sense of HIV-related stigma?
2. How do African American and Hispanic/Latina women living with HIV facilitate dialogue about HIV-related stigma using PhotoVoice?

In addition to affecting women of color living with HIV, stigma is also pervasive in health care settings. There is a vast body of knowledge that documents patient experiences of HIV-related stigma and discrimination directed from health care workers. However, less research has focused on health care worker perceptions of HIV-stigma experienced by PLWH. The second study of this dissertation, entitled "A Grounded Theory Study of HIV-related Stigma in US-based Health Care Settings," assessed health care workers perceptions of HIV-related stigma in health care settings using the principles of Straussian Grounded Theory. The research questions examined in this study were:

1. How do health care workers conceptualize HIV-related stigma in health care settings?
2. What are the pertinent concepts involved in the operationalization of HIV-related stigma in health care settings?

HIV-related stigma interferes with global efforts to achieve optimal health standards for affected and infected individuals. Health care settings must therefore, be in the frontlines of the battle against stigma. Since the advent of the epidemic, a number of stigma reduction studies have been conducted in health care settings. However, these studies have targeted health care professionals from other parts of the world. There are currently no published studies in the US that have assessed the efficacy of HIV-related stigma reduction interventions within health care settings. The third and final study of this dissertation entitled, “Assessing the Efficacy of a PhotoVoice-informed HIV Stigma Training for Health Care Workers in Southern California,” attempted to bridge this gap. Using findings from the first two qualitative research studies of this dissertation and building on stigma reduction strategies that have already shown promise (i.e., didactic education combined with contact with PLWH, clinical training of health care professionals, raising awareness), a novel stigma reduction program was designed and delivered. This PhotoVoice-informed stigma reduction intervention was tested among health care workers (i.e., physicians, nurses, allied health care professionals) employed at a university-based medical institution located in Southern California. The three-part intervention focused on knowledge synthesis, contact and interaction with PLWH, health communication, and skill building. The research questions examined in this study were:

1. Does the PhotoVoice-informed HIV stigma training of health care workers increase knowledge of HIV/AIDS?
2. Does the PhotoVoice-informed HIV stigma training of health care workers improve attitudes towards PLWH?
3. Does the PhotoVoice-informed HIV stigma training of health care workers increase observations of enacted HIV stigma in health care settings?

Conceptual Frameworks

Three conceptual frameworks guided the studies of this dissertation: the Modified Social Ecological Model of HIV Risk, Community-based Participatory Action Research, and the Structuration Theory of HIV Stigma. The traditional Social Ecological Model recognizes that social and structural factors, individual behaviors, and the physical environment engage in complex associations to predict health or absence thereof (Poundstone, Strathdee, & Celentano, 2004). The Modified Social Ecological Model, on the other hand, is a customized version of the Social Ecological Model in that it includes five layers of risk vis-à-vis HIV infection (i.e., individual, networks, community, public policy, and HIV epidemic stage). Specifically, the Modified Social Ecological Model is based on the notion that while individual-level factors (i.e., biological, behavioral) are integral components of disease transmission, they are limited in explaining population-level epidemics. For this reason, individual factors together with social and sexual networks (i.e., family, friends, neighbors, sexual partners), community environments (i.e., organizations, groups), and laws and policies (i.e., condom provisions, needle exchange programs) comprise an epidemic stage. Cumulatively, these factors lead to prevalent communication of HIV in the population (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013). The relevance of the Modified Social Ecological Model to the current dissertation is two-fold. First, HIV-related stigma often manifests as admonishments of impacted groups for perceived morally reprehensible individual behaviors. Second, those who stigmatize PLWH fail to acknowledge that social and structural determinants of health (i.e., poverty, racism, cultural norms) can amplify vulnerability to HIV infection.

In the context of public health, Community-based Participatory Action Research is a partnership-based research methodology that encompasses community members, organizational representatives, and researchers in all facets of the research process. This is done such that each participating group provides unique core competencies, shares decision-making processes, and responsibilities (Israel, Schultz, Parker, & Becker, 1998). The aim of Community-based Participatory Action Research is to enhance comprehension and conception of a specific social phenomenon, in our case HIV-related stigma, and to incorporate the acquired knowledge into intervention designs and policy changes in an effort to ameliorate health outcomes (Israel et al., 1998). Community-based Participatory Action Research, therefore, engages community members most affected by an issue, as vital components of solution synthesis, and focuses on public health problems that have local social relevance. This research methodology relinquishes the customary expert-driven approach by nurturing co-learning and capacity building with emphasis on action and policy change (Lorway et al., 2014). The salience of Community-based Participatory Action Research to the current dissertation was demonstrated by the use of PhotoVoice, a methodology that involves documentary photography, by women of color living with HIV to reflect on their experiences with HIV stigma. Additionally, PhotoVoice was integrated into a stigma training intervention designed by women of color living with HIV (Stigma Trainers) and delivered to health care workers employed at a university-based medical institution. In observance of Community-based Participatory Action Research principles, Stigma Trainers served as community members impacted by a social phenomenon (HIV-related stigma), and health care workers served as the organizational representatives.

Together, both Stigma Trainers and health care workers engaged in a partnership to increase knowledge of HIV/AIDS, improve attitudes towards PLWH, and increase awareness of the presence of HIV-related stigma in health care settings, in an effort to restructure health outcomes among PLWH.

As mentioned earlier in this chapter, stigma has been conventionally defined as an attribute or characteristic that discredits impacted groups and precludes nuanced and textured interpersonal connections with others (Goffman, 1963). With respect to HIV, stigma has been depicted as a feature that contradicts norms of a social unit (Stafford & Scott, 1986), a characteristic that expresses a socially debased identity (Crocker et al., 1998), and enactments of classification, pigeonholing, disconnection, and status loss (Link & Phelan, 2001). These definitions highlight the socio-cognitive and structural workings of stigma. They also characterize stigma as a static phenomenon, which is readily absorbed without hesitation or resistance from recipients. What is eliminated from consideration is the capability of stigmatized groups to actively respond to stigma. The Structuration Theory of HIV Stigma represents an alternative discourse to this passive narrative. Structuration Theory represents PLWH as knowledgeable agents with full capacity to affirm their rights and resist the stigma that they face, instead of passive beneficiaries of others' enacted prejudice (Misir, 2015). This Giddensian lens on HIV-related stigma recognizes the dynamic nature of stigma, the indisputable knowledge that PLWH have of social structures that oppress them, and their faculties for asserting their knowledge to produce actions, which then reproduce new structures (Misir, 2015; Giddens, 1984). The participation of PLWH and health care workers in an HIV stigma reduction program reinforces the agency power that each of these groups has in reflexively monitoring stigma and changing its course within health care settings. These factors, thereby, highlight the relevance of the Structuration Theory to the current dissertation.

Cumulatively, the studies of the current dissertation had three main purposes; to conceptualize HIV-associated stigma from the viewpoints of women of color living with HIV, a group profoundly encumbered by the epidemic and incidents of disease-related injustices; to contextualize HIV stigma by elucidating how stigma gains and maintains momentum in health care settings, an ecosystem where stigma is immensely common; and to address HIV-related stigma in health care institutions by targeting its actionable drivers, mainly lapses in education about HIV/AIDS, poor attitudes towards PLWH, and insufficient awareness of the presence of HIV stigma in health care settings.

References:

Adam, B. D., Murray, J., Ross, S., Oliver, J., Lincoln, S. G., & Rynard, V. (2011). Hiv stigma. com, an innovative web-supported stigma reduction intervention for gay and bisexual men. *Health Education Research, 26*(5), 795-807. DOI: 10.1093/her/cyq078

Audet, C. M., McGowan, C. C., Wallston, K. A., & Kipp, A. M. (2013). Relationship between HIV stigma and self-isolation among people living with HIV in Tennessee. *PLoS One, 8*(8), e69564. DOI: 10.1371/journal.pone.0069564

Baral, S. D., Poteat, T., Strömdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet Infectious Diseases, 13*(3), 214-222. DOI: 10.1016/S1473-3099(12)70315-8

Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., & Beyrer, C. (2013). Modified social ecological model: a tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC Public Health*, 13(1), 482. DOI: 10.1186/1471-2458-13-482

Baugher, A. R., Beer, L., Fagan, J. L., Mattson, C. L., Freedman, M., Skarbinski, J., & Shouse, R. L. (2017). Prevalence of Internalized HIV-Related Stigma Among HIV-Infected Adults in Care, United States, 2011–2013. *AIDS and Behavior*, 1-9. DOI: 10.1007/s10461-017-1712-y

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. PMID: 11746080

Caiola, C., Docherty, S., Relf, M., & Barroso, J. (2014). Using an intersectional approach to study the impact of social determinants of health for African-American mothers living with HIV. *ANS. Advances in Nursing Science*, *37*(4), 287. DOI: 10.1097/ANS.0000000000000046

Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, *95*(1), 53-59. DOI: 10.2105/AJPH.2003.028563

Chi, P., Li, X., Zhao, J., & Zhao, G. (2014). Vicious circle of perceived stigma, enacted stigma and depressive symptoms among children affected by HIV/AIDS in China. *AIDS and Behavior, 18*(6), 1054-1062. DOI: 10.1007/s10461-013-0649-z

Conyers, L., Boomer, K. B., & McMahon, B. T. (2005). Workplace discrimination and HIV/AIDS: The national EEOC ADA research project. *Work*, *25*(1), 37-48. PMID: 16006674

Crocker, J., Major, B., & Steele, C. (1998). Social stigma: The psychology of marked relationships. *The Handbook of Social Psychology*, 2, 504-553.

Denison, J. A., Tsui, S., Bratt, J., Torpey, K., Weaver, M. A., & Kabaso, M. (2011). Do peer educators make a difference? An evaluation of a youth-led HIV prevention model in Zambian Schools. *Health Education Research, 27*(2), 237-247. DOI: 10.1093/her/cyr093

Dizon, S. P. (2017). Reducing Stigma-Driven Health Disparities in People Living with HIV (PLWH): A Literature Review. *McNair Research Journal SJSU*, *13*(1), 7.

Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17*(2), 157-168. DOI: 10.1177/1359105311414952

Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2013). Stigma and racial/ethnic HIV disparities: moving toward resilience. *American Psychologist, 68*(4), 225. DOI: 10.1037/a0032705

Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and Behavior*, *17*(5), 1785-1795. DOI: 10.1007/s10461-013-0437-9

Enriquez, M., Kelly, P. J., Witt, J., Rodriguez, L., Lopez, N., Smueles, J., ... & Sweet, D. (2010). Silence is not golden: Invisible Latinas living with HIV in the Midwest. *Journal of Immigrant and Minority Health, 12*(6), 932-939. DOI: 10.1007/s10903-010-9346-4

Ferlatte, O., Salway, T., Oliffe, J. L., & Trussler, T. (2017). Stigma and suicide among gay and bisexual men living with HIV. *AIDS Care*, 1-5. DOI: 10.1080/09540121.2017.1290762

Feyissa, G. T., Abebe, L., Girma, E., & Woldie, M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health*, *12*(1), 1. https://doi.org/10.1186/1471-2458-12-522

Fletcher, F., Ingram, L. A., Kerr, J., Buchberg, M., Bogdan-Lovis, L., & Philpott-Jones, S. (2016). “She Told Them, Oh That Bitch Got AIDS”: Experiences of Multilevel HIV/AIDS-Related Stigma Among African American Women Living with

HIV/AIDS in the South. *AIDS Patient Care and STDs, 30*(7), 349-356. DOI: 10.1089/apc.2016.0026

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. DOI: 10.1089/apc.2007.0169

Geary, C., Parker, W., Rogers, S., Haney, E., Njihia, C., Haile, A., & Walakira, E. (2014). Gender differences in HIV disclosure, stigma, and perceptions of health. *AIDS Care*, *26*(11), 1419-1425. DOI: 10.1080/09540121.2014.921278

Genrich, G. L., & Brathwaite, B. A. (2005). Response of religious groups to HIV/AIDS as a sexually transmitted infection in Trinidad. *BMC Public Health*, *5*(1), 121. DOI: 10.1186/1471-2458-5-121

Giddens, A. (1984). *The Constitution of Society. Outline of the Theory of Structuration*. Cambridge: Polity.

Goffman, E. (1963). *Stigma. Notes on the Management of Spoiled Identity.* New York: Simon and Shuster.

Goldenberg, T., Vansia, D., & Stephenson, R. (2016). Intragroup stigma among men who have sex with men: data extraction from Craigslist ads in 11 cities in the United States. *JMIR Public Health and Surveillance, 2*(1). DOI: 10.2196/publichealth.4742

Golub, S. A., & Gamarel, K. E. (2013). The impact of anticipated HIV stigma on delays in HIV testing behaviors: findings from a community-based sample of men who have sex with men and transgender women in New York City. *AIDS Patient Care and STDs, 27*(11), 621-627. DOI: 10.1089/apc.2013.0245

Gottlieb, M. S., Schanker, H. M., Fan, P. T., Saxon, A., Weisman, J. D., & Pozalski, I. (1981). Pneumocystis pneumonia--Los Angeles. *MMWR. Morbidity and Mortality Weekly Report*, *30*(21), 250-252. PMID: 8778581

Grieb, S. M. D., Shah, H., Flores-Miller, A., Zelaya, C., & Page, K. R. (2017). HIV-Related Stigma Among Spanish-speaking Latinos in an Emerging Immigrant Receiving City. *Journal of Immigrant and Minority Health, 19*(4), 868-875. DOI: 10.1007/s10903-016-0497-9.

Hasan, M. T., Nath, S. R., Khan, N. S., Akram, O., Gomes, T. M., & Rashid, S. F. (2012). Internalized HIV/AIDS-related stigma in a sample of HIV-positive people in Bangladesh. *Journal of Health, Population, and Nutrition*, *30*(1), 22. PMID: 22524116

Herek, G. M. (2002). Thinking about AIDS and stigma: A psychologist's perspective. *The Journal of Law, Medicine & Ethics, 30*(4), 594-607. PMID: 12561266

Higgins, J. A., Hoffman, S., & Dworkin, S. L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health, 100*(3), 435-445. DOI: 10.2105/AJPH.2009.159723

HIV Among Transgender People. (2017, August 3). Retrieved from https://www.cdc.gov/hiv/group/gender/transgender/index.html

HIV in the United States: At A Glance. (2017, June 9). Retrieved from https://www.cdc.gov/hiv/statistics/overview/ataglance.html

HIV/AIDS Fact Sheet. (2017, July). Retrieved from http://www.who.int/mediacentre/factsheets/fs360/en/

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annual Review of Public Health*, *19*(1), 173-202. DOI: 10.1146/annurev.publhealth.19.1.173

Jacobs, D. B., & Sommers, B. D. (2015). Using drugs to discriminate—adverse selection in the insurance marketplace. *New England Journal of Medicine, 372*(5), 399-402. DOI:10.1056/NEJMp1411376

Jeffries IV, W. L., Townsend, E. S., Gelaude, D. J., Torrone, E. A., Gasiorowicz, M., & Bertolli, J. (2015). HIV stigma experienced by young men who have sex with men (MSM) living with HIV infection. *AIDS Education and Prevention, 27*(1), 58-71. DOI: 10.1521/aeap.2015.27.1.58

Kamen, C., Arganbright, J., Kienitz, E., Weller, M., Khaylis, A., Shenkman, T., ... & Gore-Felton, C. (2015). HIV-related stigma: implications for symptoms of anxiety and depression among Malawian women. *African Journal of AIDS Research, 14*(1), 67-73. DOI: 10.2989/16085906.2015.1016987

Kapesa, A., Magesa, D., William, A., Kaswija, J., Seni, J., & Makwaya, C. (2014). Determinants of immunological failure among clients on the first line treatment with highly active antiretroviral drugs in Dar es Salaam, Tanzania. *Asian Pacific Journal of Tropical Biomedicine*, 4, S620-S624. https://doi.org/10.12980/APJTB.4.2014APJTB-2013-0035

Kitara, D. L., & Aloyo, J. (2012). HIV/AIDS stigmatization, the reason for poor access to HIV counseling and testing (HCT) among the youths in Gulu (Uganda). *African Journal of Infectious Diseases*, *6*(1), 12-20. PMID: 23878711

Legal, L. (2010). HIV stigma and discrimination in the U. S.: An evidence-based report. *Lambda Legal: making the case for equality*, USA.

Lekas, H. M., Siegel, K., & Leider, J. (2011). Felt and enacted stigma among HIV/HCV-coinfected adults: The impact of stigma layering. *Qualitative Health Research*, *21*(9), 1205-1219. DOI: 10.1177/1049732311405684

Li, L., Guan, J., Liang, L. J., Lin, C., & Wu, Z. (2013). Popular opinion leader intervention for HIV stigma reduction in health care settings. *AIDS Education and Prevention, 25*(4), 327-335. DOI: 10.1521/aeap.2013.25.4.327

Lichtenstein, B. (2004). Caught at the clinic: African American men, stigma, and STI treatment in the Deep South. *Gender & Society, 18*(3), 369-388. DOI: 10.1177/0891243204264809

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*(1), 363-385. DOI: 10.1146/annurev.soc.27.1.363

Liu, H., Xu, Y., Lin, X., Shi, J., & Chen, S. (2013). Associations between perceived HIV stigma and quality of life at the dyadic level: the actor-partner interdependence model. *PLoS One*, *8*(2), e55680. DOI: 10.1371/journal.pone.0055680

Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: a qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Medicine, 8*(11), e1001124. DOI: 10.1371/journal.pmed.1001124

Logie, C. H., Wang, Y., Lacombe-Duncan, A., Wagner, A. C., Kaida, A., Conway, T., ... & Loutfy, M. R. (2017). HIV-related stigma, racial discrimination, and gender discrimination: Pathways to physical and mental health-related quality of life among a national cohort of women living with HIV. *Preventive Medicine,* 107*,* 36-44. DOI: 10.1016/j.ypmed.2017.12.018

Lopez, S. M. J., Ramiro, V. R., & Roxas, E. A. (2017). Measuring Stigma and Discrimination towards People Living with HIV among Health Care Workers in a Tertiary, Government Teaching Hospital in the Philippines. *Acta Medica Philippina*, *51*(4), 320.

Lorway, R., Thompson, L. H., Lazarus, L., du Plessis, E., Pasha, A., Fathima Mary, P., ... & Reza-Paul, S. (2014). Going beyond the clinic: confronting stigma and discrimination among men who have sex with men in Mysore through community-based participatory research. *Critical Public Health*, *24*(1), 73-87. DOI: https://doi.org/10.1080/09581596.2013.791386

Magnus, M., Herwehe, J., Murtaza-Rossini, M., Reine, P., Cuffie, D., Gruber, D., & Kaiser, M. (2013). Linking and retaining HIV patients in care: The importance of provider attitudes and behaviors. *AIDS Patient Care and STDs*, 27(5), 297-303.

Marcus, J. L., Chao, C. R., Leyden, W. A., Xu, L., Quesenberry Jr, C. P., Klein, D. B., ... & Silverberg, M. J. (2016). Narrowing the gap in life expectancy between HIV-infected and HIV-uninfected individuals with access to care. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *73*(1), 39. DOI: 10.1097/QAI.0000000000001014

Mhode, M., & Nyamhanga, T. (2016). Experiences and impact of stigma and discrimination among people on antiretroviral therapy in Dar es Salaam: a qualitative perspective. *AIDS Research and Treatment*, 2016. DOI: 10.1155/2016/7925052

Norr, K. F., Ferrer, L., Cianelli, R., Crittenden, K. S., Irarrázabal, L., Cabieses, B., ... & Bernales, M. (2012). Peer group intervention for HIV prevention among health workers in Chile. *Journal of the Association of Nurses in AIDS Care, 23*(1), 73-86. DOI: 10.1016/j.jana.2011.02.001

Ojikutu, B. O., Pathak, S., Srithanaviboonchai, K., Limbada, M., Friedman, R., Li, S., ... & Network, H. P. T. (2016). Community cultural norms, stigma and disclosure to sexual partners among women living with HIV in Thailand, Brazil and Zambia (HPTN 063). *PloS One, 11*(5), e0153600. DOI: 10.1371/journal.pone.0153600

Okello, E. S., Wagner, G. J., Ghosh-Dastidar, B., Garnett, J., Akena, D., Nakasujja, N., & Musisi, S. (2015). Depression, internalized HIV stigma and HIV disclosure. *World Journal of AIDS*, *5*(01), 30. DOI: 10.4236/wja.2015.51004

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, *57*(1), 13-24. PMID: 12753813

Paudel, V., & Baral, K. P. (2015). Women living with HIV/AIDS (WLHA), battling with HIV/AIDS (PLHA): Role of gender differences. *Indian Journal of Scientific Research, 5*(2), 35. https://doi.org/10.1186/s12978-015-0032-9

Pellowski, J. A., Kalichman, S. C., Matthews, K. A., & Adler, N. (2013). A pandemic of the poor: social disadvantage and the US HIV epidemic. *American Psychologist, 68*(4), 197. DOI: 10.1037/a0032694

Phillips, K. D., Moneyham, L., & Tavakoli, A. (2011). Development of an instrument to measure internalized stigma in those with HIV/AIDS. *Issues in Mental Health Nursing*, *32*(6), 359-366. DOI: 10.3109/01612840.2011.575533

Poundstone, K. E., Strathdee, S. A., & Celentano, D. D. (2004). The social epidemiology of human immunodeficiency virus/acquired immunodeficiency syndrome. *Epidemiologic Reviews*, *26*(1), 22-35. DOI: 10.1093/epirev/mxh005

Radhakrishna, K., Dass, D., Raj, T., Rakesh, D., Kishore, R., Srinivasan, K., ... & Ekstrand, M. L. (2017). Development of a Novel Tablet-based Approach to Reduce HIV Stigma among Healthcare Staff in India. *Perspectives in Health Information Management, 14*(Spring). PMID: 28566985

Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., ... & Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*, *6*(7), e011453. DOI: 10.1136/bmjopen-2016-011453

Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV- Positive women. *Journal of Nursing Scholarship, 36*(2), 122-128. PMID: 15227758

Sangaramoorthy, T., Jamison, A., & Dyer, T. (2017). Intersectional stigma among midlife and older Black women living with HIV. *Culture, Health & Sexuality*, 1-15. DOI: 10.1080/13691058.2017.1312530

Sears, B. (2008). HIV discrimination in health care services in Los Angeles County: the results of three testing studies. *Washington & Lee Journal of Civil Rights and Social Justice, 15*(1), 85-107.

Sevelius, J. M., Patouhas, E., Keatley, J. G., & Johnson, M. O. (2014). Barriers and facilitators to engagement and retention in care among transgender women living with human immunodeficiency virus. *Annals of Behavioral Medicine, 47*(1), 5-16. DOI: 10.1007/s12160-013-9565-8

Shacham, E., Rosenburg, N., Önen, N. F., Donovan, M. F., & Turner Overton, E. (2015). Persistent HIV-related stigma among an outpatient US clinic population. *International Journal of STD & AIDS*, *26*(4), 243-250. DOI: 10.1177/0956462414533318

Shah, S. M., Heylen, E., Srinivasan, K., Perumpil, S., & Ekstrand, M. L. (2014). Reducing HIV stigma among nursing students: A brief intervention. *Western Journal of Nursing Research, 36*(10), 1323-1337. DOI: 10.1177/0193945914523685

Stafford, M. C., & Scott, R. R. (1986). Stigma, deviance, and social control. In *The Dilemma of Difference* (pp. 77-91). Springer US.

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*(3Suppl 2). DOI: 10.7448/IAS.16.3.18734

Stringer, K. L., Turan, B., McCormick, L., Durojaiye, M., Nyblade, L., Kempf, M. C., ... & Turan, J. M. (2016). HIV-related stigma among healthcare providers in the deep South. *AIDS and Behavior, 20*(1), 115-125. DOI: 10.1007/s10461-015-1256-y

Sumari-de Boer, I. M., Sprangers, M. A., Prins, J. M., & Nieuwkerk, P. T. (2012). HIV stigma and depressive symptoms are related to adherence and virological response to antiretroviral treatment among immigrant and indigenous HIV infected patients. *AIDS and Behavior*, *16*(6), 1681-1689. DOI: 10.1007/s10461-011-0112-y

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. DOI: 10.1037/0278-6133.25.4.501

Takada, S., Weiser, S. D., Kumbakumba, E., Muzoora, C., Martin, J. N., Hunt, P. W., ... & Tsai, A. C. (2014). The dynamic relationship between social support and HIV-related stigma in rural Uganda. *Annals of Behavioral Medicine, 48*(1), 26-37. DOI: 10.1007/s12160-013-9576-5

Talbert-Slagle, K. M., Canavan, M. E., Rogan, E. M., Curry, L. A., & Bradley, E. H. (2016). State variation in HIV/AIDS health outcomes: the effect of spending on social services and public health. *AIDS (London, England)*, *30*(4), 657. DOI: 10.1097/QAD.0000000000000978

Tesfaw, G., Ayano, G., Awoke, T., Assefa, D., Birhanu, Z., Miheretie, G., & Abebe, G. (2016). Prevalence and correlates of depression and anxiety among patients with HIV on-follow up at Alert Hospital, Addis Ababa, Ethiopia. *BMC Psychiatry*, *16*(1), 368. DOI: 10.1186/s12888-016-1037-9

The HIV/AIDS Epidemic in the United States: The Basics. (2017, February 2). Retrieved from http://www.kff.org/hivaids/fact-sheet/the-hivaids-epidemic-in-the-united-states-the-basics/

Turan, B., Budhwani, H., Fazeli, P. L., Browning, W. R., Raper, J. L., Mugavero, M. J., & Turan, J. M. (2017). How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. *AIDS and Behavior*, *21*(1), 283-291. DOI: 10.1007/s10461-016-1451-5

Turan, B., Smith, W., Cohen, M. H., Wilson, T. E., Adimora, A. A., Merenstein, D., ... & Tien, P. C. (2016). Mechanisms for the negative effects of internalized HIV-related stigma on ART adherence in women: the mediating roles of social isolation and depression. *Journal of Acquired Immune Deficiency Syndromes (1999), 72*(2), 198. DOI: 10.1097/QAI.0000000000000948

Whetten, K., Ostermann, J., Whetten, R. A., Pence, B. W., O'Donnell, K., Messer, L. C., ... & Positive Outcomes for Orphans (POFO) Research Team. (2009). A comparison of the wellbeing of orphans and abandoned children ages 6–12 in institutional and community-based care settings in 5 less wealthy nations. PLoS *One*, *4*(12), e8169. DOI: 10.1371/journal.pone.0008169

Wohl, A. R., Galvan, F. H., Carlos, J. A., Myers, H. F., Garland, W., Witt, M. D., ... & George, S. (2013). A comparison of MSM stigma, HIV stigma and depression in HIV-positive Latino and African American men who have sex with men (MSM). *AIDS and Behavior, 17*(4), 1454-1464. DOI: 10.1007/s10461-012-0385-9

Yakhmi, S., Sidhu, B. S., Kaur, B., & Dalla, E. K. (2014). Study of HIV related stigma in people living stigma, discrimination and denial and the role of support groups as a coping strategy: a review of literature. *Reproductive Health, 12*(1), 53. ISSN: 2250-0138 (Online)

Yi, S., Chhoun, P., Suong, S., Thin, K., Brody, C., & Tuot, S. (2015). AIDS-related stigma and mental disorders among people living with HIV: a cross-sectional study in Cambodia. *PloS One*, *10*(3), e0121461. DOI: 10.1371/journal.pone.0121461

CHAPTER 2

Women of Color Reflect on HIV-related Stigma through PhotoVoice

Abstract

HIV-related stigma affects people living with HIV (PLWH), especially in communities of color. In our study, African American and Latina/Hispanic women living with HIV (WLWH) described experiences of stigma through PhotoVoice, a community-based participatory method of documentary photography. Ten WLWH from Los Angeles documented stigma experiences through photographs for up to 5 weeks and discussed their images during a focus group or semi-structured individual interview. Qualitative Interpretative Phenomenological Analysis of participant narratives and photographs revealed lack of education and cultural myths as the main triggers of the stigma our participants faced. Stigma was experienced in health care settings, and participants identified depression, fear of intimate relationships, and nondisclosure of HIV status as its consequences. Social support and faith were noted as key coping mechanisms. WLWH recommended involving PLWH and public health officials in stigma reduction campaigns and youth education. PhotoVoice was perceived as a useful tool for education and self-improvement.

Key words: African American, HIV stigma, Latina/ Hispanic, phenomenology, PhotoVoice, women of color

Introduction

Stigma and discrimination toward people living with HIV (PLWH) has been common. Research has reported that approximately one-third of PLWH experience some form of stigma due to their HIV status (Sorsdahl, Mall, Stein, & Joska, 2011). Experts have agreed that HIV stigma stems from judgment-based views about certain lifestyles, ignorance about HIV transmission, and fear of contagion (Anderson, 2009). HIV-related stigma has been shown to be more severe in women, and women experience higher rates of perceived public stigma (Aggleton, Wood, Malcolm, & Parker, 2005; dos Santos, Kruger, Mellors, Wolvaardt, & van der Ryst, 2014; Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006; Winskell, Hill, & Obyerodhyambo, 2011). Additionally, women were found to be more likely to experience internalized stigma (Sorsdahl et al., 2011). These trends are likely due to social and gender inequalities as well as economic, biologic, and environmental factors (Ramjee & Daniels, 2013). Unfavorable outcomes of HIV-related stigma include higher rates of self-isolation (Audet, McGowan, Wallston, & Kipp, 2013), depression (Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), and nondisclosure of HIV status (Jeffries et al., 2015). HIV stigma hampers prevention efforts by hindering access to life-saving services (Sevelius, Patouhas, Keatley, & Johnson, 2014).

HIV-related stigma is associated with loss of social support (Varas-Dıaz, Serrano-Garcıa, & Toro-Alfonso, 2005). The degree to which PLWH manage HIV-related stigma is associated with available resources including social support (Galvan, Davis, Banks, & Bing, 2008). Women have been more likely to seek social support compared to men (Audet et al., 2013), with women of color relying primarily on family, friends, and the community (Galvan et al., 2008). African American women and Latinos/Hispanics report higher levels of perceived HIV-related stigma and lower perceptions of social support (Galvan et al., 2008; Larios, Davis, Gallo, Heinrich, & Talavera, 2008).

Previous studies have focused on measuring stigma in different population groups as well as on stigma reduction interventions (Sekoni & Owoaje, 2013). Very few studies, however, have examined personal accounts from US-based women of color describing their specific experiences with HIV stigma within a group or a one-on-one interview setting. Furthermore, the use of PhotoVoice to facilitate dialogue about HIV stigma has also been limited (Wang & Burris, 1997). Studies have found that shared experiences and peer support by women living with HIV (WLWH) can be beneficial, particularly because addressing HIV stigma provides an opportunity to voice concerns (Jelliman, 2012). Similarly, PhotoVoice has been shown to be an effective tool for describing personal experiences and synthesizing solutions to problems (Moletsane et al., 2009). PhotoVoice also has been found to facilitate empowerment of economically disadvantaged minority WLWH (Teti, Pichon, Kabel, Farnan, & Binson, 2013), to promote adaptation of HIV prevention programs (Kubicek, Beyer, Weiss, & Kipke, 2012), define health priorities (Teti, Murray, Johnson, & Binson, 2012), and facilitate interpretation of stigma and discrimination (Moletsane et al., 2009). To address the aforementioned gaps in existing scholarship, we examined personal HIV-stigma experiences in Latina/Hispanic and African American women using Photovoice.

Methods

Recruitment and Setting

Nonrandom convenience sampling was utilized to recruit 10 WLWH from a Los Angeles-based HIV specialty center during routine clinic visits. Inclusion criteria included: ages 18 years or older, self-identification as African American or Latina/Hispanic female, fluent in English or Spanish, experience with stigma, and willingness to provide written informed consent. Once participants were screened for eligibility and agreed to participate in the study, written informed consent was obtained in a private area of the clinic. Participants also signed photo release forms for publication and exhibition of photos. The institutional review boards of the University of California, Irvine and the University of Southern California approved the study. Each participant received three $50 USD gift cards, totaling $150 USD, for study participation.

Procedures

Participants were provided with a digital camera to take photographs based on their critical reflections about HIV-related stigma. Upon enrollment in the study, participants attended a one-time, 2-hour Photo-Voice training session facilitated by a professional photojournalist. Participants learned the concept of PhotoVoice, digital camera use, photography ethics, and personal safety. After taking the photographs, participants were asked to select five to six photographs of their choice, to record the meaning of each photograph in a contextual journal, and to assign a caption to each in preparation for a focus group (FG) discussion or a semi-structured individual interview. The FG discussion and interviews were audio-recorded and transcribed verbatim for data analysis by hand as well as using ATLAS.ti (ATLAS.ti Scientific Software

Development GmbH, Berlin, Germany) to better organize and retrieve data. A certified professional Spanish interpreter was present during the PhotoVoice training session and translated the contents of the session to one monolingual Spanish-speaking participant. The interpreter also translated the semi-structured individual interview with the same participant.

Data Analysis

Interpretative Phenomenological Analysis was used to analyze FG and interview transcripts as well as the submitted photographs. Interpretative Phenomenological Analysis is the study of structures of consciousness as experienced from the first-person point of view that enables focus on the description and meaning of the experience (Groenewald, 2004). Additionally, interpretive research seeks to understand lived experiences and extract meanings of phenomena from lives, thoughts, and ideas. The purpose of this work, thus, was to comprehend HIV stigma as defined and described by women of color living with HIV and how they made sense of these experiences. The rationale for analyzing study data within a phenomenological framework was twofold. First, HIV-related stigma has been theorized in numerous studies as a phenomenon rooted in social and structural injustice that impedes quality of life. Furthermore, it has been extensively illustrated that stigma is the result of ungrounded and irrational fear of contagion as well as value-based judgments. However, nuances in minority women's experiences with HIV stigma are scarce in the literature and using phenomenology allows for such details to emerge (Moustakas, 1994).

Discussion and interview transcripts were first read in their entirety by the lead researcher to assess the global nature of the phenomenon under investigation. Photographs and their respective captions were reviewed to understand their relationships to HIV stigma. The lead researcher identified and highlighted topics in need of further clarification from study participants and wrote summaries of initial impressions, descriptions, and interpretations. Study respondents were contacted and asked if their experiences seemed accurate in the way we interpreted the findings. Based on these responses, we were able to verify and add more complexity to the findings. Following the verification process, the files were uploaded to ATLAS.ti in preparation for coding, annotations, and memo writing. Coding was also done by hand. To develop a refined coding scheme, we coded the unstructured text/data segments line by line based on their meaning and compared codes from different sections of the data to maintain organization and to reduce coding redundancies. Photographs and their respective captions were coded on the premise of their relationships to stigma and overall messages. Codes were then grouped into categories and concepts based on their specific themes and meanings. The first round of data coding led to 12 broad thematic categories, which were reviewed and subsequently collapsed into seven specific categories. From each of the seven categories, we identified and extracted common and unique clusters of meaning in the context of HIV stigma (Refer to Figure 2.1). The aforementioned steps for phenomenological data analysis of interview and focus group data were drawn from previously published works (Hycner, 1985; Palmer, Larkin, de Visser, & Fadden, 2010).

Figure 2.1 about here

Results

Participant Characteristics

We approached a total of 15 women during their routine clinic visits and 10 agreed to enroll in the study. Participants consisted of 10 women of color living with HIV and obtaining care at a Los Angeles-based HIV specialty center. Six were Latina/Hispanic and four were Black/African American. The mean age of study participants was 37.5 years (*SD*=8.24). Nine study participants had at least a high school diploma and one participant was employed at the time of the study. The majority of the women in the study was single or in a domestic partnership, with two women legally married at the time of the study. Nine participants were born in the United States and one in Mexico. Eight women were English-speaking, one bilingual, and one monolingual Spanish-speaking.

Data were collected between September 2013 and March 2014. The participants took more than 100 photos for the study. Each participant chose five to six favorite photographs for discussion during an FG or a semi-structured individual interview, for a total of 54 photos from all participants. Four participants agreed to participate in a one-time FG discussion, while the remaining six opted for a one-on-one semi-structured interview due to personal discomfort or scheduling conflicts. The participants were asked to critically reflect on their photos during the FG and interview, to provide their perspectives on the definition of stigma, causes of stigma, and the impact or consequences of stigma, as well as recommend ways to reduce stigma. The lead researcher also followed up with study respondents on at least one occasion to get their perceptions of the degree to which the analyses/interpretations reflected their experiences and to provide for triangulation of the data analysis.

Participants defined HIV stigma as a social phenomenon characterized by differential treatment. Two primary themes for the causes of stigma emerged from the narratives: (a) ignorance/lack of education and (b) cultural myths. Two sub-themes were identified in the context of stigma experienced in health care settings: (a) treatment refusal/irrational fear and (b) indiscretion with status. The consequences of stigma included (a) depression, (b) fear of dating and intimacy, and (c) unwillingness to disclose HIV status. To cope with stigma, participants highlighted social support from family members and reliance on faith. PhotoVoice helped some participants develop a more positive thought process about the diagnosis and helped with self-expression. PhotoVoice was also perceived as an effective method for health education. Community education and involvement of PLWH and public health officials in stigma reduction campaigns were identified as ways to address stigma.

Defining HIV Stigma

Study participants were asked to describe what HIV stigma meant to them and how they characterized it based on their own unique experiences. Participants defined stigma as a series of discriminatory acts resulting from people’s unwillingness to ‘‘learn the truth’’ about HIV, how it was transmitted, and whom it affected. They stated that stigma consisted of judgments, misconceptions, and inaccurate notions about PLWH, their moral characters, and lifestyle choices. As a result of these inaccurate appraisals, PLWH were made to feel ‘‘dirty,’’ ‘‘different,’’ ‘‘isolated,’’ and ‘‘stained.’’ Respondents also noted that stigma was a distinct act of segregation between the perceived ‘‘morally impure'' and the ''morally elite,'' a ''silencer of one's voice,'' a ''killer of beauty,'' and a systematic marking of PLWH as ''unworthy'' and ''blemished.'' One particular participant defined her experiences with HIV stigma as the ''Scarlett A,'' referring to Nathaniel Hawthorne's 1850 novel, The Scarlett Letter. She explained that, much like the protagonist in the novel who was ostracized by her community for committing perceived morally reprehensible acts, she was similarly condemned, blamed, and marginalized for contracting HIV. Overall, stigma was perceived as a process of devaluation. To capture the concept of devaluation using PhotoVoice, one study participant photographed one-cent coins (Refer to Figure 2.2).

Figure 2.2 about here

She reported that this photograph was a description of her internalized HIV-related stigma and it had two distinct meanings. One, pennies were virtually without value in the real world and this reflected the depreciation that PLWH often endured. And two, one of the pennies in the photograph was tarnished compared to the others, and this represented the systematic isolation of PLWH as well as their categorization as having a blemished moral character.

Triggers of Stigma

Lack of education/ignorance. Respondents felt that people held inaccurate and ignorant assumptions about PLWH and WLWH, including the notion that all PLWH and WLWH engaged in unprotected sexual behaviors with multiple partners and had sexual appetites in excess of normal. Furthermore, they shared that society assumed that these two factors inevitably placed women in precarious situations, thereby facilitating HIV acquisition. They explained that individual sexual behaviors could not always predict HIV infection or describe every woman’s story. Additionally, a monogamous relationship wasn’t always protective, and casual relationships might not necessarily expedite HIV infection. As one participant stated:

> People think that just being promiscuous, just people, feel your behavior of being promiscuous, you’re a ho, that’s why you got it, and you’re nasty. I feel like people they do stigmatize people as having overly sex drive or just having a woman happen to have more than one man.

The same woman continued to explain that stigma and discrimination of WLWH stemmed from inaccurate appraisals and the assumption that PLWH contract HIV only from illicit sexual behaviors and abnormal sexual drives.

Cultural myths. Participants described maltreatment of PLWH as not only a product of personal beliefs, but also the result of one’s unique cultural upbringing that shaped and operationalized beliefs into actions. For instance, colloquial understandings of diseases such as HIV regulated people’s behaviors and expressions and led to consensuses about what was normal and socially acceptable. With respect to cultural myths, for instance, one participant said that older members of her family often divulged information about sex and health. For instance, her mother and grandmother informed her that she could not become pregnant from her first sexual encounter. Ironically, years later she became pregnant in that very way. She explained that ‘‘stories’’ and alleged ‘‘truths’’ were deeply rooted in sociocultural norms, which, in her case, included growing up as an African American female in the South.

Another study participant described cultural myths in the context of antiretroviral medications. While she was aware that antiretroviral medications were life-saving medications, some members of her family tried to convince her otherwise by expressing their distrust of the medical community. She explained that her more ‘‘traditional’’ grandmother informed her that the efficacy of her medications would eventually fail, as they were cheaper imitations of drugs prescribed to the wealthy. She stated:

> My grandmother, she’s old school, and she was like, ‘‘Well that medicine is not going to work for you, you know, maybe down the line.’’ And I’m like, I’m distraught, I’m like, ‘‘What? What are you saying?’’ Because they’re telling me that this is the new hope like you’re gonna live you know … longer than people have lived before. I’m thinking I got something and she’s like, ‘‘No,’’ because richer people they can afford the better medicine they give you the cheap stuff, you know.

She continued to say that cultural myths about HIV were far from health care realities and could have detrimental effects on PLWH. These included diminished hope and perseverance, and derailment from appropriate treatments and support services. Participants collectively noted that cultural constructions of HIV disease had to be aggressively challenged because they trickled down from one generation to another, created potentially irreversible versions of the truth, and impacted real people. To address myths, they emphasized the critical need for people to consult with reliable sources for accurate information and to not accept things without appropriate scrutiny.

Experiences of HIV Stigma in Health Care Settings

Treatment refusal and irrational fear. Study participants reported that they experienced HIV stigma in health care settings and directed from health care providers including physicians, dentists, and medical assistants. They stated that although health care workers received more education, their service delivery to PLWH was, at times, muddled with stigma and discrimination. One respondent shared her story of being refused treatment and unreasonable precautions taken by a dentist. She said that a few years ago a dentist was reluctant to care for her because he saw in her medical chart that she had HIV and he attempted to refer her to a dental provider who specialized in infectious diseases. She reported that the staff at the dental office also ‘‘looked at her funny’’ and physically distanced themselves from her. This experience was perceived as a significant trauma and, as a result, the participant in question avoided dental care for several years. She verbalized:

> They put me aside and they started double-gloving. They dismissed me and left me to the last person. They saw everybody and saw me last, and that made me feel really bad and to the point that I didn’t go to the dentist for 7 years.

To document this reflection using PhotoVoice, the participant in question captured an image of her front teeth and captioned the photograph ‘‘HIV-stigma and Decay!’’ (Refer to Figure 2.3). The photograph was explained as having two main points. One, HIV stigma precluded her from obtaining necessary dental care and this led to severe tooth decay. While she has since fixed some of her teeth, the incident took a long time to overcome. Two, she stated that health care professionals, including dentists, needed to be educated that they could not contract HIV from touching someone’s teeth, and that their irrational fears had human costs.

Figure 2.3 about here

Another respondent recalled an incident of irrational fear at a hospital where she was admitted for pneumonia. She said that the physician in charge of her care placed a rubber glove on the stethoscope prior to examining her lungs. The same medical provider stood far away from her and avoided touching her as much as possible while attempting to perform an examination. She noted:

> When he saw my chart and he saw HIV, he instantly put a glove on the stethoscope and from really far away touched me with the glove on the stethoscope and I was like, I'm not gonna infect you just by you know touching me with that little stethoscope.

This experience left the patient incredulous and distraught because, she said, such reactions should not come from health care providers because PLWH depended on them for care. She noted that HIV-related education particularly about transmission must be reinforced because biased health care might have dire consequences for patients. To illustrate this incident visually, the participant took a photograph of a rubber glove covering a stethoscope pressed against a person's back and captioned it ‘‘Doctors Should Know Better!’’ (Refer to Figure 2.4).

Figure 2.4 about here

Indiscretion with HIV status. Ethical misconduct was also identified as a prominent form of stigma and discrimination of PLWH in health care settings. Participants described several incidents in which health care providers were indiscreet with their personal health information such as their HIV status. One participant described an incident at her physician's office where she was receiving care for asthma. She attended a health care visit with a friend and the physician began asking her questions about underlying medical conditions while reviewing her medical record. The patient denied having other medical ailments apart from asthma. The physician, unsatisfied with her response, proceeded to ask her in front of her companion whether or not she had HIV. The participant reported feeling angry that the physician failed to keep her status confidential in the presence of her friend who may have been unaware of her HIV status. She stated:

> I wanted to really take that man and strangle his freaking neck, it's like, ''Why would you do that, you don't even know if this person knows or not,'' that was the first time it was done to me.

She continued, saying that a second incident of similar nature took place when an asthma specialist approached her in the presence of other patients in a small waiting room and informed her that her T-cell count was low. She reported:

> You know it's hard enough, and then you're gonna come and ask me this, and then he's like, ''OK well … you know … you know your T-cells, your CD4 cells,'' it is what it is, it's like 100 something, 200, or I don't know, but it was low.

The participant said that during this incident, she was newly diagnosed with HIV, was pregnant, and experienced severe asthmatic attacks, and the physician's lack of discretion made her feel worse about herself.

Overall, participants thought that protection of one's personal medical information should be a top priority for health care professionals and negligence thereof was a violation of fundamental human rights.

Impact of HIV Stigma

Depression. Study participants expressed that perceived and internalized stigma related to their HIV status was responsible for intense depression that interfered with quality of life. Depression resulted from feeling ‘‘dirty,’’ ‘‘contagious,’’ ‘‘unwanted,’’ and ‘‘undesirable,’’ and for most women, these descriptions were a product of enacted stigma directed from previous intimate partners. Some respondents also noted that nondisclosure of HIV status contributed significantly to depression as they were unable to live openly and freely; seek vital social support from friends, loved ones, and the community; and carry on with their lives as whole human beings. One participant specified that having HIV and enduring stigma prevented her from fulfilling her sexual needs and this made her feel ‘‘cut off’’ from intimacy and love. A few respondents affirmed that they were unable to feel and be happy because HIV and the lingering stigma overshadowed other aspects of their lives. In reference to this particular experience, one woman stated:

> I do have other problems and HIV is just a little part of it, but dealing with HIV on a daily basis and the stigma and what people think makes me feel so stressed out and so depressed and so caged in.

She continued to say that HIV stigma silenced her voice and diminished her desire to continue working as an advocate for women. As a result, she became increasingly withdrawn from the world. Moreover, nondisclosure of her HIV status to her family and social networks made it particularly challenging to adopt effective coping skills. The inability to manage stigma resulted in depression symptoms and significant stress. A recently diagnosed participant said that her HIV diagnosis and the socially shared judgment of others about PLWH made her feel despondent and depressed. Moreover, she forced herself to hide her depression because she did not want to be perceived as ‘‘vulnerable’’ or ‘‘broken down’’ and wanted to avoid any potential questioning from others. However, suppressing her feelings actually exacerbated her depression symptoms and prevented her from experiencing joy and fulfillment.

Fear of dating and intimacy. Study respondents stated that they developed an intense fear of dating and intimacy from having experienced HIV-related stigma. They explained that the fear originated from rejection, verbal abuse, and overall disparagement from past partners. One woman said that she always disclosed her HIV status to potential partners but this disclosure often came with discouraging consequences. She specifically referred to an incident where a partner told her that she was ‘‘contagious’’ and ‘‘dirty’’ and that no man would ever want to be with her, stating:

> If it came to sex, they found it difficult to get there, you know, they’ll be like, ‘‘No I can’t,’’ or, you know, anything. So, to me I felt with the biohazard … I felt that might be a mindset of theirs, like it’s contagious, it’s infected … to me, I felt like immediately when I told them my situation, that’s how they felt like, ‘‘Oh no, we can’t have sex, it’s nasty, she’s dirty.’’ They just kind of summed up who I am.

To demonstrate the reactions of others to her HIV as well as her own internalized fear using PhotoVoice, she captured a photograph of a biohazard sign pointed toward her genital region (Refer to Figure 2.5).

Figure 2.5 about here

Other participants stated that stigma prevented them from intimate relationships altogether. The reasons for these feelings were that engaging in sexual relationships would entail disclosing their HIV status and some of them weren't prepared to do so. They anticipated harsh judgment, lack of compassion, and repudiation from potential intimate partners. Collectively, the group felt that stigma and discrimination created a forceful barrier that obstructed their intra- and interpersonal relationships and deprived them of normalcy. As one respondent verbalized:

> I feel like this disease is holding me back from what I can actually do, from I can actually have sex, or I can actually touch anybody, because at a point in time I have to then turn and have to have this conversation with them about HIV that I don't think I'm ready to have.

Unwillingness to disclose status. In our study, stigma was related to unwillingness to disclose HIV status. Participants had major concerns about disclosing their HIV status, as they feared prejudice. With respect to intimate partners, some participants feared that their HIV status would not be embraced, while others anticipated harsh moralistic and value-based judgments. Participants also revealed working hard to keep their HIV a secret because disclosure could have serious implications in the context of their personal, family, workplace, and community relationships. As one respondent stated:

> I feel like I'm in darkness and if I'm trying to disclose, I'm trying to step into the light but it keeps, I feel like something, it's a barrier that I can't get through because people are going to judge me, they are gonna say, ''You're dirty'' or ''You're nasty.''

HIV stigma was also perceived as a governing force that kept some study participants bound and controlled, and, as a result, they were unable to make good decisions. One participant explained that she felt bound by HIV because of a traumatizing experience at work. She disclosed her HIV status to her superior and over time noticed that her position and duties became increasingly restricted and she was subsequently demoted. She felt that this incident led to severe internalized stigma and self-stigmatization as she began to feel inadequate and questioned her abilities.

Another participant stated that HIV stigma kept her locked in an unhappy and unfulfilling relationship with an unfaithful partner. She stated that, despite his indiscretions, he was aware and accepting of her HIV infection. Because she didn't want to disclose her status to a prospective partner out of fear of being maligned, she made the decision to stay with him.

Coping with HIV Stigma

Social support and faith. HIV-related stigma negatively impacted the lives of the women who participated in this study. However, availability of social support and their own faith mitigated some of the effects of stigma. To combat stigma specifically, some participants reached out to family members who were aware of their HIV status and were supportive. They stressed that social support was a critical ingredient in their lives as it improved their coping skills and resiliency, and reinforced healthy behaviors such as medication adherence. One woman stated:

> If you don't have your family supporting you, and basically riding for you, you don't have that protection so you're easily stigmatized … it's like it just hits you

> like a ton of bricks and you’re not going to take your medicine you know because this is going to cause depression.

For this respondent, social support from members of her family made her feel protected, safe, and less stigmatized. Another woman added that the health care providers at the facility where she received her HIV care were also instrumental in supporting her and raising her self-esteem to cope with the disease. She expressed that she regularly referred to the staff of physicians and nurses as her ‘‘angels’’ because they helped her establish trust after being mistreated by other health care workers. Additionally, she revealed that social support from her health care team allowed her to openly discuss her feelings about living with HIV, and this was something that she hadn’t been able to do before.

Other respondents reported that having faith in God was also an effective coping strategy for dealing with HIV and the psychological harms that resulted from internalized stigma. This finding was particularly noteworthy in African American study participants. One participant shared a painful experience of suicidal ideation after her diagnosis. She revealed that being diagnosed with a potentially life-threatening illness, dealing with stigma, and not receiving support, pushed her into a dark place from which she felt she couldn’t emerge. Her strong faith, however, prevented her from taking her own life and gave her the strength to persevere. She stated:

> … I didn’t have anybody. I didn’t feel like, I still don’t have anybody, I haven’t gotten any help, you know mentally, anything, you know, and at that time I felt like I just wanted to take my life and the only thing that really kinda saved me was God.

Another participant added that stigma associated with HIV led to depression and, in order to cope with the depression, she also turned to her god. She stated:

> … There are some needs that I have that cannot be filled anymore. I'm going through depression, I have to seek other needs now, and that's pretty much what turned me to God and I needed that.

Overall, participants highlighted the importance of having faith as they navigated through their lives with HIV and stigma. They agreed that faith helped them cope and gave them the necessary self-confidence and guidance to move forward with their lives in a meaningful way.

The Role of PhotoVoice

Critical reflection through autobiographical photography was identified as a therapeutic process. Respondents said that PhotoVoice stimulated experiential expression of their struggles with stigma and compelled them to think about it in a more constructive and positive way. PhotoVoice also helped some of the study participants with their self-esteem and confidence, so that they could advocate for others. One respondent described how PhotoVoice provided her with self-assurance to educate newly diagnosed women about HIV disease. She stated:

> Honestly, I was afraid but it helped me to feel more assured of myself, like if a person were gonna tell me that you're gonna die, I would just say, ''No,'' and now it's also helping women who are just starting out.

Participants emphasized that PhotoVoice might be a useful methodological tool to educate youth about HIV, risk reduction, and social stigma. They suggested the implementation of two-pronged photography-based projects within school curricula. The first would focus on developing socially relevant photographs to facilitate discussion of controversial and sensitive topics. The second would focus on critical reflection and active dialogue between students and teachers to promote interactive learning.

PhotoVoice was also recognized as a potentially effective tool for the HIV community to voice struggles and triumphs. They thought that, because HIV often silenced people due to its unrelenting and unshakeable stigma, PhotoVoice could be tailored to promote dialogue of shared concerns and struggles, boost HIV-related education, and help communicate accurate and socially relevant knowledge to the public. With respect to specific benefits of PhotoVoice for people impacted by HIV, one study participant stated:

> I think it's a really good way for people to speak, to start talking about the issue. I think it's excellent for someone who's just learning, that's just dealing with, that's a voice, PhotoVoice, for someone who cannot speak.

She continued to say that PhotoVoice could be an effective mechanism for newly diagnosed individuals who were just learning about HIV, struggling to make sense of it, and unable to speak freely about their experiences.

Recommendations for HIV Stigma Reduction

All study participants noted that HIV-related stigma was a significant impediment to their quality of life. To address stigma, they recommended (a) involving public health officials and PLWH in stigma reduction initiatives and (b) education of health care workers. One respondent explained that over the years she had seen a lot of effort on behalf of the HIV-uninfected community to challenge stigma. However, she emphasized that for maximum impact, it was critical for PLWH to participate in stigma reduction programs. Another participant stated that while she understood the apprehension of some PLWH to come forward, it was important for those who were open with their status to tell their stories and educate the public about the perils of stigma.

Participants also suggested that public health officials convey accurate information to the public consistently to dispel myths about how HIV was spread, populations heavily affected by HIV, and how to reduce risks. They stated that, in the early days of the HIV epidemic when many factors were uncertain, public health officials made misguided statements that shaped public perceptions of HIV and gave rise to stigma. To correct these errors and the lingering stigma that has impacted global efforts to contain the epidemic, study participants recommended that public health organizations keep communities informed about HIV with evidence-based information and dialogue. As one respondent shared, ‘‘They should go back and correct it … people listen to them, people will start understanding the stigma that they created needs to be undone.’’

Participants also emphasized that education of health care workers, including nurses, physicians, and dentists, was an important area for intervention. Study participants stated that, despite their extensive education, many health care workers exhibited behaviors consistent with stigma. Additionally, because PLWH have a direct and necessary relationship with health care providers, it was critical to target this group with specialized interventions. Programs would focus on HIV-related education, training of health care staff, behavior modification, and delivery of compassionate and safe health care to PLWH.

Discussion

The participants in our qualitative study included African American and Latina/Hispanic WLWH who were asked to reflect on their personal experiences with HIV-related stigma using PhotoVoice. Respondents identified lack of education and cultural myths as key triggers for HIV stigma; depression, fear of intimate relationships, and nondisclosure of HIV were seen as the consequences of stigma. Participants reported being stigmatized in health care facilities and by care providers including physicians and dentists. Social support and faith were identified as strategies that helped participants cope with stigma; these were prominent in African American respondents. PhotoVoice helped some participants develop a more constructive thought process about stigma and was perceived as an effective education tool.

Stigma is a debilitating barrier that negatively impacts the lives of PLWH. Stigmatizing attitudes and behaviors directed toward affected populations lead to immeasurable health and social consequences. Stigma reduction programs are, therefore, necessary to improve outcomes in PLWH and at-risk populations. Experiences of HIV stigma vary across populations and contexts and it is important to understand these intricacies in order to design effective intervention programs. Our study findings elucidated some of these nuances in African American and Latina/Hispanic women living with HIV.

Many of the findings of our study were consistent with existing literature, but several important differences are worthy of discussion. PLWH often experience blame and judgment for being perceived as having contracted the disease as a result of moral fault (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012). Although our study participants also reported feeling aspersed, they also perceived stigma as an act of separation of the morally impure (PLWH) and morally elite (persons without HIV). The concept of ‘‘us’’ and ‘‘them’’ in the context of HIV has been highlighted in published studies (Link & Phelan, 2001), but the aforementioned moralistic distinction and its contextual factors have not been extensively examined. These distinctions have important implications for stigma reduction programs, which must continue to focus on normalization of HIV and PLWH to circumvent perceptions of HIV as something different or adulterated. In terms of the impact of HIV stigma, our findings were consistent with previously published research, showing that experiences with HIV stigma were associated with depressive symptoms, diminished quality of intimate relationships, and nondisclosure of HIV status (Jeffries et al., 2015; Sumari-de Boer et al., 2012). We also found that disclosure of HIV status was difficult for women due to anticipated stigma and might prevent some from seeking equitable relationships. The inferences of this finding were that it might be necessary to examine how relationship dynamics are influenced by HIV disease status and experiences with stigma in the context of power and gender.

Social support from family members was identified as a crucial factor in coping with HIV-related stigma and this has been supported by extant research (Galvan et al., 2008). However, our study participants did not identify social support from friends as a key factor, which was contrary to other published works (Galvan et al., 2008; Pichon, Rossi, Ogg, Krull, & Griffin, 2015). A possible explanation for this finding is that many study respondents anticipated stigma from their social networks and, therefore, kept their HIV status a secret. Similarly, some may have had strained social relationships to begin with and disclosing HIV was, therefore, not an option.

Existing studies have indicated that faith plays a critical role in the lives of some PLWH in the context of disease management. Religious affiliation has been shown to be a strong coping mechanism for HIV (Makoae et al., 2008). Furthermore, participation in religious events has been associated with a reduction in HIV symptoms (Chou, Holzemer, Portillo, & Slaughter, 2004). Conversely, other studies have indicated that shame related to HIV stigma was associated with religious beliefs and that HIV was the result of divine retribution (Muturi & An, 2010). For our study participants, particularly the African American respondents, faith was identified as an important method to manage stigma-related depression and HIV-disease-related suicidal ideation. Several studies also found that faith was an important coping instrument for HIV and overall psychological well-being (Trevino et al., 2010). However, the literature was scarce on the relationship between faith and suicidal ideation in PLWH, and this may be an important topic for future research.

Perhaps the most unique finding of our qualitative study was that critical reflection through PhotoVoice was a therapeutic process for self-improvement leading to improved self-esteem, confidence, and self-expression. While PhotoVoice has been used extensively in HIV research to describe the experiences of women living with HIV (Moletsane et al., 2007), little research has addressed the personal benefits of PhotoVoice. Additionally, although PhotoVoice has been widely used in the context of poverty (Teti et al., 2012), activism (Moletsane et al., 2007), healthy relationships (Teti et al., 2012), empowerment (Teti et al., 2013), and intervention endorsement (Kubicek et al., 2012), its use in defining and describing specific experiences with HIV-related stigma in women of color has been limited and is worthy of further investigation.

Our findings were consistent with a large body of evidence that HIV stigma is pervasive in health care institutions. HIV-infected persons have been refused or discouraged from health care services, have witnessed ungrounded fear of infection and excessive precaution-taking, and have endured physical distancing from their health care providers (Rahmati-Najarkolaei et al., 2010; Zukoski & Thorburn, 2009). However, some of our participants reported that health care settings and providers were also vital sources of support to reestablish trust and expression of voice about living with HIV. The implications of these findings are twofold. First, stigma-reduction programs for health care providers are necessary to reduce stigma in service delivery. Second, it may be important to examine the impact of provider-facilitated social support on health outcomes for PLWH.

Overall, the findings of our study may help inform quantitative work assessing HIV stigma in diverse populations and designing evidence-based reduction programs.

Interpretive Rigor

While our study makes significant contributions to the state of knowledge about stigma in women of color, it is also important to discuss its interpretive rigor. We drew from the published works of Yardley (2000) and Fossey, Harvey, McDermott, and Davidson (2002) to assess our qualitative interpretation of HIV stigma in women of color; we used commitment, rigor, transparency, and coherence as the evaluative criteria. Commitment and rigor were demonstrated by employing several methods of data collection and analysis. First, we used FG discussion and in-person interviews to collect data. Although phenomenological data analysis is typically applied to interview data, we were able to witness and interpret rich descriptions of HIV stigma from the group session as well as in individual interviews by asking open-ended questions. One notable difference between the FG setting and the one-on-one interview setting was that in the FG setting we witnessed group solidarity, peer support, and experience comparisons. Second, we asked each participant to record the meaning of each photograph in a contextual journal to help recall events and facilitate dialogue about their experiences, and this led to a more accurate interpretation of the data.

With respect to analysis and phenomenological interpretation of the data, several important strategies were adapted to increase validity and accuracy of the information. First, we employed an iterative and cyclical process to verify the information we collected. This entailed asking participants to clarify concepts/categories and make adjustments to the interpretation of the phenomena based on participant responses. Second, we returned to most participants with a written summary of findings to ensure that the collected data and interpretation thereof captured their specific realities. Transparency and coherence related to this work were achieved by explicitly stating how data were collected and analyzed. First, we described the setting from which participants were recruited and outlined the criteria used to select members of the target group. Second, we listed all relevant aspects of data analysis including reading through transcripts to familiarize ourselves with the phenomena under investigation, eliminating redundancies in text interpretation, and extraction of prominent themes from coded text grouped into specific categories. Third, we included verbatim quotations from the transcribed text and autobiographical photographs to illustrate specific reflections and to provide a range of opinions regarding experiences with HIV-related stigma.

Conclusion

HIV-related stigma was a considerable barrier in the lives of participants in this study and it led to a variety of unfavorable outcomes. Understanding HIV-related stigma from the perspective of African American and Latina/Hispanic women, groups disproportionately impacted by the HIV epidemic, was an important step toward developing tailored stigma reduction programs. We illustrated specific nuances in the ways HIV stigma was experienced by women of color, which must be explored to deepen our understanding of this phenomenon. For instance, we found that stigma was perceived as an act of segregation between those who were presumed to be morally elite and those who were not. Similarly, stigma might prevent some women from seeking healthy relationships due to fear of disclosure. Additionally, HIV specialty centers and health care providers can play an instrumental role in mitigating stigma experienced by women of color. Lastly, PhotoVoice is a therapeutic and empowering tool for women of color to express their voices and concerns in the context of HIV. Our study made two significant scientific contributions. First, to our knowledge this is the first research to explore personal accounts of HIV stigma in women of color using PhotoVoice. Second, although Interpretative Phenomenological Analysis is largely used to collect and analyze data from one-on-one interviews, it also generated rich experiential data in a group setting by allowing study participants to interact, compare and contrast realities, and help one another discuss difficult topics.

References

Aggleton, P., Wood, K., Malcolm, A., & Parker, R. (2005). *HIV-related stigma discrimination and human rights violations: Case studies of successful programmes*. Retrieved from http://data.unaids.org/publications/irc-pub06/JC999-HumRights Viol_en.pdf

Anderson, B. J. (2009). HIV stigma and discrimination persist, even in health care. *AMA Virtual Mentor*, *11*(12), 998-1001.

Audet, C. M., McGowan, C. C., Wallston, K. A., & Kipp, A. M. (2013). Relationship between HIV stigma and self-isolation among people living with HIV in Tennessee. *PLoS One*, *8*(8), e69564. http://dx.doi.org/10.1371/journal.pone. 0069564

Chou, F. Y., Holzemer, W. L., Portillo, C. J., & Slaughter, R. (2004). Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research, 53*(5), 332-339. http://dx.doi.org/10.1097/00006199-200409000-00008

dos Santos, M. M., Kruger, P., Mellors, S. E., Wolvaardt, G., & van der Ryst, E. (2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: The People Living with HIV Stigma Index. *BMC Public Health*, *14*(1), 80. http:// dx.doi.org/10.1186/1471-2458-14-80

Ekstrand, M. L., Bharat, S., Ramakrishna, J., & Heylen, E. (2012). Blame, symbolic stigma and HIV misconceptions are associated with support for coercive measures in urban India. *AIDS and Behavior*, *16*(3), 700-710. http://dx.doi.org/ 10.1007/s10461-011-9888-z

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry, 36*(6), 717-732. http://dx.doi.org/10.1046/j.1440-1614.2002.01100.x

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. http://dx.doi. org/10.1089/apc.2007.0169

Groenewald, T. (2004). *A phenomenological research design illustrated*. Retrieved from https://www.ualberta.ca/ iiqm/ backissues/3_1/pdf/groenewald.pdf

Hycner, R. H. (1985). Some guidelines for the phenomenological analysis of interview data. *Human Studies, 8*(3), 279-303. http://dx.doi.org/10.1007/BF00142995

Jeffries, W. L., IV, Townsend, E. S., Gelaude, D. J., Torrone, E. A., Gasiorowicz, M., & Bertolli, J. (2015). HIV stigma experienced by young men who have sex with men (MSM) living with HIV infection. *AIDS Education and Prevention, 27*(1), 58-71. http://dx.doi.org/10.1521/aeap.2015. 27.1.58

Jelliman, P. (2012). Identify needs of women living with HIV. *Nursing Times, 109*(22), 16-18.

Kubicek, K., Beyer, W., Weiss, G., & Kipke, M. D. (2012). Photovoice as a tool to adapt an HIV prevention intervention for African American young men who have sex with men. *Health Promotion Practice, 13*(4), 535-543. http://dx.doi. org/10.1177/1524839910387131

Larios, S. E., Davis, J. N., Gallo, L. C., Heinrich, J., & Talavera, G. (2008). Concerns about stigma, social support and quality of life in low-income HIV-positive Hispanics. *Ethnicity & Disease, 19*(1), 65-70.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*(1), 363-385. http://dx.doi. org/10.1155/2009/145891

Makoae, L. N., Greeff, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W., & Holzemer, W. L. (2008). Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in AIDS Care, 19*(2), 137-146. http://dx.doi.org/10.1016/j.jana.2007.11.004

Moletsane, R., de Lange, N., Mitchell, C., Stuart, J., Buthelezi, T., & Taylor, M. (2007). Photo-voice as a tool for analysis and activism in response to HIV and AIDS stigmatisation in a rural KwaZulu-Natal school. *Journal of Child and Adolescent Mental Health, 19*(1), 19-28. http://dx.doi. org/10.2989/17280580709486632

Moletsane, R., Mitchell, C., de Lange, N., Stuart, J., Buthelezi, T., & Taylor, M. (2009). What can a woman do with a camera? Turning the female gaze on poverty and HIV and AIDS in rural South Africa. *International Journal of Qualitative Studies in Education, 22*(3), 315-331. http:// dx.doi.org/10.1080/09518390902835454

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Muturi, N., & An, S. (2010). HIV/AIDS stigma and religiosity among African American women. *Journal of Health Communication, 15*(4), 388-401. http://dx.doi.org/10.1080/ 10810731003753125

Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology, 7*(2), 99-121. http://dx.doi.org/10.1080/14780880802513194

Pichon, L. C., Rossi, K. R., Ogg, S. A., Krull, L. J., & Griffin, D. Y. (2015). Social support, stigma and disclosure: Examining the relationship with HIV medication adherence among Ryan White Program Clients in the Mid-South USA. *International Journal of Environmental Research and Public Health, 12*(6), 7073-7084. http://dx.doi.org/10.3390/ ijerph120607073

Rahmati-Najarkolaei, F., Niknami, S., Aminshokravi, F., Bazargan, M., Ahmadi, F., Hadjizadeh, E., & Tavafian, S. S. (2010). Experiences of stigma in healthcare settings among adults living with HIV in the Islamic Republic of Iran. *Journal of the International AIDS Society, 13*(1), 27. http://dx.doi.org/ 10.1186/1758-2652-13-27

Ramjee, G., & Daniels, B. (2013). Women and HIV in sub-Saharan Africa. *AIDS Research and Therapy, 10*(30), 1-9. http://dx.doi.org/10.1186/1742-6405-10-30

Sekoni, O. O., & Owoaje, E. T. (2013). HIV/AIDS stigma among primary health care workers in Ilorin, Nigeria. *African Journal of Medicine and Medical Sciences*, *42*(1), 47-57.

Sevelius, J. M., Patouhas, E., Keatley, J. G., & Johnson, M. O. (2014). Barriers and facilitators to engagement and retention in care among transgender women living with human immunodeficiency virus. *Annals of Behavioral Medicine, 47*(1), 5-http://dx.doi.org/10.1007/s12160-013-9565-8

Sorsdahl, K. R., Mall, S., Stein, D. J., & Joska, J. A. (2011). The prevalence and predictors of stigma amongst people living with HIV/AIDS in the Western Province. *AIDS Care, 23*(6), 680-685. http://dx.doi.org/10.1080/09540121.2010. 525621

Sumari-de Boer, I. M., Sprangers, M. A., Prins, J. M., & Nieuwkerk, P. T. (2012). HIV stigma and depressive symptoms are related to adherence and virological response to antiretroviral treatment among immigrant and indigenous HIV infected patients. *AIDS and Behavior, 16*(6), 1681-1689. http://dx.doi.org/10.1007/s10461-011-0112-y

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. http://dx.doi.org/10.1037/0278-6133.25.4.501

Teti, M., Murray, C., Johnson, L., & Binson, D. (2012). Photovoice as a community-based participatory research method among women living with HIV/AIDS: Ethical opportunities and challenges. *Journal of Empirical Research on Human Research Ethics, 7*(4), 34-43. http://dx.doi.org/10.1525/jer. 2012.7.4.34

Teti, M., Pichon, L., Kabel, A., Farnan, R., & Binson, D. (2013). Taking pictures to take control: Photovoice as a tool to facilitate empowerment among poor and racial/ethnic minority women with HIV. *Journal of the Association of Nurses in AIDS Care, 24*(6), 539-553. http://dx.doi.org/10.1016/j.jana. 2013.05.001

Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, C. A., & Tsevat, J. (2010). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS and Behavior, 14*(2), 379-389. http://dx.doi.org/10.1007/s10461-007-9332-6

Varas-Dıaz, N., Serrano-Garcıa, I., & Toro-Alfonso, J. (2005). AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative Health Research, 15*(2), 169-187. http://dx.doi.org/10.1177/1049732304272059

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369-387. http://dx.doi.org/10. 1177/109019819702400309

Winskell, K., Hill, E., & Obyerodhyambo, O. (2011). Comparing HIV-related symbolic stigma in six African countries: Social representations in young people's narratives. *Social Science & Medicine, 73*(8), 1257-1265. http://dx.doi.org/ 10.1016/j.socscimed.2011.07.007

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228. http://dx.doi.org/10. 1080/08870440008400302

Zukoski, A. P., & Thorburn, S. (2009). Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: A qualitative analysis. *AIDS Patient Care and STDs, 23*(4), 267-276. http://dx.doi.org/10.1089/ apc.2008.0168

Figure 2.1: Process of Data Analysis

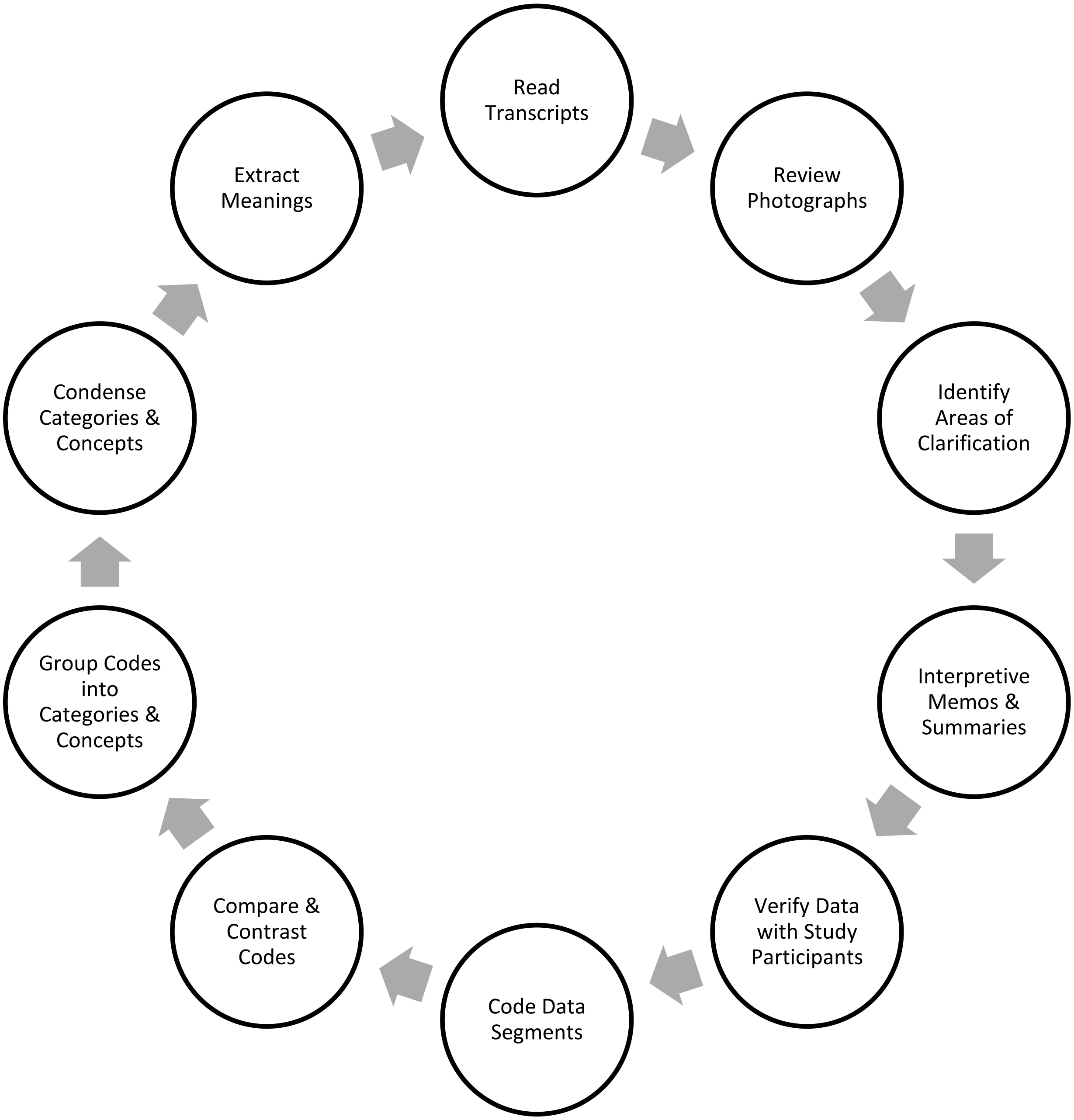


Figure 2.2: “Pennies are more valuable than me!”

Figure 2.3: “HIV Stigma and Decay!”

Figure 2.4: “Doctors Should Know Better!”

Figure 2.5: “Contagious!”

CHAPTER 3

A Grounded Theory Study of HIV-related Stigma in US-based Health Care Settings

Abstract

Despite progress made in the treatment and care of people living with HIV (PLWH), HIV-related stigma has remained persistent. Health care settings and workers have been identified as important sources of stigma. Studies have addressed the construct of stigma in US health care settings, but mainly from the perspectives of PLWH. We used Grounded Theory to understand how health care workers conceptualized HIV-related stigma and to develop a model to project a purposive view of stigma in health care settings. Our model indicates that stigma may be rooted in historically derogatory representations of HIV and intensified by power inequalities. Stigma may be triggered by fear, inadequate clinical education and training, unintentional behaviors, and limited contact with PLWH. Study participants perceived stigma as injurious to patient and provider health outcomes. Additional research on provider perceptions of stigma and programs that encourage empowerment, communication, and training may be necessary for stigma reduction.

Key Words: Grounded Theory, Health Care Workers, Health Care Settings, HIV-related Stigma

Introduction

People living with HIV (PLWH) have experienced stigma since the advent of the epidemic more than three decades ago. In spite of progress made in understanding and treating HIV, stigma remains a global impediment. Approximately 30% of PLWH have experienced stigma associated with their infection (Sorsdahl, Mall, Stein, & Joska, 2011), and many PLWH have experienced this stigma within health care settings. Health care settings and workers have been identified as important sources of stigma for PLWH (Feyissa, Abebe, Girma, & Woldie, 2012). This is particularly alarming because experiencing stigma has influenced care-seeking behaviors and has been associated with adverse health outcomes (Earnshaw, Bogart, Dovidio, & Williams, 2013).

Studies from different parts of the developing world have indicated that health care professionals display stigmatizing attitudes and behaviors toward PLWH within medical facilities (Salih, Tessema, Cherkos, Ferede, & Anlay, 2017). These beliefs and enactments also occur in US health care settings. For instance, a study of health care workers in the Southern region of the United States reported that 89% of clinical staff espoused at least one stigmatizing attitude toward PLWH (Stringer et al., 2016). A survey of health care providers and facilities in Los Angeles County found that 56% of skilled nursing facilities, 47% of obstetricians, and 98% of cosmetic surgeons refused to treat PLWH and provided no legal explanation for care refusal (Sears, 2008). Depictions of stigma in the health context have often involved poor provider conduct, suboptimal health care, and treatment refusal (Chambers et al., 2015).

Stigmatizing attitudes and behaviors exhibited by health care workers manifest in many forms. One study of HIV-related stigma reported visible discomfort, inferior treatment, patient avoidance, and care refusal as examples of stigma directed from health care personnel (Schuster et al., 2005). A similar study revealed irrational anger, physical distancing, ambiguous nonverbal cues (i.e., minimal eye contact), and blatant discrimination (i.e., physical abuse; Rintamaki, Scott, Kosenko, & Jensen, 2007) as forms of stigma. Another study categorized health care-related stigma toward PLWH as hostility, disrespect, reduced attention, and service refusal (Sohler, Li, & Cunningham, 2007). Stigmatizing attitudes and behaviors are often internalized by PLWH and lead to unfavorable health outcomes.

The harmful impact of HIV-related stigma in US-based health care settings is well documented. A study of PLWH within a statewide public hospital system in Louisiana reported that perceived stigma from health care providers was associated with previous interruptions in HIV care (Magnus et al., 2013). A comparable study of men who have sex with men (MSM) living with HIV showed that stigma from health care providers led to longer gaps in time since last HIV care appointment (Eaton et al., 2015). Experiences of stigma in health care settings have also been associated with other harmful outcomes, including higher likelihood of CD4+ T cell counts less than 200 cells/mm3 and diagnosis with a chronic illness comorbidity (Earnshaw et al., 2013).

Several studies have addressed the construct of HIV-related stigma in US health care settings and within patient–provider interactions, but this literature has primarily been from the perspectives of patients with HIV infection (Chambers et al., 2015; Eaton et al., 2015; Magnus et al., 2013). However, less research has examined how US-based health care workers themselves make sense of HIV-related stigma and the potential health effects of stigma on PLWH. One study, based in Alaska and New Mexico, reported that health care workers perceived HIV as more stigmatized compared to other diseases (Brems, Johnson, Warner, & Roberts, 2010). Moreover, that study found that behavioral health providers demonstrated more awareness of stigma compared to physical health providers. However, to our knowledge, there are currently no US-based studies that have assessed how health care workers conceptualize stigma and its health impacts on PLWH.

To address gaps in research and to contribute to the extant literature on health care worker perceptions of HIV-related stigma, we conducted a Grounded Theory study at two university-based medical institutions located in Southern California. Our study aims were to (a) understand how health care workers conceptualized HIV-related stigma in health care settings and how it might impact PLWH, (b) describe the pertinent concepts involved in the operationalization of stigma in health care settings, and (c) develop a model that projected a purposive view of HIV-related stigma in the health care context.

Methods

To conduct this study, we used Straussian Grounded Theory (SGT). SGT is an accessible method for generating concepts out of data and integrating them into a theory (Glaser & Strauss, 1967). SGT is compatible with contemporary thinking because it recognizes that broader environmental and contextual factors influence social phenomena (Corbin & Strauss, 2008). Additionally, SGT aims to produce a theory or, as in our study, a model that can guide action and practice (Corbin & Strauss, 2008).

Target Population

Health care workers who participated in our study consisted of physicians, nurses, and a clinical medical assistant. Physicians were defined as clinicians with a Doctorate in Medicine (MD). Nurses were identified as clinicians with RN, LVN, or NP licenses. Clinical medical assistants were defined as allied health care workers whose job duties entailed providing diagnostic and therapeutic patient care. Existing studies have indicated that HIV-related stigma may be directed from both clinical and nonclinical staff (Nyblade, Stangl, Weiss, & Ashburn, 2009; Rogers et al., 2014). However, for our study we elected to focus on clinical staff. Our reasons were twofold. First, stigma directed specifically from clinical staff has been associated with unfavorable care-seeking behaviors and engagement in care, including interruptions in HIV care and appointment attendance (Eaton et al., 2015; Magnus et al., 2013), as well as immunological failure and development of chronic illness comorbidities (Earnshaw et al., 2013). Second, studies have shown that more clinical staff stigmatize PLWH compared to their nonclinical counterparts (Rogers et al., 2014).

Eligibility Criteria

To be eligible for study participation, health care workers had to be at least 18 years of age, be able to speak and understand English, be employed at the participating health care institutions for at least 6 months, have some knowledge of stigma related to HIV, and be willing to sign an informed consent. To ascertain knowledge of HIV-related stigma, prospective participants were asked if they were familiar with the concept of stigma through previous education and/or from contact with patients with HIV infection.

Participant Recruitment

Purposive sampling was used to identify and recruit health care workers. The lead author, who is a research affiliate of both medical institutions, informed her professional network about the study via personal meetings, electronic correspondences, and recruitment materials. Additionally, she requested that her network members disseminate information about the study in their respective departments and include a copy of the study's informed consent and recruitment flyer. Interested health care workers were asked to email or telephone the lead author directly for study details in order to preclude the referring person from knowing which health care workers exhibited interest in the study. There was a possibility that study participants later informed the referring individual that they took part in the study, but that was beyond the control of the lead author. Once contact was established between the lead author and the prospective study participant, an in-person meeting was set up to discuss the study in depth and to sign the informed consent. The meeting took place during work hours and in a private area within the participating medical institutions. The lead author made a list of all study participants' names and their contact information. Study participants were then assigned a study-specific identification code to protect their privacy and confidentiality. Each study participant was referred to by this code throughout the data collection period and his/her name was not used during interviews. The list of study participant names and corresponding study codes were encrypted and maintained separately. Access to these documents was restricted to the lead author and not shared with others.

In keeping with the tradition of SGT, participant sampling ensued on theoretical grounds (Evans, 2013). Selection of study participants began with purposive sampling and then progressed to theoretical sampling, in which data were collected to serve the emerging model. This sampling method allowed the lead author to interview participants who could fill gaps in the data, clarify any uncertainties, confirm interpretations, and enhance the emerging model.

Five health care workers were recruited in April 2015, followed by four in May 2015, three in June 2015, six in July 2015, and nine in August 2015. Health care workers were enrolled from a variety of departments, including Pediatrics, Internal Medicine, Obstetrics and Gynecology, Allergy and Immunology, Family Medicine, Surgery, Maternal and Fetal Medicine, Intensive Care Unit, Family Planning, Psychiatry, and Emergency Medicine. Theoretical saturation was reached after 27 interviews (17 physicians, 9 nurses, and 1 clinical medical assistant). Enrollment of participants, including additional clinical medical assistants, was, therefore, discontinued because new themes or information was not observed and because the emerging model was clear, well understood, and could be substantiated from the data.

Data Collection

Between April and August 2015, study participants engaged in in-depth one-time audio-recorded in-person interviews regarding their perceptions of HIV-related stigma. Initially, 1-hour interviews were planned with each participant. However, this was found to be unfeasible due to participant scheduling conflicts and employment responsibilities. The interview durations were subsequently decreased to 20-45 minutes per interview. The lead author originally prepared 10 semi-structured interview questions with corresponding probes, but as data collection and analysis progressed, additional and more focused questions were asked to amass a wide range of perceptions about

HIV-related stigma. Examples of interview questions included, To what degree are you familiar with HIV-related stigma?, Where do you think stigma comes from?, What are some examples of stigma in health care settings?, What factors lead to stigma in health care settings?, and What do you think are the effects of stigma? Data collection was sequential, deliberate, and informed by coding and constant comparisons. Data collection and analyses were also iterative, with initial data collection being analyzed and the analysis leading to further data collection based on ongoing analysis.

Data Analysis

Individual interviews were transcribed verbatim in preparation for coding. Data fragments were coded by hand and organized using MAXQDAplus (Version 12 data; Berlin, Germany, 2016). To gain a comprehensive perspective of participant views of HIV-related stigma, the lead author first read the interview transcripts. Data were then coded using open coding, with emphasis on identifying, naming, categorizing, and describing data fragments. Open codes were generated by asking three questions: (a) What is this data a study of?, (b) What category does this incident indicate?, and (c) What is actually happening in the data? (Glaser, 1978). For instance, the concept of origin of HIV-related stigma was identified as ‘‘historical’’; described and labeled as ‘‘deadly,’’ ‘‘contagious,’’ and ‘‘deviant’’; and categorized as ‘‘negative depictions.’’ Similarly, the concept of provider-exhibited stigmatizing behaviors was labeled as ‘‘neglect,’’ ‘‘misconceptions,’’ ‘‘detachment,’’ ‘‘assumptions,’’ ‘‘referrals,’’ and ‘‘reduced opportunities,’’ and categorized as ‘‘manifestations.’’ The emergence of patterns from open coding marked the beginning of axial coding, focusing on identifying relationships between codes, categories, and concepts derived from open coding. Axial coding was facilitated by questions such as Who, When, Where, Why, How, and With, which helped relate structures to processes (Strauss & Corbin, 1998). For example, the concept fear of contracting HIV was related to the concepts of provider-experienced nervousness, anxiety, and care refusal, and categorized as a ‘‘trigger of HIV-related stigma.’’

Selective coding commenced once core themes emerged from the data. Examples of core themes included ‘‘fear,’’ ‘‘education and training,’’ ‘‘inadvertent behaviors,’’ and ‘‘contact with HIV patients.’’ Selective coding was useful for clarifying abstract concepts such as understanding how fear of contracting HIV impacted provider well-being and that HIV-related stigma directed toward PLWH might be unintentional. Selective coding of these two concepts allowed us to identify ‘‘anxiety’’ and ‘‘nervousness’’ as mental health outcomes related to fear and to explicate that the concept of unintentional discrimination might be the result of institutional practices and incognizance of personal actions.

Data analysis also involved constant comparisons. The lead author continuously examined whether the analysis of new transcripts provided similar themes and categories and/or if different patterns emerged. This process involved comparing specific incidents in the data, collecting additional data to fill gaps, recoding earlier data, and re-conceptualizing relationships between categories. Persistent investigation of developing category meanings helped to generate more refined concepts and clarify their relationships (Glaser & Strauss, 1967). For example, the concept of overspecialization of HIV emerged from comparisons of participant descriptions of hasty or clinically unnecessary referrals, inadequate HIV-related knowledge, provider noninvestment in patients with HIV, and limited contact with PLWH.

During the data collection and coding processes, the lead author also wrote 115 memos. The purposes of the memos were to (a) document generation of concepts, (b) track conceptual decisions for inclusion in the model, (c) document cross-category insights, (d) compare data findings to the literature, (e) capture developing ideas and thinking processes about codes and their interconnections, (f) summarize impressions and observations, and (g) achieve higher interpretive levels (Glaser, 1978; Montgomery & Bailey, 2007). Memos were coded, related to the collected data via constant comparisons, and transformed into theoretical accounts that assisted in comparing concepts with more incidents and constructing the final model. For instance, the lead researcher wrote a memo summarizing participant descriptions of HIV specialization as one of the reasons for limited contact with patients with HIV. The memo also summarized that HIV specialization might be advantageous for PLWH in the context of expert care, but it may also be disadvantageous in that it might deter non-specialists from investing in the care of PLWH. Furthermore, overspecialization might explain why PLWH were hastily referred back to an HIV specialist, and why they may have perceived such referrals as care refusals.

To organize and summarize the relationships between codes, categories, and concepts derived from open, axial, selective coding, constant comparisons, and theoretical memos, logic models were constructed throughout the data analysis process. These methodical depictions of data findings were helpful in two important ways. First, they helped identify, remove, and reduce redundant codes and associations, concepts, and categories, which then resulted in a more parsimonious model. Second, they assisted with visually demonstrating the construct of stigma with its pertinent concepts from origins to impacts. The use of logic models was purposeful and informed by the literature. There are several fundamental parallels between logic models and Grounded Theory that help integrate them into a model. First, both Grounded Theory and logic models involve conceptualization and summarization of data. Second, both techniques require demonstration of the relationships between conceptual categories. Third, both approaches often end with a visual representation of data findings. Fourth, both methods are used to generate and reveal a story about a particular phenomenon (Goertzen, Fahlman, Hampton, & Jeffery, 2003).

The final model contains 4 categories:

1. Origin of HIV-Related Stigma
2. Triggers of HIV-Related Stigma
3. Resulting Stigmatizing Feelings & Behaviors
4. Impact of HIV-Related Stigma on Patients

The model also includes 16 salient concepts related to HIV stigma in health care settings, including: ‘‘Historically Negative Depictions of HIV,’’ ‘‘Unequal Provider-Patient Power Dynamics,’’ ‘‘Fear of Contracting HIV,’’ Care Refusal,’’ ‘‘Nervousness,’’ ‘‘Anxiety,’’ ‘‘Education and Training,’’ ‘‘Inadvertent Behaviors,’’ ‘‘Contact with Patients with HIV,’’ ‘‘Patient Neglect,’’ ‘‘Persistent Misconceptions,’’ ‘‘Assumptions about Mode of Transmission,’’ ‘‘Detachment from Patients,’’ ‘‘Referrals,’’ ‘‘Treatment Engagement,’’ and ‘‘Psychological Function.’’ See Figure 3.1 for the final model of HIV-related stigma in the health context.

Figure 3.1 about here

Ethics

The Institutional Review Boards of the University of Southern California and the University of California Irvine approved our study and all participants signed a written consent. Each participant received a one-time $20 USD gift card for study participation.

Results

Perceived Origin of HIV-Related Stigma

Historically negative depictions of HIV. The lead author began each interview by asking study participants about their perceptions of the origin of stigma associated with HIV. Study participants expressed that historically negative depictions of HIV and PLWH have played a significant role in shaping the global landscape of the disease and contributing to the stigma that accompanies it. They stated that HIV was presented to the world as a deadly and highly communicable disease. These portrayals gave rise to intense public and private fear, hysteria, and panic. With no effective treatments in sight at the time, these reactions continued to linger and buttress stigma. Participants specified that initial identifications of HIV among MSM and injection drug users (IDUs) solidified public perceptions of HIV as a deadly disease attributable to sexually and morally ‘‘deviant’’ lifestyles. In reference to initial HIV cases in MSM and IDUs, one participant noted:

> I think there’s an unfair taint to it still. I think probably if you wanted to go way back 30 years that it was first associated with homosexuality and that it was perceived as a gay disease, for lack of a better term, and that social stigma attached to it as well. And it was associated with IV drug use and other things that are also stigmatized, that it acquired a reputation.

Another study participant stated that the high number of HIV-related deaths in the 1980s and media portrayals of HIV as uncontrollable, also adulterated public views of the disease and, as a result, the disease developed a negative reputation. This reputation could not be undone despite advances that have changed the outcome of the disease. She used a metaphor to compare HIV-related stigma to a person's ruined reputation: ''It's like a reputation. If you have a bad reputation, it follows you for decades. Even though you've corrected yourself, you've exonerated yourself, like you're better now; it's hard to get rid of that.'' A different study participant expressed that although HIV is now considered a chronic and manageable illness, its historically negative reputation prevents many people from considering it as chronic. She said:

> I think that we don't perceive it like a chronic disease necessarily. And I think a lot of like, the public, still assumes that HIV is something you're gonna – that's gonna progress to AIDS – or they even don't know it's different than AIDS and then you're gonna die from it soon.

Unequal provider–patient power dynamics. In addition to perceived inflammatory portrayals of HIV and PLWH, study participants attributed stigmatization to inherent unequal provider–patient power dynamics. Several participants said that in many health care settings, there was a tremendous power differential between patients and providers, and care was provider-centered as opposed to patient-centered. Additionally, some providers may be strongly cognizant of their power and reluctant to control it during encounters with patients.

Study participants perceived provider-directed power exertion as a means by which patients were made to feel inferior and dependent on the health care system, and therefore less inclined to communicate grievances and maltreatments when they occurred. Participants said that PLWH may feel powerless during inequitable medical transactions and this could push them toward deeper internalization of HIV-related stigma, distrust, and non-engagement in their care. Study participants interpreted power differentials between providers and patients as positions of control that precluded patients from communicating about and addressing stigma when it occurred. As one participant stated:

> If I were a patient in that situation [stigmatized due to HIV], I don’t think I could say something. I would just be like so uncomfortable and I would probably never go back to that person and I’d avoid, or be leery of pretty much any clinic that I didn’t already know. And there is, I mean, there is such a power differential between a patient and a physician for better or worse that I don’t think you can, and it’s not fair.

Perceived Triggers of HIV-Related Stigma and Resulting Feelings and Behaviors

Fear. Study participants were asked to comment on factors that led to stigmatization of PLWH in health care settings. Additionally, they were queried about how these factors might influence health care worker feelings and behaviors toward PLWH. Study participants reported that stigmatization directed from health care workers was primarily triggered by fear. They said that some health care workers feared HIV transmission because they were unaware of its pathogenesis. One participant noted:

> There’s so many people in just the general public who work in a medical facility, but may not have a lot of medical knowledge [HIV-related knowledge].

> That I would think that maybe [they’d be] a little bit more fearful and perpetuate [stigma]. Not even trying to, but just because they’re not aware.

Several participants shared that fear of contracting HIV might also be due to its incurable nature. Although most respondents acknowledged that they were familiar with HIV transmission modes, occupational risks, and safety and standard precautions, the fear of contracting an incurable disease such as HIV might be overpowering for some health care workers and this might lead to stigmatization of PLWH. As one participant stated:

> It’s just scary. It seems like it’s more scary than other diseases because there’s no cure for it. And it’s something that, once you get it, you’re gonna have it. That’s one of the reasons why, you know, there is a stigma attached to it ... is that there is no cure for it.

Another participant shared that health care workers were exposed to bodily fluids more than other workers and this could impact the level of fear when interacting with patients with HIV. She noted:

> I think a lot of fear amongst health care workers of actually contracting the disease is because we’re so involved with bodily fluids. I work in an ICU [intensive care unit] so we have very, very close contact with patients. We’ve had, you know, exposures.

When asked to give examples of fear-based stigmatization of PLWH, the majority of study participants identified care refusal. One respondent reported witnessing a provider refusing to participate in surgery on a patient with a high HIV viral load, while another recalled a provider refusing to insert a nasogastric tube out of fear that the patient would vomit and splash fluids.

Some study participants also noted that fear of contracting HIV at the workplace not only impacted health service delivery, it might also impact health care worker well-being. They stated that fear of HIV transmission when administering care to a patient with HIV could lead to provider-experienced outcomes. These included feelings of anxiety and nervousness during surgery or gynecological procedures. In reference to anxiety, one participant stated:

> We take deliberate movements and we communicate during the surgery. And you know, we're going to do the surgery safely for everybody, for the patient, and ourselves, and definitely have conversations ahead of time. I think it probably does provoke a little more anxiety.

With respect to nervousness, one participant reported witnessing a peer's reaction to a patient with HIV:

> I think that when I was working at a hospital prior and one of the co-workers I was working with found out that the patient had HIV, they seemed very nervous; they didn't want to take care of the patient.

Another participant added that she experienced nervousness while performing a cervical block on a patient with HIV in Zambia:

> I didn't have great lighting, I was in the middle of doing a cervical block for a patient who had HIV and it flew back and hit me in the eye. I finished her procedure and I did what she needed, but it definitely did make me anxious and I was really mad at myself for not having protective eyewear on.

Education and training. Study participants noted that some of the stigma directed toward PLWH in health care settings could be attributed to inadequate education and training about HIV and related stigma. They said that academic curricula for medical and nursing schools varied across institutions and, while some programs included specific content on HIV, stigma, and the impact of stigma on patient care and health outcomes, others did not.

When asked about their own professional training in the context of HIV and stigma, participants stated that they had received limited information about HIV during their respective apprenticeships, but most denied any extensive instruction. In reference to addressing stigma in health care settings, one participant said:

> I believe more like, education about what is HIV and how it's transmitted because I think a lot of people [referring to health care workers] are just scared the way HIV is transmitted and I think they still believe like, when they cough, that's gonna get them to have HIV.

Several physicians in the study reported attending lectures and panels facilitated by PLWH to gain insight into patient experiences and to develop sensitivities. The majority of the study participants, however, reported not receiving any type of stigma-specific information. One participant emphasized hospital-wide trainings for health care professionals:

> It will help with professionalism and sort of a standard and I think, in general, when people are made well aware they tend to act accordingly and be more aware every time they have an interaction. I think it would generally benefit the entire community feeling. I think it's important, not just the sensitivity training

> but also the customer service side of it since we are in the customer service business. It’s all part of a person, how do you treat people so that they feel welcome so they get the care they need so that they will want to come back?

Another physician shared that she had learned about stigma and discrimination of PLWH from witnessing how patients with HIV were mistreated at a community hospital. She emphasized that differential treatment of PLWH probably occurred because the institution in question did not routinely care for patients with HIV, and their staff was inadequately trained and poorly informed about HIV transmission and stigma. She stated, ‘‘And the stigma tends to be stronger in those settings because they tend to see that patient population less often and are, therefore, ill-prepared to be able to care for them appropriately.’’

Respondents confirmed that the lack of adequate education and training regarding HIV and related stigma allowed for misconceptions to persist, because inaccurate and incomplete conceptualizations and ideas remained unchallenged. Furthermore, they associated insufficient education and training with direct pejorative treatment of patients with HIV. Examples of such conduct included making egregious assumptions about how patients acquired HIV and patient neglect. One study participant recalled witnessing the neglect of a young, terminally ill patient with AIDS in her department:

> I’ve even had a patient who was just tucked away in a corner. It was kind of sad to see that happen. Like how can this person who’s so young, in their early 20s at the end stage, and have … no one’s even here, not even his family. Just me. And there’s no doctors even around.

Another participant reflected on the value-based assumptions some health care workers make about PLWH and how they acquired the virus:

> I think people are going to make assumptions about their lifestyle and make judgments about their lifestyle. Probably you know, homosexuality or IV drug use or promiscuity maybe. Although you know, lots of times you know, they got it through no fault of their own. It wasn't really part of their lifestyle, but even if it was part of their lifestyle, you know there's, you know, judgments being made.

Inadvertent behaviors. Study participants stated that enacted stigmatization of patients with HIV might not always be deliberate. They said that, during interactions with patients with HIV, it was possible that health care workers engaged in behaviors without knowledge or intent to discriminate. As one health care worker noted:

> And I think it's more just an awareness on how you talk to people and treat people 'cause I feel like, probably a lot of the times people don't mean to stigmatize, or to say hurtful things, but it might just be a little bit of ignorance or not understanding.

Other participants stated that some health care workers might not be aware that certain institutional practices may be unfamiliar to patients with HIV and, therefore, might be construed as stigmatizing. For instance, one physician recalled an incident in which a patient became angry and distraught because she thought that her room was tagged ‘‘red’’ due to her HIV status. In actuality, the room was tagged ‘‘red’’ as an indication of the type of provider who was in the room with the patient. She said:

> We have different colored flags outside the patient room depending on whether the MA [medical assistant] is getting them roomed or if they're ready

> to be seen by the doctor or whether they're ready to be checked out, and the flag for ready to be seen by the doctor is red. And the patient got angry about it because she thought she was being flagged as HIV positive.

Reduced contact with patients due to HIV specialization. Study participants stated that during the last three decades, HIV has become a highly specialized and even an overspecialized field of health care. They emphasized that while being evaluated by an HIV specialist was in the best interest of the patient in terms of expert care, there were certain disadvantages to specialization. These included limited contact between non-specialists and patients with HIV and hasty and perhaps medically unnecessary referrals back to HIV specialists. Participants explained that patients with HIV were managed primarily by their specialists and, as a result, non-specialists did not have sufficient interactions with PLWH. Study participants described and perceived these insufficient interactions between non-specialists and PLWH as missed opportunities for clinical education and practice, and recognition of and sensitivity to stigma.

Additionally, participants stated that without much practice caring for PLWH, health care workers were left with the difficult decision to hastily refer patients back to an HIV specialist, and this could contribute to stigma because patients might interpret it as care refusal. As one participant stated:

> You ask me something about HIV, all I can say is I would defer to your doctor. It's also an area – a big area of weakness for me [lack of knowledge about HIV]. So, I don't want to put that on display. But it's because they [PLWH] are

> all channeled away. We don’t really have exposure to them, so you probably will continue the stigma.

Some participants also revealed that because they referred patients back to HIV specialists for care, they were less inclined to invest emotionally in the patient. Furthermore, they found themselves just offering functional care and quickly detaching from the patient. As one participant described:

> I feel like a lot of times with an HIV patient, especially because I’m not an expert of HIV, I feel like the care I give is functional versus emotional. It’s almost functional like going to get your oil changed or something. ‘‘Hi doctor.’’ ‘‘Okay I’ll change your oil. Here are your meds.’’ ‘‘Okay. Thanks.’’ And it’s like, there’s not anything more than that. I think the care that for providers like me who has less exposure, less experience, I think it just comes on to just functionality.

Perceived Impact of HIV-Related Stigma on Patients

Treatment engagement. Study participants were asked to discuss if and how stigma from health care workers might affect PLWH. Respondents identified decreased use of vital health care services, distrust in the health care system and providers, and delayed diagnosis and treatment, as some examples of how perceived stigma from health care workers might impact patients with HIV. They also said that stigma could disrupt patient engagement in care by discouraging continuity and treatment compliance. With respect to diagnosis and timely treatment, one participant stated:

> You could miss somebody with PCP [pneumocystis] pneumonia. You could miss complications of the disease because you are not asking all the right

> questions. You can miss providing treatment earlier for complications of the disease, which are sometimes actually very atypical to presentations.

The participant in question explained that delayed diagnosis and treatment resulted from patients with HIV anticipating differential treatment from health care providers and presenting late for HIV care.

Regarding care engagement, one participant thought that stigma not only deterred patients with HIV from accessing health care, but might also drive individuals toward suboptimal and low-quality care. Additionally, stigma could play a role in dissuading PLWH from attending medical appointments. As one participant noted:

> The biggest thing would be decreased access to health care. And that’s probably the most important aspect of it. So, when you stigmatize someone you, you know, effectively push them away from the care that they need. You know, they might be less likely to come to appointments or seek out care. Or you know, transfer their care somewhere else, maybe it’s a less qualified community hospital.

Psychological function. Study participants stated that PLWH who experienced stigma from their providers might feel ‘‘othered’’ and subsequently unmotivated to build restorative relationships with their providers. These feelings could also manifest into stress, and reduce the patient’s desire to express health-related concerns. As one study participant shared:

> I think it really affects the patient negatively in that, you know, when we as health care providers stigmatize, I feel that that could jeopardize their access to care, perhaps, you know, with feeling comfortable building a therapeutic

> relationship with their doctor bringing these issues up and then, you know, somehow compromising the needs that they have.

Participants also explained that an HIV diagnosis coupled with other comorbidities was already a significant burden on patients and if they perceived their providers as unsympathetic and unsupportive, they might experience further psychological decline and discomfort. As one participant noted:

> I think just the emotional and mental stress that's already on these patients because, you know, someone has leukemia, or someone has another chronic illness, you know, people I feel like do treat it differently, whereas it might not get that mental psychosocial support that they need just as someone that has another chronic illness, so I think that by reinforcing, I guess, these barriers and making HIV seem like the other I think that can add to emotional stress.

Discussion

HIV-related stigma in health care settings poses a major challenge to the health and well-being of PLWH. We sought to understand how health care workers conceptualized HIV-related stigma and how stigma might impact patients with HIV. Furthermore, we aimed to identify and describe important concepts involved in the operationalization of stigma in health care settings. Based on participant responses, a model of HIV-related stigma was developed using Grounded Theory.

Study participants implicated historically unfavorable portrayals of HIV as deadly, uncontrollable, contagious, and a byproduct of deviant lifestyles as responsible for the enduring stigmatization of PLWH. These depictions were congruent with other published studies on the origin of HIV-related stigma. Saki, Kermanshahi, Mohammadi, and Mohraz (2015) noted that the initial identification of AIDS cases in MSM led many to think that HIV primarily impacted people who engaged in ‘‘unusual’’ and ‘‘unacceptable’’ behaviors. Labra (2015) illustrated how social representations of HIV as the ‘‘gay plague’’ in the 1980s, indistinguishably linked the disease to mortality, stigma, impropriety, and punishment.

Power imbalance in health care encounters was identified as inherent and a significant impediment to patient communication about and response to HIV-related stigma. These findings were in line with the existing literature. A study of provider prejudice found that stigma directed from health care providers was a mechanism by which medical power and authority were reinforced (Poteat, German, & Kerrigan, 2013). Another study reported that, although patients may want to play an active role in their health care, power differentials may prevent them from doing so out of fear of being perceived as difficult. The same study also reported that even when stakes were higher, such as when patients had HIV, power inequalities may have deterred open communication with providers (Dang, Westbrook, Njue, & Giordano, 2017).

Fear of work-related HIV transmission was described as a possible explanation for refusing care to PLWH and for provider-experienced anxiety and nervousness when administering care to patients with HIV. These findings were somewhat similar to the existing literature. Cianelli and colleagues (2011) found that health care worker fear of administering care to PLWH might be the result of anxiety. Olalekan, Akintunde, and Olatunji (2014) observed that fear of occupational infection encouraged some health care providers to refuse care to PLWH, and Rintamaki and colleagues (2007) indicated that nervousness when administering care to PLWH may be the result of fear of HIV transmission. However, these study findings were from the perspectives of PLWH rather than health care workers. In a study of health care workers, Feyissa and colleagues (2012) found that fear of occupational transmission of HIV was significantly associated with stigma and discrimination, including treatment refusal for clients with HIV infection. In a similar study of service providers, Li and colleagues (2007) found that provider-experienced anxiety was largely attributed to lack of institutional support and access to sufficient prevention resources and not to fear of occupational HIV transmission.

Participants shared that insufficient health care worker education and training about HIV and related stigmas could be responsible for persistent disease-related misconceptions and direct patient mistreatment. These results were somewhat different from existing studies. In their study of health service and social service providers, Rogers and colleagues (2014) found that lack of training in HIV prevention was associated with higher levels of stigma. However, stigma was measured in the context of blame and moral judgments of patients with HIV versus misconceptions and direct patient mistreatment. A similar study conducted by Vorasane and colleagues (2017) found that health care workers who had higher levels of HIV knowledge were less likely to demonstrate stigmatizing attitudes toward PLWH. In the same study, stigma was defined as discriminatory intent, prejudiced attitudes, internalized shame, fear of PLWH, and opinions about health care for patients with HIV. The study did not assess the effect of health worker education on persistence of misconceptions or direct maltreatment of patients with HIV.

We found that stigmatization directed toward patients with HIV might be triggered by inadvertent lack of awareness of potentially stigmatizing personal actions and institutional/organizational practices that could be interpreted as prejudicial. The concept of inadvertent HIV-related stigma in the context of health care settings has been largely unexplored in the literature. We identified one study that showed that health care workers who were unfamiliar with standard precaution protocols were more likely to exhibit unintentional discrimination (Foreman, Lyra, & Breinbauer, 2003). However, we did not find other published papers that attributed unintentional stigma to providers being unaware of personal behaviors and unfamiliar with institutional/organizational practices.

Our findings also indicated that HIV-related stigma in health care settings may be triggered by limited occupational contact with PLWH and this could lead to reduced opportunities for clinical education and practice for non-specialists, unnecessary referrals, and provider emotional detachment from patients. The literature has indicated that contact with PLWH is imperative for stigma reduction (Earnshaw et al., 2013) and that lack of experience with the HIV community may contribute to stigma (Asgary, Amin, Grigoryan, Naderi, & Aronson, 2013). In health care settings specifically, providers who interacted more with PLWH (e.g., high HIV case load) exhibited less stigmatizing behaviors than those who did not (Feyissa et al., 2012; Salih et al., 2017). Our findings that reduced contact with PLWH could inhibit opportunities for clinical education and practice, lead to unnecessary patient referrals, and drive providers to detach emotionally from patients, do not appear to be supported by the available evidence.

It is important to recognize that specialization is not unique to HIV and that specialists manage many other chronic diseases. However, what differentiates HIV from other diseases in terms of stigma is that it is often perceived as a disease of moral laxity and socially unacceptable behaviors (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012). Overspecialization of HIV care may prevent non-specialists from learning about such stigmatizing views of PLWH and recognizing that discriminatory behaviors lead to adverse health outcomes in patients with HIV.

Study participants stated that HIV-related stigma directed from health care workers might be responsible for reduced engagement in care and harmful mental health outcomes in PLWH; these findings were somewhat different from the existing literature. In one study, providers attributed patient lack of engagement in HIV care to noncommitment to health and medication side effects, rather than perceived stigma from health care workers (Bofill et al., 2014). In a different study, behavioral clinicians identified HIV as a highly stigmatized disease, but did not comment on the impact of HIV-related stigma on patient mental health outcomes (Brems et al., 2010). Other research on the impact of HIV-related stigma has shown that perceived stigma is associated with psychological distress (Rahmati-Najarkolaei et al., 2010), but these results were from the viewpoint of PLWH and not health care providers. Studies that examined provider perceptions of provider-directed HIV-related stigma on patient care engagement and mental health outcomes appear to be scarce.

To assess our study’s interpretive rigor, we drew from Gasson’s (2004) work and used credibility, dependability, confirmability, and transferability as appraisal criteria. To address credibility, we outlined the aims of the study, reviewed the relevant literature on the topic, identified gaps in research, indicated how our study would bridge those gaps, and emphasized why our study was warranted. To establish dependability, we fully disclosed our data sources, coding schemes, and categorization mechanisms. To demonstrate confirmability, we delineated our procedures for data analysis, emphasized how categories emerged, and included direct quotations from study participants. To illustrate transferability, we explicitly described how theoretical saturation was achieved, explicated the categories derived from the data, and provided a substantive description of what was discovered in the data.

Some of our findings have important implications for future research, program development, and policy:

1. It is important to emphasize that power inequalities between health care providers and patients are not unique to HIV. What distinguishes HIV from other diseases is that the related stigma plays a key role in reinforcing social differences and labeling PLWH as ‘‘other.’’ Additionally, stigma in health care systems is rooted in existing societal perceptions of how HIV is transmitted, the behaviors of PLWH, and population groups associated with HIV. Health care settings, in turn, are environments in which social differences and power are operationalized by individuals upon whom PLWH entrust their health (Chambers et al., 2015). To address power differentials in health care settings, programmatic efforts can focus on empowering patients to communicate their health care needs and protests without fear of retribution from providers. Provider-based programs that target management of provider power and improve interpersonal relationships with patients may also be of value.
2. Fear of contracting HIV was identified as a trigger of stigma that could be associated with provider mental health outcomes, including nervousness and

anxiety when delivering care to patients with HIV. To address fear as well as psychological function in health care workers, in-service trainings by HIV experts that emphasize HIV transmission pathways, standard precautions, occupational risk reduction, and stress management may be advantageous. Additional research studies that examine the extent of mental health outcomes among health care workers who provide care to PLWH may also be necessary.

3. Study participants attributed insufficient health care worker HIV- and stigma-specific education and training to care refusal, persistent misconceptions about HIV, and assumptions about modes of HIV transmission. Studies that assess the independent relationship between provider education and training and the aforementioned three outcomes may be warranted.
4. Unintentional behaviors enacted by health care workers were identified as potential stigma triggers. Qualitative studies that explore the construct of inadvertent HIV-related stigma could help researchers better understand this phenomenon, and findings from such studies may inform stigma reduction strategies.
5. Study participants stated that HIV-related stigma could play an important role in patient mental health outcomes. Research that explicitly examines provider perceptions of stigma experienced by PLWH and how this stigma is related to psychological functioning may be suitable.

6. Overspecialization of HIV was perceived as a potential impediment to clinical education and practice, as well as recognition of HIV-related stigma among non-specialists. Research that examines the role of HIV specialization on provider education, practice, and sensitivity to stigma may be particularly salient.

The Affordable Care Act and the Ryan White HIV/AIDS Program

Our finding that limited contact with patients with HIV due to overspecialization could lead to detachment from patients, medically unnecessary referrals, and compromised clinical practice and education, necessitates a discussion of the Patient Protection and Affordable Care Act (ACA) and the Ryan White HIV/AIDS Program. During the past several decades, health care, including management of HIV, has become more technologically advanced and more specialist-oriented, resulting in improved, albeit more costly, care. However, the implementation of the ACA reduced the number of specialists in its insurance plans, while raising concerns regarding access to specialty care (Dorner, Jacobs, & Sommers, 2015). Reduction of medical specialists under the ACA may have benefits as well as costs. It may reduce the number of patients being evaluated by experts. However, it may give non-specialists the opportunity to enhance their proficiency in HIV, care of patients with HIV, and recognition of stigma.

The Ryan White HIV/AIDS Program provides primary health care and important support services to PLWH who are uninsured or underinsured. Most funds from the program are used for clinical care and support services. However, a smaller portion is used to fund technical assistance, clinical training, and groundbreaking models of patient care (Health Resources & Service Administration, 2016). This smaller portion of the program’s funds may provide a mechanism by which stigmatization of PLWH can be addressed and reduced. Expanding funding allocation policies to also include training of non-specialists by HIV specialists may increase HIV knowledge, improve clinical skills, and increase sensitivity to stigma. This may give non-specialists an opportunity to develop more therapeutic interactions with PLWH, thereby potentially reducing unnecessary referrals and increasing investment in patients with HIV.

Conclusion

We aimed to develop a model about HIV-related stigma in health care settings from the perspectives of health care workers. The emerging model revealed that stigma may be rooted in historically negative representations of HIV and PLWH, and perpetuated by inherent power inequalities between patients and providers. Moreover, stigmatizing and discriminatory behaviors may be attributed to fear of contracting an incurable disease, insufficient education and training, inadvertent behaviors, and limited contact with PLWH. Study participants conceptualized HIV-related stigma as a harmful process that impacted both patients and providers in terms of health outcomes. Stigma reduction strategies are, therefore, imperative to improve patient and provider experiences in health care settings. Additional research on US-based health care workers and their perceptions of HIV-related stigma, and programmatic efforts that focus on clinical training and practice, patient empowerment, and health communication may be helpful for stigma reduction.

References

Asgary R., Amin S., Grigoryan Z., Naderi R., Aronson J. (2013). Perceived stigma and discrimination towards people living with HIV and AIDS in Addis Ababa, Ethiopia: A qualitative approach. *Journal of Public Health, 21*(2), 155-162. http://dx.doi.org/10.1007/s10389-012-0533-8

Bofill L. M., Lopez M., Dorigo A., Bordato A., Lucas M., Cabanillas G. F., . Jones D. (2014). Patient–provider perceptions on engagement in HIV care in Argentina. *AIDS Care, 26*(5), 602-607. http://dx.doi.org/10.1080/09540121. 2013.844767

Brems C., Johnson M. E., Warner T. D., Roberts L. W. (2010). Health care providers' reports of perceived stigma associated with HIV and AIDS in rural and urban communities. *Journal of HIV/AIDS & Social Services, 9*(4), 356-370. http://dx.doi. org/10.1080/15381501.2010.525480

Chambers L. A., Rueda S., Baker D. N., Wilson M. G., Deutsch R., Raeifar E., Rourke S. B. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health, 15*(1), 848-865. http://dx.doi.org/10.1186/s12889-015-2197-0

Cianelli R., Ferrer L., Norr K. F., McCreary L., Irarrazabal L., Bernales M., Miner S. (2011). Stigma related to HIV among community health workers in Chile. *Stigma Research and Action, 1*(1), 3-10. http://dx.doi.org/10.5463/sra.v1i1.11

Corbin J., Strauss A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.

Dang B. N., Westbrook R. A., Njue S. M., Giordano T. P. (2017). Building trust and rapport early in the new doctor-patient relationship: A longitudinal qualitative study. *BMC Medical Education, 17*(1), 32-42. http://dx.doi.org/10.1186/s12909- 017-0868-5

Dorner S. C., Jacobs D. B., Sommers B. D. (2015). Adequacy of outpatient specialty care access in marketplace plans under the Affordable Care Act. *Journal of the American Medical Association, 314*(16), 1749-1750. http://dx.doi.org/10.1001/ jama.2015.9375

Earnshaw V. A., Bogart L. M., Dovidio J. F., Williams D. R. (2013). Stigma and racial/ethnic HIV disparities: Moving toward resilience. *American Psychologist, 68*(4), 225-236. http://dx.doi.org/10.1037/a0032705

Eaton L. A., Driffin D. D., Kegler C., Smith H., Conway-Washington C., White D., Cherry C. (2015). The role of stigma and medical mistrust in the routine health care engagement of Black men who have sex with men. *American Journal of Public Health, 105(*2), e75-e82. http://dx.doi.org/ 10.2105/AJPH.2014.302322

Ekstrand M. L., Bharat S., Ramakrishna J., Heylen E. (2012). Blame, symbolic stigma and HIV misconceptions are associated with support for coercive measures in urban India. *AIDS and Behavior, 16*(3), 700-710. http://dx.doi.org/10.1007/ s10461-011-9888-z

Evans G. L. (2013). A novice researcher's first walk through the maze of grounded theory. *Grounded Theory Review, 12*(1), 37-55.

Feyissa G. T., Abebe L., Girma E., Woldie M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health, 12*(1), 522-534. http://dx.doi.org/10.1186/1471-2458-12-522

Foreman M., Lyra P., Breinbauer C. (2003). *Understanding and responding to HIV/AIDS related stigma and discrimination in the health sector*. Retrieved from http://www1.paho.org/hq/dmdocuments/2008/Stigma_report_english.pdf

Gasson, S. (2004). Rigor in grounded theory research: An interpretive perspective on generating theory from qualitative field studies. *The Handbook of Information Systems Research*, 4, 79-102.

Glaser B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociology Press.

Glaser B. G., Strauss A. L. (1967). *Discovery of grounded theory.* Mill Valley, CA: Sociology Press.

Goertzen J. R., Fahlman S. A., Hampton M. R., Jeffery B. L. (2003). Creating logic models using grounded theory: A case example demonstrating a unique approach to logic model development. *Canadian Journal of Program Evaluation, 18(2), 115-138*.

Health Resources & Service Administration. (2016). *Ryan White & global HIV/AIDS programs.* Retrieved from https://hab.hrsa.gov/about-ryan-white-hivaids-program

Labra O. (2015). Social representations of HIV/AIDS in mass media: Some important lessons for caregivers. *International Social Work, 58*(2), 238-248. http://dx.doi.org/10.1177/ 0020872813497380

Li L., Wu Z., Wu S., Zhaoc Y., Jia M., Yan Z. (2007). HIV-related stigma in health care settings: A survey of service providers in China. *AIDS Patient Care and STDs, 21*(10), 753-762. http://dx.doi.org/10.1089/apc.2006.0219

Magnus M., Herwehe J., Murtaza-Rossini M., Reine P., Cuffie D., Gruber D., Kaiser M. (2013). Linking and retaining HIV patients in care: The importance of provider attitudes and behaviors. *AIDS Patient Care and STDs, 27*(5), 297-303. http://dx.doi.org/10.1089/apc.2012.0423

Montgomery P., Bailey P. H. (2007). Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research, 29*(1), 65-79. http://dx.doi.org/10.1177/ 0193945906292557

Nyblade L., Stangl A., Weiss E., Ashburn K. (2009). Combating HIV stigma in health care settings: What works? *Journal of the International AIDS Society, 12*(1), 15-22. http://dx.doi. org/10.1186/1758-2652-12-15

Olalekan A. W., Akintunde A. R., Olatunji M. V. (2014). Perception of societal stigma and discrimination towards people living with HIV/AIDS in Lagos, Nigeria: A qualitative study. *Materia Socio-Medica, 26*(3), 191-194. http://dx.doi.org/10. 5455/msm.2014.26.191-194

Poteat T., German D., Kerrigan D. (2013). Managing uncertainty: A grounded theory of stigma in transgender health care encounters. *Social Science & Medicine*, 84, 22-29. http://dx.doi.org/10.1016/j.socscimed.2013.02.019

Rahmati-Najarkolaei F., Niknami S., Aminshokravi F., Bazargan M., Ahmadi F., Hadjizadeh E., Tavafian S. S. (2010). Experiences of stigma in healthcare settings among adults living with HIV in the Islamic Republic of Iran. *Journal of the International AIDS Society, 13*(1), 27-38. http://dx. doi.org/10.1186/1758 2652-13-27

Rintamaki L. S., Scott A. M., Kosenko K. A., Jensen R. E. (2007). Male patient perceptions of HIV stigma in healthcare contexts. *AIDS Patient Care and STDs, 21*(12), 956-969. http://dx.doi.org/10.1089/apc.2006.0154

Rogers S. J., Tureski K., Cushnie A., Brown A., Bailey A., Palmer Q. (2014). Layered stigma among healthcare and social service providers toward key affected populations in Jamaica and the Bahamas. *AIDS Care, 26*(5), 538-546. http://dx.doi.org/10.1080/09540121.2013.844762

Saki M., Kermanshahi S. M. K., Mohammadi E., Mohraz M. (2015). Perception of patients with HIV/AIDS from stigma and discrimination. *Iranian Red Crescent Medical Journal, 17*(6), e23638. http://dx.doi.org/10.5812/ircmj.23638v2

Salih M. H., Tessema G. A., Cherkos E. A., Ferede A. J., Anlay D. Z. (2017). Stigma towards people living on HIV/ AIDS and associated factors among nurses' working in Amhara region referral hospitals, Northwest Ethiopia: A cross-sectional study. *Advances in Nursing*, 2017. http://dx.doi.org/10.1155/2017/6792735

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. http://dx.doi. org/10.1111/j.1525-1497.2005.05049.x

Sears, B. (2008). HIV discrimination in health care services in Los Angeles County: the results of three testing studies. *Washington & Lee Journal of Civil Rights and Social Justice, 15*(1). 85, 86–107.

Sohler N., Li X., Cunningham C. (2007). Perceived discrimination among severely disadvantaged people with HIV infection. *Public Health Reports, 122*(3), 347-355. http://dx.doi. org/10.1177/003335490712200308

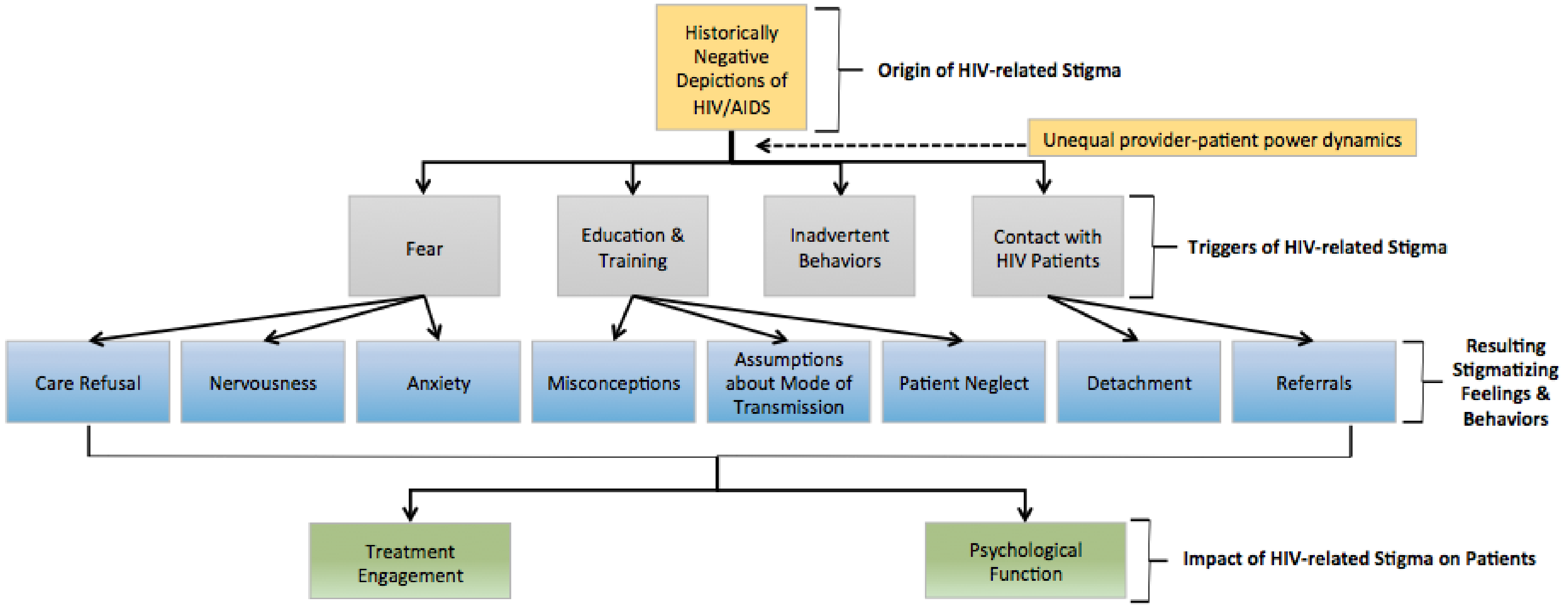
Sorsdahl K. R., Mall S., Stein D. J., Joska J. A. (2011). The prevalence and predictors of stigma amongst people living with HIV/AIDS in the Western Province. AIDS Care, 23(6), 680-685. http://dx.doi.org/10.1080/09540121.2010.525621

Strauss A. L., Corbin J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks, CA: Sage

Stringer K. L., Turan B., McCormick L., Durojaiye M., Nyblade L., Kempf M. C., . Turan J. M. (2016). HIV-related stigma among healthcare providers in the deep south. *AIDS and Behavior, 20*(1), 115-125. http://dx.doi.org/10.1007/s10461-015 1256-y

Vorasane S., Jimba M., Kikuchi K., Yasuoka J., Nanishi K., Durham J., Sychareun V. (2017). An investigation of stigmatizing attitudes towards people living with HIV/AIDS by doctors and nurses in Vientiane, Lao PDR. *BMC Health Services Research, 17*(1), 125-138. http://dx.doi.org/10.1186/s12913-017-2068-8

Figure 3.1: Model of HIV-related Stigma in Health Care Settings



CHAPTER 4

Assessing the Efficacy of PhotoVoice-informed HIV Stigma Training for Health Care Workers in Southern California

HIV stigma is a widespread phenomenon present in United States (US)-based health care settings. Stigma enacted by health care workers is associated with a multitude of undesirable consequences, including diminished care continuity and suboptimal medical compliance. However, studies of interventions targeting HIV stigma are scarce in the US health care context. The current study attempted to bridge this gap by assessing the impact of a PhotoVoice-informed stigma training program for health care workers on HIV/AIDS knowledge, attitudes towards people living with HIV (PLWH), and observations of enacted HIV stigma in health care settings. Between June 2016 and July 2017, 73 clinical health care workers were recruited from a Southern California health care institution and randomized into either an intervention or control arm. The intervention arm received targeted education on HIV/AIDS and stigma, PhotoVoice-based personal stories of stigma from PLWH, and engaged in interactive dialogue. The control arm only received targeted education on HIV/AIDS and associated stigma. Study participants were assessed at baseline (T1), within approximately a week of the intervention or control conditions (T2), and at 3-month follow-up (T3). Data were analyzed using exploratory factor analysis and linear regressions. Findings indicated that knowledge of HIV/AIDS increased ($\beta=0.50$, $p<.01$), attitudes towards PLWH improved ($\beta=0.44$, $p<.01$), and observations of enacted HIV stigma decreased ($\beta=-0.44$, $p<.01$) at T2 among participants in the intervention arm. At T3, improvements in

knowledge of HIV/AIDS and attitudes towards PLWH were also significant ($\beta = 0.53$, $p<.01$ and ($\beta = 0.48$, $p<.01$ respectively). Observations of enacted HIV stigma were once again significantly less at T3 ($\beta = -0.42$, $p<.01$). To address the full complexity of HIV stigma in US-based health care settings, additional stigma reduction interventions are warranted. Programs that are integrated into routine in-service trainings, and offer salient study incentives may be particularly beneficial.

Key Words: PhotoVoice, HIV stigma, Training, Intervention, Health Care workers, Health Care Settings

Introduction

HIV-related stigma in health care settings is a widespread and far-reaching phenomenon with debilitating consequences. The stigmatization of people living with HIV (PLWH) within health care settings constitutes a significant barrier to curtailing the epidemic long term. HIV-related stigma refers to the exclusionary attitudes, beliefs and actions of others towards PLWH and it is considered among the most powerful impediments to prevention, access, and treatment. Despite substantial developments in HIV care, stigma remains an unmitigated obstacle in health care settings. This is exceptionally unsettling because enacted HIV-related stigma in health care settings is associated with maladaptive behaviors and poor health outcomes (Kingori et al., 2012; Rueda et al., 2016) To counteract the impact of HIV-related stigma in health care settings, deliberate, methodical and impactful strategies are necessary, particularly those that address the likely drivers of stigma (Davtyan, Olshansky, & Lakon, 2018).

In health care settings, stigma is triggered by inadequate knowledge of HIV/AIDS (Platten, Pham, & Nguyen, 2014), fear of infection (Ahsan Ullah, 2011), value-laden judgments (Saki, Kermanshahi, Mohammadi & Mohraz, 2015), and lack of awareness about the presence of stigma in health care settings (Nyblade, Stangl, Weiss, & Ashburn, 2009; Churcher, 2013). Examples of HIV-related stigma in health care settings include prejudicial attitudes towards HIV patients, HIV testing without informed consent, and care refusal. In a study of health care workers in two Southeastern US states, Stringer et al. (2016) found that more than one third agreed with the statement “people get infected with HIV because they engage in irresponsible behaviors.” Moreover, a study of health care workers in a tertiary hospital in KwaZulu-Natal South Africa, found that HIV patients were tested for HIV prior to surgical procedures without informed consent due to health care worker fear of being infected (Famoroti, Fernandes, & Chima, 2013). In addition, a study of patient experiences with stigma in Iran found that many had experienced discriminatory behaviors from physicians in the form of care refusal (Saki et al., 2015).

HIV-related stigma in health care settings is heavily internalized and leads to poor treatment continuity, increased immunosuppression, suboptimal medication adherence, and mental health conditions (Baugher et al., 2017; Rice et al., 2017). In one study, provider-directed HIV discrimination, such as not listening to patients and not explaining things to them, was associated with interruptions in HIV care (Magnus et al., 2013). Similarly, Nyblade et al. (2017) found that stigma directed from health care workers was linked to higher odds of reporting delay or avoidance of HIV counseling and testing. Both Walburn, Swindells, Fisher, High, & Islam (2012) and Earnshaw, Smith, Chaudoir, Amico, & Copenhaver (2013) found that stigma was associated with a drop in CD4 counts due to lower visit proportions and higher likelihood of CD4 counts under 200 cells/mm3. Turan et al. (2016) found that internalized stigma was associated with less perceived social support, which then predicted depressive symptoms, which in turn predicted suboptimal antiretroviral medication adherence. Reducing HIV-related stigma in health care settings is therefore critical for engagement in care, treatment compliance, and improved clinical outcomes.

In the last two decades, there has been a considerable increase in stigma reduction interventions outside of the US, and many of these programs have targeted clinical health care workers and students of health care professions. These programs have focused on improving knowledge of HIV transmission and promoting contact with PLWH to maximize sensitivity (Yiu, Mak, Ho, & Chui, 2010), experiential games to increase awareness of stigma-related stressors among PLWH (Mak, Cheng, Law, Cheng, & Chan, 2015), enlisting key opinion leaders to facilitate stigma reduction activities in clinical settings (Li et al., 2013), collaborative discussions about HIV and associated stigma (Wu et al., 2008), active learning activities (Norr et al., 2012), demonstrations with corrective feedback and skill-building (Kaponda et al., 2009), and empowerment via provider-patient interactions (Uys et al., 2009). HIV-related stigma reduction programs, evidenced by the abovementioned studies, have targeted health care workers and settings in other parts of the world. However, there is a dearth of such studies in the US.

Existing studies indicate that HIV-related stigmatization is also prevalent in US-based health care settings (Stringer et al., 2016; Davtyan, Farmer, Brown, Sami, & Frederick, 2016; Davtyan, Olshansky, Brown, & Lakon, 2017). However, to our knowledge, there are currently no published studies assessing the efficacy of HIV-related stigma reduction programs in the US. To address this gap and to contribute to the existing scholarship on HIV stigma reduction in health care institutions, we designed and implemented a PhotoVoice-informed HIV stigma training program for health care workers (i.e., physicians, nurses, allied health care professionals) employed at a university-based medical institution located in Southern California. PhotoVoice is a Community-based Participatory Action Research methodology that recognizes the unique and influential insights of community members in documenting and reflecting their perceptions of reality through photographic images (Wang & Burris, 1997).

Community-based Participatory Action Research allows community members to exhibit their photographically captured experiences to leverage and negotiate change (Nykiforuk, Vallianatos, & Nieuwendyk, 2011).

The decision to use PhotoVoice as an integral part of an HIV stigma training program was informed by the literature. PhotoVoice has been shown to be an effective tool for facilitating interpretation of prejudice (Moletsane et al., 2009; Davtyan et al., 2016), defining health priorities (Teti, Murray, Johnson, & Binson, 2012), and adaptation of HIV prevention programs (Kubicek, Beyer, Weiss, & Kipke, 2012). Additionally, PhotoVoice has been recognized as a sound methodology for teaching critical thinking and for generating knowledge through visual media (Schell, Ferguson, Hamoline, Shea, & Thomas-Maclean, 2009).

The research questions examined in this study were: Does the PhotoVoice-informed HIV stigma training of health care workers increase knowledge of HIV/AIDS? Does the PhotoVoice-informed HIV stigma training of health care workers improve attitudes towards PLWH? Does the PhotoVoice-informed HIV stigma training of health care workers increase observations of enacted HIV stigma in health care settings? We hypothesized that the PhotoVoice-informed stigma training would increase knowledge of HIV/AIDS, improve attitudes towards PLWH, and increase observations of enacted HIV stigma in health care settings.

Methods

Participants & Recruitment

We recruited clinical health care workers, including physicians, nurses, and allied health care professionals into this study. Physicians were defined as health care professionals holding a Medical Doctorate (M.D.). Nurses were defined as health care professionals holding Licensed Vocational Nurse (LVN), Nurse Practitioner (NP), or Registered Nurse (RN) licenses. Allied health care professionals were defined as health care professionals who provide diagnostic and therapeutic patient care. We also recruited Stigma Trainers, who were women of color living with HIV who participated in our previous PhotoVoice study of stigma (Davtyan et al., 2016). The eligibility criteria for health care workers were: 18 years of age or older; physician, nurse, or allied health care worker by profession; contact with HIV positive patients; and willing to provide informed consent. The eligibility criteria for the Stigma Trainers were: participant of our previous PhotoVoice study of HIV stigma; willing to speak openly about personal experiences with HIV and associated stigma with health care workers; and willing to provide informed consent.

To initiate enrollment of clinical health care workers into the current study, several active and passive recruitment strategies were applied. First, we contacted our partners and colleagues at the participating health care institution and informed them of the study, its requirements, and inclusion criteria. Second, we asked that our partners and colleagues disseminate information about the study to their respective departments and staff. Third, we distributed a study flyer throughout the health care institution and nearby businesses. Fourth, the lead researcher discussed the study at hospital grand rounds and departmental meetings. Fifth, the lead researcher directly approached clinical health care workers at the participating health care institution and during work hours, and asked them if they would be interested in hearing about a study on HIV stigma. Prospective Stigma Trainers were approached during routine clinic visits at the participating health care institution and informed about the current study. Once interest was shown, study-related meetings took place during clinic or work hours in a private area within the medical campus. During the meetings, the lead researcher discussed the study at length, encouraged questions, assessed comprehension of study procedures, and obtained informed consent.

The rationale for recruiting clinical health care workers was based on findings from previous studies that enacted HIV stigma towards PLWH directly from clinical health care workers is injurious and leads to adverse patient outcomes (Eaton et al., 2015; Earnshaw et al., 2013), and that PLWH experience more stigma from clinical health professionals versus nonclinical professionals (Rogers et al., 2014). The decision to include participants of our previous PhotoVoice study of HIV stigma as Stigma Trainers was also informed by past findings that contact with PLWH is an effective stigma reduction strategy (Yiu et al., 2010; Derose et al., 2014).

Sample Size

To determine the sample size for the current study, we first conducted a literature review of similar studies of HIV stigma among health care workers. A study by Shah, Heylen, Srinivasan, Perumpil, & Ekstrand (2014) recruited 91 nursing students for an HIV stigma reduction program in India. Wu et al. (2008) recruited 138 health service providers for their stigma reduction intervention in China. Lueveswanij, Nittayananta, & Robison (2000) recruited 139 oral health personnel for a stigma reduction program in Thailand. We also reviewed systematic literature reviews and meta-analyses of HIV stigma reduction interventions to learn about effect sizes. Sengupta, Banks, Jonas, Miles, & Smith (2011) and Mak, Mo, Ma, & Lam (2017) reported baseline and post-intervention mean effect sizes between 0.2 and 0.8 across several studies for stigma reduction as an outcome variable. We then calculated the sample size based on effect size recommendations from the aforesaid studies, as well as Cohen's *d* values for social, behavioral, and intervention studies (Cohen, 1988, p. 25; Mak et al., 2017). Taking the mean effect size found in the systematic reviews and meta-analyses (0.5) and Cohen's *d* of 0.2 (small effect size), we derived an average effect size of 0.35 for the current study. Assuming 80% power, a significance level of 0.05, an effect size of 0.35, and a paired sample (i.e., paired observations), we derived a sample size of 66 pairs for a t-test. Due to significant challenges in recruiting health care workers for the current study, we were unable to reach the desired sample size of 66 pairs in the intervention and control arms.[1]

Data Collection

Data were collected using a 40-item self-administered survey, at three time points. The first survey was administered after the informed consent was signed (T1=baseline). The second survey, identical to the first, was administered within approximately a week of the intervention or control conditions (T2). The third and last survey, identical to the first two surveys, was administered 3 months after the intervention or control conditions (T3).

Measures

We collected data on demographic factors, HIV/AIDS knowledge, attitudes towards PLWH, and observations of enacted HIV stigma in health care settings. Demographic variables of interest included age, sex, marital status, race, ethnicity,

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[1] Recruitment challenges included lack of interest in the study, scheduling conflicts, heavy workload, and unwillingness to attend a training session outside of work hours.

educational level, profession, department, income, and place of birth and were informed by previous studies (Andrewin & Chien, 2008; Ekstrand et al., 2013; Ahsan Ullah, 2011; Famoroti et al., 2013). Survey items on HIV/AIDS knowledge, attitudes towards PLWH, and observations of enacted HIV stigma in health care settings were adapted from previously used questionnaires (Carey & Shroder, 2002; Nyblade et al., 2013; Feyissa, Abebe, Girma, & Woldie, 2012; Kalichman et al., 2005; Health Policy Project, 2013), and developed by the lead researcher.

Knowledge of HIV/AIDS: To assess knowledge of HIV/AIDS, participants were asked to indicate their level of agreement with the following ten statements or questions: 1) The risk of HIV transmission following a needle-prick or sharps injuries is small (approximately 1 in 300); 2) The risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small (approximately 1 in 1000); 3) Which of the following body fluids have high enough concentrations of HIV to transmit the virus?; 4)Pre and Post-exposure HIV medications greatly reduce transmission of HIV; 5) People who are infected with HIV quickly show serious signs of illness; 6)There is a vaccine that can stop adults from getting HIV; 7) I would have a strong fear of HIV transmission if I touched the sweat of a person with HIV/AIDS; 8) I would have a strong fear of HIV transmission if I touched the saliva of a person with HIV/AIDS; 9) I would have a strong fear of HIV transmission if I dressed the wounds of a person with HIV/AIDS"; and 10) "I would have a strong fear of HIV transmission if I put an intravenous drip in someone who was showing signs of AIDS. The lead researcher developed the first four statements, statements 5 and 6 were adapted from Carey & Shroader (2012), statements 7-8 and 10 were adapted from Feyissa et al. (2012), and statement 9 was adapted from Nyblade et al. (2013). The response categories consisted of a 4-point Likert scale (1-Strongly Agree, 2-Agree, 3-Disagree, 4-Strongly Disagree) for all but one statement. The response choices for the question on fluids that transmit HIV were: a-Saliva, b-Urine, c-Spinal Fluid, d-Breast Milk, and e-Pus.

Attitudes towards PLWH: The following ten statements were used to assess attitudes towards PLWH: 1) Most people living with HIV do not care if they infect other people; 2) Women living with HIV should not be allowed to have children; 3) People with HIV should expect some restrictions on their freedom; 4) HIV is punishment for bad behavior; 5) People living with HIV should feel ashamed of themselves; 6) Most people living with HIV have had many sexual partners; 7) People get infected with HIV because they engage in irresponsible behaviors; 8) Men who have sex with men (MSM) spread HIV in our community; 9) Female sex workers (FSWs) spread HIV in our community; and 10) Injection drug users (IDUs) spread HIV in our community. Statements 1 and 4-7 were adapted from Nyblade et al. (2013), statement 2 was adapted from the Health Policy Project (2013), statement 3 was adapted from Kalichman et al. (2005), statements 8-9 were adapted from Feyissa et al., (2012), and statement 10 was developed by the lead researcher. The response categories for these statements consisted of a 4-point Likert scale (1-Strongly Agree, 2-Agree, 3-Disagree, 4-Strongly Disagree).

Observations of Enacted HIV Stigma: To ascertain observations of enacted HIV stigma in health care settings, the following ten statements were included in the study questionnaire: 1) I have observed patients with HIV receive less care/attention than other patients; 2) I have observed extra precautions taken in the sterilization of

instruments used on HIV-positive patients; 3) I have observed healthcare workers using latex gloves for performing noninvasive exams on clients; 4) I have observed healthcare workers disclosing patients' HIV status to others without consent; 5) I have observed healthcare workers gossiping about a patient's HIV status; 6) I have observed healthcare workers unwilling to care for a patient living with HIV; 7) I have observed healthcare workers avoiding physical contact with a patient living with HIV; 8) I have observed healthcare workers requiring some patients to be tested for HIV before scheduling surgery; 9) I have observed a senior healthcare provider assigned to care for a patient with HIV instead of a junior healthcare provider; and 10) I have observed HIV testing without the informed consent of the patient. Statements 1-3, 5, and 8-10 were adapted from Feyissa et al. (2012), statements 4 and 7 were adapted from the Health Policy Project (2013), and statement 6 was adapted from Nyblade et al. (2013).
The response categories for these statements comprised 4-point Likert scales (1-Never, 2-Once or Twice, 3-Several Times, 4-Most of the Time) to capture frequency of observations.

To condense the information in the number of original survey items relating to HIV/AIDS knowledge, attitudes towards PLWH, and observations of enacted HIV stigma into a smaller set of combined factors, an exploratory factor analysis (EFA) was carried out. A scree plot was then constructed to display the proportion of the total variation in our dataset that was explained by each of the components in the EFA. This step assisted in visually determining the number of factors to extract. By applying the "elbow rule" to the scree plot, we decided on a three-factor extraction (Refer to Figure 4.1) (Wilson et al., 2008).

Figure 4.1 about here

We employed the principal components factor extraction method with a non-orthogonal rotation (promax) to test the loading strengths of the items on factors. Promax rotation was selected based on the assumption that the stigma variables were highly correlated. Using the Kaiser-Meyer-Olkin sampling adequacy criteria as a guide, we fixed the factor loadings (lambda) at 0.5 in the EFA. We then omitted items with factor loadings less than 0.5 and this produced a shortened scale. Due to ambiguities in the way the question was worded in the survey, we decided to remove the following question from the EFA: “Which of the following body fluids have high enough concentrations of HIV to transmit the virus.” From the loading diagram we determined that the statements used to measure “knowledge of HIV/AIDS” loaded most strongly onto Minimum Residual 1 (MR1). The statements utilized to assess “attitudes towards PLWH” loaded most strongly onto Minimum Residual 2 (MR2). The “observations of enacted HIV stigma” statements loaded most strongly onto Minimum Residual 3 (MR3) (Refer to Table 4.1).

Table 4.1 about here

The following survey items were then determined as factors of *knowledge of HIV/AIDS (MR1)*: 1) I would have a strong fear of HIV transmission if I dressed the wounds of a person with HIV or AIDS; 2) I would have a strong fear of HIV transmission if I put an intravenous drip in someone who was showing signs of AIDS; 3) I would have a strong fear of HIV transmission if I touched the saliva of a person with HIV/AIDS; 4) HIV is punishment for bad behavior; 5) I would have a strong fear of HIV transmission if

I touched the sweat of a person with HIV/AIDS; and 6) Most people living with HIV have had many sexual partners.

The following survey items were determined as factors of *attitudes towards PLWH (MR2):* 1) MSM spread HIV in our community; 2) FSWs spread HIV in our community; and 3) IDUs spread HIV in our community. The following survey items were determined as factors of *observations of enacted HIV stigma (MR3):* 1) I have observed healthcare workers avoiding physical contact with a patient living with HIV; 2) I have observed healthcare workers gossiping about a patient's HIV status; 3) I have observed healthcare workers unwilling to care for a patient living with HIV, and 4) I have observed healthcare workers disclosing patients' HIV status to others without consent.

We observed variable overlaps in the measurement of knowledge in the EFA. Two survey items which were intended to measure attitudes towards PLWH ("HIV is punishment for bad behavior" and "Most people living with HIV have had many sexual partners") in the original survey, loaded strongly onto the *knowledge of HIV/AIDS (MR1)* factor (Refer to Table 4.1). These overlaps are supported by existing studies, which indicate that the perception that HIV is a form of punishment is associated with less HIV transmission knowledge. Specifically, having the knowledge to reject HIV transmission myths is negatively associated with the perception that HIV is a punishment for socially and morally unacceptable behaviors (Abler et al., 2014; Keselman, Kaufman, & Patel, 2004). Similarly, higher knowledge of HIV is associated with lower odds of endorsing misconceptions surrounding HIV risk (i.e., sexual promiscuity) (Tenkorang & Owusu, 2013).

Intervention & Control Conditions

Prior to the implementation of the first intervention session, the Stigma Trainers met with the lead researcher. The purpose of these meetings (two in total) was to brainstorm and strategize about the content, structure, and delivery of the stigma training to health care workers. Additionally, the meetings were utilized as opportunities for Stigma Trainers to ask questions, to prepare their talking points, and to practice conveying personal stories of HIV-related stigma using selected photographs from their previous participation in our PhotoVoice study of HIV stigma (Davtyan et al., 2016). Stigma Trainers and the lead researcher also discussed research ethics, including privacy and confidentiality, the volunteer nature of their participation in this study, and the option to withdraw at any time without consequence. Each meeting lasted approximately two hours and took place at the participating health care institution.

Participants enrolled in the intervention arm of the study received a one-time 2-hour training session about HIV/AIDS and associated stigma, which consisted of three parts. The first part, entitled "Overview of HIV stigma in Healthcare Settings," was administered by the lead researcher and aimed to provide health care workers with tailored HIV/AIDS-related information. Study participants were administered a 25-minute PowerPoint presentation about HIV facts, vulnerable population groups, myths about HIV/AIDS, occupational exposure, transmission, pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), definition of stigma, the origin of stigma, types of stigma, examples of stigmatizing and discriminatory behaviors, impact of stigma, and manifestations of stigma in health care settings. The presentation was followed by a 15-minute discussion session. Discussion questions included, "What are some consequences of HIV stigma?” “How did stigma and discrimination towards PLWH come about?” and “Why is it important to reduce stigma and discrimination towards PLWH?”

The second part of the intervention entitled, “Women of Color Reflect on HIV Stigma through PhotoVoice,” was facilitated by the Stigma Trainers and aimed to sensitize health care workers, to humanize HIV, to promote contact between PLWH and health care workers, and to illustrate experiential stigma from the perspectives of PLWH. During this part of the intervention, Stigma Trainers conveyed personal stories of HIV-related discrimination using the photographs they took as part of their participation in our previous PhotoVoice study of HIV stigma (Davtyan et al., 2016). Each participant discussed a few photographically documented reflections of prejudice, including incidents of HIV stigma that took place in health care settings and directed from health care workers. The session lasted approximately 25 minutes, followed by a 15-minute question and answer period.

The third and final part of the intervention entitled, “Let’s Address Stigma Together!” aimed to promote open dialogue regarding HIV-related stigma and discrimination in health care settings, to increase awareness of enacted stigma in health care settings, and to develop practical solutions to common stigmatizing and discriminatory behaviors exhibited by health care workers. During this interactive session, participants were presented with four vignettes related to HIV-related stigma and discrimination in health care settings and asked about how they would respond to each hypothetical scenario. Scenarios included, “A co-worker is making assumptions about how a patient acquired HIV. How would you approach this co-worker and what would you say?” “A colleague in your department wears multiple gloves to perform a noninvasive exam of an HIV-positive patient? How would you address this colleague? How would you address a patient who was offended by this behavior?” Once health participants revealed how they would address each of these scenarios, Stigma Trainers offered their own perspectives on whether the health care worker responses were adequate or if further actions would be necessary. This session took approximately 40 minutes to complete.

Participants enrolled in the control arm of the study received a one-time educational PowerPoint presentation about HIV/AIDS and related stigma, identical to the presentation administered to the intervention arm, but it was delivered electronically.

Statistical Analysis

Descriptive Statistics

To describe and summarize the features of our study data, we conducted baseline descriptive statistics. These included frequencies, proportions, counts, standard deviations, medians, means, and data visualization (i.e., plots). Median group differences in baseline demographic variables were assessed using the Wilcoxon Ranked Sum test, a non-parametric alternative to the two-sample t-test.

Within Group Differences

Within-group median differences in knowledge of HIV/AIDS, attitudes towards PLWH, and observations of enacted HIV stigma in health care settings in the intervention and control arms were evaluated with the Wilcoxon matched pairs signed-rank test, a non-parametric test used to compare repeated measurements on a single sample.

Hypothesis Testing

To determine whether the PhotoVoice-informed HIV stigma training of health care workers increased knowledge of HIV/AIDS, improved attitudes towards PLWH, and increased observations of enacted HIV stigma in health care settings, several base linear regression models were constructed. Linear regression models were deemed appropriate for hypothesis testing because each of the dependent variables (MR1, MR2, MR3) was a composite variable derived from factor analysis and would be treated as a continuous variable rather than an ordinal variable. Each base model (three in total) consisted of the *knowledge of HIV/AIDS factor (MR1)*, *attitudes towards PLWH factor (MR2)*, or *observations of enacted HIV stigma factor (MR3),* respectively, as the dependent variable. The explanatory variables included in each base model were: a group indicator (intervention vs. control arm), a time indicator (T2 or T3), and demographic variable(s) that were statistically significantly different between the intervention and control arms.

Another set of models was constructed, and is referred to as the full models, which included *knowledge of HIV/AIDS factor (MR1)*, *attitudes towards PLWH factor (MR2)*, or *observations of enacted HIV stigma factor (MR3),* respectively, as the dependent variable in each model. Also included in each model was a group indicator (intervention vs. control arm), a time indicator (T2 or T3), and demographic variable(s) that were statistically significantly different between the intervention and control arms. In the full models, we also added an interaction term between the time indicator (T2 or T3) and group indicator (intervention vs. control arm) to the explanatory variables, to allow the change over time to differ by group. We then conducted ANOVA likelihood ratio tests to assess the goodness-of-fit of the base or full models.

All data were analyzed using RStudio, version 1.0.153.

Ethical Considerations

The Institutional Review Boards of University of Southern California and University of California Irvine approved the current study and each participant signed an informed consent, agreeing to participate in the study. Participants randomized into the intervention arm received a $40 USD gift card and those randomized into the control arm received a $20 USD gift card. Stigma Trainers each received $80 USD for the pre-intervention meetings with the lead researcher, as well as $40 USD for each intervention session they facilitated. Participants were also reimbursed for other study-related expenses, including mileage, parking, and childcare.

Results

Population Characteristics

A total of 73 participants were enrolled in the study between June 2016 and July 2017. Thirty-eight health care workers were randomized into the intervention arm and 35 into the control arm. The intervention group consisted of health care workers with a mean age of 42.5 years (*SD*=13.1), the majority were nurses (50%), non-Hispanic (53%), White (61%), female (89%), either now married (42%) or never married (26%), and had at least Bachelor’s degree (53%). Much of the sample was US-born (84%), employed at the Pediatrics department (42%) and earned between $30,000 USD and $59,999 USD (52%). The control group consisted of health care workers with a mean age of 41.1 years (*SD*=12.1), the majority were nurses (54%), non-Hispanic (57%), White (54%), female (89%), either now married (46%) or never married (40%), and had at least a Bachelor's degree (75%). Majority of this sample was also US-born (80%), from the Pediatrics department (37%), and with an income greater than or equal to $70,000 USD (61%). No significant differences in demographic characteristics were observed between the intervention and control groups, except for educational level, which was statistically significantly different (*p*<.05) (Refer to Table 4.2).

Table 4.2 about here

Within Group Differences:

The Wilcoxon matched pairs signed-rank tests for the intervention arm revealed that median knowledge scores were significantly higher at T2 compared to T1, T3 compared to T1, and T3 compared to T2. Median attitudes scores were significantly higher at T2 compared to T1 and T3 compared to T2, but not at T3 compared to T1. The median observations scores were not statistically significantly different across the three time points. In the control arm, the median scores for knowledge, attitudes, and observations were not significantly different across the three time points (Refer to Table 4.3 and Figure 4.2).

Table 4.3 about here

Figure 4.2 about here

Hypothesis Testing: Base and Full Models

Table 4.4 summarizes the base and full linear regression models at T2 and T3 constructed to test the first hypothesis that the PhotoVoice-informed training of clinical health care workers will increase knowledge of HIV/AIDS.

Table 4.4 about here

Below are the regression equations for the base and full models:

1) T2 Base Model: $\widehat{\textit{Knowledge of HIV/AIDS (MR1)}}$ *= 0.05 + 0.50*Intervention + 0.42*T2 - 0.09*Educational Level*
2) T2 Full Model: $\widehat{\textit{Knowledge of HIV/AIDS (MR1)}}$ *= 0.13 + 0.35*Intervention + 0.18*T2 - 0.09*Educational Level + 0.44*Intervention*T2*
3) T3 Base Model: $\widehat{\textit{Knowledge of HIV/AIDS (MR1)}}$ *= 0.17 + 0.53*Intervention + 0.03*T3 - 0.09*Educational Level*
4) T3 Full Model: $\widehat{\textit{Knowledge of HIV/AIDS (MR1)}}$ *= 0.17 + 0.52*Intervention + 0.02*T3 - 0.09*Educational Level + 0.02*Intervention*T3*

The interaction terms for the full models at T2 (β=0.44) and T3 (β=0.02) indicate that after controlling for the effect of educational level, knowledge of HIV/AIDS improved more for the intervention arm than it did for the control arm between times T1 and T2, but knowledge changes were similar for the two arms between times T1 and T3. However, the difference at time T2 was not statistically significant (*p*=.10) (Refer to Table 4.4). With respect to the base models at T2 and T3, we concluded that after adjusting for the effect of educational level and time, knowledge of HIV/AIDS among those assigned to the intervention arm increased between times T1 and T2 (β=0.50, *p*<.01) and between times T1 and T3 (β=0.53, *p*<.01).

Table 4.5 summarizes the base and full linear regression models at T2 and T3 constructed to test the second hypothesis that the PhotoVoice-informed training of clinical health care workers will improve attitudes towards PLWH.

Table 4.5 about here

Below are the regression equations for the base and full models:

1) T2 Base Model: $\widehat{\text{Attitudes towards PLWH (MR2)}} = -0.26 + 0.44 * \text{Intervention} + 0.51 * T2 - 0.03 * \text{Educational Level}$

2) T2 Full Model: $\widehat{\text{Attitudes towards PLWH (MR2)}} = -0.15 + 0.25 * \text{Intervention} + 0.20 * T2 - 0.04 * \text{Educational Level} + 0.55 * \text{Intervention} * T2$

3) T3 Base Model: $\widehat{\text{Attitudes towards PLWH (MR2)}} = -0.16 + 0.48 * \text{Intervention} + 0.17 * T3 - 0.03 * \text{Educational Level}$

4) T3 Full Model: $\widehat{\text{Attitudes towards PLWH (MR2)}} = -0.22 + 0.58 * \text{Intervention} + 0.35 * T3 - 0.03 * \text{Educational Level} - 0.35 * \text{Intervention} * T3$

The interaction terms for the full models at T2 ($\beta=0.55$) and T3 ($\beta=-0.35$) indicate that after controlling for the effect of educational level, attitudes towards PLWH improved more for the intervention arm than it did for the control arm between times T1 and T2, but attitude changes decreased for the two arms between times T1 and T3. However, the difference at time T2 was not statistically significant ($p=.05$) (Refer to Table 4.5). With respect to the base models for T2 and T3, we concluded that after adjusting for the effect of educational level and time, attitudes towards PLWH among those assigned to the intervention arm improved between times T1 and T2 ($\beta=0.44$, $p<.01$) and between times T1 and T3 ($\beta=0.58$, $p<.01$).

Table 4.6 summarizes the base and full linear regression models at T2 and T3 constructed to test the third and final hypothesis that the PhotoVoice-informed training of clinical health care workers will increase observations of enacted HIV stigma.

Table 4.6 about here

Below are the regression equations for the base and full models:

^

1) T2 Base Model: *Observations of Enacted HIV Stigma = 0.51 -0.44*Intervention + 0.19*T2 - 0.08*Educational Level*

^

2) T2 Full Model: *Observations of Enacted HIV Stigma = 0.51 -0.45*Intervention + 0.18*T2 - 0.08*Educational Level + 0.03*Intervention*T2*

^

3) T3 Base Model: *Observations of Enacted HIV Stigma = - 0.53 -0.42*Intervention + 0.09*T3 - 0.08*Educational Level*

^

4) T3 Full Model: *Observations of Enacted HIV Stigma = 0.54 -0.44*Intervention + 0.06*T3 - 0.08*Educational Level + 0.07*Intervention*T3*

The interaction terms for the full models at T2 (β=0.03) and T3 (β=0.07) indicate that after controlling for the effect of educational level, observations of enacted HIV stigma were not different in the intervention arm and control arms between times T1 and T2 and between times T1 and T3 (Refer to Table 4.6). With respect to the base models for T2 and T3, we concluded that after adjusting for the effect of educational level and time, observations of enacted HIV stigma among those assigned to the intervention arm decreased between times T1 and T2 (β=-0.44, *p*<.01) and between times T1 and T3 (β=-0.42, *p*<.01).

Discussion

The purpose of the current study was to determine if an intervention designed specifically for clinical health care workers influenced some of the possible sources of HIV-related stigma in health care settings: knowledge of HIV/AIDS, attitudes towards PLWH, and observations of enacted HIV stigma in health care settings. Our findings indicated that the intervention increased knowledge, improved attitudes, and contrary to our hypothesized outcome, decreased observations of enacted HIV stigma.

The PhotoVoice-informed HIV stigma training for clinical health care workers increased knowledge of HIV/AIDS in the context of occupational risk of transmission, prophylactic measures, and disease manifestations in PLWH. These findings were somewhat consistent with the existing evidence. In a randomized study of health care professionals (i.e., students of health care professional programs such as nursing, medicine, clinical psychology, social work) based in Hong Kong, Mak et al. (2015) found that a game-based experiential program and contact with PLWH were both successful in increasing HIV/AIDS-related knowledge. Similar to our study, Mak et al. (2015) assessed knowledge related to HIV/AIDS in terms of disease manifestations in PLWH, but also examined general knowledge of prevention through condom use, HIV tests, and testing. Williams et al. (2006) administered an HIV/AIDS educational intervention to nurses in China, consisting of a 5-day workshop comprising didactic lectures, activities, and discussions about values and personal feelings about HIV/AIDS. The intervention was successful in improving HIV/AIDS-associated knowledge among the target population. Similar to our study, Williams et al. (2006) appraised knowledge of HIV/AIDS in terms of occupational exposure risks (i.e., needle stick). However, they also gauged knowledge in the context of unfounded fear of transmission across different settings (i.e., eating in a restaurant where the cook has AIDS, using public restrooms), chemicals that can kill HIV (i.e., chlorine bleach), and transmission of blood-borne pathogens. Yiu et al. (2010) examined the efficacy of a knowledge and contact with PLWH-based training for nursing students in Hong Kong. Study findings indicated that this multicomponent intervention was successful in increasing knowledge of HIV/AIDS and improving emotional competence. Consistent with our study, Yiu et al. (2010) evaluated knowledge of HIV/AIDS in the context of disease prevention and viral transmission. However, the study also appraised knowledge of HIV progression and standard precautionary measures used in health care settings. These differences in the way that knowledge of HIV/AIDS was examined may be attributed to sociocultural differences in the drivers of HIV-related stigma. In Chinese health care settings, stigma has been linked to misunderstandings and exaggerated fears of contagion due to poor knowledge of transmission (Yiu et al., 2010). In US-based health care settings, however, HIV-related stigma is related to inadequate HIV-specific clinical training and education, availability of PEP, and perceptions of HIV-stigma policy enforcements (Stringer et al., 2016; Davtyan et al., 2017). Additionally, since HIV-associated stigma is based on socially dictated norms and practices, and presents in myriad complex ways, it can be particularly challenging to measure its potential sources (i.e., inadequate knowledge of HIV/AIDS) using universally acceptable standards (Florom-Smith & De Santis, 2012).

The present study found that the PhotoVoice-informed HIV stigma training of health care workers improved attitudes towards PLWH. This finding was somewhat inconsistent with the extant literature. Similar to our study, Pisal et al. (2007) implemented a training curriculum on basic medical knowledge of HIV/AIDS, risk reduction, patient management, confidentiality, stigma and discrimination, and ethics, and found that it ameliorated stigmatizing attitudes towards PLWH. However, the investigators of this study measured attitudes in the context of status disclosure, testing without informed consent, signs and symbols on hospital beds, treatment delays, and patient isolation. Our study measured attitudes towards PLWH in terms of opinions towards highly impacted segments of the population (i.e., MSM, FSWs, IDUs). Statements about serologic disclosure and informed consent were included in our assessment of observations of enacted HIV stigma rather than attitudes towards PLWH. Shah et al. (2014) assessed the efficacy of an HIV stigma reduction intervention among nursing students in India aimed at building knowledge and decreasing unwarranted fears of casual HIV transmission and moralistic discernments. The program reduced stigmatizing attitudes towards PLWH in terms of blaming, endorsement of coercive and discriminatory policies, and intent to discriminate. Our evaluation of attitudes towards PLWH included personal feelings towards certain groups, in addition to risky sexual behaviors and negligence about infecting others. Differences in how the aforementioned studies appraised attitudes towards PLWH compared to how we did may stem from incongruities in how stigma is enacted cross-culturally. In Indian health care settings, for instance, stigma may be more commonly operationalized by involuntary disclosure of HIV status and patient isolation based on poor attitudes of PLWH (Mahendra et al., 2007; Ekstrand, Bharat, Ramakrishna, & Heylen, 2012; Nebhinani, Mattoo, & Wanchu, 2012). Conversely, in US health care settings, displays of HIV-related stigma may include poor attitudes in the form of erroneous assumptions about how HIV was acquired and judgments about perceived “illicit” behaviors and sexual orientation (Eaton et al., 2015; Davtyan et al., 2017). Inconsistencies in how attitudes towards PLWH are assessed may also be connected to shortages of empirical studies that examine stigmatizing attitudes that reflect current vs. outdated concerns of PLWH, including stigma that arises from occasional encounters with PLWH, avoidance of personal contact with PLWH, and criminalization of HIV transmission (Beaulieu, Adrien, Potvin, & Dassa, 2014).

The current study found that the PhotoVoice-informed training of health care workers decreased observations of enacted HIV stigma. This finding was consistent with the available studies. In a quasi-experimental study of two government hospitals in Vietnam, Oanh, Ashburn, Pulerwitz, Ogden, & Nyblade (2008) assessed the efficacy of a two-armed intervention designed to reduce fear-based and value-based stigma among hospital staff. Those enrolled in Arm 1 received training on basic HIV/AIDS information, testimonials from HIV-positive individuals about their experiences, and training on universally accepted methods of precaution. Participants in Arm 2 of the study received the same program as those in Arm 1, combined with training on social stigma co-facilitated by HIV-positive individuals. Consistent with our study findings, investigators detected substantial reductions in observations of enacted HIV stigma in patient-provider interactions among participants of the combined intervention group (Arm 2). However, it is important to point out here that despite our hypothesis that the PhotoVoice-informed training would increase observations of enacted HIV stigma, a significant decrease occurred. This reduction in observations of enacted HIV stigma may be explained by the following factors: a) the survey questions we used to measure observations of enacted HIV stigma, albeit previously tested on health care worker groups in developing parts of the world, may not have measured what they intended to in the US context; b) the study sample may have been too small to detect an increase in observations of enacted HIV stigma; c) news of the current study being conducted at the participating health care institution may have triggered internal stigma reduction trainings, leading to decreased occurrences and hence decreased observations of enacted HIV stigma by study participants; d) the 3-month follow-up period may not have been sufficient to detect an increase in observations of enacted HIV stigma. A different study of correlates of observing and reporting enacted HIV stigma towards HIV patients by tuberculosis (TB) health care workers in Kenya, Namibia, and Tanzania reported that trainings in patients' rights and confidentiality increased the odds of observing discrimination and reporting it (Straetemans, Bakker, & Mitchell, 2017). These findings support our initial hypothesis that targeted training of health care workers would increase observations of enacted HIV stigma in health care settings. However, in the present study, we did not assess motivation or willingness to report observations of discrimination. Similar to our study, Straetemans et al. (2017) measured observations of enacted stigma in the context of testing without informed consent and prior to surgery, excessive sterilization measures, gossip, assigning senior health care providers to care for HIV patients, and differential care/attention. These enactments of HIV-related stigma have also been reported in other studies of African health care settings (Famoroti et al., 2013). Our study, conversely, also included measures of observations pertaining to care refusal and contact avoidance, which have been identified as present in US-based health care settings (Schuster et al., 2005; Sears, 2008).

The current study makes important contributions to the literature on HIV stigma in US-based health care settings, but we acknowledge the following limitations. First, the current study recruited physicians, nurses, and allied health care professionals. These groups may not be representative of all health care workers employed at medical institutions. Second, majority of the participants of this study were from the Pediatrics department of the participating medical institution. Their views on HIV/AIDS and stigma, as well as their frequency of interactions with HIV patients may have been considerably different from health care workers employed at other departments. Third, though participants were randomized into either the intervention or control arm (strong internal validity), recruitment barriers and a subsequent smaller sample size led to loss of statistical power. As a result, the findings of this study cannot be extrapolated to larger populations of health care workers. Fourth, HIV-related stigma was measured in the context of knowledge of HIV/AIDS, attitudes towards PLWH, and observations of enacted HIV-stigma in health care settings. These measures do not represent the full complexity of social stigma associated with HIV/AIDS. Fifth, the duration of the study follow-up measurements may have limited our understanding of the relationships under investigation.

The findings of this study have several important implications. First, to our knowledge this is the first study to assess the efficacy of a training program aimed to reduce some of the potential drivers of HIV stigma in a US-based health care setting. Given the presence of HIV stigma in US-based health care settings and its association with poor patient outcomes (Marshall, Brewington, Allison, Haynes, & Zaller, 2017), additional stigma reduction programs are merited. Second, the enrollment of physicians, nurses, and allied health care professionals represents a limited cross-section of health care workers. Studies that examine HIV stigma among US-based pharmacists, dentists, physical therapists, clinical social workers, case managers, and non-clinical health care professionals may be necessary. Third, recruitment of health care workers is a challenging process due to lack of interest, time constraints, excessive workloads, scheduling conflicts, and other employment commitments. Operationalizing passive recruitment (i.e., listservs, online stigma trainings) and active recruitment (i.e., in-service trainings, offering CME/CEU units) strategies may help demonstrate commitment to the health care community, thereby eliciting interest in and endorsement of stigma reduction programs (Davtyan et al., 2018; Estabrooks et al., 2017). Fourth, as evidenced by this study and other published works (Derose et al., 2014), HIV stigma reduction programs should combine an informational component with a contact component that involves interaction with PLWH to maximize success. However, this involvement must transcend personal testimonials and empathy elicitation. PLWH should be given the opportunity to play a more substantive role in stigma reduction programs (Pulerwitz, et al., 2010). Keeping in tandem with the tenets of Community-based Participatory Action Research, the Stigma Trainers of this study played a key role in developing the three-part PhotoVoice-informed HIV stigma training program, including approving its content and materials, and facilitating its delivery to health care workers. Fifth, while the involvement of PLWH in stigma reduction programs is indispensable, there are ethical matters that require serious consideration. Investigators must remain vigilant and closely monitor participant well-being throughout the research process. Experience sharing about HIV-related stigma for long periods of time can be tiresome and may trigger emotional distress for some PLWH. Consulting with the local Institutional Review Boards for advice, closely monitoring participant experiences throughout the study period, and reinforcing the voluntary nature of research may help identify, reduce, and resolve possible ethical dilemmas (Hlongwa, 2016).

Conclusions

In the current study, we hypothesized that a PhotoVoice-informed training of clinical health care workers would increase knowledge of HIV/AIDS, improve attitudes towards PLWH, and increase observations of enacted HIV stigma in health care settings. Study findings indicated significant improvements in HIV/AIDS-related knowledge and attitudes towards PLWH across the two follow-up time points (T2 and T3). However, contrary to our hypothesis, observations of enacted HIV stigma significantly decreased across the two follow-up time points (T2 and T3).

The current study is the first to examine the effectiveness of a stigma reduction intervention informed by PhotoVoice. To our knowledge, this is also the first randomized study of HIV stigma reduction intervention specifically designed for US-based health care settings and health care workers. Additionally, our study is one of few that involved PLWH, particularly women of color living with HIV/AIDS, in all aspects of intervention design, including its content, structure, and delivery.

Our participants comprised of physicians, nurses, and allied health care professionals, who mostly represented the Pediatrics department of the participating health care institution, limiting the representativeness of our study sample. Moreover, due to significant recruitment challenges, our sample size was less than expected, limiting the generalizability of the study results.

Rigorously designed HIV stigma reduction programs are needed for US-based health care settings and workers to gauge the depth and breadth of HIV-associated stigma. Studies that encourage participation of multiple types of health care workers and departments, embolden PLWH with meaningful involvement in intervention design, encompass efficient stigma training opportunities, and offer salient incentives may be particularly useful.

References

Abler, L., Henderson, G., Wang, X., Avery, M., Zhang, Y., & Pan, S. (2014). Affected by HIV stigma: interpreting results from a population survey of an urban center in Guangxi, China. *AIDS and Behavior*, *18*(2), 192-201. DOI: 10.1007/s10461-013-0556-3

Ahsan Ullah, A. K. M. (2011). HIV/AIDS-related stigma and discrimination: A study of health care providers in Bangladesh. *Journal of the International Association of Physicians in AIDS Care*, *10*(2), 97-104. DOI: 10.1177/1545109710381926

Andrewin, A., & Chien, L. Y. (2008). Stigmatization of patients with HIV/AIDS among doctors and nurses in Belize. *AIDS Patient Care and STDs, 22*(11), 897-906. DOI: 10.1089/apc.2007.0219

Baugher, A. R., Beer, L., Fagan, J. L., Mattson, C. L., Freedman, M., Skarbinski, J., & Shouse, R. L. (2017). Prevalence of internalized HIV-related stigma among HIV-infected adults in care, United States, 2011–2013. *AIDS and Behavior, 21*(9), 2600-2608. DOI: 10.1007/s10461-017-1712-y

Beaulieu, M., Adrien, A., Potvin, L., & Dassa, C. (2014). Stigmatizing attitudes towards people living with HIV/AIDS: Validation of a measurement scale. *BMC Public Health*, *14*(1), 1246. DOI: 10.1186/1471-2458-14-1246

Carey, M. P., & Schroder, K. E. (2002). Development and psychometric evaluation of the brief HIV Knowledge Questionnaire. AIDS Education and Prevention: Official Publication of the International Society for *AIDS Education, 14*(2), 172. PMID: 12000234

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. DOI: 10.4103/2224-3151.115829

Cohen, J. (1988). Statistical power analysis for the behavioral sciences 2nd edn.

Davtyan, M., Farmer, S., Brown, B., Sami, M., & Frederick, T. (2016). Women of color reflect on HIV-related stigma through PhotoVoice. *Journal of the Association of Nurses in AIDS Care, 27*(4), 404-418. DOI: 10.1016/j.jana.2016.03.003

Davtyan, M., Olshansky, E. F., Brown, B., & Lakon, C. (2017). A Grounded Theory Study of HIV-Related Stigma in US-Based Health Care Settings. *Journal of the Association of Nurses in AIDS Care, 28*(6), 907-922. DOI: https://doi.org/10.1016/j.jana.2017.07.007

Davtyan, M., Olshansky, E. F., & Lakon, C. (2018). Addressing HIV Stigma in Health Care. *The American Journal of Nursing, 118*(3), 11-11. DOI: 10.1097/01.NAJ.0000530921.56586.ac

Derose, K. P., Bogart, L. M., Kanouse, D. E., Felton, A., Collins, D. O., Mata, M. A., ... & Williams, M. V. (2014). An intervention to reduce HIV-related stigma in partnership with African American and Latino churches. *AIDS Education and Prevention, 26*(1), 28-42. DOI: 10.1521/aeap.2014.26.1.28

Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and Behavior, 17*(5), 1785-1795. DOI: 10.1007/s10461-013-0437-9

Eaton, L. A., Driffin, D. D., Kegler, C., Smith, H., Conway-Washington, C., White, D., & Cherry, C. (2015). The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. *American Journal of Public Health, 105*(2), e75-e82. DOI: 10.2105/AJPH.2014.302322

Ekstrand, M. L., Bharat, S., Ramakrishna, J., & Heylen, E. (2012). Blame, symbolic stigma and HIV misconceptions are associated with support for coercive measures in urban India. *AIDS and Behavior, 16*(3), 700-710. DOI: 10.1007/s10461-011-9888-z

Ekstrand, M. L., Ramakrishna, J., Bharat, S., & Heylen, E. (2013). Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *Journal of the International AIDS Society, 16*(3S2). DOI: 10.7448/IAS.16.3.18717

Estabrooks, P., You, W., Hedrick, V., Reinholt, M., Dohm, E., & Zoellner, J. (2017). A pragmatic examination of active and passive recruitment methods to improve the reach of community lifestyle programs: The Talking Health Trial. *International Journal of Behavioral Nutrition and Physical Activity, 14*(1), 7. DOI: 10.1186/s12966-017-0462-6

Famoroti, T. O., Fernandes, L., & Chima, S. C. (2013). Stigmatization of people living with HIV/AIDS by healthcare workers at a tertiary hospital in KwaZulu-Natal, South Africa: A cross-sectional descriptive study. *BMC Medical Ethics, 14*(1), S6. DOI: 10.1186/1472-6939-14-S1-S6

Feyissa, G. T., Abebe, L., Girma, E., & Woldie, M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health, 12*(1), 522. DOI: 10.1186/1471-2458-12-522

Florom- Smith, A. L., & De Santis, J. P. (2012). Exploring the concept of HIV- Related stigma. *Nursing Forum, 47*(3), 153-165. DOI: 10.1111/j.1744-6198.2011.00235.x

Health Policy Project. 2013. *Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire.* Washington, DC: Futures Group, Health Policy Project.

Hlongwa, P. (2016). Current ethical issues in HIV/AIDS research and HIV/AIDS care. *Oral Diseases, 22*(S1), 61-65. DOI: 10.1111/odi.12391

Kalichman, S. C., Simbayi, L. C., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005). Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS and Behavior, 9*(2), 135-143. DOI: 10.1007/s10461-005-3895-x

Kaponda, C. P., Jere, D. L., Chimango, J. L., Chimwaza, A. F., Crittenden, K. S., Kachingwe, S. I., ... & Norr, K. F. (2009). Impacts of a peer-group intervention on HIV-related knowledge, attitudes, and personal behaviors for urban hospital workers in Malawi. *Journal of the Association of Nurses in AIDS Care, 20*(3), 230-242. DOI: 10.1016/j.jana.2008.12.005

Keselman, A., Kaufman, D. R., & Patel, V. L. (2004). “You can exercise your way out of HIV” and other stories: The role of biological knowledge in adolescents' evaluation of myths. *Science Education, 88*(4), 548-573. DOI: https://doi.org/10.1002/sce.10135

Kingori, C., Reece, M., Obeng, S., Murray, M., Shacham, E., Dodge, B., ... & Ojakaa, D. (2012). Impact of internalized stigma on HIV prevention behaviors among HIV-infected individuals seeking HIV care in Kenya. *AIDS Patient Care and STDs, 26*(12), 761-768. DOI: https://doi.org/10.1089/apc.2012.0258

Kubicek, K., Beyer, W., Weiss, G., & Kipke, M. D. (2012). Photovoice as a tool to adapt an HIV prevention intervention for African American young men who have sex with men. *Health Promotion Practice, 13*(4), 535-543. DOI: 0.1177/1524839910387131

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. DOI: 10.2105/AJPH.2012.300854

Lueveswanij, S., Nittayananta, W., & Robison, V. A. (2000). Changing knowledge, attitudes, and practices of Thai oral health personnel with regard to AIDS: an evaluation of an educational intervention. *Community Dental Health, 17*(3), 165-171. PMID:11108404

Magnus, M., Herwehe, J., Murtaza-Rossini, M., Reine, P., Cuffie, D., Gruber, D., & Kaiser, M. (2013). Linking and retaining HIV patients in care: The importance of provider attitudes and behaviors. *AIDS Patient Care and STDs, 27*(5), 297-303. DOI: 10.1089/apc.2012.0423

Mahendra, V. S., Gilborn, L., Bharat, S., Mudoi, R., Gupta, I., George, B., ... & Pulerwitz, J. (2007). Understanding and measuring AIDS-related settings: A developing country perspective. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 4*(2), 616-625. PMID:18071613

Mak, W. W., Cheng, S. S., Law, R. W., Cheng, W. W., & Chan, F. (2015). Reducing HIV-related stigma among health-care professionals: a game-based experiential approach. *AIDS Care, 27*(7), 855-859. DOI: 10.1080/09540121.2015.1007113

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. DOI: 10.1016/j.socscimed.2017.06.045

Marshall, A. S., Brewington, K. M., Allison, M.K., Haynes, T. F., & Zaller, N. D. (2017). Measuring HIV-related stigma among healthcare providers: a systematic review. *AIDS Care, 29*(11), 1337-1345. DOI: 10.1080/09540121.2017.1338654

Moletsane, R., Mitchell, C., de Lange, N., Stuart, J., Buthelezi, T., & Taylor, M. (2009). What can a woman do with a camera? Turning the female gaze on poverty and HIV and AIDS in rural South Africa. International *Journal of Qualitative Studies in Education, 22*(3), 315-331. DOI: https://doi.org/10.1080/09518390902835454

Nebhinani, N., Mattoo, S. K., & Wanchu, A. (2012). HIV stigma and specified correlates in North India. *Indian Journal of Psychological Medicine, 34*(4), 324. DOI: 10.4103/0253-7176.108203

Norr, K. F., Ferrer, L., Cianelli, R., Crittenden, K. S., Irarrázabal, L., Cabieses, B., ... & Bernales, M. (2012). Peer group intervention for HIV prevention among health workers in Chile. *Journal of the Association of Nurses in AIDS Care, 23*(1), 73-86. DOI: 10.1016/j.jana.2011.02.001

Nyblade, L., Stangl, A., Weiss, E., & Ashburn, K. (2009). Combating HIV stigma in health care settings: what works?. *Journal of the international AIDS Society, 12*(1), 15. DOI: 10.1186/1758-2652-12-15

Nyblade, L., Jain, A., Benkirane, M., Li, L., Lohiniva, A. L., McLean, R., ... & Kwena, Z. (2013). A brief, standardized tool for measuring HIV- related stigma among health facility staff: results of field testing in China, Dominica, Egypt, Kenya, Puerto Rico and St. Christopher & Nevis. *Journal of the International AIDS Society, 16*(3S2). DOI: 10.7448/IAS.16.3.18718

Nyblade, L., Reddy, A., Mbote, D., Kraemer, J., Stockton, M., Kemunto, C., ... & Barker, C. (2017). The relationship between health worker stigma and uptake of HIV counseling and testing and utilization of non-HIV health services: the experience of male and female sex workers in Kenya. *AIDS Care, 29*(11), 1364-1372. DOI: 10.1080/09540121.2017.1307922

Nykiforuk, C. I., Vallianatos, H., & Nieuwendyk, L. M. (2011). Photovoice as a method for revealing community perceptions of the built and social environment. International *Journal of Qualitative Methods, 10*(2), 103-124. PMID: 27390573

Oanh, K., Ashburn, K., JPulerwitz, J., Ogden, J., and Nyblade, L. (2008). *Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination, Horizons Final Report.* Washington, DC: Population Council.

Pisal, H., Sutar, S., Sastry, J., Kapadia-Kundu, N., Joshi, A., Joshi, M., ... & Phadke, M. (2007). Nurses' health education program in India increases HIV knowledge and reduces fear. *Journal of the Association of Nurses in AIDS Care, 18*(6), 32-43. DOI: 10.1016/j.jana.2007.06.002

Platten, M., Pham, H. N., & Nguyen, H. V. (2014). Knowledge of HIV and factors associated with attitudes towards HIV among final-year medical students at Hanoi medical university in Vietnam. *BMC Public Health, 14*(1), 265. DOI: https://doi.org/10.1186/1471-2458-14-265

Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L., & Mahendra, V. (2010). Reducing HIV-related stigma: lessons learned from Horizons research and programs. *Public Health Reports, 125*(2), 272-281. DOi: 10.1177/003335491012500218

Rice, W. S., Crockett, K. B., Mugavero, M. J., Raper, J. L., Atkins, G. C., & Turan, B. (2017). Association Between Internalized HIV-Related Stigma and HIV Care Visit Adherence. *Journal of Acquired Immune Deficiency Syndromes, 76*(5), 482-487. DOI: 10.1097/QAI.0000000000001543

Rogers, S. J., Tureski, K., Cushnie, A., Brown, A., Bailey, A., & Palmer, Q. (2014). Layered stigma among health-care and social service providers toward key affected populations in Jamaica and The Bahamas. *AIDS Care, 26*(5), 538-546. DOI: 10.1080/09540121.2013.844762

Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., ... & Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open, 6*(7), e011453. DOI: 10.1136/bmjopen-2016-011453

Saki, M., Kermanshahi, S. M. K., Mohammadi, E., & Mohraz, M. (2015). Perception of patients with HIV/AIDS from stigma and discrimination. *Iranian Red Crescent Medical Journal, 17*(6). DOI: 10.5812/ircmj.23638v2

Schell, K., Ferguson, A., Hamoline, R., Shea, J., & Thomas-Maclean, R. (2009). Photovoice as a Teaching Tool: Learning by Doing with Visual Methods. *International Journal of Teaching and Learning in Higher Education, 21*(3), 340-352. ISSN: 1812-9129

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. DOI: http://dx.doi.org/10.1111/j. 1525-1497.2005.05049.x

Sears B. (2008). HIV discrimination in health care services in Los Angeles County: The results of three testing studies. *Washington & Lee Journal of Civil Rights and Social Justice*, *15*(1), 85-107.

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. DOI: 10.1007/s10461-010-9847-0

Shah, S. M., Heylen, E., Srinivasan, K., Perumpil, S., & Ekstrand, M. L. (2014). Reducing HIV stigma among nursing students: A brief intervention. *Western Journal of Nursing Research, 36*(10), 1323-1337. DOI: 10.1177/0193945914523685

Straetemans, M., Bakker, M. I., & Mitchell, E. M. H. (2017). Correlates of observing and willingness to report stigma towards HIV clients by (TB) health workers in Africa. *The International Journal of Tuberculosis and Lung Disease, 21*(11), S6-S18. DOI: 10.5588/ijtld.16.0913

Stringer, K. L., Turan, B., McCormick, L., Durojaiye, M., Nyblade, L., Kempf, M. C., ... & Turan, J. M. (2016). HIV-related stigma among healthcare providers in the deep south. *AIDS and Behavior, 20*(1), 115-125. DOI: 10.1007/s10461-015-1256-y

Tenkorang, E. Y., & Owusu, A. Y. (2013). Examining HIV-related stigma and discrimination in Ghana: what are the major contributors? *Sexual Health, 10*(3), 253-262. DOI: 10.1071/SH12153

Teti, M., Murray, C., Johnson, L., & Binson, D. (2012). Photovoice as a community-based participatory research method among women living with HIV/AIDS: Ethical opportunities and challenges. *Journal of Empirical Research on Human Research Ethics, 7*(4), 34-43. DOI: 10.1525/jer.2012.7.4.34

Turan, B., Smith, W., Cohen, M. H., Wilson, T. E., Adimora, A. A., Merenstein, D., ... & Tien, P. C. (2016). Mechanisms for the negative effects of internalized HIV-related stigma on antiretroviral therapy adherence in women: the mediating roles of social isolation and depression. *Journal of Acquired Immune Deficiency Syndromes (1999), 72*(2), 198. DOI: 10.1097/QAI.0000000000000948

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. DOI: 10.1089/apc.2009.0085

Walburn, A., Swindells, S., Fisher, C., High, R., & Islam, K. M. (2012). Missed visits and decline in CD4 cell count among HIV-infected patients: a mixed method study. *International Journal of Infectious Diseases, 16*(11), e779-e785. DOI: 10.1016/j.ijid.2012.06.004

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369-387. DOI: 10.1177/109019819702400309

Williams, A. B., Wang, H., Burgess, J., Wu, C., Gong, Y., & Li, Y. (2006). Effectiveness of an HIV/AIDS educational programme for Chinese nurses. *Journal of Advanced Nursing, 53*(6), 710-720. DOI: 10.1111/j.1365-2648.2006.03777.x

Wu, S., Li, L., Wu, Z., Liang, L. J., Cao, H., Yan, Z., & Li, J. (2008). A brief HIV stigma reduction intervention for service providers in China. *AIDS Patient Care and STDs, 22*(6), 513-520. DOI:10.1089/apc.2007.0198

Wilson, P. A., Hansen, N. B., Tarakeshwar, N., Neufeld, S., Kochman, A., & Sikkema, K. J. (2008). Scale development of a measure to assess community- based and clinical intervention group environments. *Journal of Community Psychology, 36*(3), 271-288. DOI: 10.1002/jcop.20193

Yiu, J. W., Mak, W. W., Ho, W. S., & Chui, Y. Y. (2010). Effectiveness of a knowledge-contact program in improving nursing students’ attitudes and emotional competence in serving people living with HIV/AIDS. Social Science & Medicine, *71*(1), 38-44. DOI: 10.1016/j.socscimed.2010.02.045

Figure 4.1: Scree Plot of the Variance of Principal Components

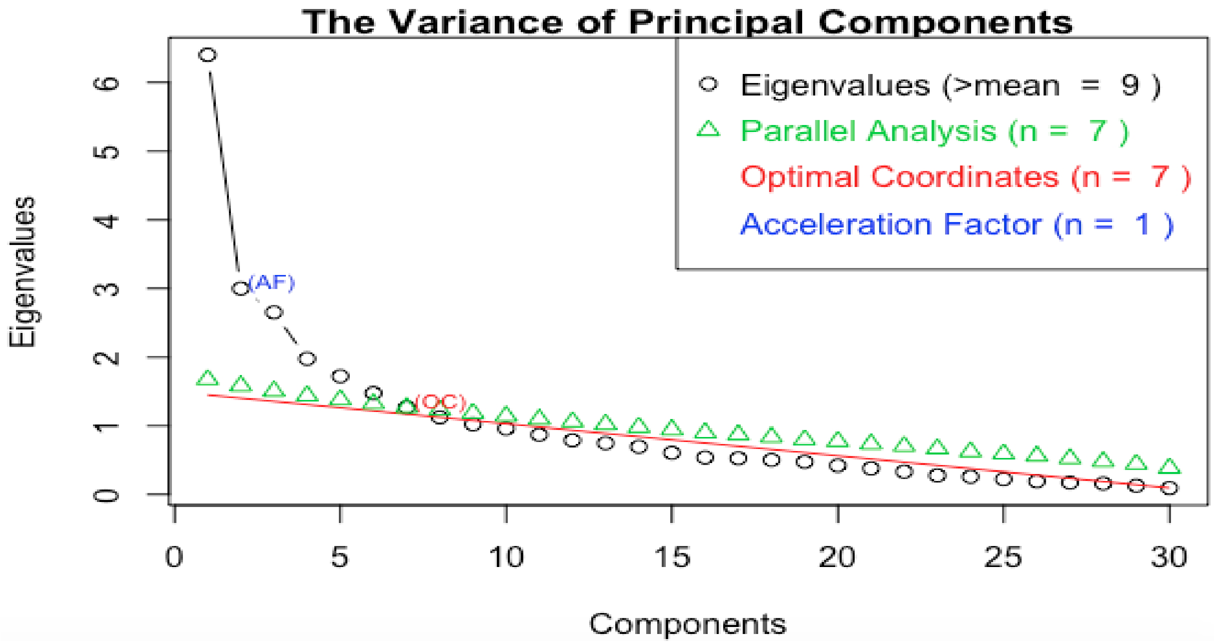


Table 4.1: Factor Loadings

Survey Item	Knowledge of HIV/AIDS (MR1)	Attitudes towards PLWH (MR2)	Observations of Enacted HIV stigma (MR3)
The risk of HIV transmission following a needle-prick or sharps injuries is small (approximately 1 in 300).			
The risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small (approximately 1 in 1000).			
Pre- and Post-exposure HIV medications greatly reduce transmission of HIV.	-0.568		
People who are infected with HIV quickly show serious signs of illness.			
There is a vaccine that can stop adults from getting HIV.			
I would have a strong fear of HIV transmission if I touched the sweat of a person with HIV/AIDS.	0.651		
I would have a strong fear of HIV transmission if I touched the saliva of a person with HIV/AIDS.	0.778		
I would have a strong fear of HIV transmission if I dressed the wounds of a person with HIV or AIDS.	0.937		
I would have a strong fear of HIV transmission if I put an intravenous drip in someone who was showing signs of AIDS.	0.894		
Most people living with HIV do not care if they infect other people.			
Women living with HIV should not be allowed to have children.			
People with HIV should expect some restrictions on their freedom.			
HIV is punishment for bad behavior.	0.723		
People living with HIV should feel ashamed of themselves.			
Most people living with HIV have had many sexual partners.	0.575		
People get infected with HIV because they engage in irresponsible behaviors.			
Men who have sex with men spread HIV in our community.		0.817	
Female sex workers spread HIV in our community.		0.848	
Injection drug users spread HIV in our community.		0.927	
I have observed patients with HIV receive less care/attention than other patients.			
I have observed extra precautions taken in the sterilization of instruments used on HIV-positive patients.			
I have observed healthcare workers using latex gloves for performing noninvasive exams on clients.			
I have observed healthcare workers disclosing patients' HIV status to others without consent.			0.597
I have observed healthcare workers gossiping about a patient's HIV status.			0.702
I have observed healthcare workers unwilling to care for a patient living with HIV.			0.591

I have observed healthcare workers avoiding physical contact with a patient living with HIV.			0.649
I have observed healthcare workers requiring some patients to be tested for HIV before scheduling surgery.			
I have observed a senior healthcare provider assigned to care for a patient with HIV instead of a junior healthcare provider.			
I have observed HIV testing without the informed consent of the patient.			

Table 4.2: Differences in Demographic Characteristics between the Intervention and Control Arms

	Intervention (n=38)	**Control (n=35)**	**W** Wilcoxon Ranked Sum test	***P*-value**
Age			603	0.5
Mean	42.54 (*SD*=13.08)	41.05 (*SD*=12.05)		
Race			783.5	0.15
Asian	2 (5%)	8 (23%)		
Black/African American	9 (24%)	6 (17%)		
White	23 (61%)	19 (54%)		
Other	4 (10%)	2 (6%)		
Ethnicity			695	0.71
Non-Hispanic	20 (53%)	20 (57%)		
Hispanic	18 (47%)	15 (43%)		
Sex			671	0.91
Male	4 (11%)	4 (11%)		
Female	34 (89%)	31 (89%)		
Marital status			622.5	0.61
Now married	16 (42%)	16 (46%)		
Widowed	3 (8%)	N/A		
Divorced	9 (24%)	5 (14%)		
Never married	10 (26%)	14 (40%)		
Educational Level			479.5	<0.05*
High school	1 (2%)	N/A		
Some college	9 (24%)	3 (8%)		
Associates Degree	8 (21%)	6 (17%)		
Bachelor's Degree	9 (24%)	10 (29%)		
Master's Degree	2 (5%)	2 (6%)		
Professional Degree	9 (24%)	14 (40%)		
Place of Birth			630	0.57
US	32 (84%)	28 (80%)		
Mexico	2 (5%)	1 (3%)		
Cuba	1 (3%)	N/A		
Other	3 (8%)	6 (17%)		
Profession			816.5	0.07
Physician	6 (16%)	10 (29%)		
Nurse	19 (50%)	19 (54%)		
Allied Health Care	13 (34%)	6 (17%)		
Income			516.5	0.1
$30,000-$39,999	7 (18%)	2 (6%)		
$40,000-$49,999	7 (18%)	4 (11%)		
$50,000-$59,999	6 (16%)	4 (11%)		
$60,000-$69,999	2 (5%)	4 (11%)		
$70,000 or more	16 (43%)	22 (61%)		
Department			601	0.47
Pediatrics	16 (42%)	13 (37%)		
Gyn/Onc/Obst	4 (11%)	3 (9%)		

Primary Care	4 (11%)	2 (6%)		
ER Medicine	3 (8%)	2 (6%)		
Surgery	3 (8%)	2 (6%)		
Other	7 (17%)	13 (36%)		

Note: *p<.05, **: p<.01

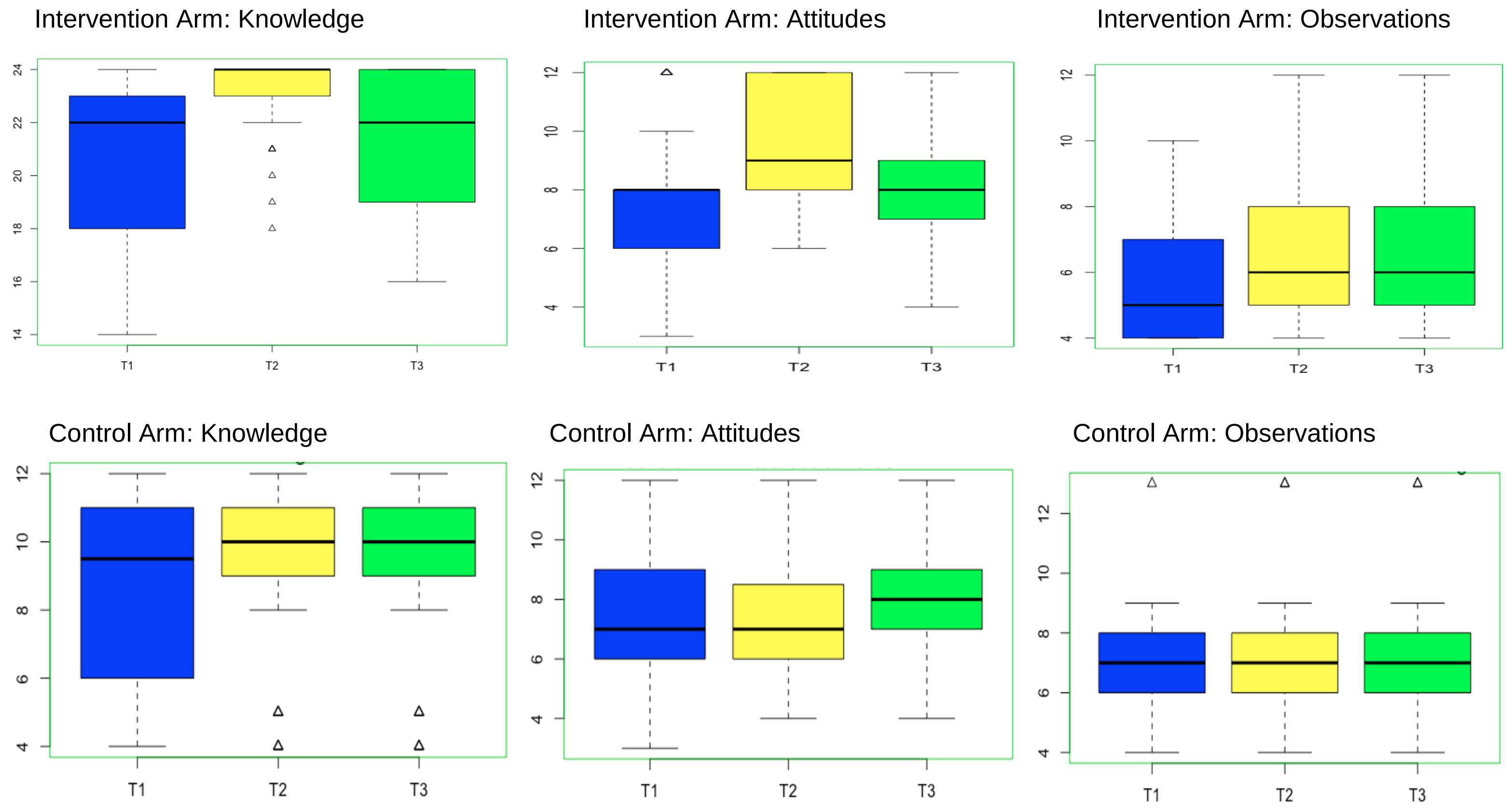
Table 4.3: Within Group Median Differences in Knowledge, Attitudes, and Observations

	Intervention Group (N=38)			**Control Group (N=35)**		
Factors	**T1 to T2**	**T1 to T3**	**T2 to T3**	**T1 to T2**	**T1 to T3**	**T2 to T3**
Knowledge of HIV/AIDS (MR1)	V=18, *p*<.01**	V=0, *p*<.01**	V=0, *p*<.01**	V=107.5, *p*=.54	V=75.5, *p*=.44	V=0, *p*=1
Attitudes towards PLWH (MR2)	V=59, *p*<.01**	V=94, *p*=.07	V=221, *p*<.05*	V=46, *p*=.08	V=30, *p*=.09	V=0, *p*=.17
Observation of Enacted HIV Stigma (MR3)	V=90, *p*=.06	V=90, *p*=.05	V=127, *p*=1	V=79.5, *p*=.81	V=32, *p* =.36	V=0, *p*=1

Note: **p*<.05, **: *p*<.01

V=the sum of ranks assigned to the differences with positive sign (Wilcoxon matched pairs signed-rank test)

Figure 4.2: Distributions of Knowledge of HIV/AIDS, Attitudes towards PLWH, and Observations of Enacted HIV Stigma at T1, T2, and T3 in the Intervention and Control Arms



Intervention Arm: Knowledge

Intervention Arm: Attitudes

Intervention Arm: Observations

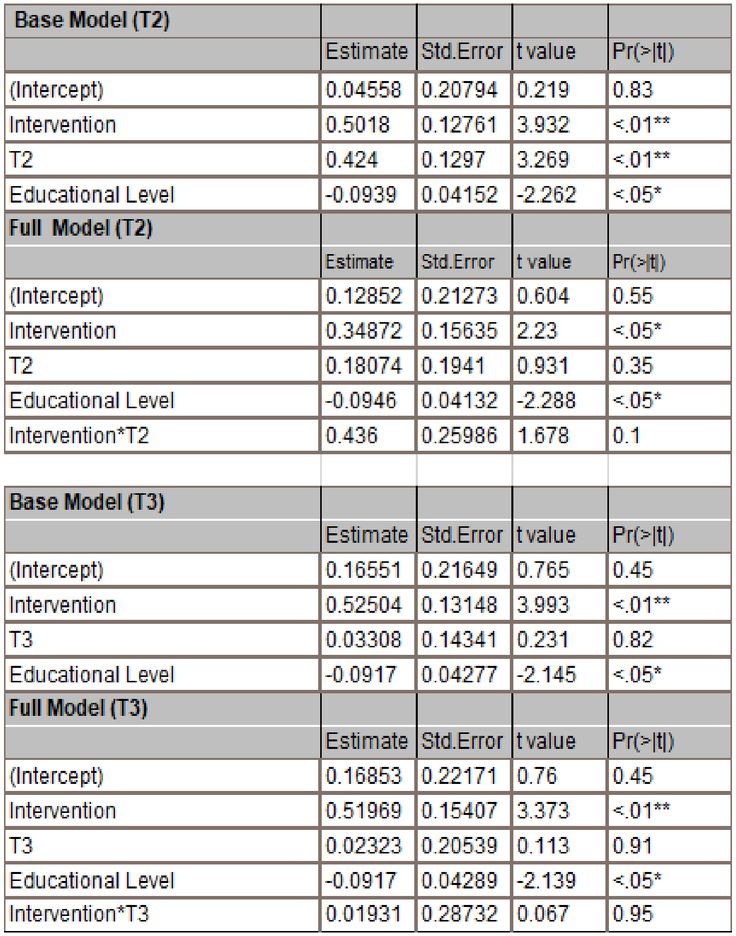
Control Arm: Knowledge

Control Arm: Attitudes

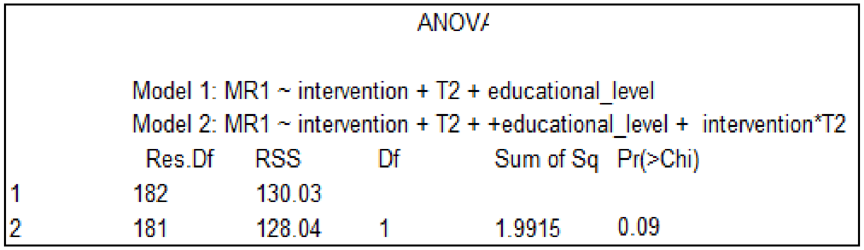
Control Arm: Observations

Table 4.4: Base and Full Regressions Models at T2 and T3 for MR1

Knowledge about HIV/AIDS (MR1)



Base Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.04558	0.20794	0.219	0.83
Intervention	0.5018	0.12761	3.932	<.01**
T2	0.424	0.1297	3.269	<.01**
Educational Level	-0.0939	0.04152	-2.262	<.05*
Full Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.12852	0.21273	0.604	0.55
Intervention	0.34872	0.15635	2.23	<.05*
T2	0.18074	0.1941	0.931	0.35
Educational Level	-0.0946	0.04132	-2.288	<.05*
Intervention*T2	0.436	0.25986	1.678	0.1
Base Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.16551	0.21649	0.765	0.45
Intervention	0.52504	0.13148	3.993	<.01**
T3	0.03308	0.14341	0.231	0.82
Educational Level	-0.0917	0.04277	-2.145	<.05*
Full Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.16853	0.22171	0.76	0.45
Intervention	0.51969	0.15407	3.373	<.01**
T3	0.02323	0.20539	0.113	0.91
Educational Level	-0.0917	0.04289	-2.139	<.05*
Intervention*T3	0.01931	0.28732	0.067	0.95



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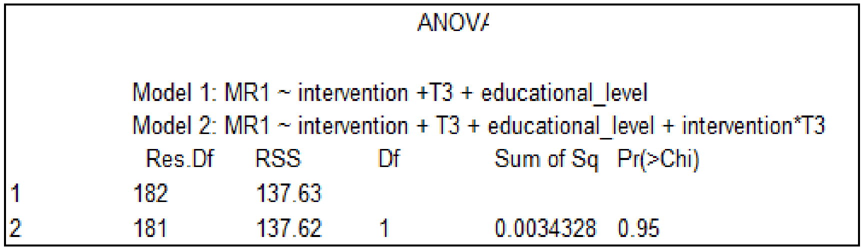
                              ANOV

          Model 1: MR1 ~ intervention + T2 + educational_level
          Model 2: MR1 ~ intervention + T2 + +educational_level +  intervention*T2
            Res.Df      RSS        Df          Sum of Sq   Pr(>Chi)
1         182         130.03
2         181         128.04     1           1.9915      0.09
```

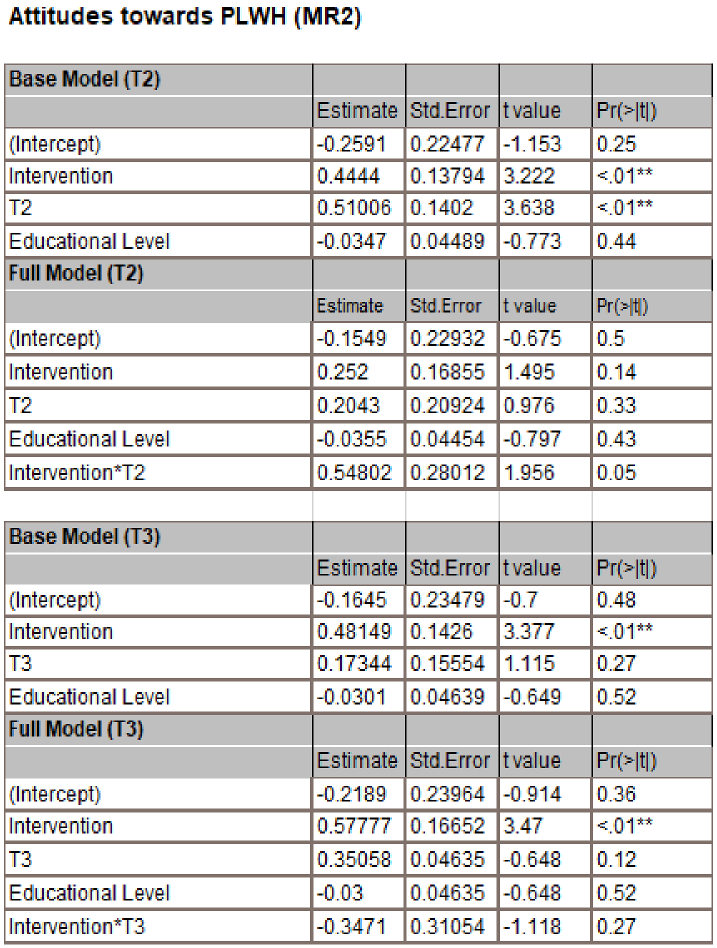


```
                              ANOV

          Model 1: MR1 ~ intervention +T3 + educational_level
          Model 2: MR1 ~ intervention + T3 + educational_level + intervention*T3
            Res.Df      RSS        Df          Sum of Sq   Pr(>Chi)
1         182         137.63
2         181         137.62     1           0.0034328   0.95
```

Note: *$p<.05$, **: $p<.01$

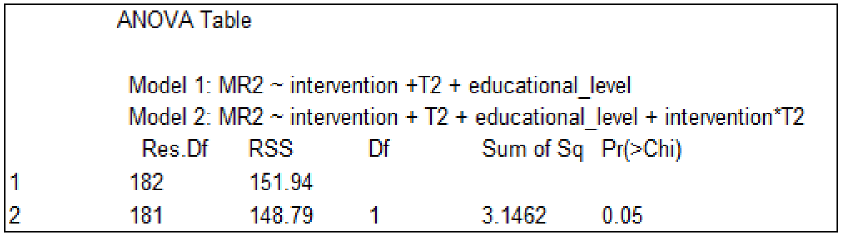
Table 4.5: Base and Full Regressions Models at T2 and T3 for MR2



Attitudes towards PLWH (MR2)

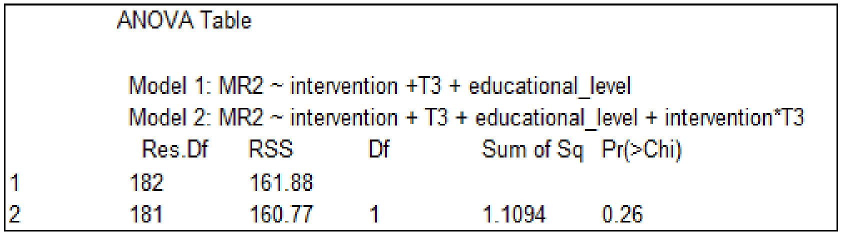
Base Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	-0.2591	0.22477	-1.153	0.25
Intervention	0.4444	0.13794	3.222	<.01**
T2	0.51006	0.1402	3.638	<.01**
Educational Level	-0.0347	0.04489	-0.773	0.44
Full Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	-0.1549	0.22932	-0.675	0.5
Intervention	0.252	0.16855	1.495	0.14
T2	0.2043	0.20924	0.976	0.33
Educational Level	-0.0355	0.04454	-0.797	0.43
Intervention*T2	0.54802	0.28012	1.956	0.05

Base Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	-0.1645	0.23479	-0.7	0.48
Intervention	0.48149	0.1426	3.377	<.01**
T3	0.17344	0.15554	1.115	0.27
Educational Level	-0.0301	0.04639	-0.649	0.52
Full Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	-0.2189	0.23964	-0.914	0.36
Intervention	0.57777	0.16652	3.47	<.01**
T3	0.35058	0.04635	-0.648	0.12
Educational Level	-0.03	0.04635	-0.648	0.52
Intervention*T3	-0.3471	0.31054	-1.118	0.27



```
          ANOVA Table

           Model 1: MR2 ~ intervention +T2 + educational_level
           Model 2: MR2 ~ intervention + T2 + educational_level + intervention*T2
            Res.Df    RSS        Df          Sum of Sq  Pr(>Chi)
1          182       151.94
2          181       148.79      1           3.1462      0.05
```



```
          ANOVA Table

           Model 1: MR2 ~ intervention +T3 + educational_level
           Model 2: MR2 ~ intervention + T3 + educational_level + intervention*T3
            Res.Df    RSS        Df          Sum of Sq  Pr(>Chi)
1          182       161.88
2          181       160.77      1           1.1094      0.26
```

Note: **p*<.05, **: *p*<.01

Table 4.6: Base and Full Regressions Models at T2 and T3 for MR3

Observations of Enacted HIV Stigma (MR3)

Base Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.50584	0.21865	2.313	<0.05*
Intervention	-0.4368	0.13418	-3.256	<0.01**
T2	0.193	0.13638	1.415	0.16
Educational Level	-0.0828	0.04366	-1.896	0.06
Full Model (T2)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.51101	0.22542	2.267	<0.05*
Intervention	-0.4464	0.16568	-2.694	<0.05*
T2	0.17782	0.20568	0.865	0.39
Educational Level	-0.0828	0.04378	-1.892	0.06
Intervention*T2	0.02722	0.27535	0.099	0.92
Base Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.53202	0.22225	2.394	<0.05*
Intervention	-0.421	0.13498	-3.119	<0.01**
T3	0.09158	0.14723	0.622	0.53
Educational Level	-0.0807	0.04391	-1.837	0.07
Full Model (T3)				
	Estimate	Std.Error	t value	Pr(>|t|)
(Intercept)	0.54326	0.22758	2.387	<0.05*
Intervention	-0.4409	0.15814	-2.788	<0.01**
T3	0.05504	0.21082	0.261	0.79
Educational Level	-0.0807	0.04402	-1.833	0.07
Intervention*T3	0.07159	0.29492	0.243	0.81

```
            ANOVA Table

            Model 1: MR3 ~ intervention +T2 + educational_level
            Model 2: MR3 ~ intervention + T2 + educational_level + intervention*T2
             Res.Df     RSS         Df           Sum of Sq   Pr(>Chi)
1           182         143.77
2           181         143.77      1            0.007762    0.9213
```

```
            ANOVA Table

            Model 1: MR3 ~ intervention +T3 + educational_level
            Model 2: MR3 ~ intervention + T3 + educational_level + intervention*T3
             Res.Df     RSS         Df           Sum of Sq   Pr(>Chi)
1           182         145.05
2           181         145         1            0.047205    0.81
```

Note: *$p<.05$, **: $p<.01$

CHAPTER 5

Conclusions & Implications

HIV-related stigma is a countervailing impediment to effective response strategies geared towards curbing the global disease epidemic. In its now fourth decade, stigma continues to reinforce existing inequities, discourage access to and utilization of vital health care services, deter optimal medical compliance, and embolden social isolation and poor self-regard. Subsequently, stigma leads to a variety of damaging psychosocial and physical pathologies, which then diminish quality of life and social interactions, prevent full and meaningful participation in society, increase the likelihood of comorbid conditions, and in some cases, facilitate progression to AIDS.

HIV stigma is intensely institutionalized and as a result, the vitriolic treatment of people living with HIV (PLWH) spans multiple contexts including in health insurance, employment, housing, religious settings, and health care service delivery. PLWH have experienced HIV status-based health insurance discrimination in the form of higher copayments for common antiretroviral medications (ARVs) (Jacobs & Sommers, 2015). In employment, PLWH have endured forced disclosure of HIV status, workplace exclusion, hiring and promotion refusals, and unlawful terminations (Sprague, Simon, & Sprague, 2011). PLWH have also been subjected to discrimination from housing providers in the form of forced disability disclosures, housing denials, and refusal of vouchers and subsidies from state HIV/AIDS service organizations (Greene, 2014). Within the religious context, PLWH have faced admonishments for perceived immoral behaviors and have had their disease status labeled a byproduct of divine retribution

(Zou et al., 2009). In health care settings, PLWH have endured care abjuration, suboptimal quality of care, physical and verbal abuse, compulsory confinement, and denial of informed choice in health care decision-making (Audet, McGowan, Wallston, & Kipp, 2013; Sears, 2008; Stringer et al., 2016).

HIV stigma has been especially harmful to ethnic and racial minorities, women, men who have sex with men (MSM), and transgender individuals. These trends have been attributed to the intersectionality of HIV stigma: that is, interdependence between multiple devalued social identities and systems of subjugation (Cole, 2009; Wingood et al., 2007). HIV-related stigmatization of ethnic minorities such as African Americans and Hispanics/Latinos is fueled by institutionalized racism and subsequent disparities in rates of disease and access to health care services within these communities. Stigma towards women living with HIV is powered by toxic cultures of gender-based and moralistic discernment that malign, blame, and shun women, while largely absolving their counterparts of any real or perceived responsibility (Airhihenbuwa et al., 2009). HIV stigma directed towards MSM and transgender communities has been largely guided by archaic paradigms that champion structural hetero- and cis- normativity, while repudiating diversity in sexual identities (Knight, Shoveller, Oliffe, Gilbert, Goldenberg, 2013).

The urgent need to confront and control HIV-related stigma has long been relegated a priority. As a result, innumerable programmatic responses have been executed in the past three decades. These programs have focused on education to improve comprehension of HIV/AIDS and related prejudices, skill building to cognize transmission pathways and risk reduction mechanisms, interactions with PLWH to build sensitivities and to normalize the disease, and macro level environmental modifications to expedite implementation of anti-discrimination procedures and policies. Target populations of such interventions have included students of health care professions, teachers, clinical and non-clinical health care workers, and PLWH.

Fewer efforts, however, have been directed towards understanding personal experiences of HIV-related stigmatization among women of color living with HIV (WLWH) in the United States (US), who bear a severe burden both in terms of disease incidence, as well as in experiences of disease-related intolerance. Despite overwhelming evidence that WLWH experience intersectional discrimination (Aziz & Smith, 2011), there is little known about how they make sense of HIV-related stigma, how it impacts their sense of well-being, and how it influences their capacity to navigate health care systems, a protuberant backdrop where stigma is widespread and powerful. Notwithstanding the indisputable presence of HIV-related stigma and discrimination in US health care settings and in the attitudes and behaviors of US health care workers (Stringer, 2016), there is a tangible paucity in research studies that explicate how US-based health care workers conceptualize enacted stigma towards PLWH and its impact on health and social outcomes. Moreover, the review of the literature revealed a noticeable absence of studies that examine the effectiveness of HIV-related stigma reduction program in US-based health care settings. The three research studies of the present dissertation attempted to contribute to the body of knowledge on HIV stigma in the US and to expand our understanding of this social phenomenon.

The first study entitled, “Women of Color Reflect on HIV-related Stigma through PhotoVoice,” examined personifications of HIV stigma from WLWH in Los Angeles. This qualitative study of African American and Hispanic/Latina WLWH illustrated that stigma manifests as a culmination of moralistic judgments about lifestyle choices and a separation from the general population based on perceived moral purity. Furthermore, the study found that HIV-related stigma is rooted in erroneous appraisals of PLWH as sexually deviant and licentious, and therefore deserving of the disease. Colloquial and antiquated conceptions of sexuality and HIV/AIDS were also identified as key drivers of stigma, as they defied biomedical truths and introduced alternative disease narratives to dissuade PLWH from appropriate treatment and care. Health care institutions were recognized as hubs of discrimination, where unfounded fear of contagion, unwarranted precautions, care refusal, and indiscretions with HIV disease status ran rampant. Internalization of enacted HIV stigma was reported as frequent, and related to psychological decline and difficulties forming healthy relationships with prospective intimate partners. Participants recognized social support from family members and HIV care specialists, and faith as robust mechanisms of resilience. The implementation of PhotoVoice as a reflective tool was perceived as instructive and transformative.

This research study made three important contributions to the literature on HIV stigma. First, this was one of few studies that described individual accounts and photographically captured reflections of HIV-related stigmatization among women of color living with HIV in Los Angeles. Second, the study employed nontraditional Interpretative Phenomenological Analysis (IPA) to collect a wide range of rich retorts about HIV stigma from both individual in-depth interviews, as well as from focus group discussions. Third, the study reinforced the beneficial aspects of group experience sharing among PLWH, which has been shown to promote solidarity, social support, and self-confidence (Bateganya, Amanyeiwe, Roxo, & Dong, 2015).

The findings from the above referenced qualitative study that HIV-related stigma is present in US-based health care organizations in the form of care denial, unfounded fear of infection, unreasonable precautions, clinically unnecessary referrals, physical distancing, and indiscretion with HIV status informed the second study of this dissertation. The second study entitled, “A Grounded Theory Study of HIV-related Stigma in US-based Health Care Settings,” examined health care worker interpretations on HIV stigma and delineated the pertinent concepts comprising stigma in US health care settings. Study participants conveyed that HIV-related stigma was a derivative of scientifically unfounded, generalized, stereotypical, and fear-mongering tactics utilized to characterize the disease in the early days of the epidemic. They affirmed that these factors quickly infiltrated and shaped health care worker attitudes and behaviors, clinical education and training, and health service delivery. Moreover, existing patient-provider power inequalities amplified HIV stigma, produced and reproduced structures of powerlessness and disempowerment, placed HIV patients in untenable positions, and curtailed their ability to voice grievances and incidents of HIV-related stigma. Participants identified fear, inadequate clinical education and training, unintentional behaviors, and limited contact with HIV patients as triggers of stigma, and poor treatment engagement and psychological functioning as its resultant reverberations.

This study made three valuable contributions to the literature on HIV stigma among health care workers in US-based medical institutions. First, the study evaluated previously unexplored US-based health care worker insights on HIV stigma and how experienced prejudice impacted physical and psychosocial outcomes among PLWH. Second, the study expounded the critical concepts involved in the legitimization and internalization of HIV stigma in US-based health care institutions. Third, the study utilized the principles of Straussian Grounded Theory (SGT) to develop a robust HIV stigma model that may guide stigma reduction initiatives in health care settings, inform clinical practice and care delivery protocols for patients with HIV, and inspire implementation of evidence-based anti-stigma organizational policies and procedures.

The results and implications of the aforesaid two qualitative studies, served as the foundation for the final study of this dissertation. Oriented by the findings that HIV stigma in health care settings is fueled by poor understanding of transmission modes, moral judgments of affected groups, and unawareness of its manifestations, the third and final study of this dissertation, "Assessing the Efficacy of a PhotoVoice-informed HIV Stigma Training for Health Care Workers in Southern California," aimed to increase knowledge of HIV/AIDS and stigma, improve attitudes towards PLWH, and increase observations of enacted HIV stigma. The PhotoVoice-informed training, designed and facilitated by WLWH (Stigma Trainers), was successful in increasing knowledge of HIV/AIDS, ameliorating attitudes towards PLWH, and contrary to our expectation, reducing observations of enacted HIV stigma in health care settings among physicians, nurses, and allied health care professionals.

This study made three critical contributions to the literature on HIV stigma reduction interventions. First, it is the first randomized controlled study to investigate the effectiveness of an HIV stigma reduction intervention targeting US-based health care workers and settings. Second, it is one of few studies to use PhotoVoice as a pedagogical instrument to educate health care workers about HIV/AIDS and stigma, and as a mechanism for critical consciousness and reflection. Third, the study invited PLWH to serve as architects, designers, planners, and facilitators of a socially relevant HIV stigma reduction program tailored specifically for health care workers.

The findings of the three studies in this dissertation have important implications for future research, clinical practice, and policy changes. The evidence is well defined in that HIV stigma transforms attitudes, behaviors, and actions, influences inter- and intra-personal relationships, diminishes quality of life, and leads to psychological debility and poor adjustment. It is also clear that stigma can be ameliorated by social support, mental health care, and institutional support. Programmatic efforts to reduce HIV stigma should therefore center on improving and sustaining instrumental (i.e., tangible aid, services), emotional (i.e., empathy), informational (i.e., advice, suggestions, information), and appraisal (i.e., information for introspection and self-evaluation) social support for PLWH (Rouhani, O'Laughlin, Faustin, Tsai, Kasozi, & Ware, 2017). Peer advocacy and patient navigator programs may be especially valuable for improving social support. If incorporated as critical components of the HIV care continuum, such patient-centered services can help foster impactful relationships with PLWH, while promoting linkage to care, care continuity, medication adherence, and viral suppression (Schumann, Westergaard, Meier, Ruetten, & Vergeront, 2017; Genberg et al., 2016)

PLWH experience high rates of mental health conditions compared to the general population and a considerable proportion of these adverse psychosomatic outcomes can be ascribed to HIV-related stigma (Johnsson, 2013; Travaglini, Himelhoch, & Fang, 2018). Irrespective of these alarming trends, only about half of HIV patients utilize mental health services and this is primarily due to unequal access to publicly funded mental health services and perceived stigma from subgroups of vulnerable populations (i.e., ethnic and sexual minorities) (Choi et al., 2016). Addressing these disparities aggressively may yield more positive patient and health service delivery outcomes. The following three strategies may be beneficial. First, offering high quality and robustly designed models of care that integrate screening, diagnosis, and management of mental health co-morbidities specific to PLWH (Chuah et al., 2017). Second, providing comprehensive on-site mental health services at medical organizations where PWLH already receive care (Winiarski, Beckett, & Salcedo, 2005). Third, implementing programs that assign mental health professionals to provide synchronized care to HIV patients upon intake (Blank, Himelhoch, Walkup, & Eisenberg, 2013).

As mentioned previously, HIV-related stigma is present in a variety of settings, including religious environments. For many years, these settings were reluctant to concede that traditional religious doctrines and rigid moral positions incite disinclination to provide support to PLWH, further fanning the flames of the epidemic (Smith, Simmons, & Meyer, 2005; Singh, 2011). However, more recently, religious settings have acknowledged the devastation that HIV has caused in communities of color and have begun to play more constructive roles. Religious organizations have empowered communities impacted by the epidemic with education and opportunities for healthy choices and behaviors, emotional support, prevention and mitigation strategies, and mechanisms for community resilience (Derose et al., 2014). Increasing and fostering opportunities for connection with PLWH, tailored to the social landscapes of religious organizations may be an efficient approach to stigma reduction (Mantell, Correale, Adams-Skinner, & Stein, 2011). Religious environments are a powerful source of social cohesion, organization, and identity for communities of color (Coleman, Tate, Gaddist, & White, 2016). Reducing HIV-related stigma within these domains can inspire treatment commitment, retention in care, thereby reducing disparities (Szaflarski et al., 2014)

The current research on HIV among women of color paints a worrisome picture. This is evidenced by excessively high incidence rates of HIV and stigma among African American women compared to White women ("HIV Among Women," 2018; Higgins, Hoffman, & Dworkin, 2010). To cognize the full scope of this stigma and to build commensurate reduction agendas, additional work is crucial. Focusing on micro-, meso- and macro-level determinants of HIV stigma such at-risk partners, testing behaviors, untreated mental health conditions, familial stress, coercive or survival sex, sexual violence, cultural norms, lack of childcare and safe housing, gender inequality, racism, poverty, sexism, and transphobia may provide some guidance (Bronfenbrenner, 1992; Logie, C. H., James, Tharao, & Loutfy, 2011). It is also important to establish rigorous data collection methods on HIV-related stigma experienced by diverse groups of women such as lesbians, bisexuals, transgender, immigrants, homeless, and female sex workers because they face unique sets of circumstances and experiences. In this regard, two strategies may be useful. Frist, requiring that HIV/AIDS service organizations amass stigma-related information from their clients and confidentially share these data in scientific forums. Second, creating a central database for stigma-specific data where a comprehensive profile of discrimination faced by women can be established. The People Living with HIV Stigma Index is an example of a systematic global effort to collect data on stigma experienced by PLWH across the globe. Since the project's initiation in 2008, ninety countries have contributed valuable information. The recent implementation of this index in North America, including the US, may provide critical insights on HIV-related stigma ("The People Living with HIV Index," n.d.).

Emerging evidence suggests that HIV-related stigma in health care is embedded in fear of transmission, inadequate clinical training, and reduced interactions with HIV patients (Davtyan, Olshansky, Brown, & Lakon, 2017). To address the actionable drivers of stigma in health care settings, methodical efforts are necessary. First, health care settings must provide scientifically contemporaneous and culturally sensitive education about HIV/AIDS and related stigma to its clinical and non-clinical personnel, as stigma is enacted from both groups (Nyblade et al., 2013). Second, health care workers must undergo rigorous instruction to be able to explicitly demarcate stigma and discrimination related to HIV/AIDS and its link to patient health and social outcomes (Audet et al., 2013). Third, clinical health care workers must be fully immersed in training to improve service delivery to HIV patients and these trainings must include direct and necessary interactions with PLWH (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Fourth, health care settings must be fully equipped with universal precaution resources and prophylactic medications (i.e., pre- and post-exposure prophylaxis), as these commodities have been shown to reduce HIV-related stigma (Li, Liang, Lin, & Wu, 2015; Grace et al., 2018). Fifth, health care settings must implement evidence-based anti-discrimination policies that protect the welfare of PLWH and hold health care professionals who do not comply with such policies accountable (Ahsan Ullah, 2011; Davtyan, Olshansky, & Lakon, 2018).

HIV-related stigma is a detrimental global phenomenon that has existed since the inception of the epidemic more than three decades ago. Notwithstanding biomedical achievements in HIV treatment, stigma remains an assiduous feature in the lives and experiences of PLWH. Stigma related to HIV constructs impenetrable barriers, shapes disease profiles, and worsens prognoses. Reducing stigma and discrimination of PLWH is therefore in the best interest of public health. Concerted efforts that involve a combination of education, training, collaborations, changes in clinical practice, and policy implementation are warranted to achieve desired outcomes. HIV-related stigma is catalytic and inherently divisive, subjecting impacted groups to unreasonable struggles and standards for attaining health and wellness. The world must acknowledge this injustice with unrelenting fervor, deploy its most effective scientific strategies, and advocate for communities faced with the most harmful symptom of HIV, stigma.

References:

Ahsan Ullah, A. K. M. (2011). HIV/AIDS-related stigma and discrimination: A study of health care providers in Bangladesh. *Journal of the International Association of Physicians in AIDS Care, 10*(2), 97-104. DOI: 10.1177/1545109710381926

Airhihenbuwa, C., Okoror, T., Shefer, T., Brown, D., Iwelunmor, J., Smith, E., ... & Shisana, O. (2009). Stigma, culture, and HIV and AIDS in the Western Cape, South Africa: An application of the PEN-3 cultural model for community-based research. *Journal of Black Psychology, 35*(4), 407-432. DOI: 10.1177/0095798408329941

Audet, C. M., McGowan, C. C., Wallston, K. A., & Kipp, A. M. (2013). Relationship between HIV stigma and self-isolation among people living with HIV in Tennessee. *PLoS One, 8*(8), e69564. DOI: 10.1371/journal.pone.0069564

Aziz, M., & Smith, K. Y. (2011). Challenges and successes in linking HIV-infected women to care in the United States. *Clinical Infectious Diseases, 52*(suppl_2), S231-S237. DOI: 10.1093/cid/ciq047

Bateganya, M., Amanyeiwe, U., Roxo, U., & Dong, M. (2015). The impact of support groups for people living with HIV on clinical outcomes: a systematic review of the literature. *Journal of Acquired Immune Deficiency Syndromes (1999), 68*(0 3), S368. DOI: 10.1097/QAI.0000000000000519

Blank, M. B., Himelhoch, S., Walkup, J., & Eisenberg, M. M. (2013). Treatment considerations for HIV-infected individuals with severe mental illness. *Current HIV/AIDS Reports, 10*(4), 371-379. DOI: 10.1007/s11904-013-0179-3

Bronfenbrenner, U. (1992). Ecological systems theory. Jessica Kingsley Publishers.

Choi, S. K., Boyle, E., Cairney, J., Gardner, S., Collins, E. J., Bacon, J., ... & OHTN Cohort Study Group. (2016). Adequacy of mental health services for HIV-positive patients with depression: Ontario HIV Treatment Network Cohort Study. *PloS One, 11*(6), e0156652. DOI: 10.1371/journal.pone.0156652

Chuah, F. L. H., Haldane, V. E., Cervero-Liceras, F., Ong, S. E., Sigfrid, L. A., Murphy, G., ... & Otero, L. (2017). Interventions and approaches to integrating HIV and mental health services: a systematic review. *Health Policy and Planning, 32*(suppl_4), iv27-iv47. DOI: 10.1093/heapol/czw169

Cole, E. R. (2009). Intersectionality and research in psychology. *American Psychologist, 64*(3), 170. DOI: 10.1037/a0014564

Coleman, J. D., Tate, A. D., Gaddist, B., & White, J. (2016). Social determinants of HIV-related stigma in faith-based organizations. *American Journal of Public Health, 106*(3), 492-496. DOI: 10.2105/AJPH.2015.302985

Davtyan, M., Olshansky, E. F., Brown, B., & Lakon, C. (2017). A Grounded Theory Study of HIV-Related Stigma in US-Based Health Care Settings. *Journal of the Association of Nurses in AIDS Care, 28*(6), 907-922. DOI: 10.1016/j.jana.2017.07.007

Davtyan, M., Olshansky, E. F., & Lakon, C. (2018). Addressing HIV Stigma in Health Care. *The American Journal of Nursing, 118*(3), 11-11. DOI: 10.1097/01.NAJ.0000530921.56586.ac

Derose, K. P., Bogart, L. M., Kanouse, D. E., Felton, A., Collins, D. O., Mata, M. A., ... & Williams, M. V. (2014). An intervention to reduce HIV-related stigma in partnership with African American and Latino churches. *AIDS Education and Prevention, 26*(1), 28-42. DOI: 10.1521/aeap.2014.26.1.28

Genberg, B. L., Shangani, S., Sabatino, K., Rachlis, B., Wachira, J., Braitstein, P., & Operario, D. (2016). Improving engagement in the HIV care cascade: A systematic review of interventions involving people living with HIV/AIDS as peers. *AIDS and Behavior, 20*(10), 2452-2463. DOI: 10.1007/s10461-016-1307-z

Grace, D., Jollimore, J., MacPherson, P., Strang, M. J., & Tan, D. H. (2018). The Pre-Exposure Prophylaxis-Stigma Paradox: Learning from Canada's First Wave of PrEP Users. *AIDS Patient Care and STDs, 32*(1), 24-30. DOI: 10.1089/apc.2017.0153

Greene, B. (2014, April 10). *Individuals Living with HIV/AIDS Fight Back Against Housing Discrimination*. Retrieved from: https://blog.hud.gov/index.php/2014/04/10/individuals-living-with-hivaids-fight-back-against-housing-discrimination/

HIV Among Women. (2018, March 9). Retrieved from https://www.cdc.gov/hiv/group/gender/women/index.html

Higgins, J. A., Hoffman, S., & Dworkin, S. L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health, 100*(3), 435-445. DOI: 10.2105/AJPH.2009.159723

Jacobs, D. B., & Sommers, B. D. (2015). Using drugs to discriminate—adverse selection in the insurance marketplace. *New England Journal of Medicine, 372*(5), 399-402. DOI:10.1056/NEJMp1411376

Johnsson, G. (2013). Management of mental health disorders in HIV-positive patients: by the Southern African HIV Clinicians Society. *Southern African Journal of HIV Medicine, 14*(4), 155-166. DOI: 10.7196/SAJHIVMED.995

Knight, R., Shoveller, J. A., Oliffe, J. L., Gilbert, M., & Goldenberg, S. (2013). Heteronormativity hurts everyone: Experiences of young men and clinicians with sexually transmitted infection/HIV testing in British Columbia, Canada. *Health, 17*(5), 441-459. DOI: 10.1177/1363459312464071

Li, L., Liang, L. J., Lin, C., & Wu, Z. (2015). Addressing HIV stigma in protected medical settings. *AIDS Care, 27*(12), 1439-1442. DOI: 10.1080/09540121.2015.1114990

Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: a qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Medicine, 8*(11), e1001124. DOI: 10.1371/journal.pmed.1001124

Mantell, J. E., Correale, J., Adams-Skinner, J., & Stein, Z. A. (2011). Conflicts between conservative Christian institutions and secular groups in sub-Saharan Africa: Ideological discourses on sexualities, reproduction and HIV/AIDS. *Global Public Health, 6*(sup2), S192-S209. DOI: 10.1080/17441692.2011.604039

Nyblade, L., Jain, A., Benkirane, M., Li, L., Lohiniva, A. L., McLean, R., ... & Kwena, Z. (2013). A brief, standardized tool for measuring HIV- related stigma among health facility staff: results of field testing in China, Dominica, Egypt, Kenya, Puerto Rico and St. Christopher & Nevis. *Journal of the International AIDS Society, 16*(3S2). DOI: 10.7448/IAS.16.3.18718

Rouhani, S. A., O'Laughlin, K. N., Faustin, Z. M., Tsai, A. C., Kasozi, J., & Ware, N. C. (2017). The role of social support on HIV testing and treatment adherence: A qualitative study of HIV-infected refugees in southwestern Uganda. *Global Public Health, 12*(8), 1051-1064. DOI: 10.1080/17441692.2015.1132472

Schumann, C. L., Westergaard, R. P., Meier, A. E., Ruetten, M. L., & Vergeront, J. M. (2017). Developing a patient navigation program to improve engagement in HIV medical care and viral suppression: a demonstration project protocol. *AIDS and Behavior*, 1-9. DOI: 10.1007/s10461-017-1727-4

Sears, B. (2008). HIV discrimination in health care services in Los Angeles County: the results of three testing studies. *Washington & Lee Journal of Civil Rights and Social Justice, 15*(1), 85-107.

Singh, B. (2001). “A Disease not a Sin.” Religious Health Organizations in Africa Face AIDS. *Conscience, xxii*(3), 16–20.

Smith, J., Simmons, E., & Mayer, K. H. (2005). HIV/AIDS and the Black Church: what are the barriers to prevention services?. *Journal of the National Medical Association, 97*(12), 1682. PMID: 16396060

Sprague, L., Simon, S., & Sprague, C. (2011). Employment discrimination and HIV stigma: survey results from civil society organisations and people living with HIV in Africa. *African Journal of AIDS Research, 10*(sup1), 311-324. DOI: 10.2989/16085906.2011.637730.

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*(3Suppl 2). DOI: 10.7448/IAS.16.3.18734

Stringer, K. L., Turan, B., McCormick, L., Durojaiye, M., Nyblade, L., Kempf, M. C., ... & Turan, J. M. (2016). HIV-related stigma among healthcare providers in the deep South. *AIDS and Behavior, 20*(1), 115-125. DOI: 10.1007/s10461-015-1256-y

Szaflarski, M., Vaughn, L. M., Chambers, C., Harris, M., Ruffner, A., Wess, Y., ... & Smith, C. (2014). Engaging Religious Institutions to Address Racial Disparities in HIV/AIDS: A Case of Academic-Community Partnership. The International *Journal of Research on Service-Learning and Community Engagement, 2*(1), 95. PMID: 28239643

The People Living with HIV Index. (n.d.). Retrieved from: http://www.stigmaindex.org/

Travaglini, L. E., Himelhoch, S. S., & Fang, L. J. (2018). HIV Stigma and Its Relation to Mental, Physical and Social Health Among Black Women Living with HIV/AIDS. *AIDS and Behavior*, 1-12. doi: 10.1007/s10461-018-2037-1

Winiarski, M. G., Beckett, E., & Salcedo, J. (2005). Outcomes of an inner-city HIV mental health programme integrated with primary care and emphasizing cultural responsiveness. *AIDS Care, 17*(6), 747-756. DOI: 10.1080/09540120412331336733

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. DOI: 10.1300/J013v46n02_07

Zou, J., Yamanaka, Y., John, M., Watt, M., Ostermann, J., & Thielman, N. (2009). Religion and HIV in Tanzania: influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes. *BMC Public Health, 9*(1), 75. DOI: 10.1186/1471-2458-9-75

APPENDIX A

HIV-related Stigma Survey Instrument

Today's Date: ___________________________
Study ID Number: ________________________

Dear Study Participant,

We are conducting a research study on stigma and discrimination against people living with HIV/AIDS among health care providers. To aid us in our research, we would like you to respond to this questionnaire truthfully. The information that we will obtain will be used only for research purposes. We assure you that your confidentiality is of primary importance to us and we will do everything possible to protect it. There is no risk to you or your organization in this study apart from the time spent answering questions. We politely request your cooperation in responding to our questionnaire. You have the right not to respond at all or to withdraw in the meantime, but your input will have great value for the success of our objective.

Section A: Socio-demographic Characteristics

In this section, we will ask you to answer some questions about your background. Please write your responses in the designated spaces and/or circle the response that applies to you.

No.	Question	Response or Code
1	What is your current age?	Age in years ☐
2	What is your sex?	Male-1 Female-2
3	What is your marital status?	Now married-1 Widowed-2 Divorced-3 Separated-4 Never married-5
4	What is your race?	American Indian-1 Alaskan Native-2 Asian-3 Native Hawaiian-4 Black/African American-5

		White-6 Other, Please Specify:-7 __________
5	What is your ethnicity?	Not Hispanic/Latino-0 Hispanic/Latino-1
6	What is the highest level of education you completed?	High school graduate-1 Some college, no degree-2 Associate degree-3 Bachelor’s degree-4 Master’s degree-5 Professional degree-6
7	What is your profession?	Physician-1 Nurse-2 Allied Health Care Professional-3
8	What department do you work in?	___________________________
9	What is your approximate annual income?	Less than $10,000-1 $10,000 to $19,999-2 $20,000 to $29,999-3 $30,000 to $39,999-4 $40,000 to $49,999-5 $50,000 to $59,999-6 $60,000 to $69,999-7 $70,000 to $79,999-8 $80,000 to $89,999-9 90,000 to $99,999-10 $100,000 to $149,999-11 $150,000 or more-12
10	What is your place of birth?	US-1 Mexico-2 Haiti-3 Puerto Rico-4 Cuba-5 Dominican Republic-6 Africa-7 Other: Specify Country-8 __________

Section B: Knowledge of HIV/AIDS

The following are questions related to the knowledge and experience of healthcare providers. Please circle the number that applies to you.

No.	Questions	Response or Code

11	The risk of HIV transmission following a needle-prick or sharps injuries is small (approximately 1 in 300).	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
12	The risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small (approximately 1 in 1000).	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
13	Which of the following body fluids have high enough concentrations of HIV to transmit the virus.	A. Saliva B. Urine C. Spinal Fluid D. Breast Milk E. Pus
14	Pre and Post-exposure HIV medications greatly reduce transmission of HIV.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
15	People who are infected with HIV quickly show serious signs of illness.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
16	There is a vaccine that can stop adults from getting HIV.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
17	I would have a strong fear of HIV transmission if I touched the sweat of a person with HIV/AIDS.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
18	I would have a strong fear of HIV transmission if I touched the saliva of a person with HIV/AIDS.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
19	I would have a strong fear of HIV transmission if I dressed the wounds of a person with HIV.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
20	I would have a strong fear of HIV transmission if I put an intravenous drip in someone who was showing signs of AIDS.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4

Section C: Attitudes towards people living with HIV/AIDS

In this section, we will ask you to answer some questions about your attitudes towards people living with HIV/AIDS. Please circle the number that applies to you.

No.	Questions	Response or Code
21	Most people living with HIV do not care if they infect other people.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
22	Women living with HIV should not be allowed to have children.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
23	People with HIV should expect some restrictions on their freedom.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
24	HIV is punishment for bad behavior.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
25	People living with HIV should feel ashamed of themselves.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
26	Most people living with HIV have had many sexual partners.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
27	People get infected with HIV because they engage in irresponsible behaviors.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
28	Men who have sex with men spread HIV in our community.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4
29	Female sex workers spread HIV in our community.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4

30	Injection drug users spread HIV in our community.	Strongly Agree-1 Agree-2 Disagree-3 Strongly Disagree-4

Section D: Observation of enacted HIV stigma

In this section, we will ask you to answer some questions about your workplace experiences with HIV/AIDS-related stigma. Please circle the number that corresponds to your response.

No.	Questions	Response or Code
31	I have observed patients with HIV receive less care/attention than other patients.	Never-1 Once or twice-2 Several times-3 Most of the time-4
32	I have observed extra precautions taken in the sterilization of instruments used on HIV-positive patients.	Never-1 Once or twice-2 Several times-3 Most of the time-4
33	I have observed healthcare workers using latex gloves for performing noninvasive exams on clients.	Never-1 Once or twice-2 Several times-3 Most of the time-4
34	I have observed healthcare workers disclosing patients' HIV status to others without consent.	Never-1 Once or twice-2 Several times-3 Most of the time-4
35	I have observed healthcare workers gossiping about a patient's HIV status.	Never-1 Once or twice-2 Several times-3 Most of the time-4
36	I have observed healthcare workers unwilling to care for a patient living with HIV.	Never-1 Once or twice-2 Several times-3 Most of the time-4
37	I have observed healthcare workers avoiding physical contact with a patient living with HIV.	Never-1 Once or twice-2 Several times-3 Most of the time-4
38	I have observed healthcare workers requiring some patients to be tested for HIV before scheduling surgery.	Never-1 Once or twice-2 Several times-3 Most of the time-4

39	I have observed a senior healthcare provider assigned to care for a patient with HIV instead of a junior healthcare provider.	Never-1 Once or twice-2 Several times-3 Most of the time-4
40	I have observed HIV testing without the informed consent of the patient.	Never-1 Once or twice-2 Several times-3 Most of the time-4

You have completed the questionnaire!
Thank you for your time and valuable contributions to this study.