

**EXPERIENCES OF FEMALE SEX WORKERS
ALONG THE HIV CARE CONTINUUM
IN SANTO DOMINGO,
DOMINICAN REPUBLIC**

**by,
Rose Zulliger**

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Abstract

Introduction

Approximately 12% of all female sex workers (FSWs) around the world are living with HIV. FSWs confront heightened vulnerability not only to HIV infection, but also to social, economic and systemic barriers throughout the HIV care continuum and have sub-optimal engagement in HIV care. Despite this large burden of disease, there is very limited evidence on the HIV care experiences of FSWs living with HIV.

Methods

This study utilized a mixed methods approach to investigate FSWs' experiences along the HIV care continuum. The first manuscript explored the experiences of 44 FSWs living with HIV throughout the HIV care continuum through in-depth interviews and focus group discussions in Santo Domingo, Dominican Republic. Informed by the findings from this thematic and narrative analysis, the second manuscript analyzed a quantitative, cross-sectional survey to describe the baseline HIV care continuum among 268 FSWs living with HIV in Santo Domingo. The manuscript then specifically examined factors associated with experience of antiretroviral therapy (ART) interruption using multiple logistic regression. The final manuscript determined the factors associated with retention in HIV care in the same study population using multiple measure of retention.

Results

FSWs living with HIV disengaged at each step of the HIV care continuum. Engagement in HIV care was not a static construct as participants continually negotiated engagement within a broader context of structural constraints and social conditions. FSWs described critical influences across multiple levels that either facilitated (re)engagement in HIV care or led to disengagement. Key individual-level

factors identified in the qualitative analysis were physical and mental health as post-diagnosis depression was often followed by disengagement in HIV care until declines in physical health were noted. Interpersonal factors centered on disclosure of HIV or FSW status and existent support. At the environmental level, participants frequently described systemic delays and the high costs of care, but good relationships with HIV care providers. Some experiences of discrimination within the clinic environment were, however, described. Lack of economic resources and pervasive HIV stigma and discrimination also complicated adherence to clinical appointments and ART.

Within the quantitative sample, most participants linked to HIV care (92%), attended HIV services in the past six months (85%) and were initiated onto ART (78%), but discontinuation of treatment and irregular adherence to clinical appointments were frequent. A total of 36% of the participants ever initiated onto ART reported lifetime experience with an interruption of ART. The odds of ART interruption were 3.24 times higher among women who experienced sex work (SW)-related discrimination (95% confidence interval [CI]: 1.28, 8.20), 2.41 times higher among women who reported ever using any drug (95% CI: 1.09, 5.34) and 2.35 times higher among women who worked in a SW establishment (95% CI: 1.20, 4.60). Self-stigmatizing beliefs related to SW were associated with higher odds of interruption as each additional point on the SW self-stigma scale was associated with a 9% increase in the odds of ART interruption (95% CI: 1.02, 1.16). Positive perceptions of HIV providers were protective with each additional point on the perception of HIV provider scale associated with a 9% reduction in the odds of treatment interruption (95% CI: 0.85, 0.98).

The final manuscript determined that a retention measure which included both attended and missed visits was the most appropriate measure of retention in this study population. A total of 37% of the women who attended HIV services in the past six months had missed at least one clinical appointment. The odds of being retained in HIV care were higher among participants with more positive perceptions of HIV service providers (adjusted relative odds [ARO]: 1.17; 95% confidence

interval [CI]: 01.09, 1.25). The odds of retention were lower among women who reported recent alcohol consumption (ARO: 0.50; 95% CI: 0.28, 0.92) and among women with self-stigmatizing beliefs related to SW (ARO: 0.93; 95% CI: 0.88, 0.98).

Conclusions

Individual, interpersonal, environmental and structural factors were important influences on engagement in HIV care among FSWs throughout the HIV care continuum. In addition to challenges faced by the general population living with HIV, FSWs confronted additional economic instability and the compounded stigma of being both HIV-infected and a FSW. Given the clear importance of improving engagement in HIV care to maximize individual and public health, there is an urgent need for multi-level interventions to help support FSWs throughout the HIV care continuum.

Dissertation Committee Members

Professor Chris Beyrer
Professor David Holtgrave
Assistant Professor Caitlin Kennedy
Associate Professor Deanna Kerrigan

Dedication

To Laurel and John Zulliger

For sharing with me your commitment to
learning, adventure and justice

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Table of Contents

Abstract.....	ii
Dedication	v
Acknowledgements	vi
List of Tables	ix
List of Figures	x
Key Terms and Abbreviations	xi
Chapter 1. Introduction.....	1
Chapter 2. Relevant Literature.....	4
HIV care continuum.....	6
Measuring engagement in HIV care	9
Barriers to engagement in HIV care	11
Model of access to health services	13
Adherence to ART	17
FSWs and HIV/AIDS	19
FSWs living with HIV	20
HIV/AIDS and the Dominican Republic.....	22
Chapter 3. Methods.....	26
Qualitative Phase Research Methods	28
Characteristics of the qualitative study sample	28
Qualitative focus	29
Qualitative data collection	29
Qualitative data analysis.....	30
Quality assurance and quality control	31
Abriendo Puertas	33
Quantitative Phase Research Methods.....	35
Characteristics of the quantitative study sample	35
Quantitative measurement.....	36
Quantitative data collection.....	38
Quantitative data management	38
Quality assurance and quality control	38
Quantitative data analysis.....	40
Protection of Human Subjects	44
Chapter 4. Experiences of female sex workers living with HIV along the HIV care continuum in the Dominican Republic.....	47
Introduction	48
Methods	49
Results	51
HIV testing and diagnosis.....	57
Pre-ART care	58
ART care	61
Discussion	63

Chapter 5. High drop-off along the HIV care continuum and ART interruption among female sex workers in the Dominican Republic.....	68
Abstract	68
Introduction	70
Methods	72
Measures.....	72
Analysis	75
Results	76
HIV care continuum.....	76
Factors associated with ART interruption.....	80
Discussion	82
Chapter 6. Retention in HIV care among female sex workers in the Dominican Republic: implications for research, policy and programming	86
Abstract	86
Introduction	87
Measuring engagement in HIV care.....	88
Methods	90
Study setting and participants.....	90
Measures.....	90
Analysis	91
Results	93
Defining retention in care	93
Factors associated with retention in care.....	95
Discussion	97
Chapter 7. Discussion.....	100
Negotiating Engagement	100
Influences on Engagement in HIV Care	101
Implications for Research, Policy and Programming	105
Strengths and Limitations.....	107
Chapter 8. Conclusion	109
References	110
Appendix A. Narratives of the experiences of FSWs living with HIV	124
Appendix B. Sociodemographic and clinical characteristics of 268 female sex workers living with HIV in Santo Domingo in the Abriendo Puertas cohort	134
Rose Zulliger <i>Curriculum Vitae</i>	135

List of Tables

Table 3.1 Overview of study aims and design.....	27
Table 4.1 Narratives of four female sex workers (FSWs) living with HIV along the HIV care continuum in Santo Domingo, Dominican Republic.....	54
Table 5.1 Definitions of the steps within the HIV care continuum.....	73
Table 5.2 Factors associated with experience of an interruption of antiretroviral therapy (ART) among HIV-positive female sex workers who have ever been initiated onto ART in Santo Domingo	81
Table 6.1 Sociodemographic and clinical characteristics of 246 female sex workers living with HIV in Santo Domingo by retention in HIV care status using two different definitions of retention in HIV care.....	94
Table 6.2 Factors associated with retention in HIV care, defined as having attended HIV care in the past six months and not missing any appointments, among female sex workers living with HIV in Santo Domingo.....	96
Table A.1 Narratives of the experiences of FSWs living with HIV.....	124
Table B.1 Sociodemographic and clinical characteristics of 268 female sex workers living with HIV in Santo Domingo in the <i>Abriendo Puertas</i> cohort.....	134

List of Figures

Figure 1.1 Organizing framework for dissertation on the experiences of FSWs along the HIV care continuum.....	3
Figure 2.1 The HIV care continuum from HIV infection to viral suppression on antiretroviral therapy.....	6
Figure 4.1 Key influences on engagement, re-engagement, and disengagement in HIV care experienced by female sex workers at the individual, interpersonal, environmental, and structural levels throughout the continuum of HIV care.....	52
Figure 5.1 HIV care continuum among female sex workers living with HIV in Santo Domingo, Dominican Republic	77
Figure 5.2 HIV care continuum among female sex workers living with HIV in Santo Domingo, Dominican Republic with emphasis on experiences between ART initiation and viral suppression on ART.....	79

Key Terms and Abbreviations

Abbreviations	Explanation
AIC	Akaike Information Criterion
AIDS	Acquired Immunodeficiency Syndrome
AP	<i>Abriendo Puertas</i> (Opening doors), a multi-level intervention implemented with FSWs living with HIV in Santo Domingo
ARO	Adjusted relative odds
ART	Antiretroviral therapy
Atlas.ti	Qualitative analysis computer software program
CD4	Cluster of differentiation 4, a type of essential white blood cell that is reduced by HIV infection
CI	Confidence interval
DIGECITSS	<i>Dirección General de Control de Infecciones de Transmisión Sexual y SIDA</i> , National HIV/AIDS/STI Control Program of the Ministry of Health of the Dominican Republic
DR	Dominican Republic
EDA	Exploratory data analysis
FGD	Focus group discussion
FSW	Female sex worker
HIV	Human Immunodeficiency Virus
HIV Care Continuum	The spectrum of HIV care which includes HIV testing, HIV diagnosis, linkage to HIV services, retention in pre-ART care, pre-ART patient preparation, ART initiation, retention in ART care, adherence to ART and HIV viral suppression
HPTN	HIV Prevention Trials Network
HRSA HAB	Human Resources and Services Administration HIV/AIDS Bureau
HVRU	HIV Vaccine and Research Unit
HVTN	HIV Vaccine Trial Network
IDI	In-depth interview
IDCP	<i>Instituto Dermatológico y Cirugía de Piel</i> , local institutional partner in the Dominican Republic
IRB	Institutional review board
JHSPH	Johns Hopkins Bloomberg School of Public Health
LTFU	Loss to follow-up
MLR	Multiple logistic regression
MSM	Men who have sex with men
NGO	Non-governmental organization
PCA	Principal component analysis
NRTI	Nucleoside reverse transcriptase inhibitors
NNRTI	Non-nucleoside reverse transcriptase inhibitors
PCA	Principal component analysis
PHDP	Positive health, dignity and prevention
PLHIV	People living with HIV
RO	Relative odds

SLR	Simple logistic regression
Stata	Statistical analysis computer software program
SW	Sex worker
STI	Sexually transmitted infection
TasP	Treatment of HIV as prevention of HIV transmission
TB	Tuberculosis
TW	Transgender women
US	United States

Chapter 1. Introduction

Approximately 12% of all female sex workers (FSWs) around the world are living with HIV.¹

Despite this large burden of disease, there is very limited evidence on the HIV care experiences of these FSWs living with HIV.^{2,3} The research that does exist suggests that FSWs confront heightened vulnerability not only to HIV infection, but also to social, economic and systemic barriers throughout the HIV care continuum⁴⁻⁶ and have sub-optimal engagement in HIV care.^{3,7-}

⁹ This is a critical health challenge as engagement in HIV care is associated with improved clinical outcomes, decreased transmission of HIV, reduced healthcare costs and increased access to antiretroviral therapy (ART).^{10,11} Access and adherence to ART, in turn, is strongly associated with reduced morbidity, mortality, and HIV transmission.¹²⁻¹⁴

The clear benefits of ART have led to growing interest in the notion of “treatment as prevention” (TasP) with people living with HIV (PLHIV) in order to turn the tide of the HIV epidemic.^{14,15} TasP will have the most impact with PLHIV who are aware of their HIV status and sexually active,¹⁶ such as FSWs diagnosed with HIV. In order to reap the individual and public benefits of ART among FSWs, we must first address the existent barriers to engagement in HIV care. Yet effective intervention requires an enhanced understanding of the facilitators and barriers to engagement.

This dissertation contributes to the evidence on FSWs’ experiences along the HIV care continuum within Santo Domingo, Dominican Republic (DR). The study utilized a mixed methods approach to address the overall research question: *What are FSWs’ experiences along the HIV care continuum?* The study aims were to:

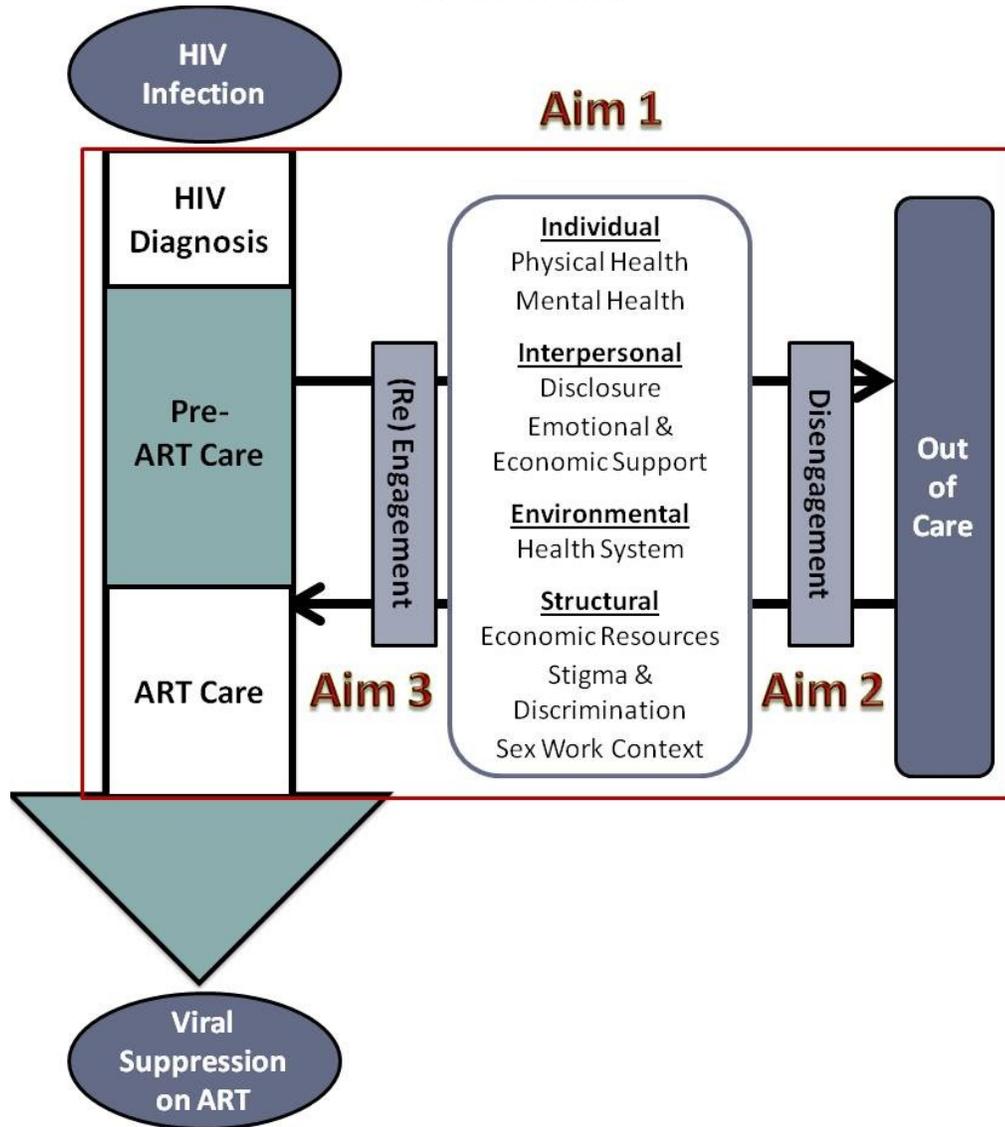
1. Explore the experiences of FSWs living with HIV along the HIV care continuum
2. Describe the HIV care continuum in FSWs living with HIV and examine the factors associated with experience of treatment interruption in FSWs living with HIV

3. Determine the factors associated with retention in HIV care in FSWs living with HIV

In order to meet these aims, this dissertation includes eight chapters which each describe various facets of FSWs' experiences along the HIV care continuum. The second chapter describes the current evidence on engagement in HIV care and the HIV care continuum, the experiences of FSWs and HIV, and the state of the HIV epidemic and services within the DR. Based on this foundation, the third chapter describes the mixed methods that were used in this dissertation to add to the existent body of evidence.

The fourth, fifth and sixth chapters present the new results that address the aims of this dissertation. Chapter four describes findings from a qualitative exploration of the experiences of 44 FSWs living with HIV throughout the HIV care continuum. This analysis demonstrated how FSWs experienced critical factors at the individual, interpersonal, environmental and structural levels that either facilitated (re)engagement in HIV care or led to disengagement throughout the HIV care continuum. Figure 1.1 depicts a modified version of the emergent framework from this analysis and shows how each study aim relates to the broader dissertation question. Informed by the findings from the first qualitative aim, Chapter five presents the findings related to the quantitative second aim, an evaluation of the baseline HIV care continuum among FSWs living with HIV. It then specifically examines the relationship between the key factors identified in the qualitative analysis and experience of ART interruption, a form of disengagement. Chapter six then explores some of the complexity in measurement of engagement in HIV care and addresses aim three by determining the factors associated with retention in HIV care. The seventh chapter provides a discussion of the mixed methods results and the eighth chapter concludes by describing the implications of these findings for public health research, policy and programming.

Figure 1.1 Organizing framework for dissertation on the experiences of FSWs along the HIV care continuum



Chapter 2. Relevant Literature

Engagement in HIV care has considerable societal and individual benefits including improved individual health outcomes, reduced transmission of HIV, lower healthcare costs and higher access to ART.^{10,11} The health benefits of early initiation onto ART, such as reduced morbidity and mortality, are well-established.¹² There is now conclusive evidence that ART can also substantially decrease the likelihood that an individual will transmit HIV to others. ART reduces the spread of HIV by suppressing HIV replication which decreases the concentration of HIV-1 ribonucleic acid (hereafter referred to as HIV viral load) within an individual's blood.^{14,17} The HIV Prevention Trials Network (HPTN) 052 study demonstrated that immediate initiation onto ART led to a 96% reduction in HIV transmissions and a 41% reduction in clinical endpoints such as extrapulmonary tuberculosis (TB).¹³

The success of the HPTN 052 study has led to growing interest in the notion of using HIV treatment as a mechanism for prevention of HIV transmission with PLHIV, commonly referred to as treatment as prevention or TasP.^{14,15,18} Subsequent research has supported the findings of HPTN 052 and has demonstrated that ART is associated with reduced morbidity, mortality and HIV transmission in diverse populations.^{14,18-20} TasP is most relevant for individuals who are currently living with HIV, aware of their HIV status and engaging in HIV transmission-related behaviors such as sexual intercourse or injection drug use.¹⁶ This provides clear evidence of the importance of initiation and retention on ART, particularly with known HIV-infected individuals that frequently engage in sexual activity, such as FSWs.

In order for TasP to be effective and to obtain optimal health outcomes, HIV services must be physically and culturally accessible and acceptable, particularly for marginalized populations. Holtgrave and colleagues highlighted that the potential of TasP will not be achieved without improved access to ART.¹⁶ In addition to increased access to ART, HIV prevention interventions

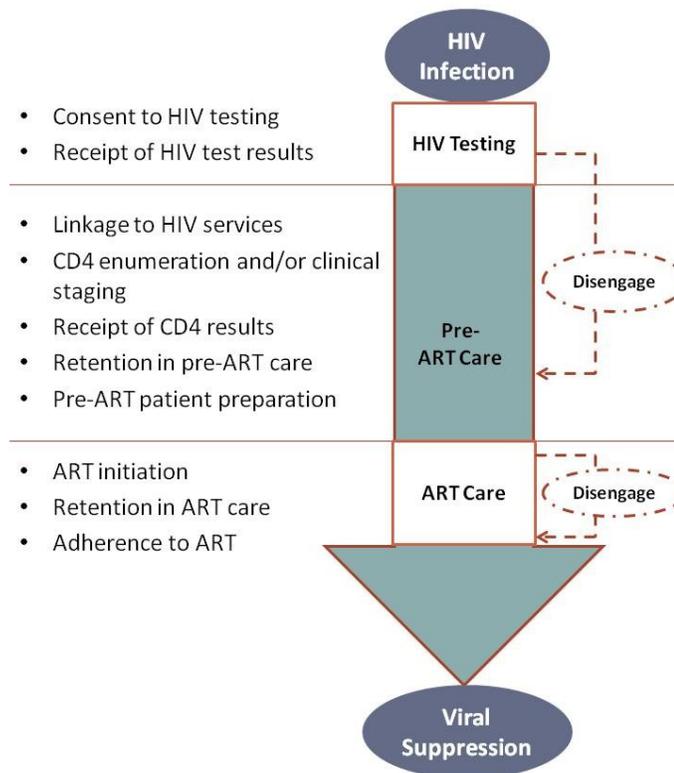
that specifically target PLHIV must also foster environments that support the overall wellbeing and human rights of PLHIV.²¹ These positive health, dignity and prevention (PHDP) interventions often address the physical and mental health and agency of PLHIV, along with the prevention of HIV transmission to others.²² The overarching goal of PHDP efforts is to "improve the dignity, quality, and length of life of people living with HIV; which, if achieved will, in turn, have a beneficial impact on their partners, families, and communities, including reducing the likelihood of new infections".²¹

Despite the considerable individual and societal health benefits of engagement in HIV care, global access to ART is sub-optimal. There has been a dramatic increase in the number of individuals receiving ART in developing countries, but coverage levels are still low and barriers to ART persist. In 2009, 5,254,000 people in low- and middle-income countries were receiving ART, representing a 13-fold increase since 2003, yet coverage of those with CD4 counts below 350 cells/mm³ was only 36%.²³ This demonstrates the importance of research on current access and barriers to HIV care and ART, particularly within vulnerable populations. It also highlights the need for guidance to inform interventions that address the multiple levels of barriers confronted by PLHIV throughout the HIV care continuum.

HIV care continuum

There has been growing interest in and attention to the HIV care continuum^{24,25} as a mechanism for understanding the HIV epidemic and identifying key unmet needs. The continuum, previously described as the HIV treatment cascade and spectrum of engagement in HIV care,^{24,26,27} delineates the steps within the successful provision of HIV services for PLHIV. The steps along this pathway include HIV testing, HIV diagnosis, linkage to HIV services, assessment of eligibility for ART, retention in pre-ART care, pre-ART patient preparation, ART initiation, retention in ART care, adherence to ART, and HIV viral suppression,^{28,29} as depicted in **Figure 2.1**.

Figure 2.1 The HIV care continuum from HIV infection to viral suppression on antiretroviral therapy



Patients temporarily or permanently disengage at each of the steps along this dynamic pathway^{28,30} and often cycle in and out of care,³¹⁻³³ as shown by the dashes leading away from and back into HIV care throughout the HIV care continuum. This movement and the numerous

barriers to engagement led researchers to conclude that the continuum “often operated more like an obstacle course than a smoothly paved road.”³⁴ Some of these challenges include late HIV diagnosis, suboptimal linkage to and retention in HIV care, low use of ART, and poor adherence to ART.²⁶

The losses along the HIV care continuum gained considerable national and global attention when a study by Marks and colleagues found that only 28% of PLHIV in the United States (US) have reached viral suppression with drop off and delays at each step.³⁵ Another study of establishment, retention and loss to follow-up (LTFU) in HIV care among 22,984 patients in the US found that 21.7% of patients did not establish long-term care, defined as more than 6 months of outpatient care visits, 57.4% of those patients who established care were not consistently retained in care and 34.9% of patients were LTFU.¹¹ A 2011 review of published literature by Gardner and colleagues determined that only 79% of PLHIV in the US were aware of their HIV status, of which 75% linked to HIV care within 6-12 months after diagnosis. Further, approximately 50% of people with an HIV diagnosis in the US were not retained in care. The authors estimated that only 25% of in-care PLHIV who should have received ART actually obtained it and just 55% of these individuals had adequate adherence to ART.²⁶

The depiction of the HIV care continuum has now been applied to describe the HIV epidemic in diverse settings. The depiction provides a striking representation of the poor state of engagement in HIV care³⁶ in the US^{26,37} and in global settings.^{25,38-40} A recent cohort study of engagement in HIV care in India found that there was high attrition during pre-ART care and that only 31% of the participants with an HIV diagnosis had reached viral suppression, despite the free provision of ART services and active tracing of patients LTFU.³⁸ Similarly, a longitudinal study of engagement in British Columbia, Canada documented high attrition throughout the HIV care continuum with only 35% of individuals in the province attaining viral suppression.²⁵

By describing losses at each step, the continuum highlights challenges that compromise the effectiveness of HIV prevention and care strategies. It can also serve as an important mechanism to mobilize change and foster improvements in HIV services.³⁴ The predominantly quantitative depiction of the continuum does not, however, address the processes or pathways from one step to the next or provide insight into patients' perspectives.²⁴ This underscores the utility of qualitative exploration of the barriers confronted by PLHIV throughout the continuum.³⁴ Despite critiques that discussion of the HIV care continuum has been largely constructed from the perspective of health care providers,²⁴ the continuum remains a useful way to determine the state of treatment and prevention⁴¹ within specific sub-populations.⁴²⁻⁴⁴ The continuum has not, however, been applied to describe the HIV epidemic within FSWs. There is a clear need for additional research on the pathways and barriers faced by PLHIV throughout the HIV care continuum^{33,34} and on facilitators of engagement in HIV care, particularly within groups most relevant for TasP.

Measuring engagement in HIV care

There is growing interest in patients' engagement (comprised of linkage, retention and re-engagement) in HIV care, but no clear "gold standard" exists for its measurement.^{30,45} Linkage to care is relatively easier to measure as the binary construct of having ever attended HIV services, but measurement of retention is more complex.³⁰ Retention in HIV care has been defined as "the consistency of service utilization after the initial care period."¹¹ It has been measured in many ways, including through missed visits, visit adherence, and treatment gaps. These measures are all calculated either through missed or kept visits with primary HIV medical providers.^{30,45} A 2012 study by Mugavero and colleagues evaluated six different commonly used retention measurements and their associations with one-another and with HIV viral suppression among in-care patients in the US. The six measures were:

1. Count of missed visits (not canceled in advance) with primary HIV medical provider
2. Dichotomous any missed visits (not canceled in advance) with primary HIV medical provider
3. Proportion of visit adherence with primary HIV medical provider (defined as the proportion of kept visits of total scheduled visits)
4. Four-month visit constancy (number of four-month-long intervals in a year during which the patient had at least one kept visit with primary HIV medical provider)
5. Six-month gap (dichotomous measure of whether 189 or more days elapsed in between kept visits with primary HIV medical provider)
6. Human Resources and Services Administration HIV/AIDS Bureau (HRSA HAB) measure (dichotomous measure of whether there were at least two kept visits with primary HIV medical provider that were at least 90 days apart within the year)^{30,45}

The authors determined that all of the measures based on missed visits were highly correlated with one-another (Spearman correlation coefficients were 0.83–0.85), as were the measures based on kept visits (Spearman correlation coefficients 0.72–0.77). There was, however, considerable variation across the measures in their categorization of patients as retained. Retention was lowest when based on perfect visit adherence and highest using the HRSA HAB measure. Despite these differences, each of the measures was strongly and significantly

associated with HIV virologic suppression, with varying sensitivity and specificity. Based on these findings, the authors concluded that there is no one best measure of retention in care. Instead, measures should be selected based on the available data, the question of interest, and the study rationale. The authors also suggested that it may be beneficial to use multiple retention measures within one study, particularly one based on missed visits and another based on kept visits.⁴⁵ An earlier study emphasized that selection of the appropriate measure of retention should also be based on clinic scheduling practices, duration of observation and study population of interest (e.g. newly initiated).³⁰

Barriers to engagement in HIV care

There is a growing body of evidence on the barriers to engagement in HIV care faced by the general PLHIV population. A recent systematic review that compared studies on factors associated with HIV testing, ART initiation and ART adherence from low and high income countries found that most studies in low income countries highlighted socioeconomic and health system barriers to HIV care, whereas studies from high income countries predominantly focused on medical and psychosocial factors. Stigma and discrimination, substance use, depression, self-efficacy and social support were salient influences across settings.⁴⁶ Some of the most frequently described barriers to HIV care noted in the literature by PLHIV at the individual-level include mental distress and feeling healthy.^{3,24,47,48} Examples of interpersonal barriers were lack of HIV status disclosure and insufficient social support.⁴⁸ Environmental barriers included inconvenient clinic hours and location, long lines within clinics, lack of available appointments, perceived low quality of HIV services, and disrespectful treatment from HIV care providers or staff.⁴⁹⁻⁵² Finally, structural barriers included poverty, gender inequity, and HIV-related stigma and discrimination.^{49,50}

HIV-related stigma and discrimination are some of the most pervasive barriers to engagement in HIV care. Stigma is a social process that reinforces differences and perpetuates existent inequities.⁵³ There are multiple forms of stigma, including enacted stigma (harassment, discrimination, or unequal access to conditions or opportunities) and internalized stigma (acceptance of perpetuated negative messages about oneself and individuals like oneself which results in negative attitudes towards self and community) related to HIV.^{54,55} This process manifests in diverse ways such as loss of social status, discriminatory treatment, and social isolation.⁵⁶ Stigma prevents engagement in HIV care in multiple ways, including delaying HIV testing, limiting disclosure of HIV status, thereby reducing opportunities for emotional and

tangible support, increasing rejection of PLHIV by sexual partners, family and social networks, and generating reluctance to be seen taking treatment or attending an HIV clinic.^{49,57,58}

Internalized stigma can also be detrimental to physical and mental health.^{54,59} Rather than acting in isolation, there is a layering or intersection of HIV-related stigma and stigmas associated with other identities such as sexism, racism and homophobia.^{53,56} Different forms of stigma may also differentially impact engagement in HIV care. For example, a study of FSWs in Russia found that HIV-related stigma was associated with lower HIV testing, but sex work (SW)-related stigma was associated with higher HIV testing.⁵ Thus, stigma and discrimination can affect access to health services in diverse ways.

Model of access to health services

Given the low rates of engagement in HIV care across the HIV care continuum, it is important to understand some of the relevant theory related to use of medical services. One of the predominant models used to characterize and predict utilization of medical care is Andersen's Behavioral Model of Access to Medical Care.⁶⁰⁻⁶² This model was developed in the 1960s to define, measure and promote equitable access to health services.⁶⁰ The original model described health service use at the family level as a function of predisposition to use services, factors that enable or impede use and the level of need for care.⁶¹ Andersen and colleagues conceptualized the model as both predictive and explanatory of health services use.⁶⁰ The model has been revisited and revised over the past decades by Andersen and colleagues to focus on the individual as the unit of analysis, to consider the influence of the health care system on access, to focus on measures of health services use and consumer satisfaction, to highlight the predisposing factors for vulnerable populations and to include feedback loops in which health service use affects predisposing factors and perceived need.^{60,62-64}

The central constructs of the model are predisposing characteristics, enabling resources, and the health need of individuals.^{60,61} Predisposing characteristics- the propensity to use services- are comprised of demographic factors, social structures such as household composition, health of the physical environment and health beliefs related to the use of health services. Enabling resources are the personal, family and community resources available to use health services. These include both the accessibility of health services and an individual's ability to use these services. Key components include income, health insurance, travel and waiting times. While named "enablers", this construct includes variables that are more generally considered to be barriers to health services such as distance to clinic. This construct also includes the social and emotional support that facilitate health services use, such as relationships with caregivers and

peer navigators. The final construct is health need. This includes an individual's perception of his/her own health state and professional judgment by medical practitioners about an individual's need for care.^{60,63,64}

Andersen and colleagues described four forms of access to health services: potential access, realized access, equitable access and inequitable access. Potential access exists when there are enabling resources. Realized access is when an individual actually uses health services. Equitable access is when most of the variance in health service use is explained by demographic and need factors. Inequitable access is when predisposing characteristics and enabling resources account for most of the variance in who receives medical care.^{60,61} Rather than serving as a falsifiable theory, inherent in the model is the understanding that different factors influence access to health services and that the composition of these factors is indicative of the underlying level and equality of access within a given population. For example, the model is not disproven if predisposing and enabling factors are not significantly associated with access to care. Rather, this situation would be indicative of more equitable access to care.

Andersen and colleagues were interested in describing current health care access, but also in informing interventions to improve access. In order to do so, they considered the mutability of each of the constructs because a construct must be changeable in order to promote better access.⁶⁵ Demographic variables and social structures are of low mutability because they are very difficult or impossible to alter; health beliefs are of medium mutability since they can sometimes be changed; and enabling resources are of high mutability because they can be addressed by interventions. Perceived and evaluated need for health care may also be influenced.⁶⁰ Thus, interventions may be most effective in influencing health care access when they target the enabling factors since these are more malleable. In the past fifty years, the Andersen model has been applied in diverse settings and topics,⁶⁴ including access to long-term

care in different racial/ethnic groups,⁶⁶ HIV testing among black men,⁶⁷ HIV primary care use in recently diagnosed individuals⁶⁸ and access to ART in vulnerable groups.⁶²

The Andersen model has evolved over time as researchers apply it to different populations and one of its most recent iterations is the Behavioral Model for Vulnerable Populations. This model was developed by Gelberg, Andersen and colleagues in 2000.^{62,69} This rendition focuses on the ways in which the individual level predisposing factors, enabling resources and health need are influenced by membership in vulnerable groups. Constructs within the vulnerable population version of the model have been found to be significantly associated with access to ART and primary care use in studies of PLHIV in the United States.^{62,68} A randomized controlled trial of primary care use among PLHIV in the US compared attendance at HIV care of individuals recently diagnosed with HIV in those who received active case management with those who received passive referral.⁶⁸ The study found that ethnicity, gender, education, IDU status, testing positive for Hepatitis, HIV-related symptoms in the past six months, having medical insurance and receiving case management were significantly associated with having been seen by an HIV service provider in the past six months. The authors concluded that active case management significantly improved linkage to HIV care within vulnerable populations, but there was no evidence of the impact of the intervention on adherence to ART.

The Andersen model has also been applied to look at access to ART in the US and within developing countries. A study of access to ART in 1996 in vulnerable groups in the US⁶² found that individuals in the greatest need of ART, as defined by CD4 count, had the highest access to ART. Predisposing factors and enabling factors were, however, also important which was indicative of some inequitable access for vulnerable populations such as women, African Americans, Hispanics, injection drug users and the less educated. In the final model, the authors found that ethnicity, lowest CD4 count, experience of HIV symptoms, age, income, location of

first HIV test, and waits for medical appointments were significantly associated with access to ART.⁶²

A systematic review of access to ART in developing countries also used the Andersen model to explore access. The authors determined that enabling factors such as lack of knowledge of ART, perceived high cost of ART, stigma, and lack of financial means were important barriers to ART across the 19 included articles. Important predisposing factors were fears of treatment side-effects and spousal permission to initiate ART. Health system barriers to access to ART were distance to health facilities, lack of systemic coordination and the limited involvement of communities within the planning of ART programs.⁵⁰

Adherence to ART

Once an individual is engaged in HIV care and initiated onto ART, it is particularly important that they are adherent to treatment in order to maximize individual health benefits, reduce the likelihood of HIV transmission and prevent development of drug resistance. Factors that facilitate the development of drug resistance include the nature of the virus itself, the need for high adherence to lifelong treatment, irregular access to ART due to stock-outs, and single dose prevention of mother-to-child transmission strategies.⁷⁰ This transmitted drug resistance reduces treatment options and can lead to diminished patient outcomes. Ultimately, it can also render national HIV treatment program less effective.⁷⁰⁻⁷² There are serious concerns that the prevalence of treatment-resistant strains of HIV is already high and will continue to increase world-wide.⁷² The highest increase in prevalence of resistance that was noted in a recent, global systematic review was found in East Africa where the increase in the prevalence of resistance was 29% a year since rollout of treatment.⁷² Within Latin America and the Caribbean, an estimated 7.6% of individuals had resistance to one or more drugs by 8-9 years after the initiation of national ART programs.⁷²

There are diverse reasons why patients are not adherent to ART. Some factors that have been documented in high income countries are depression, social instability, substance abuse, and low literacy.^{73,74} Factors identified in low income countries include lack of open communication with health providers and insufficient access to transportation, food and ART.^{51,74,75} For example, a study of barriers to adherence to ART in FSWs in Rwanda highlighted the role of structural barriers such as lack of food and imprisonment in inhibiting ART adherence.⁹

There has been very limited research on the barriers to ART adherence faced by PLHIV within the Caribbean⁷⁴ and no known study has specifically looked at barriers to ART adherence among FSWs in the region. A 2011 study by Harris and colleagues of PLHIV within the general HIV clinic

population in the DR determined the risk factors for non-adherence to ART through a cross-sectional survey of 300 patients in two clinics. Patients' one-month ART adherence was dichotomized as optimal if they self-reported greater than 95% adherence or suboptimal if less than 95% adherence. The study found that 24% of participants reported suboptimal adherence in the past month. Suboptimal adherence was significantly associated with heavy alcohol use, having children, and reporting perceptions that they had less social support in general and less social support specifically related to adherence. Patients also frequently indicated that they ran out of medications or were away from home. The authors suggested the use of adherence support by community health workers or treatment partners in order to facilitate improved adherence.⁷⁴ Treatment partners serve several important functions such as "(1) encouraging disclosure, (2) combating stigma; (3) restoring hope; and (4) reducing social difference".⁷⁶

FSWs and HIV/AIDS

There is substantial interest in FSWs within the context of HIV due to their heightened vulnerability and their role within the broader epidemic.⁷⁷ FSWs have significantly higher HIV prevalence than the general population in countries around the world.^{1,78} A meta-analysis of 99,878 FSWs included in 102 studies from around the world found that FSWs have 13.5 times higher odds of HIV infection than other women of reproductive age.¹ For example, the HIV prevalence of FSWs in the DR is between 3.3% and 8.4%, depending on geographic location.⁷⁹ This is much higher than the HIV prevalence in the general population of 0.7%.⁸⁰ FSWs are at higher risk of HIV infection for a variety of reasons, including their elevated numbers of concurrent sexual partners, their high prevalence of sexually transmitted infections (STIs), and the confluence of SW and injection drug use in some settings.¹ FSWs also confront structural barriers to HIV testing, care and treatment¹ such as stigmatization and discrimination within health services.⁸¹

FSWs' key role in the HIV pandemic has led to various targeted efforts to try to prevent HIV infection among FSWs.⁸² These interventions to reduce HIV incidence in FSWs are now a component of some national and international efforts to reduce HIV transmission.⁸³⁻⁸⁵ Interventions that have proven to be effective include peer education, condom distribution and promotion, structural interventions, and community mobilization.^{1,77,82,85-93} These interventions have been effective in increasing protective behaviors among FSWs and their clients.⁸⁵ A 2012 review indicated that over 80% of FSWs reported condom use at last sex with clients in 44 of the 87 countries where data were available.¹ Despite the effectiveness of some HIV prevention interventions with FSWs, less than 50% of SWs are able to access these HIV prevention programs and these programs do not meet the needs of the growing population of FSWs who are already living with HIV.¹

FSWs living with HIV

There is a substantial body of evidence on HIV prevention with FSWs, but there has been relatively little research on FSWs who are already HIV-infected,^{2,3} highlighting a critical gap in the literature. The limited evidence suggests that FSWs experience multiple barriers to HIV care linkage and retention⁴⁻⁶ at the individual, interpersonal, and health system/programmatic levels, along with stigma and discrimination.^{3,7,8,94,95} These barriers are largely the same as those described within the general PLHIV population, but FSWs living with HIV also confront some unique barriers. These include layers of stigma and discrimination related to each of their stigmatized identities which inhibit engagement throughout the HIV care continuum.^{2,3,7,8,53,56,96-98} No known study has, however, looked at the intersection of HIV and FSW stigma within the Caribbean or the influence of each form of enacted and internalized stigma throughout the HIV care continuum.

Engagement of FSWs in HIV care

Rather than focusing on the lived social, medical or behavioral experiences of FSWs living with HIV, most studies with this population either are highly biomedical in nature or describe factors associated with HIV-positive status among FSWs (unpublished results). There are limited studies on the experiences of FSWs in HIV care. One study of linkage to care, sexual behavior and psychosocial experiences among 141 FSWs recently diagnosed with HIV in Rwanda found that 85% of participants had enrolled in HIV care and 48% had initiated ART within approximately two years after diagnosis. Women were significantly less likely to have enrolled in care if they were breastfeeding, had a known HIV-infected sexual partner or reported condom use at last sexual act. The most frequently mentioned barriers to ART adherence were forgetting, lack of food, and interruptions due to imprisonment or hospitalization.⁹ Participants in this study were, however, diagnosed as part of a research study and received formal referral so the

generalizability of this study to a non-research setting may be limited. Of concern, separate studies of treatment outcomes in FSWs living with HIV in Burkina Faso and Benin have noted worse virologic response to ART, higher rates of treatment failure, and higher mortality than other women living with HIV.^{99,100} The authors hypothesized that the lower treatment response may have been related to lower adherence to ART and higher alcohol use among the FSWs.⁹⁹ An analysis of mortality among cohort of FSWs in India also found high HIV-attributable mortality among FSWs, despite the fact that most of the participants had attended health services and disclosed their HIV status to their families. Barriers to health services among women who had not attended health services were distrust of healthcare providers, lack of knowledge of clinic locations, perceived cost of treatment, and lack of social support for treatment.⁹⁴

There have also been various qualitative studies on the experiences of FSWs living with HIV. One study found that the main barriers to service access for 19 FSWs in India were at the family/social, health care system/programmatic and individual levels.⁷ A qualitative study with FSWs, transgender women (TW), and men who have sex with men (MSM) in India also described important personal, interpersonal and structural barriers to utilizing HIV services.⁹⁶ A different study of access to HIV care among FSWs in Zimbabwe highlighted the important role of providers in participants' engagement. These participants also noted concerns related to cost of some HIV services, lack of food, and stigma.³ Stigma and discrimination against vulnerable populations, including FSWs, within health care systems were also described in a recent review article.⁶ The review concluded that "[h]owever defined, what is shared by [most at risk populations- including FSWs] nearly universally is high vulnerability to HIV infection and low access to HIV services."⁶ There is a clear need for further research on and interventions to address engagement in HIV care among FSWs, including in countries with concentrated HIV epidemics among large populations of FSWs like the DR.

HIV/AIDS and the Dominican Republic

The HIV/AIDS pandemic in the DR is shaped by diverse external and internal factors, including its porous border with Haiti, frequent emigration and immigration of Dominicans between the US and the DR, and its reputation as a sex tourism destination.¹⁰¹⁻¹⁰³ The DR is relatively better-resourced than other low and middle income countries, but there is still considerable poverty⁷⁴ and 33.2% of Dominicans lived below the poverty line of US\$94.20 a month in 2010.¹⁰⁴ Estimates of the HIV prevalence in the DR have varied, but recent estimates by UNAIDS indicate that the epidemic has stabilized at 0.7% with approximately 44,000 PLHIV in the country.⁸⁰ This is lower than projections made in the early 2000s when some predicted that the epidemic might continue to expand considerably.¹⁰⁵ This stabilization has been partially attributed to the “proactive response” of non-governmental organizations (NGOs) early on within the epidemic.¹⁰⁶

Despite these successes, the Caribbean remains one of the most affected regions with an HIV prevalence second only to sub-Saharan Africa. The island of Hispaniola, comprised of the DR and Haiti, accounts for nearly three-quarters of HIV infections within the Caribbean.⁵⁷ There is also evidence of a considerable double burden of TB and HIV on the island: 95% of co-infections in a seven country Caribbean study occurred in either the DR or Haiti and there was a 4% co-infection prevalence in the DR.¹⁰⁷ The predominant subtype of HIV in the DR and in the Caribbean is subtype B. This is notable as the Caribbean is the only subtype B region that has predominantly heterosexual transmission.¹⁰⁸

The burden of HIV varies considerably across populations and geographic regions in the DR.¹⁰⁶ Prevalence is elevated among FSWs, MSM and Haitian immigrants who live in the former sugarcane plantations.¹⁰⁵ HIV in the DR is predominantly passed through heterosexual sexual intercourse, but there is evidence of a growing population of men who have been infected

through sex with other men and that this mechanism for transmission has been underreported.¹⁰⁵ HIV prevalence has declined in most groups, other than MSM. For example, HIV prevalence in FSWs in La Romana is estimated to have declined from 12.5% in 1996 to 4.1% in 2006. In Santo Domingo, HIV prevalence in FSWs has decreased from a median of 5% in 1991 to 3% in 2006.^{105,109} A recent analysis of the HIV epidemic trends in the DR attributed the overall decline in HIV prevalence to increases in condom use and other sexual behavior changes within the country.¹⁰⁵

The DR has developed laws to protect PLHIV, but discrimination against PLHIV remains problematic. The DR law related to HIV/AIDS enshrines the human rights and dignity of PLHIV.¹¹⁰ The law states that PLHIV have the right to health care, to information related to their health, to work and to not be discriminated against. Despite these laws, PLHIV within the DR frequently report that they have been refused employment due to their HIV status.⁵⁷ For example, multiple qualitative studies in the DR have noted the use of HIV testing during eligibility screening for employment.^{97,103} A recent survey reported in the 2013 UNAIDS report on the global HIV epidemic found that 10% of respondents from the DR indicated having been refused employment and 8% were denied health and/or dental services due to their HIV status. PLHIV also still confronted restrictions on their entry, stay or residence within the DR as of 2013.¹¹¹

ART and the Dominican Republic

The DR began the large-scale provision of ART in governmental and non-governmental clinics in 2003.^{70,107} ART is supplied for free to those who are eligible, defined as having a CD4 count less than 350 cells/mm³. Provision of ART is funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, the World Bank and the Dominican Ministry of Health and Welfare.¹⁰⁷ Approximately 30% (21–40%) of those who were eligible for ART in 2007 were receiving it²³ and

an estimated 14,000 adults were on ART by the end of 2009.¹⁰⁷ As of 2012, 21,138 people were currently receiving ART, but more than 2,500 individuals with AIDS-defining illness did not have access to this treatment. The estimated ART coverage based on the WHO 2010 guidelines was 78%^{57,112} The first line regimen in the national program is two nucleoside reverse transcriptase inhibitors (NRTI) and one non-nucleoside reverse transcriptase inhibitors (NNRTI). The second-line regimen is comprised of NRTIs and protease inhibitors.⁷⁰ A recent study of patients in two clinics in the DR, including one in Santo Domingo, found that most patients (50%) were on zidovudine (an NRTI), lamivudine (an NRTI), and nevirapine (an NNRTI).⁷⁴

It has now been established that ART can be effectively delivered in low and middle-income countries, but some challenges remain. For example, patient mortality in the first six months on treatment is higher in these countries than in more resourced settings.¹⁰⁷ A recent analysis of patient outcomes in ART-naïve patients in cohorts in seven Latin American countries documented an average early mortality rate of 20.9 deaths per 100 person years in the first three months, a rate that is comparable to other low- and middle-income countries.¹⁰⁷ The DR, however, had the highest early mortality of all the included countries with 32.4 deaths per 100 person-years. High rates of LTFU were also noted; the 1,207 person Dominican cohort was followed up for a median of 31 months during which time 13% of patients were LTFU and 15% died. The study also documented very low median baseline hemoglobin (11.1 grams per deciliter in females and 12.0 grams per deciliter in males) and CD4 count (96 cells/ mm³) in patients. A total of 51% of patients with known CD4 count at baseline visit had CD4 counts less than 100 cells/ mm³ and 45% had Stage III or IV illness. Overall, the regional baseline health indicators were similar to what has been documented in other lower income countries and are much lower than those found within Europe and North America. The authors highlighted the need for improved linkage between HIV testing and treatment centers, improved strategies for

ART enrolment and adoption of earlier initiation onto ART.¹⁰⁷ This need is likely particularly acute within marginalized populations such as FSWs. A different study conducted in 2011 in La Romana, DR also found that participants initiated ART quite late. The mean CD4 count at the time of ART initiation was 160 cells/mm³.⁷³

A cohort study conducted from 2007-2010 in the Instituto Dermatológico y Cirugía de Piel (IDCP) HIV clinic in Santo Domingo determined that 8 of the 103 (8.8%) treatment-naïve adults in the study were infected with HIV that had drug resistant mutations, with no clear risk factors.⁷⁰ It is notable that this clinic is regularly attended by many FSWs described within this dissertation. One recent study has, however, demonstrated the effectiveness of targeted individual counseling concurrent with ART initiation in significantly increasing appointment attendance and treatment response in PLHIV in the DR. Barriers in the form of transportation and work schedule conflicts, however, persisted.⁷³ There is growing evidence related to the HIV care continuum in FSWs living with HIV in the DR, but there is a clear need for additional research to address the persistent research gaps described above.

Chapter 3. Methods

The purpose of this mixed methods dissertation was to explore the experiences of FSWs living with HIV along the HIV care continuum in the DR. This study employed an exploratory sequential, mixed methods design in order to address this goal. An exploratory sequential study is one in which researchers first explore a topic qualitatively and then use findings from the analysis of these qualitative data to inform a quantitative phase. This design is often used in the development and use of a survey instrument.¹¹³ The rationale for this exploratory sequential design was to first qualitatively explore baseline experiences among a small group of FSWs living with HIV and then to determine how the qualitative findings relate to a larger group of FSWs within Santo Domingo.

Research Methods

The three study aims and the research strategy for this dissertation are summarized in **Table 3.1.**

Aim	Methods	Key Independent Variables / Domains	Dependent Variables
Explore the experiences of FSWs living with HIV along the HIV care continuum	Semi-structured, qualitative interviews with FSWs living with HIV (n=20) Three focus group discussions (FGDs) with FSWs living with HIV (n=24)	<ul style="list-style-type: none"> Participant experiences along the HIV care continuum from HIV diagnosis to time of interview Barriers to (re)engagement in HIV care Enablers of (re)engagement in HIV care 	
Describe the HIV care continuum in FSWs living with HIV and examine the factors associated with treatment interruption among FSWs living with HIV	Baseline survey with FSWs living with HIV in the <i>Abriendo Puertas</i> cohort (n=268)	<ul style="list-style-type: none"> Sociodemographic characteristics (e.g. age, household composition, income) Clinical experiences (e.g. perception of health status, health providers) SW context (e.g. venue, self-stigmatizing beliefs, substance abuse) 	Lifetime experience of ART interruption
Determine the factors associated with retention in HIV care in FSWs living with HIV	Baseline survey with FSWs living with HIV in the <i>Abriendo Puertas</i> cohort (n=268)	<ul style="list-style-type: none"> Predisposing characteristics (e.g. age, household composition) Enabling factors (e.g. perceived quality of HIV services, experience of discrimination in the clinic, cost of transportation to clinic) Perceived and evaluated health need Vulnerability (duration of SW, self-stigmatizing beliefs) 	Retention in HIV care (using two different definitions of retention)

Qualitative Phase Research Methods

The qualitative phase of the study addressed aim one, *to explore the experiences with HIV care of FSWs living with HIV*. This aim was addressed through formative qualitative interviews and FGDs with FSWs living with HIV in Santo Domingo, DR. This research was originally conducted to inform the design of the *Abriendo Puertas* intervention (discussed below). This formative research included in-depth interviews (IDIs) with 20 FSWs living with HIV and three FGDs with an additional 24 FSWs living with HIV. Data were collected between September 2011 and February 2012 by the Dominican HIV Vaccine and Research Unit (HVRU). The interviews and FGDs with FSWs explored the social and structural context of FSWs living with HIV, including stigma and discrimination against PLHIV, and examined the PHDP needs and existent services related to HIV diagnosis, health services, HIV care and treatment, and prevention of HIV transmission.

Characteristics of the qualitative study sample

FSWs were purposively selected to participate in IDIs and FGDs. They were recruited through existent relationships, HIV clinics, NGOs, and networks of PLHIV in order to include participants who had diverse perspectives and experiences related to PHDP. All participants were FSWs who met the following criteria:

- Participants exchanged sex for money in the last month;
- Participants were HIV-infected;
- Participants were able to provide verbal informed consent;
- Participants were at least 18 years old.

Qualitative focus

IDIs and FGDs first explored participants' general life experiences in order to facilitate rapport.

The key domains that were then discussed included participants' experiences of and with:

- Stigma and discrimination
- HIV diagnosis
- Health services
- HIV care and treatment
- HIV prevention, including the use of condoms and sexual negotiation

Interviews also explored participants' suggestions for how each of the above could be improved and tailored to meet the needs of FSWs.

Qualitative data collection

In-depth, qualitative interviews were conducted with 20 FSWs living with HIV on two occasions at a mutually agreed upon time. All research took place in Santo Domingo, DR within the HVRU of IDCP. HVRU is comprised of a dynamic, expert team that has extensive experience with implementation of HIV research with FSWs. The unit was established in 2003 with support from the HIV Vaccine Trial Network (HVTN) of the US National Institutes of Health and represents a partnership amongst IDCP, a Dominican non-governmental organization and the National HIV/AIDS/STI Control Program of the Ministry of Health (DIGECITSS).¹¹⁴

Prior to the start of each interview, field workers explained the study to participants and obtained verbal informed consent for participation and to audio record the conversation. The interviews were conducted in Spanish by trained, female field workers using semi-structured interview guides. Semi-structured interviews facilitate discussion of the same key domains across interviews, while still allowing for exploration of participants' experiences and for participants to guide the discussion.¹¹⁵

Three FGDs were conducted with 24 FSWs living with HIV who were different from those included in the one-on-one interviews. FGDs were conducted in the IDCP office building and were facilitated by experienced study staff. These FGDs were conducted in order to explore the same topics from a community perspective and to specifically discuss possible intervention ideas. FGDs are particularly well-suited to exploration of the suitability of interventions, such as *Abriendo Puertas*, for the intended audience.¹¹⁵

Qualitative data analysis

Data analysis was conducted by the student investigator through immersion and intimate knowledge of data. All transcripts were reviewed twice prior to analysis by the student investigator and clarification was sought from the field workers who conducted the interviews, as necessary. All interview transcripts were imported into Atlast.ti 6.2.16.¹¹⁶ Data were analyzed in Spanish to maintain fidelity to the original meaning of participants' statements. The student investigator employed thematic and narrative analysis in order to identify salient influences and to holistically explore participant experiences along the HIV care continuum.

IDIs were analyzed using narrative analysis through detailed descriptions of each participant's experience from HIV testing to the time of the interview. These narratives provided a more complete understanding of participants' experiences over time and of how participants made sense of their own experiences.¹¹⁵ The narratives of the twenty participants were compared against one another to identify commonalities and distinct experiences. During this process, the student investigator identified recurrent influences on engagement at the individual, interpersonal, environmental and structural levels. Based on this emergent framework, a table was developed that described the salient experiences at each level of the twenty participants. While this table facilitated a clearer understanding of the levels, it was noted that the chronology of participants' narratives was lost. Thus, transcripts were re-reviewed and

participant narratives were reorganized into a chronological table that described participants' experiences at HIV diagnosis, in pre-ART care and in ART care. Four participants' narratives that were representative of the breadth of participant experiences were then selected for inclusion in **Table 4.1**. The other 16 narratives are included in **Appendix A**.

FGDs were thematically coded to identify salient themes and experiences. Preliminary coding used an open coding approach. These codes were organized into an emergent framework grounded in the IDI and FGD data that focused on individual, interpersonal, environmental and structural barriers and enablers along the HIV care continuum. Efforts were made to challenge emergent theory and to identify disconfirming evidence as all remaining transcripts were coded. Throughout data analysis, the student investigator developed operational and theoretical memos on the analysis process in order to enhance transparency and facilitate consideration of the relationships between codes. The student investigator also discussed study findings with subject experts and FSWs to enhance trustworthiness of interpretation. It was not possible, given that the data were already collected, to use a fully grounded approach to the data analysis, but key elements of grounded theory were employed. Specifically, there was a cyclical process between coding and theory generation and constant comparison between the interview transcripts.^{115,117}

Quality assurance and quality control

Participants were interviewed on two occasions to enhance rapport and to explore key domains in greater depth. Each field worker had extensive experience in qualitative research with vulnerable populations and was trained on the purpose of the research study and on how to probe appropriately. Field workers completed structured reports on the interview context and experiences after each interview and all interviews were digitally recorded to ensure that data were appropriately captured. Additionally, the student investigator analyzed the transcripts in

their original Spanish in order to better understand the context and nuances of how the data were constructed. She was reflexive throughout data analysis on the influence of her own background as a public health student from the US on her understanding of participant experiences. The student investigator was in regular contact with the team in the DR in order to discuss emergent themes and findings in order to enhance the trustworthiness of her interpretation.

Analysis of the data from the qualitative phase of the dissertation informed the refinement of the student investigator's understanding of the dissertation topic and assisted in the identification of key variables for inclusion in the second, quantitative phase. In the second, quantitative phase, baseline surveys were conducted with the 268 FSWs living with HIV who participated in the *Abriendo Puertas* intervention.

Abriendo Puertas

In response to the high unmet PHDP needs of FSWs living with HIV, a team of researchers from the Project SEARCH: Research to Prevention project at the Johns Hopkins Bloomberg School of Public Health (JHSPH) collaborated with research and community partners in Santo Domingo, DR to develop the *Abriendo Puertas* (opening doors) intervention. These partners included a local research unit that has been working with FSWs in Santo Domingo for over fifteen years (HVRU), a FSW activist organization and local health clinics. *Abriendo Puertas* (AP) was a multi-level intervention with FSWs living with HIV in Santo Domingo that sought to facilitate overall well-being, including utilization of HIV services and consistent condom use with all sexual partners. The intervention was designed based on years of experience working with the study population, formative research findings with the study population and consultation with local implementation partners. This formative research, analyzed by the student investigator, included key informant interviews with 31 clinicians, NGO staff and other experts working with FSWs, MSM, TW and/or PLHIV. It also included IDIs with 20 FSWs, 16 MSM and five TW living with HIV and six focus group discussions with FSW, MSM and TW living with HIV. The IDIs and FGDs with FSWs from the formative research were the data source for the qualitative phase of this dissertation.

There were five components of the AP intervention that targeted multiple levels including the individual, interpersonal, institutional, and community levels:

- Six individual counseling sessions with trained psychologists, using a set curriculum;
- Peer navigation with FSW peer navigators who facilitated HIV care and prevention service navigation and provided additional support and education, as required;
- Monthly support group meetings and other community mobilization activities;
- Trainings of local health clinic staff on how to effectively provide services for FSWs and other key populations;

- Male partner engagement and offering of voluntary HIV counseling and testing services.

The AP intervention was piloted with 268 FSWs living with HIV in Santo Domingo, DR from December 2012 to December 2013. The effectiveness and appropriateness of the model was determined through quantitative and qualitative research methods with the AP cohort. The baseline quantitative data were the data source for the quantitative phase of this dissertation.

Quantitative Phase Research Methods

The two quantitative aims, *to describe the HIV care continuum in FSWs living with HIV and examine the factors associated with experience of treatment interruption in FSWs living with HIV and to determine the factors associated with retention in HIV care in FSWs living with HIV*, were addressed through cross-sectional surveys with the 268 FSWs living with HIV who were participants in the AP cohort. The baseline surveys, conducted from November 2012 to February 2013, included questions on participants' sociodemographic attributes, sexual practices, HIV diagnosis, HIV disclosure, experiences with STIs, perceptions of health services, existent psychosocial support, and engagement with community mobilization activities. The survey also included questions on engagement in HIV care and experience with ART. Additionally, samples were collected from each participant to test for HIV viral load and the presence of STIs.

Characteristics of the quantitative study sample

The entire AP cohort (n=268) was included in the quantitative study population. They underwent an eligibility screener prior to the baseline survey and start of the intervention to ensure that they met the following criteria:

- Participants must have exchanged sex for money in the last month;
- Participants must have been HIV-infected, as confirmed through baseline HIV screening using a Retrocheck rapid HIV test;
- Participants must have been willing to provide informed consent;
- Participants must have been at least 18 years old.

The cohort members were recruited using a non-random sampling approach through three mechanisms: referral from peer navigators; existent relationships with IDCP; and referral from other study participants.

Quantitative measurement

Aims two and three used the same independent variables from the baseline survey. These variables included sociodemographic variables and the key variables that were identified as salient within the qualitative analysis. Scales are described in greater detail in the section, *refinement of scales*.

Independent variables

- Predisposing factors
 - Age
 - Marital status
 - Number of children
 - Household composition
- Enabling Factors
 - Disclosure of HIV status
 - Existent psychosocial support scale¹¹⁸
 - Perceived HIV provider quality scale¹¹⁹
 - Perceived quality of HIV services
 - Experience of stigma and/or discrimination in health services¹²⁰
 - Experience with pre-, post-, and ART-counseling
 - Cost and travel time to attend HIV services
 - Monthly income
 - Medical insurance coverage
- Health need
 - Perceived health status
 - Evaluated health status
 - Year of HIV diagnosis
 - Year of ART initiation
 - History of opportunistic infections
- Vulnerability
 - Substance use
 - Education
 - Mobility
 - Duration as SW
 - Age at start of SW
 - Location of SW
 - Self-stigma related to SW status scale^{108,109}
 - Self-stigma related to HIV status scale^{108,109}

Aim two described the baseline HIV care continuum among AP cohort members. The definitions of each of the steps of the HIV care continuum, as self-reported by study participants or determined through laboratory testing, are described in **Table 5.1**. The key dependent variable of interest for aim two was history of treatment interruption among women ever initiated onto ART. A participant was defined as having a history of treatment interruption if she answered “yes” to the question, “Have you ever stopped or suspended taking ART (the medication for HIV)?”

The dependent variable of interest for aim three was retention in HIV care. Retention was defined in two separate ways for the study. The first definition, “Attended”, categorized participants as retained if they reported attendance at an HIV clinic in the past six months, as determined by the question, “Have you received medical attention related to HIV in the last 6 months?” The six month measure was selected for this study because it could be easily collected in operations research and was not affected by different clinical scheduling practices across clinics.³⁰ The second definition, “Perfect Attendance” categorized participants as retained if they reported receipt of HIV care in the past six months and also reported that they did not miss any HIV service appointments in the past six months, as determined through the question, “In the past 6 months, have you missed for whatever reason an appointment at [your HIV clinic]?” Missed visits were treated as a dichotomous measure, in keeping with previous research.¹²¹ This second measure included both a kept and a missed visit measure, as has been suggested as best practice.³⁶ Participants who attended HIV services in the past six months, but also missed an appointment over the six months were differentially classified by the two definitions.

Quantitative data collection

Each study participant completed baseline, paper quantitative surveys between November 2012 and February 2013. The interviews were conducted in Spanish by trained, female field workers in a private room in the IDCP. Field workers conducted mock interviews during training in August 2012 to ensure that they had clear and consistent understanding of the questions and to ensure appropriate skip patterns and flow of questions. The student investigator co-facilitated this training of field workers. The survey was then piloted with FSWs living with HIV in Santo Domingo. Following the initial piloting, the field workers and FSWs living with HIV provided the local study team and the student investigator with feedback on the questions and the overall survey. The survey was then amended and re-piloted prior to use with the study population. The student investigator was in the DR for the piloting and refinement of the baseline study instrument.

Quantitative data management

The student investigator returned to the DR to review the first completed surveys and to help refine data management procedures in November 2012. It was determined that all hard copies of quantitative surveys would be signed over from the field worker to the study data manager at the end of each day. All hard copies of the surveys were kept in a locked cabinet within a locked office at IDCP. These surveys were then dual-entered into an electronic database by trained field workers. Electronic copies of the survey data were stored on a password-protected computer at the local study office and backed up on a secure external hard-drive. These files did not contain identifying information.

Quality assurance and quality control

Diverse quality assurance (QA) and quality control (QC) mechanisms for the study included appropriate selection of field workers, efforts to minimize information bias through provision of

a comfortable, confidential environment, and active QA/QC procedures for the data collection and management. Each field worker had extensive experience in quantitative data collection with vulnerable populations and underwent further training in quantitative methods and ethical study practices prior to the start of the study to ensure quality of survey implementation. All surveys were reviewed for QC and any issues were promptly discussed and addressed with the field workers.

Mechanisms were also in place to minimize bias throughout the study. Interviews were conducted in private rooms and participants were reminded that there was no correct answer to the questions in order to reduce social desirability bias. Survey questions included clear and appropriate time references to minimize recall bias. Additionally, the survey instruments were piloted to assess face validity and validated scales were used, when possible. The local team also had extensive experience working with FSWs and had a positive reputation within the broader SW and NGO community.

Quantitative data analysis

All statistical analysis was conducted using Stata.¹²² Prior to analysis, data were cleaned using frequency distributions, histograms and other descriptive statistics. During exploratory data analysis (EDA), the distributions of all variables of interest were explored through histograms, scatterplots and descriptive statistics. There were limited missing data within participant responses. These missing data were explored and there were no significant differences in individuals with or without responses for any of the variables of interest in this analysis.

Refinement of scales

The scales used in this study were developed from responses to questions with Likert scales ranging from one (strongly disagree) to four (strongly agree). Individuals who did not respond to a particular question had a neutral response (2.5) imputed for that specific question to ensure that this missed response did not bias their overall score.

The first step in the development of each scale was to conduct principal components analysis (PCA) to determine the appropriate number of factors for inclusion. The number of factors was determined by the location of the elbow in the scree plot and comparison of eigenvalues. PCA for each scale indicated strong unidimensionality and the fit of each scale was stronger for one factor than for two. Factor loadings were determined using maximum likelihood estimation models. The communality of the factors were then calculated to ensure that the resultant factors explained a sufficient fraction of the variability in the questions ($\lambda_m^2 > 0.5$). Items were dropped if they have uniqueness greater than 0.5 and / or the highest factor loading was less than 0.4. A composite score for each scale was then created by summing each participant's responses to all of the questions included within the scale.

HIV-related self-stigma was determined through eight questions that assessed participants' level of agreement with statements, including "Having HIV makes you feel like a bad person" and "You feel guilty because you have HIV", as adapted from validated, reliable HIV stigma scales.^{123,124} PCA suggested strong unidimensionality and the scale had high internal reliability (Cronbach's alpha=0.87). Scores ranged from 8 to 32 with a median score of 18. Participants who reported more self-stigmatizing attitudes related to HIV-status had higher scores.

SW-related self-stigma was determined through the same eight questions used in the HIV stigma scale, but with "SW" replacing "HIV". The questions assessed participants' level of agreement with a series of statements, including "You feel embarrassed to be a SW" and "You feel that you are not worth anything because you are a SW". These questions were adapted from the aforementioned, validated HIV-related self stigma scales.^{123,124} The final eight question scale had one underlying factor and high reliability (Cronbach's alpha=0.88). Scores ranged from 8 to 32 with a median score of 18. Participants with more self-stigmatizing attitudes related to SW had higher scores.

Participants' perception of HIV service providers was determined through ten questions that assessed participants' level of agreement with statements, including "Your doctor is well trained to take care of medical problems like yours", and "You feel respected by your doctor". These questions were adapted from the validated Patients Reactions Assessment scale.¹¹⁹ Eight participants did not respond to these questions and were excluded from this part of the analysis. The scale was refined through iterated principal factor analysis and two questions were ultimately dropped from the scale to enhance its internal consistency. Scores ranged from 8 to 32 with a median of 26. The final, eight question scale had very high reliability with a Cronbach's alpha of 0.95. Participants with more positive perceptions of HIV service providers had higher scores.

Participants were categorized as having experienced discrimination in the clinic related to their HIV-status if they indicated that they had ever received poor services, been denied medical attention or heard health personnel gossiping about them because they are living with HIV, as adapted from Baral et al.¹²⁰ They were categorized as having experienced discrimination in the clinic related to their SW-status if they indicated that they had ever received poor services, been denied medical attention or heard health personnel gossiping about them because they exchange sex for money.

Regression analysis

The baseline characteristics of the study participants were described through bivariate analysis, comparing those who did and did not report ART interruption among those ever on ART (aim two) and comparing those who were and were not categorized as retained in HIV care by each retention definition (aim three). Categorical variables were compared using Pearson's Chi-square tests and continuous variables were compared using two-sided t-tests or ANOVA tests, as appropriate. Following these bivariate analyses, simple logistic regression (SLR) analyses were conducted with each key independent variable from the EDA and the binary outcome of ART interruption (aim two) and the binary outcome of retention in HIV care (aim three). Wald p-values were used to test for significance in categorical variables. Multiple logistic regression (MLR) analyses were then conducted to assess the association of variables that were significant in SLR and the dependent variable of interest in each aim. Models were constructed using a forward stepwise approach. Starting with a null model, variables with $p < 0.10$ in SLR were added to the model until the best model was constructed, as determined by comparison of log likelihood ratios and Akaike Information Criterion score (AIC). Additional variables were added to the model until the lowest AIC was obtained, while maintaining parsimony of model. Residual confounding was checked by comparing beta coefficients in SLR with those in MLR. Collinearity

for the logistic regression was determined by running the regression as a linear regression in order to determine the variance inflation factors. Forward and backward step-wise procedures with a p-value of 0.05 were then conducted to ensure that no variables were dropped due to collinearity. The overall degree of fit for the final model was determined using the Hosmer-Lemeshow goodness-of-fit test to test the null hypothesis that the models fit the data.

Protection of Human Subjects

The qualitative and quantitative phases of this study were approved by the JHSPH institutional review board and the IDCP review board. Rose Zulliger was included as a student investigator on both of the projects.

Informed consent

All participants had the study described to them in detail by a trained field worker prior to study enrollment. Participants were informed that their participation was entirely voluntary and that they could discontinue participation in the study at any time. Following this process, participants provided verbal informed consent using a consent form written in Spanish that was approved by the JHSPH and local ethics review boards.

Subject confidentiality

Participants completed all study interviews in a private location and data were stored without identifying information. The only document linking participants' study codes to their name, address and phone number was maintained on a secure password protected computer at the HVRU site. After each participant completed her 10 month follow-up survey, her personal information was deleted from the secure computer, unless she agreed to be contacted for involvement in future studies. Additionally, no names or contextual information that could identify an individual were included in any publication or report generated from this study.

Potential risks and risk management procedures

FSWs living with HIV are a group with heightened vulnerability to stigma, discrimination and exploitation.⁴ Participation in this study may have exposed participants to heightened social risk if others discovered that they were involved in SW or living with HIV through their study participation. Additionally, the interviews covered difficult topics that may have been

unpleasant to discuss. The research team held extensive meetings with local partners, along with the JHSPH and local Santo Domingo ethical review boards to ensure that the intervention and study were in accordance with ethical best practices. Additionally, all participants were linked to a licensed counselor through the AP intervention who could provide them with additional support, as required.

Cohort participants each spent approximately 1.5-2 hours completing the baseline study surveys. Formative, qualitative interviews and FGDs lasted approximately 1.5-2 hours.

In response to these potential risks, all participants were reminded that their participation was completely voluntary. They were also informed that they did not need to answer any of the questions that made them uncomfortable and that they could discontinue involvement at any time. Additionally, field workers were trained to recognize mental distress and could make referrals to the study counselors, as appropriate.

Potential Benefits

The main benefit of involvement in this study for participants was the opportunity to participate in the AP intervention components. This intervention may have increased participants' access to medical care, treatment and prevention and improved their social and emotional support and well-being. Participants were also provided with their STI and HIV viral load test results and were given the option of sharing these results with their HIV clinic. Participants were given the opportunity to invite their sexual partners to the study office for voluntary HIV counseling and testing without disclosure of their own HIV status. Additionally, there were substantial societal benefits from the study through improved understanding of how to operationalize PHDP in FSWs living with HIV and of the HIV care continuum among FSWs.

Compensation

Participants were compensated for their time through payment of 400 Dominican pesos (approximately US\$10) for completion of each study visit. FSWs who completed both the baseline and ten month study visits received an additional 400 pesos at the completion of the study. They also received 400 pesos for each counseling session that they attended (maximum of six) to cover their transportation costs.

Most FSWs could receive a total remuneration of 3600 pesos (\$90) if they completed both surveys, received the study completion compensation, and attend all sixed counseling sessions (400 pesos each x nine potential sessions).

Chapter 4. Experiences of female sex workers living with HIV along the HIV care continuum in the Dominican Republic

Abstract

Female sex workers (FSWs) are disproportionately affected by HIV and face additional barriers throughout the HIV care continuum. This study explored their experiences with HIV care in the Dominican Republic through 40 in-depth interviews and three focus group discussions with 44 FSWs living with HIV. Data were analyzed in Spanish using narrative and thematic analysis. FSWs living with HIV experienced considerable movement in and out of HIV care over time. FSWs described individual, interpersonal, environmental and structural factors that either facilitated (re)engagement in HIV care or led to disengagement throughout the HIV care continuum. Key individual-level factors were physical and mental health as post-diagnosis depression often led to disengagement until declines in physical health. At the interpersonal level, disclosure of HIV or FSW status and receipt of emotional or economical support were frequently instrumental in facilitating engagement with HIV care. Yet negative reactions to or lack of disclosure complicated access to support and to HIV clinics. At the environmental level, participants were generally satisfied with HIV clinic staff, but they described considerable challenges with the health system organization, frequent delays and costs of care. Participants also described pervasive stigma and discrimination related to both their HIV status and their sex work, including some experiences of discrimination within clinics. Finally, lack of economic resources complicated adherence to clinical appointments and to antiretroviral therapy. In addition to challenges faced by the general population living with HIV, FSWs confronted economic instability and the compounded stigma of being both HIV-infected and a FSW. Engagement in HIV care among FSWs was continually negotiated within a broader context of structural constraints and social conditions. Factors at multiple levels influenced engagement and experiences at one step affected subsequent engagement. These findings underscore the need for the provision of support tailored to the unique needs of FSWs throughout the HIV care continuum in order to maximize individual and public health.

KEY WORDS

HIV/AIDS; Treatment cascade; Continuum of care; Female sex workers; Engagement

Introduction

Despite the individual and public health benefits of engagement in HIV care,³⁶ people living with HIV (PLHIV) temporarily or permanently disengage from care throughout the dynamic pathway from HIV infection to viral suppression on antiretroviral therapy (ART),^{28,30} and patients often cycle in and out of care.^{31-33,125} There has been increasing interest in engagement in the HIV care continuum, but most studies have utilized cross-sectional and quantitative methods, limiting our understanding of the dynamic and lived experiences of individuals throughout the continuum.^{24,36} Additionally, previous research has noted the importance of multiple levels on engagement in HIV care,⁷ but the interplay of these levels has not been adequately described.³⁶

PLHIV frequently confront barriers along the care continuum and these can be particularly challenging for groups such as female sex workers (FSWs), a population that is disproportionately affected by HIV.¹ There is substantial evidence on the effectiveness of HIV prevention strategies with FSWs, but there has been little research on the experiences of FSWs living with HIV.^{2,3} The limited evidence suggests that FSWs experience considerable barriers to HIV care linkage and retention⁴⁻⁶ at multiple levels, including stigma and discrimination.^{3,7,8,94,95} To address these research gaps, this study explored the experiences of FSWs living with HIV along the HIV care continuum and identified factors that impeded or facilitated engagement.

Methods

In-depth interviews (IDIs) and focus group discussions (FGDs) were conducted with FSWs living with HIV in Santo Domingo, Dominican Republic (DR) from August 2011 to February 2012. The DR has a concentrated HIV epidemic with an elevated HIV prevalence of 3.3%-8.4% in FSWs¹²⁶ and a national prevalence of approximately 0.7%.⁸⁰ FSW participants were purposively selected and recruited through HIV clinics, NGOs, relationships with the study team and networks of PLHIV to include participants with diverse perspectives. All participants were over 18 years old, had exchanged sex for money in the month preceding interviews and had received an HIV-positive diagnosis. Participants' year of diagnosis ranged from 1996 to 2011.

A total of 40 IDIs were conducted with 20 FSWs living with HIV by experienced, female field workers using semi-structured interview guides. These guides explored participants' experiences with HIV diagnosis, health services, HIV care and treatment, and prevention of HIV transmission. Participants were interviewed on two occasions to facilitate interview depth and rapport. Three FGDs were conducted with an additional 24 FSWs living with HIV. These FGDs explored the same topics from a community perspective, along with possible intervention ideas. All participants provided verbal informed consent and the study received ethical approval from the Institutional Review Boards of the Instituto Dermatológica y Cirugía de Piel Dr. Huberto Bogaert Díaz and the Johns Hopkins Bloomberg School of Public Health.

Data analysis was conducted through immersion and intimate knowledge of data. All transcripts were analyzed in Spanish using Atlas.ti 6.2.16.¹¹⁶ IDIs were analyzed using narrative analysis.¹²⁷ Narratives of participants' descriptions of experiences from HIV testing to the time of the interview were developed. They specifically explored participants' trajectories of care and factors that participants viewed as enablers or barriers to their engagement in HIV care. These

narratives provided a more complete understanding of participants' experiences over time.¹¹⁵

Four participants' narratives that were representative of the breadth of experiences were then selected for more detailed presentation. The remaining 16 narratives are included in **Appendix**

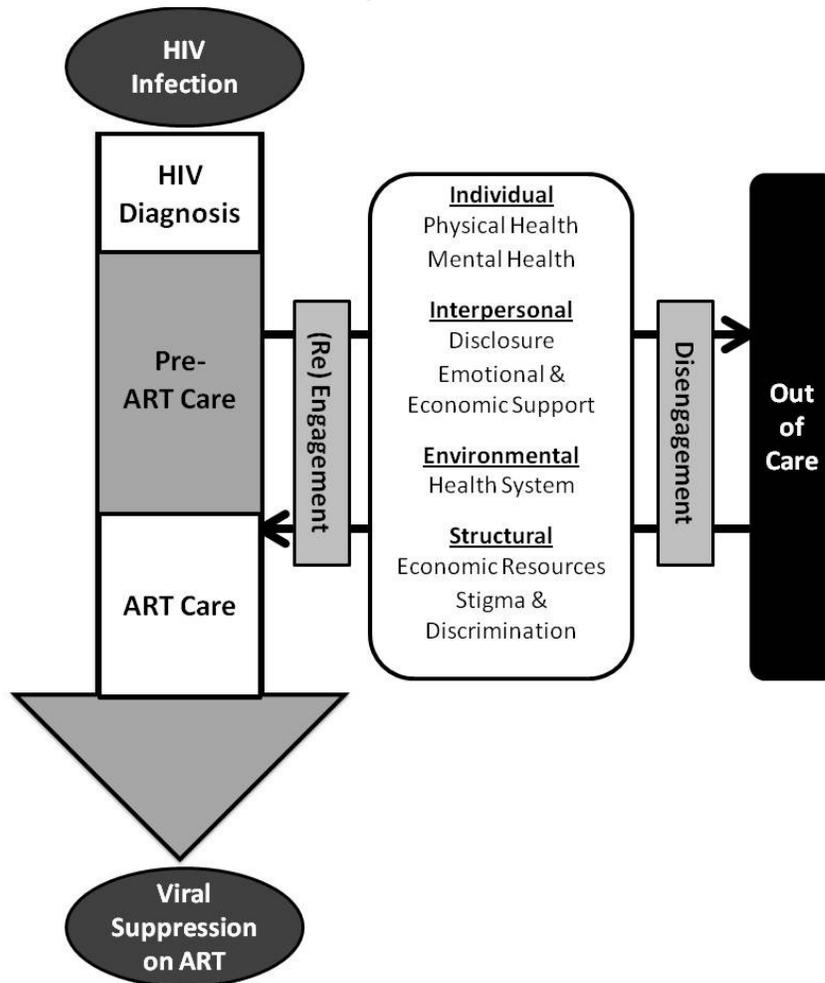
A.

FGDs were thematically coded to identify salient themes and experiences. Initial coding used an open coding approach. These codes were then organized into an emergent framework grounded in the data that focused on individual, interpersonal, environmental and structural barriers and enablers along the HIV care continuum. Efforts were made to challenge emergent theory and to identify disconfirming evidence as all remaining interview transcripts were coded.^{115,117} Study findings were discussed with subject experts and FSWs in order to enhance trustworthiness of interpretation.

Results

FSWs living with HIV in the DR described critical barriers and enablers throughout the HIV care continuum. Participants' narratives provided a holistic overview of their lived experiences along the continuum. **Table 4.1** includes summary narratives of the experiences of four FSWs living with HIV- referred to by the pseudonyms of Catalina, Carla, Lupe and Valentina- along this continuum. Participants frequently moved in and out of HIV care. They experienced distinct challenges at each step along the HIV care continuum, but there were persistent factors that emerged from the data at the individual, interpersonal, environmental and structural levels that either facilitated (re)engagement or led to disengagement in HIV care throughout the continuum, as shown in **Figure 4.1**.

Figure 4.1 Key influences on engagement, re-engagement, and disengagement in HIV care experienced by female sex workers at the individual, interpersonal, environmental, and structural levels throughout the continuum of HIV care



At the individual level, participants described the important role of their health on engagement. Participants like Carla often delayed HIV testing or HIV clinic attendance when they felt physically well, but declining health motivated (re)engagement with HIV care. Mental health issues such as depression and suicidal ideation, as described by all four participants in **Table 4.1**, often impeded sustained engagement. At the interpersonal level, disclosure of HIV or sex worker (SW) status and receipt of emotional or economical support were frequently instrumental in facilitating engagement with HIV care. Yet negative reactions to or lack of disclosure made it more difficult to access support or be seen in an HIV clinic. For example, the

involuntary disclosure of Catalina's HIV status left her depressed and planning to disengage from care. At the environmental level, health system characteristics were important as negative experiences in health services were frequently followed by disengagement in care. Thus, previous experiences with health services along the continuum influenced subsequent engagement. Finally, structural factors such as stigma and discrimination related to HIV and SW status and access to economic resources were important. The salience of each level varied for every woman, but participants consistently described the importance of these multiple levels in their engagement in HIV care. Using this emergent, organizing framework, we describe participants' experiences along the HIV care continuum.

Table 4.1 Narratives of four female sex workers (FSWs) living with HIV along the HIV care continuum in Santo Domingo, Dominican Republic				
Pseudonym	Catalina	Carla	Lupe	Valentina
HIV testing and diagnosis	Catalina went to the hospital in 2004 after experiencing stomach problems. The doctors ordered a number of laboratory tests, but Catalina did not know that they were doing an HIV test. Catalina learned of her HIV status when she overheard the clinicians tell her friend that Catalina tested HIV-positive. In response to this diagnosis, Catalina became very depressed and suicidal and her health deteriorated, <i>"I became bad, depressed, there I started to get sick and I got sicker. Then I reached the AIDS stage."</i> Catalina quit her job cleaning houses and told many people that she was dying of AIDS. Catalina's family is in Haiti, but her friend visited her after her diagnosis and brought her food. Catalina met a patient at the hospital who saw her when she was upset. The patient informally connected Catalina to a peer navigator who visited her at her house.	Carla and her husband were instructed to test for HIV in 2001 when their child was sick. The clinicians initially did not want to provide them with their test results, but they later gave Carla her diagnosis and told her that <i>"there were places where they give medications to help me and that one can live with the virus by taking care of herself."</i> Upon receiving her diagnosis, Carla was distraught and felt as though <i>"the world was falling on me"</i> and was shocked since she was a housewife. Her child later died and <i>"when my daughter died I blamed myself for this. I blamed myself that this happened to my child... I tried twice to throw myself from a bridge... I suffered and I am still suffering."</i> After her HIV diagnosis, Carla began to work as a FSW because her partner blamed her for their HIV and she felt she was lost since she had HIV.	Lupe was diagnosed with HIV in 2003 when she was required to test by work. She was very depressed and shocked, <i>"I felt that it was a dream, that it was a lie... I thought that they were wrong about the test and I had an attack, I screamed a lot... I tried to drink bleach because I thought that bleach would poison me."</i> The doctor referred Lupe to an HIV clinic, but she delayed attending. In response to Lupe's diagnosis, Lupe's mother reached out to an educator from an organization that works with FSWs. Eventually the educator brought Lupe to a psychologist.	Valentina tested HIV-positive in 1996 after her child was diagnosed with HIV. She was required to bring someone with her to receive her test result because <i>"in that time they did not have treatment for people because now and that time before are very different because in that time they did not want to tell me anything. You have to come with someone."</i> When diagnosed, Valentina thought of the discrimination against PLHIV and felt depressed, <i>"I saw the way they treated someone with the same condition as me. I said, 'look how they treat him. Look, he has AIDS. Look at this AIDS-person.'"</i>
Pre-ART care	Catalina did not receive a referral to HIV care at diagnosis, but she was brought to an HIV clinic by the peer navigator. Her relationship with peers was integral in her coming to terms with her diagnosis, <i>"It was difficult when I learned that I had HIV. I wanted to kill [myself], I did not want to live. Later I met my [peer navigator] and I started to go out, to go to workshops and those types of things. I started to see my</i>	Carla linked to an HIV clinic, but did not like it there because <i>"I saw people from my community and I left. And this lasted for four years."</i> She only returned to an HIV clinic after she was hospitalized with drug-resistant tuberculosis (TB). Carla is not on ART because her CD4 count is high, but she is still on TB treatment. Carla has received good care from both her HIV clinic and her	Lupe's mother took her to an HIV clinic, but Lupe became hysterical because of how sick people looked, <i>"When they made me the appointment I did not want to go when I saw this thin and dry person."</i> Lupe started to lose weight and did not know how to take care of herself. Her health deteriorated, but it later improved. She learned what food	While in pre-ART care, Valentina became involved in a support group that <i>"made me understand that people living with HIV have the same rights as other people."</i> Valentina's partner was supportive of her and took care of her when she was very ill. This support was incredibly important for her. <i>"He always</i>

	<p><i>colleagues who live with HIV and I said if they are living why[can't I]?"</i></p> <p>Catalina is happy with the care that she receives at the HIV clinic and has never seen anyone treated poorly there.</p> <p><i>"They are all really good. They give me a lot of support, a lot of love and sometimes they also fight with me... Because sometimes I arrive late or I forget the time to take the medicine."</i></p>	<p>deceased daughter's doctor sometimes gives her money.</p> <p>Carla experiences considerable stigma, <i>"I am suffering and I suffer because I am afraid that people know I have [HIV]."</i> She has not disclosed her HIV status to her mother for fear of giving her a heart attack or to her siblings because, <i>"I don't think that I should give this pain.... Sometimes I feel the need to tell them, to share my troubles, but I don't feel alone. I go into the bathroom and I talk with God."</i></p>	<p>helped her and is in touch with her body.</p> <p>Many people in Lupe's community gossip about her HIV status and they told Lupe's children that she has AIDS. Lupe was fired from a job for having HIV. She has also had her HIV status disclosed by other FSWs.</p> <p>Lupe later went to a private HIV clinic where she received very good care, <i>"the doctors are good and they are always giving one attention. You know that it is private and then sometimes one goes without money and they attend to you."</i></p>	<p><i>told me that I am here with you until death... and [his support] is a marvelous thing.</i></p> <p>They are still friends, but she told him that they could not be together because she did not want to infect him.</p> <p>Valentina's daughter knows that she has HIV, but not about her sex work because <i>"she has accepted one thing, I know that she has accepted everything, but I cannot manage this [disclosure of sex work] yet with her."</i> Her daughter always cheers Valentina up when she is sad.</p>
ART care	<p>Catalina was initiated onto ART in 2005 and she now has an undetectable viral load. She does not take her ART at the same time every day because she often lacks money for food and transportation. Catalina stated, <i>"I would like to quit [sex work], but sometimes I say, no, I have to do it because I have to eat and collect my treatment. For example, I have an appointment to collect medication and I do not have money to go collect it. I have to go out [as a FSW], but it is how I survive."</i></p> <p>Catalina's has a network of friends who have helped her and provided her with economic support. <i>"Sometimes I do not have money to buy [food], but I always have a friend who tells me, 'take this' or 'I store my food here.'" She has also borrowed ART other PLHIV who take the</i></p>	<p>When asked about starting ART, Carla said that she would need a psychologist to cope because it would be too difficult for her to take ART in addition to her TB treatment. Carla sometimes feels depressed because she has both HIV and TB, but she copes with HIV by not thinking about it.</p>	<p>Lupe no longer attends HIV services.</p> <p>When asked about ART, Lupe stated, <i>"I dread the medications because I don't know; I have seen how people are when they start, the nausea it gives, the side effects."</i></p> <p>Lupe feels that she has <i>"learned to control my body."</i> She is, however, active in associations of PLHIV and proud of the work that she does.</p> <p>The members of her support group take care of one-another and bring each other food, <i>"I feel happy with all of my companions when we are together it is like a tremendous happiness."</i></p>	<p>Valentina was initiated onto ART in 2007. The treatment initially made her nauseous and depressed, but the side-effects subsided. She did, however have a one month break in ART when she was sad after her daughter went to stay with Valentina's mother. Valentina later re-initiated ART. She has a very good relationship with her doctor and with the clinic counselors who <i>"give love and give kindness"</i>.</p> <p>Valentina is active in her community providing HIV-related education and support, <i>"I feel very proud of my work that I am doing. I am helping people who have the same</i></p>

	<p>same drug regimen. Catalina was happily engaged in care at the first study visit, but someone disclosed Catalina's HIV status at her sex work establishment in between the two interviews and she was attacked by the other FSWs. Following this experience, Catalina expressed desire <i>"to leave treatment and stay in the house to wait for death."</i> Her peer navigator has, however, arranged for her to speak to a psychologist.</p>			<p><i>problem as me. Because no one has to be like me."</i></p>
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HIV testing and diagnosis

Participants described a range of motivations for and experiences with HIV testing. Key individual and interpersonal motivators of HIV testing were feeling unwell or having sick or HIV-infected partners and children. Yet other factors were also influential as some women like Lupe were instructed to test when pregnant or required to do so for work. Once tested, many participants experienced considerable delays in diagnosis. They were often told by health care providers that their first HIV test was damaged and that they had to be re-tested. Participants like Catalina also reported that health care providers refused to give them their results directly and instead gave their HIV test results first to family members or friends. Delays were, however, less common among more recently diagnosed participants and one participant received her HIV test results within ten minutes. Participants described generally empathetic care from health service providers, and particularly appreciated guidance from HIV-positive counselors because they motivated participants through their own experiences.

Despite post-test counseling, almost all participants mentioned feelings of depression following diagnosis. They frequently described the time following diagnosis as “chaotic” and many were suicidal. One woman stated that at diagnosis, “For me in that instant it was a depression, a depression like something that you cannot describe. Everything hurts and you cannot really say what hurts.” This sadness was compounded for women who were pregnant when diagnosed. “It was very difficult for me,” explained one woman, “because when they told me that I was positive I was pregnant and this was double the pain for me.” Others were angry, particularly when they felt that they knew who had infected them.

Participants often came to terms with their diagnosis through interpersonal relationships with family, friends, and peer navigators. One participant explained, “I wanted to die, but my sister

helped me and told me that no, that I am going to get up and everything was going to continue normally.” Participants also drew inspiration from friends and counselors who were known to be living with HIV. Disclosure was, however, very difficult for many participants as they had to balance disclosure of both their HIV and FSW statuses. Many participants, like Valentina, only shared their HIV status with their families, but not their work. Others, like Carla, did not want to upset their families and kept both statuses a secret. Disclosure to sexual partners was particularly difficult. One participant explained that she was blamed for the HIV infection by her partner’s family, “since I am in the street [a FSW], they thought that it was me, being in the street, that it was me who infected him.”

Health care providers also facilitated engagement in HIV care. Participants frequently mentioned that providers gave them their personal phone numbers, food, money and vitamins.

One participant explained how the psychologist who diagnosed her helped:

When they told me what I had I ran away like a madwoman. They grabbed me and I started to yell, to shout out and the psychologist began to hug me and console me... I found myself in the hands of a friend, that she was my friend, my confidante, my everything.

Some participants did, however, describe upsetting experiences with HIV-related discrimination within general health clinics. One explained, “There are people in the hospitals that treat you at a bit of a distance once they learn you are [HIV-positive]” and some clinic staff involuntarily disclosed participants HIV status. These negative experiences in health services were followed by disengagement in care for some participants.

Pre-ART care

Participants generally received information about HIV clinics at the time of their diagnosis, but most delayed attending because of individual factors such as feeling healthy or interpersonal

reasons like lack of HIV disclosure. Participants like Catalina described waiting for advanced illness prior to engaging in HIV care. One participant had never attended an HIV clinic because, “I do not have any symptom that alerts me that I have to go and get checked. If one day I fall ill, then I will go and get checked.” Lack of disclosure also complicated engagement as some had “hidden HIV” and, therefore, could not be seen entering clinics that frequently had HIV-related signage.

Once their HIV status was known or assumed, many participants described pervasive stigma and discrimination within their communities. Some participants delayed engagement in HIV care because they feared HIV-related discrimination in addition to the discrimination that they already faced as FSWs.

I did not take care of myself because I was worried that people would know that I live with the illness. Because nowadays people discriminate against one for being a sex worker and also if one is infected with HIV.

Some communities learned of participants’ HIV status when it was involuntarily disclosed. Community members also inferred that some participants had HIV because they had lost weight. This discrimination affected participants’ mental and social health and led some to seek care from clinics that were further from their communities.

Despite these barriers to HIV clinic attendance, many participants linked to services through informal networks and peers. Peer navigators often reached out to participants in a discreet way and were instrumental in helping bring participants to HIV care. One participant explained,

When [the peer navigators] found me they found me very sick... In that moment they gave me a lot of support, they lifted me up and I was in a place that I wanted to die, but with help, with the experiences and the learning that they gave me, I rose up and I learned.

FGD participants explained how the navigators take care of them, “like a nurse, like a friend, like a mother”.

Once participants attended HIV services they were generally satisfied with HIV clinic staff, but they were frustrated by the health system organization and costs. Following their first HIV clinic appointment, patients in the DR are generally sent to the national laboratory for baseline assessments and then required to return to the laboratory to collect their results prior to accessing HIV clinical care, a system that participants felt was cumbersome: “You have your appointment, you go to do the labwork someplace else, the medication is not in the same place where you are... they give you a prescription to go to look for it in the other place, now here you have to wait, then there is a lot of congestion.” In addition to frustration, this system introduced additional transportation and laboratory testing costs. Some participants were able to borrow or obtain money from family or friends to defray the cost of pre-ART care, but many had competing demands for their money such as providing food for their children. This health system organization led some participants to disengage. “I attended [the clinic],” said one, “but I became disenchanted and I did not continue... doing so many turns, so many lines.” In addition to delays, participants were frustrated that they often received prescriptions to fill and pay for at the pharmacy instead of being given the medication or vitamins. One FGD participant explained, “The service in terms of the treatment from personnel I find excellent, but in terms of the availability of medicine for opportunistic infections, the services are rock bottom.”

There were, however, important enablers of retention in pre-ART care. Many participants had at least some experience with HIV support groups, although most stopped attending over time. Support groups could be helpful because, as one participant described, “when we arrive, we arrive dispirited, depressed and by listening to the experiences of the other people, the coming together, we are animated. We leave from there revived.” Additionally, while a few participants

noted harsh treatment within some services, they generally described strong, supportive relationships with their care providers that motivated them to stay engaged in care.

ART care

Prior to ART initiation, participants experienced similar systemic delays in determination of treatment eligibility through CD4 enumeration. One disengaged participant did not initiate ART because she could not obtain her CD4 count results:

The doctor sent me to the national laboratory to do a test and I went and I did it. Then when I went to look for the results I did not have money and I did not go. I did not return [to the clinic] again. I did not return because I have to do the CD4 analysis for the doctor to give me the medication.

Many participants ultimately received their CD4 count results and were initiated onto ART, yet learning that they were treatment eligible was upsetting because ART was synonymous with advanced illness. One participant recalled, “When they talk to a person about treatment I thought that the person was dying.”

Once initiated onto ART, participants described important factors influencing ART adherence such as lack of economic resources, dislike of pills, irregular schedules, experience of side effects, and access to support systems. Participants explained the importance of adherence and the value of treatment, but sometimes were not able to take all of their ART medications at the prescribed times. A common challenge was lack of transportation money to the clinic.

There are times that, that one does not have money for the transportation or there are times that I only have 100 pesos. How could I leave my children hungry to come to the doctor? If there is an emergency with my pills, I make the sacrifice with pain in my soul, but if it is for a check-up I do not do it because it hurts me to be here, knowing that my children are hungry.

Insufficient food also complicated adherence to ART. Others struggled with adherence due to ART side effects, particularly following ART initiation. Participants also sometimes reported

missing doses of ART because of their irregular schedules and alcohol consumption associated with sex work. They woke up and ate meals at different time of the day which made it difficult to take ART at regular intervals.

Within ART care, participants described some systemic challenges, but generally good relationships with their care providers. Providers were, however, sometimes exasperated with participants like Catalina when they did not take their ART at the correct times. Systemic challenges included inconsistent drug supply. Participants reported receiving only two weeks' doses instead of two months' supply when their clinic ran low on ART. This was problematic as it meant that they had to spend more on transportation.

Despite these challenges, many participants were able to develop techniques to facilitate ART adherence. These included keeping their phone with them so that they could check the time, always taking pills after breakfast and at the end of a soap opera, having family members remind them to take their doses and avoiding situations which would inhibit taking treatment.

You can invite me to your house and if I cannot bring [my ART] I will not go because I learned the importance of those medications. I understand that they are very expensive and that... it is important that we take them on time.

Participants also drew support from their social networks. A nurse at one participant's clinic brought ART to her when she lacked transportation money. Multiple other participants, like Catalina, described borrowing pills from friends. Through individual, interpersonal and environmental support, many participants were able to reach viral suppression on ART. One participant said, "I feel good and healthy and I thank God for that and all of the doctors and the medicines that have helped me so that, thank God, my viral load is undetectable."

Discussion

FSWs living with HIV in this study described considerable movement in and out of HIV care over time, dependent on their individual, interpersonal, environmental and structural experiences throughout the HIV care continuum. Rather than experiencing a seamless transition from one step to the next, participants were continually confronted with barriers that complicated continued engagement and enablers that sustained them in care. The experiences at one step then affected engagement in subsequent steps, as has previously been described,^{24,34,128} and engagement in HIV care among FSWs was continually negotiated within a broader context of structural constraints and social conditions.

The finding that each step in the HIV care continuum influenced subsequent steps has important implications for both research and practice. There is growing evidence on factors associated with distinct steps in the continuum such as linkage to or retention in HIV care.^{10,45,129,130} These studies provide important insight into key influences on engagement, but PLHIV must successfully complete each step in order to achieve the full benefits of engagement in HIV care.⁴⁷ Additionally, the process of engagement in HIV care is often non-linear as PLHIV in this study and others frequently move in and out of care.^{31,32} This underscores the importance of qualitative exploration and longitudinal documentation of the lived realities of PLHIV throughout the steps in the continuum of HIV care^{24,36} to elucidate these dynamic pathways in and out of HIV care. This understanding will help policymakers and programmers to identify the key resources that can be leveraged or factors that must be addressed to support continued engagement or facilitate re-engagement in care. Additionally, recognition of key barriers to engagement such as lack of food or depression can help clinicians to identify in-care patients who may require additional support.

This study identified critical challenges and opportunities at each level for enhancing engagement of FSWs in HIV care. At the individual level, perceived and actual physical and mental health influenced engagement, as has been noted previously.^{3,24,47,48} Post-diagnosis depression, in particular, was frequently followed by protracted disengagement in HIV care, underscoring the importance of post-diagnosis follow-up and support. Participants in this study frequently waited to re-engage in HIV services until they felt unwell which may explain previous findings that PLHIV in the DR initiate ART at advanced stages of HIV.^{73,107} There is a clear need for additional counseling and public health messaging to increase awareness of the importance of HIV care when participants still feel healthy in order to expedite linkage to HIV care and facilitate retention in pre-ART care.

At the interpersonal level, disclosure of HIV status and access to emotional and economic support were important. Participants frequently described individual depression and structural poverty, but some were able to surmount these challenges with the support from friends and family. Yet negative social experiences such as the disclosure of Catalina's HIV status at her sex work establishment inhibited sustained engagement in HIV care, as was also noted among FSWs in India.⁴⁸ More formalized support from HIV-positive peer navigators and support groups was also vital in facilitating and sustaining engagement in care amongst study participants, as has been previously described.^{33,36,95,131} Additionally, active case management has proven to be effective in improving linkage and retention in HIV care^{36,132} and warrants further examination with key populations such as FSWs.

At the environmental level, FSWs' engagement in care was influenced by the organization of the health system, the availability of medicines and the strength of provider relationships, a finding that is consistent with prior research.^{51,52,128} The important influence of transportation costs due to economic insecurity suggests that streamlining of laboratory testing procedures and

consistent delivery of multiple months of ART¹³³ could be important systemic interventions to support engagement of resource-constrained PLHIV, such as FSWs. While previous research with FSWs has highlighted negative treatment by their HIV care providers,^{3,7} participants in this study reported generally positive experiences with these providers. Participants did, however, describe some experiences of discrimination within primary health care and breach of confidentiality by clinic staff. While sensitivity training for HIV clinic staff is an important intervention to improve engagement in care, it is not sufficient as PLHIV do not exclusively access health services within HIV clinics. It is, therefore, important that staff and providers in all health clinics understand how to appropriately provide services for FSWs and for PLHIV.

Finally, economic resources- an important product of the broader sociopolitical context- and experience of stigma and discrimination at the structural level were influential. There is a clear need for stronger enforcement of existent HIV-related anti-discrimination laws in the DR to provide more economic opportunities for women living with HIV, particularly for women like Catalina who would like to find alternative employment. Additionally, poverty and associated food and transportation insecurity were critical barriers to engagement. Food incentives have been previously shown to increase engagement in HIV care in the Caribbean¹³⁴ and may represent an important intervention strategy for economically insecure PLHIV.¹³⁵ Finally, community and clinic-based HIV-related education and sensitization are essential to both reduce the further transmission of HIV and to create a more enabling environment for HIV care access among those already living with HIV.⁷ Efforts to address stigma must, however, address the multiple layers of stigma experienced by FSWs living with HIV in order to effectively reduce experienced and enacted stigma.^{53,56,98}

The experiences of FSWs described in this study resonate with research from the general PLHIV population, but there were some FSW-specific challenges along HIV care continuum associated

with FSWs' social and economic context. Some of the challenges shared by FSWs in this study and PLHIV in previous research include post-diagnosis depression, lack of disclosure, costs associated with laboratory testing, costs of access to HIV services, ART side-effects and treatment collection and food insecurity.^{3,50,74,75,136} For example, a study among PLHIV in the DR found that suboptimal ART adherence was significantly associated with heavy alcohol use, having children, and having less social support.⁷⁴ Yet, FSWs face additional challenges related to the stigmatized nature of their work, the burden of double disclosure, their frequent financial insecurity and their irregular schedules, as has been noted in other settings.^{3,7,95} For example, FSWs in this study and others reported being blamed for their HIV infection due to stigma associated with HIV infection.⁵⁶ This underscores the need for targeted interventions to address FSWs' unique needs within HIV care. For example, FSWs may benefit from opportunities to strategize with HIV clinic counselors or clinicians on development of adherence techniques that are responsive to their irregular schedules and on disclosure of multiple, stigmatized identities. Many FSWs might also benefit from support in reducing alcohol and drug dependence.

There are several important limitations to the present study. First, this study included individuals who were known by the study team or peers to be FSWs living with HIV, which may have resulted in a study population with higher engagement in HIV care. Second, this study was conducted by a research institute based within a hospital setting which may have influenced participants' discussion of negative experiences within clinical services. To try to address this, field workers received considerable training and participants were interviewed on two occasions to increase rapport and openness. Finally, interviews were conducted over a relatively short period of time. Longitudinal, mixed methods research with PLHIV as they move along the continuum would be invaluable.

In conclusion, this study found that individual, interpersonal, environmental and structural factors were important influences on engagement in HIV care among FSWs throughout the HIV care continuum. While many of these factors have been noted in studies within the general population living with HIV, the economic instability and compounded stigma of being both HIV-infected and a sex worker introduced additional barriers to engagement for FSWs. This underscores the need for the provision of psychological, social and economic support within a health system environment tailored to the needs of FSWs in order to maximize individual and public health.

Chapter 5. High drop-off along the HIV care continuum and ART interruption among female sex workers in the Dominican Republic

Abstract

Objective:

To describe the HIV care continuum among female sex workers (FSWs) and to determine factors associated with experience of antiretroviral therapy (ART) interruption.

Methods:

A quantitative, cross-sectional survey was conducted with 268 FSWs living with HIV in Santo Domingo, Dominican Republic. FSWs were asked about their engagement in HIV care, sociodemographic characteristics and sex work (SW) context. We describe the treatment cascade in this population and identify factors associated with experience of ART interruption using multiple logistic regression.

Results:

FSWs living with HIV were lost at each step of the HIV care continuum with highest drop-off after initiation onto ART. Most participants linked to HIV care (92%), attended HIV services in the past six months (85%) and were initiated onto ART (78%), but discontinuation of treatment and irregular adherence were frequent. Only 48% of participants had an undetectable HIV viral load. A total of 36% of the participants ever initiated onto ART reported lifetime experience with an interruption of ART. The odds of ART interruption were 3.24 times higher among women who experienced SW-related discrimination (95% confidence interval [CI]: 1.28, 8.20), 2.41 times higher among women who reported ever using any drug (95% CI: 1.09, 5.34) and 2.35 times higher among women who worked in a SW establishment (95% CI: 1.20, 4.60). Self-stigmatizing beliefs related to SW were associated with higher odds of interruption as each additional point on the SW self-stigma scale was associated with a 9% increase in the odds of interruption (95% CI: 1.02, 1.16). Positive perceptions of HIV providers were protective as each additional point on the perception of HIV provider scale was associated with a 9% reduction in the odds of ART interruption (95% CI: 0.85, 0.98).

Conclusions:

FSWs living with HIV confront barriers throughout the HIV care continuum resulting in low levels of HIV viral suppression. Given the clear importance in minimizing drop-off along the continuum and maximizing the potential benefits of ART, there is an urgent need for multi-level interventions to help support FSWs throughout the HIV care continuum.

KEY WORDS

HIV/AIDS; Treatment cascade; Continuum of care; Female sex workers; Antiretroviral therapy; Breakage in Care; Retention; Engagement

Introduction

There has been a dramatic increase in the number of individuals receiving antiretroviral therapy (ART) globally,²³ but people living with HIV (PLHIV) are lost throughout the HIV care continuum.^{31,32} The steps along this continuum include HIV testing, HIV diagnosis, linkage to HIV care, determination of ART eligibility, retention in pre-ART care, ART initiation, retention in ART care, adherence to ART and HIV viral suppression.^{25,28,29,36} These losses throughout the continuum are critical as the individual and public health benefits of ART, such as reduced morbidity, mortality and transmission, are well-established.^{12,13} Optimal engagement throughout the continuum, including adherence to ART, among individuals who are sexually active is an important mechanism for preventing the transmission of HIV.^{13,15,16,137}

The depiction of the HIV care continuum has provided a striking representation of the poor state of engagement in HIV care³⁶ in the US^{26,37} and globally.^{25,38} By describing losses at each step, the continuum highlights challenges that compromise the effectiveness of HIV prevention and care strategies. The continuum also serves as a mechanism to better understand the state of treatment and prevention⁴¹ within specific sub-populations.⁴²⁻⁴⁴ Given the clear societal benefits of ART for prevention of HIV transmission,¹³ it is particularly important to understand the state of engagement in HIV care among individuals who are currently living with HIV, aware of their HIV status and sexually active, as they are most relevant sub-population for treatment as prevention.^{15,16}

There is growing recognition of the challenges faced by PLHIV throughout the HIV care continuum, but evidence is lacking on the experiences of FSWs.^{2,3} FSWs are disproportionately affected by HIV around the world and have 13.5 times higher odds of HIV infection than other women of reproductive age.¹ FSWs confront heightened vulnerability not only to HIV infection,

but also to social, economic and systemic barriers to HIV care^{6,138} and have sub-optimal engagement.^{3,7,8} FSWs living with HIV also experience layers of stigma and discrimination related to each of their stigmatized identities.^{2,53,97,98} Stigma is a social process that reinforces differences and perpetuates existent inequities.⁵³ A recent qualitative exploration of the experiences of FSWs in the Dominican Republic noted important influences of individual, interpersonal, environmental and structural factors throughout the continuum of HIV care (Chapter 4). No known study has, however, quantitatively documented the experiences of FSWs along the HIV care continuum, highlighting a critical gap in our understanding of the state of HIV treatment and prevention among FSWs.

This study describes the HIV care continuum among FSWs living with HIV in the Dominican Republic, a country with a concentrated HIV epidemic.¹⁰⁵ Previous research has documented considerable movement in and out of HIV care among FSWs in the Dominican Republic (Chapter 4). Additionally, analysis of factors associated with detectable HIV viral load among the present study population noted the critical association between ART interruption and viral load.² Taking into account this important relationship, this analysis also determined factors associated with experience of ART interruption.

Methods

Trained female field workers administered a baseline, quantitative survey with all members of the *Abriendo Puertas* (AP; Opening Doors) cohort from November 2012- February 2013. This paper survey included questions on individual, interpersonal, environmental and structural factors related to HIV prevention, care, and treatment. The AP cohort included 268 FSWs who were living with HIV in Santo Domingo, Dominican Republic. The cohort has previously been described.² All members of the AP cohort were female adults who had exchanged sex for money in the month preceding enrolment. HIV-positive serostatus was confirmed prior to study enrolment and participants were recruited using a hybrid sampling approach through peer referrals, existent relationships with the study team, and referrals from HIV clinics.

All cohort members provided oral, informed consent and received \$10 for completion of the baseline survey. This study was approved by the Institutional Review Boards of the Johns Hopkins Bloomberg School of Public Health and the Instituto Dermatalógico y Cirugia de Piel Dr. Humberto Bogart Diaz.

Measures

This paper describes the baseline HIV care continuum among AP cohort members. The definitions of each of the steps of the HIV care continuum, as self-reported by study participants or determined through laboratory testing, are described in **Table 5.1**.

Table 5.1 Definitions of the steps within the HIV care continuum

HIV diagnosed All participants had HIV-positive status confirmed using the Retrocheck rapid HIV test	Currently on ART Participant reported currently taking ART
Linked to care Participant reported ever having attended HIV services	Adherent to ART Adherence to ART was determined through the AIDS Clinical Trials Group measures which included questions on 4-day adherence, adherence to specified ART intervals and to treatment instructions ¹³⁹
Stayed in HIV care Participant reported having attended HIV services in the past six months	Undetectable Viral Load Participant baseline viral load, as determined through polymerase chain reaction testing, was less than 50 cells per cubic milliliter
Initiated onto ART Participant reported having ever taken ART	Treatment Interruption Participant reported having ever stopped or suspended taking ART

Independent Variables

Independent variables of interest in the analysis of factors associated with ART interruption including, participant sociodemographic characteristics (e.g. age, household composition, income), clinical experiences (e.g. concurrent health conditions, perceptions of health status, HIV services and health providers) and sex work (SW) context (e.g. venue, self-stigma, substance use). Women were categorized as establishment-based if they indicated that they had worked in a formal SW establishment (e.g. club, disco, bar, hotel, billiard hall) in the past three months, as compared to working exclusively on the street or through phone calls.

The responses to all three scales included in this study were developed from responses to questions with Likert scales ranging from one (strongly disagree) to four (strongly agree). HIV-related self-stigma was determined through eight questions that assessed participants' level of agreement with statements, including "Having HIV makes you feel like a bad person" and "You

feel guilty because you have HIV”, as adapted from validated, reliable HIV stigma scales.^{123,124}

Principal components analysis suggested strong unidimensionality and the scale had high internal reliability (Cronbach’s alpha=0.87). Scores ranged from 8 to 32 with a median score of 18. Participants who reported more self-stigmatizing attitudes related to HIV-status had higher scores.

SW-related self-stigma was determined through the same eight questions used in the HIV scale, but with “SW” replacing “HIV”. The questions assessed participants’ level of agreement with a series of statements, including “You feel embarrassed to be a SW” and “You feel that you are not worth anything because you are a SW”. These questions were adapted from the aforementioned, validated HIV-related self stigma scales.^{123,124} The final eight question scale had one underlying factor and high reliability (Cronbach’s alpha=0.88). Scores ranged from 8 to 32 with a median score of 18. Participants with more self-stigmatizing attitudes related to SW had higher scores.

Participants’ perception of HIV service providers was determined through ten questions that assessed participants’ level of agreement with statements, including “Your doctor is well trained to take care of medical problems like yours”, and “You feel respected by your doctor”. These questions were adapted from the validated Patients Reactions Assessment scale.¹¹⁹ Eight participants did not respond to these questions and were excluded from this part of the analysis. The scale was refined through iterated principal factor analysis and two questions were ultimately dropped from the scale to enhance its internal consistency. Scores ranged from 8 to 32 with a median of 26. The final, eight question scale had very high reliability with a Cronbach’s alpha of 0.95. Participants with more positive perceptions of HIV service providers had higher scores.

Participants were categorized as having experienced discrimination in the clinic related to their HIV-status if they indicated that they had ever received poor services, been denied medical attention or heard health personnel gossiping about them because they are living with HIV, as adapted from Baral et al.¹²⁰ They were categorized as having experienced discrimination in the clinic related to their SW status if they indicated that they had ever received poor services, been denied medical attention or heard health personnel gossiping about them because they exchange sex for money.

Dependent variable

The key dependent variable of interest was history of ART interruption among women ever initiated onto ART.

Analysis

Survey data were analyzed using Stata 12.1.¹²² Participant responses were explored through histograms, scatterplots and descriptive statistics. These responses formed the basis of the description of the HIV care continuum. Baseline characteristics of study participants with and without reported ART interruption were then compared through bivariate analysis, using Pearson's Chi-square tests and two-sided t-tests, as appropriate. Simple logistic regression (SLR) examining factors associated with ART interruption was conducted with significant independent variables from bivariate analysis. Multiple logistic regression (MLR) models were constructed using a forward stepwise approach. Starting with a null model, variables with $p < 0.10$ in SLR were added to the model until the best model was constructed, as determined by comparison of log likelihood ratios and Akaike Information Criterion score (AIC). Additional variables were added to the model until the lowest AIC was obtained, while maintaining parsimony of model. The final model was checked and the model was determined to fit the data by the Hosmer-Lemeshow goodness-of-fit test ($p=0.70$).

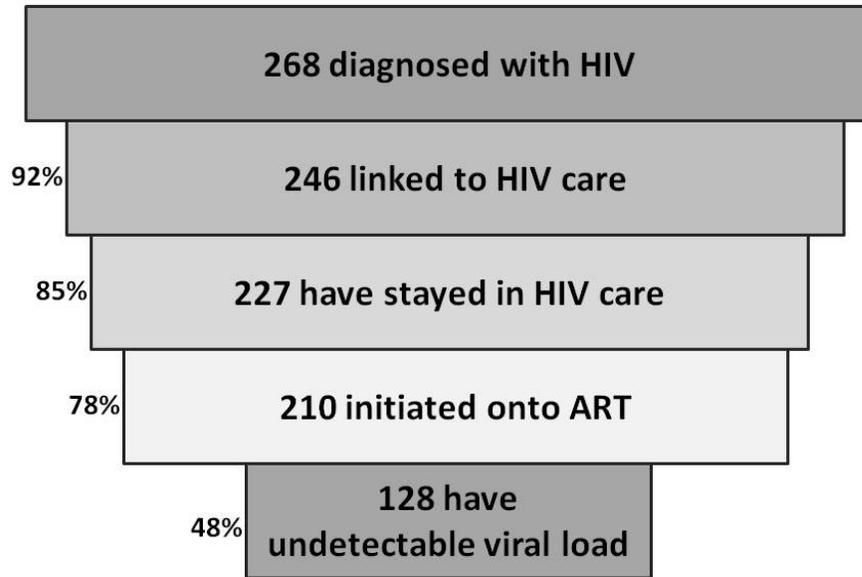
Results

The 268 study participants had a median age of 36 years old (interquartile range [IQR]: 30,42). Participants had low levels of education (64% indicated only a primary level education), and 11% had moved in the past twelve months, as shown in **Appendix B**. Nearly all (96%) of participants had disclosed their HIV status to someone and 61% described their health status as good or better, rather than fair or worse. A total of 43% of participants worked in a SW establishment in the past three months and participants had been engaged in SW for a median of 15 years (IQR: 8, 21). Participants reported generally positive perceptions of HIV care providers (median score: 26, IQR: 24, 31), but 29% and 15% reported experience of HIV-related or SW-related discrimination in the clinic, respectively. A quarter of participants reported ever using any drug and 60% reported alcohol use in the past month. Additionally, participants described self-stigmatizing beliefs related to their HIV status (median: 18; IQR: 14, 21) and to their SW status (median: 18; IQR: 14, 22).

HIV care continuum

There was drop off among the 268 FSWs living with HIV at each step of the HIV care continuum, as shown in **Figure 5.1**.

Figure 5.1 HIV care continuum among female sex workers living with HIV in Santo Domingo, Dominican Republic (n=268)



HIV diagnosis

All 268 study participants were diagnosed with HIV. The median year of HIV diagnosis was 2008 (interquartile range [IQR]: 2005, 2010). The primary motivations to test reported were pregnancy (27%) and perceived risk for HIV (21%). Less than half (43%) of participants received pre-test counseling and three-quarters (76%) reportedly received post-test counseling.

Linkage to HIV care

Almost all participants (92%) reported ever receiving medical attention related to HIV, most (61%) of whom had a medical check-up within one month of diagnosis. Of the 22 participants who never linked to care, 18 (82%) indicated that they were thinking about starting HIV care in the next six months and 13 (59%) knew the location of an HIV clinic.

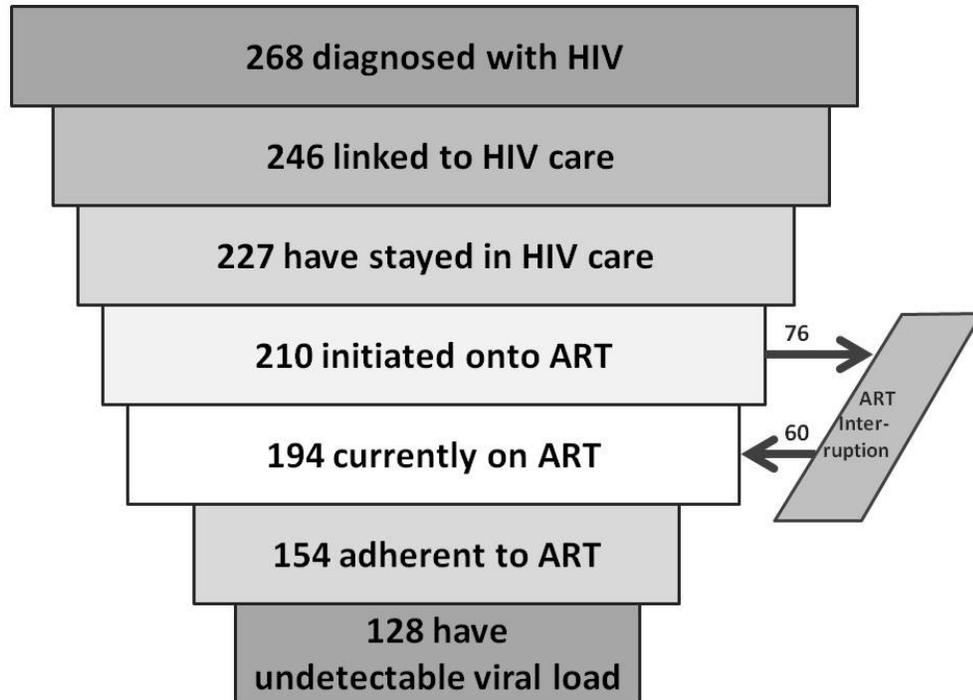
Retention in HIV care

The majority (85%) of participants attended HIV services in the six months preceding the interview. 83 of these women who attended HIV services in the past six months (37%) had, however, missed at least one clinical appointment. The most frequently mentioned barriers to attending HIV care were cost of clinic attendance (39%), lack of transportation to clinic (39%), fear that others would learn her HIV status if a participant goes to the clinic (32%) and lack of HIV status disclosure (23%).

Initiation onto ART

The largest fall-off along the HIV care continuum was between treatment initiation and viral suppression. Most (78%) participants had ever been initiated onto ART, with 72% currently taking ART. **Figure 5.2** provides greater detail on participant experiences between treatment initiation and viral suppression on treatment. A large proportion of participants ever initiated onto ART indicated experience with an interruption of ART at some point (36%). The median number of days off treatment was 30 days (IQR: 4-75). Most of these women (60 of 76) subsequently resumed ART, but 16 did not. The most frequently reported reasons for ART interruption among women currently on treatment were experience of side effects (32%), depression (8%) and personal problems (7%). The most commonly indicated reason for discontinuation of ART among the 16 no longer on treatment was experience of side-effects (38%).

Figure 5.2 HIV care continuum among female sex workers living with HIV in Santo Domingo, Dominican Republic with emphasis on experiences between ART initiation and viral suppression on ART (n=268)



Adherence to ART

Completion of all doses in the past 4 days was reported by 79% of the 194 women currently taking ART. Perfect adherence to specified ART intervals (e.g. every 8 hours) and treatment instructions (e.g. take with food) was lower at 63% and 64%, respectively. The main barriers to ART adherence in the past six months were being away from the house (22%) and forgetting (19%).

Viral Suppression

A total of 128 participants (48%) had a viral load less than 50 cells per a cubic milliliter and only 60% of participants currently on ART had viral suppression. It has previously been shown that detectable viral load in this study population was associated with younger age, diagnosis in the last 5 years, current ART status and ever interruption of ART. The odds of having a detectable

viral load were 3.09 times higher in women who reported interruption of ART (95% confidence interval [CI]: 1.44-6.59).²

Factors associated with ART interruption

Given the high prevalence of treatment interruption and its important association with viral suppression, we conducted further analysis of the factors associated with report of ART interruption. **Table 5.2** shows that in SLR, younger age, having moved in the last 12 months, worse perceptions of HIV service providers, experience of SW-related discrimination in the clinic, lifetime use of any drug, work in a SW establishment and report of self-stigmatizing beliefs related to HIV and to SW were all significantly associated with experience of ART interruption.

The final MLR model show that the odds of ART interruption were 3.24 higher among women who experienced SW-related discrimination (95% CI: 1.28, 8.20), 2.41 times higher among women who reported ever using any drug (95% CI: 1.09, 5.34) and 2.35 times higher among women who worked in a SW establishment (95% CI: 1.20, 4.60). Self-stigmatizing beliefs related to SW were associated with higher odds of interruption as each additional point on the SW self-stigma scale was associated with a 9% increase in odds of ART interruption (95% CI: 1.02, 1.16). Positive perceptions of HIV providers were protective with each additional point on the perception of HIV provider scale associated with a 9% reduction in odds of treatment interruption (95% CI: 0.85, 0.98).

Table 5.2 Factors associated with experience of a interruption of antiretroviral therapy (ART) among HIV-positive female sex workers who have ever been initiated onto ART in Santo Domingo (n=205)

	Relative odds	95% C.I.	Adjusted relative odds	95% C.I.
Age (years)	0.95**	(0.92, 0.99)		
Moved cities in last 12 months	3.74**	(1.42, 9.85)	2.74	(0.89, 8.42)
ART initiation (year)	0.93	(0.85, 1.02)		
Disclosed HIV status	4.76	(0.58, 38.8)		
Health status- good or better	0.60	(0.34, 1.08)		
Perceptions of HIV service provider scale	0.89**	(0.84, 0.95)	0.91**	(0.85, 0.98)
HIV-related discrimination in clinic	1.72	(0.93, 3.15)		
SW-related discrimination in clinic	3.99**	(1.79, 8.89)	3.24**	(1.28, 8.20)
Sex Work context				
Time as SW (years)	0.97	(0.94, 1.01)	0.97	(0.93, 1.00)
Lifetime use of any drug	2.96**	(1.52, 5.80)	2.41*	(1.09, 5.34)
Establishment-based	2.15**	(1.21, 3.81)	2.35**	(1.20, 4.60)
HIV self-stigma scale	1.10**	(1.04, 1.16)		
SW self-stigma scale	1.08**	(1.02, 1.14)	1.09**	(1.02, 1.16)

***p ≤0.05 **p ≤0.01**

Discussion

This study found that FSWs living with HIV were lost at each step of the HIV care continuum with particularly high drop-off after initiation onto ART. Most patients linked to HIV care (92%) and attended services in the past six months (85%), but participants reported considerable social, economic and health barriers at each step, as has been qualitatively described among a different group of FSWs living with HIV in the Dominican Republic (Chapter 4). The most frequently reported barriers to clinic attendance were cost- and transportation-related, but HIV status disclosure was also problematic. High levels of initiation onto ART were found, yet participants had considerable challenges with adherence and most drop-off was between initiation onto ART and viral suppression. Discontinuation of treatment and irregular adherence were frequent, likely contributing to the lower level of viral suppression (48%).

Drop off along the continuum of care in this study population of FSWs in the Dominican Republic is considerably different from what has been described in previous research. US- and India-based research among the general PLHIV population has determined that the high drop off during early steps in the continuum of HIV care drive the low rates of HIV suppression with nearly half of the loss occurring between linkage and retention in HIV care.^{26,36-38} In contrast, the present study determined that over half of all drop-off occurred between initiation onto ART and viral suppression. This underscores the continued relevance of focusing on participant experiences between ART initiation and viral suppression, as shown in **Figure 5.2**. This figure demonstrates that while a high percentage of participants were initiated onto ART, participants frequently experienced breaks in ART or lapses in adherence which may have compromised their treatment response. ART interruption, even amongst patients later reinitiated onto ART, is associated with an increase in opportunistic infections, increased HIV transmission and viral resistance to first-line therapy.^{136,140,141} Thus, the fact that 36% of participants reported

experience with ART interruption is troubling. Additionally, 40% of participants currently on ART had detectable viral load. It is possible that these previous treatment interruptions may have led to treatment resistance, resulting in a lower rate of viral suppression. This is an important finding given the important health and cost implications of development and transmission of resistant strains of HIV,^{70,137,142,143} particularly as all participants had engaged in sexual intercourse in the month preceding enrollment.

Exploration of factors associated with ART interruption highlighted the importance of broader personal, interpersonal, environmental and structural context in influencing engagement in HIV care among FSWs, as described in Chapter 4. Participants' report of positive perceptions of their HIV care providers was protective against breakage in care. This finding is consistent with previous research on the importance of providers' attitudes and behaviors on engagement of PLHIV in HIV care.^{52,99} Yet this study found that participants experienced multiple layers of stigma and discrimination^{2,53,97} related to HIV-and SW-status that affected their engagement in HIV care. In addition to experiencing these layers, participants also reported experience of stigma at multiple levels ranging from internalized stigma (acceptance of negative perceptions related to PLHIV and oneself)^{56,144} to enacted discrimination within the clinic setting, as has been noted previously.^{3,56} The odds of reported treatment interruption were significantly higher amongst FSWs who described experiences of SW-related discrimination in a clinical setting, reported lifetime drug use, worked in a SW establishment and reported self-stigmatizing beliefs related to their SW occupation.

This study demonstrated the important influence of SW context on engagement in care. The finding that work within a SW establishment was associated with treatment interruption was unexpected. This higher interruption may have been related to lower autonomy within establishments and the need for establishment-based SWs to hide their HIV status in order to

attract clients, prevent violence, and avoid getting fired. Additionally, establishment-based SWs may have had higher mobility as they switched establishments in response to HIV-status disclosure. It is possible that this broader economic and social instability may complicate sustained engagement and lead to treatment interruption. Of concern is the relatively frequent report of SW- and HIV-related discrimination within the clinical setting, as has been noted in prior research with FSWs.^{5,81} This underscores the importance of sensitivity training for clinicians in primary care clinics and HIV clinics on the appropriate provision of care for PLHIV and SWs.^{3,94} Additionally, there is a clear need for future research to explore and disentangle the different layers and levels of stigma and discrimination experienced by FSWs living with HIV.

Despite the large drop-off and the frequency of reported breakage in ART, this study found relatively high level of viral suppression, as compared to the prevalence within the US^{26,37} and India.³⁸ This may in part be ascribed to potential selection bias within the study participants as all participants in this study were diagnosed, their status was known to at least the individual who recruited them to the study, and they were physical able to participate in data collection. Thus, this study population likely had higher linkage, retention, ART initiation and viral suppression than the broader target population of FSWs living with HIV in Santo Domingo.

Scholarly and programmatic emphasis on the HIV care continuum can improve our understanding of and responsiveness to the local HIV epidemic,⁴¹ but there are some limitations in its conceptualization. Much of the emphasis has been on the population-level indicators at each discrete step along the continuum and the HIV care trajectory is often described as an almost linear path from diagnosis to viral suppression on ART. This conceptualization fails to acknowledge and account for the high movement of PLHIV in and out of HIV care, as has been shown in this study and previously^{31,32} and the important influence of engagement at one step of HIV care on subsequent engagement (Chapter 4). For example, previous experience of ART

interruption was significantly associated with current detectable viral load within this study population.² This study was cross-sectional and cannot, therefore, identify factors that are predictive of breakage in ART. There is a clear need for prospective, longitudinal research on experiences as PLHIV move along and within the continuum of care within low-resource contexts in order to guide interventions and policies that minimize losses along the continuum.⁴¹ Finally, this study is limited by its use of self-reported measurement of ART interruption due to the low feasibility of collecting these data from clinical records across the country. Despite these methodological limitations, this study provides important, new insight into the experiences of FSWs within HIV care and adds to our understanding of factors associated with ART interruption within this key population.

In conclusion, this study showed that FSWs living with HIV were lost at each step of the HIV care continuum, particularly after initiation onto ART. Factors associated with ART interruption were at multiple levels including individual drug use and self-stigma, clinic-level experiences and the broader SW context. Given the clear importance in improving engagement in HIV care to maximize individual and public health, there is an urgent need for multi-level interventions to help support FSWs throughout the HIV care continuum.

Chapter 6. Retention in HIV care among female sex workers in the Dominican Republic: implications for research, policy and programming

Abstract

There are clear benefits from retention in HIV care, yet millions of people living with HIV, including female sex workers (FSWs), are not retained. This study described factors from Andersen's Behavioral Model that were associated with retention in HIV care among FSWs using two measures of retention: a six-month measure of attendance at an HIV clinic and a measure that combined clinic attendance and missed visits. Quantitative surveys were conducted with 268 FSWs living with HIV in the Dominican Republic. Participants linked to HIV care reported high rates (92%) of six month attendance, but 37% of these participants missed clinic appointments. Using the combined measure, the odds of being retained in HIV care were higher among participants with more positive perceptions of HIV service providers (adjusted relative odds [ARO]: 1.17; 95% confidence interval [CI]: 0.109, 1.25). Lower odds of retention were noted among women who reported recent alcohol consumption (ARO: 0.50; 95% CI: 0.28, 0.92) and among women with self-stigmatizing beliefs related to sex work (ARO: 0.93; 95% CI: 0.88, 0.98). The findings from this study support the hypothesis that retention in HIV care may be best determined through a combined measure as missed visits are an important mechanism to identify in-care patients who require additional support. Retention in HIV care was associated with enabling, health need, and vulnerability factors which represent important targets for future policy and programming.

Key words

HIV/AIDS; Female sex workers; Antiretroviral therapy; Retention; Engagement; Measurement

Introduction

Retention in HIV care has considerable individual and societal benefits, including improved clinical outcomes, decreased transmission of HIV, reduced healthcare costs and increased access to antiretroviral therapy (ART).^{10,11} Access and adherence to ART, in turn, is strongly associated with reduced morbidity, mortality, and HIV transmission.^{12,13} These clear benefits of ART have led to growing interest in the notion of “treatment as prevention” with people living with HIV (PLHIV).¹⁵ Yet millions of PLHIV do not access the HIV care that they require or are sub-optimally retained in care.^{23,36} Engagement in HIV care can be particularly challenging for vulnerable groups such as female sex workers (FSWs) who are disproportionately affected by HIV^{1,78} and confront stigma and other barriers to health services.⁴⁻⁶

The likelihood of PLHIV linking to and being retained in HIV care is influenced by a variety of factors. According to Andersen’s Behavioral Model for Vulnerable Populations, health care access may be influenced by predisposing characteristics, existence of enabling resources, and the health need of individuals, all of which can be affected by membership in vulnerable groups such as FSWs.^{60-62,69} Predisposing characteristics- the propensity to use services- are comprised of demographic factors, social structure and health of the physical environment. Enabling resources are the personal, family and community resources available to use health care. These consist of both the accessibility of health services and an individual’s ability to use these services. Health need includes an individual’s perception of his/her own health state and the judgment by medical practitioners about his/her need for care.^{60,63,64} Previous applications of the Andersen model has shown that access to HIV care in the US was associated with ethnicity, gender, education, injection drug use, medical insurance coverage, concurrent health conditions and symptoms,⁶⁸ along with age and waits for medical appointments.⁶² The model has not, however, been applied to look at which factors are most salient influences on engagement in

HIV care among FSWs, a group that faces unique barriers and facilitators within HIV care (chapters 4 and 5).

Measuring engagement in HIV care

There is growing interest in patients' engagement in HIV care, but there are important methodological challenges in its measurement.¹⁴⁵ Engagement in HIV care is understood to encompass both linkage to and retention in care.³⁶ Linkage to HIV care is the binary construct of having ever attended HIV services, but there is no clear "gold standard" measurement of retention.^{30,45} Retention in HIV care has been measured in various ways, including missed visits, visit adherence, and treatment gaps. These measures include: counts of missed visits; dichotomous measure of missed visits; proportion of visit adherence; number of four-month-long intervals in a year during which the patient had at least one kept visit; dichotomous measure of whether six months elapsed in between kept visits; and the Health Resources and Service Administration (HRSA) HIV/AIDS Bureau measure (dichotomous measure of whether there were at least two kept visits with a primary HIV medical provider that were at least 90 days apart within the year).^{30,45} A recent study of the associations of the six aforementioned retention measurements with one-another and with HIV virological suppression in the United States found that there was considerable variation across the measures in their categorization of patients as retained with lowest retention (33%) using the perfect visit adherence and highest retention (77%) using the HRSA measure. Despite these differences, each of the measures was strongly and significantly associated with HIV virologic suppression. The authors concluded that retention measures should be selected based on the available data, the question of interest, and the study rationale.⁴⁵ Best practice is to utilize multiple retention measures within one study, particularly one based on missed visits and another based on kept visits,⁴⁵ yet no known study has used a measure that combined both missed visits and kept visits. There is a clear need for

further exploration of the association of these measurements, particularly in low-resource contexts. This study aims to contribute to the evidence on factors associated with retention in HIV care among a highly vulnerable group, FSWs in the Dominican Republic, using multiple retention measures.

Methods

Study setting and participants

We conducted a baseline, quantitative survey with the members of the *Abriendo Puertas* cohort. The cohort included 268 female sex workers living with HIV in Santo Domingo, Dominican Republic. The cohort has previously been described.² All members of the cohort were female adults who had confirmed HIV-positive serostatus and who had exchanged sex for money in the month preceding completion of the baseline survey. Participants were recruited through peer referrals, existent relationships with the study team, and referral from HIV clinics.

The study was approved by the Institutional Review Boards of the Johns Hopkins Bloomberg School of Public Health and the Instituto Dermatológico y Cirugía de Piel Dr. Humberto Bogart Diaz in Santo Domingo. Cohort members provided oral informed consent to participate in the study.

Measures

This paper describes results from the baseline survey conducted with all cohort members between November 2012 and February 2013. Independent variables of interest, organized in this paper by Andersen's Behavioral Model for Vulnerable Populations, included participants' predisposing characteristics (e.g. age, household composition), enabling factors (e.g. perceived quality of services, experience of discrimination in the clinic, cost of transportation to clinic), perceived and evaluated health need, and vulnerability (e.g. duration of sex work [SW], self-stigmatizing beliefs).

The key dependent variable of interest was retention in HIV care. Retention was defined in two separate ways for the study. The first definition, "Attended", categorized participants as retained if they reported attendance at an HIV clinic in the past six months. The six month

measure was selected for this study because it can be easily collected in operations research and is not affected by different clinical scheduling practices across clinics.³⁰ The second definition, “Perfect attendance”, categorized participants as retained if they reported attendance at HIV services in the past six months and also reported that they did not miss any HIV service appointments in the past six months. This second measure included both a kept and a missed visit measure, as has been suggested as best practice.³⁶ Participants who attended HIV services in the past six months, but also missed an appointment over the six months were differentially classified by the two definitions.

The HIV service provider scale, HIV-related self-stigma scale, and SW-related self-stigma scale were all adapted from validated scales^{119,123,124} and have been previously described in Chapter 5. Higher scores on the HIV service provider scale were associated with more positive perceptions of providers and higher scores on the two self-stigma scales were associated with more self-stigmatizing perceptions. All scales had high internal consistency (Cronbach’s alpha 0.87-0.95).

Analysis

Data were analyzed using Stata 12.1.¹²² During exploratory data analysis (EDA), the distribution of all dependent and independent variables of interest were described. Baseline characteristics of the study participants were explored through bivariate analysis, comparing those who were and were not categorized as retained in HIV services by each definition, using Pearson’s Chi-square tests and two-sided ANOVA tests.

Simple logistic regression (SLR) assessing factors associated with retention in HIV care was conducted with all independent variables from EDA that significantly differed amongst retention categories. Multiple logistic regression analyses were then conducted to assess the association of significant variables from SLR and *a priori* variables of interest with retention in care. During

model building, the log likelihood ratios were compared and the models with the lowest Akaike Information Criterion (AIC) score were selected. Additional variables were added to the model until the lowest AIC was obtained, while maintaining parsimony and fit of model. The final model was checked and there were no strong confounding relationships or collinearity between the included variables. The overall degree of fit was determined using the Hosmer-Lemeshow goodness-of-fit test ($p=0.38$).

Results

Defining retention in care

Of the 268 FSWs that completed the baseline survey, 246 (91.8%) had ever received HIV-related medical attention (i.e. were linked to HIV care). Of these 246 women, there was considerable variation in their categorization as retained or not by the two definitions. Using the “Attended” definition of having attended HIV services in the past six months, 227 (92.3%) of linked women were categorized as retained in care. A total of 83 (36.6%) of these women who attended HIV services in the past six months reported missing an HIV service appointment in the past six months. Thus, these women were defined as retained in HIV services using the “Attended” definition and were defined as not retained using the “Perfect attendance” definition. The 83 women with differential categorizations attended an average of 3.8 appointments in the past six months, but all missed appointments. Only 144 (58.5%) of participants were categorized as retained in care by the “Perfect attendance” definition.

Sociodemographic and clinical characteristics of the 246 women who were ever linked to care are shown in **Table 6.1**, stratified by retention status using the two different definitions of retention. In terms of sociodemographic factors, participants who were classified as not retained were less likely to be single and had more children. They were more likely to have experienced a sexually transmitted infection (STI) or STI symptoms in the past six months, had worse perceptions of their health status, HIV services and HIV service providers and reported more experiences of discrimination within health clinics. Women who were not retained were also more likely to have moved in the past 12 months and reported more substance use and self-stigmatizing perceptions.

Table 6.1 Sociodemographic and clinical characteristics of 246 female sex workers living with HIV in Santo Domingo by retention in HIV care status using two different definitions of retention in HIV care¹

	Not retained by either definition	Retained by one or both definitions		Total
		<i>Attended, but missed appointment²</i>	<i>Attended & no missed appointment</i>	
N	19	83	144	246
Predisposing Sociodemographic Factors				
Age (years)- Median (interquartile range [IQR])	37 (32, 42)	34 (29, 42)	36 (32, 43)	36 (30, 42)
Single- n (%)	2 (10.5)	12 (14.5)	34 (23.6)	48 (19.5)
Education- n (%)				
Primary	13 (68.4)	48 (58.5)	89 (63.6)	150 (62.2)
Secondary	4 (21.1)	32 (39.0)	41 (29.3)	77 (32.0)
University	2 (10.5)	2 (2.4)	10 (7.1)	14 (5.8)
Lives alone- n (%)	1 (5.3)	16 (19.3)	16 (11.1)	33 (13.4)
Number of children- Median (IQR)	3 (2, 5)	3 (2, 4)	3 (1, 3)	3 (2, 4)
Health Need				
Positive test (year) - Median (IQR)	2005 (2002, 2009)	2008 (2005, 2010)	2007 (2004, 2010)	2007 (2004, 2010)
Previous tuberculosis infection- n (%)	1 (5.3)	9 (10.8)	16 (11.1)	26 (10.6)
STI/ STI symptom in last 6 months- n (%)	12 (63.2)	49 (59.0)	61 (42.4)	122 (49.6)
Perceived health status is good or better - n (%)	8 (42.1)	45 (54.2)	100 (69.4)	153 (62.2)
Enabling Factors				
Disclosed HIV status - n (%)	17 (89.5)	82 (98.8)	138 (95.8)	237 (96.3)
Has medical insurance- n (%)	10 (52.6)	48 (57.8)	86 (59.7)	144 (58.5)
Perceived quality of HIV services- n (%)				
Excellent	6 (42.9)	28 (33.7)	52 (36.1)	86 (35.7)
Very good	1 (7.1)	17 (20.5)	43 (29.9)	61 (25.3)
Good	2 (14.3)	18 (21.7)	31 (21.5)	51 (21.2)
Adequate	2 (14.3)	10 (12.1)	8 (5.6)	20 (8.3)
Poor	3 (21.4)	10 (12.1)	10 (6.9)	23 (9.5)
Perceptions of HIV service provider scale- Median (IQR) ³	24 (20, 25)	24 (24, 28)	29 (24, 32)	26 (24, 31)
Travel time to clinic (minutes) - Median (IQR)	60 (30, 90)	60 (30, 90)	60 (30, 90)	60 (30, 90)
Roundtrip travel cost to clinic (US dollars) - Median (IQR)	3 (2, 5)	3 (2, 4)	3 (2, 4)	3 (2, 4)
Experience of HIV-related discrimination in clinic- n (%)	11 (57.9)	26 (31.3)	36 (25.0)	73 (29.7)
Experience of FSW-related discrimination in clinic- n (%)	9 (47.4)	9 (10.8)	17 (11.8)	35 (14.2)
Vulnerability				
Age when started TRSX (years)- Median (IQR)	19 (16, 20)	18 (15, 25)	19 (15, 25)	19 (15, 24)
Duration as TRSX (years)- Median (IQR)	20 (12, 23)	14 (6, 20)	15 (8, 21)	15 (8, 22)
Moved cities in last 12 months- n (%)	3 (15.8)	12 (14.5)	10 (6.9)	25 (10.2)
Average monthly income from TRSX (US dollars) - Median (IQR)	325 (163, 542)	325 (163, 542)	325 (163, 536)	325 (163, 542)
Use of any drug in last 6 months- n (%)	2 (10.5)	9 (10.8)	6 (4.2)	17 (6.9)
Alcohol consumption in last month- n (%)	11 (57.9)	58 (69.9)	76 (52.8)	145 (58.9)
HIV self-stigma scale score- Median (IQR)	17 (14, 25)	18 (14, 22)	17 (13, 20)	18 (14, 21)
FSW self-stigma scale score- Median (IQR)	21 (14, 22)	19 (16, 22)	17 (13, 20)	18 (14, 22)

¹Participants were categorized as retained in the “Attended” definition if they attended HIV services in the past six months. Participants were categorized as retained in the “Perfect attendance” definition if they attended HIV services in the past six months and did not miss any appointments

² These participants were differentially classified by the definitions because they attended HIV services in the past six months, but missed at least one appointment

For the 246 participants who were linked to care, the “Attended” measure was not significantly associated with viral suppression ($p= 0.09$). The “Perfect attendance” measure was significantly associated with viral suppression ($p<0.01$) and, therefore, most closely associated with the biologic and public health outcome of interest. Thus, the retention measure which combined clinic attendance and missed visits was utilized for subsequent analysis.

Factors associated with retention in care

SLR of the factors associated with retention in HIV care among FSWs living with HIV using the “Perfect attendance” definition are shown in **Table 6.2**. The odds of retention were significantly higher if participants reported good or better health status, as compared to those with fair or bad health (relative odds [RO]: 2.10; 95% confidence interval [CI]: 1.24, 3.56) and had more positive perceptions of their HIV care provider (RO: 1.17; 95% CI: 1.10, 1.25). The odds of retention were significantly lower among participants who had an STI or STI symptom in the past six months (RO: 0.49; 95% CI: 0.29, 0.83), consumed alcohol in the last month (RO: 0.53; 95% CI: 0.32, 0.91) or reported more self-stigmatizing beliefs related to SW (RO: 0.93; 95% CI: 0.89, 0.98).

The final model demonstrated that each additional point on the HIV service provider scale was associated with a 17% increase in the odds of retention (adjusted RO [ARO]: 1.17; 95% CI: 0.109, 1.25). The odds of being retained were 50% lower in women who reported alcohol consumption in the last month (ARO: 0.50; 95% CI: 0.28, 0.92). Finally, each additional point on the FSW-related self-stigma scale was associated with 7% lower odds of retention (ARO: 0.93; 95% CI: 0.88, 0.98).

Table 6.2 Factors associated with retention in HIV care, defined as having attended HIV care in the past six months and not missed any appointments, among female sex workers living with HIV in Santo Domingo (n=238)

	Relative odds	95% C.I.	Adjusted relative odds	95% C.I.
Predisposing Sociodemographic Factors				
Age (years)	1.02	(0.99, 1.05)		
Single	1.94	(0.98, 3.84)		
Number of children	0.87	(0.74, 1.03)		
Health Need				
Health status- Good or better	2.10*	(1.24, 3.56)	1.79	(0.98, 3.27)
STI/ STI symptom in last 6 months	0.49*	(0.29, 0.83)		
Enabling Factors				
Perceived quality of HIV services				
Excellent	Ref	-		
Very good	1.56	(0.78, 3.14)		
Good	1.01	(0.50, 2.06)		
Adequate	0.44	(0.16, 1.18)		
Poor	0.50	(0.19, 1.28)		
Perceptions of HIV service provider scale	1.17**	(1.10, 1.25)	1.17**	(1.09, 1.25)
HIV discrimination in clinic	0.59	(0.34, 1.02)		
FSW discrimination in clinic	0.62	(0.30, 1.28)		
Vulnerability				
Age when started TRSX (years)	1.02	(0.99, 1.06)		
Moved cities in last 12 months	0.43	(0.19, 1.01)	0.41	(0.15, 1.13)
Use of any drug in last 6 months	0.36	(0.13, 1.01)		
Alcohol consumption in last month	0.53*	(0.32, 0.91)	0.50*	(0.28, 0.92)
HIV self-stigma scale	0.96	(0.91, 1.01)		
FSW self-stigma scale	0.93**	(0.89, 0.98)	0.93**	(0.88, 0.98)

* $p \leq 0.05$ ** $p \leq 0.01$

Discussion

FSWs living with HIV in this study population in the Dominican Republic had high rates of six month attendance in HIV services, but participants frequently reported missing clinic appointments. There was considerable variation in the categorization of the same individuals as retained or not, depending on the retention measure used.⁴⁵ A total of 92% of linked FSWs living with HIV were retained in HIV care based on a six month measure of attendance at HIV clinic, but only 59% were categorized as retained when retention was defined as six month HIV clinic attendance with no missed visits. Within this study population, the measure that included missed visits better identified individuals who were from a broader social and clinical context that complicated retention in HIV care (high mobility, substance use, self-stigmatizing perceptions and negative experiences within HIV care). The combined measure was also more closely associated with evaluated health outcomes, as shown by its significant association with HIV viral suppression. The finding that the different retention measures resulted in vastly different portrayals of the state of engagement in HIV care among FSWs underscores the important influence of measure selection and the need for standardization across studies. Comparison of the measures in this study supports the hypothesis that retention in HIV care is best measured through kept and missed visit measures within one study.⁴⁵

The finding that the inclusion of missed visits within the definition of retention is closely associated with viral suppression has important methodological and practical implications. It underscores the importance of documenting both HIV clinic attendance and HIV clinic missed visits within research on the HIV care continuum in order to better understand factors that may ultimately compromise engagement. This is particularly important as missed visits are associated with poorer health outcomes^{47,121,146} and may indicate lower attention or concern for one's own health, as has previously been suggested.¹⁴⁶ Vulnerable populations such as FSWs

often come from a context of broader social and economic instability that can lead to missed visits and slower treatment response.^{99,147} These findings suggest that HIV care providers and services would benefit from checking whether in-care patients are missing visits as these missed visits may be indicative of a broader context that could lead to non-retention in HIV care or sub-optimal treatment response,¹⁴⁸ particularly among FSWs. In a sense, missed visits are a “canary in the mine” that can serve as a mechanism to identify patients who require additional support.^{121,148}

This study found that retention in HIV care among FSWs was associated with health need, enabling and vulnerability factors, as described by Andersen and colleagues.^{62,63,69} FSWs in this study who perceived themselves as healthy and had existent enabling resources in the form of positive perceptions of HIV service providers were more likely to be retained in HIV care. The important influence of perceived health need and perceptions of HIV providers on engagement has previously been noted.^{3,7,68} Yet FSWs’ retention was also influenced by their vulnerability with lower odds of retention among women reporting substance use and more self-stigmatizing beliefs related to SW. The lower retention associated with self-stigmatizing beliefs related to SW highlights an important way in which the experiences of FSWs with HIV care may be different from other PLHIV. Additionally, the important relationship between alcohol consumption and engagement in HIV care among FSWs found in this study has been previously described in qualitative research.⁷ Previous research has shown the importance of predisposing attributes like marital status on access to HIV care,^{62,68} but none of these variables were significantly associated with retention among FSWs. It is possible that FSWs face broader personal, social and systemic challenges that supersede the importance of predisposing factors. While the high prevalence of missed visits is troubling, all of the factors associated with retention in HIV care among FSWs in this Dominican population can be modified through public health policy and

programming. Specifically, retention in HIV care among FSWs could be improved through provision of support for FSWs to decrease alcohol consumption and reduce self-stigma related to SW, along with sensitivity training of health care providers.

This study has some important limitations related to its design and implementation. All participants knew their HIV status and their status was also known to either a peer or clinic staff member which likely biased the study towards inclusion of patients with higher engagement in HIV care. Additionally, participants were not randomly sampled and this paper reports on cross-sectional, self-reported data. Participants self-report of retention status may have led to social desirability bias, but verification of retention through clinical records at the more than 20 different clinics attended by study participants was not feasible. Finally, participants were not asked if they had missed a visit in the past six months if they had not attended a visit in the past six months, making it impossible to directly compare the combined measure with a missed visit only measure. Despite these limitations, this study contributes to the evidence on measurement of retention in HIV care using a combined measure and on factors associated with retention among FSWs.

In conclusion, this study demonstrated the value of including both clinic attendance and missed visits in the measurement of retention in HIV services among FSWs. Missed visits were indicative of a broader social, economic and community context confronted by FSWs that complicated engagement in HIV care. Retention in HIV care among FSWs was associated with not drinking alcohol, reporting better perceptions of HIV providers and possessing lower self-stigma related to sex work. These factors represent important, mutable targets for future public health policy and programming to improve retention in HIV care among FSWs.

Chapter 7. Discussion

This dissertation described three analyses of the experiences of FSWs living with HIV along the HIV care continuum. Despite using different methodological techniques, the dissertation presents consistent findings related to FSWs' engagement and disengagement in HIV care.

Previous research with the general PLHIV population in the US has demonstrated that PLHIV temporarily or permanently disengage in HIV care throughout the HIV care continuum.^{28,30-33,125}

This dissertation described a similar process amongst FSWs within the DR. These findings provide important insights into the pathways in and out of care. The dissertation also highlights important influences on FSWs' engagement at multiple levels and compares these influences to those experienced by the general PLHIV population. This discussion briefly reviews these findings and offers suggestions for future research, policy and programming related to engagement in HIV care among FSWs living with HIV.

Negotiating Engagement

Engagement in HIV care was not a static construct for FSWs as participants continually negotiated engagement within a broader context of structural constraints and social conditions. Health care providers and the health system expected FSWs to take their treatment multiple times a day and to regularly attend HIV services. Yet HIV care was not experienced by FSWs in a vacuum as participants were frequently forced to weigh the benefits of this HIV care against a multitude of barriers. FSWs in the qualitative study confronted a range of challenges which included lack of transportation money, insufficient food, hungry children, undisclosed HIV and SW statuses, internalized and enacted stigma related to both their HIV status and their SW in their homes, communities and clinics, competition from FSW peers for clients and mental distress. There were, therefore, days, weeks and years in which participants were unable or unwilling to prioritize their HIV care over these competing demands. As a result, FSWs

frequently moved in and out of care over time, as shown in the quantitative description of the HIV care continuum among FSWs in the DR. In contrast to other populations,^{26,36-38} the largest losses from care among FSWs living with HIV in the DR were after ART initiation. It is possible that many of the barriers to engagement in HIV care described in the qualitative strand are particularly problematic for FSWs who are expected to adhere to ART multiple times a day.

Influences on Engagement in HIV Care

By describing disengagement at each step, the depictions of the HIV care continuum among FSWs living with HIV highlighted challenges that compromise the effectiveness of HIV prevention and care strategies in the DR. This dissertation identified important individual-, interpersonal-, environmental- and structural-level factors which influenced engagement in HIV care. All three analyses highlighted the important role of individual-level factors such as mental and physical health on engagement. An important influence on mental health is self-stigma related to both HIV and to SW. Previous research has indicated that stigma affects engagement in HIV care in diverse ways, including delaying access to HIV testing, limiting disclosure of HIV status, increasing rejection of PLHIV by sexual partners, family and social networks, and generating reluctance to be seen taking treatment or attending an HIV clinic,^{49,57,58} as was frequently noted within the qualitative analysis. This dissertation adds to the evidence base by quantitatively examining internalized and enacted stigma associated with multiple identities: being HIV-infected and being a sex worker. While there is layering of this stigma,⁵³ self-stigma related to SW emerged as a more significant influence on retention in HIV care and ART interruption amongst this study population. This interesting finding warrants further examination to disentangle the ways in which stigmatized identities influence one-another and to explore reasons why one identity may be more salient. It also demonstrates the importance

of provision of counseling and mental health services that are tailored to meet the unique needs of individuals with multiple stigmatized identities.

Interpersonal factors such as disclosure of HIV status and access to emotional and economic support were also important influences on engagement in HIV care. FSWs in the qualitative analysis described various ways in which relationships with family, friends, peers, and HIV care providers helped them to surmount financial, emotional, environmental and structural barriers to care. Disclosure and perceived psychosocial support were not, however, significantly associated with engagement in HIV care within the quantitative analyses. This lack of association may be due to the very high level of HIV status disclosure of study participants and the fact that all participants had existent relationships with peers or the study team which facilitated their recruitment.

At the environmental level, FSWs were generally happy with the services of their HIV providers, but participants described considerable other challenges within the health system. In the qualitative analysis, participants mentioned the important role of providers throughout the continuum. FSWs described how HIV care providers gave them emotional and tangible support in the form of food, money, telephonic availability and treatment delivery. Within the quantitative analysis participants also indicated generally positive perceptions of the providers. These positive perceptions were protective against ART interruption and were associated with higher odds of retention in HIV care. These findings support previous research that emphasizes the important influence of HIV care providers on engagement in HIV care.^{52,99}

Despite these positive relationships with HIV providers, FSWs described numerous frustrations with the health system that impeded engagement. These included systemic delays in HIV diagnosis, CD4 enumeration and ART initiation. Of concern, participants frequently described

experiences of discrimination within health services in both study phases. In the qualitative analysis these negative experiences were often followed by disengagement. Within the quantitative analysis, participants reported generally positive perceptions of their HIV clinics (82% described their HIV services as good or better), but indicated frequent negative experiences within the broader health system. Over one-quarter of participants reported experiences of HIV-related discrimination in clinics and 15% reported discrimination related to their SW. Across quantitative analyses, this experience of discrimination in clinics related to SW was significantly associated with sub-optimal engagement in HIV care. Additionally, involuntary disclosure of HIV status by health care providers was noted among qualitative participants. Prior work has frequently called for sensitivity training of HIV clinic staff.^{3,6,7} The findings from this dissertation, however, emphasize the need to include staff and providers from both HIV-specific and general health clinics within these trainings in order to reduce discrimination and facilitate continued engagement in care.

Structural factors such as access to economic resources, stigma and discrimination and the broader SW context also affected engagement of FSWs in HIV care. Within the qualitative analysis, participants commonly described how lack of money for transportation, food, CD4 testing, vitamins and medication complicated engagement. Similarly, the most frequently mentioned barriers to attending HIV care described by quantitative participants were the costs of attendance and lack of transportation. It is interesting to note, however, that income and cost of transportation to HIV clinic were comparable amongst participants who were retained and not retained in care. It is possible that these costs were challenging for all FSWs living with HIV and that all participants confronted competing demands for their scarce resources, but participants who attended their appointments prioritized their HIV care more than those who

missed visits or experienced ART interruption. Future research should explore the influence of both perceived and actual HIV care costs in greater detail.

Factors associated with engagement in HIV care among FSWs in this dissertation are similar to those identified in research within the general PLHIV population, but there were some FSW-specific challenges. FSWs faced additional challenges related to the stigmatized nature of their work, the burden of double disclosure, their frequent financial insecurity and their irregular schedules, as has been noted in other settings.^{3,7,95} Additionally, previous research and this dissertation have shown the detrimental impact of the frequent association of sex work with alcohol and drug use among FSWs living with HIV.^{7,99} For example, some participants in the qualitative phase described how they would avoid taking ART on nights when they were engaging in SW because of their alcohol consumption. Substance use was also high amongst FSWs included in the quantitative phase with 60% of respondents reporting alcohol consumption in the past month and nearly one quarter indicating lifetime drug use. A form of substance use was significantly associated with engagement in each of the quantitative analyses: there were higher odds of ART interruption amongst FSWs who reported lifetime drug use and there were lower odds of retention in HIV care amongst FSWs who indicated alcohol consumption in the last month. This substance use was also significantly associated with having an STI.² In light of the high prevalence of substance use in FSWs living with HIV and its significant association with HIV service and biological outcomes, integration of substance use services within HIV care for FSWs² is an important component of efforts to enhance FSWs' engagement in HIV care.

Implications for Research, Policy and Programming

Findings from this dissertation have important implications for future research, policy and programming. There is a clear need for further mixed methods and longitudinal research on engagement in HIV care, particularly amongst FSWs and other key populations in low-resource settings. As indicated by the analysis on retention in HIV care, such studies should include both clinic attendance and missed visit measures of retention. Studies on experiences on ART and of viral suppression would also benefit from inclusion of measures of experience of ART interruption as this may have important implications for treatment response. Finally, studies that involve SWs living with HIV should include distinct measures and questions on stigma associated with SW and stigma associated with living with HIV in order to enhance our understanding of the relationships between these multiple identities and their association with engagement.

Relevant to public health policy, this dissertation documented frequent violation of the rights of FSWs living with HIV in the DR, along with systemic barriers to optimal engagement in HIV care. Participants described considerable discrimination within their homes, communities, health services and work. The DR has passed legislation that protects the human rights and dignity of PLHIV,¹¹⁰ but these laws are not sufficiently enforced. For example, PLHIV in this study and previous research have described pervasive HIV testing prior to employment and termination of employment upon discovery of HIV-positive status.^{57,97,103} FSWs also described numerous experiences with discrimination, including in health services. There is a clear need for stronger enforcement of existent legislation in the DR to create enabling environments in which FSWs can meet their PHDP needs. Additionally, participants described considerable barriers within the design of HIV services in the DR which inhibited engagement such as the provision of HIV services and laboratory services in distinct locations. Engagement of economically insecure

populations such as many of the FSWs participants from this study would likely improve if CD4 enumeration was conducted within HIV services. Policies supportive of consistent delivery of multiple months of ART also warrant further consideration.

Finally, findings from this study have important implications for programming to enhance engagement in HIV care among FSWs. This study highlighted important barriers and enablers of HIV care. Recognition of these barriers such as substance use and missed clinical visits amongst in-care patients can serve as an early warning system for HIV care providers to help them provide additional support for PLHIV before they disengage from care. In order to be effective, this support must address the multiple levels of barriers experienced by FSWs living with HIV. Multi-level interventions, such as the AP intervention, which include individual counseling, peer navigation, HIV care provider training and community mobilization,² are likely to be most effective in meeting the unique needs of FSWs living with HIV. Such interventions should be incorporated into existent health services and scaled up to optimize engagement in HIV care for all FSWs living with HIV in the DR.

Strengths and Limitations

This dissertation represents a novel contribution to the scientific evidence on engagement along the HIV care continuum among a highly vulnerable population, FSWs, but it has important strengths and limitations. The mixed methods design and relatively large sample size facilitated in-depth and generalizable exploration of participants' experiences. Within the qualitative phase, multiple data collection and analytic techniques were utilized and participants were interviewed on two occasions to allow for a more nuanced understanding of engagement in HIV care. The quantitative phase utilized validated scales which demonstrated high internal reliability, along with multiple measures of retention in HIV care. Additionally, the highly skilled local implementation team and the strong relationships between the study team and the study population facilitated a rigorous and appropriate application of both study phases.

This dissertation does, however, have some important limitations, including potential bias and limitations inherent in the study design. The first limitation to the study is in the selection of participants. The quantitative study included over 45% of the approximately 600 FSWs living with HIV in Santo Domingo (3.0% HIV prevalence in 20,000 FSWs), but it is probable that the included women were not representative of the source population because they were aware of their HIV status and their status was known to the study team or a peer. Thus, these women likely had higher engagement with HIV care than the broader population of FSW living with HIV in Santo Domingo. A second limitation of the qualitative and quantitative strands was potential social desirability bias. The interviews took place at the HVRU office which is located in a hospital setting. It is, therefore, possible that participants reported more favorable experiences with health services. One additional limitation of the study is that engagement with health services was assessed through self-report and, therefore, may have been affected by information bias in the form of recall bias or social desirability bias. Efforts were made to

minimize this bias through establishment of comfortable, open interview environments and through use of clear time references within questions, but actual attendance at health services was not measured due to logistical, ethical and feasibility considerations. Finally, data from the quantitative phase were collected at one point in time, limiting the understanding of how participants' engagement changed over time. This underscores the need for longitudinal, mixed methods exploration of engagement in HIV care among PLHIV.

Chapter 8. Conclusion

This study found that individual, interpersonal, environmental and structural factors were important influences on engagement in HIV care among FSWs throughout the HIV care continuum. Many of these factors have been identified in studies within the general population living with HIV. However, this mixed methods dissertation demonstrated that the compounded stigma of living with HIV and being a sex worker and the nature of SW introduced additional barriers to engagement for FSWs. These SW-specific barriers resulted in missed visits and disengagement in HIV care throughout the HIV care continuum. Given the clear importance in improving engagement in HIV care to maximize individual and public health, there is an urgent need for multi-level interventions to help support FSWs throughout the HIV care continuum.

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Appendix A. Narratives of the experiences of FSWs living with HIV

	Carmen	Sofia	Isabella
Current engagement with HIV services	Carmen was diagnosed with HIV two years ago after she felt ill. She was initially linked to care, but never returned to collect her CD4 count results and has left care.	Sofia was diagnosed about one year ago at a mobile testing unit. She has never attended HIV services.	Isabella was diagnosed at a mobile testing unit eight months ago. She is not attending HIV services.
Individual	Carmen decided to test for HIV because she was feeling sick and she had family and partners who had died from AIDS. Carmen is religious and draws strength from her relationship with God.	Sofia was surprised and depressed by her HIV-positive diagnosis. She has never attended HIV services because <i>"I am embarrassed to go"</i> .	Isabella was initially depressed when diagnosed, but she has come to terms with her status. She feels well and thinks that she might get sicker if she attends HIV services. She does not know about ART or CD4 counts.
Interpersonal	Carmen has close friends who are living with HIV that have motivated her. She has not, however, told anyone else her status. Her three children probably suspect it, though, because of community gossip.	Sofia has a strong relationship with a peer navigator who helps her and provides her with medication. She is the only one who knows her HIV status. She explains that she cannot access support because of this lack of disclosure, <i>"If I say to my partner, I say to my brother, 'help me' they are going to ask me, 'Why? What do you have that you feel bad?"</i>	Isabella came to terms with her diagnosis by thinking of her children. <i>"my sister was who helped me the most. She was who always gave me encouragement"</i> and reminded Isabella that she needed to live to take care of her children. Isabella's mother, a peer navigator and her sister know her status and provide her with support. Her mother, however, treats her differently, <i>"They are afraid of me because it seems as though [HIV] spreads easily"</i> and prefers that she does not cook. She also cleans up after her with bleach. She has not disclosed her HIV status to her partners or children.
Environmental	Carmen was given her HIV test results by a peer counselor at which time, <i>"I wanted to go crazy and he told me, 'look. I have been positive for eleven years' and we spoke and we always speak on the phone. I always call him from my work and when I feel bad I go there and he gives me a vitamin and he gives me money so that I can eat... And if he can live, why can't I?"</i> Carmen has attended HIV services and went to the national laboratory for CD4 count analysis, but has not collected her results because she did not have money. She has not returned to the doctor since because the doctor will require her CD4	Sofia received pre-test counseling and was given her test results two hours after testing at a mobile unit. She felt the team that tested her treated her very well.	Isabella was provided her test results ten minutes after testing at a mobile unit. She was very happy with the quality of care provided by the testers who treated her well. While Isabella is not in HIV services, she has heard about long lines, expensive ART and drug stock-outs.

	count results to start her on treatment.		
Structural	Carmen lost 60 pounds so many people in her community say that she is sick. Her biggest ongoing challenge is poverty and a lack of food.	Sofia did not describe experiences of stigma and discrimination.	Isabela has not attended services because <i>“I think that the people will realize that I have the illness and sometimes you arrive at places and the people keep looking at you.”</i>

	Elena	Sandra	Beatriz
Current engagement with HIV services	Elena was diagnosed during pregnancy. She is moderately retained in care, but has not initiated onto ART.	Sandra was diagnosed by mobile testing unit. She was previously linked to care, but is not currently attending HIV services.	Beatriz was diagnosed during pregnancy in 1999. She is currently on ART, but has had breaks in engagement in HIV services.
Individual	Elena tested for HIV during pregnancy. At the time, she had only ever been with one partner and she was shocked. She was also depressed when her child was diagnosed as HIV-positive. Elena sometimes misses her own or her child's appointments because she does not have money for transportation.	Sandra was very depressed and tried to hang herself after her HIV diagnosis. Sandra is not currently in care because she feels well and does <i>"not have any symptom that alerts me that I have to go and get checked. If one day I fall ill, then I will go to get checked."</i> She is still depressed and feels as though she is sinning by engaging in sex work as a person living with HIV because it is killing and <i>"one of God's commandments is not to kill"</i> .	When Beatriz was diagnosed, she wanted to die. Now on ART, Beatriz sometimes feels like quitting because she does not like taking pills. She generally takes her treatment, but <i>"sometimes there are days when one has her mind on so many things. Sometimes there is a lot going on in the house that I have to wash and I forget."</i>
Interpersonal		Sandra has not disclosed her HIV status to friends, partners or family. <i>"Sometimes I want to scream the truth, but if I do it I think I will lose both [partners] because not everyone is used to having an HIV-positive partner."</i> Involvement in an NGO support group for PLHIV helped make Sandra feel a bit better after she was diagnosed.	The support of friends was instrumental in Beatriz coming to terms with her HIV status. None of Beatriz's four children know her HIV her sex work status and no one knows that she is on ART. She went to a support group for four months, but grew tired of it because she did not receive any of the money that they collected.
Environmental	Despite being referred to care at diagnosis, Elena delayed until her aunt, a nurse, brought her to care. In health services she explained, <i>"There are people in the hospitals that treat you at a bit of a distance once they learn you are [HIV-positive]."</i> Within her HIV clinic, however, Elena feels she is treated well and treat her with kindness and like family. She is, however, frustrated by the long delays and lack of available medications.	Sandra had previously tested negative when she tested positive at a mobile testing unit. She did not receive pre-test counseling, but she received counselling with her diagnosis. She later attended HIV services for 2-3 months, but became frustrated by the long lines and being forced to go to so many places. Despite the waits, she felt that the care providers in the HIV clinic were very good.	Beatriz was told to test for HIV when she was five months pregnant. They first told her that the test was damaged and re-tested her, delaying her diagnosis by about 10 days. <i>"When they told me what I had I left running like a madwoman. They grabbed me and I started to yell, to shout out and the doctor began to hug me and console me... I was reflecting and I found myself in the hands of a friend, that she was my friend, my confidante, my everything. She has helped me a lot and has given me a lot of advice."</i> Beatriz attended HIV services, but was frustrated that they only gave prescriptions and not the actual medications other than ART.
Structural	A nurse disclosed Elena's HIV status in her	Sandra was referred to care, but <i>"the truth is that</i>	Beatriz experienced discriminatory care at the

	community. Elena's entire community knows she has HIV and discriminated against her and her children.	<i>when they gave me all of this advise I said yes, but later I did not take care of myself because I was afraid that people would know that I live with the illness. Because nowadays people discriminate against one for being a sex worker or also if one is HIV-infected."</i>	dentist and, as a result, has not returned in two years.
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	Luciana	Maria	Alma
Current engagement with HIV services	Luciana was tested after feeling ill in 1998. She began ART in 2004 and now has reached viral suppression on treatment.	Maria was diagnosed after feeling ill in 2000. She started ART the same year. She left treatment for a period, but is now on a second-line ART regimen.	Alma was diagnosed in 2008 after she and her partner became ill. She is on ART, but has poor adherence.
Individual	When diagnosed, Luciana was worried that her partner and child would test positive and was relieved that they did not. She draws strength from her relationship with God and feels well. <i>“I feel good and healthy and I say thanks to God for this and to the doctors and these medicines that have helped me that, thank God, my viral load is undetectable.”</i> While she sometimes lacks money to get treatment, she is supported by nurses. She has come to terms with living with HIV and is thankful that she has been able to meet many friends and projects. She does, however, see the need to attend clinic appointments is a barrier for employment.	Maria was motivated to test because she had lost over 50 pounds. Although her CD4 count was okay, Maria insisted on starting treatment because of the weight loss. Despite the doctor’s warning that the treatment was life-long, Maria ran out of money and defaulted from treatment. Maria has been re-initiated onto second line therapy, but still struggles with adherence. She has gone up to five days without taking treatment and they are probably going to change her regimen again. She knows that this will be her last possible regimen and that regimen changes are caused by not taking treatment.	Alma was motivated to test because she heard that her partner had AIDS and she felt sick for two years. She was worried that she had cancer and went to an oncologist. Alma was relieved to have HIV, <i>“I prefer to have AIDS, it is less rare [than cancer].”</i> Alma was very angry and decided to kill her partner, but later decided that it was not worth going to jail. She is now on treatment and feels that she is a healthy woman. Sometimes she grows tired of daily ART, though, and decides that she will not take any of her treatment. When she goes up to a week without taking ART it is because <i>“I forget, I get tired of taking many pills”</i> .
Interpersonal	Luciana has disclosed her HIV status to most of her family, including her children. She is a member of a support group in the clinic, <i>“I receive a lot of love, a lot of kindness from the group.”</i> She has a large group of friends that she met through the group, but many of them have died. When they die, <i>“I feel really upset. I feel melancholy. You feel that they were your friend and more than your friends, your sisters because in reality it is the same blood that runs through our veins.”</i>	Maria was with her brother when her HIV-positive diagnosis was confirmed. He has helped her a lot, but her family is less supportive, <i>“they do not discriminate against me but it is not normal either... If I come to the doctor and they tell me something I speak with [my brother] and I say, ‘look. This is happening to me’ or ‘I feel in such a way’”</i> . Maria has not told her children that she has HIV, but they see her take her treatment and remind her when she misses it. She has also received support from a peer navigator. She attended a support group for a while, but she grew tired of it.	Alma came to terms with her diagnosis by thinking of her friends who had HIV, <i>“I have a friend who has had AIDS for 15 years... then I said, fine, if she is living, why can’t I live?”</i> Alma has told all of her family her HIV status and many of her friends, but not her boyfriend of two years. Her family and friends treat her well and provide her with some financial support when she needs it. Alma has a good relationship with a peer navigator who told her where to go when she was diagnosed. Alma has attended a support group at a church where members are occasionally given money.
Environmental	Luciana did not receive any pre- or post-test counseling. She was initially told that her test was damaged, <i>“but I knew this little trick”</i> . Her HIV-positive test results were given to her cousin. Luciana initially experienced side-effects on	Maria did not receive any pre-test counseling, but she was referred to HIV care when she tested positive. Maria was treated well when she was diagnosed. Maria has been happy with the care she receives	When Alma tested for HIV, the oncology clinic called her daughter and told her that Alma’s test was damaged. Alma went to the clinic, but they would not give her the HIV test results. The clinic then told her daughter that Alma had HIV.

	<p>treatment, but the doctors switched her regimen and she feels better. She is very happy with the care that she receives in the ARV clinic and feels she is treated with love and kindness. <i>“Sometimes I do not have money to come and look for [ART] in the HIV clinic and I call one of the nurses that works here, ‘Look. I only have tonight’s [ART] left and I cannot come to look for it tomorrow because I do not have money. Do me a favor and bring it to me... And thank God that she supports me. And she makes me get it.”</i></p>	<p>from clinicians, but she developed drug-resistance from defaulting treatment after being unable to pay for private care. Despite financial problems, <i>“the doctor who attends me told me that ‘when you don’t have money you come with what you have and I will help you. I will not abandon you.”</i> Maria did not want to have to look for money each month so she switched to a public clinic where the doctor <i>“is very good. He helped me a lot”</i> and helped switch her to an effective regimen.</p>	<p>Alma receives good care at her clinic, but the doctor sometimes gets mad at her when she forgets her ART. She has missed treatment various times, including collecting it 15 days late.</p>
Structural	<p>Luciana did not describe experiences of stigma and discrimination.</p>	<p>Many people in Maria’s community gossiped about her when she lost weight. A neighbor of hers also called Maria’s partner and told him that Maria had AIDS. Maria has also been gossiped about at her local shop. Additionally, she has been sent away from a non-HIV doctor who did not want to perform an operation on her. One of Maria’s biggest barriers to ART adherence is lack of food.</p>	<p>Alma did not describe experiences with stigma and discrimination.</p>

	Mariana	Gabriela	Agustina
Current engagement with HIV services	Mariana tested positive in 1998 after her partner became sick and tested HIV- positive. She has been on ART since 2005 and is adherent.	Gabriela tested positive in 2004 after she lost weight. She has been on ART since 2008, but is only moderately adherent.	Agustina was diagnosed in 2005 while pregnant. She began ART the same year and takes her treatment every day.
Individual	Mariana was very depressed when she tested positive and had little knowledge of HIV. She later felt better and went to trainings about HIV. She is not paid for her work as a home visitor to PLHIV, but she is fulfilled by it.	Gabriela tested for HIV after giving birth. She had already been breastfeeding and her child died of HIV when he was one year old.	Agustina was very depressed when she was first diagnosed. She later became involved with a network of FSWs. She now takes her treatment every day, although she takes it at different time, depending on if she is working.
Interpersonal	Mariana's partner knew her status and also had HIV, but he later died. She was, depressed, but then met a peer navigator who connected her to support groups. She later trained to work with PLHIV and provide support to others. Mariana has disclosed her HIV status and sex work status to her two children. Mariana's daughter helped her to stay adherent when she had terrible side-effects during her first weeks on ART <i>"there was a moment when I said I am not going to take them. I got up and my daughter was my great accomplice... my daughter was in charge of giving me the pill"</i> . Her daughter still sometimes calls to remind her to take her ART. Her children's father has, however, provided her with invaluable support and told her <i>"you are not alone. You can count on me. This word is very valuable when someone tells you this."</i> She continues to have economic challenges and cannot always afford to have laboratory tests done.	Gabriela's parents know her HIV status, but not her daughters. She has only told one friend who also has HIV, but many people know her status because they saw her when she was very ill. Her parents are very supportive of her and she has a close relationship with her mother who knows about her sex work.	A peer navigator and network of FSWs have been very important in Agustina accepting her HIV status, <i>"They are my support and later they have sustained me, they have given me strength and I have continued ahead."</i> She has also learned a lot about HIV from the organization. Agustina has other friends who are FSWs living with HIV and they help one-another and loan each other money and treatment. Agustina was also connected to a psychologist through her peer navigator who helped her understand that she is not going to die soon and <i>"this is nothing, that this is like any other illness and what I have to do is take care of myself."</i> In addition to these friends, Agustina's mother, partner, and pastor know that she is positive, but her children do not. Her husband works to support her and her children, but there have been some difficult times like when he was laid off. When this happened, Agustina's friends gave her money <i>"to go to collect my treatment and sometimes I did not have transport money and they gave it to me."</i>
Environmental	Mariana's partner tested positive for HIV, but no one gave them counseling or explained what that meant. Mariana paid to be tested for HIV at the lab after her partner tested positive. The person who tested her put two gloves on each hand and a mask. The doctors first told her that her test was	Gabriela was instructed to test for HIV in 2004 after she had post-partum stomach problems. She experienced a delay in getting her result because the doctor, <i>"told me no, we will not give [the results] to you. You have to look for your mom or dad."</i> She went crying to get her mother, but the	Agustina was diagnosed in 2006 when pregnant. They did not tell her that she was positive when she tested at 2-3 months gestation, but she was sent to get medicine. She tested for HIV again at 7 months and tested positive. <i>"When you are pregnant they do all of the tests, then when they</i>

	<p>damaged. Mariana went to the hospital and lied she was her sister and said that she was collecting Mariana's results. They gave her a stapled paper that she opened when she got home and it said reactive. <i>"They never gave me a talk or told me, what was HIV? What was AIDS?"</i></p> <p>Mariana delayed attending HIV services, but is now very happy with her clinic. She works as a peer educator in the clinic and started ART in 2005. Initially she had horrible side effects, <i>"you have to understand the importance of the medications because if not you can get to a point when you have been taking them for two weeks and you say 'I am not going to take them anymore."</i> The side-effects subside and Mariana takes her treatment well. The only challenge she had was when there was an ART shortage and she was only given 15 days of ART instead of 2 months. This cost a lot in transportation.</p>	<p>doctor was gone when they arrived at the clinic. It was a Friday so on Monday her father went to get the result. Her father told her that it was something of the stomach and that she had to go somewhere they would cure her. She was brought to an HIV clinic to meet with a psychologist. She saw many signs about HIV and she asked her dad, <i>"do I have this? And he said no. Don't worry. They are going to cure you."</i> The psychologist told her she was HIV-positive and provided her with counseling.</p> <p>Gabriela attended HIV services and later started ART in 2008 when her CD4 count was 47. She is still on ART, but she sometimes goes to bed without remembering to take her treatment.</p>	<p><i>did the analysis I was positive, but the doctor did not want to tell me anything. He told me to come here [to HIV clinic]"</i> where she received a prescription for medicine.</p> <p>When she was at the hospital to give birth, she was discriminated against. Agustina was sent to many different clinics post-partum. She would arrive somewhere and they would send her to a different clinic. A friend finally introduced her to a peer navigator who brought her to an HIV clinic. Agustina is really happy with the care that she receives in the HIV clinic and she has an undetectable viral load on treatment. It is, however, frustrating when they sometimes are low on treatment and only give one month supplies since it costs the same amount to get less treatment. Additionally, Agustina has to pay to see the doctor and for medications.</p>
Societal	<p>Mariana was discriminated against by her mother and sisters who would not let her spend time with her nephews. Her mother told many people in the community that Mariana had AIDS and was dying. Mariana educated them and their relationship has improved.</p>	<p>Gabriela's neighbors learned her status when she was very sick and many of them have discriminated against her.</p>	<p>Agustina did not describe experiences with stigma and discrimination.</p>

	Ana Sofia	Fernanda
Current engagement with HIV services	<p>Ana Sofia was diagnosed with HIV in 1996 when she was pregnant. She attended HIV services and was initiated onto treatment in 2009, but quit in 2010. She is not longer attending HIV care.</p>	<p>Fernanda was diagnosed in 2003 when she was pregnant. She is now in HIV care and on ART.</p>
Individual	<p>Ana Sofia was diagnosed when she was 7 months pregnant. At the time, she did not know what HIV was, <i>"When she told me that I had the virus I said, what was that, the HIV virus, AIDS?"</i> She prayed that her baby would be born negative, but the child was not.</p>	<p>Fernanda was depressed and suicidal after her HIV diagnosis as a teenager. She gave birth to her baby who was HIV-negative, but the baby died after ten days which left her very depressed.</p>
Interpersonal	<p>Ana Sofia did not tell her family her HIV status, but her sister figured it out and told her family. Her daughters know that she has HIV, but not that she is a FSW. Her partner at the time of diagnosis knew that he had infected her and</p>	<p>Fernanda was with her nephew when she received her HIV test result. She went to go jump from a bridge, but could not leave him, <i>"If it were not for him I think that I would be dead now because I was determined to throw</i></p>

	<p>they stayed together for 11 more years.</p> <p>Ana Sofia has a good relationship with a peer navigator and actively participates in a support group for FSWs living with HIV.</p>	<p><i>myself from a bridge.”</i></p> <p>Later, she was brought by two peer navigators to HIV service. The navigators treat her well. There is, however, a lot of competition with other FSWs. Fernanda has also told her entire family and many friends her HIV status. She is a part of a support group at her clinic.</p>
Environmental	<p>Ana Sofia tested positive when she was pregnant. She had previously tested negative when required to test by her employer at a sex establishment. She did not receive pre-test counseling and was given her result by the secretary, along with a letter to give the doctors when she was in labor. She gave the letter to the doctors, but they did not pay attention to it and she gave birth vaginally without precautions.</p> <p>Ana Sofia was not provided with a referral for herself, but was given one for her daughter. She was later brought to a clinic by a peer navigator. Ana Sofia was initiated onto ART in 2009 and remained on treatment for one year. She complained that they often just gave prescriptions instead of the medication, <i>“You still go to the doctor and there is not a pill to give you, there never is; they give you a prescription so that you buy it because they never have even acetaminophen to give you.”</i> She later stopped attending because the clinic staff did not help her to deal with side effects. She was dizzy and had blisters on her skin, but they did not change her regimen so she thought, <i>“fine, if you are not going to change [my ART regimen] I am not going to keep coming.”</i></p>	<p>Fernanda was seven months pregnant when the doctor sent her to do tests. She received pre-test counseling, but was then made to take three HIV tests, going back and forth to the clinic. She was then told that she did not have anything, but that she had to come to the clinic with her mother. She had another friend have the same thing happen to her who ended up having HIV so Fernanda said to the doctor, <i>“If I have AIDS, tell me”</i> and the doctor told her that she had HIV. She received counseling that was good, <i>“they spoke to me well, they treated me well”</i></p> <p>She delivered through a cesarean section. When she was in the hospital recuperating the staff treated her very well and brought her food from outside of the hospital. They said her daughter was negative and that she could take her home, but she became ill and was brought back to the hospital where she died. She later was brought to an HIV clinic and started treatment. Initially, she had many side-effects when she first started treatment like dizziness, diarrhea, but after five months this passed.</p>
Structural	<p>Ana Sofia’s partner wanted to kill the woman who he believed infected him, but she was beaten by another man who she infected. Maribel’s partner’s family initially blamed her for his diagnosis <i>“because they that that since I am in the street [a FSW], they thought that it was me, being in the street, that it was me who infected him”</i>, but later realized it was not her who infected the man. Ana Maria frequently hears people gossiping about her HIV status and they ask her if it is true that she has HIV and she tells them that it is.</p> <p>Ana Sofia struggles has encountered many structural barriers to ART adherence, <i>“I left treatment because I did not have adequate food to take that medication and it was very potent and I said, ‘they still give me the medication. And with what, at least, with what am I going to nourish’ ”.</i> Additionally, it was difficult to take ART when she was drinking alcohol with work, <i>“you are in business, taking medication, having mala noche [nights out as a FSW]. It is not obligatory, but sometimes you have to drink drinks for the power to do things. I had to quit it when I through myself back on the streets, I had to quit it.”</i></p>	<p>Fernanda confronts considerable stigma related to her HIV status. She has been blamed by her exes’ family, <i>“they hate me because they think I killed their child, I said to her that what killed was the sickness, it wasn’t me.”</i> She does not tell her sexual partners because, <i>“they will kill me. They speak very poorly about people with HIV”.</i></p>

	Alejandra	Emilia
Current engagement with HIV services	Alejandra was diagnosed in 2003 when her partner was sick. She did not attend HIV services and became very ill and later tested positive again while pregnant.	Emilia was diagnosed with HIV in 2006. She has not attended health services in more than two years and is not on treatment.
Individual	Alejandra was very depressed when she learned her status, <i>"I arrived at my house and threw myself on the floor and it gave me depression."</i> She later became depressed again when the father of her daughter died. Now on treatment, Alejandra still sometimes has side-effects like nausea and pain, but she continues to take her treatment.	Emilia has been very depressed and suicidal. Emilia does not think about her HIV infection and continues to lead a normal life, <i>"I say that this illness is mental...this health condition... for me it is mental"</i> . Rather than going to the clinic, Emilia said, <i>"I take vitamins, I eat well. I have never had a crisis, never. I have never had the necessity."</i> She is, however, very active in various activities related to HIV like rapid testing on the beach and giving out brochures. She has a lot of books and brochures about HIV like nutrition and treatment.
Interpersonal	Alejandra decided to test for HIV because her partner was sick and another partner gave her money to test. Alejandra accessed HIV care with the help of a peer navigator who made her a clinic appointment and paid for her transportation. She also has been a member of a support group for a long time which makes her feel better and <i>"explains that this [HIV] is nothing, because there are a lot of people that have it, that have it and do not know"</i> . Many people in her community know her HIV status, including her family who she has told so that they hear it from her instead of from others. Her children do not know, but she thinks that the older daughter might because she brings Alejandra her ART.	Emilia tested for HIV after her partner tested positive. He accused Emilia of infecting him and threatened to kill her. Emilia's partner also told her entire family that she had HIV and they subsequently ended their relationship. Someone saw Emilia crying outside of the clinic when she was diagnosed and they helped her to understand, <i>"I would have gone to kill [my partner]. If I had not gotten this educator, I don't know where... I would have been imprisoned a long time ago."</i> In addition to this support, Emilia's sister and daughter have helped her and know her HIV status, <i>"I wanted to die in that moment I had depression, I wanted to die, but my sister helped me and told me that no, that I am going to get up and everything was going to continue normally."</i> Emilia has also participated in many support groups.
Environmental	Alejandra first tested positive in 2003, but she did not attend HIV services. She became pregnant and tested positive again. She had a c-section and they gave her daughter treatment. They sent a psychologist to her when she was in the hospital post-partum. She entered HIV care, but later left when she became convinced by a fake doctor that he had a cure for HIV. Alejandra later returned to care and was initiated onto treatment. She initially experienced a lot of side-effects such as dizziness and fever and had her regimen switched. Alejandra now has an undetectable viral load and she is very happy with the care that she receives, <i>"because if someone comes with a problem, once they look for a psychologist for you, she immediately leaves what she is doing and attends to one, you see, they bring you help."</i>	After her diagnosis, Emilia attended HIV services, but she has not returned because she saw many people that she knows at the clinic.
Structural	Many people in Alejandra's community know her HIV status because it was disclosed by a hospital nurse. They also could tell because, <i>"people when they see someone lose weight it is AIDS, not one is going to think she has cancer."</i>	Emilia had her HIV status disclosed at her local salon by a woman who worked in the laboratory where she was tested. Many people know that she has HIV because of the activities she participates in and have told others.

Appendix B. Sociodemographic and clinical characteristics of 268 female sex workers living with HIV in Santo Domingo in the Abriendo Puertas cohort

Table B.1 Sociodemographic and clinical characteristics of 268 female sex workers living with HIV in Santo Domingo in the *Abriendo Puertas* cohort

N	268
Predisposing Sociodemographic Factors	
Age (years)- Median (interquartile range [IQR])	36 (30, 42)
Single- n (%)	51 (19.0)
Education- n (%)	
Primary	167 (63.7)
Secondary	81 (30.9)
University	14 (5.3)
Lives alone- n (%)	34 (12.7)
Number of children- Median (IQR)	3 (2, 4)
Health Need	
Positive test (year) - Median (IQR)	2008 (2005, 2010)
Previous tuberculosis infection- n (%)	26 (9.7)
STI/ STI symptom in last 6 months- n (%)	134 (50.0)
Perceived health status is good or better - n (%)	164 (61.2)
Enabling Factors	
Disclosed HIV status - n (%)	257 (95.9)
Has medical insurance- n (%)	153 (57.1)
Perceived quality of HIV services- n (%)	
Excellent	86 (35.4)
Very good	62 (25.5)
Good	52 (21.4)
Adequate	20 (8.2)
Poor	23 (9.5)
Perceptions of HIV service provider scale- Median (IQR) ³	26 (24, 31)
Travel time to clinic (minutes) - Median (IQR)	60 (30, 90)
Roundtrip travel cost to clinic (US dollars) - Median (IQR)	2.5 (1.5, 3.8)
Experience of HIV-related discrimination in clinic- n (%)	77 (28.7)
Experience of FSW-related discrimination in clinic- n (%)	40 (14.9)
Vulnerability	
Age when started TRSX (years)- Median (IQR)	18 (15, 24)
Duration as TRSX (years)- Median (IQR)	15 (8, 21)
Establishment-based SW- n(%)	114 (42.5)
Moved cities in last 12 months- n (%)	29 (10.8)
Average monthly income from TRSX (US dollars) - Median (IQR)*	325.0 (162.5, 541.6)
Use of any drug in last 6 months- n (%)	22 (8.2)
Lifetime use of any drug- n (%)	65 (24.3)
Alcohol consumption in last month- n (%)	161 (60.1)
HIV self-stigma scale score- Median (IQR)	18 (14, 21)
FSW self-stigma scale score- Median (IQR)	18 (14, 22)

Rose Zulliger

rzulliger@jhu.edu
624 N. Broadway, Room 904
Baltimore, MD 2105
614-937-0128

PROFILE

Implementation scientist with expertise in qualitative, quantitative, and cost evaluation of public health programming, as shown through authorship of eleven peer-reviewed articles. Extensive experience in evaluation-informed program development, monitoring and strengthening within low-resource contexts.

EDUCATION

Doctor of Philosophy

2011- 2014

Health, Behavior and Society, Johns Hopkins School of Public Health

Grade Point Average: 4.0

- *Dissertation:* Experiences with engagement in HIV services among female sex workers living with HIV in Santo Domingo
- *Coursework included:* Fundamentals of Program Evaluation; Translating Research into Public Health Programs I & II; Concepts in Qualitative Research for Social and Behavioral Sciences; Statistical Methods in Public Health I-IV; Statistics for Psychosocial Research Methods; Analysis of Longitudinal Data; Multilevel Statistical Models in Public Health
- Co-chair of departmental student organization (2012-2013)
- Recipient of USAID | Project SEARCH: Research to Prevention Doctoral Student Publication Initiative Award (2012-2014); Doctoral Distinguished Research Award (2013-2014); and full departmental scholarship (2011-2014)

Masters in Public Health

2010 – 2011

University of Cape Town, South Africa

- *Thesis:* “She is my teacher and if it was not for her I would be dead”: Exploration of rural South African community health workers’ informational and mediating roles in the home
- *Coursework included:* Biostatistics 1 & 2; Epidemiology of Infectious Disease; Qualitative Research Methods; Quantitative Research Methods; Introduction to Health Systems Research and Evaluation

Bachelor of Arts- Public Health Studies

2003 – 2007

Johns Hopkins University

- *Graduate level coursework included:* Epidemiology and Public Health Impact of HIV/AIDS; Ethics of Public Health Practice in the Developing World; Urban Health in Developing Countries; Fundamentals of Health Education and Health Promotion
- Conducted research on medical pluralism in rural Bolivia with the School for International Training (2006)

PROGRAMMATIC AND ANALYTIC SKILLS

- Quantitative data analysis
- Qualitative data analysis
- Cost analysis
- Evaluation-informed program design
- Program evaluation
- Cost-utility evaluation

EVALUATION EXPERIENCE

- Conducted cost evaluation and projected scale-up costs and impact of contraceptive promotion campaign in Nigeria (2014)
- Developed and trained staff on monitoring and evaluation (M&E) system for multi-level intervention with female sex workers (FSWs) living with HIV in Santo Domingo, Dominican Republic (2012-2014)
- Managed cost evaluation of HIV testing initiative with men at clinics in 12 states within the United States (2013-2014)
- Provided technical assistance to the International Rescue Committee in the development of evaluations to determine programmatic effectiveness in Baltimore, Maryland (2013-2014)

- Developed and managed cost-utility, qualitative and quantitative evaluation of program to rapidly initiate pregnant women onto antiretroviral therapy in Cape Town, South Africa (2011-2012)
- Developed M&E system and trained staff of community-based organization working in rural South Africa (2007-2009)
- Developed project and associated evaluation plan to open 30 libraries in four provinces of South Africa (2008)

RESEARCH AND PROGRAMMATIC EXPERIENCE

SPPH/CDC Allan Rosenfield Global Health Fellow

2014- Present

Centers for Disease Control and Prevention

Maputo, Mozambique

- Coordinate, implement, monitor and analyze sentinel surveillance of quality of clinical care provided in scale up of public sector antiretroviral therapy program in Mozambique, including longitudinal analysis of aggregate and patient level data

Consultant

2014

Center for Communication Programs

- Led cost evaluation of interpersonal change agent program to promote contraceptive uptake in 16 states of Nigeria
- Estimated the cost, feasibility and expected impact of different models of programmatic scale-up to 30 states of Nigeria

Research Assistant

2012 – 2014

Johns Hopkins Bloomberg School of Public Health (JHSPH)

- Technical assistance in the development, implementation and evaluation of a USAID-funded, multi-level intervention and mixed methods cohort study with 268 female sex workers (FSWs) living with HIV in Santo Domingo, Dominican Republic
- Assistance with grant-writing to support scale-up of evidence-based intervention with HIV-positive FSWS
- Qualitative analysis of experiences of 31 key informants, 44 HIV-positive FSWS, 31 HIV-positive men who have sex with men and 9 HIV-positive transgender women in Santo Domingo, Dominican Republic
- Cost analysis of data from 17 US clinics enacting a CDC-funded HIV testing initiative with men who have sex with men
- Qualitative analysis of clinic experiences with HIV testing initiative among men who have sex with men in Chicago, Illinois
- Qualitative analysis of 90 in-depth interviews on barriers to male use of health services in Rakai, Uganda
- Quantitative analysis of 2,064 person survey of intimate partner violence in the Democratic Republic of Congo

Consultant

2012 – 2013

University Research Corporation; JHSPH

- Assisted with creation of guide for developing and strengthening community health worker (CHW) programs
- Conducted literature review and government stakeholder interviews to develop profiles of five national CHW programs
- Facilitated Delphi Process with national policy makers from 14 countries to inform CHW policy decision-making tool
- Developed report on the contribution of CHWs to meeting the health-related Millennium Development Goals

Consultant

2011

International Center for AIDS Care and Treatment Programs (ICAP), **Columbia University**

- Conducted analyses on the implementation, acceptability and feasibility of expedited patient initiation onto antiretroviral therapy (ART) and on infant feeding during pregnancy in Cape Town, South Africa

Researcher

2010 – 2011

Centre for Infectious Disease Epidemiology and Research (CIDER), **University of Cape Town**

Cape Town, Western Cape, South Africa

- Hired, trained and supervised qualitative and quantitative data collection team
- Assisted with grant writing to support implementation research on expedited ART initiation in pregnancy
- Co-investigated studies on CHWs, pregnant women and ART including:
 - Inventory of 138 health-related non-profit organizations in three sub-districts of South Africa
 - Survey of ART initiation guidelines and patient education programs in Western Cape
 - Retrospective cohort study of ART patient outcomes based on duration of patient preparation in Cape Town
 - Mixed methods study of infant feeding among 406 HIV-positive women in Cape Town

Research Coordinator

2008 – 2009

Rural AIDS Development Action Research (RADAR), University of Witwatersrand

Acornhoek, Mpumalanga, South Africa

- Hired, trained and supervised qualitative and quantitative data collection team
- Coordinated studies on TB suspect outcomes and diarrheal infection in an ART clinic in South Africa
- Assisted with development and implementation of study on the quality of care provided by CHWS in rural South Africa

Community HIV/AIDS Outreach Programmer & NGO Capacity Builder

2007 – 2009

United States Peace Corps

Acornhoek, Mpumalanga, South Africa

- Designed, piloted and evaluated a Life Skills Girls Club curriculum for 80 eighth grade girls in 2008 and trained teachers and CHWs to implement the curricula with 500 girls in ten schools in 2009 using funds obtained through PEPFAR small grant
- Developed and coordinated the Books for Peace Library Project to bring 30,000 library books to sustainably open libraries in 30 schools, including fundraising and management of over US\$15,000
- Developed template for replication and adaptation of the Books for Peace Library Project that facilitated its implementation in over 10 other African countries
- Served as NGO capacity builder for a community-based organization that supported orphans and provided home-based care services by CHWs, including coordination of distribution of food parcels, school uniforms and blankets to orphans

TEACHING EXPERIENCE

Johns Hopkins Bloomberg School of Public Health

- Lectured on decision support tools: decision tree analysis and on applications of cost evaluation (2014)
- Teaching assistant for Translating Research into Public Health Programs I & II (2013, 2014)
- Teaching assistant for Quantitative Methods for Tobacco Control (2013)

University of Cape Town

- Lectured on measures of disease frequency and on cohort studies (2011)
- Teaching assistant for Introduction to Epidemiology (2011)

University of Witwatersrand

- Delivered bi-weekly lecture on Home-Based Care to medical students (2009-2010)

FOREIGN LANGUAGES

- **Spanish**- Fluency in reading, writing, and speaking
- **Xitsonga**- Conversational in speaking

DATA ANALYSIS SOFTWARE SKILLS

- STATA 12.1
- NVivo 8.0
- Epi Info 3.5.1
- Ucinet 6
- Atlas TI 6.2.28
- TreeAge Pro 2014

SELECTED REPORTS AND BOOK CHAPTERS

- Tsui, S., Salisbury-Afshar, E., **Zulliger, R.**, & Perry, H. (In Press). Current Perspectives of Large Scale Community Health Worker Programs: Summary of Findings from Key Informants Opinions. In H. Perry & L. Crigler (Eds.), *Developing and Strengthening Community Health Worker Programs at Scale: A Reference Guide for Program Managers and Policy Makers*. Washington, D.C.: MCHIP.
- Perry, H., **Zulliger, R.**, Scott, K., Javadi, D., & Gergen, J. (In Press). Case Studies of Large-Scale Community Health Worker Programs: Examples from Bangladesh, Brazil, Ethiopia, India, Iran, Nepal and Pakistan. In H. Perry & L. Crigler (Eds.), *Developing and Strengthening Community Health Worker Programs at Scale: A*

Reference Guide for Program Managers and Policy Makers. Washington, D.C.: MCHIP.

- Kennedy, C., Barrington, C., Donastorg, Y., Perez, M., Fielding-Miller, R., Mnisi, Z., Adams, D., Dlamini, B., Baral, S., **Zulliger, R.**, & Kerrigan, D. (2013). *Exploring the Positive, Health, Dignity and Prevention needs of female sex workers, men who have sex with men and transgender women in the Dominican Republic and Swaziland.* Report prepared for USAID | Project SEARCH. Baltimore, MD: CCP.
- Perry, H. & **Zulliger, R.** (2012). *How effective are community health workers? An overview of current evidence with recommendations for strengthening community health worker programs to accelerate progress in achieving the health-related Millennium Development Goals.* Report prepared for the MDG Health Alliance. Baltimore, MD: Johns Hopkins Bloomberg School of Public Health.
- Babalola, S. & **Zulliger, R.** (2012). *Baseline survey on the factors underlying sexual and gender-based violence in Eastern DRC.* Report prepared for the International Medical Corps. Baltimore, MD: CCP.

PEER-REVIEWED PUBLICATIONS

- Zulliger, R.**, Barrington, C., Donastorg, Y., Perez, M., Kerrigan, D. (under review). High drop-off along the HIV care continuum and ART interruption among female sex workers in the Dominican Republic
- Zulliger, R.**, Kennedy, C., Perez, M., Donastorg, Y., Kerrigan, D. (under review). Experiences of female sex workers living with HIV along the HIV care continuum in the Dominican Republic
- Zulliger, R.**, Maulsby, C., Barrington, C., Donastorg, Y., Perez, M., Kerrigan, D. (under review). Retention in HIV care among female sex workers in the Dominican Republic: implications for research, policy and programming.
- Perry, H., **Zulliger, R.**, & Rogers, M. (2014) Community health workers in low-, middle- and high-income countries: An overview of their history, recent evolution, and current effectiveness. *Annual Review of Public Health.*
- Zulliger, R.**, Moshabela, M., & Schneider, H. (2014). "She is my teacher and if it was not for her I would be dead": Exploration of rural South African community health workers' information, education and communication services. *AIDS Care*, 26(5), 626-632.
- Black, S., **Zulliger, R.**, Myer, L., Marcus, R., Mark, D., & Bekker, L.G. (2014). Acceptability and challenges of rapid ART initiation among pregnant women in a pilot programme, Cape Town, South Africa. *AIDS Care*, 26(6), 736-741.
- Zulliger, R.**, Abrams, E.J., & Myer, L. (2013). Diversity of influences on infant feeding strategies in women living with HIV in Cape Town, South Africa: a mixed methods study. *Trop Med Int Health*, 18(12), 1547-1554.
- Zulliger, R.**, Black, S., Holtgrave, D.R., Ciaranello, A.L., Bekker, L.G., & Myer, L. (2013). Cost-effectiveness of a package of interventions for expedited antiretroviral therapy initiation during pregnancy in Cape Town, South Africa. *AIDS Behav.* doi: 10.1007/s10461-013-0641-7
- van Pletzen, E., **Zulliger, R.**, Moshabela, M., & Schneider, H. (2013). Non-profit organizations in the health sector: case studies and organizational networks of three South African communities. *Health Policy and Planning.* doi: 10.1093/heapol/czt058
- Black, S., **Zulliger, R.**, Myer, L., Marcus, R., Jeneker, S., Taliep, R., . . . Bekker, L. G. (2013). Safety, feasibility and efficacy of a rapid ART initiation in pregnancy pilot programme in Cape Town, South Africa. *S Afr Med J*, 103(8), 557-562.
- Myer, L., **Zulliger, R.**, Bekker, L. G., & Abrams, E. (2012). Systemic delays in the initiation of antiretroviral therapy during pregnancy do not improve outcomes of HIV-positive mothers: a cohort study. *BMC Pregnancy Childbirth*, 12(1), 94.
- Myer, L., **Zulliger, R.**, & Pienaar, D. (2012). Diversity of patient preparation activities before initiation of antiretroviral therapy in Cape Town, South Africa. *Trop Med Int Health*, 17(8), 972-977.
- Boniface, R., Moshabela, M., **Zulliger, R.**, Macpherson, P., & Nyasulu, P. (2012). Correlates of delayed diagnosis among Human Immunodeficiency Virus-infected pulmonary Tuberculosis suspects in a rural HIV clinic, South Africa. *Tuberc Res Treat*, 2012, 827148.
- Myer, L., **Zulliger, R.**, Black, S., Pienaar, D., & Bekker, L. G. (2012). Pilot programme for the rapid initiation of antiretroviral therapy in pregnancy in Cape Town, South Africa. *AIDS Care*, 24(8), 986-992.

SELECTED CONFERENCE ORAL PRESENTATIONS

- Zulliger, R.,** Barrington, C., Perez, M., Donastorg, Y., & Kerrigan, D. (2013). *Barriers on the way to treatment: Experiences of female sex workers, men who have sex with men, and transgender women along the treatment cascade in Santo Domingo, Dominican Republic*. Paper presented at XI International AIDS Impact Conference, Barcelona, Spain.
- Zulliger, R.,** Perez, M., Barrington, C., Donastorg, Y., & Kerrigan, D. (2013). *“People discriminate against one for being a sex worker and also for being infected with HIV”: Experiences of stigma among female sex workers living with HIV in the Dominican Republic*. Paper presented at IX International Association for the Study of Sexuality, Culture and Society, Buenos Aires, Argentina.
- Zulliger, R.,** Bekker, L.G., Godwana, S., Abrams, E.J., & Myer, L. (2012). *Infant feeding perceptions and experiences among HIV-positive women in Cape Town, South Africa*. Poster presented at XIX International AIDS Conference, Washington, DC, USA.
- Zulliger, R.,** Pienaar, D., & Myer, L. (2011). *Diversity of Strategies for Preparation of Patients Initiating Antiretroviral Therapy in Cape Town, SA*. Paper presented at X International AIDS Impact Conference, Santa Fe, NM, USA.
- Zulliger, R.,** & Moshabela, M. (2009). *Care in the Home Revisited*. Paper presented at IX International AIDS Impact Conference, Gaborone, Botswana.

JOURNAL PEER REVIEWER

- PLoS ONE
- AIDS and Behavior
- BMJ Open
- BioMed Research Journal
- BMC Pediatrics
- BMC Pregnancy and Childbirth