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Internalized Stigma among HIV-Positive Men on Antiretroviral Therapy in Urban India

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Internalized Stigma among HIV Positive Men on Antiretroviral Therapy

in Urban India

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Chapter One: Background & Significance

Stigma associated with HIV/AIDS is recognized as a significant barrier to the success of all aspects of HIV-related interventions globally. The damaging effects of stigma have been noted at structural levels in terms of punitive governmental policies and healthcare practices, and at the individual level, impacting HIV testing, mental health, antiretroviral treatment adherence, and the willingness to disclose HIV status.

Manifestations of stigma are often unique to specific social or cultural settings, such that differences in defining, measuring, and modeling stigma abound in the existing literature, resulting in the identification of many different types and categories of stigma in the context of HIV/AIDS. The broadest division of stigma is "Internal" (self-blame and guilt for one's HIV status) and "External" (discriminatory behaviors from other people or institutions toward HIV positive individuals), with many gradations between the two.

The aim of this thesis is to investigate the systemic, social, and behavioral correlates of "Internalized" stigma among HIV-positive adult men living in major urban centers in the State of Maharashtra, India using a mixed-method approach. All of the qualitative and quantitative data were gathered through an existing Indo-US, transdisciplinary research and intervention project entitled "*Alcohol and ART Adherence: Assessment, Intervention and Modeling in India*" (2014-2019; U01AA021990-01; S. Schensul, J. Schensul, N. Saggurti, A. Sarna, MPIs). The objectives of this thesis are to provide improve the approaches to characterize and measure Internal Stigma in the Indian context, identify the factors associated with greater or lesser internal stigma, and to build on existing approaches for reducing stigma through multi-level interventions.

Ahead of both tuberculosis and malaria, Human Immunodeficiency Virus (HIV) is the deadliest of the "Big Three" single-agent infectious diseases. HIV affects approximately 36.9 million people globally and claimed the lives of approximately 1.2 million people in 2014. Many of these deaths were the result of complications from Acquired Immune Deficiency Syndrome (AIDS), a condition caused by unmanaged infection with HIV (Bourzac, 2014; World Health Organization [WHO], 2015). HIV is an ongoing pandemic of the highest public health concern, with an approximate incidence of two million new cases diagnosed worldwide in 2014 (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2015a).

HIV infection is found in all regions of the world, yet the distribution of its burden is unequal. The great majority of HIV burden exists in Sub-Saharan Africa, carrying about 70% of all new cases, 65% of all deaths resulting from HIV complications, and a regional adult prevalence of around 5% (UNAIDS, 2015a). At the end of 2013, Sub-Saharan Africa was home to approximately 24.7 million people living with HIV (PLHIV). In the same year, the second highest global burden was in in the Asia/Pacific region, with an estimated 4.8 million PLHIV (UNAIDS, 2014b). Globally, women represent about 47% of all PLHIV, and children under the age of 15 account for 2.6 million, or about 7%, of known cases (UNAIDS, 2015a).

The primary groups of people most at risk of acquiring infection due to lifestyle exposures and disproportionally high rates of in-group seroprevalence are men who have sex with men (MSM), injection drug users (IDU), transgender people, and commercial sex workers (CSW). Unprotected heterosexual sex remains the principal transmission pathway in Sub-Saharan Africa and other areas, particularly in the context of long-term relationships (Fettig, Swaminathan, Murrill, & Kaplan, 2014).

Transmission of HIV is greatly enhanced when there are higher concentrations of the virus in the body, measured by "viral load." The risk of transmission also greatly increases when there is co-infection with other sexually transmitted infections (STIs), particularly with herpes simplex virus, bacterial vaginosis, or the presence of any type of open genital ulcer (Maartens, Celum, & Lewin, 2014).

The most damaging co-infectious relationship for PLHIV is that with *Mycobacterium tuberculosis* (TB). Globally, about one-third of all PLHIV are co-infected with TB due to their compromised immune systems and a resulting 20- to 37-fold increased chance of becoming infected with the bacteria. HIV and TB both exacerbate the effects of the other pathologically, yet tracking co-infection accurately is difficult because the presence of HIV obstructs the diagnosis of active TB (Getahun, Gunneberg, Granich, & Nunn, 2010). Approximately 26% of HIV/AIDS deaths worldwide are attributed to TB co-infection, representing the largest single cause. Of these deaths, 99% occur in resource-limited developing countries (Pawlowski, Jansson, Sköld, Rottenberg, & Källenius, 2012).

Epidemiology of HIV/AIDS in India

Despite having a low HIV prevalence of 0.26% (ages 15-49), a population of over 1.27 billion people places India third highest (and highest in Asia) in the ranking of countries of absolute number of HIV cases, currently estimated at 2.2 million PLHIV (Central Intelligence Agency [CIA], 2016; National AIDS Control Organization [NACO], 2015a). The national prevalence trend has been steadily decreasing since an estimated peak of 0.38% between 2001 and 2003. In 2015, there were approximately 86,000 new HIV infections. Children less than 15 years of age account for 6.54% of all PLHIV in India, and comprised about 12% of new infections in 2015 (NACO,2015a). Geographically, the state with the highest prevalence is

Nagaland (.88%), in the extreme northeast part of the country. Most of the states with a higher prevalence than the national level, however, are located in central and southern areas such as Andhra Pradesh (0.59%), Karnataka (0.53%), and Maharashtra (0.40%) (NACO, 2015b).

Within India, women comprise 40.5% of all PLHIV (NACO, 2015a), a proportion that has been increasing despite declines in the number of infections among female commercial sex workers (Schensul et al., 2006). This trend suggests that more women are being infected by males through sexual contact occurring within an "intimate partner" or heterosexual marriage relationship. Transmission of HIV within the context of a marriage relationship is now considered the primary HIV infection pathway for Indian women (UNAIDS, 2009a). Over 90% of HIV-positive females living in India indicate that they are married and practice monogamy, placing the likely source of HIV in men's extramarital sexual contact with an infected sex worker (UNAIDS, 2009a; Silverman, Decker, Saggurti, Balaiah & Raj, 2008). This same infection pathway mirrors a major source of HIV transmission married women elsewhere in the world, particularly in Sub-Saharan Africa and Southeast Asia (UNAIDS, 2009b; Ramjee & Daniels, 2013).

One significant exception to the heterosexual pathway of the virus in India is the presence of intravenous drug use (IDU) as the major risk factor in some Northeastern states. As of 2010-2011, the national HIV prevalence of IDU was 7.14% (Fettig et al., 2014; NACO, 2015b). Other high risk groups tracked by NACO and targeted for interventions include MSM (4.43% prevalence), Hijras and other transgender individuals (8.82%), long distance truckers (2.59%), and migrants (0.99%) (NACO, 2015b).

Antiretroviral Therapy: HIV as a Chronic Disease

Antiretroviral Therapy (ART) is a combination of drugs taken orally that suppresses the replication of HIV and it must be taken for the full extent of a patient's life. Early initiation and proper adherence to ART regimens greatly increases the overall health and survival those infected, and reduces the probability of further HIV transmission through a decrease in viral load (Deeks, Lewin, & Havlir, 2013). The increasing availability of ART globally has led to rapid declines in global mortality associated with HIV/AIDS, as well as declines in global incidence given the reduced chance of passing on the virus through sexual contact. ART has been shown to mitigate the susceptibility to opportunistic infections such as TB (World Health Organization, 2013a) and life-expectancy among PLHIV, even in high prevalence areas, is nearing that of the normal population. With decreasing mortality and greater life expectancy, the number of PLHIV (HIV prevalence) grows each year despite lower incidence rates. This increase in patients leads to an increasing burden for the Indian health care system as PLHIV must deal with aging, drug toxicity, and co-morbid conditions like cancer and cardiovascular disease (Deeks, Lewin, & Havlir, 2013; Fettig et al., 2014; Reynolds, 2011).

The clinical and public health successes of ART have led to the argument that the epidemiological profile of HIV now is more characteristic of a chronic disease (Deeks, Lewin, & Havlir, 2013; Maartens et al., 2014; World Health Organization, 2006a). Scandlyn (2000) and other anthropologists have noted that HIV as a "manageable" chronic disease is largely a Western construct and only possible in wealthy nations with relatively easy and consistent access to care and ART medications (Scandlyn, 2000). The large economic and social costs that individuals face in trying to access regular care in resource-poor, low-and-middle income countries (LMICs) does not allow them to live up to the "promise" of a normal life inherent to the Western idea of chronic diseases (McGrath et al., 2014). Some of the socioeconomic barriers

may be mitigated, however, with the availability of free or low-cost medications and public healthcare services.

ART Coverage and Delivery

As of yearend 2013, about 11.7 million people in LMICs globally were receiving ART, representing approximately 36% of PLHIV living in those areas. In high income countries (HICs), approximately 1.2 million, or 52% of PLHIV were accessing ART with consistent ART supply, advanced diagnostic capabilities, and general access to healthcare services (Sullivan, Jones, & Baral, 2014; World Health Organization, 2014). Despite great progress in global ART coverage, 64% of those infected in LMICs are not linked to care as a result of inadequate healthcare delivery systems. The continued spread of the virus among highly-stigmatized subgroups such as MSM, transgender or IDUs, the low coverage (24%) of ART in positive children, and lack of healthcare access in large special populations such as migrants and prisoners account for much of this gap in linkage to care (UNAIDS, 2014b).

ART delivery in HICs is characterized by a highly individualized approach involving specialized physicians located in centralized treatment facilities, early initiation of multiple ART regimens that are tailored to the clinical situation, the frequent monitoring of patient progress and viral load results, and the adaptation of drug regimens (switching to "Second line" ART) based on regular drug-resistance testing (Gilks et al., 2006; Maartens et al., 2014; Munderi, 2010).

In contrast, the delivery of care in LMICs has required an alternative, "public health approach" in order to get as many PLHIV treated as possible. This approach, introduced by the WHO in 2006, involves standardizing several aspects of HIV care: ART initiation (originally set at CD4 counts of 350), dosage of first line medications, limited clinical evaluation and CD4

monitoring, and population-based resistance management (WHO, 2006a). Care is recommended

to take place in decentralized facilities at the level of health districts by utilizing fewer

physicians and more nurses and community health workers (Gilks et al., 2006; Maartens et al.,

2014).

Evaluations of this public health approach to HIV treatment in LMICs have been

variable, with great benefits inherent to connecting more PLHIV with care, yet with a wide range

of early mortality numbers reported. This range may be due to later initiation of ART during

more advanced stages of HIV and the presence of deadly TB co-infections in extremely poor

areas (Bartlett & Shao, 2009; Gupta et al., 2011). The WHO has since addressed the former

mortality issue by altering clinical recommendations to begin ART treatment earlier, when CD4

counts are less than 500 (World Health Organization, 2013b).

Factors Impacting ART Adherence

Poor ART adherence directly influences the clinical progression of HIV by increasing

viral load, decreasing CD4 counts, increasing vulnerability to opportunistic infections, and

encouraging the development of viral mutations and drug resistance. These negative effects are

connected with the progression to AIDS and mortality (Kagee et al., 2011; Mannheimer et al.,

2005). Maintaining at least 90-95% adherence to a prescribed ART regimen is essential to the

success of the treatment for both PLHIVs' quality of life, and to the public health benefits of

transmission reduction and resistance control (DiIorio et al., 2009).

Several studies mentioned the need for 95% ART adherence in order to maintain viral

suppression, but this benchmark has been difficult to achieve for many PLHIV in diverse high-

income and low-income countries globally (Joglekar et al., 2011; Nachega et al., 2015). The

factors underlying ART adherence are extremely diverse and context-specific, ranging from macro-level structural and systemic barriers, to meso-level issues with communities and social support, and micro-level personal behaviors, coping mechanisms, and mental health.

Systemic and Environmental Factors

Inadequate funding of the healthcare system, delays in drug manufacturing, sociocultural barriers such as gender inequities, transportation limits, poor health literacy, food insecurity, and variable work schedules all may limit the ability of the health care system to maintain a constant supply of medication (Kagee & Delport, 2010; Kagee et al., 2011). In the context of India, the cost and time required to travel to ART centers has been cited by PLHIV as a major access barrier in Mumbai, despite the free availability of public ART medication (Joglekar et al., 2011). The issue of travel cost in Mumbai also relates to insufficient health infrastructure if the current number and distribution of ART centers is not fully meeting the needs of patients and must refer out to hospitals or other specialized care locations.

An example of a systemic issue from India occurred in 2014 when governmental budget cuts to HIV and TB control programs led to sporadic shortages of ART medications and CD4 testing kits. During this time some ART centers were only able to dispense medications for 7-10 days at a time instead of the normal 30-day set of doses (Sharma, 2015), requiring PLHIV to make multiple trips for medication per month rather than one.

Community & Social Support Factors

Social support, particularly support from families and spouses, is the most commonly discussed factor related to ART adherence across qualitative studies completed in 32 different contexts internationally, including India (Katz et al., 2013). Another meta-analysis that included

50 qualitative studies focused on a variety of chronic disease contexts, including HIV, found that practical social support (including transportation and picking up drugs) from family or friends, was consistently associated with greater medication adherence (Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012).

Alternately, it has been found that negative relationships at the family level contribute to gaps in ART use when PLHIV feel that they must conceal their medication or isolate themselves from family when physical symptoms of HIV present (Katz et al., 2013). There is also evidence from Sub-Saharan Africa that social support networks and adaptive coping strategies (acceptance of diagnosis, willingness to seek mental health care) together can mitigate the negative effects of systemic barriers and poverty on ART adherence (Ware et al., 2009). In Thailand, living in a supportive social environment in which one feels accepted as a PLHIV at the community level was found to be associated with improved mental health (Ichikawa & Natpratan, 2006).

In the Indian context, a qualitative study based in Chennai found that social support with ART medication reminders was a major facilitator of overall adherence, with non-spousal family members providing the most assistance, followed by spouses, and the least support provided by friends (Kumarasamy et al., 2005). Another study based at private ART clinics in Mumbai found that social support from family and friends in the form of ART dose reminders and fostering self-efficacy, was associated with an optimal (95%) level of adherence (Shah et al., 2007).

Mental Health Status

Major depression, anxiety, mania, suicidality, and alcohol/substance abuse are all common mental health issues among PLHIV globally (Badiee et al., 2012; Chandra, Ravi, Desai, & Subbakrishna, 1998; Cruess et al., 2003; Nakimuli-Mpungu et al., 2012; Nel & Kagee, 2011;

Rabkin, 2008). Depression is the most frequently cited mental health issue related to non-adherence because its clinical symptoms, particularly lack of motivation, lack of concentration, and feelings of worthlessness, all have direct impacts on the desire to follow a daily medication regimen (Nel & Kagee, 2011). Several studies were conducted regarding depression among HIV patients in India. One study assessed the prevalence of mood disorders among heterosexual PLHIV in Bangalore. Anxiety disorder was found in 36% of the sample, 40% were diagnosed with depressive disorder, and 47% were abusing alcohol (Chandra et al., 1998). A study of 250 PLHIV people using public ART in Delhi concluded that "sound mental health" was a vital facilitator for ART adherence (Anuradha et al., 2013). Another mental health concept of vital importance in India is a culturally-based syndrome known as *tenshun.* Physical and mental symptoms of tenshun can include sadness, worry, weakness, or even pain. The sources of tenshun in an individual can likewise be diverse, including personal, economic, social problems, or medical concerns (Maitra et al., 2015)

Alcohol Use

The casual linkage and co-occurrence between depression and alcohol use is well known, and the effects of both on public health is well established. The WHO has classified alcohol abuse as the third, and depression as the fourth, largest risk factors for both disease burden and causes of disability globally (Witkiewitz & Stauffer, 2014, p.148). In the context of HIV, alcohol has been implicated in making the symptoms of HIV more severe through a direct biological relationship with increased viral load and immunosuppression, increasing the toxicity of ART drugs, and hindering the behaviors necessary for proper adhering to ART regimens (Chander, Lau, & Moore, 2006; Hahn & Samet, 2010; Hendershot, Stoner, Pantalone, & Simoni, 2009).

Heavy alcohol use is common among men in India and has been associated with greater sexual risk behavior among PLHIV accessing female sex workers in Mumbai, a major driver of the HIV epidemic in India (Madhivanan et al., 2005). In a study based in South India, alcohol use, depression, and stigma were all cited predictor of sub-optimal ART adherence (Achappa et al., 2013).

<u>*HIV-Related Stigma*</u>

Various forms of stigma have been broadly implicated as one of the primary barriers to the success of controlling and treating HIV globally (Mahajan et al., 2008; UNAIDS, 2014a). HIV-related stigma is shown to have a direct impact on accuracy in public health surveillance (Giesceke, 2002), to hinder access to testing and prevention services (Kalichman & Simbayi, 2003), to be a barrier to accessing and adhering to HIV treatment (Katz et al., 2013; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009), to disclosing one's HIV status (French, Greeff, Watson J., & Doak M., 2015), to maintaining a supportive social network (Li, Lee, Thammawijaya, Jiraphongsa, & Jane, 2009), and to damaging the mental health status of PLHIV (Simbayi et al., 2007), across different global settings. HIV stigma may come from any level of a societal system, from systemic, institutional, community-based, social, inter- or intra-personal. Since stigma has been implicated in so many realms, there is significant diversity in its classifications, causes, expression, and effects, all highly dependent on cultural contexts (Mahajan et al., 2008).

Defining & Categorizing HIV Stigma

Since Goffman (1963) first conceptualized the modern idea of stigma, many definitions and applications have been introduced using different theoretical approaches, including a socio-

cognitive approach from psychology, a structural approach from sociology, and an embedded-moral approach from anthropology (Kleinman & Hall-Clifford, 2009; Mahajan et al., 2008). According to UNAIDS (2000, p.9), stigma is broadly defined as "*a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits.*" A recent conceptualization of stigma has been presented as a combination of the socio-cognitive and structural approaches, making it useful for public health research (Link & Phelan, 2006). In this generalized model of stigma, people (1) identify and label differences, (2) a labeled person in connected with "undesirable" characteristics and stereotypes, (3) the labeler group separates themselves from the labeled, (4) the "undesirable" group loses status and faces discrimination, and (5) the labelers exercise power (Link & Phelan, 2001). HIV-related stigma is defined as:

> "*…negative beliefs, feelings, and attitudes towards people living with HIV, groups associated with people living with HIV (e.g., the families of people living HIV) and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people.*" (UNAIDS, 2014a, p. 2)

From these generalized definitions and characterizations of stigma, researchers and interventionists have developed useful sub-categories that outline the nuances of HIV stigma. Some of the most relevant types and a selection of their varied definitions are below.

Internal Stigma (sometimes called *Internalized, Felt* or *Self-stigma*) has been characterized in several ways. Steward et al. (2008, p.1126) defined it as the "*extent to which an individual accepts stigma as valid*" and Bharat (2011, p.143) defined it as "*stigma whereby those infected tend to accept stigmatization from others, feel guilty and justify the discriminatory behavior of others towards them.*" A psychiatric definition labeled internal stigma as the "*shame*

and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help" (Gray, 2002, p.72).

*Perceived Stigma (*also called *Felt-Normative)* generally refers to *"the subjective awareness of stigma, a belief about the prevalence of stigmatizing attitudes among people in the local community, or the degree to which stigma is perceived as normative" (*Steward et al., 2008, p.1126). Related to this perception of stigma in the community is *Vicarious Stigma,* which *"helps to explain how stories about enacted stigma and its consequences are communicated and form the basis for felt normative stigma"* (Bharat, 2011, p. 145).

Enacted Stigma (also called *External Stigma* or *Discrimination)* is *"unfair and unjust treatment of an individual based on his or her real or perceived HIV status"* (UNAIDS, 2014a). Enacted/External stigma can occur in the context of families, social situations, and healthcare settings through excommunication, lost housing, lost employment, or denial of necessary services.

HIV Stigma in India

Early research on HIV stigma in India had focused on surveying the thoughts of non-PLHIV, finding that discriminatory, devaluing, and fear-based beliefs about HIV patients were widespread and embedded in a variety of settings and populations including a general adult sample, health care workers, pregnant women, and college students. Multiple studies indicated that between one-third and 50% of these groups pointed blame at the PLHIV, avoided them in everyday life, and supported their isolation in healthcare facilities (Bharat, Aggleton, & Tyrer, 2001; Bharat, 2011). Much of the research in India has since shifted to the perspective of PLHIV, as victims of stigma.

Through an extensive meta-analysis and review of existing stigma research in India, Bharat (2011) identified several common situations and settings where different forms of stigma took place. Fear of HIV status disclosure were most commonly reported, and involuntary disclosure occurring in a healthcare setting or by a healthcare worker was often the start of the PLHIV's experience with stigma (Bharat, 2011, p.142). A key facet of disclosure fear is that concern over who may learn about one's status and what the consequences may be is often not based on actual experience with enacted stigma or discrimination. In India and other Southeast Asian countries, reports of enacted stigma were relatively low, but fears of perceived or felt-normative stigma were high (Bharat, 2011, p.143). Healthcare settings are found to be the primary location of enacted stigma, discrimination, and patient avoidance in India (Bharat, 2011, p. 144). Fears of status disclosure, enacted stigma, and perceived stigma were also found as barriers to adherence in a Mumbai-based study (Joglekar et al., 2011).

For male PLHIV in India especially, blame and shame are important aspects of perceived and felt-normative stigma's effect. In 2001, Bharat found that infected men were viewed as having a "loose moral character" because of the well-known connection between HIV transmission and visiting commercial sex workers (Bharat et al., 2001). The acceptance of this sort of blame and sha1me, as well as any justification for discrimination against themselves or other PLHIV, is a hallmark of internalized stigma (Bharat, 2011). This "self-endorsement" of stigma was more explicitly modeled in a study based in southern India that demonstrated a close interaction between avoiding status disclosure, depression, and internal stigma (Steward et al., 2008). The modeling performed in this study included enacted stigma, and two forms of perceived stigma: felt-normative and vicarious. The interaction between the two perceived forms of stigma were connected to depression and psychological distress only through the mediating

variable of disclosure avoidance, while internal stigma demonstrated a robust and direct connection to depression (Steward et al., 2008). Beyond India, studies based in Sub Saharan Africa have demonstrated a close association between internal stigma and depression (Okello et al., 2015; Shittu et al., 2014; Simbayi et al., 2007).

Thesis Objectives

The first objective of this thesis is to describe internal stigma among HIV positive men who are enrolled in ART and regularly consume alcohol in urban India. The second objective seeks to examine the systemic, social, and behavioral correlates of internal stigma using quantitative and qualitative sources of secondary data. The final objective is to assess the utility of a range of approaches to addressing internal stigma within the Indian context to improve treatment and prevention programs.

Chapter Two - Methodology

The RISTHA/AIM Project

The data on which this thesis is based were collected as a part of the RISHTA / AIM Project, "*Alcohol and ART Adherence: Assessment, Intervention and Modeling in India*" (2014-2019; U01AA021990-01; S. Schensul, J. Schensul, N. Saggurti, A. Sarna, MPIs). This project is a transdisciplinary, Indo-United States collaboration known as the Research and Intervention in Sexual Health: Theory to Action (RISHTA) program. Since 2001, RISHTA has consisted of a series of India-based, NIH-funded projects that have included a focus on men's sexual health, a project on the role of marriage in HIV and STI transmission, and a study focused on women's sexual health (Schensul, Verma, Nastasi, Saggurti, & Mekki-Berrada, 2009; International Center for Research on Women [ICRW], 2014).

The formative objective of the RISTHA/AIM project was an assessment of ART services in selected urban centers of Maharashtra, India. This was achieved in part through key informant interviews (KII) with staff at India's National AIDS Control Organization (NACO), state-level and city-level HIV/AIDS control organizations, and at ART centers. In-depth interviews (IDI) with 55 male PLHIV using ART services were another aspect of this goal and are detailed in the next section. The analysis of these IDI form the qualitative basis of this thesis.

Participants for the RISTHA/AIM project were recruited across five different ART Centers across Mumbai, Navi Mumbai, and Thane. The eligible study population consisted of adult males who were 18 years of age or older, HIV-positive, had been on ART for at least six months, and consumed alcohol in the previous 30 days. Eligibility among ART patients is first determined by administration of the three-question Alcohol Use Disorders Identification Test—Consumption (AUDIT-C) used to assess if the individual consumes any alcohol in the last 30

days. If the individual was an alcohol user, they are recruited for the study and given the pre-baseline survey questionnaire used as the quantitative basis for this thesis. The RISTHA team was called on by NACO to conduct this pre-baseline survey measuring sociodemographic information, evaluation of ART services, alcohol and tobacco use, sexual behavior, the presence of co-morbidities, ART adherence across four-day and 30-day timespans, dietary intake, the individual's social support system, psychological well-being, and their experience with stigma. The 361 individuals who took this pre-baseline survey were then re-recruited into the intervention phase of the AIM project. The analysis of these 361 surveys form the quantitative basis of this thesis.

The second objective of the RISTHA/AIM project is the implementation of individual, group, and community-level interventions designed to reduce alcohol consumption among male PLHIVs and increase ART adherence. Each of the intervention types are currently being introduced at separate ART centers, with second and third levels added in different combinations and in a staggered fashion over the course of the project. Throughout the intervention phase of the project, several biopsychosocial indicators viral load, CD-4 counts will be evaluated in the participants including drug and alcohol use, co-morbidities, levels of social support, depression, and most importantly, internalized stigma.

The intention is to measure internalized stigma using two previously developed subscales that focus on "Felt-normative" stigma and "Self-stigma" in India (Steward et al., 2008). It is important to note that the Internal Stigma scale used as a dependent variable in this thesis is related to, but not a direct adaptation of, the scales developed by Steward et al, and was created from unique questions in the pre-baseline questionnaire.

The third objective of RISTHA/AIM is a synthesis and modeling of data from the first two phases of the project in order to assess the most impactful sequencing of the multi-level interventions on further HIV transmission and the quality of life experienced by PLHIVs in the study population.

Qualitative Data Collection for RISTHA/AIM

Field observations of ART Centers and key informant interviews (KII) with ART Center staff (including Counselors and Medical Officers) were used in the formative phase of RISTHA/AIM to compare and contrast the operational policies of ART Centers with actual "Ground Reality" practices. This research was completed at seven ART Centers as part of the RISTHA/AIM project's review of ART services offered in Mumbai (Brault, 2015). The KII data were used in this thesis to demonstrate gaps in the delivery of ART services, particularly those that related to HIV stigma and counseling at the individual and group levels.

For the collection of IDIs, a purposive sample of approximately 10 individuals from each of the five ART centers (N=55) involved who were deemed eligible for the study were selected and consented to participating in life course interviews. These IDI were asked about their personal experience living with HIV, specifically regarding their use and adherence to ART, the influence of alcohol consumption on ART adherence, the impact of HIV on their families and social support system, their sexual behavior, and the role HIV-related stigma plays in their lives. The interviews were conducted in either Hindi or Marathi by project staff who recorded responses on paper or an electronic recording device. These notes or recordings were then transcribed and translated into English before being uploaded into Atlas.Ti. (Version 7) qualitative analysis software. The AUDIT responses and basic demographics of the interviewee were also included in each IDI transcript. The demographic information included age, years of

education, ethno-religious category, marital status, number of children, and estimated monthly income.

The IDI data were utilized in two primary capacities. In Chapter 3, themes were identified and quotations selected to exemplify themes that arose out of the IDI's personal experiences with ART Center services and relationships with staff. In Chapter 4, IDI were analyzed for the primary objective of this thesis, to elucidate the quantitative relationships between various social and behavioral factors and internalized stigma.

Preliminary Analysis of Qualitative Data

Prior to performing the qualitative analysis, the author was employed as a Research Assistant on the RISTHA/AIM project, tasked with managing, coding, and analyzing the formative IDI data. Throughout this process, the original coding guide (Appendix 1) developed by the Research Team was utilized. This coding guide was formatted using a Tree Diagram method such that multiple Factor codes were grouped into larger Domains. To illustrate this organization, the guide includes the *Sexual Behavior* domain that is subsequently divided into three Factors: *Sexual Behavior-Wife, Sexual Behavior-Other Partners, and Sexual Behavior-Condom Use.* In another example, the *Stigma* domain is broken into *Internal* and *External* factors.

When necessary, some edits and additions were made to the guide when new themes needed investigation. One instance of such a change was the addition of the Positive and Negative Coping codes that looked at any strategies men used to deal with the challenges of living with HIV. These and other new domains/factors were produced through an Atlas.Ti Network Sorting method that assigned the new code to relevant, pre-coded quotations. The

coding process required careful reading of each IDI for accuracy. For comparative analysis purposes, each participant was assigned to one of three major families most relevant to the AIM project: those that indicated full adherence to ART, those who were non-adherent to ART explicitly because of alcohol use, and those who were non-adherent for other reasons.

In addition, the author produced Code Summaries, ART adherence diagrams visually demonstrating the behaviors and circumstances that impacted medication adherence, and coping strategy narratives for intervention purposes. The primary technique of qualitative analysis was the summarization of codes (Code Summaries), a process that is detailed later in this chapter.

Hypotheses & Logic Model

Experience with coding and analyzing the IDI data, along with reviews of the literature on HIV stigma in India, led to the choice of the independent variables included in the final statistical model. I hypothesized that the following variable groups would be associated with feelings of internalized stigma: (1) an individual's level of social support (from family, friends, NGOs, and ART Centers), (2) their mental health status (depression, tenshun, & alcohol use), (3) experience with external HIV stigma and discrimination, (4) experience with HIV & ART (time since diagnosis, time since initiation), and (5) the individual's general quality of life (General health status, food security, presence of other STIs). These hypotheses are visualized in the logic model below (Figure 1).

Figure 1. Logic Model.
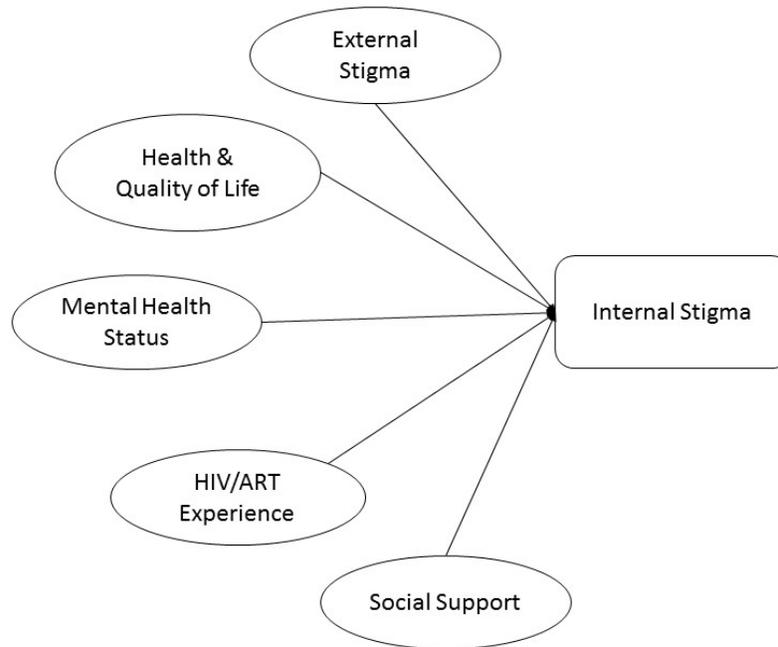
Although all of these factors were hypothesized to be connected to the development of internal stigma, it was further predicted that mental health status would demonstrate the strongest association. Preliminary analysis demonstrated that interactions among these factors could directly influence the individual's mental health status; manifesting as HIV-related stress, tenshun, depression, or suicidality.

Definition of Variables & Scale Construction

Internal Stigma

The <u>Internal Stigma Scale</u> was created by combining the response scores to 16 statements from the pre-baseline survey referring to men's experiences, beliefs, and fears regarding living

with HIV, focusing mainly on issues of status disclosure, self-blame, and loss of social networks. Two examples of statements used in this scale are *"I feel I am not as good a person compared to others"* and *"I worry that people may judge me if they knew my status"* Responses to each of the 16 statements were recorded on a four-point Likert scale, from "Strongly Disagree" (1) to "Strongly Agree" (4). Agreement with each statement on the Scale is deemed a form of negative perception, such that a higher combined score is indicative of greater internalized stigma. The Internal Stigma Scale produced a high level of internal reliability, with a Cronbach's Alpha (α) score of 0.89. All 16 statements that comprise the scale and the distribution of responses are included in Table 2 of the Integrated Results chapter.

Qualitatively, the description associated with the Internal Stigma code in the IDI Coding guide was as follows: "Self-blame, guilt, lack of self-respect or positive attitudes, any self-harm, aversion to socialization, any mention of phobia or the lack thereof." The occurrence of any of these emotions or behaviors were coded as Internal Stigma across all 55 IDI.

Depression & Emotional Status

Quantitatively, depression was measured using an adapted Center for Epidemiologic Studies Scale for Depression (CES-D Scale; α =0.69) (Radloff, 1977). This scale was based on ten statements that asked the respondent how often they felt different emotions, both positive and negative over the course of the previous week. Each emotion can be rated as being felt *"Rarely or none of the time (< 1 day),"* *"Some or a-little of the time (1-2 days),"* *"Occasionally or a moderate amount of time (3-4 days),"* or *"Most or all of the time (5-7 days)."* Some of the statements included in the CES-D Scale were, *"I was bothered by things that usually don't bother me,"* *"I felt hopeful about the future*," and *"I felt lonely."*

The External Tenshun Scale (α = .80) was another indicator of mental health status in which an individual's level of tenshun related to issues such as difficulty with work, one's financial situation, or disclosure of HIV status was assessed. The External Tenshun scale is a five-question subscale dealing with these "External" issues beyond immediate and extended family relationships. The remaining six questions in the main Tenshun scale relate to issues associated with the men's wives, children, in-law families, and sex partners. For each statement in the scale, the respondent can indicate whether it contributes to their level of tenshun *"To a great extent," (1) "To some extent," (2) or "Not at all" (3).* A lower mean in this sub-scale indicated the experience of more tenshun.

Qualitatively, several codes were used to investigate the connection between mental health issues and internal stigma. The Emotional Status domain dealt with "*Current tension (tenshun), stress, depression, anxiety, or coping strategies.*" Instances of fear and anxiety over HIV disclosure beyond one's family or other trusted individuals was frequently coded as an issue of mental health using the Emotional Status code. The Diagnosis Response code was applied to passages describing the effect of receiving their initial HIV diagnosis, including *"Immediate, ongoing, and evolving response to the news; beliefs, denial and acceptance, sharing, and trauma."* The Positive Coping and Negative Coping codes were also used to identify examples of mental health status in the IDI data. Positive Coping included examples of men finding a community with other HIV positive people, participation in religious activities, the use of prayer, positive and future-based thinking, social responsibility to protect others from infection, benefits of status disclosure, a focus on nutrition & exercise, seeking support from others, or taking pride in a craft or work. Negative coping overlapped significantly with Emotional Status and Internal

Stigma, highlighting instances of problem drinking, suicidal thoughts, feelings of guilt or blame, self-isolation, and anger.

Aside from the Alcohol Use Disorders Identification Test (AUDIT), the seven- question Reasons for Drinking Scale (α=.52) was used to quantitatively assess why the sampled men consume alcohol. For each statement, only a Yes (1) or No (2) was available, such that a lower mean indicated that the individual expressed more reasons to consume alcohol. *"I have more courage," "I have less tension,"* and *"I can cope better with HIV"* were among the statements included in the scale. The statements used in the creation of this scale were developed through preliminary analysis of the qualitative data by MPIs for the RISTHA/AIM project.

Several codes were utilized to assess past and present drinking behaviors among the men in the IDI sample. Most relevant for this study was Alcohol_Post-Diagnosis, a factor that focused on the effect HIV diagnosis had on the individual's frequency, quantity, and justification for drinking. Further, the Alcohol Reasoning code identified responses to an interview probe questioning why men (in a general sense) consumed alcohol. Finally, two codes meant to evaluate the effect of alcohol on ART adherence were useful to investigate for this thesis. Adherent_Alcohol was used whenever the interviewee discussed how he was able to maintain adherence to his medication regimen despite the use of alcohol. The Non-Adherent_Alcohol code was used when the men attributed their non-adherence to ART to their own drinking behavior.

Social Support

The 11 questions that comprised the NGO (α=0.73), ART (α=0.57), and Family (α=0.91) Support Scales referred to receiving assistance from each of these groups in a variety of realms,

including ART adherence and medical treatment, meeting psychological and emotional needs, financial support, informational and legal support, and in participation with social networks or programs. The separate scales were able to be created because answers corresponding to each group were embedded within a series of Yes/No questions. For instance, for the category "Psychological/Emotional support," respondents can answer whether or not they receive support in that realm from each of Family, Friends, NGOs, and/or ART centers. Since each category gets an answer, separate scores could be calculated.

Social support was also measured quantitatively in the Network of Positive People Support (NMP+) Scale (α=.85). This scale measured the amount of support received specifically from the Network of Maharashtra People with HIV (NMP+) NGO across 19 different categories. The respondent could answer Yes (1) or No (2) to each type of service, so that higher mean on this scale indicated that fewer supportive services were received. Some examples of the services asked about in this scale include, *"Counseling on positive living and acceptance of HIV positive status," "Provided with information on STI/HIV/AIDS,"* and *"Education on importance of adherence and side effects of medication."*

The presence or lack of social support in relation to internalized stigma was again defined and extracted using multiple codes across the IDI data. A Social Support code domain was used as an overall guide, with additional codes used to specify different support relationships. The primary Social Support code referred to any people in the respondent's personal network who provided money, transportation, support of the family, assistance with medication pick-up and adherence, and/or emotional support. At the family level, the Wife code was utilized extensively to identify the presence (or absence) of social and emotional support for the interviewed men. This code was for any examples of non-sexual aspects of the marital relationship, including

issues of communication, blame for HIV, domestic violence, and support. The <u>Household Dynamics</u> and <u>Extended Family</u> codes were used to identify positive or negative examples of social support among the rest of the sample's families. Finally, support originating from NGOs and ART centers could be located using the <u>NGO Involvement</u> code and any factors within the <u>ART Centers</u> code domain.

External Stigma

The 19 component questions of the <u>External Stigma Scale (α=.80)</u> refer to discriminatory situations originating from a variety of sources: spouses, family members, sex partners, employers, neighbors, medical personnel, banks, and other social services. The questions were answered in a Yes (1)/No (2) format such that lower values are given to negative outcomes (more experiences with enacted stigma). Example questions from the baseline survey that were combined to form the External Stigma Scale include: *"Have any of your own family members shunned or rejected you because of your HIV infection?" "Has your spouse left you permanently or temporarily?"* and *"Has any neighbor said negative things about you to others because of your HIV infection?"*

The <u>External Stigma</u> code was applied during preliminary analysis of the interviews when examples of negative reactions or outright rejection occurred from medical personnel, community members, friends, family, or co-workers. Any positive reactions from these groups were also highlighted using this code. Thematic overlap with other codes was also evident during the process of qualitative analysis for this thesis, leading to the discovery of additional examples of enacted stigma or fear of enacted stigma after individuals heard stories of HIV-based discrimination perpetrated on others.

To avoid repetition, only the scales that were found to significantly contribute to the Standard Multiple Regression model have been defined in this section. Likewise, the only qualitative definitions included here are those that correspond to the IDI codes that best characterized the significant relationships. All of the scales were created by combining the scores of their respective component questions through written syntax within IBM SPSS (Version 23) software.

Statistical Analysis

All statistical analysis and survey database management were performed using IBM SPSS (Version 23) software. This thesis examined the correlates of internal stigma across the entire sample eligible for inclusion in the AIM study, thus, all statistical tests were performed using the full sample of 361 surveys. Quantitative analysis of the survey data (n=361) began with univariate descriptive statistics for all of the 21 chosen variables in order to characterize the study population. This included frequency distributions for all of the categorical variables and measures of central tendency for continuous variables. Bivariate statistics were then performed using Pearson's r correlations to determine interrelationships among the chosen independent variables and that with the dependent Internal Stigma Scale variable.

A Standard Multiple Regression model was then created to determine if any of the independent variables were significantly associated with the variation of the dependent outcome scale. In the Standard Multiple Regression model, all of the variables were run simultaneously using the "Enter" method on SPSS. Following this, in order to determine the relative contribution of the variables that significantly contributed to the first regression model, a Stepwise Multiple Regression was performed using the "Backward Deletion" method. This method removes independent variables from the original 21-variable model in a staggered fashion until only the

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statistically significant predictors remain. The R^2 value from the Stepwise regression was subtracted from the R^2 of the Standard regression to determine the percentage of variation that non-significant variables accounted for in the Internal Stigma scale.

Multicollinearity analysis between the 21 independent variables was also performed to ensure the validity of each multiple regression model. This was initially completed by analyzing the Correlational Matrix (see Table 5) and then by calculating Tolerance scores in the regression model. Any variables found to significantly contribute to the regression model with internalized stigma as the dependent variable then entered the second portion of the study and were investigated qualitatively.

Qualitative Analysis

All qualitative analysis and IDI management were performed using Atlas.Ti (Version 7) software (Atlas.Ti., 2014). There were no inclusion criteria for the sample of interviews in this thesis, thus, all 55 IDIs were included in the qualitative analysis. The process of extracting appropriate quotations from the interviews was nearly identical to that of producing Code Summaries for the prior qualitative work completed with the IDI data for the RISTHA/AIM project. First a query was performed to gather all of the examples of a given code from any of the 55 interviews. This initial set of quotations was reviewed in full and the best examples of the theme under investigation were highlighted and grouped by theme. To search for quotations regarding a specific relationship between two variables, a more focused query was performed that extracted quotes featuring overlapping or co-occurring code domains or factors.

A total of 77 quotations were originally coded as examples of Internal Stigma through preliminary analysis. However, many additional examples of internalized guilt and self-blame

arose as closely-related code domains were analyzed. An identical situation with the External

Stigma code was described in a previous section. Domains that contained the most information

indicative of internalized stigma included Emotional Status, Diagnosis Reaction, Post-diagnosis

Alcohol Use, and External Stigma. This overlap was due to similarities in the behaviors these

three codes were intended to identify based on the AIM Coding Guide. Each time a quotation

was identified as a clear narrative example of a particular relationship, basic demographic

information for that individual was paired with the quote, including age, marital status, and

number of children.

Human Subjects Protections

All survey and interview data utilized in this thesis has been de-identified. Procedures for

primary data collection, intervention and evaluation have been reviewed and approved by the

Indian Council for Medical Research, the National AIDS Control Organization within the

Ministry of Health and Family Welfare, the India Health Ministry Screening Committee, and the

institutional review boards of UConn Health, Population Council, the Institute for Community

Research and the International Center for Research on Women. The author of this thesis is an

approved personnel member for the RISTHA/AIM project on IRB submissions at UConn Health.

Chapter Three – Structure & Function of HIV Treatment in India

Overview of India's Healthcare System

The healthcare system in India represents a complex and uneven mixture of public and private sources for medical care at all levels. The system as a whole is deeply underfunded to meet the health challenges of over one billion people, accounting for only about 4% of India's Gross Domestic Product (World Bank, 2016). It is "uneven" because about 80% of outpatient services, and 60% of inpatient-care, comes from private providers located primarily in urban, single-doctor practices or in a private clinic setting (Reddy, 2015). With the majority of health care focused on urban areas, nearly 70% of the total population of India living in rural areas have poor access to the already-strained system (CIA, 2016). About 70% of the costs in the unregulated, profit-based system is directly out-of-pocket for patients and operates on a purely fee-for-service basis, further limiting healthcare access among poor people in urban areas. The fee-based system may negatively impact overall healthcare quality since competition between doctors for patients who can afford treatment is the norm (Prinja, Kaur, & Kumar, 2012). The tiny fraction of publicly funded facilities that do exist provide free or low-cost care, but are underutilized in many states due to a prevailing belief that lack of cost translates to lack of quality. Although the population using public facilities is higher in rural areas, the majority of people still prefer private sources or rely on non-allopathic medicine. (Government of India, 2013; International Institute for Population Sciences, 2006).

The disciplines of non-allopathic medicine, including the traditional practices of *Ayurveda, unani, siddha*, homeopathy, naturopathy, and yoga are embedded into the cultural understandings of health, disease, and medical practice in India. Some 70 – 80% of the Indian population utilizes or relies on some form of non-allopathic medicine, particularly in rural areas

for the treatment of all forms of chronic, infectious, and mental health disorders (Gogtay, Bhatt, Dalvi, & Kshirsagar, 2002). There are extensive non-allopathic education programs located in medical colleges where graduates can be officially registered as practitioners by the Indian government through the Ministry of Health and Family Welfare (Schensul, Mekki-Berrada, Nastasi, Saggurti, & Verma, 2006). In major urban centers like Mumbai, more men utilize private practitioners of non-allopathic medicine, widely known as *daktars,* than the public healthcare system. This ubiquitous use of traditional Indian medicine puts its practitioners in a unique and powerful position as avenues for public health interventions (Schensul, Mekki-Berrada, Nastasi, Saggurti, & Verma, 2006).

Substantial changes to the healthcare system at the national level have been proposed in the most recent *Five Year Plan* (2012-2017) released by the Indian government (Government of India, 2013). The intention was to significantly increase central government funding toward a plan for universal health care, with the ambitious goal of providing free medication, diagnostic services, and insurance for all citizens by 2019. This core restructuring of the system, however, faces extraordinary challenges in political will, funding, and implementation moving forward (Reddy, 2015; Kalra, 2014; Kalra, 2015).

National AIDS Control Organization & Public Antiretroviral Therapy

Since its establishment in 1992, the National AIDS Control Organization (NACO) has been a subsidiary division of the Ministry of Health and Family Welfare, the Indian government's highest authority on matters of public health and health policy. NACO directs a network of 35 HIV control and prevention societies that are distributed across India's 36 states and union territories (NACO, 2016a). The programmatic functions of NACO are divided into two primary aims: Prevention activities and Care, Support, and Treatment for existing PLHIV.

Prevention activities undertaken by NACO include targeted interventions for groups at higher

risk of HIV transmission (such as migrant workers, intravenous drug users, and female sex

workers), condom promotion, STI/RTI control, and educational mass media campaigns. Direct

patient care activities directed by NACO include laboratory CD4/viral load testing, distribution

of pediatric and adult ART, and the administration of Care and Support Centers (CSC) that aim

to improve quality of life among PLHIV (NACO, 2015b).

NACO Care and Support Centers

There are 325 currently-operating CSCs (44 in the state of Maharashtra) that provide

medication adherence education, linkage to external support or social welfare services, and

counseling on common psychosocial issues for PLHIV and their families, including internal and

external forms of stigma (Maharashtra State AIDS Control Society[MSACS], 2015;

NACO,2015b). According to the most recent (2013) Operational Guidelines for CSC's, stigma

should be addressed at the client and family level through contact with Peer Counselors who

"Motivate the PLHIV to address the issue of self-stigma," and educate individuals on how to

"overcome self-perceived stigma" (NACO, 2013, p. 24, 36). No examples or further instructions

are given as to how stigma counseling should take place with PLHIV or their families.

At the community level, counselors are tasked with documenting any cases of HIV-

related stigma or discrimination that they hear about, and including them in an area report for use

in advocacy. Stigma reports from the field shape the audience and message of advocacy

campaigns that may use mass media, petitions, or public rallies (NACO, 2013). Discrimination

Response Teams can also be operated through CSCs, directly investigating individual acts of

discrimination, providing moral support to victims, and seeking justice through legal means

(NACO, 2013). Stigma is further addressed in an outreach branch of NACO programming called

Information, Education, and Communication (IEC). IEC utilizes scripted "Folk Media" performances that tailor messages of safe sex, women's issues, and anti-discrimination in culturally-specific ways (NACO, 2015b). These individual and community-level programs addressing HIV stigma are in fulfillment of NACO's vision statement: "*Effective prevention, care and support for HIV/AIDS is possible in an environment where human rights are respected and where those infected or affected by HIV/AIDS live a life without stigma and discrimination,*" (NACO, 2016b).

Rollout of Public ART Services

Amidst a WHO-led effort to expand HIV treatment in low-and-middle-income countries (LMIC), NACO has been providing free, publically-funded ART medication since 2004 (NACO, 2015b; WHO, 2006b). The rollout of free ART began with the opening of eight ART Centers within Government hospitals located in areas with the highest HIV prevalence. The program expanded rapidly across India in the 10 years after the rollout, with 453 ART Centers operating as of 2014 (NACO, 2015b). The state of Maharashtra has 72 ART centers, 24 of which are located in the city of Mumbai (MSACS, 2015).

Several types of ART Centers serve specialized roles in the ART distribution system. The 870 Link-ART Centers each serve a smaller number of patients and offer no additional services but are located in more convenient locations for improved access to medication. Thirty-seven ART-Plus centers provide the same services as standard centers, with the addition of Second-line ART medication. Ten ART Centers-of-Excellence exist within major hospitals and can provide specialized care, Alternative First-Line and Second-Line ART, training, and research (NACO, 2015b).

The total number of PLHIV in India using public ART was approximately 851,000 between 2014 and 2015, representing 38% of the 2.2 million total nationwide (NACO, 2015a; 2015c). This figure is slightly higher than the estimated ART coverage across the entire Asia/Pacific region (33%), but lower than the Southeast Asian LMIC with the second highest HIV burden, Thailand (57%) (UNAIDS,2014).

Initiating Patients on ART

The description of the testing and ART-enrollment process that follows in this section was derived from NACO's most recent Operational Guidelines for ART Centers (NACO, 2012). Integrated Counseling and Testing Centers (ICTC) are the first contact most individuals have with the public HIV-care system in India. ICTCs conduct free HIV testing and offer basic counseling and health education services for high-risk populations who may access testing by choice or be referred from a medical provider or NGO. Only individuals who test positive for HIV at an ICTC can be referred to an ART center for enrollment in care. Therefore, even individuals who may have tested positive in a private clinic setting need a confirmatory test from an ICTC before entering the public system. The patient's first visit to an ART center involves the issuing of the "White Card" and "Green Book" for the tracking of future HIV care and a baseline medical assessment that screens for existing opportunistic co-infections (such as TB and STIs), assigns a WHO clinical stage of HIV, and conducts CD4 testing. The results of these initial tests are available for the patient's second visit to the Center, in which it is determined if they are eligible for ART. Generally, ART will begin if the patient's CD4 count is less than 350, or if other opportunistic infections are present.

After meeting NACO's eligibility criteria, initiation on ART should begin with a 14-day supply of ART drugs, counseling on ART adherence, and the identification of family or

community support (through a Care & Support Center). Patients return to an ART center counselor after the first two weeks in order to assess issues with adherence, medication side-effects, receive psychological support, and recommendation of spousal HIV testing. A clinical examination and any follow-up on previously identified infections is also given.

Process of Monthly ART Center Visits

Subsequent visits to the ART center occur approximately once-per-month for medication pick-up by the patient or a family member. Prior to receiving medication from the Center pharmacist, an ideal sequence for each monthly visit would first bring patients to a counselor for adherence assessment (pill counting), advice on addressing adherence barriers, positive living techniques, and transmission prevention. If needed, "management of co-morbid psychiatric illness should be carried out" (NACO, 2012, P.37), along with linkage to group support meetings (held at some large ART Centers) and community-based rehabilitation centers. No further information is given about how psychiatric illness is managed in the Operational Guidelines. Of, note ART Center counselors can either have Masters-level training in social work, sociology, or be trained in nursing with the addition of NACO counselor training. When possible, preference is given to qualified PLHIV for the counselor role.

Following the visit with a counselor, the patient then is assessed by a nurse who checks for HIV-related symptoms, weight loss, and screens for TB. Unless required sooner due to clinical need, regular CD4 counts are ordered by nurses approximately every six months. The final assessment before ART dispensary is with a Medical Officer who should give an exam, review notes from the counselor and nurse, and look for further problems with medication adherence and effectiveness. Of note, all ART Center Medical Officers must have an MBBS degree (the equivalence of a Medical Doctor) with additional training in HIV care from NACO.

Addressing Patient Loss to Follow-Up on ART

People who enter the public HIV care system through testing at an ICTC can be lost to follow-up (LFU) at any step of care prior to, during, and well after ART initiation. The 2012 ART Center Operational Guidelines assigned stages to the four points in which LFU occurs. Most relevant here is Stage 4, accounting for any loss of patients that occurs after they have started an ART regimen. Internal efforts to address Stage 4 LFUs begin with a "Daily Due List" of people who should be arriving on any given day for their next month's supply of medication. This list is maintained by the pharmacist on staff, and those who do not arrive within 48 hours should be contacted by telephone. If individuals cannot be contacted, outreach workers from ART centers, CSCs, or NGOs may be used to locate the patient. People who retrieve their medications irregularly (not within the month of their original appointment) are considered "MIS" patients. If a patient maintains MIS status after 4 consecutive months, they are considered "LFU." Lists of MIS and LFU patients should be maintained and tracked by all ART centers (NACO, 2012).

<u>*ART Center Services – "Ground Realities"*</u>

All of the information regarding NACO/ART Center policies and procedures in the previous section refers to the operation of their facilities under ideal conditions of center location, staffing, funding, medical supplies, and medication availability. At any given time, there may be inadequacies in one or more of these areas that lead to gaps between what is suggested in the ART center guidelines, and the so-called "ground realties" of actual services offered to PLHIV and their families. In this section, two forms of analyses are presented that investigated these gaps; in the first, field observations of ART Centers and key informant interviews (KII) with Center staff (including Counselors and Medical Officers) were used to

directly compare personal experiences with the content of the 2012 Operational Guidelines for ART Centers. This existing research was completed at seven ART Centers as part of the RISTHA/AIM project's review of ART services offered in Mumbai (Brault, 2015).

Discrepancies between NACO Policies & Practice in ART Centers

The KII analysis showed discrepancies across most aspects of ART Center infrastructure, staffing, and programing compared to the NACO guidelines that could have a negative impact on the quality and consistency of patient care. The greatest concern in terms of infrastructure was that the size of the facilities themselves did not meet the volume of patients utilizing them, leading to insufficient and unpleasant waiting spaces and lack of privacy for conversations with medical officers and counselors. In terms of ART Center staffing, it was found that every Center included in the analysis was understaffed compared to guidelines, and that existing staff complained of inadequate training and high turnover. This lack of appropriate staff in overcrowded ART Centers leads to long waiting times, and the high rates of staff turnover likely results in further training gaps.

Many discrepancies were found within the areas of treatment procedures and counseling services that stem from the infrastructural issues above, all directly impacting the quality of care and support provided by the sampled ART Centers. For instance, time spent with medical officers seems to be limited in many cases, with physical exams being skipped and inadequate passage of updated patient histories occurring. Counseling at the individual level is hindered by low staffing, causing many sessions to be cut short without covering all of the recommended topics. Alcohol use is not explicitly addressed in the recommended topics, and only an encouragement to quit drinking is included if abuse is suspected. Finally, frequent turnover causes a lack of counselor continuity, making long-term relationships with patients difficult to

develop. Space, staffing, and training were also barriers to the running of group counselling sessions at most locations.

Issues of stigma are not directly addressed in the ART Center Guidelines. The KIIs indicate that outside referrals for treatment of other conditions may not be followed through due, in part, to fears of enacted stigma or discrimination. Similarly, disclosure-related stigma fear was believed to be a reason why patients may not want to access group sessions. While the interviews indicated a view that the impact of stigma is improving through educational campaigns and street performances, it remains an issue at the community and family level.

Patient Perceptions of ART Center Services

From the In-depth Interviews, PLHIVs commented on their ART Center experiences. Most participants reported that they had an overall positive experience with the services and staff provided at the ART centers and seven reported a negative experience overall.

General Positive View

"When I came here, it was very nice experience. First of all, [this center] is at the entrance. So it is very easy to locate it. No need to ask anybody where it is. In this center, everybody was there to serve me. All the staff members are very good... Each of them knows me personally."

All staff in [this ART Center] are very good. They are giving such an expensive medicine in free of cost so we are grateful."

General Negative View

"Some of the patients go to [another ART Center] and get it done there. But why such basic test was not being done at this center. Patient get irritated as such facility is not provided by the center. They have to run here and there for CD4. Service provided at this center is of poor quality as compared to that [the other] ART center."

"They are not good. They do not do their work fast. Every time we have to stand in the queue for long time. I get irritated to wait in the queue. Every time we have to spend 2- 3 hours in the ART center... Sometimes I think I should stop the medicine because of irritability."

Ten respondents indicated that they have transferred between different ART centers throughout the course of their treatment. The reasons for this vary. Some were changed at the recommendation of their private or local doctor, others were seeking a higher quality facility, or were forced to move to another center due to travel time or because of work.

"I found that the [first] hospital was dirty and patients from my area is also coming to the first hospital for HIV treatment. Then I came to the [second hospital], it was looking better, clean and spacious. I said to the [third] hospital doctors to shift me and my wife to the [second] hospital."

"I was taking ART treatment from [this ART center] for 18 months. Travelling here was costing a lot, so upon the doctor's suggestion, I got transferred to this center which is near to my house. For that they gave me the transfer certificate and changed my address of ART center to [another] Hospital. Since last 1 and half year I have been seeking treatment from this center."

The most frequently mentioned complaint was the length of time patients were required to wait in the ART center to see a doctor and/or counselor, or to simply receive their medications. Several men did not like how impersonal the staff was at the larger hospitals, with a few also noting that new patients receive a disproportionate amount of attention while recurring patients see little ongoing support. Medicine shortages were explicitly recalled by five respondents, and three recalled ART center closures due to a strike.

"These people (ART personal) doing their job, because as a part of their duty. Otherwise they do not have concern about HIV patient and their illness."

"Before 3- 4 years there was a strike. So I was not received medicine for two months, no patients received medicine during that."

"Last there was shortage of medicine in this center. I came to collect the medicine but when I came here, and then counselor told me about the shortage of medicine…. I missed my more than 8 days of medicine."

Many of the respondents discussed the quality of the staff at the ART centers. There were several mentions of how staff "shouted" at people waiting in line or who were not timely to appointments or with medication adherence. The quote below discusses staff quality, both good and bad, across four different ART centers.

> *"When I was taking the treatment from [Center #1], those staffs were good and co-operative. They talked with me nicely and always asked about health. [Center #2] was the best, because their staffs were so nice and they are so enthusiastic. [Center #2] staffs were also cooperative and having good nature, sometimes I reached there late but they didn't shout at me. But here in new [Center #3], I don't like to come, these staffs don't have any manners about talking. They shout on the patients."*

Only four men said that they do use (or would use) the ART center for anything other than medications. Some may not want to be seen going there on more occasions than necessary, others may not return simply due to the waiting time. One respondent returns for non-HIV related issues because of the free medication.

> *"If I catch fever and cold then also I come here and inform the doctor to get medicines. These medicines are free of cost. So why should I go to some private doctor for any health problem?"*

Interviewees were asked about the content of any medical advice given by the ART center physicians. The topics covered were generally diet, medication adherence, sexual health, and alcohol use. There were surprisingly few assessments of the quality of this medical care specifically, positive or negative. Most reviews focused on the staff as a whole. Two of the 4 positive assessments both talk about a female doctor at one of the ART Centers.

> *"She properly guided me. She told me in detailed what this illness is and how with the help of medicines I can live the fullest of my life. She assured me that if I take my medicines on time, nothing would make my life shorter."*

"The doctor…. I don't remember her name…. told me not to worry. She gave me mental support and encouraged me to come here regularly. She said that if I take the medicines on time, then I can live longer life."

A couple of respondents mentioned that they received little or no advice from the doctors themselves, but were just referred to the counselors. Several more men said that advice about diet, medication adherence, and alcohol use were given only at their first visit.

"The doctor has prescribed some medicines to me, and explained me to take these medicines along with ART medicine. Apart from this, doctor didn't say anything."

"My first time, doctors and counselor here in [this Center] were asking so many questions about other health problems, diet, and sexual relation with wife and others. But now they stopped all these talking. Just they look face and write date for medicine. Even if I share any problem doctors/counselors are not listening now in [this Center]."

Nearly all of the interviewed men discussed being seen by counselors at the ART centers. Common issues with counselors include a lack of personable service, not enough time spent with each patient, or favoring new patients over returning ones. Several respondents were upset how the counselors scold or shout at patients who do not follow advice.

"They hadn't shouted on me, because I always come here and I don't talk with anyone or with them. I come for only my medicine. I collect and go. Sometimes they shout on patients who are not coming regular to collect the medicine, and some of them come and always complained about their family. Some patients have to hurry, then they shout at the patients."

The following list represents the major topics covered by the ART Center counselors in order of salience, as relayed by the men in the interviews: Advice regarding ART medication adherence (mentioned in 16 interviews), Nutritional advice (14 interviews), information about sexual behavior (9 interviews), Alcohol/Tobacco control or cessation (8 interviews), and general HIV knowledge (7 interviews). Only two respondents said that the counselors did not mention

alcohol control. In relation to group meetings, at least 15 respondents said either that no group

meetings occurred at their ART center, or that they were never informed of the existence of such

meetings. Only eight said that they had attended or at least were aware of group meetings taking

place.

> *"I attended three sessions in [this hospital]. They were group sessions. They talked about the disease, food and sex. They gave the information about the HIV and AIDS. They said 'HIV is the first step of disease and AIDS is the last. If we eat nutritive food for good health, then we can increase our immune power. And use condom when you want to have sex. It is better for the other partner. And always think positive, if you take any tension then you will invite the other disease which is not good for your health.'"*

> *"I have not attended any such group meeting. Nobody tells about such things here."*

Special requests for extra medication for travel reasons were generally accepted, although

there were several men who said they are denied at every request or only occasionally receive the

extra doses. Ease of obtaining extras was one of the many suggested improvements made by

respondents. When these are not given, lengthy spans without ART are possible. Extra

medication was often requested prior to traveling for work or for vising family at their native

home.

> *"Yes, one year ago, I had gone to native place, and at that time I had requested counselor to provide two months' medicine. I was not provided extra medicine, which I was supposed to have after going to native place. That time I had not taken medicine for one and half months."*

The majority of patients seem to receive their ART medication in 30-day prescriptions.

Several men indicated that their center only gives out medication for 15-day spans, and some

vary between 15 and 30 days due to supply issues.

> *"After the Counselor, we go and meet the doctor. The doctor asked about my problems and wrote medicines. Then we collected medicines from another woman. Sometimes medicines were given for 15 days some time they gave us for one month."*

Chapter Four – Results

This chapter will include both the qualitative and quantitative results of this thesis. First, demographic information from both sources will be presented in Table 1 and detailed separately. Following this, a description of how internal stigma was defined and characterized both quantitatively and qualitatively will be described. The remainder of the chapter will present integrated survey and in-depth interview results related to the independent variables that correlate with internal stigma, primarily using the qualitative data to explain the quantitative relationships. Inter-correlations among the contributing variables will also be discussed.

Sample Demographics

Table 1
Demographics of Pre-Baseline Survey Group and In-Depth Interview (IDI) Group

Characteristic	Survey Group	IDI Group
Sample Size	361	55
Mean Age (Range)	41.5 (21 - 66)	39.3 (22 – 55)
Ethno-Religious Category		
Hindu	88.6%	74.5%
Buddhist	7.8%	12.7%
Muslim	1.9%	7.2%
Christian	--	3.6%
Jain	--	1.8%
Currently Married	82.5%	87.2%
Mean Number of Children	2.2	2.3
Mean Years of Education	7.3	8.6
Currently Employed	92.5%	89%
Monthly Median Income (Rupees)	10000 ($150)	11500 ($173)
HIV Positive Family Members		
Wife	42.3%	38%
Child	15.5%	5.4%
Other Family	1.16%	--
Years Since HIV Diagnosis	5	--
Years Since ART Initiation	3.8	--

The mean age of the 361 men who completed the full pre-baseline survey for the RISTHA AIM project was 41.5 years, with ages ranging from 21 to 66 years. On average, this group has known their HIV status for 5 years and have been on an ART regimen for a mean of 3.8 years. The majority (88.6%) of the sampled men were Hindu, yet unlike the broader religious composition of the region, this sample included more Buddhists (7.8%) than Muslims (1.9%). In terms of familial composition, 82.5% were "currently married," Of this total, most indicated that they lived with their wives (71.5%) within a nuclear family structure (77%), including a sample mean of 2.2 children. The wives' age averaged at 36.2 years and mean marriage length was 17.8 years, indicating that many of the women became married in their late teenage years. An explanation for the 11% difference between men that are currently married and those that live with their wives was articulated in the qualitative data and is explained later in this chapter.

In terms of education, this group attended a mean of 7.3 (SD=3.9) years of schooling, with 10.8% illiteracy and 22% completing school through grade 10. In terms of employment, 92.5% were reported holding a job. Slightly more than half (51.8%) were employed in private business, while others worked in petty businesses such as food stands, or paan shops, (13.6%). Daily wage earning, often in the form of strenuous labor, was reported by 12.5% of the sample, and 10% were employed as drivers or mechanics. The median monthly income for their households was 10,000 rupees, or approximately US $150. A median was reported because of a small percentage (1.4%) of high incomes over Rs 50,000 that skewed the mean.

Of the sampled married men, 126 (42.3%) had wives that were currently HIV positive, while 8.1% of the men were unaware of their wives' HIV status. Of the wives that were known to be HIV-positive, 71% were concurrently receiving ART. Out of 129 men who responded to a

question regarding the HIV status of other family members, 15.5% indicated having an HIV-positive child, 1.1 % had a positive brother, and 0.6% had a positive mother.

In-Depth Interview Demographics

The mean age of the 55 men who contributed in-depth interviews to the AIM project was 39.3 years, with an age range extending from 22 to 55. Forty-eight, or 87.2% of this group were either currently or previously married, with an average marriage length of about 15 years. Among the 42 men with children, they have an average of 2.3 offspring, identical to the survey group. Six of the men were widowed at some point in their lives, with three of them knowing that the cause of their wife's death was from HIV infection. Sixteen, or 38% of the currently married men have partners that are HIV positive, and three have HIV positive children.

The average monthly income for IDI sample was 11500 rupees, or approximately US $173. Also slightly higher in the IDI group was the average number of years in education at 8.6, with two indicating that they hold college degrees. Despite reporting greater amounts of income and education than the survey population, the percentage that were employed at the time of interview was slightly lower, at 89%. The ethno-religious distribution of the interview group was similar to those who participated in the survey, with the majority of those interviewed considering themselves Hindu (74.5%), followed by Buddhist (12.7%), and Muslim (7.2%). This distribution is similar to the survey group, with the addition of two Christians and one man who was Jain.

Characterizing Internal Stigma

Table 2 includes the Likert-scale results from each of the 16 component questions that comprise the scale. The histogram in Chart 1 demonstrates visually the distribution of Internal

Stigma scores, ranging in this sample from a minimum mean of 1.0 (minimal to no feelings of internal stigma) to a maximum of 4.0 (The highest level of internal stigma). The sample mean for the scale was 2.58 (SD = 0.55, Skewness = 0.26) signifying that the entire group trends toward some feelings of internalized stigma. The reliability of the internal stigma scale was high, with a Cronbach's Alpha score of .89.

Table 2
Internal Stigma Scale Component-Statement Percentage Results (n=361).

Paraphrased Statement from Survey	Strongly Disagree	Disagree	Agree	Strongly Agree
In many areas of life, no one knows I have HIV	11.1	17.5	32.1	39.3
Telling someone I have HIV is risky	9.4	11.9	37.2	41.4
People with HIV lose jobs when employers find out	12.2	27.1	35.5	25.2
I work hard to keep my HIV a secret	8.6	18.1	45.6	27.8
I feel I am not as good a person compared to others	11.9	38.2	33.5	16.3
I am very careful who I tell about my HIV	4.2	14.1	52.9	28.8
Most people believe a person with HIV is dirty	10.8	42.9	28.5	17.7
Having HIV makes me feel unclean	9.7	33.0	42.7	14.7
I worry that people may judge me if they knew my status	5.0	19.9	42.4	32.7
Hurt by people's reaction to knowing my status	16.7	47.9	19.8	15.6
I regret having told some people about my status	17.5	48.9	21.1	12.5
People I care about stopped calling after learning my status	19.8	53.5	14.5	12.3
I have stopped socializing with some due to their reactions	17.6	53.6	20.1	8.7
People don't want me around their children	19.7	59.7	12.1	8.5

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People who know my status tend to ignore my good points	16.4	38.4	34.0	11.1
I have lost friends telling them of my status	20.7	47.8	20.7	10.9

Chart 1. Distribution of Internal Stigma Scale Scores (n=361)
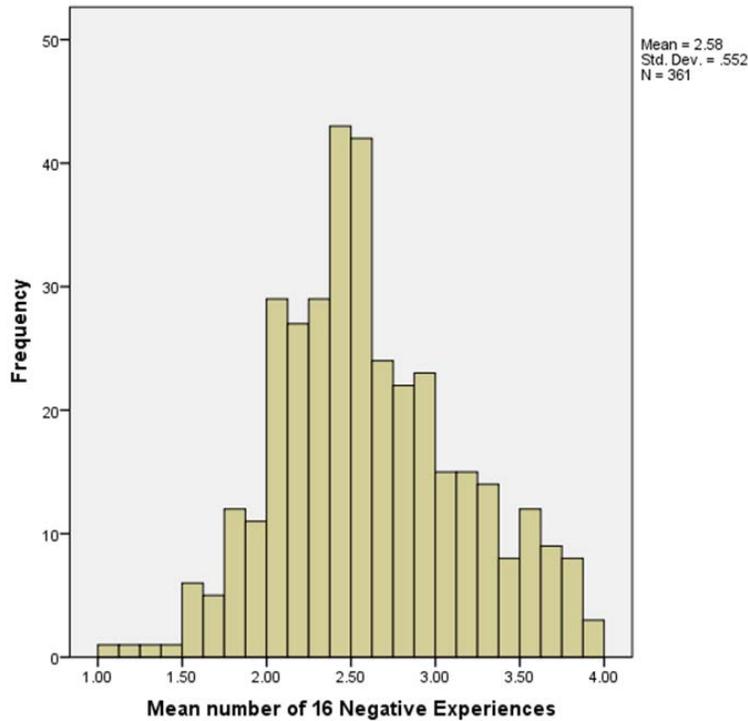
The results of Table 2 and Chart 1 indicate that issues surrounding disclosure of one's HIV status are the most commonly reported negative perceptions or experiences in this sample of HIV-positive men. Over 70% of respondents either agreed or strongly agreed with five statements directly regarding disclosure. Three of these statements relate to general actions taken by the individual to protect their disease status from being widely known: "*In many areas of life, no one knows I have HIV*" (71.4% agree), "*I work hard to keep my HIV a secret*" (73.4% agree), and "*I am very careful who I tell about my HIV*" (81.7% agree). The other two statements are perceptions or beliefs about disclosure: "*Telling someone I have HIV is risky*" (78.6% agree) and

"I worry that people may judge me if they knew my status" (75.1% agree). The men tended to disagree with statements probing for specific negative actions that have occurred to them because of the disclosure of their HIV status, fearing negative reactions rather than actually experiencing them as enacted stigma. The statement "*People with HIV lose jobs when employers find out*" is an example of anticipatory stigma to which 60.7% of the men agreed, "*Most people believe a person with HIV is dirty,*" is another to which nearly half agreed (46.3%). This form of stigma is another anticipatory perception rather than an actual lived experience. Finally, two statements were aimed at directly identifying instances of guilt: 49.8% agreed that "*I feel I am not as good a person compared to others,*" and 57.3% agreed that "*Having HIV makes me feel unclean.*" These final two statements relating to self-directed blame and guilt adhere closely to how the occurrence of internal stigma was articulated throughout the qualitative data.

Qualitative Characterization of Internal Stigma

The interview data provides a diversity of internal stigma expressions, ranging from serious mental illness coupled with the danger of self-harm, to very positive and optimistic outlooks on the individual's health and emotions. Common to all discussion of internal stigma across this spectrum were themes of self-directed guilt and blame for their current status as PLHIV. The primary pattern of internal stigma was associated with regret for past encounters with sex workers, which was the likely source of their infection with HIV.

> *My present condition is because of that habit [of visiting sex workers]. I am thinking, "Why did I go to that side [the Red light district]?" If I didn't go to that side, I should not need this treatment. (Age 38, Single, No Children)*
>
> *I feel sad, because I am responsible for my problem. If I didn't go to Kamathipura Red light district for sex, this problem would not have happened to me…it is a shame for me, because it is my fault. (Age 35, Married, 2 Children)*

A thought come into my mind, Why I did I have a sexual relation? [with a sex worker] Then I repent for my mistake. But now what do I do? I have done mistake. (Age 35, Married, 2 Children)

The qualitative data included some examples of more extreme forms of internal stigma intensity. Here, indicators of internal stigma, namely, self-directed guilt, anger, and fear were directly cited as contributing to the suicidal tendencies by some of the men. In the examples below, both men are single with no family.

Then I came back to home, whenever I was alone I was feeling worried about my status; I was feeling guilty that I have done a big mistake in my life. I was having tension. Negative thoughts were coming in to my mind. I was thinking of suicide.
(Age 33, Single, No Children)

Sometimes I got angry on myself. I always ask the question to myself, what I did? And how you will face to the society? But I knew this is happened because of me. But I have fear of society. And I have guilt also. And sometime I feel to finish myself.
(Age 36, Single, No Children)

On the other end of the internal stigma continuum, some individuals expressed positive or optimistic perceptions of their experience with HIV. When specifically asked about aspects of internalized stigma such self-blame or guilt, individuals who followed a pattern of positive coping felt that it was wrong to direct blame at themselves or anyone else. Also notable was the frequent connection these men made to these positive emotions and the improvement of their adherence to ART medications and their current and long-term health outcomes.

I don't regret my illness. As I told you, I don't want to take any tension. I want to live my life with joy and happiness. If I do this, then it will increase one year of my life.
(Age 38, Married, No Children)

I take medicines on time, I eat on time, I have non veg food at the hotel where I work almost every day, I take proper sleep, I do not think much about my illness, I try to be happy every time, and I do not worry much about my death. So I think this helps me to improve my health. (Age 36, Single, No Children)

No I am not blaming my luck on another person…So I am not taking any type of tension. One thing is that I always remember that I have this disease and I should take medicine and food proper. (Age 42, Married, 2 Children)

Additional direct expressions of self-guilt and self-blame were found across the qualitative data and are included in the following sections as narrative examples of the associations found in the multiple regression analysis.

Factors Associated with Internal Stigma

Twenty-one variables were used to explore the associations of a series of independent variables with the internalized stigma scale using standard multiple regression analysis (Table 3). The model accounted for 39.1%, or 35.3% when adjusted for overestimation, of the variance found in the Internal Stigma scale (R=.625, R^2=.391, R^2_{adj}=.353, F $(21,339)$ =10.369, p < .001). None of the resultant Tolerance scores were below the collinearity cutoff threshold of 0.1. Descriptive statistics for all variables used in the regression model are included in Table 4.

Table 3
Results from the Standard Multiple Linear Regression Analysis ("Enter" Method) for factors
associated with the Internal Stigma Scale (n=361).

Independent Variables	B	β	t	Sig.	Bivariate R*	Collinearity Tolerance
Depression Scale	1.361	0.278	5.443	< .001***	.465***	0.69
External Tenshun Scale	-0.189	-0.196	-3.649	< .001***	-.424***	0.62
Network of Positive People (NMP+) Support Scale	0.584	0.198	3.206	0.001***	-.164***	0.47
NGO Support Scale	-0.880	-0.197	-3.294	0.001***	-.225***	0.50
Family Support Scale	-0.186	-0.118	-2.359	0.019**	-.156***	0.72
External Stigma Scale	-0.563	-0.109	-2.161	0.031**	-.286***	0.70
Reasons for Drinking Scale	-0.277	-0.119	-2.154	0.032**	-.360***	0.59
ART Center Support Scale	-0.489	-0.101	-2.059	0.040**	-.236***	0.743

Variables that did not significantly contribute to the Standard Multiple Regression model: Mean Number of STIs†, Alcohol Use (AUDIT Scale), General Health, Food Insecurity Scale, Quality of Life Scale, Length of ART Use (Years), Time since HIV Diagnosis (Years), Education Level, Age, Friend Support Scale, ART Adherence (4-Day), Family-Related Tenshun Scale, ART Adherence (30-Day)

*Note: ***p < .01, **p < .05;*
* Bivariate R value is a Pearson's Correlation with the Internal Stigma Scale;
†" Mean Number of STI" scale was found to be significant in the subsequent Stepwise Multiple Regression model

Eight of the independent variables significantly contributed to the standard regression model at, or below, the .05 Alpha level. The CES depressive symptom scale, External Tenshun Scale, PLHIV scale, and the NGO Support Scale were found to be significant at the $p < .01$ level. The Family Support Scale, External Stigma scale, Reasons for Drinking scale, and ART Center Support Scale were significant at the $p < .05$ level. None of the variables related to demographics were found to contribute to the model, including age, education level, years since HIV diagnosis, and years since ART initiation. Likewise, four- and 30-day ART adherence, AUDIT Scores, and

the General Health, Quality of life, Food insecurity, Family-related tenshun, and Friend Support scales failed to reach significance as predictors of internal stigma. The

To determine the relative importance of these significant variables independent of the others, a stepwise multiple regression analysis using the "backward deletion" method was performed. This method removes independent variables from the original 21-variable model in a staggered fashion until only the significant predictors remain. The results of this second regression model (shown in Table 6) demonstrated that nine key variables predicted 37.6% (or 36% when adjusted) of the Internal Stigma scale variance (R=.613, R^2=.376, R^2_{adj}=.360, F $(9,351)$ =23.517, $p < .001$). All eight variables found to be significant in the Standard Multiple Regression were also found to be significant in this Stepwise model, with the addition of Mean Number of STIs (β= -0.104, p= .025). The remaining 12 independent variables together were associated with only 1.5% (Standard R^2=.391 minus Stepwise R^2=.376) of the variance in the outcome of Internal Stigma.

Of note, the stepwise multiple regression model placed a measure of the presence of sexually transmitted infection as a significant factor associated with internal stigma. This association suggests that facing more co-occurring STI diseases symptoms such as genital ulcers, genital warts, swelling in the groin, urethral discharge, or pain upon urination is associated with higher levels of internalized stigma. While other indicators of sexual risk behaviors were not included in this analysis, such a significant finding warranted further analysis of the connection between past or present risky sexual behavior and internal stigma in the qualitative data. The specific relationship between STIs and stigma was not well articulated in the qualitative data, but the discussion of guilt surrounding risky sexual behavior and the use of sex workers shown above was considered proxy topic for this association.

The eight significant variables in the regression have been grouped into three categories based on the similarity of their subject matter and overlapping themes found in the IDI data. The ordering of these categories roughly approximates the order of statistical significance found in Table 2, with aspects of mental health (depression, tenshun, and alcohol use) discussed first, followed by the influence of social and organizational support from Families, NGOs, and ART centers. Finally, the relationship between internal stigma and external stigma has been separated into its own category for analysis.

Mental Health Status

Issues of mental health and alcohol use were among the strongest factors that contributed to the regression model. First, there was a significant positive relationship between the CES-Depression scale and Internal Stigma, such that an increased level of depression was associated with a more negative internalized stigma. A significant relationship was also found between the External Tenshun scale and the dependent measure such that greater experience with tenshun was associated with greater internal stigma. Reasons for Drinking was also associated with the Internal Stigma Scale such that that more reasons for drinking was paired with greater internalized stigma.

Several themes emerged from the interview data regarding the relationship between mental health and internal stigma, generally beginning with strong emotional responses to the individual's initial HIV diagnosis. Great variation was noted in these initial reactions. On one end of the response spectrum, a small group (3) demonstrated a feeling of expectation and acceptance of the news. This reaction seemed to concur with their understanding the risks of their current or past lifestyles. These men three spent time as young adults drinking and visiting commercial sex workers.

I took it easy (Mi ekdam shantpane ghetale!). Before getting the reports I was mentally prepared for the results. I had told myself that let the report be positive, I am not going to collapse. (Age 32, Married, 1 Child)

I knew it that HIV can happen to anybody. Nobody can say it confidently that it cannot happen to him or her. When I had my friends around me who were HIV positive, I had realized that I have also been maintaining the same life style as they were, so I am also at the risk of acquiring it, sometime or the other in life. (Age 45, Married, 2 Children)

I was bit shocked, but I was knowing that it could happen. Her face (the sex worker with whom he had sex) was ringing in my mind. (Age 44, Married, 3 Children)

The majority of men (34) indicated a general feeling of shock, loss, tension, confusion, or fear upon receiving their diagnosis, forming the primary pattern of emotional reaction found in the sample. Some men specifically said that the news brought immediate sadness or depression.

When I was diagnosed HIV positive, I was in tension, having stress because of my illness. I was feeling so sad about my status, I thought that now I have very few days to live. (Age 35, Married, 2 Children)

I was depressed for many days because of that reasons and got more depressed once I finally learned that I was HIV positive. (Age 38, Married, 3 Children)

And when I got the report of my HIV, then I was in depression. I was talking with myself only, I hadn't talked with anyone else. Four months I hadn't talked with a single person, I was sitting in my house only and crying, talking with only myself. Those days were worst days in my life. I was confused and totally blank. (Age 35, Married, No Children)

There were eleven men who said that they had, or continue having thoughts about suicide. Several stated that they actually attempted suicide or came very close. For two of them, this mental status existed prior to their HIV diagnosis; the rest arrived at this mental state as the after effects of diagnosis overwhelmed their lives with stressors and guilt.

Yes, I was tensed. That time doctor asked me, "What you are going to now?" I replied, "Madam, you tell me what to do." That time I was feeling like stepping in front of the train, or hanging myself. I was wondering what I should do to end my life. (No Age Indicated, Married, 1 Child)

Now days I don't feel like living anymore…I have experienced. Every living being dies one day or the other. If we are living, then I will die and it is for sure. I know I am suffering from this disease. So why should die with pain? (Age 38, Married, No Children)

Feelings of self-guilt, self-blame, or personal shame were expressed throughout the interviews, most often in relation to their fear of disclosure and the resulting negative responses they believe could follow release of personal information. Many indicated feelings of profound and continuous stress or tenshun stemming from this fear. Most of the men did not disclose beyond their wives and close relatives for fear of damaging their standing in society and the reputation of their entire family. There were only a few examples of disclosure to trusted friends or to their employers. Eight of the respondents had shared their status with their wives exclusively, while only two said that they had not disclosed their status to anyone.

First thing is fear in my mind, as I didn't share with anybody that I am HIV positive. If anybody comes to know, it will be not good for me. (Age 35, Married, No Children)

It is a bad disease. Cancer and other diseases are much better than HIV. Other diseases don't create any bad name. But this creates a very bad image in family and society. (Age 52, Married, 2 Children)

Another fear was that of losing their source of income once friends and others in the community learn of their HIV status. Both of the examples below do not mention experiencing actual discrimination nor do they mention hearing vicariously about specific act of stigma against other positive people.

Then there is risk of losing my job. Also, I have to face the torture and agony of the world (duniya ki nafarat!). Everybody in the world will come to know about it. They will say, "Look at this 'famous man'! He has 'this disease'!" Thus they will look down upon me. They may not say these things in front of me, but certainly they will say these things on my back that this fellow has HIV. (No age indicated, Married, 1 Child)

I am feeling scared of being HIV positive; if someone comes to know about my status then I have to close my shop. No one will take Paan from me. I will not able to survive

among friends. I cannot eat together with friends. Hence I sometimes feel very negative. (Age 35, Married, 2 Children)

There were many examples of drinking as a coping mechanism that arose across the qualitative data. The patterns described below involved drinking as a way to forget or ignore the guilt and stress of being HIV positive. This HIV-related guilt, in addition to fears about the wellbeing and support of their family in the future provided reasons for alcohol consumption that were pervasive throughout the qualitative data.

> *I want to forget about my HIV, and I always think about my family. I pray to the god for my long life. Because I have to take care of my family, these things always come in my mind. I drink to forget these things. (Age 41, Married, 2 Children)*

> *When I am feeling tense, that time I drink alcohol. I try to ignore the situation when there is tension, stress and guilt feeling, sometimes I cry when I become emotional. Most of the time I try to ignore negative feelings and tension, but if that tension increase, then I go alone in the bar and drink alcohol.* (Age 33, Single, No Children)

> *The guilt was so strong that I used to have maximum amount of alcohol until I attain profound sleep. Again after getting up, I used to drink a lot. I felt like ending my life this way. I never wanted to be in a state of consciousness. I started withdrawing from others. I never felt like having food. The whole day I used to drink and sleep at home. I never felt like going out or meeting friends, too. (Age 38, Married, 1 Child)*

An alternative to the pattern of mental health issues, alcohol use, and internalized stigma outlined in the quotes in this section are the descriptions of positive coping methods found in some of the interviews that indicate less feelings of internalized stigma. A common form of positive coping was a general expression of optimism and forward, future-based thinking, often referring to the desire to survive for their children and families.

> *However, I do not think more about my illness, I don't like having tension and stress. Now I only think that to take care for family, my mother and father, and to educate my son for his good future, to keep my family happy (Ghrchyana sukhi thevayache). HIV positive people taking tension, I don't like that. This patient should not take tension of*

*having HIV illness, "Tension mansala marun takte" (tension kills the patient!). He
should think about his future life and family. (Age 31, Married, 1 Child)*

*I have no fear of death. I have no guilt for what I did in past. If my death is fixed this
way, no one can change it. I am only worry for my wife and son. I want to be alive and
healthy till my son grew. (Age 32, Married, 1 Child)*

Social Support

The next group of significant relationships found in the multiple regression models

related to various avenues of potential support, or lack of support, received by the men. The

Network of Positive People (NMP+) scale measures the amount of support received specifically

by the Network of Maharashtra People with HIV NGO. There was a significant positive

relationship between the NMP+ scale and Internal Stigma such that less NMP+ support was

associated with higher scores on the internal stigma scale. A similar association was found

between our dependent measure of internal stigma and support from other NGOs. The significant

relationship between lack of organizational support and greater feelings of internalized stigma

continued with the ART Center Support Scale. At the level of the family, a significant

association with Internal Stigma was found with the Family Support Scale. The questions that

comprise the NGO, ART, and Family support scales refer to receiving assistance in a variety of

realms, including ART adherence and medical treatment, psychological and emotional needs,

financial support, informational and legal support, and in participation with social networks or

programs.

The regression analysis indicated a significant association between family support and

internal stigma among the study population, such that individuals with greater amounts of

support demonstrated less internalized stigma. It was clear from the qualitative data that support

from spouses was the most essential form of family support for the men's overall well-being,

particularly in the realm of emotional and moral support, as well as with assistance in ART

adherence and supplying medication from ART centers.

> *She is my life (owh meru jaan hai). I am surviving because of her. (Mai sirf uski wajah say jinda hun). She takes care of me, gives me food on time, medicine on time, manages household expenses, and the children's education with limited money. She never argues with me because of my HIV infection. In fact, she is still not understanding the severity of this problem. (Age 38, Married, 3 Children)*

> *My wife gives me moral support; she is concern about my illness. She used to say that if you getting well then we will do everything for children and family.*
> *(Age 35, Married, 2 Children)*

> *She stood beside me in my bad days. When I was depressed and wanted to die, she took charge of my life. She said not to worry. She assured that she is there with me forever.*
> *(Age 51, Married, 2 Children)*

While most of the married men indicated a positive relationship with their wives, there

were a few examples of negative spousal relationships, with five indicating fighting or some

form of domestic violence. While most men did not describe reactions to initial spousal

disclosure as anything beyond shock, sadness, and support, some wives reacted to the news in a

negative way, placing blame and shame onto their husband. The connection between such

immediate, enacted stigma from wives could be a facilitator of internalized stigma

> *My wife and my brother-in-law fired on me. My wife told me that you went out for sex and this is the result (tumne bahar jakar ganda kaam kiya usi ka natija hai ye). "How you get these disease?" They blame me a lot that you are not good person. Why you get married if you are having this kind of diseases? You are cheater, you are not good person, and you are bewda (drinker) and so many things. I will not excuse you.*
> *(Age 53, Married, 1 Child)*

Relating to the difference between those currently married (82.5%) and those actually

living with their wives (71.5%) found in the quantitative data, eight of the married men

interviewed lived separately from their wives after their HIV diagnosis (17%). Most of these

involved the wife returning to her natal family village home, yet the exact reasons for (and

lengths of) all of these separations varied between tension and fighting in the household and a

desire to protect children and other family members from the disease.

> *Lots of fighting and discussion were held in that night in my house… My wife decides that she will not going to stay with me. She has left home along with daughter went to her native place. That time my daughter was just 2 years old. I was in big tension. (Age 53, Married, 1 Child)*

> *I don't know, I told you I stayed with her only two months in two years. She is staying in village and I am staying here. I go to village after long period. I didn't like village that's why not going frequently. My mood not allowing to me go to village.*
> *(Age 35, Married, No Children)*

> *One way it is good that I am here and she is at native. This way there is no opportunity for sex and infection to her. (Age 35, Married, 2 Children)*

In one case, a man did not reveal the fact that he had contracted HIV from a sex-worker

until an undisclosed amount of time later. In this case, the wife returned to her native home

specifically for fear of societal stigma.

> *But I didn't disclose my sexual relation with sex worker in initial days. Later I told her…My wife asked me, "How it happened?" and blamed me that I am responsible for my ill health and putting all family in to dark…My wife is more concerned. She said if people know, they will neglect us from village and society. (Age 52, Married, 2 Children)*

Instances of wives living separately from their husbands for fear of HIV infection or any

perceived shame the diagnosis brings upon the family can be considered forms of enacted or

external stigma directed at the men in the sample, thus there is significant overlap between

spousal support and external stigma.

Beyond the marital relationship, support from other family members was also very important in addressing tension, depression, and HIV-associated guilt. Such support after disclosure to family may be protective against development of internal stigma. Directly below are examples of this beneficial relationship.

> *I didn't felt much bad, because all my relatives were with me. They were support me. They know about it, so I didn't get any tension. Now I have my mother, father, and 4 children at my home. One daughter got married and one is enough grown for marry. I have lot of support from them. I am earning okay, so there is not much tension in my life. My all relatives know about me and my HIV problem. (Age 42, Married, 4 Children)*

> *My family is very cooperative, my friends also know about my status, so I never spent a time alone. Hence I do not feel bad.   I enjoy every moment even I am HIV positive. Also I do not feel guilty myself. (Age 51, Married, 4 Children)*

> *So I started taking medicines in front of all. I think I am getting love from all. Today my son was asking me whether I need him to accompany me to the ART center. I felt very good when he asked me this. (Age 48, Married, 3 Children)*

Given the prominence of familial support for the well-being of these men, it follows that lack of support or expressions of enacted discrimination originating from family members could have a magnified negative effect. These experiences seemed to have the most negative effect on their mental health, internalized stigma, and welfare.

> *Sometimes I feel guilty, sometimes negative thoughts come in to mind. Most of the time my family (brothers) have spoken very badly. So I don't want to meet them even I don't want to talk with them, since I am not feeling well as I was in past. Sometimes I blame on myself, why do I did this test? When my brother came to know about my status he asked me to leave the home, I was left there, I had no place to stay, and sometimes I used to sleep on the road. (Age 33, Single, No Children)*

> *We were living together few years back, but since HIV was diagnosed to me, my brothers asked me to live separate. My parent wish to live with me, but my bothers don't allow them to live with me. They said my HIV status is creating bad name and image in family and relatives. Slowly it will start negatively impact on my child once they will know my HIV problems. They asked me to live alone. (Age 32, Married, 1 Child)*

Like the negative actions of spouses in reaction to the HIV status of their husband, discriminatory behavior originating from other family members demonstrates further overlap between the lack of family support and external stigma. The most common examples of external stigma found in the interviews were initiated by the men's extended family. In the next section, other aspects of external stigma are shown.

Direct support from ART center staff seemed to be very important for individuals in getting beyond feelings associated with internalized stigma, as best seen in the quotes below. This could be because of a higher level of trust when such support comes directly from authoritative figures such as the ART center doctors. These examples were not ubiquitous in the interviews, but the majority of the men indicated an overall positive experiences with their ART center.

> *Initially, when I came to know that I am HIV positive I felt ashamed of myself. I thought that the whole world will come to know about this. Even when I went to the hospital I was feeling very awkward to ask anybody where the ART center is located. But fortunately, those around me who know it are taking every effort to save my life.*
> *(Age 51, Married, 2 Children)*

> *I was in big tension. My thinking power was finished and not understating what to do and what to not do. The doctor gave me solace and said many people are living with this disease. Don't worry everything will become normal. Doctor has suggested to me to start the medicine from another doctor. This doctor is very much familiar to me.*
> *(Age 45, Married, No Children)*

An additional supportive function of ART centers that addressed some aspects of internal stigma was simply the sight of many other positive people seeking treatment. This made some men feel as if they were not alone in their struggle and seemed to improve their emotional status and overall outlook on life.

> *After HIV diagnosis, I was hopeless for life. But once I saw many HIV patients in these centers, I got encouragement for survival. (Age 32, Married, 1 Child)*

But when I visited the ART center then I saw I am not alone who is living with HIV. I come every month and see the patients more than 30, and they feel good. And it is more important to feel good. And I also feel good, because they also got the same treatment which I had taken from the doctors and counselors. (Age 38, Married, 1 Child)

The primary pattern found in the qualitative data to explain the association between NGO support and internal stigma seems to be that positive, supportive interactions with NGOs and ART centers that were described improved their outlook, reduced tension, and gave men a more optimistic perception of their illness.

Finally, in terms of NGOs, when men were asked about their knowledge or involvement with them, many said that they had seen NGO representatives at ART centers, but had not sought or received any help from them, or that they have never been approached by NGO representatives. Some men conveyed negative experiences or beliefs about NGOs for a variety of reasons such as lack of time, lack of need, or non-follow-up, as demonstrated in the quotes below.

There is some people who stand outside of the ART center. One day they told me about the government schemes and then they told me to show my green card. I denied them. And told them I don't want to fill any form and I don't want any support. I am earning and I don't like to waste my time. (Age 44, Married, 3 Children)

Till today I haven't received any benefit from NGO. I have given them my documents and my form was also filled by them. They were talking about a pension scheme, under that scheme I was supposed to get money. But I haven't received money yet. (Age 47, Married, 1 Child)

They are not doing work for the patients. They create more tensions for us. They fill up their records only; they are not providing any help to the patients. They are asking only who is your father is who is your mother? Taking only information from us for our work. What is meaning talking to them? It is wasted of time to talk them. You are doing your own work, let me do my work. (Age 42, Married, 4 Children)

There were, however, important positive experiences described in regards to the support offered by NGOs. The support described was largely emotional, providing a venue for discussion, education on leading a healthy life, and group counseling. Such support could be protective against the development of internalized stigma.

> *When we go there, then they treat us very nicely. And there are lots of HIV positive patients who come for the prayer. And they also know (staffs of the NGO), they can't cure us, but they want to see the smile on patients face. And if patients have some problems in their life then they share with the staffs of NGO.*
> *(Age 41, Married, 2 Children)*

> *They had explained many cases, how they survive and living healthy since 25 years of HIV diagnosis. I got encouragement to live healthy by learning these examples.*
> *(Age 55, Married, 3 Children)*

> *These NGO people are doing noble job. They are providing love and support. The ART staff is also very good. (Age 38, Married, 3 Children)*

Two of the men had successfully utilized an NGO service that connected men with HIV positive women for marriage. As demonstrated in another section, wives are the most important figure in many men's lives in terms of social and emotional support, as well as for health support with adherence to ART.

> *I came to know my wife through SATHI project (a NGO working with HIV people at an ART center). I was HIV positive since birth, therefore I was knowing that no one fresh (non-HIV positive) would marry with me. While visiting the ART Center I understand that SATHI project staff are helping people like us to get marry with HIV positive if both are agreeing. They (SATHI project staff) learned about me and my family while filling a form. They told me about my wife that she also from Nepal. They help me to meet my wife in his Dharavi NGO project office. (Age 22, Married, No Children)*

External Stigma

The External Stigma Scale demonstrated a significant association with Internal Stigma in the multiple regression model, such that more experience with discrimination directed towards

the men because of their HIV status is associated with greater Internalized stigma. Actions by

family members followed by enacted discrimination in the workplace were the most common

types of external stigma mentioned. Some manifestations of these types of external stigma

include withholding payments for completed work and withholding opportunities further

employment due to their HIV status.

> *My transport office is not giving me job. They have not paid my full dues. They are saying, "Not much work is here now." They are saying, "You are on treatment, therefore driving is not good for me at present." (Age 44, Married, 3 Children)*

> *The Supervisor did not say anything beyond, "Get tested properly. Take your medicines." After that I went to my village. When I returned from my village a few days later, then I was suspended from work. (Age 49, Married, 2 Children)*

Since most of the men have not disclosed their HIV status beyond close family members,

there were limited examples of external stigma at the community level. In two of the prominent

cases that were shared, the occurrence of mistreatment from strangers seems to instill self-

directed guilt and blame.

> *They serve me separately or hesitate to use bathroom after I use it. They generally tell me to have my meal before them. Everybody is aware that HIV does not spread this way. But it is their right to protect their health first. I feel very sorry for that. But somewhere I feel that they are right. (Age 27, Single, No Children)*

> *However, the place where I work there is one fellow who is aware about my status; he often visits my Paanshop. Yesterday he was come in the evening and he had drunk alcohol, so he was using abusive language using my name. Hence I was feeling sad, and felt hurt. I used to blame on myself for that. Because of that big mistake people are behaving with me badly. (Age 35, Married, 2 Children)*

Living in a large urban area like greater Mumbai may instill some anonymity in people's

lives, helping them avoid local disclosure and discrimination that may be more common in

smaller village settings.

I had a very good relationship with my neighbor at my native place. Once they knew my HIV, they stopped coming my home and also stopped talking with me. My children were teased in schools. People and other student say that his father is an HIV patient. It was difficult for children to cope with that situation. It is not only with me; it was with many other people at my native. The village was small, such things can't be hidden… I have not disclosed my HIV status here in Mumbai. (Age 55, Married, 3 Children)

Below are examples of vicarious stigma in which PLHIVs hear stories of discrimination or personally observe how other people with similar circumstances are treated, leading to their own internalized fear of stigma and disclosure.

I have seen how others behave with positive people. In past, there was one man at my work place who was HIV positive. Now he is no more. Everybody knew that he was positive. They used to avoid talking to him. But in his absence people used to talk about his sexual life in a cheap manner. They used to make fun of him. When I got infected I decided to keep my illness to myself and not to discuss about it to anybody else. (Age 35, Married, 2 Children)

People hate us. Last month I heard about someone with HIV who died. Till the last moment, people refused to touch him. For this reason, I began to worry that people who find out would discriminate against me. (Age 49, Married, 2 Children)

Interrelationships between Factors

The qualitative results in this chapter have demonstrated close affiliations among the variables shown through the multiple regression model to be individually associated with expressions of internal stigma. For instance, a significant contributor to HIV-related depression and tenshun was the fear of experiencing external forms of stigma. This stigma, when enacted or imagined, could be on a more immediate level from one's family or workplace, or on a broader level from one's community or society at large. In terms of support, we see its close relationship with mental health in the emotional benefits of support from either spouses, other family members, or from organizations. Alternately, we see the emotionally destructive effect of

deficient support or enacted stigma from these figures in the men's lives. Through all of the

interconnecting factors that affect an individual's mental health and perception of their illness,

patterns of self-blame, shame, and guilt emerge as our primary indicators of internal stigma

expression.

Figure 2. Path Analysis for Regression Model as Suggested by Qualitative Data.
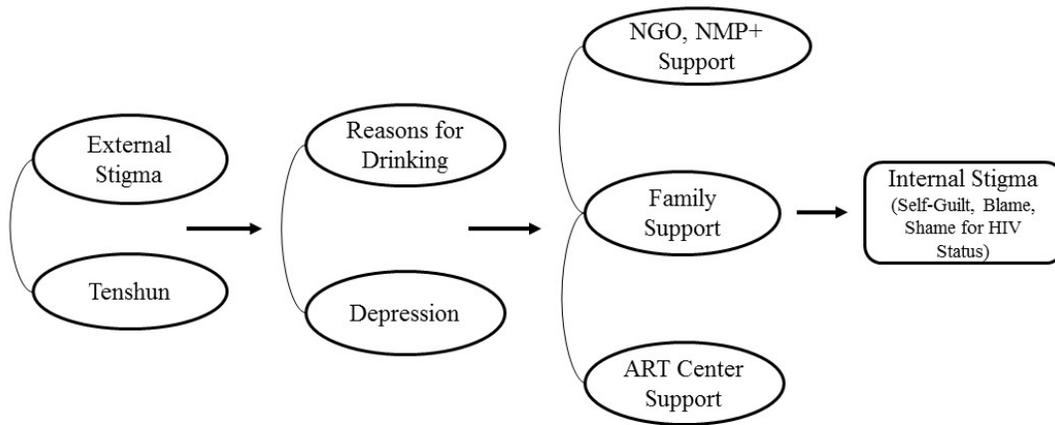

Figure 2 demonstrates a suggested path analysis of the variables found to be significantly

associated with internal stigma in the standard multiple regression analysis (Table 3). Although

the research for this thesis was cross-sectional, this approximated path analysis was suggested by

the qualitative results and would require a longitudinal study for confirmation. The origin of a

general pattern towards the development of internal stigma was experience with or fear of

external stigma. This real or perceived experience with stigma was paired with tenshun and

anxiety, which for some contributed to reasons for consuming alcohol and symptoms of

depression. Social support from family, NGO, and ART Centers then acted as mediators in this

path. The lack of support from these areas, with particular emphasis on practical and emotional

support from immediate family members, led to expressions of internal stigma (self-blame,

shame, and guilt) given the presence of previous mental health issues.

Chapter Five - Discussion & Conclusion

From a broad perspective, the outcomes of this research have demonstrated the mental health consequences of dealing with a permanently life-altering disease. These consequences stem from the interaction of both internal and external forces, particularly the relationships among how an individual perceives their illness, what coping strategies they use to deal with its effects, and the quality and variety of social support that they can access. In light of the results, the presence of high internal HIV stigma may influence all of these forces in a negative way, ultimately leading to decreased ART adherence, accelerated morbidity, and the further spread of HIV. External stigma perceived and/or expressed by family, healthcare workers, community members, or institutional policy inherently obstructs the delivery of social support that is critical to positive health and mental health outcomes for patients on HIV treatment. Real or perceived stigma from such sources may lead to additional depression and anxiety, mental states that are commonly expressed after initial diagnosis with HIV. Experiences with external stigma and the resultant impact on mental health may influence an individual's own perception of their illness, an internalization of stigma characterized by stigma acceptance, guilt, and self-directed blame and shame for their disease status.

The results of this thesis indicate a strong relationship, both qualitatively and quantitatively, between internalized stigma and mental health status among the sampled male population who consume alcohol and are on antiretroviral therapy in urban Maharashtra. The primary pattern indicated that self-directed blame, shame, and guilt regarding HIV status, paired with greater expressions of depression, tenshun, and reasons to consume alcohol was associated with greater internal stigma. The qualitative data indicated that this association was often set in place very soon after HIV diagnosis and that fear of enacted stigma following disclosure was the

most common vehicle for immediate and continued mental distress. The close relationship between internal stigma and mental health status confirms the initial hypothesis and supports much of the existing literature on HIV stigma across different international contexts, including India.

At the other end of the continuum, PLHIV with lower internal stigma expressed the ability to overcome feelings of self-blame through techniques that could be identified as positive and adaptive coping strategies. The techniques used by some of the men included an optimistic and future-oriented mindset that did not dwell on or feel guilty about past risky behaviors. This way of thinking allowed for some to focus on ART adherence, stress avoidance, and healthy living as a path toward a normal spent with family and friends. Feelings of social responsibility to protect others from infection and finding a sense of community among other people living with HIV also accompanied positive coping.

A major additional finding from this analysis was the quantitative relationship between social support from families, NGOs, and ART Centers and internalized stigma. The qualitative results indicated that support from these sources positively impacted men's mental health status and was associated with avoidance of self-blame for their HIV status. Of all sources of social support, support from family, and in particular spouses, was found to have the most influence on mental health and successful outcomes with ART adherence.

There was an expected relationship between internal and external stigma, with the most damaging form of external stigma seemed to originate from family members. This phenomenon, along with the generalized fear of external stigma in the absence of directly experiencing it, limited disclosure, which in term limited support.

Interventions Addressing HIV Stigma

Stigma-focused intervention projects have been increasing in both number and scope, with more studies involving PLHIV directly and taking place at multiple levels (group, community, institutional). However, many efforts to reduce both external and internal stigma must address the deficiencies in past programs that include: lack of sustainability, limited evaluation of effectiveness; a narrow focus on individual level HIV education for prevention of enacted stigma; and lack of proper attention or measurement on internalized forms of stigma (Bharat, 2011; Mahajan et al., 2008; Sengupta, Banks, Jonas, Miles, & Smith, 2011; Stangl et al., 2013).

Internal Stigma & Mental Health-Related Interventions

An independent search of existing literature and the content of four HIV-stigma literature reviews conducted since 2008 yielded only two studies that specifically focused on interventions for internalized stigma. One study by Rao et al. (2012) adapted the HIV Stigma Toolkit developed by ICRW for use in small population (N=24) of HIV-positive female African-Americans. Across two workshops, groups of women viewed "triggering" videos about HIV discrimination and then shared and discussed personal coping strategies they have used to deal with the effects of real or perceived stigma. A role-playing portion of the intervention guided the women through dealing with difficult situations triggered by stigma. A pre-and post-assessment of engagement and internal stigma feelings showed an overall acceptance of the methods and a measured reduction of stigma (Rao et al., 2012). Another intervention recruited a sample of female PLHIV from an urban area in the southern United States to pilot test the Integrated Model of Health Promotion through "Emotional Writing Disclosure" activities. The writing focused on the psychological effects of HIV diagnosis and the internalization of stigma feelings. The model

that was successfully piloted in this study aimed for cognitive re-organization and improved

psychological, physical, and behavioral health outcomes (Abel, Rew, Gortner, & Delville, 2004).

While few interventions have specifically addressed internal stigma, more have used a

broad focus on improving mental health among PLHIV. In both Uganda and Zambia for

example, home-based counseling and testing programs showed success integrating psychosocial

support, counselling for individuals and couples, community mobilization, and health education

in reducing HIV stigma and improving both status disclosure and ART adherence (Jürgensen,

Sandøy, Michelo, & Fylkesnes, 2013; Nuwaha, Kasasa, Wana, Muganzi, & Tumwesigye, 2012).

On a more systemic level, recommendations for the early integration of mental health treatment

into HIV care through collaborative teams have been proposed due to the high prevalence and

morbidity of psychological disorders among PLHIV that directly prevent treatment success and

HIV control (Kaaya et al., 2013; Prince et al., 2007).

For the most part, interventions in India have not addressed internal stigma directly,

although it has been examined and encouraged by Steward et al. (2008) through the creation of

four stigma surveys that measured enacted, vicarious, felt-normative, and internalized stigma in

the context of India. Another study with PLHIV in the context of South India explored positive

coping strategies such participation in positive networks and maintenance of family well-being to

deal with stigma, particularly the fear of being labeled "immoral" (Kumar, Mohanraj, Rao,

Murray, & Manhart, 2015).

Social Support-Related Interventions

One of the major gaps found among existing HIV stigma interventions is a lack of

evaluation on the lasting impact of stigma reduction on social support among PLHIVs (Sengupta

et al., 2011). Of the few existing stigma interventions relating to social support, many have focused on high risk populations such as female sex workers and injection drug users (Knowlton, Hua, & Latkin, 2004; Qiao, Li, & Stanton, 2014). In Nigeria, mass media educational campaigns were demonstrated to successfully improve individual PLHIV's perception of social support availability (Fakolade, Adebayo, Anyanti, & Ankomah, 2010). In Uganda, collective activities to challenge stigma and the use of peer support groups for the delivery of HIV services and treatment was demonstrated to foster social support among PLHIV and reduce community stigma levels (Mburu et al., 2013).

Family-involved HIV stigma interventions were found to be very rare despite a recognized need to address the problem based on evaluations of stigma's impact at the family level, including in the Indian context (Bharat, 2011; Bogart et al., 2008). One study determined the viability of a psychoeducational intervention between serodiscordant couples that addressed depression, anxiety, perceived social support, and spousal stigma (Gordon-Garofalo & Rubin, 2004).

External Stigma Interventions

Globally, the most common type of HIV stigma interventions have attempted to address the issue at an individual level, primarily targeting healthcare workers and students with education about HIV to decrease the fears and misconceptions that lead to discriminatory beliefs and enacted stigma (Bharat, 2011; Stangl, Lloyd, Brady, Holland, & Baral, 2013). In LMICs, a common form of stigma intervention has been utilizing mass media campaigns to distribute HIV education or situational narratives aimed at reducing levels of community-level stigma, to which some success was demonstrated (Fakolade, Adebayo, Anyanti, & Ankomah, 2010; Mahajan et al., 2008).

Interventions addressing external stigma at higher, systemic levels such as organizational and public policy often require significantly more resources and political leverage. In a review of stigma interventions, only 10% of studies were focused on these levels with negligible evaluation efforts (Stangl et al., 2013). One of the most damaging sources of HIV discrimination globally comes from punitive laws and policies that criminalize HIV non-disclosure or the transmission of HIV. Such laws are in place in more than 100 countries, codifying and reinforcing stigma within societies (UNAIDS, 2015b). In the United States alone, over half of all legal jurisdictions have such punitive laws in place. Suggested policy changes to diminish or abolish such laws include the wide adaptation of harm-reduction policies and the modernization of existing statutes to remove criminal penalties (Lazzarini et al., 2013).

Many of the same issues identified with previous stigma-reduction interventions have been replicated in India, particularly with negligible efforts at evaluation and a general lack of interventions aimed at multiple levels. Likewise, the most common method of past interventions in India focused on behavior change of individual nurses or other health care workers with the goal of reducing fear and discrimination through education (Bharat, 2011). While this form of intervention may be important, the commonality of healthcare-associated stigma calls for more organizational or systemic-level projects.

Addressing Stigma in the RISTHA/AIM Project

The intervention phase of the RISTHA/AIM project includes individual, group, and community-level activities. These different levels are all are aimed at reducing alcohol use and increasing ART adherence among PLHIV, while simultaneously addressing a range of biopsychosocial factors that impact adherence such as mental well-being, social support, and stigma.

Individual Level

At the individual level, ART center counselors received training to utilize the Solution Focused-Narrative Intervention Model with participants during one-on-one sessions. This counseling model allows participants to identify a problem, set goals for themselves, identify personal strengths and weaknesses for addressing the problem, and then utilize and build on existing strengths to reduce the problem. Over the course of four sessions, issues of relationships, tenshun, alcohol use, adherence, and status disclosure are addressed. An assessment of internal stigma and disclosure is given before the first topic session. Internalized stigma is incorporated during the session on disclosure after the participant relays his personal story of sharing or not sharing his HIV status with others. The benefits and consequences of both disclosure and non-disclosure are discussed before a personal disclosure plan developed. Internal stigma, depression, and lack of social support as a result of non-disclosure is pointed out, and improved mental health paired with greater support is mentioned as a benefit.

RISTHA/AIM intervention activities at the individual-level relate to the results of this thesis by focusing specifically on the mental health effects of non-disclosure and generating techniques to overcome personal fears over the perceived aftermath of sharing one's HIV status. A generalized fear of experiencing stigma following disclosure was found in the qualitative data to be a significant source of mental health distress and connected to acceptance of stigma through self-blame, shame, and guilt. The direct measurement of baseline internal stigma levels using a scale further addresses issues that arose in this thesis regarding gaps in the literature and past interventions that did not focus on or acknowledge stigma internalization.

Group Level

At the group level, facilitators from NMP+ and RISTHA staff run four sessions regarding healthy living strategies, tenshun, relationships, and alcohol's impact on ART adherence. These sessions are intended to produce both individual and group-level outcomes. In the healthy living portion, group participants learn that stigma and disclosure are some of the things that are linked with alcohol use and adherence, and that positive thinking is a strategy for maintaining health. During the relationships session, participants learn that self-stigma can negatively affect relationships and social support through activities that have groups map out the size and quality of their social networks both before and after diagnosis. A portion of the relationship session further stresses the significance of reciprocity for maintaining key relationships and for developing new social connections in the men's lives. Positive coping strategies and their connection with general health are also discussed in the session on tenshun, including improving family relationships, avoiding risky habits such as drinking, and seeking out support from counselors or Positive People networks. The group sessions end by connecting all of the topics in a framework that collectively affect each other and ultimately the outcome of ART adherence.

The highlighted group-level intervention activities regarding positive coping methods for healthy living and tenshun-reduction directly connect with the results of this thesis. These techniques were identified as ways some men overcame the mental health effects of living with HIV and rejected the feelings of self-imposed blame, shame, and guilt comprising internal stigma. Incorporating the importance of relationship maintenance into the group meetings also links to the present research findings that point to multiple sources of social support as a vital part of ART adherence and positive mental health. Working with participants to then list and find solutions to issues within key life relationships, the focus will likely be on spouses and immediate family members. The results of this thesis found that family members serve opposite

functions in terms of social support; they are the most important source of practical and emotional support, as well as the primary source of external stigma.

Community Level

At the community level, larger groups of 15-20 participants living in same general area are gathered and assessed for their perception of and experience with stigma in their shared community. Intervention activities begin with discussions about human rights issues in relation to their experience as PLHIV and about forms and uses of collective action. The group then works collectively to identify a solvable issue in their community that contributes to stigma, discuss its causes, and determine what realistic outcomes they could hope to achieve through their collective voice and action. After planning and practicing their action plan, it is actually implemented and then self-evaluated by the group. The overall goal of the community level intervention is to target social isolation of PLHIV by getting them to achieve a goal through collective work in a public setting, demonstrating the prospect of change in the way PLHIV are treated and recognized publically.

Specifically addressing the harmful social isolation of PLHIV caused by real or perceived external stigma through collective action relates the RISTHA/AIM community intervention with the results of this thesis. Quantitatively and qualitatively, experience of external stigma and fear of its occurrence was associated with greater internal stigma, perpetual mental distress, and non-disclosure of HIV status. The social isolation that results from these fears directly impacts the willingness to seek practical and emotional social support from different sources, a key form of positive coping. The collective action used in this intervention to enact realistic change may also be beneficial in getting at any feelings of hopelessness and depression among participants that nothing can be done about stigma at higher levels.

Suggestions for Further Interventions

The results of this thesis have suggested several openings for intervention at multiple levels to address the effects of internalized stigma. First, the profound psychological effect of receiving an HIV diagnosis was well-demonstrated. The majority of men interviewed indicated feeling high levels of anxiety, shock, depression, and in several cases, suicidality, that was expressed concurrently with personal shame and guilt for behaviors that may have led to their HIV infection. Thus, addressing perceptions of stigma as early as possible may be critical to avoid its later internalization. It is suggested that stigma-focused counselling sessions occur within the first two ART Center appointments after referral from an ICTC. Through these initial counselling sessions, assessment and discussion about the effects of stigma could occur with follow-up for problematic cases upon subsequent monthly visits the ART Center. At this stage there may be value in educating patients about the relatively low prevalence of community discrimination that nonetheless elicits much fear and distress in the population. This could be paired with the promotion of physical and psychological benefits of status disclosure and the generation of personal support systems.

Given internal stigma's close relationship with depression and tenshun, repeated expressions of shame and guilt should be evaluated and addressed as a mental health issue within the context of individual or group-level counseling at ART Centers during patient's monthly visits. Follow-up sessions should focus on the impact of guilt, blame, self-imposed anger, and hopelessness. These topics could be discussed along with introducing the idea of HIV as a manageable disease and that the avoidance of internalized stigma and the use helps to improves health outcomes and social relationships. While it was demonstrated in this thesis that patients do not always have adequate time for interactions with counseling staff at ART Centers, current

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guidelines should be changed to include some content or staff training the expressions of HIV stigma and its effects. Patients should be periodically assessed for the presence of external and internal stigma, utilizing the aforementioned stigma measurement tools adapted for India by Stewart et al. (2008). Specific methods to challenge internal stigma should be based on teaching positive thinking and adaptive coping strategies. Looking to the Solution Focused-Narrative Intervention Model used by the RISTHA/AIM project in their individual-level intervention, people who report frequent internalized stigma, an activity could be utilized that allows patients to identify their own sources of guilt, shame, and blame and develop personalized strategies based on personal strengths to address them.

The relative commonality and negative impact of external stigma within the context of families was well demonstrated in this population and warrants serious attention. Extensive research is needed to better assess and investigate the pervasive yet hidden nature of familial stigma that may perpetuate it as something felt as normative (and therefore internalized) in the Indian population. Further, the direct positive effects of family support on mental health status and ART adherence build the case for proposing a family-level HIV-stigma intervention. Since families are composed of many inter-relationships between individuals and between groups of individuals, as well as existing as distinct units itself ("close" family & "extended" family), intervention activities within the families ideally would have multiple levels.

Individual members could first be assessed for stigma beliefs and the level of social support they provide the family member with HIV. The positive family member would be assessed for both experiences with external stigma from other family members and the extent to which stigma has been internalized. Individual counseling and education sessions could be used to identify and address negative beliefs held by family members and convey the importance of

supporting the positive member in terms of their physical and mental health outcomes. Intervention in the marital unit would be essential given the importance of this relationship for all aspects of successful HIV care. Based on efficacious intervention research involving heterosexual couples aimed at reducing sexual risk behavior in the context of Mumbai (Kostick, Schensul, Singh, Pelto, & Saggurti, 2011) and the United States (El-Bassel et al., 2003), couples' stigma counseling may involve topics such as communication, problem solving skills, and negotiation to address shaming and guilt, building beneficial and emotionally supportive relationships. Finally, multiple family members could be gathered as a unit for a stigma intervention to facilitate positive coping, mutual trust, and family support. This may be achieved by targeting specific expressions and effects of stigma through a narrative role playing or group performance technique, similar to those presented at a community level by NACO. Future research and intervention on family-level stigma may be a highly effective means of reducing the harmful individual and public health effects of internalized stigma in the context of India.

Conclusion

Living with HIV, managing a lifelong course of ART medication and consuming alcohol, men in this study are adapting to life in a variety of positive and negative ways that are dependent on their personal perception of the illness and the sources of support accessible to them. Through a mixed methods analysis of interrelated organizational, social, behavioral, and psychological factors, this thesis has demonstrated the pervasive influence of stigma in their lives. The close affinity between the internalization of stigma, the negative mental health consequences, and poor coping strategies calls for making internalized stigma a key aspect of a comprehensive and holistic HIV treatment program. This thesis has identified two empirically-based strategies, early psychological counseling to reduce internalized stigma and engagement of

spouse and other family members to reintegrate the PLHIV into familial support. It is the hope of

the author that this study can make a small contribution both to the effectiveness of ART Center

programs and the lives of people with HIV.

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Tables

Table 4 – Descriptive Statistics for all Independent Variables Used in the Standard Multiple Regression (n=361).

Dependent Variable	Mean	Standard Deviation	Skewness	Range	Cronbach 's Alpha
Internal Stigma Scale	2.58	0.55	0.25	1 – 3.88	.89

Independent Variables	Mean	Standard Deviation	Skewness	Range	Cronbach 's Alpha
Age	41.53	8.70	0.17	21 – 66	--
Education Level	7.32	3.94	-0.35	0 – 17	--
General Health	1.05	0.22	4.02	1 - 2	--
External Stigma Scale	1.94	0.10	-2.74	1.37 - 2	.79
NMP+ Scale	1.82	0.18	-0.62	1.32 - 2	.85
Family Support Scale	1.47	0.34	0.07	1 -2	.91
Friend Support Scale	1.87	0.17	-1.59	1.09 - 2	.75
NGO Support Scale	1.93	0.12	-2.40	1.36 - 2	.73
ART Support Scale	1.87	0.11	-2.08	1 - 2	.57
Food Insecurity Scale	1.86	0.30	-2.08	1 - 2	.91
Quality of Life Scale	1.27	0.31	1.25	1 - 2	.73
CES-Depression Scale	0.32	0.11	1.52	.09 - .77	.69
30-Day Adherence	0.54	0.49	-0.16	0 - 1	--
Family-Related Tenshun Scale	2.89	1.69	1.81	1 - 9	.82
External Tenshun Scale	1.80	0.57	0.40	1 - 3	.80
AUDIT Scale	8.15	5.67	1.18	1 - 35	.77
Reasons for Drinking Scale	1.57	0.23	-0.39	1 - 2	.52
Co-Occurring STI Scale	1.91	0.14	-2.21	1.11 - 2	.66
4-Day ART Adherence	0.91	0.24	-3.29	-0.5 - 1	--
Years on ART	3.85	2.40	0.94	.58 - 15	--
Years Since HIV Diagnosis	5.00	3.42	1.36	.58 - 22	--

Table 5 – Pearson's Correlational Matrix among primary variables (n=361).

Variables	Internal Stigma								
Depression (CES-D)	0.47**	CES-D							
External Tenshun (EXT)	-0.42**	-0.39**	EXT						
Reasons for Drinking (RD)	-0.36**	-0.29**	0.45**	RD					
External Stigma (EXS)	-0.29**	-0.15**	0.35**	0.30**	EXS				
NMP+	-0.16**	-0.16**	0.32**	0.35**	0.23**	NMP+			
Family Support (FS)	-0.16**	-0.04	0.18**	0.27**	0.11*	0.21**	FS		
NGO Support (NGO)	-0.23**	-0.18**	0.11**	0.13*	0.13*	0.57**	-0.11*	NGO	
ART Support (ART)	0.24**	-0.21**	0.11**	0.19**	.02	0.23**	-0.07	0.37**	

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

Table 6 - Results from the Stepwise Multiple Linear Regression Analysis ("Backward Deletion" Method) for predictors of Internal Stigma (n=361).

Independent Variables	B	β	t	Sig.
Depression Scale	1.418	0.290	6.137	$< .001$**
External Tenshun Scale	-0.207	-0.215	-4.128	$< .001$**
PLHIV Scale	0.580	0.197	3.400	0.001**
NGO Support Scale	-0.875	-0.196	-3.469	0.001**
Family Support Scale	-0.179	-0.113	-2.434	0.015*
External Stigma Scale	-0.551	-0.107	-2.262	0.024*
Reasons for Drinking Scale	-0.259	-0.112	-2.165	0.031*
ART Center Support Scale	-0.467	-0.097	-2.078	0.038*
Mean Number of STIs	-0.407	-0.104	-2.247	0.025*

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

Appendix 1 – RISTHA / AIM In-Depth Interview Coding Guide

Domain	*Factor*	*Explanation*
Logistics		Screening, setting up the interview, finding a location, number of sessions, availability of time, any mention of interruption during the case intake
Appearance		Clothes, cleanliness, degree of strength or frailty, (aversion) willingness to respond, any sign of depression/ anxiety, speech evaluation, comfort, eye contact
Health Status	Pre-diagnosis	First symptoms of HIV, onset of the problem, symptoms noticed for the first time
	Post diagnosis	Within 6 months, degree of disease progression, improvement
	Current	Symptoms and complaints, any mention of current ailment, medication side-effects, opportunistic infections, co-morbidities
	CD4 counts	Trajectory, procedure of testing, initiation of treatment. Delays-in and recommendations-for treatment based on CD4 counts from physicians.
	TB	Any mention, diagnosis and treatment
Alcohol	Pre-diagnosis	Life story of alcohol use
	Post-diagnosis	Immediate response (6 months) in-terms increase use of alcohol, Changes to drinking after learning HIV+, justification given by patients for his use of alcohol
	Current	Pattern of drinking behavior, types of alcohol, activities associated with alcohol use
ART Medication	Schedule	When and how they take the medication
	Adherence	Description of adherence and misses in taking medication, justification in missing
	Storage	Where the respondent keeps the medication, how they transport it
	Support	Individuals who remind the respondent to take the medication, other person collecting medicines on patient's behalf, permission/leave granted by the employer
	Initiation	Anything relating to the start of treatment, or lack thereof.
	Side Effects	Anything related to physical side effects of ART medication
ART Centers	General	Respondents use of ART services, the evaluation of the services, complaints, medication availability, any other challenges in receiving services, awareness or lack of

		awareness of services offered at ART center, distance, transfer from other centers, comparison among multiple ART centers, cooperation and real or perceived barriers to services, any suggestions to improve the services
	Medical Care	Medical treatment/advice from physicians received at ART center, mention of MOs and SMOs
	Record Keeping	Maintaining record of respondent's medication schedule on White Card & Green Book
	Counseling	Counseling from ART center staff about HIV details, nutrition, adherence, mental issues
	Pharmacy/Medication	ART Center process of dispensing medication
	Group Meetings	Mention of ART Center offering group counseling sessions and/or education to patients
Work		Lifelong history of work including pre- and post-diagnosis, voluntarily discontinuation of job, switching over the career, unemployment, nature of work,
Household dynamics		Who lives with the respondent, the nature of the interaction, other HIV+s in the household, stressors, triggers to use alcohol derived from household; anxiety related family future, conflict within family. Interpersonal interactions within the household.
Extended family		Both Husband and Wife's family, awareness/support/ stigma by extended family
HIV etiology		Source of infection, including not knowing, personal attribution of the HIV infection as an attempt to conceal the real cause
Diagnosis		Description of diagnosis of HIV
Diagnosis response		Immediate, ongoing, and evolving response to the news; beliefs, denial and acceptance, sharing, and trauma
Wife		Non-sexual aspects of relationship, communication, blame for HIV, violence, support, ignorance,
Emotional status		Current tension (*tenshun*), stress, depression, anxiety, coping strategy,
Finances	ART Expenses	Costs for travel, other medications, time away from job, any other prescribed tests, if patient buys privately in case of shortage of medicine

	Income/other expenses	Sources, his own and family income, debt, loan, mortgage
Tobacco		Smokeless tobacco, cigarettes, *beedi, gutkha,* any addiction to *Paan* or any other tobacco habit
Friends		Individuals in the respondent's social network and activities in which they participate, their role in their use of alcohol or seeking the treatment
Social support		Which people and what supports for money, transport, support of the family, picking up of medication (other than family members), emotional support who provide, availing of government scheme benefits. In regards to respondent's personal network, not support from the ART Center.
Disclosure		Who has the respondent told, who else knows, who suspects, Decision to disclose the status, immediate reaction of that person
Nutrition		All mention of food including counselor advice, family member advice and cooking, food scarcity, his own belief about the diet, any change in the dietary plan, limitations in following the prescribed diet
Stigma	Internal	Self-blame, guilt, lack of self-respect or positive attitudes, any self-harm, aversion to socialization, any mention of phobia or the lack thereof.
	External	Rejection and reactions from medical personnel, community members, friends, family, co-workers or positive reactions from these sectors
NGO involvement		There are NGOs and the Positive Peoples' Network that work with the ART services for referral, support and tracing those "lost to follow-up." Respondents can be members, give services to others and be a beneficiary of services. Also includes NGO activities (Street performance, posters, education)
Childhood/adolescence		Life history and details of growing up
Other Treatments		Medications (e.g. over-the-counter, Ayurvedics), visits to private doctors (allopathic, *Ayurvedics, unani*, homeopathy, naturopathy), *pooja* and prayers and other alternative approaches, exercise/ Yoga, attending prayers or accepting/ changing the religion
Sexual Behavior	Wife	Marital sexual relationship, decision to have children, abstinence

	Other partners	Regular or causal relationships with partners other than spouse, high risk behavior, visit to CSW
	Condom use	Any mention of use of condoms pre or post diagnosis, awareness/ counseling about use of contraceptive
HIV Knowledge		Information and misinformation on treatment, etiology, transmission etc. Excludes how they believe they became infected.
Children		Including grandchildren, voluntary or forced withdrawal from children
Residence		Mention of current or past residence or community, location
Social Responsibility		Concern for not infecting others, concern for the well-being of others involved
Desire Marriage&Children		Any pressure to marry, any desire to marry on the part of single or widowed men
AlcoholReasoning		Answers to the question: why do men drink alcohol?
Negative Coping		Any coping behaviors with negative physical, mental, or social consequences: Examples include drinking, suicidal thoughts, feelings of guilt/isolation, anger, feeling ashamed, anxious
Positive Coping		Any positive behaviors to cope with illness: connecting/finding community with other HIV+ people, prayer/religion, positive & future thinking, social responsibility to protect others & keep living, benefits of status disclosure, focus on nutrition & exercise, seeking support form others, taking pride in work
Adherence_Alcohol		Any description of how they adhere to the ART medication despite the fact that they still use alcohol
Non-Adherent_Alcohol		Any description of how alcohol use negative affects adherence to ART medication, ex. Skipping/missing doses when drunk
Non-Adherent_Other		Any description of skipping/missing doses of ART for reasons other than alcohol. Ex. Work, cannot pick up medication, vacation, travel, lack of reminder
Wife HIV Status		Any mention of the HIV status (positive, negative, or unknown) of the current or former wife of the interviewee.
Sexual-Domestic Violence		Any mention of sexual violence or domestic violence against any family member.