The People Living with HIV Stigma Index

Resultsfrom 3 provinces in Lao P.D.R.
Luangprabang, Vientiane Capital and Champasack

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Draft

Contents

Acknowledgements

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
APN+	Asia Pacific Network of People Living with HIV and AIDS
APLHIV	Association of Peopling Living with HIV (in Lao PDR)
ARV	Antiretroviral
ART	Antiretroviral treatment
CHAS	Center for HIV/AIDS/STI
CLHIV	Children Living with HIV
FLHIV	Females Living with HIV
FRC	French Red Cross
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV and AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women living with HIV and AIDS
ILO	International Labor Organization
IIDI	Individual In-Depth Interviews
IDP	In-Patient Department of hospital
IDU	Injecting Drug User
IPPF	International Planned Parenthood Federation
IRR	Incidence Rate Ratio
LNP+	Lao National Network for People Living with HIV and AIDS
LRC	Lao Red Cross
MSM	Men who have Sex with Men
NCCA	National Committee for the Control of AIDS
OI	Opportunistic Infection
OPD	Out-Patient Department of hospital
PCA	Principal Component Analysis
PCCA	Provincial Committee for the Control of AIDS
PLHIV	People Living with HIV
SW	Sex Worker
TG	Transgender
UNAIDS	The Joint United Nations Program on HIV and AIDS
ZIP	Zero-inflated Poisson regression

Executive Summary

Chapter 1: Introduction

It is widely accepted that combating HIV-related stigma and discrimination plays a central role in controlling the AIDS epidemic, improving the quality of life of people living with HIV (PLHIV), and protecting their rights. In addition to the debilitating impact stigma can have on the life of an person living with HIV, it has been found to act as a barrier to preventing further infection, alleviating impact, and providing adequate support, care, and treatment services.[1–4] Furthermore, HIV-related stigma and the resultant discrimination constantly violate the rights of people living with HIV, as well as the rights of their families, who are often denied the right to healthcare, work, education, privacy, family planning, freedom of movement, among other things.[5]

The Declaration of Commitment on HIV/AIDS, adopted by the General Assembly of the United Nations in June 2001[6] further reflects the consensus on the importance of tackling HIV/AIDS-related stigma and discrimination. The Declaration acknowledges that stigma and discrimination "undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities, and nations" and further reaffirms that HIV-related discrimination is a violation of human rights.

HIV-related discrimination is not only a human rights violation, but it can also be an impediment to the achievement of public health goals. The barriers stigma poses can be explained using the "prevention to care to treatment cycle".[7] In an ideal situation, individuals should be able to seek confidential HIV testing and counseling to identify their HIV status without fear of repercussions. Those who test HIV-positive should then receive available treatment, care, counseling and encouragement to change their behaviors to protect others from infection. Their communities should be capable of supporting PLHIV, and their integration into society allows others to learn from their experiences, thereby aiding prevention efforts. A stigmatizing and non-supportive social environment, however, poses barriers at all stages of this cycle. In this setting, people fear discrimination and thus refrain from seeking testing or information about how to reduce their risk of HIV. HIV-positive individuals may refuse treatment, may refuse to disclose their status and may even refuse to practice safer behaviors for fear of raising suspicions in their community. HIV-negative individuals thus live in a community where the secrecy of HIV infection makes them believe that they themselves are not at risk of HIV infection. Lack of support and counseling may also lead individuals to feel shame, guilt, and other negative feelings that may cause them to isolate themselves from society and healthcare. In this way, the negative reactions caused by related stigma and discrimination hinder HIV prevention, identification, and treatment.[7,8]

However, despite widespread recognition of the discrimination that PLHIV experiencefrom societies, institutions, and governments, over the first 25 years of the epidemic, there has only been limited success in combating the negative effects of HIV-

related stigma and discrimination.[9] Peter Piot, the former Executive Director of the Joint United Nations Program on HIV/AIDS, acknowledged that HIV-stigma and discrimination remain seriously neglected issues in most national responses to HIV, which often lack funding to support such activities.[10,11]Some claim that the failure of many interventions and actions taken to address HIV-related stigma is due to the fact that these have not been grounded in a broad biosocial understanding of HIV-related stigma and discrimination and therefore fail to conceptualize the social inequalities underlying stigma.[12]The debates about how to view and approach HIV-related stigma and discrimination make it clear that the mechanisms by which this phenomenon affects the epidemic require further exploration.

In this report, we present the results of the People Living with HIV (PLHIV) Stigma Index Survey conducted in Lao P.D.R. from October 2011-February 2012. Through these results, we aim to shed light on the HIV-related stigma and discrimination situation in the country, contribute to the exploration of the large biosocial mechanisms that affect stigma and the epidemic, and propose comprehensive interventions to battle HIV-related stigma and discrimination.

1.1. Theoretical Framework

The first step in exploring HIV-related stigma and discrimination is to understand their definitions, identify their manifestations, and adopt a conceptual framework to place stigma in a larger social context.

The term stigma originated in ancient Greece, where it was meant to refer to signs—either burned or cut into the body of a person who was seen as morally unusual or bad.[13]These signs were used on slaves, criminals, or traitors to mark them and advertise that they should be avoided, especially in public places. Although the term today retains some of its original meaning, it has evolved to refer more to the disgrace itself of belonging to such groups, rather than the physical evidence of it.[13] In his seminal publication based on his work with psychiatric patients, prisoners and homosexuals, sociologist Erving Goffman established what has become the benchmark social theory on health-related stigma. He explains that society categorizes individuals (or groups of individuals) as well as the attributes (physical, behavioral, or social traits) that are seen as natural for each of the categories. Our category and attributes make up what he calls our "social identity." However, there can be a discrepancy between our actual social identity, that which is real, and our "virtual social identity," that which societal norms expect us to have. When an individual possesses an attribute that makes him different from others in his expected category and places him in a less desirable one, this individual is said to suffer from stigma. In short, stigma is an attribute that has a very discrediting effect on the individual, reducing him in others' minds "from a whole and usual person to a tainted, discounted one".[13]Goffman warns, however, that analyzing stigma simply in terms of individual attributes is misguided. An attribute that discredits and stigmatizes one individual may

confirm the normality of another, and vice-versa. Therefore, an analysis of stigma in terms of relationships rather than simple individual attributes is necessary.[13]

Furthermore, stigma need not be viewed as an individual process—how some individuals act toward other individuals, but rather as a social process that has deeper social, political, and economic roots.[14,15] In the past decade, some have argued that not viewing stigma in this socialized way has limited our analysis of the underlying causes of stigma and has misled our responses to battle it. Parker and Aggleton tell us that stigma is not an "isolated phenomena or an expression of individual attitudes," but rather a constantly changing social process that is used by dominant groups to "create and maintain social control and produce and reproduce social inequalit[ies]." These inequalities tend to be linked to gender, race and ethnicity, and sexuality. For example, in a society with long-standing gender inequalities that has historically blamed women for sexually transmitted infections, a woman is more likely to be stigmatized for her HIV status even when the source of infection is her husband. Similarly, in societies where transgender individuals or men who have sex with men are already stigmatized due to assumptions about their sexual practices and lifestyles, their HIV-related stigma will build on the pre-existing one to create further inequalities. The authors draw on theoretical frameworks of power, domination, hegemony, and oppression to explain that stigma creates and recreates inequality by making some groups in society feel superior and others devalued, thereby reinforcing the production and reproduction of inequitable power relations.[4]They also describe the compounding of pre-existing stigma of marginalized groups and HIV-related stigma as the result of a vicious circle of stigmatization and marginalization that has two steps: (1) HIV/AIDS is associated with marginalized behaviors, and people living with HIV/AIDS are stigmatized because they are assumed to be from marginalized groups; (2) Already marginalized groups are further marginalized because they are assumed to have HIV/AIDS. This cycle of stigmatization and discrimination is illustrated in Figure 1.

Figure 1.The vicious circle of stigmatization and marginalization[14]
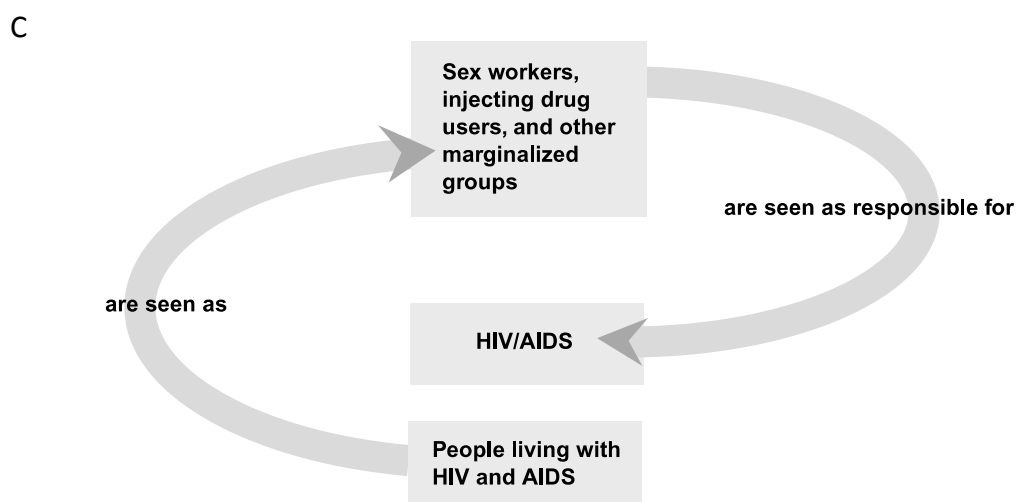
Castro and Farmer also put forward a social conceptual framework for understanding HIV-related stigma: structural violence.[12]The term and the concept date back to 1969, when it was used by Johan Galtung to describe violence that does not have a personal or direct actor, but rather is "built into the structure and shows up as unequal power and unequal life chances."[16(p171)]Farmer describes it as "violence that is exerted systematically—that is indirectly—by everyone who belongs to a certain social order."[17(p307)]Structural violence is sculpted by large-scale social forces such as racism, sexism, political violence, poverty, and other social inequalities that shape every society and have historical and economic roots.[12] Farmer and Castro have used this framework to show that structural violence shapes the distribution and outcome of the AIDS epidemic in several ways. For example, structural violence makes some individuals more vulnerable to infection by the virus by determining their risk of exposure and their immunological ability to battle disease. Structural violence also determines which individuals have access to resources like effective medications, food, diagnostic services, and HIV counseling. Similarly, structural violence can determine who suffers from HIV-related stigma and discrimination.[12]This leads to implications similar to those put forth by Aggleton and Parker. In societies with marked racial or ethnic discrimination, we would expect racial and ethnic minorities with HIV to be more stigmatized than in less racist settings. Sexism, poverty and other social forces play a similar role in determining the course of HIV stigma.

We can therefore view HIV-related stigma as being *layered*, since it can build on multiple stigmatizing attributes that an individual may already have.[4,12,14,15,18]These factors may be personal characteristics (gender, race, age, religion, etc.), as mentioned above, but they can also be high-risk behaviors associated with common routes of transmission (injecting drug use, sex work).[18]As Reidpath and Chan tell us, deconstructing and understanding this complex layering of HIV-related stigma is imperative in developing and implementing comprehensive and effective interventions to battle HIV-related stigma.

Many authors make the distinction between two main forms of stigma—*felt* and *enacted* stigma.[5,19,20]Felt stigma, also referred to as *internal* or *self-stigma* can result when people living with HIV internalize the negative responses they receive from others. Self-stigma can manifest itself in feelings of guilt, shame, worthlessness, isolation, fears of potential discrimination, and can ultimately lead to depression, self-withdrawal, and even suicidal feelings.[4]Enacted stigma, by contrast, is what external actors deliberately do, or fail to do, in order to harm PLHIV and deny them services or entitlements, thereby constituting actual experiences of discrimination. Thus, we can think of discrimination as the result of stigma being acted upon by others; a harmful consequence of stigma. Malawu, Parker and Aggleton define discrimination as, "when, in the absence of objective justification, a distinction is made against a person that results in that person's being treated unfairly and unjustly on the basis of belonging or being perceived to belong, to a particular group."[5] In the case of HIV-related discrimination, this group can be characterized by individuals known

to be living with HIV, suspected of being HIV-positive, or closely associated with individuals living with HIV (such as spouses or other family members).

HIV-related discrimination may occur in many different settings and at many different levels.[4,21,22] It can occur within the *family and community* setting. Some examples of discrimination against PLHIV in this setting include:

- Ostracization after first signs of illness or after their partner has died of AIDS, such as not allowing them entry or membership into a group, or by not being willing to be associated with them.
- Shunning or avoiding everyday contact.
- Physical isolation, such as not allowing them to use the same eating utensils as other members of the household.
- Verbal and physical harassment and assault.
- Verbal discrediting and blaming.
- Gossip.

HIV-related stigma and discrimination can also occur in *institutional* settings, such as work places, educational institutions, health care settings, prisons, or other formal institutions. Examples of discrimination in this setting include:

- Workplace: supervisor disclosing HIV-positive status to work colleagues without PLHIV's consent, denial or dismissal from employment based on HIV-positive status, mandatory HIV testing, exclusion of PLHIV from pensions or medical benefits.
- Educational institutions: HIV-affected children or adults are denied entry into schools, or are dismissed from their programs.
- Healthcare setting: segregation of PLHIV from other patients in a health facility, denying them access to health care services or medical insurance because of their HIV status, reduced standard of care for PLHIV, HIV testing or disclosure of status without consent, negative attitudes and degrading practices by health care workers.
- Prisons: segregation of PLHIV from other inmates, exclusion from collective activities.

Thirdly, discrimination can occur at the *national* level through enacted laws, policies, or procedures that restrict the rights and freedoms of HIV-affected individuals. Countries that adopt such policies are contributing to the sanctioning and legitimization of HIV-related stigma and discrimination. Examples of such policies include:

- Refusing a person living with HIV entry into a country because of their HIV positive status, or deporting HIV-positive foreigners.
- Prohibiting PLHIV from certain occupations and types of employment.
- Obligatory HIV testing and screening of certain individuals or groups.
- Isolation, forced arrest or detention of PLHIV.
- Compulsory medical exams and treatment of HIV-positive individuals.

Furthermore, a government's failure to implement and enforce laws and policies that protect the rights of PLHIV and offer them redress in their country can also be considered HIV-related discrimination.[4]

1.2.   HIV Stigmain Lao PDR and LNP+

Lao PDR is unique in its HIV situation, as it is one of the only countries in the Mekong region that has maintained a low prevalencein the general population since the start of the epidemic.[23] Most recent estimates (2010)put the prevalence at 0.2% among adults aged 15-49, representing 9,000 individuals.[24,25]However, Lao PDR's low prevalence does not necessarily mean low risk. Its central location in the Mekong region and its rising economic expansion are transitioning Laos from a landlocked country to a "land-linked one," making the HIV vulnerabilities imminent.[23]Increased mobility across borders, proximity to drug trafficking routes, a rise in high-risk behaviors, and the widening poverty gap are just some of the factors that place Lao PDR on a continued alert of a new HIV threat [23–26]. The latest National Strategic and Action Plan for HIV/AIDS/STI Control and Prevention (2011-2015) states concern about the "possibility of a concentrated epidemic amongst more vulnerable groups in the society."[25]These populations at higher risk have been identified as sex workers, men who have sex with men (MSM), injecting drug users (IDU) and clients of sex workers. Unprotected sexual contact is the main mode of transmission, and mobility and migration in the region play an important role in the spread of the virus.[26]Migration occurs within and between the countries of the Mekong region, and is generally due toeconomic factors. Migrant workers are another high-risk population, as language and cultural barriers, economic circumstances, lack of support systems, and being away from traditional structures and values make them more vulnerable to contract HIV while they are abroad.[26]Thismobile population can then act as a bridge between the epidemic in neighboring countries and the one in Laos.

Although the first case of HIV was reported in 1990,[27] anti-retroviral (ARV) treatment did not arrive to Laos until 2003 when*Médecins sans Frontières* (MSF Suisse) began administering the treatment free of charge in one province hospital of Savannkhet.[28] Since then, ARV treatment coverage has been scaled up through the national health care system with the help of The Global Fund to fight AIDS, Tuberculosis and Malaria and is now delivered free of charge at 7 ARV centers around the country to individuals whose CD4 count is below 350 cells per mm^3. According to UNAIDS, as of 2007, more than 95% of HIV infected women and men in Lao PDR were receiving ARV therapy.[29] However, the WHO 2011 Progress Report on the Global HIV/AIDS Response reports the number of people receiving ARV therapy as 1,690, and calculates the coverage rate as 51%.[30]This rate measures the proportion of people currently receiving ARV treatment in relation to the number of people in the country who are estimated to need it (those with CD4 counts below 350 cells per mm^3, following the WHO 2010 revised recommendation[30,31]). However,

this rate is 71% when you take the denominator to be the number of people in the country that are currently registered for ARV therapy (ART), which is 2,835 individuals.[32]Data from the Center for HIV/AIDS/STI in Lao PDR further shows that out of the 1,690 individuals accessing ART at the beginning of 2010, 16% were lost to follow up, and 3% decided to stop taking the medicines for personal or health reasons, meaning that at 19% of individuals are dropping out of treatment after starting it.

The Lao National Network of People Living with HIV/AIDS (LNP+) was established with the support of the Lao Red Cross (LRC) and the Australian Red Cross (ARC) in 2003 as a way to promote the participation of people living with HIV (PLHIV) in the national HIV response to prevent further HIV infection, battle HIV-related stigma and discrimination, and support access to newly emerging treatments, care and support activities. LNP+'s use of the Greater Involvement of Persons Living with HIV and AIDS (GIPA) principle has gained them expertise in certain activities such as peer support and peer counseling.

In August 2010, LNP+ applied for registration as a non-profit association (NPA) within the framework of the 115/PM/2009. They registered successfully on February 14, 2012 and on March 23rd, 2012 the LNP+ had its inaugural meeting. During this meeting, they changed their official name from Lao National Network of People living with HIV/AIDS into Association of People living with HIV/AIDS (APLHIV), they established the role and regulations of the association and they elected the five members of the association's management broad. Today, APLHIV has 14 self-support groups in 2 provincial branches with more than 900 members. In each self-support group, three representatives are selected President, Vice President and Treasurer by the vote of their peers. The 12 provinces self-support groups have organized and work in close collaboration with ARV treatment centers.

The available information on HIV-related stigma and discrimination in Lao PDR is limited. In 2005, a qualitative study conducted by UNICEF that involved 57 PLHIV aimed at understanding the HIV care and support interventions, but it did not provide sufficient information on stigma and discrimination issues.[33]A baseline qualitative survey of GIPA and stigma and discrimination in the Greater Mekong Region undertaken by Asia Pacific Network of People living with HIV and AIDS (APN+) in Lao PDR (21 PLHIV participants), Thailand, Vietnam, and the Guangxi and Yunnan Province of China, provides some insight into HIV-related stigma and discrimination within the workplace, families and health care settings. However, the small sample size of the PLHIV population, the lack of quantitative data, and the fact that it was only conducted in Vientiane Capitalresulted in an incomplete view of the stigma and discriminationsituation in the country.[34]Ourstudyhas been designed to use LNP+'s experience with GIPA and their relationship with the ARV centers across the country to complement past research and obtain a more comprehensive understanding of the current condition of stigma, discrimination and human rights violations affecting PLHIV in Lao PDR.

1.3. The People Living with HIV Stigma Index

The People Living with HIV Stigma Index was developed and implemented by and for people living with HIV. Those who contributed to the design and development of the survey tools include the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (CIW), the International Planned Parenthood Federation (IPPF), and the Joint United Nations Program on HIV/AIDS (UNAIDS).[22]Since 2005, the PLHIV Stigma Index has been implemented and validated in more than 30 countries around the world.

The PLHIV Stigma Index aims to: 1) document the various experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination, 2) compare the situation of people living with HIV in one country or across different countries with respect to a particular issue, 3)measure changes over a period of time so that we can observe if the stigma and discrimination situation has worsened or improved over time in a certain community, and 4) provide an evidence base for policy change and programmatic interventions.[22]

Since 2008, many countries in the Asia Pacific regionincluding Bangladesh, Pakistan, Sri Lanka, China, Fiji, Myanmar, Thailand and Cambodia have used the Stigma Index survey as their main research tool for exploring stigma and discrimination. Until now, Lao PDRhad not yet conductedsuch a comprehensive survey relating to the HIV-related stigma and discrimination situation in the country.

The People Living with HIV Stigma Index survey in Laos was implemented by LNP+ with technical support from Center of HIV/AIDS/STI (CHAS), Lao Red Cross (LRC) and French Red Cross (FRC), with ILO/UNAIDS funding. We slightly modified the IPPF questionnaire and developed the survey methods and data-collectingtechniques to conduct the study in 4 treatment centers in hospitals of Luangprabang, Vientiane Capital and Champasack.

The process of implementing the Stigma Index survey is as important as the results themselves. This is because the process will empower PLHIV, LNP+, government, and other organizations to better understand and deal with experiences of stigma and discrimination. This principle is specifically in line with the GIPA (Greater Involvement of People Living with HIV and AIDS), which supports the process to be driven by PLHIV and their networks.

1.4. Objectives and Hypotheses

The results of from the PLHIV Stigma Index Survey (SIS) will benefit advocacy and build an evidence base for HIV and AIDS programmatic interventions, particularly LNP+ and associated partners. At the national level, the information gained from the study will

strengthen national program planning, development and monitoring efforts. The main objectives of this study are the following:

1. Document and understand the situation of HIV-related stigma, discrimination and human rights violations amongst those PLHIV accessing services at HIV treatment centers in Lao PDR.

2. Analyze the role gender plays in shaping the experiences of a person living with HIV, the stigma and discrimination that they are subject to, and their subsequent effects on psychological health.

3. Explore the accessibility of healthcare and counseling services, the knowledge of PLHIV rights and laws, and the membership in support organizations, and the effect these have on the stigma and discrimination experiences by PLHIV, especially amongst the different geographical regions of Lao PDR.

4. Analyze the effect that selected social, demographic, and clinical characteristics of an individual have on the stigma and discrimination experiences he will suffer from and provide quantifiable measures of association between sub-populations in our sample.

5. Build the capacity of LNP+ and local PLHIV networks to be able to lead the study, use research skills and assist in field data-collecting and processing, and involve them along every step of the study.

6. Provide an evidence base that serves to provide recommendations to the national and international stakeholders in order to plan for policy change, programmatic interventions, and future studies that might serve to document stigma and discrimination over time or across different countries.

Because our study is grounded in a well-researched and validated biosocial theoretical framework, we are able to make certain hypotheses regarding the differing experiences amongst PLHIV regarding HIV-related stigma, discrimination and violations of rights. With regard to our objectives above, we present the following hypothesis to be tested through our study:

1. HIV-related stigma, discrimination and violation of rights events are prevalent in Lao PDR and negatively impact the lives of PLHIV accessing services at treatment centers, affecting their social relationships, health, and psychology.

2. Females and TG females living with HIVare suffer more from stigma and discrimination events because of the sexual inequalities that exist in Lao society.

3. Accessibility to healthcare services varies by the geographical region where PLHIV visit the treatment center.

4. HIV-related stigma and discrimination in Lao PDR affects certain individuals living with HIV more than others, specifically those who are victims of structural violence and are marginalized, stigmatized, or discriminated against in society due to their gender, sexual preference, high-risk behaviors, socio-economic status, ethnicity, or other characteristic that makes others regard them social "deviants."

5. PLHIV currently on ARV or medicines for opportunistic infection suffer less from stigma than those not on ARV. We believe this might be the case because of evidence presented by Castro and Farmer[12] indicating that healthier individuals suffer less from stigma and discrimination by society.

6. Those PLHIV belonging to a support group or having knowledge of PLHIV laws suffer from less stigma and discrimination events because they are offered more support, knowledge and empowerment to defend themselves against individuals that might try to stigmatize them.

Chapter 2: Methodology

2.1. Survey location and target population

The Stigma Index survey took place in three provinces of Laos—Luangprabang, Vientiane Capital, and Champasack, which represent the country's three regional centers (North, Center and South). Data collection took place at selected ARV centers in those regions. The ARV centers were selected for their representative samples of the region's PLHIV population, the diversity of services offered (ARV therapy, counseling, and support groups), as well as provided support from the medical staff at the center. Two centers were chosen in the Vientiane Capital (Setthathirath and Mahosot), one in Luangprabang (Luangprabang hospital) and one in Champasack (Champasack Hospital).
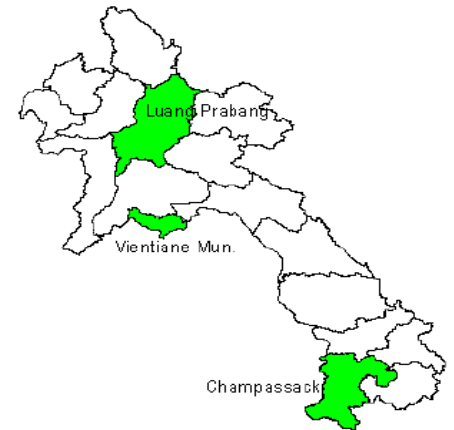
The target population of this study is PLHIV who access ARV treatment in the country's ARV centers.The selection criteria for those PLHIV were the following:

1. Be at least 15 years of age, with the ability to decide and give their consent to participate in the survey.

2. Should not be undergoing psychiatric treatment or be under the influence of alcohol or drugs during the interview process.

3. Should be socially, physically, and mentally willing to participate in the survey and have the right to stop answering at any time.

4. Must not be barred by any condition or disabilities (e.g. deaf and/or speechless person) since this can make communication a challenge.

5. Could not have been a participant in studies with topics similar to stigma and discrimination orhuman rights in the last 12 months.

2.2. Sampling methods

We used probability sampling to reach the target population. The process of selecting our sample to interview had 4 steps:

Step1: The size of our target population (PLHIV who utilize the services at our 4 selected ARV centers) was 1004 PLHIV users. We calculated our sample size with a standard error of 5%. This calculation resulted in a sample size of 286 participants. In order to account for the people who might refuse to participate, or who might not meet the selection criteria, we added 5% of the sample size to obtain 302 PLHIV as our desired sample size.

Step2: Dividing the desired sample size by the total population size ([302/1004]x100= 30%),we determined that the sample size proportion that needed to be selected for our survey was 30%. This means that 30% of the PLHIV population in each center should be selected for this study. Table 1 shows the number of PLHIV selected from each ARV center.

Step 3: We used systematic random sampling to identify the PLHIV to be interviewed. As patients approached the check-in counter of the out-patient department of the ARV center on the day of their scheduled service appointment, the nurse at the reception selected every third patient that arrived (1 in 3 represents a 33% sample ratio) and briefly introduced the purpose of the Stigma Index Survey, handed them a piece of paper to identify them to the LNP+ data collection team leader, and asked if they would like to participate in the study. The team leader would then approach the selected individual to further explain the study and ask for the patient's consent in participating. Interviews were conducted in private rooms in the ARV center and each respondent received about 5 USD as a compensation for their time.

Step 4: To further explore HIV-related stigma and discrimination with a qualitative approach, individual in-depth interviews were conducted with selected PLHIV participants. These case studies were identified by the surveyor based on the respondent's suffered events of stigma and discrimination and were referred to the team leaders for further evaluation. Case studies were chosen to reflect a wide variety ofgenders, at-risk populations, and HIV-related stigma and discrimination experiences. Furthermore, semi-structured qualitative interviews were also conducted with health care providers and peer counselors from each ARV center, as well as leaders of self-support groups at the provincial level.

Table 1 lists the final number of participants in our study by treatment center and category. The final sample for the quantitative questionnaire included 305PLHIV who utilize the services at ARV treatment centers (3 more than expected). We also conducted 16 individual in-depth interviews with PLHIV, 11 with healthcare providers, 4 with peer counselors, and 3 with self-support group leaders.

Table 1: List and number of study participants by region and treatment center

	Vientiane capital		Luangprabang	Champasack	
	Setthathirath	Mahosot	Luangprabang	Champasack	Total
Total number of PLHIV	545	186	68	205	1004
PLHIV sample (30%)	165	55	20	63	305
PLHIV Case studies	5	0	3	8	16
Health care provider	2	3	3	3	11
Peer counselor	1	1	1	1	4
Leader of self-support group (at provincial level)	1		1	1	3

2.3.   Data collection methods

We used a combination of quantitative and qualitative data collecting methods. The quantitative approach used the PLHIV Stigma Index standardized tool with 3 added questions important for the Lao context: Ethnicity, province, and district. Although most questions recorded close-ended responses, four questions in the survey were open-ended and allowed for more qualitative answers. Thequestion itemscaptured a wide array of information regarding the participants' experiences with HIV-related stigma and discrimination over the past 12 months and were organized in the following categories:

- Respondent's demographic information including: ethnicity, age, income, etc.
- Experiences of stigma and discrimination from other people
- Access to work, health and educational services
- Self-stigma
- Rights, Laws and Policies
- Effecting change
- Testing/Diagnosis
- Disclosure and confidentiality
- Treatment
- Having children

The qualitative method involved semi-structured individualin-depth interviews (IIDI) with key informants such as PLHIV, health care providers, peer counselors and self-support group leaders. The topics discussed with healthcare providers, peer counselors and self-support group leaders included:

- Amount of time the service has been available, and type of services are provided.
- Amount of workers in the center and amount receiving training on HIV.
- Availability of services, number of patient and their health problems.
- Transfer or referral of cases to other service providers.
- Issues and challenges of working with PLHIV and coordinating with other service departments.

The PLHIV case studies were selected depending on their experiences with stigma and discrimination. We recruited respondents with negative experiences to explore how stigma and discrimination affect an individual's life, but we also attempted to recruit respondents with positive experiences or stories of surpassing stigma and discrimination. Therefore, the 16 individual in-depth interviews (IIDI) conducted were with PLHIV who had at least one of these events: stigma from the community, friends, and/or family members (6 cases),problems at the work place (2 cases), disclosure violations without consent and health consequences (3 cases), psychological or economic problems (4 cases), positive experience receiving care and support (1 case), and positive experience with community support (1 case) (although some of these instances overlapped with one another). Of the 16

interviewees, 10 were males, 5 were females, and 1 was TG.These instances of HIV-related stigma and discrimination were investigated with the following categories of questions:

- Description of event (timing, nature, place)
- Reactions and consequences to PLHIV and family members.
- Problem resolution (process, actors involved, support received or sought)
- Future needs and suggestions

The PLHIV Stigma Index Survey took an average of 45 minutes to complete and the individual in-depth interviews about 30 minutes to complete.

2.4. Ethics and confidentiality

Ethnical clearance: The PLHIV Stigma Index Survey methodology and research tool presented by LNP+/LRC/FRC was approved by the Center for HIV/AIDS/STI (CHAS) in Lao PDR andsubmitted to the National Ethnics Committee for Health Research for review, who provided an authorization to conduct the study ata national level.

Interviewees' consent: Every participantwas well informed by the facilitator at the treatment center and the survey team leader. They also received an informed consentform thatincluded the survey objective, a description of the interview process and their rights in the study before every interview. During the interview they had the freedom to decide to answer or not answer any question or to stop the interview process whenever they wished.

Confidentiality: All of the paper documents used in the survey were put in the coding system without any records of the names of participants. The documentswere handled by the survey team leader everyday and were kept in securelocations before transferring to the data processing team. Additionally, all of our teamwas strongly aware of the confidentiality agreements and did not share any material or information with anyone outside the survey team.

2.5. Training the Survey Team

The 12 surveyors included 6 females, 4 males and 2 MSM selected among PLHIV in the 3 provinces. All of them received 3 days of training from the 9th -11th ofJanuary in Vientiane city. The following topics were covered during their training:

1. Basic informationof HIV/AIDS law and HIV situationin Laos by CHAS representative

2. Policy at the work place by LRC HIV program director

3. Survey concepts and planning by LNP+ director

4. Basic knowledge of quantitative and qualitative survey by FRC researcher

5. Surveying skills and role playby director/coordinator ofLNP+ and FRC

After the training, each survey team received one more day to refresh their practice withthe Provincial Committee for the Control of AIDS(PCCA) before conducting surveys at the provincial level. The surveyors were divided into four teams (one for each treatment center); each team included a survey team leader and two interviewers (a male and a female). Each team also had one supervisor from CHAS/PCCA, LNP+, LRC, or FRC in order to provide them with technical support.

The data collection phase of our study took place from January 18, 2012- February 23, 2012.

2.6. Data Processing and Analysis

2.6.1. Quantitative Data Processing

LNP+ staff collected the 305 quantitative questionnaires from all around the country and sent them to Vientiane city for analysis. FRC staff and data clerks from LNP+ checked and coded the data. Four LNP+ data clerks further received two additional days of training and practice on IBM SPSS version 13.0 before entering the data in the statistical software. The data clerks workedin pairs to ensure the quality of the data entry and FRC staff supervised and checked the final database. The data entry process lasted 13 working days, and took place from February 20, 2012 to March 5, 2012.

2.6.2. Development of a Multidimensional Measure of HIV Stigma and Discrimination

Although a descriptive analysis of our survey data can provide us with a general view of the HIV stigma and discrimination situation in Laos, a more comparative approach is needed to determine if stigma and discrimination affect certain populations more than others, or if there are differences between the types of stigma that these subgroups suffer from. In order to allow for a standardized comparison of individuals belonging to different demographic characteristics, we set out to develop a measure of HIV stigma and discrimination based on the question items in the PLHIV Stigma Index Survey. Because of the large amount of question items and the wide variety of topics that they covered, we predicted that our stigma measure would be composed of multiple dimensions. In order to identify these dimensions and to reduce the amount of indicators into converged components, we decided to conduct exploratory factor analysis using a principal component solution on our data.

We reviewed the PLHIV Stigma Index questionnaire for items that identified clear instances of stigma, discrimination, and/or violation of rights due to a person's HIV status. In order to maintain a standardized measure applicable to all individuals, items that excluded certain individuals from answering them because of relevance were not included in our analysis. This selection resulted in 54 question items that were answered in either (1) a 4-point likert scale (ranged 0-3 for Never, Once, A few times, and Often) or (2) a Yes/No

dichotomous scale. Of these 54 question items, 11 related to stigma in the community and in the family, 8 related to pressure to disclose their HIV status and instances of disclosure of status without consent, 22 dealt with internal feelings, fears, and self-isolating attitudes, 4 dealt with stigma at the institutional level, and 13 asked about stigma and discrimination in the healthcare setting.

Because of the possibility of obtaining biased results when conducting exploratory factor analysis with dichotomous items,[35] we decided to compute sums of groups of three dichotomous items that asked respondents about similar issues. These item sums, termed parcels[36] allowed us to include the dichotomous items in our analysis by converting them to a 4-point likert scale (ranged none of these, one of these, two of these, or all of these). Dichotomous items that did not have similar partners to be grouped with were excluded from the analysis. 33 dichotomous items were parceled into 11-likert scale questions, and 11 separate items had to dropped because they could not be parceled. These transformations resulted in 25 likert-scale items that represented all the types of stigma mentioned above. We obtained descriptive statistics for these 25 items and followed the guidelines suggested by Floyd to ensure the quality of data for exploratory factor analysis. Six items were eliminated because they did not correlate at least moderately ($r > 0.20$) with at least one other item on the list, they had more than ten missing values, or had a combination of both undesirable criteria. Furthermore, 3 items that measured rare, but similar events (and thus had low variance), were parceled together in order to increase the suitability of their distribution for the analysis. This data quality procedure finally resulted in 17 carefully selected items that were appropriate for principal component analysis.

We used eigenvalues greater than 1.0 and the scree plot from a principal components solution to provide an indication of the number of the underlying factors. As suggested by Floyd, we also examined the interpretability of alternative solutions with differing number of components and took into account the number of variables loading on each component. This analysis indicated three underlying components. This three-component solution was rotated using an oblique factor rotation (PROMAX) to allow for inter-factor correlations. We dropped three of the 17 items from our analysis because they had low factor loadings (standard regression coefficients <0.40). This procedure was repeated with the 14 items retained from the first rotation and one more item was subsequently dropped due to low factor loadings. Our exploratory factor analysis resulted in a three-component solution using 13 question items. Internal consistency reliability was estimated for each of the three subscales and the overall stigma scale using Cronbach's coefficient alpha. PCA analysis was done using IBM SPSS version 13.0.

2.6.3. Statistical Analysis

The first part of our analysis uses descriptive statistics to describe the number and percentage of individuals responding to key survey question items. We also use statistical tests of significance to explore the differences on stigma issues by geographicallocation and gender.

The second part of our analysis uses the subscales developed for each domain of stigma to explore the differences between the stigma and discrimination events that different subpopulations might suffer from. We calculated stigma count scores for every individual by summing the points obtained on each of the questions of the subscales, which had a point scale from 0-3. The first and second subscales had 5 question items each, and so had a possible range of 0-15 points, while the third subscale had 3 items and ranged from 0-9 points. The overall stigma scale was constructed by adding all three subscale scores, resulting in a 13 question scale with a range of 0-39 points. A score of 0 represented no stigma in that domain.

We conducted univariate analyses using Kruskal-Wallis and Mann-Whitney tests to evaluate if the stigma scale scores were associated with selected demographic and clinical characteristics recorded by the Stigma Index Survey. These characteristics included: gender (female, male, transgender), age (16-29, 30-39, 40+), ethnicity (Laolum, Khmou, Hmong, Katang), education (no schooling, some schooling, high school graduate, technical college/university graduate), income (continuous), relationship status by civil situation (married/in a relationship, not married/not in a relationship), household type (rural, small town/village, large town/city, remote area), geographical location (center, north, south), time living with HIV (<1 year, 1-4 years, 5-9 years, 10+ years), sexually active (yes, no), MSM (yes, no), sex worker (yes, no), history of injecting drug use (IDU) (yes, no), migrant worker (yes, no), prisoner (yes, no), physically disabled (yes, no), currently on ARV (yes, no), currently on medicines for opportunistic infection (yes, no), health status (excellent, very good, good, fair, poor), have children (yes, no), have a child living with HIV (yes, no), belong to HIV support group/network (yes, no), involved in developing HIV legislation, policies or guidelines (yes, no), heard of international or national laws that protect the rights of PLHIV (heard of none, heard of one, heard of two, heard of three, heard of four), disclosed HIV status (yes, no).

In order to account for possible confounding effects and understand more precisely how these demographic and clinical variables affected our stigma scale scores, we built a multivariate model for each stigma scale. Variables that were not associated with at least one of the stigma scale scores on a univariate level (*p*> 0.20) or that were not suggested to be important by the literature were not included in the multivariate analyses. Because the stigma scale scores can be seen as count data over the past 12 months (the time period that the questionnaire covered), Poisson regression and zero-inflated Poisson regression (ZIP) models were constructed to assess the incidence rate ratios (IRR) of experienced stigma

events. Separate models were fit for each stigma scale (dependent variables), but the same demographic and clinical characteristics (independent variables) were used for all models. We used IBM SPSS version 13.0 and Stata version 11.0 to conduct all statistical analyses.

2.6.4. Qualitative Analysis

The 16 individual in-depth interviews (IIDI) with PLHIV and the 18 IIDI conducted with healthcare providers, peer counselors, and leaders of self-support groups were conducted in the Lao language by four supervisors who wrote notes during the interview and then drafted a summary report of each interview with key quotations. These summaries were then analyzed by the primary investigators for common themes in the respondents'answers and summarized these in the English language. These interviews are meant to add another dimension to understanding the results reflected by the quantitative data.

Chapter 3: Results

3.1. Overview of the HIV-related Stigma and Discrimination Situation

3.1.1. Health service information by region

The qualitative interviews conducted with health care providers and peer counselors served to understand the profile of each ARV treatment center and set the stage for some results to be presented by regional areas.

Vientiane Capital has two available ARV treatment centers: Setthathirath hospital and Mahosoth hospital. Setthathirath hospital is about 7 km from the center of town, and the ARV treatment center it houses is the Department of Microbiology. This center has provided ARV treatment since 2006, and currently it is staffed by 3 medical doctors, 2 medical assistants, 10 nurses and two peer counselors. They offer medical and counseling services 4 days a week (Monday through Thursday) and they see an average of 20 patients per day (min 10-max 50). Since 2006, the Setthathirath ARV center has treated about 1,140 patients from the northern and center regions. Mahosot hospital is close to the city center and it houses an ARV treatment center in the Epidemiology department that has been operational since 2008. The center provides services 3 days a week (Tuesday through Thursday) and it sees an average of 10 patients per day (min 7, max 20). Since 2009, they have treated about 410 patients, and about 55% of those have received ART.

The Luangprabang treatment center is in the In-Patient Department (IPD) of the hospital, which is about 5 km away from the town. The center started delivering ARV treatment in 2009, and they currently have 3 doctors, 4 nurses and 1 peer counselor. They currently see about 131 patients (75% receive ART)who come mainly from Luangprabang, but also from the provinces of Sayyaboury, Oudomxai, Phongsaly and Bokeo. The center provides services to patients 4 days a week.

The treatment center in Champasack is in town, in the In-Patient Department of Champasack hospital. This center is then newest in the country, having started offering their services in 2010. Their staff includes 2 doctors, 2 medical assistants, 5 nurses, and 2 peer counselors. The center provides 2 days of counseling and health services on Tuesdays and Thursdays. Theycurrently have about 306 service users (73% are receiving ART) and they receive an average of 20 visitors per week.

3.1.2. Respondents' profile

Of all of the individuals asked to participate in the PLHIV Stigma Index survey, only six declined. Our resulting population of 305 PLHIV included153(50%) females, 130 (43%) males and 22 (7%) transgender (TG)females. Table 3 presents this information by region.

The age of participants ranged from 16-67 and the average age was 35.6. Figure 2 shows the age distribution of our sample layered by gender. We see that females and TG females in our sample tend to have an age distribution that is generally younger than the male participants. In fact, by observing the average age of each gender group we can see that on average, males living with HIV (37.7 years old) are about 3 years older than females living with HIV (34.7) and 4 years older than the TGs living with HIV (33.7).

Table 3. Sex of respondents by survey site

	VTE (n=222)	LPB (n=20)	CPS (n=63)	Total (n=305)
Female	49%	55%	51%	50%
Male	44%	40%	40%	43%
Transgender	7%	5%	9%	7%

Figure 2. Age distribution by gender
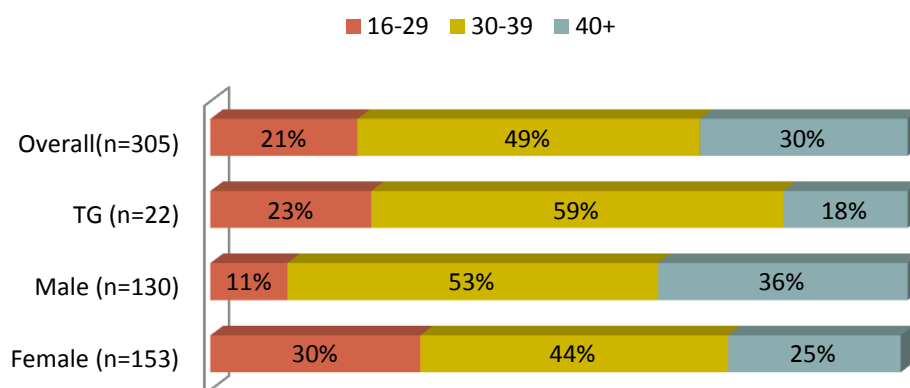
Most survey participants belong to theLaolummajority ethnic group(97.6%), while only 2.4% belonged to an ethnic minority (Khmou, Hmong orKatang). With regard to marginalized populations, 9% of the individuals in our sample are men who have sex with men (MSM), 8% are sex workers (SW), 1.6% have a history of injecting drug use (IDU), 15% are migrant workers, and 1.6% were prisoners. We calculated a household's income per capita using the information provided by respondents and found that 63% were living under the poverty line of USD$1.25/day. The majority of respondents were in a relationship (60%). This group is composed of those individuals who aremarried or cohabiting and the partner is currently in the household (55%), those married or cohabiting but their partner is temporarily living or working away from the household (4%) and those in a relationship but are not living together (1%). Furthermore, we found that 23% of respondents were single and 17% were widow(er)s. Over half of the respondents were living in a large town or city nearthe provincial center, 39.7% of them were living in a small town or villagenot far from the provincial center and hadaccess to public transportation, and 7% were living in rural or remote areas which lack of easy access to public transportation (Table 4).

Table 4. Respondents' demographic characteristics

Characteristic	Number	Percentage (N=305)
Ethnicity		
Laolum	298	97.6%
Khmou	3	1%
Hmong	2	0.7%
Katang	2	0.7%
High-risk group		
MSM	28	9.2%
Sex Worker	24	7.9%
IDU	5	1.6%
Migrant Worker	47	15.4%
Prisoner	5	1.6%
Family income		
Under poverty line 1.25USD/days	193	63%
Above poverty	101	32%
NA*	11	4%
Relationship status		
Married or cohabiting	168	55%
Married or cohabiting (spouse away)	13	4%
In relationship (not living together)	1	0.3%
Single	72	23%
Widow	51	17%
Household location		
Remote area	3	1%
Rural area	19	6.2%
Small town or village	121	39.7%
Large town or city	162	53.1%

*the respondent relies on other relatives and is unable to calculate income

About 11% of participants had graduated froma university or vocational school (completed at least 14 years of schooling), while 23% had completed upper secondary school (11 years of schooling), 28% had completed secondary school (8 years), 27% had completed primary school (5 years), 8% had not completed primary school (less than 5 years of schooling) and 3% had no schooling at all (Figure 3).

64% of respondents have children and of those who have a child, 15% have a child living with HIV (CLHIV), while 4% have never had their child tested for HIV (Figure 4).
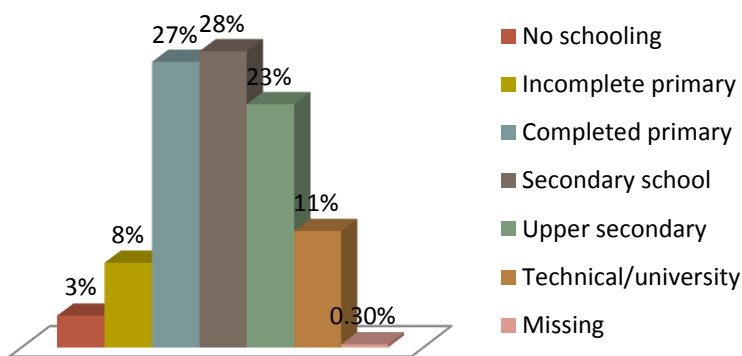
Figure 3. Educational level (n=305)

Figure 4. HIV status of PLHIV's children n=196
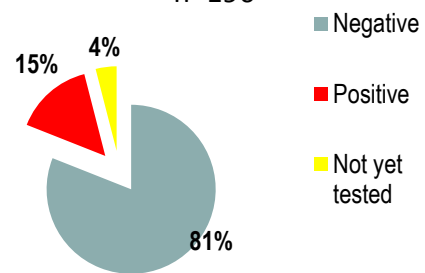
In regard to occupation, 15% of respondents were full-time permanent employees, 17% were working full-time as temporary volunteers or interns, 21% were farmers, 24% wereself-employed with a business (shop keeper, mobile sellers, etc.), and 15% were unemployed.

Many of these characteristics can describe an individual's socioeconomic vulnerability. For example, living in a remote area or rural area that has no or little access to public transportation and healthcare services can negatively impact the life of a PLHIV. Being unemployed or a farmer can mean an unstable income, making it difficult to support a family or yourself. A widow(er) status, especially widow, means lack of emotional and economic support, as these individuals have lost their spouse, usually belong to an older age group, and may be unhealthy themselves, limiting their economic sustainability. Exploring the amount of individuals with these characteristics by geographical region can give us an idea of the differences in socioeconomic vulnerability between the regions. Table 5 provides these values along with the *p*-values for Fisher's tests of significance to understand if these geographical differences are statistically significant or not. PLHIV in Luangprabang face life in a remote or rural area about 20% more of the time than PLHIV in the other two regions of the country (*p*<0.01).Similarly, they have a higher proportion of widows, though this difference is not significant. Champasack province seemsto face more socioeconomic issues, as 79% of the respondents' family income are under the USD$1.25 poverty lines, compared to 64% in Vientiane and 45% in Luangprabang (*p*<0.01). Similarly, the southern region has a higher percentage of farmers or unemployed individuals, but this difference is not statistically significant.

Table 5. Socioeconomic vulnerabilities by region

	VTE (n=222)	LPB (n=20)	CPS (n=63)	P-value*
Living in rural or remote area	7%	25%	5%	0.00
Un-employed or farmer	36%	32%	44%	NS
Family income under poverty line	64%	45%	79%	0.00
Family status as widow	14%	25%	24%	NS

* *p*<0.05 is significant and NS= not significant

Comparing some of these socioeconomic factors by gender also provides a clearer picture of the sexual inequalities present in Lao PDR. Table 6 presents some factors that differ by gender. The rate of having a higher education background (university or vocational school graduate) is much higher for males (18%) than for females (5%) or transgender PLHIV (0%) (*p*<0.05). Being a female widow is more common (22%) than being a male widower (12%) or a TG widow (0%) (*p*<0.01). Females also seem to be more vulnerable in terms of having a child infected with HIV and of living under the poverty line, but these differences did not prove to be statistically significant.

Table 6.Socioeconomic vulnerabilities by gender

	Female (n=153)	Male (n=130)	TG (n=22)	*p*-value
Higher education background	5%	18%	0%	0.02
Widow(er)	22%	12%	0%	0.00
Having child infected	17%	11%	0%	NS
Family income under poverty line	68%	62%	31%	NS

* *p*<0.05 is significant and NS= not significant.

3.1.3. Social environment

3.1.3.1. Stigma in the community and in the family

The survey found that30% of the respondents had disclosed their status toat least one of their friends or neighborsand 20% had community leadersthat knew of their status. Overall, 36% of participants were disclosed to at least one of their friends, neighbors or community leaders, although not always with consent. The respondents also described their experiences in the past 12 months regarding the way people in the community act towards them because of their HIV status. The main stigma and discrimination events suffered due to their HIV status included: being gossiped about (23% of whole sample), being forced to change their place of residence (4%),and being verbally insulted (11%). However, as Figure 5 shows, the frequency of these events varied greatly when we analyze the data by gender. We see that a much higher proportion of TG females suffered social discrimination events. The figures for the instances of discrimination previously listed are then: 14% of TG were forced to change their residence, 41% were gossiped about, 27% were verbally insulted, and even 5% were physically assaulted because of their HIV status. Females also had higher frequencies than males for almost all events.

Figure 5. Social discrimination events by gender
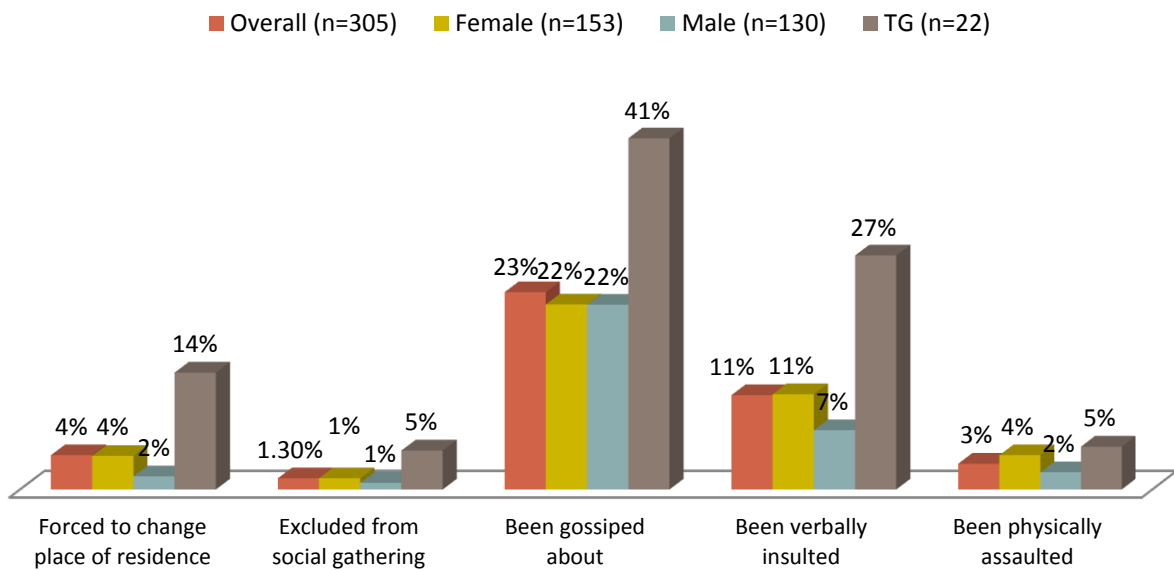
The respondents that had informed at least one of their family members of their HIV positive statusaccounted for 90% of our sample. A breakdown of this question indicated that 90% of individuals with a partner had informed theirpartner, 76% of all individuals had told anotherfamily member, and 42%of the participants with children had told them of their HIV status.

In the last 12 months, PLHIVhad also faced a variety of stigma and discrimination issues in their family due to their HIV status. Figure 6 shows the percentage of the PLHIV that experienced these events as well the percentage of each gender that suffered discrimination events. We see that a higher percentage of TG individuals were excluded from family activities such as cooking or eating together (4.5%) compared to males (2.3%) or females (1.3%). Similarly 9% of TG PLHIVreportedbeing psychologically manipulated by theirpartner, compared to 2.3% of males and 5% of females. Furthermore, 2.6% of all individuals had been discriminated by their own family members, although this number was once again higher amongst TGs (9%).

Figure 6. Family discrimination events by gender
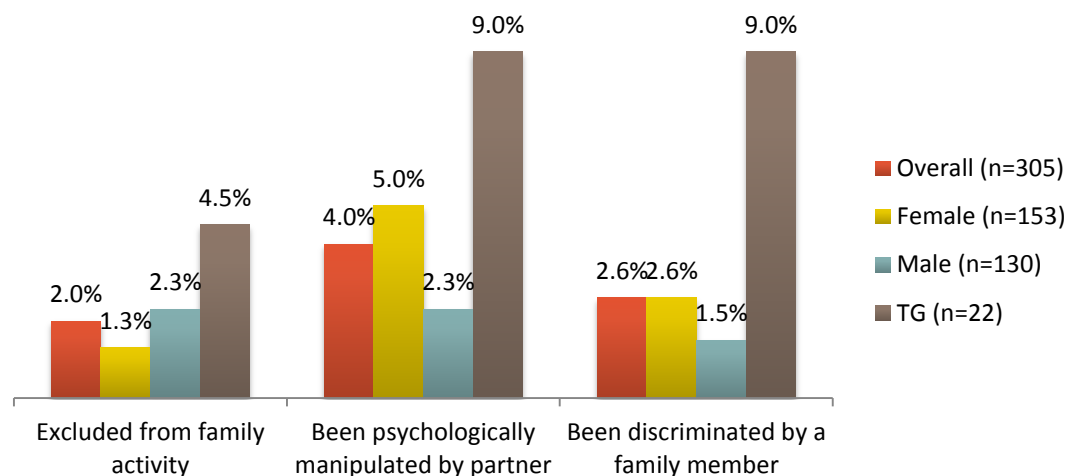
IIDI with the PLHIV case studies revealed similar instances of discrimination within the community and family structure. Some common themes found through the interviews analyzed were: (1) refusal of family to live in the same place or to share the same food, (2) refusal of family member to take care of HIV-positive individual during illness, (3) refusal of individuals in the community to allow PLHIV to join social gatherings and (4) verbal insults. The quotes below were taken from interviews with PLHIV to exemplify the kind of situations that these already vulnerable individuals have to live with.

> *"My brother and sister-in-law provided me a temporary house next to their garden. Since I came back from Thailand with illness of AIDS 3 years ago, my sister nor my brother, no one would invite me or eat with me. They only brought me some food when I could not find the food in the field."* -Male, 36, PLHIV

> *"My sister told me not to join the people at the ceremony places in the village. She was very concernedthat the villagers will not be satisfied and insult me"*
> -Male, 36, PLHIV

> *"Since my husband died of AIDS last year…the family of my husband is awarethat me and my daughter are HIV infected, but they care less and would not touch my daughter any more."*-Female, 33, PLHIV

> *"I had 4-5 close friends, we often had party together. But now, no one even shares food together. They just visit me but it's not the same as usual"* -Male 59, PLHIV

Individual in-depthinterviews (IIDI) with family members of PLHIV also revealed discriminatory attitudes towards the PLHIV. This quote, taken from the 32-year old sister of a PLHIV, exemplifies the fears and discrimination that negatively affect not just a person living with HIV, but everyone around him.

"I was angry and yelled to my brother not to feed our niece because I was scared that he may transmit the disease to her" - Female, 32, younger sister of PLHIV

3.1.3.2. Stigma in Work and Educational Settings

Figure7 presents the rates of institutional stigma events that the PLHIV respondents suffered from. Although only 10% of respondents had disclosed their HIV status at work, 18% of respondents reported losing their job or income because of their HIV status (4% because ofco-worker discrimination, 4% because of poor health, and 10% because of a combination of both or another reason). Furthermore, 2% of respondents had been dismissedor suspendedor prevented from attending an educational institution because of their HIV status and an additional 2% of those who have children had their child face similar discrimination events in school.

Figure 7. Instances of Institutional discrimination

	Child has been prevented from attending school	They have been dismissed from an educational institution	Lost job or income
■ Never	57%	94%	63%
■ At least once	1%	2%	18%
■ NA	40%	4%	19%
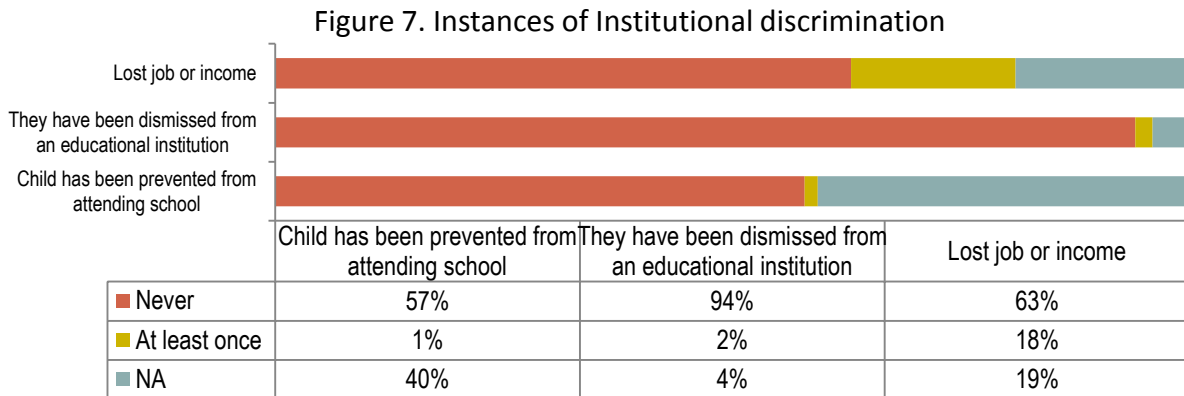
Individual in-depth interviews with PLHIV who had experience problems at the workplace revealed that they prefer not to be disclosed because they worry about losing their job, losing respect or loyalty from people, receiving bad reactions, behaviors, or discrimination from the people around them. They also reveal that many times workers are the victims of speculations and may lose their economic stability because of it. The following quotes illustrate these facts:

"I wantthe health care center to keep my records as confidential as possible. I do not want anybody to know of my status otherwise my colleagues and those under my supervision will lose loyalty to me. I think it's better not to tell anybody because the level of understanding of HIV of people is different. I feel that only those who work on the subject understand and not discriminate, 90% of them don't discriminate, the other people around they maybe 60-70% do discriminate."–Male 46, PLHIV

"After being disclosed, my colleagues did not want to share food with me. I had been forced to leave my job even though my age did not yet reach retirement. I tried to convince them and at the end I kept working, but they provide me with less work or a lower position and my income was reduced to 3 times less that of my previous position"–Male, PLHIV

"I lost my job without any reason while I was on a contract, but I think people assume that I am HIV positive because they knew my wife was positive" –Male, PLHIV

"People in my work place, especially my employer did not allow me to stay in the staff place. I think they suspected of my HIV or recognized it and my co-worker said: they are very scared to eat or to share something with an infected person and often said the infected person should leave the working place"–TG, 31, PLHIV

3.1.4. Self-Stigma

The survey also asked participants about the way they feel about themselves, their fears, and their self-stigmatizing actions that are due to their HIV status. Table 7 presents the frequencies of negative actions that are due to self-stigma in the overall PLHIV population and in each gender category. In the last 12 months, 22% of PLHIV excluded themselves from usual social gatherings and 13% have isolated themselves from their family and/or friends. This self-exclusion also extends to their professional lives, as 19% decided to stop working, 15% decided not to apply for a job and 9% have withdrawn from educational or training opportunities in the past 12 months due to their HIV status.PLHIV further exclude themselves from leading a normal life, as they may decide not to have sex again or not to have (more) children after finding out about their HIV-positive status (13% and 58%, respectively). We also see that more than one third of people living with HIV avoided going toa clinic or local hospital when they needed to go because of their HIV status. These results are further explored by layering these figures by gender. Except for the actions that involve going to the hospital or clinic, self-stigmatizing actions tend to be less common in males than in females and TG. Although only one of these differences proved to be statistically significant ($p<0.05$), they all indicate possibly different experiences between genders in terms of self-stigma.

Table 7. Respondents' self-stigma actions

Action	Overall (n=305)	Female (n=153)	Male (n=130)	TG (n=22)
Chosen not to attend social gathering	22%	25%	19%	23%
Self-isolated from family and/or friends	13%	16%	10%	14%
Decided to stop working	19%	23%	14%	31%
Decided not to apply for job	15%	19%	12%	13%
Withdrew from education/training	13%	18%	8%	13%
*Decided not to have sex	13%	19%	8%	6%
Decided not to have (more) children	58%	60%	59%	41%
Avoided going to clinic	36%	35%	37%	36%
Avoided going to hospital	33%	31%	35%	36%

 * *p*<0.05 for difference between 3 gender groups

A person's HIV status also affects his decision to get married or remarried and have a romantic relationship with someone else. Figure 8 shows that over 2/3 of those individuals who are single or widowed decided not to get (re)marriedafter they found out that they are HIV-positive.

Self-stigma can also be expressed as internal fears that the PLHIV might have about being rejected or discriminated

Figure 8. Decision to marry after HIV positive result

Single (n=72)   Widow (n=51)

against by individuals in society. The survey asked respondents if they were fearful of certain things happening to them—whether or not those things had actually happened to them. The results to these questions are reported below in Table 8. Over half of the PLHIV from all genders had a fear of being gossiped about by other people and more than one third of each particular group was fearful of being verbally insulted, although females and TG has higher frequencies of this fear than males. A higher frequency of TG (68%) is afraid that someone would not want to be sexually intimate with them than females (41%) or males (45%).

Table 8. Fears due to self-stigma by gender

Fear of:	Overall (n=305)	Female (n=153)	Male (n=130)	TG (n=22)
Being gossiped about	59%	61%	55%	64%
Being verbally insulted	42%	46%	35%	45%
Being physical harassed	26%	28%	24%	27%
Being physically assaulted	13%	14%	12%	14%
*Facing sexual rejection	45%	41%	45%	68%

* *p*<0.05 for difference between 3 gender groups

We also identified high levels of negative feelings that are indicative of HIV-related self-stigma. Table 9 shows that in the past 12 months, 62% of the PLHIV respondents have felt ashamed because of their HIV status, 75% have felt guilty, 57% blame themselves, 14% blame others, 33% have low self-esteem, 47% feel they should be punished, and 9% feel suicidal. Here once again, males seem to have lower frequencies than females and TG of these debilitating feelings, except for feelings of guilt and blame. In fact, compared to females, more males tend to blame themselves and feel guilty about their HIV status, while females actually tend to blame others at a much higher rate (24%) than the other two groups (5% for males and 0% for TG). This difference is statistically significant (*p*<0.05), and may indicate that females blame their partner for their HIV status.

Table 9. Psychological impact of self-stigma by gender

Feeling	Overall (n=305)	Female (n=153)	Male (n=130)	TG (n=22)
Feel ashamed	62%	67%	54%	73%
Feel guilty	75%	73%	76%	63%
*I blame myself	57%	47%	64%	86%
*I blame others	14%	24%	5%	0%
Low self-esteem	33%	39%	27%	32%
Feel should be punished	47%	51%	42%	50%
Felt suicidal	9%	11%	5%	14%

 * *p*<0.05 for difference between 3 gender groups

We further explored the proportion of people suffering from these negative feelings be region. Table 10 displays these results. Here we observe that PLHIV in the south (CPS) have higher rates of feelings of shame (68%), guilt (90%), blaming themselves (63%), blaming others (19%) and low self-esteem (46%) than PLHIV in the other two regions. The north (LPB) had a higher proportion of individuals feeling they should be punished (45%) and feeling suicidal (15%) than the other two regions.

Table 10. Psychological impact of self-stigma by region

Feeling	VTE (n=222)	LPB (n=20)	CPS (n=63)	P-value
Feel ashamed	61%	45%	68%	NS
Feel guilty	73%	55%	90%	0.003
I blame myself	55%	60%	63%	NS
I blame others	13%	10%	19%	NS
Low self-esteem	29%	40%	46%	0.037
Feel should be punished	43%	45%	38%	NS
Felt suicidal	9%	15%	3%	NS

* *p*<0.05 is significant and NS= not significant.

IIDI with PLHIV further contextualized self-stigma by providing examples of how individuals developed fears, negative feelings, and even suicidal actions. The quotes below show how enacted stigma and discrimination can be internalized by a PLHIV and result in very unhealthy psychological thoughts.

> *"My husband died of AIDS last year and my two year-old childis infected too…I had no support from my husband's relatives anymore since then. Sometime I fell depressed and want to commit suicide."* –Female, 33, PLHIV

> *"My colleagues always verbally insulted me. The way they treat me was not very friendly, I often worry and I'm scared most of the time"* –TG, 31, PLHIV

> *"My husband died due to AIDS and my family did not support me and discriminated me because of my status. I tried to commit suicide twice in the last two years. After I got better I decided to become a nun"*–Nun with HIV

3.1.5. Access to Health care Services

We asked participants about the reason why they first tested for HIV and found a wide variety of answers. Out of our 305 respondents, 26% were referred for the test because of suspected HIV-related symptoms, 23% tested after the AIDS-related illness or death of a partner or family member and 11% of them tested because their partner had a positive HIV test. We also found that 7% of females living with HIV (FLIHIV)found out during pregnancy, 4% were referred by STI clinic and 5% had other reasons to get tested, such as health check-ups or planned trips abroad. Of all the PLHIV, only 23% had gotten tested just because they wanted to know.

Figure 9 presents the self-perceived health statuses of the respondents in our survey. 31% perceive their health to be in a very good or excellent status, 37% of them feel they are in good health, and more than a third of them feel their health is in a fair or poor status.

Figure 9. Self-perceived health status
n=305
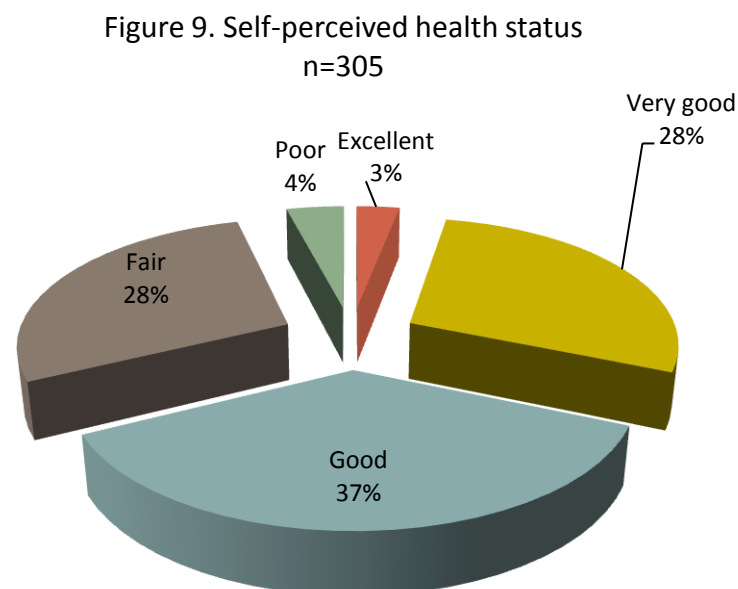
The majority of respondents had discussed their HIV treatment options with a health care professional (72%), yet only 31% had hada discussion with a health care professional about sexual health, emotional well-being or drug use, and only 23% had received counseling on reproductive options in the last 12 months (Figure 10). In regard to treatments, 90% and 78% of respondent were already taking ARV treatment and medicines for opportunistic infections (OI), respectively. However, when asked if they knew how to access ARV and OI medications, 7% reported not knowing how to access OI and 9% not knowing how to obtainmedicines for OI.The open-ended question on ARV concerns that was part of the survey revealed that PLHIV worry about the accessibility and effectiveness of ARV treatment. Although many PLHIV are now receiving it free of charge thanks to the Global Fund scale-up project, they worry about their ability to afford it once this funding ends. Furthermore, they expressed concerns about the continued effectiveness of the ARV medicines and the possibility of their bodies rejecting the treatment.

Figure 10. Knowledge and Access to healthcare services
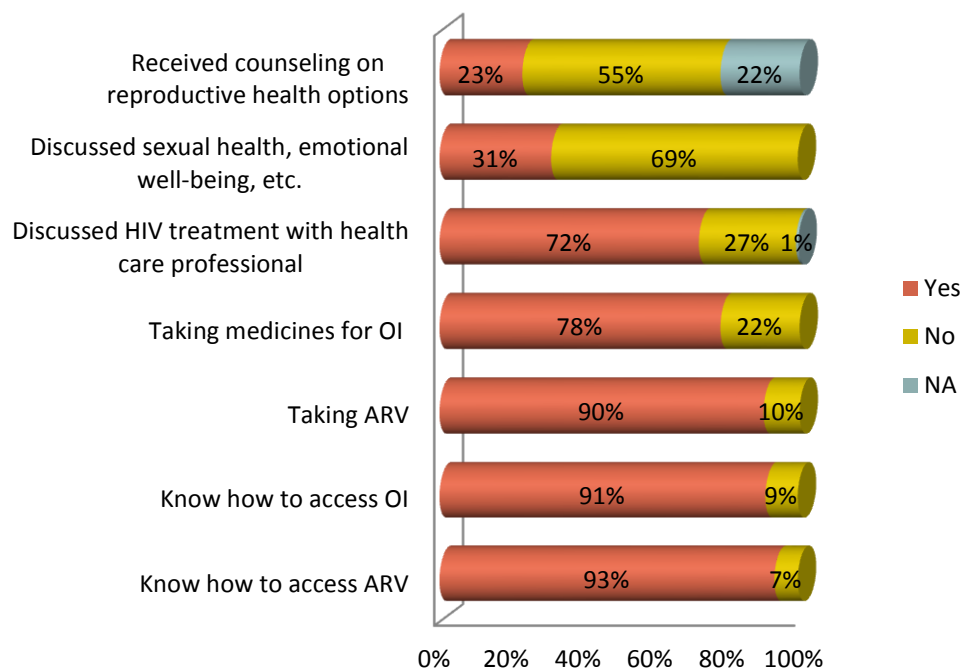
Some of these health care questions were further explored at the regional level to see if there exist differences between the health services provided by each of the provinces that represent the main regions of the country. Table 11 shows that most patients in Vientiane Capital and Luangprabang are currently taking ARV (98-100%), but only 76% of patients in Champasack are. Similarly, in terms of having discussions with healthcare professionals regarding HIV treatment, sexual health, emotional well-being, and receiving counseling on reproductive health options, Luangprabang (northern region) does much better than Champasack (southern region) and slightly better than Vientiane Capital (center region). All of the differences proved to be statistically significant.

Table 11. Access to health care services by survey location

Services	VTE (n=222)	LPB (n=20)	CPS (n=63)	*p-value
Taking ARV	97%	100%	76%	0.00
Discussed HIV treatment	74%	90%	60%	0.01
Discussed sexual health, emotional well-being	32%	90%	11%	0.00
Received counseling on reproductive health options	26%	30%	10%	0.01

* $p<0.05$ is significant

We further explored the region of Champasack to understand which individuals were receiving poor health services and we decided to analyze the relationship between access to ARV treatment and access to counseling services. Figure 11 below graphs the percentage of individuals receiving counseling and discussion services by whether or not they are currently on ARV treatment (ART). Although there does not seem to be a large difference between the percentage that discussed HIV treatment with a health care professional amongst those taking ART and those not on ART, there is a very large difference between both groups in terms of discussing sexual health and emotional well-being with a professional (13% for those on ART compared to 0% for those not on ART) as well as on receiving counseling on reproductive health options (12% for those currently on ART compared to 0% for those not on ART). This indicates that people infected with HIV that have not progressed to the AIDS stage (CD4 count below 200 cells per mm^3) are receiving minimal counseling and discussions with health care providers.

Figure 11. Health services in Champasack by ART status
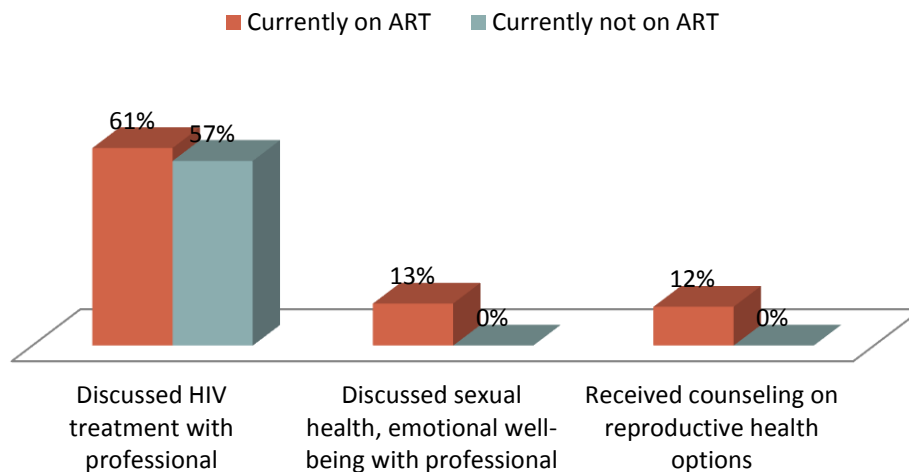
The individual in-depth interviews with peer counselors and health care providers also revealed some of the challenges that arise in the treatment centers when delivering care and providing counseling services. A challenge cited by many individuals was the poverty that their patients live in. Although the treatment is offered free of charge thanks to the Global Fund round 10 grant, patients are responsible for paying their transportation costs to get to the treatment center, their accommodation when they have to stay overnight far away from home, as well as food in the cities where the treatment centers are, which is more expensive for the individuals coming from rural areas or villages. These added costs to seeking healthcare in the ARV centers cause many PLHIV to delay their care, to miss their appointments, or to not access healthcare at all. This theme of economic vulnerability and limitations to healthcare also arose during the interviews with PLHIV. Many, like the two patients below, cite transportation costs as a barrier to proper healthcare delivery.

"I take ARV treatment with my wife on the health follow-up. Each month we have to visit the health counseling but as I am an old case, the transportation and accommodation fees support is over. So, each time we visit the health care center, I have to borrow the money to pay the transportation for two of us. It's around 2,000,000 LAK for two for 5 days of traveling. I do not have good health so I cannot work for two years. So, now my debt has increased and people do not want to lend me money. I think many other PLHIV face the issue of transportation to access the center." -Male 42, PLHIV

"After my husband died of AIDS, I used to live with rice meal owner for food; my daughter was very young. I had no transportation means when I needed to visit health care center and had other expenses such as milk for my daughter, food and schooling tuition. I wanted to have an additional small selling business to save money for her, but I had no source and did not know to find the resources and advice as I do not belong to the support group" - Female 33, PLHIV

Furthermore, there are only two peer counselors per treatment center, and a majority of them feel overwhelmed by the number of visitors per day and the process that they must follow. Interviews with PLHIV similarly revealed that many complain about the high number of patients in each center and the limited time for each consultation. Every counseling session is limited to 30 minutes per patient, and it consists of asking the patients ten questions about their sexual behaviors, condom use, medication use, adherence to treatment, and other healthcare issues. However, there are no questions regarding psychological support. If the counselor notices a problem or question about a topic during this interview process, they explain to the patient what they must do. They also report that this is many times challenging, as patients with poor reading skills have trouble accessing information through pamphlets or literature, and many fail to remember all of the instructions given during counseling regarding their treatment process.

3.1.6. Knowledge of Rights, Laws, and Support Organizations

Participants were also questioned about the national and international laws, policies, and declarations that protect the rights ofpeople living with HIV. Table 12 shows the results for these questions items within the total sample as well as within each geographical region. Less than half of the survey respondents had heard about the international *Declaration of Commitment on HIV/AIDS*, 32% of them had heard of the National Strategic and Action Plan on HIV/AIDS/STI Control and Prevention, 30% had heard of the National Policy on HIV/AIDS, and only 22% of PLHIV interviewed had heard of the Law on HIV/AIDS Control and Prevention, which serves as the main protection of PLHIV rights in Lao PDR. Of those individuals who had heard of any of these documents (only 22% of total sample), 68% were able describe a specific part of the policy or law that is appropriate for them, meaning that if they had heard of it, they were likely to know it well. Because of the low level of knowledge

regarding these laws, only 21% of all PLHIV respondents believe that these policies could effectively protect their rights. These low figures are even more alarming amongst PLHIV in the south of the country. The frequency of individuals in Champasack who were aware of these policies and laws was always at least one-fourththe frequency of individuals who knew about these laws in Luangprabang. Furthermore, only 6% of people in Champasack (compared to 55% in Luangprabang) believe that these policies could protect their rights as PLHIV.

Table 12. Awareness of PLHIV laws and policies by region

	Overall (n=305)	VTE (n=222)	LPB (n=20)	CPS (n=63)
*Heard of *Declaration of Commitment* on HIV/AIDS	41%	44%	65%	25%
*Heard of National Strategic Plan on HIV/AIDS	32%	33%	80%	13%
*Heard of National Policy on HIV/AIDS	30%	28%	85%	19%
*Heard of Lao HIV/AIDS law	22%	23%	55%	11%
If yes, able to describe the mentioned policies	15%	18%	60%	17%
Believe that these policies can protect their rights	21%	14%	55%	6%

* *p*<0.05 for difference between 3 regions

These same questions relating to knowledge of laws and policies were further analyzed when they were layered by gender. Table 13 shows that for every law and policy in question, there was a lower percentage of awareness amongst women than men or transgender individuals. In fact, the highest percentage of awareness of all policies was amongst TG.

Table 13. Awareness of PLHIV laws and policies by gender

	Female (n=153)	Male (n=130)	TG (n=22)	p-value
*Heard of *Declaration of Commitment* on HIV/AIDS	36%	46%	56%	NS
*Heard of National Strategic Plan on HIV/AIDS	27%	35%	56%	NS
*Heard of National Policy on HIV/AIDS	24%	33%	63%	NS
*Heard of Lao HIV/AIDS law	16%	25%	56%	0.017
If yes, able to describe the mentioned policies	10%	19%	19%	NS
Believe that these policies can protect their rights	15%	25%	36%	NS

* *p*<0.05 for difference between 3 gender groups

We also explored the knowledge of individuals regarding an organization or group that they could go to for help in case they experience stigma or discrimination, as well as their membership status in a PLHIV support group (Figure 12). Overall, we found that less than half (43%) of PLHIV are aware of an organization where they can seek help and a similar amount of them (42%) are members of PLHIV support groups. Because of the difference in access to health services and knowledge of laws we found by region, we decided to also explore these two questions by survey site. Similar to health care services, Luangprabang seems to be doing better in informing their PLHIV about organizations and

support groups. However, in this case, it is not Champasack that has the lowest rate, but Vientiane Capital. Compared to Luangprabang (80%), only 36% of individuals in Vientiane are aware of an organization that can protect them against stigma and discrimination and only 36% of individuals are members of a PLHIV support group in Vientiane city (compared to LPB's 60%). The differences in rates for both of these questions by region proved to be statistically significant (*p*<0.01 in both cases).

Figure 12. Knowledge and membership in support groups by region
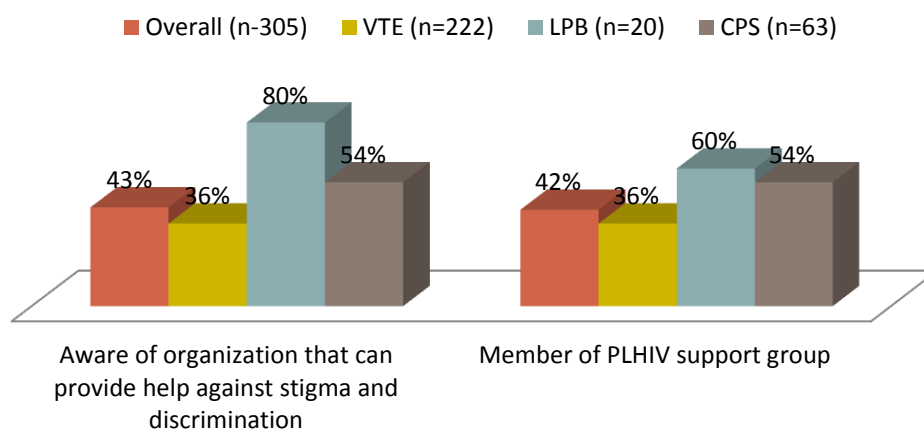
3.1.7. Disclosure Violations

When asked about disclosure violations and received pressure from other individuals to disclose the respondent's HIV status, about 1 out of 5 respondents reported feeling pressure to disclose from someone in the community (family member, social worker or government staff), 1 out of 10 felt pressure to disclose from other PLHIV or network groups, and around 1 out of 6 respondents had already been disclosed to other people by a health care professional without consent. Furthermore, a significantly large percent of individuals in Champasack face pressure from other PLHIV and PLHIV networks to disclose their HIV status. However, they also experience the least amount of disclosure violations from their health care professional, while PLHIV in Luangprabang face the most (Table 14).

Table 14. Disclosure concerns by region

	Overall (n=305)	VTE (n=222)	LPB (n=20)	CPS (n=63)
Pressure from community to disclose HIV status	21%	24%	20%	13%
*Pressure from other PLHIV/network to disclose HIV status	6%	4%	5%	16%
*Disclosure violation by health care professional	15%	18%	20%	3%

* *p*<0.05 for difference between 3 gender groups

Disclosure without consent by a healthcare professional was also brought up during the individual in-depth interviews with PLHIV. When they were asked about what they thought could be improved about the health services, some individuals cited the lack of confidentiality as a problem, as they had been disclosed to family members or friends this way, without consent:

"My HIV status was disclosed while I was hospitalized to my co-worker when they visited me in the hospital because they heard medical doctors talk out loud about my status to each other. I think they should not talk out like that."- Male, PLHIV

Disclosure violations are further explored in Figure 13, which presents different groups of people in the life of a PLHIV and how they were each first told about the HIV status of the respondent. We see that 30% of the respondents have disclosed their HIV status to their friends or neighbors, but that more than one quarter of these disclosure events happened without the consent of the PLHIV respondent (27%). Similarly, 11% of disclosures to social workers or counselors happened without consent, 30% of those disclosed to communityleaders were disclosed without consent,and 5% of disclosures to family members occurred without the respondent's consent.

Figure 13. Nature of disclosure to certain groups in a PLHIV's life
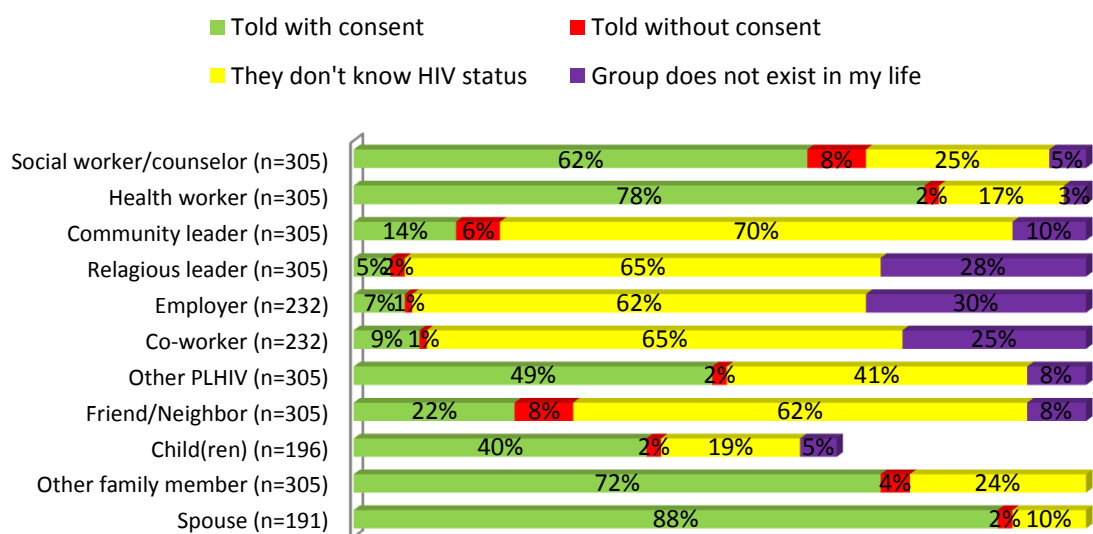
3.1.8. Recommendations from PLHIV

We also sought to get opinions from PLHIV about the best way to combat HIV-related stigma and discrimination. To this end, the survey team asked PLHIV what they would recommend an organization working on HIV-related stigma and discrimination to focus on. Table 15 shows the responses to this question in the whole sample population and within the three geographical regions. We found that more than a quarter of the people in general recommend advocating on the rights of PLHIV, and about just as many believe that

the public should be more informed about HIV and AIDS. However, there are also regional differences. Respondents in the southern region (where we have seen knowledge of PLHIV rights and laws to be fairly low)believe in a higher proportion that the main strategy should be to raise public awareness and knowledge of AIDS (39%), while PLHIV in the northern region believe more on advocating for the rights of PLHIV (35%) and educating PLHIV about living with HIV (25%).

Table 15. PLHIV recommendations about what an organization working against S&D should do

	Overall (n=305)	VTE (n=222)	LPB (n=20)	CPS (n=63)
Advocating for the rights of PLHIV	26%	25%	35%	27%
Provide support for PLHIV (emotional, physical and referral)	12%	13%	10%	9%
Advocating/supporting particularmarginalized groups (MSM, sex worker, IDU)	1%	1%	0%	1%
Educating PLHIV about living with HIV (including treatment literacy)	11%	11%	25%	5%
Raising awareness/knowledge of the public of AIDS	25%	22%	15%	39%
No comment	25%	28%	15%	19%

3.2. Principal Components Analysis

Our exploratory factor analysis resulted in a 3-component solution that explains 48% of the total variance using 13 items. Table 16 presents the standardized regression coefficients for the 13 final stigma items in the 3-component oblique solution. Standardized regression coefficients represent the individual and non-redundant contribution that each component is making.[37]All items loaded consistently on one component with a standardized regression coefficient of at least 0.47. Five items loaded on component 1 with a range of 0.59-0.80 and related to instances of enacted stigma and discrimination from the community and from the family, so we titled this domain "social stigma."Component 2 similarly loaded five items with coefficients of 0.47-0.80 that dealt with internal feelings, fears, and self-isolating behaviors, so this subscale was titled, "self-stigma." Finally, three items loaded on component 3 with a range of 0.53-0.87. Because these items dealt with either already occurred disclosure violations or perceived pressure to disclose HIV status, we titled this domain, "disclosure concerns." Because of the parceled nature of some of the items, the five items that loaded on component 1 (social stigma) actually represent seven questions from the PLHIV Stigma Index survey. Similarly, the five components that loaded on component 2 (self-stigma) represent 15 questions from the survey (because all five items were parcels of three questions). Finally, the three items that loaded on component 3 (disclosure concerns) represent seven questions from the PLHIV Stigma Index survey.

Table 16. Three-factors pattern matrix (standard regression coefficients) for 13 final stigma scale items

Items	Component		
	1	2	3
Factor 1- Social Stigma			
[a] 1. In the last 12 months, how often have you been verbally insulted, harassed and/or threatened because of your HIV status or because of your HIV status and another reason?	**0.80**	-0.03	-0.20
[a] 2. In the last 12 months, how often have you been aware of being gossiped about because of your HIV status or because of your HIV status and another reason?	**0.79**	0.02	-0.10
[b] 3. In the last 12 months, have you been excluded from any of these social activities: social gatherings, religious activities or places of worship, or family activities (eg. Cooking, eating) because of your HIV status or because of your HIV status and another reason? (parcel)	**0.65**	0.00	0.01
[a] 4. In the last 12 months, how often have you been physically assaulted because of your HIV status or because of your HIV status and another reason?	**0.60**	0.01	0.20
[a] 5. In the last 12 months, how often have you been forced to change your place of residence or been unable to rent accommodation because of your HIV status or because of your HIV status and another reason?	**0.59**	0.03	0.15
Factor 2- Self Stigma			
[b] 6. In the last 12 months, have you experienced any of the following feelings because of your HIV status: "I feel ashamed", "I feel guilty", "I have low self-esteem"?	-0.13	**0.80**	-0.08
[b] 7. In the last 12 months, have you experienced any of the following feelings because of your HIV status: "I blame myself", "I feel I should be punished", "I feel suicidal"?	-0.01	**0.78**	-0.10
[b] 8. In the last 12 months, have you done any of the following things because of your HIV status: "I have chosen not to attend social gathering(s)", " I have isolated myself from my family and/or friends", "I decided not to have sex"?	0.09	**0.49**	0.10
[b] 9. In the last 12 months, have you been fearful of any of the following things happening to you--whether or not they have actually happened to you: "Being gossiped about", "Being verbally insulted, harassed, an/or threatened", "Being physically harassed and/or threatened"?	0.13	**0.48**	0.23
[b] 10. In the last 12 months, have you done any of the following things because of your HIV status: "I avoided going to a local clinic when I needed to", "I avoided going to a hospital when I needed to", "I took the decision to stop working"?	0.06	**0.47**	-0.01
Factor 3- Disclosure concerns			
[b] 11. Has your HIV status been disclosed without your consent to any of these figures of authority: religious leaders, community leaders, or social workers/counselors?	-0.11	-0.15	**0.87**
[b] 12. Has your HIV status been disclosed without your consent to any of these people: adult family members, friends/neighbors, or other PLHIV?	0.17	-0.03	**0.63**
[a] 13. How often did you feel pressure from individuals NOT living with HIV (e.g. family members, social workers, non-governmental organization employees) to disclose your HIV status?	-0.08	0.27	**0.53**

[a]Responses to these questions are on a 4-point likert scale (Never, Once, A few times, Often)
[b] Responses to these parceled questions are on a 4-point likert scale (None of these, One of these, Two of these, All of these)

Table 17 reports the descriptive statistics and internal reliability measures for the stigma subscales and overall scale. Figures 14-17 present histograms of the stigma scale scores reporting the percent of respondents with each score. As we can see from this data, each scale had a very unique distribution. Subscale 1, social stigma, had a possible range of 0-15 points, but had a mean of 0.81 and a median of 0. Although all scales were positively skewed, social stigma was the most skewed with a value of 2.77. Figure 1 more clearly reveals this fact, and shows that 74.8% of the respondents scored a zero on this scale. The social stigma subscale therefore proved to be zero-inflated. Self-stigma also had a possible range of 0-15, but unlike social stigma, it had respondents under every score. This was the least skewed scale (0.48), and therefore had the most normal distribution out of all the scales with the median score closely approximating the mean score of 5.52. Subscale 3, disclosure concerns, had a mean score of 0.79 and a median of 0, even though it had a possible score range of 0-9. Its measure of skewness of 1.69 shows that it was positively skewed and Figure 3 reveals that this scale is also zero-inflated, with 65.7% of the respondents scoring a 0. Finally, the overall stigma scale had a slightly skewed distribution (1.06) but was not zero-inflated. The median score (7) closely approximated the mean score of 7.09. With the exception of the disclosure concerns scale (alpha =0.49), all other scales had a Cronbach's alpha of at least 0.62.

Table 17. Descriptive statistics and internal reliability measures for three stigma subscales & overall stigma scale

Domain/subscale	No. of items	Possible Range [a]	Mean Score	Median Score	SD	Skewness of Scale	Internal Consistency [b]
Social stigma	5	0-15	0.81	0	1.76	2.77	0.73
Self Stigma	5	0-15	5.52	5	3.13	0.48	0.62
Disclosure concerns	3	0 - 9	0.79	0	1.30	1.69	0.49
Overall stigma	13	0-39	7.09	7	4.56	1.06	0.72

[a] Higher scores are indicative of greater experienced stigma
[b] Cronbach's coefficient alpha on standardized items
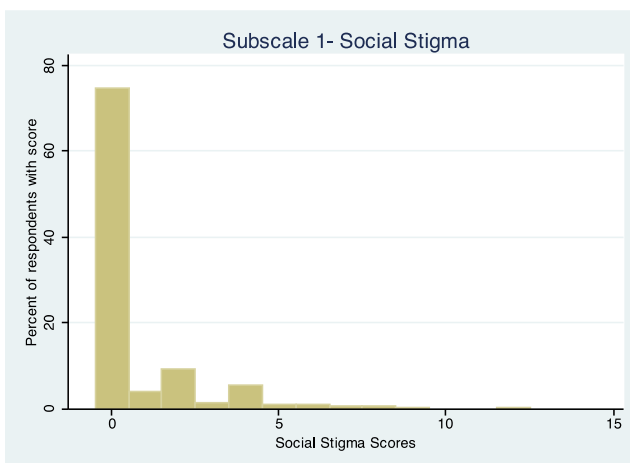
Figure 14. Histogram of Social stigma scores
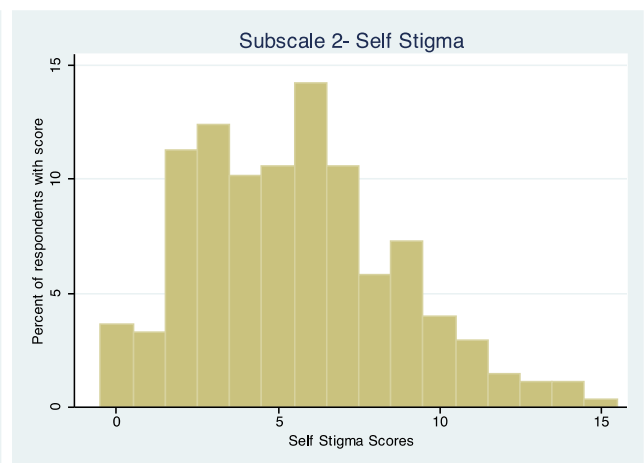
Figure 15. Histogram of Self-stigma scores
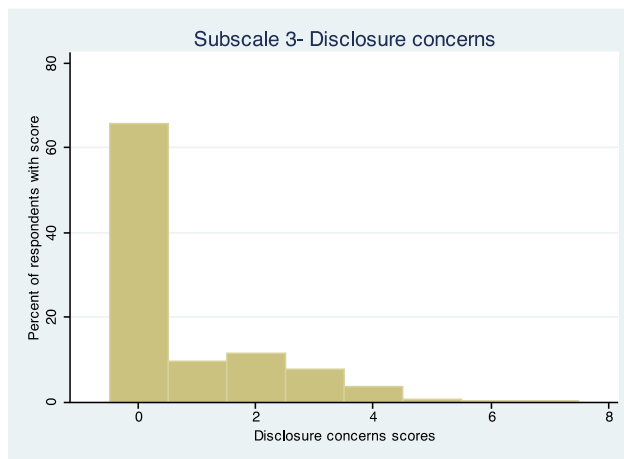
Figure 16. Histogram of disclosure concerns scores   Figure 17. Histogram of Overall stigma scores
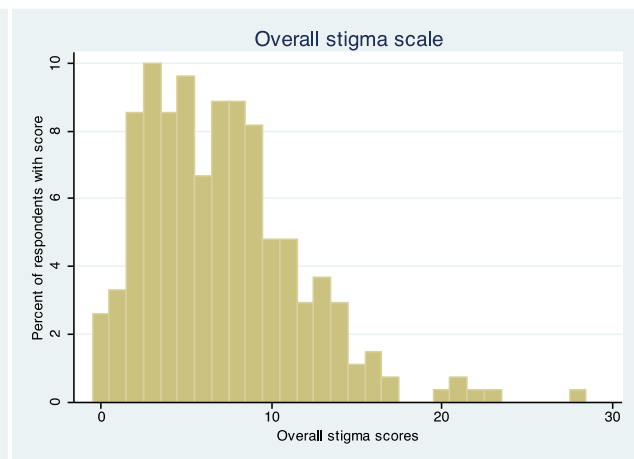

3.3.   Multivariate Analysis

Of the 25 demographic and clinical variables tested at the univariate level for association with the stigma scale scores using Kruskall-Wallis and Mann-Whitney tests, three were excluded from the multivariate models for lack of minimal association ($p<0.20$). These were: history of IDU, prisoner, and physically disabled. The remaining 22 variables were included in all regression models.

Due to the zero-inflated distribution of the social stigma scale and the disclosure concerns scale, zero-inflated Poisson regression (ZIP) analysis was used to fit their multivariate models. ZIP models are based on the theory that excess zeros are generated by a separate process from the count values and that the excess zeros can be modeled independently.[38] In other words, these excess zeros exist due to other variables different from the ones that predict the counts, and would exist even if the count predictors did not play a role. The designated "inflate" variables use a logistic regression model to predict excess zeros while the "count" variables use a Poisson regression model to predict the stigma count, or score. The count variables generate incidence rate ratios (IRR) while the inflate variables generate regression coefficients. The self-stigma scale and the overall stigma scale do not follow the same zero-inflated pattern of the other two scales. Therefore, a traditional Poisson regression model to predict the stigma score was used. In these models, all variables can be thought of as count variables since there are no inflate variables to explain excess zeros.

Additional regression models for count data (zero-inflated negative binomial and negative binomial) were also used to test the goodness of fit of several models. However, Vuong tests and likelihood ratio tests of alpha=0 proved that the models chosen are the most appropriate for our data. All models used robust standard errors for the parameter estimates as recommended by Cameron and Trivedito control for mild violation of the distribution assumption that the variance equals the mean.[39] Apart from obtaining IRRs to

determine how the demographic and clinical variables affected stigma scores, we also conducted post-estimation Wald tests to determine if each variable, overall, was a statistically significant predictor using the same parameters of the multivariate model.

Table 18 presents the results of our multivariate analyses. Of the 22 variables included in the models, 12 were found to be significant count predictors of at least one of the stigma scale scores, one was found to be a significant inflate predictor of the excess zeros in the social stigma scale, and one was found to be a count predictor for two scales and an inflate predictor for the other two scales. The remaining eight variables (income, relationship status, MSM, sex worker, currently on ARV treatment, having children, membership in HIV support group, and involvement in developing HIV legislation) are not displayed in the table because they did not prove to be statistically significant predictors of the stigma scores (IRR 95% CI crosses one), but they were included as covariates in the multivariate model.

We see that gender plays a role in predicting 3 out of the 4 stigma scores. For social stigma, the incidence rate ratio (IRR) for men is 0.55 (95% CI [0.31,0.99]) as compared to women (the referent group), given that all other variables in the model are held constant. This value means that the incidence of social stigma events over the past 12 months for men is 0.55 times smaller than the same incidence for women. The IRR can also be divided by 1 to say that the incidence of social stigma events for women is 1.82 times larger than it is for men. Finally, we can talk about differences between both groups by saying that the incidence of social stigma events is 82% higher for women than for men. Women also experienced about 3.1 times more disclosure concerns than transgender individuals (IRR=0.32; 95% CI [0.12,0.89]). The gender variable as a whole proved to be a significant predictor of the overall stigma score, even though no individual IRRs were significant for this scale. Age was a significant predictor variable for all stigma domains except social stigma. Compared to individuals aged 40 and above, those aged 16-29 suffered 1.3 times more self-stigma (IRR=0.77; 95% CI [0.62,0.95]) and 1.32 times more overall stigma events (IRR=0.76; 95% CI [0.61,0.94]). However, compared to those aged 16-29, respondents aged 30-39 experienced 1.61 times more disclosure concerns (IRR=1.61; 95% CI [1.03,2.52]). Ethnicity played a similarly important role in predicting three domains of stigma. The incidence of self-stigma in Laolum individuals was 1.9 times greater than in Khmou respondents (IRR=0.52; 95% CI [0.32,0.86]). However, compared to the respondents in the majority ethnic group (Laolum), Khmou individuals suffered 33 times more disclosure concerns (IRR=33.08; 95% CI [5.12,213.64]), Hmong experienced about 11 times more disclosure concerns (IRR=10.84; 95% CI [1.58,74.16]), and Katang individuals experienced 1.77 times more overall stigma events (IRR=1.77; 95% CI [1.23,2.53]). Although education as an overall variable did not prove to be a significant predictor of the stigma scores, we do observe that technical college or university graduates have an incidence rate of social stigma that is 0.34 times smaller than those with no schooling (IRR=0.34; 95% CI [0.12,0.99]). In terms of geography, we see that individuals living in the south of Laos experience about 2 times more

social stigma events than those living in the center of the country (IRR=1.97; 95% CI [1.25,3.12]), and that in general, geographical location is a very significant predictor of social stigma (*p*<0.01). Being sexually active was found to increase the incidence of disclosure concerns by a factor of 1.75 (IRR=0.57; 95% CI [0.33,0.99]) and the incidence of overall stigma by a factor of 1.23 (IRR=0.81; 95% CI [0.67,0.98]). Similarly, being a migrant worker increases the incidence rates of all domains of stigma; social stigma increases by a factor of 2.7 (IRR=0.37; 95% CI [0.2,0.71]), self-stigma increases by a factor of 1.19 (IRR=0.84; 95% CI [0.7,0.1]), disclosure concerns increase by 1.89 (IRR=0.53; 95% CI [0.33,0.84]), and overall stigma increases by a factor of 1.37 (IRR=0.73; 95% CI [0.6,0.9]). Compared to patients who are currently taking medicines for opportunistic infections (OI), those individuals not taking them suffered from 2.21 times more social stigma events (IRR=2.21; 95% CI [1.27,3.87]). By contrast, self-assigned health status did not predict social stigma, but it did prove to be a very significant predictor of self-stigma, disclosure concerns, and overall stigma (*p*<0.01 for all three). More specifically, those individuals who judge themselves to be in poor health at the moment suffered from 1.78 times more self-stigma (IRR=1.78; 95% CI [1.02,3.11]), 3.83 times more disclosure concerns (IRR=3.83; 95% CI [1.33,11]), and about 2 times more overall stigma events (IRR=2.06; 95% CI [1.12,3.79]) than those individuals who believe they are in excellent health. Individuals who do not have children living with HIV had an incidence of disclosure concerns that is 11.5 times greater than that of individuals who do have children LHIV (IRR=11.5; 95% CI [3.67,36.03]). Individuals who had heard of all four PLHIV rights laws that the questionnaire asked about had an incidence of social stigma that was 0.61 times smaller than that for individuals who had heard of none of these laws (IRR=0.61; 95% CI [0.38,0.98]). Disclosing HIV status was a significant predictor of disclosure concerns, with individuals who have not disclosed their status suffering about 0.60 times less disclosure concerns than those individuals who have disclosed (IRR=0.60; 95% CI [0.36,0.99]).

The amount of time a person has been living with HIV proved to be a significant predictor of the excess zeros in the social stigma scale (*p*<0.05). More specifically, the log odds of being an excess zero on the social stigma scale for individuals that have been living with HIV for more than 10 years is 2.24 less than the log odds of being an excess zero on the social stigma scale for individuals that have been living with HIV for less than one year (regression coefficient= -2.24; 95% CI [-3.82, -0.67]). In other words, individuals who have been living with HIV for less than a year are more likely to have been an "inevitable" zero on the social stigma scale. The variable household type was a very significant predictor on all four scales (*p*<0.01), although its role was different for the ZIP models and for the Poisson models. For social stigma and disclosure concerns, household type served as an inflate variable and predicted excess zeros, while for self-stigma and overall stigma, it predicted the stigma scores. The log odds of being an excess zero on the social stigma scale for individuals living in remote areas was 20.93 higher than the same log odds for individuals living in rural areas (regression coefficient= 20.93; 95% CI [18.58, 23.28]). Similarly, the log odds of being

an excess zero on the disclosure concerns scale for individuals living in remote areas was 23.53 higher than the same log odds for individuals living in rural areas (regression coefficient= 23.53; 95% CI [20.7, 23.36]). Compared to respondents living in rural areas, those living in remote areas experienced 0.6 times less self-stigma (IRR=0.6; 95% CI [0.42,0.87]) and 0.47 times less overall stigma (IRR=0.47; 95% CI [0.31,0.72]).

Table 18. Effects of demographic and clinical characteristics on HIV stigma scores over the past 12 months using zero-inflated Poisson (ZIP) regression for subscale 1 and subscale 3 and Poisson regression for subscale 2 and overall stigma scale, reporting IRR for count variables and regression coefficients for inflate variables

Characteristics	Subscale 1- Social Stigma	Subscale 2- Self Stigma	Subscale 3- Disclosure violations	Overall Stigma Scale
Count Variables				
	IRR [95% CI]	IRR [95% CI]	IRR [95% CI]	IRR [95% CI]
Gender	**			*
Female (ref)	1.00	1.00	1.00	1.00
[a] Male	**0.55 [0.31 , 0.99]**	0.91 [0.78 , 1.07]	0.9 [0.64 , 1.27]	0.88 [0.74 , 1.04]
TG	2.05 [0.99 , 4.22]	1.27 [0.91 , 1.77]	**0.32 [0.12 , 0.89]**	1.26 [0.92 , 1.74]
Age		*	*	**
16-29 (ref)	1.00	1.00	1.00	1.00
30-39	1.05 [0.61 , 1.83]	0.99 [0.84 , 1.16]	**1.61 [1.03 , 2.52]**	1.03 [0.87 , 1.22]
40+	0.58 [0.28 , 1.18]	**0.77 [0.62 , 0.95]**	1.08 [0.47 , 2.45]	**0.76 [0.61 ,0.94]**
Ethnicity		*	**	**
Laolum (ref)	1.00	1.00	1.00	1.00
Khmou	2.52 [0.28 , 22.86]	**0.52 [0.32 , 0.86]**	**33.08 [5.12 , 213.64]**	0.82 [0.48 , 1.4]
Hmong	1.84 [0.7 , 4.82]	0.93 [0.57 , 1.5]	**10.84 [1.58 , 74.16]**	1.22 [0.65 , 2.3]
Katang	1.21 [0.55 , 2.68]	1.16 [0.84 , 1.59]	1.73 [0.4 , 7.52]	**1.77 [1.23 , 2.53]**
Education				
No Schooling (ref)	1.00	1.00	1.00	1.00
Some schooling	0.41 [0.14 , 1.2]	0.85 [0.61 , 1.18]	0.87 [0.22 , 3.52]	0.84 [0.6 , 1.18]
High School grad	1 [0.3 , 3.34]	0.89 [0.61 , 1.3]	0.57 [0.13 , 2.54]	0.76 [0.51 , 1.13]
Higher education grad	**0.34 [0.12 , 0.99]**	0.85 [0.59 , 1.23]	1.02 [0.22 , 4.67]	0.85 [0.57 , 1.26]
Geographical location	**			
Center (ref)	1.00	1.00	1.00	1.00
North	0.61 [0.25 , 1.51]	0.89 [0.63 , 1.25]	0.5 [0.17 , 1.49]	0.76 [0.53 , 1.1]
South	**1.97 [1.25 , 3.12]**	1.09 [0.91 , 1.31]	0.79 [0.31 , 2.03]	1 [0.81 , 1.24]
Sexually active			*	*
Yes (ref)	1.00	1.00	1.00	1.00
No	0.78 [0.45 , 1.35]	0.93 [0.79 , 1.1]	**0.57 [0.33 , 0.99]**	**0.81 [0.67 , 0.98]**
Migrant Worker	**	*	**	**
Yes (ref)	1.00	1.00	1.00	1.00
No	**0.37 [0.2 , 0.71]**	**0.84 [0.7 , 1]**	**0.53 [0.33 , 0.84]**	**0.73 [0.6 , 0.9]**
Currently on Med. for OI	**			
Yes (ref)	1.00	1.00	1.00	1.00
No	**2.21 [1.27 , 3.87]**	1.03 [0.84 , 1.27]	1.41 [0.91 , 2.18]	1.14 [0.92 , 1.41]

Table 18. continued

Characteristics	Subscale 1- Social Stigma	Subscale 2- Self Stigma	Subscale 3- Disclosure violations	Overall Stigma Scale
Count Variables				
	IRR [95% CI]	IRR [95% CI]	IRR [95% CI]	IRR [95% CI]
Health Status		**	**	**
Excellent (ref)	1.00	1.00	1.00	1.00
Very good	1.47 [0.52 , 4.14]	1.11 [0.66 , 1.89]	1.05 [0.36 , 3.05]	1.12 [0.65 , 1.91]
Good	1.17 [0.37 , 3.67]	1.01 [0.59 , 1.74]	1.47 [0.51 , 4.24]	1.03 [0.6 , 1.78]
Fair	1.98 [0.66 , 5.9]	1.17 [0.68 , 2.01]	1.88 [0.61 , 5.75]	1.34 [0.77 , 2.33]
Poor	2.55 [0.79 , 8.19]	**1.78 [1.02 , 3.11]**	**3.83 [1.33 , 11]**	**2.06 [1.12 , 3.79]**
Have CLHIV			**	
Yes (ref)	1.00	1.00	1.00	1.00
No	0.78 [0.32 , 1.87]	0.86 [0.63 , 1.18]	**11.5 [3.67 , 36.03]**	0.97 [0.69 , 1.37]
Heard of LHIV laws	*			
Heard of None (ref)	1.00	1.00	1.00	1.00
Heard of all four	**0.61 [0.38 , 0.98]**	0.91 [0.72 , 1.15]	1.22 [0.63 , 2.35]	0.91 [0.7 , 1.19]
Disclosed HIV status			*	
Yes (ref)	1.00	1.00	1.00	1.00
No	1.23 [0.78 , 1.94]	1.02 [0.87 , 1.19]	**0.6 [0.36 , 0.99]**	0.95 [0.8 , 1.12]
[b] **Inflate Variables**				
	Regression coefficients [95% CI]		Regression coefficients [95% CI]	
Time living with HIV	*			
<1 year (ref)	0.00	1.00	0.00	1.00
1-4 years	-0.54 [-1.62 , 0.53]	0.94 [0.72 , 1.22]	-0.19 [-1.54 , 1.16]	0.89 [0.65 , 1.22]
5-9 years	-0.55 [-1.65 , 0.54]	0.86 [0.65 , 1.13]	-0.92 [-2.44 , 0.59]	0.84 [0.6 , 1.18]
10+ years	**-2.24 [-3.82 , -0.67]**	0.8 [0.55 , 1.16]	-0.5 [-3.09 , 2.09]	0.88 [0.58 , 1.33]
Household type	**	**	**	**
Rural (ref)	0.00	1.00	0.00	1.00
Small town/village	0.2 [-1.07 , 1.48]	0.99 [0.75 , 1.31]	0.83 [-1.4 , 3.06]	1.02 [0.75 , 1.39]
Large town/city	0.24 [-1.07 , 1.54]	0.84 [0.64 , 1.09]	1.01 [-1.05 , 3.07]	0.95 [0.72 , 1.27]
Remote Area	**20.93 [18.58 , 23.28]**	**0.6 [0.42 , 0.87]**	**23.53 [20.7 , 26.36]**	**0.47 [0.31 , 0.72]**

Note: Other covariates not displayed for lack of significance but included in the model are: income, relationship status, MSM, sex worker, currently on ARV, have children, membership in HIV support group, and involvement in developing legislation.

[a] Bolded values indicate that the 95% CI does not include 1 and $p < 0.05$

[b] Only applies to Subscale 1 and Subscale 3, which were regressed with a ZIP model.

* Post-estimation Wald test= $p < 0.05$ for association between overall variable and scale score in multivariate model

** Post-estimation Wald test= $p < 0.01$ for association between overall variable and scale score in multivariate model

Chapter 4: Discussion

The results presented in this report have allowed us to explore many aspects of the HIV-related stigma and discrimination situation in Lao PDR ranging from the characteristics of the individuals who live with this condition to the social environment that surrounds them and shapes their daily experiences. The sample of people living with HIV on which we base our study comes from various sub-groups of the population, with many ages, ethnicities, occupations and socioeconomic classes represented, reminding us that this disease knows no boundaries and can have an effect on all of our lives. However, this is not to say that HIV and AIDS affect everyone the same way, or even that everyone is equally susceptible to its deleterious effects. This fact is clearly demonstrated by our results.

In our representative sample of PLHIV that access healthcare services in Lao PDR, it can be concluded that HIV-related stigma and discrimination is prevalent in the country in different forms including social stigma, self-stigma, and disclosure violations, which negatively affect the lives of PLHIV. Stigma in the community presented itself mostly in high levels of PLHIV being gossiped about by members of their community and receiving verbal insults. These two forms of community stigma were also some of the most common amongst other Asian Pacific countries including China, Myanmar, Thailand, and Cambodia. [40]China, Myanmar, and Thailand all had higher levels of gossip events, but the rate of verbal insults in China and Cambodia were similar (14% in China, 15% in Cambodia, compared to 11% in Lao PDR). Similarly, the percentage of people excluded from social gatherings in Lao PDR was low (1.3%), which was similar in Cambodia (4%). Overall, Lao PDR's rates for these instances of community stigma closely reflect those in Cambodia, a close geographic and cultural neighbor. Stigma in the family setting occurred at relatively low levels, but the figures once again matched those of Cambodia; the proportion of individuals excluded from family activities in Laos was 2%, while it was 3% in Cambodia. This is not to say that stigma in the family setting is not important, however. As the qualitative data showed, stigma and discrimination from family members are some of the most devastating experiences that PLHIV face. Once they have been rejected by society, losing family support can mean not having much left. The quotes presented also demonstrated that many of these discrimination events are due to simple lack of understanding of the disease, since family members are scared of touching, sharing food, or even sleeping in the same room as their HIV-infected relative. These multiple forms of enacted stigma are internalized by PLHIV and present themselves as self-stigma. Self-stigmatizing actions that affect an individual's social life, professional life, family life, and health were common across all regions and genders. Similarly, internal fears and negative feelings occurred amongst a very high proportion of the population, indicating the heavy psychological toll that HIV can take on a person. It's also interesting to note that the proportion of people that fear discrimination is higher than the percent of people that actually suffer the discrimination events, indicating that they are

aware that these events have occurred to other PLHIV. A different form of discrimination, disclosing a person's HIV status without his consent, is a violation of the rights of PLHIV that is unfortunately highly prevalent in Lao PDR, even in the health sector. In fact, disclosure violations by healthcare professionals even came up during the qualitative analysis, which points to a lack of respect for the rights if PLHIV, not just in the community, but even in the healthcare settings.

We also report very low levels of counseling in the treatment centers on a variety of topics including sexual health, drug use, emotional well being, and reproductive options. In the general population, there also exist very low knowledge of the laws that protect the rights of the PLHIV, low knowledge of support organizations, and low membership rates in PLHIV support groups. Because of the large differences between genders and regions on some of these knowledge questions, we will discuss these further below.

Of all the PLHIV in our sample, 63% lived under the poverty line of USD$1.25/day. This very high figure provides an idea of the economic vulnerability that most people living with HIV and AIDS in Lao PDR suffer from. Furthermore, only 15% of the population surveyed had a full-time permanent job. This proportion represents the only sector of the PLHIV population receiving a stable and constant paycheck. The remaining 85% are interns, volunteers, farmers, self-employed, or unemployed. Education also plays a role in this schematic, since only one third of the people had completed upper secondary (high school) or more, not leaving the remaining two thirds with many job options. Combine all of this with the fact that HIV-related discrimination at the work place caused 18% of respondents to lose their jobs or income,and suddenlythe 63% rate of poverty seems explicable. Economic vulnerability is an example of how HIV-related stigma and discrimination are not only consequences of social inequalities, but also causes of them.[15] The poor are not only more vulnerable to contract HIV because of structural violence, but are also more affected by HIV-related stigma and discrimination since poverty presents an almost universal form of stigma that layers with HIV stigma.[12]Moreover, if the stigma and discrimination that PLHIV experience causes them to lose their job or income (as is the case in our study), then they will only become poorer and fall into an uncontrollable cycle of vulnerabilities.

Socioeconomic vulnerabilities also seemed to differ between the regions of Lao PDR. Champasack, representative of the southern region of the country, had a higher proportion of unemployed individuals, of farmers, and of people living under the poverty line than the other two regions. However, PLHIV in the south seem to be suffering from more than just higher socioeconomic vulnerability. They also had the lowest rates of ARV use in the whole country (almost 25% less than the north), much lower levels of counseling on sexual health, drug use, emotional well-being, reproductive options, and even treatment options. What's even more shocking is the fact that in Champasack, these forms of counseling for individuals not currently on ART are literally non-existent, as 0% of patients not on ART reported receiving these services in the south. These forms of counseling and informational

discussions are an essential part of treating a patient with HIV and preventing future infections. Not surprisingly, negative feelings due to self-stigma are more prevalent amongst the PLHIV in the south. It can be expected that with lower access to counseling and discussions with healthcare professionals, PLHIV will be more psychologically and emotionally vulnerable to self-stigma. The individual in-depth interviews conducted with healthcare providers and peer counselors in the treatment centers also provide some qualitative information that helps us understand these healthcare discrepancies. We found that the treatment center in Champasack in the south currently treats more than twice the number of patients than the center in Luangprabang (the north), yet it only offers healthcare services to PLHIV two days a week (compared to Luangprabang's 4 days/week services). Furthermore, both centers have just about the same number of staff. The severely understaffed and overworked center of Champasack, open for only 2 days a week, is not able to keep up with the needs of a vulnerable PLHIV population. Therefore, a question of resources and economic disparity at the regional or provincial level can have great impact on the healthcare that PLHIV in that region receive and subsequently, their mental and physical health. The south also proved to be the region of the country with the lowest level of knowledge regarding declarations, laws, and policies that deal with the protection of rights of people living with HIV. Interestingly, our multivariate model showed that independent of region, knowledge of these policies reduces the incidence of social stigma by 39%. It also showed that independent of knowledge of laws,geographical region is a highly significant predictor of the incidence of social stigma events, with the south experiencing about 97% more social stigma events than the center region. These two facts combined tell us that regional location and knowledge of laws are actually two independent predictors of social stigma and may layer on each other to make the individuals living in the south with low knowledge of laws extremely vulnerable to social stigma events.

Gender was found to play a major role in stigma and discrimination issues. To begin with, we found that females and TG females living with HIV were younger than the males in our sample. This points to the fact that these groups might be more vulnerable to contract HIV at a younger age. Women were also found to be more socioeconomically vulnerable than men and TG, as they had lower frequencies of higher education, were less knowledgeable about HIV laws and policies, were more likely to be widowed, and had a higher poverty rate than the other genders. As is suggested by biosocial theory, these vulnerabilities are all the result of structural violence in Lao society and they have a resulting effect on the layering of HIV-related stigma and discrimination. [12,18] As expected, a higher frequency of TG individuals and females had experienced discrimination events in their community than males. Similarly, TG PLHIV had higher rates of discrimination within their own families than both females and males. These results were further confirmed by the multivariate model the predicted the incidence of social stigma events; women were found to have an incidence of social stigma events that is 82% higher than the same incidence for men. Given that self-stigma is the result of internalizing instances of stigma and

discrimination that comes from outside sources, we would also expect females and TG to have higher rates of self-stigma. This was indeed the case, as females and TG females were more likely than males to suffer from self-stigmatizing and isolating behaviors, internal fears, and negative feelings about themselves. Our multivariate model also showed that as a whole variable, gender was a significant predictor of overall stigma events in our population of PLHIV, which is a fair statement given that gender played a role in determining all types of stigma, from social, to self-stigma, to disclosure concerns.

Other than gender and geographical location, there were other social, demographic, and clinical characteristics also proved to be significant predictors of the incidence of stigma events. In our population, PLHIV reported higher incidences of stigma if they were in the younger age group (16-29), were an ethnic minority, had a low level of education, were sexually active, were migrant workers, had a poor health status, and were not taking their medications for OI. Most of these results do not require further explanation, since our theoretical framework of structural violence predicted that marginalized populations would experience higher levels of stigma. However, it is interesting to note that migrant workers and sexually active individuals are more stigmatized in the Lao context not only because of this, but also because they represent two groups of people in society that is highly associated with the two most common transmission routes of HIV in the country— unprotected heterosexual contact and migration. Therefore, society might blame these individuals and cause them to suffer higher levels of stigma. Health status and medication is also key in testing our hypothesis of the effect of ARV and OI medicines uptake on stigma. In this case, not taking medicines for OI means higher levels of social stigma. This can be explained by the fact that individuals on OI medication probably look healthier and are not rejected by society. This is further evidenced by the fact that on all other scales where OI was not a predictor of stigma, perceived health status was. Therefore, healthier individuals suffer less of all types of stigma. Although taking ARV did not prove to a predictor of stigma, the underlying hypothesis is proven, which is that healthier looking individuals suffer less HIV-related stigma and discrimination. This result, which was shown by Castro and Farmer with case studies in Haiti,[12] provides evidence to the idea that stigma and discrimination does not need to be battled with interventions that specifically target education or knowledge, but rather focus on socioeconomic and health characteristics that are determinants of suffered stigma. Finally, our choice to use zero-inflated Poisson models for two of the multivariate models was validated by the fact that two variables were significant predictors of the individuals who scored excess counts of zero stigma social and disclosure stigma events. Individuals living in a remote areawere more likely to have no stigmatizing events or disclosures happen to them. They were had decreased incidences of self-stigma and overall stigma events. Although we had not expected this result, it makes sense since being away from society, people, and their judgments can decrease their exposure to stigmatizing events, and result in less internalized stigma and negative feelings about themselves. We also found that individuals who have been living with HIV for less than a

year are more likely to have an "inevitable" score of zero on the social stigma. In light of our other results, we understand this to be because one year of living with the disease has not yet given these individuals time to get disclosed in society, to appear unhealthy to others, and to suffer stigmatizing events from their community or family. The fact that our developed stigma scales were sensitive to these social, demographic and clinical characteristics that can layer on HIV stigma further adds to the construct validity of our measures.

There were several limitations to our study. To begin with, our sample of PLHIV cannot be said to be representative of the PLHIV population in the entire country. Because we recruited the participants in ARV treatment centers, we limited the opportunity for individuals not seeking medical care or counseling to take part in our study. Thus, our sample may be biased toward people with positive experiences in ARV centers, and we can only generalize our results to the PLHIV population that access services at these treatment centers. This also means that our results can be taken to be a conservative measure of HIV-related stigma and discrimination in Lao PDR, since many of the most stigmatized and isolated individuals would not likely visit a treatment center. The lack of research and interview skills in the survey team also provided several challenges. Even though all surveyors received training with the research tool, many did not understand the meaning of certain words or questions, which might have affected their interview procedures. Furthermore, the team leaders, which were meant to provide technical support while on the field to the surveyors, also had limited experience with research. The survey tool itself provided some limitations, as some questions, such as occupation, were difficult to answer for some of the participants that belonged to multiple groups or identified with none of the groups. The survey captured stigma and discrimination events that occurred in the last 12 months, which failed to include many events that happened to individuals outside of this time period. Finally, although 3 of the 4 stigma scales developed had good internal reliability, the disclosure concerns scale had low reliability (Cronbach's alpha= 0.49). We also acknowledge the fact that our scales are not validated against a "gold standard" of stigma measurement, but their sensitivity to the demographic variables in the univariate and multivariate analyses along with the results obtained indicate that they are good measures.

The results presented in this study build on the knowledge of HIV-related stigma and discrimination that exists in the social and scientific literature, as well as in PLHIV Stigma Index surveys being carried out throughout the world. Our study has many strengths that provide several contributions to this field of research. To our knowledge, our study is the first to explore HIV-related stigma and discrimination in Lao PDR using both qualitative and quantitative methods with a large enough sample size that is representative of the population of PLHIV accessing services at ARV treatment centers. Almost all individuals asked to participate in our study agreed, reducing our selection bias in terms of choosing individuals who may differ from those who chose not to participate. Our results add to the understanding of the layering of HIV-related stigma and discrimination in marginalized

populations, which provide the base for targeted interventions in these populations. Additionally, we provide important information regarding the HIV health care services and the regional differences in terms of accessing services that exist across Lao PDR. Furthermore, our construction of stigma scales to measure stigma events and the use of regression models to understand how various demographic characteristics affect the level of stigma an individual might suffer fromalso provides a more holistic and comparative way to analyze the data collected from the PLHIV Stigma Index survey. Furthermore, along every step of our study, from the planning, to the implementation and collection of data, tothe data entry and analysis, we employed the GIPA principle, involving PLHIV in the process, providing technical support, and building the capacity of local PLHIV networks and Lao staff to lead data collection efforts in the future. Finally, the successful collaboration and coordination between all the partners and government counterparts like the Center for HIV/AIDS/STI, the National Committee for Health Research and the Ministry of Health serves as a great way to establish a strong relationship between them and LNP+ to in order to authorize and conduct similar studies in the future.

Chapter 5:Conclusion and Recommendations

It is clear from the information presented in this report that HIV-related stigma and discrimination is a very complex problem with social, economic, cultural, geographic, historical and even demographic roots. As such, it requires a complex solution that can properly rid all groups and subpopulations oh PLHIV of this added burden. The first step in achieving such a solution is accepting that this is not a problem to be solved by pinning the guilt on a few individuals and begin to realize that this is a systematic problem caused by the society to which we belong. Secondly, we must acknowledge that the way an individual or group of people experience stigma and discrimination is an individual experience and cannot be solved with one general intervention that aims to rid stigma from the entire society. In order to do approach the problem, we need comprehensive research and to understand how layers of stigma can affect the lives of people possessing multiple stigmatizing characteristics. Evidence of this is not only found in social theory, but also in quantitative studies that have modeled layers of stigma and have shown that even an intervention that successfully removes the quantity of general stigma that an individual suffers due to HIV, it will fail to remove the compacted stigmas of most individuals and will ultimately fail as an intervention.[18] In our case, we have seen that women, TG individuals, migrant workers, ethnic minorities, unhealthy individuals and younger PLHIV suffer higher levels of stigma. This means that if we are to implement successful interventions that can effectively decrease levels of stigma and discrimination in Lao PDR, we must target them to these specific groups and at the underlying factors that make them more vulnerable to stigma and discrimination. Thirdly, we must recognize reconcile the above facts and treat stigma as a social process. As Aggleton suggests, social problems are challenged with social movements, [14] and these movements need to come from the PLHIV themselves. Grassroots involvement through organizations such as LNP+ and concrete action plans that make use of the GIPA (greater involvement of people with HIV and AIDS) principle are crucial for the success of interventions battling issues of stigma and discrimination. Furthermore, involvement needs to come from not just PLHIV, but also from PLHIV who belong to other marginalized populations, such as TG individuals. We therefore argue for the greater involvement of marginalized populations (GIMP). For example, our study involved PLHIV surveyors that were MSM and women, but we failed to recruit any TG or individuals from other marginalized groups, such as ethnic minorities. Research, policy development, and implementation of interventions should involved higher numbers of these marginalized groups, not only to empower the individuals themselves, but also to have people involved in the process that are able to understand the issues that other PLHIV with similar characteristics might experience. For example, a TG peer educator or counselor who speaks with TG patients at treatment centers might be more successful at empathizing and communicating with a patient that has had similar experiences of stigma and discrimination.

Based on our results on health services, counseling, and regional discrepancies, we recommend increasing the number of days that treatment centers are open in order to increase the capacity of patients that a center can treat and counsel (especially in the south). There is no price for adequate medical and psychological treatment, and every PLHIV should have access to these precious services. Furthermore, these services should to be offered to all individuals infected with HIV, not just to those who have progressed to AIDS, as is currently being done in Champasack. This is critical not just to the health of the PLHIV, but also to preventing future transmissions, since uniformed and uncounseled individuals with HIV might not change their high-risk behaviors. This increased demand for counseling and psychological support will be difficult to meet at the ARV treatment centers, so we recommend implementing national hotlines where PLHIV can phone in and receive counseling, information, and mental health support whenever they need it. This intervention would decrease the burden of transportation costs that most PLHIV have to take on in order to reach the treatment centers and would decongest the treatment centers of patients only seeking counseling or emotional support. This hotline project could also be an opportunity for capacity building in PLHIV, since the counselors should be recruited from all sectors of the diverse PLHIV population and include doubly(or triply) marginalized groups. This hotline service could also provide people with more information about the international laws, declarations, and policies that protect their rights, which is critically needed at the moment as we saw from the results in this study.

Programmatic interventions that address the economic vulnerability of PLHIV are also relevant to decreasing stigma and discrimination events in Lao PDR. Given the high poverty rate of PLHIV in our sample, and their lack of economic stability, it is recommended that training in income-generating activities to help PLHIV support themselves are considered as possible solutions to this problem. For example, migrant workers coming from Thailand tend to be unskilled laborers and are most vulnerable when they come back to Lao PDR as they can be infected with HIV, have no employment, and very little skills or education. Current programs in skills building, agricultural training, animal husbandry, and marketing supportimplemented by multiple NGOs and government programs around the country could be modified and targeted at PLHIV. Training and skills building is appropriate not only for individuals living with HIV, but also for PLHIV networks. Although they are currently existent and functional in the country, they lack organization and skills in managing their projects. Capacity building of these networks is an important key in making sure that GIPA is in place at its fullest potential.

Addressing stigma and discrimination needs to be a main component of any intervention to prevent, treat, and control HIV. Although the appropriate solution to this critically important problem might seem daunting and complex, it is one that must be found if we are to control the epidemic and ensure individuals living with HIV a life full protection of their rights and their quality of life. It is our hope that this study gets us one step closer to that goal.

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