Experience of Stigma and Discrimination by People Living with HIV

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Letter of Recommendation

This Master of Philosophy in Sociology dissertation entitled **"Experience of Stigma and Discrimination by People Living with HIV"** has been prepared by **Mr. Prabin Shakya** under my supervision and guidance. This dissertation has been prepared in fulfilment of the requirements for the Degree of Master of Philosophy in Sociology at Tribhuvan University.

I hereby recommend this dissertation to the Dissertation Committee for its final acceptance and approval.

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Letter of Approval

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Declaration

I hereby declare that the Dissertation entitled **"Experience of Stigma and Discrimination by People Living with HIV"** submitted by me to the Central Department of Sociology, Tribhuvan University, is entirely original work prepared under the supervision and guidance of Prof. Madhusudan Subedi. I have made due acknowledgment of all ideas and information borrowed from different sources in the course of writing this thesis. The result presented in this study has not been submitted or presented anywhere else for the award of any degree or other reason. I am solely responsible if any evidence is found against my declaration.

Prabin Shakya
July 14, 2024

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Thank you.

Prabin Shakya
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Abstract

HIV stigma denotes to the irrational or negative beliefs, attitudes, behavior and judgment towards people living with HIV (PLHIV) followed by discrimination which is the biased and partial treatment of PLHIV having context specific manifestation and diverse impacts. This study aimed to assess the lived experience of HIV stigma and discrimination, identity issues its impact, factors, support system and coping mechanism. A descriptive and exploratory study design was made with qualitative data collected among 60 PLHIV (49 female and 11 male respondents). The qualitative data were collected by using open ended structured questionnaire. The data gathered were analyzed using a thematic meaning making approach to form the results of the study.

It was concluded that the research respondent undergoes the identity crisis after the discovery of HIV due to different contextual factors like physical appearance, lack of knowledge about HIV, self-shaming, absence of social and economic support that lowers their self-esteem, confidence and status. Simultaneously, the respondents rebuild their identity based on their personal resilience, selective and limited disclosure, silent and secrecy, coping mechanisms, outreach and support mechanism through people and organization and access to available resources which is the positive aspects that impact the life of PLHIV. Furthermore, they focused on the health, social and economic aspects of their lives and these enabled them to gradually reconstruct their identity. The thesis pursues to back contributions in the sociology HIV stigma and discrimination. It also seeks to revise the perspectives of symbolic interactionism to better understand the emotive and embodied nature of identity processes in HIV stigma and discrimination.

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List of Acronyms and Abbreviation

AIDS	:	Acute Immunodeficiency Syndrome
ART	:	Antiretroviral therapy
ARV	:	Antiretroviral
CHBC	:	Community and home based care
FHI	:	Family Health International
FSW	:	Female Sex Worker
HIV	:	Human Immunodeficiency Virus
IDU	:	Intravenous Drug User
KMC	:	Kathmandu Metropolitan City
NCASC	:	National Center for AIDS and STD control
NHSP	:	Nepal Health Sector Programme
PLHIV	:	People living with HIV
PLWHA	:	People living with HIV and AIDS
PMTCT	:	Prevention of Mother to Child Transmission
PTSD	:	Post-traumatic stress disorder
QOL	:	Quality of Life
STI	:	Sexually Transmitted Infection
TU	:	Tribhuvan University
UN	:	United Nations
UNAIDS	:	Joint United Nations Programme on HIV/AIDS
VCT	:	Voluntary Counselling and Testing
WHO	:	World Health Organization
PEPFAR	:	U.S. President's Emergency Plan for AIDS Relief

Chapter One: Introduction

1.1. Background of the Study

Nepal has a concentrated HIV epidemic, with an adult HIV prevalence (ages 15 to 49) of 0.02% in 2023. Recent estimates indicate that approximately 30,000 people are living with HIV in the country. Each year, there are about 488 new infections, with 308 men and 180 women contracting the virus. Heterosexual transmission accounts for 69% of HIV cases in Nepal (NCASC, 2023). The key populations affected by the HIV epidemic include intravenous drug users, sex workers and their clients, men who have sex with men, transgender people, male labor migrants and their wives, and prisoners (NCASC, 2023).

Recent efforts in Nepal to implement evidence-based, targeted HIV prevention interventions focusing on key populations have significantly reduced new infections. However, despite continuous efforts to combat stigma and discrimination, these barriers remain significant impediments to accessing information and services (Chaudhary & Kakchapati, 2022). Stigma and discrimination related to HIV, along with socially constructed negative connotations of HIV and AIDS, are major barriers to health service access and effective utilization (NCASC, 2023). People living with HIV (PLHIV) are often stigmatized and discriminated against due to prevalent misconceptions, lack of accurate knowledge, sociocultural beliefs, and false information about HIV and AIDS (Beine, 2003).

Nepal's national HIV strategic plan (2021-2026) aims to mitigate HIV stigma and discrimination through mass awareness and dissemination campaigns. The strategic plan emphasizes mass-level campaigns and programs to promote HIV knowledge for its prevention and to achieve the ambitious target of 95-95-95. Additionally, the plan highlights the importance of effectively implementing government policies, programs, and strategic approaches to provide access to services and information for PLHIV (NCASC, 2023). The strategic plan also aims to strengthen the Community Home-Based Care (CHBC) program, which provides access to primary health care services for PLHIV in their homes and communities through trained CHBC workers. This initiative is expected to ensure ART adherence,

reduce stigma and discrimination, and improve the quality of life and positive living for PLHIV (NCASC, 2023).

The Nepal government has developed a national HIV Strategic Plan for 2021-2026, which adopts a people-centric approach grounded in the principles of human rights and health equity. This plan is expected to significantly reduce new HIV infections and HIV-related deaths, improving the health and quality of life for people living with HIV (PLHIV). Key elements of the plan include the effective implementation of HIV prevention efforts, promotion of HIV testing, increased access to antiretroviral therapy, and the advancement of inclusive, sustainable healthcare for PLHIV, all while working to reduce persistent HIV-related stigma and discrimination (NHSP, 2021).

Canadian sociologist Erving Goffman first defined stigma as "an attribute that is significantly discrediting," which diminishes the social standing of the individual or group associated with the stigma (Goffman, 1963). Further research in sociology and social psychology has explored stigma processes from individual to structural levels. Stigmatization involves labeling deviance with negative traits, leading to separation, loss of status, and discrimination. These outcomes are heavily influenced by the presence or absence of power (Link & Phelan, 2001; Mwale, 2006).

Since the concept of stigma was introduced, it has been closely linked with diseases such as mental illness, leprosy, and tuberculosis. Being infected with a disease is often viewed as socially discrediting. The degree to which specific infections or diseases are stigmatized varies over time and across cultures. However, certain diseases exhibit nearly universal aspects of stigma that persist across different cultures for decades. Common expressions of stigma include social or physical isolation of individuals or families with stigmatized characteristics. Yet, some manifestations of stigma are culturally specific, showing variations from one place to another (Abdullah & Brown, 2011).

Stigma has been associated with HIV since the beginning of the epidemic, quickly becoming linked with negative social attributes. UNAIDS defines HIV-related stigma as "a process involving the devaluation of individuals living with or

connected to HIV and AIDS" (2003, p. 1). This broad term encompasses multiple components of the devaluation process. Stigma can be internalized when experienced by an individual and enacted when society discriminates or stereotypes, but self-inflicted bias has also been observed (Mahajan et al., 2008). Anticipated stigma, particularly concerning HIV and other illnesses, often stems from prior experiences or anxieties about potential stigma (Alonzo & Reynolds, 1995; Gilbert & Walker, 2010). HIV-related stigma, like other disease-related stigmas, is produced and exhibited through a process involving stereotyping (the "notion"), prejudice (the "emotion"), and discrimination (the "action") (Phelan, Link, & Dovidio, 2008).

HIV-related stigma is a social phenomenon where an individual is perceived by others to possess a discrediting characteristic, causing them to be viewed as damaged, tainted, or flawed (Mwale, 2006; Adane et al., 2020; Jugeo & Moalusi, 2014). Research worldwide has shown that psychological discomfort for PLHIV is not solely caused by their health status or HIV-related symptoms but also by HIV-related stigma (Jugeo & Moalusi, 2014; Rinehart et al., 2019). Perceived stigma and discrimination significantly impact the quality of life for PLHIV, their families, communities, and healthcare professionals working with them (Stangl et al., 2013; Fido et al., 2016; Feyissa et al., 2016). When perceived stigma is combined with the adverse effects of antiretroviral therapy (ART), it can lead to shame, loss of self-efficacy, low self-esteem, low confidence, and hopelessness. These factors can result in poor adherence to ART, treatment failure, the rise of drug-resistant HIV strains, and even fatalities (Fido et al., 2016; Feyissa et al., 2016).

In Nepal, HIV stigma and discrimination are not new issues. HIV and AIDS are often perceived as outcomes of either extramarital sexual activities or needle sharing for drug use, which are considered outside the norms and values of Nepalese society. Consequently, PLHIV are stigmatized and discriminated against by family, friends, institutions, and society at large. Studies on HIV stigma and discrimination in Nepal have found that many healthcare providers hesitate to provide care to PLHIV due to fear of contracting HIV themselves, often referring PLHIV to other health facilities. Medical professionals involved in invasive medical and surgical procedures report a higher fear of self-HIV transmission. However, those experienced and frequently involved in providing treatment and care to HIV patients perceive few risks

of HIV transmission when appropriate precautions are in place. Some PLHIV experience poor treatment in workplaces and educational institutions, which violates their rights, psychologically impacts them, and hinders their access to HIV testing and treatment. PLHIV and other key affected populations are often disregarded by their families, peers, and the larger community (Moktan, 2023).

In Nepal, gender inequality and poverty have made women more susceptible to HIV risk behaviors and exposure. Gender and the intersectionality of stigma and discrimination are critical issues. Due to their social roles, low status in the social hierarchy, lack of decision-making autonomy, economic dependence, and low literacy rates, women are more likely to face stigma and prejudice from the community, their families, and medical professionals (Addison, 2023).

1.2. Research Problem

HIV stigma and discrimination has been the major issue from the very start of the HIV epidemic and different research conducted earlier has found social determinant factors of HIV stigma. People living with HIV and AIDS who have disclosed their HIV status has been perceived as the deviant and abnormal including dangerous that leads to spoiled identity or identity crisis, loneliness, isolation and degradation of self respect. However, the study on HIV and AIDS and its impact on the PLHIV and diverse intervention strategies have aided in the mitigation of HIV stigma and prevention of HIV infection. Social construction of HIV stigma and reconstruction or management of spoiled identity is the significant issues that need to have in depth understanding because of its complicated phenomenon and its linkages with spoiled identity, that all intersect with the wider social, cultural, economical and political structures and social process that socially construct different stages of identity to PLHIV (Tsarenko & Polonsky, 2011).

Erving Goffman, propounded the stigma theory under the symbolic interactionism that led to the development of notion of spoiled identity management and dramaturgical viewpoint in sociology that proposed individual life as a theater and people as an actors on a stage and also conceptualized stigma as the major factor for the different stages of social identity (Mwale, 2006).

In context of Nepal, there has been many research on HIV stigma has been done in epidemiological perspective. Furthermore, there is increased significance of HIV stigma and discrimination for the mitigation and prevention of HIV infection. However, there lack the research from sociological view point to address the influence of HIV stigma and discrimination on social identity and this study will address the research gaps on social construction of HIV stigma and discrimination, disruption and management of spoiled identity.

In this study to address the research problem, explored about the HIV infected people discovered infection of HIV, their initial reaction and ways explore to manage the HIV stigma including, the social construction of HIV stigma.

What is the status of HIV stigma and discrimination as experienced by people living with HIV and AIDS in the of Kathmandu valley?

1.3. Research Question:

What is the status of HIV stigma and discrimination as experienced by people living with HIV and AIDS in the Kathmandu Valley.

1.4. Objectives of the Study

The general objectives of this study is to explore, HIV related stigma and discrimination, support system and coping mechanism as experienced by people living with HIV and AIDS in Kathmandu valley. The specific objectives is denoted below

- To explore stigma and discrimination as experienced by PLHIV residing in Kathmandu valley
- To find the disclosure status, supporting system and coping mechanism of HIV and AIDS related stigma and discrimination as experienced by PLHIV residing in Kathmandu valley

1.5. Rationale of the study

In context of Nepal, HIV is taken as the infection that ultimately lead to death. The common social opinion of HIV and AIDS is that the infection occurs after the sexual intercourse outside of marital relationships or to people who have sexual relationship with sex workers. However, in Nepal the society doesn't tolerate the premarital or extramarital relationship due to these perception people living with HIV face the stigma and discrimination in society and PLHIV are finding it hard to reside in their own family and communities which has been found to forced them to migrate to new places leaving their family and communities (Jha, Plummer & Bowers, 2011).

Among the diverse reason of HIV stigma, the general belief is that someone get infected of HIV because of sin which will lead their early death and this bereavement is taken as punishment for making those sin (Nepal & Ross, 2010). In Nepal most of the people follow hindu religion and it plays major role in Nepalese society and in their everyday life. As per the Hindu religion, premature death is perceived as a punishment for the wrong deed done in the past life, hence this religious perception creates the HIV belief in society and cause stigma and discrimination to HIV positive people (Nepal & Ross, 2010). Furthermore, Hindu religion, hindu cultural beliefs and practices also creates some of the fallacy in HIV infection and its transmission like caste based purity and philosophy of karma. Some of the misconceptions about HIV and its transmission are also rooted in the Hindu cultural beliefs and practices, such as caste-related purity and philosophy of karma and HIV infection is comprehended due to the bad karma or God's punishment (Pokhrel et al., 2008). HIV stigma is effected by the educational level and economic status. The society shows fear, hatred and rejects the HIV infection and its transmission due to the fact that they don't have the required knowledge and have misconception about the infection. In the study conducted by Nepal & Ross (2010), found that the well educated PLHIV encounter less stigmatization than the uneducated PLHIV. Similarly, economically well to do PLHIV also faced less stigma and discrimination than one with lower economic capital. Furthermore, in the study conducted by Jha & Madison (2009) found that the doctors and nurses showed stigma and discrimination against PLHIV even though they are well educated which was due to the lack of proper knowledge of HIV and its mode of transmission including lack of sensitivity to treat the HIV infected people with dignity and respect. Furthermore,

some of the medical health professional denied to provide health services to PLHIV due to the fear contracting infection and being known to be associated with HIV.

HIV stigma and discrimination is socially constructed and community and society plays significant role in its generation. Hence, social norms, belief, behavior and actions can either reduce or increase the HIV stigma. Joint families are common in Nepal and women after marriage move to live with their in-laws. And in these joint families, daughter in-law are significantly stigmatized if they became HIV infected and won't get support or care from their in–laws and the husband, however if the male counterparts get infected with HIV then it is normally accepted belief that the daughter in-law will take care of him and provide the necessary support (Nepal & Ross, 2010). Furthermore, HIV stigma and discrimination also manifest as restrictions such as denial of entry into the kitchen, not sharing the same bathroom or bed and restricting the PLHIV in daily tasks or errands these all behaviors of family and community rejection is also taken as a result of HIV stigma (Nepal & Ross, 2010).

1.6. Limitation of the study

The study primarily focuses on the social aspects of HIV stigma and discrimination, neglecting other factors such as technological resilience. As this research is for the partial fulfillment of a Master's degree in Philosophy, it is not an interdisciplinary study. Instead, it aims to demonstrate the respondents' experiences of stigma and discrimination within their homes and communities. The study specifically targets people living with HIV and AIDS in the Kathmandu Valley, using a small sample size. Consequently, the findings may not be applicable to other regions.

The research design is descriptive, exploratory, and inductive, rather than based on predefined questionnaires. Due to time and resource limitations, and considering the scope of the field areas, the study relies on a series of interviews and semi-structured questionnaires. The scope of this thesis is primarily centered on the experiences of respondents living with HIV and AIDS.

Chapter Two: Literature Review

2.1. Theoretical Review

2.1.1. Erving Goffman's Stigma Theory

Erving Goffman pioneered the concept of stigma, tracing its historical usage back to the Greeks, where it referred to bodily signs designed to reveal something unusual and bad about the moral status of the signifier. Goffman defined stigma as a social construct that significantly discredits a person, marking them as abnormal by a group considered normal within any social and cultural context. He emphasized that stigma should be understood as a language of relationships and categorized it into three types: physical deformities, blemishes of individual character, and those transmitted through family lineage. According to Goffman, possessing these discrediting attributes reduces the individual from a whole person to a tainted and discounted being.

Goffman argued that members of normal society exercise various forms of discrimination that diminish the life chances of stigmatized individuals. He further differentiated between stigmatized persons based on their attributes, labeling them as either discredited or discreditable. A discredited person is someone whose stigmatizing attribute has been revealed, whereas a discreditable person possesses stigmatizing characteristics that are not immediately noticeable during initial interactions (Goffman, 1963; Tyler, 2018; Maharjan, 2019).

The concepts that Goffman had proposed were refined and elaborated upon after his book on stigma was published in 1963 and featured in a variety of stigma literature. The concept of stigma has been applied to an extraordinarily wide range of various conditions, notably in regard to health, ranging from leprosy, to cancer, urine incontinence, and mental illness (Parker and Aggleton, 2003; Maharjan, 2019).

Jones et al., (1984) expanded Goffma's work, defining stigma as a "mark" that associates an individual with negative traits, like stereotype in a social connection. He also distinguished six dimension of stigma, which included concealability (the extent to which the mark is visible), course (the pattern of change over time usually due to the mark), disruptiveness (block or hamper interaction), aesthetic (extent up to which

the mark makes the possessor degrade or repellent), origin (condition of the origination of the mark), and peril (kind of danger and seriousness due to the possession of the mark) and emphasized its influence. origin (circumstances on the origination of the mark), and peril (the kind of danger posed by the mark and its seriousness), and highlighted its influence (Maharjan, 2019).

Herek (1999) divided HIV-related stigma into two categories: "instrumental" and "symbolic." Instrumental stigma reflects the fear and apprehension associated with any lethal and transmissible illness, while symbolic stigma encompasses attitudes toward the social groupings or lifestyles thought to be connected to the disease. This categorization implies that attributions of stigma can be linked either to a fatal disease or to the social groups afflicted by it (Maharjan, 2019).

Similarly, Scambler (1998) provided another categorization of stigma as "enacted" and "felt" stigma. Enacted stigma refers to actual discrimination or unacceptability, often associated with pre-stigmatizing conditions that exist before HIV infection. Felt stigma is the fear of such discrimination, based on the personal feelings of the stigmatized individual. Hence, stigma is a complex social process involving the interaction between social and economic factors and the emotional concerns of stigmatized individuals.

2.1.2. Labeling Theory

The theoretical and empirical origins of labeling theory have a long history in sociology (Gibb and Erickson, 1975). Scheff (1966) was the first to specify the fundamental hypotheses regarding mental illness, considering it the result of breaking the unnamed residual laws of social life. These norm breaches, often unrecorded and of transient consequence, occur in various ways and are widespread in society. When a residual rule violator is publicly identified as mentally degraded or ill, they may be subjected to a stereotype of mental illness that they received in early infancy and that is repeatedly reinforced. Labeled deviants are thus rewarded for performing a stereotyped role and penalized for refusing to play it. Despite criticisms of Scheff's data, methods, and analysis (Maharjan, 2019), his work laid important groundwork for understanding labeling.

Labeling theory refers to the process by which society labels individuals who break its consensus on values and norms. People can be labeled based on specific characteristics deemed negative by society, such as laziness, a history of criminal behavior, or living with HIV. These labels can persist long after the individual's death and influence their attitudes, beliefs, and behaviors. The labels are inescapable and can even lead to self-labeling when the stigmatized individual accepts the label (Maharjan, 2019; Muda and Yosuff, 2022).

2.1.3. Modified Labeling Theory

Link and Phelan (2001) expanded on labeling theory by identifying five components of stigma: labeling, stereotyping, separation, status loss, and discrimination. Labeling is the process of conferring a negative label to a person. Stereotyping involves forming negative perceptions based on the label. Separation refers to the exclusion and isolation of the stigmatized individual from the public sphere, leading to status loss. Discrimination then takes place against the stigmatized person (Link & Phelan, 2001; Maharjan, 2019).

2.1.4. Attribution Theory

Attribution theory posits that people try to understand others by making personal or situational attributions about their behavior, providing a framework for explaining the relationship between stigmatizing attitudes and discriminatory behavior (Weiner, 1995). According to Weiner's attribution theory, behavior is determined by a cognitive-emotional process through which people make attributions about the causes and controllability of a person's behavior. This leads to inferences about their responsibility, creating emotional reactions like anger or pity, which in turn affect the likelihood of helping or punishing behaviors. If a person's behavior is attributed to factors outside their control, they are less likely to be judged responsible, and people's emotional reactions and behaviors toward them will be less negative. Conversely, if behavior is attributed to factors within the individual's control, they are more likely to be judged responsible, resulting in negative emotions and behaviors toward them (Maharjan, 2019).

Corrigan (2000) applied Weiner's theory specifically to the stigmatization of mental illness, highlighting the relationship between signaling events (such as

encountering a person with mental illness), mediating knowledge structures (such as attributions), emotional/affective responses, and behavioral reactions.

2.1.5. Earnshaw and Chaudoir's Framework of HIV Stigma

The sociocognitive model of stigma, which focuses on the individual, does not fully account for the social, economic, and political processes that are structural components in the creation and reinforcement of HIV stigma and discrimination. To address this limitation, Misir (2015) highlighted how Link and Phelan combined sociocognitive and structural aspects of stigma. They defined stigma as existing when the elements of labeling, stereotyping, separation, and discrimination occur together in relation to the exercise of power. This conceptual model suggests that interventions to prevent HIV stigma and discrimination should consider both sociocognitive and structural factors, acknowledging that social, political, and economic inequalities and the exercise of power are major drivers of HIV stigma and discrimination (Maharjan, 2019).

Earnshaw and Chaudoir's work aimed to bridge the gap left by the sociocognitive/structural model, which does not adequately explain how individuals experience stigma in terms of health, psychological, and behavioral outcomes that fuel the HIV and AIDS pandemic. They argued that if individual-level interventions are a fundamental component of HIV prevention activities, understanding how HIV stigma impacts individual outcomes becomes critical. This justification underpins the Earnshaw and Chaudoir framework (Maharjan, 2019).

2.1.6. Talcott Parsons’ Sick Role Theory

Functionalism views health as essential for the stability of society, and therefore, ill health is considered a form of deviation. Talcott Parsons introduced the concept of the "sick role," outlining the expected behavior of sick individuals and their caregivers. According to Parsons, sick individuals have both rights and responsibilities. He posits that a sick person is not responsible for their illness and should not be blamed for their condition. As a result, they are granted the right to be exempt from normal social duties and are not expected to fulfill the same obligations as healthy individuals. This exemption, however, is conditional and depends on the

severity of the illness, which must be legitimized by a physician. Essentially, a medical professional must confirm that the illness is genuine (Varul, 2014).

Additionally, the sick person has two primary responsibilities: to strive to get well and to seek and cooperate with technically competent health professionals. Society uses various mechanisms to regulate the behavior of the ill and to reintegrate them into their normal roles. Hence, the sick role theory grants doctors the authority to determine an individual's health status and to allocate the necessary resources or treatments (Crossley, 1998; Varul, 2014).

2.1.7. Structuration Theory

Stigma has been examined through various frameworks, from sociocognitive models at the individual level to structural models at the macro level. Giddens' theory of structuration posits that understanding agents and structures requires consideration of time and space, as actions vary according to context. The stigma associated with HIV has evolved over the past decades due to concerted efforts to expand effective interventions. These interventions address different forms of stigma experienced by people living with HIV (PLHIV) at various societal levels and situations (Tran et al., 2019).

2.1.8. Foucauldian Perspective of HIV Stigma

Foucault's analysis focuses on the cultural production of differences such as stigma within the framework of power dynamics (Parker and Aggleton, 2003). He argues that in modern times, power has evolved beyond the sovereign's ability to take life (juridical power) to include the power to control and optimize life itself. This new form of power operates through comprehensive regulations and social norms aimed at governing and disciplining behaviors that deviate from established norms (Carrasco et al., 2017; Vaugan, 2019).

From a Foucauldian perspective, HIV stigma can be understood as a mechanism to enforce societal norms around sexuality and personal responsibility for health (or healthism). Stigma and marginalization, therefore, serve as tools to discipline individuals who engage in behaviors perceived to threaten social order (Carrasco et al., 2017; Vaugan, 2019).

2.1.9. Pierre Bourdieu's Theory of Habitus

Pierre Bourdieu's concepts of capital, field, habitus, and symbolic violence provide insights into the experiences of HIV-positive women within public health-care systems. Bourdieu's theory emphasizes how power dynamics influenced by biomedical hegemony, sociocultural practices, material conditions, fear, discrimination, and stigma shape the lives of women living with HIV, potentially hindering their empowerment (Vaugan, 2019; Franca et al., 2021).

Within Bourdieu's framework, capital represents the various forms of power individuals wield within specific social fields. These forms include economic, social, and cultural capital, which are recognized as legitimate within their respective fields. The distribution of capital among people living with HIV varies based on factors such as symptoms, access to treatment, utilization of support services, and adherence to biomedical norms (Vaugan, 2019; Franca et al., 2021).

Bourdieu's concept of symbolic violence is useful for understanding the stigma experienced by PLHIV. Symbolic violence, perpetuated with the consent of the socially subordinated, naturalizes existing hierarchies and encourages self-blame among those structurally disadvantaged. In the context of HIV and AIDS, symbolic violence, coupled with dominant discourses, reinforces social control and limits resistance against discriminatory practices (Vaugan, 2019; Franca et al., 2021).

Moreover, Bourdieu's notion of habitus describes the system of pre-reflexive dispositions shaped by tradition and history, influencing individuals' unconscious behaviors and perceptions. Within public health care, therapeutic compliance expectations reshape women's habitus to align with prescribed treatment regimens, illustrating the complex interplay of gender, symbolic violence, and cultural expectations in HIV care settings (Vaugan, 2019; Franca et al., 2021).

2.1.10. Social Construction Theory

Peter L. Berger and Thomas Luckmann's social construction theory posits that social reality is continually constructed by individuals through social interactions, forming subjective realities that are shared and shape societal norms and values (Asrina et al., 2023). In the context of HIV stigma and discrimination, this theory

suggests that perceptions of HIV are socially constructed based on fears, misconceptions, moral interpretations, religious beliefs, and societal norms, associating HIV with shame and violations of social and religious norms (Asrina et al., 2023).

Aggleton and Parker (2003) contribute to this perspective by framing stigma as a social process deeply intertwined with power dynamics and domination. They argue that stigma should not be viewed merely as an individual imposition but understood within broader social, cultural, political, and economic contexts. Stigma, stigmatization, and discrimination, therefore, perpetuate and reproduce structural inequalities within society (Aggleton & Parker, 2003).

Given the theoretical perspectives discussed, the symbolic interactionism theory of stigma was chosen to study HIV stigma and discrimination among people living with HIV (PLHIV) in Kathmandu Valley. Symbolic interactionism, a micro-level perspective, focuses on how individuals construct meaning through social interactions. It explores the development of self-concepts, individual consciousness, and the negotiation of social roles within collective contexts. This perspective is particularly relevant for understanding how PLHIV navigate their identities and experiences in relation to societal attitudes and interactions (Asrina et al., 2023).

2.2. Empirical Findings

2.2.1. Global Scenario

HIV-related stigma has profound implications across various aspects of life for people living with HIV (PLHIV) globally. Research indicates that stigma is linked to decreased rates of HIV testing and increased lifetime risk of acquiring HIV, as stereotypes about HIV can lower perceived risk (Earnshaw et al., 2012). Moreover, HIV-related stigma negatively affects adherence to antiretroviral (ARV) medication, leading to poorer health outcomes for PLHIV and increasing the risk of virus transmission (Katz et al., 2013).

Beyond physical health, stigma significantly impacts mental health outcomes among PLHIV. Studies show that stigma is associated with higher levels of post-traumatic stress disorder (PTSD), depression, and suicidal ideation across different

age groups and cohorts (Garrido-Hernansaiz et al., 2018). PLHIV also report higher levels of social exclusion, loneliness, and lower overall quality of life due to stigma (Logie et al., 2018). This effect is particularly pronounced among those facing intersecting stigmas related to gender identity, sexual orientation, and race (Logie et al., 2018). In some cases, stigma itself has been identified as having a more detrimental impact on quality of life than the HIV diagnosis itself (Holzemer et al., 2009).

Practical repercussions of HIV stigma extend to employment and travel opportunities. Many PLHIV experience discrimination in employment settings, with employers hesitant to hire individuals once their HIV status is disclosed, thereby limiting access to secure jobs that are crucial for maintaining quality of life, adhering to ART, and improving health outcomes (Pena Longobardo & Oliva-Moreno, 2018; Nachega et al., 2015). Furthermore, certain countries, such as Singapore, Jordan, Qatar, and the UAE, enforce travel bans for PLHIV, restricting their freedom to live and work internationally (hivtravel.org).

In their exploration of HIV and AIDS stigma, Bharat, Aggleton, and Tyrer (2001) identify various domains such as healthcare, the home, workplaces, insurance, education, and post-death services where individuals living with HIV/AIDS encounter discrimination. They highlight the healthcare sector as particularly rife with discrimination, stigma, and denial related to HIV/AIDS. Their study, conducted in Mumbai and Bengaluru, involved 31 participants from Mumbai and 13 from Bengaluru recruited from both private and public hospitals. The forms of discrimination observed included refusal of medical services, expulsion from home and community, and termination of employment.

Moreover, the authors underscore the gendered nature of HIV/AIDS stigma, often intertwined with a sexual double standard (van Hollen, 2013). This perspective illuminates how societal norms around gender and sexuality exacerbate stigma for those living with HIV/AIDS, influencing their experiences across various social contexts.

In a related study focusing on self-disclosure among 68 individuals with HIV in South India (Chandra, Deepthivarma, & Manjula, 2003), the authors explored the impact of felt normative stigma on disclosure behaviors. They found that participants anticipated high levels of normative stigma, leading them to limit disclosing their HIV status, especially after learning about others' negative experiences (social learning). This non-disclosure was hypothesized to be driven by the fear of stigma and its consequences, including social isolation and reduced access to support networks.

The study confirmed that non-disclosure due to felt normative stigma correlated with higher levels of depression among participants. This isolation from social support and resources underscores the profound psychological impact of stigma on individuals living with HIV/AIDS, affecting their mental health and well-being.

These studies collectively highlight the pervasive influence of stigma on the lives of people with HIV/AIDS, impacting their access to essential services, employment opportunities, and mental health outcomes. Addressing stigma in these varied contexts is crucial for improving the quality of life and overall health outcomes for individuals affected by HIV/AIDS.

According to Stangl et al. (2013), significant efforts have been made by UNAIDS, UN, and PEPFAR to include stigma and discrimination reduction as a crucial component in the global fight against AIDS. These initiatives reflect a strong political commitment aimed at mitigating the impact of HIV-related stigma. However, the authors emphasize the need for national governments to develop evidence-based intervention strategies that can effectively integrate stigma reduction into national plans at various levels—from individual to societal. They highlight a current challenge where diverse approaches to stigma reduction make it difficult to compare and determine their effectiveness.

Arrey et al. (2017) conducted a qualitative study involving 44 HIV-positive sub-Saharan African immigrant women residing in Belgium. The study aimed to assess stigma and discrimination experienced by these women, particularly within healthcare institutions. The findings revealed that these women faced stigma in the form of fear of infection, discriminatory institutional procedures related to HIV

management, and negative public attitudes toward immigrants and HIV. Stigma manifested as blame, humiliation, stringent precautions, and instances of delayed or refused healthcare services, leading to psychological distress, irregular healthcare seeking behavior, and non-disclosure to healthcare providers. The study recommended effective stigma prevention interventions, specialized training for healthcare providers, and educational initiatives to address these issues.

Rahmati et al. (2010) conducted a qualitative study exploring the perceptions and experiences of people living with HIV in Iran regarding healthcare quality and the attitudes of healthcare providers. The study involved 69 PLHIV from HIV care clinics in Tehran and highlighted experiences of stigma and discrimination from healthcare providers. Forms of discrimination included refusal of care, suboptimal treatment, excessive precautions, and instances of humiliation. Due to perceived stigma, PLHIV avoided or delayed seeking healthcare, withheld HIV disclosure, and sometimes sought spiritual healing instead. Stigma also contributed to feelings of undeserving care, reduced motivation for health, anger, and emotional stress. The study recommended interventions targeting stigma in healthcare settings, specialized training for providers, and national policies aimed at stigma reduction.

Monterio et al. (2013) conducted a systematic literature review focused on understanding the intersection between social inequality, exclusion, and marginalization related to HIV stigma and discrimination. The review aimed to illuminate how various axes of inequality intersect with stigma experiences among individuals living with HIV. By exploring these dynamics, the study aimed to provide insights into the complex factors contributing to stigma and discrimination in the context of HIV/AIDS.

These studies collectively underscore the pervasive impact of stigma and discrimination on individuals living with HIV/AIDS, emphasizing the need for multifaceted interventions at global, national, and local levels to mitigate stigma, improve healthcare access, and enhance the well-being of affected populations.

Based on Asrina et al. (2023), their study aimed to explore the triggers of stigma and discrimination among individuals living with HIV in Wakatobi, Southeast Sulawesi, using a quasi-qualitative design with a case study approach. The researchers identified several factors that triggered stigma among PLHIV, including fear, perceptions of unattractiveness, anxiety related to associations with the disease, and concerns about lack of confidentiality. Discrimination, on the other hand, was fueled by feelings of disappointment, insecurity, diminished self-esteem, and factors like competition and exploitation. The study delineated various forms of stigma experienced by PLHIV, such as public stigma, self-stigma, verbal discrimination, and avoidance behaviors. The authors highlighted that stigma and discrimination significantly impacted the quality of life of PLHIV, hindering their ability to seek assistance and improve their well-being. They emphasized the urgent need for extensive educational initiatives on HIV/AIDS to eradicate stigma and discrimination from social interactions.

In the study by Abachi and Behravan (2013), the research focused on exploring the effects of stigmatization on the quality of life among PLHIV. Conducted in Mashhad, Iran, the study involved 8 HIV-infected individuals (5 men and 3 women) from two behavioral-infectious centers. Through interviews, the researchers identified dimensions of HIV-related stigma such as fear, perceptions of unattractiveness, anxiety, and associations with the disease, alongside concerns about confidentiality. The participants reported experiencing discrimination due to factors like disappointment, insecurity, and competition. Similar to Asrina et al. (2023), the study identified forms of stigma including public stigma, self-stigma, verbal discrimination, and avoidance behaviors. The findings underscored that stigma and discrimination had a profound impact on the quality of life of PLHIV, complicating their access to support and self-improvement opportunities. The study emphasized the importance of educational initiatives to combat HIV-related stigma and discrimination effectively.

These studies collectively highlight the pervasive nature of stigma and discrimination experienced by PLHIV, emphasizing the urgent need for comprehensive educational efforts and supportive interventions to alleviate their negative effects on individuals' lives and well-being.

2.2.2. Manifestation of HIV Stigma and Discrimination in Nepal

Numerous studies on HIV and AIDS in Nepal highlight stigma as a significant issue requiring deeper understanding and attention (Beine, 2001; Jha & Madison, 2009). HIV stigma manifests universally, characterized by refutation, denial, seclusion, avoidance, and renunciation. In Nepal, people living with HIV encounter stigma and discrimination within their families, social circles, neighborhoods, communities, educational institutions, workplaces, and notably within medical facilities (Aryal, 2017).

Additionally, Acharya et al. (2022) conducted a demographic study using data from the Nepal Demographic and Health Surveys conducted in 2006, 2011, and 2016. They examined the impact of factors such as low educational status, economic disadvantage, rural residence, unemployment, poor socioeconomic conditions, and limited media exposure (especially newspapers and television) on the stigma and discrimination faced by PLHIV.

2.2.2.1. Internalized Stigma

Internalized or self-stigma among people living with HIV (PLHIV) occurs when individuals internalize negative societal attitudes and perceptions about HIV, leading to feelings of shame, guilt, and diminished self-worth. In Nepal, the PLHIV Stigma Index 2.0 (NCASC, 2022) reported an overall internalized stigma rate of 22%. Enacted stigma, discrimination, and prejudice against PLHIV contribute significantly to internalized stigma, which in turn correlates with increased levels of depression and poorer overall health outcomes (NCASC, 2022). Shrestha et al. (2018) conducted a cross-sectional study with 599 PLHIV in Nepal, examining perceived social support, quality of life, coping strategies, and internalized stigma. They found that internalized stigma undermines the beneficial effects of problem-focused coping strategies and social support on quality of life among PLHIV. Enhancing problem-focused coping mechanisms and social support can potentially improve the quality of life for PLHIV facing significant stigma.

2.2.2.2. HIV Stigma at Family, Friends, and Community Levels

Family support plays a crucial role in promoting adherence to antiretroviral therapy (ART) among PLHIV, but fear of stigma and discrimination within families

can negatively impact ART adherence. Studies, such as those by Neupane et al. (2012) and Poudel et al. (2012), have documented instances where families stigmatize and discriminate against their own members living with HIV, affecting their health outcomes and overall well-being. Efforts to increase awareness and support within families are crucial for improving ART adherence rates.

Chaudhary and Kakchapati (2022) highlighted the prevalence of public stigma and personalized stigma among community members towards PLHIV in Nepal, indicating low levels of community acceptance and high levels of rejection. Such attitudes contribute significantly to the social exclusion and discrimination experienced by PLHIV.

Moktan (2023) conducted a study in Makwanpur district involving 205 PLHIV, revealing widespread discrimination, stigma, and exclusion experienced by PLHIV, especially women who faced heightened levels of discrimination and social exclusion, often being labeled as immoral or unworthy members of society.

2.2.2.3. HIV Stigma at Institutional Levels

Subedi et al. (2012) conducted a study focusing on children living with HIV in Nepal, revealing that a significant proportion had experienced disclosure of their HIV status at school, resulting in adverse treatment such as discrimination and denial of educational support. Such institutional stigma underscores the need for educational interventions and policy measures to protect the rights and dignity of PLHIV, especially among vulnerable populations.

According to Beine (2002), cultural attitudes in Nepal often perpetuate misconceptions and stigma surrounding HIV/AIDS, fueled by fear, hatred, and blame. These cultural beliefs contribute to stigmatizing behaviors directed at PLHIV, particularly those perceived to have acquired HIV through socially stigmatized behaviors such as drug use or sex work.

2.2.2.4. Support Systems

Research by Pahadi (2022) in Nepalgunj Submetropolitan City highlighted the use of digital communication and peer support networks among gender minority

groups and female sex workers to access HIV-related information confidentially. However, stigma and discrimination against PLHIV remain pervasive in these communities, underscoring the need for supportive and non-judgmental environments for effective HIV care and support.

FHI Nepal (2003) reported on the stigma experienced by HIV-infected women in Nepal, emphasizing gender disparities and socioeconomic factors that exacerbate stigma and discrimination against women living with HIV. The report advocated for gender-sensitive approaches and policies to address the unique challenges faced by HIV-infected women in Nepal.

2.2.2.5. Coping Strategies

Jha et al. (2011) conducted a study on coping strategies among PLHIV in Nepal, highlighting the significant psychosocial impact of HIV diagnosis, particularly among women. Negative coping strategies such as substance abuse were observed among men, while peer support emerged as a crucial coping mechanism for newly diagnosed individuals.

Giri et al. (2013) assessed the quality of life among PLHIV receiving ART in Nepal, revealing lower psychological domain scores and advocating for targeted interventions to improve mental health support for PLHIV.

Research by Aryal (2018) explored the enduring stigma and discrimination faced by PLHIV in Nepal, linked to cultural norms and societal attitudes that condemn behaviors associated with HIV transmission. The study underscored the need for policy interventions to address HIV-related discrimination and stigma effectively.

Subedi et al. (2019) investigated perceived stigma among PLHIV in Pokhara, highlighting its detrimental effects on disclosure and access to healthcare services. The study called for comprehensive interventions to mitigate stigma and improve health outcomes for PLHIV.

Thapa et al. (2018) focused on HIV disclosure among PLHIV in Achham district, revealing community and public health system dynamics that influence disclosure decisions and highlighting the need for supportive environments to facilitate disclosure and reduce stigma.

These studies collectively underscore the pervasive nature of HIV stigma and discrimination in Nepal across various levels—individual, family, community, and institutional—highlighting the urgent need for targeted interventions, policy reforms, and community awareness campaigns to mitigate stigma and improve the lives of PLHIV.

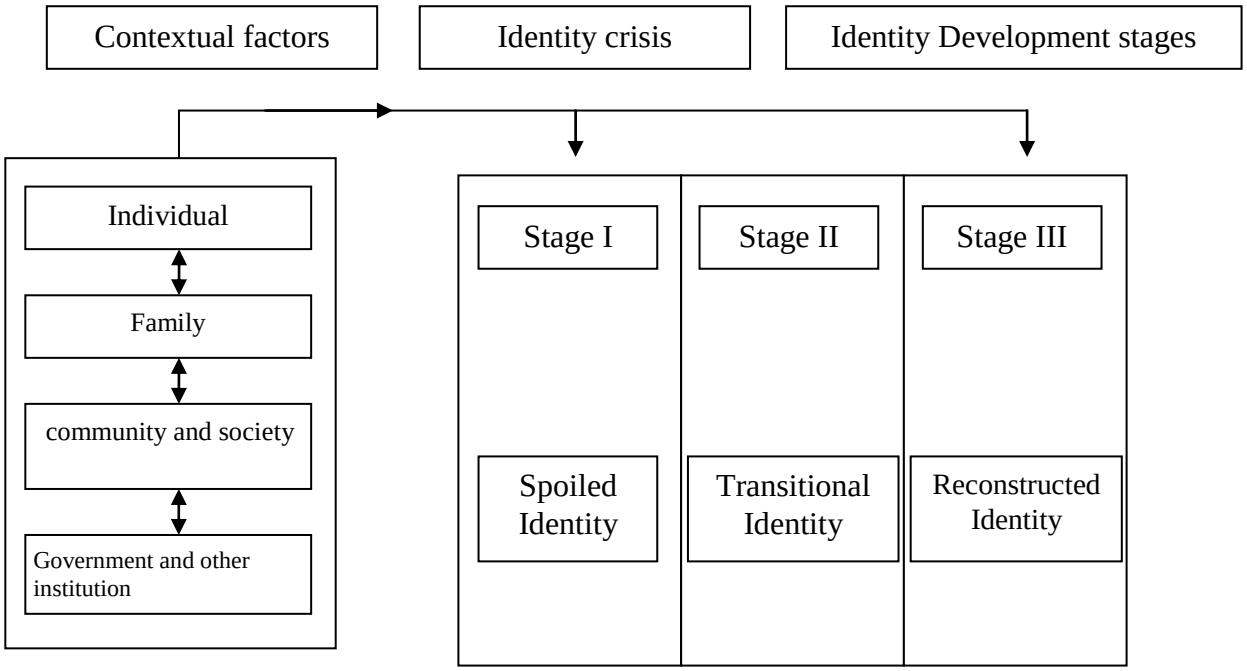
2.3. Research Gap

HIV stigma and discrimination remain significant barriers to HIV prevention, access to healthcare, and the delivery of standard health services. While Nepal has made strides in expanding access to treatment and care, pervasive stigma and discrimination against people living with HIV (PLHIV) persist at individual, community, and societal levels. There is a noticeable dearth of research on the sociological perspectives of HIV stigma and discrimination in Nepal. This study aims to fill these gaps by exploring the various forms and levels of stigma and discrimination experienced by PLHIV, investigating their impacts, identifying contributing factors, and exploring strategies for managing stigma and discrimination. Additionally, the study will examine the support systems available to PLHIV and the coping strategies they employ.

2.4. Conceptual Framework

The conceptual framework for this study draws upon insights from the literature review and is based on the framework proposed by Aryal (2018). This framework provides a comprehensive structure for understanding the multifaceted dimensions of HIV stigma and discrimination, including its social, cultural, and structural determinants. It guides the exploration of how stigma manifests at individual, family, community, and institutional levels, and how it impacts the lives of PLHIV in Nepal. The framework also integrates perspectives on support systems available to PLHIV and the coping strategies they utilize to navigate stigma and discrimination.

By utilizing this conceptual framework, the study aims to provide a nuanced understanding of HIV stigma and discrimination in Nepal and contribute to the development of effective interventions and policies to address these issues.



Chapter Three: Research Methodology

This chapter outlines the methodology employed to conduct the thesis work, including the rationale for the study area, research design, universe and sampling, methods of data collection, data analysis procedure, and study limitations.

3.1. Research Design

The research design utilized for this study is descriptive and exploratory, aiming to investigate the nature of stigma and discrimination experienced by people living with HIV (PLHIV) in Kathmandu valley. The exploratory approach seeks to understand how HIV status influences experiences of stigma and discrimination within family, community, and institutional contexts, as well as examining the support systems and coping mechanisms employed by PLHIV.

3.2. Research Area and Study Participants

The study is conducted in Kathmandu valley due to its accessibility and concentration of PLHIV who have migrated there. This location provides valuable insights into the extent of stigma experienced by PLHIV. Data collection was facilitated through the national network and organizations established by PLHIV, as well as visits to ART (Antiretroviral Therapy) centers overseen by NCASC (National Center for AIDS and STD Control) in Kathmandu.

Participants in the study are between 19 to 59 years old, living with HIV and currently receiving ART. They were selected based on their experience of HIV-related stigma. Qualitative data were gathered through structured interviews conducted with 60 PLHIV, ensuring saturation was reached, and included 5 case studies and 5 key informant interviews with individuals possessing substantial knowledge about HIV stigma and discrimination.

The study ensured ethical considerations by obtaining verbal and written consent from all participants and maintaining clarity on the study objectives throughout the data collection process.

3.3. Nature and Sources of Data

Both primary and secondary sources were utilized for data collection. Primary data were collected through fieldwork using open-ended interviews and key informant interviews. Secondary data were gathered from various reports, books, journals, and research papers. The qualitative data collected from the study area were instrumental in meeting the study objectives.

3.4. Sampling Procedure

Due to the nature of the study, non-probability sampling (specifically, snowball sampling) was employed. This method leverages social networks to include participants, ensuring diverse experiences are captured. Data saturation, as defined by Shaw and Holland (2014), was reached after 60 participants (49 female and 11 male), indicating no further participants were needed to capture additional relevant responses.

3.5. Data Collection Technique

Qualitative research methods were predominantly used in this study to explore the "why" behind social phenomena and human experiences. Data were collected using structured interview schedules, case studies, and key informant interviews to gather comprehensive insights into stigma and discrimination experiences, support systems, and coping strategies among PLHIV.

3.5.1. Interview Schedule

The structured interview schedule was used that allowed more freedom to extract important facts from the respondents' narratives. The topics of discussion included identity disruption, stigma, and reconstruction of identity. Furthermore, a semi-structured interview schedule provided autonomy and interviewee are asked the same questions (Shank, 2006). A interview schedule was prepared which was used to collect data by face to face interview from the selected respondents in Kathmandu valley. The structured interview schedule provided the information related to personal identification, population structure, family size, religion, education, ethnic distribution, occupation, family income and those related to HIV stigma and discrimination, social factors of HIV stigma and discrimination, support support system and coping mechanism of HIV stigma and discrimination as experience by

PLHIV. For the ease of getting more clarity and prevalence of theme percentage and number of participants has been tabulated and it also provide aid in highlighting patterns and commonalities within the extracted data (Sandelowski, 2001; Maxwell, 2010; Verdinelli and Scagnoli, 2013).

3.5.2. Case Study

Five case studies were conducted with PLHIV to delve deeper into their experiences of stigma and discrimination. These studies were conducted in the homes of participants using a voice recorder to capture conversations, which were later transcribed and analyzed to triangulate findings from other data collection methods.

3.5.3. Key Informant Interviews

Key informant interviews with five selected individuals provided additional insights into HIV stigma and discrimination from the perspectives of experts in HIV, PLHIV leadership, healthcare, and peer education. These interviews helped validate and expand upon information provided by study participants.

3.6. Data Processing and Analysis

The primary data collected through different process were initially categorized, transcribed and then analyzed in different forms. Data analysis was done by using the descriptive and exploratory analysis tools. The qualitative data were collected and analyzed as per the nature and aim of the research. The qualitative data collected, for the easier understanding proper editing, coding, and tabulation was done as per the objective of the research. The analysis and interpretation of the facts, data and information collected during the research was done following five steps. First, the data collected were prepared, organized and marked. Second, the collected data were then reviewed and explore for the required information, relevancy and reliability. Third, initial codes were created by categorizing the data and information followed by establishing connection with the data. Fourth, the code were reviewed and developed into themes, the categorized facts, data and information were categorized and analyzed thematically. Fifth, the data and information were brought together for the thesis.

3.7. Ethical Consideration

Verbal and written consent was obtained from all participants and key informants, clarifying the study's objectives and ensuring confidentiality and anonymity of their data. Ethical guidelines were strictly followed throughout the research process to protect participants' rights and well-being.

3.8. Reflective Methodology

Initially, I visited various organizations and networks established by PLHIV, including ART centers, with a reference letter from the Central Department of Sociology, TU, where I have been employed for the last five years. Upon presenting the verbal and written objectives of my dissertation to these organizations, I obtained their consent. Subsequently, I signed confidentiality and data protection forms in accordance with organizational policies to ensure the privacy of participants' personal data. The organizations also provided me with dedicated space within their offices for conducting face-to-face interviews. Using the PLHIV network, I commenced meeting with individuals interested in participating in the study, adhering to criteria such as age (between 18 and 65 years) and having experienced at least one form of stigma and discrimination related to HIV. Participants willingly signed consent forms after I thoroughly explained the study objectives both verbally and in writing.

The efficiency of data collection was significantly aided by the support extended to me by these organizations. Building rapport with both the organizations and PLHIV participants was crucial for conducting effective research on HIV stigma and discrimination. My deep understanding of Nepali culture, empathetic approach, and established relationships with PLHIV and organizations were instrumental in eliciting the necessary information and data. Moreover, my involvement in HIV and AIDS prevention efforts strengthened my ability to collect data successfully. During data collection, I observed that women were generally more willing to share their experiences than men, possibly influenced by their higher levels of exposure to external social environments. Throughout the process, the organization's representatives introduced me to participants and shared the study objectives, motivating individuals to contribute their experiences in a safe environment where their well-being was prioritized and no harm was encountered.

Chapter Four: Socio-Demographic Information of Respondents

4.1. Socio-demographic Characteristics of the Respondents

The respondents were selected from diverse backgrounds. The following table presents the demographic distribution of respondents based on sex, age group, religion, employment status, education level, permanent and temporary addresses, residence type, income level, source, duration and treatment status of HIV.

4.1.1. Age of the Participants

Table 4.1. Age Distribution of PLHIV Respondents

Age Range	Female	Male	Total	Percentage
21-30	4	1	5	8%
31-40	11	0	11	18%
41-50	29	8	37	62%
51-60	5	2	7	12%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

According to Table 4.1, the study included a total of 60 participants. Among them, 5 (8%) respondents were aged 21-30 years, 11 (18%) were aged 31-40 years, 37 (62%) were aged 41-50 years, and 7 (12%) were aged 51-60 years. Regarding gender distribution, there were 49 (82%) female respondents compared to 11 (18%) male respondents. In Nepali, male PLHIV disclose their HIV status less frequently than females, due to factors like as patriarchal societal norms, societal expectations, fear of stigma, and potential consequences of disclosure (Adeoye-Agboola et al., 2016).

4.1.2. District-wise distribution of the participants

Table 4.2. Temporary address of respondents

District	Female	Male	Total	Percentage
Bhaktapur	2	2	4	7%
Kathmandu	37	7	44	73%
Lalitpur	10	2	12	20%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As depicted in Table 4.2, out of the total 60 respondents, 4 (7%) were residing in Bhaktapur district, 44 (73%) in Kathmandu district, and 12 (20%) in Lalitpur district. Many people living with HIV migrate to Kathmandu valley for treatment, employment opportunities, and sometimes to escape stigma and discrimination. Migration has been identified as a significant strategy among PLHIV to manage HIV-related stigma and discrimination (Aryal, 2017).

4.1.3. Ethnicity of the participants

Table 4.3. Ethnicity distribution of respondents

Ethnicity	Female	Male	Total	Percentage
Hill Brahmin	14	4	18	30%
Hill Chhetri	10	2	12	20%
Hill Dalit	2	0	2	3%
Hill/Mountain Janajati	16	3	19	32%
Newar	5	1	6	10%
Muslim	1	1	2	3%
Tarai Janajati	1	0	1	2%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

Among the total respondent, 18 (30%) respondents were from Hill Brahmin, 12 (20%) respondent were Hill Chhetri, 2 (3%) respondents were Hill Dalit, 19 (32%) respondents were Hll/Mountain Janajati, 6 (10%) respondents were Newar, 2 (3%) respondents were Muslim and 1 (2%) respondent was Tarai Janajati respectively

4.1.4. Religion of the participants

Table 4.4. Religion of respondents

Religion	Female	Male	Total	Percentage
Boudha	11	2	13	22%
Christian	5	1	6	10%
Hindu	32	7	39	65%
Islam	1	1	2	3%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

In the total of 60 respondents, 39 (65%) identified as Hindu, followed by 13 (22%) Buddhist, 6 (10%) Christian, and 2 (3%) Islamic respondents, as illustrated in Table 4.4. According to the CBS data of 2021, 81.19% of Nepal's total population follows Hinduism, with 8.21% adhering to Buddhism, which likely contributes to the higher representation of Hindu and Buddhist PLHIV participants (CBS, 2021). Additionally, various religious perspectives generally hold similar views condemning the moral judgments associated with HIV (Varas-Díaz et al., 2010).

4.1.5. Education of the participants

Table 4.5. Education status of respondents

Education	Female	Male	Total	Percentage
illiterate	14	2	16	27%
Read and Write only	3	1	4	7%
Lower Secondary	11	1	12	20%
Primary	7	1	8	13%
Secondary	4	1	5	8%
SLC or above	10	5	15	25%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in the Table 4.5., among the 60 participants, 16 (27%) respondents were illiterate, 4 (7%) respondents can Read and write only, 12 (20%) respondents had studied up to lower secondary level, 8 (13%) respondents educated up to Primary, 5 (8%) respondents studied up to Secondary level, and 15 (25%) had SLC or above education level. In this study more than half that is 75% of the respondents had got education up to or below the secondary level with 27% respondents were illiterate and 7 % respondent can read and write only, as per the previous research education is one of the prime vulnerability factor for poverty which made them prone to HIV infection due to the lack of knowledge of mode of HIV infection transmission and to undertake risky sexual activities (Subedi et al., 2019).

4.1.6. Employment of the participants

Table 4.6. Employment Status of respondents

Employment	Female	Male	Total	Percentage
Business	1	1	2	3%
Daily wage labor	8	2	10	17%
Domestic Maid	9	0	9	15%
Driver	0	1	1	2%
Farming	2	0	2	3%
Handicraft	0	1	1	2%
Hospital	2	0	2	3%
Office	19	5	24	40%
School	1	0	1	2%
Shop	2	0	2	3%
Tailoring	1	0	1	2%
Unemployed	4	1	5	8%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

According to Table 4.6., in the total of 60 respondents, 2 (3%) respondents were doing business, 10 (17%) respondents were employed as a daily wage labor, 9 (%) respondents were employed as domestic maid, 1 (2%) respondent was employed as driver, 2 (3%) respondents were doing farming, 1 (2%) respondent was employed in handicraft, 2 (3%) respondent were working in Hospital, 24 (40%) respondents were employed in office, 1 (2%) respondent was working in school, 2 (3%) respondents were employed in their own shops, 1 (2%) respondent was working as tailor whereas 5 (8%) respondents were unemployed. In this study, 40% respondents were found to be engaged in organization either working in the field of HIV or established by PLHIV which has been one of the supporting mechanism for them to achieve economic independence (Aryal, 2017). The income and economic standing of any individual dictate the majority of life opportunities and the viewpoint towards social realities. According to UNAIDS (2021), HIV infection increase the risk of stigma and discrimination, marginalization, violence and reducing the opportunities to education, justice and employment.

4.1.7. Other sources of income of the participants

Table 4.7. Other sources of income of respondents

Other Sources of Income	Female	Male	Total	Percentage
From Family	3	1	4	7%
Help form organization	1	0	1	2%
Loan	7	0	7	12%
Other-Handicrafts	1	1	2	3%
Other-Shop	1	2	3	5%
sister in law	0	1	1	2%
No other sources of income	36	6	42	70%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

Among the total of 60 respondents 42 (70%) respondents do not have any other sources of income, whereas 4 (7%) respondents take support from family members, 1 (2%) took help from organization, 7 (12%) respondents took loan, 2 (3%) respondent have handicraft as source of secondary source of income, 3 (5%) respondents have shop as the other sources of income, and 1 (2%) respondent took support from sister in law respectively. It is found that most of the PLHIV respondents that is 70% didn't have any other second sources of income and are mostly dependent on primary sources of income. In the previous study, the HIV infection create a significant economic burden in the life of PLHIV and their families residing in Nepal (Poudel et al., 2017). The low income level of PLHIV is due to high prevalence of HIV in lower working people, associated higher medical expenses, Furthermore, person infected with HIV had to face stigma at employment and PLHIV are the forced to leave the job though have productive years (UNAIDS, 2021).

4.1.8. Type of family of the participants

Table 4.8. Type of family of respondents

Type of Family	Female	Male	Total	Percentage
Joint	8	2	10	17%
Nuclear	41	9	50	83%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As indicated in Table 4.8, among the total 60 respondents, 10 (17%) were living in joint families, while 50 (83%) were living in nuclear families. In this study, many respondents were spouses of migrating males who have passed away, living separately, or PLHIV couples and their children who have migrated and settled in Kathmandu. Nepal's society is family-oriented, where family members serve as crucial sources of support for PLHIV. However, due to family stigma, many PLHIV choose migration as a coping strategy (Soskolne and Shtarkshall, 2002).

4.1.9. Marital status of the participants

Table 4.9. Marital Status of respondents

Marital Status	Female	Male	Total	Percentage
Divorcee	5	0	5	8%
Married	18	8	26	43%
Unmarried	1	1	2	3%
Separated	1	0	1	2%
Single Men/widower	0	2	2	3%
Single Woman/widow	24	0	24	40%
Total	49	11	60	100%

Source: Field data, Kathmandu 2024

Among the 60 respondents, 5 (8%) respondents were divorcee, 26 (43%) respondents were married, 2 (3%) respondents were unmarried, 1 (2%) respondent was separated, 2 (3%) respondents were single men and 24 (40%) respondents were single women respectively. In this study most of the women participants were spouses of migrant male which according to NCASC factsheets (2023) are one of the key population for HIV infection (Soskolne & Shtarkshall, 2002).

4.1.10. Type of residence of the participants

Table 4.10. *Type of residence of respondents*

Type of Residence	Female	Male	Total	Percentage
Own Residence	10	1	10	17%
Rent	39	10	50	83%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

According to Table 4.10., in the total of 60 respondents, 10 (17%) respondents were residing in their own resident whereas 50 (83%) respondents were residing in a rent. Most of the participants in this study has either migrated or came to Kathmandu due to stigma and discrimination or to grab the better opportunities, whereas few of the participants were the local inhabitants of Kathmandu valley and staying with other members of their joint families (Soskolne and Shtarkshall, 2002).

4.1.11. Source of HIV infection of the respondents

Table 4.11. Sources of HIV infection of respondents

Source of HIV infection	Female	Male	Total	Percentage
From Husband	40	0	40	67%
IDU	0	1	1	2%
Other-Sex Trafficking	2	0	2	3%
Parents	2	0	2	3%
Sex Worker	4	0	4	7%
Unsafe Sexual activity	0	10	10	17%
Infected Syringe	1	0	1	2%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

In the total of 60 respondents, 40 (67%) respondents were infected with HIV from their husband, 1 (2%) respondent was infected from HIV due to intravenous drug used, 1 (2%) respondent got infected with HIV from infected syringe, 2 (3%) respondents got infected with HIV due to sex trafficking, 2 (3%) respondents were infected with HIV from their parents, 4 (7%) respondents were infected with HIV due to sex work, and 10 (17%) respondents were infected with HIV due to unsafe sexual activities respectively. Most of the study respondents were spouses of migrants who got infected due to her husband. According to Thapa et al., (2016), spouses of migrant men are at highter risk and vulnerable to HIV infection due to the illiteracy, poor economic conditions, gender inequality which lead to their lack of knowledge and unprotected sexual behavior and put them at higher risk of HIV infection.

4.1.12. Time period of HIV infection detection

Table 4.12. Time period of HIV infection detection of respondents

Time period of HIV detection	Female	Male	Total	Percentage
<1 year	1	0	1	2%
2-5 years	5	2	7	12%
6-10 years	9	2	11	18%
11-15 years	11	1	12	20%
16-20 years	15	4	19	32%
>20 years	8	2	10	17%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

In the total of 60 respondents, 19 (32%) respondents detected their HIV positive status 16-20 years before, 12 (20%) respondents detected their HIV status 11-15 years before, 11 (18%) detected their HIV positive status 6-10 years before, 10 (17%) respondents found out their HIV status more than 20 years before, 7 (12%) discovered their HIV positive status 2-5 years before and 1 (2%) got HIV positive test result less than or equal to one years before respectively. The data of the time period of HIV infection shows that nearly 86% of the PLHIV discovered their HIV status more than half a decade earlier, which signified that they have profound experience of HIV stigma and discrimination. Furthermore, HIV stigma changes over time and in society, the magnitude of HIV stigma on different statuses, attitudes increase and decrease overtime and at individual level, the HIV stigma changes across human development like people are more vulnerable or more resilient t stigma at different stages of their lives, moreover, the experience and outcomes of stigma, stigmatized statuses also change over time (Earnshaw et al., 2022).

Chapter Five: Stigma and Discrimination as Experienced by People Living with HIV

Stigma is an ongoing social process shaped by societal perceptions and interpretations. HIV stigma and discrimination often stem from fear and the perception of HIV/AIDS patients as morally flawed individuals. When individuals deviate from societal norms and values, they are labeled as different and stigmatized, with discrimination manifesting as discriminatory actions (Kaur, 2012). HIV stigma involves the devaluation of individuals living with HIV/AIDS based on their health status or behaviors, which society considers socially discreditable (Scambler, 2009; UNAIDS, 2011). Discrimination against HIV/AIDS patients can range from thoughtless actions to outright rejection, fueled by fear and moral judgments associated with the virus's transmission (Kaur, 2012; Pescosolido and Martin, 2015).

Fear of discrimination and rejection leads many individuals to avoid HIV testing or disclose their status. HIV stigma and discrimination occur across various settings—within families, communities, workplaces, and healthcare facilities (Campbell, 2021). Individuals, including women, often face severe stigma and prejudice due to their HIV status and gender, exacerbating their vulnerability (Kaur, 2012; Link and Phelan, 2001; Tyler, 2018).

5.1. Discovery of HIV Infection

The discovery of being HIV-positive marks a significant life-altering moment, dividing the lives of those infected into "before" and "after." It profoundly impacts their economic, social, and cultural spheres, affecting access to resources, healthcare options, and social acceptance (Aryal, 2017). People living with HIV (PLHIV) must navigate a journey of self-concept redefinition post-diagnosis, often in the face of stigma and discrimination from family, community, and institutions (Tsarenko & Polonsky, 2011).

Despite the challenges posed by stigma and discrimination, knowing one's HIV status can lead to increased life expectancy, better health outcomes, and personal fulfillment, fostering self-esteem and societal acceptance. Overcoming these barriers allows PLHIV to strengthen their self-identity and improve their socioeconomic status

within their families and communities (Aryal, 2017). Through this process of identity reconstruction, PLHIV empower themselves, gradually overcoming stigma and discrimination with improved self-identity and socio-economic status (Tsarenko & Polonsky, 2011). This study, building on Aryal's (2015) dissertation, explores the details of self-initiated, family-initiated, and routine HIV testing, as outlined in the table below.

Table 5.1. Discovery of HIV infection by respondents

Discovery of HIV infection	Female	Male	Total	Percentage
HIV test done by self	11	6	17	28%
HIV test done by family	32	4	36	60%
HIV test done by support of other	2	0	2	3%
Regular HIV test	4	1	5	8%
Total	49	11	60	100%

Source: Field Survey, 2024

Among the total of 60 respondents, the majority, 36 (60%), discovered their HIV infection through family-initiated HIV testing, followed by 17 (28%) through self-initiated testing, 2 (3%) through other forms of HIV testing initiation, and 5 (8%) through routine testing.

Self-initiated HIV testing involves individuals voluntarily choosing to undergo HIV testing, often prompted by perceived risk factors or exposure to the virus. For instance, individuals may opt for testing due to risky behaviors or being in a relationship with an HIV-infected partner. This form of testing is significant among intravenous drug users and spouses of HIV-infected individuals who may initially delay testing due to fear or uncertainty about their HIV status (Aryal, 2018).

> *A 50 year old respondent shares that her husband has got lesion or ulcer in his stomach and I went with him to the hospital where died after three days of treatment. After his death the doctor told me that they were not able to save him and also informed that he was HIV positive and told me to have the HIV test, but I ignored. After death of my husband, I began to work in the shelter as*

a kitchen support, while working there I began to regularly became sick, have fever and headache. There also used to visit the medical personnel, I informed him about my condition and the doctor informed me to have blood test and then after the blood test I came to know that I am HIV positive." - Rita (name change), female, 50 years old

Family-initiated HIV testing refers to situations where individuals undergo HIV testing after a family member, such as a spouse or child, is diagnosed with HIV during hospital treatment for another condition. Often, HIV is incidentally discovered during the course of medical care, without prior suspicion of the virus (Aryal, 2018). In this study, many respondents learned about their HIV status while accompanying their spouse to the hospital for treatment. An example illustrating this scenario is provided below.

My husband was intravenous drug user and after two years of marriage, he became ill, and had skin lesions, fever and cough. I went to hospital with him for his checkup and while doing blood test the doctor informed me about his HIV positive status and informed me to check my blood also, and after my blood check there, I found my HIV status - Rama (name change), women, 46 years old

After 15 days of my marriage I suddenly got sick, prior to that I have rarely been so severely sick, then I went to hospital for check up and during the blood test showed that I am HIV positive and later I came to know that I got infected by my husband who already know about his HIV status and didn't share me about that…"- Gita (name changed), female, 25 years old.

HIV testing facilitated by support from others involves individuals outside the family who assist HIV-infected individuals in getting tested. This support often arises from prior risky behaviors.

"I became the victim of human trafficking from carpet industry when I was only 10 years old in brothel of India, where I became victim of child sexual exploitation and harassment, I became severely ill while staying there then the

owner of the brothel call the health service providers and did my blood test then I think I became HIV positive but I exactly don't know. Later after four years when I was rescue and repatriated to Nepal a medical test was done by some NGOs then I was informed that I am HIV positive - Gita (name change), female, 43 years old

Routine testing, as part of visa applications for overseas employment and other health-related eligibility criteria, can inadvertently reveal HIV status (Aryal, 2014). Below are examples illustrating how routine testing led respondents to discover their HIV status.

"I was planning for foreign employment for which I had prepared all the documents, and consulted the foreign employment companies and during that process I had to do the health check up, and while doing that I had to do the blood test also after which I came to know that I am HIV positive." - *Sita (name change), female, 42 years old*

"I went to hospital with my wife for routine pregnancy test, during which in routine blood test was done. After this blood test I came to know about my HIV status including my wife." - *Sabbir (name change), male, 44 years old*

"My husband used to work in Punjab and used to come back home during festival leave. I have two daughter and one son and during the birth of my smallest son I was admitted to the hospital, I was tested HIV positive during the routine pregnancy blood test, after which my husband and two of my daughter were also found to be HIV positive," - *Devaki, female 45 years old*

5.2. Initial reaction after HIV infection

After receiving their HIV-positive diagnosis from hospital officials, participants' initial reactions varied significantly. Many participants viewed HIV as a life-threatening "disease," while others were unaware of their HIV infection. Upon diagnosis, their emotional responses included suicidal thoughts, denial, anger, hopelessness, and other complex feelings. Some attributed their HIV infection to their

own past behaviors, such as sexual contact with infected partners or spouses, influence from friends, drug addiction, or sharing needles (Aryal, 2014).

Table 5.2. Initial reaction of PLHIV after knowing HIV infection

First impression HIV infection	Female	Male	Total	Percentage
Depressed	4	1	5	8%
Disbelief/Shock	9	6	15	25%
Fear	31	3	34	57%
Normal	2	0	2	3%
Sad	2	0	2	3%
Worried	1	1	2	3%
Total	49	12	60	100%

Source: Field data, Kathmandu, 2024

As shown in the table above, among the 60 respondents, 5 (8%) experienced depression upon learning about their HIV infection, 15 (25%) were in disbelief or shock, 34 (57%) felt fear, 2 (3%) took their HIV diagnosis in stride, 2 (3%) were saddened, and 2 (3%) were worried about their HIV-positive status.

In the early stages of discovering their HIV status, most participants perceived HIV as a severe threat to their lives. They often believed that receiving an HIV diagnosis meant their life was nearing its end, influenced by media portrayals of HIV as a fatal disease.

> *"I got HIV from my husband, and when he got hospitalized during his illness in hospital, I came to know that he is HIV infected and after his death, I also did HIV test, since I was confirmed about my HIV status so when the test result came out. I feel it normal because I was well prepared to confront it" - Anita (name change), female, 45 years old.*

> *"When my husband got sick, one of the village people informed me about his stay in India and he may be HIV infected, after which I checked his blood and came to know about his HIV status. After his death, I checked my blood and*

found that I am also HIV positive, at that time I was only 22 years old and didn't know about the HIV and I thought it will be cured so I took it in normal way, but my mother cried." - Durga (name changed), female, 38 years old

HIV infection significantly impacts the overall quality of life, affecting mental, physical, social, and spiritual well-being. It often instills fear of social and economic losses, job insecurity, and rejection by family members, which can lead to various physical and psychological issues such as depression, anxiety, and stress (Jahromy et al., 2021).

5.3. Initial response to PLHIV

The initial reactions of nearby HIV-negative individuals upon learning that a participant was HIV-positive are crucial for understanding community and familial perceptions of HIV-positive status (Aryal, 2015).

Table 5.3. Initial response to PLHIV

First response to PLHIV	Female	Male	Total	Percentage
Supportive	28	10	38	63%
Unsupportive	10	1	11	18%
Normal	4	0	4	7%
Expelled from home	3	0	3	5%
Not Disclosed	4	0	4	7%
Total	49	12	60	100%

Source: Field data, Kathmandu, 2024

As shown in above table, among the 60 respondents, 38 (63%) respondents found the supportive response, 11 (18%) respondents found unsupportive response, 4 (7%) respondents found normal response, 3 (5%) respondent were expelled from home where as 4 (7%) didn't disclosed their status in the initial response to PLHIV while sharing their HIV status respectively.

"I got HIV infected due to the unsafe sexual relation after which I instantly informed my family as all of them were well educated and have extensive knowledge about HIV, they supported me and help me to get my medications and when I was depressed and worried, my father, mother and even my brothers counsel me not to worry and to take regular medications and to have nutritious food, which greatly helped me to come out of my depression and have the positive outlook to my life" - Shyam (name change), Male, 43 years old

"I used to be intravenous drug user and my family admitted me in rehabilitation center, there when I got blisters in my skin along with fever my blood test was done, when I came to know about my HIV status, which I informed my spouse, she was highly supportive she helped me to come out of the drug addictions and regularly took care of me, and encourage me that I should not worry much as there is medications and told me to focus on taking regular medication. Due to her support I believe that I could able to come out of drug use and live positive life"- Ramesh (name changed), male, 59 years old

I got married at very early age, my husband used to work in India where he got infected with HIV which he didn't disclose to anyone. After short period of my marriage my husband got ill during which I including my in-laws, family, communities all knew about his HIV infection. I also tested positive for HIV. After this my father in law decided not to keep me in my in-laws home due to the fear of stigma and discrimination in the communities and he expelled me from my home and my father in laws brother took me to the shelter established for people living with HIV" - Maya (name changed), female 42 years old

Previous research has indicated that family members and caretakers often exhibit stigma and discrimination towards PLHIV, driven by fears of rejection, community shaming, and a lack of understanding of HIV infection (Subedi et al., 2019; Jugeo and Moalusi, 2014; Fauk et al., 2022). Conversely, a study by Amiya et al. (2014) found that families can also be supportive towards PLHIV, offering

practical assistance such as preparing meals and administering medications, as well as emotional support.

5.4. Experience of HIV Stigma

Participants in the study encountered personal stigmatization related to their HIV status, particularly in interactions with healthcare professionals and within society at large. They internalized stigma due to their pre-HIV lifestyles, feeling devalued and ashamed as they reflected on their behaviors that led to HIV infection (Aryal, 2014). These experiences underscore the impact of social norms and beliefs on their perceptions of self-worth.

5.4.1. Self Stigma

Self-stigma in the context of HIV pertains to the negative emotions or thoughts individuals with HIV develop about themselves as a result of their HIV status. It occurs when individuals internalize societal stereotypes and apply them to their own self-concept (Earnshaw et al., 2013).

Table 5.4. Self Stigma of PLHIV respondents

Internalized Stigma	Female	Male	Total	Percentage
Hated self	3	0	3	5%
Isolation	4	0	4	7%
lack of worth	1	0	1	2%
self blame	5	5	10	17%
No self stigma	36	6	42	70%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table 5.4. 18 (30%) of respondents said they had experienced self-stigma (e.g. feelings of self-blame, worry, guilt, lack of worth, need for secrecy) very often in which 3 (5%) respondents have feelings of self hatred for being the HIV positive, 4 (7%) respondents prefer to be in isolation, 1 (2%) respondent lack self worth, 10 (17%) respondent self blame for being HIV positive.

One of the respondent who worked as a female sex worker aged 38 years old when got infected with HIV, she was shocked and she shared that she had a feeling of self hatred and began to hate herself for being HIV positive, similarly, similarly one of the other participants Rita (name changed), female, 44 years old after knowing her HIV status began to hate herself for being HIV positive.

Another respondent Gita (name changed), female, 25 years old, who got infected with HIV by her husband migrated to Kathmandu, and is living now with her husband in a rented room has been living an isolated life with no contacts with her in-laws, families including friends and other peer support group due to her HIV status. Similarly, one of the respondent, Puspa (name changed), 28 years old has a feeling of self-worthlessness after knowing her HIV status. She even tried to do suicide and need to take medication of depression. She felt that after being HIV positive her life is worthless now.

In Nepal, internalized HIV stigma presents a significant challenge. According to the PLHIV Stigma Index 2.0 published in 2022, the overall rate of internalized stigma was reported to be 32% (NCASC, 2022). Research indicates that enacted stigma, discrimination, and prejudice against PLHIV can contribute to internalized stigma, where individuals internalize negative perceptions about their HIV status. This can lead to depression and adversely impact the overall health of PLHIV (Jason et al., 2021).

5.4.2. HIV Stigma and Discrimination at Healthcare

HIV-related stigma poses a significant challenge within Nepal's healthcare system, leading to discrimination, marginalization, and social rejection of individuals living with HIV. A stigma hierarchy exists, where those infected through sexual transmission and women often face more pronounced stigma compared to those infected through injecting drug use and men. These societal attitudes not only hinder access to healthcare services but also perpetuate myths surrounding HIV transmission. Efforts aimed at reducing stigma and increasing awareness are essential to ensure equitable and compassionate healthcare for all individuals living with HIV (Jha and Madison, 2009).

Table 5.5. Status of Stigma and Discrimination at healthcare institution as experience by PLHIV

Experience of Stigma and Discrimination at healthcare	Female	Male	Total	Percentage
No	18	5	23	38%
Yes	31	6	37	62%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table 5.5., among the 60 respondents, 23 (38%) respondents didn't faced stigma and discrimination at healthcare and 37 (62%) respondents faced stigma and discrimination at healthcare.

Table 5.6. Types of Stigma and discrimination at healthcare as experience by PLHIV

Stigma and Discrimination at Healthcare	Female	Male	Total	Percentage
Being advised not to have children	2	0	2	3%
Condescending and judgmental remarks	6	0	6	9%
Denial of treatment	5	2	7	10%
Disclosed the HIV status publically	9	0	9	13%
Disposal of clothes and bed sheets used by PLHIV	2	0	2	3%
Excessive use of barrier precautions	10	2	12	18%
Extra cost of treatment	2	0	2	3%
Fear to touch	13	2	15	22%
Referral to other hospital service providers	2	0	2	3%
Segregation and labeling of patients	4	1	5	7%
Delay in treatment	4	2	6	9%

Source: Field data, Kathmandu, 2024

As shown in Table 5.6., among the interviewed 60 respondents, 2 (3%) respondents while taking the services in healthcare center were advised not to have children due to their HIV status, 6 (9%) respondents had to bear the Condescending and judgmental remarks by the health service providers, 7 (10%) respondents were denied of the medical services due to their HIV status, 9 (13%) respondents HIV status was disclosed publically without their consent, 2 (3%) respondents bed sheets and clothes used were disposed, 12 (18%) respondents felt that the health service providers used excessive use of barrier precautions, 2 (3%) respondents had to bear extra cost for the treatment due to their HIV status, 15 (22%) respondents felt that the health service providers fear to touch them due to their HIV status, 2 (3%) respondents were referred to other health service providers, 5 (7%) respondents were segregated and labeled by health service providers, and 6 respondents had the delayed excess to treatment by health service providers due to their HIV status. The experience of stigma and discrimination as experience by respondents are illustrated below.

"While I was in routine check in the hospital, one of the health professional advice me not to have children, when you are yourself HIV infected why you want to have children. Your children will have hard time. After hearing this I was totally amazed" - Bina (name changed), female, 46 years old.

Similarly, incident happened to Basanti (name changed), female, 43 years old, she shared that during the delivery of her youngest son, one of the nurse in the hospital said why you are having children to make their life difficult what will they do after your death, I felt so angry and sad hearing such kind of thinking of the medical personnel"

"Due some health problems, I visited the health care center, there the doctor asked me when I returned from India, at such a young age how I reached India. I was totally amazed to hear that, the doctor was linking me to the prostitution. Then I told him that I got infected from my husband." - Sita (name change), female, 42 years old.

Similarly, one of the respondent also experience the condescending and judgmental remarks which she shares as "Around five years ago, just before

the COVID 19 pandemic, I went to hospital for the high fever and cough, I informed the doctor about my HIV status, he then began to inquire me linking me with the prostitution, I had to informed him that all the people living with HIV are not due to prostitution, it was quite embarrassing to hear such kind of thing form medical personnel, though I know that all the health personnel are not such it depends on individuals"- Devi (name changed), female, 56 years old.

The respondents experienced the greatest amount of stigma and discrimination from medical workers in a healthcare setting. At every level of the workforce, including that of doctors, nurses, and ward boys, they encountered discrimination and stigma. Because the ward boys did not want to touch the responders' surroundings or medical waste, the doctor did not properly diagnose them, and the nurse did not give them their medications and injections on time.

HIV infection is linked to death was common during its initial phase of global HIV pandemic, which cause dire consequences in the life of PLHIV and determine the utilization of health services. The stigma and discrimination in healthcare is rooted in culture and its linkage with negative notations as viewed by society that ultimately compromised the the health services and care to PLHIV (Jha and Madison, 2009).

5.4.3. HIV stigma and Discrimination at Family

Families are the primary sources of care during a member's illness. They also influence a person's social identity and participation in society. Families can provide HIV care and moral support, thereby sharing the burden of a deadly disease. However, families can be harsh and unsupportive, and HIV positive members may react with extreme fear. Thus, families can either become a safe haven for infected members to seek refuge from the dehumanizing forces of society, or they can become a living nightmare, exacerbating the AIDS victim's misery. To acquire insight into the family's experiences with stigma and discrimination, a series of reactions were designed to assess the family members' previous and current attitudes toward HIV/AIDS afflicted members. The favorable response of the family is critical for HIV patients. The future course of an individual's HIV infection is heavily influenced by the attitudes and support of family members (Subedi et al., 2019).

Table 5.7. Stigma and discrimination in Family

Experience of Stigma and Discrimination in family	Female	Male	Total	Percentage
No	13	5	18	30%
Yes	22	6	28	47%
Not Disclosed	13	0	13	22%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in table 5.7., among the total of 60 respondents, 18 (30%) respondents didn't have any experience of stigma and discrimination in family, 28 (47%) respondents had experience some types of stigma and discrimination in family, where as 13 (22%) had not yet disclose their HIV status to their family respectively.

Table 5.8. Type of Stigma and discrimination in family

Family Stigma and Discrimination of PLHIV	Female	Male	Total	Percentage
Avoidance of physical contacts	4	2	6	21%
Expelled from Home	4	2	6	21%
labelling them as dangerous people	2	0	2	7%
Rejected by family members	2	1	3	10%
Separation of their personal belongings from those of other family members	6	3	9	31%
Stigmatizing attitudes and behaviors	9	3	12	41%
Verbal and Physical violence	1	2	3	10%
Took control of my children	3	0	3	10%

Source: Field data, Kathmandu, 2024

As shown in Table 5.8., among the interviewed 27 respondents who experience the stigma and discrimination in family, 6 (21%) respondents experience the avoidance of physical contacts by family members, 6 (21%) respondents were expelled from home, 2 (7%) respondents were labelled as dangerous people, 3 (10%) respondents were rejected by their family members, 9 (31%) respondents had to experience the separation of their personal belongings from those of other family members, 12 (41%) respondents felt the stigmatizing attitudes and behaviors from their family members, 3 (10%) respondents had to bear verbal and physical violence, 3 (10%) respondents children were taken into control by their family members after they disclose their HIV status. The experience of stigma and discrimination as experience by respondents are illustrated below.

Mina (name changed), female, 40 years old shared how her family showed stigma and discrimination due to her HIV status, she stated, "After I disclosed my HIV status to my family, they avoided to touch me and used to stay at distance which I belive was due to the lack of knowledge of HIV, they had the perception that HIV may get transmitted to them by touching me, for me it was very humiliating and embarrassing"

One of the respondents shared how she was expelled from the home after they came to know about her HIV status and Separation of their personal belongings from those of other family members

"After the death of my husband from HIV, my in laws came to know about my HIV status, and they blamed me for the HIV infection due to my immoral behavior and to prevent the communal and social ostracization, they expelled me and my children from the home, at that point of time I didn't know about the HIV, then one of the community member took me to the Maiti Nepal Shelter."- Devi (name changed), female, 56 years old.

One of the respondent shared how her family labelled as dangerous person after knowing her HIV status

"I got HIV infection from my husband, when it was disclosed to my in laws, and due to the lack of knowledge of HIV my in laws family used to considered as dangers for community and society as I can spread the disease to other, they also separated the personal belongings such as utensils, comb, towels, toothpaste, soap, and also used to show stigmatizing attitudes and behavior such as fear of contact, blaming and shaming, and also did verbal and physical abuse towards me and my children due to my HIV status" - Parbati (name changed), female, 50 years old.

In families of people living with HIV (PLHIV), shame becomes a collective burden where all members share in the stigma and blame within the community. This reshapes the family's identity, often leading to a sense of shame that restricts social interactions. The stigma and blame are typically rooted in the misconception that HIV is associated with immoral behavior or social deviance (Li et al., 2008).

Moreover, women experience heightened stigma due to social and gender inequalities in patriarchal societies where male dominance prevails. This inequality often renders women inferior to men, limiting their access to support systems and making them more vulnerable to gender-based violence (Subedi et al., 2019; Addison, 2023).

5.4.4. HIV stigma and Discrimination by Friends, Neighbors and other community members

HIV stigma and discrimination pose significant challenges for many people living with HIV (PLHIV). These negative attitudes and behaviors can originate from friends, neighbors, and members of the community. Stigma can profoundly impact the mental and physical health, overall quality of life, economic stability, and access to care of individuals living with the condition (Subedi, 2019).

5.4.4.1. HIV Stigma and Discrimination by Friends

Friends can also contribute to HIV stigma and discrimination, often resulting in rejection, neglect, avoidance, ridicule, verbal abuse, insults, and harassment

towards PLHIV. The study participants were asked about their personal experiences of stigma and discrimination within their circle of friends.

Table 5.9. Status of Stigma by non HIV friends

Experience of Stigma and Discrimination from friends	Female	Male	Total	Percentage
No	4	2	6	10%
Yes	8	2	10	18%
Not Disclosed	35	8	43	72%
Grand Total	48	12	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table No. 5.9., among the 60 respondents, 6 (10%) didn't got stigmatized by friends, 10 (18%) got stigmatized and discriminated by friends for their HIV status whereas 43 (72%) has not disclosed their HIV status to their friends.

Table 5.10. Type of Stigma by friends

Family Stigma and Discrimination of PLHIV	Female	Male	Total	Percentage
Gossip	7	0	7	64%
Labelling	1	0	1	9%
Physical avoidance	4	0	4	36%
Physical Isolation	2	1	3	27%
Social Isolation	4	1	5	45%

Source: Field data, Kathmandu, 2024

As shown in Table 5.10., among the 10 respondents stigmatized and discriminated by friends, 7 (64%) respondents shared that their friends gossip about their HIV status with other, 1 (9%) respondent shared labelling based on HIV status, 4 (36%) respondents shared that their friends did physical avoidance after knowing their HIV status, 3 (27%) respondents shared physical isolation done by friends after knowing their HIV status, 5 (45%) shared being socially isolated by their friends. The

response provided by the study respondents regarding their experience of stigma and discrimination in school, colleges and other education center is provided below.

> *"I got HIV infection from my parents, and I hadn't disclose my HIV status to my friends in the school, however one of my teacher became aware of my HIV status, that he later disclosed to my other teachers and my classmate. After that I became the prime gossip topic with my classmates, my morality, behavior came into question. Some of my friends began to labelled me as HIV infected, my close friend began to keep distance from me, my friends were in fear when I even accidently touch them. I know that its due to their lack of knowledge on HIV, but it was quite embarrassing and depressing for me"*

HIV-related gossip serves as both an indicator and a catalyst of HIV-related stigma, creating barriers to HIV testing and treatment. Generally, HIV-related gossip functions as a social control mechanism used to enforce cultural and social norms when individuals or their actions are perceived as threatening to these norms. Thus, gossip serves as a platform for expressing and perpetuating harmful social stereotypes and the accompanying stigma processes that enable discrimination. This facilitates the widespread labeling of people living with HIV (PLHIV) and reinforces societal norms by associating PLHIV with deviations from cultural expectations (Smith et al., 1999; Stadler, 2003; Poku et al., 2023).

Similarly, social isolation is defined as the perception of being isolated due to a lack of connections and engagement with peers and the broader community (Cornwell & Waite, 2009; Greysen et al., 2013). HIV-related stigma often leads to reduced social networks and interactions due to self-imposed isolation and avoidance of negative judgments and guilt associated with HIV (Tsai et al., 2013). Research indicates that disclosing one's positive HIV status to family, friends, or healthcare providers can result in social stigma, isolation, or exclusion from the community (Earnshaw and Chaudoir, 2009; Armoon et al., 2022).

5.4.4.2. HIV Stigma and Discrimination in Neighborhood and Community

Many people living with HIV/AIDS (PLWHA) face negative labeling and discrimination from their neighborhoods, which can profoundly impact their mental

health. Such negative treatment often leads to feelings of sadness, anger, and even depression among PLWHA. Consequently, some individuals may become antisocial, experiencing mental health disorders due to reduced social interactions. Despite the pervasive stigma and discrimination, some PLWHA demonstrate resilience, surviving, adapting to, and coping with these challenges (Putri et al., 2019).

Table 5.11. Neighborhood and community stigma and discrimination as experience by PLHIV

Neighborhood stigma	Female	Male	Total	Percentage
No	6	2	8	13%
Yes	6	1	7	12%
Not Disclosed	37	8	45	75%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table 5.11., out of the 60 respondents, 8 (13%) respondent didn't experience any kind of stigma and discrimination from neighborhood, 7 (12%) respondents experience the stigma and discrimination, whereas 45 (75%) hadn't disclose their HIV status to their neighborhood.

> *"I got HIV infection from my husband which was disclosed to my neighborhood and community members in my village, and after knowing my HIV status my daughter and family were segregated and labeled as immoral and linked the HIV status to our behavior and also didn't allow my children to play with other due to which we migrated to Kathmandu" - Seema (name changed), female, 46 years.*

Stigma and discrimination from neighbors and the community often stem from misconceptions about HIV infection, linking it with negative stereotypes such as prostitution, multiple sex partners, and drug use. This lack of understanding contributes to growing suspicion and discrimination against individuals living with HIV/AIDS (Putri et al., 2019).

5.4.5. HIV stigma and discrimination in workplace and employment

Every individual has the right to work and earn a livelihood to sustain themselves and meet their economic needs. Since employees spend a significant amount of time in the workplace, it is crucial that the working environment is supportive. Despite minimal risk of HIV transmission in workplaces, stigma and negative attitudes from employers and colleagues pose significant challenges for people living with HIV/AIDS (Aryal, 2018). The study aimed to document the instances of stigma and discrimination experienced by HIV-positive individuals in their work environments.

Table 5.12. Status of Stigma and discrimination in workplace as experience by PLHIV

Employment stigma and discrimination	Female	Male	Total	Percentage
No	14	7	21	35%
Yes	3	0	3	5%
Not Disclosed	32	5	36	62%
Total	49	12	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table 5.12., among the 60 respondents 21 (35%) respondent didn't faced any stigma and discrimination after revealing their HIV status and most of them were working in organization either led by people living with HIV or working in prevention of HIV, 3 (5%) respondents faced the stigma and discrimination at their workplace after which they were expelled from the job and one of them was also not paid her wages or dues where as 36 (62%) respondents have not disclosed their HIV status.

Employment did not emerge as a significant source of stigma and discrimination in this study, largely because the majority of respondents chose not to disclose their HIV status at work. Fear of social ostracism, stigma, and potential job loss deterred many from revealing their HIV status. Moreover, those who did disclose often worked in organizations established by or for people living with HIV/AIDS, or

in institutions focused on HIV prevention. Several instances illustrating stigma and discrimination experienced by PLHIV are detailed below.

> *"I was working in school as a kitchen helper in a school in Kathmandu, I don't know how, but I believe my brother in laws disclosed my HIV status to the school management, after which they forced me to do HIV test and after confirming that I am HIV positive they expelled me from the school without paying my half month wage. The primary reason of the school management for expelling me from the school was that if I stay in the kitchen as a helper, I may infect the children and other workers in school and my presence in the school will also tarnish the image of school if it is known to the parents and they will also not admit their children in the school. I was totally devasted by their decision as I was economically dependent on the school wages." – Ganga (name changed), female, 59 years old*

Similarly, a study conducted in India reported minimal stigma in the workplace, as most PLHIV chose not to disclose their HIV status out of fear of job loss. Instances of emotional isolation due to negative attitudes and instances of employment denial were also noted (Lalhruaimawii et al., 2022). Likewise, research in Uganda found that employees were reluctant to disclose their HIV status due to concerns about stigma and discrimination in the workplace (Twinomugisha et al., 2020; Stutterheim et al., 2017).

5.4.6. HIV Stigma in school and other educational institution

HIV stigma in schools manifests through various forms of discrimination, social exclusion, and stigma that can significantly impact the education and well-being of affected students. The societal perception of HIV as a morally judged disease exacerbates challenges faced by young people living with HIV or children of PLHIV. Educational institutions play a pivotal role in either perpetuating or combating this stigma and discrimination. Studies indicate that comprehensive sex education and inclusive school policies can effectively mitigate HIV stigma, fostering a supportive environment for all students (Lichtenstein, 2014).

Table 5.13. Status of Stigma in school and college as experienced by PLHIV

School and College Stigma and discrimination	Female	Male	Total	Percentage
No	2	2	4	7%
Yes	3	1	4	7%
Not Disclosed	44	8	52	87%
Total	49	12	60	100%

Source: Field data, Kathmandu, 2024

As shown in Table 5.13., among the 60 respondents, 4 (7%) respondents didn't faced any stigma and discrimination in school or educational institution after disclosing their HIV status, 4 (7%) respondent shared that after disclosing their HIV status they were stigmatized and discriminated in school and colleges, whereas 52 (87%) respondents didn't disclosed their or their children HIV status in school.

> *"I got HIV infection from my husband and my child also got HIV infected and my HIV infection was disclosed without my consent by health service providers and after the disclose of our HIV status, the school expelled my child from school due to the HIV status stating that it will degrade the reputation of school and other parents are also complaining about it" – Puspa (name changed), 28 years old*

According to Link and Phelan's conceptualization of stigma (2001), stigma emerges from labeling individuals based on perceived negative attributes, thereby categorizing them as different and often victimizing them. Children living with HIV experience distinct forms of stigma that set them apart from "normal" peers, hindering their participation in typical activities. Parker and Aggleton (2003) describe HIV stigma as a pervasive sense of shame and a collection of customs entrenched in social contexts. Individuals marginalized due to their HIV status are devalued and excluded from full participation in society. Discrimination, as per this perspective, involves the application of stigma. HIV-related stigma prevents the integration of children living with HIV into the school system, as they are viewed as different from their peers (Nginya et al., 2016).

Chapter Six: Disclosure Status, Supporting System and Coping Strategies of HIV Stigma as Experienced by PLHIV

6.1. Disclosure of HIV Status

The process of disclosing HIV status is highly individualized and varies depending on the social relationship dynamics involved. Disclosure may occur in various contexts such as healthcare settings, intimate relationships, family interactions, friendships, support groups, and workplaces. While HIV disclosure is often considered a private matter, it is influenced by cultural norms and expectations, which can sometimes lead to stigma or resistance but also foster empathy, concern, and support. The interpretation and reactions to HIV disclosure are shaped by the recipient's knowledge of HIV and their relationship with the person disclosing, resulting in a range of responses, some of which may be unexpected (Watkins-Hayes, 2014).

Table 6.1. HIV Disclosure status of respondents

Disclosure	Female	Male	Total	Percentage
Brother	2	0	2	3%
Daughter	1	0	1	2%
Son	3	0	3	5%
Spouse	18	3	21	35%
Husband and daughter	1	0	1	2%
Father only	1	0	1	2%
Parents only	1	0	1	2%
Family	14	3	17	28%
in Laws	0	1	1	2%
Friends	1	2	3	5%
Disclosed to all	4	2	6	10%
Not Disclosed	3	0	3	5%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in above table, among the 60 respondents, 6 (10%) respondents has disclosed their HIV status to all, 3 (5%) respondents have not disclosed their HIV

status to anyone, 21 (35%) have disclosed their HIV status to spouse, 17 (28%) respondents have disclosed their HIV status to their family, 3 (5%) respondents have disclosed their HIV status to their son, 3 (5%) respondents have disclosed their HIV status to their friends, 2 (3%) respondents have disclosed their HIV status to their brother, and 1 (2%) each respondent has disclosed their HIV status to their Daughter, Husband and Daughter, Father only, Parents only, and in laws only respectively. Most of the respondent who got infected due to their husband instantly shared the information to their husband, or to their family members, where as most of the respondents selectively disclosed their HIV status due to the fear of HIV stigma and discrimination and some even shared that its' not necessary that I need to share my HIV status to all. One coping strategy for dealing with HIV stigma and discrimination is the deliberate disclosure of one's HIV status. People living with HIV (PLHIV) often choose to disclose their status after careful consideration of the potential outcomes (Poindexter, 2010).

Similarly, Chandra, Deepthivarma, and Manjula (2003) discovered that HIV-related stigma prompts behavioral changes, such as reluctance to disclose one's HIV status, often influenced by observing others' experiences of stigma post-disclosure. Disclosure of HIV status can lead to potential negative consequences, including violence and rejection by family, friends, and intimate partners (Campbell, 2021). Gender, anticipated outcomes, marital status, and knowledge of partner status are significant factors influencing the decision to disclose HIV status (Adeoye-Agboola et al., 2016). Examples of HIV disclosure experiences and contex reported by respondents and key informants are detailed below.

> *"Due to the poverty I got engaged in sex work and I came to know about my HIV infection just two years ago, my husband had already died due to kidney failure and now I am staying with my two son in a rented room. My sons do not know about my profession and my HIV status. I haven't share them due to the fear that they will not accept me. However, I have shared my HIV status with my friends and they have supported me a lot and linked me to medication and organization working in HIV" – Rita (name change), female, 42 years old*

One of the women who got infected by her husband shared her experience as "I got HIV infection from my husband, he left me and we got legally divorce and now I am with my daughter and I do tailoring for daily expenses. I have shared my HIV status only with my Ex-husband and nobody else due to the fear of stigma and discrimination and not even my daughter. But once I got sick and need to be admitted and at that time I disclose my HIV status to my daughter, but after that I found that her behavior changed a lot, and nowadays she doesn't talk much with me." – Durga (name changed), female, 42 years old

"The HIV stigma and discrimination is not as much prevalent as it used to be earlier, but it still exist in the mindset of people, when HIV is said, the people normally associated it with prostitution, sex work, and multiple sex partners and take it in negative sense, though these are modes of HIV transmission. Hence, PLHIV fear to disclose their status and only selective and limited disclosure is done. Since, still today in rural and urban area fear exist on HIV, we have found instances where PLHIV have been stereotyped as Bombay wali and the landlord denied to give rent to organization working on HIV in Kathmandu. But disclosure has also aided in getting the voice of the PLHIV heard by government and access to support"- Padam Bdr. Lama, HIV activist

6.2. Time period of first disclosure after HIV detection

Table 6.2. Time period of first HIV status disclosed by the respondents

Time period of Disclosure	Female	Male	Total	Percentage
Instantly	39	10	49	82%
after 6 months	0	1	1	2%
after 1 year	1	0	1	2%
after 2 years	1	0	1	2%
after 3 years	2	0	2	3%
after 5 years	3	0	3	5%
Not Disclosed	3	0	3	5%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in above table, among the 60 participants, 49 (82%) respondents disclosed their HIV result instantly, 1 (2%) respondents each reveal their HIV positive status after the discovery of HIV after 6 months, after 1 year, after 2 years respectively, 2 (3%) respondents reveal the HIV test result after 3 years, 3 (5%) respondents shared their HIV status after 5 years of HIV testing whereas 3 (5%) respondents have not yet disclosed their HIV status respectively.

"I was planning for foreign employment for which I had prepared all the documents, and consulted the foreign employment companies and during that process I had to do the health check-up, and while doing that I had to do the blood test also after which I came to know that I am HIV positive." - *Sita (name change), female, 42 years old*

One of the respondent who is a single women living with her daughter shared "I got infected with HIV by my husband who went missing since last one decade, I have not shared my HIV status with my family member along with my daughter. The major reason for not disclosing has been due to the fear of HIV stigma and discrimination and negative impact to my daughter as well"

Most PLHIV choose to disclose their HIV status voluntarily to select close or trusted individuals, such as their spouse or family members, after carefully weighing the potential risks and benefits (Yang et al., 2018). Previous studies suggest that HIV disclosure is typically a gradual process, often correlated with the duration since the initial HIV diagnosis, indicating that disclosure may occur after a significant period (Yin et al., 2019). Moreover, while it may take some PLHIV a considerable amount of time to disclose their HIV status, those who do often find support from family members who either have experience with HIV or are understanding and supportive during their emotional challenges post-infection (Yang et al., 2023).

6.3. Major reasons for not disclosing the HIV status

Table 6.3. Reasons for not disclosing the HIV status by the respondents

Major reason for not disclosing	Female	Male	Total	Percentage
Fear of Hatred	1	0	1	2%
Fear of mis-behaviour	1	0	1	2%
Fear of revealing the HIV status	1	0	1	2%
Fear of stigma and discrimination	23	4	27	45%
Fear of unacceptability by family members	14	3	17	28%
Negative impact on Children	5	2	7	12%
Disclosed to all	4	2	6	10%
Total	49	11	60	100%

Source: Field data, Kathmandu, 2024

As shown in above table, among the 60 participants, 1 (2%) respondent each major reasons for non disclosure by PLHIV is due to the fear of hatred, fear of misbehavior and fear of revealing HIV status, 27 (45%) respondents believe that the HIV status is not disclosed due to the fear of stigma and discrimination, 17 (28%) respondents stated the reason for disclosure is due to the fear of unacceptability by family members, 7 (12%) respondents said that the major reasons for non disclosure of HIV is due to the fear of negative impact on whereas 6 (10%) respondent has disclosed their HIV status to all respectively.

> *"I got HIV from infected syringe and came to know about my HIV infection from local health post, which was then disclosed to my family, including my neighbors, community members and my friends. All the people supported me a lot and I did not come across any kind of stigma and discrimination after disclosing my HIV status" Ram (name changed), male, 50 years*

In the study, the primary reason for not disclosing HIV status was the fear of experiencing hatred, mistreatment, unwanted disclosure, rejection by family, and negative impact on one's children. This finding aligns with previous research conducted in the Far Western Province of Nepal, where non-disclosure of HIV status

was similarly associated with stigma and discrimination within households and communities, along with concerns about negative personal repercussions (Chaudhary and Kakchapati, 2022).

6.4. Social support system and wellbeing in HIV stigma

Table 6.4. Support system against HIV stigma as experience by PLHIV

Support mechanisms	Female	Male	Total	Percentage
Peer support	48	11	59	98%
Family support	13	5	18	30%
Shared identity	45	11	56	93%
Support of organization and network	47	11	58	97%

Source: Field data, Kathmandu, 2024

As shown in Table 5.19.,(multiple response), the 59 (98%) respondent stated that they got the peer support was highly significant for them to face the HIV stigma and discrimination which not only built the sense of unity but also have some one to share their problems and challenges, 18 (30%) respondents believe that family support played significant role in their life to tackle the HIV stigma and discrimination, 56 (93%) respondents believe that the shared identity has been the major support system in their life to counter the HIV stigma and discrimination, 58 (97%) respondents stated that the major support system has been the support from organization and network which not only build their self-confidence but also provide them counseling and better understanding of HIV and AIDS

Peer support groups for HIV-positive individuals emerged in the 1980s, initially focusing on mutual assistance, information exchange, and advocating for improved care and treatment. Today, these interventions are known by various names and conceptualized in diverse ways, evolving into more person-centered approaches that include tailored outreach to link individuals living with HIV to healthcare services and support active management of HIV infection (Simoni et al., 2011; WHO, 2016; Ogard-Repal et al., 2019; Berg et al., 2021).

In previous studies, peer support has been defined as "the giving of assistance and encouragement by an individual considered equal" (Dennis et al., 2003, p. 323). Four main pillars of peer support have been conceptualized, including assistance with daily management, provision of social and emotional support, connecting individuals to clinical treatment and community resources, and offering ongoing support for chronic illness (Fisher et al., 2018). Peers are individuals who share common characteristics with those they support, allowing them to relate to and empathize with them in ways that non-peers cannot (Doull et al., 2017).

6.5. Coping mechanism to counter the HIV stigma

The third objective of the study aimed to explore the coping strategies employed by individuals facing HIV and AIDS-related stigma. From their narratives, several themes emerged: isolation, silence and secrecy, fostering a positive self-concept and practicing self-care, limited and selective disclosure, gaining a deeper understanding of HIV, and striving for economic independence.

Table 6.5. Coping mechanism of HIV stigma as experienced by PLHIV

Coping mechanism	Female	Male	Total	Percentage
Isolation	12	6	18	30%
Silence and secrecy	20	6	26	43%
positive self concept and self care	44	9	53	88%
limited and selected disclosure	39	8	47	78%
Better understanding of HIV	40	9	49	82%
Economic independence	37	8	45	75%

Source: Field data, Kathmandu, 2024

Due to the nature and impact of the stigma surrounding HIV and AIDS, some PLHIV prefer to remain isolated than to be confronted with stigma in most of their lives. They opt to withdraw from the support groups and other available structures. To them spending time indoors remains an active coping strategy to overcome HIV- and AIDS-related stigma. As shown in Table 32.,18 (30%) opt the isolation as a coping strategy. which involves removing oneself from social situations in which the stigma (or the condition) may be apparent.

As per Smart and Wegner (2000:220) most people might prefer to keep their medical conditions secret in order to avoid labelling and rejection. This is the coping strategy that is adopted by most PLHIV to avoid the stigma that surrounds the disease. They prefer to keep quiet and hide any symptom that might expose them, and pretend that everything is fine in their lives. Secrecy is described as a choice that the afflicted person makes to keep the condition to himself or herself and to avoid situations where the affliction can be recognized, hence in this study, 26 (43%) respondents opt for the silence and secrecy as the coping mechanism.

Self-esteem can be defined as the assurance in one's skill to reason, manage with the contests of life and a acknowledging of being worthy of happiness and success. Self-esteem is also related to people self value, pride and worthvalue of themselves. Furthermore, the major principle of self esteem is trusting one's mind and being aware that one is worthy of greatness. 53 (88%) respondents feels that positive self esteem and self care is the prime coping strategy for them to counter HIV stigma and discrimination.

Disclosure is the gateway to access support and care. It is disclosure that enables PLHIV to be accepted unconditionally and to receive the relevant support which will further enable them to fight the stigma through. However, disclosure does not always earn support for PLHIV. Some become more stigmatised as a result of their disclosure. Since disclosure is a process that involves decisions about time, the person to whom one discloses, the procedure that one would follow to disclose and conditions under which one would disclose (Makin et al 2008:908). Hence, 47 (88%) respondents believes that limited and selective disclosure aid them form the negative impact of HIV stigma and discrimination.

Furthermore, 49 (82) and 45 (75%) respondents believes that better understanding of HIV infection, it mode of transmission, risk factors and medication had aided in coping with the HIV stigma and discrimination shown towards PLHIV, and strongly states that more awareness and knowledge build at all level of country is required to mitigate the HIV stigma and discrimination and economic independence helps oneself to keep a distance from other people, and it protect them from facing the HIV stigma and discrimination.

Chapter Seven: Summary, Conclusion and Theoretical Reflection

7.1. Summary

7.1.1. Identity Crisis and Social Construction of Identity

This study provides insights into the experiences of people living with HIV (PLHIV) regarding HIV stigma and discrimination, associated social factors, impacts on their lives, support systems, and coping mechanisms. It explores how PLHIV navigate through spoiled, transitional, and reconstructed identities in the context of various contextual factors, support systems, and coping strategies (Aryal, 2014).

Spoiled Identity: Upon discovering their HIV status, respondents experienced significant identity crises due to societal reactions and negative treatment at home, in society, and within various institutions. The revelation of HIV split their lives into distinct before and after phases (Aryal, 2014). Respondents reported severe identity crises, particularly those who had been living with HIV for over 15 years without access to adequate treatment, which significantly impacted their self-esteem, confidence, and social status (Aryal, 2014; Baumgartner & David, 2009). Initial emotional reactions included shock, fear, denial, sadness, and fatalism, despite awareness of available treatments.

In this study, a majority (82%) of participants were women, many of whom were widowed, separated, divorced due to HIV, or infected through various means such as from parents, spouses, contaminated syringes, or surviving human trafficking, all of whom faced heightened stigma and discrimination in healthcare institutions and families due to their HIV status. These women often found themselves either single or divorced, living with their legal partners, and were often stigmatized in their communities and families. Female respondents typically delayed disclosing their HIV status to avoid societal stigma and discrimination, family rejection, and negative impacts on their children (Aryal, 2014).

From the perspective of those considered "normal," stigmatized PLHIV are viewed as possessing a discrediting attribute, leading to diminished respect and value (Varas-Diaz et al., 2005). Institutional stigma was also prevalent, with respondents reporting stigmatization in government hospitals, schools, and workplaces. Healthcare

professionals sometimes discouraged reproduction (3%), made judgmental remarks linking HIV to prostitution (9%), denied treatment (10%), publicly disclosed HIV status without consent (13%), disposed of bed sheets and clothing (3%), imposed excessive barrier precautions (18%), referred patients to other healthcare providers (3%), segregated and labeled patients (7%), and caused treatment delays (9%). Some respondents were even terminated from their jobs upon disclosing their HIV status.

Children of PLHIV and those attending school were often ostracized from mainstream educational settings. The study highlighted the pervasive effects of stigma, discrimination, and identity disruption, including self-stigma.

Judgeo and Moalusi (2014) conducted a qualitative study in South Africa involving 10 PLHIV to explore attributes that tarnish identity. Respondents described profound life changes post-HIV infection, including physical decline, social life redefinition, and stigma-driven perceptions of irresponsibility, uncleanliness, and immorality from friends, family, employers, and society. Supportive significant others, whether friends or family, played crucial roles in mitigating social isolation and providing social support. Fear of stigma and discrimination motivated many PLHIV to manage their HIV status disclosure carefully to protect their families from negative consequences. The study emphasized themes of spoiled identity, disrupted social relations, and the necessity of information management.

Meyer (2003) noted that women, LGBTQ+ individuals, and ethnic minorities experience compounded stigma, exacerbating the impacts of spoiled identity. Smit et al. (2012) found that stigma against women with HIV is often gender-based, with assumptions about their ability to parent and engage in sexual activity further complicating their identities and access to resources.

Reconstructed Identity: Despite facing stigma and discrimination, PLHIV also reported positive impacts on their lives. Respondents reconstructed their identities post-HIV diagnosis by rationalizing their infection, focusing on socioeconomic factors, healthcare access, and gradually rebuilding their self-identities (Aryal, 2014). Learning more about HIV/AIDS empowered PLHIV to adopt health-

focused behaviors like regular check-ups and balanced nutrition, promoting overall well-being (Aryal, 2014).

Economic independence emerged as a critical factor enabling PLHIV to secure sustainable livelihoods and engage in meaningful work commensurate with their skills and education. Migration to escape stigma, access better opportunities, and receive HIV treatment was another strategy employed by PLHIV. Peer support networks and HIV organizations provided extended family-like support, fostering resilience against stigma and discrimination. These networks also facilitated knowledge-sharing about HIV and supported efforts toward economic independence and family reunification (Aryal, 2014).

7.2. Conclusion

This study underscores the pervasive stigma and discrimination experienced by PLHIV across various domains including self, family, friends, neighbors, community, healthcare settings, schools, and workplaces. While some respondents noted reduced stigma and discrimination due to legislative efforts and awareness campaigns, stigma persists in community and institutional settings, leading many PLHIV to practice selective disclosure. Disclosing HIV status often results in stigma and discrimination from friends, neighbors, and communities, and may lead to job loss and school expulsion.

Healthcare settings were identified as particularly discriminatory, with PLHIV experiencing service denial, public disclosure of HIV status, reproductive discouragement, judgmental remarks, treatment delays, and economic burdens. These experiences negatively impact PLHIV's mental health, adherence to antiretroviral therapy (ART), and human rights.

Effective strategies to mitigate stigma and discrimination include raising awareness through mass campaigns involving PLHIV, enforcing existing laws to protect PLHIV's human rights, and enhancing capacity-building initiatives. Positive self-concept and self-care emerged as crucial coping mechanisms enabling PLHIV to maintain good health and withstand stigma and discrimination. Selective HIV disclosure, improved knowledge about HIV/AIDS, and economic independence were

also identified as effective coping strategies empowering PLHIV to navigate the challenges posed by stigma and discrimination (Aryal, 2014).

In conclusion, this study illustrates the profound impact of HIV-related stigma and discrimination on the lives of PLHIV, emphasizing the need for concerted efforts to address stigma through awareness, legal protections, and support systems. Efforts to enhance understanding and mitigate stigma will contribute to improved quality of life for PLHIV, fostering inclusive and supportive communities.

7.3. Theoretical Reflection

HIV stigma and discrimination experienced by people living with HIV (PLHIV) are socially constructed through ongoing social processes that develop and reinforce negative societal norms and connotations surrounding HIV infection. This social construction of stigma creates a situation where PLHIV's social identities are "spoiled," leading to reduced social esteem and self-respect. Internalization of these negative societal views can result in self-stigma among those infected with HIV, causing feelings of shame, guilt, and diminished self-worth (Mwale, 2006).

Erving Goffman's stigma theory, articulated in his seminal work in 1963, provides a framework for understanding the social dimensions of stigma associated with HIV. Goffman defines stigma as a trait that significantly discredits a person, transforming them from a "whole and ordinary" individual into a "tainted and discounted" one in the eyes of society. Applied to HIV, this theory underscores how individuals living with HIV/AIDS often face prejudice, discrimination, and social exclusion due to their illness. Goffman's concept of a "spoiled identity" is particularly relevant, as it highlights how PLHIV may internalize negative societal attitudes, leading to feelings of shame, guilt, and diminished self-esteem. Internalized stigma can have profound psychological effects, potentially hindering access to necessary medical care and HIV status disclosure (Mwale, 2006).

Throughout history, diseases such as mental illness, leprosy, and tuberculosis have been heavily stigmatized. The extent of stigma associated with a specific disease typically evolves over time and varies across cultures. However, certain aspects of stigma remain nearly universal, persisting across diverse cultural contexts for

generations. Stigma manifests in various forms, including social or physical isolation of individuals or families with stigmatized attributes. Other manifestations of stigma are culturally determined, displaying variations from one societal context to another (Abdullah & Brown, 2011).

This study explores the spoiled social identities of PLHIV following their HIV diagnosis, detailing the public and self-stigma and discrimination they encounter. Goffman's concept of spoiled identity is particularly pertinent, as PLHIV may internalize societal norms and negative perceptions, resulting in feelings of shame, guilt, and diminished self-esteem. This internalized stigma, or self-stigma, significantly impacts the psychological well-being of PLHIV, potentially leading to non-adherence to HIV medications and even suicidal ideation. Goffman's theory distinguishes between discredited and discreditable individuals, where those who disclose their HIV status experience heightened stigma, isolation, and loneliness, while those who conceal their status live in constant fear of disclosure and face ongoing stigma and discrimination. Anticipated stigma can lead to negative outcomes such as social withdrawal, depression, and reluctance to seek healthcare services.

Goffman's insights into managing spoiled identities suggest that PLHIV often conceal their HIV status, selectively disclosing it only to close confidants or individuals who can offer support. Migration is another strategy PLHIV may use to manage stigma and discrimination, seeking environments where their HIV status is less known or stigmatized. Strategies such as isolation, secrecy, and silence, along with practices of self-care, improved understanding of HIV, and achieving economic independence, empower PLHIV to cope with their spoiled identities. Peer educator support, family networks, shared identity with other PLHIV, and support from HIV organizations play crucial roles in fostering positive coping mechanisms.

The social identity of PLHIV is fluid and dynamic, influenced by access to resources and social capital that facilitate movement towards a reconstructed identity. Intersectionality further complicates HIV stigma and discrimination, particularly affecting marginalized groups based on gender, income, caste, and other factors (Mwale, 2006).

References

Acharya, D., Adhikari, R., & Badal, K. (2022). Determinants of Discriminatory Attitudes Towards People Living with HIV Among Women of Reproductive Age in Nepal: A Trend Analysis From National Surveys. *Journal of Population and Social Studies, 30,* 391–407. https://doi.org/10.25133/jpssv302022.023

Adane, B., Yalew, M., Damtie, Y., & Kefale, B. (2020). Perceived stigma and associated factors among people living with HIV attending ART clinics in public health facilities of Dessie City, Ethiopia. *HIV/AIDS, Volume 12*, 551–557. https://doi.org/10.2147/hiv.s274019

Addison, M. (2023). Framing stigma as an avoidable social harm that widens inequality. *Sociological Review*, *71*(2), 296–314. https://doi.org/10.1177/00380261221150080

Adeoye-Agboola, D., Evans, H., Hewson, D., & Pappas, Y. (2016). Factors influencing HIV disclosure among people living with HIV/AIDS in Nigeria: a systematic review using narrative synthesis and meta-analysis. *Public Health*, *136*, 13–28. https://doi.org/10.1016/j.puhe.2016.02.021

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine, 41*(3), 303–315. https://doi.org/10.1016/0277-9536(94)00384-6

Amiya, R. M., Poudel, K. C., Poudel-Tandukar, K., Pandey, B. D., & Jimba, M. (2014). Perceived Family Support, Depression, and Suicidal Ideation among People Living with HIV/AIDS: A Cross-Sectional Study in the Kathmandu Valley, Nepal. *PloS One, 9*(3), e90959. https://doi.org/10.1371/journal.pone.0090959

Armoon, B., Fleury, M., Bayat, A., Fakhri, Y., Higgs, P., Moghaddam, L. F., & Gonabadi-Nezhad, L. (2022). HIV related stigma associated with social support, alcohol use disorders, depression, anxiety, and suicidal ideation among people living with HIV: a systematic review and meta-analysis. *International Journal of Mental Health Systems*, *16*(1). https://doi.org/10.1186/s13033-022-00527-w

Aryal, R. P. (2014). *The reconstruction of identity in people living with HIV in Nepal* [Doctoral Dissertation, Massey University]. Massey Research Online http://hdl.handle.net/10179/6956

Aryal, R. P. (2018). HIV stigma and Discrimination Management in Pokhara, Nepal. Janapriya *Journal of Interdisciplinary Studies/Janapriya Journal of Interdisciplinary Studies*, 6, 97–109. https://doi.org/10.3126/jjis.v6i0.19312

Asrina A., Ikhtiar, M., Idris, F.P., Adam, A. and Alim, A. (2023). Community stigma and discrimination against the incidence of HIV and AIDS. *J Med Life*. *16*(9):1327-1334. http://doi.org/10.25122/jml-2023-0171.

Beine, D. (2011). Causes of HIV and AIDS Stigmatization in Nepal: a Proposed Model to Reduce Stigma. *Global Journal of Health Science*, *3*(2). https://doi.org/10.5539/gjhs.v3n2p3

Berg, R. C., Page, S., & Øgård-Repål, A. (2021). The effectiveness of peer-support for people living with HIV: A systematic review and meta-analysis. *PloS One*, *16*(6), e0252623. https://doi.org/10.1371/journal.pone.0252623

Carrasco, M. A., Barrington, C., Kennedy, C., Perez, M., Donastorg, Y., & Kerrigan, D. (2016). 'We talk, we do not have shame': addressing stigma by reconstructing identity through enhancing social cohesion among female sex workers living with HIV in the Dominican Republic. *Culture, Health & Sexuality*, *19*(5), 543–556. https://doi.org/10.1080/13691058.2016.1242779

Chaudhary, S., & Kakchapati, S. (2022). Social stigma, discrimination, and their determinants among people living with HIV and AIDS in Sudurpashchim Province, Nepal. *HIV & AIDS Review*, *21*(3), 230–238. https://doi.org/10.5114/hivar.2022.117230

Crossley, M. (1998). 'Sick Role' or 'Empowerment'? The Ambiguities of Life with an HIV Positive Diagnosis. *Sociology of Health & Illness*, *20*(4), 507–531. https://doi.org/10.1111/1467-9566.00113

Dahal, S., Pokharel, P. K., & Yadav, B. K. (2013). HIV/AIDS Related Stigma among Male Labor Migrants in Nepal. *World Journal of AIDS*, *03*(04), 305–312. https://doi.org/10.4236/wja.2013.34039

Dennis, C. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, *40*(3), 321–332. https://doi.org/10.1016/s0020-7489(02)00092-5

Doull, M., O'Connor, A. M., Welch, V., Tugwell, P., & Wells, G. A. (2017). Peer support strategies for improving the health and well-being of individuals with chronic diseases. *Cochrane Library*. https://doi.org/10.1002/14651858.cd005352.pub2

Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A Review of HIV Stigma Mechanism Measures. *AIDS Behav, 13*(6), 1160–1177. https://doi.org/10.1007/s10461-009-9593-3

Earnshaw, V. A., Watson, R. J., Eaton, L. A., Brousseau, N. M., Laurenceau, J., & Fox, A. B. (2022). Integrating time into stigma and health research. *Nature Reviews Psychology*, *1*(4), 236–247. https://doi.org/10.1038/s44159-022-00034-2

Fauk, N. K., Gesesew, H. A., Mwanri, L., Hawke, K., & Ward, P. R. (2022). HIV-related challenges and women's self-response: A qualitative study with women living with HIV in Indonesia. *PloS One*, *17*(10), e0275390. https://doi.org/10.1371/journal.pone.0275390

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

Fido, N. N., Aman, M., & Brihnu, Z. (2016). HIV stigma and associated factors among antiretroviral treatment clients in Jimma town, Southwest Ethiopia. *HIV/AIDS*, *8*, 183–193. https://doi.org/10.2147/hiv.s114177

Fisher, E. B., Ballesteros, J., Bhushan, N., Coufal, M. M., Kowitt, S. D., McDonough, A. M., Parada, H., Robinette, J. B., Sokol, R. L., Tang, P. Y., & Urlaub, D. (2015). Key features of peer support in chronic disease prevention and management. *Health Affairs*, *34*(9), 1523–1530. https://doi.org/10.1377/hlthaff.2015.0365

Giri, S., Neupane, M., Pant, S., Timalsina, U., Koirala, S., Timalsina, S., & Sharma, S. (2013). Quality of life among people living with acquired immune deficiency syndrome receiving anti-retroviral therapy: a study from Nepal. *HIV/AIDS*, 277. https://doi.org/10.2147/hiv.s50726

Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Englewood Cliffs, N.J.: Prentice-Hall

Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist, 42*(7), 1106–1116. https://doi.org/10.1177/0002764299042007004

Jahromy, H. S., Hemayatkhah, M., Dehnavi, S. R., & Rahmanian, V. (2021). Experiences of People Living with HIV (PLHIV) in Jahrom, Southern Iran: A Phenomenological Study. *International Journal of High Risk Behaviors and Addiction, 10*(2). https://doi.org/10.5812/ijhrba.108414

Jha, C. K., & Madison, J. (2009). Disparity in health care: HIV, stigma, and marginalization in Nepal. *Journal of the International AIDS Society, 12*(1), 16. https://doi.org/10.1186/1758-2652-12-16

Jha, C. K., & Madison, J. (2013). Strategies for reinventing and reinforcing the disrupted biography of people with HIV in Nepal. *Health Sociology Review, 22*(2), 221–232. https://doi.org/10.5172/hesr.2013.22.2.221

Jha, C. K., Plummer, D., & Bowers, R. (2011). Coping with HIV and dealing with the threat of impending death in Nepal. *Mortality, 16*(1), 20–34. https://doi.org/10.1080/13576275.2011.535999

Judgeo, N., & Moalusi, K. (2014). My secret: The social meaning of HIV/AIDS stigma. *Sahara J, 11*(1), 76–83. https://doi.org/10.1080/17290376.2014.932302

Karki, T. B. (2015). Feminist Perspective of HIV and AIDS: Cases from the Kathmandu Valley of Nepal. *Humanities and Social Sciences Letters, 3*(2), 94–104. https://doi.org/10.18488/journal.73/2015.3.2/73.2.94.104

Karki, T. B. (2017). Association between Socio-Cultural factors and HIV and AIDS. *Journal of Advanced Academic Research, 2*(2), 76–89. https://doi.org/10.3126/jaar.v2i2.16608

Kaur, A. (2012). *HIV/AIDS stigma and discrimination* [Doctoral Dissertation, Guru Nanak University]. Shodhganga a reservoir of Indian theses http://hdl.handle.net/10603/23455

Lekganyane, R. (2010). *Anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa* [Master's Dissertation, University of South Africa]. Unisa Institutional Repositoryhttp://hdl.handle.net/10500/3758

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

Lo Hog Tian, J. M., Watson, J. R., Ibáñez-Carrasco, F., Tran, B., Parsons, J. A., Maunder, R. G., Card, K. G., Baral, S., Hui, C., Boni, A. R., Ajiboye, M., Lindsay, J. D., & Rourke, S. B. (2021). Impact of experienced HIV stigma on health is mediated by internalized stigma and depression: results from the people living with HIV stigma index in Ontario. *BMC Public Health, 21*(1). https://doi.org/10.1186/s12889-021-11596-w

Maharjan, P. (2019). *Schizophrenia: social causes and stigma* [Master's Dissertation, Tribhuvan University]. Tribhuvan University Central Library Repository

Manzo, J. F. (2004). On the Sociology and Social Organization of Stigma: Some Ethnomethodological Insights. *Human Studies, 27*(4), 401–416. https://doi.org/10.1007/s10746-004-3338-0

Maxwell, J. A. (2010). Using numbers in qualitative research. *Qualitative Inquiry*, *16*(6), 475–482. https://doi.org/10.1177/1077800410364740

Misir, P. (2015). Structuration theory. *Journal of the International Association of Providers of AIDS Care*, *14*(4), 328–334. https://doi.org/10.1177/2325957412463072

Moktan, D. B. (2023). Problems Faced by People Living with HIV/AIDS in Makawanpur, Nepal. *Journal of Advanced Academic Research*, *10*(2), 41–55. https://doi.org/10.3126/jaar.v10i2.60194

Müller, T. (2020). Stigma, the moral career of a concept: some notes on emotions, agency, teflon stigma, and marginalizing stigma. *Symbolic Interaction*, *43*(1), 3–20. https://doi.org/10.1002/symb.473

Mwale, S. (2006). *The experiences of people living with HIV and AIDS receiving health care services at Lighthouse clinic, Lilongwe-Malawi "A contribution to an understanding of the basis of HIV and AIDS related stigma in Malawi."* [Master's Dissertation, University of Oslo]. UiO: DUO Research Archive. http://urn.nb.no/URN:NBN:no-13463

National Centre for AIDS and STD Control. (2015). Factsheet 2: Cumulative HIV cases in Nepal, as of Asar 2072 (July 2015). Kathmandu, Nepal. In https://ncasc.gov.np/uploads/frontend/tabData/6337fc975403c.pdf.

Nepal, V. P., & Ross, M. W. (2010). Issues related to HIV stigma in Nepal. *International Journal of Sexual Health*, *22*(1), 20–31. https://doi.org/10.1080/19317610903393142

Neupane, D., Khanal, V., Sharma, S., & Aro, A. R. (2012a). Perceived discrimination among people living with HIV in Nepal. *DOAJ (Directory of Open Access Journals)*, *10*(21), 136–140. https://doi.org/10.33314/jnhrc.v0i0.313

Neupane, D., Khanal, V., Sharma, S., & Aro, A. R. (2012b). Perceived discrimination among people living with HIV in Nepal. *DOAJ (Directory of Open Access Journals)*, *10*(21), 136–140. https://doaj.org/article/238548ef9eaf40c5bf78b0fe38277818

Nginya, M. (2016). Effects of Stigma and Discrimination on the Right to Education of Children with HIV/AIDS Aged 4-8 Years in Kikuyu Sub-county, Kenya. *International Journal of Elementary Education*, *5*(1), 1. https://doi.org/10.11648/j.ijeedu.20160501.11

Øgård-Repål, A., Berg, R. C., & Fossum, M. (2021). Peer support for people living with HIV: a scoping review. *Health Promotion Practice*, *24*(1), 172–190. https://doi.org/10.1177/15248399211049824

Pahadi, T. N. (2022). Experiences of key populations in getting and sharing HIV and AIDS-related information: A descriptive phenomenological study. *Journal of Health Promotion, 10*(1), 49–58. https://doi.org/10.3126/jhp.v10i1.50987

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine, 57*(1), 13–24. https://doi.org/10.1016/s0277-9536(02)00304-0

Pescosolido, B. A., & Martin, J. K. (2015). The stigma complex. *Annual Review of Sociology, 41*(1), 87–116. https://doi.org/10.1146/annurev-soc-071312-145702

Phelan, J. C., Lucas, J. W., Ridgeway, C. L., & Taylor, C. J. (2014). Stigma, status, and population health. *Social Science & Medicine, 103*, 15–23. https://doi.org/10.1016/j.socscimed.2013.10.004

Poku, O. B., Eschliman, E. L., Entaile, P., Rampa, S., Mehta, H., Tal, D., Silvert, L., Li, T., Becker, T. D., Govindasamy, D., Stockton, M. A., Adedimeji, A., Ho-Foster, A., Blank, M. B., Dangerfield, D. T., Yang, L. H., & Murray, S. M. (2023). "It's Better If I Die Because Even in the Hospital, There is a Stigma, People Still Gossip": Gossip as a Culturally Shaped Labeling Process and Its Implications for HIV-Related Stigma in Botswana. *AIDS and Behavior, 27*(8), 2535–2547. https://doi.org/10.1007/s10461-023-03980-x

Poudel, A. N., Newlands, D., & Simkhada, P. (2017). The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study. *BMC Health Services Research, 17*(1). https://doi.org/10.1186/s12913-017-1976-y

Poudel, A. N., Simkhada, P., & Tull, K. I. (2018). Exploration of better policies and programmes to improve socioeconomic status of HIV-affected individuals in Nepal: a qualitative study. *J Public Health Policy Plann, 2*(2), 90–101. https://www.alliedacademies.org/articles/exploration-of-better-policies-and-programmes-to-improve-socioeconomic-status-of-hivaffected-individuals-in-nepal-a-qualitative-st.pdf

Poudel, K. C., Buchanan, D. R., Amiya, R. M., & Poudel-Tandukar, K. (2015). Perceived family support and antiretroviral adherence in HIV-Positive individuals. *International Quarterly of Community Health Education, 36*(1), 71–91. https://doi.org/10.1177/0272684x15614220

Rinehart, R., Rao, D., Amico, R. K., Ruiz, E., Brandes, P., Correa, C., Pasalar, S., Lama, J. R., Duerr, A., & Molina, Y. (2018). Experienced HIV-Related Stigma and Psychological Distress in Peruvian sexual and Gender Minorities: A longitudinal

study to explore mediating roles of Internalized HIV-Related Stigma and coping styles. *AIDS and Behavior*, *23*(3), 661–674. https://doi.org/10.1007/s10461-018-2348-2

Sandelowski, M. (2001). Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing & Health*, *24*(3), 230–240. https://doi.org/10.1002/nur.1025

Scambler, G. (1998). Stigma and disease: changing paradigms. *Lancet*, *352*(9133), 1054–1055. https://doi.org/10.1016/s0140-6736(98)08068-4

Shrestha, S., Chataut, S., Kc, B., Acharya, K., Pradhan, S. K., & Shrestha, S. (2023). Knowledge, Attitude, Practice, and Adherence to Antiretroviral Therapy among People Living with HIV in Nepal. *AIDS Research and Treatment*, 1–14. https://doi.org/10.1155/2023/7292115

Shrestha, S., Shibanuma, A., Poudel, K. C., Nanishi, K., Abe, M. K., Shakya, S. K., & Jimba, M. (2018). Perceived social support, coping, and stigma on the quality of life of people living with HIV in Nepal: a moderated mediation analysis. *AIDS Care*, *31*(4), 413–420. https://doi.org/10.1080/09540121.2018.1497136

Simoni, J. M., Franks, J. C., Lehavot, K., & Yard, S. S. (2011). Peer interventions to promote health: Conceptual considerations. *American Journal of Orthopsychiatry*, *81*(3), 351–359. https://doi.org/10.1111/j.1939-0025.2011.01103.x

Smit, R. (2007). Living in an age of HIV and AIDS: Implications for families in South Africa. *Nordic Journal of African Studies*, *16*(2), 161–178. http://www.njas.helsinki.fi/pdf-files/vol16num2/smit.pdf

Smith, L. C., Lucas, K. J., & Latkin, C. (1999). Rumor and gossip: Social discourse on HIV and AIDS. *Anthropology & Medicine*, *6*(1), 121–131. https://doi.org/10.1080/13648470.1999.9964577

Stadler, J. (2003). Rumor, Gossip and Blame: Implications for HIV/AIDS prevention in the South African Lowveld. *AIDS Education and Prevention*, *15*(4), 357–368. https://doi.org/10.1521/aeap.15.5.357.23823

Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV- related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*, *16*(3S2). https://doi.org/10.7448/ias.16.3.18734

Subedi, B., Timilsina, B., & Tamrakar, A. P. N. (2019). Perceived stigma among people living with HIV AIDS in Pokhara, Nepal. *HIV/AIDS, 11*, 93–103. https://doi.org/10.2147/hiv.s181231

Subedi, L., Sah, R. B., & Regmi, M. C. (2016). Status of children infected and affected by HIV/AIDS in eastern Nepal. (2012). *Int. J. Adv. Multidiscip. Res*, *3*(2), 72–77.

Thapa, S., Bista, N., Hannes, K., Buve, A., Vermandere, M., & Mathei, C. (2015). Vulnerability of wives of Nepalese labor migrants to HIV infection: Integrating quantitative and qualitative evidence. *Women & Health*, *56*(7), 745–766. https://doi.org/10.1080/03630242.2015.1118726

Thapa, S., Hannes, K., Buve, A., Bhattarai, S., & Mathei, C. (2018). Theorizing the complexity of HIV disclosure in vulnerable populations: a grounded theory study. *BMC Public Health*, *18*(1). https://doi.org/10.1186/s12889-018-5073-x

Tran, B. X., Than, P. Q. T., Tran, T. T., Nguyen, C. T., & Latkin, C. A. (2019). Changing Sources of Stigma against Patients with HIV/AIDS in the Rapid Expansion of Antiretroviral Treatment Services in Vietnam. *BioMed Research International*, 1–9. https://doi.org/10.1155/2019/4208638

Tsai, A. C., Bangsberg, D. R., Kegeles, S. M., Katz, I. T., Haberer, J. E., Muzoora, C., Kumbakumba, E., Hunt, P. W., Martin, J. N., & Weiser, S. D. (2013). Internalized stigma, social distance, and disclosure of HIV seropositivity in rural Uganda. *Annals of Behavioral Medicine*, *46*(3), 285–294. https://doi.org/10.1007/s12160-013-9514-6

Turan, J. M., Elafros, M. A., Logie, C. H., Banik, S., Turan, B., Crockett, K. B., Pescosolido, B., & Murray, S. M. (2019). Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Medicine*, *17*(1). https://doi.org/10.1186/s12916-018-1246-9

Twinomugisha, B., Ottemöller, F. G., & Daniel, M. (2020). Exploring HIV-Related Stigma and Discrimination at the Workplace in Southwestern Uganda: Challenges and solutions. *Advances in Public Health*, *2020*, 1–10. https://doi.org/10.1155/2020/8833166

Tyler, I., & Slater, T. (2018). Rethinking the sociology of stigma. *Sociological Review*, *66*(4), 721–743. https://doi.org/10.1177/0038026118777425

United Nations Programme on HIV/AIDS. (2003). *UNAIDS Fact Sheet on Stigma and Discrimination*. In https://data.unaids.org/publications/fact-sheets03/fs_stigma_discrimination_en.pdf. UNAIDS, Geneva.

Varas-Díaz, N., Neilands, T., Rivera, S. M., & Betancourt, E. (2010). Religion and HIV/AIDS stigma: Implications for health professionals in Puerto Rico. *Global Public Health, 5*(3), 295–312. https://doi.org/10.1080/17441690903436581

Varul, M. Z. (2010). Talcott Parsons, The Sick Role and Chronic Illness. *Body & Society, 16*(2), 72–94. https://doi.org/10.1177/1357034x10364766

Vaugan, E. (2019). *Sex, stigma, and silence: The discursive construction of HIV in Ireland* [Doctoral Dissertation, University of Galway]. University of Galway Research Repository. http://hdl.handle.net/10379/14994

Verdinelli, S., & Scagnoli, N. I. (2013). Data display in qualitative research. *International Journal of Qualitative Methods*, 12(1), 359–381. https://doi.org/10.1177/160940691301200117

Wilson, E. C., Dhakal, M., Sharma, S., Rai, A., Lama, R., Chettri, S., Turner, C. M., Xie, H., Arayasirikul, S., Lin, J., & Banik, S. (2021). Population-based HIV prevalence, stigma and HIV risk among trans women in Nepal. *BMC Infectious Diseases, 21*(1). https://doi.org/10.1186/s12879-021-05803-7

Wilson, E., & Pant, S. B. (2010). Stigma and HIV risk behaviors of transgender women in Nepal: implications for HIV prevention. *Retrovirology, 7*(S1). https://doi.org/10.1186/1742-4690-7-s1-p122

Wilson, E., Pant, S. B., Comfort, M., & Ekstrand, M. (2011). Stigma and HIV risk among Metis in Nepal. *Culture, Health & Sexuality, 13*(3), 253–266. https://doi.org/10.1080/13691058.2010.524247

World Health Organization. (2014). *Global Health Sector Strategy on HIV: 2016-2021 Towards Ending AIDS.* In https://www.who.int/publications/i/item/WHO-HIV-2016.05

Yadav, S. (2010). Perceived social support, hope, and quality of life of persons living with HIV/AIDS: a case study from Nepal. *Quality of Life Research, 19*(2), 157–166. https://doi.org/10.1007/s11136-009-9574-z

Yang, Y., Wang, W., Kelifa, M. O., Li, J., Yao, X., Li, S., & Yan, H. (2020). HIV Disclosure Patterns and Psychosocial Correlates Among People Living with HIV in Nanjing, China: A Latent Class Analysis. *AIDS Research and Human Retroviruses, 36*(3), 220–226. https://doi.org/10.1089/aid.2019.0212

Yin, Y., Yang, H., Xie, X., Wang, H., Nie, A., & Chen, H. (2019). Status and associated characteristics of HIV disclosure among people living with HIV/AIDS in Liangshan, *China. Medicine, 98*(31), e16681. https://doi.org/10.1097/md.0000000000016681

Annex:

APPENDEX A: INTERVIEW SCHEDULE

अन्तरवार्ता अनुसुची

(INTERVIEW SCHEDULE)

१. समाजिक र जनसांख्यिकीय विवरण (1. Socio-demographic Details)

१.१. नाम (1.1. Name) ……..

१.२. उमेर (1.2. Age) ……

१.३. लिगं (1.3. Sex) …….

क. महिला ख. पुरुष ग. अन्य

१.४. जाति (1.4. Ethnicity) ……...

क. बाह्मण/क्षेत्री/ठकुरी (a. Brahman/Chhetri/Thakuri) ख. नेवार (b. Newar) ग. जनजाती (c. Ethnic) घ. दलित (d. Dalit) ङ. अन्य (e. Other).....

१.५. पेशा (1.5. Job) …….

१.६. मासिक पारिवारिक आम्दानी (1.6. Monthly Family Income) …….

१.७. तपाईको आम्दानीले बर्ष दिनको खर्च पुग्छ? (1.7. Is your income enough to sustain your yearly expense).....

१.८. यदि पुग्दैन भने त्यसको लागि के गर्नु हुन्छ? (1.8. if not enough how do you manage)

क) परिवारबाट (from family) ख) ऋण (b. loan) ग) सम्पती बेचेर (c. by selling properties) घ) अन्य (d. other).....

१.९. शैक्षिक योग्यता (1.9. Educational Qualification)…….

१.१०. पारिवारिक प्रकार (1.10. Family Type)

क. एकल (a. Nuclear) ख. संयुक्त (b. Joint) ग. बृहत (c. Extended)

१.११. वैवाहिक स्थिति (1.11. Marital Status) ……

१.१२. धर्म (1.12. Religion)

क. हिन्दु (a. Hindu) ख. बौद्ध (b. Newar) ग. ईसाइ (Christian) घ. मुस्लिम (d. Muslim) ङ. अन्य (e. Other).....

१.१३. निवास (1.13. Residence)

क. भाडामा (a. Rent) ख. आफ्नै निवास (b. Own resident) ग. पुर्नस्थापना केन्द्रमा (c. Shelter) घ. अन्य (d. Other) .....

१.१४. तपाईलाई एच.आई.भी संक्रमित कसरी हुनु भएको हो? (1.14. How did you got infected with HIV?)

क) असुरक्षित यौन (a. unsafe sexual activity) ख) संक्रमित रगतबाट (b. infected blood transfusion) ग) अविभावक बाट (c. from parents) घ) सुइ बाट (d. infected syringe) ङ) अन्य (e. others).....

२. कृपया मलाई बताउन सक्नुहुन्छ कि तपाईलाई एच.आई.भि. संक्रमन कसरी भयो र सो बारेमा कसरी थाहा पाउनुभयो? (थप स्पष्टता: कति समय अगाडी? त्यो समयमा तपाईलाई कस्तो लाग्यो? पछाडि हेर्दा, तपाईलाई त्यो समय कस्तो लाग्छ?) (2. Can you please tell me how you found out you had HIV. (Prompts: How long ago? How did you feel during that time? Looking back, how do you feel now about that time?)

३. तपाईंले आफु एच.आई.भी संक्रमित भएको कसलाई भन्नुभयो? (थप स्पष्टता: तपाईंले सो बारेमा कहिले भन्नुभयो? कस्तो प्रतिक्रिया देखाए? तपाईं एच.आई.भी संक्रमित हुनुहुन्छ भनेर अरूलाई बताउँदा तपाईंलाई कस्तो लाग्यो? जब तपाईंले अरूलाई भन्नुभयो, तपाईंको परिवार, साथी, समुदाय, रोजगारदाता र अन्यबाट कस्तो प्रतिक्रिया दिनुभयो?
(3. To whom did you disclose your HIV status? (Promts: When did you tell them? How did they respond? How did you feel about telling others that you are HIV positive? When you told others, how did your family, your community, and your place of employment respond?)

४. तपाईको जीवनमा तपाईको परिवार, साथी, समुदाय, सामाजिक, संस्थागत (विधालय, अस्पताल, धार्मिक स्थल आदी) एच.आई.भी. संक्रमित भएको कारणले लान्छना वा भेदभाव महसुस गरेको घटनाको बारेमा मलाई बताउनुहोस् । के तपाई लाग्छ कि, तपाई एच.आई.भी संक्रमित भएको थाहा पाएको कारणले यी अवस्थाहरू उत्पन्न भयो?
(4. Tell me about any instances in your life that you felt stigmatized because of having HIV in your family, friends, neighborhood, community and society, intuitionally, in hospital, at work place. Do you believe that because others knew you had HIV, these situations occurred?)

५. के तपाइँ एच.आई.भी.मा सहयोग प्रदान गर्ने कुनै समूह, सन्जाल वा सामुदायिक संस्थामा संलग्न हुनुहुन्छ? सो निकायमा आबद्ध हुने विधि के थियो ? (5. Do you participate or involve in any groups/community/network/organization that works for HIV support? What was your method of getting involve in this organization?)

६. तपाईंले आफ्नो जीवनलाई एच.आई.भी. सगँ सम्बन्धित लान्छाना र भेदभाव विरुद्ध सहयोग प्राप्त गर्नु भएको छ? (थप स्पष्टता: परिवार, साथी, समुदाय, सामाजिक, संस्थागत (विधालय, अस्पताल, धार्मिक स्थल, रोजगारदाता आदी)

(6. In what other ways has your life been supported? (Prompt: Family, Friends, community, social and institutional organizations like school, hospital religious site, employer etc.)

७. के तपाइँ लान्छाना र भेदभाव तपाइँको स्वास्थ्यका लागि ठूलो व्यवधान हो जस्तो लाग्छ? किन विश्वास गर्नुहुन्छ ? (थप स्पष्टता: लान्छाना र भेदभावका कारण स्वास्थ्य सेवामा असर, वा मानसिक तनाव आदी)

(7. Do you think stigma or your health pose a greater threat to you? Why do you believe that? (Prompts: due to stigma and discrimination problem in health care, depression or non-adherence in ART services))

८. के तपाइँ नेपालमा एच.आई.भी. संग सम्बन्धित लान्छना र भेदभाव छ भन्ने विश्वास गर्नुहुन्छ? नेपाली समाज वा संस्कृतिमा एचआइभी संक्रमित व्यक्तिहरू विरुद्धको लान्छाना वा भेदभावलाई सहयोग वा बढावा वा प्रोत्साहन गर्ने पक्षहरू के छन्?

(8. Do you believe that there is stigma associated with HIV in Nepal? Exist any facets of Nepalese society or culture that support the stigma against HIV-positive individuals?)

९. के तपाईंले अन्य एच.आई.भी संक्रमित व्यक्तिहरूबाट लान्छना र भेदभावको कुनै उदाहरण सुन्नुभएको छ? यदि छ भने, के तपाइँले सुनेका केहि घटनाहरु बताउन सक्नुहुन्छ? ती घटनाहरूबाट तपाईलाई कस्तो प्रभाव वा महसुस भयो? के तपाईंले त्यसता घटनाहरूबाट बच्न वा नपर्नका लागी कुनै सावधानी अपनाउनुभयो?

(9. Have you heard of any instances of stigma from other HIV-positive individuals? If yes, could you elaborate on some of the stories you have heard others tell you? What impact did you feel from those stories? Did you take any precautions to avoid being impacted by these stories?)

१०. मलाई कुनै त्यस्तो घटनाको बारेमा बताउनुहोस् जसमा तपाईंले आफु एच.आई.भी संक्रमित भएको कारणले कठिन परिस्थितिमा पर्नुभयो । तपाईंले यी परिस्थितिहरूलाई कसरी सामना गरि आफ्नो राम्रो जीवनको सुनिश्चित गर्नुभयो? तपाईंले के स्रोतहरु प्रयोग गर्नुभयो?

(10. Tell me about any instances in which you felt that your HIV was putting you in a tough situation. How did you handle these circumstances and overcome them to create a better life for yourself? Which sources did you make use of?)

११. तपाईंले आफु एच.आई.भी. संक्रमित भनेर थाहा पाउनु भएको क्षण सम्झनुहोस्। एचआईभी सँगै जीवन बिताउन तपाईंलाई कसरी असर गरेको छ? (थप स्पष्टता: एच.आई.भी. संक्रमन पछि तपाईको जीवनमा परेका सकारात्मक र नकारात्मक पक्षहरु)
(11. Recall the moment you received your HIV diagnosis. How has living with HIV affected you? (Prompts: The positive and negative impact on you life after you got HIV infection))

१२. के तपाईंले आफु एच.आई.भी. संक्रमणका कारणले मानसिक तनाव वा डिप्रेसनको समस्यामा पर्नुभएको छ? तपाईंले यसलाई कसरी सामना गर्नुभएको छ?
(12. Have you ever experienced anxiety or depression since your diagnosis? How have you coped with that?)

१३. एच.आई.भी. संक्रमण सम्बन्धि लान्छना र भेदभावको कारणले गुणस्तरिय वा राम्रो जीवन बिताउनका लागी तपाईंले के लक्ष्यहरू बनाउनुभयो? के तपाईंले आफ्नो उद्देश्यहरू प्राप्त गर्न सफल हुनुभयो? (थप स्पष्टता: यदि त्यसो हो भने, कसरी? यदि ती सबै होइन भने, तपाईंले पहिले नै कुन लक्ष्य प्राप्त गर्नुभएको थियो (वा अनुभव गर्नुभएको थियो)? तपाईंले आफ्नो रणनीतिहरू कसरी पूरा गर्नुभयो? यदि कुनै छैन भने, तपाईंको विचारमा, किन छैन?
(13. What goals did you make to live a better life in the wake of HIV prejudice and stigma? Did you succeed in achieving your objectives? (Prompts: If so, how? If not all of them, then what fraction have you already received (or experienced)? How did you carry out the strategies you achieved? If none, in your opinion, why not?

१४. तपाईंको विचारमा एच.आई.भी. संक्रमणले तपाईंको सामाजिक स्थितिलाई कसरी प्रभाव पारेको छ वा परिवर्तन गरेको छ? (थप स्पष्टता: तपाईंको जीवनमा सहायताका स्रोतहरू वर्णन गर्नुहोस्। तपाईंलाई कस्ता स्रोतहरूले बल प्रदान गरेको पाउनु ुभयो?
(14. How has HIV influenced or altered your social status, in your opinion? (Prompt: Describe the sources of assistance in your life. What sources of strength do you find?)

१५ तपाईं एच.आई.भी. संक्रमित भएको थाहा पाउनु भए पछि तपाईंको आफ्नो जीवनको बारेमा वर्णन गर्नुहोस् । तपाईले चुनौतीहरू र समस्याहरु कसरी सामना गर्नुभयो ?

(15. Describe your life following your HIV diagnosis. How do you handle challenges?)

१६. के तपाईले आफ्नो भविष्यका लक्ष्यहरूको बारेमा बताउन सक्नु हुँन्छ ।

(16. Tell me about your future goals.)

समाप्त

(The End)

APPENDEX B: LIST OF PARTICIPANTS

S.No	Pseudonym	Age Range	Sex
1	Ram	41-50	M
2	Laxmi	41-50	F
3	Reeta	41-50	F
4	Saraswoti	41-50	F
5	Gita	21-30	F
6	Nisha	41-50	F
7	Laxman	41-50	M
8	Aamir	41-50	M
9	Mina	31-40	F
10	Deena	51-60	F
11	Prakash	41-50	M
12	Ganga	51-60	F
13	Seema	41-50	F
14	Bikash	41-50	M
15	Prakriti	41-50	F
16	Mamata	41-50	F
17	Ratnamaya	41-50	F
18	Sunita	31-40	F
19	Narmada	41-50	F
20	Kabita	41-50	F
21	Dinesh	51-60	M
22	Umesh	51-60	M
23	Goma	41-50	F
24	Ganesh	41-50	M
25	Anil	21-30	M
26	Suresh	41-50	M
27	Sahiba	51-60	F
28	Neha	41-50	F
29	Harimaya	41-50	F
30	Anju	31-40	F
31	Ranju	31-40	F
32	Bina	41-50	F
33	Rima	31-40	F
34	Sarita	31-40	F
35	Urmila	41-50	F
36	Ranjita	41-50	F
37	Kamala	21-30	F
38	Dolma	31-40	F
39	Bidhya	41-50	F
40	Indu	31-40	F
41	Sukumaya	41-50	F
42	Dilkumari	41-50	F
43	Kumari	41-50	F
44	Krishna	41-50	F
45	Sunila	41-50	F
46	Rammaya	41-50	F
47	Binita	31-40	F
48	Suryamaya	51-60	F
49	Sushma	31-40	F
50	Puspa	21-30	F
51	Rojina	21-30	F
52	Mahima	41-50	F
53	Manisha	31-40	F
54	Devaki	41-50	F
55	Ramita	41-50	F
56	Durga	41-50	F
57	Mahesh	41-50	M
58	Parbati	41-50	F
59	Shanti	51-60	F
60	Preeti	21-30	F

APPENDEX C: LIST OF KEY INFORMANTS

S.No	Pseudonym	Age Range	Sex	Role	Organization
1	Padam	41-50	M	HIV activist	NAPN+
2	Devi	51-60	F	PLHIV leaders	Shakti Milan Samaj
3	Setu	31-40	F	IDU PLHIV leaders	Recoverying Nepal Women
4	Kirti	31-40	F	PLHIV activist	Maiti Nepal
5	Pragya	31-40	F	Peer educator and PLHIV leaders	Shanti Foundation

APPENDIX D: CASE STUDIES

CASE 1: Kamala (name changed), 29 years old, female

Kamala is a 29 years old female she is originally from Kavre and now living in KMC and due to poverty she got engaged as female sex worker. During 2075 when she got pregnant, she came to know about her HIV status. She was totally frighten and terrified and self-blame herself for HIV infection though now she took it in normal way and taking regular medication for sake of her child, and had also taken the insurance card as provided by Nepal Government and she had disclosed it to her family only and not being able to disclosed it to other due to the fear of bad behavior, as the society take HIV infection is due to bad moral character and it's also communicable infection with no completely curative medications. She is now living alone with no contacts with anyone and maintaining the HIV status secret and also removed the label of medicine and if anyone ask she shared that she is taking heart medication. Due to PMTCT, her new borne child was not infected with HIV. Since my husband was also with me, he instantly knows my HIV status. Her husband also did HIV test and he was found to be HIV negative. Initially, her husband was supportive, it's our fate, though she told him to leave her but he denied and said that he will stay with her. Later, after sharing her HIV status to her husband family and they were not supportive and began to stigmatized and discriminate her, then her husband in the influence of her in-laws began to change his behavior and he remarried and she was expelled from home and they also took control of her son. She had also been stigmatized and discriminated in healthcare center as well, as she has got stones in kidney and lesion in her intestine. She visited the hospital in Kavre, where she was denied treatment due to her HIV status after that she had not visited the hospital. She is not in contact with any peer support or organization. She thinks she should not think much about the HIV and its related stigma and discriminations and need to divert form such kind of things. She have got no such big plans for future just hope that she will be able to fulfill my basic needs.

CASE 2: Ganga (name changed), 59 years old, female

Ganga (name changed) is 59 years old female, her husband used to work in India and came back after being prolonged illness after the diagnosis of HIV, he died after one month of return. For one year she thought that she had not been infected

with HIV. During visit in hospital she came to know about her HIV status but all of her five children were found negative. She was frighten and feels that she got HIV due to her past life bad deed she got infected and all of my family, community members came to know about my HIV status, and my children were also expelled from school, her family members and community also segregated her and her children, didn't allow her children to play with other, separated eating and sleeping places. After which one of the health post staff referred her along with her children to HIV shelter in KMC, from where she was reintegrated in Kathmandu. She faced stigma and discriminated in hospital where she wasn't provided service due to her HIV status, similarly once she was employed in school as a kitchen helper, where she believe that one of her relative revealed her HIV status after which the school management forced her to do HIV test and when it came positive she was expelled from school and also didn't pay her 15 days giving reasons that it would be risk to the children and the parents and community will have negative impact. Furthermore, in her youngest daughter marriage, the groom break the relations and denied the marriage due to her HIV status, she is bit worried for her daughter. She has got the peer support and linked with HIV network and organization due to which she now doesn't feel alone, she regularly joins organization and network meeting that has developed the sense of unity and she also got support, for her livelihood and now she is running shop and she has got no plan but to get her younger daughter married then she wish if there is any shelter for HIV she would got there and live rest of her life.

CASE 3: Puspa (name changed), 28 years, female

She got HIV infected due to her husband who after prolonged illness died after which she also came to know about her HIV status. She couldn't believe it and after confirmation she felt her life worthless and began to take the depression medicines and she tried to end her life for several times and left the medication for nearly 2 years but later for the sake of her son she began the ART. And due to her husband medication all the community, family members know about her HIV status. Her family used to regularly tell her to use separate utensils, towels, combs etc. and even blamed her for the HIV infection, all her friends didn't talk with her or come near to her, her neighbor kept distance with her and she became the gossip topic in her village, her children were expelled from school due to her HIV status, after which she came to decision to migrate to Kathmandu as the condition in her village became

highly unbearable to her. She thinks that due to the hatred towards PLHIV and since HIV need life time medication and if its left then people die and its also the communicable disease that need medicines due to these fear the people showed stigma and discrimination towards her. After migrating to KMC she remained in her rented room only and rarely came out, she removed the labeled of her medicines also, and kept her HIV status with her only. But during the visit to the ART center she got to know the peer support and linkage to HIV network and organization after which she didn't felt along and develop sense of unity, from the organization she was able to develop better knowledge of HIV and positive self esteem and sefl care and got access to Health insurance and child education support as provided by Nepal Government. She hope that she will be more economically independent is she find job after which she can also support her child better future.

Case 4: Kumari, female, 43 years old

She got HIV infection from her husband who was an intravenous drug user, she got sick and when she went to checkup, she found her HIV status including her husband. She got very frightened due to the fear of death. Her husband took it in normal way, Her family knows about her HIV status and they are supportive to her and frequently give her encouragement and reminds to take medicines on time. Beside that she has not disclose her status to other due to the fear of unacceptability and the society views the people living with HIV in negative sense and connect us to prostitution, durg used etc. She when disclosed her HIV status in hospital the health professional were shocked and they fear to even touch her. She got linked with organization and peer support group due to the referral of medical professional after which she thinks had a positive impact in her life especially knowing other people living with HIV she got he sense of self confidence and build up unity and through netowork and organization she was able to generate her knowledge on HIV and got the opportunity for economic independence. She think that the HIV stigma and discrimination are very low now but it still exist and mainly the HIV stigma and discrimination is due to the link of HIV infection to prostitution, drug used which is taken as bad in the society so the if I disclose that I am HIV positive, I am also linked with it and can get stigmatized and discriminated. Further, people don't know the mode of its transmission and have misconception on this and fear of getting HIV

infected and lifelong medication requirement is the prime factors for HIV stigma and discrimination.

Case 5: Gita (name changed), 25 years old

After 15 days of marriage she became severely ill, otherwise she used to quite healthy person and when checked she came to know about her HIV status including her husband, she couldn't believe it she was completely in shock. Initially her family and in laws blamed her for the HIV infection and suspected her characters but later she came to know that her husband has been to Malaysia and he returned after the prolonged sickness where as prior to marriage she has been doing regular checkup and had no record of HIV infection. But since she did the HIV checkup in nearby clinic her family HIV status was known by all the villages and their behavior became quite different, then she along with her husband migrated to Kathmandu, where she used to engaged in daily wage labor and now she is jobless and hope that she will gets some job so that it will be easier for her to handle her daily expenses. She has been stigmatized and discriminated due to her HIV status in hospital where the nurse fear to touch her, and wore more than one gloves, behave her differently, stayed in distant and publically reveal her HIV status without her consent.

APPENDIX E: CONSENT FORM

Oral Consent (to be used in conjunction with short form written consent)

STUDY TITLE:

INVESTIGATOR:

BACKGROUND AND PURPOSE: You are being asked to take part in a research project, which is being organized for the completion of MPhil Sociology thesis, Tribhuvan University of Prabin Shakya. The purpose of this research is to learn about the people living with HIV and AIDs experience of of HIV and AIDS stigma and discrimination, its support mechanism and coping and resilience. My research is contributing to generate sociological analysis of stigma and discrimination on HIV and you are in a position to provide me with insight into the situation, and I would appreciate it if we could interview you.

PROCEDURES: The format of the interview will be an interview and discussion. I expect that the interview will take no longer than 1 hour. With your permission, I will audiotape the interview solely for the purposes of accurately transcribing the conversation. With your permission I would also like to take photographs. The audiotapes and photographs, as well as the transcriptions will be stored securely and destroyed after the completion of study. The photographs will be used to present our research at the University.

CONFIDENTIALITY AND RISK: There is some risk involved if, for example, you divulge confidential information. Therefore, if you wish pseudonyms to be used to protect your privacy and confidentiality, I will be happy to do so. Alternately, if you wish to be quoted by name on anything in particular I am also happy to accommodate this request. Please know though that you do not have to answer any questions or discuss any topics that make you feel uncomfortable.

WITHDRAWAL OF PARTICIPATION: Should you decide at any time during the interview or discussion that you no longer wish to participate, you may withdraw your consent without prejudice.

COSTS BENEFITS TO YOU: There are no direct costs involved with participation, although you may miss an hour of work and possibly pay for that time. There are also no direct benefits to you. However, your participation will contribute to a greater awareness Sociological analysis of HIV stigma.

REQUEST FOR MORE INFORMATION: You may ask more questions about the study at any time.

SIGNATURE: I confirm that the purpose of the research, the study procedures, the possible risks and discomforts as well as benefits have been explained to the participant. All questions have been answered. The participant has agreed to participate in the study.

Signature of Person Obtaining Consent Date

STUDY TITLE:

INVESTIGATOR:

Short-Form Written Consent

I confirm that the researcher has explained the elements of informed consent to the participant. The subject knows that their participation is voluntary, and that they do not need to answer all questions. The purpose of the research as well as the risks and benefits have been explained. The procedures as well as the time commitment have been outlined. The participant understands issues of confidentiality.

I agree to be audio-taped (it will be destroyed after the completion of research)	YES/NO Initial
I agree to be photographed	YES/NO Initial
I agree to be videotaped	YES/NO Initial
I agree to use my name	YES/NO Initial

Witness Name ……
Witness Signature …….
Participant Name ……..
Participant Signature …….

सुचित मौखिक सहमति

अध्ययन शीर्षक:

शोधकर्ता:

भुमिकाः प्रवीण शाक्यको त्रिभुवन विश्वविद्यालय एमफिल समाजशास्त्र थेसिस पूरा गर्नका लागि आयोजना हुन लागेको अनुसन्धानमा सहभागी हुन आग्रह गर्दछु। यस अनुसन्धानको उद्देश्य एचआईभी र एड्स संक्रमित व्यक्तिहरूले एचआईभी र एड्स लान्छना र भेदभावको अनुभव, यसको सहयाता संयन्त्र र सामना गर्ने र उथ्थानशिल को बारेमा जानको लागी गरिएको हो । मेरो अनुसन्धानले एचआईभी मा लान्छना र भेदभावको समाजशास्त्रीय विश्लेषणमा योगदान गर्ने छ र यस शोध कार्यका लागी म तपाइके सहयोको लागी अनुरोध गर्दछु।

प्रक्रियाहरू: यस शोध कार्यको ढाँचा अन्तर्वार्ता र छलफल हुनेछ। म आशा गर्छु । यो अन्तर्वार्ताको समय १ घण्टा भन्दा बढी लाग्ने छैन । तपाईंको अनुमतिको साथ, म कुराकानीलाई सही रूपमा ट्रान्सक्राइब गर्ने उद्देश्यका लागि मात्र अन्तर्वार्ता अडियो टेप गर्नेछु। तपाईको अनुमतिले म पनि फोटो खिच्न चाहन्छु। अडियोटेपहरू र फोटोहरू, साथै ट्रान्सक्रिप्सनहरू सुरक्षित रूपमा भण्डारण गरिनेछ र अध्ययन पूरा भएपछि नष्ट गरिनेछ। फोटोहरू विश्वविद्यालयमा हाम्रो अनुसन्धान प्रस्तुत गर्न प्रयोग गरिनेछ।

गोप्यता र जोखिम: यदि, उदाहरणका लागि, तपाईंले गोप्य जानकारी दिनुभयो भने त्यहाँ केही जोखिम रहने छ। तसर्थ, यदि तपाइँ तपाइँको गोपनीयता र गोपनीयता को रक्षा गर्न छद्मनाम प्रयोग गर्न चाहनुहुन्छ भने, म त्यसो गर्नेछु। वैकल्पिक रूपमा, यदि तपाईं कुनै पनि कुरामा नामद्वारा उद्धृत गर्न चाहनुहुन्छ भने, म यो अनुरोधलाई समायोजन गर्नेछु। कृपया म तपाइलाइ यो जानकारी दिन चाहान्छु कि यदी कुनै पनि प्रश्नको जवाफ दिन चाहानु हुन्न वा तपाईंलाई असहज महसुस गराउने कुनै पनि विषयहरू छलफल गर्न आवश्यक रहने छैन।

सहभागिता फिर्ता लिनु: यदि तपाईंले अन्तर्वार्ता वा छलफलको क्रममा कुनै पनि समयमा निर्णय गर्नुभयो कि तपाईं अब भाग लिन चाहनुहुन्न भने, तपाईंले कुनै पनि पूर्वाग्रह बिना आफ्नो सहमति फिर्ता लिन सक्नुहुन्छ।

खर्च वा लागत र लाभहरू: तपाइँले एक घण्टाको काम गुमाउन सक्नुहुन्छ तर यस शोध कार्यमा अन्य कुनै लागत रहने छैन । तपाइँलाई कुनै प्रत्यक्ष लाभ पनि छैन। यद्यपि, तपाईको सहभागिताले एचआईभी र एड्स सम्बन्धी लान्छना र भेदभावको समाजशास्त्रीय विश्लेषणलाई योगदान पुऱ्याउनेछ।

थप जानकारीको लागि अनुरोध गर्नुहोस्: तपाईंले कुनै पनि समयमा अध्ययनको बारेमा थप प्रश्नहरू सोध्न सक्नुहुन्छ।

हस्ताक्षर: म पुष्टि गर्दछु कि अनुसन्धानको उद्देश्य, अध्ययन प्रक्रियाहरू, सम्भावित जोखिमहरू र असुविधाहरू साथै लाभहरू सहभागीहरूलाई व्याख्या गरिएको छ। सहभागीहरूका सबै प्रश्नहरूको जवाफ दिइयो। सहभागी अध्ययनमा भाग लिन सहमत हुनु भएका छन्।

सहमति मिति प्राप्त गर्ने व्यक्तिको हस्ताक्षरः

अध्ययन शीर्षक:

शोधकर्ता:

सुचित लिखित सहमति

म पुष्टि गर्छु कि अनुसन्धानकर्ताले सहभागीलाई सूचित सहमतिका तत्वहरू व्याख्या गरेको छ। विषयलाई थाहा छ कि उनीहरूको सहभागिता स्वैच्छिक छ, र उनीहरूले सबै प्रश्नहरूको जवाफ दिन आवश्यक छैन। अनुसन्धानको उद्देश्यका साथै जोखिम र फाइदाहरू व्याख्या गरिएको छ। कार्यविधि र समय प्रतिवद्धता पनि उल्लेख गरिएको छ। सहभागीले गोपनीयताका मुद्दाहरू बुझ्छन्।

म अडियो टेप गर्न सहमत छु (यो अनुसन्धान पूरा भएपछि नष्ट गरिनेछ)	छु/छैन
म फोटो खिच्न सहमत छु	छु/छैन
म भिडियो टेप गर्न सहमत छु	छु/छैन
म मेरो नाम प्रयोग गर्न सहमत छु	छु/छैन

साक्षीको नाम .....

साक्षीको हस्ताक्षर .....

सहभागीको नाम .....

सहभागी हस्ताक्षर .....