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# **The Reconstruction of Identity in People Living with HIV in Nepal**

**A thesis submitted in partial fulfilment of the requirements  
for the degree of Doctor of Philosophy**

**Massey University, Albany  
New Zealand**

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## **Dedication**

I dedicate this thesis to my illiterate parents and grandparents, my mother, Chetana Aryal, and father, Ngachchha Prasad Aryal, and grandmother, Gita Aryal, and grandfather, Dandapani Aryal, who never attended any school, but who dreamed, and pampered and navigated me towards my education.



## **Abstract**

This research is about the experiences of people living with HIV (PLHIV) in Nepal, especially with regard to the processes of reconstructing their identities. The processes of identity reconstruction include migration, concealing and disclosing HIV status, movement towards economic independence, gaining knowledge on Human Immuno-deficiency Virus (HIV) and Acquired Immuno-deficiency Syndrome (AIDS), practising HIV treatment, receiving support of organizations, and practising spirituality. Despite the availability of some studies on HIV and AIDS in Nepal, most have focused on epidemiological facts. There is a dearth of Nepalese HIV and AIDS literature on identity reconstruction of PLHIV.

This study investigated the lived experiences of 33 PLHIV related to their HIV stigma, discrimination and identity issues in Kathmandu and Pokhara valleys in Nepal, using semi-structured, face-to-face, in-depth interviews. The field data were analysed using a thematic, meaning-making approach. This research contributes to HIV literature by showing that the economic stigma and discrimination due to HIV experienced within a family are often stronger than social stigma and discrimination. This research proposes a model entitled “the reconstruction of identity in PLHIV in Nepal”, based on the data derived in an inductive way from the two research sites, then moving from data to theory. There are various stages of identity ranging from spoiled to reconstructed. This proposed identity model is based on the economic and social empowerment of the PLHIV, together with identity transformation from one stage to another, and the situations participants experience in the contemporary Nepalese socio-political context.

The identity of PLHIV is fluid and non-linear. This research suggests that access to resources often determines the degree of family and social stigma and discrimination. Moreover, PLHIV also reunite with both family and society *after* becoming economically independent and socially empowered. Indeed, HIV has been a catalyst, especially for in-migrant women with limited access to resources. This study has significant policy implications for improving the quality of life for PLHIV, reducing family and social stigma and discrimination as well as reconstructing their identity in Nepal, and in South Asian countries with similar socio-cultural and economic settings.

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## Acronyms

AIDS– Acquired Immuno-deficiency Syndrome

ARV – Antiretroviral

*BS – Bikram Sambat* (Nepali calendar year, around 57 years ahead of the English calendar)

CBOs – Community Based Organizations

FPAN – Family Planning Association of Nepal

HIV – Human Immuno-deficiency Virus

IBBS – Integrated Biological and Behavioural Surveillance

IEC – Information Education and Communication

INGOs – International Non-governmental Organizations

MDGs – Millennium Development Goals

MSM – Male Having Sex with Male

MUHEC – Massey University Human Ethics Committee

NAC – National AIDS Council

NGOs – Non-governmental Organization

NHRC – Nepal Health Research Council

PLHIV – People Living with HIV

PPTCT – Prevention of Parent to Child Transmission

STD – Sexually Transmitted Disease

UNAIDS – Joint United Nations Programme on HIV/AIDS

UNESCO – United Nations Educational, Scientific and Cultural Organization

UNGASS – United Nations General Assembly Special Session

VDC – Village Development Committee

## Glossary of Terms

*Bahini* – Younger sister

*Bhakal* – Promise

*Brahman* – The highest group of castes in the hierarchy of the caste system

*Brata-* –Fasting

*Dai* – Elder Brother

*Dalit* – Those people belonging to the lowest socio-economic and caste groups

*Dashain* – The biggest Hindu festival

*Doro* – Sacred thread

*Garun Puran* – A religious Hindu book preaching during the days of a funeral

*Gurkhas* – Soldiers in the British army originating from Gorkha, Nepal

*Janai Purnima* – A Hindu festival day when people put sacred thread on their wrist

*Kshetree* – The second highest group of castes in the hierarchy of the caste system

*Muglan* – A strange place

*Nag* – Serpent (the shape of a serpent made with flour)

*Newar* – People belonging to *Vaishya* in the hierarchy of the caste system

*Panchayat* – A party-less political system of Nepal from 1961-1990

*Pandit* – Priest

*Phohori* – Yucky

*Puja* – A religious programme worshiping gods and goddesses

*Rana* – Rulers of Nepal on the basis of dynasty from 1846 till 1951

*Rashtriya Panchayat* – Parliament of Nepal during the period 1961-1990 when kings ruled

*Sudra* – The lowest group of castes in the hierarchy of the caste system

*Swasthani* – A Hindu book worshiping the goddess of the same name

*Terai* – Plain area of southern Nepal running from east to west

*Tihar* – The second biggest Hindu festival

*Vaidhya* – Herbal medicine healer

*Vaishya* – The third-highest group of castes in the hierarchy of the caste system



# **Chapter One: Introduction**

## **1.1 Background**

This study is about the experiences of PLHIV in Nepal, especially with regard to the stages and the processes of their identity reconstruction following their HIV diagnosis. PLHIV are generally perceived as being in a state of “spoiled” identity, associated with HIV stigma, discrimination and life disruption after being HIV diagnosed. However, not all PLHIV experience this, though many in this study have, especially early after their diagnoses. This study explores how HIV stigma and discrimination, as well as a person’s identity status, are impacted by the HIV infected persons’ access to resources and gender power relationships, along with the ways in which their HIV is discovered. The research explains the processes of identity reconstruction in terms of transitional identity and reconstructed identity.

PLHIV work through the processes of identity reconstruction after their discovery of HIV despite family, societal and institutional stigma, discrimination and disruption (Baumgartner, 2007; Tsarenko & Polonsky, 2011). This is because discovery of HIV in their lives provides opportunities not only to prolong their life expectancy, but also to improve their health and physical appearance for their own satisfaction, and in the eyes of other people surrounding them. This develops self-esteem as they move into their future, alongside positive socio-economic changes that further improve their identity in respect of their families and societies. PLHIV gradually reconstruct their identities by managing the stigma, discrimination and disruption they have faced in their lives within families and societies as well as by empowering themselves to live with an HIV-positive status (Tsarenko & Polonsky, 2011). After struggling with the transitional

identity stage of identity reconstruction, PLHIV experience a marked improvement in their identity, namely, a reconstructed identity as they progressively overcome their issues of stigma and discrimination. Management of stigma and discrimination is aided by improving their health and socio-economic status.

Nepal's relatively recent socio-political changes are presumed to have created a supportive environment in transformation of the identity status of PLHIV in the country. This study focuses on the lived experiences of PLHIV in a scenario of a changing political situation and socio-cultural transformation, together with attempts to integrate HIV and AIDS programmes into the mainstream of development activities in the country. Going back in Nepal's political history, the new civil code of 1963, the *Panchayat* (a party-less political system), stated that all citizens are equal, irrespective of caste and tribes, and it prohibited untouchability (Central Bureau of Statistics, 1987). However, such values could not forge ahead in a Nepalese feudal society. Therefore, a significant movement took place in the country in 1990: firstly the *Panchayat* system was overthrown, and replaced by a multi-party democracy. Later, the "People's War" (or "Maoist War") from 1996-2006 was joined by a "second movement" of 2006, with the then underground Maoist party and most other political parties, in order to fight against feudalism and the kingship regime. These political movements have weakened the pillars of feudalistic Nepalese society, and have gradually restored people's human rights, focusing on marginalised communities with a view to attaining gender, caste, and class equality (Yami, 2007). Within such a situation, this study has significance in regard to one of the marginalised and ostracised groups of people, the PLHIV in Nepal, following the discovery of HIV in the country in 1988 (Joshi, Banjara, Subedi, Sharma, & Karki, 2004).

## **1.2 Research Problem**

Since the beginning of the epidemic of HIV and AIDS, the stigma attached to HIV identification has been one of the major problems needing to be overcome. People who define themselves as inherently different are perceived as damaged or dangerous (Goffman, 1963). HIV stigma and discrimination leads to identity crises, isolation, loneliness and low self-esteem (Valdiserri, 2002). In 2011, the United Nations reflected back over three decades of the HIV pandemic. The Secretary-General noted substantial human rights and treatment successes, but described these as “insufficient and in jeopardy”, because stigma and oppression continue to undermine efforts to achieve prevention, testing, care, and treatment goals (United Nations, 2011, p. 1). The United Nations declared that HIV is an urgent international issue, and stated that “the HIV response faces a moment of truth” (United Nations, 2011, p. 3). As elsewhere, there is an urgent need to substantially reduce the number of PLHIV, with a view to getting zero new HIV infections, zero discrimination, and zero deaths in Nepal, as set out in the Millennium Development Goals (MDGs) by 2015 (Lawn, 2012; Ministry of Health and Population, 2011).

The study of HIV and AIDS in the lives of PLHIV, as well as intervention strategies in reduction of stigma and prevention of HIV and AIDS, all contribute greatly to the achievement of the United Nations’ MDGs of halting and reversing the spread of the HIV and AIDS epidemic. A deep understanding of the reconstruction of identity in PLHIV is now a very important issue. This is because the complex phenomena of mobility, sexuality, HIV and AIDS, stigma and discrimination, spoiled identity, integration in PLHIV’s network, all intersect within the wider social, political, economic and cultural structures and processes to position PLHIV at different stages of



identity (Thomas, Haour-Knipe, & Aggleton, 2010; Tsarenko & Polonsky, 2011; UNAIDS, 2010). There is “an endless process of negotiation whereby the individual’s identity is reconstructed” (Tsarenko & Polonsky, 2011, p. 466). This includes an involvement of PLHIV in social networks.

In dealing with the Nepalese context, this research begins with the basic premise that most previous studies have focused on epidemiological data on HIV and AIDS. There are now growing concerns about HIV-related stigma and discrimination in PLHIV in Nepal. However, there is a dearth of research on the impacts on identity of family and social stigma, discrimination and life disruption. Therefore, this study focuses on stigma associated with HIV and its resulting impacts on the identities of PLHIV. Importantly, findings of earlier research with regard to HIV stigma, discrimination and disruption have conventionally been associated with homosexuality, heterosexuality with multiple partners, partner’s multiple sexual partners, substance usage, and cultural perspectives on people’s karma. However, there has been only limited study of the roots of stigma, discrimination, and the disruption of human needs (marriage, sex, social relationship, etc.) in PLHIV. Therefore, this study intends to identify the sources of HIV stigma and discrimination in family and society so that the findings might help to improve the quality of lives of PLHIV.

This research concerning PLHIV has been undertaken following the researcher’s previous related experiences, and to some extent from previous research related to HIV. I have been engaging in research work related to migration, sexuality, contraception, and HIV issues for more than ten years. Recent research, entitled “HIV and AIDS Prevalence in the Pokhara Valley” (Aryal, Tiwari, Thapa, & Pandey, 2011) supported

by the United Nations Population Fund-Nepal, was headed by me as a principal investigator with a team, before I commenced my PhD research. This background encouraged me to undertake further research in this area. Although this 2011 research was undertaken using mainly quantitative methodology, it also captured people's lived experiences of stigma and discrimination, involving some semi-structured questionnaires. Indeed, their heartfelt experiences, especially regarding their family and social stigma and discrimination, strongly motivated me to undertake further research, especially in finding the hidden roots of this kind of stigma and discrimination. At the same time, this research was the catalyst for me to become an HIV researcher with a deeper understanding of the HIV-related issues of PLHIV.

In order to accomplish the present research, I will first explore how PLHIV discover their HIV status, and how they react to it, and then explore the ways in which they can reconstruct their identity, as they seek HIV treatment and a deeper understanding about HIV and AIDS. Since they also experience issues related to HIV stigma, discrimination and disruption of human needs in family and society, they need to know ways to manage these issues. Secondly, my interest is to understand whether issues of stigma, discrimination and disruption of human needs differ between various groups of PLHIV, especially with respect to their gender, caste and class differences. If the issues are found to vary among different groups, this research intends to explore the underlying factors that influence these differences in the context of a traditionally hierarchical Nepalese society. Thirdly, I consider management strategies adopted by the different groups to address these issues in their lives after they have been HIV diagnosed. Effective management incorporates individual as well as family, societal and organizational efforts. I am equally interested to analyze these management efforts

according to different genders, castes and classes, especially with regard to types of family support, as this support plays an important role in managing such issues in Nepalese society. Finally, this research intends to look at the outcome of efforts made by PLHIV over the period after their being diagnosed HIV positive. This research intends to focus on the ways in which changes in the lives of PLHIV shape their identity.

Following global and national efforts in preventing HIV and reducing stigma and discrimination, recent studies reveal that PLHIV are moving towards identity reconstruction, especially in countries other than Nepal. Indeed, active engagement by PLHIV, taking ownership of HIV, is very important in reconstructing identity. Moreover, social support and instrumental support (medical, social and psychological services, housing assistance, etc.) play important roles in facilitating the daily lives of PLHIV and reconstructing their identities positively (Tsarenko & Polonsky, 2011). Drawing on Goffman's "spoiled identity", a basic concept of identity fluidity (Goffman, 1963), and spoiled identity attached to HIV and AIDS (Rohleder & Gibson, 2006) as well as recent findings on identity reconstruction of PLHIV (Baumgartner, 2007; Fouché et al., 2011; Frye et al., 2009; Tsarenko & Polonsky, 2011), there seems to be a path of identity movement from spoiled identity to identity reconstruction. Applying this concept of identity reconstruction to Nepalese PLHIV on the basis of socio-political changes to be discussed in Chapter Two, and some positive changes in the field of HIV and AIDS in Nepal to be reviewed in Chapter Three, two postulates can be made:

- a) It is possible for Nepalese PLHIV to move from a spoiled identity to reconstruct their identity in successive years of their lives after HIV diagnosis, depending

upon their own individual resilience, access to health care services, and support mechanisms.

- b) Differences in the levels of stigma and discrimination, access to health services, and availability of support mechanisms, may all contribute to different stages of identity, whether in spoiled, or transitional, or reconstructed identity among PLHIV.

### **1.3 Purpose of the Study**

The overall purpose of this study is to examine the lived experiences of PLHIV in Nepal. However, the specific objectives of this study are to identify the forms of HIV-related stigma and discrimination that take place in Nepal, the context in which they occur and various influential factors. This study also assesses the experiences of family and social stigma and discrimination, together with their impacts on identity issues. In addition, this study also attempts to explore factors that encourage the PLHIV in reconstructing their identity as well as their experiences relating to their identity over various life trajectories.

### **1.4 Research Question**

This research draws on previous research that finds that Nepalese PLHIV are stigmatized and discriminated against, and that historically their lives have been disrupted from satisfying basic needs. Social support mechanisms through various national and international organizations have been working actively in providing HIV treatment, distribution of antiretroviral drugs, and prevention of parent-to-child transmission (PPTCT), through service to the PLHIV, especially in recent years. In addition, there is counselling on HIV and AIDS, as well as vigorous work by media

people disseminating HIV knowledge. In this prevailing situation, a genuine question arises as to whether the PLHIV are still facing the same situation regarding stigma and discrimination, or rather moving ahead towards rebuilding a more positive identity in Nepal. In addition, support mechanisms working in favour of PLHIV, together with recent socio-political changes, are expected to result in some positive changes in their lives, as there have been government efforts in other marginalized communities such as the so-called *untouchable* (the lowest caste group) caste and widows (as detailed in Chapter Two). With this country's political scenario changing in favour of marginalised people, irrespective of gender, caste, and class, the broad research question is established that frames the study as follows:

What are the lived experiences of PLHIV in a Nepalese context?

The above broad question can be developed further into the following:

- a. What are the experiences of stigma and discrimination and their impacts on PLHIV in relation to identity?
- b. What are their experiences of spoiled identity?
- c. What are their experiences of identity reconstruction?

The accomplishment of this project builds to a certain extent on the foundation of Goffman's theoretical framework and qualitative research methodology. Although Goffman's stigma theory was developed in 1963 before the discovery of HIV in 1981, his theory is also relevant, especially with regard to stigma, discrimination and people's identity issues associated with HIV (Attell, 2013). The present study uses a qualitative research methodology in an attempt to understand the experiences of PLHIV. Micro-

level data are sought, with follow-up questions probing for greater clarity and detail. In this research, thematic analysis is used, looking for themes within the data set and attempting to understand the significance of HIV discovery and further processes of identity reconstruction.

### **1.5 Terminology**

It is important to define terminologies that have been used in this thesis, whether they are interlinked in terms of literature, specific country context or with a view to capture the expression of participants' experience in interviews for this research. Initially, when HIV was identified in people in Nepal, HIV was viewed as an outcome of "bad" sexual behaviour, meaning having sex with multiple partners, something that has been considered outside social norms and values in Nepalese society (Beine, 2002; Nepal & Ross, 2010). In this thesis, "discovery" refers to the diagnosis of HIV, usually after a medical test in a hospital or clinics run by organizations working in the field of HIV. Many PLHIV in the present research expressed surprise at this discovery of the new "disease" (HIV infection). The research thus attempts to capture the feelings expressed when HIV was discovered in their lives. "Stigma" is widely used to refer to the disgrace of a person in terms of physical disorder and, more than that, its structural precondition, meaning explanations of how it could happen to somebody (Goffman, 1963). Stigma as used by Goffman is the shame or disgrace attached to HIV as well, considering what other people would think if it became apparent that one was involved in sexual activities with others beyond their married spouse, and/or sharing needles for drug use. Such behaviours cut across social norms and values in Nepal.

“Discrimination” refers to PLHIV being treated differently in family, society and workplaces because of their HIV (Parker, Aggleton, Attawell, Pulerwitz, & Brown, 2002). In this study, discrimination is used as a relative term, contrasting two groups: PLHIV and HIV-negative people. Because of HIV stigma and discrimination, PLHIV are adversely affected in attaining their optimum quality of life: this is termed “disruption” (Hatzenbuehler, Phelan, & Link, 2013). Stigma and discrimination associated with HIV have affected the quality of life of PLHIV in terms of limiting their chances of being married or remarried, having sexual relations with their spouse, and earning money by going overseas. Such deficits of opportunities are termed disruption.

“Stigma”, “discrimination” and “disruption” are attached to the identity of PLHIV, resulting in a “spoiled identity” (Anderson et al., 2008). These negative impacts on their lives are termed spoiled identity in this study consistent with the existing stigma literature. “Transitional identity” describes the movement of PLHIV from spoiled identity toward reconstructed identity, involving positive changes in their lives as previously mentioned: “a transition to ordinariness after the diagnosis of a chronic illness” (Baumgartner, 2007, p. 920). From transitional identity, PLHIV move further into identity *reconstruction*, managing stigma, discrimination and disruption to a greater extent, as a result of experiencing better health and positive socio-economic changes in their lives. This is termed “reconstructed identity” in this study. The term “relapse identity” applies to what results when PLHIV again devalue themselves after having experienced identity reconstruction. Relapse identity may result, for instance, from economic hardship because of job termination. This is explored in this research.

“Collectivism” is used to describe the collective spirit of all family members caring for each other, and “individualism” primarily focuses on self-development (Kastenmüller, Greitemeyer, Jonas, Fischer, & Frey, 2010). Many PLHIV in this study, especially females, experienced a collective spirit before being HIV diagnosed, when they and their husbands contributed to their family economically, with the husband often working outside the home, and the wife doing household chores. “Individualism” is used to refer to an individual spirit, giving priority to self-development socially and economically, rather than to co-operative living with other members of the family. It often occurs after a person has been stigmatised and discriminated against by family and society, because of his/her HIV status.

“Resource” in the Nepalese literature, especially in the field of migration, has been widely used in terms of availability of public services, overseas employment, and land, , and especially in terms of economic opportunities, economic motives, their access, including aspects of and family economic support. Availability of public services (especially access to communication, transportation, hospitals, health personnel, etc.), as well as the availability of fertile land, jobs and good income in Nepal have often been regarded as pull factors for migration as resource bases (Subedi, 1988; KC, 2003, 2004). Land is also seen as an important resource that in rural-to-rural migration, previously western to eastern Nepal along the hills and north to south after the success of a malaria eradication programme after the 1950s (Subedi, 1988). In addition, a resource is a source of any external help or internal strength which a person has available to draw upon. External resources include family as economic supporters (especially, in this study, such as husbands or parents). An example of an internal resource is resilience



that can help a successful individual's development in an adverse situation (Kalil, 2003).

In the Nepalese context, the term “formal” education generally refers to a process of learning or education through recognised schools and campuses, with a view to gaining recognised qualifications at various levels of attainment. “Informal” education refers to training or teaching by parents, relatives, community leaders or organizations, conducting casual or short-term education programmes for those people who do not have opportunities of attending any formal education through a school or college, because of their poor economic status, gender status, or illiteracy. Informal education does not usually lead to a recognised qualification, but can help equip a person for everyday life, employment or other roles in society.

## **1.6 Structure of the Study**

After the first chapter introduces the research area of this study, the second chapter briefly describes the contextual background of Nepal. The second chapter primarily focuses on the geographical location of Nepal, and the country's changing scenarios of population, democratization and development processes, with a view to providing information on how various factors are shaping sexuality, drug injection and vulnerability to HIV and AIDS. It will also consider how recent socio-political changes have made people aware of their health and reproductive rights, as well as developing concepts about economic independence and individualist norms and values. It further considers how socio-cultural transformations have provided a conducive environment in rebuilding the identity of PLHIV after they have been HIV diagnosed.

The third chapter introduces a global understanding of HIV stigma and discrimination, and the impacts on identity crises and identity transformation. This chapter then uses Goffman's stigma theory to help refine the understanding of stigma and discrimination related to HIV status from the perspective of health hazards. This understanding will be studied in the context of South Asian and Nepalese understandings about HIV and its stigma, discrimination, and the disruption of human needs. Likewise, it will also provide a glimpse of practices that reduce stigma, discrimination, HIV prevention and treatment, and the PPTCT service. Finally, the conceptual framework of this study will be introduced with reference to Goffman's theoretical framework. This framework provides a way to develop a proposed reconstruction identity model in the analysis Chapter Nine.

Chapters four and five explain the methodology applied in this research. The methodology is divided into two chapters. Chapter four discusses the research methodology in a traditional way. It outlines the qualitative research, design, and methods of data collection and analysis used in this research. It also explains the processes of ethical approval, data transcription, translation and data management at pre- and post- phases of data collection. On the other hand, chapter five is a more reflective consideration of what actually happened during the data collection. It provides a deeper understanding of the process of field work and data collection in the socio-political context and geographical localities of Nepal. In this chapter, I discuss how I was able to collect data through various organizations working in the field of HIV, including my perceptions of the field work as a researcher, especially in relation to the sensitivity of the HIV issue from gender perspectives.

Chapter six introduces the diagnosis, or discovery of HIV in individuals. This chapter considers ways PLHIV discovered their HIV positive status, their immediate reactions, and especially their feelings when hearing this from health personnel. Similarly, it also explains how they experienced responses from family and in wider society when disclosing their HIV status for the first time. This chapter primarily focuses on the discovery of HIV, along with illustrations of their feelings, reactions, and others' responses in relation to their identity status.

Chapter seven addresses the spoiled identity which results from family and social issues involving the stigma, discrimination and disruption of human needs of PLHIV. This chapter focuses mainly on the family and social issues after an individual has been HIV diagnosed, describing varying degrees of discrimination experienced, depending on available access to resources. It also focuses on impacts on identity where there has been disruption of relationships with family members, relatives, and the community. Finally, this chapter examines the socially significant issues associated with marriage and remarriage, fulfilment of sexual desires, challenges of conception, international visits and work, and other such issues of HIV-infected people that push them towards a spoiled identity.

Chapter eight considers the transitional identity of PLHIV, and how they strive to carefully manage their stigma and discrimination after being HIV diagnosed. It provides an overall picture of how PLHIV move to transitional identity, by adopting various ways of managing stigma and discrimination as well as disruption of human needs. The various ways of managing stigma and discrimination in PLHIV include migration, disclosing and hiding HIV status, economic independence, the practice of HIV

treatment, support of organisations, and spirituality. In this chapter, there is discussion of how migration, ways of semi-disclosing, concealing and disclosing HIV status publicly helped PLHIV to manage stigma, discrimination and disruption, as well as ways of becoming economically independent in their daily lives. Thereafter, the chapter contrasts the methods of traditional and modern allopathic medicines, with a view to prolonging people's lives beyond what they might have expected immediately after HIV discovery. Finally, this chapter is intended to deal with organizational supports as PLHIV receive counselling, HIV treatment, informal education, assistance finding jobs, leadership training on fighting stigma and discrimination for other PLHIV, including spirituality with a sense of meaning-making processes for their lives.

In the ninth chapter, the results of these various strategies for managing HIV stigma and discrimination are thematically discussed. This chapter firstly explains the results of stigma and discrimination management strategies applied in the participants' lives and identity reconstruction. Secondly, it focuses on health status, dealing with changes in physical health and physical appearance, and the impact of the PPTCT service on identity reconstruction. Thirdly, it deals with how other positive socio-economic changes affect identity reconstruction in PLHIV. Thereafter, a proposed identity reconstruction model is developed under the heading of "identity crisis and its transformation", based on data analyses in this chapter and the preceding chapters of this study.

The final chapter of this thesis discusses the results of the study, and synthesizes with the existing literature, as explained in earlier chapters, especially regarding the country

contexts and the literature review as explained in chapters two and three respectively. It also deals with the strengths of this study, and policy implications for reducing family, social and economic stigma and discrimination of PLHIV on the one hand, and for improving their identity on the other. Finally, it recommends future research areas for those who are interested in doing research in the fields of HIV which could not be addressed in this present research.

## **1.7 Conclusion**

Chapter one has briefly introduced ways of reconstructing the identities of PLHIV despite facing their family, social stigma and discrimination. Then, it briefly explains research problems, research objectives and research questions that have been addressed in this research. In addition, this chapter also explains the research methods and theoretical framework for this study.

## **Chapter Two: Country Background**

The purpose of this chapter is to consider the geopolitical and social contexts of Nepal that inform issues of HIV and AIDS in the country and to make clear how recent development activities and socio-cultural transformations facilitate managing the issues. Nepal's geography has led to demographic shifts. Democratization in Nepal has brought changes in the country through development activities. These development activities include migration, as well as an increase in youth emigration to other countries because of lessening unemployment, especially since the introduction of multi-party system in the country in 1990. Other key developments include the "People's War" (or the "Maoist War"), the democratic movement of 2006, and changing economic activities, expansion of transportation and communication, and an integrative approach to reproductive health and socio-cultural transformation. Finally, this chapter synthesizes these contextualization factors in view of the epidemic of HIV and AIDS, including its management, in the country.

### **2.1 HIV in Nepal**

The history of HIV in Nepal can be traced back to 1988. Since then, reported statistics show that the number of PLHIV has been increasing significantly, especially from 1996 (Joshi et al., 2004). As of July 2013, there were 22,994 reported cases across the country (National Centre for AIDS and STD [Sexually Transmitted Disease] Control, 2013a). Among the total reported PLHIV, there were 14,560 males, 8,408 females and 26 transgendered people. However, the estimated actual number of PLHIV across the country is considered to be around double the total reported figure of HIV in 2014 (National Centre for AIDS and STD Control, 2013b). The difference in the figures of

reported and actual cases of PLHIV conceals the actual incidence of HIV in family and society. HIV prevalence in Nepal is a gendered phenomenon, with more than three-fifths of the total reported PLHIV being male. This is probably due to both the dominant volume of temporary labour male migration in the country and poor investigation of HIV and AIDS among females (New Era, 2009). The epidemic of HIV and AIDS in Nepal is attributed mostly to heterosexual transmission, although there is also evidence of males having sex with males (MSM) contributing to the epidemic (National Centre for AIDS and STD Control, 2013a; Nepal, 2007). HIV is spreading rapidly, especially in the adult age group 15-49 years, and AIDS is now one of the major causes of death within this age group. In Nepal, as in most Asian countries, the epidemic of HIV and AIDS is centred around particular high-risk groups, seasonal labour migrants, sex workers and their partners, MSM and injecting drug users (Ministry of Health and Population, 2007; National Centre for AIDS and STD Control, 2010).

Sharing of needles among people engaging in substance use is also one of the major modes of HIV transmission in Nepal, in addition to sexual contact and parental transmission. Although Nepal has a long history of substance use in the form of tobacco and alcoholic drinks, injecting drugs by the Nepalese younger generation began with the entrance of many foreigners into the country from the 1960s onwards. There are increasing numbers of injecting drug users (IDUs) in the country and it is estimated that more than 3,000 people are drug addicted in the Kathmandu and Pokhara valleys alone (Neupane & Mishra, 2014). With government and non-government organizations' efforts in preventing HIV infection in the country, the HIV prevalence rate among drug users has decreased substantially (National Centre for AIDS and STD Control, 2011).

## 2.2 Nepal's Physical Location and Demographic Shifts

Nepal's physical location regarding neighbouring countries and the country's geographical topography are likely to have an influence on HIV and AIDS in the country. Nepal is a small, landlocked country with a total land area of 1,47181 square kilometres surrounded by the two giant countries of the world mostly familiar with issues of HIV and AIDS: India to the east, west and south; and China in the north. Stretching over a length of 885 kilometres (east–west) and a width of 145 to 241 kilometres (north–south), the country is divided into three major ecological regions: the mountains, the hills and the *terai* (plain areas of southern Nepal). All three regions are parallel to each other, from east to west, being continuous ecological landscapes. There is wide altitudinal variation in Nepal, and therefore great ecological diversity. The mountains have a steep topography ranging in altitude from 4,877 metres to 8,848 metres above sea level, including the highest peak in the world, Mount Everest. The hills lie between 610 metres and 4,877 metres above sea level. They incorporate a number of fertile and diversely settled areas, notably the Kathmandu and Pokhara valleys, where the research sites for this study are located. The *terai* region is a low altitude and fertile tropical lowland. There are a number of plain valleys located within the hills, including the Kathmandu Valley; and fertile plain areas of the *terai* region with better economic prospects from an agricultural perspective, and other infrastructural development such as electricity, roads, expansion of communication and other advantages. Thus, there are various geographical proximities that lead to diversities in people, with various economic strata. The country's geographical location is one of the more influential factors because people naturally tend to move from resource-poor areas to resource-rich areas (Subedi, 1988). With increasing urbanization and modernization in the country, significant numbers migrate from rural to urban areas



in search of urban jobs and study opportunities, which are not so readily available in rural areas. There has also been significant emigration as people move outside the small country with a view to better opportunities, especially for jobs (New Era, 2009; Wagle, 2012).

Although the annual population growth rate has started declining according to the latest census of 2011, the absolute population size has been constantly increasing in the country. This has created more unemployment, and people inevitably move to other areas inside and outside the country in search of work. Census enumeration into population dynamics of Nepal reveals the total population size of the country is 26.5 million according to the latest 2011 census, with an annual population growth rate of 1.35 percent between 2001-2011 (Central Bureau of Statistics, 2012). Although the annual population growth rate reduced to 1.35 percent from the previous rate of 2.25 percent during the period 1991-2001, absolute population figures indicate a continuously increasing in Nepal from 1941 onwards. This is mostly due to demographic shifts, especially a gap between fertility and mortality (Central Bureau of Statistics, 2012; Pantha & Sharma, 2003). Nepal's population is unequally distributed in the three broad regions: the mountains, the hills and the *terai*. More than 50 percent of the country's total population live in the *terai* flat region as per the latest census figures of 2011, although this region is less than one-fourth of the country's total landmass (Central Bureau of Statistics, 2012). The unequal distribution of population and demographic shifts in these regions is due mainly to socio-economic variations in different regions that lead to internal and international migration in the country (Gurung, 1989; Subedi, 1988, 1991; KC, 2003, 2004).

### **2.3 Democratization, Development and Socio-cultural Transformation**

Nepal has been moving from a socio-political autocratic structure towards democratization with a multi-party system since the 1950s. Although the political system has changed time and again, development activities have been moving ahead, more or less in pace with the country's contextual background. The country's political situation, autocracy, democratization and development are closely interrelated with each other (Bista, 1991). With the commencement of development plans and policies after the introduction of democracy in 1951 in Nepal, development activities such as education, practice on elimination of castes, resettlement, expansion of transportation, modern communication and enhancement of reproductive health services with an integrative approach are moving forward gradually (Bista, 1991; Lawoti, 2008; Ministry of Health and Population, 2011). In later years issues concerning lesbian, gay, bisexual, transgender and intersex people are also a growing concern, especially in recent years (Ministry of Health and Population, 2011). Therefore, in the next section, an attempt has been made to explain briefly the process of democratization and development activities since the 1950s. The background of democratization and development also makes it easier to understand the epidemic of HIV and AIDS since 1988, and its management through integrative development activities.

#### **2.3.1 Democratization in Nepal**

Nepal has been moving from the autocratic regime of the *Rana* (Rulers of Nepal on the basis of dynasty) family to democratization since 1951. Before 1951, the *Rana* family ruled the country in autocratic ways without giving genuine human rights to the general population, even including reading and writing (Borgstrom, 1980; Fisher, 1998). At that time, education opportunities were limited to the *Rana* family members and their close

elite social members. Although there was a king of the state, the king was also within the boundaries of the *Rana* regime and had no opportunity to interact with the general population in different parts of the country. The *Rana* families and elite classes lived very sophisticated lives, having many servants in their palace, indicating a vast difference in the lifestyles of the rich and poor (Liechty, 2003). The monarchy did not figure prominently in the beginning as the *Rana* families were the symbol of Nepal's feudalism, whereas the Shah kings became mere nominal heads of state (Borgstrom, 1980). Realising the tyranny of this despotic regime, the then king Tribhuvan and the Nepalese people overthrew the *Rana* regime of more than 100 years and declared democracy in the country in 1951 (Whelpton, 2005). With the dawn of democracy in Nepal, the then government introduced a five-year development programme (1956-1961) in 1956 and addressed major development plans and policies in every subsequent five-year development plan. These were basically education, health, agriculture, resettlement programmes, transportation facilities and such other necessary development programmes (Central Bureau of Statistics, 1987; Ministry of Health and Population, 2011). So far, the 10<sup>th</sup> five-year development plan (2002-2007) has been completed, and interim development plans are in place after the initiation of the peace process agreement among parties after a ceasefire was agreed to by the Maoist party in the country (Ministry of Health and Population, 2011). The two subsequent three-year interim development plans (2007-2010 and 2010-2013) have been completed since the 2002-2007 development plan.

After democracy was introduced in 1951, it took a long time to stabilise the government and there were contentions among different parties of Nepal. Realizing the political situation the then king introduced the *Panchayat* system in 1961 (Khadka, 1991). The

development activities and every five-year development plan gradually moved the country ahead, except for the three-year development plan of 1962-1965 because of the political upheaval in the country (Ministry of Health and Population, 2011). The king promulgated the 1962 Constitution under which the country was divided into zones, districts and villages with a view to launch development activities proportionately in all areas of the country (Central Bureau of Statistics, 1987). The king also promulgated the National Code Act in 1963 making all castes and tribes equal and dictating that there must not be discrimination in the name of any caste or tribe. In favour of the poor people, the Land Reformation Act was declared by the king in which people who have cultivated land of others for a long period of time were able to claim one-fourth of the total land in their own names forever (Central Bureau of Statistics, 1987; Community Self-Reliance Centre, 2009).

Although there were electoral members in the *Rashtriya Panchayat* (the parliament) from throughout the country in the *Panchayat* system, a handful of people had more opportunities than the general population; and the *Panchayat* system could not abolish the feudal system and eliminate caste discrimination. These improvements were on paper only and could not come into practice. The Nepalese king was above the constitution. The hidden political parties commenced a movement against the king and the government in 1990 to get rid of the *Panchayat* system in favour of a multi-party democracy. Finally, the then king declared the multi-party system with the king under the constitution in 1990 (Khadka, 1991). After the introduction of the multi-party system, the development activities were more active at village levels in comparison to the previous period. However, the old feudal traditional system, especially the gap between poor and rich people, gender and caste discrimination, could not be totally

abolished. Thus the Maoist movement paved the way to raise marginalized people's voices and strengthen the social movement for change during the period 1996-2006 (United Nations, 2012). The Maoist movement began in the western regions of Nepal where many marginalised people live (Thapa & Sharma, 2009). A significant proportion of the excluded and marginalized population participated in the Maoist-led insurgency, including a considerable number of women, with the hope and desire to change the current hierarchical society and to end social discrimination (Yami, 2007). Eventually, many parties came to the same conclusion as the Maoist party, to overthrow the king, and the Maoist party also agreed with the multiparty democracy and republic although the earlier purpose of the Maoist party was to bring socialism (equality in a radical way) into the country directly. Almost all parties in Nepal commenced the second movement in 2006 (the first movement was in 1990) to overthrow the king, whose lineage had ruled the country for the last 240 years, succeeded in this purpose and established a multiparty democracy and a republican state in Nepal (Joshi & Mason, 2010; Lawoti, 2014).

These political movements gave opportunities and space for the *dalit* (lowest socio-economic and caste people) to engage in political activities. The Constituent Assembly election in 2008 brought many *dalit* representatives into the Assembly and the interim government finally overthrew the kingship system in 2008 (Thapa & Sharma, 2009). The interim government has also passed Acts in favour of females and other marginalised groups of people by castes and ethnic minorities. Before 2006, the proportion of females in the parliament was only about 6 percent. After the peace process agreement of 2006, the interim government provided more quotas in favour of females (up to 33 percent of the total number of parliament members in the Constituent

Assembly) and of marginalised groups of people in Constituent Assembly elections (Vollan, 2011). Likewise, after the introduction of the multiparty system, the Nepal government has focused on lower-caste people and disadvantaged groups with reservation and priority seats in various sectors of development, especially in scholarship quotas for education and in employment. Furthermore, the proportion of cultivated land reached 50 per cent for people who had been cultivating land for a long period of time (Community Self-Reliance Centre, 2009). The democratic process here seems to favour poor people, lower caste, and females (especially helpless widows after certain age), 60 years and above, providing an allowance to some extent (National Planning Commission, 2012).

### **2.3.2 Development in Nepal**

As stated above, due to the process of democratization since 1950s, the processes of development are moving ahead, more or less, with plans and programmes in accordance with the country's geographical and political situations. After the previous despotic rule of the *Rana*, the dawn of development activities began with the introduction of the first development plan (1956) as mentioned above. The then government focused on internal migration with the resettlement programme, educational opportunities for as many people as possible, and narrowing the educational and economic gaps especially between genders, castes and classes. Moreover, a family planning and a reproductive programme began to flourish with a more integrative approach (integrating with other development activities such as education, agriculture, etc.) than ever before. Later, the Nepal government responded to the epidemic of HIV and AIDS gradually as an important component in its development plan and policies after HIV was detected in the country in 1988. Development activities were associated

with democratic processes in Nepal and the ways in which these relate to the management of epidemic of HIV and AIDS.

## **Migration**

Many Nepalese people have considered migration (both internal and international) for centuries as an intrinsic part of their lives, especially with regard to economic motives. In the migration history of Nepal, people have moved from west to east along the hills, as eastern land is considered to be the more fertile. After the introduction of democracy, the government of Nepal placed an emphasis on a resettlement programme to the lowland plain areas of *terai* from the hills and the mountains. This internal migration became possible after a successful endemic malaria eradication programme as well as the clearing of a dense forest in the *terai* and inner *terai* valleys, a region containing around one-fifth of the total land of Nepal (Gurung, 1989; Subedi, 1988). These projects have been ongoing since the late 1950s. Then, the direction of internal migration changed from the north highlands (mountains and hills) to *terai* in the south, replacing the earlier western-to-eastern population movement along the hills (Subedi, 1988). The country has been experiencing an increasing volume of internal migration towards the plain *terai* region because of the mostly fertile agricultural land which promises a better economic future (Gurung, 1989; KC, 2003; Subedi, 1988). The government's resettlement programme assisted the people of the hills and the mountains who had suffered from landslides especially in the heavy rainy season, with their new destination being much safer than their places of origin (Gurung, 1989). Rural to urban migration in Nepal has increased considerably with the attraction of urban facilities and a perceived better quality of life, especially after the 1980s. The reasons behind the urban-oriented migration include availability of educational and health facilities, and better

communication and transportation (KC, 2003). In other words, migration is intrinsically related to the aspirations of people with regard to better economic and social lives. Nepalese internal migrants' lives seem to be enhanced economically and socially in terms of higher agricultural productivities and educational opportunities for their children in the place of destination (*terai*), rather than their places of origin (Gurung, 1989; KC, 2003; Subedi, 1988).

In the migration history of Nepal, international migration is not new. There have been both emigration to other countries and immigration to Nepal, especially from neighbouring India. Historically, the Nepal–India border has remained as an open and free border for both peoples so travel between the two countries can be made easily from all directions in the south (KC, 2004). After the colonization of India by the British, world famous *Gurkhas* (soldiers) were used in both Indian and British armies, and even after India won independence from the British government, Nepalese people continued working in India, joining Indian and British armies (Bruce, 1928; Kansakar, 2003). In addition, Nepalese people, especially emigrants from western Nepal, have been working in India, even with low-paid jobs for their families' economic survival (New Era, 2009). Similarly, significant numbers of people coming from India have been staying in Nepal for lengthy periods. In later times the government of Nepal emphasized emigration to other many countries beyond India, especially for jobs after the introduction of the multi-party democracy in the country in 1990, in order to lessen the burden of late adolescents and youths in the country (KC, 2004). Additionally, in recent years, there have been many working labour-class people emigrating to other countries beyond India, especially the Gulf countries, with a view to receiving better earnings (Nepal Institute of Development Studies, 2011).



Migration cannot be viewed as merely a contributing factor to better economic perspectives; it is also linked with the epidemic of HIV and AIDS in Nepal. Although HIV was detected in Nepal in 1988, its rapid growth appeared after the mid-1990s. By 1996, the general population ratio of males to females remained almost the same, though the number of females living with HIV and AIDS was somewhat higher when compared with males. After 1996, the number of males with HIV and AIDS increased tremendously, more than doubling in the survey years of 2001 and 2006 (Ministry of Health, 2002; Ministry of Health and Population, 2007). Although a direct relationship between migration and HIV has not been ascertained, the HIV epidemic has been growing rapidly with an increasing volume of both internal and international migration in Nepal. Migrant populations both inside and outside the country are also highly vulnerable to HIV and AIDS (KC, 2004). With an increasing volume of internal and international migration, there has been an accelerating incidence of HIV and AIDS in Nepal over the years. Reportedly, there is also an increasing tendency of students to engage in risky sexual behaviours with multiple partners within and outside the country; and there are a considerable number of females working abroad (Aryal et al., 2011; Mahat & Eller, 2009). A long-standing conflict of around 10 years (1996-2006) led by the Maoist party against the government in Nepal exacerbated rural to urban migration and migration to other countries. Male migrants are known to frequent sex workers more than non-migrants, thus increasing their risk of HIV infection (Poudel, Jimba, Okumura, Joshi, & Wakai, 2004). Many female spouse of male labour migrants in Nepal have contracted HIV due to their husband's risky sexual behaviour at the time of their work away from home (Nepal, 2007). Consequently, Nepalese HIV statistics suggest that around 40 percent of HIV-infection in Nepal originates from labour migration (National Centre for AIDS and STD Control, 2010).

In recent years, Nepal has received a considerable amount of migrant remittance (Nepal Institute of Development Studies, 2011), together with having to deal with issues of HIV and AIDS as part of development activities. It is acknowledged as very important to develop the country in multi-dimensional ways, including migrants' knowledge and their experiences gained in other countries. Beneficial outcomes from international migration are not only the accumulation of money to be sent home but also the gaining of first-hand knowledge on external development activities. Remittances brought in by Nepalese migrants are helpful economically both for family and for social reasons (Tiwari, 1996). On their return, they are also bringing skills and ideas that they learn from their stay in foreign countries, including knowledge of reproductive health and contraception. There are examples of these working in the field of public services like schools, colleges, and hospitals. The returnees have earned both money and fame for their family and donations for schools, health institutions and other social services in their villages and the community. The returnees from overseas have contributed to increasing the knowledge base on HIV and AIDS through various organizations working in Nepal. In the course of my HIV research during the period July-November 2012, it was a privilege for me to be one of the eye witnesses observing this reality. Participants, after their return to their homeland, have been transferring their knowledge on HIV and AIDS to their illiterate village people through various organizations. Even rural-urban migration within the country provides a chance to gain more knowledge on family planning and reproductive health, as that information is more likely to be available in the cities than in rural areas.

## **Economy**

A country's economy is invariably associated with that country's geographical landscape, population situation and other prevalent, related socio-cultural factors (Gurung, 1989; Karan, Ishii, & Ito, 1996; Subedi, 1988). Most developing countries with poor economic bases are facing problems over the HIV and AIDS epidemic. Nepal, one of the least developed countries in the world, is no exception. The Nepalese economy has always been handicapped by the fact that the country is landlocked and, within the country, the transportation system has not been as developed as it could be due to the terraced slopes of the hills and the mountains. Implementing any government programmes in the mountains and the hills has been difficult due to the lack of good transportation and communication services. However, in recent times, several attempts have been made to improve people's lives through increasing transportation and communication facilities (Pun, 2013; Thapa, Sein, & Sæbø, 2012).

To some extent in recent years, Nepal has been successful in reducing the poverty prevalent in the country considerably. The country has been predominantly an agricultural economy for centuries. The agriculture sector provides around one-third of the country's gross domestic product (Ministry of Health and Population, 2012). Remittance from overseas, people working in business and services have contributed a considerable proportion of the country's domestic product. The declining trend of engaging in the agricultural sector suggests people would begin engaging in non-agricultural areas which are known to reap more income than the traditional ways of agriculture. Even working in the agricultural sectors, people use modern fertilizers as well as tractors in plain lands and grow more products than during the previous period, which has significantly increased their income. The country's latest figures on Nepalese

people living below the poverty line is 23.8 per cent, down from 42 per cent in 1996, which is a very positive result considering the critical political situation (Ministry for Foreign Affairs of Finland, 2013; National Planning Commission, 2013). There has been a paradoxical relationship with the conflict of the Maoist war (1996-2006) and the remarkable progress in poverty reduction immediately after the peace process of 2006 in Nepal. The paradox comes from the fact that people generally do not expect to improve their socio-economic status significantly in a country enduring any kind of war.

People's better incomes and the seeking of information on family planning and reproductive health are closely interrelated in that hungry people first need to eat before considering other things such as contraception and overall reproductive health. The increasing levels of income either by engaging in modern agriculture sector, business, services or remittances from migrants has given people more spending money for transportation costs and receiving information about contraception (i.e., condoms) which helps in avoiding HIV and AIDS. In comparison to the previous period, Nepalese people are paying much more attention to reproductive health and family planning that has reduced the fertility level to around replacement level. Also the level of knowledge on HIV and AIDS has increased gradually. Around 85 percent of females and around 95 of males aged 15-49 years have heard of HIV and AIDS in Nepal (Ministry of Health and Population, 2012).

### **Expansion of Transportation and Communication**

Nepal has the highest mountains and hills in the world, and that has made it difficult to construct roads everywhere in the country. Nevertheless, the government has realized

that the overall development of the country is not possible without connecting roads into remote areas. This is exemplified by Nepal's development policies and programmes that focus on transportation and communication. The development of roads facilitates agricultural products being sent to urban areas from rural areas with a growth of agricultural products. That is why the Nepalese government has given priority to construction of roads up to remote rural areas. With increased road construction, rural people are able to send their agricultural products into the cities in better ways than ever before. The process of constructing roads has also made it easier to promote health services in the rural areas. In comparison to earlier times, rural people are more able to receive information on family planning and HIV and AIDS (Ministry of Health and Population, 2007, 2012). Of course, the expansion of the road construction in the remote rural areas has not only increased the incomes of the rural people but also has made it much easier for them to receive information about development activities. In the lowlands of the *terai* areas of Nepal, there are better transportation facilities in comparison to higher country. After the 1990s political movement, political parties dedicated energy to construct and expand roads into remote areas using slogans like "let us make our village by ourselves", and budgets are being provided directly to both village development committees (VDCs) and municipalities. This has given the villagers favourable impressions of development. With the expansion of roads into village areas, rural people are able to connect with their family, relatives and friends in urban areas and their periphery and they are getting more information about reproductive health than in the previous period, although not all rural Nepalese people are yet receiving adequate information delivered from the centres (Ministry of Health and Population, 2012).

Modern means of communication provide the backbone for conveying information about reproductive health, and HIV and AIDS from central to village levels. Modern technological development, especially in the field of communication and internet access, has expanded, not only in the urban areas but also in the rural areas at acceptable levels in recent years after the people's movement of 1990 (i. e., multi-party democracy). The 2011 census shows that around two-thirds of households have mobile phones, including rural and urban areas of Nepal (Central Bureau of Statistics, 2012). Internet access, basically still only in urban areas, and increased access to the telephone and mobile phones even in rural areas, have made it easy for people to find information on prevention and treatment of HIV and AIDS. They are also able to find new information in such a country as Nepal where collectivism works well regarding updating and sharing of the latest information on HIV and AIDS to other PLHIV at least within their own circle. Wireless internet services in rural Nepal have been set up and now interlink with the rest of the world. For example, very remote rural areas of hill districts now have internet available thanks to the efforts of a Nepalese scholar who has studied abroad (Sein & Thapa, 2014).

### **Reproductive Health with an Integrative Approach**

The concept of reproductive health was introduced into Nepal in the early 1960s and reproductive health policies and programmes were later launched in an integrative way such as: formal and informal education and reproductive health; forest and reproductive health; agricultural and reproductive health; and posters on contraception such as “Two Children, the Gifts of God”, “Let us use condoms and avoid HIV and AIDS”, etc. (Barker, Bird, Pradhan, & Shakya, 2007; Joshi, 1995). In the first development plan period, the Family Planning Association of Nepal (FPAN) was established in 1959 with

a view to reducing the birth rate after enhancing the knowledge, attitude and practices on family planning services in the country (Central Bureau of Statistics, 1987). In each development plan, reproductive health and rights have been addressed with a view to providing information and knowledge about family planning and services to the general population (Ministry of Health and Population, 2011). Although Nepal's population was not large, the population growth rate was high, increasing future population size and growth during the period of the 1960s. Speculating on future population and population growth, the then king announced the family planning programme in 1965 to reduce the fertility rate, population growth and to manage population size in the country (Central Bureau of Statistics, 1987). By the year 1986, 15 per cent of the total reproductive population aged 15-49 years were contraceptive users. After HIV diagnosis in four persons in Nepal in 1988, the government and non-governmental organizations (NGOs) working in the field of family planning and reproductive health, such as the FPAN, also started working in the field of HIV and AIDS, increasing information, education and communication to people (Suvedi, 2006; Wasti, Simkhada, Randall, & Teijlingen, 2009).

The preliminary concept of information, education and communication (IEC) was developed and has been used primarily by health planners since the 1960s, initially in the field of reproductive health and family planning (Bista, 2003). The initial purpose of IEC was to narrow the gap (as an unmet need) between the relatively high level of knowledge of family planning and the low level of practice. This was expected to be achieved through a combination of information and education (knowledge-based activities), and communication (motivation-based activities) that were all geared towards behaviour change. The contraceptive prevalence rate is going up, being 50 per

cent among currently married females of reproductive ages (15-49 years) in Nepal (60 per cent in urban areas and 48 per cent in rural areas) and the average fertility rate of a couple in the country is not far away from the replacement level, and this is much lower (1.6 children per woman) in urban areas (Ministry of Health and Population, 2012). The increasing availability of IEC materials has helped people to understand the importance of family planning services in birth spacing, birth control and prevention of HIV and AIDS to a greater extent.

### **2.3.3 Socio-cultural Transformation**

I now turn back to Nepalese history for a discussion of gender, caste and class as important elements in Nepal's socio-cultural transformation: traditionally Nepal is a male-dominated society in which women are often treated as second-class citizens in both the household and in the public domain (Lamichane, Puri, Tamang, & Dulal, 2011; United Nations, 1996). Rural Nepalese society metaphorically keeps women within the four walls of their houses. These walls symbolize a lack of communication with the modern world and little opportunity to enter into decision-making processes. Likewise, in Nepalese traditional practice, there are main four caste groups, namely, the highest rank Brahman followed by Kshetree, Vaishya, and Sudra respectively. The lowest caste, Sudra, is known as "untouchable" – those from whom water is not acceptable for higher caste people (Dahal, 2003; Hofer, 2004; Subedi, 2010). These distinctions categorized the communities according to the hierarchy that led to the practice of caste-based untouchability and discrimination against the scheduled caste as in some neighbouring South Asian countries' contexts (Jodhka & Shah, 2010). As a result of the male-dominated and caste-hierarchical society, women's low levels of education and the continuation of traditionally and historically explained practices of social discrimination



make their position difficult (United Nations, 1996). Involvement in childcare and household work and the low economic status of women in the family, all result in low levels of knowledge of reproduction, sexual behaviour and contraception amongst women (Furuta & Salway, 2006).

Likewise, lower-caste-and-class people are dominated by higher-caste-and-class people in Nepal, with ostracization occurring everywhere in society. Considering the low socio-economic status of girls and women generally, and especially when from lower caste backgrounds, these people are more likely to be vulnerable to HIV and AIDS in Nepalese society (Smith-Estelle & Gruskin, 2003). On the one hand, males with poor socio-economic background who spend their lives as migrants far away from their home with a view to gaining better economic situations are also more vulnerable to HIV and AIDS (New Era, 2006; Poudel et al., 2004). Some male migrants transmit their HIV to their partners after returning home. On the other hand, a few people, especially those with better economic situations are also engaged in substance use and multiple sexual partners as part of their lifestyles, especially in urban areas (Neupane & Mishra, 2014). Going back to Nepal in the *Rana* rule, even prior to 1951, very rich *Rana* males had many wives in their palace. That legacy still remains in rich families even though the marriage act is strictly monogamous in Nepal.

Although most of these situations described above still exist, especially in remote rural Nepal, there have been tremendous improvements in education since the introduction of democracy in 1951 (Rachapaetayakom, 1988). The common Nepalese people did not have the opportunity to study until 1950 while the despotic and autocratic *Rana* families held political power (Borgstrom, 1980; Lawoti, 2008). The overall literacy rate of the

country was only around 5 per cent of the total population during the *Rana* regime until 1951 (Ministry of Health and Population, 2011). After democracy, the Nepalese government focused on the expansion of education for all Nepalese people irrespective of gender, caste and class throughout the country as much as possible. The latest census of 2011 provides information that the overall literacy rate has increased in an unprecedented way, and has reached 66 per cent of the total population, whereas the literacy percentages for males and females are 75.1 per cent and 57.4 per cent respectively (Central Bureau of Statistics, 2012). In the Nepalese school curriculum, courses on population and health are often compulsory for students. This has provided the opportunity of studying about reproductive health, family planning and HIV and AIDS. The recent development plans have focussed on informal education to eradicate illiteracy for those people who have not yet benefitted from the opportunity for formal education (Acharya, Yoshino, Jimba, & Wakai, 2007; Robinson-Pant, 2000). At the same time, they do have the opportunity to receive information about family planning and HIV and AIDS as NGOs and international non-governmental organizations (INGOs) have multiple purposes in launching informal education programmes for both young and old people. The NGOs and INGOs provide knowledge of reproductive health with IEC approaches to the people who join in informal education where they have opportunity to learn about HIV and AIDS and prevention measures (Bista, 2003; Posner et al., 2009; Thapa, 1997).

After the introduction of the *Panchayat* system in Nepal in the early 1960s, the then king declared that all people, irrespective of caste and gender, are equal, amending the National Code in 1963 (Central Bureau of Statistics, 1987). With an increase in the level of education in the country, educated Nepalese people began to realise that all

people are equal and that caste and gender-based discrimination was undesirable in Nepalese society. The Maoist movement (especially from 1996 to 2006) helped to reduce caste-based untouchability in most areas as they taught villagers about their human rights; this was in contrast to the fact that traditional customs were favoured only upper caste and rich people (Yami, 2007). Rural people, especially those marginalised by caste and class, were encouraged to become involved in the Maoist war for equality with upper castes and higher class people in all social and economic aspects of their lives. With the peace agreement between the Maoist people and the government, the main focus of development has been on lower-caste-and-class people and females, bringing them into the development mainstream (Devkota, 2007; Yami, 2007). The Interim Constitution provided for the precedence in jobs for females and for lower caste people (so-called untouchable). These activities of the government have made it easier for lower-caste people and females to be involved in development activities, such as education and health, and that has made receiving information on reproductive health, and HIV and AIDS easier as well. For example, in the course of my data collection for this research, I also interviewed so called *untouchable* caste females who have been working in the field of HIV for the last few years.

To narrow down the discrimination between various castes and ethnic groups, the Nepali government has recently promoted inter-caste marriage, providing a state fund of Nepalese Rupees 100,000 (around \$USD 1000) in two instalments over six months as an incentive to a couple who marry with untouchable caste people (Sharma & Rauniyar, 2010). There is now an increasing trend of inter-caste marriage in Nepal that is going to narrow the gap between lower- and upper-caste people in every aspect of life. This government initiative has increased the opportunities for lower- to interact

with upper-caste people. These days, a marriage for reasons of love is also one of the normal conditions for getting married, especially in younger generations irrespective of caste and class. The aspirations of the younger generations and the government efforts are similar and contribute to make all castes and classes equal and to provide development opportunities to all people equally. The recent government efforts are enabling people who are marginalised by gender, caste, and marital status (widowhood) to be brought into the mainstream of the country, by providing marriage incentives, educational scholarships, and job priorities.

## **2.4 Discussion**

The Nepalese socio-economic and political systems have been undergoing transition from a very conventional type of agrarian economy and autocratic political system to democratic norms and values. With the dawn of democracy in Nepal in 1951 and the various democratic movements as mentioned in previous sections, the foundation of the feudal patronage system has been gradually weakened. The increasing number of schools and colleges and the increasing awareness level in the general population has meant that the feudal patronage system is now on a downward trend in Nepal. With the success of the first democratic movement of Nepal (1990), the then king who was previously above the constitution was under the constitution after the movement (Whelpton, 2005). Later on, with the Maoist War, 1996-2006, and the second democratic movement of 2006, these movements overthrew the king from his palace. Accordingly, the feudal system that prevailed in communities and societies is now being gradually overthrown, replaced by the rights of the poor and deprived castes and the tribes of the country. The Nepal government has recently emphasised equity rather than equality, which has benefitted marginalised and deprived groups such as widows, and

elderly people, by providing allowances and priority to females and lower caste people in jobs and scholarships quota. Consequently, many marginalized people are benefitting in terms of their livelihood and have paid attention to social and economic development activities. With these circumstances, PLHIV have a conducive environment to integrate into the mainstream of development activities through jobs and training. Thus, change in the political system from autocracy to democracy has gradually created a conducive political environment everywhere in favour of marginalised communities, including PLHIV.

The Nepalese socio-economic and political systems are based on a philosophy that assigns work division based on gender, caste and class differently. It also affects the level of education and working jobs differently in Nepalese society, though the country has recently been declared as a secular country. *Brahman* people were assigned the work of instructor as *pandit* (priest), *Kshetree* people as warrior and administrator, *Vaishya* people as trades and agricultural, *Sudra* people as servants assisting the upper caste people. Therefore the people's work is assigned and understood differently on the basis of their caste and ethnic tribes (Von Fürer-Haimendorf, 1957). The same types of labour division are assigned by gender, with males doing hard work outside the home, working either in the farm or anywhere else to earn money, and females working in the kitchen and caring for children. Over time, there developed rich and poor people under the labour division. The work of the rich people seemed to be in higher class jobs and of the poor people to be knowingly and unknowingly in lower class jobs. Similarly, there are also labour differentials between literate/educated and illiterate people. The literate and educated people hesitate to do the jobs undertaken by lower class people (carrying of loads, sweeping/cleaning as well as labour jobs). The class and educational

attainment etc., and their social interactions follow on the same ways (intra-caste marriage, social customs and so forth). The norms and values of gender, caste and class have created visible power relations based on social hierarchical orders, such as, gender based roles, caste based roles (including so called touchable and untouchable castes), and rich and poor people's working roles. There is also a clear picture that the social customs that prevailed in Nepalese society enabled upper class and upper castes to grasp power. Therefore, there have been a number of historical socio-political events in Nepalese society as discussed above that have enabled lower caste and class people to benefit to some extent: the movement to democracy in 1951, multi-party democracy in 1990, and republic with multi-party system in 2006 (Aasland & Haug, 2011).

The caste, class, and gender roles assigned in the philosophy, which were interdependent on each other, are now diminishing following the demands of society. The living standards of Nepalese people are increasing and people are consuming more and more facilities (Central Bureau of Statistics, 2011). Everyone seems to be involved in work for better remuneration irrespective of the job category - upper and lower level jobs. In this situation, with their increased remuneration, most people can cope with modern demands of home and society. On the other hand, many people are not fully convinced about the view that they stay in their present employment just because "God has put them there". Therefore, people are now moving from collectivism and interdependence to independence. This applies not only for caste and class but also for gender as family structure is now drastically changing from extended family and joint family to nuclear family. Even in the nuclear family with only husband, wife and their children, if the husband and wife are not in the same place because of their job or study or something else, their role cannot be assigned differently. At present, people are trying

to do everything independently within the home and outside home. The changed pattern of diminishing collectivism and interdependence are working well enough in Nepalese societies irrespective of caste, class and gender; that seems visible with an increasing trend of modernization and urbanization. These norms and values of modernization and urbanization are evident in PLHIV after previously being stigmatised and discriminated in family and society.

Although there have been socio-cultural transformations associated with Nepalese political history for various segments of Nepalese society as discussed above, in general, it still remains to examine the experiences of low socio-economic status people. In this study, one of the marginalised groups of people in Nepalese socio-cultural settings is PLHIV whose experiences are likely to parallel experiences of people marginalised by gender, caste, and class, in addition to marginalisation by HIV and AIDS. Therefore, this study must also consider, in the Nepalese context, the experience of the marginalised group that PLHIV represent; those people who have experienced the socio-political changes in the country in terms of these issues. After analysing the issues of research participants, seen especially in chapter seven, and their experiences of socio-economic transformations (see, particularly, chapters eight and nine), their experiences are seen as imperative for describing the changing socio-economic status of marginalised people in general and of PLHIV in particular. It is necessary to see how issues of gender, class and caste are interconnected, especially when it comes to the formation of policies, which I will discuss in Chapter Ten.

## **2.5 Conclusion**

This chapter describes a complex, intertwined process between democratization, development and socio-cultural transformation. In Nepal, socio-cultural transformations have been progressing as the processes of democratization and development gradually proceed and strengthen over time. Two key aspects of socio-cultural transformation are the movement from collectivism to individualism on the one hand, and its effects, both facing economic constraints and creating a conducive environment for socio-economic empowerment on the other. PLHIV, especially women without economic supporters, face both economic constraints and an opportunity to engage in economic activities outside the home – a result of changing socio-cultural norms, and the value attached to becoming independent, both economically and socially. In addition, issues of HIV and AIDS have been integrated gradually into government family planning and reproductive health policies and programmes since the discovery of HIV in the country in 1988. Other development activities such as the expansion of transportation and communication technology, empowerment of women in terms of providing wider education opportunities, expansion of HIV and AIDS knowledge even from emigrant returnees, have all made it easier to gradually tackle and manage HIV issues in the country.





## **Chapter Three: Literature Review**

Chapter three reviews existing studies in the field of stigma, discrimination and disruption of human needs associated with HIV from a global perspective outside Nepal, alongside studies in the context of Nepal. This chapter also reviews those studies undertaken in the field of HIV, especially in identity crisis and identity transformation from an outside country perspective. Likewise, it also reviews existing studies on the impacts of stigma, discrimination, and disruption associated with HIV on identity issues with a view to investigating the research gap in a Nepalese context. Finally, taking into account the existing literature, an attempt is made to provide theoretical and conceptual frameworks for contextualising the present study with a focus on identity issues.

### **3.1 Identity Crisis and Identity Transformation**

#### **3.1.1 Identity Crisis**

There are number of misconceptions and a lack of knowledge with regard to the epidemic of HIV and AIDS that associate stigma and discrimination with the discovery of HIV that also devalues the identity of PLHIV. Even though the biological fact has long been established that HIV is transmitted primarily through blood or sexual fluids, there are still various misconceptions and ignorance about HIV and AIDS. In much of the world there is a misconception that HIV can be transmitted by casual contact. In this regard, previous studies have demonstrated that casual contact such as hugging, kissing on the cheek, shaking hands; sharing a bed, toilet, bath or shower; and using the same glasses and dishes does not lead to “catching” HIV (UNESCO, 2005). However, people are still fearful that HIV is transmitted through simple, daily interactions without the

involvement of blood or body fluids. Casual contact like shaking hands, kissing, eating together with a PLHIV or sleeping in the same room as a PLHIV are frightening, not only to the general population, but also to health personnel (Campbell & Waters, 1987; Stangl, 2010). Consequently, there has been an issue of devaluing PLHIV due to not disseminating accurate HIV knowledge as it relates to daily life. Thus, lack of knowledge, and various misconceptions on HIV and AIDS, as well as not applying theoretical knowledge to practical matters (such as in the case of health personnel) are associated with identity issues in PLHIV in most parts of the world.

Many people view the identity of PLHIV as the result of a personal choice of engaging in “bad” practices such as homosexual behaviour, extramarital sexual behaviour, and injecting drug use (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012; UNAIDS, 2013). There exists a perception that when a person contracts HIV, it is due to his/her lifestyle. These lifestyles are considered to be risky sexual behaviour with multiple partners, male-to-male sexual activities, and drug-taking activities sharing needles with HIV-infected people. In many societies, these lifestyles are considered to be different from cultural sexual norms and values. Therefore, people contracting HIV and AIDS are associated with marginalized behaviours and groups. These behaviours, or the conditions resulting from those behaviours, are given different labels such as: “gay plague”; “spread by sex workers”; “woman’s disease”; brought by “white men”; “African disease”; or “disease of the poor” (Jolly, 2010; Parker et al., 2002). Thus, the already marginalized groups associated with those labels are further stigmatized with HIV diagnosis and their identity has been spoiled in the eyes of family members, other relatives and people living in their societies.

HIV-related stigma is not only linked with marginalised groups in terms of homosexuality, extramarital heterosexuality and drug use as mentioned above but is also linked to gender and class. In a society where the status of women in terms of education and economic independency is low, HIV is regarded as a disease of women since HIV is considered to be the outcome of risky heterosexual behaviour. Likewise, PLHIV are also stigmatised either due to class, whether poor or rich. People of lower economic status, especially females, are often accused of engaging in risky sexual behaviours. On the other hand, in some contexts, the epidemic has been characterized by assumptions about the rich and about higher educational attainment, and HIV is often associated with affluent lifestyles (Jolly, 2010). The affluent can spend money on a variety of things, including sexual activities. Likewise people with higher education often have the ability to earn money, and they also spend money on sexual behaviour with multiple partners. There is also a belief that rich people are also involved in affluent lifestyles involving the buying and using of drugs. Thus, people with different social status are viewed differently in their being HIV infected, from gender and class perspectives (Parker et al., 2002). PLHIV are discriminated against by forms of social isolation and rejection by their family and by wider society (UNAIDS, 2005).

There are also institutional forms of stigma and discrimination in hospitals, work places and schools. Health personnel can also play discriminatory roles in providing health services to PLHIV. Regarding this, some of the studies conducted in South Asia (including Sub-Saharan Africa) demonstrate that health providers' attitudes towards HIV positive individuals is not very much different from that of the general population (Greeff et al., 2008). A study conducted among PLHIV in Bangladesh from March 2005 to May 2007 found that they are stigmatized, discriminated against and viewed

negatively, not only by the general population, but even by health providers and hospital staff who are connected to them (Ullah, 2011). The study demonstrates that an overwhelming majority of health personnel such as physicians and nurses demonstrated behaviours towards HIV-positive individuals that were discriminatory. In this study of Bangladesh, although the nurses and the physicians have the theoretical knowledge about the routes of transmission, they did not seem to wish to apply that knowledge personally to their own situation. In another study carried out in Thailand regarding the attitudes of health personnel towards PLHIV, nurses held the dominant social perception that women living with HIV were perceived as violators of gender norms, and thus “guilty” victims (Chan, Rungpueng, & Reidpath, 2009).

As mentioned above, the various forms of HIV stigma and discrimination have negative effects on the quality of life experienced by PLHIV and their networks (MacQuarrie, Eckhaus, & Nyblade, 2009). HIV stigma and discrimination discourage people from getting tested for HIV, seeking medical care and social services, disclosing to sex partners, or learning how to prevent further transmission (MacQuarrie et al., 2009; UNAIDS, 2010). Consequently, the stigma and negative discrimination contribute to the marginalization of minority population groups, increasing their vulnerability to HIV, which, in turn, exacerbates the original stigmatization and discrimination (Parker et al., 2002). Studies on HIV stigma in African countries show that it leads to individual outcomes such as internal self-devaluation, social isolation, lack of diagnosis disclosure, and to discriminatory actions such as verbal and physical abuse, avoidance, gossip, loss of privacy, and medical mistreatment (Greeff & Phetlhu, 2007; Holzemer et al., 2007).

Moreover, there are violations of human rights in South Asia although all people are equal from a genuinely humanitarian perspective (Stangl, 2010). There are many contradictory examples from nominally humanitarian perspectives in many countries of the world; these include travel restriction for PLHIV (UNAIDS, 2010). This situation has inhibited efforts to expand access to life-saving HIV prevention, treatment, care, and support.

### **3.1.2 Identity Transformation**

Although there are many negative aspects associated with HIV and AIDS documented in the literature, increasing access to information and services in HIV and AIDS has led to reduction in stigma and discrimination, and has improved the lives of PLHIV (UNAIDS, 2005). PLHIV and many other stakeholders, international organizations and non-governmental organizations are actively working to let people know more (irrespective of HIV status) about HIV and AIDS. As a result, PLHIV are, in some cases, experiencing improved identity after HIV prevention and treatment programmes as well as some reduction in HIV stigma and discrimination. These are some of the positive experiences of PLHIV as illustrated from HIV research in countries outside the Nepalese context.

After this brief review of HIV and its related stigma, discrimination and disruption of human needs in the global context, including South Asia, this study is now directed towards a review of HIV in terms of identity transformation from spoiled identity to reconstruction identity. PLHIV have an undesired “possession” that can be referred to as “ownership”. For the PLHIV, the HIV virus is an undesired possession. They often accept this ownership over time. Despite the illness of HIV, individuals can undergo a

transformation process from spoiled identity in which people report having a deep feeling of detachment, and proceed to acceptance of their illness, and then to feeling empowered and in control of their HIV status and their lives. This process is very complex and non-linear as it involves many iterative progressions in identity transition (Whitehead, 2006). Those HIV-status people with a more positive path are those who focus on their new lives without thinking about what they have lost. In the process of identity transition, the PLHIV rework, negotiate and transform their roles, actions and behaviours through their active engagement with support mechanisms (Tsarenko & Polonsky, 2011). One study carried out concerning primary prevention research demonstrates that there are two ways of preventing HIV infection: by scaling up education and testing, and by continued stigma reduction (Hendriksen et al., 2011). According to this study, doctors and NGOs working with HIV and AIDS do an excellent job educating newly diagnosed individuals about routes of transmission, condom use and behaviour change.

In an attempt to understand how PLHIV challenge, reject, or integrate a stigmatized identity, researchers have explored common strategies for coping with stigma. These coping strategies fall into two general categories: stigma avoidance and stigma control (Stangl, 2010). Linking with the view given by Goffman (1963) on the impact of stigma in the construction of a spoiled identity, Liamputtong, Haritavorn, and Kiatying-Angsulee (2009) explain that the identity of PLHIV is constantly changing. HIV-related stigmatization and discrimination can be reconceptualised within a broader social, cultural, political, and economic framework rather than as individual processes (Parker et al., 2002). Regarding the identity of PLHIV, they state that “social actors, on the basis of whatever cultural materials are available to them, build a new identity that

redefines their position in society and, by so doing, seek the transformation of overall social structure” (Parker & Aggleton, 2003, p. 19).

PLHIV manage stigma and discrimination carefully with different strategies, especially with some concealment and control and both voluntary and involuntary disclosure. They disclose their HIV diagnosis, depending on their careful consideration of expected results and reactions (Poindexter, 2010). In this regard, Norman, Chopra, and Kadiyala (2007), in a South African study, found that HIV disclosure was a carefully managed, cost-benefit process. One finding in this study is that there are various steps, including a psychological analysis regarding who to tell instantly after discovering of one’s HIV status. The steps are, basically, feeling pressure to access medical treatment or social services, testing potential reactions from family members, full disclosure to one’s network (circle of PLHIV), and active disclosure as part of activism, education, or care of other PLHIV. Thus, HIV disclosure can perhaps be understood in various categories with some concealment and control, and with voluntary and involuntary disclosure (Obermeyer, Baijal, & Pegurri, 2011).

Tajfel and Turner (1979), writing with regard to social identity theory, identify three variables contributing to the emergence of in-group favouritism. In this respect, individuals firstly identify with an in-group to internalize that group membership as an aspect of their self-concept. Secondly, the prevailing context provides ground for comparison between groups. Thirdly, there is the perceived relevance of the comparison group, which itself is shaped by the relative status of the in-group. In social identity theory, individuals are likely to display favouritism to the in-group when that in-group



is central to their self-definition. This theory considers that group membership creates self-categorization and enhancement in ways that favour the in-group at the expense of the out-group. After being categorized with a group membership, individuals seek to achieve positive self-esteem by positively differentiating their in-group from a comparison with an out-group. In relation to HIV infection, social stigma includes prejudice and discrimination directed at persons either perceived to be or actually infected with HIV, and the social groups (out-groups) with whom they are associated (Rohleder & Gibson, 2006; Sontag, 1991; Tsarenko & Polonsky, 2011).

### **3.2 HIV Issues in Nepal**

Earlier studies undertaken in the field of HIV found that Nepalese people perceive HIV differently (Beine, 2002; Mukherjee, 2014). HIV is often culturally perceived as the outcome of previous lifestyles, especially extramarital sexual behaviour which goes beyond Nepalese socio-cultural norms and values. In this context, HIV is associated with engaging in extramarital sexual behaviour, fear of HIV transmission from a PLHIV as well as negative feelings toward the “bad person”. Likewise, HIV is also synonymously perceived as the “Mumbai disease” locally, especially in western Nepal. That term symbolises a disease being brought back by Nepalese who return home after spending a few months or years in Mumbai, India (Mukherjee, 2014; Nepal, 2007). The literal meaning of this term is that there are some places in Nepal, especially the economically poorer western regions, where many migrant workers travel to India for (mostly) seasonal jobs and a few people among them carry HIV when they return home. The expression Mumbai disease is often also justified by the fact that Nepalese people returning from Mumbai were more often HIV infected than the people returning from anywhere else in India – a research finding from a study conducted among Nepalese

emigrants living with HIV (Nepal, 2007). People with HIV going anywhere else in India are now also considered as having Mumbai disease, especially in a western Nepalese context (Nepal, 2007). The expression Mumbai disease leads to fear in the people hearing the term, and this fuels the stigma and discrimination associated with HIV.

As mentioned above, HIV creates denial and rejection responses from individual to institutional levels because of the fear of HIV transmission. Blame is laid for presumed extramarital sexual behaviour as well as hatred towards the infected person, who is then considered to be a bad person (Beine, 2002; Nepal & Ross, 2010). Therefore, PLHIV often deny that they have been HIV diagnosed, and later deny their own roles in becoming HIV diagnosed. Similarly, community people and people working in institutions, even health institutions such as hospital staff, often refuse to provide health services, to the extent of not giving admission for PLHIV. The reasons for denial are possibly related to a lack of proper knowledge about the mode of HIV transmission or misconceptions about the transmission (Nepal & Ross, 2010).

HIV-related stigma and associated discrimination are prevalent in Nepal. A study conducted in Nepal by Family Health International-Nepal revealed that PLHIV were ostracized from home; they were not introduced to guests or invited to any ceremonies. This is possibly due to the fear of losing family honour and social respect (Family Health International, 2004). Many people in Nepal perceive HIV and AIDS as a result of bad karma (Beine, 2002). Findings from earlier research work in Nepal, as in other countries of South Asia, demonstrate that health personnel also view PLHIV negatively as they are also guided by cultural norms and values (Mahat & Eller, 2009). It is

reported that HIV-infected people lose social and economic opportunities compared with the general population (Family Health International, 2004).

Further deepening the issue of HIV stigma and discrimination, females face more discrimination than their male counterparts (Family Health International, 2004). The females living with HIV are more stigmatised and discriminated against, as family members support males more than female members (Mahendra et al., 2007; Stangl, 2010). This is closely linked with gender inequality in Nepalese society. Moreover, poverty contributes to the increase of HIV stigma toward women, as HIV-infected women are often stereotyped as having contracted HIV through extra-sexual behaviours (Wilson, Pant, Comfort, & Ekstrand, 2011). Even males living with HIV stigmatise and discriminate against their female counterparts in many ways (Family Planning Association of Nepal, 2011). There is a gender gap with greater stigma and discrimination experienced by females than males. There is a prevalent gender inequality, and poverty has contributed to the increase of HIV stigma in women (Family Health International, 2004). Women with HIV are belittled, and their HIV is automatically assumed to have been contracted through immoral sexual activities, even if the actual route of transmission is different. There are significant differences in the support provided to HIV-infected men and women (Family Health International, 2004 ; Nepal & Ross, 2010).

Aryal et al. (2011) accomplished a study on HIV and AIDS prevalence in the Pokhara Valley. This study showed that the problems of economic hardships for many PLHIV are more serious than HIV itself, including discrimination and social stigma. Most PLHIV in this study expressed that social stigmatisation is minor compared with

financial problems. Failing to manage medical expenses, house rent, children's tuition fees and daily meals are big problems among PLHIV. They also faced family and societal stigma and discrimination after their HIV diagnosis. Some PLHIV experienced loneliness, insomnia, mental tension, and thoughts of suicide after their HIV diagnosis. They were also afraid of how family and society would discriminate against them once the family and the society came to know about their HIV-positive status. In the case of women, a few of their husbands divorced them because of their HIV-positive status. Some women living with HIV expressed that society practised untouchability after the death of their husbands due to AIDS. Some PLHIV were not able to work collaboratively with other societal members, and their children were not allowed to play with the children of HIV-negative people in their social groups. A number of PLHIV were also sacked from their jobs after their bosses came to know about their employees' positive status, which further aggravated their economic condition. This forced them to change their occupation as well, and to do blue collar jobs working physically, despite their HIV status.

Although stigma and discrimination associated with HIV are prevalent in Nepal as mentioned above, some PLHIV now have feelings of gradually decreasing stigma and discrimination in regard to their families and society. This has become possible, it is argued, through the efforts of organizations working in the field of HIV stigma and discrimination-reduction programmes. It is arguable that after there has been education on HIV knowledge, stigma and discrimination through support groups, PLHIV have found their socially perceived stigma and discrimination has decreased. It is suggested that both interpersonal and personalised approaches have also been more supportive in lessening their stigma and discrimination. The World Bank (2010, p. 161) states that

HIV stigma and discrimination have decreased gradually in Nepal with efforts made by various organizations working in the field:

The project staff [HIV support group] reported that this more personalized approach led to reductions in the incidences of discrimination toward PLHIV. For example, PLHIV made fewer reports of being prevented from using public taps, from sharing food with their families at home, and from participating in social events. Also, a large increase has occurred in the number of clients coming for voluntary counselling and testing since the outreach efforts began.

The overwhelming majority of participants interviewed in a study undertaken in the Pokhara Valley found that self-esteem and hope for their future life was increased by gaining knowledge about HIV and its treatment (Aryal et al., 2011). Coming into contact with other PLHIV, and sharing their stories with them, helped them understand that life can be extended largely by anti-retroviral drugs (ARV). Some PLHIV have expressed that HIV is “nothing”, as they can live as HIV-negative people do by getting support from various organizations, and death is not nearer despite what they thought when they were first HIV diagnosed (Aryal et al., 2011). Some hope that, after some years, medicine will provide a complete cure, and until then their life can be extended by ARV. The matter of concern with HIV is taking care of their own health, practising good sanitation, concentrating on nutritious foods, and being active in normal activities. Many PLHIV are happy being in a network of new friends, working for the betterment of other PLHIV through the supporting organizations working in the field. Some PLHIV claim that they would have died if they had been infected with diseases other than HIV infection. This suggests that HIV is not a killing disease, but it is a warning

against taking risky sexual behaviour, and sharing needles for drug use. It is believed by some that whoever limits such behaviours and practises healthy living, can extend their life, even after HIV infection.

Many initiatives undertaken by the Nepal government have played important roles in decreasing HIV stigma and reduction programmes as mentioned above, together with a reduction in new HIV infections in recent years (National Centre for AIDS and STD Control, 2013a, 2013b). Since the mid-1990s when there were increasing levels of new HIV infection in Nepal, numerous initiatives have been undertaken to address HIV issues. In 1995, a national HIV/AIDS policy was endorsed to work with HIV and AIDS in the country. The National Centre for AIDS and STD Control has been conducting Integrated Bio-behavioural and Surveillance Surveys (IBBS) at planned intervals since 2002. The surveys have been focused on high-risk groups, especially among injecting drug users, men having sex with men, and migrants. In 2002, the National AIDS Council (NAC) was established to raise the profile of HIV and AIDS in Nepal. The NAC was intended to set overall policy, lead high-level advocacy, and provide overall guidance and direction to the national HIV and AIDS programme. The National HIV and AIDS Strategy 2011-2016 was developed to continue the best practices from the previous strategies and innovate new strategies to deal with the changing global scenario and the epidemic itself. The current national HIV and AIDS strategies (2011 to 2016) focus on a prevention to treatment care and support continuum as well as on integration of HIV services into the public health system (National Centre for AIDS and STD Control, 2011b).

Nepal has gradually made progress in the field of HIV, especially in HIV prevention and treatment, together with the introduction of the PPTCT service. HIV prevalence began declining in Nepal after the launch of an effective HIV prevention programme, particularly among key high-risk population groups such as IDUs, and female sex workers and their clients. The adult (15-49) HIV prevalence is trending downwards, and is much lower in 2011 than the previous figure (National Centre for AIDS and STD Control, 2011b). A PPTCT service has been available although its coverage is not as wide as it needs to be in Nepal. This service was initiated in 2005 (Ministry of Health and Population, 2011). Although many people do not have knowledge about the PPTCT service in the country, awareness of it in people of reproductive ages is gradually increasing. Some PLHIV (10 per cent of total women who are pregnant) have received antiretroviral prophylaxis with a view to reducing HIV transmission from mother to child during the pregnancy period (Family Planning Association of Nepal, 2011; Ministry of Health and Population, 2012). In addition, community-based PPTCT model has begun recently in a remote district (Achham) which is one of the HIV high-burden districts (National Centre for AIDS and STD Control, 2012). Community-level volunteers have been trained to refer people to PPTCT services in their communities with a view to facilitating help for needy pregnant women. If either husband or wife is HIV positive, the couple may have an HIV-negative baby through the precaution of using a condom when having sex most of the time to ensure safety from the partner's HIV infection. When a couple want a baby they can practise by not using a condom when trying to have HIV-negative baby (taking a risk with the possibility of the HIV-negative partner being HIV positive) at the mid-period of the menstruation cycle by applying the PPTCT practice as recommended by doctors. This period of the menstruation cycle has a high chance of conceiving a zygote in the female during sexual

intercourse. Even if husband and wife are HIV positive, they can have HIV-negative baby by using the PPTCT intervention (National Centre for AIDS and STD Control, 2011c).

There is very limited research on the impact of stigma and discrimination from the perspective of identity. Although some studies on identity shift from one stage (spoiled) to another (identity reconstruction) have been undertaken, they are mostly oriented to African contexts. Studies in South Asian contexts rarely consider the issue from the identity perspective of PLHIV, but rather from the perspective of the epidemiological facts of HIV and AIDS, levels and trends over the past years. Although there are some studies on stigma and discrimination associated with HIV in South Asian and Nepal contexts using a qualitative approach, they have focused mainly on overall pictures of such events rather than the segregating nature of those events by gender, marital status, caste and class. It is contended that the factors behind HIV stigma and discrimination are all associated with social and cultural perspectives connected with extra-marital sexual behaviour and drug usage. With this in mind, this study intends to investigate the hidden roots of HIV stigma and discrimination in family and society. In spite of the great efforts in HIV prevention and enabling access to HIV treatment along with awareness of HIV knowledge made by government and non-government organizations in Nepal, there is still not any study done to investigate the present experience of PLHIV. Furthermore, this study uses qualitative research to look at identity shifts, if any, along with changes in their family and societal stigma and discrimination. The PLHIV Stigma Index on Nepal recommended this investigation be carried out (Family Planning Association of Nepal, 2011); this study is consistent with that recommendation.



### **3.3 Goffman's Theoretical Framework**

This study follows a theoretical framework based on Goffman's work on stigma and its strategic management. It focuses on the impacts of family and social stigma and discrimination on identity issues. Goffman's theoretical framework is still important in the field of stigma (Franco, 2007) even though his framework was developed before the discovery of HIV. His framework considers how a person can be either discreditable or discredited; how the person feels self-hate, self-isolation, and depression; how the person passes information to a variety of social groups with the use of information control mechanisms; and how the stigmatized person develops his/her identity through himself/herself, family and social groups (Burns, 1992; Franco, 2007). Accordingly, this study follows Goffman's stigma framework in relation to the interaction between people stigmatized with HIV and their counterparts, social groups.

Goffman (1963) defines stigma as a relationship of devaluation in which a person is disqualified from full acceptance in a society; consequently the person is socially discounted. As he said, stigma can relate to physical or character "deformities", or membership of a "marginal" social group. HIV infection is related to the criteria he mentions. The stated purpose of the present study is to look at identity transition caused by HIV and AIDS in relation to reconstruction of identity from the perspective of how PLHIV are stigmatized and labelled as those who possess some undesired deviance and difference, suggesting what Goffman (1963) terms a "spoiled identity". According to Goffman's stigma framework, as given above, the stigmatized persons (HIV-infected persons in this study) can use the following strategies in managing their identity:

- a) Socialization of personal identity and information control;
- b) "Passing"; and

c) Group alignment.

Goffman describes the socialization of the personal identity of a stigmatized person as a process of “information control”. The discreditable person manages information, continually judging whether or not to reveal their stigmatic quality. The information control relates to the management of signs and symbols (covering up) that carry social information. Others who share the same stigma can provide instruction on the “tricks of the trade”: how to navigate through society as a discreditable person; a social sphere within which to feel “normal” (Franco, 2007).

“Passing” is a central concept developed by Goffman, which he uses to help describe information control. This refers to when a person with a stigmatic quality manages information so that they can partly, or fully, “pass” as normal. The stigmatized people continually assess who does, or does not, know about their “secret”. People possessing stigmatic qualities frequently live biographical discontinuities, as they live double lives – normal with themselves and different with others who stigmatize them (Burns, 1992; Goffman, 1963). Passers draw on several information-control strategies. These can include the concealment of stigmatic symbols, such as covering up or removing special devices. Family members can create a protective capsule in the home where the person will feel accepted as normal and may be able to live in ignorance of their deviance from other people and the difficult social challenges that lie ahead.

The stigmatized persons may be involved in their own group of people with same disease; and they can acquire skills for handling and interpreting their lives as normal so that they do not undermine themselves (Franco, 2007). They discover that they will

have more “pleasant” social interactions if they marginalize their feelings and self-expression and adapt themselves to the social views of the group. The relationship of the stigmatized with normal society highlights their deviation from societal norms. Consequently, the stigmatized manage their social deviance against what is normal, alienating themselves from the community that upholds the stigmatizing norms, or employing a variety of passing techniques to manage information and their status among both the stigmatized and other populations (Burns, 1992).

### **3.4 Conceptual Framework**

The conceptual framework of this study follows the stigma in relation to PLHIV as outlined by Goffman’s stigma and management strategies in his theoretical framework in relation to social stigma. In addition, my study also considers a conceptual framework provided by Parker et al. that “S & D [stigma and discrimination] are social processes and that, consequently, S & D can be resisted and challenged by social action” (Parker et al., 2002, p. 9). According to this framework, HIV-related stigma and discrimination are not limited to individuals as a static form: rather these are socially constructed phenomena that can be resisted by social supports. It follows that the stigma and discrimination displayed against PLHIV can be reduced by the collective efforts of family, community and institutions.

As stated in the special session on AIDS to the 42<sup>nd</sup> session of the United Nations General Assembly Special Session (UNGASS) in 1987, there are three phases of HIV epidemics:

- a) The epidemic of Human Immunodeficiency Virus (HIV): HIV is a particular type of virus, a lentivirus that causes Acquired Immunodeficiency Syndrome,

AIDS. In the initial stage, HIV infection is asymptomatic; and people may feel healthy for many years. However, they can transmit the virus to others, especially through bodily fluids, such as semen or vaginal secretions (Smith, 1998).

b) The epidemic of AIDS: The last stage of HIV infection is AIDS, which is diagnosed only when the immune system has been damaged by the HIV virus (Wachs, 2005).

c) The epidemic of social, cultural, economic and political reaction to AIDS: The third phase is worldwide and is “as central to the global AIDS challenge as the disease itself” (Mann, 1988, p. 131) and is connected with the first two phases.

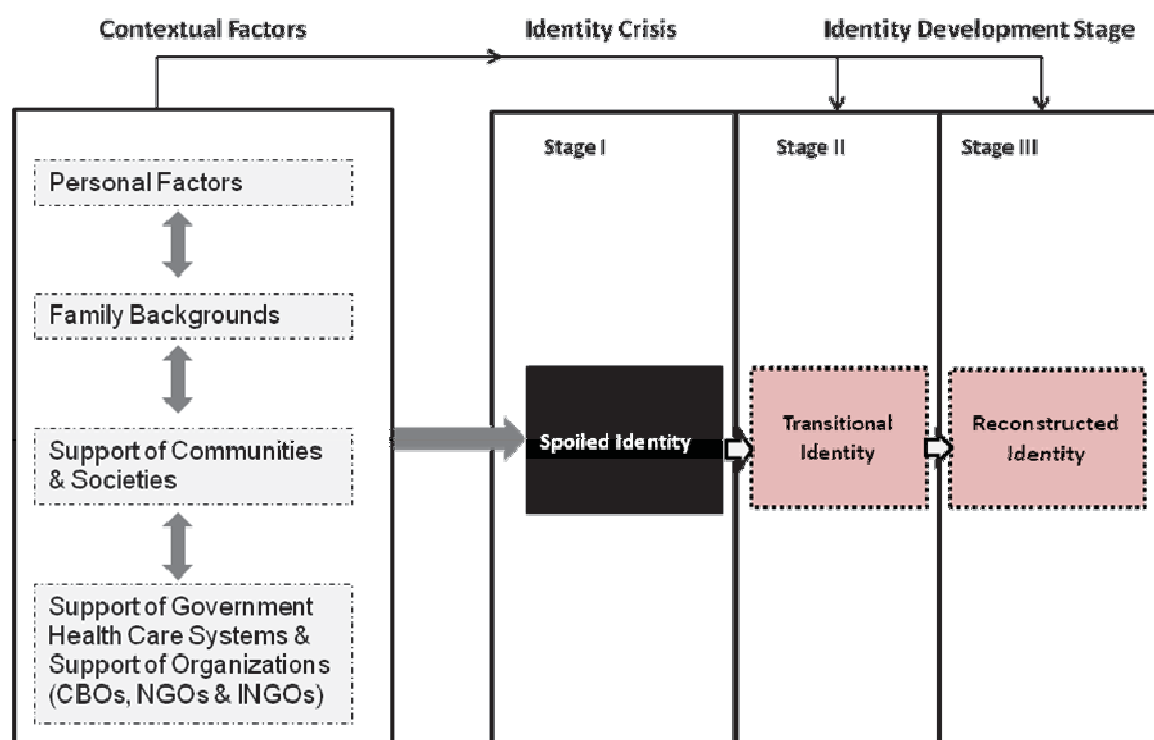
With regard to stigma and discrimination as stated in the UNGASS on AIDS to the 42<sup>nd</sup> session as mentioned above at c), Sontag (1991, p. 101) mentions that AIDS and its metaphor, compared with cancer, emerged as a disease “whose charge of stigmatization, whose capacity to create spoiled identity, is far greater”. Most studies demonstrate that marginalized groups are further marginalized in terms of the vicious circle of stigmatization and discrimination as they are assumed to have HIV and AIDS (National Centre for AIDS and STD Control, 2010). This study argues that further marginalization is questionable if individual, family, community and societal efforts, and the support network of PLHIV all actively work in every aspect of their lives, such as in reducing stigma and discrimination. Importantly, efforts can be made in reducing family and social stigma and discrimination through health counselling, increasing

discourses on HIV and AIDS, and conducting programmes in favour of their needs through community based organizations (CBOs), NGOs, and INGOs.

In the Nepalese context, the epidemic of HIV stigma and discrimination as well as identity status is a central issue for PLHIV as many PLHIV do not readily disclose their HIV status. This has resulted in a hindrance of access to HIV information, care and support in PLHIV. This study is thus directed towards the identification of major factors that lead to social stigma and discrimination in relation to HIV and AIDS, and the impacts of those factors on their identity based on their lived experiences. Importantly, this study aims to look at the situation of PLHIV at various stages of identity. On HIV diagnosis their identity is often presumed to be spoiled. Their identity then progresses through a transitional identity stage, to a reconstructed identity according to some of the studies in other countries' contexts as reviewed above. However, there is a dearth of studies on HIV with various stages of identity development in Nepal.

To place this study in perspective, it is important to note that, as reviewed in earlier studies in the context of a few other countries regarding stigma, discrimination and identity reconstruction, there is a general framework of interactions between various factors after HIV diagnosis. There is a *development of identity* in PLHIV, depending upon personal factors, family background, rural and urban community and societal structures, support given by organizations and a sense of spirituality in PLHIV and in their families (see the contextual factors listed in Figure 1 below).

**Figure 1: Conceptual Framework for the Study of Identity Development in Nepal**



### Conceptual Framework Developed by Author

This study intends to examine the contextual factors which influence how PLHIV feel about their identity crisis and how they reconstruct their identity. Among the contextual factors, personal factors may include gender roles in the family (from economic perspectives); the interpersonal capacity of a PLHIV for convincing his/her family members about who is responsible in being HIV infected; the empathetic capacity of one's family; and the availability of economic supporters. Other factors may include whether any family members are exposed to knowledge about HIV and AIDS as well as community and societal structures such as place of residence (whether rural or urban), and whether or not knowledge about HIV and AIDS is provided to HIV-negative people as well as the PLHIV. Furthermore, the support of organizations may also play an

important role in assisting PLHIV. Such supports include HIV counselling, HIV treatment and empowerment through the provision of informal education and help in seeking jobs. Similarly, spirituality may also have a supportive role for an individual and in his/her family, enhancing harmony in the family and in society as a whole. Indeed, all these factors often interconnect with each other. If such family and societal supports are absent, this can lead to spoiled identity and negative behaviour towards PLHIV. On the other hand, availability of these supports can greatly assist in the formation of transitional and reconstructed identities, and can lead to the PLHIV not even going through a spoiled identity experience.

Furthermore, as we have seen, especially in recent studies, an individual's resilience, family and societal supports, and support of organizations can change one's spoiled identity into transitional identity, and then from transitional identity into a reconstructed identity. This study aims to explore how and why stigmatized Nepalese PLHIV remain in the position of spoiled identity and thereafter, whether they are able to reconstruct their identity in the Nepalese context or not, given their personal and contextual factors. From the conceptual framework, an attempt is made to develop a proposed reconstruction of identity model with detailed analytical factors that lead to a spoiled identity as well as the factors that lead to transitional and reconstructed identity (see Chapter Nine). This study utilizes a qualitative research methodology for data collection and data analysis, with a view to achieving the research objectives and finding answers to the research questions identified in Chapter One.

### **3.5 Conclusion**

This literature review has found that in studies on HIV stigma, discrimination and disruption of human needs, as well as identity issues of PLHIV, there is a dearth of HIV studies on identity issues, particularly with reference to transitional and reconstructed identity stages. Therefore, this study is important with regard to identity issues in Nepal, as well as in South Asian contexts. To bridge the current research gap, this study utilises a qualitative research methodology, keeping in mind Goffman's stigma theory. Based on the existing literature review on identity issues and identity reconstruction, and taking into account the contextual background of Nepal, the author has proposed a conceptual framework for conceptualising the study and the progression of identity development in PLHIV.





## **Chapter Four: Research Methodology**

The consideration of methodology is divided into two parts, research methodology and reflective methodology. Chapter four deals with the first part, research methodology. This includes epistemological understandings of the researcher in the particular area of study, qualitative research, research design, and the methods of data collection and analysis used in this research. This chapter also explains the process of ethical approval, data transcription, translation and data management at pre- and post- data collection phases. I discuss the research concerns that underpinned my methodology. The particular emphasis in this chapter is on how I managed procedures for collecting data from PLHIV, after receiving approvals from the relevant institutions and organizations.

### **4.1 Epistemological Understandings of the Researcher**

This section briefly addresses my epistemological perspectives, especially my understandings of PLHIV in relation to their identity reconstruction and conceptual framework (Figure 1). These perspectives are developed in light of my experiences of people living with HIV and AIDS, and my understandings of Nepalese socio-cultural transformations. It is my research purpose and research questions, together with my understanding of experiences of PLHIV from my previous HIV research, which led to the development of my conceptual framework (Figure 1), which was set out in Chapter Three.

In qualitative research a researcher sets out with some preliminary ideas and his/her own blend of epistemologies and procedures, based on his/her own understandings in the particular area of research without knowing exactly where the research findings will

lead (Miles & Huberman, 1984). The researcher brings to the task a philosophical outlook on how knowledge is acquired in his/her field (Tolich & Davidson, 1998). In this context, I developed a conceptual framework (Figure 1) based on an inductive research approach. In this study, I proposed to study the experiences of PLHIV, especially how they move from one stage of identity to another. In this way I hoped to gain an understanding of how *transitions* start and proceed, and the interplaying factors inherent in these phenomena. In my previous HIV research (Aryal et al., 2011), the lived experiences of research participants were shared via semi-structured questionnaires involving both qualitative and quantitative data. I found that their lived experiences with HIV and AIDS changed with time, especially in terms of their feelings before and after HIV counselling and treatment (Aryal et al., 2011). In this previous study, their feelings about living with HIV and AIDS improved after HIV counselling and treatment. It became clear that PLHIV can resist HIV stigma and discrimination if family and their social network play supportive roles towards them (Parker et al., 2002). Since the discovery of HIV and AIDS, international, national and community based organizations have been playing supportive, if contended, roles in HIV counselling and treatment, and providing advocacy against HIV stigma and discrimination (UNESCO, 2005; UNAIDS, 2010, 2013; Ministry of Health and Population, 2012).

As discussed in Chapter Two, Nepalese society assigns different roles and responsibilities, and hierarchical positions according to gender, caste, and class. For example, there are hierarchical positions in male and female gender, as well as within gender; for instance, women who have a husband being higher, and widows lower (Uprety & Adhikari, 2009; Yami, 2007). These rankings based on gender, marital status, caste and class have been changing considerably in Nepal since the movements

to multi-party democracy and the Maoist War. Nepalese people have been experiencing gradual socio-cultural transformation in recent years. An impetus to this study was provided by recent socio-political changes in Nepal, including the government's increased focus on marginalised groups of people. These intersecting phenomena, my previous experience in research with PLHIV, and the dynamic socio-cultural transformation of Nepal, have led to my own epistemological standpoint in this research. The development of my conceptual framework was enhanced by the literature on identity reconstruction and various processes of identity incorporation (see Parker et al., 2002, Whitehead, 2006; Baumgartner, 2007; Tsarenko & Polonsky, 2011; Hendriksen et al., 2011).

#### **4.2 Qualitative Research**

Qualitative research is often employed to answer the “why and how” of human behaviour and experience that is difficult to obtain through quantitative methods of data collection and analysis (Bryman, 2012). Therefore, this method is often used in the context of exploratory studies, where little is known about a subject or phenomenon (Silverman, 2004). Nevertheless, some methods are more conducive to certain types of qualitative inquiry than others. In this study, it was expected that subjective understandings would emerge which would allow more complete insights into people's experiences of living with HIV. These insights emerge through the provision of greater detail and rich descriptions, rather than merely obtaining data through participants ticking a box or choosing their response on a scale in a questionnaire (Silverman, 2004; Smith, 2003). In this study, I engage in an interpretive and meaning-making process in relation to the experiences of research participants. This means that this study is oriented to often dynamic local settings, and attempts to make sense of, or interpret the

phenomena in terms of the meanings people themselves bring to them (Taylor & Bogdan, 1998). The intent is to generate knowledge that is faithful to human activities as a way to enable me to deepen my understanding of the experiences of Nepalese PLHIV.

The research area of HIV and AIDS is regarded as a sensitive topic in Nepalese cultural settings (Beine, 2002). It is sensitive because HIV is understood as the outcome of activities related to homosexuality, sexual “misbehaviour” and substance use that are outside of mainstream social norms and values in Nepal. As a result, there is a greater than usual risk of stigma and discrimination for PLHIV, and even for service providers and researchers working in the field of HIV in Nepal (Family Health International, 2004). Considering these risks, I deliberately protected all research participants, organisations and stakeholders working in this field by maintaining confidentiality and using pseudonyms in the processes of data collection, analysis and reporting.

### **4.3 Research Design, Field Plans and Procedures**

#### **4.3.1 Research Design**

My inductive approach and conceptual framework necessitated the development of semi-structured questionnaires, addressing my research objectives and research questions. My own previous research understandings of the lives of PLHIV, together with the conceptual framework, suggested a tentative order in which interview questions should be presented, with certain basic questions being addressed to each participant. Commenting on semi-structured questions, Shank (2006, p. 50) states that “a semistructured interview allows the interviewer some latitude in how questions are asked, and in what order, but it is still the case that all interviewees are asked the same

basic questions”. Following Miles and Huberman (1984), the conceptual framework that guides the present research grows from my previous research with PLHIV, my subjective experience of Nepal culture and Nepalese ways of interacting socially.

Thematic analysis is widely used in qualitative research methodology (Braun & Clarke, 2006). This method was chosen for this study because it seeks to understand and describe how people (PLHIV in this study) feel, think and behave within a particular context (Bryman, 2012; Guest, MacQueen, & Namey, 2012). Themes are derived from data relative to a specific research question. In thematic analysis, semi-structured questionnaires guide the conversations with research participants, which enable a researcher to ask further clarifying questions to explore particular themes more deeply (Wengraf, 2001). In developing questions (interview schedule), I paid attention to the purposes of this research, research questions, and my conceptual framework. The semi-structured interviews would also, I hoped, be of interest to participants, because it would allow them an opportunity to seek and articulate deeper understandings of their own experiences in a very literal language (Gillham, 2000; Ritchie & Lewis, 2003). In this way, I expected that every interested participant could not only understand my questions at the time of each interview, but perhaps improve their understandings of their own experiences.

In order to dig out deeper understandings of life experiences of people, a researcher needs to follow an appropriate sample size, designing the sampling method, and appropriate methods of data collection and data analysis in accordance with research objectives and research questions (Becker, Bryman, & Ferguson, 2012; Shaw & Holland, 2014). Data collection is generally concerned with discovering who, what, and where of events or experiences that take place in people’s lives (Thomas, 2006; Tolich

& Davidson, 1998). Fieldwork is essential, with a view to undertaking face to face in-depth interviews with participants, and for following up questions in accordance with participants' responses, based on the research interests of the researcher (Tolich and Davidson, 1998). After ascertaining the group of people that the researcher wants to investigate, and undertaking an interview with an interested participant, additional cases are often chosen by means of snowball sampling in a qualitative research (Sarantakos, 2013). Snowball sampling takes advantage of social networks to recruit participants. Sample size is determined when data saturation is reached. According to Shaw & Holland (2014), data saturation is achieved once the same sorts of experiences are repeated again and again from different participants.

An inductive approach is a common means of linking research objectives and summary findings and involves developing a theory by using a systematic set of procedures for analysing qualitative data (Thomas, 2006; Braun & Clarke, 2006). This research is intended to result in a theory of identity reconstruction based on an inductive analysis of participants' lived experiences, in contrast to a deductive theory/model testing approach (Shank, 2006). Field plans, data collection procedures and methods of data analysis are discussed further in the following sections, from the perspectives of this research.

#### **4.3.2 Field Plans and Procedures**

The researcher implemented the research design in two ways: firstly, by developing a good relationship with the institutions that I had to deal with for ethical approval and consents prior to data collection; and secondly by preparing field instruments, selecting research sites, and describing demographic and social characteristics of participants

needed for collecting data. Firstly, in order to obtain ethical approvals from ethics committees a good relationship with research participants and the organizations working in the field of HIV would have to be established. Because of the political and social environment, this process proved to be more complex than expected, and is explained below in section 4.4.

I then developed an implementation plan using a flexible research design. This design included preparing a semi-structured interview questionnaire, choosing a wide range of research sites, and developing as wide an age range as possible to include a wide variety of participants, irrespective of gender, caste, class and sexual orientation. I developed a semi-structured interview schedule to be asked *with* research participants in my field work (see Appendix 3). The semi-structured interview tool encouraged openness, allowing new ideas to be brought up as a result of what research participants said during interviews with them. This further provided me with a way to develop additional questions based on participant responses. The ‘structured’ part of the interview tool prevented participants from going too far beyond my research objectives, and the research questions were constructed in a way that focused on the process of identity reconstruction (Wengraf, 2001).

A field plan was prepared to recruit research participants through a snowball sampling method with the help of community support groups located in the Kathmandu and Pokhara urban areas. This method makes it a little easier to find participants for this HIV- sensitive topic, benefitting from social networks and information provided by earlier participants in interviews. Many PLHIV do not want to disclose their own health status with other people beyond their own network. I already knew, to some extent,



some friends working in the field of HIV in the course of doing my previous HIV research (Aryal et al., 2011) before coming to New Zealand for this study. I tried to develop a relationship for data collection using the references of contact persons from some community support groups which I already knew. From this perspective, I designed two ways of finding PLHIV as research participants: one was from snowball sampling through earlier participants to be interviewed for this study, and the other was networking from one organization to another based on the connections between various organizations.

I chose for research the Kathmandu and Pokhara Valleys, two of the largest regions most affected by HIV in Nepal. Both valleys are major urban centres of Nepal, known to have the most internal and international migrants. I chose these areas expecting that migrants are more vulnerable to health issues, particularly HIV and AIDS, than indigenous people (Brummer, 2002), although this study does not focus on any particular differences between migrants and non-migrants. The research sites consist of three districts, Kathmandu, Lalitpur and Bhaktapur from the Kathmandu Valley and three districts, Kaski, Syangja and Tanahu from the Pokhara Valley and its adjoining locations. Understanding the reluctance of people to discuss their HIV, I made an effort to cover a wide range of research sites, thinking that the wider the coverage, the more likely it would be to find research participants for data collection.

A research plan was prepared to collect data from PLHIV aged 18 years and above. The reason behind this was PLHIV are infected at sexually active ages as well as the ages most common for using drugs. Moreover, the basis for choosing this age range was that

according to the prevailing laws of Nepal, the legal age for marriage, without the consent of parents, is 18 years for females (Aryal, 2007). After this age, female can have sex with her legal partner. However, younger people, aged down to 12 years, irrespective of gender, who were infected due to parental transmission or any other mode of transmission (blood transfusion) were also considered for data collection depending upon ethical approvals from the institutions concerned.

While participants' real names were used to attest to their consent, they were invited to choose a pseudonym in order to protect their confidentiality; once consent was obtained pseudonyms were used throughout the interview and data analysis processes, including in this report. Likewise, organisations were arbitrarily assigned numbers (Organisation One, Organisation Two, and so on) in order to protect their confidentiality and integrity. Thus confidentiality of participants and organisations was obtained and protected.

Finally, I considered compensating research participants in one way or another. In the absence of funding for research participants, I could not provide them with costly things. However, I wanted to express my appreciation to them verbally in return for their time and the effort of sharing their experiences. Furthermore, I thought of offering a diary for literate research participants working in an organisation, and writing pads for the school-aged children of participants whose economic status was poor. I intended to give participants a choice of either the diary or writing pads as a token of appreciation.

#### **4.4 Process of Ethical Approvals**

Due to my research being undertaken in my home country of Nepal, I had to obtain two ethical approvals, one from my study institution, MUHEC, New Zealand, and another from NHRC, Nepal. The ethical approval processes took more than three months. The process of ethical approvals is explained below along with some of the challenges I faced during the application processes.

##### **4.4.1 Ethical Approval from MUHEC**

To receive ethical approval from Massey University, I applied to MUHEC providing a justification for my HIV research, and expectations of the outcomes of this research, including its possible risks to people involved with this study, and strategies to mitigate those risks. I obtained ethics approval from MUHEC on May 2, 2012.

##### **4.4.2 Ethical Approval from NHRC**

After reaching Kathmandu in the third week of May, 2012, I focused on ethical approval process from NHRC with a view to collect data from PLHIV in Kathmandu and Pokhara Valleys. In order to obtain that approval, I had my research proposal, ethical approval from MUHEC, and other supporting documents from Massey University. Having reached Kathmandu, I determined what needed to be completed before commencing the field work of data collection: the application for ethical approval at NHRC, the preparation of documents necessary for the application including an English–Nepali translation and visits to organizations working with HIV and AIDS in order to build rapport and obtain their consent letters.

In line with the above, I visited NHRC and applied for ethical approval in Kathmandu. I introduced myself with my area of research to NHRC personnel. They were convinced of the importance of my research study and seemed to be cooperative. Then they accepted my application for ethical approval on the condition that I had to submit consent letters from some organizations through which I had to interview PLHIV. After approaching some organizations through the help of my senior colleagues, I obtained consent letters from these organizations working in the field of HIV located in Kathmandu and Pokhara Valleys and submitted those letters to NHRC for ethical approval. In section 4.5, an attempt will be made to discuss how I obtained support letters from various organizations, prior to ethical approval. The purpose of this was to gain guidance on the way this research should be conducted from people and organizations working in the field of HIV. NHRC raised issues regarding the inclusion of young people between the ages of 12 and 18, and oral consent. These issues were negotiated to the satisfaction of MUHEC by providing all the related documents received from Massey University. I was given the approval letter from NHRC as per my field research design on the third week of July, 2012. Thus, I crossed two hurdles of ethical approval, one from MUHEC, New Zealand and another from NHRC, Nepal.

#### **4.5 Organizational Visits Prior to Ethical Approval and Data Collection**

As stated above, after lodging my application for ethical approval for my research at NHRC, I started visiting organizations working in the field of HIV in the Kathmandu and Pokhara Valleys. The purpose of these visits was to develop positive relationships with heads of organizations as well as to request consent letters from the respective organizations through which I could collect data from PLHIV. In the case of some of

the Kathmandu visits, I discovered that obtaining consent letters from organizations working with HIV is difficult.

I tried to obtain consent letters from the organizations working in the field of HIV by strategically seeking acquaintance through senior people who are in contact with these organizations. As a member of Nepalese society, I knew very well that there was little likelihood of completion of any stage of research field work, including obtaining consents of organizations to interview PLHIV, without producing references. As part of this process, I visited the FPAN in Lalitpur, one of the districts in Kathmandu Valley to see my senior friend and ask her to find organizations that could help me to find PLHIV who are under their support and care. The senior friend assisted me greatly by providing a list of possible support people including the donor of a funding agency who could help me in finding organizations and contact people working in the field of HIV. At the suggestion of the persons working at FAPN and a donor agency, I went to one of the organizations led by PLHIV with great expectation that would work well in building up a positive relationship for obtaining consent letter and finding PLHIV. I was given a consent letter of the organization for data collection. I considered this consent letter obtained from the organization located in Kathmandu as a victory in the process of obtaining ethical approval. Then I also started developing positive relationships from some organizations working with PLHIV in Pokhara with the help of my senior friends. I received support letters for my data collection from PLHIV through the organizations. Then, I submitted the letters of support from organizations to NHRC for ethical approval.

#### **4.6 Organizational Visits for Data Collection**

After obtaining ethical approval for field research from NHRC following ethical approval from MUHEC, I started field work of data collection from one of the large organizations working in the field of HIV located in Kathmandu. I interviewed 15 participants from organizations, which will be identified as Organization One, Organization Two, Organization Three and Organization Four located in the Kathmandu Valley. Thereafter, I moved to Pokhara and interviewed 18 participants from the next four organizations, identified as Organization Five, Organization Six, Organization Seven and Organization Eight. After having interviewed 33 participants in the two valleys, Kathmandu and Pokhara, I re-interviewed 17 participants for further clarification over the responses given by them, asking additional questions wherever I realised they were needed. At this point I realised that I had achieved data saturation, since I was hearing much the same information from different participants. The following section is intended to provide as much detail as possible on how I proceeded and successfully collected data in the first and second rounds.

##### **4.6.1 First Round Interviews in Kathmandu Valley**

I started collecting data from research participants at the premises of a large organization in Kathmandu from 22<sup>nd</sup> July 2012. Organization One provided me its guest room for conducting the interviews with interested participants. At the start of each interview, I introduced prospective participants who came to me for interviews and asked if they would like to continue talking with me after I described to them the purpose of this study. Participants were also encouraged to express themselves in a way that was meaningful to them. I interviewed five of the participants at the guest room of the organization and interviewed one female participant at her home. I recorded

interviews with four participants using my recorder and took verbatim notes with two participants in accordance with their permission.

I moved to Organization Two in Kathmandu with a view to collecting data from other participants. After hearing all the details of my project, this organization was willing to help me find PLHIV for research interviews. Fortunately, I found a research participant to interview at the same day. Having interviewed her, I also asked her and other staff working there for interviews with other people. I discovered that PLHIV were at great distances from that organization and that they would also not be comfortable with me seeing them at their place of residence because of HIV stigma and discrimination. However, they made it clear to me that they would help me find interviewees if anyone possible came into contact with them.

I moved on to Organization Three and Organization Four working with PLHIV located in Lalitpur within the Kathmandu Valley. Having explained my research project with the programme manager in the third organization, she showed interest in assisting me find PLHIV, on the condition that I had to apply for consent from this organization, consent that needed to be approved by various bodies of other organizations associated with her organization. As advised I applied for consent from this organization with my supporting documents. She suggested that I contact the organization again after a week. Then, I moved to Organization Four which is also located in Lalitpur where I found that my friend, a student of Central Department of Population Studies, was also working there. All the staff seemed to be very positive in assisting me to find PLHIV once they understood about the importance of my project. They assured me they would tell me if anyone was interested. I found this organization was the most likely place to find

PLHIV for research interviews as there were many staff working with HIV treatment and temporary rehabilitation for needy people infected by HIV who came from outside the Kathmandu Valley.

After building rapport with Organization Three and Organization Four, I kept contact with all four organizations frequently for data collection. Organization Three gave me verbal approval for data collection. I reached there to interview PLHIV who were interested in my research study. There was only one woman who spoke Nepali and others were non-Nepali speakers. I did not have knowledge of mother tongues other than Nepali and turned to only one woman speaking Nepali. Then I started conducting an interview with her in a yard of this organization (Organization Three), giving her my purpose of the project and confidentiality assurances. I came back from Organization Three after conducting one interview, telling the staff of this organization that I would be happy to return for further interviews if anybody was interested. Likewise, I followed up with Organization Four for research interviews. The organization told me to go there for interviews with PLHIV. After my introduction and explanation of my research project, I found seven males living with HIV and interviewed them in detail over 10 days. This organization offered various interview places, either the roof top or balcony or research participants' individual rooms, wherever they felt most comfortable for the interview.

#### **4.6.2 First Round Interviews in Pokhara Valley and its Periphery**

After interviewing 15 research participants in Kathmandu, I began data collection in Pokhara, as set out in my field plans. First, I went to a large organization (Organization



Five) located in the heart of Pokhara city. I had already taken a consent letter for data collection through this organization. But a staff member at this organization told me to now apply for a consent letter from the donor agency as circumstances had changed. This added another hurdle for me to obtain approval from the donor agency. However, understanding the changing circumstances, I proceeded to obtain the consent of the donor after obtaining details from the organization of the person in charge of the donor agency located in Pokhara. When talking to him in person it was easy to describe my project. Then, he assured me he would assist me by informing Organization Five to provide me the opportunity for data collection and suggested that I commence data collection the following day. I started collecting data from PLHIV through this organization. I also asked the person in charge of this organization to make contact for me with other organizations located in Pokhara city. She had already received consent from her superiors to help me locate PLHIV. She contacted the other organization in Pokhara and received a positive response for data collection. Thus, I had two organizations, Organization Five and Organization Six in the core city of Pokhara.

I went to Organization Six to develop a relationship of trust and mutual respect with them so that I could commence data collection. The manager of Organization Six gave me consent to conduct interviews with females and I asked them to find other prospective participants in Pokhara who among their contacts. They assured me there could be some other females who could come there at their own request for an interview, in accordance with their time availability. I regularly followed up with Organizations Five and Six, and subsequently interviewed nine people, including four males from Organization Five and five females from Organization Six.

Then I started collecting data with Organizations Seven and Eight located in the rural hills. In Organization Seven, I had already built rapport in my first visit at the time of obtaining consent letters to be submitted for ethical approval at NHRC. I spent one night at Organization Seven and completed interviews with four females and one male. I continued to Organization Eight and interviewed four additional participants, two males and two females. During the latter interview, research participants were repeating the same things mentioned by earlier research participants; I found a saturation point of data collection.

#### **4.6.3 Second Round Interviews in Kathmandu and Pokhara Valleys**

I started to revisit participants where I wished to clarify issues arising from the first visit. When I sent some of the translated Nepali–English copies of interview transcripts from the first interviews to my supervisors for feedback, it became clear to me what I had missed and that I had to ask further questions after having received the feedback. In addition, I also realised that I had not asked some of questions related to sexual matters, condom use, widow status, and remarriage, especially in case of female participants. Asking questions in regard to sexual matters and condom use involves cultural taboos in Nepalese society. I went back to the relevant organizations I had visited earlier for my study, four in Kathmandu and three in Pokhara, and I re-interviewed 17 research participants. In my second visits to the organizations for more clarification, I found it easier to ask research participants my remaining questions and they also responded to me openly.

#### **4.7 Data Management, Transcription and Translation**

Confidentiality was paramount in this HIV research. The information collected from participants was held by me during the time of information gathering and afterwards. While gathering data in the field, I stored my field notes and recorder in a locked box in the room where I stayed. At the time of data collection and after my field work I stored all the recordings and note copies in a locked box at my home. I brought all the data information safely back to New Zealand for data analysis. As I assured the two ethical committees, I fully observed the regulations of the Code of Conduct of the Ethical Committees of Massey University and the Nepal Health Research Council in the field of data collection and managed my data safely.

As mentioned in the process of ethical approval, I used an audio recorder to interview 31 out of the total 33 participants, with their consent for using the recorder. The remaining two participants agreed to give their interview as I took verbatim notes. Thereafter, I transcribed all the 31 recordings into Nepali script. The participants' first and second interviews were so lengthy some of them spent more than three hours in their interview, which made the length of time to transcribe in Nepali and then translate into English very long. These are around 400 pages translated into English altogether from the two rounds of interviews. As stated in my ethical process, translator, Professor Bhim Prasad Subedi of Tribhuvan University, translated my Nepali transcription into English, maintaining confidentiality with this sensitive issue. Later on, I did not find the translation of all Nepali writings was possible, due to the length of each interview with the translator's time constraints. I became personally engaged with translation which gave me more knowledge about my data, taking the interviews, transcribing the voices

into Nepali, and Nepali into English. Thus, all the processes of Nepali–English translation made me more familiar with a sense of the data from various perspectives.

#### **4.8 Method of Analysis**

After undertaking face to face in-depth interviews, transcribing them verbatim into the Nepali language and then translating the texts into English, I became very familiar with the data, and how it answered the research questions of this study. This is a kind of pre-analysis of the researcher, myself, prior to analysing data, applying various steps of data analysis (Braun & Clarke, 2006; Harding, 2013). It should be acknowledged that some sensitivity of the data is inevitably lost in translating Nepali words and experiences into English, but I made every effort to reproduce the feeling and experience of the participant as well as the words.

I used thematic analysis as explained before. Thematic analysis, an inductive method of data analysis, begins with preparation of raw data files, close reading of the text, creation of categories, overlapping coding, and continuing revision and refinement of the category system (Braun & Clarke, 2006; Thomas, 2006). Close readings of the text involves consideration of the multiple meanings that are inherent in the text. In this research, I began with close readings in Nepali of the interviews of the 33 participants, one by one, to identify the constituent parts of the description, and to attribute implicit and explicit meanings in relation to HIV and AIDS issues (Smith, 2003). After gaining a clear understanding of the participants' descriptions, I began to identify common themes and sub-themes that were emerging from the data. I then coded these according to various categories and organised them under main themes and sub-themes,

recognising where these overlapped, grouping and regrouping as necessary. These main themes and sub-themes were used to answer the research questions of this study (Bryman, 2012; Guest, MacQueen, & Namey, 2012). This method enabled me to generate themes and sub-themes from the field data for the presentation of the findings through a process of inductive thematic analysis (Thomas, 2006; Braun & Clarke, 2006).

After having grouped the field data into various broad themes and sub-themes, I analysed the data by hand through a meaning-making process. There may be many possible constructions of reality after the event (in this study, HIV diagnosis) has taken place (Lincoln & Guba, 1985). There are likely to be multiple meanings of AIDS constructed by people: for example, AIDS is perceived variously as “a woman’s disease”, “an African disease”, “a disease of the rich”, “a disease of the poor”, and “a death sentence” depending on the contexts (Jolly, 2010; Parker et al., 2002).

In the course of data analysis, this study followed Bourdieu’s (1986) forms of capital, where one form of capital (such as social) can be converted into other forms of capital (such as cultural or economic). This study used the categorisation of these forms of capital (social, cultural and economic) propounded by Bourdieu and applied them to PLHIV. A PLHIV’s social capital (their nuclear and extended families, friends and other social networks), cultural capital (knowledge/training), and economic capital (regarding materials such as employment, income, property etc.) are interchangeable (Sen, Aguilar, & Goldbach, 2010). Bourdieu’s ideas about social capital have been widely extended to include access to resources in terms of social supports in the field of health (Carpiano, 2007). This concept has been applied in various ways in the field of

HIV and AIDS, especially this view of social capital as including access to networks of supporting people (Sen, Aguilar, & Goldbach, 2010). Bourdieu (1986) also draws attention to the importance of reciprocity and association. Further elaborating this idea, the act of giving among equals often generates some sort of a return, whereas this act among unequal persons could bind the weaker party (for example, a widow living with HIV and her children) to the stronger party (extended uninfected family members) through feelings of obligation.

Likewise, this concept of reciprocity may apply to family and societal relationships of PLHIV, especially where there have been constructive economic and social relationships with the extended family and society prior to HIV infection. On the other hand, if the widow and her children cannot give support to the extended family economically and socially, she is more likely to be ostracised by the extended family. Consistent with Bourdieu's views, this study analyses how research participants move towards identity reconstruction by receiving social capital support and converting this into cultural capital (HIV knowledge, leadership training, literacy etc.). Likewise, this study analyses field data on how research participants convert cultural capital into economic capital (work and income) at an individual level, while engaging with organisations or other entities. In Nepal, the various forms of social capital, cultural capital, and economic capital identified by Bourdieu cohere with this description of "access to resources" as introduced in Chapter 1. These forms of capital have been interchangeably used as either a particular form of capital or access to resources in general throughout this study to contextualise these forms in the context of Nepal.

Utilising these concepts of social, cultural, and economic capitals (access to resources), and using a meaning making approach as explained above, the field data have been analysed on the basis of research participants' lived experiences. In general, they expressed how their experiences of HIV stigma, discrimination and their identity formation interlinked with their access to resources, especially with the social capital available to them from their extended families and societies, as discussed in Chapter Seven. Analysis of field data, for instance, showed that research participants, especially widows, and women who were separated or divorced from their husbands, experienced greater stigma and discrimination in their extended family and society. They perceived their status to be "low" socially and economically, especially before expanding their circle of relationships with other PLHIV. Widows interpreted their life situation to be a result of their husbands' deaths, and separated and divorced women attributed their situation to HIV itself. As a Nepali researcher, I understand their interpretations in light of their social norm that husbands are generally considered to have greater economic and social responsibilities for their family, especially their wife and children. Women who have lost their husbands need to rely on their own income, in addition to rearing, caring for, and schooling their children. Such women have a lower profile financially and socially in their extended family and society, although I found their lived experiences varied widely. By contrast, other research participants, especially males, and females who have their husbands, have not experienced such issues of stigma and discrimination to the same extent in their extended family and society, because of the availability of social capital (especially their spouse/parents). Analysing the field data, I have taken into account both the traditional Nepalese socio-cultural context, and recent socio-cultural changes since the advent of multi-party democracy and the Maoist War.

The findings chapters of this study are organised sequentially, from diagnosis of HIV to reconstruction of identity so that the reader can follow the processes of reconstructing identity. These chapters were developed in accordance with main themes such as HIV discovery, spoiled identity, transitional identity and reconstructed identity based on the inductive approach, and the emerging themes from the data, these becoming major chapter headings. Likewise, sub-themes such as ways of HIV discovery, initial reactions and responses; and HIV stigma, discrimination, and life disruption, were created under the main themes of HIV discovery and spoiled identity respectively. Similarly, sub-themes such as migration, disclosing and hiding HIV status, economic independence, the practice of HIV treatment, support of organizations, and spirituality; and stigma and discrimination management, improved health status, and positive socio-economic changes, were developed as the processes of transitional identity, and better experiences of reconstructed identity respectively.

At the end of the data analysis, an attempt is made to develop a proposed theory on identity reconstruction, based on the inductive approach from the data to theory (Strauss and Corbin, 1998). In developing the proposed theory entitled “the reconstruction of identity in people living with HIV”, I have utilised the three forms of capital- social capital, cultural capital and economic capital, and their inter-convertibility (Bourdieu, 1986). Likewise, I have also borrowed ideas from Caldwell’s Intergenerational Wealth Flow Theory, which considers how economic capital reciprocity functions and acts in a family, and how family members change their behaviour in terms of fertility, with a high number of children in agrarian society and a low number of children in modern society (Caldwell, 2001). In addition, I have also considered the notion of Todaro’s model of internal migration which states that people



have economic rationales for migrating, although his study is oriented towards rationalisation on economic grounds, especially in the case of rural to urban migration (Todaro, 1976). I have applied a similar analogy in terms of the way that extended family members rationalise their attitudes to the nuclear family, especially to a widow participant and her children with the death of a husband due to AIDS. This analogy has been illustrated in several places in the findings chapters, especially where a widow has been detached from her extended family with the loss of her husband's financial and social support. When the widow is incorporated into a wider social network (social capital) and she converts this social capital into cultural and economic capitals, then she is reunited into the extended family, since she has now become economically and socially independent (see Chapter Nine). In addition to economic points of view, there are also social aspects that are pertinent. In the case of PLHIV, other members in an extended family are likely to fear the loss of the extended family honour and social respect from their neighbours and societal members, because they have person (s) living with HIV in the family (Family Health International, 2004). Consequently, other family members may dislike PLHIV, as illustrated later in the analysis chapters.

## **Chapter Five: Reflective Methodology**

This chapter provides a deeper understanding of the process of field work and data collection in a given contextual political background and a chosen time for field research along with the country's geographical difficulties in a heavy rainy season. The purpose of this chapter is to reflect in greater depth in a more specific way on the ethical, structural and practical challenges faced by the researcher over the period of ethical approval, rapport building with organizations working in the field of HIV, and data collection. Despite these constraints, I discuss how I managed data collection successfully. This chapter also includes my perceptions of the field work as a researcher, especially in relation to the sensitivity of the HIV issue from gender perspectives.

### **5.1 Constraints with Ethical Approval, Field Work and Data Collection**

There are series of layers that one needs to cross in the field of HIV research in a non-linear way within a high-risk category of ethical approval to interested participants living with HIV. The series of layers involve mainly ethical committees, funding agencies, organizations working with HIV, PLHIV, and the interested research participants. Research on HIV presents difficulties in respect to dealing with ethics approvals due to it being a highly sensitive topic, obtaining consents from funding agencies and the organizations working with HIV, and from the research participants themselves. After receiving the consent of the funding agencies and organizations working with HIV, the last, but the most important, step is to get consent from the interested participants for research among PLHIV. Therefore, I had to negotiate various critical steps one layer after another due to the nature of HIV research.

Although this study is not concerned with the study of funding agencies and the organizations, I had to go through these organizations as per the necessity of finding PLHIV. To find my participants, I started a journey of obtaining consent letters from organizations located in Kathmandu through which I was targeting my data collection. I had no reference from anybody else in the initial stages. The organizational responses were not supportive in providing the consent letters for data collection. I thought my mere individual efforts in getting consent for data collection from some of the organizations were not good enough and I needed to make approaches through a political network. After meeting political leaders, I did not find any progress in convincing the authorities of the organizations for my data collection. Finally, I tried to go through references of donor agency to develop a positive relationship with the authorities of organizations working in the field of HIV and this endeavour worked well to get consent letters for data collection. Even after meeting PLHIV, I felt there was also a layer of interested and not interested groups of the people with which I had to deal to find interested participants for my research. I felt the way of seeking consents from various organizations through which I had expected to collect data was non-linear as I had to obtain consents even from the funding agencies themselves.

At the time of negotiating the ethical process from NHRC in Nepal, I realised that having to meet the different requirements of two different ethical committees from two different countries is a big challenge. In my case of ethical approval, there was some debate, especially on the age of participants and regarding verbal consent to be obtained for interviews as the research committee required a minimum age requirement for interviews of 19 years and also there was a requirement for written consent. Before

handing my application for ethical application in to the research committee at NHRC, I was told to propose only interviewees aged 19 years and above in regard to age and written consent from the interviewees; whereas I had already received participants aged 12 years and above, and verbal consent from the MUHEC. I needed to clarify whether, given the circumstances of my approval letter from MUHEC, I could interview someone aged down to 12 years who wanted to share with me their experiences with HIV after having verbal approval from the interviewee. These two issues, age and written consent, made the process of ethical approval difficult as I had to obtain approval in accordance with the approval already received from MUHEC.

Between May and November is often not a good time for data collection in Nepal due to the rainy season and festival holidays. When I was the field, it was rainy season (from May to September). The rainy season made me postpone my field work time and again. I was also sometimes obstructed due to heavy rain fall and a landslide in Dhading district, which is on the way from two research sites (Kathmandu to Pokhara). In the continuous rainy days, I had to wait till the rain stopped to go to perform field work. Likewise, there are *Dashain* (the biggest festival) and *Tihar* (the second biggest festival) festivals in Nepal that take place in October and November every year. All the government and private offices are closed for the celebration of these two festivals. Therefore, I had to postpone my interviews with my participants due to these festivals as I had to go through organizations to see my participants.

A transportation strike was one of the constraints that I faced as a researcher in the process of ethical approval, developing a rapport building and collecting data in the

field. Arriving in Nepal from New Zealand on 20<sup>th</sup> May 2012, there were three days of transportation strike in Nepal declared by various indigenous groups who demanded that the government should include their demands in the new constitution. Coincidentally, I arrived just a week before the proposed date for the declaration of the new constitution (27 May). The transportation strikes continued over my stay at the time of field work and data collection as the Nepali government failed to declare the new constitutions in the country on the stipulated date and the various political parties and student unions demonstrated at rallies declaring one-two days' strikes against the government with a view to pressure it from its position. Therefore, I had to remain at home at the time of the strikes instead of building up positive relationships with organizational heads, PLHIV and proceeding forward to data collection. At that time, I had to reschedule the organizational visits for the rapport building and data collection phase in the research sites.

## **5.2 Factors Contributing to Successful Negotiation of Data Collection**

Although it was hard for me to get entry into organizations in the initial phase for granting consent letters and assistance for data collection, I completed my data collection efficiently in the later phase. There was great support from the organizations working in the field of HIV. I managed to convince people of the need for HIV research on identity issues. There are important things that helped me to accomplish this field work. They include: my good understanding of Nepalese culture; my empathetic attitude in dealing with PLHIV in the initial stage of becoming aware of HIV stigma and discrimination and the high expectations of research participants regarding HIV prevention, and reduction in HIV stigma and discrimination after giving information to me. Addition assets include my earlier HIV research experience, as well as choosing a

wider research sites (Kathmandu Valley, Pokhara Valley and its peripheral locations). I touch on these stories briefly below.

Organizations working in the field of HIV and AIDS were actively involved in enabling me to complete this research. Their co-operation was in part due to my capacity to convince people, and to explain that research on identity reconstruction is a new research area. During my visits to them, I felt that I could convince people working with PLHIV of the importance of this study. Although there had been some studies carried out in the field of HIV stigma and discrimination, people were aware that no studies about the impacts of stigma and discrimination on identity issues had been done before in Nepal. This made it easier for me to convince the people working at the organizations to become willing to help me through their collective efforts. This resulted in smooth completion of data collection.

Interviews were more effective where the researcher, agency workers and participant(s) discovered a common connection with either associates or relatives, or a common connection to a geographical location. After my introduction to a woman working at a big organization working in the field of HIV, we discovered that her parental home was near the border of the Dahachok village development committee in Kathmandu where my family lives. Immediately, we established a relationship of *Dai* (Me, as Elder Brother) and *Bahini* (She, as Younger Sister) as per our Nepalese culture. I came to know that she was working there in one of the key positions at the organization and she helped me a lot in finding PLHIV, introducing me with the interested research participants. I felt that our cultural relationship, of *Dai* and *Bahini*, and the proximity of

our homes from a geographical point of view worked effectively when doing field work.

I wanted to ensure that no member of the public or organization would raise any issues or complaints at the time of data collection. I made strenuous efforts not to do anything that would harm any of my interviewees or the people working in the HIV field at any of the organizations I worked with. In some of the circumstances, I adopted an empathetic attitude, especially when dealing with PLHIV for the first time. I also gained clues about the interviewees from facial gestures and the body language of others in the helping organisations. Then, I learned to recognise the helpers' gestures that indicated a particular person was living with HIV. However, I never asked for an interview with anyone living with HIV without getting introduced by someone from the respective organization. Some HIV-negative people would just point at someone to assist me to get an interview with the person. I did not take up any interview with anyone who was simply pointed out to me as one living with HIV. This approach helped me to avoid any negative issues during my field visit.

I believe that my success during the field work has been a result of my education and experience working in Nepal. Gaining educational attainment from school to university level inside and outside the country with a prestigious scholarship and working in different organizations helped me develop skills to deal with people in difficult situations. The work I did with Population Women Environment Development Organization, Society for Co-operation and Development funded by foreign agencies, teaching at Gramin Adarsha Multiple Campus in Kathmandu, Birendra Adarsha Multiple Campus in Chitwan as well as teaching Master's courses doing research on

reproductive health (Knowledge, Attitude and Practices of School Going Students) all contributed to finding organizations working with HIV and AIDS, rapport building and asking for support with data collection. In the field of HIV and AIDS, working as a principal investigator exposed me to many people working at governmental and non-governmental organizations in Kathmandu and Pokhara.

Furthermore, I was successful in creating good networks while working as a Programme Coordinator at Masters level in the Population, Gender and Development Programme from 2008-2011, including roles and responsibilities of headship of Faculty of Humanities and Social Sciences, Pokhara University for eight months, in the absence of the usual dean, before coming to New Zealand for this PhD study. In the absence of the dean at the Faculty, I successfully managed the Faculty. Thus, these various opportunities in the course of gaining education and working in various jobs provided me an opportunity to interact with many people working at various levels. The people I had worked with before helped me to interact with people working in the field of HIV and AIDS by taking me to organizations. I was also assisted by telephone conversations with senior officers in regards to my research. This helped me to accomplish my tasks at the various levels with enthusiasm. In some of the places I did the fieldwork with the support of former students of Pokhara University who helped by giving me organizational details that allowed me to interact with organizational heads in regard to finding PLHIV. All this support and cooperation from people I had previously worked with reassured me that I had been successful in creating good fellowship during my tenure in various jobs that also helped me in accomplishing this research field work successfully and enthusiastically.



A crucial reason behind the success of data collection was to take a wider coverage of geographical areas, gain consent for research in six districts from the ethics committees, MUHEC and NHRC, and understanding the sensitivity of HIV research. Indeed, I had already figured out, to some extent, if the areas of study are narrowed, the process of data collection would be harder if I could not find PLHIV. It is clear that finding PLHIV is not easy; that is why I had to go to many organizations. In this study, I have used four districts only, Kathmandu, Lalitpur, Kaski and Syangja out of the six possible districts for which I had received ethical approval for data collection. Nevertheless, including a wider approval area gave me more options to proceed in field work which can be attributed as a reason for success in data collection.

### **5.3 Lessons from Field work and Data Collection**

Referral is vitally important in the Nepalese context in developing a positive relationship with organizations working in the field of HIV research due to its being a culturally sensitive topic. As explained before under the heading of “constraints”, there was initially no positive response from some organizations through which I had a plan for data collection. When I changed my strategy and sought references from some people working in the particular field, then I received positive responses to go ahead in obtaining consent letters for data collection from these organizations. I realised that the Nepalese saying is absolutely true, even among academic people, that “this is Nepal, nothing can be gained without references from those in power”.

My understanding that theoretical knowledge differs from practical knowledge was confirmed when I stayed overnight at a participant’s home. After I woke up the following day, I saw some mosquitoes flying here and there in our room where we had

slept without mosquito nets. I did not know how many mosquitos had bitten me in my sleep during the night. I had not worn adequate protective clothing because of hot season. Then, my heart became cold as I wondered whether a mosquito bite could have transmitted the HIV virus to me. I kept these thoughts to myself. Although I was teaching my students that HIV cannot be transmitted to anyone by mosquito bite, my mind wondered whether it is true. Nevertheless, I consoled myself thinking, “I have been a Laboratory testing whether a mosquito bite can transmit the HIV virus”. I discovered that there is a vast difference between our theoretical knowledge and what we believe based on real practical experiences.

I understood that qualitative research is more powerful than quantitative research. On the way to Pokhara after completing data collection at my seventh organization, while going down the hill I realised the importance of qualitative research from the findings drawn from the interviews and that nothing can be as predictable as it can be in the quantitative research. A story was related where there were three family members living with HIV, one mother and her two children, a daughter and a son aged below 10 years who did not drink even a single drop of water or any type of fruits except meals of millet and the urine of cows for one year as instructed by a herbal doctor with a view to HIV treatment. This puzzled me as to how people could survive without drinking water for so long. After all, I came to a conclusion that qualitative research can be more powerful than a quantitative method where variables are predetermined. In addition, this study gave me a glimpse of how predefined variables cannot capture as much data as the qualitative method has captured; that many aspects of people’s lives are not easily categorised.

In my field visits for data collection, I found that Nepalese culture has changed significantly, especially since the introduction of multiparty democracy in 1990. For example, the old cultural practice that currently married females must wear red clothes is no longer compulsory in practice in recent years. In contrast, widows were not allowed to wear red clothing after their husband's death. Now widowed females also wear red clothes, since the recent government prohibited making a bias in wearing different coloured clothes once a husband is deceased. There is no the practice of remarriage in Nepalese society. Consequently, in my field visits, I could not easily recognise females' marriage status by the colour of their clothing. Likewise, I could not ask questions related to remarriage as the practice of remarriage is rare in Nepal. There was no provision for a widow to remarry though there is a gradually changing scenario of marriage forms these days. In my study, I also found a case of remarriage of a female participant from a so-called untouchable caste at age 25 when her first husband died due to HIV. In this case I tried to maintain an impartial researcher viewpoint in the cultural balance between previous strict cultural society in terms of marriage, sexual matters and the changing scenarios of liberalism in these matters, in recent political changes in the country.

Rewarding research participants by offering verbal appreciation and something practical as a token of respect is accepted practice in Nepalese culture. As stated in my research design, I rewarded them by verbally offering respect for their help in being research participants. In addition, I offered them a choice of either a diary or writing pads for their school-aged children. I was very happy to see the happiness in the research participants when they received these as tokens of respect.

#### **5.4 Researcher's Perception and Experience of the Field Work**

PLHIV appeared more willing to give interviews enthusiastically than HIV-negative people; this was different from earlier interviews conducted for Nepal Demographic Health Survey 1996 as a supervisor in Bardia district of Nepal and such other interviews conducted for our faculty researches funded by United Nations Population Fund-Nepal. I easily discovered that these people do not have opportunities to tell their stories to others as they are stigmatized and discriminated against in their society. In this respect, I also demonstrated to them that I was an eager listener to all their stories, whether they had positive or negative experiences of their lives after HIV diagnosis. Furthermore, PLHIV, especially females, wanted to share their positive experiences and saw me as a willing messenger in our society conveying various trajectories of their HIV lives.

Among PLHIV, I found females are more willing to give information than males. Most of the females in my study who were brought up in rural areas were not literate. They were very naïve in the sense that they did not have knowledge to help them give their responses to the questions asked of them. Indeed, when they could not give relevant response to questions they gave answers to me with open hearts and those answers remained very useful for this study. I understand Nepalese society is informal. Females are relatively more informal than males as they are not as exposed to the outside world. More importantly, they gave me information and enabled me to see the feelings of their inner hearts. What they had in their hearts and minds has given me valuable information and they have been very helpful and cooperative in this research. In the interviews with research participants, I found males were more formal and weighed their responses to my questions although they also gave me useful information. As males are more

exposed to the outside world they try to be more formal than informal as they are trained accordingly in a male-dominated society.

I also realised that the research participants who had grown up in rural ways of life expected more updated information from me on HIV, and shared their experiences enthusiastically about being HIV diagnosed. They expected to hear, and were interested in how PLHIV are proceeding with their HIV prevention and treatment, and identity reconstruction in urban areas of Nepal, including any such experiences from other countries. As I understand they thought that I should have more new information to tell them as I was from a university studying abroad. Perceiving their enthusiasm, I also shared what I could with them, based on my study in the field of HIV, especially PLHIV in urban Nepal and other countries' examples of identity reconstruction as studied in the course of extending my HIV knowledge. I did this in a very basic rural Nepali language, explaining the success of medical treatment and PPTCT services. Research participants appeared to enjoy listening to my knowledge and in some of the organizations I was proposed to be an advisor to their organizations to speed up their development by approaching funding agencies. In response to their queries, I asked them to wait until completion of my PhD study.

In general, PLHIV are assumed to be worried about their HIV most of the time. Some of the PLHIV who were working at senior positions were worried about deadlines of report writings to donor agencies irrespective of their HIV-positive status which I came to know when I had the privilege of conversing with them, although they were not all research participants, especially in big organizations. PLHIV are generally perceived by HIV-negative people to be dirty and unhealthy. In contrast, they often assume

themselves to be healthier than HIV-negative people because they are more trained in the course of HIV treatment and health training through the organizations.

I have found HIV research on Nepal to be much easier than people's general understanding of the difficulties, especially in the process of data collection. With increasing knowledge and changing attitudes and behaviours of PLHIV through formal and informal education, they are not reluctant to talk about sexual matters and HIV these days as they might have been previously. In the beginning I was a bit scared that PLHIV would hesitate to give information on HIV transmission and how they were HIV infected because of cultural restrictions. I was also advised to use secondary data even by my senior good supporter at Family Health International working in the field of HIV. But I had already decided to use primary data obtained through face-to-face interviews. Research participants of both Kathmandu and Pokhara provided me with good information. Since I am male, I had expected it to be little bit harder to conduct interviews, especially with females. In contrast, female participants provided me with more rich data on their lived experiences than male participants. Knowing Nepali culture, I balanced data collection equally with both males and females.

In my field visits, I found that the villagers' attitude was negative towards PLHIV. At the time of the first visit to an organization located in the hills, a periphery to Pokhara Valley, I met a rural man hiking up the hill. He shared his attitude towards the PLHIV. As we climbed the hills together we shared our experiences of life. In Nepali rural culture, we generally share with a new person met on the way the details of our home, work, purpose of visit to a particular place, marital status and number of children, and other curiosities from village perspectives such as the number of cattle owned at home.

As a member of Nepali society, brought up in both rural and urban environments, I enjoyed sharing with him my personal life. However, his curiosities in regard to the purpose of my visit to the organization gave me problems as I had already known that villagers do not treat PLHIV well. I responded accordingly to his questions, balancing my response in such a way that could not hurt anyone in regard to the HIV issue. As I guessed, I found him to have a negative attitude in regard to PLHIV, hearing that nobody was happy with them in that village. He asked me, “What is your view in regard to PLHIV in this village?” He added furthermore that villagers are worried about possibilities of HIV transmission to others. I was careful in how I responded to him. Indeed, I gave general answer to his question telling him that people have various views in this respect. Then we separated to our destinations, me to the organization and he to his home close to this organization. In a corner of my mind, I wondered whether my conversation with him would interfere with my field visit and data collection.

## **5.5 Conclusion**

There were many challenges involved in the lengthy process of gaining research approvals and participants’ consents. However, these challenges were overcome gradually, networking with references from people working at donor agencies and organizations working in the field of HIV and AIDS. The capacity for HIV research was greater when done through donor agencies rather than political alliances. Moreover, the researcher’s personal factors, such as earlier research experience dealing with PLHIV, and personal contacts with people working at organizations related to HIV and AIDS, could be very important in conducting HIV research with an effective way.

## **Chapter Six: Discovery of HIV, Initial Reactions and Responses**

Discovery of HIV-positive status is a critical event in the lives of participants. It clearly divides their lives into two parts: life before, and another part of life after being HIV diagnosed. This discovery of HIV changes the lives of people economically, socially and culturally depending on access to resources, such as their own economic resources, human capital, access to treatment based on place of residence, and knowledge on HIV and AIDS. This chapter explains the individual processes of the discovery of HIV and initial reactions of participants, including responses to them in family and in wider society.

### **6.1 Discovery of HIV**

As explained above, discovery of HIV makes participants aware of their health status with a view to prolonging their lives following HIV treatment and to be aware of preventing HIV transmission. This section addresses various processes of HIV diagnosis, self-initiated HIV testing, family-initiated HIV testing, others' initiation of HIV testing and routine HIV testing. The purpose of this section is to look at the factors that encouraged participants to explore their HIV status, and which are leading them to receiving HIV treatment.

#### **6.1.1 Self-initiated HIV Testing**

Among the processes of discovery of HIV, self-initiated testing is one in which someone decides to get his/her blood tested based on someone's previous risky behaviour or a spouse's HIV diagnosis. In this study, self-initiated HIV testing is



intended to identify those persons who were injecting drugs or those whose spouses were HIV diagnosed but did not have the chance to test themselves immediately after a spouse's HIV diagnosis, although they suspected they may have been HIV infected. There were a significant number of research participants who discovered their HIV-positive status through self-initiated HIV testing. They found themselves to be HIV positive based on their historical sexual contacts with an HIV-diagnosed spouse, or through sharing needles once used by HIV-infected persons. Female participants whose husbands had died from AIDS and who had no chance of HIV diagnosis immediately after the identification of their husbands' HIV status suspected that they may have been HIV positive. Similarly, after receiving information from organizations working in the field of HIV that drug users have an extremely high possibility of being HIV positive, individuals suspected they may have been HIV positive and went to the hospital for blood testing. There are also some cases of HIV discovery from the blood tests for diagnosis and treatment of other diseases. Some of the stories of people's suspicions and discovery of HIV are given below.

An example of self-initiated testing is in the case of a wife's suspicion after identification of her husband's HIV-positive status. In this study, the overwhelming majority of HIV transmission is from sexual contacts, especially in females from their husbands. Some of the female participants initiated their blood testing on their suspicion after their husband's HIV diagnosis and found out that they were also HIV positive. In my research, some participants suspected their HIV status once their husbands had been diagnosed while working overseas. For example, Pushpa, a participant interviewed in Pokhara, who was HIV infected by her husband, advised that she had concerns about her HIV status after her husband had returned from Abu Dhabi (a city in the United

Arab Emirates). He did not seem to care about his HIV status. After suspecting that she may also have been infected, she went to a clinic of an organization working in the field of HIV in Pokhara with her aunt-in-law. Her blood was tested and she was found to be HIV positive. This was about eight years ago which was around five years after her husband's HIV diagnosis in Abu Dhabi. Pushpa shared her story that she went for blood testing because her husband was already HIV diagnosed, and she suspected she might be HIV infected.

On the third days of the birth of my first daughter my husband went to Abu Dhabi and he returned from there after two months of stay. Before our marriage my husband at age about 17-18 years had gone to Singapore and returned to Nepal... I came to know later that he had returned to Nepal because of such disease [HIV]... Thinking that my husband came from abroad I went to a clinic nearby for a medical checkup with my aunt-in-law and found to be HIV positive.

– Pushpa, Female

Likewise, there were some females who initiated their HIV testing once their husbands had died from HIV. Rita B, one of research participants, who suspected she may have become HIV infected through her husband's sexual contact went to the hospital to be tested. Her brother-in-law suggested a blood test after her husband's death. He convinced her everything about her HIV status would be kept secret. For a period of three months she had her blood tested from time to time with the results coming out negative. However, one day she also fell sick. She told the doctors about her husband's HIV status and they tested her again.

My husband used to go to India since long back. Three years after our marriage, he returned home, sick. He never spoke a word to us about his worries. He had already come to know of it [HIV] in India. I asked my brother-in-law to take him to Palpa and Pokhara for treatment. My brother-in-law came to know of it but didn't tell me anything... My husband fainted on the floor and couldn't utter a word. He was like that for three months. Then I pleaded my brother-in-law, asked him about what had actually happened to my husband. He then told me about my husband's HIV... Then up to three months, I got my blood tested from time to time but the results came out negative. I was happy. Until one day, I also fell sick. I told the doctors about my husband's HIV status and they tested my blood. After that the doctors asked me if I could control my emotions, I said I could. I had lost my husband. I had struggled a lot in my life. Thereafter, the doctors told me that I was HIV positive.

– Rita B, Female

In contrast to sexual contacts of spouses, another category of HIV testing under self-initiated testing is that listening to other people's HIV stories about sharing needles, it is important for anyone to go to hospital for blood tests to find out their HIV status. There were research participants sharing stories of HIV testing by listening to others' stories with a similar background of drug use. As a drug user, Jwala tells his story of his blood test. He had seen and listened to stories from his drug-user friends. Some of them were HIV positive. He became aware of HIV once his mother and elder sister left him at a rehabilitation centre to help him kick his drug habit. Although he was young, he kept in mind the knowledge of a high probability of HIV infection for drug users. Listening to

that story made him seek a blood test which identified him as being in the early stage of HIV.

From my older drug user friends, I came to know that there are high possibilities of having HIV – around 90 percent among those who use and share syringes for drugs. I had a friend who generally used my syringes after I had used them. Firstly, I sent him to check up his blood and the report of his blood came out HIV negative. Then I went to [a] clinic for a blood test. But my blood test report came out HIV positive.

– Jwala, Male

In contrast to sexual contacts and sharing needles for drug use, people are also HIV diagnosed in the course of treatment for other diseases at hospital under self-initiated treatment. This is another category of discovering HIV by way of self-initiated testing. However, the nature of their sickness and treatment differs from person to person. Whether by being sick from tuberculosis, chronic stomach pain, injured in a vehicle accident, coughing, lost appetite, fever, and weight loss; their blood is tested and they are found to be HIV positive. Basant, one of research participants, tells his story about being HIV positive and of his discovery of HIV after he had gone to Malaysia for work. After working there for one and half years, he started going to restaurants (which provided prostitution as well) with his friends, having alcoholic drinks and having unprotected sex with many sexual partners. When he returned to Nepal after four years in Malaysia he had stomach pains. In the course of treatment over a year and a half, his blood was tested and he was found to be HIV positive. He had learned of his HIV status 10 days ago prior to our interview for this research and was taking medicine under one of the organizations working in the field of HIV.

I had a stomach problem since one and half years. I came to know that I have HIV just 10 days ago in the course of treatment about my stomach problem...I had sexual activity in one and a half years after I first went to Malaysia. I had many sexual partners. I blame myself for this at first. There were also friends in Malaysia who to go to restaurants. When friends told me to go to restaurants or anywhere else, then I followed them. We had too much alcoholic drink. That was the main reason of being HIV.

– Basant, Male

### **6.1.2 Family-initiated HIV Testing**

In contrast to the self-initiated testing mentioned above, family-initiated testing deals with HIV diagnosis immediately after having the diagnosis of a family member, as a result of either a spouse or child's HIV diagnosis in the course of treatment for other diseases at hospital. In this study, there was no suspicion of HIV before diagnosis as it was identified in the course of treatment for other diseases. There were research participants who were found to be positive immediately after their spouse or child's HIV diagnosis at hospital.

A significant number of participants are identified as a result of their spouse's treatment for other diseases. In regard to this, one illustration can be taken from one of the research participants, Lila, who had gone to India with her husband after their marriage and subsequently found herself to be HIV positive, along with her two children. Her husband became sick and she took him to a hospital for treatment. After the testing of her husband's blood in India, she was also recommended to have her blood tested. After they were both tested, they were told to leave for home in Nepal for rest, but were not

given any indication of their HIV status. When they arrived in Nepal; her husband became sicker and he was taken to a hospital in Pokhara. As in India, she and her children were also recommended to have their blood tested after her husband was identified as HIV positive. Lila, being illiterate, did not understand the reports of their blood tests. In Nepal, especially illiterate females do not understand hospital reports as they have difficulty in knowing where to make contact and how long it takes to get reports of the blood tests and so forth. Lila was no exception to this. Meanwhile, her husband died at the hospital. After a few days, the hospital sent their reports through the post of their blood tests showing that she and her children were HIV positive. Firstly the reports were given to her mother-in-law and she gave information on HIV to Lila. Thus, she and her two children, daughter and son, were identified as HIV-positive persons.

My husband was seriously sick and taken to a hospital for treatment. In the course of his treatment, the hospital asked for our blood test, me and two children. The hospital had sent our reports to the VDC...Then the VDC handed them to our relative, my father-in-law's brother. And then, his son gave the reports to my mother-in-law (who is literate). After that, my mother in law had read the reports at home that we all were HIV positive.

– Lila, Female

Likewise, parents follow the process of HIV discovery after reports of their children's HIV diagnosis. In the course of treatment for another illness, children have been HIV infected. This sometimes follows the doctor's suggestion that the parents be tested and they are also found to be HIV positive. Rana was identified as HIV positive after his daughter's HIV diagnosis. Six years ago his daughter became sick and his wife took his daughter to hospital for treatment in Pokhara. After her blood was tested she was found

to be infected by HIV. His wife sent him a message to come to the hospital for blood tests at the doctors' recommendation the same day. In the course of treating her daughter at the hospital, she died due to HIV. Blood tests were done for Rana, his wife and two children; all members of his family were found to be HIV positive. Thus, all members of his family were found to be HIV positive after his sick daughter's treatment at the hospital.

I came to know this fact [HIV] from my daughter who became sick and was taken her to hospital for treatment. I did not know about this in India as well. She died at age 17 months due to this disease [HIV]. I had not gone to hospital at first. My wife took our daughter to hospital. Then, my wife called me to go to hospital at the doctors' suggestion... Then we, both husband and wife, had our blood tested at [a] hospital in Pokhara and found out that both are HIV infected. After HIV appeared in my daughter, we were called to check up our blood and came to know that we both were HIV infected.

– Rana, Male

Similarly, there are some cases of discovery of HIV in mothers after having identified a child's HIV status. Six years ago a child aged two-and-a-half years old who was taken to a hospital in Pokhara for his treatment but he did not recover for three or four days. When his blood was tested he was found to be HIV infected. His mother, Durga, and other family members at home did not know anything about his HIV status although his father had died due to HIV. After having identified child's HIV-positive status, doctors recommended she have a blood test. She got confused as to why they were asking her to have her blood tested, as it was her son who was sick. After her blood was tested, the

result came out negative. The doctor asked her whether this child was hers. She told the doctors the child belonged to her and they suggested her blood be tested again at an organization working in the field of HIV. When she went there for her blood test, the result was HIV positive.

My son became sick. He was two and half years old. I took him to [a] hospital for his treatment but he did not recover for three-four days. When his blood was tested he was found to be HIV infected. We did not know anything at all at that time. They [doctors] also suggested to me to have a blood test. I asked them why I need to check my blood whereas [it was] my child [who] is sick. After my blood was tested, the result came out negative at the hospital. The doctor asked me whether this child is mine. Yes, this is my own child, I said to the doctor. Then, the doctor sent my blood to be tested again at [an] organization, the result came out to be positive [HIV]. Thus, I came to know that I have HIV.

– Durga, Female

### **6.1.3 Other Initiation of HIV Testing**

Another way in which HIV is discovered is other-initiated HIV testing. In this study non-family members rather than family members have helped PLHIV in identifying their HIV-positive status either from knowing about earlier risky behaviour, such as sharing needles for drug use, or from having information about family members' HIV status. These non-family members include a property owner while living at a rental home, supporters at the time of vehicle accident as well as people working in the field of HIV. There were research participants who discovered their HIV status through



others' initiation on HIV testing. Some examples are given in regard to HIV diagnosis below.

A rental property owner's initiation and motivation remain very important in identifying one person's HIV status. In regard to this, the rental property owner encouraged Buddha to test for HIV after her husband was HIV diagnosed. Her husband was a drug user and she took him to a police camp in Kathmandu for treatment as well as to "kick his habit" of taking drugs. He was admitted there. The police camp did his blood test and found that he was HIV positive. Immediately, the police camp personnel called her to take him away from the camp because of his HIV-positive status. She came and took him to her rented home. The owner of the apartment suggested to her that she also have a blood test. She was also identified as an HIV-positive person. After her identification as HIV positive, she kept it secret for five years and then suggested to doctors, because of her husband's reason of death, to test her blood (pretending that she did not know her HIV status). After that second blood test, five years after her first HIV diagnosis, she was again identified as HIV positive. Thus, her relatives came to know about this from the hospital doctors and she received treatment in accordance with the stage of her HIV virus. She has now been living with HIV for around 15 years.

My husband was a drug user. He used to have drugs. I took him to a police camp... They did his blood test and found that he was HIV positive. Before that I never knew about HIV. Immediately, they [police camp] called me too and they told me, "Your husband has got AIDS, so he will live a few months from now. This disease [AIDS] may be transmitted to others as well. So, we can't keep him here, take him away"... He was taken to our apartment. The owner of the apartment suggested me to have the [blood]

test on the same day. I did the test. I had the same result [HIV positive] from the blood test.

– Buddha, Female

Furthermore, when Buddha suffered from heavy diarrhea five years after being HIV infected, she was taken to hospital and told the doctor that her husband had died due to HIV.

I suffered from a heavy diarrhea. I became black and nobody was there to take me to hospital. At that time, my elder brother and brother-in-law took me to hospital for a check-up. At the same time, I requested a blood check for HIV diagnosis with the doctors with a soft and low voice pretending that I did not know about this [indeed, she knew about her HIV already] in front of my brother and sister-in-law saying that my husband died due to HIV. The intent was also to give information to my elder brother and sister-in-law, and then they came to know that my husband died due to this disease [AIDS]. After the blood test, HIV was found in me in 2060 *Bikram Sambat* (*BS*). This was not strange for me as I had already known about this in 2055 *BS*.

– Buddha, Female

Neighbours also become helpful in encouraging HIV testing once they come to know about someone's previous family background. In the present study, neighbours encouraged Bishnu that she and her second husband should have their blood tested after her second marriage. She heard a message that HIV might be with her, from other people in her village after she got remarried. The rumour behind this was that her first husband, who used to work in India, died due to TB and HIV two months after having

returned to Nepal. She had not been told about HIV either by her first husband or other family members.

My former husband had such disease [HIV]. He used to work driving in India. He became sick in India and phoned me at home telling me of his health problems. He came back to Nepal after he got sick but he did not talk anything about this disease. He was taken to several places for his treatment. Later, TB appeared in him. One of his sisters staying in the same village had taken him to doctor for his check-up. He told his sister but did not tell me. He died two months after his return from India. His sister hid the reality of being such disease. She did not show me his hospital records as well.

– Bishnu, Female

After people gossiped about her health, she went to hospital with her second husband and was identified as HIV positive.

People started talking to me about remarriage telling me that a second marriage is not a big deal; it is acceptable and so on. Finally, I got remarried. The villagers from my first husband's village began to gossip that he was HIV infected. Then, I and my second husband went to Bagar, a nearby hospital and found out that I was HIV positive. But, thank God! My second husband was safe.

– Bishnu, Female

Testing initiation can also come from people's support in identifying someone's HIV status in the course of treatment when any big accident occurs in life. With reference to this, there is a story from Nimesh, a Buddhist monk, who was identified as HIV positive in the course of treatment after having been seriously injured from a motorcycle

accident in Pokhara. He was a tourist guide for foreigners from Malaysia and Thailand who came to see the mountains and hills of Nepal. As a tourist guide, he had enough money for entertainment and used money for sexual entertainment with many women, especially in restaurants (including those serving prostitution) in Nepalese cities. After the accident, his supporters took him to a hospital in Pokhara and the hospital referred him to a hospital in Kathmandu for further treatment. In the treatment of his injury, he was identified as HIV positive. He was still on treatment under one of the organizations working in the field of HIV at the time of my field visit. After discovery of his HIV, he was donated money by foreign Buddhist monks to live and to have treatment for his injuries under one of the HIV organizations located in Pokhara. Nimesh, through the support of people who saw the accident, received hospital treatment, and in the process he was identified as HIV positive.

I had met with a motorcycle accident. Two and half years back, a bus and motorcycle collided. At that time, all the people in Pokhara had given up hope of my survival. At a hospital in Pokhara, the doctors said that I could be saved by being given oxygen for 24 hours and that I be immediately rushed to Kathmandu... At that moment, my guru [a spiritual teacher who is also a Rotary club member] and my well-wishers from Pokhara raised money and took me to Kathmandu. In about three weeks of my hospital stay there, nine hundred thousand Nepali rupees were spent on my treatment. After that, I was discharged. There I was informed that I was an HIV positive. While discussing among themselves, the doctors used to say that I was positive [HIV], that they needed to wear gloves.

– Nimesh, Male

Some participants also discover their HIV positive status through the help of other people, especially those working in the field of HIV. In this context, people who work in the field of HIV have been attempting to identify PLHIV in the areas where drug users have been staying for a long time. They provide them with incentives to have their blood tested, with a view to further precautions in regard to HIV treatment. In the course of testing the blood of drug users through these organizations, some research participants were identified as being HIV positive.

People from different organizations used to come to our area where the place was known as the avenue of drug users. They recommended to us that we test our blood. I came to know I was HIV positive when I had a blood test.

– Sandeep, Male

Some of the organizations provided an incentive of 100 Nepalese rupees to drug users and anyone who wanted to test their blood if they were identified as HIV positive. As a result, they were informed about their HIV-positive status and commenced precautions about their health. After organizational efforts in identifying HIV among high-risk people such as drug users, they were identified as HIV positive and they received HIV education and treatment from the organizations.

#### **6.1.4 Routine Testing**

Finally, routine testing is also a way for discovery of HIV. This process includes visa application for overseas jobs and eligibility criteria of health in the process of sterilization in this study. There were research participants who discovered their HIV status through routine testing. Some examples are given in regard to HIV diagnosis under routine testing.

HIV is also diagnosed in the course of routine testing for work. In regard to this, Deepak gave his blood for testing as part of other medical check-ups for a visa application process to go to other country. He was told that his blood was not clear at the accepted level and it was suggested to him that he go to a hospital immediately in Kathmandu. As a result of his blood test in the hospital, he was identified as HIV positive. After that he thought about how he could survive his remaining life being an HIV-positive person.

I was trying to go to a foreign country for a job...Malaysia. When I went to a manpower company [in Kathmandu], I was asked to have a blood test including other medical check-ups, then the doctors told me to go to [a] hospital. After the blood test was done, I was told that I am an HIV positive person. Then, I came here directly [to an organization working in the field of HIV].

– Deepak, Male

Another such case was found from the blood test of a female participant who had gone overseas for a job. When company staff came to pick up her at the airport, they first took her to a hospital for a blood test. The report of her blood test came to be HIV positive and she was confined to an embassy of Nepal.

...When my blood was tested abroad, I was identified as HIV positive...On my arrival in Kuwait, my employer received me at the airport and I was straight way taken to a hospital for medical check. The blood test showed that I was infected by HIV and therefore, I had to return to Nepal immediately.

– Sarita A, Female

The process of male sterilization is also another way of discovery of HIV under routine testing. Among male participants, Ram was an Indian national living in Nepal who had gone to hospital for sterilization after fathering three children. To identify eligibility for male sterilization, his blood was tested and found to be HIV positive. His own statement on the discovery of HIV positive status is: “I had been to the hospital for family planning. I had already two sons and a daughter. In my blood test, HIV was found”. He was easily convinced that he was HIV positive, as he had sexual intercourse with women other than his wife while lodging in restaurants in places he travelled for his business. His HIV diagnosis was about a week before my interview with him.

## **6.2 Initial Reactions of PLHIV**

This section deals with reactions of participants when they were first informed their HIV positive status by health personnel at hospital. Almost all participants considered HIV as a life-threatening “disease”. But their reactions varied from silence to thoughts of suicide, denial, anger, loss of hope and other emotions after being HIV diagnosed. Meanwhile, they explained their past behaviour, giving reasons for their behaviour such as receiving HIV from sexual contacts with husband only, their sexual partners’ healthy physical appearance, having sex at one intimate partner’s home rather than having many partners in commercial sex areas, the influence of friends to drink alcoholic drinks and have sex at restaurants, drug addiction and sharing needles. They tried to explain their past behaviour, each giving their own reasons for being HIV positive, rather than it being their own fault. Their initial reactions to HIV and their life story are reviewed below.

### **6.2.1 Initial Reactions towards HIV**

In the initial stage of HIV discovery, most participants consider HIV to be a life-threatening virus. When they are advised by doctors that they are HIV infected, they think their life is near its end, as people are assured by various media, radio, television and newspapers. The HIV virus and subsequent AIDS are considered to be a death sentence. Almost all participants expressed the thought that HIV would be a life-threatening virus. Jwala, who has been HIV infected for the last 16 years, expressed his previous understandings about HIV.

I was overwhelmingly afraid of HIV. In the beginning, I felt as if I would die the next day. It was also said that no one would survive if one contracted HIV and AIDS. I was tremendously terrified wondering if my death would be today or tomorrow.

– Jwala, Male

A similar expression is found in another case of a female. She compares her success life story in her study while being a student at school in her past life and the failure in life due to HIV.

When I came to know that I had HIV, I became like I had fallen from the sky. I was also thinking to jump down the floor from the top of the hotel, and could hardly console myself. At that time, I became very sad recalling my past life, that I was a good student in my school, but now I was almost to die...Out of 92 students who appeared in the examination, only seven students passed SLC, two girls and five boys. I was proud being a successful.

– Sushma, Female



In general, most participants express that they consider HIV to be a life-changing event, as it affects their entire lives in one way or another. Their individual stories give us a picture of their anxious memories. In regard to this, Sarita A who reached one of the Gulf countries for work was identified as HIV positive after her blood was tested in the course of routine testing. She recalls her experiences in this way: “It was a situation which I never experienced in my life before. Even now when it comes to my memory, I start trembling. I cannot express that event in words”. After her diagnosis as HIV positive, the staff left her at the Nepalese Embassy where she spent three months before returning to Nepal. She was not given a chance to work her assigned job there before leaving Nepal. She had real experiences of fear and experiences of being hated because of her HIV by people who resided at the embassy; she carries this as a life-long memory.

Most PLHIV often become silent about their status, with a view to protecting their own identity. In this study, research participants were afraid of being known to have HIV, as PLHIV were treated differently. They found even health personnel were not dealing with them well because of this. In this context, as already stated in the above section, there are significant numbers of research participants who were HIV infected by their husbands through sexual contact.

When I used to go to hospital, doctors were afraid of touching me due to HIV. I was also afraid of HIV as even doctors were afraid of this disease. Like doctors, if family members did not touch me, there might have a big problem. That is why I did not tell anybody at my parental and husband's homes.

– Buddha, Female

Therefore, both wife and husband decided to fight against HIV but not to let others know and keep silent about the infection, as the doctors did not even want to touch her husband who was sick due to HIV. Similarly, it was believed the same behaviour would result from family members and relatives if they were told about their HIV positive status, so they decided not to tell anyone.

Some participants deny their HIV positive status. When they are advised of their HIV virus by health personnel, they are not ready to accept the HIV virus at the initial stage. Some participants denied their HIV status in the very beginning after receiving their HIV-positive result. They rechecked their blood several times to make sure of the given result.

It was difficult, very difficult then. I didn't feel like I had HIV. I thought they [doctors] might be bluffing me. I got my blood rechecked two-three times but the results still came out positive. I even spent 2200 Indian rupees to send my blood to USA to get it tested for HIV. I thought I could trust these results. When I got the results after about a month, the result was still positive. Then, it got really difficult for me.

– Santosh, Male

Some participants denied even having blood tests in the course of treatment at hospital. In regard to this, Nimesh was taken to hospital for surgical treatment, but he was identified as HIV positive during the course of his treatment. He was committed to protect his identity by denying the results of his blood test at the hospital. He expresses difficulty in accepting HIV in this way: “I used to constantly ask the doctors about HIV. I used to constantly quarrel with them. I would increase my blood pressure. I used to refuse to take my medications, remain adamant”.

A husband's sexual relationship with other partners and without using condoms made his wife upset. Misa expressed that she was very angry with her husband because he did not tell her anything about his sexual relationship with other women while working in India. After hearing about the HIV diagnosis of her husband, she felt tension, wept and cried alone, thinking that she would have been HIV infected. She was very angry and told him that he betrayed her trust. He should have told her about his sexual behaviour so that she would be safe and could earn for their livelihood. But her husband said nothing about her reactions. They did not talk with each other for three months. Later on, she was also identified as HIV positive. She was very sorry at that time. She expressed her anger with her husband.

I did not like to speak with him. I was very angry and told him that he betrayed my trust, he had to tell me about his behaviour so that I and my children would be safe, I could earn our livelihood.

– Misa, Female

### **6.2.2 Initial Reactions towards Life Story**

A person's healthy physical appearance is not indicative of his/her HIV status. To illustrate this, Ram has been staying in Nepal for almost two decades, being away from his home in India. He paid for sexual relations with women in Bhairahawa and Butwal cities of Nepal who did not seem to have been infected by HIV at all. He had sex few times with them in these cities just two years ago before being HIV diagnosed while spending nights out at local restaurants. He never thought about contracting HIV while having sex with them as they both seemed to be healthy and beautiful. He did not realize he had been infected by HIV until he had his blood tested.

They looked healthy and beautiful. It was not easy to distinguish looking at them. I also didn't know I was infected with HIV... I used to go to Bhairahawa to bring wood for furniture. Sometimes, I had sexual relation in Bhairahawa and sometimes, in Butwal when I had to spend night there.

– Ram, Male

People can contract HIV irrespective of whether they are paying for sex in a commercial red-light area, or in a private home with close friends. With reference to this, after HIV discovery, Santosh whose mode of HIV transmission was sexual contacts recalled his sexual life history. His sexual partner was an Indian married woman whose husband was also his close friend while working in India. In the course of building a relationship, Santosh and the married Indian woman started a relationship which eventually led to unprotected sex. He did not know about the necessity of using a condom while having sex with someone at her home, and not in a commercial sex area. Furthermore, he does not like to use a condom as it gives him less satisfaction. He was sure that he was only one to have had sex with her except for her husband.

Her husband was a friend of mine. Her husband used to call me and I used to go. In this process, I also got to know her better. Whenever one of us [the female] had to go somewhere, we had to inform each other; so, there was no question of going to the red light area for me. I used to arrange meetings with her on Sundays because of my office holiday. And whenever we went out, I spent money on her. As time passed, she started asking me for money sometimes in the name of phone bill, sometimes electricity bill but she never returned the money. In this manner, she took almost 20-25,000 Indian rupees from me. I only understood that it was actually a business later on. I

used to see other men like me in their house and then I realized that I was being used. After that slowly we became estranged. She had taken this occupation in consensus with her husband. I didn't know that before.

– Santosh, Male

There is a saying that if the first marriage collapses, it affects everything after that, as in the case of a female when there is not a good relationship with her husband after the first marriage. There are many such cases of female participants in this study who were identified as HIV positive in their later life. In Nepalese traditional culture, females should go to their parental home with the permission of their mother- and father-in-law if they are still alive, in accordance with cultural obligations. In regard to this, Gita expressed that her husband accused her of frequenting the parental home even she went there as per the cultural obligations with the permission of her mother- and father-in-law. Next thing she was also accused by her husband that she could not bring enough dowry from her parental home, not as much as her husband had expected. Therefore, her husband married another female within a year of marriage. The participant gave birth to a daughter from her first husband and stayed there with her mother- and father-in-law for nine years. After getting pressured by her first husband time and again to get out of the house, she went to her parental home.

There are cultural rituals during the period of first year after marriage. I had to go to my natal home frequently in the first year in accordance with cultural obligations. My first husband told me I had gone to my natal home frequently. Next thing I could not bring enough dowry from my natal home.

My parents gave property but that was not as much as he had expected at home.

– Gita, Female

Later on, she was married to a person infected by HIV. It was some time later that she came to know about the HIV virus. Consequently, she also became an HIV-infected person due to her sexual contact with her second husband. There are other, similar, stories of female participants whose first married lives were not successful due to issues of smaller dowries given by parents to their husbands' homes at the time of marriage ceremony. Consequently, they were bound to go to their parental home. They also did not get peace, especially after their brother's marriages, as brothers' wives own their husbands' property.

It isn't considered nice for a girl to stay at her parental home for too long, hence, my second marriage. My younger brothers also got married. There is a saying that those who look after their daughters don't look after their daughter-in-laws. People started talking behind our backs. Tomorrow you'll get old, you need someone to look after yourself, people used to advise me. He will look after you in sickness and in health also. I think it's my karma. I didn't want to get married. When pressure started mounting from everywhere, I remarried.

– Rita B, Female

There is no special provision in Nepalese law to provide property to a married daughter. As a result, the female had to get remarried to a man who is not faithful to his wife. Then, the remarried female was HIV infected due to sexual contacts with her HIV-infected husband. As stated in a Nepalese proverb, the next marriage cannot be

successful when the first marriage has collapsed for some reason, which is evident in this study.

Research participants, drug users, reported feelings of inner curiosity about knowing what would happen after taking drugs and felt regret over their habits of drug use that made them HIV positive. Personal inner curiosity, or wanting to be a hero by using drugs, and to be different from other contemporary friends, were reasons given by research participants to become drug users. It is perhaps in the nature of human beings: some want to be different from others so that other people recognize them easily through their behaviour and whether they are pursuing either for reasons of fashion, or to be seen wearing bigger rings than average or drinking alcohol to express themselves in some way.

This was all about my curiosity. I wanted to see it what happens if I take the drugs. I used drugs not because I am from a very rich family. I am from a middle class family...These days I do not remember drugs even in dreams as drugs made me an HIV positive person [sharing needles for drug use].

– Raju A, Male

Similarly, a habit of sharing needles for injecting drugs resulted in the HIV infection of some research participants who felt regret after being infected with HIV.

I started taking drugs. This habit of using the drugs is really rubbish thing. The drugs brought me HIV [virus]...Without them I could not think or do anything. So I had to leave the school. Drugs became a “battery” for me and remained so necessary and powerful, without which I could not do anything more. Then I was trapped by the habit of drugs...At the time of beginning

drugs, we could not get syringes easily. An organization used to provide syringes to needy persons in a very limited way... I used a syringe and put it in the bush with a view that nobody cares there and then others used the same. I also used the syringes used by others. In this way I became HIV positive.

– Shyam, Male

Research participants also attributed their drug addiction to their friends' influences that pushed them into sharing needles used by others which consequently made them HIV positive. Since a significant number of research participants became drug users due to their drug-addicted friends at school and their surroundings at home. They were motivated to take drugs by their friends.

At first my friends used to encourage me to use drugs. I did not have to buy then. When I asked them what would happen if it was taken. They said to me, "You can fight with others, you will be an extra you will be energetic by using it".

– Raju A, Male

In the initial stage, research participants, coming from drug-using backgrounds were lured to take drugs by the influence of their friends. Later on, they could not survive themselves anymore without having these drugs. That is why research participants considered drugs as giving them energy for life in the same way as a "battery" of electronic goods works to make them function.

After being HIV diagnosed, due to sharing needles with friends, there were research participants who were also questioning role of parenthood's responsibility for caring for



them while being at school age. In fact, mothers' and father's roles in caring for children properly are complementary agents.

My parents used to quarrel with each other taking an issue of my study. My mother used to take me to school for my study but sometimes, I ran away on the way to school. When my father used to come back home from his work in the evening, then he used to abuse and beat her badly time and again on why she could not control me on the way to school and the school hostel if I did not go to school. If both mother and father had taken good care of me [father did not give him time], I would not have been an HIV positive person... I went in a wrong direction slowly.

– Shyam, Male

### **6.3 Initial Responses to PLHIV**

This section deals with initial responses to participants in regard to their HIV when other HIV-negative people came to know about the HIV-positive status of someone in their surroundings. Some of the people have expressed their responses orally, and some of them expressed their responses by facial expression, which also provides useful information as to how other people consider HIV-positive status at home and generally in society.

After identifying a person's HIV-positive status in the course of treatment at a hospital, family members seem to be very sad. They often start shouting and crying loudly for reasons of sympathy and grief as HIV is considered to be death sentence. There are multiple possible interpretations for these responses: thinking about the uncertainties of

life; an immediate death sentence due to HIV; the effects on both the individual and the family members.

I had gone there with my parents and wife. My family members were expecting that the treatment in such a big hospital would cure me well but they came in a lot of tension once they found out that I had HIV, ..., saying it was a dreadful disease. They cried.

– Min, Male

Facial expressions of people after hearing about someone's HIV positive status give an understanding about how they see HIV. In this study, family members of research participants simply remained silent, showing that they thought of HIV as a dreadful disease. Often the PLHIV could not tell their HIV status to their family members and others at once. For instance, Rita B, a female, was taking medicine routinely and her parents saw her taking medicine. She felt reluctant to share her HIV status rather than to say she had HIV. When she told her parents about the medicine for HIV, both her father and mother made eye contact with each other and did not say any words for the time being. Here this facial expression illustrates how people consider HIV as a big issue in Nepal.

I had to take medicines regularly. So they [parents] asked me what disease was it that I suffered from. So I told them. I told them that their son-in-law, my husband, had passed away because of HIV. I got the disease from him. He hadn't taken medicines properly. But now I am taking medicines and living a life...They didn't say anything for some time. They feared that their daughter would die of a disease unexpected to them and they would have to

see their daughter die before their eyes. The daughter who they thought would cremate them, they would have to cremate.

– Rita B, Female

When a family comes to know of a member having HIV, parents often seek to guarantee their future security. The parents would not be able to depend on an HIV infected son. They think that HIV is considered to be a life-sentence “disease”. This study found such a case in Kathmandu, where the *Newar* (third group of caste hierarchy) people who belong to *Vaishya* caste group and are usually rich people, have been living for a long period of time.

My parents gave birth to my younger brother when I was 21 years of age thinking that I would die soon after becoming an HIV positive. Before my HIV positive status, we were elder sister, me, mother and father. I was a single son for a long period of time. When I disclosed my HIV status to my parents, then my younger brother was born. My parents might have thought that it was necessary to have a son to hand over their big property and continuity of inheritance for future generations.

– Shyam, Male

The above statement shows how some people think of HIV in Nepal. The HIV issue is taken as a dreadful life event and there is no future certainty of life after being diagnosed as HIV positive. The parents of this participant gave birth to another son to hand over their property for future generations.

## **6.4 Discussion**

Most participants expressed the view that being HIV infected was not their fault. Most research participants, from the very beginning after HIV discovery, started reconstructing their identity by rationalizing their HIV infection. Some male participants living with HIV due to their sexual contact expressed their views that the females with whom they had sex seemed to be healthy and very beautiful, and there was no indication of HIV infection. Some other male participants expressed that they did not have sex in the red light area, such as at a brothel and commercial sex places. Similarly, most female participants expressed that being HIV infected was due to sexual contacts with HIV-infected husbands and husbands' unfaithfulness to their wives. A few female research participants reflecting on being HIV infected also attributed it to their fate, including bad deeds from previous lives by husbands' family members. Likewise, some male participants attributed their behaviour to friends' influences in having alcoholic drinks and sharing needles. Thus, they started making meaning of the life situations that led to their being HIV infected.

There was a misconception that HIV and AIDS are synonymous with a death sentence. The earlier purpose of giving information on AIDS to people by media was to keep distance from sexual contacts beyond one's own spouse. In contrast, the people started considering HIV as AIDS itself, the last stage of HIV, and equally treated HIV as a death sentence. That information came to people irrespective of HIV status through mass media newspapers, radio and television. Therefore, HIV-negative people have been using the phrase "people with AIDS" for PLHIV since the very beginning of HIV discovery, to describe people who are not even at the last stage of HIV. This has

negative impacts on both PLHIV and not with HIV as they commonly perceived HIV as a death sentence.

Research into PLHIV by country and nationality reveals that HIV is everywhere to a certain degree, and is definitely not confined to one nationality. In most of the Nepalese HIV literature, the earlier Nepalese perception was that people going to India are infected with HIV if not taking precautions while having sex. In this study, there are cases of people infected with HIV within Nepal and in the Nepalese emigrants going to third-world countries beyond India. Furthermore, there is also the case of a foreign national contracting HIV while having sex with women working at restaurants in Nepal. This shows that there is likely to be HIV infection everywhere within and outside Nepal, beyond India. Similarly, other nationals are also HIV infected in Nepal.

Research participants suggest that HIV seems to be an outcome of fragmentation of family structures partly as a result of internal and international migration. Another common factor is the sharing of needles for drug use. These days, people are moving from rural to urban areas and from one country to another country, especially for work. As a result, couples are away from their own spouses, which has resulted in them finding extramarital sexual partners to fulfill their sexual desires at the time of being away from home. In this study, research participants had gone to other countries for work which made them away from spouses of home, and they had unprotected sex. In addition, some young males in Nepalese urban areas are drug addicted due to the influence of their other drug-addicted friends sharing needles. Consequently, a significant number of the current male generation is becoming HIV positive. In this

study, around one-fourth of the total research participants are HIV positive due to sharing needles for drug use.

## **6.5 Conclusion**

The initiatives for HIV testing and discovery can come from self, family, or others, or discovery may result from routine testing. At the beginning stages of HIV discovery, most participants considered HIV as a life sentence, especially those participants who were HIV diagnosed a long time ago. Similarly, family members and non-family members, including health personnel, also considered HIV as a life sentence, when they came to know someone's HIV status. For the person who has been HIV diagnosed, discovery of HIV divided their lives into two distinct parts, before and after the HIV diagnosis. The HIV diagnosis also gave an opportunity of engaging with their HIV treatment and then prolonging their life expectancy.



## **Chapter Seven: Spoiled Identity**

This chapter focuses on HIV stigma and discrimination in the lives of participants, their feelings to varying degrees depending on their previous personal background. This chapter also deals with disruption to human needs that are associated with the issues of personal relationships, even with a person's own biological children, marriage and remarriage, fulfilment of sexual desires, and overseas work. Finally, it discusses reasons for HIV stigma, discrimination and disruption to human needs and how these issues affect the lives of participants negatively with regard to their identity. A major focus of this chapter is to discuss how HIV is perceived as spoiling the identity of participants, including interventions on their daily lives related to relationships with family members, marriage, sex, and visits to other countries in search of jobs.

### **7.1 Stigma**

Participants feel personally stigmatised because of their HIV history and stigmatisation from other people in the presence of health personnel working in the field of HIV, listening to people talking about HIV and through talking with other people about HIV including any other diseases with symptoms similar to HIV. All these things make participants feel devalued in society. They feel stigma from within based on their life before HIV infection. This is related to societal norms and values as they think they could have controlled their personal behaviour which led to HIV infection if they had tried to have protected sex or using sterilised syringes for drug use. They recall their previous histories of being HIV infected and within themselves feel shame and look down on themselves.



[HIV] is through sexual contact. I was a drunkard and had such friends going to restaurants. I have not gone anywhere else [a foreign country] from my place. I never take cigarettes but took alcoholic...PLHIV are assumed to be low level people and doing low level work [e.g.,sex with multiple partners, irrespective of HIV status]. It seems to me that people may think that PLHIV who are poor did not work well previously.

– Rajesh, Male

Apart from self-stigma, participants expressed feeling other people backbite and gossip about them when they are in contact with health personnel working in the field of HIV and even if they listen to others talking about HIV during the course of daily life. If someone asks about HIV in a general sense, they feel ashamed. Furthermore, this significantly humiliates them in their lives. In regard to this, Pushpa expresses her experiences in this way:

I saw people gossiping, backbiting, and pointing out telling- look that woman and man have HIV ... Someone might have suspected me of being HIV positive. It is because people have seen me talking with health personnel working for the HIV infected people... My heart aches when people say indirectly that I have HIV infection.

– Pushpa, Female

Seeing and listening to stories of HIV stigmatization and discrimination which has happened to others makes participants terribly fearful. The stories of seeing other PLHIV being put in an isolated place in a cattle shed (Mamata), not being given food enough to eat by their family members at home (Gita), people telling others in their

society not to sit and eat together with such HIV-infected persons (Suku); such stories made them ache in their hearts that similar stories may happen to them once people know about their HIV. Similarly upsetting is listening to stories that HIV is a life-threatening virus and that people contracting HIV have their skin turn dark and their body becomes very skinny showing their skeleton (Buddha). In addition, some PLHIV suicide after experiencing hatred at home and in wider society (Gita). All such stories have made them extremely fearful of what may happen in the near future.

I had seen mistreatment and discrimination done to a sister living in a village. She was also my relative. Her husband used to work in India. First, her husband was identified as HIV positive. Thereafter her blood was checked while getting sick and she came to know that she was also an HIV infected. Then, her family members put her at an isolated place, at a cattle shed. They did not give her permission to enter the home. Because she was sick, if anybody brought her fruits they did not give to her. Her parental family members used to come there to wash her dress, because at home nobody was doing it. I was so small at that time. Even if she was sick, she had to bring grass/fodder for cattle from homeland or forests. That's why my parents used to send someone to cut grass and I used to go there to help her sometimes. One day I cut my finger while cutting grass. That scratch is still on my finger. When I see this scratch, I recall my sister [the then HIV positive] still now and the event of that time makes me scared of HIV. Doctor had also suggested me to be careful with PLHIV as it can be transmitted to anyone at the time of my finger treatment.

– Mamata, Female

Anu, a female, heard of a story related to HIV as a life-threatening “disease” that caused her heart to ache when thinking society would discriminate against her once people knew of her HIV.

I had heard that a young boy was identified as HIV positive at [a] hospital. There was a rumour that he would live only for 10 years. There was also a rumour that he would get pimples and injuries on his body very quickly. It is not good to stay close to persons with HIV and it can be transmitted through the mosquito bite as well. My neighbours used to gossip about this. At that moment, many people were saying the same thing, that HIV is a life threatening disease. After I had HIV I worried that society would know about my health condition and they would discriminate against me.

– Anu, Female

Participants stigmatised themselves from socio-cultural perspectives, especially in the belief of luck written by birth. Pratima shared her experiences on her poor luck in this way:

I stigmatize myself in my heart because of my poor luck. Though I know that it is not good to blame myself but such foolish things go through my mind. This leads to weakness. I am wondering if the neighbours know about my [HIV] status. If some people do talk about such things, I think they are pointing out my status though it might not necessarily be the case. If someone treats me differently from before, I will be wondering if he/she knows about my status.

– Pratima, Female

A similar statement was also made by Durga in regard to both her and her son's HIV status due to the husband's family's fault (i.e., the previous generation):

My previous generation has done some wrong in their earlier life. My child [her son] got HIV without doing any wrong. Even I have not done any wrong in this life [e.g., extramarital sexual relations], I have also contracted HIV. People say that you are now suffering from this as your ancestors did sinful things in their own lives and the reactions of those people are this disease [HIV] on you. I think this may be true, that is why, and we are suffering from this disease without doing any mistake in our lives. Even my child is now suffering from this disease. That is all related to the sins of our ancestors.

– Durga, Female

## **7.2 Discrimination**

Participants reported being ostracised at home and they did not feel their home to be a conducive environment for them to stay in. They shared their experience that their family members told them to go away from their home (Gita). Their clothes were thrown from the veranda by their family members (Rita A). Their family members, relatives and neighbours also told them not to touch clothes used by some participants because it was believed that they might get HIV infected if they touched the clothes (Gita). Consequently, participants became detached from their family members and eventually were cast out their homes (Rita A, Sushma, Mamata, Buddha, Sarita A, Durga, Sarita B, Gita, Rita, Anu, & Pratima). Some examples in regard to discrimination are as follows.

First, I was looked down upon at home. My dad told me to leave the house. My brother and sister-in-law discriminated against me. It all starts from home. I had saved some money when I returned in 2007 in order to get my wife and son tested for HIV, my father knew of my saving. He said I was bluffing about my HIV. They suspected that what I actually wanted to do was to separate from the joint family and stay away with my wife and son. When I finally succeeded in making my parents believe that I had HIV, the word spread among my family members. They started misbehaving towards me, my wife and son. They wouldn't drink water given by my wife, they wouldn't eat the food my wife had cooked and instead told us that we should have it ourselves. They threatened us saying that if we [me and my family] didn't leave the house immediately, there would have to be a division of the household that they would desert our parents. I thought that rather than tearing the family apart, it would be better if I left the house.

– Santosh, Male

Another example of ostracising participants is from the perspective of physical problem, pointing out their pimples on skin. This example comes from Gita, a widow who started staying at a new place in an urban area. She shared her experiences on HIV discrimination when she goes back home with her small son occasionally.

When I and my son living with HIV go home... My mother in law, father in law and others used to say to us *Phohori! Phohori!!* [Yucky! Yucky!!] Do not come and stay here, pointing out pimples on our body, and rather it is better for you to go anywhere else far away from here than going close to them at home.

– Gita, Female

Anu, a female divorced from her husband, expressed her experience of divorce due to HIV in this way:

All members of my husband's family told my parents not to allow me to come to their home in Pokhara because of my HIV status. Then my parents filed a case at Court of Law against my husband's family members for not taking care of me, even not allowing me to eat food and to wear clothes after I became HIV positive. After one year of the filing of the case, thinking that it is better to reconcile, there was an agreement and I was given 500 thousands (Nepalese Rupees) and there was the reconciliation.

– Anu, Female

People in society discriminate against many participants by keeping their distance from each other if they know someone has contracted HIV. There is also a saying concerning a person convicted of bad activities that it is not good to see even the face of the person and HIV is considered to be the same category. Some of the female participants shared their experiences that people did not come to their home to say hello at the time of being ill once villagers came to know that the participants were HIV diagnosed (Rita B). The immediate villagers would only come up to garden to say hello instead of coming inside the home. They also warned a few participants not to walk near their home, or even to walk in his/her own way.

The villagers even said that they wanted to drink the buttermilk but were dubious because it was made by people with such disease [HIV]. They sprinkle salt on our wounds. My husband was bedridden. Villagers would come outside our home to call us but wouldn't come any nearer fearing they may catch this dreadful disease and die...He [a villager working together

with her husband in India] told many of the villagers about my husband's condition. He told everyone that so and so person had HIV that he [her husband] was untouchable. No one was to eat anything he gave, not even drink water he gave.

– Rita B, Female

Mamata, a female, shared her experience of mistreatment done by villagers and became desperate to leave her home.

I had experience of mistreatment done to me by villagers. When I was going to buy something in a retail shop through the yard of my neighbour, one sister living in the village told me not to walk through that way due to my HIV positive status and also not to enter their home. This is my unforgettable event for my life. I felt really sad. I thought it would be better to leave my village. Thereafter I came to Kathmandu. I had not visited the village since then.

– Mamata, Female

Female participants are stigmatized and discriminated by HIV-negative males and even by males living with HIV from the perspectives of gender roles assigned in Nepalese society. Females are treated as second-class citizens in society and females living with HIV are not given any human value although they might have contracted HIV through their husbands. Even males living with HIV put females with HIV down because of their lower status in society.

Woman cannot speak openly about their rights and other similar things. HIV infected men look down on HIV women and discriminate against them as if men do not have the infection. Males living with HIV mistreat females

living with HIV. They do not care what they are doing towards the HIV infected females.

– Pushpa, Female

In Nepal, females have been experiencing intra-gender discrimination for centuries, especially female-to-female discrimination because of positional power held by mothers-in-law and females with husbands as their economic supporters. Females who have husbands as their economic supporters have discriminated a lot against widows from economical and socio-cultural perspectives. Pushpa also shares her experiences in regard to the hate experienced as a daughter-in-law by her mother-in-law, both verbally and physically.

Most of the time there is quarreling at my home. My mother-in-law physically mistreats me by holding my neck... Once she was abusing me using bad words and I listened to it patiently. But she abused me for such a long time that I lose my patience and I wanted to see what happens if I also do same to her. So only for once, I repeated what she said to me. At this she caught my neck...My throat and neck were swollen. I have blue mark on my neck, “You can see it here”. Just a day before there was a big quarrel at my home.

– Pushpa, Female

Lila, a widow, shared her experiences on how females are discriminated against by females:

Women accuse other women of practising witchcraft. Women whose husbands are alive think that widows are bad news, their bad karma got their husbands killed and by mingling with them, their bad stars will also affect



them. Also, there is nobody to stand for or defend widows. If females are already angered for some reasons, they think it appropriate to dominate widows in the situation of having lost their husbands due to their death. The husband is the only person fighting to save his wife. But if he is not there, females consider it appropriate to dominate other females like widows and helpless ones. Indeed, females are more stigmatized and discriminated by females than by males.

– Lila, Female

From socio-cultural perspectives, females discriminate against females. Gita, a widow, expressed her experiences of how socio-cultural factors influence women's lives in Nepal.

When I used to walk on the way, sometimes I heard people were saying that it is not good to see a widow while walking somewhere. My husband's brothers bought white colour cloths to wear and females in my village used to say it was bad fortune if we see such widow on the path and work would not be good. At that time, my heart was telling them that one day they could get it – everyone dies in this world. I will just wait for this day. Most females of my village told me I was bad luck when they saw me going somewhere.

– Gita, Female

Discrimination is still pervasive among various castes in Nepal and this has affected the lives of participants. With several efforts made by governmental and non-governmental organizations working in the field of human rights, there is now less discrimination than

was previously the case in Nepal. However, there is still discrimination in rural Nepal where illiteracy is high. In this study, research participants from a lower caste expressed that they had to clean utensils after eating food when they went to higher-caste people. Currently, this is not applicable in urban areas though this type of discrimination still exists in rural Nepal.

Previously, we had to clean our utensils if we ate food at Brahman families, because we were of a lower caste. Nowadays we do not need to clean utensils after having food even after being HIV positive. This custom of cleaning utensils by lower caste people is still pervasive in some places [rural areas].

– Rana, Male

Suku, a widow from a so-called untouchable caste, shared her experiences of discrimination by caste:

We lived in a *Brahman-Kshetree* village and I had to face the problems of untouchability there. They did not let us to go into their house, and did not eat food touched by us. They told us to go away if we go to their veranda also. Brahman priests used to tell us not to put on *doro* [secret thread] around our wrists in *Janai Purnima* [a Hindu festival day]. It is because we are lower caste people.

– Suku, Female

Even government institutions like hospitals, schools, police offices, and the embassy dealing with emigration mistreat participants in various discriminatory ways, which affect preventative check-ups and treatment at hospital, studying at school, exacerbate

feelings of insecurity at police offices, and preventing people from going overseas for jobs. Some examples in regard to institutional discrimination are given below.

Health personnel at hospitals discriminate against participants by delaying treatment and transferring HIV cases to other hospitals, and speaking rude words to them. Research participants shared their bitter experiences of health personnel dealing with them badly after they and their family members with HIV were admitted to hospital.

My wife was taken to [a] hospital to give birth to our youngest, fourth child...She was second in line for a delivery operation, after doing the first woman in the queue. My wife was asked to wait after she was asked to wear the operation dress when hospital staff came to know that she had HIV. She was then asked to change into her own dress again, telling her that the delivery operation was not possible at the hospital for her because of this disease [HIV]. She was asked to go to [another] hospital. Later, she was asked to return back to the same hospital [the hospital where she had gone first time]. In this way her operation was deliberately delayed. Then the operation was done in the next morning at the hospital where she had gone for delivery at first.

– Rana, Male

Health personnel also treat participants differently in terms of asking unnecessary questions in regard to the mode of HIV transmission. This can be easily interpreted with a stereotypical mindset that PLHIV in Nepal have been HIV infected through the trade of prostitution in India. Indeed, health personnel are dealing with participants at hospital

with unnecessary questions which may be far beyond the reality of how participants are blamed in association with the trade of prostitution.

I suffered a lot from such hatred and discrimination after becoming HIV positive. At that time HIV was not spreading out as it is now. Doctors did not know much about it so they discriminated against us...When the doctor visited me; they used to ask me for how long I stayed at Bombay. I had never heard of Bombay. Before asking me about my details, they used to think that I had been to India and asked me about it...When I was in hospital, staff came and handed over medicine to a relative who was looking after me instead of giving the medicine to me because of HIV.

– Buddha, Female

Pushpa had a similar experience of discrimination at hospital and she shares her experience:

Whenever PLHIV need to have an operation, the health personnel try to escape from them saying this kind of operation is not available in their hospitals and request them to go to another hospital in another place or district. In the second hospital, the health personnel also give them the same excuse.

– Pushpa, Female

She has also a bitter experience of discrimination at hospital in the case of woman living with HIV from a *dalit* ethnic group on how the woman died due to unavailability of treatment.

Once there was a woman from the *dalit* ethnic group who had a problem in her uterus. She had to have an operation but when she told the health

personnel there that she was HIV positive, they did not do the operation and delayed it deliberately. So she ultimately died.

– Pushpa, Female

Children living with PLHIV in this study have been discriminated against at school by people treating them badly and even discarding them from school. Research participants shared their experiences with regard to discrimination against their children by not allowing admission to school and mistreatment by school teachers and contemporary student friends. Some examples provided can be illustrative in regard to discrimination that happened their children's education due to their own HIV-positive status. Sarita uttered her bitter experiences after the school teacher knew of her and her children's HIV status:

The school teacher came to me and said that they want to send away my children...because the parents of other children came with complaints that if my children will not leave school, they will be compelled to stop their children from going to the school, I stop sending them to the old school.

– Sarita A, Female

Gita, a widow, expressed her experiences in regard to her son's schooling in relation to discrimination from his school teachers and friends.

There is a school for my son, not far from my home. He was enrolled there. But teachers did not give him homework. My son had to stay alone on the bench of the classroom. Nobody stayed around him because of HIV. My son said, "Nobody cares about me in my school neither teachers nor my friends". One of the reasons for migrating to other places from my home is

to teach my son. Therefore, I am now here and what will be tomorrow I do not know.

– Gita, Female

Some participants are sacked from their job after employers know their employees have contracted HIV. In this study, participants working as a carpenter at a furniture factory and as servants at houses had to leave their jobs when employers came to know they had HIV after hearing of HIV from other people (Harsit & Suku). They were told indirectly that their work was not necessary anymore for some reasons. Harsit reported that he was fired from his job. Likewise, Suku, a widow expressed her experience of halting her work to continue her household job working with an owner's home in this way: "I was told not to come to work there pretending they did not need anybody once the house owner knew her HIV positive status".

Participants are mistreated badly at police offices. Police officers discourage them from surviving any more due to HIV infection. One of the male participants shared his experience when he was in custody for a different reason rather than his HIV status. A police officer abused him telling him that "it would be better to die like such a person with HIV rather than to survive in this world" while asking for an HIV medicine (Nabin). The participant was strongly recommended by a doctor to continue his medicine for better health but he had to abstain for more than 40 days.

Once I was taken into custody. There, we had some arguments. Though they knew about my health condition and I asked them not to keep me from taking medicine for more than 4 days, they did not provide me with medicine and kept me from taking lifesaving medicine for more than 40

days. I had the impression that the police wished me to die at an earlier stage because of my disease [HIV]. This was the worst experience I ever had.

– Nabin, Male

Likewise, Sandeep was mistreated by his other prisoners telling him to stay away from them pointing out the corner of the room at the time of sleeping. Police staff did not take any notice in regard to his problem though it was their responsibility to listen to problems of prisoners.

There were people come from theft cases in the police station. They treated me badly. I had to sleep along with them. While sleeping with those people they sent me away from their place pointing out [by finger and mouth] to the corner. So I could not know where to sleep. This type of mistreatment made me heart-broken as well as I got angry against them.

– Sandeep, Male

### **7.3 Disruption**

Apart from other family members and people living in society, biological children are also reportedly keeping their distance from their parents living with HIV for various reasons and relationships between children and parents do not seem good as they have been. The reasons behind children keeping their distance might be their presumption of sexual relationships with outsiders, although this was not specified. Moreover, there may be the fear of a future with daily life spent mistreated by other people due to their parents' HIV-positive status. In my study, there are very interesting examples of how HIV-negative children kept their distance from their mothers living with HIV. Anu, a female being divorced from her husband after being HIV diagnosed, shared her

experience of her son's behaviour while seeking a talk on telephone after her son arrived home from abroad with his father.

Once when they came to Nepal, I telephoned him [her son]. My son answered the telephone. He just said "hello!" but did not say any more word to me when he noticed my voice and put the phone down. Now he is aged 15 years.

– Anu, Female

In this instance, it may be the case that her husband, his sisters and other family members might have told him some bad things about his mother so that he did not like to talk to her.

Likewise, Buddha expresses her distress at having to keep her distance, either far behind or far ahead, of her son going to secondary school with the hope that others do not recognise her on the path going school if she needs to go there for some reason, such as paying tuition fees and parents' day.

...There is fear that society will recognize him as a son of a mother with HIV...When some time his mother has to go to her son's school, my son will say not to disclose. If you will disclose, I will have no friends at the school, I will have difficulty in studying. My son will not prefer to go with me and specially, due to his HIV positive mother, there is a fear that there will be insult from everywhere. Therefore, my son walks either far behind or far ahead if I need to go to his school.

– Buddha, Female



Some participants reported finding it hard to get life partners without HIV for marriage. In Nepal, an arranged marriage is given more priority than a love marriage, although these days the trend of dating and love marriage is increasing with increased educational attainment and the influence of Western culture. Generally, parents and relatives play important roles in finding a partner for their boy and girl. But it is hard for their guardians to find an HIV-negative partner for their offspring's marriage because of their HIV-positive status. In my interview with unmarried males, they expressed that they have resisted proposing marriage with an HIV-negative partner because of their HIV-positive status. Those unmarried persons were anxious whether birth may give rise to an HIV-positive baby. These things are a hindrance on the path of getting married all their lives.

I could not marry a normal-health girl [HIV-negative girl] because of my HIV positive status. The big thing I missed is my marriage... I could marry a girl by telling a lie but the relation would not be long lasting. I am deprived of married life due to HIV.

– Jwala, Male

Furthermore, even after marriage, if someone wants to get remarried either due to separation from their spouse or the death of spouse, he/she is not easily remarried to another person because of HIV. The reason behind this seems to be as with the case of unmarried persons as stated above, participants hesitate to disclose their HIV status with the persons proposing for remarriage with them. This creates a vacuum in regard to remarriage. Pratima, a woman separated from her husband, expressed how HIV has obstructed her from making a decision on remarriage.

...Sometimes, he rings me [from overseas] but I talk him bitterly telling that my fate has been already broken. I am avoiding his marriage proposal though I want to get remarried with him as well. I have not decided because of my positive [HIV] status.

– Pratima, Female

Moreover, participants have found difficulties in fulfilling sexual needs because of their HIV-positive status. One of the main purposes of being married is to have sex in a society where sex is socially sanctioned only after marriage. Participants face barriers to having sex because of a lack of available sex partners, as stated above. Even after marriage, an HIV-positive person cannot have sex with an HIV-negative spouse, even if the HIV-positive person has an interest in having sex with his/her spouse. In Nepal, females are less likely often to propose having sex with their male spouses. As a result, females face difficulties in fulfilling their sexual needs even when applying safe sex techniques such as using condoms. Sarita B, who contracted HIV through her first husband and remarried to her second husband and stayed away due to HIV, expressed that her second husband who is HIV negative does not have sex when she goes home at every *Dashain* festival. She shared her experiences on disruption of sexual life in this way: “...My husband is scared of HIV I think. We talk about other things but he does not want to have sexual intercourse. I cannot propose this to him if he does not want”.

Participants reported not having the opportunity to go overseas for work. After introducing multi-party democracy (1990) in Nepal, many unemployed males and females were encouraged by the government to go overseas for work. But this did not

apply to the PLHIV. Most of the research participants who tried going overseas for work faced barriers preventing them completing the process once they were identified as HIV positive at the time of the required routine health checks. Deepak prevented in going to other countries for work due to HIV, shared his experiences:

I just knew that I had HIV. I got a passport seven years ago in order to go to foreign countries but I could not find a good country [for work]. Now I found a good country to go [Malaysia]. I went to Manpower Company. I paid Rupees 2500 for a medical check-up. After that, I failed from the report of my medical check-up. I was recommended to go to [a] hospital for HIV testing.

– Deepak, Male

Rita B shared a similar experience of obstruction in seeking a foreign job due to HIV.

Nowadays more women are opting for foreign employment in order to earn good money. If I didn't have HIV, even though I am not much educated, I think I could've gone abroad to earn money. I've lost that chance.

– Rita B, Female

There is an apparent increased aggressiveness of participants towards HIV-negative people that indicates there is a widespread opinion about a spread of HIV and AIDS in society due to a heavy stigma and discrimination. Nabin expressed his aggressiveness against HIV stigma and discrimination that he considers is resulting in an increase of the spread of HIV and AIDS everywhere.

If this problem [an issue of HIV stigma and discrimination] will continue, one day even their own child will suffer. No one can deny it. This is life and

anything might happen in life. This might happen knowingly or unknowingly. Everything is not under your control. If you look at me I don't look HIV positive. If, I have bad or destructive intention I can transfer this disease [HIV] to 10-12 persons every day. But the good thing inside me will not allow me to do so. But one day, if PLHIV lose their patience because of mistreatment and discrimination, it will burst and become destructive leaving at least one HIV affected person living in each home.

– Nabin, Male

A male expressed his aggressiveness indicating HIV stigma and discrimination being made by HIV-negative people.

Those who are violent towards us [PLHIV] should be held responsible. It seems reasonable to fine a person who treats us with contempt and put him/her in jail. I've thought about this in some cases that I've seen. Throwing someone out of the house, not letting them come anywhere near and other such kind of activities; if my hands and feet were working, I would directly strike them with a syringe. If similar degrading behavior happens, I swear I will strike them with a syringe myself.

– Nimesh, Male

## **7.4 Discussion**

HIV stigma, discrimination and disruption of human needs as mentioned above occur mainly due to the lack of economic independence of the person living with HIV. What family members seems to figure out is that an HIV-infected person is nearing the end of their life and a person living with HIV is unproductive both at present and will be in the future. In a rich family where a person is associated with a good enough property, that

person is often not discriminated against as much as a person who does not have enough property at their own home. As a researcher, I observed that a participant with access to resources who lives in an urban area has not faced HIV discrimination in the family. Most of the women living with HIV, especially widows who do not have economic supporters, such as husbands, have been cast out from their family as has been described in the section above. In the joint family with the husband's mother and father, there is high discrimination due to not enough economic support outflow from the nuclear family to the joint family. These assertions are supported by participants. For example, Pushpa shared her experiences of HIV discrimination from an economic point of view as well as intra-gender discrimination:

I feel that my mother-in-law will treat me properly if I had given her some money ... If my husband had earned a lot and given to her, she would have treated me as nicely as she was doing to her other daughters-in-law. My mother-in-law abuses me daily. I am her second daughter-in-law and our earning is just hand to mouth for my small family. Therefore, my husband is not giving her money, I feel that my mother-in-law is discriminating and abusing us due to lack of our economic support to her.

– Pushpa, Female

Nepalese society is built on a hierarchical basis with a high respect for the wealthy and a low respect for the poor, even in public institutions. For example, people are treated at hospital on the basis of how they are dressed with an indication of rich and poor while going to hospital for health check-up. Participants feel discrimination based on the clothing they are wearing.

In hospital patients are treated in the way they are dressed. If you go there wearing poor clothes, they [health personnel] will delay your treatment. But when my relatives and aunts go there wearing nice dresses, they are treated very well. They are immediately taken in a waiting room for providing them hospital cabins. When my husband and I go there for treatment, they always discriminate us because we are not wearing nice clothes. When they learnt that my husband and I are HIV infected, they kept us farther away from other patients and put us close to the toilet, a dirty place with an awful smell. Staying in those places may make the situation worse for PLHIV.

– Pushpa, Female

Social hierarchical systems arguably make PLHIV stigmatised and discriminated in terms of the hierarchically based words used for lower class and marginalised people in their society. Marginalised people (from economic and social perspectives) who seem to be lower than others are looked down upon by society. The lower-ranking pronoun words are used for PLHIV while addressing them in their daily lives as they are for other marginalised people such as untouchable castes and ethnic groups. Addressing PLHIV with such lower-rank words from economic, socio-cultural and health perspectives puts them much lower down. This spoils their identity compared to the upper-ranking words used before being HIV diagnosed.

In the village, there are ranks of castes so called upper and lower castes. The upper caste people use rude words to call the lower caste people. There are a vast difference due to the caste system and superstitious beliefs... This has really made PLHIV to be stigmatized and discriminated in the society.

– Raju A, Male

Apart from economic reasons, a lack of knowledge on HIV and AIDS, and social and cultural norms and values have played significant roles in stigmatizing and discriminating PLHIV in their families and societies. Those participants in this study who were HIV infected around 15 years ago have expressed that they did not have any knowledge of HIV and AIDS at all. Therefore, they were stigmatised by both themselves and by others due to the lack of knowledge that their life could be prolonged by using HIV treatment and eating nutritious foods.

The role of the media reinforces stigma and discrimination for the participants although the role of people working in media seems to be very positive towards keeping other HIV-negative people from sexual misbehaviour and the sharing of needles for drug use. From the beginning of HIV discovery in a global context, HIV was considered as a very dreadful life-threatening virus in the absence of life-prolonging modern allopathic medicine and with a lack of health personnel in this particular field, the message of HIV as a frightening virus spread globally. Nepalese media did the same, depicting a person living with HIV as extremely thin, without any muscle, as just a skeleton (Buddha & Raju B). Consequently, many people were afraid of HIV when they saw persons infected by HIV and AIDS on TV and newspapers. This image of skeletal figures shown on the TV and the newspapers is apparently still vivid in the minds of Nepalese people.

At the beginning when I saw it [HIV] on TV, I felt that an HIV infected person is one who is black, burnt, thin and with small legs. It was made public in the media, by showing a funeral profession, in which the dead body of a HIV infected person was made of straw. I have watched this on TV. I felt this is cause for fear to me and many people like me, who are

infected by HIV that PLHIV die after their skin colour turns dark and their skin goes dry.

– Buddha, Female

Furthermore, the media is still not capturing the positive aspects of allopathic medicine on the improvement of the health of PLHIV; their positive experiences have yet to be effectively and consistently communicated through the Nepalese media, TV, radio and newspapers. After having allopathic medicine, PLHIV have experienced remarkably positive improvements to their health. However, those positive experiences regarding their health are not often broadcast by the media. Research participants did not seem content with details of their physical health being broadcast through the media. Buddha, widow, also expressed her experiences that information on HIV and AIDS have not been as updated as it has to be.

Many friends said that the advertisement in the media did not clearly describe how an HIV affected person looks like. Friends, who received ARV medication for 5-7 years weigh up to 100 kg. It means as shown in the media, all will not be underweight like that. It would be better if medicine and food are taken timely. All will lose weight if there is no medicine and proper food.

– Buddha, Female

## **7.5 Conclusion**

HIV stigma, discrimination and disruption of human needs caused by a lack of economic independence, socio-cultural factors, a lack of HIV knowledge in people and the role of media in broadcasting information on HIV and AIDS have all affected PLHIV negatively on their identities. However, the degree of HIV stigma,



discrimination and disruption to human needs varies with access to resources. The PLHIV in urban areas as well as those participants having economic supporters, such as husbands, experience these issues to lesser degrees. Those participants living in rural areas at the time of HIV diagnosis without economic supports after their husbands' death due to HIV faced these issues to a high degree. When people discriminate against PLHIV in different discriminatory forms, HIV stigma and discrimination become identity issues and lead to spoiled identity. In the absence of HIV treatment, an HIV-positive person's physical appearance turns dark and they appear as if handicapped. This further aggravates their identity as physically horrible, socially detached and economically very poor.

## **Chapter Eight: Transitional Identity**

This study has found that the management of stigma appears to depend on the availability of, and access to, resources. These resources can be either tangible or intangible, as will be shown below. This chapter will explore theoretically the process by which individuals living with HIV begin and sustain the process of reconstructing their identities by accessing resources available to them in order to address and overcome the stigma and discrimination they encounter. Research participants reworked, negotiated and transformed their roles; they took action through their robust engagement with their personal networks, their social and economic environments, and in particular with other PLHIV. The purpose of this chapter is to provide an overall picture of how participants started reconstructing their identities by adopting various ways of managing stigma and discrimination as well as the disruption of their human needs. These various ways included attempts at migration, hiding or disclosing their HIV status, economic independence if possible, practice of engaging in HIV treatment, using the support of organisations, and their own spirituality.

### **8.1 Migration**

Migration is found to be the most important stimulating factor for managing stigma and discrimination as well as fulfilling human needs for many participants, especially widows, and females detached from their husbands while moving into a transitional identity. The females with less access to resources who have only resilience as their resource migrated to urban areas of the Kathmandu and Pokhara valleys, settling there with a view to managing stigma, discrimination and the disruption of human needs they faced daily in their places of origin. Before migration, HIV-diagnosed people have

already prepared a vision of an alternative way of living, involving migration to the cities, due to their expectations of stigma and discrimination at their homes and in their society. In addition to less access to resources, there were few participants with moderate access to resources living in rural areas; these people also migrated to the urban valleys.

The research participants generally had good rapport with their friends living with HIV to develop a migration strategy that protected them from stigma and discrimination in family and society if anything bad happened in the future. There are some examples related to a strategic plan of migration that had already been established in their minds to cope with expected social ostracism. They had developed such plans of migration in the course of HIV treatment at hospital in the cities and on their first stay at an organization when they met their own circle of friends with HIV. Sarita B, separated from her husband, as she had imagined before going home after staying nine months at an organization in the Kathmandu Valley in the course of HIV treatment she had good rapport with her friends living with HIV. She found her home environment not suitable to her HIV status as she imagined before she went home from the organization. She shared her experience of migratory strategy in coping with HIV stigma and discrimination.

After finding an organization housing for such persons like me in Kathmandu, I stayed there. I spent nine months in Kathmandu... I was thinking whether my family members would not treat me well because of HIV. That is why I had taken phone numbers of my friends living with HIV when I met them in Kathmandu.

– Sarita B, Female

As she had expected earlier, prior to her going home, she faced being discriminated against at home and used her strategy of migrating to Pokhara by contacting her friend by phone.

When I reached home, my husband's first wife did not allow me to get entry into our home. I did not say anything and also did not force to get in. Then, I slept outside my home on the ground at that night... I thought deeply and remembered that if my family members showed such misbehaviours, villagers outside home would do the same, and I should not stay there anymore. With the situation, I realised I could not stay at home any longer. So I phoned a sister [Lila] in Pokhara. I received a positive response to come to Pokhara on Friday and I had phoned her on Wednesday... I left home for Pokhara at 4 am in the morning, taking my sick son. Sometimes, I wonder how I could do such things at that time.

– Sarita B, Female

Similarly, Gita told of her experiences of coping with HIV stigma and discrimination by migrating to the city. She had good interpersonal skills with people, especially with her own circle of friends living with HIV. In addition, she expressed that she moved to the city for her son's schooling, having been heavily ostracised and discriminated against in her home and in society.

I have visited many places. If we behave well, many people support us. Everything depends upon our mouths, what we speak and how we behave with others...I went to Kathmandu and to other places for my shelter...One

of the reasons for migrating to other places from my home is to teach my son. Therefore, I am now here, and what will be tomorrow I do not know.

– Gita, Female

Furthermore, participants have gone through a temporary type of migration depending upon the availability of shelters provided by different organizations located in different cities of Nepal. They are not allowed to remain for a long-term stay at the same organization. Their stay depends upon the availability of jobs and shelter at support organizations. There is also an organization located in semi-urban areas where some illiterate participants have been living for a couple of years without any external funds. They rely on their physical labour for their livelihood. Nevertheless, they have been migrating from one organization to another located in different places. They found places to stay based on the information from their own circle of other PLHIV as well as people working in various organizations. Sarita B shared her experiences of migrating from one organization to another depending upon the availability of shelters:

I tried to find suitable places to live in and I am here now. Organizations working for us [PLHIV] are not also giving a long term stay. We have to find one after another for our shelter. After my stay in Kathmandu with an organization, I arrived here [in the Periphery of Pokhara Valley]. I am moving in accordance with circumstances depending upon the availability of shelter under any organization.

– Sarita B, Female

There is also family migration into cities from rural areas after being stigmatized and discriminated against at home and in society, especially in the cases of both partners living with HIV with moderate access to resources (Rita A).

## 8.2 Disclosing and Hiding HIV Status

Disclosing and hiding HIV status in accordance with the personal backgrounds of participants are ways of managing stigma, discrimination, and disruption of human needs. There are some female participants who, irrespective of their stay either rural or urban, have disclosed their HIV status to family members so that they can save themselves from the blame for becoming HIV infected, and stigma and discrimination, if they have been infected by their husbands. The purpose of disclosing HIV status by females before their spouses' death is to emphasise that they were not infected by HIV from anywhere else. For example, Suku, who lives in the city shared her experiences in how she strived to manage stigma and discrimination from family members by disclosing her HIV status to her family members with a view of maintaining her identity in the future in case her seriously ill husband died due to HIV.

My husband had told me not to tell it [HIV] other family members. Later, when he was in the last stage, my heart compelled me to tell it to other family members because I thought nobody would tell me that the disease [HIV] was transmitted to me by my husband. So, I told it to my family members too. I told my mother-in-law that HIV was found in her son's blood test.

– Suku, Female

Thus, she had a far-sighted mind and this saved her from possible HIV stigma and discrimination by family and society by disclosing her husband's and her own HIV status in the family before her husband's death. She was brought up in the Pokhara Valley with urban facilities having a more extensive health awareness programme through various organizations. Therefore, she was aware of the HIV issues prevalent in Nepalese society.

Participants with better access to resources often followed hiding their HIV status with a greater attention to managing their identity to minimise stigma and discrimination from their society. Some participants disclosed their HIV status to close family members but not to distant family members, and some participants have not disclosed their HIV status even to their own family members. They have also attempted managing their possible stigma and discrimination without disclosing their HIV status to their relatives by keeping their distance. Shyam shared his experiences of how he is aware of stigma and discrimination with a view to managing his own identity:

Whether relatives know about my HIV or not, I am not sure. I do not go to relatives thinking that they may say something [bad]. I am afraid of thinking that somebody may open this topic of HIV. So I do not go anywhere to see relatives. I like to go to my relatives but if somebody talks about my disease [HIV] in front of many people as there are many people in a special function [such as *Dashain*]. This makes me a little bit troubled if any person talks about this anonymously. All people know about this [HIV] but I have distanced myself from my relatives. Nobody has pointed me out, saying “this is an HIV positive person and he contracted AIDS”.

– Shyam, Male

Some participants do not want to disclose their HIV even to family members because of not desiring to disturb anyone’s life by giving them this information. This has limited possible HIV stigma and discrimination from family members. Raju expressed his experience about why he did not disclose his HIV status to his parents and how he has also managed HIV stigma and discrimination indirectly.

My parents are getting older and older...I do not like to tell mum, "I have an HIV infection and make her to be shocked anymore". My mother often watches TV at home. Sometimes my mum goes to Church or anywhere else in accordance with her own will. She is enjoying her own way and I do not want to cause her any disturbance by telling about my health status.

– Raju A, Male

### **8.3 Economic Independence**

Economic independence is another way of managing stigma and discrimination. If participants become economically independent, it is easier for them to keep their distance from other people, and this helps to protect them from stigma and discrimination. Some participants with moderate access to resources, especially males, work towards being economically independent so that they do not need to ask for money from other people. In Nepalese society, people ask for money from either relatives or neighbours in cases where they need it for important tasks such as marriage ceremony or other such functions, and sometimes even for daily expenses. When asking for money from relatives or neighbours, it is necessary to disclose the reason to them, especially while going to hospital for HIV treatment in the case of PLHIV. They are very likely to further disclose HIV status while conversing with each other. Therefore, participants do not ask for any financial help from others, because economic independence makes it easier to keep distance from them and protect themselves from the stigma of HIV. They thus have a strong resolution to become economically independent, perhaps by running a retail shop or by engaging extensively in their own farming.



Some participants developed a vision of being economically independent, engaging vigorously in their own economic activities so that they do not need to ask money from others as stated above. Some participants developed this idea after being discriminated against by their distant family members. For example, Rajesh from outside the Kathmandu Valley, with moderate access to resources (the participant was living in a rural area) has not visited his relatives and not given information even to his wife (HIV-negative) to protect himself from discrimination. He shared his experience of managing his potential stigma and discrimination by not going to relatives' places once he knew that he was not allowed to go to the relatives' home located in Kathmandu.

...Then, I did not go to my relative's home after hearing conversation with my mother through phone, and I have not gone so far. While I am alive, I will work myself and eat myself. Since then I thought, "I will not go anywhere else". When I come to Kathmandu for a health checkup in regard to HIV, I stay here at this organization [where the interview took place] and will return home from the organization. I do not make any trouble to anyone because of my disease [HIV]. If someone says that it is difficult if I go there, what is the point to go there? So I do not go there. I am doing everything by myself. I have courage to run my business and doing well though I am an HIV positive person.

– Rajesh, Male

Some participants reported making a resolution to engage in farming as their earning source after being HIV diagnosed. In addition, they do not want to disclose their HIV status even to family members, thereby protecting themselves from HIV stigma and discrimination. They wanted to be engaged in agriculture activities for their daily

livelihood, which they find easier to continue after failing to go overseas for better earnings. With these two different visions of not disclosing HIV status even with family members as well as engaging in farming for earnings, they plan to manage their expected stigma and discrimination as well as to manage their own livelihood. Such is the experience of Deepak, who was diagnosed as HIV positive less than a month before his interview for this research, in the process of routine testing to go to overseas jobs. He has not disclosed his HIV status, even to his wife (HIV-negative) and rest of the family members with a view to managing the expected stigma and discrimination. He has made plans to spend the rest of his life in agriculture. He shared his experience of making his future economic planning instead of going to any other countries.

...I was planning to go to a foreign country for work. I do not have any service [at government or non-government office jobs]...I am thinking to engage in farming. There is not a way of thinking going abroad because of this disease [HIV]. I have settled my mind in doing agriculture...I have kept it [HIV] silent within myself. Only I know it.

– Deepak, Male

Some participants have had dual economic visions, either by working in their farmland in rural areas or moving somewhere else with a view to managing expected discrimination in accordance with their family treatment. If they find positive treatment from family members, they stay at their home, giving them continuity with their earlier job that they have been doing for years. Basant, diagnosed with HIV 10 days prior to his interview for this research, expressed that his future economic strategy was conditional on the basis of family treatment, good or bad, to be experienced in the

future. His economic planning either to stay at home or to migrate to cities will depend upon the reactions of his family members.

My parents and family [wife] will know about this [HIV] sooner or later. I will do accordingly as what they do [good or bad]. If they do not treat me well, then I will leave home and I may be able to do any small job. I am thinking and hoping so. When I get well, I will try to find a job and work at whatever I receive.

– Basant, Male

Thus, he has already made his strategy of migrating to another place if he experiences stigmatization and discrimination even prior to reaching home from hospital, and the organization where his stay was for two weeks in accordance with the general rules of the organization.

#### **8.4 The Practice of HIV Treatment**

HIV treatment, engaging with various practices of traditional and modern medicines, is an important aspect of managing stigma and discrimination. It helps participants move to a transitional identity following HIV treatment. When they follow HIV treatment, their health and appearance improve, which ultimately also helps to reduce stigma and discrimination in their lives. In the Nepalese context, where physical appearance is considered to be a measurement of an individual's identity, a healthy physical appearance following HIV treatment is an important aspect of reducing stigma and discrimination. In this section an attempt is made to provide an overall picture of how research participants attempt to manage HIV treatment with health treatment practices, notably traditional healing methods and modern medicine.

In the course of seeking HIV treatment, some participants, irrespective of access to resources have maintained continuity in their health treatment using both herbal and modern medicine persistently one after another depending upon their effectiveness. In Nepal, people believe that herbal medicine has no side-effects on their health and they often find it easier to follow traditional practices. Therefore, they generally follow the herbal treatment first, especially in the rural areas. If the medicine given by a traditional healer does not work well, then they follow modern medicine going far away to hospital. In the course of HIV treatment, there were participants who followed both herbal and modern medicines one after another. Lila, a widow, shared her experiences of HIV treatment, describing how she followed instructions on limiting most eating items and not drinking even water given by traditional healer, and then followed modern medicine.

I did not drink even a drop of water for a year as a traditional healer suggested that I should not drink water at all for HIV treatment and my two children, son and daughter aged below 10 years, who were also HIV positive, did the same, but they drank the urine of cows, buckwheat, and millet without any fruits.

– Lila, Female

Although Lila and her children followed all the instructions of traditional healer one full year, they felt their health still deteriorated more day by day. After having fainted and fallen down on the ground without consciousness for long hours, she found herbal medicine did not work well for HIV treatment. That day all the three family members living with HIV, she and her two children, started breaking the instructions of traditional healer and they turned to modern medicine through an organization. Lila also

shared her experiences of how she broke down the instructions to refrain from most eating items and not drinking even water given by traditional healer and then she followed modern medicine.

After regaining consciousness, I asked my mother-in-law to give me and my children normal food from then on and that we would eat to our heart's content. She said there were six more months to go after which we would be free of HIV for ever [as instructed by traditional healer]. I retorted that I was going to die anyway, better die with a full stomach. Then, I went to an organization where the health personnel told me to eat well and to take proper care of myself; the organization was in its early days then. If any medicines for the disease are discovered, we will provide them to you, they had told me then.

– Lila, Female

Like Lila, there were participants in my interviews who turned from their way of herbal medicine to modern medicine and obtaining counselling knowledge on HIV and AIDS. Buddha followed a traditional healing method as suggested by traditional healer and finally she ended up with a conclusion that anyone infected with HIV should follow modern medicine for better HIV treatment.

My present experience [experience after joining an organization and following modern medicine] says that I could not get medicine for HIV; my body became black as if it was burnt [like black grape] and I went to see a traditional healer. The traditional healer after looking at me told that there is wrong in the part of father god. Then three *Brahmans* performed rituals on my behalf. After all my body turned to black colour all told me that I was

attacked by a *Nag* [serpent] and asked me to worship the *Nag* and it will cure my infection. Four times I had taken a *Brahman* to worship at Guheswari temple for getting freed from the *Nag*. To my experience now, it is due to not taking medicine [modern] for HIV. I had seen other people affected by HIV with black *body* and its cause is not getting modern medication.

– Buddha, Female

Many participants gained knowledge about HIV and importance of nutritious food that minimizes the impact of HIV on physical health when they came into contact with organizations and health personnel. They also saw lifestyles of rich people living with HIV especially good dietary habits and its positive impact on physical health. Buddha expressed her knowledge on HIV and dietary food and its impact on physical health.

The main thing is that I have to eat a balanced diet and if I can eat and take good care of my health, that's it. I have come across many people who have been suffering from this infection and are surviving for 15 years without taking any medicine. That person whom I met at the hospital has not reached such a stage of HIV infection that he has to take the medicine... I have now come to know and understand that HIV infection is not like all other diseases if one is able to live free of tension, and take a prescribed balanced diet every day. It is the tension that makes PLHIV weak. I have met HIV infected people not worn out or become thinner but succeeding in living without tension and taking a balanced diet. So I think, in Nepal, the

majority of the people die due to hunger, not due to disease whether HIV or other diseases.

– Buddha, Female

Like Buddha, Min also expressed his experiences of having information through organizations working in the field of HIV following the recommendation of the hospital:

There is a hospital in Kathmandu where this [HIV] is examined and treated. Then I went to [a] hospital and got admitted in emergency ward. I was given saline. I felt a little better. After I stayed in the hospital for 8-9 days, I was discharged and advised to contact an organization. It was a care home just like here [Community Support Group]. There I was given a lot of information about HIV and I started feeling a little calmer. I didn't have to take medicines. I was given vitamin B complex. I had a fine appetite. I realized that HIV wasn't such a big "disease". Again, I stayed there for almost 17 days and I could work as well as others. I could walk around like other healthy people.

– Min, Male

With the medical advancements in the health sector, PLHIV started gaining knowledge of giving birth to an HIV-negative baby as either one of couple or both living with HIV following the practices of the PPTCT service. In this study, some participants have been given knowledge on PPTCT services for HIV-negative babies as per their curiosity and need through organizations and hospitals. According to a doctor's instructions, couples can make practices of having HIV-negative babies even though both or one of them is

living with HIV. In regard to counselling on bearing an HIV-negative baby, Buddha shared her experiences of gaining knowledge about the PPTCT service.

To get protection from HIV, use a condom most of the time and take a risk by not using a condom when there is more chance for pregnancy while having sex (mid period of means 12-17 days, a high possibility of discharging female egg/ovum). When the doctor tells you not to use a condom on certain days, if you are active in sex, the woman will become pregnant and may have negative baby in taking one or two risks of having sexual intercourse without condom.

– Buddha, Female

Participants with better access to resources have been persistently following HIV treatment for the physical wellbeing. These people have very good knowledge of where to go for HIV treatment and how to get medicine by going to hospital as well as making very close friends with people working at organizations caring for PLHIV. Shyam went alone to hospital for HIV treatment on his own motorbike and received medicine from doctors, bringing his friend as a guardian. This person worked in the organization where he had been taking HIV treatment, living there for two weeks.

I had knowledge on where to go and how to get medicine... Indeed, I came alone to check up my health in hospital, doctors asked me about my guardians and nobody was there. One doctor said to me, "I will not give you medicine". Doctors told me they would not give me medicine if I go home. They told me they would give me the medicine only if I come along with my guardian. They wanted me to stay in an organization caring for PLHIV. So I asked one of my friends to be my guardian as I saw him in the hospital



at the same time... I knew him a long time ago as I had also come here [the organization]. Then I succeeded in taking the medicine with the help of him and came here. I am receiving support from this organization and family members.

– Shyam, Male

He further made clear that he has been receiving good support from his family members, mother and wife for his HIV treatment, and he did not bring his family members because of his own good knowledge and experience of his HIV treatment.

My mum does not want to sit with me on my motorbike...She gave me money for my health check up and what you do is all for you. She said to me, “Check up everything in a good way, whatever you need to check up”... I did not bring [his wife] as it takes time to check up everything associated with this [HIV]. I have to go everywhere, and I felt that she may have difficulty to follow me everywhere. Therefore, I suggested to her not to come to hospital. I had already known what to do in hospital. So I did not bring anyone with me.

– Shyam, Male

Participants also attended meetings frequently to update their knowledge on HIV and AIDS organized by various organizations working in this field. Pushpa shared her experiences on her interest in attending meetings of the HIV awareness programme:

There had been awareness programmes and meetings concerning HIV and other related problems. I am still interested in them and have been attending every meeting related with HIV held in Pokhara...This updates latest

information on HIV and AIDS what is going on in this field. I am here now to know more information on this [HIV] like you coming from up [Kathmandu].

– Pushpa, Female

In addition, participants with better access to resources in urban and semi-urban areas have started finding updated HIV information on the internet and exchanging this with their friends through Facebook. The modern means of communication has allowed them to access new information on HIV. Jwala said, “I have a laptop. I read news, watch movies and use Facebook”. Of course, there are other means of communication, such as newspapers these days, especially in urban areas. People with better access to resources are benefitting from modern means of communication, internet and newspapers in finding new information on HIV. According to one participant, rich people have more opportunities to get HIV treatment in time due to availability of phones, emails and internet (Rita A). As a result of better HIV treatment through the combined efforts of hospitals and organizations involved in the HIV field, together with the advancement of communication and internet, PLHIV might gradually manage their good health and reduce HIV stigma and discrimination. More importantly, people with better access to resources did not need to contact anybody anywhere else for more HIV information, and this further helped them in not disclosing their HIV-positive status. Consequently, they found it better to take information from the internet.

## **8.5 Support of Organizations**

In addition to modern practices of treatment through organizations working in this field as explained above, participants, especially females with less or only moderate access to

resources started resisting stigma and discrimination issues with the help of various organizations. They gained collective strength in fighting the issues mainly by becoming united with a circle of extended family members living with HIV through various organizations. Furthermore, they started finding opportunities to get jobs, including informal education and leadership training related to HIV through the support of organizations. Consequently, PLHIV, especially females, in this study, thought of empowering themselves through obtaining these opportunities and gradually reducing their stigma and discrimination.

Some participants with less access to resources have moved forward to disclosing their HIV status publicly with a view to resisting HIV stigma and discrimination with collective support from both government and non-government organizations. When the people came into contact with various organizations, they were able to make approaches to these for help in lessening the prevalent problems. With a view to building their profile as separate from others, even within PLHIV, there were participants who disclosed their HIV status publicly in functions hosted by government and non-government organizations, so that most people across the country came to know him/her through the media. This process has drawn attention to stigma and discrimination reduction and management programmes to be launched by government bodies and non-government organizations. Lila disclosed her HIV status at a big event organised jointly by government and non-government organizations, with a view to raising her profile. She said, “I opened up in 2062 *BS* (2005) on World AIDS Day, amidst 400-500 people on the grounds of [a] hospital”. There were few research participants who had disclosed their HIV status openly (Misa, Santosh, & Nimesh). They wanted to give their real names instead of pseudonyms, which are often used in society by PLHIV.

Some participants made their most of their contacts with an organization through their relatives living with HIV with a view to treatment as well as to find a job. They go to the organizations through their friends and relatives who already have knowledge on where to go. In the Nepalese context, some PLHIV are working at various organizations, so that newcomers with HIV do not feel shyness or shame with their own friends. In this regard, Sarita A shared her experiences on how she attempted to get HIV treatment and a job:

My eldest brother-in-law and sister-in-law were also infected with HIV. Thinking that brother-in-law knows many things and I can get cooperation from him, I went to see him. My eldest brother helped to get in contact with an organization. ... I proposed before them. They advised me to go to the organization and check if children were also affected by HIV.

– Sarita A, Female

She proposed to get a job at an organization working in the field of HIV showing that her home environment was not conducive.

...Then I went to organization in Chitwan and told them that both children were also found to be HIV positive and for me too there is no environment to live in the village. I would like to stay by the side of you. Whatever job, you will give it to me and I will do it. Then they called me. There is no environment to stay elsewhere after we had HIV positive and we never stayed at home [husband's home].

– Sarita A, Female

A few participants have used old friends working as trainers in finding a job, who were involved in the HIV field in one way or another. They have received encouragement for

their remaining life from their old friends who gave training related to HIV and AIDS knowledge in their village before being HIV diagnosed. In this context, Misa, who was trained by a person in her village in regard to HIV from an organization before being HIV diagnosed, shared her experiences in seeking a job.

...I told him [trainer] everything in detail ...and he told me to address him as brother not sir from that day. He consoled me that he would help me as far as he could. ...When he came to Kathmandu on behalf of a funding agency to launch program in an NGO, he told a female staff, the president of the NGO about me. Then he called me to come to Kathmandu if I desired... When I read the details of that organization, I desired to work there.

– Misa, Female

Once participants joined organizations for their job one way or another (Rita A, Jwala, Misa, Sushma, Mamata, Buddha, Sarita A, Raju A, Suku, Sabina, Pratima, Durga, Raju B, Rita B, Anu, & Santosh), their scope for learning things, such as informal education, became much wider in addition to gaining more knowledge on HIV and AIDS as well as for seeking a job. Participants, especially illiterate females, have had the chance of attending informal education when they were in contact with organizations working in the field of HIV. In Nepal, females were previously not given priority to be sent to school by their guardians. After becoming HIV infected, when people came in contact with different organizations for a job, they were provided with informal education. Buddha had a chance to attend informal education through an organization while working there. She shared her experiences as to why she did not have education

previously and how she had a chance of attending education with an informal education programme.

I did not get a chance to study... A daughter was not insisted by anyone to go to school. So I did not go even once to school... Later, I attended informal class every day one hour up to 2 years when I joined here at this organization where I am working now.

– Buddha, Female

Participants who had better access to resources were often self-motivated and had the self-confidence to do something better for other PLHIV facing many problems in their lives. For this, they started doing something better in the field of HIV and AIDS by making joint efforts irrespective of their place of origin, even going outside the Valleys. Raju A, who had better access to resources, shared his experience on how he proceeded in the process of a rapport building with other PLHIV for their welfare in providing information on HIV and AIDS and in lessening HIV stigma and discrimination, for which he migrated to the periphery of Pokhara Valley from Kathmandu.

I got to know about this [an organization] from my friends and acquaintances. I came to know that PLHIV have been hated and excluded from family members and society. These events made me self-determined do something better for the excluded people. At the same time, I met a sister in one of the HIV trainings, then we talked about how to initiate an effective programme for PLHIV. When a person who worked here [the organization] passed away, then I came here to work together with the sisters. The main thing you need in Nepal is self-confidence. The confidence is affected by

the discriminations, superstition and so on. Those HIV infected people should not be affected by these trivial things.

– Raju A, Male

Likewise, Jwala started working in the different organizations working in the field of HIV one after another.

I started working with HIV field as my career in 2004. Hiding myself in the community as an HIV infected person, I have helped many people like me and the outcomes of my work helping the people are also good. I have feelings of respect from others who really received my help in terms of treatment in hospital through advocacy on treatment for PLHIV. As stigma and discrimination on people with leprosy in our country has reduced in comparison to the past, the same behaviours are also applied into the HIV sector if we focus on the treatment of PLHIV. If treatment is to come continuously from NGOs/INGOs, such discrimination would be gone. I have argued many times for this. I have advocated for transportation expenses of PLHIV to be met, including their accommodation for those who come to Kathmandu from the countryside. I am very happy with the work that I have done for PLHIV. I have a self confidence that I still can do more for them.

– Jwala, Male

## **8.6 Spirituality**

In this study, many PLHIV have considered spirituality to be a powerful tool in one way or another to manage family and social issues of stigma, discrimination and disruption. They thought of God, irrespective of any religion, who helped them in solving their

family and the social issues they faced after being diagnosed HIV positive. The family and social issues that the participants who do not face issues of stigma and discrimination in families and societies like other PLHIV are also believed to be the outcome of their longing for God, especially getting love instead of discrimination from their parents (Jwala & Raju A). In addition, finding a job, better HIV treatment, and obtaining leadership training and informal education through organizations working in the field of HIV are also attributed to the grace of God. Participants considered spirituality to be a reliable resource for their betterment, and a directive force for their remaining lives. They redefined the purpose and meaning of their further lives.

Many participants had a strong faith in God in accordance with their background from childhood, and use spiritual beliefs go towards their transitional identity in terms of coping with stigma and discrimination. There are various ways of coping with their situation and continuity for their future lives, relying on God in terms of saving their lives by preventing suicide attempts, finding ways of HIV treatment, and gaining a deep love from family members, despite their HIV status. For some participants, God gives punishment to people who discriminate; they pray for continuity of their children's education and peaceful lives while facing discrimination at school. As well, they give credit to God for finding a job irrespective of which religion they adhere to or their access to resources.

Many participants believe in God for their betterment in their present and future lives, and pray to God. In Nepalese society, it is believed that God sees everywhere (Gita) and God should be considered as a companion at the time of any pains and happiness. People learn about God in their families and societies from their childhood, and



participants pray for their better future lives. Rajesh shared his experience like this, “I remember God. When I have a deep grief, I remember God. I have in faith of God. Every time I take medicine and sleep on the bed, I remember God”. Similarly, Lila shared her experience on how she learned about, and developed a strong faith in, God.

I am a Hindu. I prayed to God since I was a child and have faith in God. I used to take *brata* [fasting] and attend *puja* [a programme associated with worshiping God]. My parents also had immense faith in God. They used to go on different pilgrimages in hope of recovery for their disabled sons. Both my brothers couldn’t eat or drink by themselves. My father bought a he-goat and worshipped it and offered it to the Goddess. After that my younger brother who couldn’t even get out of bed started eating and drinking himself. Then, my parents’ faith in God grew further still... I have immense faith in God.

– Lila, Female

Some participants have used spirituality as a life saver, preventing suicide attempts. Homilies preached by priests have “recalled” participants and directed them towards their own and family obligations. Therefore, some participants expressed that they gave up thinking of suicide, realizing that suicide in the present life is considered to be a highly sinful deed (Lila). At the same time, fulfilling their family obligations, especially rearing children is seen as imperative as a mother and this is a virtue of life in this present world which one needs to do in each situation, as stated in their religious book. In this context, Lila shared her experience on how she gave up her decision to suicide after her husband’s death due to AIDS “...Then, I remembered the teachings of *Garun*

*Puran* [a Hindu religious book] and decided that I would not take the poison and that I would live on, at least for my little children”.

Participants also believe that God has helped them in finding a traditional healer for HIV treatment, and things have been made simpler as they have desired because of their *Bhakal* (promise) given to God. In this context, Lila shared her experience as to how she was able to find a traditional healer and how life became simpler by the grace of God.

[God] made things simpler. After my husband’s demise, I heard people say that HIV could be cured by taking herbal medicines given by [a] *Vaidhya* [traditional healer] who lived in [a] district. So, I sold my gold locket to get there and seek treatment. While starting my journey, I saw a temple and pledged that I would get the medicines. I took his medicines for one year. I don’t know if they worked or not ... On returning, I told my mother about the *Bhakal* I had made at the temple. She said that my pledge had been fulfilled, that I had met the man and got his medicines and so now I had to offer something to that temple. So, I worshipped with a sheep’s kid and prayed again that nothing bad would happen to me and my children for the next five years. After the promised five years, I again went back to the temple and made offerings in the names of my father, father-in-law, my husband’s grandfather, my husband and my step-mothers. I also recently made offering in my late mother’s name after her yearly rites were performed. Once a soothsayer told me that I had witnessed a lot of troubles in my life because the Goddess had come inside of me; to get rid of my misery I needed to observe difficult fasting and praying. My ageing mother

told me that the whole process was very difficult to follow. I should only do as much as my body would allow. I did so. I had immense faith in God.

– Lila, Female

Some participants believe that they receive deep love in their family, even with HIV status and they give credit for this to the grace of God from a religious point of view. There were some Christian participants who never felt HIV stigma and discrimination from all their family members. They believe that their family members have been taught love to others instead of hatred as per the philosophy of Christianity. In this context, Jwala (from a Christianity background) expressed his experiences concerning love which obstructed HIV stigma and discrimination by his family members.

I am from a Christian background. We believe in Jesus that God cures all kind of diseases. When my elder sister knew that I was HIV positive, she did not take it very seriously. When my mother knew it, she loved me...I have never seen God but I believe that God is the healer. I believe in God very much. My father also believes on God very much...I think it is Christianity that made our homely environment very lovely and cooperative. All the family members have learned to love and serve from Christianity and so they love me.

– Jwala, Male

Some participants believe in a God that is the supreme judge to give punishment to someone who has hurt anyone for no reason. In Nepalese society, it is believed that if someone is hated and ostracised by a person for not any solid reason, the person is also punished by God even if there is no human punishment for this, as God sees

everywhere. Gita shared her experiences of how she and her son were hurt by her mother-in-law and how God gave punishment to her mother-in-law later.

If villagers came home and took my son on their lap giving two-four Rupees, my son's grandmother used to tell them not to touch my son, saying it was *Phohori* [Yucky] and showing the pimples of his body. Pointing to my son and me, she told others that they have a bad disease [HIV] and can transmit it to others if anybody is close to them and touches them. At the last moment of her life, she faced the problem of wounds over her body. She had hurt us badly before. Consequently, God showed her sin hurt us as we had not done anything wrong. We were in truth. God always shows truth. She died after her long suffering of pimples caused by other diseases and did not move anywhere from her bed.

– Gita, Female

Those participants who were illiterate felt discriminated against by their society because of their illiteracy, and they prayed to God for their children's education and their peaceful lives without stigmatization and discrimination. Lila expressed her prayer to God for children's education and peace in her life.

I was illiterate so the society looked down upon me. By the time I realized the importance of education, it was too late. I thought that HIV would make my children's future dark like mine; it would prevent them from receiving education. I thought that if others' children could get education, why not mine? I was really upset and felt like crying. The society, the silent discriminator, was a primary requisite for survival. I couldn't sleep or eat worrying about my children. I used to pray to God, I used to ask God to

provide them with a chance at education. If God starved us or threw us out of the house I wouldn't complain; please let us live in peace.

– Lila, Female

Spirituality is considered to have helped some participants in finding a job. Becoming economically independent by working in a job was found to be a way of reducing stigma and discrimination. The participants prayed to God and attributed their success in the finding of a job to the grace of God. Buddha believes in God and in ancestors who have made efforts to save her life from many ordeals and to get a job. She believes credit for this goes to God and to the blessings of the ancestors.

I believe in God and in blessings of ancestors. I am doing all the rituals of the anniversary of my late husband and mother in law... I think it is not good to leave everything that our ancestors had shown in the path of worshipping God and the ancestors. I think that the credit goes to God for helping me make a success of my life by saving me from many ordeals... It seems to me that God has sent me to work at this organization.

– Buddha, Female

Like Lila, Sushma shared her experience on how God has helped her in being economically independent by the grace of God:

Although I lost my husband due to HIV, I had reached to the mouth of death, I am now able to live by myself [economically independent] and I do not need any supports from others. I feel that all these things [HIV treatment and economic independence] are attributed to God.

–Sushma, Female

## **8.7 Discussion**

This section has explored the differences in how participants began managing stigma and discrimination based on their access to resources. It also deals with public judgement in terms of support for PLHIV by government and non-government organizations, especially in the case of females who are widows, separated or divorced and those who were ostracised and discriminated against in their homes and who have migrated to cities or their peripheries.

There are considerable differences in managing HIV stigma and discrimination between the participants with limited access to resources, and those with moderate and better access to resources. Participants with less access to resources realised sharing the pain associated with HIV with their own circle of friends living with HIV lessened their feeling of pain significantly. They have opportunities to share their experiences in the weekly, fortnightly and monthly meetings organised by the organizations working in the field of HIV. A few participants with limited access to resources have also disclosed their HIV status publicly with a view to gaining collective strength in resisting the stigma and discrimination prevalent at home and society as well as in getting a subsidy for HIV treatment. By contrast, the participants with better access to resources as well as moderate access to resources generally do not want to disclose their HIV status with a view to managing their HIV status even within their circle of friends living with HIV, and even with their spouses and parents at home as explained in the above section. In this regard, they have been managing their identity while undergoing HIV treatment by not disclosing their HIV status either in foreign countries or in expensive nursing homes (in the case of rich participants), whereas not everyone can afford the heavy financial costs and keep themselves confidential. In regard to this, Pratima expressed her

experiences based on observation in the hospital and hearing from others about how PLHIV with better access to resources manage their identity by not disclosing their HIV status.

Many rich PLHIV go to India for their treatment. Even to know this CD4 count, they go to another place [nursing home, an expensive place far from home]. They do not disclose their HIV status so nobody can stigmatize them. In such a situation, there is no matter of stigma and discrimination as nobody knows about the case[s] of rich PLHIV.

– Pratima, Female

Pratima also shared her experiences on how rich PLHIV manage their identity by not disclosing their HIV status, by dressing well, and not interacting with each other among other PLHIV.

This is clearly visible that if rich people go to hospital for CD4 check up, it is hard to recognise them as they do not put off their helmet of motor bike, they put on a mask and they cover all their body. Another interesting point is that they do not want to introduce each other. Health personnel working in the field of HIV also share these things in general from which I came to know the fact of rich PLHIV.

– Pratima, Female

Most of the female participants with less access to resources have undergone a continuous migratory process from one organisation to another, located in different places, with a view to finding shelter and livelihood, in addition to managing ongoing stigma and discrimination. This can be explained as a process of migration which is concerned with the place of origin: rural areas, with negative factors, and HIV stigma

and discrimination made by family and society. On the other hand, if their destinations are urban areas, this is associated with positive factors, including a network of PLHIV and their collective supports, HIV treatment, opportunities of attaining knowledge on HIV and AIDS, informal education, and the possibility of finding jobs. The concept of place of origin and the destination in the process of migration as explained by Lee also applies to cases of participants in relation to why they migrate to urban areas (Lee, 1966). However, their migration is limited to their purposes of finding livelihood and shelter instead of attaining the higher aspirations of life with step-by-step migration as explained in this Lee's theory. Nevertheless, the process of migration has assisted in reducing stigma and discrimination on the one hand as well as given them comfort in meeting basic human needs such as HIV treatment, jobs and shelter on the other.

The female participants with less access to resources have been more supported than males as also have the participants with moderate and better access to resources, on the basis of judgement and humanitarian perspectives from organizations working in the field of HIV. Many widows, separated and divorced females who have left their homes have joined in these organizations with a view to finding work and shelter. Indeed, society is composed of heterogeneous components: some people are happy to help others in terms of providing supports and the necessities of their life. There are some examples of females living with HIV who have received support in obtaining their property in their names even though their family members were not happy to give property; especially in the case of HIV-infected widows help from people working in the government body (VDC). For example, Gita shared her experience on how she received her property from her family members after her husband's death with the support of the secretary working in VDC.



It [An intention of not giving husband's inheritance property] is because of HIV. But later I was given the property of my husband. After death of my mother and father in laws and my husband, my name was replaced instead of husband's name at VDC when I went there. But one of my husband's brothers was arguing an objection against my name instead of my husband's name at VDC. The secretary of the VDC asked me to tell the closest person of the deceased husband and I told him to put my name as the closest person, his wife [herself]. He did it as required for me ... After my death, my son and daughters will share the property of my name. I wish them a long life.

– Gita, Female

There are many examples of such females, as explained already, who were taking charge of their lives with the support of people working in the field of HIV through various institutions.

From the field work of data collection, I found there was very good collaboration in support of participants not only for HIV treatment and knowledge but also finding a job and shelter on the basis of necessity of PLHIV and on the basis of access to resources. Priority is given to widows, and separated and divorced females. There is a very good networking of health personnel, people working in the field of HIV and PLHIV in sorting out issues associated with HIV. The health personnel and the staff working in the organizations have paid more attention to PLHIV to improve their lives from health, social and economic perspectives. Suku shared her experience on how she had tried to join an organization for work.

While visiting a hospital to feed my husband ARV, a sister, the staff of the hospital told me to take my husband to Care Home. My husband could not recover though he had a lot of medicine. Then, a male staff member came from their Care Home and took him to their Care Home, and gave him some recommendations about HIV. I met his wife too. I kept friendly relation with them. When I met her, I got relief. I met her when I worked as a labourer and a shopkeeper. On the way from hospital to Care Home, she told me to apply for the post when there was a vacancy. Since then I have been involved here in the organization.

– Suku, Female

## **8.8 Conclusion**

Many participants are moving towards an identity transition in a positive way – from spoiled identity to transitional identity – by managing the stigma and discrimination associated with HIV. The major factors in moving to a transitional identity are migration and either hiding or disclosing their HIV status in accordance, mostly, with their existing access to resources. In this study, those participants with limited access to resources started creating strategies through migrating to cities and by finding a network of PLHIV through organizations, friends and relatives, and even by disclosing HIV status in public with a sense of building the collective strength of people to fight against social stigma and discrimination. In contrast to this, the participants having moderate and better access to resources have often received family support to cope with the stigma and discrimination prevalent in society. In a family where there is a conducive positive environment to live there is also a good environment to live in the society outside home; this mostly applicable for the participants with moderate and better

access to resources. A Nepalese proverb applies here: *if ghar baliyo bhayo bhane ban baliyo hunchha* (if home is strong, there is a supportive environment everywhere). Overall, PLHIV in this study have moved from a spoiled identity to a transitional identity by applying several strategies including migration, disclosing and hiding HIV status, achieving economic independence, their sense of spirituality, in managing stigma and discrimination as well as following both traditional and modern techniques of HIV treatment. For that purpose, there were participants who started developing new mindsets and various strategies to become economically independent, physically healthy and socially respectful in society, fighting stigma and discrimination and moving ahead in changing their socio-economic status positively within their given environment either at their homes and/or in their society.

## **Chapter Nine: Reconstructed Identity**

The major purpose of chapter nine is to look at what sort of changes were experienced by participants after applying various strategies for managing HIV stigma and discrimination, following HIV treatment, and joining organizations working in the field of HIV. This chapter firstly explains the results of the stigma and discrimination management strategies they applied in their lives. Secondly, it focuses on health status, dealing with changes in physical health and physical appearance, the impact of PPTCT service, and comparisons of HIV with other diseases. Thirdly, it deals with other positive socio-economic changes in participants with varying levels of access to resources. Finally, an attempt is made to sketch a proposed identity reconstruction model which considers identity crisis and its transformation, based on data analyses in this chapter and the preceding chapters of this study. The purpose of this model is to schematise experiences of participants with various identity trajectories over the course of their lives.

### **9.1 Stigma and Discrimination Management**

The participants in this study have managed their stigma and discrimination utilising various approaches depending on the degree to which they are able to access resources. The overwhelming majority of participants with limited access to resources managed their stigma and discrimination by migration, by leaving their place of origin after experiencing heavy stigma, ostracization and discrimination. Thus migration helped in managing HIV stigma and discrimination at their place of origin (by leaving it behind) whereas keeping their HIV status secret helped in managing these kind of problems in their new locations (Misa, Sushma, Mamata, Buddha, Sarita A, Pratima, Durga, Sarita

B, Gita, Rita B, & Anu). When they moved to a new place most of them did not disclose their HIV status to other people except to certain health personnel, doctors, nurses and the people working in organizations related to HIV who commit to keep personal information confidential. This managed the confidentiality of their HIV status in their new location, whereas the urban people who had been living in urban areas for a long period of time often knew how to maintain the confidentiality of anyone because of their enhanced awareness of personal matters in urban areas.

Publicly disclosing HIV status after making a network of PLHIV won the sympathy of people working in government bodies (both VDC and Municipality) and non-government organizations related to HIV. This helped participants in resisting prevalent stigma and discrimination. In my study, I came across a few participants who disclosed their HIV status publicly so that they were able to cope with the challenges related to HIV stigma and discrimination collectively with assistance from people working in this particular field. The females with limited access to resources are more likely to disclose their HIV status publicly than males. Disclosure could be motivated by seeking the collective strength and support of other people in resisting stigma and discrimination as well as in improving their identity status from social and economic perspectives. Lila shared her experiences of having better self-esteem and the support of public inspiration after publicly disclosing her HIV status. People expressed appreciation, telling her that she was a “brave woman” after she gave a speech on her experiences of living with HIV.

When I spoke in front of everyone, they were all praises for me, calling me “a brave woman”. I had a talent to speak in public, one I had never realized.

I think my life has been easier since I came clean of the fact I had HIV in

public, if not in my personal life then my social life at least. I don't know what people say behind my back but they don't say anything bad to my face.

– Lila, Female

Like Lila, there were other participants who publicly disclosed their HIV status (Misa, Nimesh, & Santosh). They have been able to win public sympathy in reducing HIV stigma and discrimination prevalent in society through the accumulated assistance of people, irrespective of HIV status, working in the field of HIV. This also opened doors to work with HIV stigma and management programmes launched by various organizations working in this area.

On the other hand, most participants who had moderate and better access to resources managed their stigma and discrimination without disclosing their HIV status in their societies. Family members also helped them by not disclosing their HIV status either. Some participants, those with both moderate and better access to resources have kept their HIV status completely confidential, not even disclosing it to their family members. Nobody knows their HIV status and thus there is no chance of experiencing HIV stigma, discrimination and spoiled identity (Raju B, Pushpa, Hardik, Basant, Rajesh, & Deepak).

Many participants eventually found themselves turning from their own blood relatives to an extended family of PLHIV to assist them dealing with issues associated with HIV. This provided more collective strength in fighting against the HIV stigma and discrimination prevailing in their family and society, irrespective of their degree of access to resources. Consequently, this collective strength enabled them to experience greater self-esteem and to seek better health, education and jobs. They are now enjoying

their own circle of PLHIV to cope with any problems related to HIV. In my field research, I found a strong collective strength created by both so-called touchable and untouchable castes living together in the same building and sharing the same kitchen (organization building). There was no sense of touchable and untouchable castes among the participants living there and it seemed that everyone felt equal in every aspect of daily life.

There were a few participants who have never faced stigma, ostracization and discrimination even after disclosing their HIV status. These participants did not need to go through transitional identity to enter into reconstructed identity with a view to managing stigma and discrimination. In contrast to HIV stigma and discrimination, the few participants also have received several inspirational words for their betterment in life. The reasons behind this may be that some people in Nepalese society also look for the reason for being HIV infected, either from self or partner's involvement in sexual activities before marriage. The females living with HIV with high family and social status who were HIV infected by their husbands are not generally stigmatised and discriminated against in their family and society (Sabina). Likewise, the sexual activities being at an immature age before marriage are generally considered not to be a big deal in a *Muglan* (a strange place) as it is also expected that there have been circumstances for being involved in sexual activities, such as peer pressure. For example, I had the privilege of interviewing Rana (participant) who had gone to India at a very young age for work and who had sex with multiple partners, due to peer pressure, before his marriage. He never faced stigma and discrimination either in his family or wider society. The reason for this could be that he had sex at a very immature age and both he and his wife are working actively for their earnings. Rana shared his

experiences of how his friends in his village inspire him time and again to go ahead with HIV treatment and love him giving him hope for future days.

...Friends come and spend their time with me. They do not discriminate against me. They console me saying that everyone has got one disease or other. Everyone dies one day sooner or later. They even say that you may find a remedial medicine for HIV...

– Rana, Male

People living in this society also encourage some PLHIV, collectively inviting them and handing over responsibility in functions being hosted by villagers. Rana also shared his experiences of involvement in the functions hosted by neighbours and villagers in this way:

Almost all people treat me well. In my village the people allow me to be the main cook in their feasts though I tell them that I have HIV. Villagers really love me. I make it clear to them not to invite me to cook food for their feasts, with me having HIV. They say that I can't escape from this service telling so many unnecessary things.

– Rana, Male

## **9.2 Improved Health Status**

Participants, regardless of their degree of access to resources, have felt their health status improved following health counselling and obtaining modern medicines available at hospitals and the organizations working in the field of HIV. They appear as physically well as HIV negative people. Most participants are now physically fit to work any job just like they were before, just as other HIV-negative people do now. Some participants, especially females who had been HIV positive for a long time,



looked dark and physically weak before taking modern medicine. Now after taking medicine, they appear to look as good as others seem physically.

When I got sick due to HIV, I thought that I would die immediately. At that moment, I had thought that this was end of my life. But after treatment at hospital, nobody can say by looking at my face and body that I am an HIV positive person. I am more content now than before.

– Sushma, Female

Like Sushma, most participants expressed that they are as physically fit as HIV-negative people are now.

HIV treatment (through ARV) has prolonged life expectancy of the PLHIV in this study substantially. Having been informed by their doctors they have had HIV, almost all participants had started counting their days to the end of life; maybe that day or tomorrow in accordance with their earlier thinking about their future life. In my field visits, I had the opportunity to obtain data from people who have been living with HIV for up to 16 years (Jwala & Buddha).

It is possible for PLHIV to give birth to HIV-negative babies (Rana & Buddha). Even though both husband and wife are HIV positive, their children have been born HIV-negative using the PPTCT service by applying measures recommended by hospital doctors. In my field visit, I had the privilege of conducting an interview with a male whose fourth child is HIV negative although both husband and wife were HIV positive, and whose other three children were also born HIV positive prior to their HIV diagnosis. He happily shared their experience: “We now have a fourth child aged 18 months whose blood was tested three times but she is found to be safe from this disease

[HIV] using PPTCT service” (Rana). I found the couple have been extremely happy in having an HIV-negative baby, when both husband and wife are HIV positive. Thus there has been a good measure of success with the PPTCT programme enabling the birth of an HIV-negative baby from the couple living with HIV. There are also some other similar stories regarding HIV-negative babies from HIV-positive parents. Regarding this, there were some participants who shared such types of wonderful experiences such as having HIV-negative babies in their lives with either partner being HIV positive in this way: “...I have known of many couples, either one or both husband and wife, being HIV positive, who successfully had HIV negative babies through using the PPTCT service... It is so nice to see it. Now there is a big change” (Buddha & Rana).

Participants feel deeply that HIV does not rank highly in this study in terms of health problems like other diseases, such as diabetes, blood pressure and cancer. This indicates that HIV is not like those other conditions, with the message that HIV is not a life-threatening condition if they get timely treatment. The reason behind this is that they do not need to abstain from any food available to them but other people with diabetes, blood pressure and cancer have to be careful about many foods (Jwala, Buddha, & Rita A). In addition, they have seen that people suffering from these other diseases soon die from them. Most research participants expressed their feelings which echoed each other's statements.

HIV is nothing for those persons who have enough money. Of course, I can eat anything I like. The main thing is that I have to eat a balanced diet and if I can eat and take good care of my health, that's it. I have come across many people who have had this [HIV] infection and have been surviving for 15

years without taking any medicine. That person whom [in an economically better position] I met at the hospital has not reached such a stage of HIV infection that he has to take the medicine.

– Buddha, Female

They also compare HIV with other diseases, and then they consider HIV as a lower level of problem, like this: it is better to have HIV than diseases like cancer, diabetes and blood pressure (Lila & Buddha). HIV is not a disease, but an infection (weakening the immune system) as told by research participants. Jwala shared his experiences comparing HIV with other diseases with an example of his father's disease.

Disease is disease whatever it is. Every disease causes suffering to its patient in one way or the other. My father has a transplanted kidney and stays at home... My father does not get some types of food even if he wants to have it. I am free to eat anything. So, my mother gives me everything that she cooks. I only have to take medicine. In fact HIV is far better than diabetes. If one can spend his/her normal life having nutritious food, HIV is not a disease for him/her. This is not a disease but an infection.

– Jwala, Male

As stated above, there are many participants who did not feel seriously sick due to HIV. Sarita A shared her experience of HIV in this way: "I never felt seriously sick due to HIV. After becoming infected with HIV, I felt the same as other general [HIV-negative] people. After I was diagnosed with HIV, I started receiving treatment from the concerned organizations".

### **9.3 Positive Socio-economic Changes**

Some participants, mostly females with limited access to resources, shared their experiences as to how they found themselves undergoing radical socio-economic changes through the support of organizations working in the field of HIV and they reported associated improvements in self-esteem. As already explained, migration not only reduced the stigma and discrimination prevalent in their place of origin, migration from their previous home to cities also opened doors for enhancing their future lives, especially in changing their socio-economic status. This section addresses the experiences of the participants with varying degrees of access to resources, especially focusing on positive socio-economic changes.

In this study, all women with limited access to resources (lack of family support after husband's death due to AIDS or women divorced/separated from husband) changed their place of residence from rural to urban and they were consequently able to gain a better quality of life there. They are now enjoying urban facilities, electricity, schools and colleges for their children, government offices, and shopping centres that relate to an improved quality of life. Moving from rural to urban areas, they were now finding their lives easier, especially for HIV treatment at hospitals and this changed their lives markedly. All female research participants with lower access to resources migrated to urban areas where these sorts of facilities are available. Urban people do not care so much about others' personal lives and that made the participants comfortable in managing their stigma and any discrimination. A few female participants with their husbands living with HIV with an average access to resources migrated to cities (Rita A & Sabina) in the course of seeking employment and this reportedly enabled them to enjoy the improved quality of urban lives.

With changing residential status, HIV changed participants' occupational status, especially for most women with limited access to resources (lack of social capital) who were working as housewives before migration to cities (Rita A, Misa, Sushma, Mamata, Buddha, Sarita, Pratima, Durga, Rita B, & Anu). They obtained jobs related to their HIV experiences through community support groups located in urban areas. Changing their occupation made them economically independent due to now having paid jobs. This not only increased their income but also their social identity in the eyes of other people like family, relatives and other societal members. In this study, few females with limited access to resources have continued working in their original occupation mostly engaged as agricultural workers for other people even after migration due to their illiteracy (Sarita B & Gita). Even though they continued their original pre-HIV-diagnosis occupation, they achieved reduction of stigma and discrimination prevalent in their family and society at their place of origin and enjoyed the collective strength of their own circle of PLHIV. On the other hand, participants with average and above access to resources changed their occupation moderately. In these categories, female participants with moderate access to resources changed their occupation from housewife to service workers (Rita A & Sabina), whereas male participants in this category have largely stayed in their own homes in rural areas and worked in the same occupation on their farmland as farmers as they did prior to their HIV diagnosis (Hari A, Basant, Rajesh, Deepak, & Min). Likewise, Suku, who now belongs to this category (moderate access to resources), and who dropped from the better access to resources category after her husband's death, by living in an urban area worked at any job she could get for her family. Later she obtained a job at an organization working with PLHIV. Analysing occupation in the participants by gender with better access to resources, it was apparent that at least one female relied on her family income (Pushpa). Male participants in this

category have contributed to the improvement of lives of other PLHIV, especially for those people coming to urban areas from the countryside for HIV treatment. This is more oriented towards advocacy for PLHIV for better HIV treatment at hospitals as well as resisting HIV stigma and discrimination, rather than their economic motives (Jwala & Raju B).

After having migrated to cities, participants, especially females with less access to resources, felt liberty from family members and society to develop their future career independently. They did not need to obtain permission from their family members for attending to their basic needs such as HIV treatment, and training related to HIV for finding job or for making other personal decisions. Their liberty allowed them to engage in various development sectors independently, especially enhancing the empowerment of women. All participants who were from the limited access to resources category experienced a sense of liberty through migration, after being previously ostracised. Pratima shared her experience of receiving liberty with various opportunities through coping with new challenges after being diagnosed HIV positive and separated from her husband.

My life was only to make others happy. New challenges came to me with my HIV positive status and I learned to struggle to cope with new challenges. I think I was not born before being HIV positive, I was born only after being HIV positive. I had no idea how to talk with others and I had no courage before being HIV infected. I had not seen any other alternatives except weeping after being beaten seriously by my husband.

– Pratima, Female

Pratima also shared her experiences about her life after engagement in social activities as a social worker, in comparison to her life prior to HIV diagnosis. This has enhanced her self-esteem, doing work as a social worker and she has concluded that HIV is not the end of life but rather the start of life after having received liberty from family members and now engaging in social activities.

Now my philosophy about life has changed. An interest in doing social welfare has developed within me. I think I have to be involved in awareness programs concerning the PLHIV. What happened to me should not happen to others. My attitude towards life has been totally changed and I desire to serve as a social worker and now many people know me. Now I have visited almost all the places of [the] district. I now think that HIV is not the end of life but a start of life for me. I was just concerned about my life before, but now I think about others. I have reached a very high level in the life now.

– Pratima, Female

Many participants working in the field of HIV in support of other PLHIV expressed their extreme contentment as they have saved others' lives. Many males and females in this study who have lived with HIV for a long time, either from less, moderate or better access to resources, have expressed their extreme contentment that they are now supporting other PLHIV who do not have knowledge on HIV treatment. Sarita A, with less access to resources, shared her heartfelt contentment while working with HIV-infected, orphaned children in this way: "My job is to look after HIV-infected orphaned children and provide them with the necessary care. I feel proud and satisfied when they call me Mummy". Likewise, Jwala with better access to resources expressed his

experiences of caring for other PLHIV on HIV treatment, something which makes him very happy in his life.

As to positive aspects of my life after being diagnosed as HIV positive I got a chance to work at organizations working in the field of HIV and AIDS. I started working in the HIV field as my career in 2004. Hiding myself in the community as an HIV infected person, I have helped many people like me and the outcomes of my work helping the people are also good. I have feelings of respect from others who really received my help in terms of treatment in hospital through advocacy on treatment for PLHIV. As stigma and discrimination on people with leprosy in our country has reduced in comparison to the past, the same behaviours are also applied to the HIV sector if we focus on the treatment of PLHIV. If treatment is to come continuously from NGOs/INGOs, such discrimination would be gone. I have argued many times for this. I have advocated for transportation expenses for other PLHIV to be met, including accommodation for those who come to Kathmandu from the countryside. I am very happy with the work that I have done for other PLHIV. I have a self confidence that I still can do more for them.

– Jwala, Male

Research participants started a development of leadership skills following meetings related to issues around HIV. They are often actively involved in weekly, fortnightly, and monthly meetings being organized by different organizations working in the field of HIV. In these meetings, they have opportunities to share their pain and happiness as they have emerged from HIV, healthy and relatively free from HIV stigma and



discrimination. They learned where to go for health check-ups, the importance of HIV medicine and its regular use, CD4 counting and whether it is necessary or not to have medicine based on CD4 counts. In addition, they have been provided with knowledge of human rights which made them aware of their rights. This has enabled them to speak of HIV to people living in the society, irrespective of HIV status after developing their leadership skills.

Furthermore, after gaining HIV knowledge and HIV treatment, participants across all economic strata started teaching other new friends facing the same problems of HIV under various organizations (Rita A, Misa, Sushma, Mamata, Buddha, Sarita A, Pratima, Durga, Rita B, Anu, Raju A, Raju B, Suku, Sabina, Durga, & Santosh). Gradually, they developed their leadership skills, teaching their new friends (who were HIV positive) through organizations and personal contacts. After enhancing their knowledge on HIV and AIDS together with their leadership skills, they found jobs in the areas of HIV, especially providing knowledge about HIV to the people living in urban, semi-urban and rural areas irrespective of HIV status (people either living with HIV or HIV-negative people). With leadership skills, they also developed good speaking skills.

These days, marriage is also taking place between PLHIV and HIV-negative people, especially where there is better access to resources, especially in urban areas. With advancement in HIV treatment and an increase in knowledge on HIV and AIDS, people started realizing that there is no point considering HIV status if people fall deeply in love. In my data, a few male participants married HIV-negative females. The reason behind this is the deepest love between males and females. Moreover, the females were

lured with economic property and the good jobs of the males. As noted above, medical advancements in HIV treatment and PPTCT service made people realize that HIV is not as big a problem as it once was. In my field visits, I found some participants married with HIV-negative people based on love, economic prospects and urban amenities (Shyam & Sandeep). In regard to this, Shyam said, “I got married after becoming HIV infected when I was 20 years. My wife is an HIV-negative person”. Similarly, Sandeep shared his experience in this way: “I got married about 3 years ago...She [his wife] is not an HIV positive person. I got married for love affection. She had known everything about me and my HIV”.

Some participants, especially females, who had been illiterate became literate through the informal education provided by organizations working in the field of HIV. Nepal has given priority to commencing multi-integrated approaches in development activities for decades. People working in the field of HIV have been using the multi-integrated approach and participants gained informal education in addition to HIV treatment and knowledge through the organizations with which they were in contact. With reference to this, a female shared her experiences in this way “...I learned to read general reading and writing and could read *Swasthani* [a Hindu religious book worshipping Goddess]... I can now read a field report slowly” (Buddha). There were other female participants sharing such experiences of becoming literate after being engaged in such organizations.

Some participants with limited access to resources have found a conducive environment for family reunion after becoming economically independent and socially respected even after being excluded from home. They found themselves reunited emotionally and physically at home as well. They reported feeling reunited emotionally as a family

member when they go back home in festive seasons such as at *Dashain*, the biggest festival in Nepal. Gradually, they have been regaining respect even in public places and various institutions. Rita A, who migrated to Kathmandu after being ill-treated at home and in society due to her HIV, shared her experience of family reunion and societal reunion emotionally:

I do not spend a long time at home. When I go home to [the] district, my family members treat me well. I am now standing on my own because of my job.

Whenever I meet anyone anywhere in my village I find them treating me well.

– Rita A, Female

Likewise, Durga, who was badly treated at home due to HIV, and then who moved to Pokhara city, shared her experiences of physical family reunion after becoming economically independent through working at an organization related to HIV. She shared her experience on family reunion like this: “Now my father-in-law came here seeking me and started staying with me... He says that he looks after his small grandson [HIV positive] and lives with us [Durga and her son] for ever”.

#### **9.4 Identity Crisis and Its Transformation**

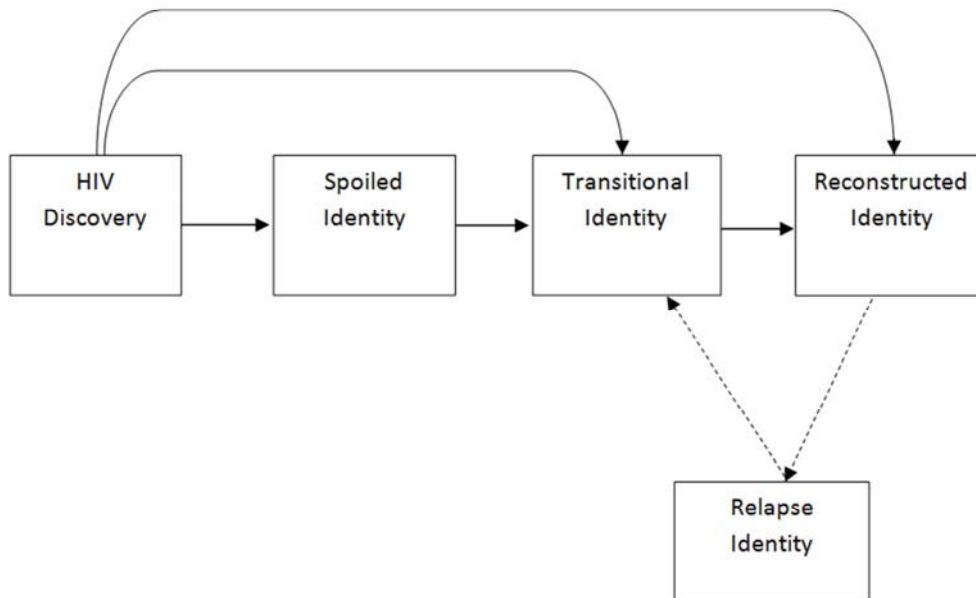
As mentioned in earlier chapters, participants often experienced identity crises at the time of HIV discovery and strived to manage their identity in accordance with their personal circumstances. Therefore, this proposed identity reconstruction model, based on data analyses in this chapter and the preceding chapters of this study, is schematised to look at the experiences of the participants as a life journey. They have experienced stigma and discrimination as well as the disruption of their human needs in varying degrees depending upon their access to resources. The varying degrees of stigma and discrimination denote different stages of identity after being HIV diagnosed, from

spoiled identity to reconstructed identity along with transitional identity. Therefore, the identity reconstruction model explains experiences of stigma and discrimination and their relation to different stages of identity based on access to resources, human capital (spousal or parental), and place of residence (either rural or urban) combined with the personal resilience inherent in the participants, especially in the females moving to cities. An attempt is made here to create an identity reconstruction model with a view to schematically provide an overview of experiences of participants. This model has the following propositions:

- 1) Interdependent collective economic force (accumulation of economic contribution of each member) generally works well in a family until anyone is expected to contribute at the same level as before being HIV positive;
- 2) Participants have experienced varying degrees of stigma and discrimination depending upon their available access to resources, human capital as economic supporters, their place of residence whether in urban or in rural areas, and personal resilience;
- 3) Participants residing in urban areas have greater access to resources, knowledge on HIV and AIDS with easier accessible to HIV treatment, health personnel, hospitals and the organizations working in the field of HIV than people living in rural areas; and
- 4) A family weighs present and future economic contributions to be made by someone living with HIV, including the burden of social stigma and discrimination to the family. This is parallel to Caldwell's theory of intergenerational wealth flows saying the expected number of children to be borne by parents depends upon the economic contribution to be made by their

children to the parents, especially in the context of developing countries (see Caldwell, 2001).

**Figure 2: The Reconstruction of Identity in PLHIV in Nepal**



**Source: Developed by Author**

After their discovery of HIV, as explained in Chapter Six, participants considered HIV as a life-threatening virus and a significant life event, thought of their health problems and the expected social stigma and discrimination. People who are identified as HIV positive through self-initiated HIV testing often accept their HIV status as they already expected having such HIV infection from their earlier background or their spouses' HIV history. People who are HIV diagnosed through other initiated and routine testing often do not accept their HIV status so easily. Whatever the reasons for testing their blood, discovery of HIV pushes them towards having stigma and discrimination in their lives and they are scared for their future situation both from a health perspective and their expectations of family and societal stigma and discrimination.

As expected after discovery of HIV, many participants experience family and social stigma and discrimination in varying degrees personally and socially. Personal background such as the level of understanding about HIV and AIDS, and availability of resources leads them to expect varying levels of social stigma and discrimination, including scarcity of livelihood. This is particularly evident in widows and single females without human capital living in rural areas. Reasons behind the family stigma and discrimination in people could include a lack of human capital, and gender differentials among other things. The main economic supporters in Nepalese society for women are their husbands.

In this study, many female participants have lost their husbands due to death because of AIDS, leaving the females with HIV status (Misa, Sushma, Buddha, Durga, Bishnu, Gita, Lila, Rita B, & Suku). Few females living with HIV who have been HIV infected through sexual contact with husbands, especially in the case of remarried females, have not been supported economically by their present husbands (Sarita B). The people who are stigmatised and discriminated against in their family are also stigmatised and discriminated in wider society as family members break confidentiality in regard to their HIV status (Gita & Lila). Consequently, they are major victims of family and social stigma and discrimination in the absence of human capital (as husbands are economic supporters) as explained in Chapter Seven. Indeed, the level of family and societal stigma and discrimination seems to be in parallel with Caldwell's theory of intergenerational wealth flows in which the parents' number of children depends upon the future economic contribution to be made by their children in the traditional economy, a high number of children; and in the modern economy, a low number of children because of higher expenses in their schooling in the context of developing

countries. Likewise, in this identity-reconstruction model, human capital and place of residence whether rural or urban, play important roles in determining whether high or low-level HIV stigma and discrimination is experienced from livelihood and economic perspectives. Social status (family profile in society) and knowledge of HIV and AIDS are also contributing factors.

The impact of family and social stigma and discrimination on participants affects their identity adversely. They tend to think they are less valued than any other HIV-negative people after experiencing stigmatisation and discrimination in their family and society. They feel their identity is badly spoiled as shown in Figure 2. This is the stage at which most participants thought their life had been adversely affected. This was more likely to be true for PLHIV in this study, especially for females living in rural areas with extremely limited access to recourses and without having human capital (spouse/parents). These people, especially females without husbands, experienced “doubled” stigma and discrimination because of their HIV and their inability to earn a livelihood (Gita, Sarita B, & Lila). There are many participants who felt their identity had diminished due to HIV, after their discovery of HIV.

I feel that HIV made me small in respect of others’ eyes. I got a worse life than others [HIV-negative people]. At the moment of talking, it comes into my mind that I am smaller than others. When I see other normal people [HIV-negative people] I tend to be jealous. When I speak to them, I always tend to bow as I am small. I feel sorry for myself mentally when I come across other people. It is because I have HIV.

– Sandeep, Male

Many participants enter into their transitional identity as shown in Figure 2 through vigorous efforts in managing the stigma and discrimination prevalent in their family and society in various ways depending upon their personal backgrounds. Their personal background is associated with their access to resources, their resilience, human capital, and place of residence, whether rural or urban. Their ways of managing stigma and discrimination differ in accordance with their access to availability of resources. In this study, all women without husbands as economic supporters migrated to urban areas. Their reasons for doing so were protecting themselves from family and social stigma and discrimination prevalent at their place of origin and to manage their own livelihoods. They also did not disclose their HIV status at their new location except within their own circle of friends living with HIV and health personnel and the people working in the field of HIV. As a result, they gradually started to gain feelings of security from those family and social issues to a greater extent at both their place of origin and their new location. With more contacts with organizations working in the field of HIV, the people, especially the women, started disclosing their HIV status publicly so that they could benefit from the collective strength in resisting social stigma and discrimination from other PLHIV as well as from people working in the field of HIV. Similarly, the participants with moderate and better access to resources, especially males, started managing their social stigma and discrimination by not disclosing their HIV status, especially outside their home. In their cases, their family members cooperated with them in managing social stigma and discrimination by not disclosing their HIV status anywhere. For example, Sabina, living in a rural area with her husband, and mother- and father-in-law, shared her experience on how she attempted to manage social stigma and discrimination with the support of family members:



I have not felt any difficult situation so far. I was told to start ARV while staying in a care home but I remained at home and took this. Though it was easy for me to stay in a care home for instruction and everything I did not go anywhere else because there was a fear of villagers if they knew. This was in 2064 *BS* (2007) when I began ARV and my CD4 was also low.

– Sabina, Female

Furthermore, participants, especially females with limited access to resources after moving locations simultaneously turned to manage family stigma and discrimination created as a result of their lack of livelihood in the absence of economic supporters. For this, they enquired about possible employment working with some organizations at their new place of residence. Whatever work they found available to them, they did. They have also moved from one organization to another for their livelihood based on the information provided by their own circle of friends living with HIV and previous organizations where they spent their time after HIV diagnosis (Sarita A, Sarita B, & Gita). Some people with moderate access to resources struggled, but became economically independent by doing well enough in their own business or agriculture activities so that they did not need to ask for money with others. This way of becoming economically independent was, for them, a means of lessening stigma and discrimination because of HIV as well as for income purposes. Some people, especially females with moderate access to resources, also started looking for, and finding, jobs under various organizations working in the field of HIV.

Many participants felt their identity has been reconstructed following varying degrees of personal effort in managing stigma and discrimination as well as in their management of

livelihood in accordance with their access to resources. In this study, some participants never faced stigma and discrimination in their lives because of their HIV status in their family and society (Sabina, Suku, Rana, & Jwala). The reasons for this include a high family profile, taking precautions about expected HIV stigma and discrimination by giving information of their HIV diagnosis to family members prior to their partner's death from AIDS, sex at premature age before marriage, and their spirituality (in the participants with moderate and better access to resources). As discussed earlier, all females with limited access to resources managed their stigma and discrimination through migration from their place of origin, and they often did not disclose their status at their new location except with their immediate friends living with HIV and health personnel. Later on, some of these participants have disclosed their HIV status publicly (Lila, Misa, Santosh, & Suku). Moreover, migrant females became economically independent through employment at their new location, which also lowered their stigma and discrimination even at their place of origin. They felt their identity was improved with an increase in their socio-economic status through HIV treatment, informal education, leadership training and employment.

In the past, people just show pity to me as an HIV positive person and said “what a pity!” but now they say that I am a courageous and hard-working individual. All people praise me now. My youngest uncle said, “Misa is not our daughter, she is our son, she has progressed a lot.” I heard it from other people but he has not said to my face. He treats me well and praises me. I am very happy.

– Misa, Female

For some of the participants, this study found that they felt their identity had been improved in better ways than ever before. They considered HIV as a catalyst that

changed their lives remarkably as they obtained liberty from home when they were ostracised due to HIV (Lila, Pratima, Buddha, & Rita A). They made their networks very strong by including all new members with HIV in one union, as an extended family, that could work not only in resisting stigma and discrimination but also for other opportunities in managing livelihoods, including gaining informal education and other necessary skills.

With their independence and reconstruction of their identity, participants, especially females, start reuniting with their close family members who had rejected them because of their HIV status. In this study, it is notable that family members who rejected the HIV-positive family members living with them are now trying to reunite with the rejected family members after HIV diagnosis now that they have created a better identity for themselves after a long struggle. Some participants expressed their feelings, both physically and emotionally, to reunite with their family members after achieving a better quality of life (Durga, Misa, Lila, & Pratima). Some of the examples from my study are more relevant in this reunion context. Durga, who was badly treated at home because of her HIV, and who then moved to Pokhara city, shared her experiences of physical family reunion after becoming economically independent through working at an organization related to HIV as explained in an earlier section of this chapter. Some participants working in urban areas felt they have been able to reconstruct their identity by obtaining successful medical treatment, finding an economically independent life, and living with access to urban amenities (Rita A, Suku, Pratima, Rita B, Buddha, & Sarita A). Some participants in rural areas have also felt they have been successful in finding good HIV treatment with the support mechanisms of NGOs and a good network of PLHIV (Rana & Min).

Few participants also experienced a relapse in identity when HIV stigma and discrimination lead to a decrease in their economic wellbeing due to lack of a job, even after experiencing feelings of improved identity. Indeed, identity is a combination of all factors, management of stigma and discrimination, livelihood, as well as exposure to the outside world with leadership and speaking skills. They did not feel their identity was maintained if one or more of the necessary factors were missing in their lives. They generally compared their present lives with their past lives of reconstructed identity and find themselves with a lower status than previously if they were missing a factor(s). That is why there may be a relapse of identity as shown in Figure 2 and the association between reconstructed identity, transitional identity and relapse identity appears to be non-linear. This identity may not go back to the spoiled identity stage as participants have already gained knowledge and experience in regard to HIV and they never feel as they felt before (at the time of HIV discovery) from a health perspective (Courtenay, Merriam, & Reeves, 1998). However, they felt afraid that, if something bad happens, their identity may revert to a relapsed identity, remembering what they felt in the past. The arrow between reconstructed and relapse identity shows the possibility of going down to the relapse identity without a purpose, and that is why the arrow line is different from others. Thereafter, the people moves into transitional identity, seeking things in their lives as needed.

I worked in an office of [an] organization where street children are cared for. When I had that job I did not feel negative as much. All things were going well. Street children used to call me “brother, brother”. I also used to put on neat and clean clothes. At that moment, I did not feel lower in my dignity in comparison to others [HIV-negative people]. Everyone in the

office used to love and to respect me. I was also paid for caring for the street children. Staff brothers loved me very well. I felt really well.

– Sandeep, Male

## **9.5 Conclusion**

With management of stigma and discrimination, improvement of health and positive socio-economic changes, many participants, especially women, have moved to a reconstructed identity from their transitional and spoiled identities. Those people with limited access to resources significantly improved their lives through migration as they became successful in creating an accumulated strength as a network of their own circle that helped them in managing stigma and discrimination. Likewise, they found their own health status improved significantly and they seemed to be the same as other HIV-negative people in physical appearance after HIV treatment. As mentioned above, some participants with moderate and better access to resources had already entered into a reconstructed identity, most importantly with personal efforts and family supports by improving their health status. They also developed an improved socio-economic status more significantly than previously in their lives even before HIV diagnosis. All these factors improved their identity significantly in some cases, much better than ever before. Likewise, with management of stigma and discrimination and improvement of health status, some other participants, both males and females, with moderate access to resources have moved to a reconstructed identity from their transitional identity either through migration or working the same job as in their homeland. As is shown in the reconstruction identity model, the state of participants' identity is fluid. Their identity alters with changing family and the social issues of stigma and discrimination, and with their changing socio-economic status. In this study, personal resilience, medical

treatment and support mechanisms are shown to be very important in moving the identity of participants from spoiled identity to other progressive stages of their identities.



## **Chapter Ten: Discussion and Conclusion**

The purpose of this chapter is to consider findings of this study in the context of the existing theoretical literature, to explore the implication of the proposed model, and to suggest pathways for next steps. This chapter deals with key research findings and discusses these, policy implications, and recommendations for future research. The key research findings of this study are discussed in the way participants experience their various identities, namely, spoiled, transitional, reconstructed, and relapsed. The leading factors shaping these various identities include family and social issues such as the nature of HIV stigma, discrimination and disruption of human needs whether from family, societal or institutional perspectives. The family and social issues also depend upon the existing contextual backgrounds of participants. These contextual backgrounds include human capital and place of residence, whether rural or urban. These backgrounds often determine the varying degrees of stigma, discrimination and disruption experienced. In turn, the varying degrees of stigma, discrimination and disruption affect the identity of participants, in differing ways, mostly in accordance with their access to resources.

### **10.1 Key Research Findings**

The key findings of this study relate to identity crisis and identity development as well as the underlying factors shaping the identities of participants. The identities of participants can be categorised as spoiled, transitional and reconstructed. The key research findings of this chapter are divided into two main stages: spoiled identity and identity reconstruction. The spoiled identity is a result of contextual factors, especially the lack of social and economic support and whether the person's place of residence is



rural or urban. Concurrently, participants start reconstructing their identity based on their personal resilience, outreach in their community, their dealings with people through organizations and the availability of access to resources.

### **10.1.1 Spoiled Identity**

This section considers how participants reacted to their HIV status after an HIV diagnosis and how they were treated negatively at home and in society as well as in various institutions while dealing with their HIV issues. Discovery of HIV divides the lives of participants into two parts: life before and after the HIV diagnosis. The discovery of HIV causes most people to feel a form of identity crisis when comparing their previous HIV-negative status as well as comparing themselves with other HIV-negative people. At the beginning point of HIV discovery, most participants considered HIV as a life sentence, especially those participants who were HIV diagnosed a long time ago. Similarly, family members and non-family individuals, including health personnel, also considered HIV as a life sentence, when they came aware of someone's HIV status in earlier times. On the contrary, people who have been HIV diagnosed in recent years do not generally seem to consider HIV as a life sentence from health perspectives.

Participants generally experienced their identity crisis because of a change in perspective towards HIV and associated health problems irrespective of access to resources. In the beginning, those participants who spent a long time living with HIV (around 15 years) experienced a serious identity crisis because of their physical appearance. In those days, they had less knowledge of HIV available. They lost hope and some participants were identified as living with HIV because of their appearance

due to the unavailability of HIV treatment. These health problems increased the severity of their identity crises by lowering their self-confidence, not only within themselves but also their status in the eyes of other people. At that time, HIV treatment was not as easily available as it is today. In the Nepalese context, one of the factors determining someone's identity depends upon their physical appearance. Consequently, participants found themselves suffering this kind of identity crisis.

Participants, especially widows and those women separated and divorced due to HIV, experienced heavy stigma and discrimination in their families as a result of their HIV status. In this study, almost all women participants were infected with HIV through sexual contacts with their husbands. Many women living with HIV were living alone due to their husband's death from AIDS. Some females had been divorced and separated from their second HIV-negative husbands due to contracting HIV as a result of their first husband's sexual contacts and HIV transmission. In Nepalese society, widows and females separated and divorced from husbands are generally considered to have a low profile from family and social security perspectives. Therefore, these women feel their identity is adversely affected.

Furthermore, widows and women separated and divorced faced economic stigma, discrimination and disruption as well as negative effects on their identity. As mentioned in Chapter Seven, they were ostracised, resulting in not being given enough food to eat, being addressed as *Phohori* (Yucky), and having their clothes cast outside their homes. They also faced further identity crises associated with economic stigma, discrimination, and disruption. In Nepalese society, evidence exists that husbands are considered to be strong economic supporters for their wives and their family. In the absence of husbands,

many widows, including women separated and divorced, were economically stigmatised, ostracised and discriminated against in their homes. Consequently, the female participants heavily experienced a spoiled identity due to the absence of economic support from their husbands in the family, and their economic dependency upon other family members.

Almost all the participants, irrespective of access to resources, had experienced spoiled identity from a societal perspective. Almost all participants, after being HIV diagnosed in the initial stages, were heavily stigmatised by people living in their society. People in the society discriminated against the participants, by keeping their distance if they know someone has contracted HIV. Some female participants shared their experiences, saying that people did not come to their home to greet them while they were ill, especially once villagers came to know that someone was HIV diagnosed. The immediate neighbours would come up only to the garden to say hello instead of coming inside their home. They also warned participants against walking near their homes. Findings from this study suggest that participants, especially females, faced both family and societal stigma, discrimination and disruption of human needs in their lives. In contrast, participants, especially males, with moderate and better access to resources shared their experiences of stigma readily, especially at the time of their HIV diagnosis. Women, however, seem to be terribly anxious about knowledge of their HIV status being known in society. Some of them have not met distant relatives since their HIV diagnosis even on festival days; as well, they experienced discrimination due to their HIV.

Many participants, especially females, experienced institutional stigma, discrimination and disruption of human needs. Even government institutions like hospitals, schools,

police offices, and the institutions dealing with emigration mistreated them in various discriminatory forms. For example, health personnel at hospitals discriminated against them by delaying treatment and transferring HIV cases to other hospitals, including using derogatory language. Some participants were also sacked from their job when employers came to know that their employees were HIV positive. Police personnel, generally known for providing security to each individual also treated participants badly while in police custody. Due to their HIV status, they were not given the chance to take HIV medicine for many days while being held in custody. Likewise, participants' children did not have the opportunity to attend school alongside children of HIV-negative people. All this discrimination and disruption including self-stigma, being made to feel unsafe, due to their association with HIV caused their identity crisis to adversely affect their lives.

#### **10.1.2 Identity Reconstruction**

In contrast to the negative aspects of life as mentioned above, there were also many positive aspects of life for participants despite facing stigma and discrimination. Participants, irrespective of access to resources, redefined their life purpose in terms of how they would live with HIV after it had been discovered. This section deals with the present research findings on how participants entered into a transitional identity and some of them reconstructed their identity, consoling themselves by finding meaning in their lives despite their circumstances. Furthermore, they focused on the health, social and economic aspects of their lives and these enabled them to gradually reconstruct their identity.

Participants, irrespective of their access to resources, started reconstructing their identity by consoling themselves, giving explanations for being HIV infected relating to their previous circumstances. Most female participants consoled themselves that being HIV infected was due to sexual contacts with their HIV infected husbands and that was not their fault. There was no way of escaping from HIV in view of their husbands' sexual behaviour. A few female participants attributed their HIV infection to fate, including the influence of bad deeds committed by previous generations of their husbands' family members. Likewise, most male participants after HIV diagnosis started reconstructing their identity by thinking of the reasons for their HIV infection: the influence of friends and sex while being of an immature age. Some male participants rationalized to themselves that they did not have sex in the red light areas, in brothels or commercial sex places. Some other male participants attributed their behaviour to the influence of friends, too much alcohol and to sharing needles. A few participants considered that there was no indication of possible HIV infection, as the females with whom they had sex seemed to be healthy and very beautiful. Thus, they started reconstructing their identity making meaning of the life situations that had led to their being HIV infected.

With the discovery of HIV, participants had an opportunity to learn about HIV and AIDS increasing their knowledge as well as finding comfort reconstructing their identity from health perspectives. As a result they could take precautionary measures to protect themselves from HIV, i.e., checking up levels of CD4, seeing the importance of ARV if needed, and importance of balanced food in managing the effects of HIV on their health. Indeed, discovery of HIV provided the people with opportunities to seek HIV treatment and to create better identities from health perspectives. The relationship and understanding of HIV and AIDS, and their knowledge, physical health and better

appearance are positively interrelated in the reconstruction of anyone's identity. The better HIV and AIDS knowledge made participants mentally at peace in a chaotic environment where HIV was once considered to be a death sentence. After seeking and receiving HIV treatment at hospital, participants seemed to be in better physical health and appearance. One might assume that this might cause HIV-negative people to think that PLHIV are similar to them. With better HIV treatment, the participants looked more physically fit and able to socialise with HIV-negative people and feel more self-respect. Better physical health and appearance reduces HIV stigma and discrimination. This means the effect of physical appearance on identity associated with HIV is reduced. Thus, better physical health and appearance in participants is very important in Nepalese society where the identity of a person is partially determined by reading his/her facial appearance.

Good health was also associated with economic independence. This helped participants as they are considered fit to work for their daily livelihood. They can grasp economic opportunities by working in organizations or somewhere else based on their skill and educational attainment. They do not have to rely on anyone else for their livelihood. Being economically independent raises people's self-image. Many participants have been doing physical work for years, after HIV treatment, and did as much as they did before their diagnosis, and did as much as HIV-negative people can do. Some of participants are also working official jobs in many organizations working in the field of HIV. Reportedly, their identity is not considered to be different from HIV-negative people working in the same place. As a researcher, I have observed that participants are in key positions in various organizations and HIV-negative people are working there under the leadership of the participants.

This research also suggests that there are alternative ways of living in a new and changing situation if the old way of living does not work. Such alternative ways involve an identity reconstruction within participants. This can be illustrated with examples of the participants, especially with widows, and females separated and divorced from their husband after their HIV diagnosis. There was a new situation filled with stigma, discrimination, and disruption in their families and societies with the discovery of HIV status. The participants chose a new strategy as an alternative way of life to cope with the new situation of being away from their family and society, even not getting family support in their lives. The alternative way of life was to leave their home, following a new aspiration of living in an urban area, a strange location where they did not have to inform anyone about their HIV-positive status. Thus, they followed migration strategies and started living in urban areas.

This migration strategy provided them the opportunity of not only liberating themselves from their family members, it also provided them with a chance to seek opportunities, and to seek HIV treatment. For participants this largely involved a network of extended family members living with HIV (participants living in new locations) and feelings of new and extended collective strength. The new collective strength made it more possible for them to manage their HIV stigma and associated discrimination. In addition, the migrant females strived to gain education and leadership training in their lives through organizations working in the field of HIV. They used their knowledge in working through organizations, even going to other rural areas after finding their jobs. Thus, they found themselves making their own identity, better socially and economically, after finding jobs.

This study has found that PLHIV convert their social networks of people (social capital) to economic capital. This process was especially obvious in multiply marginalised persons including single women. Using social networks research participants, especially marginalised women, gained educational and HIV knowledge, leadership training about family and social stigma and discrimination, and awareness of organizational advocacy for human rights. Social networks not only reduced HIV stigma and discrimination, but these social networks have also become pillars of their economic prosperity after they became more physically fit following HIV treatment. They have feelings of radical economic positive changes as a result of becoming economically independent in society. Participants reported having become more socially and economically independent; although this depends upon the amount of working opportunities available and their personal attributes. This, they said, has made them self-reliant and they have gained respect from other people living in their surroundings irrespective of their HIV status, which is a prerequisite for identity reconstruction.

Participants, especially females, have been reunited in family and society, especially after regaining economic independence. After gaining a job in a new place they became economically independent. The participants turned into productive people in the eyes of their family and society. Consequently, the relationship between HIV-negative family members and family members living with HIV created a conducive environment for reuniting with their families. Thus, better economic conditions often reunite the family and the community even after out-migration. Eventually, some participants have come to live in a new way through their personal efforts, and public and effective organizational support mechanisms. This is really the re-imagined society for which people aim to gain in their lives.



This research demonstrates that participants, especially females with sparse resources, are not always in the same poor economic position or even lower after diagnosis (Myrdal, 1957; World Bank, 2001). With migration to cities, they were involved in attending informal education and leadership training especially in the field of HIV in areas such as resisting HIV social stigma and discrimination. The social factors mostly comprise social awareness, of a sense of equal rights with other people living in their surroundings irrespective of class, gender and caste. They have benefitted by informal education, health and HIV knowledge, to some extent, through support mechanism after the radical political changes reducing feudalism in Nepal. Gradually, they found jobs based on their basic skills (education, working skills) either through support of organizations or through public support. The main back-forces in economic independence for marginalised people are generally the social factors that help them to become economically independent. Consequently, they achieve economic independence from unpaid jobs at their place of origin to paid jobs in their new locations. Thus, economic independence enhanced their identity further.

This study further explored positive aspects of collectivism and individualism with respect to identity reconstruction, giving priority to a group of family members rather than self, and individualism; giving a priority to self rather than the rest of his/her family members, to some extent. The participants, especially females, have expressed both types of experiences, collectivism before being HIV diagnosed and individualism after HIV diagnosis. Before their diagnosis, they sacrificed their lives working in the family as an economic support even not going to school while young. After being HIV diagnosed, along with facing family and social stigma and discrimination, they experienced a more supportive environment for reconstructing their identity in

individualism rather than in the family collectivism's norms and values. They had to stand on their own feet without having even basic education or family support. When they moved to cities and entered into a job through an organization, they felt that lack of education was a bigger issue than HIV. After they started gaining education informally with the help of organizations, they felt their identity improved, both socially and economically. When they started looking after themselves, they really felt some advantages of individualism. They felt they had greatly benefitted from individual norms and values that were provided by being HIV diagnosed. Individualism is most important to improving self-esteem from an individual development perspective, such as education, a job, and income. In general, individualism and extended collectivism, a group spirit, for participants, are more supportive factors in reconstructing identity than family collectivism after being found to be HIV positive, especially for those people with less access to resources.

Some participants expressed feelings of identity reduction from having experiencing reconstructed identity. Likewise, other participants are expecting to face identity crises in the future if all things in their lives do not go as well as expected. As suggested in the findings of this study, income is one of the most important factors in shaping anyone's identity. After termination of a contract job from organizations, some participants expressed that they felt their identity had relapsed losing their job and income. They felt their identity was reconstructed once they were working in a job and earning money. Everything seemed positive in their office and home. After termination of their job, family members now nagged them about their weak financial matters. Similarly, some other participants, especially females, expect to have an identity crisis, such as being ostracised by their daughters-in-law after their sons' marriage because of HIV status.

There is also the likelihood of job problems in their organizations if international organizations do not continue to provide funds and if the government does not start providing funds in a better way to improve the identity of participants. These things occupy their minds about possible identity crises in the future if everything does not go as expected. However, it is not expected that their identity will return to a spoiled identity stage because they have already gained HIV knowledge (Courtenay et al., 2000). Nevertheless, their identity seems to be fluid.

## **10.2 Discussion**

Going back through findings of this study, participants, especially females who migrated to cities, have reconstructed their identity spectacularly, even better than before their HIV positive status became known, despite facing several challenges over family and social stigma and discrimination. Therefore, this section aims at discussing and interlinking the findings of this study to how it could be possible for participants to gain wonderful experiences, especially with the changing socio-political contexts of the country. Furthermore, it articulates some aspects of identity crisis and identity reconstruction as well as the processes of moving forward to progressive identities.

There are complex phenomena involving contextual factors that shape identity crisis and identity reconstruction in Nepalese PLHIV. These are discussed in Chapter Two. However, there are some different contextual factors that are pertinent to identity crises and others that are more pertinent to identity reconstruction. Again, some contextual factors play a role in both forming identity crisis and identity reconstruction. Nepal's geo-physical contextual factors such as being a small country, and having relatively little fertile flat land for agriculture are pertinent when it comes to finding alternative

sources of income for Nepalese people, especially for the people living in the rural parts of Nepal. More importantly, an increasing population size in the country over the last few decades, irrespective of the tempo of population growth rates, has made people think of alternative sources of income. In this respect, an increasing trend for modern communication and transportation has made it easier for them to find information about prospective destinations. Overall, the country's contextual factors reinforce people's movements both inside and outside the country.

Therefore, there are a series of linkages within a crisis of identity, these range from being HIV positive to seeking good economic earnings to involvement in HIV-transmission activities. In Nepal, the single, male movement to other countries as well as to urban areas inside Nepal creates family fragmentation. As a result, migrants have an environment conducive to engaging in sexual activities with multiple partners irrespective of their HIV status, even PLHIV (New Era, 2009). The result is the spread of infection, as many wives were HIV infected by their husbands' sexual contact when their husbands returned home (Aryal et al., 2011). Similarly, some participants with drug-use backgrounds were HIV infected due to needle sharing. The reasons behind drug users becoming HIV positive could be a lack of knowledge of sterilizing needles, peer influence, personal curiosity, and parental issues (i.e., less time allocation for their children while studying at school), as was suggested by study participants. Whatever the reasons for being HIV infected in their lives, their contextual factors also played important roles in being HIV positive. Eventually, the discovery of HIV, irrespective of the mode of HIV transmission, affected the participants' identity to various degrees, depending upon their access to resources.

However, democratization and development processes, together with socio-cultural transformations have been gradually moving ahead in Nepal, creating a conducive environment for reconstructing the identities of participants, especially over the last few years. Each political movement since 1951 gradually freed the country more from the despotic *Rana* rule and the autocratic *Panchayat* system, moving forward to a multiparty democracy within a republican country. Consequently, the different historical movements enabled people to assert their rights more efficiently politically than ever before. Importantly, different political parties in the country strove to work in favour of marginalised groups of people, with a view to bringing them into the mainstream of development activities associated with political changes in the country. In this sense, people working with marginalised communities started giving them priority on the basis of equity rather than equality, so that deprived groups of people have had a chance of empowering themselves efficiently. There are several organizations established to work with participants in the country through which they can take advantage of HIV treatment, counselling on HIV and AIDS, and informal education as well as PPTCT services as required. It is notable that political changes and development activities have made them feel protected, with government and non-government organizations working in the field of HIV having made it easy for them to reconstruct their identity in better ways than ever before.

Importantly, treatment and counselling on HIV and AIDS are being made more available through each development activity such as education, finance, agriculture, forestry providing information through hanging pamphlets on their office noticeboards. This information has not only made people more aware of HIV and AIDS, but also encouraged them to seek information, HIV treatment and counselling in hospitals and in

organizations as needed. As discussed in Chapter Two, Nepal has focused on a family planning programme since the late 1950s with a view to limiting birth rates in the country. After the discovery of HIV, the country started supporting HIV and AIDS programmes, and there has been a gradual expansion in their services. The service providers, hospitals and organizations working in the field of HIV strengthened their services to their clients (PLHIV), updating their services in accordance with global innovations such as ARV, and PPTCT. As discussed above, PLHIV have experienced a more conducive environment for utilising these services in recent years compared with the past, within changing political and social environments. Importantly, the changing environment made them aware of their rights alongside other people in the country. These democratization and development processes, as well as socio-cultural transformation, have assisted them in reconstructing their identity by gaining HIV and AIDS knowledge, HIV treatment, as well as becoming economically and socially independent as discussed in Chapter Eight. Consequently, all these attempts to reconstruct their identity have been very helpful to many participants as discussed in Chapter Nine. Indeed, PLHIV are in different stages, some are at the spoiled identity point, some at transitional identity and some others at reconstructed identity stages.

As discussed in Chapter Three (see Figure 1) on the identity reconstruction of PLHIV, a range of contextual factors, such as personal factors, family background, support of communities and societies, support of the government health care system and support of organizations, influence each of the three stages of identity reconstruction. Consistent with the literature (Parker et al., 2002; Whitehead, 2006; Baumgartner, 2007; Tsarenko & Polonsky, 2011; Hendriksen et al., 2011), the findings of this study demonstrate that the contextual factors are interlinked in various ways in the lives of

PLHIV. These contextual factors generally determine the degree of HIV stigma and discrimination that are experienced in each of the stages of identity reconstruction as briefly discussed below:

Contextual factors such as personal factors, including gender, family background, societal factors, and support of organisations interlink with each other in a way that influences the degree of HIV stigma and discrimination. In this study, most male participants, irrespective of whether they reside in rural or urban areas, have not reported experiences of being discriminated against in their families and societies. This is possibly because of their assigned dominant gender role which is a socially constructed phenomenon in Nepalese societies (Uprety & Adhikari, 2009; Yami, 2007). Most male participants interviewed seemed to be economically independent, whether they originated in urban or rural areas. Although they were HIV infected because of their unsafe sexual behaviour or sharing unsterilized syringes, they were not discriminated against within their family. Their families tend to be keenly supportive, with females supporting their husbands, in the case of married male participants, and parents supporting unmarried male participants. In this study, wives were very supportive as their husbands underwent HIV treatment, and were happy to hide their husband's HIV status (this information came from male interviewees). Discussing various forms of organizational support, such as HIV counselling and treatment, those participants who had family supports, and a good support network of organizations in HIV treatment and counselling, were able to get HIV information quickly when needed. Family members, who accompanied PLHIV to hospitals, were also provided with information that made them aware of how to better care for, and help, persons living with HIV in their homes. Thus, personal, family background or family relationship,

societal factors (including socially assigned roles of the male gender, and those who are economically independent), and the support of organisations are inter-related in shaping stigma and discrimination and the identity status of male participants. In this study, male participants have often moved to a reconstructed identity, managing their stigma and discrimination without passing through spoiled identity as shown in Figure 1.

Likewise, there are also contextual factors supporting women living with HIV in a very positive way. For example, one personal factor is a woman's ability to explain her situation to her extended family. If she can explain that she is not responsible for being HIV positive because she was infected by her husband, this is very significant in determining the degree of HIV stigma and discrimination. In this context, women participants who are able to convince their joint and extended families have not faced HIV stigma and discrimination, irrespective of their place of residence, whether rural or urban. Family background is very important in determining HIV stigma and discrimination because female participants who originated even from rural areas whose family members were exposed to the outside world (e.g. India, United Kingdom) and worked as social workers in their villages were not stigmatised and discriminated against in their families. Likewise, those female participants brought up in urban areas whose family members were well informed about HIV, did not face such issues of HIV stigma and discrimination. In Nepalese society, people who are treated well in the family are often treated well in their communities and societies. As with the male participants as explained above, these female participants have received information on HIV and AIDS from organizations and hospitals; and their family members have supported them empathetically for HIV treatment and counselling. Many male participants and some female participants have been able to reconstruct their identity



with support of social networks. In this study, many males and some females were able to progress fairly quickly to a reconstructed identity, not needing to pass through lengthy stages of spoiled identity and transitional identity. Some other male participants and female participants followed other strategies, such as achieving economic independence and hiding their HIV status from their families and societies, in addition to HIV treatment and counselling, as they moved to a reconstructed identity through a transitional identity stage.

In contrast, there are other contextual factors that have pushed many female participants into a spoiled identity stage, facing HIV stigma and discrimination, especially those participants who are widows, and women separated and divorced from their husbands (Family Health International, 2004; National Centre for AIDS and STD Control, 2010). In this study, most female participants who were brought up in rural areas were highly vulnerable to HIV stigma and discrimination. They had to rely on themselves, economically and socially, in the absence of their husbands. They are perceived to have the main economic and social responsibilities for rearing, caring for, and schooling their children, though additional supports are expected and provided for a while from their extended families, neighbours and communities. Furthermore, younger aged widows are perceived to be cursed from their previous life's bad karma. Likewise, those women who are separated and divorced from their husband are perceived to be unable to please their husband and such women have a low profile economically and socially in Nepalese societies (Yami, 2007). Consequently, widowed, separated and divorced women with a low caste family and social profile were heavily ostracised, stigmatised and discriminated, as discussed in Chapter Seven. They experienced an adverse effect on their identities. Nevertheless, such female participants were able to move to a

reconstructed by adopting various strategies such as rural-urban migration, following HIV treatment and counselling after coming in contact with organizations working in the field of HIV and AIDS. Some of these participants managed their stigma and discrimination, and reconstructed their identities very effectively, as demonstrated in the conceptual framework.

The findings of this study are expected to have great implications for reconstructing the identity of PLHIV inside and outside Nepal. This study suggests that there are three major factors that reduce the likelihood of PLHIV being stigmatised and discriminated against in family and society: the individual's personal ability, their family background, and their social network. With regard to an individual's personal ability, a person living with HIV, who is literate and is able to convince his/her family members (often extended family) about the reasons for their HIV positive status, as illustrated earlier with some female participants, is less likely to be stigmatised and discriminated against in family and society. This suggests that each individual needs to be literate and aware of HIV and AIDS knowledge. Likewise with family background, extended family members who are exposed to HIV and AIDS knowledge, irrespective of whether they live in rural or urban areas, are very supportive in managing stigma and discrimination. Each family, whether nuclear or extended family, needs to be aware of HIV and AIDS knowledge, in order to lessen HIV stigma and discrimination in persons living with HIV in their family. Furthermore, this study suggests that PLHIV, especially widows, and separated and divorced women, who experienced their identity being adversely affected due to stigma and discrimination in family and society, could circumvent their issues with the support of their circle of PLHIV, and their social network of organizations. These women were able to reconstruct their identity in an unprecedented

way after converting their social capital into cultural capital and the cultural capital into economic capital. This provides very important lessons in working with PLHIV, who are experiencing heavy stigma and discrimination in their families and societies inside Nepal, and also outside the country, especially in developing countries with similar socio-economic settings.

### **10.3 Limitations of the Study**

There are a few apparent limitations in this study, especially relating to participant recruitment as well as in theoretical perspectives. In the beginning, the researcher aimed to collect data from PLHIV irrespective of the proportion of males, females and third gender people, because HIV is a sensitive issue in Nepal, as mentioned in Chapter Four. Fortunately, there is about the same proportion of males and females; however, there is not anyone from the third gender PLHIV in this study, so the richness of that perspective is missing. Moreover, field work was accomplished through organizations working in the field of HIV. This process has ignored identifying and recruiting PLHIV who are not in contact with any organization. Their experiences may have differed from those of the participants whose experiences have been studied through the organizations. In addition, this study is based on urban areas of Nepal, Kathmandu Valley, and Pokhara Valley and its peripheral locations. Thus it may not characterise the experience of PLHIV living in rural areas, although there are assumed to be rural characteristics from in-migrant participants in the valleys, to some extent. This research project aimed to explore and describe the experiences of PLHIV in Nepal, and while it has proposed key features of a theory of the reconstruction of identity in people living with HIV, it has not explored specific aspects of such a theory in depth. These aspects provide pathways for future research.

#### **10.4 Contributions of the Study**

This study contributes to methodological strength in the Nepalese literature, especially in the study of HIV. It has addressed research objectives and research questions with regard to the experiences of participants of their spoiled identity and identity reconstruction using a qualitative research methodology. Earlier studies undertaken in the field of HIV were often based on the epidemiological and medical aspects of HIV, especially in the context of Nepal. This HIV research, however, was carried out on the basis of a meaning-making process, a relativist epistemological perspective rather than the positivist approach dealing with epidemiological facts. In this study, an attempt has been made to study the data through thematic analysis with the given texts. There is little research on HIV using thematic analysis, especially in the field of the identity of Nepalese PLHIV. This study is proposed to be a pioneering work in the discipline of HIV, especially with regard to different stages of identity studied from methodological and analytical perspectives.

Once again, going through the findings of this study mentioned above, this research contributes to HIV literature in demonstrating that economic stigma and discrimination in a family is often stronger than social stigma and discrimination due to HIV. The economic stigma and discrimination often causes detachment between a family member living with HIV and the remaining family members who are HIV negative, for example, in the case of women without human capital in the form of economic supporters such as husbands. This link between economic independence and family acceptance is further reinforced by the observation that women living with HIV have been reunited with their family and society after becoming economically independent, together with being socially empowered (gaining education, HIV knowledge, and finding a job). Therefore,

this research claims that there is strong evidence of economic stigma and discrimination in many families when considering cases of those women living with HIV with less access to resources. Economic factors such as economic supporters, husbands and parents, are major contributing factors in alleviating economic stigma and discrimination for many participants with moderate and better access to resources. Thus, this research suggests that economic factors are instrumental in overcoming social stigma and discrimination in family and society, adding to knowledge from earlier studies undertaken in the HIV field. Indeed, this study has answered the research queries, especially with regard to the roots of stigma and discrimination in the Nepalese context.

This research proposes a model entitled “the reconstruction of identity in PLHIV in Nepal” based on the data derived from two urban research sites, Kathmandu and Pokhara valleys. Although this research was carried out in urban areas, half of the total participants were from rural areas, having migrated to cities, mostly because of HIV stigma and discrimination. In this sense, this research and the proposed model of identity reconstruction includes both urban characteristics of PLHIV, and also rural to some extent. In this proposed reconstruction of identity model, there are various stages of identity from spoiled to reconstructed and to relapse identities. In comparing this proposed reconstruction model with Goffman’s stigma theory as discussed in the literature review, we find that this identity model goes far beyond Goffman’s stigma theory, which does not explain the processes of identity reconstruction. Moreover, this proposed model supports a model of the HIV and AIDS identity incorporation process and identity transformation (Baumgartner, 2007; Tewksbury & McGaughey, 1998). This model is based on the economic and social empowerment of people and reduction

in stigma and discrimination, together with identity transformation from one stage to another as previously discussed. This new model may be valuable for academicians and people working in the field of HIV, including the Ministry of Health, for better planning and policy making.

For people working in the field of HIV, including academics and others, this research also demonstrates an exciting optimistic view, that HIV has often been a catalyst for good, especially for people marginalised by gender, caste, and class, as well as those who are widowed, separated or divorced. It shows considerable progress in the field of HIV treatment in Kathmandu and Pokhara valleys, and lessons from this could be applied in other similar urban settings of Nepal. At the same time, there could be debate over the findings of this study, especially from the point of view of people who are still concerned with the stigma and discrimination associated with HIV. Nevertheless, it is expected to have positive outcomes as discussions are entered into over the progress made in the field of HIV as found in this study. Personal factors such as the resilience inherent in the marginalised women, who have left their home, were instrumental in achieving positive changes in their lives as they integrated themselves with the network of other PLHIV. In addition, the recent socio-political changes in Nepal seem to have fuelled their efforts to achieve positive changes in their lives. Thus, this study points out that the collective efforts of individuals, together with their various supports from people working in helping organizations, as well as the country's conducive contextual background, can really improve the wellbeing of marginalised people, even those in extreme difficulties such as PLHIV. This optimistic view could have further applications to those people who are badly treated in their societies because of gender, caste, class, and widowhood status.

## **10.5 Policy Implications**

As we saw in Chapter Two, the government of Nepal has formulated an ambitious plan which promotes economic opportunities and social equality for all peoples. This is an admirable plan, but, as we have seen, there are still vulnerable and marginalised people in Nepal who are living with HIV who have not yet benefitted from these policies and there is work yet to be done in these areas. This study has proposed a model for “the reconstruction of identity in PLHIV in Nepal” to aid in the progression of policies and programmes that promote economic opportunity and social equality, and to reduce the stigma and discrimination of PLHIV in family and society. This model could assist in the development of social, economic, and health policies that empower PLHIV and other vulnerable and marginalised communities (such as those stigmatised by leprosy). This model could also assist policy makers to develop programme initiatives appropriate for each of the stages of identity reconstruction for PLHIV. It is proposed that policy initiatives should be developed or progressed in the following areas:

Firstly, civil society organisations which serve people living with HIV should be supported to the maximum extent possible, with public, private or international donor funds. These organisations provide both education and support to PLHIV. We have seen from this study that PLHIV who were educated and supported were more likely to have reconstructed their identities, and therefore have improved health outcomes, an improved quality of life, and are more likely to be economically independent. In addition, through their various networks, government and non-government organizations can recruit PLHIV who have already reconstructed their identities, and who have better understandings about HIV and AIDS as well as exhibiting willingness to support those PLHIV who are at the earlier stage of spoiled identity. Supporting HIV

and AIDS service organizations and recruiting PLHIV who have successfully reconstructed their identities will not only provide effective support to other PLHIV with spoiled identity, but it will also reduce government costs even while targeting greater numbers of the most marginalised PLHIV. This would allow for greater efficiencies of support. After being provided with education and leadership training through organizations, as well as support from family and community, PLHIV can sustain themselves socially and economically and could experience reduced stigma and discrimination, as is suggested by the findings in this study. In this respect, PLHIV are not only support *receivers*, they are also service *providers* by engaging with various organizations in Nepal that assist in re-imagining society with a strong network of PLHIV. Such networks of PLHIV could be extended to other parts of Nepal, including rural areas.

Secondly, even though this study was not designed as a generalizable study, it seems clear from participants that the challenges faced by women living with HIV are significantly greater than those faced by men. The experiences of women with HIV are amplified by the existing traditional social structures and attitudes of Nepali society towards women. Their stories of social and economic disadvantage are well documented in this study. The Nepali government will, it is argued, want to increase its efforts towards supporting the full equality of women in Nepal, including creating educational and economic opportunities specifically for women.

Thirdly, we have seen that some PLHIV, particularly those in rural areas, seek out traditional healers to help them deal with the symptoms of HIV. This may be because traditional healers are a first and affordable option, they may be more culturally



desirable, or simply because allopathic-style (Western) treatments are simply not available in those regions. Yet the experience of the woman who drank nothing but cow urine for one year with dire effects, tells us that these traditional treatments are not the best option for PLHIV. Existing allopathic health care providers, with their armamentarium of antiretroviral therapies and extensive experience of providing health care to PLHIV, will perhaps wish to enter into collaboration with traditional healers, offering them education and support for referral of PLHIV into allopathic care as soon as possible. This would not only improve health outcomes for PLHIV, but is likely to also reduce the likelihood of further transmission of HIV to sexual partners and for PPTCT. Traditional healers could become valuable resources of referral into care and education if collaborative relationships are developed and supported by existing publicly funded health care providers.

Fourthly, irrespective of their HIV status, people in general can be informed by anti-stigma public awareness campaigns promoting the fact that HIV does not make people skinny, black and dry-skinned following HIV treatment. Awareness and anti-stigma programmes can utilise public media (newspapers, radio and TV). In addition, it is vital to give clear information to the public, irrespective of HIV status, that “HIV is not AIDS” so that people are less afraid of HIV. This would work to reduce self-stigma and enhance self-esteem in the remaining years of PLHIV, and arguably would reduce the effects of stigma and discrimination on the part of others, as they gradually gain more knowledge on HIV and AIDS.

Finally, in order to meet a national goal of reducing poverty and illiteracy in Nepal, it is also possible to replicate this proposed identity model and the policy interventions, for other groups of people who are marginalised socially and economically. Groups apart from PLHIV also experience similar issues, including discrimination based on gender, caste, class, and marital status. Based on the experiences of in-migrant women in the Kathmandu and Pokhara valleys, this study suggests there is still a long way to go for all agencies working with marginalised people. Although, as explained in Chapter Two, some initiatives in favour of marginalised people have been operating in Nepal following the historical movements seen since 1990, the Maoist movement of 1996-2006, and the initiatives from 2006 targeted against gender, class, and caste discrimination, achievements have been much less than initially expected, especially in rural areas.

## **10.6 Recommendations for Future Research**

There were significant numbers of participants, especially female participants, who expressed that their sense of identity and self-worth is much better now than in the period before their HIV diagnosis. It may be interesting and beneficial if there could be further research in regard to identity, interviewing participants living with HIV, and others in the social networks in order to continue to analyse how various sociocultural factors contribute to stronger senses of self. Identity transformation can be evaluated in multiple ways, engaging not only PLHIV themselves but also their HIV negative friends. In this sense, participants' identity transformation may be crosschecked against their HIV negative friends' statements, by interviewing friends who work or spend most time with them. Therefore, I suggest future researchers who intend to do research in the

area of identity of PLHIV include some participants among HIV-negative people. This may provide further validation of this study of identity with reference to PLHIV.

There have been encouraging results as PLHIV giving birth to HIV-negative babies, using the PPTCT service in Nepal. It would be beneficial if HIV research could be conducted focussing on prenatal, neonatal and postnatal care received by parents living with HIV who have given birth to HIV-negative babies. In this context, the research would be more effective to draw information if researchers were able to interview those health personnel (doctors and nurses) who have been providing instructions for giving birth to an HIV-negative baby from such parents. It is expected that future researchers could further explore the functions of the PPTCT service in enabling the birth of HIV-negative babies.

Importantly, this study has proposed a model of reconstruction of identity in PLHIV following on from a schematic overview of experiences of participants, whether spoiled, transitional, or reconstructed identities, as well as people's movements and processes through these stages. It would be interesting to test this model in other similar socio-cultural and economic settings, especially in South Asian countries' urban contexts, so that other researchers can justify this model's validity, and also expand this model in a broader context of addressing HIV issues, especially in reconstructing the identities of PLHIV.

## **10.7 Conclusion**

The identity status of PLHIV is fluid, but for participants with adequate capital identity moves in the direction of a more positively reconstructed identity as a person with HIV.

The study has explored how the attraction and repulsion forces in relation to their family members (often extended family) depend upon their capital and their gender power, with males having greater power and females less. Significantly, a family member living with HIV with economic, cultural, and social capitals tends to be more attractive to his/her extended family, and a member with less such capital tends to be repelled from the extended family. The fact that PLHIV in this study are often reunited into their extended family and society after becoming economically and socially independent illustrates these attraction and the repulsion forces at work. Society also treats PLHIV on the basis of how their family (often extended) treats them. While going through processes involving individualism, collectivism, family and society, a person or group of persons living with HIV with economic, cultural and social capitals can ostensibly fit anywhere. It is gratifying to see that, as PLHIV improve their health and socio-economic status, their sense of identity changes, and they experience less family and social stigma and discrimination. Social capital has been a foundation to gain two other capitals- cultural capital and economic capital- especially for widows, and women who are separated and divorced from their husband. Finally, it has been noted that this study has important policy implications for managing the quality of life, and reconstructing the identity of PLHIV by improving their health and socio-economic status, and that government is in a position to do this.

## Appendix 1: Research Ethical Approval from MUHEC

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**MASSEY UNIVERSITY**  
ALBANY

2 May 2012

Ram Prasad Aryal  
c/- Associate-Professor M Henrickson  
College of Humanities and Social Sciences  
Massey University  
Albany

Dear Ram

**HUMAN ETHICS APPROVAL APPLICATION – MUHECN 12/022**  
**Reconstruction of Identity in HIV Positive People in Nepal**

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'R Bathurst'.

Dr Ralph Bathurst  
Chair  
Human Ethics Committee: Northern

cc: Associate-Professors M Henrickson & A Dupuis  
College of Humanities and Social Sciences

Te Kunenga  
ki Pūrehuroa

**Research Ethics Office**  
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0800 ex 9539 [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz)

## Appendix 2: Research Ethical Approval from NHRC



# Nepal Health Research Council

Estd. 1991

**NHRC**

Ref. No. 27

**Executive Committee**

**Executive Chairman**

Prof. Dr. Chop Lal Bhusal

**Vice - Chairman**

Dr. Rishi Ram Koirala

**Member-Secretary**

Dr. Shanker Pratap Singh

**Members**

Prof. Dr. Meeta Singh

Prof. Dr. Suman Rijal

Dr. Narendra Kumar Singh

Dr. Samjhana Dhakal

Dr. Devi Gurung

**Representative**

Ministry of Finance

National Planning Commission

Ministry of Health & Population

Chief, Research Committee, IOM

Chairman, Nepal Medical Council

19 July 2012

Mr. Ram Prasad Aryal

Principal Investigator

Massey University

New Zealand

Ref: Approval of Research Proposal entitled Reconstruction of Identity in HIV Positive People in Nepal (Kathmandu and Pokhara Valleys)

Dear Mr. Aryal,

It is my pleasure to inform you that the above-mentioned proposal submitted on 25 May 2012 (Reg. no. 55 /2012 please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 16 July 2012 (2069-04-01).

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, total research amount is NRs. 65,000.00 and NHRC processing fee is US\$. 100.00.

If you have any questions, please contact the research section of NHRC.

Thanking you.

Sincerely Yours,

Dr. Shanker Pratap Singh  
Member Secretary

### **Appendix 3: Interview Schedule**

Interview Schedule number:

Date

Research Site:

Recording:

Remarks:

1. Please tell me something about yourself.

(Prompts: How do you occupy your time? Can you read and write? How much school did you finish? Tell me about your family)

2. Tell me how you first learned you had HIV.

(Prompts: How long ago was it? How did you feel at that time? Looking back, how do you feel now about that time?)

3. Who did you tell about your HIV?

(Prompts: When did you tell them? How did they react? What was it like for you to tell other people about your HIV? How did other people react when you told them?)

4. Tell me about any experiences you have in your life with HIV where you felt stigmatized. Do you think these experiences were because people knew you had HIV?

5. Would you say your health or stigma is a more serious issue to you? Why do you think so?

6. Have you heard of experiences of stigmatization from other people living with HIV? If so, can you describe some of those what sorts of stories you have heard from others? What effect did those stories have on you? Did you do anything to keep yourself from being affected by these stories?

7. Have you felt stigma or discrimination ever before for any reason in your life? If yes, in which what circumstances did you feel stigmatized and discriminated, and who did you? Can you give me a few examples?
8. Tell me about any circumstances when you felt yourself to be in difficult situations because of HIV? How did you manage such situations and work through them to find a better life for yourself? What resources did you use?
9. Think back to the time when you were first diagnosed with HIV. How has HIV changed your life?
10. Do you think that people with HIV are stigmatized in Nepal? Are there aspects of culture or society in Nepal that contribute to stigma of people with HIV?
11. What goals did you make to improve your life after experiencing HIV stigma and discrimination? Did you achieve your goals?  
  
(Prompt: If yes, how? What portion have you received (or experienced) so far, if not all of them? How did you fulfill those plans you attained? If none, why not, do you think?)
12. Are you involved in any community organizations that provide HIV support or outreach? How did you get involved with this organization?
13. What other support have you received in your life?  
  
(Prompt: Family, relatives, friends, community and organizations)
14. How do you think HIV has changed or shaped your social status?  
  
(Prompt: Tell me about what support you have in your life. What do you find gives you strength?)
15. Tell me about your life after HIV diagnosis. How do you manage difficulties?



16. Tell me about your plans for the future.

This is the end of the interview. If you have any questions about this research or think of anything you wish to add, you can contact me to the contact address I have provided.

#### Appendix 4: Pseudonyms of Research Participants and their Socio-demographic

##### Characteristics

Serial Number	Pseudonym	Gender	Marital Status	Place of Origin	Education	Working for an HIV Organization at least part time
1	Anu	Female	Divorced	Rural	SLC*	Yes
2	Basant	Male	Married	Rural	Literate	No
3	Bishnu	Female	Married	Rural	Illiterate	No
4	Buddha	Female	Widow	Rural	Literate	Yes
5	Deepak	Male	Married	Rural	Literate	No
6	Durga	Female	Widow	Rural	Intermediate	Yes
7	Gita	Female	Widow	Rural	Illiterate	No
8	Hari A	Male	Married	Rural	Literate	No
9	Hari B	Male	Married	Urban	Literate	No
10	Jwala	Male	Unmarried	Urban	Literate	Yes
11	Lila	Female	Widow	Rural	Illiterate	No
12	Mamata	Female	Separated	Rural	Literate	Yes
13	Min	Male	Married	Rural	Literate	No
14	Misa	Female	Widow	Rural	Literate	Yes
15	Nabin	Male	Unmarried	Urban	Undergraduate	No
16	Nimesh	Male	Unmarried	Rural	Literate	No
17	Pratima	Female	Separated	Rural	Literate	Yes
18	Pushpa	Female	Married	Urban	Literate	No
19	Rajesh	Male	Married	Rural	Literate	No
20	Raju A	Male	Unmarried	Urban	Literate	Yes
21	Raju B	Male	Unmarried	Urban	Literate	Yes
22	Ram	Male	Married	Rural	Literate	No
23	Rana	Male	Married	Rural	Literate	No
24	Rita A	Female	Married	Rural	Literate	Yes
25	Rita B	Female	Widow	Rural	Literate	Yes
26	Sabina	Female	Married	Rural	Literate	Yes
27	Sandeep	Male	Married	Urban	Literate	No
28	Santosh	Male	Married	Rural	Literate	Yes
29	Sarita A	Female	Separated	Rural	Literate	Yes

30	Sarita B	Female	Separated	Rural	Illiterate	No
31	Shyam	Male	Married	Urban	Literate	No
32	Suku	Female	Widow	Urban	Literate	Yes
33	Sushma	Female	Widow	Rural	SLC*	Yes

\*SLC stands for School Leaving Certificate (secondary school).

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