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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**

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Ram Prasad Aryal

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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 Immunodeficiency 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 worshipping 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 worshipping 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