

CULTURAL SCHEMA AND SUFFERING FROM LEPROSY

(A Case Study of Green Pasture Hospital and Rehabilitation Center, Pokhara)

A Dissertation Submitted to the Faculty of Humanities and Social
Sciences, Department of Sociology/Anthropology for the
Partial Fulfillment of Master Degree in
Anthropology

By

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Tribhuvan University
Prithvi Narayan Campus
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Under one despot, I need only stand up against a wall when I see him coming by; or prostrate myself, or knock my forehead against the ground, according to the custom of the country. But under a body of perhaps a hundred despots, I may be obliged to repeat this ceremony a hundred times a day; which is not a little troublesome to those who are not very nimble.

- Voltaire

You take what comes, when comes, you do not struggle against the war, or against life or against death. You pretend and the only master of this world is time.

- Sebastian Japrisson

LETTER OF RECOMMENDATION

This is to certify that Mr. Bhuwan Raj Gairhe has completed this dissertation entitled, "Cultural Schema and Suffering of Leprosy: A Case Study of Green Pasture Hospital and Rehabilitation Center, Pokhara" under my supervision. This is an original work. I, therefore, recommend this dissertation for final approval and acceptance.

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Date: 15th August, 2014

LETTER OF APPROVAL

This thesis entitled “Cultural Schema and Suffering from Leprosy: A case study of Green Pasture Hospital and Rehabilitation Center, Pokhara” submitted to the Department of Sociology/Anthropology; Prithvi Narayan Campus by Mr. Bhuwan Raj Gairhe has been approved by the undersigned members of the Dissertation Evaluation Committee.

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ACKNOWLEDGEMENTS

I am so grateful to the department of Sociology/Anthropology PNC, Pokhara which had granted permission and had provided continuous suggestion for the study. I want to express special thanks to Mr. Janardhan Thapa as a research guide, Dr. Lekhanath Bhattari as an external supervisor, Mr. Paul as a superintendent of Green Pasture Hospital and Rehabilitation Center and Mrs. Ruth as a counselor of GPH who had greatly assessed the study at different stages.

At last, I would like to thank to "Quick Computer Service and Photocopy House for computer typing and format making with much care and diligence.

Date: 14th August, 2014

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(Bhuwan Raj Gairhe)

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ACRONYMS

ELCP	-	Eastern Leprosy Control Project
GPH	-	Green Pasture Hospital
HD	-	Hansen's Disease
ILEP	-	The International Federation of Anti-leprosy Association.
INF	-	International Nepal Fellowship.
LLSC	-	Lalgadh Leprosy Service Centre
MDT	-	Multi Drug Therapy
MOH	-	Ministry of Health
NIAID	-	National Institute of Allergy and Infectious Disease
PLWHA	-	People Living with HIV/AIDS.
STEP	-	Stigma Elimination Programme

ABSTRACT

Leprosy has been a highly stigmatized disease from the remote past. Its antiquity goes as far back as our history of civilization. Still in this period of nanotechnology, we have accompanied by those archaic values. Those who have suffered from leprosy are two dimensional sufferers of disease and society. Participation restriction, loss of income, boycotting from job opportunities, psychological harassment, ignorance from close relatives and low social status are common matters among them.

In this study, researcher has tried to know the cultural world view of leprosy of community people (non-patients) around the periphery of rehabilitation center. In the same study participation restriction of leprosy patients and their lifelong experiences of suffering have tried to reveal. It was carried out in three different areas (Lamtara Rehabilitation Centre, Tutunga Camp and GPH of Pokhara). Total eighty respondents were taken for the interview. Fifty-five respondents who were non-patients but neighbors of leprosy patients were selected for cultural schema of leprosy. Twenty-five respondents (patients) were asked for participation restriction. Twenty respondents who were also involved in the study of participation restriction were asked for their lifelong experiences of leprosy. Semi-structured interview schedule were launched for cultural schema, a standard scale (P-scale) was used for participation restriction and in-depth interview was carried out for suffering. This study was carried out qualitatively and quantitatively both. Secrecy and neutrality had maintained as far as practicable.

In this study, respondents' views such as leprosy appears due to the weakness of blood, no believe in divine curse, poor explanation of germ theory, contraction of leprosy through sexual intercourse and prohibition of physical contact were the facts of personalistic cause. Comparing the schemas on different aspects between two generations (i.e. < 40 years and 40 > years), some sort of positive changes were noted in favor of leprosy patients. Regarding with different kinds of stigma, enacted stigma (imposed by outsiders) was being sharply reduced but internalized stigma (perceived by patients) was still working strongly. This internalized stigma had adversely affected marital lives (i.e. refusing marriage proposal and demolition of marriage prospects) and enacted stigma was found to be responsible for economic constraints (even in new generation also). Incase of 'Suffering', many respondents were suffering from economic problems and break up of marital ties. Similarly, they were ignored from their own relatives, had been homeless, were suffered from psychological morbidity, had lost creativity and in their late age they were just waiting for death. They were

expelled from their birth places and had missed relatives forever. Their parental property had seized by their own relatives. They had lost their rights to entertainment. They had become beggars, cheaters, disposed laborers. They had even the problem of bus fare and regular check up. They were suffering from home sickness, had contemplated for suicide and had tried to rush from hospital premises. They had no citizenship card, were not getting allowance for disabled and were refusing discharge from hospital. Some of them were forced for sterilization, changed religion for two times and were refusing government allowances. At last, it was concluded that leprosy patients are being victimized by family members, their relatives, from community and state at large.