

Stigma and Coping Patterns among Patients having Leprosy

Thesis

*Submitted for Partial Fulfillment of Master
Degree in Psychiatric / Mental Health Nursing*

By

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

قَالَ

سَبَّحَانَكَ لَا يَلْمُ لَنَا
إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ
الْعَلِيمُ الْعَظِيمُ

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List of Abbreviations

<i>Abb.</i>	<i>Full term</i>
<i>AIDS</i>	<i>Acquired immune deficiency syndrome</i>
<i>BB</i>	<i>Borderline leprosy</i>
<i>BC</i>	<i>Before Christ</i>
<i>BL</i>	<i>Borderline lepromatous</i>
<i>BT</i>	<i>Borderline tuberculoid</i>
<i>IEC</i>	<i>Information, education and communication</i>
<i>LL</i>	<i>Lepromatous leprosy</i>
<i>M.leprae</i>	<i>Mycobacterium leprae</i>
<i>MB</i>	<i>Multi-bacillary</i>
<i>MDT</i>	<i>Multidrug therapy</i>
<i>NE</i>	<i>National encyclopedia</i>
<i>PB</i>	<i>Pauci-bacillary</i>
<i>PE</i>	<i>Patient empowerment</i>
<i>STEP</i>	<i>Stigma Elimination Program</i>
<i>TB</i>	<i>Tuberculoid bacillary</i>
<i>TT</i>	<i>Tuberculoid leprosy</i>
<i>WHO</i>	<i>World Health Organization</i>

Abstract

This study aimed to assess the stigma and coping patterns among patients having leprosy. **Research design;** a descriptive cross-sectional design was utilized. **Setting;** the study was conducted at the leprosy Colony Hospital in El-Khanka City. **Subjects & methods;** a random sample of 80 patients of both sexes, different age groups, **Tools of data collection;** interview questionnaire, medical history sheet, stigma scale and coping scale. **Results;** There was a highly positive correlation between leprosy patients' age and coping scale pattern; there was a statistical significant relation between total score of stigma scale and socio-demographic characteristics of leprosy patients as regards the working conditions and the physical illnesses and the onset of illness. **Conclusion;** Leprosy patients were facing many types of stigma denoting that, the community still has a negative attitude towards them, which in turn the leprosy patients counter acting this attitude by avoiding communicating with people and they were preferring to live in a separate colony. **Recommendations;** designing and conducting a national-level mass campaign of health education for the general public and encouraging a better coordination between all healthcare partners to settle all the issues and to help in achieving the eradication goals of leprosy disease.

Keywords: Stigma, coping Patterns, Leprosy

INTRODUCTION

Leprosy is a slowly progressive chronic granulomatous disease caused by the intracellular parasite *Mycobacterium leprae*. *M. Leprae* mainly affects peripheral nerves and skin cells and is viable for up to 36 hours in an optimal environment. The time of incubation is usually between two and seven years, Leprosy, also known as Hansen's disease (*Guimarães et al., 2009*). However, reports have been made of incubations of up to 20 years (*Ofosu & Bonsu, 2010; WHO, 2013g*).

According to *Stevelink et al. (2011)*, the early signs of leprosy include spots on the skin that may have a different color compared to surrounding skin. Usually these appear on the arms, legs and back. However, spots don't always appear and in some cases the only noticeable symptom is numbness in one or a few of the fingers and toes. If leprosy goes untreated small muscles become paralyzed and the entire hands become numb which causes the fingers to curl. When leprosy affects the legs it affects the communication of sensation in the feet (*American Leprosy Mission, 2014*).

The ability to feel pain is lost and wounds may go unattended and cause infections leading to tissue loss. When the nerves in the face are affected the ability to blink is lost which eventually leads to dryness, ulceration and blindness (*Stevelink et al., 2011*). When bacteria enter the mucous lining of the nose it can lead to scarring and internal damage which in

time causes the nose to collapse. If leprosy goes untreated it can lead to crippling, blindness and deformities (*American Leprosy Mission, 2014; WHO, 2014b*).

Factors such as gender, race and age have no effect on the occurrence of leprosy. Those who are primarily at risk of being infected are people living in low socioeconomic conditions and those with weak immune status (*Guimarães et al., 2009*). The disease is transmitted via droplets from the nose and mouth during close contact with infected people who are untreated (*WHO, 2013a,b,h*).

Stigma is the social process that drives from a situation of power imbalance, separation, status and discrimination occur (*Corrigan, 2015*). The world health Organization describes Stigma as one of the remaining greatest obstacles to the treatment of mental illness (*Nummally, 2008; Hosoda, 2010*).

According to *Lazarus (2013)*, coping is defined as "the cognitive, behavioral and emotional efforts to manage particular external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Patients with leprosy in endemic countries also suffer from marked economic and social dependency and inferiority, despite assuming enormous responsibility of the family (*Maunder, 2012*). Thus being away from the family for hospitalization generates much stigma which must be suitable addressed by every health care

professional, especially nurses, who are largely responsible for hospital care (*Yayasan, 2008*).

Significance of the study:

The number of registered cases of leprosy in the world was under 1 million for the first time since registration began (*Varkevisser et al., 2016*). Reports received from 115 countries and territories for the first quarter of 2013, showed that the registered prevalence of leprosy worldwide amounted to 189,018 cases (*WHO, 2013f*). Thus Leprosy and disability produce significant change and consequently psychosocial problems. So stigma and coping patterns among patients having leprosy need to be assessed to describe patients suffering (*Ofosu & Bonso, 2010; Kneck, 2014*).

In 2016 it is estimated that prevalence of leprosy in Egypt less than one case per 10.000 populations (*Ministry of Health, 2016*).

AIM OF THE STUDY

This study was aimed to assess stigma and coping patterns among patients having leprosy.

Research questions:

- How can describe stigma facing patients with leprosy?
- What are coping patterns used by leprosy patients’?
- What is the relation between stigma and coping patterns among patients with leprosy?

Chapter 1

LEPROSY

1- History of leprosy and introduction:

Leprosy is not as common as it used to be. Much of work has been done to reduce the number of cases worldwide. However, it is still widespread in developing countries. Leprosy has long been associated with social stigma and taboo especially in the third world. This infectious disease was mentioned in the bible and even then, it was met with fear and revulsion (*Edmond, 2006; Karlborg, 2011; Burman, 2013*).

The people affected were seen as having a lower value than others and being unclean. Sufferers were also forced to wear a bell around their necks in order to warn people that they were in the vicinity (*Karlborg, 2011*). The disease still has stigma attached to it due to both a lack of knowledge and cultural issues. (*Karlborg, 2011; WHO, 2013 b,c*).

Moreover, leprosy is a chronic infectious; disease it has affected humanity for over 4,000 years, and was well recognized in the civilization of ancient China, Egypt and India (*Hussain, 2007; WHO, 2010b*). Named after physician Gerhand Henrik Armaure Hansen, Leprosy, also called Hansen's disease (*Walsh, 2007; Karlborg, 2011*).

“In medieval and early modern Europe leprosy was very often a generic term for a wide range of skin diseases and,