

**STIGMA AND THE MANAGEMENT OF LEPER IDENTITY IN ASKIRA/UBA
LOCAL GOVERNMENT AREA OF BORNO STATE, NIGERIA**

BY

CHINAMPI ANAMJA THLIZA
M.SC/SOC-SCI/05439/2009 (OLD NUMBER)
P15SSSG8003 (NEW NUMBER)

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SUPERVISORS:

DR. A.S. MALIKI
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**A THESIS SUBMITTED TO THE POSTGRADUATE SCHOOL, AHMADU
BELLO UNIVERSITY, ZARIA, IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE AWARD OF MASTER OF SCIENCES DEGREE IN
SOCIOLOGY**

JANUARY, 2018

DECLARATION

I declare that the work in this thesis entitled “**Stigma and the Management of Leper Identity in Askira/Uba Local Government Area of Borno State**” has been carried out by me in the Department of Sociology under the supervision of Dr. A.S Maliki and Prof. A.J. Oluwabamide. The information derived from the literature has been duly acknowledged in the text and a list of references provided. No part of this thesis was previously presented for another degree or diploma at this or any other institution.

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Name of student

Signature

Date

CERTIFICATION

This thesis entitled “**Stigma and the Management of leper identity in Askira/Uba Local Government Area of Borno State, Nigeria**” by Chinampi Anajma Thliza meets the regulations governing the award of the degree of Master of Science (M.Sc) of Ahmadu Bello University, Zaria and is approved for its contribution to knowledge and literary presentation.

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DEDICATION

This research work is dedicated to The Department of Sociology, Faculty of Social Sciences, Ahmadu Bello University, Zaria.

ACKNOWLEDGEMENTS

Glory be to Almighty God for his mercy on my life. Special acknowledgement to Dr. A.S Maliki my supervisor for his constructive criticism, love and mercy throughout the process of this work. My gratitude goes to my supervisor Prof. A.J. Oluwabamide for reasoning and guidance. My special thanks also go to Prof. B.F. Okeshola who was in the picture of my conditions and added meaning to my academic standard. Also my gratitude goes to Dr. T. Haliru, Postgraduate Coordinator and all academic and non-academic staff of Sociology Department as well as my course mates.

I will not fail to appreciate my lovely wife Mrs. Japari Chinampi, my children Janada, Joanna and Usiju Chinampi for their endurance, support and prayers during the course of my studies. I will ever remain grateful to my Late parents Anamja and Abigana Thliza who started the journey of education in my life.

To my family friends, Mrs. C.A. Ajibola and Mr. & Mrs. I.U. Gadzama, I am eternally grateful.

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LIST OF ACRONYMS

IEC: Information, Education, and Communication

NLT: Nepal Leprosy Trust

SER: Socio-Economic Rehabilitation

STEP: Stigma Eradication Project

WHO: World Health Organization

ABSTRACT

Leprosy also known as Hansen's disease, unlike most diseases, attracts a significant level of discrimination. Stigma attached to the disease negatively affects individuals infected with leprosy. This study sought to understand stigma and the management of leper identity in Askira/Uba Local Government Area of Borno State, Nigeria. The objectives of this study are; to determine the prevalence of leprosy in Askira/Uba Local Government Areas of Borno State, to identify the public perception of major causes of leprosy in Askira/Uba, to examine stigma attached to leprosy and the major factors contributing to leprosy stigma in Askira/Uba, to ascertain the effects of stigma on individuals infected with leprosy in Askira/Uba, to identify the coping strategies adopted by individuals infected with leprosy in Askira/Uba and to proffer suggestions on how to mitigate the effect of stigmatization of leprosy in Askira/Uba. Goffman's theory of stigma served as the theoretical framework of the study. Qualitative and Quantitative data were collected for the study. Quantitative data were generated from two hundred and nine (209) questionnaires retrieved from sampled survey respondents. The qualitative data were generated from ten (10) in-depth interviews and three (3) focus group discussions. The findings of the study revealed that, there is high rate of leprosy in Askira/Uba LGA. The public perceptions on the major causes of leprosy are: contact with an infected person, environmental conditions (dirt) and inheritance/genetics. Factors that contribute to leprosy stigmatization were; discrediting beliefs and misconceptions regarding the causation and transmission of leprosy, fear of transmission and misconceptions regarding the incurability and high infectiousness of leprosy. The effects of stigma on individuals infected with leprosy were: social disengagement/isolation, loss of status and economic hardship. The coping strategies adopted to mitigate the effect of leprosy stigmatization include: spiritual remedies, excessive consumption of drugs, social detachment and finally migration. Based on these findings, the following recommendations were made; provision of more health facilities and drugs at the ward levels by the Government and regular seminars/workshops in the local government to sensitize the people more about leprosy causes, transmission and curability as well as the need for positive attitude toward individuals infected with leprosy.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

The disease of leprosy among other types of diseases has been described as a disease that destroys not only the body but the soul (Olawale, 2013). The disease has afflicted humanity for a long time. It has once affected every continent and it has left behind a terrifying image in history and human memory of mutilation, rejection and exclusion from society. Since ancient times, leprosy has been regarded by many communities as contagious, mutilating and incurable with accompanying stigma that has adverse consequence for leprosy patients (WHO, 1996).

Leprosy or Hansen's disease is a chronic granulomatous disease caused by mycobacterium leprae, an acid fast, rod – shaped bacillus principally affecting the peripheral nerve, mucosa of the respiratory tract and the skin of human being (Ryan, 2004 in Ajibade et al, 2015:1298). Hence, victims of Leprosy often suffer physical disability and social stigma which prevents them from seeking medical treatment and often thwarts public health intervention to curb further spread of the disease. Worldwide distribution of leprosy in 2003 revealed that two to three million people are estimated to be permanently disabled because of leprosy disease with India having the highest number of cases, Brazil as second and Burma as the third (WHO, 2003; Olawale, 2013).

The social stigma, alienation, discrimination and violence against sufferers of leprosy are attitudes that have continued through the ages up to the 20th century and these still exist,

though in a diluted form. For instance, in Japan; the “no leprosy patients in prefecture” movement started in 1930 in which absolute isolation was supported based on the social belief that; “leprosy is a shameful disease and the purity (absence of leprosy patients) of the nation should be maintained, thus justifying isolation”. In the United States, laws in some States allowed local health officials to arrest and confine anyone suspected of carrying the disease. In China (1937), 80 victims with leprosy, including women and children, were shot and thrown into a lime pit; and in Korea (1957), a mob beat 10 patients from a leprosarium to death to mention but a few (Dogra et al, 2013:18).

Although, the contagion paradigm or infectious nature of the disease radically transformed the way it is managed, the discovery of the microbiologic origin of leprosy did not radically change its management and the stigma and discrimination associated with it. The causal agent of leprosy ‘*Mycobacterium leprae*’ was first discovered by Gerhard Armauer Hansen in 1873. Hansen was a proponent of the segregation strategy in Norway. He facilitated and championed the formulation of Norwegian law on the seclusion of people diagnosed with leprosy (Dogra et al, 2013:19).

As at 2006, Nigeria was one of the seven countries in Africa reporting more than 1,000 new cases of leprosy in a year, the other countries being Angola, the Democratic Republic of Congo, Ethiopia, Madagascar, Mozambique and Tanzania (Ajibade et al, 2015). Within Nigeria, leprosy is known in the southern part as "Opo", "Ete" in West and "Mekuturu" in the North and Eastern region. The Leprosy Mission International of Nigeria has described Benue, Cross River, and Gombe State as having the highest level of disease in Nigeria

followed by Adamawa, Kano, Taraba, Yobe and Zamfara (WHO, 2008 in Ajibade, et al, 2015: 1299).

Untreated or late detected leprosy causes nerve damage, which can result to physical impairment and disfigurement, and in some cases, eye defects (Mesele, 2005). Moreover, the psycho social impacts of the disease become hazardous problem, which affects the economic and social life of the individuals. In most cases, the physical deformity or impairment due to the disease provokes the stigmatized attitudes of the society towards persons affected by leprosy. This stigmatized attitude breaks the social bond of the person within the society, and results in isolation and discrimination of the leprosy affected persons from the society. Aside disability due to the disease resulting to stigmatization and exclusion, people who are clinically cured with no clear manifestations of the disease suffered the social consequence of the disease. Moreover, persons from leprosy affected family who are not infected by the disease are also isolated, discriminated and excluded from the community (ENAELP, 2004). The social exclusion does not only prohibit individuals' relationships with the society, it affects the material and social assets of the affected persons. Moreover, according to White (2007), it also has a significant impact on leprosy affected persons decision making and treatment success of the disease.

Above all, awareness of leprosy in Nigeria especially in the North-Eastern region (Borno State inclusive) seems low. It is against this background, that this study is undertaken to examine stigma and management of leprosy victims in Askira/Uba local government area of Borno State.

1.2 Statement of the Research Problem

In 1991, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000 using the prevalence as a measurement. Elimination was defined as a level of prevalence below one case per 10,000 people. Also, one of the achievements of this worldwide effort was the introduction of Leprosy Elimination Campaigns (LECs), which trained health workers in case finding, educate communities in order to increase awareness, and performed active case finding and patient treatment. These campaigns can thus be said to have had considerable success in many countries, especially since the diminishing stigma associated with leprosy resulted in a better outlook for patients (Naff, 2006). Despite this considerable success, victims have suffered stigmatization.

Stigma continues to have a negative effect on individuals, families and leprosy control programmes. Some patients diagnosed with leprosy may conceal their illness out of fear of rejection and exclusion from society. Others may stop their treatment prematurely out of fear of stigmatization because they experience drastic appearance changes due to side effects of treatment e.g. uneven darkening of skin due to clofazimine and facial swelling and weight gain because of prednisone (Bainson et al 1998; White, 2007). There are times when people report late, due to stigma and because of that the opportunity for the transmission of the disease increases.

Leprosy and the social stigma attached to the disease change the lives of its victims completely. Victims of leprosy are continually denied employment chances, dismissed from existing opportunities, often suffer verbal abuse, social isolation and in some

societies; they are forbidden to interact with others. The stigma of leprosy is often compounded by gender inequalities and lack of protection. Hence, women may experience physical and sexual abuse and at times they are forced into prostitution (Barrett, 2005).

The socioeconomic consequences of leprosy stigma negatively impact on economic prospects of leprosy victims, which include job loss, reduced income, reduced prospect of securing job, increased dependence on others for survival, as well as poverty in households that have breadwinners who are infected with leprosy. Stigma also affects interpersonal relationship, social status of leprosy victims, extent of individuals' involvement in social/community activities, marital relationship as well as marriage prospect.

Given the foregoing, it is pertinent to note that there is much more to a disease than just its pathological processes. For Leprosy, it is a complex condition that does not only affect patients physically; it has social and psychological implications that must be considered. Leprosy is a chronic disease which is one of the most socially stigmatized diseases known today. Stigma of leprosy leads to isolation of sufferers or marginalized group of the community. Stigma towards persons affected by leprosy and their families has also affected their quality of life due to its impact on mobility, interpersonal relationships, marriage, employment, leisure and social activities. Stigma has adverse consequences for leprosy control. Some patients would rather conceal their illness than suffer the social rejection of being stigmatized.

Much of the literature available centers on the prevalence, nature, causes and consequences of the disease with little on the effect of stigmatization, control, treatment and management of Hansen's (leprosy) disease especially in developing countries. For instance, Kaur &

Ramesh (1994) opined that leprosy is a contagious and mutilating disease which has affected people for thousands of years, and that its mode of transmission is still not exactly known but most likely it happens via; droplets from the nose and the mouth, during close contact with untreated cases. For Bainson et al (1998) and Lockwood et al (2005), Man is the most important host and unfortunately, there is no effective vaccine developed yet against the disease of leprosy. They also maintained that throughout history, the disease has been feared because people thought it was highly infectious and incurable.

On his part, LeGrand (1997) concentrated on the severity and socioeconomic effect of leprosy as a disease. According to him, leprosy can exist on a spectrum of symptoms depending on a number of factors which include: the host's immune response, genetics and the number of bacteria that initially infected the body. Also, the socio-economic status of a person is considered a major determinant of exposure to the disease risk. Withington et al, (2003) identified poor housing, lack of clean water, poor sanitation and lack of adequate nutrition as some other conditions associated with leprosy, which undermines the immune system and increases vulnerability to get sick. Thus, it is widely assumed that leprosy is a disease of the poor because most leprosy-affected people have no formal or limited education and that limits their choice of jobs.

This study varies from others by focusing on the stigma and management of leprosy.

1.3 Research Questions

1. How prevalent is the disease of leprosy in Askira/Uba Local Government Areas of Borno State?
2. What is the public perception on the major causes of leprosy in Askira/Uba Local Government Areas of Borno State?

3. What are the major factors contributing to leprosy stigma in Askira/Uba Local Government Areas of Borno State?
4. What are the effects of stigma attached to individuals infected with leprosy in Askira/Uba Local Government Areas of Borno State?
5. What are the coping strategies adopted by individuals infected with leprosy in Askira/Uba Local Government Areas of Borno State?
6. What are the suggestions on how to mitigate the effect of stigmatization on leprosy victims in Askira/Uba Local Government Areas of Borno State?

1.4 Aim and Objectives of the Study

The aim of this study is to examine stigma and management of leprosy identity. However, the specific objectives of this study are as follow:

1. To determine the prevalence of leprosy in Askira/Uba Local Government Areas of Borno State.
2. To identify the public perception on major causes of leprosy in Askira/Uba Local Government Areas of Borno State.
3. To examine stigma and the major factors contributing to leprosy stigma in Askira/Uba Local Government Areas of Borno State.
4. To ascertain the effect of stigma attached to individuals infected with leprosy in Askira/Uba Local Government Areas of Borno State.
5. To identify the coping strategies adopted by individuals infected with leprosy in Askira/Uba Local Government Areas of Borno State.
6. To proffer suggestions on how to mitigate the effect of stigmatization on leprosy victims in Askira/Uba Local Government Areas of Borno State.

1.5 Significance of the Study

This study has two major significances: theoretical and practical significance. The theoretical significance is that the study provides a basis for theoretical constructions for scholars in the area of leprosy victimization and management. The practical significance is for policy makers in particular and indeed, the government in general. For policy makers, the study will be useful for the formulating and implementing of policies that are suitable for ameliorating victimization of lepers. For the government, the study will provide it with a body of information, which will assist in policy formulation that criminalizes undue victimization of lepers in the country. This study also contribute to the existing body of knowledge in the area of victimization and management of leprosy, and serves as a source of literature and reference sources for future scholar as studies in the area advance.

1.6 Scope of the Study

This study is interested in the effect of stigmatization in the management of leprosy identity in Askira/Uba local government areas of Borno State. The approach and scope of this study is dictated by the objectives of the study on one hand and the study area on the other. The time frame of the study is 2015-2016. The geographical coverage of the study is confined to the Askira/Uba local government areas of Borno State. In terms of scope, the study is limited to the prevalence, causes, major factors contributing to stigma of leprosy, effects of stigma and coping strategies adopted by those infected with leprosy in Borno State and Nigeria.

1.7 Definition of Key Terms

Leper: An individual suffering from a contagious disease that affects the skin, mucous membranes, and nerves, causing discoloration and lumps on the skin and, in severe cases, disfigurement and deformities.

Stigma: A social identity associated with a particular circumstance, quality, or person.

Coping: The process of contending with life difficulties in an effort to live or work through them.

Prevalence: The fact or condition of being prevalent; commonness.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Introduction

In this chapter, previous scholarly works or literature are reviewed in line with the research objectives of the study. This is with a view to critically examine previous works in order to identify the gap in knowledge. Relevant theory was reviewed and adopted to aid the explanation of the issue under study.

2.2 Conceptual Clarification of Stigma

Stigma is used by the Greek to refer to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people (Rebecca, 2003). These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting. In relation to health, Goffman (1963) defines stigma as an attribute that is deeply discrediting. The one who possesses an attribute of undesired 'difference' is as a result tainted and devaluated in the eyes of society. In his discussion on the categorizing of people as 'normals' and 'deviant' individuals, he stated that the deviant individual is different from 'normal' people as they are seen 'of a less desirable kind in the extreme, a person who is bad, or dangerous or weak.

Researchers in the area of health-related stigma have proposed that "Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that result from experience or reasonable anticipation of an adverse social judgment about a person or a group. This judgment is based on an enduring feature

of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma” (Weiss and Ramakrishna, 2004).

Jones et al (2004) defined stigma as “a mark or attribute that links a person to undesirable characteristics or stereotypes”. This definition implies that one group sees the other as abnormal. It introduces the concept of ‘them and us’. Stafford and Scott (2006) proposed that stigma is “a characteristic of a person that is contrary to a norm of a social group or unit”. They defined ‘norm’ as a “shared belief that a person ought to behave in a certain way at a certain time”. For Crocker et al (1998) “stigmatized individuals possess or are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context”. Link and Phelan (2004) referred to stigma as “a dynamic process that is linked to competition for power and tied into existing social mechanisms of exclusion and dominance”. Parker and Aggleton (2002) defined stigma as “a social process that involves identifying and using difference between groups of people to create and legitimize social hierarchies and inequalities”. Castro (2005) commented that stigma is “a result of structural violence perpetrated by the larger social forces that are rooted in historical and economic processes”. Jacoby (2005) pointed out that stigma is “a

label associating a person to a set of unwanted characteristics that form a stereotype”. Weiss and Ramakrishna (2004) defined stigma as “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem”. It is interesting to note that, while some Goffman definitions focuses on individual attributes, the definitions created in the later years, such as those of Link and Phelan, Parker and Aggleton, Castro, and Weiss and Ramakrishna, focused more on the societal context. Link and Phelan (2001) further expanded the nexus between an attribute and a stereotype identified by Goffman with a wider set of meanings for the term. They stated that: “stigma exists within the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics and negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of ‘us’ from ‘them’. In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes”. Although their definition of stigma did not include societal issues, Stafford and Scott (2006) elaborated that society could create negative stereotypes to preserve the social structure or to permit exploitation of a group or its resource. They also pointed out that social inequality dramatically influences the process of stigmatization of certain individuals or groups. Those who have control in a society have the power to impose their norms, values and beliefs, including cultural meaning of an attribute and the stigma attached to it, on people who are powerless.

Link and Phelan (2001) described five basic components of stigma to include: labeling, stereotyping, separation, status loss, and discrimination within the context of power differential. Labeling is the recognition of differences and the assignment of social salience to those differences. In the context of disability, it is the recognition that a certain biological trait differs from the norm in ways that have social significance. Stereotyping is the assignment of negative attributes to socially salient differences. Stereotypical differences are differences that matter and are also deemed by others to be undesirable. Separation occurs when the reactions of others to these differences lead to a pronounced sense of “otherness.” When individuals with disabilities perceive that they are labeled, stereotyped, and separated from others, they experience stigma (Green et al, 2005:197).

While it is easy to stigmatize those suffering from leprosy, the fact is that being associated with individuals suffering from leprosy also attracts some certain level of stigma. Sociologist Erving Goffman (1963) introduced the idea of the “courtesy stigma” to refer to the stigma that attaches to those who are merely associated with a stigmatized person. Goffman (1963) describes what he calls 'courtesy stigma' as being the extension of a person's stigma to people who are related through the social structure. The relationship leads the wider society to treat both individuals in some respects as one - there is an obligation to share some of the discredit of the stigmatized person.

2.3 Prevalence of Leprosy

In 1985, 122 countries in the world had a leprosy prevalence of 1 case per 10,000 populations. This number fell to 24 countries in 2000 and to 4 countries by 2007 and the global registered cases of leprosy at the beginning of 2007 were 224,717 cases while the number of new cases reported during 2006 was 259, 017 (WHO, 2007). In 1991, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000 using the prevalence as measurement. The definition of the elimination of leprosy as a public health problem was a prevalence rate of less than one case per 10,000 persons. Because of the widespread use of DT (Drug used for Treating Leprosy), the burden of disease has been reduced dramatically. More than 14 million cases were detected and treated with DT (Drug used for Treating Leprosy) between 1982 and 2005 (WHO, 2005).

According to reports received from 115 countries and territories, the global registered prevalence of leprosy at the beginning of 2006 stood at 219,826 cases, while the number of new cases detected during 2005 was 296,499. The number of new cases detected globally has fallen by more than 111,000 cases (a 27% decrease) during 2005 compared with 2004. During the past four years, the global number of new cases detected has continued to decrease dramatically, by about 20% per year (<http://www.who.int/lep/en/> 1st October 2006). Most previously highly endemic countries have now reached elimination and those few that remain are very close to eliminating the disease. However, pockets of high endemicity still remain in some areas of Angola, Brazil, Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania (<http://www.who.int/lep/en/> 1st October 2006).

According to World Health Organization (WHO (2002)), leprosy is now found in parts of Asia, Africa and central and South America. The distribution and prevalence of Leprosy is neither uniform nor random. In some parts of Africa more men than women are diagnosed with leprosy but there are some African countries where more women than men are affected (WHO, 2002). Worldwide distribution of leprosy in 2003 revealed that two to three million people are estimated to be permanently disabled because of leprosy disease with India having the highest number of cases, with Brazil as the second and Burma as the third (WHO, 2003; Olawale, 2013).

In Nigeria, new leprosy cases detected annually declined from 226 cases in 2004 to 140 cases in 2008. The prevalence has remained between 0.3- 0.4 per 10,000 population. Child proportion among new cases dropped from 12% in 2004 to 5% in 2007 and increased to 9% in 2008 and grade 2 disability among new cases have remained very high between 21% -27% (Nsagha et al, 2011:2). Similarly, Adagba (2011) was very critical that prevalence of leprosy among children in Nigeria is still high and unacceptable. Hence, in 2008, Nigeria was ranked fifth among nations with high leprosy burden in the world, and in Africa, second only to Republic of Congo (WHO, 2008 in Nwankwo, 2015:7). However, approximately 219,000 new cases of leprosy were reported worldwide during 2011, occurring mainly in Africa, Asia and South America. Control of leprosy has improved significantly over the last 20 years due to national campaigns in many countries around the world. In Australia, leprosy is rare and found mainly in Northern Australian Aboriginal people and migrants from overseas countries in Asia, the Pacific and Africa where leprosy is more common (Centre for Disease Control, June 2013: www.nt.gov.au/health).

2.4 Causes of Leprosy

In 1873, a Norwegian physician named Gerhard Henrick Armauer Hansen discovered leprosy in tissue samples and theorized that the causing agent was bacterium. He continued to research the disease and six years later, Hansen gave the tissue samples to German physician Albert Neisser who confirmed Hansen's findings that leprosy is indeed caused by bacteria. Hansen's disease or leprosy is a chronic infectious disease that can affect all age groups and both sexes. Prior to this medical discovery, people thought leprosy was hereditary or even caused by sin, especially since the Bible uses the terms "leprosy" and "lepers" in reference to a wide range of disfiguring skin conditions. Consequently, social taboos were created about leprosy patients being "unclean" or "cursed by God" (Fulwood-Powell, 2006: 7-8).

Leprosy is a stigmatizing disease, causing deformities in the hands, feet, eyes and nose. It is caused by an infectious disease called *mycobacteriumleprae*. Leprosy can possibly be transmitted from person to person contact, through a respiratory route, or by insects. The bacterium is transmitted from one person to another primarily through infected droplet. Unfortunately, more than half of those with the disease have no confirmed contact with an infected person. Other factors that play major roles in the cause of leprosy include but are not limited to genetics, the extent of exposure, and environmental conditions (Arthur, 2006 in Ajibade, 2015:1300).

Other causes of leprosy which people traditionally believe are; witchcraft, a curse, trespassing of food taboos, contagion, and being hereditary. A study in Nigeria by Alubo et al (2002) elaborated the belief that some think leprosy was inherited and that people with

the same bloodline were more vulnerable to the disease. People with different blood were therefore considered to have no risk. The same study also recorded that this belief was also present among trained leprosy workers. One leprosy worker said that he was not afraid of contact with the disease as his blood was strong and the disease did not occur in his family. In Thailand, it was also reported that leprosy was thought to be hereditary, because the community often saw many cases of leprosy in one family (Predaswat, 1992).

Beliefs about the causation of leprosy have differed over time and between places. These beliefs affect how the disease and those who have it are perceived. Some groups believe that leprosy is a judgment from God or the gods for wrongdoing either in this life or a previous life (Van Brakel, 2003). Those with leprosy are avoided as they are seen as sinful, and those around them do not themselves want to incur that wrath. Likewise, those with leprosy may be avoided in places where leprosy is viewed as a sexually transmitted disease (Gilman, 1999) as something contracted by victims of witchcraft, or as something that witches themselves have (Scott, 2003). Try (2006) revealed that in Nepal it was commonly believed that touch or close contact was the main cause of transmission. In the same country, people also believed that transmission could occur through food, water, air, faeces, and patients' excreta, such as urine, sweat, pus from ulcers, semen, and vaginal fluid. Stigter et al (2000) indicated that, although, there is no one common perceived cause of leprosy, all the beliefs described above are negative and usually imply that the sufferer has done wrong and brought the disease upon himself.

Socio-economic status is recognized as a major determinant of exposure to disease risk (Le Grand, 1997) such as leprosy. Leprosy is seen as a disease of the poor .Some other

conditions associated with that are; poor housing, lack of clean water and poor sanitation. Also, associated is lack of nutrition, which undermines the immune system and cause people to be more vulnerable to get sick (Withington et al, 2003).

2.5 Factors Contributing to Leprosy Stigma

The disease of leprosy or illness is experienced by the patient and shaped by the social cultural influences. Sickness is perceived by society and may be expressed as social stigma (Stigter et al, 2000). Jopling (1991) stated that, “the problem with leprosy is not what the disease is, but what the people believe it to be”. The stigma against leprosy is partly due to traditional beliefs and misconceptions about the causes and transmissions of leprosy. A common belief is that leprosy is hereditary. Other beliefs and theories among various cultures are bad blood; bad spirits/curses, curse of God, supernatural causes; touch, sweat; water, air, defecation; food/breaking of food taboos; sex with prostitutes and therefore a punishment for moral lapse; sexual contact in the open air, sex with a woman during her monthly period; a spell/witchcraft/evil magic; disturbing the djinn (ghosts); direct punishment by God for one’s sins or evil character; getting the disease as a consequence for one’s own irresponsible actions.

Some traditional and religious beliefs also play a major role. For example, in many Hindu societies, persons affected by leprosy are blamed for their condition, which is thought to be a punishment for something they have done wrong in a previous life. In this case, stigma involves a moral judgment (Seddon et al, 2006). In Thailand, Pisuthipan (2007) asserted that, many people with leprosy related disability were sent to a leprosy colony by their families as they were thought to be cursed and deserved social segregation. Other

misconceptions and beliefs as posited by Barkataki et al (2006) are that leprosy is highly contagious, incurable and disabling. These misconceptions and discrediting beliefs regarding leprosy (Subramaniam, 2003:13) according to Idawani (2002), tend to marginalize patients socially and bring shame upon them.

In the past, leprosy hospitals and colonies used for segregating patients have played a role in promoting and sustaining stigma (Subramaniam, 2003:13). The fear of contracting leprosy was sometimes perpetuated by methods of tackling the disease. Treating leprosy apart from other diseases in separate programmes and hospitals unfortunately sent out the message that, leprosy is somehow different and more infectious than other diseases. Many people still hold this belief and want those infected with leprosy to be treated far away from their communities to avoid others getting the disease (Stigter et al, 2007). The Leprosy Acts that were enforced in many countries perpetuated the misconceptions regarding the disease (Jopling, 1991); the words “leprosy”, “leper”, or “leprous” are still used to imply something evil, degrading or immoral by writers, journalists and politicians (Skinses and Evolve, 1970 in Subramaniam, 2003:13).

Reports reveal different situations in which the people affected by leprosy are stigmatized and discriminated by the health care system. In Guyana, a study was conducted in two hospitals with the aim to assess attitude, knowledge and ideas of the disease amongst health care workers. A self-completing questionnaire was distributed and 185 questionnaires returned. It was found that, half of the health care workers did not know leprosy is curable and many still thought it could be transmitted through touch (Briden and Maguire, 2003). A study amongst nursing students in Nigeria revealed that, they thought

leprosy is a highly contagious disease and that deformities are inevitable in leprosy (Awofeso, 1992). Scott (2000) documented that, fear of leprosy still exists among many health workers in general hospitals in South Africa. These misconceptions often lead to negative attitudes towards people affected by leprosy.

Another reason for the stigma associated with leprosy is the deformity and disability caused by the disease. In lepromatous leprosy, there is a characteristic facial appearance that marks out a patient as having the disease. The skin becomes ridged and thick and the nose wider. This means that at first glance, other people can see that such individual has leprosy. Research in Myanmar found it was believed that, all leprosy patients would inevitably end up with some deformity, which increases the dread of the disease. It was observed that in India, the greater the disability, the greater the level of stigma (Prabhakara, Rao and Palande, 2007).

The fear of transmission is evidently one of the main reported causes of concern for people in a community. This fear is enhanced by the visible signs that make people want to keep a safe distance and especially take care that their children, considered most vulnerable to infectious, stay away from a leprosy patient. Fear has also been reported to be based on prevailing inaccurate beliefs. In Brazil, traditional notions that leprosy is an incurable, disabling and highly infectious disease widely prevail and this leads to unnecessary fears and stigmatization of patients (Moreira and Varkevisser, 2002). Similarly, villagers in Thailand believed that, once the person with leprosy was deformed, there was no cure and that the patient cannot return to a normal state (Predaswat, 1992).

2.6 Effects of Leprosy Stigmatization

More than any other disease except perhaps acquired immune deficiency syndrome (AIDS), leprosy has a very negative image. In literature, leprosy and stigma have been almost synonymous. For centuries, it was a feared disease, the very word invoking shame and disgust. For many leprosy sufferers, stigma is the hardest part of the burden to bear. Research by Van Brakel (2003) have shown that, leprosy and its stigma have a pervading affect on a patient's life, affecting marriage, employment, interpersonal relationships, leisure activities and attendance at social and religious functions. In Nepal, people with leprosy are often ostracized by their communities, reporting insults, rejection and hate (Stigter et al, 2000). Scott (2000) found that, one-third of leprosy patients were left by their spouses. In South Asia where people's identity is bound to their role in their family and wider community, experience of rejection as a result of leprosy is a dreadful experience. For leprosy suffers to lose family and community identity, it implies to lose a large part of who they are. One patient summed it up like this, 'We can endure losing fingers and toes, eyes and nose, but what we cannot endure is to be rejected by those nearest and dearest'.

Stigmatization in leprosy is not limited to the affected persons and is often extended towards their families, friends and even those providing care for them (Kant, 1984; Ulrich et al., 1993; Kumaresan and Maganu, 1994). These people according to Seddon et al (2006) do not have any signs of leprosy but are stigmatized. Stigma impact weighs heavily on their lives as prospect of getting a job or getting married can be at stake. Goffman (1963) labels the extension of stigma to others as courtesy stigma. Leprosy stigma can be so intense that children affected by the disease are expelled from schools and persons affected by the disease are banished from their villages (Stigter et al, 2000). Younger

people who develop leprosy experience restriction in their education, with schools being unwilling to admit them or placing limitations on what they can do. Many leprosy-affected people have no formal or limited education and that limits them in their choice of jobs (Withington et al, 2003).

Due to misconception and discrediting beliefs on the cause and transmission of leprosy, some members of the community feel justified discriminating people affected by leprosy and, as a result, the latter may delay seeking help. Negative attitudes may also affect adherence to treatment. These attitudes have an effect on the psychological wellbeing of the leprosy-affected person. Most leprosy patients tend to keep their diagnosis a secret, due to the wrong belief that the disease is incurable and disfiguring (Jopling, 1991). Often, to prevent discrimination, some persons infected with leprosy hide their disease by not immediately seeking medical help. When they do, they may have significant disabilities and deformities. This in turn makes the stigma of leprosy worse and perpetuates the cycle. Once treatment for leprosy has commenced, patients may stop going to clinics or taking their medication (non-compliance) because of fear of rejection by their community or a lack of acceptance of the condition. Non-compliance with treatment is a major problem in some areas; for example in East Nepal, the non-compliance rate for the leprosy control programme is greater than 40% (Stigter et al, 2000).

People with leprosy may lose their employment because of the disease, the disabilities associated with it and negative attitudes of employers. When this happens, they lose the means of supporting their families and often the respect of their communities, with loss of self-esteem. There can be severe financial burdens to bear. A study in India found that 16–

44% of those with leprosy reported a fall in their income because of their disease (Prabhakara et al, 2000). Employers may dismiss an employee affected by leprosy out of fear of getting the disease and of losing customers in their businesses. Another reason for dismissing according to Calcraft (2006) is that, people with impairments due to leprosy may not be able to perform well on the job. For a leprosy-affected person not being able to work will mean to become more dependent on the family, and if resources are scarce, this will give a lot of tension. The feeling of uselessness because of not being able to contribute to the income of the family will lead to loss of identity and self-worth.

Kaur and Van Brakel (2002) indicated that leprosy-affected people end up in beggary. Leprosy and the social stigma attached to the disease changes their lives completely. They had a job before, lost it because they got leprosy and were discriminated by the community. Verbal abuse and being forbidden to use common places in the community make life unbearable, causing them to leave their villages. Sometimes, a person leaves his/her home in order not to be in the way of his/her siblings' chances of getting married. This kind of situation gives rise to a lot of emotional stress and anxiety. Others were rejected by their families and with their physical impairments worsened, which restrict them from earning a living. Some beggars live in slum areas. Many of their children do not go to school, but get involved in beggary.

The stigma of leprosy is often compounded by gender inequalities and lack of protection. The effects of poverty can be more severe on women. Women may experience physical and sexual abuse and at times they are forced into prostitution (Barrett, 2005). Women are a particularly vulnerable group of leprosy patients. Studies show that women are more

affected by leprosy stigma, suffering more isolation, loss of touch, rejection and have more restrictions placed on them than men with the same level of disease. If a mother has leprosy, the health and well-being of the whole family can suffer. Fear of passing on the disease can prevent emotional closeness and bonding with her children and also reduce positive health behaviour. In Nagpur, India, 49% of breast-feeding mothers with leprosy stopped breast-feeding their children (Zodpey et al, 2009).

Sometimes the stigma and ostracism of leprosy can affect the psychiatric state of the patient. World Health Organizations (2000) states that sometimes, the stigma and ostracism of leprosy can affect the psychiatric state of the patient. Leprosy itself attacks the peripheral nerves; the brain and central nervous system, yet many patients are affected mentally, not because of the disease, but because of society's rejection of them. Negative attitudes towards people with leprosy act to destroy the patient's psychological and social health, but also can affect them physically. According to Scott (2000), one third of black leprosy patients studied in South Africa were found to have contemplated suicide after their diagnosis of leprosy. Negative attitudes toward people with leprosy destroy the patient's psychological and social health, but also can affect them physically. The shame associated with this disease can prevent people suffering from leprosy seeking treatment until significant disability has occurred, while those who have been treated may never be cured in a truly holistic way nor be accepted back into society.

The social consequences of being affected with leprosy can be devastating, causing victims to be humiliated or isolated from society. Apart from ostracism of those with leprosy, lies the fear of infection. In the past, in certain epidemiological settings, leprosy ran in families

to the extent that many authorities considered it an inherited rather than an infectious disease. So marriage into a leprosy family was forbidden (Rafferty, 2005) as practiced in Thailand, villagers were proscribed from allowing their children to marry people/families with leprosy (Predaswat, 1992).

Some patients with leprosy may have a distinctive odour caused by infected ulcers. This smell can be nauseating. This is made worse in cases when their communities do not allow people with leprosy to wash in communal water, as in Madhya Pradesh, India (Danlep, 2003). As well as making them outcasts, bad odour can affect the patients' sense of worth and dignity. Self-stigmatization is a very real issue. People with leprosy may become ashamed, possibly because of local attitudes and deformity, and may isolate themselves from society, thus perpetuating the idea that leprosy is something shameful to be hidden away. Patients may find it difficult to value themselves and have a positive self-image. The self-loathing associated with leprosy can be permanent; persisting after the disease is cured (Scott, 2000).

It can be hard for some patients to accept that they have leprosy. They may never be able to come to that point, refusing to believe it is true, while others may not believe they are actually cured after treatment (Ben, 2012). Leerapun et al. (1989) concluded that, visible deformity correlates positively with the level of stigmatization in the community. Some patients perceived rejection by their families and communities and voluntarily left their homes for treatment at hospitals or colonies. Some patients were treated at home but shunned contact with the community. Spouses and children were more likely to accept and take care of patients, although they too feared contagion. Some couples separated

permanently. Community members reacted to leprosy patients with fear and disgust, but their condemnation was not overt. Even if patients are cured of their mycobacterial disease, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life. Negative perceptions of leprosy still can be a barrier to the process of reintegration into their families, jobs and wider society. Complete cure requires that the barrier be overcome.

Delay in diagnosis and treatment due to stigma can have adverse physical, psychological, economic and social effects. The occurrence of deformity is the most important concern, since the social response to those suffering from leprosy related deformity and their families are often tragic, harsh, and unsympathetic accompanied with insult, ostracism and even the deliberate killing of those affected. These actions negatively impact on the dignity and behaviour of those affected by leprosy. Consequently, those affected with leprosy will develop anger, distress, dread, aggression and show a preference for living somewhere where no one knows of their history (Kaur and Brakel, 2002).

2.7 Coping Strategies Adopted by Leprosy Victims

Hyland (1993) in her socio-cultural study of leprosy in Nepal also developed a kind of stigma trajectory in which the different coping styles of the stigmatized people are explained. She described this process as the “concealment cycle”. The concealment cycle is based on the assumption that persons affected will try to conceal their disease for as long as possible, and this is in order to keep their social integrity intact. According to the concealment cycle people affected by leprosy will try to manage stigma by concealing the disease and if questions are asked about symptoms, or the person needs to go to the clinic,

attention is distracted by telling “stories.” This “story telling” is a kind of concealment in which the person is “*saying something* and not saying what (it is) wished to keep secret”. In the next step of the concealment cycle, the person affected feels that his or her social integrity is threatened. This may happen when questioning or the curiosity of the community increases. To preserve his or her social integrity the person affected may cope by withdrawing. Withdrawal during this stage results in people stopping their treatment, leaving the village together with their families, or leaving alone in order to work in another community.

Demelash’s (2016) study identified various coping strategies adopted by leprosy victims. Loss of sensations on the hands and feet’s of persons affected by leprosy exposed them for burn injuries and wounds. However, to deal with their situation, they use long tools and appliances with protective (molded) handles at home and at place of work. The finding also showed that persons affected by leprosy cope with injuries in anesthetic feet while executing daily routine by special footwear made by orthopedic specialists. Similarly persons affected by leprosy who experienced problems in their marriage, leave their home town and marry another spouse who are their “own kind” . To avoid rejection by the community, persons affected by leprosy abstained request to participate in social events. The finding also reveals that to cope with lack of patronage in their businesses, “healthy” family members are engaged to sell commodities.

2.8 Strategies for Addressing Leprosy Stigma

Stigma for any disease (leprosy) is a pernicious and obnoxious complication which must be eliminated if we are to be successful in our efforts to take full advantage of modern

therapy (Lichtenstein, 2003, Weiss et al, 2006 in Rao, 2010:117). Due to prevailing high stigma in leprosy, many great developments in the management of the disease and its complications such as DT (Drug used for Treating Leprosy), Corticosteroids and even reconstructive surgery have failed to effectively address the problem. In fact, stigmatization continues to weaken, hinder and affect efforts made by several national governments towards eradicating and controlling the disease of leprosy (Rao et al, 2008, WHO, 2006, Dongre, 2003 in Rao, 2010:117).

Heijnder (2004) suggested that, to address stigma associated with leprosy, communities need to be targeted with information regarding leprosy and stigma, efforts should be made to change negative attitudes and practices. Particularly the linkage with the stereotypes dangerousness and infectiousness provokes adverse reaction among the public. Messages like “leprosy is not infectious anymore after starting treatment” should be one of the key targets for anti-stigma interventions. Chen and Sim (1986) suggested a culture specific health education. Culture-specific health educations programme for instance in Malaysia incorporated, local cultural beliefs and considered the people’s sensitivities, social structure, values and beliefs. This strategy has also been found to increase the acceptance of leprosy messages and improved knowledge and attitudes toward leprosy.

Interventions to address stigma and discrimination of leprosy are needed at five levels: the intrapersonal, interpersonal, organizational/institutional, community and governmental/structural level reduction programs should use a combination of approaches. Promising interventions are empowerment, counseling, contact with affected persons and education. Activities to reduce stigma can be grouped into four as given below:

1. Spread the demystifying messages and its interpretations, mainly regarding nature of disease, whether hereditary, whether leprosy cases are touchable, role of immunity in occurrence of leprosy, what is burnt out case and so on.
2. In discriminatory behavior of health workers / medical officers while examining and treating e.g. dressing the ulcers and counseling.
3. Community counseling, Group meetings and discussions using live case stories, incidences and involving Leprosy cases in discussion. This can be clubbed with developing “self care groups” and involving community in treatment provisions.
4. Integration of leprosy services into general health care practicing no isolation – no discrimination in wards (www.nlep.nic.in/pdf/stigma). In many countries, leprosy services have been integrated into general health services, aiming to provide care for leprosy patients near to their homes and to reduce the feeling of difference between leprosy patients and those with other diseases. A study conducted in Maharashtra, India, compared stigma levels between areas with integrated and vertical care approaches to leprosy control (Arole, Premkumar and Arole, et al., 2002) It established there was less self-stigmatisation among leprosy patients and less social stigma in communities where leprosy was integrated into general health services (Sermrittirong, Van Brakel and Bunbers-Aelen, 2014).

In addition to integration of leprosy services in general health care, Sermrittirong, et al., (2014) identified these interventions to reduce stigma: socio-economic rehabilitation (SER); changing the name of the disease; counseling and Information, Education and Communication (IEC) programmes. To empower self-reliance, social-economic

rehabilitation (SER) has been launched in many leprosy programmes. In Southern Nepal, Cross & Choudhary (2005) launched the Stigma Elimination Project (STEP) in 2002. The project started by appointing 10 people affected by leprosy to act as facilitators to develop self-care groups in their villages. These people had attended self-care training, a core feature of the programme run by the Nepal Leprosy Trust (NLT). After the training, the facilitators were assigned to encourage people affected by leprosy in their village to establish self-care groups with the primary objective of controlling impairment. After one year, the groups took on the form of self-help groups for credit and micro enterprise development and had expanded their membership to include other marginalized people. The groups contributed to the development of their communities. The effectiveness of the programme was confirmed by measuring the level of social participation reported by the members of the group. The STEP participants had significantly higher levels of participation compared with controls that had not been part of the intervention and their levels of social participation were higher than would be expected even for the general population. In addition, leprosy-affected people without visible signs or ulceration (whether in STEP group or not) did not appear to suffer participation restriction.

Ebenso et al. (2006) studied the impact of SER on leprosy stigma in five northern states of Nigeria. A set of quantitative questionnaires and semi-structured interviews were conducted with 20 randomly selected SER participants. Five focus group discussions and 10 key informant interviews were also conducted to complement individual interviews. SER was found to improve self-esteem, financial independence, acquisition of new skills, and access to public institutions. SER also influenced the process of social integration, resulting in a positive attitudinal change towards SER participants.

To address stigma, the idea of changing the name of the disease has been suggested. As the term 'leprosy' may lead to discrimination, there were attempts to change the name to Hansen's disease after the Norwegian medical scientist who discovered *Mycobacterium leprae*. Zen-Ryo-Kyo, the National Hansen's Disease Sanatoria Residents' Association of Japan, began to promote the new term in 1952. The term was gradually accepted and Japan's mass media started using 'Hansen's disease' in the mid-1960s. By the end of the 1970s, the word 'leprosy' had been mostly abandoned in Japan (Hosoda, 2010). In Thailand, an attempt to change the name 'leprosy' to be 'Numbness skin disease' was initiated at a meeting of leprosy workers at national and regional levels in 2003. The new name was used by some regional leprosy programme in IEC campaigns. The 'Leprosy clinic' of the National Leprosy Organisation changed its name to 'Numbness skin disease clinic'. There is no evidence to show to what extent the new name has changed attitudes towards leprosy (Sermittirong, et al., 2014).

Counseling may help people affected by leprosy to cope with physical and psychological effects of the disease. A pilot study of group counseling for people affected by leprosy was conducted in Nepal from 1994 to 1998 (Richard and Gurung, 2000). Groups composed of 5-7 individuals meet for 2-hour sessions for 5 weeks. They met as single-gender adult or children's groups. Patients were included after a psychological assessment in which they had demonstrated at least one of the following: their own recognition that their low self-esteem is due to stigmatisation, rejection by their families, or that they were despondent but not clinically depressed. Participants were encouraged to share their life stories with the other members of the group. This developed bonds between group members as they heard others tell about their own painful experiences and they could comfort each other.

The patients learned to forgive other people who hurt them, and prepared to return home to cope with expected stigmatisation (Richard and Gurung, 2000).

Information, Education and Communication (IEC) is an approach used to raise the general population's awareness of leprosy, aiming to reduce stigma, and to encourage people who suspect that they may have contracted leprosy to report early to a health unit before developing disability. The social marketing campaign undertaken in Sri Lanka is an example of a successful IEC intervention. It was launched in 1990, encouraging people with suspicious skin lesions to seek diagnosis and also aiming to change the negative attitudes of the general population towards leprosy (Williams, Dewapura, Gunawardene and Settinayake, 1998). Health providers were trained to diagnose leprosy and to refer persons with suspicious lesions to leprosy staff. The costs of seeking care, such as bus fares and lost wages, were reduced by improving the network of clinics. In addition; public health messages were conveyed using different media, informing people that leprosy is a 'normal' disease that can be cured and does not necessarily lead to disability if treatment is sought early. Before creating the content of messages, the campaign undertook community-based surveys on knowledge, attitudes and practices related to leprosy, as well as focus groups to explore public perceptions of leprosy. These rounds of consultation established that leprosy was perceived to be an extremely infectious, incurable and dreaded disease that caused fingers to fall off. This information was used to develop targeted IEC materials. After less than a year, newly detected cases increased by 150% with a dramatic increase in self-reporting (Williams et al., 1998).

However, IEC may result in more stigmatization, if done carelessly (Predaswat et al, 1992). Posting pictures of impairments related to leprosy to encourage people to get early treatment, and mentioning the transmission of the disease, without mentioning the small chance of being infected and effective drug treatment, may provoke a negative image of leprosy and a fear of transmission among the target population. Leprosy is not the only disease in which stigma may be increased by IEC interventions. IEC interventions in tuberculosis sometimes yield similar unintentional results. Inaccurate health education messages by health professionals were mentioned by the community participants of Dodor's (2008) study in Ghana as the basis of their attitudes and behaviours towards leprosy patients. The message commonly used reminds people to avoid sharing household items with leprosy patients. This makes people think that the patient should be isolated and his plates separated from those used by the rest of the household and families with a patient who had deformities faced 10 times higher societal problems than those having patients with no deformities.

2.9 Theoretical Framework

In sociological analysis, theories are indispensable. Theories form an integral part of sociological research, as they enable a researcher to understand and comprehend the most difficult aspect in an area of study. It is a general principle that explains or predicts facts, observations or events. McQuade (2006), defined a theory as an interrelated and testable set of propositions that explain a phenomenon. Osuala (1992), also defined a theory to be an attempt at synthesizing and integrating empirical data for maximum clarification. In the same view, Haralambos and Holborn (2008), also defined sociological theories to be a set of ideas that provide an explanation for something. In order to understand and explain

stigma and the management of leprosy identity in Askira/Uba local government area of Borno state, Nigeria, Goffman's theory of Stigma, Social Identity and Labeling is adopted.

2.9.1: Goffman's Theory of Stigma, Social Identity and Labeling: Consequences for Health and Illness

Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial English usage. Stigma remains a very real problem for those affected by the disease and a major challenge for implementation of effective public health interventions. The stigma of mental illness: the negative attitudes toward and rejection of the mentally ill is a topic that has received increasing attention in recent years. The term stigma comes from the Greek and means a mark or brand on the body, especially one that signifies shame and brings discredit to the individual. The earliest reference to the idea of stigma appears to be in the Bible. In Genesis (4:8-16) we learn that Cain slew his brother Abel, and that God punished Cain by banishing him from Eden and making him a fugitive and a wanderer. God set a "sign" on Cain's forehead; so that no one would smite him (thereby lifting the punishment) and that everyone would know the terrible deed he was guilty of (Weinstein, 1981:88).

The most important theoretical work on stigma is undoubtedly that by Goffman (1963). He posits that the term stigma is today still widely used in the original Greek sense, but is applied more to the disgrace itself than to the bodily evidence of it. Hence, Goffman differentiates three types of stigma: abominations of the body (physical deformities or handicaps), blemishes of individual character (mental disorder, alcoholism, drug addiction, homosexuality, criminality), and social impairments (of race, nationality, religion, caste, or class).

Stigma is universal, as all societies establish the means of categorizing persons and determine which human attributes are praiseworthy and which are discrediting. Goffman emphasizes strongly that stigma is a characteristic that is imputed by society to a given attribute and is not inherent in the attribute itself. Stigmatization thus varies according to time, place, and circumstance. The character bestowed on an individual becomes, in effect, a social identity (Weinstein, 1981:89).

Society teaches its members to categorize persons by common defining attributes and characteristics (Goffman, 1963). Daily routines establish the usual and the expected. When we meet strangers, certain appearances help us to anticipate what Goffman called “social identity.” One’s social identity may include physical activities, professional roles and the concept of self. Hence, anything that changes one of these attributes, such as disability; changes the individual’s identity and thus, potentially creates stigma (Markowitz, 1998).

Stigma greatly influences a person's self-conceptions and interactions with others. Hence, Goffman (1963) maintains that, the stigmatized are primarily concerned with the management of their spoiled identity. The management of stigma: how to conceal it, disavow it or claim a more favorable social identity depends largely on such factors as the visibility of the stigma and the stigmatized personality, techniques of information control, and group alignments.

Based on participant observations of a large State mental hospital, Goffman (1961) maintains that, institutionalized patients feel a strong sense of stigma. They have identity problems, experience greater social distance between them and others, and suffer anxiety over loss of self-esteem. The hospital's bureaucratic and authoritarian structure leads to a

"mortification of self" in patients: restrictions on liberties, depersonalization of relationships, dispossession from normal social roles, abuse by staff, profanations by other patients. Furthermore, in a study conducted by Link et al., (1997), it was revealed that, perceived devaluation and discrimination as well as actual reports of discrimination continued to have negative effects on clients (patients) even in situations where they have responded well to treatment. Thus, they concluded that, health professionals attempting to improve the quality of life and wellbeing of clients with mental illness must first contend with the effects of stigma in its own right in order to be successful.

Based on the assumptions of Goffman's theory of Stigma, Social identity and labeling, the label or attribute given to person negatively influences the social interaction between the labeled person and others. A leprosy victim is often labeled as (someone abnormal with deformed fingers, leg and face). This label influences the social interaction between the labeled person and others. The person is labeled negatively, his or her status is devalued, and consequently the label could have negative consequences for this person, personally and socially. The label modifies the actions of others towards the labeled person. The physical marks such as deformity of fingers, leg and face in leprosy generate a negative response in other people. It is evident that, an individual suffering from leprosy can be discriminated against, treated as an outsider, and eventually stigmatized in the society. This stigma has a long lasting effect on the victim. It affects their every-day social activities, economic activities, and even their participations in religious gatherings. Evidently, families and loved ones or anyone who has any form of transactions with them are being stigmatized. Therefore, this study adopts this theory as it helps explain how label by others leads to stigma and the effects of stigma on social interaction.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter is aimed at presenting a detailed description of all the processes that were employed in the execution of this study. This chapter contains a description of the location of study, population of the study, types and sources of data, methods of data collection, sampling techniques and methods of data analysis.

3.2 Location of Study

The location of study is Askira/Uba Local Government Area of Borno State. The local government area is geographically located at the southern part of Borno State (a State in the North-eastern geo-political zone of Nigeria). Askira/Uba Local Government Area lies between latitude 11° 15N and longitude 11°30E. The Nigeria Official Gazette (2007) stated that, the local government area are made up of a population of about 138, 091 and has 13 political wards with two chiefdom (Askira chiefdom and Uba chiefdom). Askira/Uba local government is one of the oldest local governments in the State. The inhabitants of the area are predominantly farmers and traders with a few government workers. The major agricultural products are: maize, groundnuts, guinea corn, beans etc. The local government area is a border town to Adamawa State and it was established in 1976. The local government has many ethnic groups; Margi tribe, Chibok tribe (Chibok is both a tribe and a town) and Fulani. The local government area is one of the settlement areas of Christian missionaries in northern Nigeria. However, Islam and Christianity are practiced in the area.

Askira/Uba local government area has one of the highest rates of leprosy in Borno State, as it recorded two hundred and ten (210) new cases of leprosy while other local government

areas recorded below one hundred and fifty (150) new cases in 2013/2014 (Borno State tuberculosis and leprosy annual report, 2013/2014).The prevalence of leprosy cases in Askira/Uba local government area necessitated the choice of the study area.

3.3 Population of the Study

The target population (unit of response) of this study consisted of individuals infected with leprosy, health care providers, chiefs, religious leaders, market leaders, road transport leaders and people residing within the area of study. Askira/Uba Local Government has a population of 138, 091 as at 2006 Census.

3.4 Types and Sources of Data

Primary and Secondary data were used for the study. The data were collected from the people of Askira/Uba Local Government Areas through survey, in-depth interview (IDI), and Focus Group Discussion (FGD).

3.5 Sample Size and Sampling Techniques

The sample size for the study was arrived at based on Krejcie and Morgan (1970) sample size table (See appendix III). Krejcie and Morgan (1970) prepared table which present the sample size in line with a certain degree of reliability and population size. This Table was used to determine the sample size for the study. The estimated population of Askira/Uba Local Government Area as at 2006 census report is 138, 091. Based on the Krejcie and Morgan (1970) table and the population of Askira/Uba Local Government Area, the study's required sample size is 384.

Sampling refers to the process of selecting a sample or a subset or a portion of the population to represent the entire population in a study (Akpabio and Ebong, 2009).

According to Gyong (2011:10), a “reasonable” sampling size should be selected mainly based on the scope and resources available to the researcher. For this study, samples were drawn from two categories. The first categories are the residents of Askira/Uba local government areas. The second categories are the patients, doctors, chiefs, market leaders; roads transport worker leaders and religious leaders of Askira/Uba local government areas.

Simple random sampling through ballot process was adopted to select six wards (Lassa, Husaratampul, Ngulde, Mussa, Uba and Askira) out of the thirteen wards since it is a cumbersome task for the researcher to cover all the wards. From each selected political ward, a settlement was selected at random. To select a settlement, the names of the settlements were written folded and placed on a tray then picked at random; the ones picked in the process represented the samples for the study. From the selected settlements, starting from a major street and moving in clockwise direction, thirty two (32) houses with occupants were identified. From each household, two eligible respondents were selected at random. Where eligible respondents were more than two, the eldest adult household member either male or female and the youngest adult household member either male or female were selected. From each of the six sampled settlements, sixty four (64) respondents were selected for the study. Table 3.1 shows the sample frame for the study

Table 3.1 Sample Frame for the Quantitative Data

| Selected Ward | Selected Settlement | Number of respondents selected |
|----------------------|----------------------------|---------------------------------------|
| Lassa | | 64 |
| Husara-Tampul | | 64 |
| Ngulde | | 64 |
| Mussa | | 64 |
| Askira | | 64 |
| Uba | | 64 |
| Total | | 384 |

Source: Pre-field Survey, 2017

For the qualitative data, purposive sampling technique was adopted to select the key informants for the in-depth interviews and the participants for the Focus Group Discussions. For the IDIs, twelve (12) key informants were selected for the study; they consisted of two leprosy victims, two doctors, two community heads, two spiritual leaders, two market leaders and two roads transport leaders. The position of individuals and level of interaction with members of community and knowledge on the issue being studied informed the selection of these key informants. Being a victim of leprosy and the need to get first hand information on experience of stigma and coping strategy necessitated the choice of leprosy victims. Doctors were selected because of being care providers for leprosy patients they are also knowledgeable on the issue being investigated.

For the FGDs, three (3) FGD sessions were organized. The first session was organized with leprosy victims below the age of 18 years; the second with adult male victims of leprosy and the third with friends and acquaintances of victims of leprosy. FGD session with leprosy victims below the ages of 18 years had five male participants. Adult male victims of FGD session had six participants while FGD with friends and acquaintances of victims of leprosy was made up of five participants. The total number of

participants for the FGD was sixteen (16). The FGD and interview sessions lasted for 1hour-1hour 30 minutes each.

3.6 Method of Data Collection

In order to collect reliable data and capture the range of information required in pursuance of the research objectives, both quantitative and qualitative data collection techniques were used. The quantitative data was obtained through survey by administering questionnaires. The questionnaire consisted of seven sections (A-G). Section A covered the socio-demographic profiles of respondents while sections B-G are designed according to the objectives of the study. This enabled the researcher to obtain the data he needed to address the subject of investigation. Both open and closed ended questions were used in the questionnaire. The open-ended questions allowed respondents to express their opinions on particular issues. On the other hand, the closed-ended questions restricted the respondents to pick a particular option from a wide range of options available.

For the researcher to obtain access to the target population, an introductory letter was obtained from the school. The researcher was assisted by two research assistants (male and female) to administer questionnaires to respondents. The research assistants were residents of Askira/Uba Local Government Area, who speak the local dialects and English fluently. The research assistants were undergraduate students from social science discipline. The researcher trained them by explaining the various items in the questionnaire and the correct ways to record responses respondents provided. The purpose and nature of the study was explained to respondents to obtain verbal consent before inclusion in the study. They were assured of anonymity and confidentiality to gain their cooperation to participate in the

study. For respondents that are literate, they filled the questionnaire themselves while for those that are not literate, the research assistants and the researcher filled their questionnaires by asking them questions and recording their responses on each item on the questionnaire. In each sampled settlement, questionnaires were administered to household members' age 18 years and above. Individuals who are resident in the area for a period of less than 6 months prior to the study were not eligible for the study.

The qualitative data was obtained through in-depth interview (IDI) and Focus Group Discussions (FGD). The IDI and FGD were collected through the use of 'Guides' which contained questions the researcher used during the interviews and discussions. The Key informants were briefed on the objective of the study and were assured that their anonymity and confidentiality would be maintained. For the focus group discussions, it was based on focus group discussion guide that contained statements and probe based on the objectives on the study. The focus group discussions were moderated by the researcher. Brief introduction to the study and the purpose of involving the discussants was discussed. They were assured of anonymity and confidentiality. Participation of informants below the ages of 18 years suffering from leprosy was based on their acceptance and willingness to participate in the study and consents of their parents/guardians.

The researcher sought key informants and focus group participants' permission to use a tape recorder. The researcher made use of a tape recorder and a field note in order to capture both the audio conversation and body language of the key-informants and discussants during the interviews and focus group discussion sessions. The in-depth interview guide and focus group discussion guide were carefully designed in such a way that, they encompassed the objectives of the research and gave the interviewer a rich and comprehensive data. Thus, the use of both

methods of qualitative data collection enabled the researcher to enrich data for the study and ensured reliability and validity of data collected.

3.7 Method of Data Analysis

Data collected through the quantitative technique (administration of questionnaires) were edited, coded and analyzed using the statistical package for social science (SPSS). The result was presented in the form of frequency tables and percentages with an explanation at the end of each table for easy comprehension. The data that were collected through the use of in-depth interview and focus group discussion were transcribed verbatim by the researcher. After that, the thematic and narrative analyses were used to analyze the data. Furthermore, the qualitative data were incorporated and synergized (triangulated) to show the similarities and differences in the responses provided by the study participants.

3.8 Ethical Considerations

In conducting this research, such ethical issues were observed. For instance, the research introduced himself and also made known the purpose of the study, to the respondents and the key informants and participants. Involvement of any respondent for survey and any key informant and participant for interviews and discussion in the research was voluntary. No one was forced to participate in the research in any way. This was achieved by enquiring from the populations their willingness to be involved in the study. Only members of the community who were willing to participate in the study were sampled and administered the questionnaires to or interviewed. Anonymity and confidentiality of the respondents and the informants were also maintained in the research.

In the case of anonymity, no response is presented in a way identifiable by the researcher or the readers of the findings with any respondent. In the case of confidentiality, no response made by an informant known to the researcher is identified with the informant to make known to anybody or the public. The assurance of anonymity and confidentiality is indicated by the nature in which the instruments for the data collection were designed. For instance, in the survey instrument, there was no provision for name of respondent, which made the responses anonymous as the researcher could not identify a particular filled questionnaire with a particular respondent. For in-depth interviews, letters such as a, b, c and so on were used to differentiate one informant's responses from another, instead of using the names of the informants, which made their information confidential, as the researcher could not identify a particular response with a particular informant in the analyses.

3.9 Methodological Challenges

The fact that it is not easy or possible to carry out a research work smoothly, from the beginning to the end, without problems, was no exception in this study. At a point I became discouraged but, determination, courage and confidence coupled with hard work, on the side of the researcher, and success stories of others who went through similar process before this work, became the veritable tools the researcher used to achieve the success of this study. Although the respondents were receptive and showed enthusiasm about the work, they were reluctant in returning the questionnaires. It took the researcher weeks to retrieve the served questionnaires, after the administration. Up till the time the data were analysed some respondents did not return their questionnaires.

On the side of the IDIs and FGDs, since the wards and the settlements are not in the same place, but scattered across the study area, shuttling from one political ward and settlements to others, was a herculean tasks in terms of time, energy, and finance, which the researcher grappled with. He also encountered difficulty in accessing the Key informants for interviews and organizing groups for the FGDs which were at their convenience. To be able to overcome all these problems, the researcher had to scheduled and rescheduled meetings with the people concerned. He also had to deny his family some rights of being giving certain attention and provision of resources just to see that he makes the study a reality. Thus, the concern of the respondents, key informants, the participants, who provided the needed data, and the research assistants who were so patient and committed to see that the work is a success story cannot be underestimated. However, in spite of the challenges the researcher encountered in the field, he never become discouraged in any way.

CHAPTER FOUR

ANALYSIS AND INTERPRETATION OF DATA

4.0 Introduction

The content of this chapter is on the analyses and interpretation of the quantitative and qualitative data collected from the field. This is done thematically based the objectives of the study. The purpose of this research is to examine stigma and the management of leprosy identity in Askira/Uba Local Government Area of Borno State. This chapter comprises of seven sections which are; socio-demographic characteristics of the respondents, prevalence of leprosy in Askira/Uba LGA, causes of leprosy in Askira/Uba LGA, factors contributing to leprosy stigma, effects of stigma on leprosy victims, coping strategies adopted by leprosy victims and finally, recommendations on how to mitigate leprosy stigma.

The study adopted the use of triangulation in the analyses and interpretation of data. The triangulation method involves the combination of both quantitative and qualitative method in the interpretation of the findings collected from the field. This method automatically increases the validity of the study as findings from the various methods of data collection complement each other. Two hundred and nine questionnaires were successfully retrieved out of three hundred and eighty four distributed. Ten (10) key informants were interviewed and three FGD sessions were held. Although 384 questionnaires were distributed, the researcher was able to retrieved 375. Thus, the analysis of the quantitative data is based on 375 questionnaires retrieved.

4.1 Socio-Demographic Characteristics of Respondents

This section presents the socio-demographic characteristics such as sex, age, marital status, religion, occupation and level of education of the respondents.

4.1.1 Socio-Demographic Data of Respondents

| Variable | Frequency | Percentage (%) |
|---------------------------|------------|----------------|
| Gender | | |
| Male | 224 | 59.7 |
| Female | 151 | 40.3 |
| Total | 375 | 100.0 |
| Age | | |
| Below 21 years | 84 | 22.5 |
| 21-30 years | 100 | 26.8 |
| 31-40 years | 99 | 26.3 |
| 41-50 years | 81 | 21.5 |
| 51 years and above | 11 | 2.9 |
| Total | 375 | 100.0 |
| Marital status | | |
| Single | 110 | 29.3 |
| Married | 183 | 48.8 |
| Divorced/separated | 50 | 13.4 |
| Widow | 23 | 6.2 |
| Widower | 9 | 2.4 |
| Total | 375 | 100.0 |
| Religion | | |
| Christianity | 156 | 41.6 |
| Islam | 151 | 40.3 |
| Traditionalist | 63 | 16.7 |
| None | 5 | 1.4 |
| Total | 375 | 100.0 |
| Occupation | | |
| Civil/public servant | 82 | 22.0 |
| Business/petty trader | 61 | 16.3 |
| Farmer | 135 | 35.9 |
| Artisan | 18 | 4.8 |
| Student | 48 | 12.9 |
| Beggar | 2 | .5 |
| None | 29 | 7.7 |
| Total | 375 | 100.0 |
| Level of education | | |
| None | 66 | 17.7 |
| Quranic education | 74 | 19.7 |
| Primary | 104 | 27.8 |
| Secondary | 47 | 12.4 |
| Tertiary | 84 | 22.5 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

Table 4.1.1 shows the socio-demographic data of the respondents. The result collected indicates that males were most represented in the study as majority of the respondents 59.8% were males while 40.2% were females. Most of the survey respondents are young adults as ages of 21-30 years made up 26.8%, while very few elderly persons age 51 years and above participated as they make up respondents 2.9%. Individuals that are married made up majority 48.8% while widowers were least represented as they made up 2.4%. There is no significance difference in the number of survey respondents that practices Christianity and Islam as 41.6% are Christians and 40.2% practiced Islam. This implies that the two religions are dominant in the area. Data collected on the occupational practice revealed that 35.9% of the respondents are farmers, followed by civil/public servants 22.0%. The level of formal educational attainment of survey respondents is low as 27.8% have primary school education while few 17.7% have no formal education.

4.1.2 Distribution of Retrieved Questionnaires according Wards

| Wards | Frequency | Percentage (%) |
|-------------------|-----------|----------------|
| Lassa ward | 72 | 19.1 |
| Husaratampul ward | 56 | 14.8 |
| Ngulde ward | 73 | 19.6 |
| Mussa ward | 63 | 16.7 |
| UBA ward | 61 | 16.3 |
| Askira ward | 50 | 13.4 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

The table 4.1.2 shows the distribution of the retrieved questionnaires according to wards of the respondents. The data on the table shows that 19.1% of the questionnaires were retrieved from Lassa ward, 14.8% of them are from Husaratampul ward, 19.6% are from Ngulde ward, 16.7% are from Mussa ward, while 16.3% are from UBA ward, and 13.4%

are from Askira ward. This shows that most of the questionnaires were retrieved from Ngulde ward, followed by Lassa ward. This means that most of the respondents that participated in the survey are from the aforementioned wards. It is worthy to note that Lassa ward, Mussa ward, and Husara ward belongs to Uba chiefdom while Ngulde and Askira ward belongs to Askira chiefdom.

4.2 Prevalence of Leprosy in Askira/ Uba LGA

The focus of this section is to examine the prevalence of leprosy in the study area.

4.2.1 Respondents Awareness of Leprosy Disease in Askira LGA.

| Response | Frequency | Percentage (%) |
|----------|-----------|----------------|
| Yes | 250 | 90.9 |
| No | 125 | 9.1 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

Table 4.2.1 shows respondents awareness of leprosy in Askira LGA. One hundred and ninety 90.9% were aware of leprosy but 9.1% were not aware. This means that overwhelming majority of the respondents were aware of leprosy in Askira local government area. All discussants in the FGD and key informants interviewed acknowledged that, they are aware of leprosy in the area.

An informant, a cleric from Musa ward said:

Yes, am aware of leprosy. The disease was here in the area for long time ago, but gradually it is going off but the only reason why the disease is still here is because they are not taking serious action on it.

Similarly, another victim of leprosy from Uba stated that:

I am aware and I am a victim. It has been for long time and when I take drugs the symptoms will subside but when there is no drug, the symptoms increases.

In the course of the research, majority of respondents 184(88.0%) knew individuals suffering from leprosy infection but 25 (12.0%) were not. This means that overwhelming majority of the respondents studied knew someone that is suffering from leprosy infection. Both IDI and FGD data concurred survey finding.

A discussant (family member to a victim) indicated that:

It is sad, but we have to live and deal with the disease. There is hardly anyone in this community who can boldly say I do not know one person suffering from leprosy.

Similarly, a victim (male below age 18 years) was of the view that:

Leprosy is not a new thing is Askira/Uba, a lot of people are aware of the disease and also know one or more people with the disease.

4.2.2 Respondents Relations with Victims of Leprosy

| Relations with victims | Frequency | Percentage (%) |
|------------------------|-----------|----------------|
| Relative | 151 | 40.2 |
| Family member | 106 | 28.3 |
| Friends | 49 | 13.0 |
| Neighbor | 69 | 18.5 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

Table 4.2.2 reveals the proportions of respondents' relationship with leprosy victims. The data show that 40.2% of the respondents indicated that a relative of theirs has leprosy, 28.3% identified a family member, 13.0% a friend, while 18.5% a neighbor.

4.2.3 Prevalence of Leprosy Disease in Askira LGA.

| Response | Frequency | Percentage (%) |
|----------|-----------|----------------|
| Yes | 329 | 87.6 |
| No | 46 | 12.4 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

The table above shows that 87.6% of the respondents affirmed that leprosy is prevalent but 12.4% indicated that it is not. The finding implies that majority of the respondents studied are of the view that, leprosy is prevalent in Askira/Uba Local Government Area. Similarly, key informants and focus group discussants affirmed that leprosy is prevalent in Askira/Uba Local Government Area.

A discussant (friend of leprosy victim) is of the view that:

Leprosy is well pronounced here in Askira/Uba, we interact with lepers on daily basis.

A discussant (a victim below 18yrs) revealed that:

There is high rate of the disease among elderly people, but among my peers, it is not common.

A key informant (head of transporters) shared this view:

In fact the disease is popular in our area but if you take serious action on the treatment you will be free.

The researcher could not layhands on hospital records on leprosy prevalence in Askira/Uba local government area as the hospitals were destroyed as a result of insurgency attacks. The few clinics functioning in the area did not have a good documentation on leprosy rate.

4.3 Causes of Leprosy in Askira/Uba LGA

This section investigates respondents' views on causes of leprosy in Askira/Uba local government area. The views of the respondents are represented on table 4.3.1 below.

4.3.1 Causes of Leprosy in Askira/Uba Local Government Area

| No. | Causes | Agree | Strongly agree | Disagree | Strongly disagree | Undecided | Total |
|-----|---------------------------------|----------------|----------------|---------------|-------------------|-----------|-----------------|
| 1 | Contact with an infected person | 201 (53.6%) | 90 (23.9%) | 36 (9.6%) | 29 (7.7%) | 19 (5.2%) | 375 (100.0%) |
| 2 | Environmental condition | 147 (39.2%) | 75 (20.1%) | 65 (17.3%) | 75 (20.1%) | 13 (3.4%) | 375 (100.0%) |
| 3 | Consumption of Fat and Oil | 91 (24.4%) | 126 (33.5%) | 64 (17.2%) | 74 (19.6%) | 20 (5.3%) | 375 (100.0%) |
| 4 | Spiritual infliction | 81 (21.5%) | 95 (25.4%) | 50 (13.4%) | 133 (35.4%) | 16 (4.3%) | 375 (100.0%) |
| 5 | Inheritance/genetic | 142 (37.8%) | 140 (37.3%) | 25 (6.7%) | 57 (15.3%) | 11 (2.9%) | 375 (100.0%) |
| 6 | Dirty Environment | 117 (31.1%) | 124 (33.0%) | 43 (11.5%) | 82 (22.0%) | 9 (2.4%) | 375 (100.0%) |
| 7 | Curse | 86 (23.0%) | 93 (24.9%) | 47 (12.4%) | 117 (31.1%) | 32 (8.6%) | 375 (100.0%) |
| 8 | Blood transfusion | 81 (21.5%) | 115 (30.6%) | 63 (16.7%) | 96 (25.6%) | 20 (5.4%) | 375 (100.0%) |

Source: Fieldwork, 2016

The result collected revealed that most respondents 53.6% agreed that contact with an infected person causes leprosy, 39.2% agree on environmental condition, 70 (33.5%) strongly disagree that sin causes leprosy, 33.5% strongly agree that consumption of oil and fats causes leprosy infection, 35.4% strongly disagree that leprosy is caused by spiritual infliction, 37.8% strongly agree that leprosy is an inheritance/genetic, 33.0% strongly agree that environmental factors causes leprosy, 31.1% strongly disagree that leprosy is a curse, while 30.65 strongly agree that blood transfusion causes leprosy.

In response to the question on causes of leprosy, an informant who is Doctor in Askari said that:

It is caused by bacteria. Any infected person can transfer the disease through contacts with others and blood transfusion can also be responsible. Lack of environmental sanitations can't be ruled out as a causal factor.

An informant (head of the market) in Uba shared his view as follows:

Through eating, sleeping and staying in same place with those with the disease, one can be contact the disease. Also, there is this belief that it is inevitable because in some families it is generational, and others belief that, it is a curse. There are many causes of leprosy like eating fats and oil.

Also another informant (head of transport) in Husaratampul was of the view that:

It is believed that the disease is inherited. What I know is that somebody can only get the disease genetically.

A discussant (victim below 18yrs) said that:

Neither my parents nor Grandparents, have leprosy. I for one think leprosy is not genetic rather it has to do with witchcraft and diabolical use of charms. There are relatives who have seen ones star and will go to any length in cutting down ones glory.

Another discussant (Family member) shared his view as follows:

I know that there are various factors that are responsible or play a major role in contacting the disease. These factors range from spiritual to contacts with people who have it and so on. But, if it is diet or cleanliness rate, I totally disagree because we are mindful of our surrounding and also very particular about our diets.

Most findings from the survey are supported by in-depth interviews and focus group discussions data. The study respondents believed that leprosy is caused by consuming oily and fatty food, poor environment, and contact with an infected persons, spiritual attacks and leprosy is hereditary. It was observed during the in-depth interview that, education and occupation influenced perception on the cause of leprosy. The medical practitioners were more articulate while the heads of market and transporters still largely believe in the spiritual/ curse as causes of leprosy.

4.4 Contributing Factors to Leprosy Stigma in Askira/Uba LGA

Presented in this section are views of respondents on factors that contribute to leprosy stigmatization. Table 4.4.1 presents views of the respondents on leprosy stigmatization

Table 4.4.1 Views of Respondents on Leprosy Stigmatization

| Are victims of Leprosy stigmatized? | Frequency (F) | Percent (%) |
|--------------------------------------------|----------------------|--------------------|
| Yes | 359 | 95.7 |
| No | 16 | 4.3 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

Majority of the respondents 95.7% were of the view that, victims of leprosy are stigmatized in the community but 4.3% disagreed. This finding was supported by data from the in-depth interview and focus group discussions. By implication, the leprosy victims suffer a lot of stigma in their day to day dealing. Contributing factors to leprosy stigma are as presented in Table 4.4.2 below.

4.4.2 Contributing Factors to Leprosy Stigma in Askia/Uba LGA

| No. | Factors | Agree | Disagree | No response | Total |
|-----|---------------------------------------------------------------------------------------------|----------------|----------------|-------------|---------------------|
| 1 | Discrediting beliefs and misconceptions regarding the causation and transmission of leprosy | 337 (89.9%) | 30 (8.1%) | 8 (2.0%) | 375 (100.0%) |
| 2 | Misconceptions regarding the incurability and high infectiousness of leprosy | 238 (87.4%) | 38 (10.1%) | 9 (2.5%) | 375 (100.0%) |
| 3 | Fear of his/her deformities/look | 287 (76.6%) | 84 (22.4%) | 4 (1.0%) | 375 (100.0%) |
| 4 | Fear other people will think I have leprosy too | 266 (70.8%) | 102 (27.3%) | 7 (1.9%) | 375 (100.0%) |
| 5 | Fear of transmission | 313 (83.3%) | 52 (13.9%) | 10 (2.8%) | 375 (100.0%) |
| 6 | Think leprosy patients are bad people | 371 (72.2%) | 82 (22.0%) | 22 (5.8%) | 375 (100.0%) |
| 7 | Think leprosy person are cursed and don't want to associate with them | 278 (74.1%) | 70 (18.7%) | 27 (7.2%) | 375 (100.0%) |

Source: Fieldwork, 2016

Table 4.4.2 shows the factors contributing to leprosy stigma. The result gathered indicated that discrediting beliefs and misconceptions regarding the causation and transmission of leprosy contributes to leprosy stigmatization; this is indicated by 89.9% of the respondents. Misconceptions regarding the incurability and high infectiousness of leprosy are also a contributing factor to leprosy stigmatization in the study area; this is revealed by 87.4% of the respondents. The study further discovered that fear of the deformities/looks of leprosy victims, fear that other people will think they have leprosy too, fear of transmission, and the thought that leprosy victims are cursed and don't want to associate with them are contributing factors to leprosy stigmatization; these are indicated by 76.6%, 70.8%, 83.3%, 72.2%, and 74.1% of the respondents respectively.

Amongst these contributing factors to leprosy stigmatization, fear of leprosy transmission was the major contributing factor to leprosy stigma was the most expressed view by some key informants and participants in the IDI and FGD.

An informant (Doctor in Askari) said:

Victims of leprosy suffer from various stigmas. They are stigmatized at home, hospitals, market centers, and even religious centers. We doctors that come in contact with them are often stigmatized; people try as much as possible not to come in contact with us especially if they know a leprosy patient came to the hospital earlier. If we that are not suffering from the disease can be avoided that much, picture the pains and level of stigma the leprosy patient suffers.

Also, an informant (Head of transporters in Uba) said:

We try to avoid them; I for one will not stop to pick a person suffering from leprosy. It is not because I see them as lesser humans or insignificant but because I owe it to myself to protect myself against such a deadly disease. If I contact it because I am trying to be nice, I endanger the lives of my family and every passenger I come across.

Similarly, an informant (Head of market Askari) said:

I often try as much as possible to be as brief as possible when they come to my shop. At times, when they come to buy something other customers keeps a reasonable distance from them and at times some customers had complained of me selling to them. The truth is, they are still humans and they have needs and I try to encourage people to sell to them. Who knows tomorrow, God forbid, what if I contact it tomorrow won't traders sell to me.

Similarly an informant (a cleric in Lassa) said:

We try as much as possible to encourage members to sit with them. It was observed some years back that members do not sit close to them and they are treated like a caste. So it was decided that in the house of God we will not treat them as caste and we will not compound their predicaments. So CAN agree that we preach on the love of God and His protections and ever since then members sit close to them but not so close.

A discussant (Victim of Leprosy in Uba) said:

Life is difficult for anyone with leprosy. It is surprising how friends and families avoid someone. It is so difficult that people cover their nose at times when we work past them. One is treated like shit, an alien and it is a very depressing experience. The most surprising is people in the House of God when asked to shake your neighbor in church will not shake you, they will pretend as if they didn't hear that part.

According to the (Head of Transport Uba):

In fact, people naturally fear bad things. So, if they see the victim's condition as bad, then they will not associate with the victim because of fear of being like the victim.

A discussant (victim of leprosy in Askira) said that:

There are so many factors, fear is one of them and this is so because the disease can be transmitted through contact. In fact, people fear the disease because of what they observe on the victims.

Furthermore, an informant (Ngulde Doctor) revealed that:

Some of the factors that lead to the stigma are due to misconception of the disease, and deformity looks.

A discussant (friend of leprosy victim) was of the view that:

Fear of contacting the disease contributes a lot to the level of stigma existing.

Key informants and discussants have varying perception with regard factors contributing to the stigma of leprosy. Their claims and the findings from survey show that, the different meanings people attached to the disease and fear of the disease leads to stigma.

4.5 Effects of Stigmatization on Leprosy Victims in ASkira/Uba LGA

The views of study respondents on the effects of stigmatization on leprosy victims are examined in this section. Table 4.5.1 presents the views of the respondents on challenges faced by leprosy victims in Askira/Uba Local Government Area.

Table 4.5.1 Challenges faced by Leprosy Victims in Askira/Uba LGA

| Challenges | Yes | | No | | Total | |
|------------------------------------------------------|---------------|-------------|---------------|-------------|---------------|-------------|
| | Frequency (F) | Percent (%) | Frequency (F) | Percent (%) | Frequency (F) | Percent (%) |
| Victims Exemption from community activities | 267 | 71.3 | 108 | 28.7 | 375 | 100.0 |
| Victims treated differently from others in community | 332 | 88.5 | 43 | 11.5 | 375 | 100.0 |
| Victims are not respected | 264 | 70.3 | 111 | 29.7 | 375 | 100.0 |

Source: Fieldwork, 2016

Table 4.5.1 shows that leprosy victims are exempted from community activities in the Askira/Uba Local Government Area; this stance is indicated by 71.3% of the respondents who indicated ‘yes’ to the view. Similarly, the leprosy victims are treated differently from

others and they are also not respected in the community; these are indicated by 88.5% and 70.3% of the respondents indicating ‘yes’ respectively. However, some leprosy victims still earn respect from people; this is revealed by 29.7% of the respondents who objected the view by indicating ‘no’ to the view. Table 4.5.2 presents leprosy stigmatization effects.

4.5.2 Effects of Leprosy Stigmatization on the Victims

| No. | Effects | Agree | Strongly agree | Disagree | Strongly disagree | Undecided | Total |
|-----|------------------------------------------------------------------------------------------------------------|-------------|----------------|------------|-------------------|-----------|--------------|
| 1 | Viewed as a lesser human | 187 (49.8%) | 154 (41.1%) | 9 (2.4%) | 11 (2.9%) | 14 (3.8%) | 375 (100.0%) |
| 2 | Status loss | 163 (43.5%) | 167 (44.5%) | 20 (5.3%) | 11 (2.9%) | 14 (3.8%) | 375 (100.0%) |
| 3 | Suffers discrimination | 146 (38.8%) | 190 (50.7%) | 14 (3.8%) | 11 (2.9%) | 14 (3.8%) | 375 (100.0%) |
| 4 | Experience social disengagement/isolation | 154 (41.1%) | 181 (48.3%) | 9 (2.4%) | 17 (4.4%) | 14 (3.8%) | 375 (100.0%) |
| 5 | Rejection from their families, friends | 135 (35.9%) | 159 (42.6%) | 20 (5.3%) | 45 (12.0%) | 16 (4.2%) | 375 (100.0%) |
| 6 | Suffer of economic hardship | 212 (56.5%) | 110 (29.2%) | 39 (10.5%) | 9 (2.4%) | 5 (1.4%) | 375 (100.0%) |
| 7 | Ex-patients with uniform deformities faced difficulty in adapting when they were back in their home | 174 (46.4%) | 124 (33.0%) | 48 (12.9%) | 24 (6.3%) | 5 (1.4%) | 375 (100.0%) |
| 8 | People with leprosy are not allowed to wash in the community water, eat, sleep on the same bed with others | 163 (43.5%) | 138 (36.8%) | 48 (12.9%) | 20 (5.3%) | 6 (1.5%) | 375 (100.0%) |
| 9 | People with leprosy are withdrawn from school | 140 (37.3%) | 140 (37.3%) | 45 (12.0%) | 37 (10.0%) | 13 (3.4%) | 375 (100.0%) |
| 10 | People with leprosy suffers retrenchment from their employees | 158 (42.1%) | 137 (36.4%) | 39 (10.5%) | 30 (8.1%) | 11 (2.9%) | 375 (100.0%) |
| 11 | People with leprosy face difficulties accessing health care services | 168 (45.0%) | 137 (36.4%) | 36 (9.5%) | 23 (6.2%) | 11 (2.9%) | 375 (100.0%) |
| 12 | Suffer of loneliness | 185 (49.3%) | 154 (41.1%) | 11 (2.9%) | 11 (2.9%) | 14 (3.8%) | 375 (100.0%) |
| 13 | Suffer emotional and psychological trauma | 169 (45.0%) | 160 (42.6%) | 22 (5.8%) | 12 (3.3%) | 12 (3.3%) | 375 (100.0%) |

Source: Fieldwork, 2016

Table 4.5.2 above shows the effects of leprosy stigma on the victims. The result gathered indicated that 104 (49.8%) of the respondents agree that they suffer stereotype, 93 (44.5%) strongly agree that victims suffer status loss, 106 (50.7%) agree that they suffer discrimination, 101 (48.3%) strongly agree that the victims experience social disengagement/isolation, 89 (42.6%) strongly agree that the victims suffers rejection from their families, friends, 118 (56.5%) strongly agree that they suffer economic hardship, 97 (46.4%) agree that ex-patients with uniform deformities faced difficulty in adapting when they were back in their home, 91 (43.5%) agree that people with leprosy are not allowed to wash in the community water, eat, sleep on the same bed with others, 78 (37.3%) strongly agree that people with leprosy are withdrawn from school, 88 (42.1%) agree that people with leprosy suffer retrenchment from their employees, 94 (45.0%) agree that people with leprosy face difficulties accessing health care services, 103 (49.3%) agree that victims of leprosy suffer loneliness, and 94 (45.0%) agree that victims of leprosy suffer emotional and psychological trauma.

The IDIs and FGDs conducted are in consonance with the survey; the data revealed. The data show that victims of leprosy face many challenges such as marginalization, economic and social. Also, leprosy victims suffer educational challenges, isolation, psychological and physical neglect. Responding to the general comments above, an informant (Doctor at Ngulde) said:

Victims of leprosy are humans with emotions, they want to be loved and cared for. When stigmatized it affects them psychologically or mentally and socially.

A discussant (victim below 18yrs) revealed that:

Leprosy and its victims are treated with disgust. The attitude of people makes me feel less of a human.

A discussant (victim of leprosy from Uba) narrated his experience as thus:

While I am getting used to the social effects of the diseases, the biggest challenge is lost of economic, educational and social rights. At a certain time, I had to stop schooling, since I don't have the resources to support myself, the physical rejection of my colleagues is one thing that has seriously affected me psychologically. Most times, I survive under the mercy of charity from people because especially for those of us whose symptoms are obvious, hardly can we be employed. That is why we are very vulnerable to poverty.

A key informant (cleric) further stressed that:

The discrimination towards leprosy victims is too much, even in football pitch, in the family, in the church among many other places. They lack access to education and suffer loneliness.

A discussant (friend of leprosy victim) said that:

The pain of the sickness is much. Victims are treated as outsiders and the funny thing is how they treat us who are close to some of the lepers. At times, I am been referred to or described as Abubakar, friend of the leper. This nick name makes some of my friends to be watchful of body contacts with me. Some even stopped shaking hands with me.

4.6 Coping Strategies Adopted By Leprosy Victims in Askira/Uba LGA

This section examines the various coping strategies adopted by leprosy victims.

The data on whether leprosy victims employs means of coping with the day to day challenges of stigma show that 359 (95.7%) of the respondents indicated 'yes', while 16

(4.3%) indicated 'no'. this means the victims employ means of coping with the day to day challenges of stigmatization; this is shown by 95.7% of the respondents.

Table 4.6.1 Various Coping Strategies adopted by Leprosy victims

| Coping strategies adopted by victims of leprosy | Frequency | Percentage |
|--------------------------------------------------------|------------------|-------------------|
| Social withdrawal | 54 | 14.4 |
| Denial | 63 | 16.7 |
| Drug abuse (alcohol etc.) | 125 | 33.5 |
| Religiosity | 133 | 35.4 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

Table 4.6.1 reveals that most respondents 35.4% were of the view that religiosity is a coping strategy adopted by victims of leprosy. Next, dependence on drug/alcohol was identified by 33.5%, 16.7% revealed that denial is adopted as a coping strategy while social withdrawal was identified by 14.4%. Social withdrawal means avoiding contacts with people. They try as much as possible not to interact with people. Denial means pretending as if they are not sick while religiosity stands for always attending church services, believing that they can be whole again through miraculous means.

The qualitative data corroborated the quantitative data. The data from the FGDs and IDIs revealed that various coping strategies are adopted by victims of leprosy. An Informant (Cleric Lassa ward) when asked about coping strategies adopted by victims of leprosy said:

A lot of them are members of my church; they come for Sunday services as well as week day fellowship. There is nothing too big for our God to do, we serve a very big God and various examples are in the bible. God cured a leper in the bible so there is nothing he cannot do. Some victims of leprosy also adopt other means like alcoholism and all forms of drug abuse and seeking other gods.

Also, a discussant (a victim of leprosy at Uba) narrated his experience as follows:

At the initial stage I didn't believe I had contacted the disease, I believed I can't have leprosy, but when it started escalating because I refused to use any form of medication I realized it was real. So I started taking medication and right now I believe God can heal me and he will heal me at his own time.

Similarly, an informant (a victim of leprosy at Askira) narrated his coping strategy as thus:

Since I realized I have gotten sick, most of my friends and families try as much as possible to avoid me. Life is too short for us to dwell in sorrow so I drink and merry as much as I can. When I get access to codeine I take it too. But it is expensive and scarce to get now so I chill with alcohol and weed (marijuana). Joint is the one place where people hardly discriminate so when I am there I feel normal once again.

Also, an informant (Doctor at Askari) said:

I have seen a lot of patients suffering from leprosy. Different strokes for different people. People can easily withdraw completely because of stigma, people can live in denial. It is important to note that, denial is the first stage of grief so a lot of my patients at first were living in denial. Most of them actually believe in spiritual healing and there is nothing God cannot do. A lot of people have left this community because of shame, they migrated to where they are not known and you can't blame them. With stigma comes shame most times.

A discussant (victim below 18yrs) said that:

Most times I refuse socializing with people. I watch the way I relate with others before I am insulted. At a point I tried not going out but my parents insisted that I have to go to school and place of worship. At school I sit at the back of the class and I have very few friends. These few friends have been my friend for years before I contact the disease.

Another discussant (Friend of leprosy victim) is of the view that:

When my friend got the disease he became a heavy drinker. Funny enough he is not allowed to sit in the bar, he will buy his drinks and sit outside in a shade. Later he started picking up quarrels with some of us stating that we have neglected him in his trying time. Now he is calm and I think he is getting to realize that picking up unnecessary fights and beer won't cure him.

Another discussant (family member) stated that:

I had to help my brother to adjust. Initially he was unnecessarily angry. At a point, he shamefully cursed God saying all sorts of evil and sick words. Now, he has realized his mistakes and he has started attending mass (church) and we are positive that God will heal him completely.

4.7 Suggestions on How to Mitigate the Effect of Stigmatization on Leprosy Victims in Askira/Uba LGA

This section examines views of respondents on measures adopted by government as well as non governmental agencies to address leprosy stigma in the study area. Also examined are suggestions that can mitigate leprosy stigma.

The data on awareness of measures adopted by the government or nongovernmental organization in management of leprosy stigmatization in the LGA revealed that 169 (45.0%) of the respondents are aware, while 206 (55.0%) indicated they are not aware that there are such measures. This shows that most of the residents are not aware of government or nongovernmental organization measures in management of leprosy victimization in the study area, this is indicated by 55% of the respondents who indicated no. were of the view that no measure adopted to manage stigmatization of leprosy in the LGA.

4.7.1 Measures put in place by government and nongovernmental organization to reduce leprosy stigma

| Responses | Frequency | Percentage (%) |
|----------------------------------------------------------------------------------------|------------------|-----------------------|
| Construction of leprosy missionary clinic/ introduction of primary health care centers | 56 | 33.0 |
| Free treatment and drug provision | 36 | 21.3 |
| General and missionary hospitals for eradication of the disease | 45 | 26.6 |
| Leprosy eradication campaigns and orientations | 32 | 19.1 |
| Total | 169 | 100.0 |

Source: Fieldwork, 2016

Table 4.7.1 above shows that among respondents that were aware of measures adopted to mitigate leprosy stigma, 33.0% identified construction of leprosy missionary clinic/ introduction of primary health care centers, 21.3% free treatment and drug provision, 26.6% general and missionary hospitals for eradication of the disease, while 19.1% leprosy eradication campaigns and orientations. Majority 68.9% affirmed that the measures adopted have not been effective but 31.1% indicated that the measures adopted have been effective. Table 4.7.2 is preoccupied with views of respondents on recommendation on the most effective measures of reducing leprosy stigma in Askira/Uba Local Government Area. Table 4.7.2 shows recommendation on the most effective measures to reducing leprosy stigma.

4.7.2 Recommendation on the most effective measure to reducing Leprosy stigma

| Responses | Frequency | Percentage (%) |
|-------------------------------------------------------------------------------------------|------------------|-----------------------|
| Provision of modern medicine and traditional medicine can help reduce the rate of leprosy | 70 | 18.7 |
| There should be functional clinics and center's for managing leprosy | 63 | 16.7 |
| Seminar/orientation on leprosy drug uses | 64 | 17.2 |
| Re-training of health personnel's on leprosy | 61 | 16.3 |
| Government and NGO should embark on sensitization campaign on leprosy in the community | 88 | 23.4 |
| Others | 29 | 7.7 |
| Total | 375 | 100.0 |

Source: Fieldwork, 2016

The response of the respondents indicate that 18.7% suggested provision of modern medicine and traditional medicine to reduce the rate of leprosy, 16.7% provision of functional clinics and center's for managing leprosy, 17.2% seminar/orientation on leprosy drug uses, 16.3% re-training of health personnel's on leprosy while 23.4% government and NGO should embark on sensitization campaign on leprosy in the community. Given the data distribution on the table it can be deduced that embarking on sensitization campaign on leprosy in the communities by government and nongovernmental organizations, is the most effective measure of reducing stigmatization against leprosy victims in the area; this is indicated by 23.4% of the respondents.

The FGD and IDI data revealed bear varied views with the survey data concerning the efforts or measures to deal with stigma have not been effective.

According to an informant from Ngulde (Doctor) said:

Things are deteriorating. When the missionary hospital for leprosy victims were handled by missionaries, the hospital was operating at a full level. It was well equipped and adequate man power was available. The moment they handed over the hospital to Government, the hospital depreciated and now it is not functioning at all.

Also, a discussant (family member) stated that:

A functional hospital will be of help, but it is rather unfortunate that our government, the people we voted for do not care about our wellbeing. Whenever elections are close they organize rallies, sensitization programs and they keep promising us of building a better hospital and equipping them.

In addition, another informant (Head of transporters Uba) said that:

Government has put in little effort, individuals are trying but if the patient is close to you or your relations, organizations are not reaching the place because it is remote.

Similarly, an informant (Victim at Askari) said that:

The government presence is not felt in this location and there is no organizational intervention only the individuals. The management of the disease is very difficult due to financial aspect, and there is no standard action by government only individual's relations assist in managing the disease.

The views expressed above clearly revealed that, the measures to tame stigmatization are left to the government and individual victims.

Speaking on measures the most effective measure of reducing leprosy stigmatization, the views of key informants and the participants are in tandem with those of the respondents;

the responsibilities are placed on the shoulders of government and nongovernmental organizations.

According to an informant (Cleric at Mussa ward):

Government should have a standard plan in curing it. Government should take control, and also people should not deny the victims from their social lifestyle.

Also another informant (Doctor at Askari) said that:

Government should take control on both the management and treatment. This is because the government has money to provide the necessary drugs and treatment for the victims of leprosy and can also employ or hire even foreign medical practitioners to assist in the treatment of the diseases.

While glancing through the effort put by the government to check mate the challenges, an informant (Head of market Askari) said that:

Though the government has put measures on ground but the government should be serious in the way they are handling it. There is consistency or timely continuity as the response of the government is too weak. He added that the traditional medicines also are helpful and should be encourage if it can be handled carefully.

Another informant (Chief of Uba) supported the inclusion of traditional medicine:

If government can liaise with traditional medicine practitioners and provide them with the necessary funds, they can go a long way to providing even better treatment of the diseases. The government should intervene and the community should also help themselves. Government commitment to the treatment of leprosy regardless of cost involve will not only help wipe away the diseases, it will help

cure it completely and avoid possible contagion and community conception of the diseases and at the whole make the environment healthy for people to strive and achieve their goal in life.

A discussant (family member) said:

Good health facilities should be built, equipped and functional. Specialist doctors should be employed. Government should also provide adequate security for the hospital against Boko Haram attack.

4.8 Discussion of Major Findings

The purpose of this study is to examine stigma and the management of leprosy identity in Askira/Uba Local Government Area of Borno State. This was achieved with the following objectives; to examine the prevalence of leprosy in Askira/Uba LGA, identify the causes of leprosy in Askira/Uba LGA, examine the factors contributing to leprosy stigma, find out the effects of stigma on leprosy victims, identify the coping strategies adopted by leprosy victims and finally, recommend how to mitigate leprosy stigma.

Objective one of the study is to determine the prevalence of leprosy in Askira/Uba Local Government Area of Borno State. It was discovered that leprosy is prevalent as 183(87.6%) of the respondents affirmed that leprosy is prevalent in the area and 184(88.0%) knew individuals that are suffering from leprosy infection. The prevalence rate recorded in this study implies that leprosy is a public health challenge in Askira/Uba Local Government Area.

Objective two of the study is to identify the major causes of leprosy. The findings reveal that, respondents' belief leprosy is caused by consuming oily and fatty food, poor environment, contact with an infected persons, spiritual attacks and leprosy is hereditary.

The finding of this study on consumption of oily and fatty food has not been corroborated by other studies. However, findings on perceived cause such as inheritance is support by Alubo et al's (2002) study, and close contact by Try (2006). The findings of this study suggest that study respondents do not hold biomedical view on the cause of leprosy. This demonstrates insufficient knowledge on leprosy which to a large extent will impact negatively on how the disease can be appropriately managed.

Objective three of the study is to identify the contributing factors to leprosy stigma. The study revealed that misconceptions regarding incurability, high infectiousness, causes and transmission, and fear of transmission and deformities of leprosy victims are factors that contribute to leprosy stigma. Similar observations were made in other studies. For instance, Barkataki et al (2006) identified misconceptions that leprosy is highly contagious, incurable and disabling influences stigma, Prabhakara, Rao and Palande, (2007) identified fear of deformity as the greatest disability, the greater the level of stigma while Moreira and Varkevisser (2002) identified fear of transmission. The implications of these beliefs are; it influences discriminatory attitude toward people affected by leprosy and, as a result, the latter may delay seeking help. Negative attitudes may also affect adherence to treatment as well as the wellbeing of leprosy-affected persons.

Abnormality of body (facial, leg and hand deformities) forms a label for victims of leprosy. In line with Goffman's theory of stigma, this label influences social interaction between the labeled person and others. In the case of leprosy, the person is labeled negatively, his or her status is devalued. The label modifies the actions of others towards

the labeled person. For respondents in this study, the physical deformity of leprosy victims creates fear which perpetuates isolation and discrimination of leprosy victims.

Objective four of the study is to ascertain the effects of stigmatization on leprosy victims in Askira/Uba Local Government Area. The result gathered indicated that, victims of leprosy face suffer stereotype, status loss, discrimination, economic hardship, experience social disengagement/isolation, and suffer loneliness, emotional and psychological trauma. This implies that leprosy stigma affect victims' social, economic and psychological wellbeing as well as overall quality of life of victims. This finding is in line with the research by Van Brakel (2003) who found that leprosy stigma have a pervading affect on a patient's life such as, employment, interpersonal relationships, leisure activities and attendance at social and religious functions.

The theory of stigma, social identity and labeling consequences for health and illness by Goffman stated the universality of stigma as one of its major assumption. All societies establish means of categorizing persons and which humans are praise worthy and which are discrediting. Based on the physical deformity associated leprosy, most victims of leprosy are stigmatized in the society. This stigma has social, economic and psychological effects on victims of leprosy. This stigma also extends to anyone associated with victims of leprosy. This form of stigma is referred to as courtesy stigma. Family members, loved ones and health care providers are also stigmatized based on the level of association that exists between them and victims of leprosy.

Objective five of the study is to identify the coping strategies adopted by leprosy victims in Askira/Uba. Research finding reveals that majority 35.4% of respondents were of the view

that, religiosity is the most adopted coping strategy by leprosy victims. Religious beliefs such as faith in divine healing power of God and teachings provide a form of solace for dealing with life challenges such as illness. As such, leprosy victims rely on their religious belief to cope with the effects of leprosy stigma. Other coping strategies adopted include drug/alcohol use, denial and social withdrawal. This finding supports the finding on withdrawal which was identified by Hyland (1993) in the concealment cycle of coping with leprosy stigma. Similarly, denial as a coping strategy identified in this study is consistent with work of Scott (2000), he indicated that it is hard for some leprosy patients to accept that they have leprosy.

Objective six of the study is to proffer possible solutions that can mitigate the effects of stigmatization of leprosy victims in Askira/Uba Local Government Area of Borno. The study result indicated that sensitization campaign on leprosy disease in the community by government and NGO was the most recommended to address leprosy stigma. Also, identified were provision of modern medicine and traditional medicine to reduce the rate of leprosy, provision of functional clinics and center's for managing leprosy, and seminar/orientation on leprosy drug uses. Sensitization campaign on leprosy disease identified by most respondents is in line with one of the recommended strategies in the literature that is, Information, Education and Communication (IEC). The recommendations offered by respondents' addresses the management of leprosy in terms of health care provisioning as well as stigma reduction through education of the community on leprosy.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter is mainly concerned with the summary of the major findings and presents some conclusion and recommendations on stigmatization and the management of leprosy identity in Askira/Uba L.G.A of Borno State.

5.2 Summary of Major Findings

This study is aimed at addressing stigma and the management of leprosy identity. A set of objectives were drawn to examine the prevalence of leprosy, perceived causes of leprosy, factors that contribute to leprosy stigma, effects of leprosy stigmatization on leprosy victims, coping strategies adopted by leprosy victims to manage leprosy stigma, with a particular reference to Askira/Uba Local Government Area of Borno State. Relevant literature was reviewed and Goffman's Theory of Stigma, Social Identity and Labeling was adopted as the theoretical framework of the study. Both qualitative and quantitative data were employed, a total of 209 retrieved questionnaires were analyzed, 10 in-depth interview sessions were held and three focus group discussion sessions. The findings of the study revealed that:

Objective one focused on prevalence of leprosy in Askira/Uba Local Government Area of Borno State. To this end the study found that leprosy is prevalent in the Local Government Area; 87.6% of the respondents affirmed this and the key informants and the participant who partook in the study also confirmed it. The study also found that leprosy victims are

neighbors, family members, friends, or relations to the people who participated in the study. For instance, 88.0% of the respondents indicated they know individuals that are suffering from leprosy infection in the Local Government Area.

Cause of leprosy was the concern of objective two. Mediating on this the study found that there are beliefs that consumption of oily and fatty food, poor environment, contact with an infected persons, spiritual attacks, and hereditary are causes of leprosy in the study area. Other causes of leprosy identified were environmental condition and blood transfusion.

The object of objective three dwelt on contributing factors to leprosy stigma in Askira/Uba Local Government Area of Borno State. In response to this a number of factors have been identified. The study found that the beliefs and misconceptions regarding the causation and transmission, and incurability and high infectiousness of leprosy are contributing factors. Other factors are fear of his/her deformities/look, fear that other people will think the individual has leprosy too, fear of transmission, belief that leprosy patients are bad people, and leprosy person are cursed and should not be associated with.

Objective four contributes in the area of the effects of leprosy stigma on the victims. Under this objective the study revealed that leprosy victims suffer stereotype, discrimination, experience social disengagement/isolation, and suffer economic hardship. Other effects are people with leprosy are not allowed to wash in the community water, eat, sleep on the same bed with others, people with leprosy face difficulties accessing health care services and lastly; ex-patients with uniform deformities faced difficulty in adapting when they were back in their home. These stigmatization effects subject the leprosy victims to loneliness and consequently emotional and psychological trauma.

Objective five is concerned with coping strategies adopted by leprosy victims in Askira/Uba Local Government Area of Borno State. The coping strategies revealed by the study are religiosity, drug/alcohol use, denial and social withdrawal.

Solutions on how to mitigate the effect of stigmatization on leprosy victims in Askira/Uba Local Government Area of Borno State is the concerned of objective six. In response to this the study found that to mitigate the effects of stigmatization of leprosy victims, sensitization campaign on leprosy disease in the community by government and NGOs, provision of modern medicine and traditional medicine to reduce the rate of leprosy, provision of functional clinics and centers for managing leprosy, and seminar/orientation on leprosy drug uses are necessary.

5.3 Conclusions

This study on leprosy stigma presents that,

- i. Beliefs such as heredity, incurability and high infectiousness people hold about leprosy are misconceptions and negative attitudes toward leprosy victims.
- ii. Deformities arising as a consequence of untreated leprosy play a significant part in increasing the stigma to leprosy victims.
- iii. The body abnormality of leprosy victims is a label which makes them vulnerable to victimization and negatively influences the social interaction between the labeled person and others; this in turn affects their wellbeing and devalues their status.
- iv. Religiosity and other strategies such as alcohol/drug use, denial and withdrawal are measures adopted by leprosy victims to manage their spoilt identity or stigmatization.

- v. Intervention programs focusing on health education will likely correct the wrong perceptions and increase understanding of leprosy in the study area.

5.4 Recommendations

Base on the conclusions of this study the following recommendations are made:

- i. Government, through the relevant health authorities, should educate the public on the predisposing factors to leprosy contraction and early signs of leprosy and on the need of leprosy victims to be attending leprosy clinics for treatment because leprosy is curable.
- ii. The government should organize seminar/workshops that are capable of debunking the beliefs such as heredity, incurability and high infectiousness people hold about leprosy; this will help in changing the misconceptions and negative attitudes toward leprosy victims. Leprosy is curable.
- iii. Government should make leprosy anti-stigmatization and anti-discrimination laws to deter people from stigmatizing and discriminating against leprosy victims. Leprosy victims are members of society.
- iv. Government and Non-Governmental Organization should embark on sensitization campaign of leprosy in the community, by enlightening the public on the misconception regarding the causation, transmission and prevention of the leprosy disease. In addition, to the education and health awareness programs, empowerment of the leprosy affected persons through technical education,

vocational training and social participation might be helpful to increase self-esteem and reduce economic hardship.

- v. Since religiosity has been identified as a coping strategy adopted by the leprosy victims, religious leaders need to involve in the fight against leprosy stigmatization.

5.5 Contributions to knowledge

The following are the contributions to knowledge of this study:

- i. Consumption of fatty and oily food does not cause of leprosy.
- ii. Leprosy stigmatization negatively affects the social, economic and psychological wellbeing of leprosy victims.
- iii. Religiosity is a major coping strategy adopted by leprosy victims to mitigate stigma.

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**APPENDIX I
QUESTIONNAIRE**

Dear Sir/Madam,

I am a Postgraduate student of the Department of Sociology, Ahmadu Bello University, Zaria carrying out a research on ‘**Stigma and the Management of Leprous Identity in Askira/Uba Local Government Area of Borno State.**’ Be assured that, this research is purely for academic purposes and information given will be treated with utmost confidentiality. Hence, you are expected to kindly answer the questions below honestly.

Thank you. CHINAMPI ANAMJA THLIZA, M.Sc/SOC-SCI/05439/2009

SECTION A: SOCIO-DEMOGRAPHIC DATA OF RESPONDENT

1. Gender: a. Male [] b. Female []
2. Which ward are you from? _____
3. Age: a. 18- 20 years [] b. 21-30 years [] c. 31-40 years [] d. 41-50 years []
e. 51 years and above []
4. Marital Status: a. Single [] b. Married [] c. Divorced/Separated [] d. widow []
e. Widower []
5. Religion: a. Christianity [] b. Islam [] c. Traditionalist [] d. None []
6. Occupation: a. Civil/public servant [] b. Business/petty trader []
c. Farmer [] d. Artisan [] e. Others (specify) _____
7. Educational qualifications: (a) Primary () (b) Secondary () (c) Tertiary () (d) Quranic education () (e) None ()

SECTION B: PREVALENCE OF LEPROSY IN ASKIRA UBA LGA

8. Are you aware of leprosy disease in Askira LGA? (a) Yes [] (b) No []
9. Do you know of anyone suffering from leprosy infection? (a) Yes [] (b) No []
10. Through which means do you get to know of leprosy? (a) Relative [] (b) Family member [] (c) Friends [] (d) Neighbor [] (e) Others Specify: _____
11. Do consider leprosy a common disease in LGA? (a) Yes [] (b) No []
12. How common is the disease in the LGA?
- a. Not common [] b. Common [] c. Very common [] d. Undecided []

SECTION C: CAUSES OF LEPROSY IN ASKIRA/UBA LGA

In this section, tick under agreed or disagreed against each question below. What can you identify as the major causes of leprosy in Askira LGA?

| 13 | Causes | Agreed | Disagree |
|----|---------------------------------|--------|----------|
| 14 | Contact with an infected person | | |
| 15 | Environmental conditions | | |
| 16 | Fat and oil | | |
| 17 | Spiritual infections | | |
| 18 | Inheritance/genetic | | |
| 19 | Dirty environments | | |
| 20 | Curse | | |
| 21 | Blood transfusion | | |
| 22 | Others: Specify | | |

23. Which is the major cause of leprosy? -----

**SECTION D: CONTRIBUTING FACTORS TO LEPROSY STIGMA IN
ASKIRA/UBA LGA**

24. Are victims of leprosy stigmatized? (a) Yes () (b) No ()

25. How are they stigmatized?

Against each question on this table are options (agreed and disagreed), choose and tick the one that answers the question. What are the major factors contributing to leprosy stigma in Askira LGA?

| No. | Factors | Agreed | Disagreed |
|-----|---------------------------------------------------------------------------------------------|--------|-----------|
| 26 | Discrediting beliefs and misconceptions regarding the causation and transmission of leprosy | | |
| 27 | Misconceptions regarding the incurability and high infectiousness of leprosy | | |
| 28 | Deformed beggars on the streets | | |
| 29 | Infected persons are isolated from other members | | |
| 30 | Infected persons may be expelled from school/work | | |
| 31 | Denied rights and opportunity to work | | |
| 32 | Psychological and emotional trauma | | |
| 33 | Suffers from loneliness | | |
| 34 | Others: Specify | | |

SECTION E: EFFECT OF STIGMATIZATION ON LEPROSY VICTIMS

35. What do you think are the challenges faced by victims of leprosy? -----

36. Are victims of leprosy exempted from community activities? (a) Yes () (b) No ()

37. Are victims of leprosy treated differently from others in the community? (a) Yes ()

(b) No ()

What to you constitutes to be the most severe social effects of leprosy on the leprosy victims?

A=agree, SA=strongly agree, D=disagree, SD=strongly disagree and UN=undecided

| No. | Effects | A | SA | D | SD | UN |
|-----|------------------------------------------------------------------------------------------------------------|---|----|---|----|----|
| 38 | Viewed as a lesser human | | | | | |
| 39 | Status loss | | | | | |
| 40 | Suffers discrimination | | | | | |
| 41 | Experience social disengagement/isolation | | | | | |
| 42 | Rejection from their families, friends | | | | | |
| 43 | Suffer of economic hardship | | | | | |
| 44 | Ex-patients with uniform deformities faced difficulty in adapting when they were back in their home | | | | | |
| 45 | People with leprosy are not allowed to wash in the community water, eat, sleep on the same bed with others | | | | | |
| 46 | People with leprosy are withdrawn from school | | | | | |
| 47 | People with leprosy suffers retrenchment from their employees | | | | | |
| 48 | People with leprosy face difficulties accessing health care services | | | | | |
| 49 | Suffer of loneliness | | | | | |
| 50 | Suffer emotional and psychological trauma | | | | | |

SECTION F: COPING STRATEGIES ADOPTED BY VICTIMS OF LEPROSY AND STIGMA

51. Are there means employed by victims of leprosy to help them cope with day to day challenges of stigma? (a) Yes () (b) No ()

52. If yes, kindly list them

SECTION F: SUGGESTIONS THAT CAN MITIGATE THE EFFECTS OF STIGMATIZATION OF LEPROSY VICTIMS

53. Are you aware of any measure(s) adopted by the community, government or non-governmental organization towards managing stigmatization of leprosy in the LGA?
a. Yes [] b. No []

54. If yes, what are some of those measures?

55. Kindly explain which of the measures you consider more effective and why

56. What do you think can be done to help address leprosy stigma in Askira/Uba local government area of Borno states?

APPENDIX II
IN-DEPTH INTERVIEW GUIDE/ FGD GUIDE
On Stigma and the Management of Leprosy Identity in Askira/Uba Local
Government Area of Borno State

Occupation: _____

Status: _____

1. Are you aware of the existence of leprosy disease in Askira/Uba LGA? Could you explain please?
2. How can you describe the prevalence of the disease in the LGA?
3. Could you explain the various ways in which leprosy disease is caused?

Probe for:

- Contact from an infected persons
- Environment factors
- Genetic
- Spiritual/curse

4. What are the factors contributing to leprosy related stigma?

Probe for:

- Discrediting beliefs and misconception regarding the causation and transmission of the disease
- Misconceptions regarding the incurability of the disease

5. What are the effects of stigmatization and handling of leprosy by the victims?

Probe for:

- Stereotypes
- Loss of status
- Suffer discrimination
- Economic hardship and isolation

6. What are the coping strategies employed by victims of leprosy and stigma?

Probe for:

- Denial

- Excessive abuse of drugs
 - Withdrawal
 - Migration
7. What is government efforts/community/non-governmental organization in stemming the effects of stigmatization of leprosy on the victims?
 8. What are your suggestions on best practice and management of leprosy related stigma on infected persons?

APPENDIX III

THE KREJCIE & MORGAN (1970) TABLE

Table for Determining Sample Size from a Given Population

| N | S | N | S | N | S |
|-----|-----|------|-----|---------|-----|
| 10 | 10 | 220 | 140 | 1200 | 291 |
| 15 | 14 | 230 | 144 | 1300 | 297 |
| 20 | 19 | 240 | 148 | 1400 | 302 |
| 25 | 24 | 250 | 152 | 1500 | 306 |
| 30 | 28 | 260 | 155 | 1600 | 310 |
| 35 | 32 | 270 | 159 | 1700 | 313 |
| 40 | 36 | 280 | 162 | 1800 | 317 |
| 45 | 40 | 290 | 165 | 1900 | 320 |
| 50 | 44 | 300 | 169 | 2000 | 322 |
| 55 | 48 | 320 | 175 | 2200 | 327 |
| 60 | 52 | 340 | 181 | 2400 | 331 |
| 65 | 56 | 360 | 186 | 2600 | 335 |
| 70 | 59 | 380 | 191 | 2800 | 338 |
| 75 | 63 | 400 | 196 | 3000 | 341 |
| 80 | 66 | 420 | 201 | 3500 | 346 |
| 85 | 70 | 440 | 205 | 4000 | 351 |
| 90 | 73 | 460 | 210 | 4500 | 354 |
| 95 | 76 | 480 | 214 | 5000 | 357 |
| 100 | 80 | 500 | 217 | 6000 | 361 |
| 110 | 86 | 550 | 226 | 7000 | 364 |
| 120 | 92 | 600 | 234 | 8000 | 367 |
| 130 | 97 | 650 | 242 | 9000 | 368 |
| 140 | 103 | 700 | 248 | 10000 | 370 |
| 150 | 108 | 750 | 254 | 15000 | 375 |
| 160 | 113 | 800 | 260 | 20000 | 377 |
| 170 | 118 | 850 | 265 | 30000 | 379 |
| 180 | 123 | 900 | 269 | 40000 | 380 |
| 190 | 127 | 950 | 274 | 50000 | 381 |
| 200 | 132 | 1000 | 278 | 75000 | 382 |
| 210 | 136 | 1100 | 285 | 1000000 | 384 |

Note.—N is population size.
S is sample size.