

ALIENATION AND SUICIDAL TENDENCIES AMONG LEPROSY PATIENTS IN ANAMBRA STATE

Nwankwo, Ignatius Uche

Department of Sociology/Anthropology,
Nnamdi Azikiwe University, Awka

Abstract

This study focused on psychosocial problems facing leprosy patients in Anambra State with emphasis on alienation and suicidal tendencies. Questionnaire containing 17 close ended and 3 open ended items was administered on 34 patients at Okija and Nnewi Leprosy Clinics which were purposively selected for the study. Frequency tables and simple percentages were used for analysis. It was found that patients encounter stigmatization, alienation, segregation, low self-esteem, self-destructive tendencies and other forms of psychosocial morbidity and dysfunctions. The level of alienation and contemplations of suicide was relatively high. It was recommended that Psychologists and Sociologists who have expertise to understand and respond to these problems should be part of leprosy control teams. Patients, their families and the community should also be properly informed about leprosy in order to improve their understanding of the disease, stimulate appropriate coping responses and improve efficiency of leprosy control programme in the State.

Key words: *Psychosocial, Leprosy, Alienation, Segregation, Persons affected by leprosy.*

INTRODUCTION

Leprosy control activities started in Anambra state around 1939 when the Roman Catholic Mission established leprosaria at Okija and Nnewi/Amichi. The two centres now serve as Leprosy Clinic and Leprosy Referral Hospital with inmates and out-patients respectively.

Currently, the state leprosy control team is made up of the State Control Officer and his assistants at the state level, and 21 trained Tuberculosis and Leprosy (TBL) Supervisors and their assistants at the local government level. There are more than 23 leprosy clinics manned by TBL Supervisors across the state. However, activities of these clinics are essentially vertical in nature and are yet to be fully integrated into the general healthcare delivery system (Nwankwo, 2000).

The State Government established a Tuberculosis and Leprosy Referral Hospital at Nnewil Amichi in 2000. However, because it is still not fully operational, cases requiring intensive care, surgery and full hospitalization are referred to Mile 4 Hospital Abakaliki, in Ebonyi State. However, the state leprosy control programme enjoys the support of German Leprosy Relief Association in the areas of funding, training, provision of logistics, and supply of drugs and treatment materials.

The word 'Leprosy' was derived from a Greek word 'Leptos' which means scaly (Ezekpeazu, 2000). Nigeria's Federal Ministry of Health (FMOH, 2004:84) defined leprosy as a chronic, infectious disease caused by *Mycobacterium leprae* that mainly affects the skin, peripheral nerves, and mucous membrane of upper respiratory tract.

Leprosy presents with many signs and symptoms but their degree of manifestation or clinical picture vary in individuals due to different levels of immune response (Ezekpeazu, 2000). World Health Organization (W.H.O 2000) and FM OH (2004) outlined the major signs and symptoms of leprosy disease to include:

- i. Presence of skin lesions/patches (hypopigmented areas of skin) with definite loss of sensation to touch.

- ii. Enlargement and or pain in one or several peripheral nerve trunks. 111. Positive skin slit smear for acid fast bacilli (*Mycobacterium leprae*)
- iii. Numbness (loss of feeling) of the hands, feet or areas of the skin.
- iv. Weakness or total loss of function of hands and feet.

Chukwu (2006) observes that among human beings, untreated lepromatous or multi bacillary type of leprosy carry largest load of organisms and pose very high risk of transmission to others. According to him, paucibacillary type of leprosy is less virulent because it carries minimal load of infectious organism. W.H.O (2000), reports that the commonest mode of spread of leprosy from infected person to an uninfected one is by means of droplets. This means that tiny drops of liquid coughed/sneezed out from the nose, throat or mouth of leprosy patients carry leprosy bacilli which can easily be inhaled by an uninfected person.

Nigeria's Federal Ministry of Health (FMOH, 2004) sums up factors affecting transmission of leprosy as follows:

- * The infectiousness of the infected person (index case).
- * The susceptibility of the contact which depends on host immune status.
- * The closeness, frequency and duration of contact of an individual with the source of infection.

Leprosy has remained a public health problem in Nigeria despite its historical antecedent as one of the oldest diseases of mankind. Nigeria had a registered prevalence of 5890 leprosy cases in 2002 (FMOH, 2004) but it declined to 5381 at the beginning of 2008 (W.H.O, 2008). This figure may not reflect reality on the ground because it does not take cognisance of patients who prefer patent medicine vendors, traditional healers and prayer houses for care or treatment. Similarly, there are patients who resort to self-medication and could not enlist with the leprosy control programme. Chukwu (2006), notes that long distance between service point and patients' residence, difficult terrain, wrong timing of clinic days, and ignorance are some of the factors that affect registration of patients. These situations are contributory to Nigeria's ranking as the fifth "high leprosy burden" nation in the world (see W.H.O, 2008 for list of high leprosy burden nations).

The National Tuberculosis and Leprosy Control Programme (NTBLCP) were established in Nigeria in 1988 to address leprosy and its related problems. The programme has recorded modest achievements (Ezekpeazu, 2000), but persons affected by leprosy across the country still encounter problems which cut-across medical, social and psychosocial dimensions.

It is regrettable that as Scott (2000) observed, leprosy research worldwide have concentrated on medical perspectives without commensurate emphasis on other aspects. This has compounded psychological and social needs of patients especially in developing countries. The situation of leprosy patients in Anambra State, South-east Nigeria is not different hence this study to investigate the nature and extent of their psychosocial problems with a view to providing solutions.

Psychosocial Dimensions of Leprosy.

Psychosocial refers to an individual's psychological and social development. It is the overt and covert behaviours that emanate as a result of interaction with a social environment. It describes the unique internal processes that occur within the individual as he relates with his social environment. Applied to the disease of leprosy, it examines the unique feelings, experiences, and responses of persons affected by leprosy as they interact with their social environment.

According to W.H.O, 1999; Lockwood, 2000; and Valsa 1999, scholars have found that leprosy is associated with diverse psychosocial problems. Lockwood (2000) laments that although leprosy patients face a far better future than before in terms of their medical treatment, the social image of the disease has not greatly changed in many parts of the world. He attributed this to the attitude of the community where affected persons are unable to work, or marry and thus become dependent for care and financial support on others.

The W.H.O (1999) is very critical of the insecurity, shame, isolation and consequent economic loss to which leprosy patients are exposed. They advocated for strengthening actions against social, economic and psychological consequences of the disease for persons infected and their whole families and communities.

Brycesson and Pfaltzgraff (1990) observe that persons affected by leprosy in many parts of the world experience intense grief, rejection of self as worthless, stigmatization, and loss of social ranking and properties like land. Valsa (1999) sums up the social and psychological problems of persons affected by leprosy and argued that they could be traced back to unmet needs in three areas as follows:

1. Problems Related to Need for Self-Acceptance: These include fear of the disease, anxiety, depression, guilt, suicidal tendency, and feeling of insecurity and loss of motivation.
2. Problems Related to Acceptance by the Family - They include strained relationship or complete rejection, desertion by spouse, identity crisis characterized by loss of respect and role reversal, including suspicion that patient offended gods of the land.
3. Problems Related to Acceptance by Community: These include attitude of neighbours, employers and friends; problems in attending social and religious functions, lack of support from the community.

This paper is anchored on phenomenological and Marxian theoretical perspectives. Phenomenology locate the problem of leprosy in society to the meaning or social interpretations given to the disease which have produced far reaching consequences like segregation of victims and psychosocial abnormalities.

On their part, Marxists posit that capitalist institutional structure which produces wealth and comfort for the bourgeoisie, produce frustration and hardship for the lower class. Such frustrations and hardship are fertile grounds for emergence of diseases like leprosy. The poor are constrained by economic factors to live in dirty slum environments without access to adequate diet, wholesome water and quality housing. All of these put them at higher risk of contracting diseases like leprosy.

Marxian and phenomenological perspectives explain alienation and suicidal tendencies among persons affected by leprosy as psychological states produced by inequities in resource distribution and the social definition given to leprosy. These States give rise to social and other forms of dysfunctions.

The general objective of this study is to identify psychosocial problems of persons affected by leprosy in Anambra State and to articulate how the disciplines of Psychology and Sociology should be relevant in mitigating such needs.

Accordingly, the following questions are asked.

1. What are the psychosocial problems encountered by persons affected by leprosy in Anambra State?
2. What are the causes of psychosocial problems affecting leprosy patients in Anambra State?
3. What roles can the disciplines of Psychology and Sociology could play to mitigate psychosocial problems of leprosy patients in Anambra State.

METHOD

Participants consisted of all patients registered at the Okija Leprosy Clinic and Leprosy Referral Hospital, Nnewi/Amichi which are the only centres in Anambra state that have both inmates and out-patients. This is made up of 34 persons affected by leprosy (10 inmates and 24 out-patients). They were aged between 18 and 54 years old with mean age of 38. The sex distribution was 19 males and 15 females. 21 of these respondents are still on anti-leprosy treatment while others are registered for post treatment care only. The duration of treatment is between 12 to 18 months for Multibacillary patients and 6 to 9 months for Paucibacillary patients (FMOH, 2004). The entire population was selected because their numerical strength is small and they were accessible. Nwoke and Olaitan (1988) support that a whole population could be used as sample if the population is within the reach of the researcher.

The **instrument** for the study was a questionnaire that contained 17 close and 3 open-ended items which addressed psychosocial issues. It was pre-tested on persons affected by leprosy at Oji-River Leprosy Settlement during which its validity and reliability in respect of measurement for which it was developed. A test-retest reliability index (r) of .67 was obtained.

Procedure

The items on the instrument were translated and administered in Igbo language for all respondents in the two centres. Administration of instrument was undertaken on clinic days on individual basis by Leprosy Control Supervisor, who was co-opted as research assistant. The process continued until all the participants responded. It took an average of twenty minutes for each to complete the form.

Design and Statistics

The study adopted the survey design. Data collected through questionnaire were analysed using frequency tables and simple percentages. This approach was adopted because the number of respondents was small and it best answers the research questions.

RESULTS

The results of this study show that psychosocial problems of persons affected by leprosy in Anambra State are enormous. They include:

- * Intense grief and rejection of self as worthless. This characterised the emotion of 82% of our respondents upon diagnosis of leprosy. It is evidenced by responses to Item No.1 of the questionnaire presented in the preceding table below.

Table 1: Distribution of Respondents According to their View on whether they felt intense Grief and Rejection upon Diagnosis.

Responses	Frequency	Percentage (%)
Yes	28	82%
No	4	12%
Don't know	2	6%
Total	34	100%

- There are a lot of negative stereotypes about leprosy and its victims. 100% of our respondents accept that they are stigmatized in the state.
- About 80% of people affected by leprosy believe the myths about leprosy. Such beliefs negatively affect their self-concept.
- All respondents (100%) described their association with the society as characterised by alienation, segregation, hatred, rejection, isolation or total ostracism (see Table 2 below). 60 of our respondents said that their spouses deserted them due to fear of contracting leprosy from them.

Table 2: Distribution of Respondents according to their Opinion on whether they Experience Alienation from their Family and Community

Responses	Frequency	Percentage (%)
Yes	34	100
No	-	-
Don't know	-	-
Total	34	100%

Our results also show that marriage and family ties are negatively influenced by leprosy. 90% of our respondents agree that a case of leprosy in the family makes marriage of sons and daughters difficult.

76% of respondents agree to have contemplated suicide on account of leprosy on more than three occasions. Suicidal tendency is therefore high as shown in Table 3 below.

Table 3: Distribution of Respondents according to whether they have Contemplated Suicide on more than three Occasions since they were diagnosed of Leprosy.

Responses	Frequency	Percentage (%)
Yes	26	76
No	5	15
Don't know	3	9
Total	34	100%

- Leprosy is a handicap to economic activities of victims. 80% of respondents submitted that they are unable to provide economic support to spouses and family on account of the disease. Individual's social ranking and security are also affected by leprosy. 90% of respondents opined they could no longer provide security (psychological, social and economic) to spouses and family members Relations and family members of leprosy patients who associate with them suffer similar fate with the patients. All (100%) of respondents agree that their family members are also seen as "unclean"
- 70% of respondents have the belief that the community consider them as nuisance and wish them dead.
- 80% of respondents accept that they have no meaningful contribution to development of society since diagnosis of leprosy was pronounced on them.
- 90% of respondents subscribe to the view that stigmatization and isolation of leprosy patients is compounded by uncomplimentary bible references to the disease.

- Deprivation of land, property and employment are common among patients. 80% of respondents acknowledge such problems.
- Respondents were divided on the issue of causes of negative societal response and psychosocial problems of leprosy. Some attributed it to the belief that leprosy is very contagious and incurable (30%), some to passages in the bible, others to disability arising from leprosy (40%).
- Most respondents (70%) live below an income level of N3000 per month. Only 20% completed primary school. Their occupational distribution shows that 60% are farmers, 20% are petty traders, while 10% each are artisans and unemployed respectively. This suggests that leprosy affects mainly people of low socio economic status.

DISCUSSION

Leprosy has no direct effect on the brain or mind (Stigter, Gaus and Eeyenders; 2000). Psychological damage and mental trauma are due to society's prejudice which could be far more lethal than the disease itself. As our study has shown, psychological damages manifest in the forms of devalued personality, loss of self-acceptance and suicidal thoughts. Indeed, low self-esteem, anti-social behaviour and self-destructive contemplations like suicide are products of the strains and trauma of facing enormous psychosocial problems associated with leprosy in the social system. These problems are quite significant in the case of Anambra State as responses of our subjects have shown.

Our statistics show that in addition to low self-esteem and self-destructive tendencies, a significant proportion (70%) of respondents feel that the community wish them dead. Also, about 80% believe the myths that surround the disease. These situations contribute to high level of psychosocial dysfunctions or psychosocial morbidity among persons affected by leprosy. This is manifested in lack of meaningful socio-economic development or atrophy of psychosocial self attested to by leprosy cases. It is not surprising therefore that 80% of respondents stated that they have made no meaningful contribution to development of society since they were diagnosed of leprosy. This should however not be, if social acceptance by family members, friends and community are left intact.

Segregation of persons affected by leprosy is one of the greatest psychosocial problems facing victims. The practice is very strong in the study area and reinforces stigma and society's prejudices about leprosy. The medical, economic, social and psychological costs of segregation are numerous and complicate other problems associated with leprosy. Our results show that most psychosocial problems of leprosy in Anambra State derive from the segregation of victims of the disease. We can further appreciate the magnitude of the problem of segregation or alienation on persons affected by leprosy from their lamentations. Many of them emphasized that they "can endure losing fingers and toes, eyes and nose but cannot endure to be rejected by those nearest and dearest to them" (Oforah, 2008).

CONCLUSION

The study has shown that leprosy patients in Anambra State encounter many psychosocial problems, particularly alienation and suicidal tendencies. The social image of leprosy arising from disabilities, passages in the bible, belief that the disease is incurable, and its highly contagious nature are central to the level of stigmatization and segregation of patients in the state.

We advocated that Psychologists and Sociologists become part of leprosy control teams to attend to psychosocial needs of patients. Such arrangement will stimulate proper understanding and response to leprosy by both patients and society at large. It will also encourage co-operation between individuals and groups towards attainment of leprosy free society. The role of counselling, health education and

social support towards full integration of persons affected by leprosy into their society cannot be over-emphasized.

THE WAY FORWARD

(a) Roles Disciplines of Psychology and Sociology Should Play in Leprosy Control.

We have seen that leprosy has strong social and psychological dimensions even as it is also a medical problem. The physical or medical aspects of leprosy often degenerate into severe complications on account of unaddressed psychosocial needs. We need the disciplines of Psychology and Sociology for proper understanding of individual patients and their reactions to disease situation. Such reactions are often shaped by the characteristics and cultural orientations of the wider society.

The relevance of the psyche of the patient in stimulating passive or active participation in his treatment process cannot be ignored, just as a good understanding of the social structure and cultural attributes are crucial to stimulating a new and positive interpretation to the problem of leprosy in society. In these two tasks, psychologists and sociologists are better equipped. The present practice of allowing health workers to address medical and psychosocial aspects of leprosy has yielded unimpressive results.

Secondly, while medico-physical aspects of leprosy may respond to drugs, the psychosocial dimensions are likely to respond more to social engineering and craftsmanship. Prescriptions for attitudinal and social change in the areas of societal response and definition of leprosy could be best articulated by Psychologists and Sociologists working as members of leprosy control teams. There are vast theories in the areas of motivation, attitude change, social change, institutional analysis etc. which could be harnessed to advantage in this regard.

The concept of 'social diagnoses' of individuals and communities; which is usually followed up with 'social therapy options', is best managed by sociologists collaborating or working in health setting with medical experts. This aspect of Sociology, termed 'Sociology in Medicine' is particularly relevant to the field of leprosy control. This is because it will understand and address issues in social dimension of leprosy which are outside the competence of medical experts and their drugs. Similarly, 'psychotherapy' with its rudiments in Psychology constitutes a vital tool in relieving persons affected by leprosy of their too many delusions, low -esteem self destructive tendencies and suicidal thoughts. A clinical psychologist is likely to better administer psychotherapy regimen on a leprosy patient than any other health worker. Furthermore, it must be emphasized that many psychological manifestations of leprosy patients require treatment by psychologists or psychiatrists. In the same way, negative social image and 'labelling' require articulated counter strategies of the sociologist. There is also need for psychosocial support similar to what victims of disaster, catastrophe or violence receive in order to enable patients resume normal life. In sum psychosocial problems need psychosocial interventions or social support which the disciplines of psychology and sociology are competent to provide.

b. Other Measures

- i. Correct information about leprosy should be provided through health education to the general public. Upon diagnosis, patients and their family members should be adequately informed about the disease to reduce their psychosocial worries.
- ii. Religious bodies should be involved in leprosy control. They should package spiritual tonics to reduce feeling of guilt and suicidal thoughts from patients. Chukwu (2006) insists that leprosy is not a product of anger of the gods, but a curable disease caused by a germ.

- iii. Marriage enrichment and family integration programmes should be organised by Anambra Leprosy Control Programme to reduce desertion of leprosy patients by spouses and family members.
- iv. Post diagnosis social and economic support should be used to cushion the harsh effects of the disease on patients.
- v. Counselling should be an integral part of leprosy control project. It will help many patients to cope with their problems.

REFERENCES

- Brycesson A and Pfaltzgraff, R. (1990). *Leprosy, 3rd edition*. Britain: Talmilep Pub.
- Chukwu J.N. (2006). *Trends In Leprosy Control. Being an address to Tuberculosis and Leprosy Supervisors in Anambra State on the occasion of their Quarterly Review Meeting*.
- Eboh W. (1999). *Leprosy Control in Nigeria: Past, Present and future*. TBL Magazine Vol.1, No.1
- Ezekpeazu J.I. (2000). *Leprosy: Causative Organism, Spread, Signs unci Symptoms and Diagnosis*. Paper presented at a World Leprosy Day Conference at Madonna University, Okija.
- Federal Ministry of Health (FMOH, 2004). *National Tuberculosis and Leprosy Control Programme: Revised Workers Manual, 4th Edition*.
- Kaufmann .A, Senkenesh G.M. and Neville. J. (1993). *The Social Dimension of leprosy*. Britain: TAMILEP
- Lockwood, D. (2000). *Consequences a Leprosy and Socio-Economic Rehabilitation*. Leprosy Review 71; Number4,417-419.
- Scott.I. (2000). *The Psychosocial Needs of Leprosy patient*. Leprosy Review Vol. 71, No.4.
- Stiger D., Geus, L. and Heyenders M.L. (2000). *Leprosy: Between Acceptance and Segregation. Community Behaviour Towards Persons Affected by Leprosy in eastern Nepal*. Leprosy Review Vol, 71, No.4.
- Nwankwo LU. (2000). *Case Finding and Case Holding Strategies for the Leprosy Control Programme in Nigeria*. Paper Presented at World Leprosy Day Conference at Madonna University Okija.
- Nwoke G.L and Olaitan S.O. (1988). *Practical Research Methods in Education*. Onitsha: Summer Pub. Co. Ltd.
- Oforah 1.1. (2008). *The Psychosocial Dimension of Leprosy: A Review of literature*. An Unpublished paper submitted to the Department of Sociology, NAU Awka.
- Valsa .A. (1999). *Psychological Aspects in Leprosy*, in Partners, Vol. 2, N036.
- World Health Organisation (WHO 1988). *A Guide to Leprosy Control*. Second Edition, Geneva: Switzerland
- World Health Organisation (WHO 1997). *A Guide to Eliminating Leprosy as a Public Health Problem*. Geneva Switzerland
- World Health Organisation (WHO 2008). *Weekly Epidemiological Report*, No. 33, 2008,83 Pp 293-300, Geneva: Switzerland.