

Disability Level, Physical Activity Limitations, Self-esteem and Self-efficacy of Persons Living with Leprosy in Selected States in Nigeria

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ABSTRACT

Leprosy-related disability is a challenge to public health, social and rehabilitation services in endemic countries. The study investigated self-esteem, self-efficacy, disability level and physical activity limitations of persons living with leprosy (PLL) in Nigeria. The cross-sectional study involving 123 purposively sampled PLL from 5 randomly selected Nigerian states using the Morris Rosenberg self-esteem scale (RSES), General self-efficacy scale (GSES), World Health Organization Eyes, Hands and Feet (EHF) scores, and the Screening of Activity Limitation and Safety Awareness (SALSA) instrument. Mann-Whitney U-test and Spearman Rank Order correlation were used to analyze data at < 0.05 level of significance. The Mean age of participants was 43.39±16.48 years. Mean scores on the RSES and GSES and EHF were 13.82 5.52,

30.56 5.42 and 6.46 respectively; and 50.42 14.53 on the SALSA, with significant negative correlation between RSES and SALSA ($\rho = -0.344$; $p = 0.0001$); GSES and SALSA ($\rho = -0.423$; $p = 0.0001$) and GSES and WHO-DG ($\rho = -0.181$; $p = 0.023$). No significant difference was found between males and females on the RSES, GSES, EHF and SALSA ($p > 0.05$ in all cases). PLLs had moderate levels of self-esteem, self-efficacy, and disability with severe limitations of physical activity, with significant correlations among all.

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INTRODUCTION

Leprosy is one of the most disabling and deforming disease conditions. Leprosy poses a great risk of permanent and progressive physical disability if left untreated, leading to blindness, loss of neural sensation, and local paralysis (Bryceson & Pfaltzgraff, 1990). It was reported that two to three million people were estimated to be permanently disabled because of Leprosy globally, with India being the most affected country followed by Brazil and then Burma (WHO, 1995). Multidrug therapy (MDT) protocol has effectively controlled the disease, hence contributing to the global elimination programme. Hence, the disease is no longer the dreaded disease it used to be and its sufferers face a far better future than rejection and exclusion from society (Deepak, 2000).

However, the social image of Leprosy has not greatly changed in many parts of the world and this is all too well reflected in the attitude of the community, particularly, towards individuals disabled due to the disease. Leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries (Wong, 2004). Stigmatization by the general population and their negative attitudes towards leprosy negatively impact patients' mental health and so too does the patient's perception of that stigma (Link & Phelan, 2001). All these underline the need for strengthening action against social, economic and psychological consequences of the disease, not only for persons having the disease but also for families and communities.

Stigma is a complex issue, with the capacity to affect all facets of a leprosy-affected person's self-esteem, self-efficacy, and physical activity level. Rafferty (2005) suggested that people with Leprosy may lose their employment because of the disease, the disabilities associated with it and negative attitudes of employers with consequent loss of self-esteem. Self-esteem is a personal judgment about worth and accepting or rejecting of self that appears in one's attitude (Mohammad & Tavakko, 2010). Low self-esteem unsettles human

balance and vitality and negatively influences efficacy (Mohammad & Tavakko, 2010). On the other hand, according to Luszczynska, et al. (2005), self-efficacy is the belief in one's competence to take on difficult or novel tasks, and to cope with adversity arising from specific demanding situations and makes a difference in how people feel, think and act (Bandura et al., 1997).

Extensive research has examined self-esteem within chronic diseases using Rosenberg's self-esteem scale (RSES). The General self-efficacy scale (GSES) has been widely considered and applied to various areas such as chronic disease management (O'Leary et al., 1988). Studies these past few decades have shown positive effects of Physical Activity (PA) and exercise training on exercise capacity, quality of life, and biomarkers with relatively few complications during training (O'Connor et al., 2009). Screening of Activity Limitation and Safety Awareness (SALSA) scale is a measurement scale for assessment of activity limitation in the daily lives of people suffering effects of peripheral neuropathy (Ebenso et al., 2007) The SALSA Scale was developed from 2000 – 2006 as a standardised tool to measure activity limitations and safety awareness encountered by people affected by leprosy, diabetes and other peripheral neuropathies in both low-income and developed areas.

Disability caused by leprosy may be associated with stigma. Disability in leprosy is graded to judge the extent of impairment, progress, early detection of any deterioration in the disability status of the leprosy-affected person, to decide the line of management for the person, to monitor the quality of services available and plan services for the management of leprosy in the area. The WHO Disability Grading was used to grade disability secondary to leprosy using the Eye, Hand and Foot score (EHF score).

The reported success of the current approach to the management of Leprosy using multi- Drug therapy (MDT) has no doubt reduced the possibility of stigmatisation. There appears to be a

dearth of literature on the physical activity limitations of the persons and the psychosocial aspects (self-esteem and self-efficacy) of leprosy. The study was aimed at investigating the self-esteem, self-efficacy, and physical activity limitations of persons living with leprosy; and determining if there would be a significant correlation among the level of disability, self-esteem, self-efficacy and physical activity level of persons living with leprosy in selected states in Nigeria.

METHODOLOGY

Research Design, population and sampling technique

This study had a cross-sectional survey. A purposive sampling technique was used to select volunteer persons living with leprosy residents in five (5) currently operational leprosy hospitals/rehabilitation centres in selected states in Nigeria (Benue, Enugu, Abia, Anambra, and Akwa-Ibom states).

Research Instruments

1. Morris Rosenberg Self-Esteem Scale (RSES):

The RSES is a Likert-scale type instrument, with ten items answered on a four-point scale with responses ranging from strongly disagree (0) to strongly agree (3). Items 2, 5,6,8,9 are reverse scored. A cut-off score of 15 or more indicates high self-esteem while scores of less than 15 indicate low self-esteem. RSES has good internal consistency, with a Cronbach's alpha of 0.86.

2. General Self-Efficacy Scale (GSES):

The GSES consists of 10 items that are rated on a scale from 1 (not at all true) to

4 (exactly true). The GSES sum score is calculated by summing the item scores and ranges between 10 (lowest GSES) and 40 (highest GSES). The GSES has Cronbach alpha ranges from 0.75 to 0.94 across some different language versions (Luszczynska, et al., 2005; Rimm & Jerusalem, 1999). Also, it was

found to be configurally equivalent across 28 nations, and it forms only one global dimension (Leganger, et al., 2000; Scholz, et al.,2002).

3. Screening of Activity Limitation and Safety Awareness (SALSA) Scale: The SALSA scale consists of 20 items answered on a 5-point response scale that is scored between 0 (I don't need to do this) and 4 (I physically cannot). A low score indicates little difficulty with activities of daily living, while higher scores indicate increasing levels of activity limitation. One would expect a score of 20 if the respondents practised all the activities listed without difficulty. Higher scores reflect increasing activity limitations. It is recommended to classify respondents who score 24 or less as not having activity limitations and respondents who score 25 or higher as having activity limitations. Individuals with SALSA scale scores of 10-24 were categorized as having no activity limitations, those with scores of 25-39 had slight limitations, 40-49 moderate limitations, 50-59 severe limitations and individuals with scores of 60-80 had very severe limitations. The SALSA Scale has good psychometric properties and internal consistency, with a Cronbach's alpha of 0.884. The SALSA score varied from 10 to 75 with a mean of 32.

4. World Health Organisation –Disability Grading using Eyes, Hands and Foot (WHO-DG): It classifies each eye, hand, and foot as 0, 1 or 2, where the highest value attributed to these points represents the "maximum disability grade" of the individual and is used as an indicator of the severity of impairment (DG 0 - no disability caused by leprosy in eyes, hands and feet; DG 1 - Eye problem caused by leprosy, but vision is not severely affected (equals 6/60 or better; fingers can be counted at six meters apart), loss of sensitivity in hands or feet; DG 2 - Eyes:

lagophthalmos and/or ectropion, trichiasis, visual impairment (fingers not counted at 6m), Hands and feet: with visible damage i.e. claw hands, foot drop, and reabsorption of fingers or toes, wounds). Since the disability grade can be scored as 0, 1 or 2 EHF

score, the sum of all the individual’s disability grades for the two eyes, two hands, and two feet, ranges from 0 (zero) to a maximum of 12 points. A score of 12 indicates grade 2 disability of both eyes, both hands, and both feet. Individuals with EHF scores of 0 were categorized as having no disability, those with scores of 1-4 had mild disability, 5-8 had moderate disability and individuals with scores of 9-12 had severe disability.

Procedure for Data Collection

The ethical approval was sought and obtained from the Ethical Review Committee of Nnamdi Azikiwe University Teaching Hospital, Nnewi, Nigeria before the commencement of the study. The assistance of the appropriate Non- Governmental and Governmental agencies to access the Leprosy control/rehabilitation centres and the list and address/contact of persons who had been treated and declared cured of leprosy were sought out and obtained before embarking on the study. The persons living with leprosy were approached and the aim of the study was explained to them and their informed consent obtained. The researchers then administered the instruments only to those who volunteered to participate in the study after obtaining their informed consent.

Data Analysis

The obtained data from this study were summarized using descriptive statistics of frequency distribution tables, mean and standard deviation and charts; and inferential statistics of the Mann-Whitney U test and Spearman’s Rank Order correlation was used to analyze obtained data. The level of significance was set at <0.05.

RESULTS

A total of 123 persons living with leprosy comprising 81 males (65.9%), 42 females (34.1%) within the age range of 17-85 years (mean age 43.39 16.48) participated in the study; 81 (65.9%) were single while 42 (34.1%) were married. The self-esteem of participants was found to be

moderate with a mean of 13.82 5.52 on the RSES, the self-efficacy of participants was moderate with a mean score of 30.56 5.42 on the GSES, the disability level has a moderate disability with a mean score of 6.46 on the EHF while the physical activity level of participants appears to have severe limitation with a mean score of 50.42 14.53 on the SALSA.

The obtained data were analyzed using the Mann-Whitney U test and no significant difference was found between male and female participants in RSES (p>0.05 in all cases). No significant difference was found between male and female participants in GSES (p>0.05 in all cases). No significant difference was found between male and female participants in SALSA (p>0.05 in all cases). No significant difference was found between male and female participants in EHF (p>0.05 in all cases). Spearman Rank Order Correlation was used to analyze the data and a positive significant correlation was found between self-esteem, self-efficacy, disability level, and physical activity level; self-esteem and self-efficacy (p<0.05, ρ= 0.522); physical activity level and disability level (p<0.05, ρ= 0.517)

Table 1: Mean Scores of Persons living with leprosy on GSES, RSES, SALSA, and EHF

(N=123)	Mean X	Standard Deviation SD
Age (Years)	43.39	±16.477
RSES score	13.82	±5.522
GSES score	30.56	±5.417
SALSA score	50.42	±14.528
EHF score	6.46	2.536

Key:
 N denotes the number of participants
 RSES denotes Morris Rosenberg Self-Esteem scale
 GSES denotes the General Self-Efficacy scale
 SALSA denotes Screening of Activity Limitation and Safety Awareness
 WHO-DG (using EHF) denotes World Health Organization-Disability Grading using eyes, hands, and feet.

Table 2: Comparison between Scores of Male and Female Persons living with leprosy on RSES, GSES, SALSA and EHF using the Mann Whitney U test

	Males (N=81)	Females (N=42)	U-value	p-value
RSES score	55.99	73.60	-2.602	0.009
GSES score	60.33	65.23	-0.724	0.469
SALSA score	63.47	59.17	-0.635	0.525
EHF score	63.19	59.71	-0.528	0.598

Key:

N denotes the number of participants
 RSES denotes Rosenberg Self-Esteem Scale
 GSES denotes General Self-Efficacy Scale
 SALSA denotes Screening of activity limitation and safety awareness
 WHO-DG (using EHF) denotes World health organization- disability grading using eyes, hands and foot scores.

Table 3: Correlation of scores of Persons living with leprosy on the RSES, GSES,

	ρ -value	p-value
RSES vs. GSES	0.522	0.0001*
RSES vs. SALSA	-0.344	0.0001*
RSES vs. EHF	-0.148	0.051*
GSES vs. SALSA	-0.423	0.0001*
GSES vs. EHF	-0.181	0.023*
SALSA vs. EHF	0.517	0.0001*

Key:

* denotes Significant correlation at p = 0.05

DISCUSSION

Leprosy is more than a disease, as the disease can nowadays be medically cured but the illness remains. Leprosy can be explained in terms of disease (biomedical), illness (self-perception) or sickness (social perception) (Robbinson, 1990). In this tripartite, leprosy refers to the associated physical symptoms. The illness, leprosy, is experienced by the person and is shaped by social and cultural influences. The sickness, leprosy, is the problem as perceived by society and named by society and thus reflects social stigma (Valencia, 1989). This tripartite contributes to the negative behaviour and psychological factors affecting leprosy patients even post-cure (Valencia, 1989). Persons with leprosy often have emotional and social difficulties because of the disease.

The stigma of leprosy is a real phenomenon in many people’s lives that affects their physical, psychological, social and economic well-being. Physical and socio-economic rehabilitation is worthwhile in restoring self-worth and status in the community with a consequent improvement in

self-competence and overall perception of life. In this study, the self-esteem, self-efficacy, disability level and physical activity limitation of persons living with leprosy were investigated.

This present study found that persons living with leprosy had moderate levels of self-esteem, self-efficacy, level of disability but with severe limitations of physical activity. This may be due to the current holistic approach to the care of post-Leprosy persons which is not limited to drugs but also includes several rehabilitation measures. Thus, it is possible that the current treatment and rehabilitation approach has brought about a significant reduction in associated deformities and may have had a positive impact on affected persons. One explanation for this is maybe that treatment of leprosy and of the psychosocial problems involving patients, which is being carried out more on an outpatient basis encourage patients to establish social interactions at work, school, during leisure activities and in the family without

major problems. Additionally, it can be inferred that each individual develops their own manner to live with the restrictions related to the disease. Thus, it is possible to come to terms with conflicts related to mental health, and emotional and social aspects.

The results from this current study suggest that no significant difference existed between males and females, possibly because of the improvement in the attitude of the society towards women and increased acceptance from spouses, children, and relatives. This may imply that the impact of the disease is not gender-biased, which is in a contrast to a previous finding (Mhasawade, 1983). This might also be due to a better social status accorded to women, as a woman's role is no longer viewed as secondary and the fact that women are now seen as active participants in society. Thus, women are given equal treatment and rehabilitation with men, thus enhancing their self-esteem and self-efficacy. The earlier study by Mhasawade (1983) was carried out in an era when multi-drug therapy (MDT) was just being introduced and rehabilitation and equalization of opportunities were still concepts in infancy.

Mhasawade (1983) concluded that leprosy had been demonstrated to harm the psychological, physical and social wellbeing, mental health and quality of life of affected persons and to progressively rehabilitate such persons. Self-esteem is a personal judgment about worth and accepting or rejecting of self that appears in one's attitude. It is also the person's judgment of personal worth obtained by analysing how well his or her behaviour conforms to self-ideal because of stigmatized illness. Self-efficacy is the belief in one's competence to take on difficult or novel tasks and to cope with adversity arising from specific demanding situations. Low self-esteem unsettles human balance and vitality and negatively influences efficacy (Mohammad and Tavakko, 2010). Hence the levels of self-esteem either positively or negatively affect the levels of self-efficacy.

There were significant levels of perceived participation restriction amongst people with visible impairments. This may be because the impairments physically restrict their abilities to participate socially or it could be that such individuals suffer the effects of an insidious type of stigma: i.e. people may discriminate against them for reasons as yet poorly understood (it may be that people are fearful of their appearance, or there could be deeply rooted cultural beliefs which attribute blame on people adversely affected by leprosy). Alternatively, it may be that people with visible impairments may voluntarily withdraw from participating in the community as an effect of shame (self-stigma). It is essential to expand the current knowledge of these important but neglected factors. Although no study was encountered that explored the self-esteem, self-efficacy, disability level and physical activity limitations of persons living with leprosy, these constructs significantly correlated positively. This may be attributable to the positive effect of MDT, rehabilitation and the increasing public awareness/education embarked upon about the disease, thereby leading to greater acceptability, reduced negative attitude towards affected persons, and reduced social stigma which has possibly helped them overcome the psychological effect of the disease, such that they are more at ease relating with others, making them friendlier with the environment thus leading to a consequent improvement in the perception of self-worth and competence which enhances self-confidence and reduces the occurrence of anxiety and depression all of which may positively impact on quality of life. Also, the significant correlation which existed between self-esteem and self-efficacy in table 3, maybe due to the reduced stigmatization which may have led to an increased acceptance of self, such that affected persons view themselves as worthy; consequently, leading to a positive belief in their ability to cope and manage adversity arising from specific demanding situations.

CONCLUSION

From this study, it can be concluded that:

1. The level of self-esteem and self-efficacy of persons living with leprosy was moderate, although there is a severe limitation of physical activity of persons living with leprosy living in selected states in Nigeria.

2. There is a significant correlation among self-esteem, self-efficacy, disability level, and physical activity level among persons living with leprosy in selected states in Nigeria.

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