Lepr Rev (2017) **88,** 43–57

Assessment of stigma among people living with Hansen's disease in south-east Nigeria

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Accepted for publication 15 August 2016

Summary
Objectives: The purpose of this study was to assess the stigma situation in Hansen's disease from the perspective of both people affected by Hansen's disease and those living in the surrounding community in southeast Nigeria.
Design: A cross-sectional survey was conducted among affected people and non-affected people using the Explanatory model interview catalogue stigma scale for the community adjusted for leprosy and for leprosy patients, internalised stigma of mental illness scale adjusted for leprosy, Participation Scale and the Social distance scale. Data obtained were analysed using descriptive statistics of frequency, distribution tables, mean and standard deviation as well as inferential statistics of Mann-Whitney U test, Kruskal-Wallis H test and Spearman rho correlation rank. A total of 434 participants including 63 affected people and 371 community members all within the age range of 12–89 years participated in this study.
Result: The perception of stigmatisation was higher in single participants, female participants, cooks, traders, crafts people and participants with primary and secondary school certificates, while beggars recorded the least perception of stigmatisation. The outcome of this study showed that females living in the community had a higher tendency of keeping a social distance than males. It also showed that on average, severe participation restrictions were found among people with WHO disability Grade II, traders, males, beggars, married people and those without any formal education while crafts people did not have significant participation restrictions.
Conclusion: There is an urgent need to intensify the stigma reduction strategies and the necessary rehabilitation support. A standardised instrument should be developed to monitor the efficiency of such programmes.

Keywords: Stigma, Social distance, Hansens' disease, Nigeria

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0305-7518/17/064053+15 $1.00

Introduction

Hansen's disease, also known as leprosy, is one of the oldest disabling diseases known to man.[1] It is a chronic granulomatous disease caused by *Mycobacterium leprae* (an acid fast, rod-shaped bacillus) principally affecting the peripheral nerves, mucosa of the respiratory tract and skin of human beings.[2] The bacterium was first identified in 1873 by the Norwegian physician, Gerhard Henrick Armauer Hansen, hence the name of the disease.[3] There is a high degree of misunderstanding and misconceptions about the cause, methods of transmission, and treatment.[4]

Leprosy has a great probability of causing a permanent and progressive physical disability if left untreated.[5] In 2000, the World Health Organization (WHO) estimated that between two and three million people were permanently disabled because of leprosy (WHO, 2000). Since the inception of multi-drug therapy (MDT) in 1982 there has been at least 85% reduction in its global prevalence.[6] Visible disabilities have been found to be the chief contributor of stigma and negative attitudes in and towards affected people.[7]

Link and Phelan defined stigmatisation as a social process that exists when elements of labeling, stereotyping, separation, status loss and discrimination occur in a power situation that allows them, and it is also an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one.[8] Van Brakel indicated that stigma can be broadly categorised into two groups: Stigma within the person affected (internal stigma) and stigma from community attitudes and/or practices (external stigma).[9]

ILEP also classified stigma felt by affected people into four: anticipated stigma, self-stigma, experienced stigma and impact stigma.[10] All these types of stigma can be measured with the following outcome measures: *The Explanatory model interview catalogue (EMIC-α)* stigma scale adjusted for leprosy which measures perceived stigma; *The internalised stigma of mental illness scale (ISMI)* adjusted for leprosy-affected people measures self or internalised stigma, alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance; *The Explanatory Model Interview Catalogue (EMIC)* stigma scale for the community adjusted for leprosy which measures community perceived stigma; *The social distance scale (SDS)* which measures social distance as applied by the community to affected people in this case those living with leprosy; *The Participation scale*: (*P*-Scale), is a standardised tool used to quantify perceived participation restrictions against affected people by the community while *Eye, Hand & Foot impairment (EHF) Score* measures level of disability and impairment among people living with leprosy. Leprosy is often used as a metaphor for stigmatisation and social exclusion.[11] Following the social views on leprosy, there was a need to investigate the stigma situation in the community of those affected by leprosy and among people affected by leprosy in South-east Nigeria because there is still concern that people affected by leprosy who have been offered rehabilitation may have inferior outcomes and continue to suffer stigmatisation.

This research has brought to light the stigma situation of people affected by leprosy and from those living in the community surrounding the leprosy settlement in Oji River, Enugu State, Nigeria. It may provide information that will assist educators, physiotherapists in CBR, doctors in community medicine, public health nurses, other health workers, social workers and policy makers in the elimination of discrimination; this in turn may enhance greater acceptability for people living with leprosy. The upshot of this study may draw attention to the need to add more strength to the on-going strategies of the United Nations Convention on

the Rights of People with Disabilities (UNCRPD) interventions to reduce stigma. The findings of this study have brought out the need to intensify the level of on-going public awareness/education in Oji River about the disease and encourage increased health education and media campaigns to help correct false beliefs and raise awareness of new advances and also address misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured of the disease. Recent studies indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries.[12,13] According to the Secretariat for the Convention on the Rights of People with Disabilities, many of the manifestations of stigma in Hansen's disease are violations of human rights specified in the Convention on the Rights of People with Disabilities (CRPD) and also the effects of stigma can be addressed through social and economic rehabilitation.[14] Cornielje *et al.* implied that the Community Based Rehabilitation (CBR) strategies will give individuals post-Hansen's disease, access to rehabilitation and health services, as well as the right to access work and employment on an equal basis with others thereby reducing the level of stigmatisation.[15] According to WHO, people with a stigmatizing condition like leprosy may conceal or deny their condition and delay seeking treatment which may result in the disease getting worse and increasing the risk of complications and disease transmission in the community, making it difficult to trace their contacts.[16] Social stigmatisation is frequent such that affected people with clear signs are often unable to work or to marry; and become dependent for care, requiring financial support leading to insecurity, shame, isolation, and consequent socioeconomic loss.[17] All of these negative effects result from poor community knowledge of the disease, and the misconceptions held about them.[18] The aims of this study are to determine:

1. Perceived, internalised stigma, social distance and impairment level for people living with leprosy in the leprosy settlement and those living in the surrounding community.
2. The distribution, influence and comparison of internalised and perceived stigma, social distance and impairment level across selected variables (age, sex-difference, marital status, occupation, educational status).
3. The relationship among perceived, internalised stigma, social distance and impairment level of people living with leprosy in the leprosy settlement and those living in the surrounding community.

Methodology

The study was conducted in the Oji River Local Government Area (Oji River is a Local Government Area of Enugu State, Nigeria to the South bordering Anambra State and Abia State) and its headquarters are in the town of Oji River. The towns within Oji River L.G.A are: Inyi, Achi, Awlaw, Akpugoeze and Ugwuoba. It has an area of 403 km^2 and a population of 126,587 at the 2006 census. Oji River town has one of the largest and oldest running leprosy rehabilitation settlements in the south-east. Two groups participated in this study Group A and Group B.

Group A included all people affected by leprosy in the concerned community in the period when this study was conducted.

Group B included all other residents living in the community that were available in the period when this study was conducted.

FOR GROUP A

1. ***The Explanatory model interview catalogue (EMIC-α)*** stigma scale adjusted for leprosy: It was developed to elicit illness-related perceptions, beliefs and practices. The EMIC questionnaire has 15 items related to the perception of stigma in leprosy. The higher the score obtained by EMIC scale higher the level of perceived stigma. It has been classified as the instrument to measure perceived stigma in leprosy by ILEP and the stigma research workshop held in Amsterdam in 2010. An ICC agreement of at least 0·70 is considered evidence of good reliability, test–retest reproducibility coefficients is 0·70 for the EMIC score. Floor and ceiling effects are considered to be present if 15% or more of the respondents have the lowest or highest score, respectively.[19]
2. ***The internalised stigma of mental illness scale (ISMI)*** adjusted for leprosy-affected people: ISMI Scale is a 28-item instrument.[20] Alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance will be examined with a 4-point agreement scale, a higher score indicating a higher level of internalised stigma. Before calculation of the sum score, items 24–28 should be recoded to get the correct results (score 1 to 4, 2 to 3, 3 to 4 and 4 to 1). After this, the scores on the single items can be summed and divided by the total number of questions (28). The higher the mean score, the greater the evidence of self-stigma. Each item asks the respondents to express, using a 4-point Likert scale, how much they agree with the description. The ISMI was validated in 2003, and the internal consistency and test-retest are acceptable for the original version; the Stigma Resistance subscale, however, has α of 0·58.[20] The ISMI has been shown to have good internal consistency and reliability.[21] The scale has an internal consistency of α 0·66; ICC value of 0·52 Test–retest reproducibility coefficients is 0·62 for the ISMI score and r of 0·02.
3. ***The Participation scale***: *P*-Scale, developed in 2006, is a standardised tool used to quantify perceived participation restrictions; this questionnaire is based on the participation domains of the International Classification of Functioning, Disability and Health of the World Health Organization.[22] Each of the 18 items of the *P*-Scale was scored with a value of 0 in the case of no perceived difference to peers or, when a difference was perceived, with values between 1 (no problem) to 5 (large problem), thus resulting in a total score (*P*-Score) of between 0 and 90 points. A *P*-Score higher than 12 points is considered a significant restriction with the need for social rehabilitation.[22] The score from 0–12 signifies no significant restriction, 13–22 mild restriction, 23–32 moderate restriction, 33–52 severe restriction while 53–90 is extreme restriction. The psychometric properties of the *P*-scale include a Crohnbach's alpha of 0·92, intra-tester stability of 0·83, inter-tester reliability of 0·80, test–retest reproducibility coefficient of 0·80 and discrimination between controls and clients was good at a participation score threshold of 12. It is very reliable in measuring the impact of stigma and client perceived participation in people affected by leprosy or disability.[22]
4. ***Eye, Hand & Foot impairment (EHF) Score***: This uses the World Health Organization – Disability Grading (WHO-DG) using Eyes, Hands and Foot. 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.[23] The EHF score sums the six individual scores and ranges from 0–12; a score of 12 indicates Grade 2 disability of both eyes, both hands and both feet. (DG 0 - no disability caused by leprosy in eyes, hands and feet. DG 1 - Loss of sensitivity in hands or

feet. DG 2 - Eyes: visual impairment, Hands and feet: with visible damage and wounds). Individuals with EHF scores of 0 were categorised 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.

FOR GROUP B

1. ***The Explanatory Model Interview Catalogue (EMIC)*** stigma scale for the community adjusted for leprosy: Rensen *et al.* (2010) found an alpha value (internal consistency) of 0·83. Test–retest reproducibility coefficient is 0·70. There is no strict interpretation of scores, however the higher the score the more severe is the stigma.
2. ***The social distance scale (SDS)*** which includes seven items representing different degrees of social distance: The Social Distance Scale originated in the Bogardus study in 1926, which was designed to measure the level of acceptability of various types of social relationships of Americans with members of common ethnic groups.[24] In 1987, Link *et al.* modified the Bogardus scale to understand the importance of labels attached to those with former mental illness. Respondents could indicate to what extent they would, in the situation presented, accept the person described in a vignette, using a Likert scale. A good internal consistency was found in several studies, with Cronbach's alpha of 0·92. In addition, there are some results pointing to the construct validity of the scale. The higher the score the greater the tendency of maintaining social distance from affected people.

For Group A: Purposive or judgmental sampling technique was engaged to reach subjects who met the inclusion criteria for the study.

For Group B: Consecutive sampling technique was engaged to reach subjects who met the inclusion criteria for the study.

This research was a cross sectional survey design whereby respondents were given questionnaires. It was conducted at the leprosy rehabilitation settlements and the community of one of the south-eastern states in Nigeria. Ethical approval was sought and obtained from Nnamdi Azikiwe University Teaching hospital in Southeast Nigeria. The researchers considered the burden on the respondents, the time the questionnaire would likely take to be filled. The researchers also sought the assistance of the appropriate non-governmental organisation (NGO) to gain access to the people affected by leprosy. The research was carried out from 17th of April to the 26th of May 2015 at the leprosy settlement and surrounding community of Oji River local government area. Four research assistants were trained for 2 days as this was essential to obtaining quality information. Out of the four research assistants, the first, was a lady who has had leprosy with minimal deformity, the second assistant, a lady and a social worker with an NGO, the third also a lady who works as a secretary in a rehabilitation hospital while the fourth was a young man, an undergraduate who hails from the surrounding community. All of them were proficient in English and the local language of communication. The research assistants were trained in the necessary knowledge about stigma and the importance of assessing it, the right attitude and skills to administer the interview. The average time for administering the questionnaires to each person was 20 minutes. Before administering the questionnaire, informed consent was obtained from each participant in a way that was understandable to

them. The respondents were approached and the aims of the study were explained to them and they were encouraged to volunteer. Some people from the leprosy settlement and the surrounding community were reluctant to participate demanding to know the benefits, others were not interested while some did not want to disclose the information required, complaining of not having the time to participate. Nobody was coerced into participating. The interviews were both self and researcher administered; only those who met the inclusion criteria and volunteered to participate in the study after their informed consent was obtained participated. Two people living with leprosy from the settlement refused to participate while three people from the surrounding community declined to participate for lack of time. People were eligible if they were affected by leprosy, living in the leprosy settlement or if they were unaffected people living in the community surrounding the leprosy settlement. The anonymity of the participants was secured by not including their names, phone numbers or residential address. No incentives were paid for their time. Prior to the day of data collection, the management of the NGOs were approached and their co-operation was sought in terms of helping to announce the study to their members, and encouraging them to be part of the study. Information was collected on socio-demographic variables (age group, gender, religion, occupation, educational level, disability level, marital status). This data was analysed using descriptive statistics of frequency distribution tables, mean and standard deviation; and inferential statistics of Spearman's rho correlation

Table 1. Frequency and percentage distribution of participants' age group, gender, marital status, WHO disability grades and religion

Demographics and category	PPHD Freq. $N = 63$	%PPHD 100%	PLC Freq. $N = 371$	% PLC 100%
Age group				
0–14	1	1·6	7	1·9
15–29	2	3·2	146	39·3
30–44	17	27	122	32·9
45–59	17	27	74	19·9
60–74	16	25·4	18	4·9
75–89	10	15·8	4	1·1
Gender				
Male	26	41·3	160	43·1
Female	37	58·7	211	56·9
Marital status				
Married	49	77·8	174	46·9
Single	14	22·2	197	53·1
WHO disability grade				
Grade 0	9	14·3		
Grade II	54	85·7		
Religion				
Christianity	63	100	352	94·9
Islam	0	0	5	1·3
Tradition	0	0	5	1·3
Others	0	0	9	2·4

KEY:
PPHD = People affected by Hansen's disease
PLC = People living in the community

test, Mann-Whitney U test and Kruskal Wallis test since these scores were not normally distributed. Level of significance was set at 0·05.

Results

PARTICIPANT PROFILE

This study assessed the stigma situation of people affected by Hansen's disease in southeast Nigeria. A total of 434 people (63 people who had had leprosy and 371 people living in the community) participated in the study.

Table 1 shows the frequency and percentage distribution of categories in the participant's age group, gender, marital status, WHO disability grade and religion.

Table 2 shows the frequency and percentage distribution of participants' occupations and educational levels.

PARTICIPANTS' RANGE STATISTICS AND MEAN SCORES FOR THE ISMI, EMIC-a, *P*-SCALE, SDS, EMIC-c AND EHF

Table 3 shows the range statistics and mean scores for the participants in the ISMI, EMIC-a, *P*-scale, SDS, EMIC-c and EHF.

Table 2. Frequency and percentage distribution of participants' occupations and education

Demographics and category	PPHD Freq. $N = 63$	%PPHD 100%	PLC Freq. $N = 371$	% PLC 100%
Occupation				
Student	0	0	164	44·2
Teacher	0	0	28	7·5
Lecturer	0	0	21	5·7
Healthcare worker	0	0	33	8·9
Force	0	0	32	8·6
Clergy	0	0	9	2·4
Trader	10	15·9	39	10·5
Craftsperson	9	14·3	8	2·2
Cook	3	4·8	2	0·5
Beggar	26	41·3	5	1·3
Others	15	23·8	30	8·1
Educational level				
No formal	38	60·3	13	3·5
Primary school certificate	20	31·7	36	9·7
Senior secondary certificate	5	7·9	101	27·2
OND/NCE	0	0	114	30·7
HND/Bachelor's degree	0	0	79	21·3
Post graduate degree	0	0	28	7·5

KEY:
Freq. = Frequency
PPHD = People affected by Hansen's disease
PLC = People living in the community
OND = Ordinary National Diploma
NCE = National Certificate of Education
HND = Higher National Diploma

Table 3. Descriptive statistics of participants in the EHF, ISMI, EMIC-a, *P*- Scale, SDS, EMIC-c

Scales	N statistics	Minimum statistics	Maximum statistics	Mean ± S.D
EHF	63	0·00	10·00	4·32 ± 2·878
ISMI	63	0·17	3·36	2·50 ± 0·503
EMIC-α	63	4·00	38·00	22·76 ± 8·169
P-Scale	63	0·00	73·00	35·63 ± 21·106
SDS	371	0·00	18·00	7·67 ± 4·265
EMIC-c	371	0·00	30·00	17·10 ± 5·710

KEY:
EHF = Eye, Hand and Foot Scores
ISMI = Internalised Stigma of mental illness scale adjusted for leprosy
EMIC-α = The Explanatory model interview catalogue stigma scale for leprosy affected people
P-Scale = Participation scale
SDS = Social Distance Scale
EMIC-c = The Explanatory model interview catalogue stigma scale for the community adjusted for leprosy
S.D = Standard deviation

DISTRIBUTION OF THE MEAN RANK OF THE SDS, EMIC-c, ISMI, EMIC-a, P-SCALE ACROSS AGE GROUP

The mean rank of people affected by leprosy above 75 years was lowest in the SDS (42·50), EMIC-a (119·88). The Mean rank of the participants in the SDS, EMIC-c, ISMI, EMIC-a, *P*-scale for each age group are shown (Table 4).

DISTRIBUTION OF THE MEAN RANK OF THE SDS, EMIC-c, ISMI, EMIC-a, *P*-SCALE ACROSS MARITAL STATUS, GENDER AND WHO DISABILITY GRADE

The mean rank of married people was lower in the ISMI (29·57), EMIC-a (29·29) but higher in the *P*-scale (35·50) for people who had had leprosy while unaffected males in the community had a lower mean rank in the SDS (173·30). Table 5 shows the distribution of the mean rank of scores in the SDS, EMIC-c, ISMI, EMIC-a and *P*-scale.

DISTRIBUTION OF THE MEAN RANK OF THE SDS, EMIC-c, ISMI, EMIC-a, *P*-SCALE IN OCCUPATION

Community members that were cooks had the highest mean rank in the SDS (304·50), EMIC-c (253·00), while affected people that were cooks had the highest in the ISMI (44·50),

Table 4. Distribution of the mean rank of scores of SDS, EMIC-c, ISMI, EMIC-a, *P*-Scale across age group

Age group	SDS	EMIC-c	ISMI	EMIC-α	*P*-Scale
0–14	206·29	255·64	49·00	9·00	26·00
15–29	203·34	189·07	43·50	31·50	8·50
30–44	186·39	185·79	38·47	38·91	26·15
45–59	166·03	175·50	26·24	27·68	30·06
60–74	148·83	193·31	32·41	33·13	36·69
75–89	42·50	119·88	26·15	28·20	43·05

KEY:
The higher the score the more severe.

Table 5. Distribution of the mean rank of scores of SDS, EMIC-c, ISMI, EMIC-a, *P*-Scale across marital status, gender and WHO Disability Grade

Variables	ISMI	EMIC-α	P-Scale	SDS	EMIC-c
Marital status					
Married	29·57	29·29	35·50	173·36	187·53
Single	40·50	41·50	19·75	197·16	184·65
Gender					
Male	29·15	26·48	37·60	173·30	188·49
Female	34·00	35·88	28·07	195·63	184·11
WHO disability grade					
Grade 0	30·61	33·33	15·50		
Grade II	32·23	31·78	34·75		

KEY:
The higher the score the more severe.

EMIC-a (42·33) but not in the *P*-scale (20·67) where the highest were beggars (40·96). Table 6 shows the mean rank of the SDS, EMIC-c, ISMI, EMIC-a, *P*-scale in different occupations.

DISTRIBUTION OF THE MEAN RANK OF THE SDS, EMIC-c, ISMI, EMIC-a, *P*-SCALE IN EDUCATIONAL LEVEL AND RELIGION

The mean rank of people that had no formal education was lowest in the EMIC-a (30·54) while those with a post-graduate degree had the lowest in EMIC-c (175·30) and SDS (149·16).

Table 7 shows the mean rank of scores in the SDS, EMIC-c, ISMI, EMIC-a, *P*-scale across different educational levels and religion.

COMPARISON BETWEEN DIFFERENT VARIABLES AND SCORES IN THE SDS, EMIC-c, ISMI, EMIC-a, *P*-SCALE

The data were analysed using the Mann-Whitney U test and Kruskal-Wallis H test (Table 8). There were significant differences between age groups in the SDS ($P = 0{\cdot}01$), between

Table 6. Comparison between occupation and mean rank in the scores of SDS, EMIC-c, ISMI, EMIC-a, *P*-Scale

Occupation	ISMI	EMIC-α	*P*-Scale	SDS	EMIC-c
Student	–	–	–	199·35	182·97
Teacher	–	–	–	193·68	228·23
Lecturer	–	–	–	151·21	165·74
Healthcare worker	–	–	–	153·97	202·21
Force	–	–	–	183·95	202·64
Clergy	–	–	–	79·11	149·39
Trader	39·00	37·75	35·70	195·21	180·79
Craftsperson	37·89	35·11	9·22	193·00	225·44
Cook	44·50	42·33	20·67	304··50	253·00
Beggar	31·40	28·27	40·96	106·90	74·40
Others	22·33	30·70	29·93	191·12	163·12

KEY:
The higher the score the more severe.

Table 7. Distribution of the mean rank of scores of SDS, EMIC-c, ISMI, EMIC-a, *P*-Scale across education level and religion

Variables	ISMI	EMIC-a	*P*-Scale	EMIC-c	SDS
Educational level					
No formal	31·34	30·54	34·33	179·23	164·31
Primary sch.	33·08	33·78	30·80	198·10	215·15
Senior sec.	32·70	36·00	19·10	183·50	191·61
OND/NCE	–	–	–	195·17	201·45
HND/Bachelor's	–	–	–	175·35	159·87
Post graduate	–	–	–	175·30	149·16
Religion					
Christianity	–	–	–	187·54	186·43
Islam	–	–	–	272·00	210·20
Tradition	–	–	–	157·50	95·40
Others	–	–	–	93·89	206·22

KEY:
The higher the score the more severe.

married and single in the ISMI ($P = 0{\cdot}05$), and between males and females in the EMIC-a ($P = 0{\cdot}05$), *P*-scale ($P = 0{\cdot}04$) and SDS ($P = 0{\cdot}05$).

CORRELATION BETWEEN SCORES IN THE SDS, EMIC-c, ISMI, EMIC-a, *P*-SCALE, EHF

The data were analysed using the Spearman rho correlation rank (Table 9). There was no significant correlation between ISMI and *P*-scale ($P = 0{\cdot}23$), ISMI and EHF score ($P = 0{\cdot}34$), EMIC-a and *P*-scale ($P = 0{\cdot}08$), EMIC-c and SDS ($P = 0{\cdot}09$), EMIC-c and EMIC-a ($P = 0{\cdot}80$).

Discussion

A total number of 434 people (63 living with leprosy and 371 living in the community) participated in the study in Oji River in South East Nigeria. The study revealed that there was

Table 8. *P*-values of different variables in the ISMI, EMIC-a, *P*-Scale, SDS and EMIC-c scores

Variables	ISMI	EMIC-α	P-Scale	SDS	EMIC-c
Vs. age*	0·26	0·36	0·08	0·01	0·37
Vs. marital status**	0·05	0·03	0·01	0·03	0·80
Vs. gender**	0·30	0·05	0·04	0·05	0·70
Vs. educational level*	0·94	0·72	0·20	0·02	0·78
Vs. occupation*	0·09	0·50	$<0{\cdot}01$	0·01	0·08
Vs. WHO disability grade**	0·81	0·81	$<0{\cdot}01$		
Vs. religion				0·24	0·02

KEY:
Vs. = Verse
* = Test statistic; Kruskal-Wallis Test
** = Test Statistic; Mann-Whitney Test
$> 0{\cdot}05$ = Significant *P* value

Table 9. Correlation between the ISMI, EMIC-a, *P*-Scale, EMIC-c, SDS, EHF using Spearmann RHO correlation rank

Scores	Correlation coefficient	*P*-value
ISMI vs. EMIC-α	0·41	0·01
ISMI vs. P-scale	−0·15	0·23
ISMI vs. EHF	−0·12	0·34
EMIC-α vs. P-scale	−0·22	0·08
EMIC-α vs. EHF	−0·26	0·04
P-scale vs. EHF	0·60	0·01
EMIC-c vs. SDS	0·09	0·09
EMIC-c vs. EMIC-α	−0·03	0·80

Key:
$> 0{\cdot}05 =$ Significant *P*-value.

no significant relationship between participation restriction and self-stigma, disability scores and self-stigma, participation restriction and perceived stigma, negative attitudes from community members and perceived stigma in affected people. This was not consistent with the findings of other authors, which revealed that significant associations were observed between the negative attitudes from community members and perceived stigma in affected people.[21]

The study did show that there was a significant relationship between self-stigma and perceived stigma, disability scores and perceived stigma in affected people. Similarly, there was a significant relationship between disability scores and social participation restrictions, a tendency of keeping a social distance and negative attitudes from the community member. The study showed that, on average, affected people had severe social participation restrictions. This is consistent with the work of Heijnders whose work indicated that after a person is labeled as 'leprous', there are negative social consequences for this person and his or her family.[25]

FEAR OF STIGMATISATION/AWARENESS OF NEGATIVE ATTITUDES TOWARDS AFFECTED PEOPLE

The Explanatory model interview catalogue stigma scale for the community adjusted for leprosy (EMIC-c) which is a 15 item questionnaire was used to measure the fear/awareness of negative attitudes towards affected people in the study. The higher the score obtained by EMIC scale higher is the level of perceived stigma. In this study, age did not significantly influence the awareness of negative attitudes towards affected people. Negative attitudes and fear of stigmatisation was higher in males and participants that were married, although this was not statistically significant. There was no significant difference between occupation and levels of negative attitudes towards affected people. The fear of stigmatisation/awareness of negative attitudes towards affected people was highest among cooks, teachers, healthcare workers, force officers and crafts people, it was also high among students, lecturers and other participants without specified occupations but it was lower among clergy and beggars. This can be compared with the study of Sermrittirong *et al.* who found that healthcare workers had significantly negative attitudes and lacked awareness that affected people had been stigmatised by the community; and Kaehler *et al.*

found that people with a lower duration of formal education had higher perceived stigma.[26,27] Non-affected people who had a higher diploma (HND), bachelor's degree and post-graduate degrees had less tendency towards negative attitudes, while those without formal education had a more negative attitude towards affected people. Muslims had significantly more negative attitudes towards affected people, while traditionalists and other participants with unspecified religion had the least negative attitudes towards affected people. This can be compared with the study of De Stigter *et al.* which revealed significant negative community behaviours.[28]

ATTITUDES: SOCIAL DISTANCE

The Social Distance Scale (SDS) was used to measure the levels of social distance, high scores indicating a high tendency to keep more social distance from affected people. The study showed that non-affected people who had a higher diploma (HND), bachelor degree and post-graduate degree had a lower tendency towards keeping social distance, while those without formal education had a higher tendency to keep social distance from affected people. In this study, age, occupation, marital status, gender and educational level significantly influenced the level of how close people living in the community were willing to be with affected people, while religion was not significantly related. This disagrees with the findings of Briden and Magure, who showed that there was no significant influence between occupation and attitude towards leprosy.[29] The desire to keep a social distance was higher in females but lower in participants that were married. This is consistent with a study conducted in Indonesia, which indicated that females and people with post-secondary school qualification had a higher tendency to keep a social distance.[30] The level of social distance towards affected people was highest among cooks, Muslims and other participants with an unspecified religion. It was also high among Christians, students, lecturers, teachers, healthcare workers, force officers, crafts people and other participants without specified occupations but it was lower among traditionalists, clergy and beggars. The study recorded that there was a lower tendency to keep social distance among people who were 60–89 years old while it was higher among younger people. This disagreed with the findings from Indonesia, which indicated that older people (>60 years) had higher tendency to keep social distance from leprosy affected people.[30]

LEVEL OF PERCEIVED STIGMA

The Explanatory model interview catalogue stigma scale for affected people adjusted for leprosy (EMIC-a) which is a 15 item questionnaire was used to assess the level of perceived stigma. The study revealed that affected participants were all Christians, probably because the leprosy settlement was owned by a Christian organisation.

In this study, age, educational level, occupation and WHO disability grade did not significantly influence the extent affected people perceive that they would be stigmatised while marital status and gender did significantly influence it. This was not consistent with the study conducted by another author, who found that there was no significant difference between gender and the extent of affected people's fear or anticipation that they would be stigmatised.[4] This may be due to socio-cultural differences. The perception of stigmatisation was higher in single participants, female participants, cooks, traders, crafts people and participants with primary and secondary school certificates. These can be compared to the

study from Nepal, which showed that a higher perceived stigma score was found in the illiterate and those who had less than 5 years of education, also that the WHO grade did not significantly influence perceived stigma.[4] Other studies also found that a higher level of perceived stigma was associated with visible deformity.[7]

Beggars recorded the least perception of stigmatisation, probably because they were looked upon with pity and they tended to receive alms from people in society. The study showed that affected people were not students, lecturers, teachers, healthcare workers and force officers, probably because they stopped going to school after they were diagnosed with the disease and the occupations mentioned require a high level of literacy.

PERSONAL NEGATIVE BELIEFS AND SELF-STIGMA

The internalized stigma of the mental illness scale (ISMI) adjusted for leprosy, is a 28 item instrument used to assess self-stigma: the higher the mean score, the greater the evidence of self-stigma. The study showed that that the WHO disability grade did not significantly influence the extent of self-stigma although the mean rank of affected people who had WHO disability Grade II was higher than those who had WHO disability Grade 0 - the higher the score the more severe. The study revealed that age, gender, education and occupation did not significantly influence the level of self-stigma but marital status did.

Females, single people, cooks, traders, crafts people, first school leaving certificate holders and senior secondary school holders had a higher level of self-stigma. This can be compared with a study conducted in Brazil where the level of stigma was higher in Grade II disabled patients compared to Grade 0 and Grade I.[31] Other studies in different parts of the world have shown that disabilities are associated with leprosy stigma.[4] Affected people that were 45–89 years had a lower self-stigma mean rank, while that of younger people was higher.

SOCIAL PARTICIPATION RESTRICTION

The participation scale (*P*-scale) was used to assess social participation restrictions: scores of more than 12 indicated significant social restrictions. The study showed that the mean score on the *P*-scale was 35·63, indicating severe participation restriction. This was not in keeping with the findings of another author in India, who found that the mean score on the *P*-scale was 10·1, indicating no significant restriction.[32]

The study showed that age and educational level did not significantly influence the social participation of affected people. This is in line with a study conducted in Brazil, which showed that there was no significant difference between age and social participation.[11] It also brought to light that marital status, sex difference, occupation and WHO disability grade significantly influenced social participation in people affected by Hansen's disease. In a study in north-east Brazil, gender had no significant influence on the *P*-scale Score.[11]

Severe participation restrictions were found among people with WHO disability Grade II, traders, males, beggars, married people and people without any formal education, while crafts people did not have significant participation restrictions. During the testing phase in the development process of the *P*-Scale, *P*-Scores were shown to be significantly higher when physical impairment was observed.[33,34]

Unmarried people, cooks, people with WHO disability Grade 0 and senior secondary school certificate holders recorded mild social restrictions on average, whereas females, first

school leaving certificate holders and people in other unspecified occupations had moderate restrictions on average. Although both genders are negatively affected by the fact that they were diagnosed with Hansen's disease, the impact varies across cultures and is often more severe in women than in men as a result of other socio-cultural factors.[35]

Conclusion

People affected by Hansen's disease had relatively severe participation restrictions in south-eastern Nigeria. Severe participation restrictions were found among people with WHO disability Grade II, traders, males, beggars, married people and people without any formal education while crafts people did not have significant participation restrictions. There was a significant relationship between self-stigma and perceived stigma, disability scores and perceived stigma in affected people, participation restrictions and disability scores. Educational level and age did not significantly influence the social participation of affected people. Marital status, gender, occupation and WHO disability grade significantly influenced social participation in people affected by Hansen's disease.

Age, occupation, marital status, gender and educational level significantly influenced how close people living in the community were willing to be with affected people.

The study has brought out the need to intensify the level of on-going public awareness/education in South-east Nigeria about the disease and encourage increased health education and media campaigns to help correct false beliefs and raise awareness of new advances and also address misconceptions and traditional beliefs about leprosy, using positive images of leprosy and testimonies of people successfully cured of leprosy.

Acknowledgements

Nchechukwube Ndubuizu of the department of social work (GLRA) for contacts that made the work possible.

Funding: No funding was given for this work.

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