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Impacts of the diagnosis of leprosy and of visible impairments amongst people affected by leprosy in Cebu, the Philippines

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Summary

Purpose: To quantify the impact of the diagnosis of leprosy and of visible impairments in people affected by leprosy.

Subjects and Methods: Three interview-based questionnaires designed to measure activity limitation, participation restriction, and general self-efficacy were used to collect data from three Groups. Group 1: leprosy affected people with visible impairment, Group 2: newly diagnosed leprosy patients with no visible impairment, Group 3: patients with other skin diseases symptomatic for more than 1 month.

Results: One hundred and eight subjects were recruited. The subjects with visible impairments (Group 1) had higher levels of participation restriction than those with skin disease (P0·012), and participation restriction was similar between subjects in Groups 2 and 3 (P0·305). The people in Group 1 (35 subjects) also reported significantly more activity limitation compared to the people in either Group 2 (35 subjects) or Group 3 (38 subjects) (P 0·001, respectively). The subjects in Group 2 had no significant activity limitation compared with those in Group 3 (P0·338). A multivariate analysis showed that severe visible impairment was a risk factor for activity limitation (odds ratio 5·68, 95% CI: 1·09–29·7, P0·039) and a low level of self-efficacy (Odds ratio 6·38, 95% CI: 1·06–38·3, P0·043) among people affected by leprosy.

Conclusion: Visible impairments affected the activities and attitudes of people affected by leprosy. However, others without visible impairment, had activity

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limitations, participation restrictions and levels of general self-efficacy that were similar to patients with other skin diseases. Prevention of visible impairments should be considered a key intervention for stigma reduction.

Introduction

In some societies, when people affected by leprosy have visible impairments, this can evoke stigma.[1,2] The ways in which visible impairments cause dehabilitation among people affected by leprosy is described in detail by Kaur *et al.*[3] To quantify this burden three instruments – the Participation scale (P-scale), Screening of Activity Limitation and Safety Awareness (SALSA) scale, and the General Self-efficacy (GSE) scale – can be used. The P-scale can be used as a proxy measure of stigma.[4,5] The SALSA scale is a new measurement scale for activity limitation in the daily lives of people suffering affects of peripheral neuropathy.[6] The GSE scale[7] measures people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives.[8]

For patients who suffer from chronic and stigmatising illness, participation restriction can be more important than the underlying health condition. However, participation is a relatively new concept, and so there are few instruments to measure it.[5,9] The P-scale was designed to measure participation restriction in low and middle income countries.[5,9] This scale has been tested on patients in rural and urban settings.[5] There are two studies which used this scale to assess people affected by leprosy.[10,11] Nicholls *et al.* used the scale to select subjects for an analysis of the risk factors which could cause participation restriction in Brazil, India, and Nepal.[11] Cross and Choudhary used this to evaluate the effect of stigma elimination campaign in Nepal.[10]

The SALSA scale measures activity limitation in daily life, and was specifically designed for assessing patients with peripheral neuropathy and disability. It was based on the research in diabetic and leprosy patients.[6] SALSA also assesses the safety awareness in the daily lives of people.[6,9]

The GSE score has been translated in 28 languages and validated in many countries in various settings.[12,13] Individuals' ability to cope with difficulties in their lives can be hindered by a lack of confidence. 'Perceived self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives'.[8] Self-management based on self-efficacy is essential in the management of chronic illness,[14] such as leprosy. However, low self-efficacy could be an obstacle because 'self-perceived inefficacy can and does nullify the motivating potential of desirable outcome expectancies',[15] which could introduce a vicious cycle combined with deterioration of the visible impairments.

We used these three scales together to quantify the impact of diagnosis of leprosy and visible impairments in people affected by leprosy. We hypothesised that people affected by leprosy would feel the highest level of participation restriction, activity limitation, and the lowest level of self-efficacy amongst these three groups of people; that patients with other skin diseases would be least affected; and that recently diagnosed leprosy patients without any visible impairment would have intermediate levels of restriction.

Subjects and Methods

Approval from the Ethics committee at London School of Hygiene and Tropical Medicine and Institutional Review Board at Leonard Wood Memorial (LWM) were obtained.

After a review of clinical charts, people aged between 16 and 45 years were recruited from the two LWM clinics in Cebu, the Philippines: Cebu Skin Clinic (CSC) and the LWM Clinical Branch (CB). CB is located in the Eversley Childs Sanitarium (ECS) which has an adjacent colony (ECS community) populated predominantly by people affected by leprosy, their families and other relatives. Some of the people affected by leprosy who live there routinely attend the CB. The study subjects were categorised into the following three Groups.

Group 1: People affected by leprosy with visible impairments
Group 2: Leprosy patients without any visible impairment diagnosed with leprosy within the 6 months prior to the study.
Group 3: Patients with other skin diseases who had been symptomatic for more than 1 month prior to the study.

INSTRUMENTS

The P-scale has 20 questions with responses scored either 0 to 3 or 5. The sum score suggests the level of participation restriction that a respondent perceives. According to van Brakel *et al.* the following participation restriction scores apply[5]:

- 0 to 12 – no significant participation restriction
- 13 to 22 – mild participation restriction
- 23 to 32 – moderate participation restriction
- 33 to 52 – Severe participation restriction
- 53 to 90 – Extreme participation restriction

The SALSA scale consists of 18 questions with answers scored between 0 and 4. The sum score suggests the level of activity limitation but it is also possible to calculate the level of safety awareness which may be a factor that prevents certain activities.

The GSE scale has 10 statements with responses scored between 1 and 4. The sum scores were compared between three Groups. A high SALSA score was defined as that above 75 percentile and low GSE score as that below 25 percentile of whole study population. Participation restriction was defined as the score above 12.[5]

For subjects in Group 1, visible impairments on hands and feet were graded and scored using a classification of hand and foot impairment according to severity of impairment (Table 1).

The only eye impairment to be recorded was lagophthalmos. The sum score above 50 percentile of that obtained from the patients in Group 1 were categorised as severe visible impairment.

People in Group 3 had their skin diseases diagnosed by physicians at the CSC. Localised lesions without active inflammation were classified as mild, generalised lesions, lesions with active inflammation, or unbearable conditions were classified as severe, others were classified as moderate.

Table 1. Classification of Hand and foot Impairment and Scoring

Classification of Hand Impairment	
Grade 1	Anesthesia
Grade 2.1	Wound but no other impairment
Grade 2.2	Ulnar weakness (mobile claw fingers)
Grade 2.3	Ulnar paralysis (fixed claw fingers) and/or loss of phalanges (not including proximal phalanges and not including thumb)
Grade 2.4	As grade 2.2 but also with loss of any proximal phalanx or median paralysis (loss of opposition)
Grade 2.5	As with grade 2.2 and median paralysis (loss of opposition)
Grade 2.6	Radial paralysis (wrist drop) or mitten hand (no fingers or thumb)
Grading Foot Impairment	
Grade 1	Anesthesia
Grade 2.1	Wound but no other impairment or foot drop accompanied by any sensory loss on the same foot
Grade 2.2	Claw toes or loss of any small toes (i.e. NOT hallux)
Grade 2.3	Loss of hallux
Grade 2.4	Loss of hallux and claw toes
Grade 2.5	Loss of any bones proximal to the small toes or hallux
Grade 2.6	Tarsal disintegration ('boat foot')

STATISTICAL ANALYSIS

All analyses were done by STATA™10.0 (StataCorp, Texas, USA). For categorical data, chi-square and Fischer's exact test were applied. For continuous data, either ANOVA or Kruscal Wallis test was applied. Scores obtained from interviews were compared between three groups. Logistic regression analysis was applied to identify risk factors for participation restriction, activity limitation, and low perception of general self efficacy.

Results

One hundred and eight subjects were recruited (Table 2).

The subjects in Group 1 had significantly less education at secondary and tertiary level than those in Group 2 or 3.

Diagnosis of other skin diseases amongst subjects in Group 3 included: 13 contact/allergic dermatitis (34%); 7 tinea infection (18%); 4 seborrheic dermatitis (11%); 3 psoriasis (8%); 2 prurigo nodularis (5%) cases; 2 acune (5%) cases; and 7 other conditions/diseases (18%) were coagulopathy suspected (pytiriasis rosea, striae distensae, carbunculosis, neurodermatitis, verruca plana, and lichen planus). Twenty two (58%) were categorised as mild, 12 (31%) moderate, and 4 (11%) severe.

The 75th percentile in the range of SALSA scores, the 25th percentile in the range of GSE scores, and the 50th percentile of the impairment grading scores for the study population were 28·5, 32, and 7·5, respectively, and the subjects in those categories in each interview/examination were labelled as high SALSA, low GSE score, and severe visible impairment, respectively (Table 3).

Significantly more patients in Group1 reported participation restriction than those in Group 3 (Table 3). The Group 1 subjects had the highest SALSA scores whilst the SALSA scores for Groups 2 and 3 were similar. The GSE score was similar between all three Groups.

Table 2. Demographic data of the subjects

	Group 1	Group 2	Group 3	
Number of subjects	35	35	38	
Number of males (%)	25 (71%)	28 (80%)	24 (63%)	$P = 0{\cdot}283$
Age (median)	29 (25, 35)	27 (22, 34)	7 (21, 38)	$P = 0{\cdot}335$
Working status				$P = 0{\cdot}838$
Currently on full-time job	16 (46%)	17 (49%)	20 (53%)	
Currently not working	19 (54%)	18 (51%)	18 (47%)	
Marital status				$P = 0{\cdot}748$
Single	22 (63%)	24 (69%)	27 (71%)	
Married or living with partner	13 (37%)	11 (31%)	11 (29%)	
Final education level				$P < 0{\cdot}001$
Primary	17 (48%)	3 (9%)	3 (8%)	
Secondary	10 (29%)	22 (63%)	17 (45%)	
Tertiary	8 (23%)	10 (29%)	18 (47%)	
Living condition				$P < 0{\cdot}001$
With family, partner or relatives	15 (43%)	33 (94%)	30 (79%)	
With other people (patients etc)	20 (57%)	2 (6%)	5 (13%)	
Alone	0	0	3 (8%)	
Living inside ECS community	26 (74%)	1 (3%)	0	$P < 0{\cdot}001$
Duration living in ECS community				
$<$ 1 year	4 (11%)	0	NA	
1–3 years	6 (17%)	0	NA	
3–6 years	6 (17%)	0	NA	
6–10 years	3 (9%)	0	NA	
$>$ 10 years	7 (20%)	1 (3%)	NA	
Ridley-Jopling Classification				
LL	10 (29%)	25 (71%)	NA	
BL	6 (17%)	7 (20%)	NA	
BB	2 (6%)	1 (3%)	NA	
BT	6 (17%)	1 (3%)	NA	
TT	0	0	NA	
I	0	1 (3%)	NA	
Unknown	11 (31%)	0	NA	
History of steroid medication	28 (80%)	17 (49%)	NA	$P < 0{\cdot}001$
Current steroid prescription	10 (29%)	17 (49%)	NA	$P < 0{\cdot}001$
History of clofazimine treatment	8 (23%)	0	NA	
Current clofazimine treatment	1 (3%)	0	NA	

1. Numbers in ( ) in age shows 25 and 75 percent quartile.
2. We could not get the information on leprosy type from 11 patients in Group 1, who had completed MDT a long time previously elsewhere, admitted to the ECS for wound care, and did not have detailed records and few scar or lesion on the surface.
3. *P* values shown in the right column represent difference between three groups. *P* values less than 0·05 indicates statistically significant difference.

Univariate analysis was done to identify the risk factors for participation restriction, high SALSA scores and low GSE scores. The variables analysed were: visible impairments (Group 1 or not), age ($\geq$30), sex (female), working status, marital status, living with family or not, final education at primary level, living in ECS community, history of steroid treatment, and severe visible impairment (Table 4).

Living in ECS community was the only variable identified as a risk factor for participation restriction although whether living at ECS is a cause or an effect of participation restriction was not established.

Table 3. Participation restriction, SALSA score, GSE and visible impairments in the three groups of participants

	Group 1	Group 2	Group 3	
Number of participants	35	35	38	
Participation restriction				$P = 0{\cdot}019$*
No (0–12)	18 (51%)	25 (71%)	31 (82%)	
Yes (13–90)	17 (49%)	10 (29%)	7 (18%)	
SALSA score (median)	31 (25, 40)	23 (19, 24)	23 (20, 25)	$P < 0{\cdot}001$**
High SALSA score (≥75 percentile (28·5) of study population)	22 (63%)	3 (9%)	2 (5%)	$P < 0{\cdot}001$***
The GSE score (median)	33 (30, 36)	36 (33, 38)	34 (32, 37)	$P = 0{\cdot}271$
Low GSE score (≤25 percentile (32) of study population)	12 (34%)	8 (23%)	11 (29%)	$P = 0{\cdot}572$
Severe visible impairment (≥50 percentile (7·5) of Group 1)	18 (51%)	NA	NA	

P values indicated in the right column show the result of chi-square and Fischer's exact test between three groups. *P* values less than 0·05 was considered to be statistically significant and post-hoc analysis was performed for each analysis as shown below:
*$P = 0{\cdot}012$ compared between Group 1 and 3, 0·086 between Group 1 and 2, and 0·305 between Group 2 and 3.
**$P < 0{\cdot}001$ compared between either Group 1 and 3 or Group 1 and 2, and 0·338 between Group 2 and 3.
***$P < 0{\cdot}001$ compared between Group 1 and 3, 0·023 between Group 1 and 2, and 0·345 between Group 2 and 3.

Risk factors for a high SALSA score included: Visible impairments, final education at primary level, living in ECS community, and severe visible impairment.

The only risk factor for a low GSE score was severe visible impairment.

Table 5 shows a multivariate analysis for the risk factor for participation restriction, high SALSA score, and/or low GSE.

The variables analysed were: visible impairments (Group 1 or not), severe visible impairment, final education at primary level, and living in the ECS community. Severe visible impairment was identified as a significant risk factor for high SALSA and low GSE score.

Table 4. Univariate analysis of risk factors for high SALSA score, participation restriction, and low GSE score amongst subjects in Group 1 and 2

	Participation restriction		High SALSA score		Low GSE score	
	Odds ratio (95% CI)	*P* value	Odds ratio (95% CI)	*P* value	Odds ratio (95% CI)	*P* value
Visible impairments (Group 1 or not)	2·36 (0·88–6·34)	0·09	18·1 (4·60–70·9)	<0·001*	1·76 (0·61–5·05)	0·29
Age (above 30)	0·64 (0·23–1·80)	0·40	2·27 (0·82–6·27)	0·11	0·70 (0·23–2·13)	0·53
Sex (female)	1·16 (0·38–3·52)	0·80	1·36 (0·44–4·17)	0·59	1·06 (0·32–3·51)	0·93
Working status	0·66 (0·25–1·74)	0·40	0·64 (0·24–1·72)	0·37	0·67 (0·23–1·91)	0·45
Marital status	1·21 (0·44–3·34)	0·70	0·85 (0·30–2·41)	0·76	1·42 (0·48–4·15)	0·53
Living with family or not	0·50 (0·18–1·40)	0·19	0·09 (0·03–0·28)	<0·001*	0·58 (0·20–1·73)	0·33
Final education at primary level	1·73 (0·90–7·52)	0·08	4·27 (1·43–12·8)	0·009*	1·53 (0·50–4·67)	0·45
Living in ECS community	3·22 (1·18–8·87)	0·02*	14·7 (4·44–48·4)	<0·001*	1·45 (0·51–4·17)	0·49
History of steroid treatment	2·77 (0·93–8·23)	0·07	1·29 (0·46–3·63)	0·63	1·43 (0·47–4·36)	0·53
Severe visible impairment	2·57 (0·86–7·70)	0·09	21 (5·08–86·8)	<0·001*	3·73 (1·19–11·6)	0·024*

*P values less than 0·05 was considered to be statistically significant.

Table 5. Risk factor for high SALSA score, participation restriction, and low GSE score among patients in Group 1 and 2

	Participation restriction		High SALSA score		Low GSE score	
	Odds ratio (95% CI)	*P* value	Odds ratio (95% CI)	*P* value	Odds ratio (95% CI)	*P* value
Visible impairment (Group 1 or not)	0·88 (0·18–4·32)	0·88	4·14 (0·66–26·1)	0·13	0·91 (0·20–6·09)	0·91
Severe visible impairments	1·22 (0·28–5·25)	0·79	5·68 (1·09–29·7)	0·039*[1]	6·38 (1·06–38·3)	0·043[2]
Final education at primary level	1·60 (0·46–5·56)	0·46	0·88 (0·18–4·14)	0·97	1·03 (0·25–4·14)	0·97
Living in ECS community	2·61 (0·52–13·2)	0·25	3·00 (0·54–16·5)	0·21	0·42 (0·06–2·91)	0·38

**P* values less than 0·05 was considered to be statistically significant.
[1]$R^2 = 0{\cdot}363$.
[2]$R^2 = 0{\cdot}074$.

Discussion

People affected by leprosy with visible impairments (Group 1) reported more significant activity limitation and participation restriction compared to those with other skin diseases (Group 3). Recently diagnosed leprosy patients without visible impairments (Group 2) were similar in activity limitation or participation restriction when compared to those with other skin diseases.

It is not surprising that the subjects in Group 1 reported the highest SALSA scores because as patients have more severe impairment so they will have activity limitations. However, some subjects in Groups 2 and 3 also had relatively high SALSA scores: these patients were having leprosy reactions or were anaemic; this suggests that SALSA is also sensitive to impaired general conditions. Further evidence that impairments per se, may not predict high SALSA scores is illustrated in the following example: the subject who had the highest SALSA score (68) in Group 1 had a right wrist drop and some minor clawing of the toes, whereas another subject who scored 30 on SALSA also scored the highest impairment score; that subject had bilateral lagophthalmos, bilateral median paralysis, loss of the hallux on the right foot, and bone absorption of proximal phalanx of the small toe on the left foot. We postulate that this subject had adapted to his impairments and had found alternative methods to conduct his activities.

Regarding *P* Scale results, the finding that subjects in Group 2 did not show any significant participation restriction compared to subjects in Group 3 was important. The finding suggests that the diagnosis of leprosy per se does not cause people to perceive any greater disadvantage than people diagnosed with other skin conditions. Physicians at Cebu Skin Clinic reported that most patients listen to the diagnosis calmly especially after they are reassured that leprosy is curable. MDT was introduced to the Philippines 20 year ago[16] so awareness of the disease and the treatment thereof may have had a positive effect on the population, which could also mitigate the negative impact of the diagnosis on the subjects in Group 2 who were diagnosed later compared to those in Group 1, as some of the subjects in Group 1 were diagnosed in 1990s or earlier. A laboratory worker at LWM located in ECS

reported that during the1990s people would stare at staff as they entered the sanitarium, but that this no longer occurs. ECS now has a functioning general hospital and is no longer solely as sanitarium. Whether the subject belonged to Group 1 or not might have reflected the time difference some extent although it was not identified to be significant in this study. The sample size was too small to do detailed sub-analysis. The small sample size could also obscure the difference between Group 1 and 2 regarding the participation restriction as the recommended sample size is noted as 50 for P-scale application.[5]

Our sample size was constrained because participant recruitment was done during a four-week study period. CSC had 52 newly diagnosed patients aged between 16 and 45 during the previous six months, which was the maximal number of subjects for Group 2, but we were only able to contact 35. During the study period, we simultaneously recruited the candidates for Group 3 who met the inclusion criteria. Group 1 subjects were taken from the 212 people aged between 16 and 45 followed by CB and ECS annually, we strictly applied the inclusion criteria and recruited only the subjects who had visible impairments.

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 perceive stigma which is not intended or that they voluntarily withdraw as an effect of shame (self stigma). It is essential to expand the current knowledge of these important but neglected factors.

The finding that living in the ECS community was a risk factor for participation restriction should be interpreted cautiously because this might reflect a reverse causal relationship. Some subjects reported that they were living in ECS because their families preferred living there. Cross and Choudhary reported that good levels of family and community support reduced the stigma against people affected by leprosy in Nepal,[10] which supports the suggestion of reverse causal relationship in this study. Some subjects in Group 2 were found to have high levels of participation restriction, and these might only be understood by using more detailed interviews.

Being categorised in Group 1, having visible impairments, overlaps with other factors, such as living in ECS community. As 74% of the subjects in Group 1 were recruited from ECS community, the impact of this factor might have been different if the participants had been recruited from wider community. Socio-economic backgrounds and the effect of diagnosis of leprosy might be differentially bound in each subject. Recruiting the subjects from wider community could also mitigate the difference in socio-economic backgrounds between groups.

The GSE score was similar in the three groups, however, severe visible impairment was identified as a risk factor for low GSE score. A larger study might alter this effect because a higher proportion of patients with severe visible impairment in Group 1 (9/18, 50%) had lower GSE score than those with less severe impairment (3/17, 18%), whereas the proportion of the patients with low GSE score in Group 2 was 23% (8/35).

LIMITATION OF THE STUDY

Although some risk factors were identified through the univariate analysis, fewer were identified as a risk factor in multivariate analysis. This could have been due to a small sample

size; a larger sample in terms of both number and the area of recruitment will give clearer indications. This was a relatively small, one-point case control study in which it was not possible to consider all the factors that may have been significant. It would have been useful to conduct a comprehensive analysis of socio-economic status and community dynamics, greater study of the actual causal relationships between risk factors and results would also have been enlightening.

Conclusion

Visible impairments did impact on the activities and attitudes of people affected by leprosy, however, the diagnosis of leprosy *per se* did not have significant impact. If the potential for leprosy to cause impairments could be addressed, the stigma of leprosy might be eliminated. This was a small one-point, case–control study; further prospective follow-up studies of people newly diagnosed with leprosy will be useful to investigate the true causal relationship between risk factors and the results. To procure an adequate sample size and to be able to validate conclusions a multi-centre study might be more desirable.

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