

## **Dehabilitation in the era of elimination and rehabilitation: a study of 100 leprosy patients from a tertiary care hospital in India**

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### *Summary*

*Objectives:* To study the clinical profile of leprosy patients; to assess dehabilitation in leprosy patients and to study the factors affecting dehabilitation.

*Design:* A cross-sectional questionnaire-based study was carried out on 100 leprosy patients visiting the All India Institute of Medical Sciences (AIIMS), New Delhi between February 2009 and February 2010. Demographic and clinical data were collected and subjects were administered the 52-item Anandaraj Dehabilitation scale which measures the negative impact of leprosy on family relationships, vocational condition, social interaction and self-esteem.

*Results:* The mean patient age was 30.9 years, 81% were males, 51% were at the lepromatous end of the spectrum, 87% had multibacillary leprosy, 22% each had Type 1 and Type 2 reactions, 22% had Grade 1 disability and 39% had Grade 2 disability. The mean duration of symptoms before diagnosis was 20 months. On the Anandaraj scale, 23% had high levels of dehabilitation; on an average, scores were in the range of medium level dehabilitation. Nearly 80% of patients avoided meeting friends, one-third hid the diagnosis from their families and worried about losing their jobs due to the disease, while around a quarter avoided sexual relations, used separate utensils and avoided touching children. Over 40% of unmarried patients faced matrimonial difficulty due to leprosy. Anxiety and guilt were common and incidence of suicidal ideas was much higher than the lifetime incidence in general population. Lack of education, Type 2 reactions, Grade 2 disability and lower age were predictors of greater dehabilitation.

*Conclusions:* Dehabilitation of leprosy patients continues in this post-elimination era of rehabilitation. A large segment of preventable disability and resultant

dehabilitation is likely being missed. There is an urgent need for corrective and preventive measures.

## Introduction

Leprosy has mystified mankind from time immemorial. It has been termed a 'social disease'<sup>1</sup> and a 'disease of the soul'.<sup>2</sup> With the advent of highly effective multi-drug therapy, WHO has declared it eliminated as a public health problem from most of the world. In India, the world's leprosy 'leader', the prevalence has fallen drastically from 57/10,000 population in 1981 to the 'elimination' level set by WHO of below 1/10,000 in 2005.<sup>3</sup> Despite reduction in prevalence, large numbers of new cases continue to be detected (135,000 in 2012-13).<sup>4</sup> It has been questioned whether elimination has truly been achieved<sup>5,6</sup> and evidence to the contrary has been accumulating.<sup>7-9</sup> The present emphasis is on disability prevention and rehabilitation. The psychosocial impact of this disease can at times be more devastating than the physical deformities it causes.

Earlier work has shown that leprosy and its stigma have a pervading effect on the life of a person affected by leprosy; affecting marriage,<sup>10-12</sup> employment,<sup>13-15</sup> interpersonal relationships<sup>13,16,17</sup> and social participation.<sup>11,14,18,19</sup> Psychological consequences of leprosy stigma can be particularly severe.<sup>20-24</sup> Though prior studies have looked into the impact of leprosy on life, most have dealt with only a few specific aspects. The lack of an appropriate scale is another stumbling block in this area. The negative impact of leprosy and its stigma on people's lives has been termed 'dehabilitation'. The Anandaraj scale<sup>25</sup> developed for measurement of dehabilitation was used in this study because other available scales were more limited in scope. The Anandaraj scale is comprehensive, covering most aspects of family relationships, vocational conditions, social interaction as well as self-esteem.

## Materials and methods

After approval by the Ethics Committee, this study was conducted on 100 people affected by leprosy recruited by purposive sampling from the Dermatology outpatient department and leprosy clinic at AIIMS, New Delhi between February 2009 and February 2010. People affected by leprosy irrespective of treatment status were included. In the case of people who had completed treatment, those who had received MDT within the last 25 years were eligible for inclusion. People treated in the pre-MDT era were not included because the concept that leprosy is a disease like any other, with a treatment of finite duration, was popularized only after the introduction of MDT. The major exclusion criterion was age below 14 years to ensure adequate intellectual maturity.

Written informed consent was obtained. Demographic data and clinical details were recorded. The proposed revision of the Kuppaswamy Scale by Patro *et al.* was used to calculate socio-economic status.<sup>26</sup> Patients were classified using the Ridley-Jopling scheme based on clinical, bacteriological and histopathological features. In case of patients on treatment and treated patients, the classification at the time of diagnosis was used. Lepromin test was not done. The pure neuritic variant was diagnosed when applicable. In a chronic disease with a broad spectrum, several patients could not be accurately fitted into the Ridley-Jopling (R-J) scheme and were classified as BT downgrading to BL, BL/LL subpolar or LL subpolar.

## SCALE USED

The Anandaraj scale<sup>25</sup> is a quantitative scale with 52 items covering four broad areas, namely family relationships, vocational condition, social interaction and self-esteem. Most items have five-level Likert type grading; few are of the yes-or-no response type. The score quotient is calculated by dividing the score obtained by the maximum possible score and multiplying by 100. The score quotient determines the level of debilitation; values between 76 and 86 indicate a medium level of debilitation while values above and below this range indicate low and high levels respectively.

A recent review mentions that the Anandaraj Debilitation Scale is the best developed instrument measuring the effects of stigma on the leprosy affected.<sup>27</sup> Other available instruments include the Participation Scale,<sup>28</sup> the Internalised Stigma of Mental Illness Scale (modified for leprosy),<sup>29</sup> the Explanatory Model Interview Catalogue Scale,<sup>30</sup> and the General Self-Efficacy Scale.<sup>31</sup> All these scales have their own limitations. Though the Participation Scale has been validated in leprosy patients, one drawback is that it does not measure the impact on self-esteem.<sup>29</sup>

The Anandaraj scale<sup>25</sup> is freely available in English. It was translated into Hindi and back-translated into English to ensure accuracy. The language more comfortable to the respondent was used. Literate subjects had the option of filling up the scale questionnaire on their own. The chief investigator was present to clarify any doubts and would verbally administer the scale to illiterate subjects. Adequate privacy was ensured to study participants. After the questionnaire was filled, the investigator would educate the patients about the disease. Often, the interview was a highly emotional experience and lengthy reassurance and counseling were required. Statistical analysis was carried out using SPSS software.

## Results

### DEMOGRAPHIC CHARACTERISTICS

The age of the people interviewed ranged from 14 to 60, with a mean of 30.9 years. The majority (60%) were between 14 and 30 years old. There was a predominance of males (81%) and 63% were married. Though most (92%) were literate; only 51% were educated beyond middle school. Leprosy patients were most commonly from Delhi (36%), followed by neighbouring states such as Uttar Pradesh (27%) and Bihar (22%). Among the 36 presently residing in Delhi, 21 belonged to Bihar and 14 to U.P. The mean monthly income was Rs.6990 and the majority (41% each) belonged to upper lower and lower middle socio-economic classes (as classified by Kuppuswamy).

### CLINICAL CHARACTERISTICS

BT was the most common type followed by BL (Table 1).

Almost 70% of patients had impairments; most commonly, glove and stocking hypoesthesia and claw hands (Table 2).

The WHO disability grading does not record all impairments. Using the WHO disability grading, 22 people had Grade-1, 39 had Grade-2 (Figure 1). Both grades of disability were most common in BL patients (Figure 1). Reactions were seen in 44% of patients; 22 had Type 1 reactions, 21 had Type 2 reactions and 1 had both. Type 1 reactions occurred

**Table 1.** Subjects disaggregated by leprosy classification, age and disability grade (n = 100)

Spectrum	Total	Grade 0			Grade 1			Grade 2		
		14-24 yrs	25-44 yrs	45-60 yrs	14-24 yrs	25-44 yrs	45-60 yrs	14-24 yrs	25-44 yrs	45-60 yrs
		BT leprosy	7	11	5	0	1	0	4	3
BT downgrading to BL	3	4	1	0	0	0	2	1	0	
BB leprosy	0	0	0	0	0	0	0	0	1	
BL leprosy	2	1	0	2	6	1	5	6	0	
BL/LLs leprosy	1	0	0	2	1	0	2	2	1	
LLs leprosy	0	0	0	0	7	1	0	4	2	
LLp leprosy	0	1	1	0	0	1	0	3	0	
Pure neuritic leprosy	1	1	0	0	0	0	1	2	0	
<b>Total</b>	<b>14</b>	<b>18</b>	<b>7</b>	<b>4</b>	<b>15</b>	<b>3</b>	<b>14</b>	<b>21</b>	<b>4</b>	

**Table 2.** Types of deformities impairments seen in 67/100 patients studied\*

Impairment	Total	Pure neuritic	BT	BT to BL	BL	BL/LLs	LLs	LLp	BB
Glove & stocking hypo/anaesthesia	40	0	0	1	15	8	12	4	0
Claw hand	24	2	5	2	8	2	4	1	0
Facial/earlobe infiltration	21	0	0	1	2	7	5	6	0
Trophic ulcers/blisters	15	1	2	1	2	4	3	2	0
Motor weakness	15	1	3	2	2	5	1	0	1
Low vision	8	0	1	1	2	1	3	0	0
Callosities	6	0	0	0	2	0	3	1	0
Foot drop	5	0	1	0	2	1	1	0	0
Claw toes	3	0	1	0	0	0	1	1	0
Lagophthalmos	3	0	0	1	1	0	1	0	0
Reabsorption of digits	2	0	0	0	0	0	2	0	0

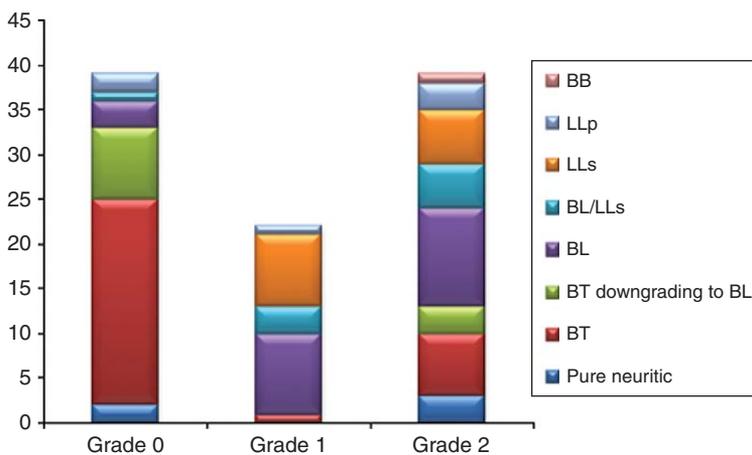
\*the other 33 had no impairments

throughout the borderline spectrum while Type 2 reactions were most frequent in lepromatous cases.

The duration of leprosy symptoms before diagnosis varied from 2 weeks to 15 years, with a mean of 20 months (median, 12 months). Twenty one percent of patients had symptoms for more than 2 years before diagnosis. Around half (53%) were on treatment at the time of interview; 26% were untreated and 21% had completed treatment. Most patients (87%) required MB-MDT.

DEHABILITATION SCORES

The mean dehabilitation score according to the Anandaraj scale was 82.8 (standard deviation 14.2, median 85.9, range 34 to 100), reflecting medium level of dehabilitation. Further details of scores are provided in Table 3 and patients’ responses to the salient parameters of all four domains of the scale are depicted in Tables 4 and 6.



**Figure 1.** Distribution of patients by WHO disability grading and leprosy spectrum.

**Table 3.** Levels of dehabilitation in leprosy patients

Level of dehabilitation	Range of scores	No. of patients
Low	87–100	49/100 (49%)
Medium	76–86	28/100 (28%)
High	75 and below	23/100 ( <b>23%</b> )

#### EFFECT OF LEPROSY ON FAMILY RELATIONSHIPS AND VOCATIONAL CONDITION OF PATIENTS

Family relationships were significantly impacted in many (Table 4). One-third of those who knew they had leprosy hid it from their families, fearing stigmatisation. Elaborate precautions were in vogue to ‘prevent disease transmission’. One-fourth of married patients avoided sexual relations or used barrier contraceptives, and similar numbers avoided touching their children. One-fourth of all patients used separate utensils. Six people had been thrown out of their homes. Two of them landed up in leprosy colonies. One, who was forced out of his home during graduation, became a rickshaw puller and stayed unmarried by choice. The other three started fresh lives after a struggle in places far from their hometowns.

**Table 4.** Effect of leprosy on Family relationships and Vocational condition

Parameter	No. affected*	Male			Female		
		14–24 yrs	25–44 yrs	45–60 yrs	14–24 yrs	25–44 yrs	45–60 yrs
Experienced major change in family relationships	13/100 (13%)	2	7	3	1	0	0
Hide leprosy diagnosis from family members	25/76 ( <b>33%</b> )	4	13	2	2	2	2
Not respected by family members	10/100 (10%)	2	6	1	1	0	0
Thrown out of house	6/100 ( <b>6%</b> )	1	4	1	0	0	0
Avoiding sexual relations with spouse	15/61** ( <b>25%</b> )	1	8	2	1	1	2
Use separate utensils/eat separately	25/100 ( <b>25%</b> )	4	12	4	2	1	2
Avoid touching children	14/62 ( <b>23%</b> )	0	8	2	1	0	3
Separated from children	5/58 (9%)	0	4	0	1	0	0
Worried that family future will be affected	71/100 ( <b>71%</b> )	17	34	6	7	3	4
Vocational condition affected	16/67 ( <b>24%</b> )	4	10	2	0	0	0
Not going to work due to the disease	4/67 (6%)	0	3	1	0	0	0
Suspended from/lost/changed job	8/67 (12%)	0	6	2	0	0	0
Worried about losing job	26/67 ( <b>39%</b> )	6	18	2	0	0	0
Hide leprosy diagnosis from work colleagues	59/63 ( <b>94%</b> )	14	36	9	0	0	0
Not able to do work well	18/67 ( <b>27%</b> )	5	10	3	0	0	0
Face discrimination at work	7/67 (10%)	0	7	0	0	0	0
Fear of begging	15/100 (15%)	4	10	1	0	0	0

\*who chose “Strongly agree” or “Agree” for questions with Likert scale responses

\*\* 37 patients were single; 2 were widows

**Table 5.** Change in occupation of leprosy patients

Patient no.	Age	Gender	Leprosy classification	WHO disability grade	Earlier occupation	Present occupation	Reason
P4	28	Male	LLp	2	Farmer with own farm	Security Guard	Moved from Bihar to Delhi for treatment
P10	30	Male	LLs	2	Juice vendor	Labourer	Couldn't squeeze fruits due to clawing
P17	41	Male	LLs	2	Farmer with own farm	Farming in leprosy colony	Banished from village
P30	52	Male	LLs	2	B.A student	Rickshaw puller	Left home due to humiliation
P79	46	Male	BT	0	Cycle repairing outfit	Shop assistant	Motor weakness
P91	32	Male	BT downgrading to BL	2	Security guard	Farm labourer	Motor weakness

#### EFFECT OF LEPROSY ON VOCATIONAL CONDITION OF PATIENTS

Around one-fourth of the respondents who were working felt that leprosy had affected their vocational situation (Table 4). Nearly 40% were worried about losing their jobs; 12% had lost or changed their jobs due to the disease and 15% feared that they might have to take to begging. Almost everyone working with others tried to hide their disease from co-workers. Among six people who changed their occupation, three did so due to motor weakness, two due to stigma and one, for treatment (Table 5). In addition, one had deferred a promotion fearing discovery of his disease. Of note, five of these six had Grade 2 disability; one had motor weakness without visible deformity, which does not fit into the WHO grading scheme.

#### EFFECT OF LEPROSY ON SOCIAL INTERACTION OF PATIENTS

Social interaction and self-esteem were markedly affected (Table 6). Nearly 80% voluntarily avoided their old friends due to shame and fear of discovery. Of the unmarried patients, 41% faced difficulties in getting married. Among them, seven had voluntarily postponed marriage until treatment was over. Two had resolved never to marry – one because he believed leprosy is genetic and the other because he feared his wife would also be stigmatised. The remainder had been rejected by potential suitors. The reasons for rejection were mostly leprosy. Clofazimine pigmentation was the culprit in two distraught girls. Nearly one-third felt they were not useful to society and around half complained they had nobody to share their feelings with.

#### EFFECT OF LEPROSY ON SELF-ESTEEM OF PATIENTS

Extreme dissatisfaction with life and constant preoccupation with the disease tormented around three-fourths of our patients (Table 6). Close to two-thirds felt ashamed and guilty for having contracted the disease. Of note, 22% had suicidal ideas at the time of the interview; 16 others admitted to having suicidal ideas in the past and two had attempted suicide. Many with suicidal ideas broke down during the interview. On further probing as to why they had such thoughts, reasons given were mostly related to misconceptions about the disease.

**Table 6.** Effect of leprosy on Social interaction and Self-esteem

Parameter	No. affected*	WHO Disability Grade		
		Grade 0	Grade 1	Grade 2
Avoid contact with friends	78/100 (78%)	33	18	27
Nobody to share feelings	49/100 (49%)	14	12	23
Not a useful member of society	29/100 (29%)	4	7	18
Experienced fear of touch from others	14/100 (14%)	1	3	10
Felt discarded by society	14/100 (14%)	4	1	9
Not able to get married due to the disease	13/32 (41%)	8	4	1
Not satisfied with life	75/100 (75%)	30	17	28
Suicidal ideation <i>at the time of interview</i>	22/100 (22%)	5	5	12
<i>In the past</i>	16/100 (16%)	2	6	8
Worried that family future will be affected	71/100 (71%)	25	15	31
Feeling of worthlessness	14/100 (14%)	3	2	9
Mostly sit idle	26/100 (26%)	7	6	13
Constantly think about disease	76/100 (76%)	29	18	29
Feel ashamed and guilty	64/100 (64%)	24	13	27

\*who chose "Strongly agree" or "Agree" for questions with Likert scale responses

Some had witnessed other patients dealing with extreme segregation or restrictions. They all felt better at the end of the counselling session where they were given detailed information about the disease. Clinical depression was present in two patients; one was already on treatment for it and one was subsequently started on treatment.

#### FACTORS AFFECTING DEHABILITATION

Stepwise multiple linear regression analysis showed that, after adjusting for inter-relationships between factors, low education (below or up to primary school level) ( $\beta = -0.461$ ,  $P < 0.001$ ), history of Type 2 reactions ( $\beta = -0.366$ ,  $P < 0.001$ ), presence of Grade 2 disability ( $\beta = -0.276$ ,  $P = 0.001$ ) and lower age ( $\beta = 2.155$ ,  $P = 0.034$ ) were independent predictors of dehabilitation. The combination of these factors accounted for 42% of variation in dehabilitation scores ( $R^2 = 0.423$ ). Note that dehabilitation scores and level of dehabilitation have an inverse relationship. Hence the *negative* predictors of dehabilitation scores predict greater dehabilitation and vice versa.

#### Discussion

Though the main focus of the study is dehabilitation, discussion of patient data in the context of elimination provides some useful insights. The demographic data is reasonably representative of adult Indian leprosy patients in terms of age group and socio-economic status.<sup>32</sup> Our male-female ratio is higher than the usual community-based figure of 2:1,<sup>32</sup> possibly because males are more likely to travel long distances to a tertiary care centre for treatment. Patients most commonly belonged to Uttar Pradesh and Bihar, states in which nearly one-third of Indian leprosy cases are registered.<sup>4</sup>

Disability is an important contributor to loss of productivity and debilitation. Our rates of disability (Grade-1 in 22%; Grade-2 in 39%) are disturbing. Leprosy reactions, important precursors of disability were also quite common. Jindal *et al.* report figures comparable to ours,<sup>33</sup> while the national Grade-2 disability rate is 3.45%.<sup>4</sup> Figures from studies like ours may be ignored stating selection bias at a tertiary centre, but even large screening studies have picked up greater Grade 2 disability than official figures,<sup>7,8</sup> which indicates that a large segment of potentially preventable disability is missed by our reporting system.

Coming to the crux of the study, though Anandaraj gives a complex definition,<sup>25</sup> debilitation is basically an umbrella term for the negative effects of leprosy and its stigma on the patient's life. While the absolute values obtained by the Anandaraj scale have doubtful importance, useful information was obtained from patient responses to its 52 statements. Perhaps, ours is the first study of its kind, covering such a broad range of effects of stigma.

Studies suggest it is a common practice to hide the diagnosis from family members<sup>16,34,35</sup> and such secrecy was seen in 33% of our patients. Interestingly, only 13% reported that leprosy significantly impacted their family relationships, suggesting that fear of stigmatisation may exceed its actual occurrence. Unfortunately, the attempt to hide the disease can have serious consequences like delayed treatment seeking and disability.<sup>36-38</sup> Disturbance of marital and sexual relationships due to leprosy was prominent in our sample, in agreement with earlier work.<sup>10-12,39</sup> One new finding that we came across, was use of barrier contraceptives to prevent leprosy transmission. Other important negative effects included use of separate utensils, avoidance of contact with children, forced separation from children, disrespectful behaviour and unwillingness for touch by relatives. Our findings concur with results from other centres regarding such restrictions and discriminatory practices.<sup>38-40,35</sup> Six of our subjects were thrown out of their homes, depicting extreme debilitation occurring in the present day and age. In the past, such occurrences have been widely reported<sup>11,14,40,41</sup> and the thriving leprosy colonies of India bear testimonial to this unpleasant reality.

Leprosy affects vocational condition by causing disability and also via stigmatisation at the workplace.<sup>14</sup> Many authors have documented reluctance to employ leprosy-affected people.<sup>42,43,19,39</sup> In our study, there was prominent anxiety regarding losing employment. Undesirable events in significant numbers included loss or change of job, inability to work well, discrimination at work and fear of begging. One patient changed his occupation just because he shifted to Delhi for treatment; this instance highlights ignorance regarding treatment availability. All our patients who changed occupations had to settle for lesser paying jobs. Kopparty has reported severe socioeconomic problems in 20% of leprosy families.<sup>13</sup> Calcraft found a negative impact of leprosy on income generation with employment being lost due to stigma in many cases.<sup>15</sup> Though not reflected in the Anandaraj scale, three of our school-going patients were severely affected - one was made to drop out by the management; the other two voluntarily stopped going due to shame and avoidance by classmates.

Avoidance of the leprosy-affected by friends and relatives and restraint of their participation in community affairs is well described.<sup>13,40,44,19</sup> In our study, around 15% had directly experienced fear of touch, but overt restriction in community participation was not so prominent. However, voluntary avoidance of old friends due to fear of discovery was rampant. Perceived social stigma has been noted to influence social functioning and psychological well-being of patients.<sup>45</sup> Our results regarding diminished marital prospects also corroborate earlier findings.<sup>13</sup> Interestingly, clofazimine pigmentation was the reason for

rejection in two young females; this issue has also received attention as a reason for treatment non-compliance.<sup>46,38</sup> Counselling regarding the self-limiting nature of this common adverse effect is important. Apart from problems in patients, 'courtesy stigma' often hampers the marriage prospects of the family members.<sup>17</sup> Thus, social consequences of leprosy can be quite disastrous.

The most tragic aspect of dehabilitation is its impact on the psyche. The majority of our patients were preoccupied by the disease and felt ashamed and guilty about contracting it. It has been recorded that leprosy patients have a higher prevalence of psychiatric morbidity than the general population.<sup>24,20</sup> Scott found fear, grief and confusion to be the most common emotions following the diagnosis of leprosy. In his series, as high as 11 out of 30 patients, had suicidal ideas.<sup>16</sup> Wang opines that suicide prevention in leprosy patients should be taken seriously.<sup>47</sup> From India, Behere and Chatterjee *et al.* have reported suicidal ideation in leprosy patients to the tune of 60% and 33% respectively.<sup>21,22</sup> Our study reaffirms these findings with a history of suicidal ideas in 38% and two suicide attempts. This data suggests that risk of suicidal ideation in leprosy is much higher than the background lifetime risk in general population, estimated as 7.8%.<sup>48</sup> Mental status evaluation of leprosy patients is important. In addition, education about the disease, dispelling of myths and reassurance can help in correcting the psychological upset.

Congruent with our results, other workers have also correlated low education<sup>19,49</sup> and presence of visible impairments,<sup>50,13,44,51</sup> with greater stigma. Disability leads to dehabilitation by affecting vocational conditions and inviting social stigma due to the deformed appearance. It is well-known that reactions contribute to disability and our findings lend support to this fact.

Singh *et al.*<sup>44</sup> and Nardi *et al.*<sup>52</sup> have observed a link between low socio-economic status and participation restriction. We did not find such an association, however we did find a weak correlation between dehabilitation scores and monthly income, which is one of the predictors of socioeconomic status. Another aspect highlighted by others is greater stigma in female patients.<sup>17,53-55</sup> Such a gender difference was not found in our study, obviously because we had very few female patients. A point to note is that dehabilitation scores did not show any relationship to treatment status, implying that treatment alone does not do much to correct dehabilitation. Supporting this argument, Nardi *et al.* report significant participation restriction in patients who have completed treatment.<sup>52</sup>

A limitation of our study is that the population of leprosy patients visiting an urban tertiary care centre may not be a representative sample leading to selection bias. Also, though the Anandaraj Dehabilitation Scale was the best option available to comprehensively measure the negative impact of leprosy, lacunae in Anandaraj's original paper are that sample-size calculation needed to achieve adequate statistical power was not performed and certain parameters determining validity and reliability such as Cronbach's  $\alpha$ , intra-tester stability and inter-tester reproducibility were not measured. Another problem is that items of drastically different significance have been given equal weighting. Moreover, in a complex issue like leprosy stigma, while scales are valuable screening tools, more in-depth qualitative methodology would provide a clearer picture. Even so, our study draws attention to the unpleasant reality that dehabilitation of leprosy patients does occur in this day and age. It re-emphasizes the link between reactions, disability and dehabilitation. The number of patients presenting with potentially preventable disabilities is disconcerting. We cannot afford to be complacent because leprosy has been 'eliminated'.

The routine approach to a leprosy patient should include psychosocial assessment and intervention apart from clinical diagnosis and treatment. Improvement of general awareness and attitude related to leprosy is the need of the hour. This in turn, would enhance early detection, timely treatment and disability prevention, thereby stopping this disease from negatively impacting lives and ultimately eliminating the tragic term, debilitation, from the leprosy vocabulary.

### Contributorship

Dr. Divya Seshadri, Dr. Binod K. Khaitan, Dr. Neena Khanna and Dr. Rajesh Sagar were involved in planning the study. Dr. Divya Seshadri was responsible for data collection. Progress of the work was reviewed every 6 months by Dr. Binod Khaitan, Dr. Neena Khanna and Dr. Rajesh Sagar. The manuscript was prepared by Dr. Divya Seshadri, Dr. Binod K. Khaitan, Dr. Neena Khanna and Dr. Rajesh Sagar. We acknowledge Dr. V. Sreenivas, Associate Professor, Department of Biostatistics, AIIMS for his expert advice and help with statistical analysis. We acknowledge Netherlands Leprosy Relief for their encouragement and token financial support.

### Guarantor

Dr. Divya Seshadri and Dr. Binod K. Khaitan accept full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

This study was approved by the Institutional Ethics Committee of the All India Institute of Medical Sciences, New Delhi, India

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### References

- <sup>1</sup> Williams HW. Leprosy-a social disease. *Canadian Medical Association Journal*, 1977; **116**: 834–835.
- <sup>2</sup> Aronson SM. Leprosy: a disease of the soul. *Medicine and Health, Rhode Island*, 2004; **87**: 127.
- <sup>3</sup> Joshi P. National Scenario, NLEP and New Paradigms. In: Kar HK, Kumar B (eds). *IAL Textbook of Leprosy*. 1st ed, Jaypee Brothers Medical Publishers, New Delhi, 2010; pp. 35–43.
- <sup>4</sup> NLEP - Progress report for the Year 2012–13. Central Leprosy Division Directorate General of Health Services; 2013. 20 p.
- <sup>5</sup> Rao PN, Lakshmi TSS. Final push of leprosy in India: What is being pushed? *Indian J of Dermatology, Venereology and Leprology*, 2005; **71**: 226–229.
- <sup>6</sup> Khaitan BK, Tejasvi T, Aggarwal K, Khanna N. Final push of leprosy: it is prudent to pause before declaration!. *Ind J Dermatol, Venereol Leprol*, 2006; **72**: 151–153.
- <sup>7</sup> Shetty VP, Thakar UH, D'souza E *et al*. Detection of previously undetected leprosy cases in a defined rural and urban area of Maharashtra, Western India. *Lepr Rev*, 2009; **80**: 22–33.
- <sup>8</sup> Shetty VP. Challenges facing the control of leprosy in the Indian context. *Annals of the Academy of Medicine, Singapore*, 2010; **39**: 1–3.
- <sup>9</sup> Shetty VP, Pandya SS. One year follow up of a cohort of suspected leprosy cases: findings from a leprosy "Selective Special Drive" in Gadchiroli district, Maharashtra, India. *Lepr Rev*, 2012; **83**: 64–70.
- <sup>10</sup> Davey TF. Psychological aspects of leprosy. *Lepr Rev*, 1976; **47**: 71–74.
- <sup>11</sup> Kumar A, Anbalagan M. Socio-economic experiences of leprosy patients. *Leprosy in India*, 1983; **55**: 314–321.

- <sup>12</sup> De Oliveira MH, Gomes R, de Oliveira CM. [Leprosy and sexuality: living with a difference]. *Revista Latino-Americana De Enfermagem*, 1999; **7**: 85–91.
- <sup>13</sup> Kopparty SN, Kurup AM, Sivaram M. Problems and coping strategies of families having patients with and without deformities. *Indian Journal of Leprosy*, 1995; **67**: 133–152.
- <sup>14</sup> Kaur H, Van Brakel W. Dehabilitation of leprosy-affected people—a study on leprosy-affected beggars. *Lepr Rev*, 2002; **73**: 346–355.
- <sup>15</sup> Calcraft J. The effects of the stigma of leprosy on the income generation of leprosy affected people in the Terai area of south east Nepal. *Asian Pacific Disability Rehabilitation Journal*, 2006; **7**: 73–89.
- <sup>16</sup> Scott J. The psychosocial needs of leprosy patients. *Lepr Rev*, 2000; **71**: 486–491.
- <sup>17</sup> Try L. Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Disability Rehabilitation Journal*, 2006; **17**: 55–72.
- <sup>18</sup> Rafferty J. Curing the stigma of leprosy. *Lepr Rev*, 2005; **76**: 119–126.
- <sup>19</sup> Rao PSS, Raju MS, Barkataki A *et al*. Extent and correlates of leprosy stigma in rural India. *Ind J Lepr*, 2008; **80**: 167–174.
- <sup>20</sup> Kumar JH, Verghese A. Psychiatric disturbances among leprosy patients. An epidemiological study. *Int J Lepr Other Mycobact Dis*, 1980; **48**: 431–434.
- <sup>21</sup> Behere PB. Psychological reactions to leprosy. *Leprosy in India*, 1981; **53**: 266–272.
- <sup>22</sup> Chatterjee RN, Nandi DN, Banerjee G *et al*. The social and psychological correlates of leprosy. *Ind J Psychiatry*, 1989; **31**: 315–318.
- <sup>23</sup> Tsutsumi A, Izutsu T, Akramul Islam *et al*. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. *Lepr Rev*, 2004; **75**: 57–66.
- <sup>24</sup> Chaturvedi SK, Singh G, Gupta N. Stigma experience in skin disorders: an Indian perspective. *Dermatologic Clinics*, 2005; **23**: 635–642.
- <sup>25</sup> Anandaraj H. Measurement of dehabilitation in patients of leprosy—a scale. *Indian Journal of Leprosy*, 1995; **67**: 153–160.
- <sup>26</sup> Patro BK, Jeyashree K, Gupta PK. Kuppaswamy's Socioeconomic Status Scale 2010—The Need for Periodic Revision. *Ind J Pediatr*, 2012; **79**: 395–396.
- <sup>27</sup> Van Brakel WH. Measuring leprosy stigma—a preliminary review of the leprosy literature. *Int J Lepr Other Mycobact Dis*, 2003; **71**: 190–197.
- <sup>28</sup> Van Brakel WH, Anderson AM, Mutatkar RK *et al*. The Participation Scale: measuring a key concept in public health. *Disability and Rehabilitation*, 2006; **28**: 193–203.
- <sup>29</sup> Ritsher JB, Otilingam PG, Grajales M. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research*, 2003; **121**: 31–49.
- <sup>30</sup> Van Brakel WH. Measuring health-related stigma—a literature review. *Psychology, Health & Medicine*, 2006; **11**: 307–334.
- <sup>31</sup> Rensen C, Bandyopadhyay S, Gopal PK, Van Brakel WH. Measuring leprosy-related stigma—a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 2011; **33**: 711–719.
- <sup>32</sup> Thorat DM, Sharma P. Epidemiology. In: Kar HK, Kumar B (eds). *IAL Textbook of Leprosy*. 1st ed, Jaypee Brothers Medical Publishers, New Delhi, 2010; pp. 24–31.
- <sup>33</sup> Jindal N, Shanker V, Tegta GR *et al*. Clinico-epidemiological trends of leprosy in Himachal Pradesh: a five year study. *Ind J Lepr*, 2009; **81**: 173–179.
- <sup>34</sup> De Groot R, Van Brakel WH, De Vries HJC. Social implications of leprosy in the Netherlands—stigma among ex-leprosy patients in a non-endemic setting. *Lepr Rev*, 2011; **82**: 168–177.
- <sup>35</sup> Atre SR, Rangan SG, Shetty VP *et al*. Perceptions, health seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India. *Lepr Rev*, 2011; **82**: 222–234.
- <sup>36</sup> Bekri W, Gebre S, Mengiste A. Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia. *Int J Lepr Other Mycobact Dis*, 1998; **66**: 1–9.
- <sup>37</sup> Nicholls PG, Wiens C, Smith WC. Delay in presentation in the context of local knowledge and attitude towards leprosy—the results of qualitative fieldwork in Paraguay. *Int J Lepr Other Mycobact Dis*, 2003; **71**: 198–209.
- <sup>38</sup> Heijnders ML. Experiencing leprosy: perceiving and coping with leprosy and its treatment. A qualitative study conducted in Nepal. *Lepr Rev*, 2004; **75**: 327–337.
- <sup>39</sup> El Hassan LA, Khalil EAG, el-Hassan AM. Socio-cultural aspects of leprosy among the Masalit and Hawsa tribes in the Sudan. *Lepr Rev*, 2002; **73**: 20–28.
- <sup>40</sup> De Stijter DH, de Geus L, Heynders ML. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev*, 2000; **71**: 492–498.
- <sup>41</sup> Kaur H, Van Brakel W. Is beggary a chosen profession among people living in a leprosy colony? *Lepr Rev*, 2002; **73**: 334–345.
- <sup>42</sup> Tekle-Haimanot R, Forsgren L, Gebre-Mariam A *et al*. Attitudes of rural people in central Ethiopia towards leprosy and a brief comparison with observations on epilepsy. *Lepr Rev*, 1992; **63**: 157–168.
- <sup>43</sup> Kaur H, Gandhi A. People's perception of leprosy—a study in Delhi. *Ind J Lepr*, 2003; **75**: 37–46.

- <sup>44</sup> Singh S, Sinha AK, Banerjee BG, Jaswal N. Participation level of the leprosy patients in society. *Ind J Lepr*, 2009; **81**: 181–187.
- <sup>45</sup> Bharath S, Shamasundar C, Raghuram R, Subbakrishna DK. Correlates of psychiatric morbidity in patients with leprosy. *Ind J Lepr*, 2001; **73**: 217–228.
- <sup>46</sup> White C. Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil. *Health Education Research*, 2008; **23**: 25–39.
- <sup>47</sup> Wang J. Take suicide prevention seriously in leprosaria. *Lepr Rev*, 2011; **82**: 322–323.
- <sup>48</sup> Bernal M, Haro JM, Bernert S *et al*. Risk factors for suicidality in Europe: results from the ESEMED study. *Journal of Affective Disorders*, 2007; **101**(1–3): 27–34.
- <sup>49</sup> Sinha A, Kushwaha AS, Kotwal A *et al*. Stigma in leprosy: miles to go!. *Ind J Lepr*, 2010; **82**: 137–145.
- <sup>50</sup> Kumaresan JA, Maganu ET. Socio-cultural dimensions of leprosy in north-western Botswana. *Social Science & Medicine*, 1994; **39**: 537–541.
- <sup>51</sup> Boku N, Lockwood DNJ, Balagon MV *et al*. Impacts of the diagnosis of leprosy and of visible impairments amongst people affected by leprosy in Cebu, the Philippines. *Lepr Rev*, 2010; **81**: 111–120.
- <sup>52</sup> Nardi SMT, Paschoal VD, Zanetta DMT. Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev*, 2011; **82**: 55–64.
- <sup>53</sup> Zodpey SP, Tiwari RR, Salodkar AD. Gender differentials in the social and family life of leprosy patients. *Lepr Rev*, 2000; **71**: 505–510.
- <sup>54</sup> Kumar R, Singhasivanon P, Sherchand JB *et al*. Gender difference in socio-epidemiological factors for leprosy in the most hyper-endemic district of Nepal. *Nepal Medical College Journal: NMCI*, 2004; **6**: 98–105.
- <sup>55</sup> Varkevisser CM, Lever P, Alubo O *et al*. Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. *Lepr Rev*, 2009; **80**: 65–76.