

Changes in Social Participation of Persons Affected by Leprosy, Before and After Multidrug Therapy, in an Endemic State in Eastern India

Senthilkumar Ramasamy¹, Pitchaimani Govindharaj^{2*}, Archana Kumar¹,
Karthikeyan Govindasamy³, Annamma S John³

1. Bethasda Leprosy Mission Hospital, Champa, Chhattisgarh, India

2. Sri Ramachandra Institute of Higher Education and Research (DU), Chennai, Tamil Nadu, India

3. The Leprosy Mission Trust India, New Delhi, India

ABSTRACT

Purpose: In general, multidrug therapy (MDT) completion rate and the change in disability levels before and after medical treatment are reported as outcomes in leprosy programmes. Changes in activity and social participation levels are rarely reported, possibly because the parameters are more difficult to measure. The study aimed to assess and evaluate the changes in social participation among leprosy-affected persons after completion of MDT.

Method: An observational study was conducted among 108 newly-diagnosed leprosy-affected clients, who were registered at the Leprosy Referral Hospital in Champa, Chhattisgarh. Their disability levels pre- and post- MDT were assessed using the WHO Disability Grading, and their social participation level was assessed using the Participation Scale.

Results: Of the 108 clients registered during the study period, 90 completed the full course of MDT and were included in the analysis. The majority of these 90 clients or 83% were multibacillary and 23% had Grade 2 disability at the time of diagnosis. At the end of MDT with steroids therapy for reaction and neuritis, the proportion of clients with no participation restriction increased from 76% to 93%. Clients with visible impairments had more restriction as compared to those with no deformity or no visible deformity, before and after MDT. Among those with visible impairments, 78% had mild to severe restriction before MDT and it declined to 26% on completion of treatment.

Conclusion: Presence of Grade 2 disability at the time of diagnosis was significantly associated with participation restriction. MDT and steroid

* **Corresponding Author:** Pitchaimani Govindharaj, Lecturer, Department of Allied Health Sciences, Sri Ramachandra Institute of Higher Education and Research (DU), Chennai, Tamil Nadu, India. Email: pitchu_mani83@yahoo.com

therapy for management of reaction and/or neuritis improves the participation level of leprosy-affected clients, suggesting that early detection and appropriate management would reduce their risk of participation restriction.

Key words: *leprosy, disability, participation restriction, multidrug therapy*

INTRODUCTION

Leprosy is a chronic infectious disease and remains a major public health problem in some low-resource countries. India accounts for over 60 % of the global leprosy burden (World Health Organisation, 2016). Leprosy affects the skin and peripheral nervous system and Leprea reactions and/or neuritis can occur before, during and after completion of multidrug therapy (MDT) (Jain et al, 2000). If nerve involvement is not detected and treated in time, it leads to irreversible sensory, motor and autonomic impairments in a substantial proportion of people affected by leprosy (Van Brakel & Officer, 2008). Moreover, these disabilities affect social participation of an affected individual (De Souza et al, 2016).

Early detection of disease and prompt treatment with MDT is the main strategy to prevent impairments and disabilities among leprosy clients (WHO, 2013). However, people still seek medical treatment long after the development of impairments and deformities. Even after completion of treatment, a significant proportion of clients develop disability from neuritis and damage to affected limbs, requiring continued self-care to limit further secondary damage (Van Brakel et al, 2012).

To cure leprosy, the World Health Organisation (WHO) prescribes regular administration of MDT over 6 to 12 months depending on the severity of the disease. This does not always mean that the client will not have any of the physical problems caused by leprosy. Even if he or she has visible physical impairments, he/she is still considered cured. Several dimensions of disability are recognised in the International Classification of Functioning, Disability and Health (ICF): body structure (impairment), activity (activity limitations) and participation (participation restrictions). The classification also recognises the role of physical and social environmental factors in affecting disability outcome (Van Brakel et al, 2012).

Disability is more than mere physical dysfunction, and includes activity limitation, stigma, discrimination, and social participation restrictions (Stigter et al, 2000; Senturk & Sagduyu, 2004; Van Brakel et al, 2012; WHO, 2013). In

general, MDT completion rate and change in disability levels after medical treatment are reported as treatment outcomes in leprosy programmes. Persons affected by leprosy also experience limitations in activities and participation restrictions irrespective of the presence of impairments, and these specific issues usually receive only limited attention during treatment (Malviya, 2014). Therefore, changes in participation level need to be taken into account in any analyses of the social and economic burden of leprosy, as well as in evaluations of the general disability or in the outcomes of treatment completion. Since they are rarely considered as an outcome in leprosy programmes, the aim of this study is to determine the changes in social participation among leprosy-affected persons after completion of MDT and to study the factors associated with social participation.

METHOD

Study Design

An observational study was conducted among newly-diagnosed persons affected with leprosy to assess any changes in social participation and disability level after completion of their medical treatment (MDT) for leprosy.

Study Settings

The study was conducted at the Leprosy Referral Hospital in Champa, situated in Janjgir district of Chhattisgarh, India. This is a 60-bed, tertiary referral hospital for treatment of leprosy and its complications. Annually, over 350 new leprosy-affected clients are registered for treatment and over 2,500 clients are treated for various complications due to leprosy. The electronic medical records system is in place since 2008, to store and retrieve clinical details of the clients, and every client is given a unique identification number.

Participants

All newly-diagnosed leprosy-affected clients registered for MDT at the Leprosy Mission Community Hospital, between January and December 2014, were considered for inclusion in this study. Those who opted to continue their MDT at this hospital were included, while those who wanted to continue MDT at Primary Health Centres were excluded from the study. All those who completed the full course of MDT were included in the final analysis.

Participants' demographic and clinical information such as type of leprosy, impairment status and disability level were obtained from their electronic medical records at the hospital.

Permission to conduct the study was obtained from the Research Committee, Bethesda Leprosy Mission Hospital, and Research Domain, The Leprosy Mission Trust India, New Delhi. Informed consent was obtained from the participants before their inclusion in the study.

Tools

Disability Grade - The level of disability of the leprosy-affected person was measured by World Health Organisation disability grade system (Brandsma & Van Brakel, 2003). Clients with leprosy are graded according to disabilities of the eyes, hands and feet. The highest grade of disability of any of these body sites is used as an overall indicator of the disability status of a person with leprosy (shown in Table 1).

Table 1: WHO Disability Grade

Hands and Feet	
Grade 0	No anaesthesia, no visible deformity or damage
Grade 1	Anaesthesia present, but no visible deformity or damage
Grade 2	Visible deformity or damage present
Eyes	
Grade 0	No eye problem due to leprosy; no evidence of visual loss
Grade 1	Eye problems due to leprosy present, but vision not severely affected as a result (vision: 6/60 or better; can count fingers at 6 metres)
Grade 2	Severe visual impairment (vision worse than 6/60; inability to count fingers at 6 metres); also includes lagophthalmos, iridocyclitis and corneal opacities

Participation Scale (P-Scale) - The Hindi version of the Participation Scale (P-Scale) was used to measure the level of social participation restriction (Van Brakel et al, 2006). It is a validated questionnaire comprising 18 items to measure client-perceived participation in people with disability due to various causes and in people affected by leprosy. The scores ranged from 0 to 90; people with scores from 0 - 12 were considered as having no restrictions in social participation, with scores from 13 - 22 as mild restrictions, with scores from 23 - 32 as moderate restrictions, with scores from 33 - 52 as serious restrictions, and with scores from

53 - 90 as severe restrictions. To study the association between participation restriction and other variables, the score of the P-scale was dichotomized. Those with score of 12 and above as having 'some participation restriction' and those with score of below 12 as no participation restriction.

Data Collection

A physiotherapist experienced in leprosy rehabilitation and trained in basic interviewing techniques was assigned to recruit participants and conduct interviews. The interview was always conducted in a separate room to maintain privacy of the participants. Special attention was paid to each participant, especially whenever they shared any distressing experience because of the diagnosis of leprosy and its complications, and appropriate counselling was given. Assessment of participation using P-Scale was done within 1 or 2 months from the time of diagnosis and repeated on completion of MDT. Assessment of nerve function impairment and disability grade was assigned as per WHO guidelines before the start of MDT and at the time of completion of MDT, and at regular intervals during treatment. The rehabilitation and awareness programme was provided to all the participants.

Data Analysis

Data were entered into Excel and analysed using SPSS. A descriptive analysis and chi-square test were performed to study the association between the variables.

RESULTS

A total of 158 clients were registered for MDT during the study period. The 50 clients who opted to continue MDT at their nearest Primary Health Centre (PHC) were given referrals and the remaining 108 clients were included in the study. At the end of the study period the 90 clients who completed their full course of MDT were included in the final analysis. A total of 18 clients were lost to follow-up; hence they were excluded from analysis.

Demographic and clinical profile of study participants are given in Table 2. Of the 90 study participants, 63% were male. The mean (SD) age of participants was 35 years (15.8). Among them, 64% were literate and 67% were in gainful employment (farmers, daily wagers, and skilled labour). Majority of the participants (83%) had multibacillary leprosy (MB), 26% had visible impairments (Grade 2 disability)

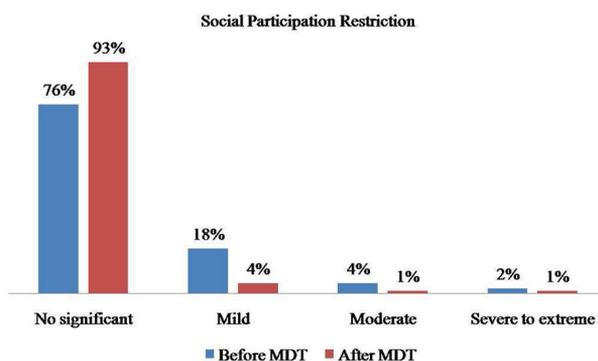
and 44% had positive slit-skin smear, at the time of diagnosis.

Table 2: Demographic and Clinical Characteristics of Study Participants

Characteristics		Frequency	Percent
Gender	Male	57	63%
	Female	33	37%
Age	Below 30 years	51	57%
	Above 30 years	39	43%
Education	Literate	58	64%
	Illiterate	32	36%
Occupation	Gainful employment	60	67%
	No gainful employment	30	33%
Type of Leprosy	Multibacillary leprosy (MB)	75	83%
	Paucibacillary leprosy (PB)	15	17%
Disability	No visible deformity (Grade 0 & 1)	67	74%
	Visible deformity (Grade 2)	23	26%
Bacteriological Index	Negative	50	56%
	Positive	40	44%

On completion of MDT with steroid therapy for those who had reaction and neuritis, the proportion of clients who had no restriction increased from 76% to 93%, at before and after MDT respectively; proportion of clients with mild restriction decreased from 18% to 4%; and proportion of clients with moderate to extreme restriction reduced from 6% to 2%. Overall, 22 participants (24%) had participation restriction at the time of diagnosis, but at the end of MDT, it declined to 6 participants (7%), as shown in Fig1.

Figure 1



Relationship of participation restriction with demographic factors and disease factors is shown in Table 3. Gender, age and occupation were not associated with participation restriction, either before or after MDT. The MB clients had more participation restriction before and after MDT, whereas no participation restriction was observed among pauci-bacillary (PB) clients. Before MDT, significant association was observed between participation restriction and education level ($p < 0.05$) and type of leprosy ($p < 0.05$). It was no longer significant at post-MDT treatment. However, association was not significant post-MDT treatment. The analysis revealed that before MDT, people above 30 years of age had more restriction in participation than those below 30 years, and illiterate people had more restriction in participation than the literate ones.

Significant association was observed between participation restriction and the disability level, both before and after MDT assessments. Those with visible impairments (Grade 2 disability) had more restriction as compared to those with no impairments or no visible impairments (Grade 0 or 1 disability). The proportion of participants with some restriction reduced noticeably from 78% before starting MDT to 26% after completion of MDT (Table 3).

Table 3: Factors associated with Participation Restriction before Start of MDT and after Completion of MDT

Participation Restriction	Before MDT			p-value	After MDT			p-value
	No restriction n=22	Some restriction n=68	Total n=90		No restriction n=6	Some restriction n=84	Total n=90	
Gender								
Male	40 (70)	17 (30)	57	>0.05	52 (91)	5 (9)	57	>0.05
Female	28 (85.)	5 (15)	33		32 (97)	1 (3)	33	
Age								
<30 years	42 (82)	9 (18)	51	>0.05	48 (94)	3 (6)	51	>0.05
>30 years	26 (67)	13 (33)	39		36 (92)	3 (8)	39	
Education								
Literate	48 (83)	10 (17)	58	<0.05	55 (95)	3 (5)	58	>0.05
Illiterate	20 (62)	12 (38)	32		29 (91)	3 (9)	32	
Occupation								
Gainful employment	43 (72)	17 (28)	60	>0.05	55 (92)	5 (8)	60	>0.05
No gainful employment	25 (83)	5 (17)	30		29 (97)	1 (3)	30	

Type of Leprosy								
MB	53 (71)	22 (29)	75	<0.05 ^a	69 (92)	6 (8)	75	>0.05
PB	15 (100)	0 (0)	15		15 (100)	0 (0)	15	
Disability Status								
Grade 0 or 1	63 (94)	4 (6)	67	<0.001	70 (99)	1 (1)	71	<0.001 ^a
Grade 2	5 (22)	18 (78)	23		14 (74)	5 (26)	19	

Note: Numbers in parentheses indicate row percentages.

^a. Fisher's exact test

DISCUSSION

According to the International Classification of Functioning, Disability and Health domains (ICF), disability is a term that concerns impairment, limitation of activity and restriction of participation. One of its dimensions is social participation which is the involvement in life situations, including domains such as education and applying knowledge, communication, mobility, self-care, domestic life, interpersonal interactions, social and civic life, and major life area (Van Brakel et al, 2006). This study reports the changes in social participation among clients with leprosy, before and after MDT.

Among the clients with Grade 2 disability, there was a notable reduction in the proportion of those with participation restriction, after MDT treatment. The restriction level is comparable with studies from other countries. In Brazil, Nardi et al (2011) evaluated the degree of disability and social restriction after completion of multidrug therapy and found that 32% of persons had some degree of disability and 35% had participation restriction. Another Brazilian study by Barbosa et al (2008) found that 41% of persons had some degree of disability and 7% had participation restriction.

Studies have found that the presence of physical disability, Grade 2 according to WHO classification, was associated with social participation restriction (Barbosa et al, 2008; Sinha et al, 2010; Nardi et al, 2011; De Castro et al, 2014). A study from India (Singh et al, 2009) observed that the people affected with leprosy are restricted by themselves from social participation, with the progression of the disease. Nardi et al (2011) conducted a study in Brazil, and found 68% among those with Grade 2 disabilities had participation restriction after completion of MDT. In the present study, participation restriction was present among 78% of those with Grade 2 disabilities pre-MDT and it declined to 26% post-MDT and

treatment for complications due to leprosy.

The study by Nardi et al (2011) from Brazil, found 27% restriction in males and 23% in females after MDT completion, while another Brazilian study by Barbosa et al (2008) observed that participation restriction among males and females was 31% and 39%, respectively. A study from India by Singh et al (2009) found that females had more restriction than males, both in moderate and severe participation restriction categories. In the present study, participation restriction was more among males (30%) than female participants (15%) at the start of MDT and it reduced after completion of MDT to 9% in males and 3% in females. However, there is no statistical association found among gender in participation restriction.

In the present study, majority of participants were diagnosed with multibacillary leprosy (83%). Nearly half of them (44%) had positive bacterial index and a quarter of the clients reported with Grade 2 disabilities at the time of starting MDT. Singh et al (2009) reported that timely access to MDT prevents the participants from falling prey to deformity but those participants who fail to get treatment on time develop deformity and as deformity increases, the level of participation restriction also increases.

De Castro et al (2014) in Brazil, reported 31% restriction in MB and 17% in paucibacillary leprosy (PB) after completion of MDT. In the present study also, only 29% of MB participants had participation restriction before start of MDT, which reduced to 8% after completion of MDT. There was no restriction observed among PB clients, either before or after MDT. This suggests that early detection and appropriate and timely treatment will reduce the complications caused by leprosy and the resulting participation restriction, even among those with severe forms of the disease like MB leprosy.

Limitations

This study had a few limitations. The cohort is relatively small, heterogeneous (disease classification and disability status at start of treatment) and the follow-up was relatively short. Impact of disability grade at start of treatment, reactions and interventions may change activity/participation problems beyond the MDT period. The cohort seems too small to determine significance when considering age and gender, or when taking into account disability grade and leprosy status at the start of treatment.

CONCLUSION

Timely detection and early initiation of multidrug therapy and management of reaction and/or neuritis improves the participation level of clients, irrespective of the severity or classification of the disease. Participation restriction was independent of age, gender and occupation. Presence of visible deformities at the time of diagnosis was found to be significantly associated with participation restriction. Early detection and management through regular monitoring of leprosy clients would reduce the risk of participation restriction among them.

ACKNOWLEDGEMENT

The authors express their sincere thanks to Dr. Sandeep Kumar, Superintendent, Bethasda Leprosy Mission Hospital, Champa, for his guidance and encouragement. They would like to thank The Bethasda Leprosy Mission Hospital, Champa Trust India and Research Domain for their support. They are also grateful to all the study participants.

REFERENCES

- Barbosa JC, Ramos AN Jr, Alencar MJ, Castro CG (2008). Post-treatment of Leprosy in Ceará: activity and functional limitation, safety awareness and social participation. *Rev Bras Enferm*; 61: 727-33. <https://doi.org/10.1590/S0034-71672008000700012> PMID:19009115
- Brandsma JW, Van Brakel WH (2003). WHO disability grading: operational definitions. *Lepr Rev*; 74: 366-373.
- De Castro LE, da Cunha AJ, Fontana AP, de Castro Halfoun VL, Gomes MK (2014). Physical disability and social participation in patients affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev*; 85: 208-17.
- De Souza VTC, Da Silva WM Jr, De Jesus AMR, De Oliveira DT, Raptis HA, De Freitas PHL, Schneiberg S (2016). Is the WHO Disability Grading System for Leprosy Related to the Level of Functional Activity and Social Participation? *Lepr Rev*; 87: 191-200.
- Jain M, Singh N, Bhatia A, Arora VK (2000). Histological assessment of dermal nerve damage occurring during multidrug therapy for leprosy. *Int J Lepr*; 68: 167-71
- Malviya GN (2014). Disabilities in leprosy-The new concepts. *Indian J Lepr*; 86: 121-27.
- Nardi SM, Paschoal VD, Zanetta DM (2011). Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev*; 82: 55-64.
- Senturk V, Sagduyu A (2004). Psychiatric disorders and disability among leprosy patients; a review. *Turk Psikiyatri Derg*; 15: 236-43.
- Singh S, Sinha AK, Banerjee BG, Jaswal N (2009). Participation level of the leprosy patients in society. *Indian J Lepr*; 81: 181-187.

- Sinha A, Kushwaha AS, Kotwal A, Sanghi S, Verma AK (2010). Stigma in leprosy: Miles to go!. *Indian J Lepr*; 82: 137-145.
- Stigter DH, Geus L, Heynders ML (2000). Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev*; 71: 492-98. <https://doi.org/10.5935/0305-7518.20000051> PMID:11201904
- Van Brakel WH, Anderson AM, Mutaktar RK, Bakirtzief Z, Nicholls PG, Raju MS, Das-Pattanayak RK (2006). The Participation Scale: Measuring a key concept in public health. *Disabil and Rehabil*; 28: 193-203. <https://doi.org/10.1080/09638280500192785> PMID:16467054
- Van Brakel WH, Officer A (2008). Approaches and tools for measuring disability in low and middle-income countries. *Lepr Rev*; 79: 50-64.
- Van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, Kurniasari I, Kasim M, Kesumaningsih KI, Wilder-Smith A (2012). Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Global health action*; 5: 18394. <https://doi.org/10.3402/gha.v5i0.18394> PMID:22826694 PMCID:PMC3402069
- World Health Organisation - WHO (2013). Frequently asked questions on leprosy. Regional Office for South-East Asia, New Delhi. Available at: http://apps.searo.who.int/PDS_DOCS/B5044.pdf. [Accessed on 14 Jul 2018].
- World Health Organisation - WHO (2016). Global leprosy update, 2015: time for action, accountability and inclusion. *Wkly Epidemiol Rec*; 91: 405-20.