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Original Article

Health Status of Leprosy Affected People in Rehabilitation Colonies of Uttarakhand

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In the post elimination era for leprosy in India, with changing disease epidemiology and controlled incidence rates, now the focus must shift to rehabilitative strategies for leprosy affected persons (LAP) residing in leprosy rehabilitation colonies. For this, firstly it is important to reassess their socioeconomic and health status before making any recommendations. This study has been conducted among 137 LAP residing in 7 such colonies in Uttarakhand, who were interviewed on a predesigned, pretested questionnaire with aims to study the overall health status of LAPs, to assess their awareness about the disease and to assess their access to various health facilities and make recommendation for their rehabilitation. Out of 137 participants, 72% belonged to 41-80 years' age group. 85% of study participants were either illiterate or had less than or equal to primary education. More than half of the participants were engaged in begging. 87% LAPs had disabilities in hands and feet, 28.3% had disability in eyes. 24% participants had BMI <18.5. 13.9% participants had diabetes, 28.5% - Hypertension, and 13.1% had history of Tuberculosis. NGO's hospital/ private clinic is the nearest health facility for 62.8% of LAPs. Although all inhabitants (100%) are getting support from the government in form of land for rehabilitation colonies, disability cards etc., however, 44.53% had not been visited by any government functionary in the last month indicating need for proper supervision. Socioeconomic and health status of LAPs was found to be poor with most being illiterate, disabled, having comorbidities like diabetes mellitus. Strategies should be considered to improve the access to government services and developing collaboration with certain NGO's for strengthening of health infrastructure and administration, disability care and rehabilitation.

Keywords : Leprosy, Leprosy Affected People (LAP), Leprosy Rehabilitation Colonies, Disability, Morbidity

Introduction

Leprosy is usually a painless chronic inflammatory condition which affects skin and nerves due to infection with a tuberculosis like bacteria- *Mycobacterium leprae* which has a long incubation period (CDC 2013). It has very low rates of mortality, but by the time the symptoms of the disease are visible, the disease has progressed enough to cause irreversible nerve damage, which results in different kind of deformities (Suzuki et al 2011). It is this huge amount of disability and morbidity that makes leprosy an important public health problem world over. This disability in Leprosy is also a

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cause for stigma and discrimination. In India, the generalized Hindu belief that leprosy is a punishment for heinous sins of past life has long led to many a Leprosy Affected Persons (LAPs) being subordinated and oppressed socially, economically and psychologically by the rest of the society (Awofeso 2011, Jacob & Franco-Paredes 2008). This results in lack of social support, which is a major deterrent to reduction of disease burden.

India achieved the goal of elimination of leprosy as a public health problem, defined as less than 1 case per 10,000 population, at the National Level in the month of December, 2005. As on 31st December 2005, prevalence rate recorded in the country was 0.95/10,000 population (NLEP 2005-6). This happened following the introduction of multi-drug therapy (MDT) for the treatment of leprosy in 1981, which changed the epidemiological situation of leprosy worldwide (WHO 2018). However, according to the latest WHO report (2018 Global Leprosy Update), the South East Asian Region accounts for 61.77% of the total disease burden of Leprosy of the World, wherein India alone accounted for 59.88% of the total new leprosy cases detected in the world in the year of 2017. After elimination of leprosy as public health problem in India in 2006, situation has remained stagnant for next 10 years (NLEP 2015-16, NLEP 2016-17).

Uttarakhand, which is a newly formed state in northern India, is known for its Hindu pilgrimage sites. It is often referred to as the *Devbhumi* (literally: "Land of the Gods") due to many Hindu temples and pilgrimage centers found throughout the state. There has been an old practice that most of the LAPs from the nearby states come to the area of Haridwar, Rishikesh, and Roorkee to spent the rest of their lives. This has led to development of many Leprosy rehabilitation colonies in the area which support LAPs economically and socially.

There have been number of studies regarding the living conditions of people living in such rehabilitation colonies. Many such studies like one conducted in Jharkhand (Majumder 2015) suggest poor living conditions with such colonies being situated in slums, with most patients being illiterate, relying on begging as their sole means of livelihood, with rampant tuberculosis among members. Another study by Govindharaj et al (2018) suggested low family income (below Rs. 5000/ month) with 40% of study participants having physical disability and poor quality of life. Such trends indicate the dismal state of people living in these colonies. However, it is difficult to extrapolate such findings over to the general population. On the other hand, there has been very scant data available regarding the health status of LAPs living in various Leprosy rehabilitation colonies in the state of Uttarakhand. Hence, the present study was planned to assess the health and socioeconomic condition of LAPs as well as to assess the accessibility and availability of various facilities health services available to them, so that appropriate recommendations can be given for the improvement of their health conditions.

The study aims at i) studying the overall health status and living conditions of people with leprosy, ii) assessing their awareness about the disease and government facilities available for them, iii) assessing the access of LAPs to various health facilities, iv) giving recommendations for improving the health status of LAPs.

Materials and Methods

An observational, cross sectional study was conducted from 15th June to 30th July, 2016 in 7 leprosy rehabilitation colonies after approval from the Institutional Ethical Committee.

The study was conducted in 7 leprosy rehabilitation colonies of Haridwar, Roorkee, Rishikesh

situated in south western part of Uttarakhand state of India. These three adjacent cities lie within the range of 50 km.

Haridwar city has a population of 310,562 (Haridwar District Population Census 2011). The study was conducted in 3 rehabilitation colonies of Haridwar: Chandrashekhar Azad Kushth rehabilitation center, Shri Ganga Mata Kushth Rehabilitation center, Chidanand Kushth Rehabilitation center.

Rishikesh, a Nagar Palika Parishad city under district Dehradun with a population of 70,499 people (Census 2011) has 3 leprosy rehabilitation colonies - Brahmpuri Leprosy Rehabilitation Center, Brahmpuri; Tapovan Kushth Colony, Laxman Jhula; Kushth Colony, Dhalwaala respectively.

Roorkee, a metropolitan region under district Haridwar with a population of 118,200 (Roorkee Census 2011) has one leprosy rehabilitation Center: Chandrapuri Kushth Rehabilitation Center.

All inhabitants of these 7 leprosy rehabilitation colonies (total 137 participants) who were meeting the inclusion criteria were included in the study:

- **Inclusion criteria:**
  1. All diagnosed cases of leprosy - either treated or currently undergoing treatment.
- **Exclusion criteria:**
  1. Suspected but not a confirmed case of leprosy.
  2. Very ill or bedridden LAP.

Informed consent in writing was obtained from all the study participants prior to interview. Data was collected using predesigned and pretested questionnaire, which was administered after one hour of orientation.

Questionnaire for the LAPs included information regarding their demographic profile, socio-economic status, disease epidemiology and availability of various government and non-government facilities.

Basic physical examination for height and weight was done for calculation of Body Mass Index - BMI (Nuttall 2015) defined as Weight in kilograms (Kg) divided by his/her height in meters, squared.

WHO Disability Grading (Alberts et al 2011 and Brandsma & van Brakel 2003) was done for 1) Hands and feet and 2) eyes as per criteria given below :

WHO grading system		
1.	**Hands and feet**	
	Grade 0	No anesthesia, no visible deformity or damage
	Grade 1	Anesthesia present, but no visible deformity or damage
	Grade 2	Visible deformity or damage present
2.	**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 meters).
	Grade 2	Severe visual impairment (vision worse than 6/60; inability to count fingers at 6 meters); also includes lagophthalmos, iridocyclitis and corneal opacities.

Data was analyzed using Microsoft Excel 2013.The categorical variables were presented as frequency and percentages.

Results

Present study included total 137 participants from the leprosy rehabilitation colonies. 65% of participants were male and 35% female. Mean age of male was 55.5 years and of female was 56 years. It was noted that most of the people (72%) of people were in the age group of 41-80 years. Only 17% of participants belonged to 21-40 years age group.

Hindus make the majority with 98.5% people. Approximately half of the participants (75) were general while 32.9% belonged to Schedule Caste, 13 belonged to Other Backward Class (OBC), and only 4 belonged to Schedule Tribe.

As it can be seen from Table 1, 85% of LAPs were either illiterate (60.3%) or have less than or equal to primary education. Only 37.2% (51 out of 137) people belonged to Uttarakhand. More than half of the participants (55.07%) were engaged in begging. 55.4% Of participants feel that their illness has been completely cured, while 24.1% feel their disease to be getting worse. 95.6% LAPs feel that leprosy can be completely cured with the help of medications.

As shown in Table 2, approximately 75% participants (102) had grade 2 disabilities of Hands and feet as per the WHO Disability Grading guidelines for LAPs. While 71.53% participants had no disability of eyes, 21.16% had grade 1 disability of eyes and only 7.29% participants (10) had Grade 2 disability of Eyes.

When BMI was assessed, it was found that only half of the participants (58) had BMI in normal range (18.5 - 24.9). Around 1/4th of the participants (33) were underweight (BMI < 18.5). Similarly, around 1/4th of the total participants (36) were overweight (BMI > 24.9). 13.9% participants had Diabetes mellitus, 28.5% had Hypertension, and 13.1% had taken treatment for Pulmonary Tuberculosis.

All study participants above eighteen years of age had Voter ID. Four participants had driving license.

88.3% participants had Leprosy Disability Card. For 62.8% people health services provided by NGOs run hospital is the nearest health facility that is available to them. All the study participants are receiving government support in form of either Pension (92.7%), disability card (89.7%), health checkup (52.6%), rehabilitation colony land and buildings (82.5%) or only rehabilitation colony land (4.8%). 23.35% participants reported that their colony was visited by a government official who came to keep the track of number of inhabitants in the colony and update records while 32.12% participants reported that they were visited by a health functionary (Medical Officer or Auxillary Nurse Midwife (ANM) in last 1 month for updating disability card or provide treatment.

Around two-third participants (88) were getting support from Non-Government Organizations while rest one third study participants (49) were not getting any kind of support from any NGO or Individual. Around half of the participants of the study are getting support from NGO and Individuals in the form of Health check-up (67), medicines (73), and commodities of daily needs (67).

Discussion

Leprosy, a painless chronic inflammatory condition with low rates of mortality but by the time its symptoms become visible, disease has progressed enough to cause irreversible nerve damage, which results in deformity. It is this huge amount of disability and morbidity associated that makes this disease an important public health problem world over. LAPs being ostracized by society are forced to live in leprosy rehabilitation colonies. They display poor socio-

Table 1 : Demographic and socioeconomic profile of the LAPs (N=137)

S.No.	Variable	Number (n=137)	Percentage (%)
1.	**AGE**		
	≤ 20 years	1	0.73
	21-40 years	23	16.79
	41-60 years	63	45.99
	≥ 60 years	51	37.23
2.	**Sex**		
	Male	89	64.96
	Female	48	35.03
3.	**Religion**		
	Hindu	135	98.5
	Muslim	1	0.7
	Sikh	0	0
	Christian	1	0.7
4.	**Caste**		
	General	75	54.74
	Schedule Caste	45	32.85
	Schedule Tribe	4	2.92
	Other Backward Caste	13	9.49
5.	**Educational Status**		
	Illiterate	82	60.3
	Just Literate	19	14
	Primary (5THClass)	15	11
	Middle (8th class)	10	7.4
	High (10th class)	7	5.1
	Intermediate(12th class)	2	1.5
	Graduate/PG	1	0.7
6.	**Place of original Residence**		
	Uttarakhand	51	37.23
	Other State	86	62.71
7.	**Occupation**		
	Labor	2	1.5
	Farming	0	0
	Own business	18	13.0
	Beggar	76	55.07
	Others	41	29.7

Table 2 : Health status and disease epidemiology in LAPs (N=137)

S. No.	Variable	Number of participants (n=137)	Percentage (%)
1.	**Perception about present status of disease**		
	Cured	75	54.7
	Getting better	4	2.9
	Getting worse	33	24.1
	No change	25	18.2
2.	**Study participants who think that leprosy is curable**		
	Yes, it is curable	131	95.6
	No, it is not curable	6	4.4
3.	**WHO disability grade**		
a.	**Hands and Feet**		
	0	16	11.68
	1	18	13.14
	2	102	74.45
b.	**Eyes**		
	0	98	71.53
	1	29	21.16
	2	10	7.29
4.	**Body Mass Index (Kg/m^2)**		
	<18.5	33	24.08
	18.5-22.9	45	32.85
	23-24.9	23	16.79
	$\geq$25	36	26.28
5.	**Co- Morbidities among study participants**		
	Diabetes mellitus	19	13.9
	Hypertension	39	28.5
	Tuberculosis	18	13.1
	Any other	25	18.2

economic and health status indicators which acts as the main obstacle in improving quality of life of these LAPs.

Present study revealed that most participants (72%) were more than 40 years of age while only one participant belonged to age group less than 20 years and only 17% were in 21-40 age groups. This result was in conformity with the findings of Majumder (2015) who found that only 4 LAPs belonged to age group less than 10 years and only 20% belonged to age group 20-35 years. This is due to the reducing incidence of the disease, which has changed the disease epidemiology, consequently reducing number of new entrants in the rehabilitation colonies.

Similar to the result of two studies conducted in

Table 3 : Availability/ accessibility of various services for LAPs

S. No.	Variable	Number of participants (n=137)	Percentage (%)
1.	**Availability of card**		
	a. Voter Identity Document	136	99.27
	b. Driving license	4	2.92
	c. Adhaar card	117	85.40
	d. BPL card	115	83.94
	e. Any specialized card indicating leprosy status	121	88.32
2.	**Nearest health facility**		
	a. Community Health Centre	35	25.5
	b. District hospital	7	5.1
	c. Private-hospital/ hospital run by NGO	86	62.8
	d. None	9	6.6
3.	**Are you receiving any government support**		
	a. Yes	137	100
	No	3	0
	b. Kind of support (n=137)		
	Pension	127	92.7
	Disability Card	123	89.7
	Rehabilitation colony land and buildings	113	82.5
	Rehabilitation colony land	6	4.8
	Health checkup	72	52.6
4.	**Visited by any government functionary /worker in last one month**		
	a. Government officer	32	23.36
	b. Medical officer /ANM	44	32.12
	c. No one	61	44.53
5.	**Support from any NGO**		
	a. Yes (n=137)	88	64.2
	b. Kind of support(n=137)		
i)	Health check-up	67	48.91
ii)	Medicines	73	53.28
iii)	Commodities of daily need	67	48.91
iv)	Any aid or equipment for disability	19	13.87
v)	Monetary help	21	15.33
vi)	Rehabilitation Centre building	16	11.68

Jharkhand (Majumder 2015, Doshi et al 2018) and international studies from Bangladesh (Tsutsumi et al 2004), Brazil (Duarte et al 2007) and Ghana (Bello et al 2013), present study too

indicates low literacy level of LAPs as majority of them were either illiterate or have not completed even primary level of education.

The study also found that more than half of the participants were involved in begging. Similar results have been reported by Majumder (2015) where 54% LAPs and leprosy cured people (mostly with visible deformities) were found to practice begging as their sole means of livelihood.

It was also found that more than half of the study participants had improved with medications (57.6%) and now feel to be completely cured, while 42.3% participants reported either deterioration in condition or no change. A Study based in a tertiary care center of Ranchi (Doshi et al 2018) too showed that 59% study participants reported improvement after taking MDT while 24% participants did not show improvement due to irregularity in taking of medicine. A majority of population (95%) had basic knowledge about the disease that it can be cured with medications which is contrary to the findings by Doshi et al (2018) in his study where 41.3% participants did not have any knowledge about the disease and only 10.86% study participants knew the name of the disease.

Most of the study participants (87%) were found to have disability in hands and feet (grade 1 or Grade 2 Disability). Similar findings have also been reported by Rao & John (2012) in his study, where 72% LAPs had Grade 2 disability. Jain et al (2011) with 62.63% participants having grade 1 or 2 disability. Therefore, it is essential that to periodically assess LAPs for proper care of individuals with grade 2 disabilities and prevention of Grade 1 disability from progressing into Grade 2 disability.

However, it is important to note that according to the NLEP report for year 2015–2016, disability rate among newly diagnosed cases of leprosy is 4.46% which has increased from 1.97% in 2005–2006. Increase in G2D rate among new cases can be attributed to the fact that leprosy is being detected late (Rao & Suneetha 2018). Studies based on newly diagnosed cases of leprosy like by Sarkar et al (2012), in endemic leprosy endemic district of Bengal showed 11.5% participants having grade 1 disability and 8.2% having grade 2 disability of hands and feet.

In our study, 21.16% study participants had grade 1 disability of eyes and 7.29% participants (10) had Grade 2 disability of Eyes. A study by Sarkar et al (2012), based on newly diagnosed leprosy cases in an endemic district of Bengal showed much lower disability in eyes with 2.9% and 1.2% having grade-1 and grade-2 disability respectively. It is suggested that a periodical ocular examination of all leprosy patients is essential for the early diagnosis and treatment of eye complications, which finally will progress to grade 2 disability which eventually will result in blindness if left untreated.

A number of factors attribute to higher prevalence of disability in leprosy rehabilitation colonies as compared to general population. Firstly, these colonies inhabit people who have been diagnosed and have either been treated or have been under treatment for leprosy for long periods of time which leads to a greater prevalence of disability. Secondly, those who are grossly disabled/ disfigured find it even more difficult to be accepted in their own families, so they end up stay in these rehabilitation colonies, while others leave which gives a greater prevalence of disability in such colonies. Lastly, LAPs in such colonies usually get irregular medical attention leading to progression of their disability.

Regarding BMI of the LAPs, the findings have been striking. The number of underweight and overweight LAPs was approximately equal (24% and 26.3%). This was similar to the results obtained from a study based in a Leprosy Referral

Hospital in Delhi (Rao & John 2012) where 33% of the study population had BMI less than 18.5. Our study has also revealed that a high proportion of study population had one or the other comorbidity with 13.9% participants having diabetes mellitus, 28.5% had Hypertension, and 13.1% had taken treatment for Pulmonary Tuberculosis. Saraya et al (2012) reported similar findings with 13.3% having diabetes mellitus. As a result, we recommend that all leprosy patients should be screened for Diabetes mellitus.

The study also found that participants had due access to government facilities as all study participants had Voter ID. Even few (4) had driving license. This shows that the discriminatory laws have been abolished and participants were aware of their rights. This is a very positive picture that most people were found to be receiving government support in form of pension, rehabilitation center land, and health check-ups. Moreover, around two-third participants were receiving help from Non-Government Organizations, mostly religious colonies based in Haridwar and Rishikesh in varied forms like health check-up, medicines and even monetary help. But still some fallacies were reported on part of administration as many study participants (45%) reported that no government functionary had visited the rehabilitation Centre in last one month, ideally ANM or ASHA workers are supposed to pay at least one visit in a month for routine medical care of mother and child, immunization, conducting blood pressure check-up and Blood sugar examination, health education etc. This is routinely done in other parts of state. So these activities were not happening in these colonies, and the participants (62%) have to go to private hospitals and clinics for getting medical treatment.

The study has revealed that most of the LAPs were illiterate, having disability of hands and feet along with comorbidities like diabetes mellitus, hypertension and pulmonary tuberculosis. Hence, most rely on begging as their sole means of livelihood.

In February 2017, WHO hosted Rehabilitation 2030: A Call for Action, which brought together over 200 rehabilitation experts from 46 different countries (WHO 2017). It emphasized that as now leprosy related stigma has reduced, these patients can easily be rehabilitated in their own communities within their families resulting into less discriminatory and more inclusive society. Therefore, with changing disease epidemiology, it is time that our focus shifts on disability care and rehabilitation. It is important to provide vocational training and jobs to the disabled, so that they can become self-reliant, independent members of the society and can lead a dignified life. Most LAPs are receiving support from government in the form of pension. However routine health services are inadequate and LAPs have to rely on private clinics for medical assistance. The health infrastructure must be strengthened to support people in these rehabilitation colonies.

During the study, various Non-Government Organizations were found to be doing great work in the service of LAPs. WHO's Global strategy for leprosy 2016–2020 (WHO 2016) acknowledges that in the program for leprosy control, meaningful engagement of all stakeholders, including private providers is still limited and partnership with the private sector for care and/or social support of leprosy patients must be strengthened. Hence, there is need for further strengthening the public–private partnership for providing better health services and support to these LAPs.

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