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SOCIAL ENTITLEMENTS ACCESSED BY PERSON AFFECTED BY LEPROSY IN INDIA

Social Science

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ABSTRACT

INTRODUCTION: Leprosy is a leading cause of disabilities in India and limited access to Government entitlements are influenced by socio demographic variables and cultural aspects of the states.

Objective: To study the level of access to specific entitlements and also the difference between the states for the persons affected by leprosy among the four states (UP, CG, AP and TN) of India.

METHODS: This was a Cross sectional descriptive study carried out from the four states, to get information about their access to all the schemes and entitlements applicable for the leprosy affected. A total sample size of 379 includes from Uttar Pradesh (UP) 100, Chhattisgarh(CG) 100, Andhra Pradesh(AP) 101 and Tamil Nadu(TN) 78, This study was an outcome of baseline survey carried out during Dec 2016 to Sept 2017 for the CREATE Project,

RESULTS: In the present study198 (52.2%) were male and 181 (47.8%) were females. The age ranges from 20 to 65 years. 57.5% were uneducated, 57.5% were living in general community, Majority of their occupation 34% were Housewife and dependents. 82.1% belong to Grade II disability. Disability certificate was the most accessed scheme 79.9% followed by Disability pension by 65.2%, MCR footwear by 50.7% and Bus pass by 40.9% and other schemes are least accessed.

CONCLUSIONS: The study concludes that Varied differences exists among the four states from maximum to minimum in order of AP, TN, UP and CG determines the influence of local demographic and culture on the accessibility.

KEYWORDS

Person affected by leprosy, entitlements, states

Introduction:

Leprosy affects approximately a quarter of a million people throughout the world, with majority of these cases being reported from India by WHO (2011)[1]. In 2017 WHO reports that 59.89 % new cases of leprosy reported from India out of 150 countries[2] .

Walter CS (1998) reported that Leprosy and its consequences are described as a complex human problem, which leads to discrimination, stigma and prejudice. It is determined that equal rights for people affected by leprosy to develop their full potentials, is a matter of human rights. There is lack of complete understanding about the global need for rehabilitation. Concentration on medical care of people affected with leprosy (MDT, Surgery etc) though vastly beneficial, has led to highly inadequate psycho-social-economic rehabilitation in holistic manner resulting in poor quality of life[3].

The PWD Act 1995 constitutes an important step towards enabling the disabled in India. Based on the provisions of the Act those who are 40 per cent disabled, as certified by a Governmental medical authority, are entitled to receive particular benefits from the Government of India[4].

In the New RPwD (Rights of Person with Disabilities) act 2016 there is inclusion of 21 types of disabilities along with Leprosy cured person and needed 40 percent to avail the government benefits entitled for the person with disabilities[5].

It is often noticed the level of accessibility to the available benefits by the potential beneficiaries is very low in general and especially in case of the persons affected by leprosy. The possible reasons may be - the persons affected by leprosy is not aware of their rights and entitlements to access them[6], the authority which provides the entitlements are not well equipped with adequate knowledge to deliver their services[7], and various administrative and financial constraints. In some cases the person is aware and the authority just denies the entitlements due to incomplete documentation and the follow up mechanisms.

Community and health providers lack the right attitude and sensitivity, thus falling to assist in the empowerment of people affected with leprosy in an integrated manner. There is insufficient coordination between the NGOs and Government to utilize scare resources to allow the full development of people affected by leprosy.

AIMS AND OBJECTIVES

1. To study the level of access to specific entitlements for the persons affected by leprosy among 4 endemic states of India.
2. To find out the differences between the states in access to specific entitlements

METHODOLOGY

Study Design, Sample and Setting

This is a Cross sectional descriptive study carried out from the four states, designed to compare the level of accessibility to schemes and entitlements applicable for the leprosy affected, specifically in each state and on aggregate of the four states of AP, TN, CG and UP.

The total sample size of 379 includes from Uttar Pradesh (UP) 100, Chhattisgarh(CG) 100, Andhra Pradesh(AP) 101 and Tamil Nadu(TN) 78, out of which 52.2% were males and 47.8% were Females. This study is out of baseline data collection carried out during December 2016 to September 2017 for the CREATE Project, which was approved by TLM Research ethical committee and received financial support from European union and TLM England and Wales.

Study Tools:

Interview Schedule: An interview schedule was used to gather the information about the demographic details and data about the schemes and entitlements accessed by persons affected by leprosy. This information comprises of 11 specific schemes like Disability Certificate, Disability Pension, Old age pension, Bus Pass, Train Pass, MCR (Micro Cellular Rubber) Foot wear, Tricycle, Aids and appliances, RCS (Reconstructive surgery) economic assistance, SHG (Self Help Group) Loans available for the person affected by leprosy in India.

The data was collected by trained research workers in interview schedule by asking simple questions about the possession of the entitlements from all the respondents of four states. A verbal consent was taken from each respondent beforehand and anonymity was ensured. The data so collected was analyzed in SPSS using appropriate statistical tests.

RESULTS

Table 1: shows the distribution of socio-demographic variables and

states in person affected by leprosy in 4 states. Out of 379 person affected by leprosy 198 (52.2%) were male and 181 (47.8%) were females. The age ranges from 20 to 65 years and the mean age was 47.30 years and was grouped into younger 22.4%, Middle age 64.4% and old age 13.2%. maximum of them 57.5% were uneducated, 31.1% were educated upto 9th class and 11.3% were 10th class and above. Majority 57.5% were living in general community and 42.5% were from Leprosy colony. Majority of their occupation 34% were Housewife and dependents, 33.8% were laborers and farmers, 23.5% belong to begging and very few 8.7% were employed and doing business respectively.

Table 2 shows the percentage of Person affected by leprosy and WHO Disability Grades across all four States and majority of them 82.1% belong to Grade II disability. The difference between the states and WHO Disability Grades are statistically highly significant at p<0.01.

Table 3 shows the percentage of access to specific schemes and states in Person affected by leprosy. Disability certificate was the most accessed scheme 79.9% and seen maximum 96% in AP and least 51% in CG and the difference is significant at P<0.01. Disability pension was accessed overall by 65.2% and seen maximum 84.2% in AP and least 35% in CG and the difference is significant at P<0.01. MCR footwear was accessed overall by 50.7% and seen maximum 63.4% in AP and least 32% in CG and the difference is significant at P<0.01. Bus pass was accessed overall by 40.9% and seen maximum in 68.3% in AP and not accessed in CG. The schemes which are least accessed less than 25% overall are Train Pass (23.7%), SHG loans (19), Tricycle (13.5%), Aids and appliance (12.9%) and old age pension (2.4%) and the difference between the states are significant at P<0.01. RCS economic assistance (17.9%), and old age pension (2.4%) and the difference between the states are significant at P<0.05.

TABLE 1: Distribution of Socio-Demographic variables and states in person affected by leprosy

Demographic Variables	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379
Gender					
Male	47 (60.3)	51 (50.5)	42 (42)	58 (58)	198 (52.2)
Female	31 (39.7)	50 (49.5)	58 (58)	42 (42)	181 (47.8)
Age Groups					
Younger (20 to39 yrs)	5 (6.4)	17 (16.8)	24 (24)	39 (39)	85 (22.4)
Middle (40 to 59 yrs)	54 (69.2)	71 (70.3)	64 (64)	55 (55)	244 (64.4)
Old age (60yrs to 65 Years)	19 (24.4)	13 (12.9)	12 (12)	6 (6)	50 (13.2)
Education					
Un educated	42 (53.8)	58 (57.4)	56 (56)	62 (62)	218 (57.5)
Educated up to 9th	32 (41)	32 (31.7)	37 (37)	17 (17)	118 (31.1)
10th Std and above	4 (5.1)	11 (10.9)	7 (7)	21 (21)	43 (11.3)
Locality					
Colony	6 (7.7)	60 (59.4)	47 (47)	48 (48)	161 (42.5)
Community	72 (92.3)	41 (40.6)	53 (53)	52 (52)	218 (57.5)
Occupation					
Begging	0	40 (39.6)	24 (24)	25 (25)	89 (23.5)
Labour/Farmer	33 (42.3)	19 (18.9)	42 (42)	34 (34)	128 (33.8)
Wage employed/ business	2 (2.6)	14 (13.9)	11 (11)	6 (6)	33 (8.7)
Housewife/ Dependents	43 (55.1)	28 (27.6)	23 (23)	35 (35)	129 (34)

TABLE 2: Proposition percentage of Person affected by leprosy and WHO Disability Grades across all four States

WHO Disability Grades	TN N=78	AP N=101	CG N=100	UP N=100	Total N=379	P values
Grade 0	0	2	16	12	7.9	0.000**
Grade I	12.8	5.9	14	8	10	
Grade II	87.2	92.1	70	80	82.1	

** Statistically highly significant at p<0.01

TABLE 3: Percentage of access to schemes and states in Person affected by leprosy

Specific Schemes	TN (n=78)	AP (n=101)	CG (n=100)	UP (n=100)	Total (n=379)	P values
Disability Certificate	94.9	96	51	81	79.9	0.000**
Disability Pension	79.5	84.2	35	65	65.2	0.000**
MCR Footwear	61.5	63.4	32	48	50.7	0.000**
Bus Pass	33.3	68.3	0	60	40.9	0.000**
Train Pass	11.5	44.6	2	34	23.7	0.000**
SHG Loans	24.4	48.5	3	1	19	0.000**
RCS Economic Benefit	20.5	19.8	9	23	17.9	0.051*
Tricycle	5.1	11.9	4	31	13.5	0.000**
Aids and appliances	9	5.9	8	28	12.9	0.000**
Old Age Pension	0	3	6	0	2.4	0.016*

* Statistically significant at p<0.05, ** statistically highly significant at p<0.01,

DISCUSSIONS

Access to Specific schemes by Persons affected by leprosy much depends on the awareness and socio demographic variables which influence their access to resources. In the present study the Disability certificate was maximum 96% in AP, 94.9% in TN, 81% in UP and least 51% in CG. The findings are more in access to earlier study done in Gujarat[8], 71 per cent of the disabled people had certificates, but 19 per cent did not know about the certificate at all[9].

Even with a disability certificate, benefit entitlements vary enormously across the country. The Disability pension was maximum accessed by 84.2% in AP, 79.5% in TN, 65% in UP and less in 35%in CG. In contrary to earlier studies done at Karnataka where Only 40 per cent of the participants in the focus group held in Kolor district, Karnataka, receiving the state disability allowance. Even when official records indicated that a large number of medical camps had been organized, many people remained unaware of them and were unable to get themselves assessed by a doctor for a disability certificate[10].

The other entitlements like MCR footwear maximum accessed by 63.4% in AP and 61.5% in TN. Buss pass maximum accessed by 68.3% in AP and 60% in UP. Train pass maximum 44.6% in AP. SHG Loans maximum 48.5% in AP. Whereas the other entitlements like RCS economic assistance 23% in UP, Tricycle 31% in UP, Aids and appliances like crutches 28% in UP. Old age pension 6% in CG.

One of the reasons for low accessibility as also stated in earlier studies may be the procedures to obtain the benefits are often byzantine and costly. Lack of awareness influenced by illiteracy also may be other reasons as stated in earlier studies that many disabled people are not aware of their rights under the act. In a country with 15 Major languages, and low levels of literacy, dissemination of information is a problem[11] and people affected by leprosy are still illiterate and not aware of their rights and entitlements[12].

Access to services is time-consuming and cumbersome government procedures and corruption both act as additional barriers that prevent disabled people from accessing services. Most informants noted the difficulty in obtaining disability certificates, required in order to access state subsidized disability services and entitlements[13].

CONCLUSION:

The study concludes that Varied differences exists among the four states from maximum to minimum in order of AP, TN, UP and CG determines the influence of local demographic and culture on the accessibility process which needs for state specific intervention approaches.

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Contributions of each author

MDM was involved in the study conceptualizations and design, obtaining permission for conducting the study, monitoring the study and manuscript writing.

MSR was involved in data analysis and interpretation, drafting first draft of manuscript and finalizing it for submission.

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