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Leprosy- A Reflection Through The Current Status Of The NTD In The States Of M.P. & Odisha

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Abstract

Leprosy is a disease that everyone fears & it is obvious that people are fearful about leprosy not only because of its pathology but also for its strong & deratory social taboos. Besides the affected individual, it also affects their family, friends & community. It also affects emotion, financial status & increases the associated social challenges.

The current article discusses various interventions of leprosy through the National Leprosy Eradication Program (NLEP) & various stake holders. It also discusses the social & community level intervention in leprosy that has strategies on the lines of the mass interventions through the leprosy related programs. The article suggests an intervention protocol that can be rolled out based on the systematic strategic approach through application of outreach & inreach principles of epidemiology related to leprosy. The article has multiple elements of the interventions in leprosy on the lines done at national & state level by the public & private stakeholders.

The application of hydra headed approaches in leprosy that help the public, private, corporate & civil society based system to cover the masses backed up by a National Health Policy (NHP) are also discussed in the article. The recent National Health Policy of 2017 is referred here. The article aspires that the multi stage approach in the public, private, corporate & community based system plays a significant role in dealing with the current Neglected Tropical Disease (NTD) menace like leprosy in the national & the state level. The article has the reflections of the interventions in the state of Madhya Pradesh & Odisha.

Key Words- NTD, Leprosy, NLEP, ANCDR, NHP

Glance at Leprosy

Mahatma Gandhi said 'Eliminating Leprosy is the only work I have not been able to complete in my life time'. He also said Leprosy work is not only medical relief: it is transforming the frustration in life into the joy of dedication, personal ambition into selfless service.[1]

The unfinished work by the Father of the Nation continues to motivate masses to work in the field of leprosy. The current article is only a small step in this direction.

The article focuses on two states of Madhya Pradesh & Odisha based on the endemicity of leprosy, need based response of the state governments towards the stake holders of the leprosy programs & finally the new challenges that have emerged because of the obstacles in the form of determinants of health to check the surged incidence of the cases.

Under the sub heading 'reduction of disease prevalence/incidence' in the NHP 2017, regarding Leprosy, the NHP mentions to 'achieve & maintain elimination status of Leprosy by 2018'. The elimination status is achieved once the prevalence of leprosy is less than 1/10,000 population.[2]

Despite progress, India continues to account for highest number of new cases of leprosy reported globally each year. India shared an average 63% of global leprosy burden in the last two decades (4.1 million out of 6.5 million cases). In the year 2019-20 India recorded 57% of the global new leprosy cases (1,14,451 out of 2,02,185).[3]

A total of 65,147 new cases were detected during the year 2020-21, which gives Annual New Case Detection Rate (ANCDR) of 4.56 per 100,000 population, as against 1,14,451 cases in 2019-20. A total of 57,672 leprosy cases are on record as on 1st April 2021, giving a Prevalence Rate (PR) of 0.40 per 10,000 population, as against 79,898 cases in1stApril 2020. The year 2020-21 was an exception as the Covid-19 slowed down the new case detection rate, however, the experts felt that there are still a huge number of latent, hidden or occult cases that are yet to be detected.[3]

Justification of the current article

In terms of overall health performance among large states, according to the NITI Aayog Health Index Report 2019-20, the 4th round of ranking since it was initiated in the year 2014 & thats why the year 2014 is the base year. Madhya Pradesh ranks 6th out of 19 larger states. The other two categories are smaller states & Union Territories. Madhya Pradesh has a score of 36.72 on NITI Aayog's Health Index. Similarly, Odisha has a score of 44.31 has the 14th rank. The index is a weighted composite score consisting of 24 indicators covering key aspects of health performance. Table 1 gives the current details of the index of these two states.[4]

Table 1- NITI Ayog health index of M.P. & Odisha[4]

State	Base year (2014)	2019-2020	Incremental Progress	Rank
Madhya Pradesh	40.77	36.72	-4.05	6
Odisha	40.19	44.31	4.12	14

The above table shows that if Madhya Pradesh has gone down by 4 points in the index in the decadal period of 2014-2024, Odisha has just gained by 4 points. The decadal period is applicable here since this is the updated data available in the public domain as on 2024.[4]

Further, the NLEP report of 2020-2021 informs that the percentage of enrollments of leprosy cases in the state of Madhya Pradesh is 39.52 where as in Odisha, the enrollment is 28 which is 11 percentage points below Madhya Pradesh.[3]

The data on SPARSH (the sparsh leprosy awareness campaign) shows that while Madya Pradesh covered 88.25% of villages, Odisha could cover only 81.44% of villages.[3] This campaign is a nationwide campaign that aims to raise awareness about leprosy to reduce the stigma of discrimination associated with Leprosy.[3]

As per the Nikusth portal, the state of Madhya Pradesh & Odisha are categorised under moderate level performing states.[3]

Basically, the National Leprosy Eradication Program (NLEP) annual report on states focuses on the number of districts in each state followed by 12 indicators. These are the number of new cases, Annual New Case Detection Rate, the denominator of which is 10,000 population. The next reporting indicator is the number of cases on record at the end of March month of the reporting year. The Prevalence Rate taken per 10,000 population is the next indicator. The percentage of Multi Bacillary cases is the next indicator. The subsequent indicators are percentage of female cases, child cases, percentage of child cases. The number of new cases with grade II deformity is the next indicator which is followed by Grade 2 Disability per million population. The last two indicators are on children. Theses are children with grade 2 deformity from among the total number of deformity cases. The last is the percentage of child deformity with grade 2 cases.[3]

This article focuses on these indicators towards the rationale of focusing on these two states. Madhya Pradesh & Odisha states are the priority states in the field of Leprosy Control Program by the Government of India. The annual report of 2020-21 reveals the following points which make both the states as the top priority states[3]

Madhya Pradesh state contributes 8.3% of the country's case load where as Odisha contributes 9.2% of the country's case load. One State among the above two Odisha along with Chattisgarh and the Union Territory of Dadra & Nagar Haveli have prevalence rate of more than 1 per 10,000 population. In India, there are 61 districts out of 724 having prevalance rate more than 1,10 districts are from Odisha out of 31 districts & 4 districts in Madhya Pradesh out of 51 districts. 12 districts of Madhya Pradesh & 18 districts of Odisha have G2D rate per million is more than 2 in a total of 204 districts in India.

As per the National Health Mission of Odisha state, the NLEP started in the state in the year 1983. The Prevalence Rate (PR) was 121.4/10,000 population in 1983 & as on 31st January 2023, the PR is 1.19/10,000 population. The following table number 2 gives the trend of indicators of the state in the last 5 years.[5]

There are three primary indicators. These are the number of new cases detected, PR per 10,000 population. The last indicator is Grade 2 Disability Rate among new cases with absolute numbers.

Table 2- Indicators of Odisha state (2018 to 2023)[5]

Indicator	2028-19	2019-2020	2020-2021	2021-22	2022-2023
New Case Detected	10786	10077	6148	5729	6088
PR/10,000 population	1.53	1.45	1.1	0.89	1.19
Grade 2 Disability Rate among new cases with absolute numbers	3.16 (341)	2.0 (200)	2.9 (178)	2.9 (164)	2.6 (157)

The following table gives a snapshot of the two proposed districts & the current district with intervention on 6 indicators. The rank 2 & 7 are the selected districts for future interventions in these two sates at the district level. The ANCDR of these two states are lower than Chhatisgarh. The PR of Chhatisgarh & Odisha are almost similar albeit with 0.1 difference. While Madhya Pradesh shows a low PR currently, the state is much bigger geographically than the other two states. As already seen leprosy bounced back after achieving the elimination status, the same challenge lies with the state of Madhya Pradesh.[3]

The Child Case Rate (CSR) of Odisha is higher than Chhatisgarh state where as the Grade 2 Disability Rate of the two proposed states are lower than Chhatisgarh state. The two reflected states of the current article presents a comparable intervention strategy using the CSR approach as one of the the two reflected states along with Chhatisgarh state have low score as the state of M.P. has relatively high score than the other two.[3] These three state's relevant data are highlighted in the table given below.

Table-3: NLEP Data of last 2years in the above-mentioned three states[3]

Sl. No	State	Nos of Districts	Annual New Case Detection Rate		Prevalence Rate/10000		Child Case Rate		Grade-2 disability Rate		Score	Overall Ranking
	Year wise		2019-20	2020-21	2019-20	2020-21	2019-20	2020-21	2019-20	2020-21		
1	Jharkhand	24	15.58	8.44	0.98	0.73	7.14	6.58	1.83	3	34	4
2	Chhattisgarh	27	29.65	15.62	2.08	1.2	5.38	4.74	3.47	3.72	22	1
3	Bihar	38	13.07	6.32	0.77	0.57	10.21	8.16	2.76	3.38	30	3
4	Delhi	11	9.17	4.18	0.99	0.75	3.18	2.95	14.04	11.92	42	6
5	Odisha	31	21.35	12.86	1.45	1.1	6.76	6.85	1.98	2.9	26	2
6	Gujarat	33	5.77	3.59	0.36	0.24	5.12	5.47	0.98	0.08	71	9
7	Madhya Pradesh	51	9.46	5.69	0.8	0.55	3.64	3.01	3.58	2.2	56	7
8	Maharashtra	35	12.21	9.51	0.79	0.8	8.19	7.42	1.56	1.51	40	5
9	Uttar Pradesh	75	6.58	3.72	0.43	0.3	3.41	2.16	1.02	1.13	64	8
10	West Bengal	27	6.04	3.24	0.58	0.35	8.33	6.14	1.05	1.16	72	10

The scoring pattern adopted in the data analysis of the above table are done as per a tetra criteria. These four criteria are described in the section given below.

All the four indicators showing rate are considered. Each state has been assigned a rank and the corresponding number as per the rank e.g. Chhatishgarh rank 1 in 2019-20 ANCDR and so it has been given 1 point. Similarly, Gujarat ranks 10 and it has been assigned 10. The cumulative ranks as suggested is the score of the state. The set criteria is that lowest is the score, higher is the need

The table below gives the profile of the state of M.P. through the lens of HPD & HE districts in the state.

Table-4: NLEP Data of 10 high priority & 3 high endemic districts of M.P.[6,7]

State	Name of the district	ANCDR/100,000	Percentage of Grade 2 against new cases
M.P.	Alirajpur	38.07	5.00
M.P.	Barwani	44.27	9.56
M.P.	Khargone	30.74	1.99
M.P.	Khandwa	21.80	1.80
M.P.	Indore	22.48	0.57
M.P.	Anuppur	20.93	6.96
M.P.	Burhanpur	16.28	1.61
M.P.	Dhar	16.61	2.88
M.P.	Hoshangabad	15.18	1.09
M.P.	Katni	14.38	0.00

From among these 10 districts that are taken from the list of High Priority Districts (HPD) of GOI of February 2022-2023. There are 21 HPDs in Madhya Pradesh out of 51 districts. This list was matched with the list of High Endemic Districts (HED) of NLEP, 2019 & three HEDs are there in the 2022-2023 list. The following table gives the details of the 5 indicators of these three HEDs of M.P. state.[6,7]

Table 5- Indicators of three HEDs of Madhya Pradesh[6,7]

Names of districts	Population as on March 2019	NCDR	PR	G2D Rate	Number of new child cases	Composite Index
Alirajpur	829582	24.84	1.96	17.0	15	17.19
Barwani	1577540	25.91	2.12	15.4	30	20.32
Khargone	2131699	19.77	1.35	19.4	31	18.98

Table-5: NLEP Data of 10 High Priority Districts & 7 High Endemic districts of Odisha[6,7]

State	Names of Districts	ANCR/100,000	Percentage of Grade 2 against new cases
Odisha	Boudh	78.18	2.29
Odisha	Nuapada	51.50	2.34
Odisha	Bargarh	40.66	1.83
Odisha	Sonepur	38.79	2.38
Odisha	Balangir	36.62	0.54
Odisha	Dhenkanal	34.01	1.10
Odisha	Jharsuguda	33.98	0.00
Odisha	Kalahandi	26.52	0.52
Odisha	Sambalpur	26.33	11.52
Odisha	Anugul	25.09	1.74

From among these 10 districts that are taken from the list of High Priority Districts (HPD) of GOI of February 2022-2023. There are 16 HPDs in Odisha out of 31 districts. This list was matched with the list of High Endemic Districts (HED) of NLEP, 2019 & seven HEDs are there in the 2022-2023 list. The following table gives the details of the 5 indicators of these seven HEDs of Odisha state.[6,7]

Table 6- Indicators of seven HEDs of Odisha[6,7]

Names of Districts	Population as on March 2019	NCDR	PR	G2D Rate	Number of New Child Cases	Composite Index
Boudh	488576	50.00	2.71	10.9	18	26.94
Dhenkanal	1324900	37.78	1.93	9.2	38	25.30
Jharsuguda	643597	39.12	1.49	3.4	19	20.72
Kalahandi	174709	22.44	1.36	20.2	29	19.46
Nuapada	673574	35.99	2.20	14.2	18	21.77
Sambalpur	1159931	27.29	1.58	17.6	24	19.86
Sonepur	724236	53.47	2.92	11.8	29	30.72

Disability in leprosy is a cause for the distress of people affected by leprosy due to physical disability resulting from nerve damage. Lack of availability of disability preventive and care services in the public health system at primary (Primary Health Centre-PHC) and Secondary (Rural/sub-district hospital) is a major challenge. It is estimated that about 60-70% of the people affected by leprosy are deprived of quality leprosy services that affect their quality of life due to disability and allied complications.[3,6,7]

Poverty & Nutrition- Determinants of Leprosy

Poverty is a state of health that is enumerated through a multidimensional approach through NITI Ayog in India. Currently, 14.96% of India's population is multidimensionally poor as per NITI Ayog that used the micro data of household level collected during the NFHS 5 round. However, a World Bank (WB) report of 2024 informs that 129 millions Indian populations live in extreme poverty which means they earn less than $2.15 or ₹ 181/day. The threshold of WB is $6.85 or ₹576/day.[8,9]

Further, in the state of Madhya Pradesh, NITI Ayog report informs that 20.63% of populations are multidimensionally poor where as 15.68% of populations in the state of Odisha are multidimensionally poor. This is a strong rationale to implement leprosy program in these two states as these number of populations are at risk of being afftected by leprosy.[9,10,11,12,13]

The progress in reducing poverty in India from 2013-14 to 2022-2023 is highly encouraging. During this 9 period, in our nation, about 25 crores or 250 millions of individuals have exited from Multi Dimensional Poverty (MPI).[9,10,11,12,13]

Under nutrition is one of the significant determinant of leprosy since leprosy is a chronic phenomenon. From among all the age groups, it is the children who are at the highest risk. Hence, it is prudent to note the status of the under nutrition among U5 children in the two proposed states. Similarly, undernutrition among adults is also a risk factor for leprosy cases. The following table gives the undernutrition status among adults & U5 children from the 5th round of the National Family Health Survey published in 2019-2021.[9]

Table 6- Nutritional status of children & adults in MP & Odisha (Source-NFHS 5, 2019-2021)[9]

Target Group	Indicator	Madhya Pradesh	Odisha
U5 Children	Percentage who are stunted	35.7	31.0
U5 Children	Percentage who are wasted	19.0	18.1
U5 Children	Percentage who are severely wasted	6.5	6.1
U5 Children	Percentage who are underweight	33	29.7
Women in the age group of 15-49 years	Percentage whose Body Mass Index is below normal	23	20.8
Men in the age group of 15-49 years	Percentage whose Body Mass Index is below normal	20.8	15.3

The following table gives the data on leprosy related to the children as a risk group in both the states.

Table 7- Children & Leprosy[3]

State	Population	Number of child cases	Rate per 100,000 population	Number of new child cases with Grade 2 Disability	Rate among child cases
Madhya Pradesh	86374598	148	0.2	3	2.03
Odisha	47825159	421	0.9	7	1.66

The table given below reflects on the percentage of new cases, reconstructive surgery & the details of deleted cases of leprosy in the two states.

Table 8- Deformity, RCS & Deleted cases[3]

State	Number & Percentage of new cases with Grade 1 deformity	Number & Percentage of new cases with Grade 2 deformity	Reconstructive Surgeries performed (RCS)	Total number of RCS performed	Cases Deleted (RFT)	Cases otherwise Deleted	Total number of cases deleted
Madhya Pradesh	669 (13.61%)	108 (2.20%)	By Government – 58 By NGO- 12	70	6056	187	6243
Odisha	416 (6.8%)	178 (2.90%)	By Government- 125 By NGO- 35	160	7565	157	7722

The table below gives the modalities related to New Disability Case Rate compared with the total population in Madhya Pradesh & Odisha.

Table 8- NDCR in M.P. & Odisha[3]

State	Population as on March 2021	Number of New Cases with Grade 2 Disability	Rate per Million population
Madhya Pradesh	86374598	108	1.25
Odisha	47825159	178	3.72

The table below gives the elimination status related indicators along with the total population. There are eight indicators that are related to this status. The details are given in the table mentioned below.

Table 9- Elimination related indicators in M.P. & Odisha[3]

State	Population as on March 2021	Percentage of country's population	Number of Cases on Record	Percentage of country's Case Load	Prevalence Rate per 10,000 population	Number of new cases detected	Percentage of country's new case	ANCDR per 100,000 population
Madhya Pradesh	86374598	6.0	4757	8.3	0.55	4917	7.5	5.69
Odisha	47825159	3.34	5271	9.2	1.1	6148	9.43	12.86

The next table gives the profile of the districts in these two states on ANCDR

Table 10- ANCDR at district level in M.P. & Odisha[3]

State	Total Number of Districts	ANCDR/10,000 in Number of Districts				
Indicators		Less than 10	10 to 20	More than 20 to 50	More than 50 to 100	More than 100
Madhya Pradesh	51	45	6	0	0	0
Odisha	31	14	9	8	0	0

The following table gives the district level status per Prevalence Rate in M.P. & Odisha

Table 11- PR in the two proposed states[3]

State	Total Number of Districts	PR/10,000 in Number of Districts					
Indicator		Less than 1	1-2	More than 2-5	More than 5 to 10	More than 10 to 20	More than 20
Madhya Pradesh	51	46	4	1	0	0	0
Odisha	31	14	10	7	0	0	0

The following table gives the details of the districts as per Grade 2 Disability

Table 12- Grade 2 Disability in M.P. & Odisha[3]

State	Total Number of Districts	Grade 2 Disability Per 10 Lakh Population			Grade 2 Disability Rate Per 10 Lakh Population
Indicator		Less than 1	1-2	More than 2	
Madhya Pradesh	51	28	11	12	1.25
Odisha	31	07	06	18	3.72

Next table regarding these two states is about the details of the new cases that were Released From Treatment (RFT)

Table 13- RFT in M.P. & Odisha[3]

State	RFT	Otherwise	Total	Percentage of cases relaeased as cured
Madhya Pradesh	6056	187	6243	97.00
Odisha	7565	157	7722	97.97

The following table is about other cases that were released from treatment in the state of M.P. & Odisha

Table 14- Other cases that were RFT in M.P. & Odisha[3]

State	Cases Deleted (RFT)	Otherwise	Total	Percentage of case released as curved
Madhya Pradesh	175	24	199	87.9
Odisha	410	15	425	96.5

Following this table is the status of Active Case Detection & Regular Surveillance in the states of M.P. & Odisha at the district level. There are 8 indicators in the context of ACD & RS.

Table 15- ACD & RS in M.P. & Odisha state[3]

State	Districts Covered	Report Duration	Enumerated Population	Population Eligible for Screening	Screened Population	Suspects Covered	Suspects examined	New cases detected	Cases Started MDT
Madhya Pradesh	51	December 2020 to 31st March 2022	59140793	16212334	14748678	51507	45305	1516	1516
Odisha	31	December 2020 to 31st March 2021	4477560	40910771	37829022	60652	53828	3808	3808

The following table is on the issue of Post Exposure Prophylaxis with four indicators related to the state of M.P. & Odisha

Table 16- PEP status in M.P. & Odisha[3]

State	Number of Index Leprosy Cases	Number of contacts examined	Number of contact found eligible for PEP out of total examined	Number of SDR administered
Madhya Pradesh	3088	9933	6237	1481
Odisha	6318	78690	69284	52571

Subsequently, the details of the Disability Prevention & Medical Rehabilitation (DPMR) services in these two states is given in the next table. There are seven indicators in the table given below.

Table 17- DPMR services in M.P. & Odisha[3]

State	RCS performed by Government	RCS performed by NGO	Relapse cases through suspect at PHC level	Relapse cases through confirmation at District Hospital	Cases developed new disability after MDT	Cases provided with Foot Wear	Cases provided with Self Care Kit
Madhya Pradesh	58	12	6	12	384	4860	2867
Odisha	125	35	2	4	11	6283	6952

Leprosy has a strong outreach component without which the program on leprosy can not be implemented effectively. However, it has to be backed up by a strong inreach component through tertiary care. The following table gives the details of the involvement of Accredited Social Health Activist (ASHA) in the NLEP in the states of M.P. & Odisha. There are 5 indicators related to the involvement of ASHA in NLEP.

Table 18- ASHA involvement in NLEP in M.P. & Odisha[3]

State	Number in position	Number trained in NLEP till April 2022	Number of Leproy cases diagnosed out of referral by ASHA	Number of cases completed treatment with ASHA supervision	Incentive paid to ASHA in ₹ on diagnosis & completion of treatment
Madhya Pradesh	52549	24841	2819	3475	33079
Odisha	46681	46681	4798	5963	1779

One of the most significant strategy in NLEP is the capacity building efforts of the staffs who are involved in the effective roll out of the leprosy related programs. There are five types of stake holders in this category that are given in the below-mentioned table.

Table 19- Training activities in M.P. & Odisha[3]

State	Medical Officer	Health Supervisor	Laboratory Technician	Non Medical Staff member	ASHA/Angan Wadi Worker
Madhya Pradesh	614	476	195	3008	24841
Odisha	933	733	25	48	46681

Vulnerable population in the two proposed states

The following table shows the percentage of new cases detected. It is significant to note the Sceduled Tribe & Scheduled Caste population in the two states reflected here.

Table 7- Vulnerable Population & NDCR in the proposed states[3]

State	Multi Bacillary	Female	Child (MB)	Child (PB)	Total	ST	SC	Population as on March 2021	Number of new cases with Grade 2 Disability	New Disability Case rate per Million Population
Madhya Pradesh	3282 (66.75 %)	1869 (38.01 %)	77 (1.6 %)	71 (1.4 %)	148 (3.01 %)	1652 (33.6%)	861 (17.51 %)	86374598	108	1.25
Odisha	3207 (52.16 %)	2532 (41.18 %)	118 (1.9 %)	303 (4.9 %)	421 (6.85 %)	1910 (31.07 %)	1162 (18.9%)	47825159	178	3.72

The following table gives the details of the cases on record in the proposed states

Table 8- Cases on record[3]

State	Census population as on March 2021	Cases on record	Number of new cases detected (PB)	Number of new cases detected (MB)	Total number of cases detected	Cases on record at the end of April 2021
Madhya Pradesh	86374598	6796	1635	3282	4917	4757
Odisha	47825159	6845	2941	3207	6148	5271

The above table shows that the state of Odisha has more cases on record than the state of Madhya Pradesh.

Collaboration & Approach

The approach should be to achieve the goal includes championing progress toward leprosy targets and commitments to upholding human rights, ensuring that everyone is included. By aligning the many voices of the leprosy community, stake holders of leprosy need to facilitate development of a powerful force for change.[3,4,5]

Since leprosy is a chronic disease, the nation has committed itself working in collaboration with the government at all levels so as to increase its reach and enhance its impact. The proposed interventions need to be implemented in district and state level exclusively by all stakeholders in consensus with the state leprosy society and the district health department. Apart from the government, there has to be functional & working relationship in close collaboration with each other for all relevant stakeholders like the ILEP agencies, local NGO/s working on the issue of leprosy, people's association etc.[3,4,5]

Stakeholders should use a two-pronged approach as a core mandate in all leprosy related interventions. Work with communities as well as strengthen the existing government health system to deliver quality health services are the key strategies. The figure below gives a snapshot of the ideal approach to deal with leprosy.[3,4,5]

Fig1- Suggested Approach in a leprosy related intervention[3,4,5]

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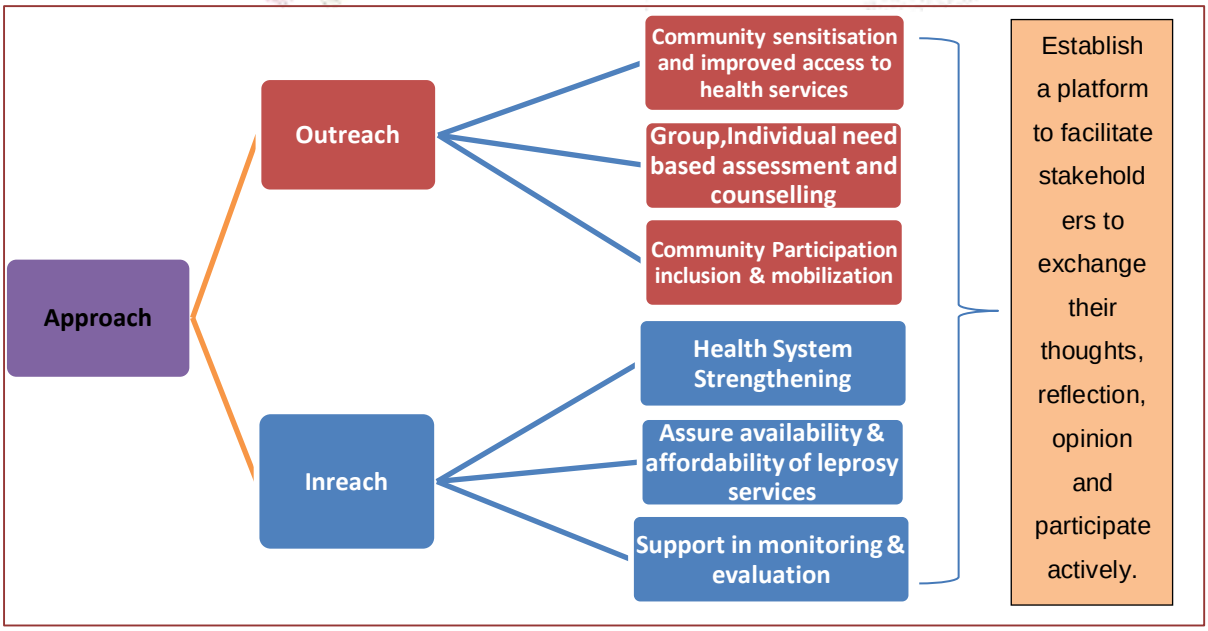

Prototype of Objectives in a leprosy related intervention

The main objectives of any leprosy related intervention should be to comply with the objective of achieving Zero Leprosy, Zero Disability and Zero Stigma & Discrimination. This can be achieved through following sub objectives. Following that, the related expected results & outcomes are mentioned under each of the sub objective.[3,4,5]

The first one is to strengthen the existing public health care delivery system for detection of new cases of leprosy and disability management. The next one deals with generating community level participation and strengthening home-based care for rationalization of the tertiary care. The final one is to develop capacity of the community and community organisations to enable them to lead, participate and influence actions that promote dignity and respect at all levels through inclusion.[3,4,5]

Prototype of Research Questions in a leprosy related intervention

There are two RQs under each of the sub objective. Through the roll out of these leprosy related programs, the answer to the RQs are elicited & further through these answers the objectives are fulfilled. The RQs are given below.[3,4,5]

RQs of sub objective 'a' are 'What are the areas that need to be strengthened in the health system?' & the next RQ is 'how the process of strengthening is to be rolled out?'[3,4,5]

RQs of sub objective 'b' are 'Who are the stakeholders in participation & how the home based care strengthening will be done?' & the next RQ is 'What are the elements of rationalization of the tertiary care?'[3,4,5]

RQs of sub objective 'c' are 'What are the areas in which capacity needs to be developed?' & the next RQ deals with 'What are the elements & actions towards dignity & respect of the CBOs?'[3,4,5]

Prototype of Outcomes in a leprosy related intervention

These outcomes are given as per the three sub objectives.

The first one as mentioned above is to strengthen the existing public health care delivery system for detection of new cases of leprosy as well as reaction and neuritis cases early enough before development of any deformity. The related activities are given below.[3,4,5]

The first one is on early identification and referral to the PHC for diagnosis and treatment. This is followed by improved documentation of people receiving services. The next one is regarding the availability of other services including counselling, MDT (Multi Drug Therapy), steroids, MCR (Micro Cellular Rubber), self-care kits, referral etc at the service delivery centres.[3,4,5]

The last one is to facilitate availability of psychological support at points of care like availability of therapeutic counselling andreferral services to address mental health needs.[3,4,5]

As mentioned above, the second sub objective is towards generating community level participation and strengthening home-based care for rationalization of the tertiary care. The related steps are given below.[3,4,5]

In the beginning, elderly & immobile people to be provided domicilliary services. Next in line is dealing with various government, private, corporate social schemes that are to be linked with leprosy affected people & provide the related services to the leprosy affected individuals.[3,4,5]

Active involvement of people in improving self-care should be the highlight of the intervention. This is the second step. The third step is to ensure regular supply of self-care materials needs that should be a key aspect of the intervention. The step to follow this one is that community and Community Based Organisations (CBO) lead, participate and influence actions that promote dignity and respect through inclusion.[3,4,5]

Facilitate the development of associations of persons affected by leprosy for self-help and advocacyand link to district and state level disability people's organization is the fifth step.[3,4,5]

The sixth one deal with initiatives need be taken to nurture, support and strengthen the capacity of regional and national community-based organisations and networks of persons who are affected by leprosy. Further, they can provide meaningful engagement on issues relevant to them at all decision-making & administrative levels.[3,4,5]
The last duo deal with access by persons affected by leprosy to social entitlements and community-based rehabilitation services that are sustainable & to facilitate a platform where, both the service provider and the service receiver exchange their views, support, and complement each other in the best interest of the community.[3,4,5]

Mythology related to Leprosy from Odisha

Before concluding, it is prudent to mention a bit of mythology from Odisha, one of the reflected state in the current article in the context of Leprosy.

In the state of Odisha, on the 10th day of the shukla pakshya (the fortnight after the new moon or the waxing phase of the moon) in the month of Pausha (the first month of the 'Late Winter' season as per the Hindu calendar called as the 'Saka' calender), 'Samba Dasami' festival is celebrated across the state every year. 'Samba' was the son of Lord Krishna (Hindu God) & 'Dasami' means the 10th day. The festival is celebrated to honor the 'Surya' (Sun) God.[14]

Legends say that 'Samba' was afflicted by Leprosy & he was cured by 'God Surya' after 12 years of penace near Konark, Odisha. The sun temple of Konark, Odisha is an UNESCO site. On this day, mothers observe special puja & rituals dedicated to Lord Surya for the good health & long life of their children. On this day, people prepare nutritious food at their house holds based on their socio-economic status thus signifying the fact that nutrition is a strong determinant in leprosy as mentioned above.[14]

Conclusion

As all interventions in leprosy have to address mental as well as physical symptoms, the suggested prototype is and will be effective against all leprosy cases in general as it takes care of not only the mental/psychological issues but also the internal inflammation in leprosy affected population as well. However, it should be also seen that along with generalised approach, specific approaches that cover all aspects & complications of leprosy are also required to deal with the cases at mass level. One such specific approach is the Reconstructive Surgeries (RCS). It is critical to note that the resistant social taboos related to Leprosy takes a heavy toll on the mental health of the leprosy affected individuals & the

family as well as the population at large as well. Thus a link to the National Mental Health Program (NMHP) with the leprosy cohort is also essential.

It should be ensured that nutrition, counseling, physical activity and all psychic health modalities like life style modification, diet and stress reduction are adhered in each case of Leprosy. In fact, the detailed rolled out plan for each of the phenomenon or complications that occur in the body during the leprosy stages have to be accounted. Hence, as a part of intervention for leprosy, the supportive therapy like reading, socializing, mobilizing activities at individual & group level are to be prioritized in each leprosy case for optimal overall health.

To get optimal results, the medical & social science fraternity should be ready to cover the leprosy cohort through screening & identification from among the masses. There is no single approach in the health system that can cover the masses effectively, therapeutically, economically & socially when dealing with leprosy cases. Multi tasking approach play an active role in the current scenario as the leprosy situation is already complicated by the surged incidence issues in the community since the last 3-4 years. The therapeutic, physiological, surgical, rehabilitative approaches in the system can deal with the physical, mental & psychological issues that are exacerbated by the chronicity nature of leprosy, the most resistant Neglected Tropical Disease (NTD). A sum of these approaches in a holistic intervention that is implemented collectively & cohesively among all the related stake holders can thus reduce the risk & burden of leprosy optimally.

Declaration of the lead author

Prof. Shankar Das, a co-author of the current article was the Ph.D. guide of the lead author at Tata Institute of Social Sciences, Mumbai. Prof. D.P. Singh was the teacher of the lead author at TISS, Mumbai during 1995-1997. Prof. Dwivedi is the coordinator of the program where the lead author currently teaches. The lead author also certifies that he has expressed his personal opinion through the prototypes based upon his public health and clinical experiences. The content & approach mentioned are only reflective in nature.

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Conflict of interest

Nil

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