Leprosy and Migration

Pilot Study in India

Final Report | March 2021-March 2024

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PREFACE

Leprosy, a disease that has plagued humanity for centuries, remains a critical issue in India today, despite decades of efforts to eradicate it. India continues to account for the largest share of the global leprosy burden, with significant implications for public health, social well-being, and human dignity. Although substantial progress has been made through the National Leprosy Eradication Programme (NLEP), the path towards complete eradication faces persistent challenges, one of the most pressing being the inconsistency in how migrant leprosy cases are reported and managed across the country.

This report aims to provide insights into the challenges faced by migrant individuals affected by leprosy, particularly regarding the availability, accessibility, and delivery of treatment at the source, along migration routes, and at migrants' destinations. It also seeks to understand the impact of migration on leprosy-affected migrants and their households.

Based on the findings of the study, the report offers evidence-based recommendations aimed at strengthening the national programme concerning migrant patients. The goal is to influence policy and programme design to ensure improved management, support, and treatment options for leprosy-affected migrant patients and their families, addressing gaps identified through the research.

The report also presents a draft definition of migrants in the context of leprosy. It highlights existing gaps in leprosy management, presents the case for national-level intervention, and provides actionable recommendations for policymakers and public health professionals. Only through coordinated efforts at the national level can India truly achieve the vision of a leprosy-free future. Addressing the issues faced by migrant patients at the national level will also contribute to achieving the goal of Zero Leprosy in India by 2023.

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Mr. John Kurian George
Principal Investigator and
Executive Director, Swiss Emmaus Leprosy Relief Work India

ABBREVIATIONS

ABSULS	ASHA Based Surveillance for Leprosy Suspects
ACDRS	Active Case Detection and Regular Surveillance
APAL	Association of People Affected with Leprosy
ANM	Auxiliary Nurse Midwifery
ASHA	Accredited Social Health Activist
DLC	District Level Consultant
DLO	District Leprosy Officer
DPMR	Disability Prevention and Medical Rehabilitation
HH	Household
ICMR	Indian Council of Medical Research
ICF	Informed Consent Form
ILEP	International Federation of Anti-Leprosy Associations
IRB	Institutional Review Board
LCDC	Leprosy Case Detection Campaign
MCR	Micro Cellular Rubber
MDT	Multi Drug Therapy
MIS	Management Information System
MO	Medical Officer
NGO	Non-Governmental Organization
NLC	National-Level Consultation
NLEP	National Leprosy Eradication Programme
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
PIP	Programme Implementation Plan
PHC	Primary Health Centre
PI	Principal Investigator
RFT	Released from Treatment
SEI	Swiss Emmaus Leprosy Relief Work India
SLC	State-Level Consultation
TB	Tuberculosis
TTF	Technical Taskforce
UP	Uttar Pradesh
UT	Union Territory
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

The Government of India's commitment to eliminating leprosy from India has led to significant progress in reducing the disease burden over the last decade. The prevalence of leprosy has decreased from 0.69 per 10,000 population in 2014-15 to 0.45 in 2021-22, while the annual new case detection rate has reduced from 9.73 per 100,000 population to 5.52 during the same time. In this process, the Government of India recognises migration as a substantial challenge in eliminating leprosy. Monitoring and tracking migrant patients under treatment, both at their state of origin and destination, are essential to ensure a continuum of treatment. In the absence of adequate information about migrant patients, Swiss Emmaus India (SEI), in collaboration with the Government of India and Novartis Healthcare, undertook a pilot study to understand the needs of migrant patients and provide recommendations to address existing gaps.

The goal of the project is to **"conduct a three-year pilot study to understand the impact of migration on people affected by leprosy and its consequences on treatment in four states of India."**

Objectives of the Primary Research

The primary research objectives are as follows:

1. To study the availability, accessibility, and delivery of treatment among migrant patients affected by leprosy at the source, along migration routes, and at their destinations.
2. To understand the impact of migration on migrant patients affected by leprosy and their households.
3. To influence the design of the NLEP programme for the management of migrant patients affected by leprosy and their households through evidence-based recommendations.

Additionally, the project, through an extensive consultative process, outlined a standard definition of a migrant in the context of leprosy, which is currently missing from the national programme.

The study was conducted in four states of India: Uttar Pradesh and Bihar, which have a high number of people migrating out of the state with high leprosy-endemic districts, and Delhi and Chandigarh, which have a high migrant population from these states. An attempt was made to contact all migrant patients from Uttar Pradesh or Bihar currently under treatment, along with their household members, in Delhi or Chandigarh (396 migrant patients and 236 household members were contacted). If they were unavailable, follow-ups were conducted in selected districts of Uttar Pradesh[1].

In addition, in-depth interviews were carried out with various stakeholders at the state, district, and block levels. Case studies were conducted with patients currently undergoing treatment, defaulters, and those released from treatment (RFT) to gain further insights.

Key Primary Research Findings

Profile of Migrant Patients:

Most migrant patients belong to a lower socio-economic stratum. 21% of patients were illiterate, with women having lower educational levels than men. Men primarily migrated for higher studies or referrals, while women migrated for treatment or marriage. Nearly all the patients (97%) were registered under the new patient category, and all were undergoing MB treatment. More than one-third (37%) of the patients had Grade 1 (17%) or Grade 2 (20%) disability. Regarding duration of stay, three-fifths (60%) of the patients had lived in Delhi/Chandigarh for an average of nine years, while two-fifths (40%) came solely for treatment purposes. Healthcare providers in Delhi and Chandigarh reported a significant influx of patients from states such as Uttar Pradesh and Bihar.

Diagnosis and Treatment of Patients:

The study identified delays in the diagnosis of leprosy, primarily due to a lack of awareness among patients about where to seek a diagnosis. 64% of the respondents indicated not knowing where to go for a diagnosis, with this lack of awareness being higher among women.

As a result, patients visited multiple health facilities (an average of 2.2 facilities) and service providers (an average of 3.2 healthcare providers) to receive a diagnosis. Most patients (95%) were diagnosed at their destination, even though 58% noticed symptoms at their place of origin. Skin specialists were the primary professionals diagnosing leprosy (73%).

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[1] Ministry of Health & Family Welfare- Press Release: Press Information Bureau (pib.gov.in)

Pathway to Care:

Most respondents reported receiving MDT (Multi-Drug Therapy) immediately—on the same day of diagnosis (83%) or within a week (12%). Patients currently on treatment generally adhere to guidelines for regular MDT intake. However, monthly visits pose a significant challenge for those travelling to Delhi or Chandigarh solely for treatment. Qualitative data revealed that patients travel an average of 750 km to receive leprosy treatment.

The study also highlighted gaps in the information provided to patients during MDT, including guidance on continuing MDT during pregnancy and engaging in physical relations while undergoing treatment.

Support System:

The study found that more than three-fourths (78%) of patients received counselling, primarily focused on the importance of adhering to treatment. However, uptake of other support services was lower. Counselling primarily centred on continuing MDT, managing side effects, and practising self-care, but it often neglected aspects such as patients' psychological well-being, dietary habits, substance consumption, lifestyle behaviours, and physical intimacy.

Most patients reported that their family members were aware of their leprosy status, but community awareness remained low. Many healthcare facilities lacked a dedicated counsellor. In larger hospitals, staff find it challenging to provide proper counselling due to high patient loads. Additionally, some facilities lacked female staff, limiting their ability to address gender-specific issues.

Contact Tracing:

Fewer than 7% of the 396 respondents reported that another family member had been affected by leprosy. Only 14% reported that their close contacts had been screened. Discussions with service providers highlighted significant challenges in contact tracing and screening of household members of migrant patients. Patients often did not bring their families to the healthcare facility and referred providers to their place of origin. However, service providers often struggled to trace families at the patients' place of origin.

In Uttar Pradesh, service providers reported that patients frequently refused to have their families and neighbours screened. Patients often insisted that service providers ensure no one outside their immediate family learned about their leprosy status.

Nikusth - MIS for Leprosy Patients:

Almost all healthcare providers acknowledged the potential benefits of Nikusth for data recording, monitoring, and tracking migrant patients. They emphasised that Nikusth could play a significant role in monitoring and tracking migrant patients. However, at the time of the study, Nikusth did not have a provision for tracking migrant patients.

Recommendations

After brainstorming during national- and state-level consultations with the participation of various stakeholders working in the field of leprosy, and with inputs from the Technical Taskforce, the following draft definition of migrant in context of leprosy was developed.

- Person (Men, women, transgender, children, also includes contact/cohabitants) who migrates from one location to another location temporarily or permanently–irrespective of district/state and place of diagnosis.
- A person affected by leprosy who moves outside his place of residence to another district/state for purposes of treatment** and management of conditions caused during treatment (includes MDT, disability care, etc.).

MIS to Track Migrant Patients Through a Uniform Recording Mechanism:

Establish a standardised record-keeping mechanism for migrant patients across states to reduce duplicate data entry, improve contact screening, enable timely follow-ups, ensure prompt referrals, and track treatment completion rates. Incorporate a tracking mechanism into the MIS to ensure efficient case management for migrant leprosy patients, which will further improve treatment completion rates and address disability prevention and management. In this regard, a unique ID could be created to identify migrant patients anywhere within the country.

Standard Operating Guidelines for Counselling:

Develop standardised operational guidelines to strengthen counselling services, with a special focus on women-centric counselling. This should address their unique needs, such as the continuation of MDT during pregnancy and concerns about physical relationships while on MDT. Additionally, counselling should cover topics such as side effects of medicines, what to expect after completing treatment, leprosy transmission, the importance of contact screening, and more. Recruitment of trained counsellors to provide effective guidance on leprosy and related services is essential.

Contact Screening at Source and Destination, Along with SDR:

The MIS for tracking migrant patients and proper record-keeping may help improve contact screening. Further strategies could include screening household members who accompany patients to the facility during treatment, providing SDR to patients, and encouraging them to distribute SDR to their family members.

Development of IEC Materials:

Develop a systematic strategy to increase community awareness about leprosy, inform the public about available treatment facilities, and publicise various government schemes. This can be achieved through various channels, such as interpersonal communication (individual or group), electronic media platforms (radio, TV, cinema), social media, print media (posters, banners, hoardings), and street plays. Involve leprosy champions, such as celebrities, local influential public figures, and role models, to generate interest and catalyse behaviour change among the public. Lessons can be drawn from campaigns for TB, HIV/AIDS, or the Swachh Bharat Abhiyan. Evidence from the field suggests that over 90% of respondents have smartphones, making them ideal for receiving health education messages.

Engagement of members from the Indian Association of Dermatologists in the NLEP Programme:

The members of the Indian Association of Dermatologists can further be engaged in the key activities of the NLEP, which will boost early diagnosis of leprosy, treatment adherence, timely follow-up, and prompt referrals. Engaging members from the IADVL (Indian Association of Dermatology, Venereal Disease & Leprosy), especially those practicing at Government hospitals, is critical.

Strengthening the Healthcare System and Upskilling Service Providers at the Source:

It is essential to strengthen the healthcare system in the source states to provide timely diagnosis of leprosy. This will help patients receive treatment locally, without facing unnecessary hurdles. Additionally, it is important to upgrade the knowledge of healthcare providers regarding leprosy, which may also help reduce migration to places like Delhi and Chandigarh due to large hospitals.

Training and Sensitization of Other Service Providers:

Other healthcare providers, such as traditional medical practitioners, private doctors, and private hospitals, need to be included in the NLEP after undergoing appropriate training to strengthen the early detection system for leprosy and provide MDT services. Sensitization of the PRI members would also play an important role in early detection.

Peer Training:

RFT patients can be used to motivate others to complete their treatment. This will not only help patients discuss their problems more openly but also assist in strengthening their mental health.

CHAPTER 1: INTRODUCTION

Leprosy is an ancient disease and has been endemic in India since time immemorial. The earliest evidence of the disease has been discovered in the Indus Valley Civilization[2]. Leprosy, or Hansen's Disease, is classified by the World Health Organization (WHO) as one of the twenty-one Neglected Tropical Diseases (NTDs) worldwide. Like other NTDs, its occurrence is often related to poor socio-economic conditions in tropical and sub-tropical areas[3]. It is a communicable disease caused by the bacillus Mycobacterium leprae. The incubation period of the disease is, on average, 5 years. Symptoms may appear within 1 year but can also take as long as 20 years or even more.

Leprosy can lead to damage to the nerves, respiratory tract, skin, and eyes. This nerve damage may result in a loss of sensation, making individuals unable to feel pain. As a result, repeated injuries or unnoticed wounds can lead to the loss of parts of a person's extremities due to infection. There were few options for effective treatment until the discovery of multi-drug therapy (MDT) in the 1980s, which significantly reduced the disabilities caused by the disease. Prior to this, patients often experienced irreversible disabilities, leading to stigma and discrimination associated with those affected by leprosy.

1.1 Prevalence of Leprosy in India

India has made significant progress in reducing the burden of leprosy, successfully reducing its prevalence rate from 57.8 per 10,000 in 1983 to less than 1 per 10,000 in 2005[5], achieving the "elimination as a public health problem" target. By the end of March 2012, India had achieved elimination at the state level in 34 out of 36 states and Union Territories (UTs). The number of new leprosy cases detected fell down to 103,819 in 2022-23, from 125,785 in 2014-15. Despite this progress, India still accounts for about 60%[4] of the new cases reported globally each year (174,087 new cases reported worldwide in 2022).

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[2] Indus Civilization Collapsed Amid Illness and Injury in Archaeology Magazine - A publication of the Archaeological Institute of America dtd Dec 31, 2013- https://www.archaeology.org/news/1683-harappa-tuberculosis-leprosy-sinus-monsoon

[3] WHO: NTD roadmap 2021-30

[4] https://www.who.int/publications/journals/weekly-epidemiological-record

[5] Sengupta, Utpal (Spring 2018). "Elimination of Leprosy in India: An Analysis". *Indian Journal of Dermatology, Venereology and Leprology. 84 (2): 131–136*

Leprosy remains endemic in several states and union territories of India. According to the Annual Report of 2022-23 from the Ministry of Health and Family Welfare, the prevalence rate of leprosy was 0.57 per 10,000 population, with an annual new case detection rate of 8.09 per million population. Of the new cases detected in 2022, 2.17% had Grade 2 disability (G2D). The rate of G2D among new cases per million population decreased to 1.74. The WHO's Global Leprosy Strategy has set a target for new cases with G2D disability to be reduced to 0.92 per million population by 2023.

Trends of cases among children at national level shows a steady decline over the decade from 16,112 (9.98%) in 2005-06 to 11389 (8.94%) in 2015-16[5a] to 4,107 (5.45%) in 2021-22[6].

The key indicators of leprosy for key states is given below:

Table 0-1. Key Indicators of Leprosy for Key States:

States/UTs	**2014-15**				**2019-20**				**2022-2023**	
	New Cases Detected	**PR/10,000**	**Rate per million population with G2D**	**Rate of child cases per million**	**New Cases Detected**	**PR/10,000**	**Rate per million population with G2D**	**Rate of child cases per million**	**New Cases Detected**	**PR/ 10,000**
Bihar	16185	0.79	5.02	1.98	16595	0.77	3.61	10.21	8563	0.76
Chhattisgarh	10440	2.38	26.74	2.62	8905	2.08	10.29	5.38	5143	1.77
Jharkhand	4432	0.69	2.80	1.12	6160	0.98	2.86	7.14	5922	1.58
Maharashtra	15695	0.83	3.28	1.46	16572	0.79	2.01	8.19	17893	1.23
Odisha	10174	1.35	13.24	1.90	10077	1.45	4.24	6.76	5581	1.26
Uttar Pradesh	22777	0.65	4.06	0.63	15484	0.43	0.67	3.41	10145	0.41
Chandigarh	136	1.10	8.76	0.61	134	1.03	4.94	8.96	121	1.40
Dadar & Nagar Haveli	425	6.15	18.72	23.16	200	2.61	0.00	12.00	70	1.09
Delhi	2068	1.38	16.04	0.61	1824	0.99	12.88	3.18	1091	0.75
All India	**127,334**	**0.69**	**4.50**	**0.86**	**114451**	**0.57**	**1.96**	**6.87**	**79312**	**0.57**

Source: *NLEP Annual Report 2015-16, NLEP state-wise report 2019-20, Annual Report of M/o Health & Family Welfare- 2022-23*

Note: *Data regarding prevalence of G2D state wise and rate of child cases is not available in the Annual Report of M/o Health & Family Welfare- 2022-23*

At the state level, the **Annual Report of the Department of Health and Family Welfare, 2022-23** indicates that six states/UTs have a prevalence rate of **greater than 1 per 10,000**, which is a matter of concern. These include Chhattisgarh, Jharkhand, Maharashtra, Odisha, Chandigarh, and Dadra & Nagar Haveli (1.09). Data trends for prevalence rates show that Odisha, Maharashtra, and Chandigarh, which had achieved elimination earlier in 2011–2012, have now shown a prevalence rate of **greater than 1 per 10,000 population**, raising concern for the programme[7].

[5a] NLEP Annual Report, 2015-16

[6] NSP and Roadmap for Leprosy-2023-27: Central Leprosy Division, M/o Health & Family Welfare

[7] Current Situation of Leprosy in India and its Future Implications P. Narasimha Rao and SujaiSuneetha

The prevalence rate for Delhi increased substantially in 2014-15, but it has now declined to 0.75 per 10,000 population, which remains higher than the national prevalence rate. A greater concern is that the prevalence rates in Maharashtra and Jharkhand have increased significantly post-COVID.

In 2022-23, the states of Maharashtra, Uttar Pradesh, Bihar, Jharkhand, and Odisha reported the highest number of new leprosy cases[8]. This represents a substantial decline from the new cases reported in 2015-16 in Bihar, Uttar Pradesh, Jharkhand, and Odisha. However, only Maharashtra has reported a higher number of cases in 2022-23. Delhi and Chandigarh reported relatively fewer new cases, despite having higher prevalence rates (Chandigarh: 1.26 and Delhi: 0.75). Both Bihar and Uttar Pradesh have reported a decline in their prevalence rates.

This data should be viewed and interpreted with caution, as the period mentioned coincided with the peak of the COVID-19 pandemic.

1.2 Vision of Zero Leprosy

The Global Leprosy Strategy 2021–2030, "Towards Zero Leprosy," is one of the disease-specific roadmaps supporting the WHO roadmap for Neglected Tropical Diseases (NTDs) 2021–2030. The strategy aims to eliminate leprosy (interruption of transmission) by 2030. *Elimination (interruption of transmission), has been defined*[9] *as no new autochthonous cases as a result of interruption of transmission.* The strategy **calls on countries to develop “zero-leprosy roadmaps” and provide chemoprophylaxis to all contacts of confirmed cases**. The targets of the strategy are outlined as follows:

WHO's four high-level 2030 targets are:

- 120 countries reporting zero new autochthonous cases
- 70% reduction in annual number of new cases detected
- 90% reduction in rate per million population of new cases with grade-2 disability
- 90% reduction in rate per million children of new child cases with leprosy

WHO's **Global Leprosy Strategy 2021-30'** reported that in 2019, 202,256 new leprosy cases were registered globally across 161 countries. Of these, 14,983 were children under 14 years, with a rate of 7.9 per million among the child population. The detection of cases in children is considered an indicator of recent transmission within the community. Among the new cases, 10,816 were diagnosed with Grade 2 disabilities (G2D), corresponding to a G2D rate of 1.4 per million population[10]. The presence of G2D at the time of diagnosis indicates late detection of the disease.

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[8] M/o Health & Family Welfare- pib.gov.in/pressreleaseiframepage.aspx?prid=1909081
[9] WHO: The NTD Roadmap 2021-30 in 'Towards Zero Leprosy': Global Leprosy Strategy 2021-2030
[10] WHO: Towards Zero Leprosy': Global Leprosy Strategy 2021-2030

The strategy emphasises **contact tracing** as the most effective tool for identifying new cases and considers it a key component of leprosy control in the next decade. The contacts of migrants are dispersed across both their district/area of origin and their destination region. Historically, migration has played a significant role in facilitating disease transmission between endemic and non-endemic areas. In fact, leprosy was introduced to the Americas by the Europeans[11]. Therefore, WHO's contact tracing strategy requires the tracing of all migrant contacts to achieve the goal of zero leprosy.

The Government of India is committed to eliminating leprosy in the country. India has been implementing the **National Leprosy Elimination Programme (NLEP)** for several decades. The Central Leprosy Division of the Ministry of Health & Family Welfare, in collaboration with WHO, ILEP, and experts in the field of leprosy, developed the **National Strategic Plan and Roadmap for Leprosy 2023-27** to accelerate the elimination of leprosy. This strategy aligns with the **WHO Roadmap for Neglected Tropical Diseases 2021-2030 and the Global Leprosy Strategy 2021-2030**.

While the NLEP has achieved considerable success, India remains one of the three countries reporting more than 10,000 new leprosy cases annually. Major challenges in the programme's implementation include migration and urbanisation[12]. Migration is one of the key forces driving urbanisation. India's urban population comprises 36% of its total population in 2023[13], up from 31% in 2011[14]. The annual growth rate of urban population was recorded at 2.2% in 2023.

The COVID-19 pandemic demonstrated that the spread of infectious diseases can be controlled through frequent testing and requiring travellers or migrants to provide proof of good health before being allowed to travel. Leprosy's long latency period and its clinically non-symptomatic presentation frequently leads to its presentation long after the period of travel that brought a carrier infected migrant to his new destination[15]. Thus the standard protocol of screening and quarantine does not work in the case of leprosy. This highlights the importance of screening as well as contact tracing of migrants at the source itself.

1.3 Role of Migration in the Spread of Leprosy

Migrants and other mobile populations reflect the health characteristics of their place of origin and carry these with them when they move. Migration facilitates the movement of diseases between endemic and non-endemic areas and has been considered a possible factor in the continued incidence of leprosy. Thus, trends and patterns in the mobility of populations need to be considered before formulating public health policy at the national and subnational levels.

[11] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India.

[12] NSP and Roadmap for Leprosy-2023-27: Central Leprosy Division, M/o Health & Family Welfare

[13] https://data.worldbank.org/indicator/SP.URB.TOTL.IN.ZS?locations=IN

[14] Census data 2011

[15] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India.

The majority of migration in India is internal migration, i.e., migrants move from one part of the state/country to another—whether intra-state or inter-state. At the same time, a large number of people emigrate from India, and India also receives immigrants, generally through its land borders—mainly from Nepal and Bangladesh.

Migrants fuel the Indian economy and consist mostly of people moving from rural India to urban areas for work, generally returning every year to their states of origin. It is an important pathway out of poverty. This circular migration is generally male-dominated and is driven by the sheer need to earn a basic living. A large percentage of rural–urban migrants, or "Circular Migrants," leave behind their families and property in their area of origin. These migrants are largely drawn from the lower consumption quintiles and are mostly male. They retain their links with the rural hinterland, returning occasionally during spells of unemployment, for holidays, or when work in rural areas peaks. Some of them may stay on permanently in urban areas.

Circular migrants include those who have acquired a tenuous foothold in the urban job market and may not have identity papers at their area of destination. They also participate in the labour market in less favourable ways than non-migrants because of debt interlocking, involvement in subcontracting chains, greater isolation, fragmentation, and segmentation of the **labour** market. These migrants are generally away from their homes for an average of about 7.5[16] months in a year. Most reside at work-sites or in the open, or live in crowded tenanted places. They are more likely to be from households that are poor, socially disadvantaged, less educated and employed in agriculture.

A systemic review[17] of literature investigating socio-economic risk markers of leprosy pointed to associations between leprosy and socio-demographic risk markers such as crowding, sanitation, and poverty. In most studies, literacy and high levels of education were associated with lower leprosy rates, probably due to better health knowledge and access to improved work conditions. Person-to-person contact within the household is one of the most likely sources of leprosy transmission. Migrants are, therefore, at high risk of developing leprosy.

No precise estimates exist on the number of migrant workers in India. Both the census and the National Sample Survey office are unable to correctly capture short-term circular migration[18]. The 2016-17 Economic Survey estimates the circular migrant population to be between 5 and 9 million annually leading to an inter-state migrant population of about 60 million and an inter-district migrant population as high as 80 million.

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[16] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[17] Socioeconomic risk markers of leprosy in high-burden countries: A systematic review and meta-analysis Julia Moreira Pescarini, Agostino Strina, Joilda Silva Nery, Lacita Menezes Skalinski, Maria Lucia F. Penna, Elizabeth B. BrickleyLaura C. Rodrigues, Mauricio Lima Barreto, and Gerson Oliveira Penna, Peter Steinmann, Editor in Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[18] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

It is observed that the share of migrants moving within states is much higher than that that of migrants moving across states[19].

Since the migrants are mainly circular (i.e people who migrate for temporary periods, either moving from place to place or to a fixed destination, returning to their place of origin after brief periods, at the most, after a few months), it is essential to increase systematic and routine disease surveillance in states/districts with high migration rates coupled with endemicity.

In India, the majority of inter-state migrants come from the states of Uttar Pradesh and Bihar. The Report of the Working Group on Migration, based on the 2001 Census, identified the top 17 districts that accounted for 25% of all male out-migrants across state boundaries. All these districts are practically contiguous and concentrated in Eastern Uttar Pradesh and Bihar, with the exception of Ganjam district in Odisha[20]. Another 36 districts accounted for an additional 25% of inter-state out-migrants. Again, these districts lie mostly in Uttar Pradesh and Bihar. Most of the migrants move to Delhi, Maharashtra, Punjab, and Haryana. Recently, there has also been an increase in migrants moving to the South Indian states of Tamil Nadu and Karnataka. A majority of the districts reporting high migrant outflows are also high leprosy-endemic districts. In fact, Delhi and Chandigarh (and now Maharashtra as well), which had previously eliminated leprosy as a public health hazard, are now exhibiting higher rates of leprosy transmission. Chandigarh consistently depicts a high prevalence rate, with an increase observed post-COVID.

A review analysis of published studies[21] in PubMed related to migration and leprosy identified migration as one of the significant obstacles to achieving the elimination of leprosy, as affected individuals may continue to unknowingly spread the disease. Migration can also lead to defaults in the treatment of already diagnosed cases, especially against the backdrop of the NLEP program not systematically capturing such information regarding migrants, in such cases, the disease may progress, and the patient may develop serious disabilities and deformities. These patients also become a source of infection to the community[22]as well as to their nearest kith and kin.

A number of studies conducted at hospitals in large migrant-receiving cities like Delhi and Mumbai revealed that a preponderance of patients with leprosy were migrants, mostly from Uttar Pradesh and Bihar[23]. The above studies indicate that migration facilitates transmission of leprosy from endemic to non-endemic areas and is a factor in its continued incidence.

[19] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[20] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[21] Impact of Migration on Epidemiology and Control of Leprosy 1 2 3 S Rathod , A Jagati , P Agarwal in Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[22] https://www.who.int/docs/default-source/ntds/leprosy/faq-leprosy-mdt.pdf

[23] Leprosy Scenario at a Tertiary Level Hospital in Delhi: A 5-year Retrospective Study-Namrata Chhabra, Chander Grover, Archana Singal, Sambit Nath Bhattacharya, and Ramandeep Kaur in Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

This evidence is also supported by a number of international studies[24].

Delhi is the most preferred destination for migrants from Uttar Pradesh and Bihar. According to the National Sample Survey (NSS) 64th round, about 43% of Delhi's population are migrants, with over half coming from Uttar Pradesh and Bihar. Another important urban destination is Chandigarh, which can also be described as a city of migrants. More than 60% of its population comprises migrants, as per the 2011 Census, with a majority migrating for work. The largest number of migrants to Chandigarh are from Uttar Pradesh (17.4%) and Bihar (5%). The influx of migrants from endemic states to Delhi and Chandigarh could be influencing the prevalence rate in these two cities.

In addition to inter-district and inter-state migration, India also attracts a large number of immigrants from its neighbouring countries[25]. While immigration from Pakistan, Sri Lanka, and Myanmar is limited, there is large-scale immigration from Bangladesh and Nepal, driven by economic factors and the need to earn a living. Immigration from Bangladesh is mainly illegal, while that from Nepal is legal. No firm data exists on the extent of immigration from Nepal, as India and Nepal share an open border.

Nepal reports a high leprosy rate, though the number of cases reported is much lower than in India. It reported about 3,200 cases in 2018. Leprosy-endemic districts increased from 17 to 21 between 2017 and 2018. Nepal has a registered prevalence rate PR[26] of about 0.78 per 10,000 population in 2022, down from 1.02 per 10,000 population in 2018.

In 1998, WHO declared that leprosy was eliminated in Bangladesh, i.e., it had fewer than one case per 10,000 people. Bangladesh now detects about 4,000 leprosy cases every year, though its PR is lower than India's. According to WHO, Bangladesh still has the fifth-highest number of leprosy cases in the world. The PR of Bangladesh was 0.14 per 10.000[27] in 2022 a significant decline from the PR of about 0.20 per 10,000 registered in 2018. Pockets with high infection seem to exist in Bangladesh. The Leprosy Mission has stated that the vast tea plantations of Sylhet in the northeast have the highest rate of leprosy in the world[28]. The tea plantations employ about 600,000 workers mostly women.

The continuous immigration across the border – both legal and illegal is a risk factor in the continuance of leprosy in the subcontinent.

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[24] Epidemiology of Leprosy in Spain: The Role of the International Migration and (Ramos et al 2016) and Factors Associated with Migration in Individuals Affected by Leprosy, Maranhão, Brazil: An Exploratory Cross-Sectional Study (Murto et al 2013) in Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[25] Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

[26] WHO Global Health Observatory data: https://apps.who.int/gho/data/node.main.NTDLEPR4?lang=en

[27] WHO Global Health Observatory data: https://apps.who.int/gho/data/node.main.NTDLEPR4?lang=en

[28] https://www.theguardian.com/global-development/2023/apr/07/spreading-faster-than-ever-why-bangladeshs-tea-pickers-have-the-worlds-highest-rate-of-leprosy

CHAPTER 2:
STUDY RATIONALE AND DESIGN

This chapter presents the rationale for undertaking this primary research. It further details the objectives of the research, along with the overall methodology and sampling design adopted. The final methodology used for the study was developed through extensive processes, which are also outlined in this chapter.

The current primary research is part of a comprehensive project, which not only aims to gain insights into the issues faced by migrant people affected by leprosy, but also to provide recommendations for addressing these issues specific to migrant leprosy patients. This chapter also outlines the various components of the comprehensive project.

2.1 Rationale for the Study

NLEP has recognised migration as one of the challenges facing the elimination of leprosy[29] in the country. Migrants affected by leprosy may become aware of their status at the destination district and subsequently become a source of infection, carrying the infection back to their district of origin. Migration can also lead to default in treatment for already diagnosed cases. In such cases, the disease will progress, and the person may develop serious disabilities and deformities.

Migrants are generally employed in low-paying, precarious jobs, mostly in areas such as construction, brick-kilns, manufacturing units, and domestic work. Circular migrants tend to be poorly educated and come from relatively poorer households. A significant portion of them live at worksites and/or in slums—congested, crowded settings with poor ventilation and sanitary conditions.

A systemic review[30] of literature investigating socio-economic risk markers of leprosy

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[29] NSP and Roadmap for Leprosy-2023-27: Central Leprosy Division, M/o Health & Family Welfare

[30] Socioeconomic risk markers of leprosy in high-burden countries: A systematic review and meta-analysisJulia Moreira Pescarini, Agostino Strina, Joilda Silva Nery, Lacita Menezes Skalinski, Maria Lucia F. Penna, Elizabeth B. BrickleyLaura C. Rodrigues, Mauricio Lima Barreto, and Gerson Oliveira Penna, Peter Steinmann, Editor in Leprosy and Migration in India: A Secondary research Report-2022; Supported by Novartis Healthcare Private Ltd. India

pointed to associations between leprosy and socio-demographic risk factors such as crowding, sanitation, and poverty. In most studies, literacy and higher levels of education were associated with lower leprosy rates, probably due to better health knowledge and access to better work conditions. Person-to-person contact inside the household is one of the most likely sources of leprosy transmission. Migrants are at high risk for developing leprosy when exposed to the bacteria.

Despite the recognition of migration as a challenge in the elimination of leprosy, no data is available with NLEP to provide insights into migration patterns. This information is essential for the early diagnosis of leprosy in migrants and the initiation of early treatment, for which recording migrant information at the first point of contact is critical. Migrants are at high risk of developing leprosy due to limited access to healthcare, poor living conditions, and limited health-seeking behaviour[31].

Given the absence of studies, both nationally and internationally, on the impact of migration on people affected by leprosy and its consequences on treatment, it was deemed essential at this stage to undertake a pilot study to examine this impact. While NLEP prioritises the challenges faced by migrants, it has not established the detailed systems required to facilitate early diagnosis of leprosy among migrants, nor to monitor and treat migrant leprosy patients and their contacts, which was identified as a gap in the existing program.

Swiss Emmaus Leprosy Relief Work - India (SEI), which has been working in leprosy in India since 1960, took the initiative to design a study examining the impact of migration on people affected by leprosy. SEI collaborates with the Government of India (GoI), especially in activities related to national leprosy elimination and in the prevention and rehabilitation of disabilities. In view of the critical role of migration in achieving the elimination of leprosy, SEI recognised the need to undertake a comprehensive study to gain insights into the issues surrounding migrant people affected by leprosy and their households. This includes the demand and supply of healthcare services at the source of migration, along the migration routes, and at the destination of migrants. Based on the understanding of the gaps that exist for patients who migrate, the project developed recommendations at all levels to address these gaps.

Changescape Consulting, a consulting firm providing end-to-end solutions to those working in the development sector, is the research partner of SEI on this migration study. This study is being supported by Novartis Healthcare Private Limited.

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[31] https://sansad.in/getFile/loksabhaquestions/annex/1712/AS226.pdf?source=pqals

2.2 Objectives of the Study

Project Goal: The goal of the project is "To conduct a three-year pilot study to understand the impact of migration on people affected by leprosy and its consequences on treatment in four states of India."

Objectives of the Primary Research

The objectives of the primary research are as follows:

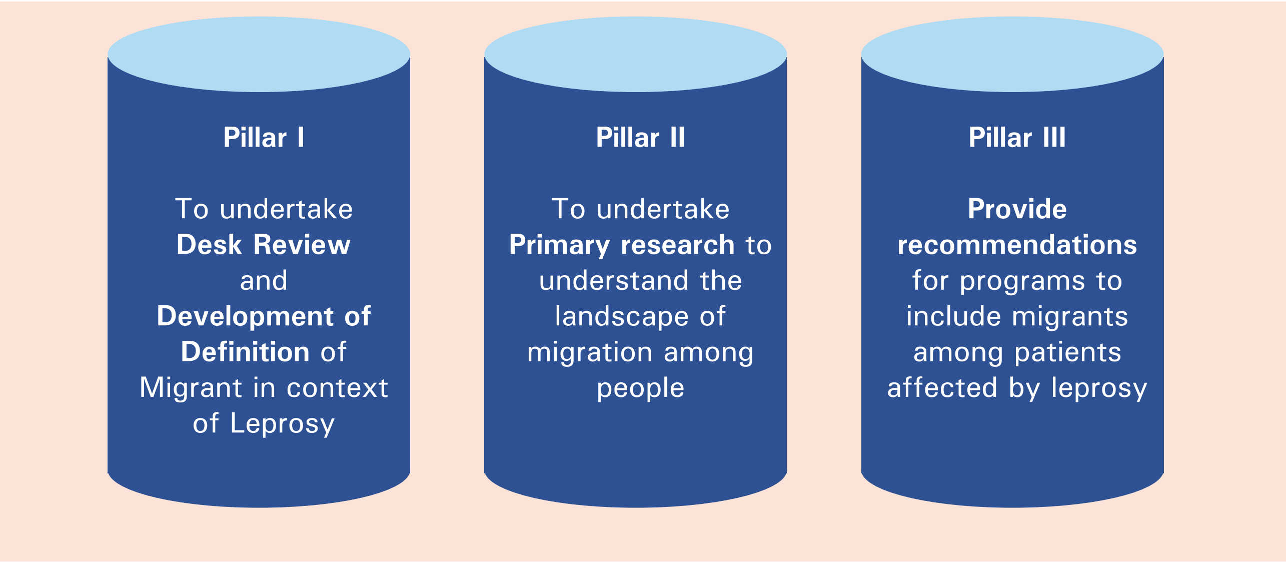
- To study the availability, access, and delivery of treatment among migrant patients affected by leprosy at the source, along the route, and at the destination of migration.
- To understand the impact of migration on migrant patients affected by leprosy and their households.
- To influence the NLEP programme design related to the management of migrant patients affected by leprosy and their households through evidence-based recommendations.

The primary research, the findings of which are outlined in this report, is part of a more comprehensive effort to gain insights into the issues surrounding migrant patients. The approach adopted by the project, of which the primary research is a part, is outlined in the section below.

Overall Project Outline

The overall project is built on three pillars depicted in the figure below:

Figure 2.1. Key Study Pillars



Pillar I

To undertake **Desk Review** and **Development of Definition** of Migrant in context of Leprosy

Pillar II

To undertake **Primary research** to understand the landscape of migration among people

Pillar III

Provide recommendations for programs to include migrants among patients affected by leprosy

Under the **first pillar**, a literature review of secondary information was undertaken to gain insights into global efforts addressing problems related to migration. The desk review helped to understand how other disease programmes, such as HIV/AIDS and Tuberculosis—both of which have prolonged treatment regimens and face the challenge of migration among patients—address the issue of migration. The secondary research highlighted the definitions used by these programmes to define migration in the context of their respective diseases, and provided key learnings for the leprosy programme, particularly in terms of defining "migrant" in the context of leprosy. In the absence of a standard definition of "migrant" in the context of leprosy, the project also included the development of this standard definition. Details of the processes undertaken to arrive at the definition and the final definition being proposed are outlined in Chapter 3. This definition was developed simultaneously with the primary research study.

The **second pillar** of the project involved undertaking primary research. Primary data collection was conducted with key stakeholders, including service providers, migrant patients and their household members, ILEP India, WHO, State and District Health Officials, Panchayati Raj Institutions (PRI), the Association of People Affected by Leprosy (APAL), and others.

The **third pillar** of the project focused on outlining recommendations for migrant patients to be included in the national leprosy programme. These recommendations, discussed with key stakeholders, were based on the findings of the first and second pillars. This pillar also addressed the gaps in capturing data on migrants in NIKUSTH, the NLEP Management Information System (MIS). In view of this gap, an MIS framework for integration into NIKUSTH to track migrant patients was also designed by SEI.

2.3 Geographic Coverage

Figure 2.2 Map of Selected States and UT

The pilot project was conducted in Bihar, Chandigarh, Delhi, and Uttar Pradesh. Both Chandigarh and Delhi experience high migration from Uttar Pradesh and Bihar. The states of Uttar Pradesh and Bihar have significant out-migration from high leprosy-endemic districts. Uttar Pradesh contributed nearly 12% of the active cases, while Bihar contributed nearly 13% of the active cases detected in India in 2022–23 (data compiled from the Annual Report of 2022–2023 of Ministry of Health and Family Welfare)[32].

Chandigarh and Delhi represent Union Territories (UT) and states with high in-migration from Bihar and Uttar Pradesh. According to the 64th round of the NSS, about 43% of Delhi's population are migrants, with over half coming from Uttar Pradesh and Bihar. According to the 2011 Census, more than 60 percent of Chandigarh's population comprises migrants, with the largest numbers coming from Uttar Pradesh (17.4%) and Bihar (5%).

2.4 Study Design and Methodology

In the absence of primary research on migrant leprosy patients, there were no available learnings from past study designs for reference by the project team. Therefore, rigorous processes were adopted to finalize the research design. These included discussions with key stakeholders to draft the methodology, consultations on the draft methodology at four state-level meetings held in Bihar, Chandigarh, Delhi, and Uttar Pradesh, exploratory visits to the study states, and the conduct of a pre-testing exercise across all study states. The methodology adopted for this primary research is the result of all these processes. The details of the evolution of the study design are outlined in Annex 2.2.

Given the nature of the study, ethical approvals were obtained both for the pre-testing phase and after the finalization of the methodology and study tools.

The study followed a descriptive design with a mixed-methods approach, where primary data was collected using qualitative tools such as In-Depth Interview Guidelines and case studies, as well as quantitative tools, including structured and semi-structured questionnaires.

To provide continuous guidance on all technical aspects of the project, including study design, tools, and recommendations, SEI formed a **Steering Committee** (Technical Task Force - TTF) comprising key stakeholders and experts in leprosy. Representatives from NLEP, WHO, and members of ILEP were part of this committee. A detailed list of TTF members is included in Annex 2.1. The TTF provided technical inputs throughout the duration of the study.

Additionally, in order to engage a wider set of stakeholders SEI conducted national and state level consultations in the selected states/UT finally culminating in a national leprosy consultation (NLC) as well where all relevant stakeholders were invited to hear the dissemination of the study.

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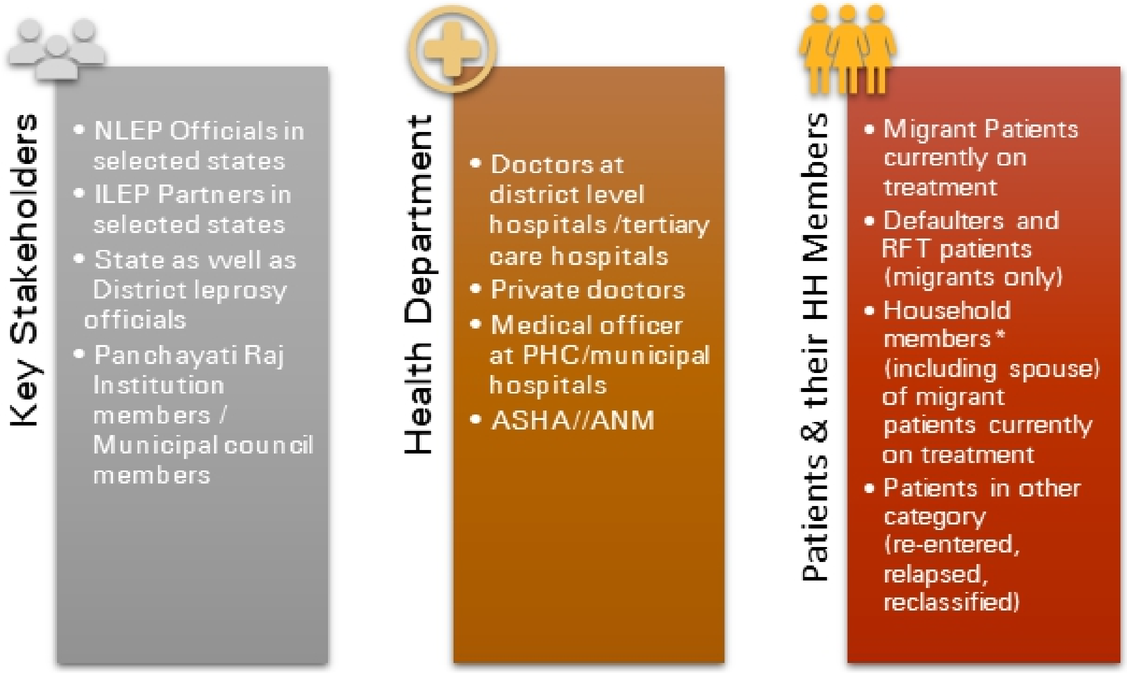
[32] https://timesofindia.indiatimes.com/india/leprosy-cases-increased-by-15-7-in-2021-22-over-88k-active-cases/articleshow/99016244.cms

2.4.1 Target Respondents

To examine the impact of migration on people affected by leprosy and its consequences on treatment, the study engaged key stakeholders involved in the implementation of NLEP at various levels in the identified sample locations, along with migrant patients affected by leprosy and their household members. Additionally, the study included defaulters and patients who were released from treatment (RFT). The following figure outlines the target respondents contacted for this study.

Figure 2.3. Target Respondents



Key Stakeholders

- NLEP Officials in selected states
- ILEP Partners in selected states
- State as well as District leprosy officials
- Panchayati Raj Institution members / Municipal council members

Health Department

- Doctors at district level hospitals /tertiary care hospitals
- Private doctors
- Medical officer at PHC/municipal hospitals
- ASHA//ANM

Patients & their HH Members

- Migrant Patients currently on treatment
- Defaulters and RFT patients (migrants only)
- Household members* (including spouse) of migrant patients currently on treatment
- Patients in other category (re-entered, relapsed, reclassified)

**In case the household member was not available for the face-to-face interview telephonic interviews were done post taking consent of the patient. The study followed standard definition provided by NLEP for identifying above mentioned categories of patients.*

Migrant patients: For the purpose of sampling and identifying the target group, it was necessary to define migrant patients. During the exploratory visits, the team discovered that a standard definition of migrant patients in the context of leprosy was missing. In the absence of a standard definition under NLEP, discussions were held with the State Leprosy Officers (SLOs) of Delhi, Chandigarh, and Uttar Pradesh to gain insights into the current definitions used by both the source and destination states/UTs to define migrant patients. Based on these discussions, the following definition of migrant patients affected by leprosy was adopted as part of the NLEP program and used for the purpose of this study.

Patients having permanent address of Uttar Pradesh and Bihar in the records maintained at Delhi and Chandigarh were treated as migrant patients.

Migrant patients in Delhi/Chandigarh also included migrant patients who were coming from any other state to Delhi/Chandigarh only for treatment purpose.

The study also defined the inclusion and exclusion criteria for patients (both current and previously treated) and their household members covered for the purpose of this study.

Inclusion Criteria:

- People who are currently undergoing MDT treatment at a recognised center or any government facility in Delhi or Chandigarh.
- People who are currently on MDT treatment and also receiving steroid treatment.
- Migrant patients who travel to Delhi/Chandigarh for MDT treatment from Uttar Pradesh and Bihar, and who either stay at the destination (Delhi/Chandigarh) or may return to their place of origin in Uttar Pradesh or Bihar on the same day or after a few days.
- Any household member of the patient.

Exclusion Criteria:

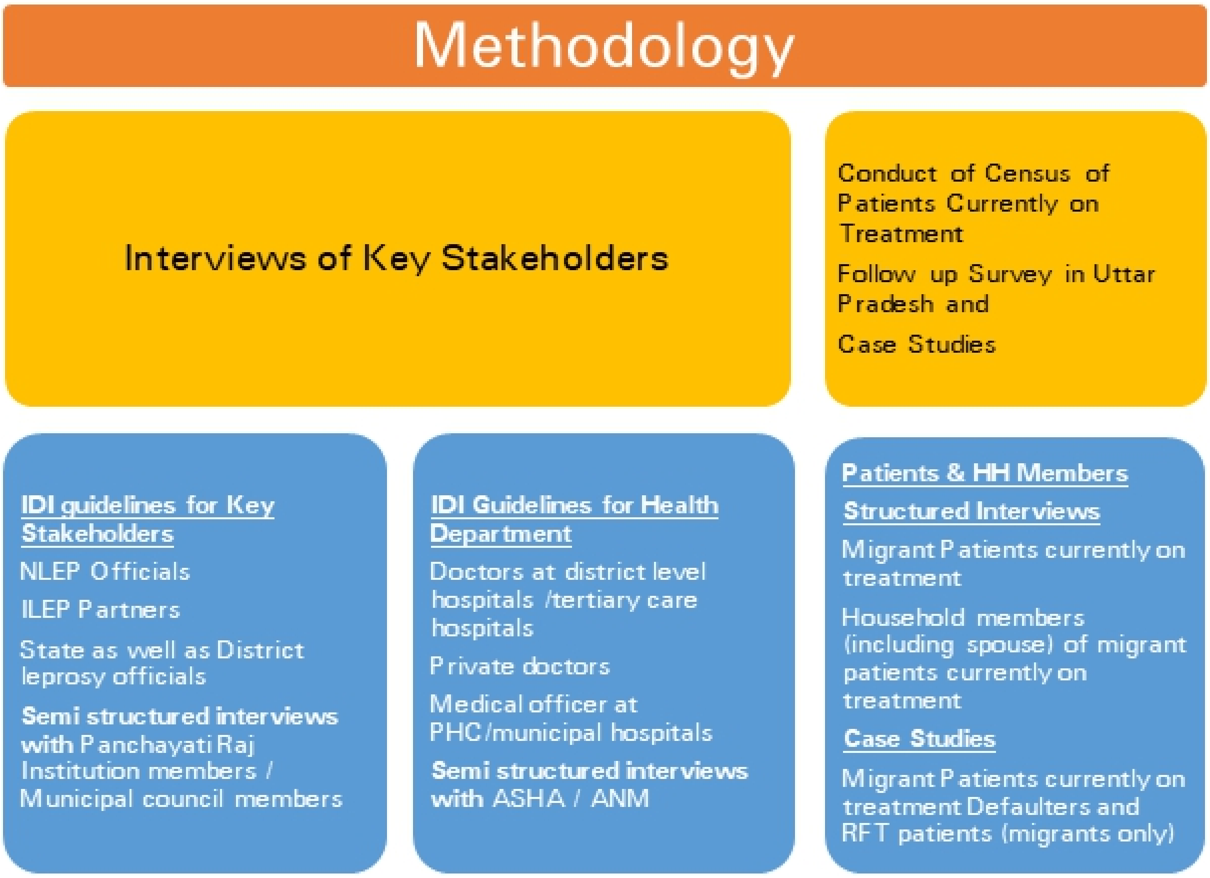
- Children under 12 years of age.
- Persons receiving treatment from non-government facilities.

2.4.2 Methodology

In Delhi and Chandigarh, a census of all available migrant patients originating from Uttar Pradesh or Bihar was conducted. The survey covered all government health facilities providing leprosy treatment in Delhi (23 facilities) and Chandigarh (3 facilities). Efforts were made to contact migrant patients who could not be reached in Delhi or Chandigarh by following up with them in selected districts of the source state viz Uttar Pradesh. However, follow-up interviews in Bihar could not be conducted due to the lack of approval from the Bihar government for data collection.

The following diagram outlines the methodology and research tools used across various target segments for the survey.

Figure 2.4.: Methodology and Research Tools Used Across Target Respondents



Methodology

Interviews of Key Stakeholders

Conduct of Census of Patients Currently on Treatment

Follow up Survey in Uttar Pradesh and

Case Studies

IDI guidelines for Key Stakeholders

NLEP Officials

ILEP Partners

State as well as District leprosy officials

Semi structured interviews with Panchayati Raj Institution members / Municipal council members

IDI Guidelines for Health Department

Doctors at district level hospitals /tertiary care hospitals

Private doctors

Medical officer at PHC/municipal hospitals

Semi structured interviews with ASHA / ANM

Patients & HH Members

Structured Interviews

Migrant Patients currently on treatment

Household members (including spouse) of migrant patients currently on treatment

Case Studies

Migrant Patients currently on treatment Defaulters and RFT patients (migrants only)

Selection of Districts for Follow up in Uttar Pradesh

For the follow-up of migrant patients currently undergoing treatment but unavailable in Delhi and Chandigarh at the time of the survey, efforts were made to contact them in six selected districts of Uttar Pradesh. The selection of these six districts followed the steps outlined below:

Figure 2.5.: Map of Uttar Pradesh with Selected Districts for Follow Up

- The districts from which patients had migrated to Delhi and Chandigarh were mapped using data from 2022–23 and 2023–24 (up to July 2023). According to registers maintained in Delhi and Chandigarh, patients receiving treatment in these cities were found to originate from 63 districts in Uttar Pradesh. Of these, 47 districts had fewer than 10 patients currently undergoing treatment in Delhi and Chandigarh. Due to the small numbers in these districts excluded from consideration for district selection.

- Based on the above analysis, districts with a higher number of patients receiving treatment in Delhi and Chandigarh were identified, and those with significant out-migration were selected. Care was taken to ensure a geographical spread across the state and along the international border to make the sample representative of Uttar Pradesh.
- The six districts selected in Uttar Pradesh for the survey were Amroha, Bareilly, Ghaziabad, Lakhimpur Kheri, Shravasti and Unnao.

2.5 Process of Training, Data Collection and Analysis

The data collection was conducted from 27th November 2023 to 27th February 2024. Before the fieldwork began, the survey team underwent a three-day intensive training session in Delhi. This training was facilitated by officials from SEI, senior research team members, and the field executive of Changescape Consulting. The team was also sensitised on how to communicate effectively with leprosy patients.

In line with approved ethical guidelines, interviews with patients and their household members were conducted at or near the health facilities where the patients were receiving MDT. To schedule these interviews, patients were contacted by the NMS or other leprosy staff, and consent was obtained to interview their household members. Patients were also requested to bring a household member along if they consented to their participation in the interview.

Visits to the health facilities were planned on Outpatient Department (OPD) days to minimise the additional travel efforts of patients and their household members. For planning purposes, a list of migrant patients (excluding personal identifiers) was collected in advance from the respective SLOs for Delhi and Chandigarh. A physical meeting was organised with the leprosy staff in Delhi to discuss their suggestions regarding data collection.

A detailed field plan was shared in advance with the leprosy staff at the relevant health facilities. A virtual meeting was also held with the leprosy staff in Delhi and Chandigarh to brief them on the field plan and outline the support required for data collection. Based on these plans, the leprosy staff invited the patients to the health facilities for interviews.

Case studies were conducted with patients currently undergoing treatment who were not included in the quantitative study. These patients were identified in consultation with local leprosy staff, considering their migration history. RFT patients, defaulters, and others in relevant categories were also contacted for case studies, depending on their availability.

For patients from selected districts in Uttar Pradesh who were unavailable in Delhi or Chandigarh at the time of the interviews, follow-ups were conducted in their native districts. The DLO/DLC in each of the six selected districts contacted these patients and requested them to visit the nearest health facility for interviews. Respondents were also asked to bring their household members along if they consented to participate.

Case studies were conducted with patients currently undergoing treatment who were not included in the quantitative study. These patients were identified in consultation with local leprosy staff, considering their migration history. RFT patients, defaulters, and others in relevant categories were also contacted for case studies, depending on their availability.

For patients from selected districts in Uttar Pradesh who were unavailable in Delhi or Chandigarh at the time of the interviews, follow-ups were conducted in their native districts. The DLO/DLC in each of the six selected districts contacted these patients and requested them to visit the nearest health facility for interviews. Respondents were also asked to bring their household members along if they consented to participate.

2.6 Sample Size

2.6.1 Quantitative Sample Size

Following table shows the coverage of the quantitative sample. The facility wise coverage is presented in the Annex 2.3

Table 2.1.: Sample Size Achieved (Quantitative survey) against target

State	Total Migrant Patients*	Total Patients Invited by Health Facility	Patients currently on treatment interviewed	Achievement (%)	Household F2F + telephonic	Front Line Workers (FLW)	Panchayati Raj Institution (PRI) members
Delhi	410	514**	349	68.0	193	9	9
Chandigarh	113	63**	47	75.0	28	2	2
Uttar Pradesh #					15	24	24
	523	**577**	**396**	**69.0**	**236**	**35**	**35**

**List of migrant patients was received from SLOs of Delhi and Chandigarh till 30th September, 2023 which was 410. The survey was conducted between November 2023 to February 2024. Hence migrant patients registered in October as well as November and not included in the number of total migrants initially provided by SLOs were also invited for the interviews. Hence the total number of migrant patients identified by SLOs is lower than those invited for interviews.*

***These includes patients from sector 16 & 32, while patients in PGIMR were interviewed during OPD only.*

#48 patients who could not be contacted in Delhi and Chandigarh, were followed up in Uttar Pradesh and 26 patients could be interviewed. Response rate was 54%.

2.6.2 Qualitative Sample Size

Case studies and in-depth interviews (IDIs) with migrant patients currently undergoing treatment, defaulters, RFT patients, and others were conducted to gain insights into the reasons for discontinuing treatment, seeking treatment outside their district of origin, their current situation, and the impact of migration on their treatment. These qualitative discussions explored these aspects in greater detail.

All qualitative discussions were conducted and recorded after obtaining the written consent of the respondents. These discussions were carried out at the state, district, and facility levels to understand the challenges faced by service providers and their experiences in managing migrant patients.

Semi-structured interviews were conducted with frontline workers, including Female Health Workers (FHWs), ASHAs, and ANMs, who were actively involved in screening leprosy-affected patients and their follow-up care. Additionally, semi-structured interviews were held with PRI members to understand community awareness and the stigma associated with leprosy.

The scope of the qualitative data collection is presented below:

Table 2.2.: Sample coverage for the qualitative survey against the target

Respondent Category	**Target**	**Completed**
Patients Currently on treatment and migrant – Case Study	12	9
RFT and defaulters – Case Study	12	13
ILEP partners functionaries at the state/district level	3	3
District Leprosy Officials (high - endemic districts)/Doctors at District Hospitals/Other Tertiary Care Hospitals/ State level Health officials (SLO/Other staffs like NMS)	22	18
Private-sector doctors/Traditional medical practitioners*	25	4
Medical officer at Primary Health Centre/Municipal Hospital	34	33

**The achievement of private doctors/practitioners is low. Those doctors/practitioners who recommended patients to the health facilities treating leprosy were to be contacted and their details were to be collected from the district leprosy staff. However very few identifications of private doctors/practitioners recommending patients for treatment from the leprosy staff were received.*

2.7 Institution Review Board (IRB) Clearance

IRB approval for the survey was obtained twice. The first approval was granted prior to the pre-testing exercise in September 2022. The IRB was keen to review the results of the pre-testing, as this is a unique study in the field of leprosy. Based on the pre-testing exercise, the sampling design and methodology were revised. Subsequently, IRB approval was obtained again in November 2023, following the finalisation of the study design and tools.

The data collection team adhered to all ethical protocols while conducting the interviews at each phase of the survey.

The census exercise aimed to cover all migrant patients with a permanent address in Uttar Pradesh or Bihar who were undergoing treatment in either Delhi or Chandigarh. The list of patients was provided by the health facilities after removing personal identifiers. The leprosy staff at these health facilities then contacted the patients and invited them for interviews at the facility.

All questionnaires are securely stored at the research agency's office. The devices used for data collection were brought to the agency's office, and the data was transferred to a password-protected system via USB. The data is maintained on SEI's secure server, with access restricted to the Principal Investigator (PI).

Qualitative data collection discussions were audio recorded using recorders after obtaining consent from the respondents. Additionally, detailed notes were taken during these discussions to capture key observations and information. All personal identifiers were removed from the recordings. Furthermore, care was taken to ensure personal identifiers were omitted during the transcription of interviews.

Informed consent was read aloud to all respondents before commencing the interview. For patients aged between 12 and 18 years, parental consent was obtained prior to the interview.

The study team members and supervisors were well-trained in research ethics and were sensitised to the importance of maintaining privacy and confidentiality while handling participants, research materials, and data.

In cases where district or state officials were unavailable for physical interviews, telephonic interviews were conducted. These telephonic interviews were scheduled only after obtaining prior appointments.

2.8 Study Limitations

Although the study followed a scientific approach to data collection, the following limitations were identified:

- Considering the nature of the respondents and the study duration, the non-response rate was approximately 31%.
- Despite the census exercise, the sample size for Chandigarh is slightly low. Therefore, the findings should be interpreted with caution.
- The study does not cover immigration through international borders, such as Nepal and Bangladesh.
- The study does not include intra-state migration, which comprises a significantly higher proportion of migrants compared to inter-state migration.
- The study focused only on patients currently on MDT, whose details were recorded in the MDT register by the treating facility.
- Defaulter patients were difficult to interview, resulting in a deficit in the sample.

CHAPTER 3:
DEFINITION OF MIGRANT IN THE CONTEXT OF LEPROSY

As highlighted in the previous chapter, there is an absence of a standard definition of a migrant in the context of leprosy, both in India and globally. For the purpose of the primary research, the definitions being used by the study states have been adopted to define a migrant patient. However, a strong need was identified to address this gap and develop a standard definition.

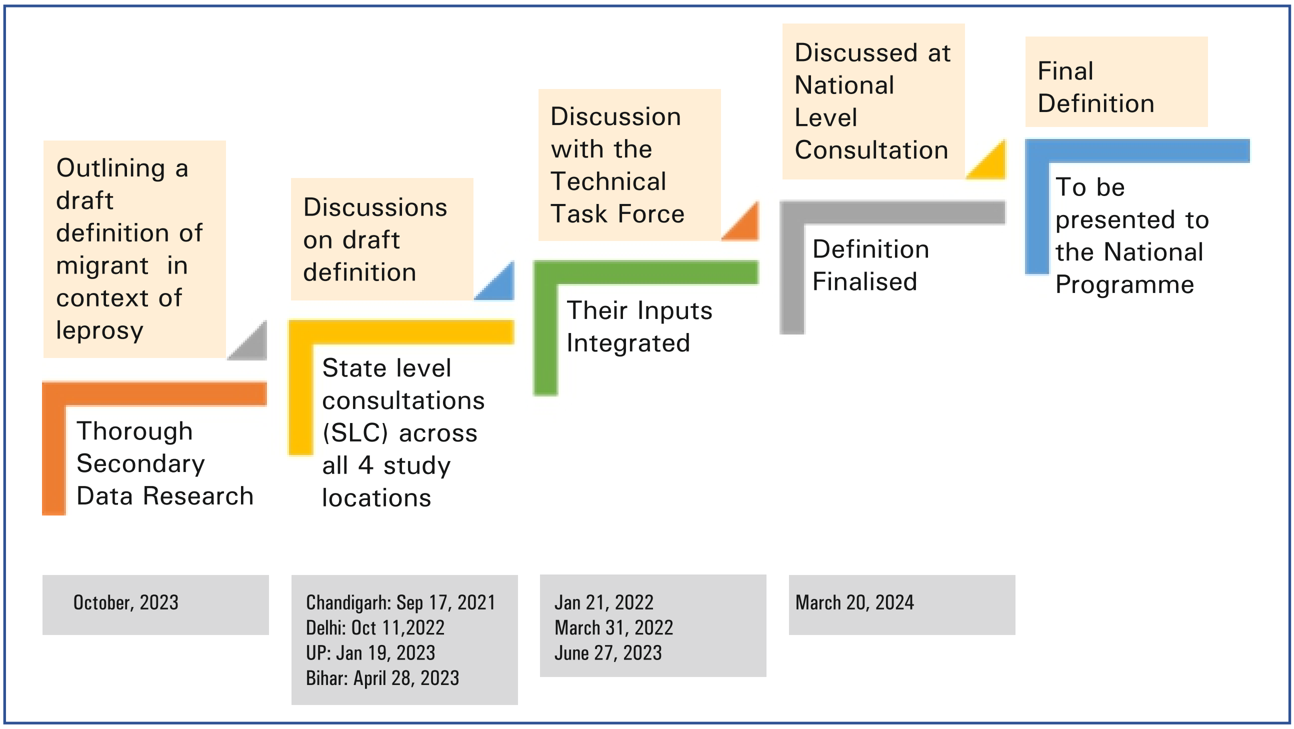
Adopting a standard definition of a migrant in the context of leprosy under the national programme will ensure uniformity across all states—a crucial step for tracking, treating, and recording data on migrant patients. Since migration has been identified as a significant obstacle in achieving the elimination of leprosy, this is considered an important measure in the broader efforts to eliminate the disease.

The standard definition of a migrant in the context of leprosy, a key deliverable of the overall project, is presented in this chapter. This definition was developed through an extensive consultative process. The chapter details the various consultative steps undertaken and the final definition that has been formulated.

3.1 Processes Followed for Drafting the Definition

Rigorous processes were followed to draft the definition of a migrant in the context of leprosy. This draft definition was presented at a national consultation attended by experts and key stakeholders in the field of leprosy and was finalized based on the various inputs received. The following diagram highlights the processes undertaken to arrive at the definition.

Figure 3.1: Processes Followed for Defining Migrant in the Context of Leprosy



Step 1. Outlining a Draft Definition of Migrant in the Context of Leprosy

For the purpose of outlining the draft definition of a migrant in the context of leprosy, the standard definitions of a migrant, as well as the definition of a migrant in the context of various diseases, such as TB and HIV/AIDS, were reviewed. The definition of a migrant outlined by WHO, the International Organization for Migration (IOM), UN organizations, and the definition outlined by the census were also reviewed. The definitions of migrants reviewed are outlined in the figure below:

Figure 3.2: Definition of Migrant Outlined by Various Sources

WHO Definition: The movement of a person or a group of people from one geographical unit to another for temporary or permanent settlement[33].

Temporary travel abroad for purposes of recreation, holiday, business, medical treatment or religious pilgrimage does not entail an act of migration because there is no change in the country of usual residence.

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[33] https://www.euro.who.int/__data/assets/

(IOM), UN Definition: A person who moves away from his or her place of usual residence, whether within a country or across an international border, temporarily or permanently, and for a variety of reasons[34].

Census: The Census identifies people as migrants if they are enumerated in a place other than the Place of Birth or have changed their Usual Place of Residence (UPR) where the latter refers to place of residence for 6 months or more[35].

Additionally, a detailed review of the definition of migrants used by the National Programme for Prevention and Control of HIV/AIDS was undertaken.

Upon completion of the secondary research, a draft definition of a migrant in the context of leprosy was developed for discussion with various stakeholders.

Step 2: Discussions on Draft Definition at State Level

The draft definition was discussed with the Technical Task Force (TTF) and through state-level consultations in the four study states, namely Bihar, Chandigarh, Delhi, and Uttar Pradesh. With each discussion, the definition was modified, and the various iterations were shared in the next round of discussions. The state-level consultations were attended by the NLEP staff working at the state level, including the State Leprosy Officer, State NHM representatives, WHO representatives at the state level, Non-Medical Supervisors, District Leprosy Officers, and para-medical staff from all districts in Delhi and Chandigarh and from selected districts in Bihar and Uttar Pradesh.

Step 3: Discussions on Draft Definition with Technical Task Force (TTF)

In addition to the discussions with key stakeholders at the state level, discussions were also held with the TTF members at various points in time, and their inputs and feedback were incorporated into the definition.

Step 4: Discussions at the National Level Consultation

Upon completion of the various consultative processes, the modified draft definition was presented at the National Level Consultation (NLC). This consultation was attended by NLEP National-level representatives, State Leprosy Officers from the study states, the WHO National Professional Officer (Leprosy), as well as leprosy experts from various INGOs and ILEP partners, migration experts, Novartis Healthcare Private Limited (NHPL),

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[34] https://www.iom.int/node/102743

[35] India's Internal Labor Migration Paradox -The Statistical and the Real by Gaurav Nayyar and Kyoung Yang Kim

and others. Their inputs were collated, and the definition was finalized based on their feedback. The discussion in the NLC was intense, with numerous suggestions being made.

Step 5: Final Definition to be Presented to National Programme

The inputs and feedback received from the NLC were incorporated into the definition before it was finalized.

3.2 Final Definition to be Presented to National Programme

Based on the various discussions and feedback the final definition to be presented to the National Programme is outlined in the figure below:

Figure 3.3: Definition of Migrant in the Context of Leprosy

- Person who migrates from one location to another location temporarily or permanently– irrespective of district/state and place of diagnosis.
- A person who moves outside his place of residence to another district/state for purposes of treatment and management of conditions caused during treatment**.

**Men, women, transgender, children, also includes contact/cohabitants*
*** includes MDT, disability care, etc.*

For the purpose of the primary research, the existing definition of migrant patients as outlined by the State Leprosy Officers of Chandigarh, Delhi and Uttar Pradesh was used. Please refer to chapter 2, section 2.5.1 for further details.

CHAPTER 4:
PROFILE OF MIGRANT PATIENTS AND THEIR HOUSEHOLDS

Understanding the socio-economic and demographic profile of migrant patients, along with the role of family members in managing the severity of leprosy, is essential for interpreting healthcare and migration behaviour in context. Additionally, it underscores the need to interview household members to better understand the challenges they face due to their family member's leprosy status. This chapter presents information on patients' background characteristics, including socio-economic, demographic, disease, and migration profiles.

4.1 Demographic & Socio-Economic Profile of Patients and Household Members

This section explores the demographic and socio-economic characteristics of migrant patients affected by leprosy to identify potential barriers to accessing and adhering to treatment.

4.1.1 Demographic Profile

The study covered patients between the ages of 13 to 74 years, with a mean age of 35.3(±12.7) years. The mean age of women patients [33.4 (±11.1) years] was lower than men [35.8 (13.0) years]. The mean age of the qualitative study participants was 40.7 (±15.7) years (women 34 (±13.8) years and men 44 (±14.9) years). More than half (56%) of the household members interviewed were aged 25-39 years, followed by 27% who were over 39 years of age.

Overall, 70% of the migrant patients interviewed were men, indicating a higher mobility rate among men compared to women for leprosy treatment. This finding aligns with the master patient data from Delhi and Chandigarh, which shows that two-thirds of migrant patients are men and only one-third are women. It was also observed that a higher proportion (63%) of male household members compared to female household members (37%) accompanied the patients (Fig. 4.1).

Figure 4.1: Demographic Profile of Patients and HH Members

Patients
(N – 396)

Mean age :
44 years (Men)
34 years (Women)

Gender
Men -70%
Women - 30%

Marital Status:
Currently married - 76%
Never married - 23%
Widowed: 1%

HH Member
(N – 236)

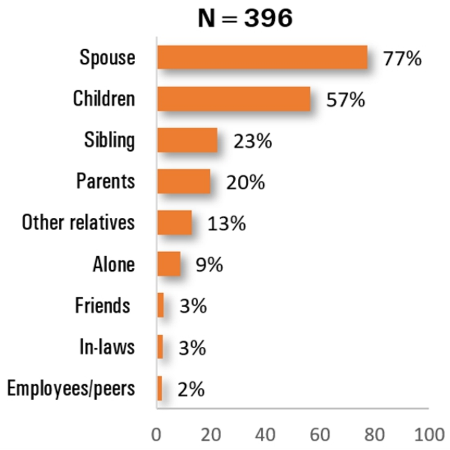
Mean age :
34 years

Gender
Men - 63%
Women - 37%

Findings show that more than three-fourths (76%) of the patients were currently married at the time of the survey, and more than three-fourths (77%) of the married patients were living with their spouse. Furthermore, most of the married patients (93%) had at least one child (mean number of children 2.9 ± 1.5 years), and 57% of them were living with their children

To understand the dynamics of living arrangements, patients were asked about the persons they were living with. The findings show that 91% of the patients were living with someone, and only 9% were living alone. Among those living with others, the majority (77%) were living with their spouse, followed by children (57%) (Fig. 4.2).

Figure 4.2: Percentage of Patients Living With



Further findings show that about half (49%) of the patients were living in a place where the average number of dwellers was five or more. The overall average household size of the respondents was 4.9 (±2.8) persons (Table 4.1). Additionally, 49% of the patients reported sleeping in a room with 3-5 other people, and 31% reported sleeping in a room with 6-20 people. On average, 4.7 (±2.7) people were sleeping in the same room as the patient affected with leprosy.

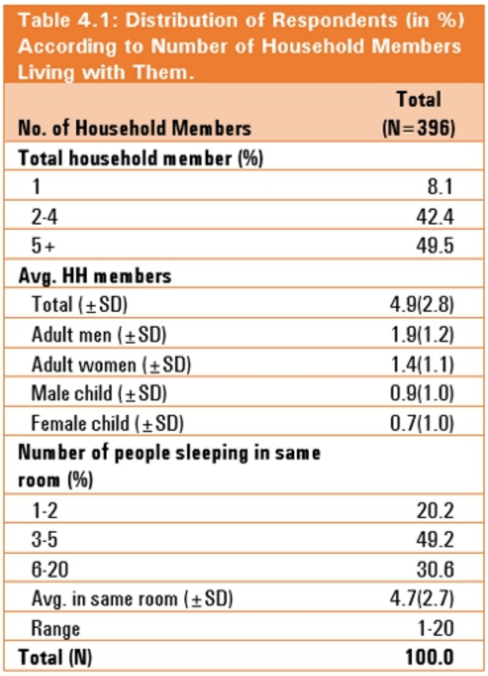


Table 4.1: Distribution of Respondents (in %) According to Number of Household Members Living with Them.

No. of Household Members	Total (N=396)
Total household member (%)	
1	8.1
2-4	42.4
5+	49.5
Avg. HH members	
Total (±SD)	4.9(2.8)
Adult men (±SD)	1.9(1.2)
Adult women (±SD)	1.4(1.1)
Male child (±SD)	0.9(1.0)
Female child (±SD)	0.7(1.0)
Number of people sleeping in same room (%)	
1-2	20.2
3-5	49.2
6-20	30.6
Avg. in same room (±SD)	4.7(2.7)
Range	1-20
Total (N)	**100.0**

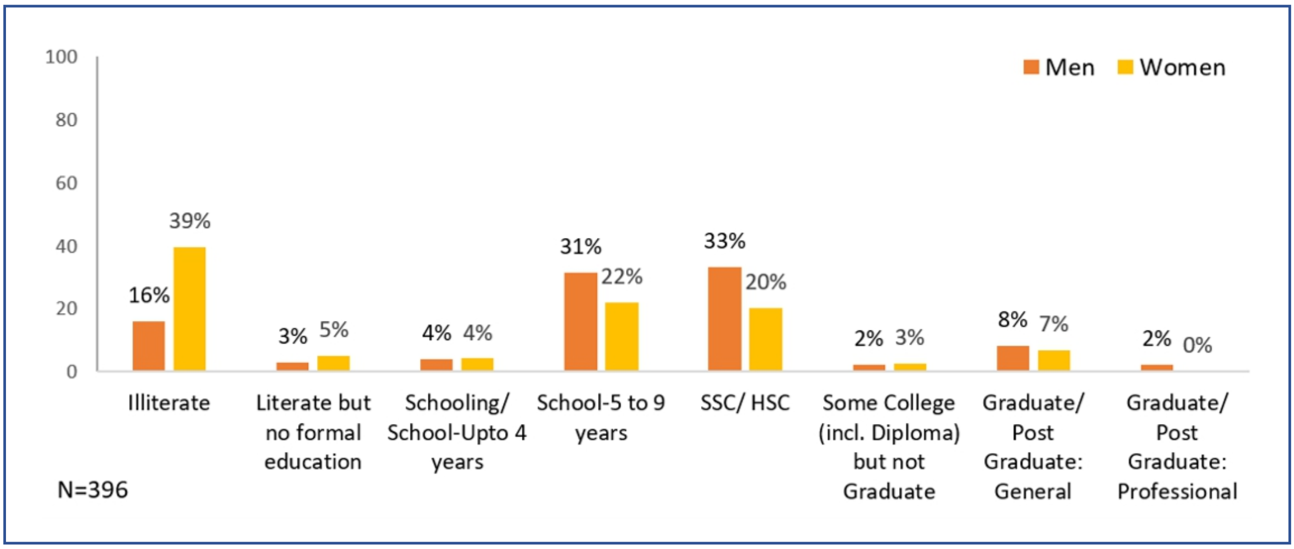
4.1.2 Socio-Economic Profile

This section presents the socio-economic profile of the patients interviewed in the survey. It analyses the patients' level of education, occupation profile, economic dependency, possession of the Aadhar card, and household socio-economic category.

Education Profile

Education is a crucial factor positively associated with comprehension, and it presents an opportunity to raise awareness and encourage the utilization of healthcare services. Figure 4.3 shows that more than one-fourth (27%) of the patients who participated in this study were either illiterate (23%) or not formally educated (4%). In contrast, approximately 30% of the patients had studied up to Secondary School Certificate (SSC)-class 10th or Higher Secondary Certificate (HSC)-class 12th, while 28% had studied up to grades 5-9. When examining the educational level of patients through a gender lens, it was found that women were more likely to be illiterate than men—about 2.5 times more illiterate.

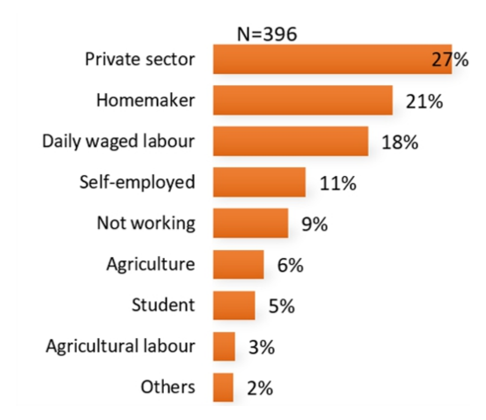
Figure 4.3: Level of Education of Patients



The qualitative findings of this study also show a similar education profile among the participants. About half of the 23 patients were either illiterate or had studied only up to the primary level. Only two patients were graduates or post-graduates.

An analysis of the patients' occupational profile revealed that the largest proportion (27%) were working in the private sector, followed by daily

Figure 4.4: Occupation Profile of the Patients

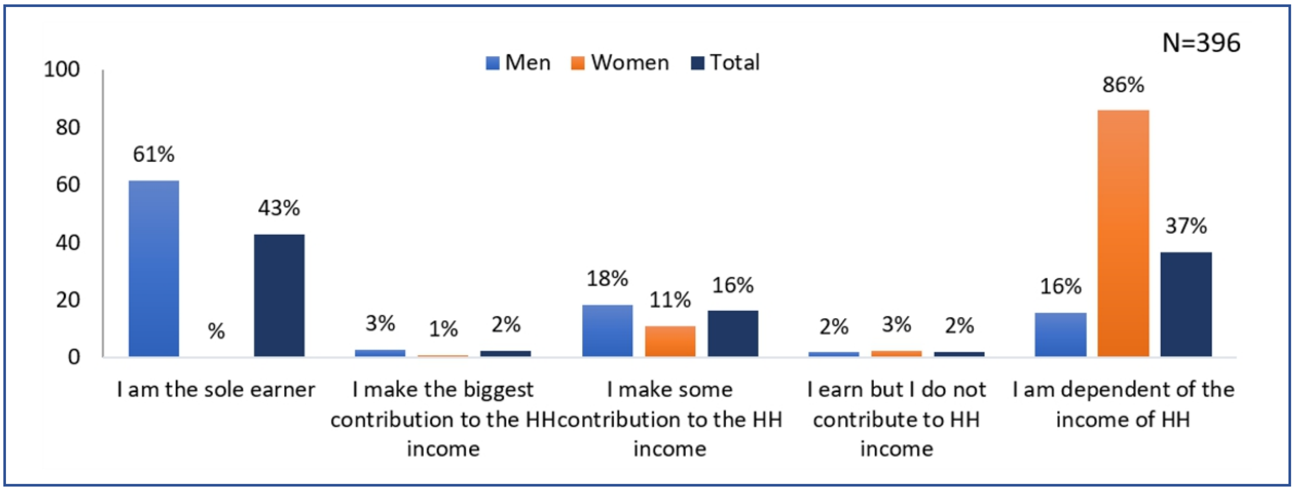


wage labourers (18%) and those who were self-employed (11%). Additionally, 21% of the patients were homemakers, with 95% of them being women. The qualitative findings also reflected a similar occupational pattern, with some participants staying at home (specifically female participants), while others worked as farmers or daily wage labourers.

Findings from household members show that approximately 31% were working in the private sector, followed by 29% who were homemakers and 11% who were self-employed. Additionally, about 8% of household members were students.

It was also observed that about two-thirds (61%) of the patients contributed to the household income, with more than two-fifths (43%) being the sole earners of the household. However, more than one-third (37%) of the respondents reported being dependent on the household income. When considering gender, the majority (70%) of women did not contribute to household income. Further analysis revealed that more than one-third (35%) of the patients who did not contribute to the household income had grade 1 or grade 2 disabilities. Only 2% of the patients reported being the biggest contributors to the household income. The biggest contributors included both illiterate and well-educated patients.

Figure 4.5: Patients' Contribution in HH income: By Gender



Possession of ration cards (government subsidy cards) and Aadhar cards plays a crucial role in ensuring essential benefits for needy persons, including those affected by leprosy. The findings indicate that just over two-thirds (67%) of the patients possessed a ration card, which included mostly Antyodaya cards (37%), Below Poverty Line (BPL) cards (39%), and Above Poverty Line (APL) cards (20%). This highlights that most of the migrant patients belonged to low socio-economic classes. Nearly all patients (99%) possessed an Aadhar card, and health facilities visited by the patients collected Aadhar card details for almost all of them (99%).

All patients were also asked about their money-saving behaviour, and two-fifths of the respondents reported that they had saved money. However, around 6% of patients did not respond to this question.

The study also investigated smartphone ownership among patients to understand how smartphones could be used to reach, sensitise, educate, and communicate with them. The findings show that more than four-fifths (81%) of the patients owned a smartphone, but only 71% had regular access to it. The gender gap in smartphone ownership was only 2%, but in terms of access, it was 13%. This suggests that although women patients may own smartphones, they may not always have access to them, which could affect their ability to use smartphones effectively. As a result, health programs should consider alternative ways to connect with women patients, besides relying solely on smartphones.

Information on all these variables was collected from the patients during the survey and the patients were categorized into the various SEC classifications viz. SEC-A, SEC-B, SEC-C, SEC-D, SEC-E.

SEC A is the highest classification and SEC E is the lowest classification

Economic Profile

The economic status of a household is influenced by a wide range of factors. A consolidated index of these factors provides a comprehensive understanding of the economic status of the household, rather than merely using household income. The Market Research Society of India (MRSI) has developed and periodically updated variables for socio-economic classification (SEC), which are commonly used by researchers in India. MRSI's NEW SEC Classification categorises households based on two variables viz. education of chief wage earner and number of “consumer durables” (from a predefined list) - owned by the family. The list has 11 items, ranging from 'electricity connection' and 'agricultural land'- to cars and air conditioners[36].

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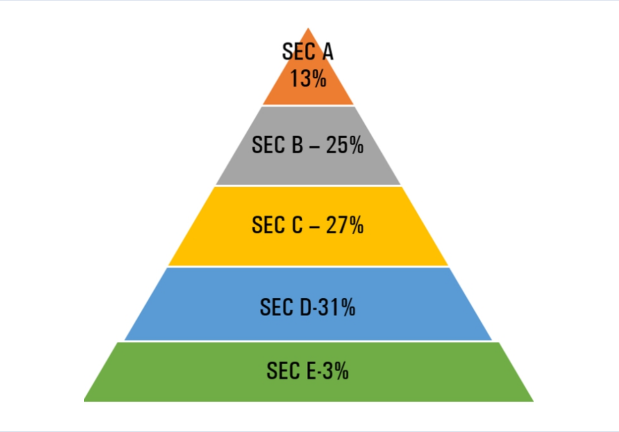
[36] https://mruc.net/assets/frontend/new-consumer-classification-system.html

The percentage distribution of households according to the new SEC system is shown in Fig. 4.6. As depicted, only 3% of patients fell into the SEC-E category, while 31% were in the SEC-D category. Only 13% of patients were classified in SEC-A, which represents the wealthiest category. However, nearly two-thirds (61%) of patients were in the SEC-C, SEC-D, and SEC-E categories, with SEC-A being the richest and SEC-E the poorest. (Fig. 4.6).

Figure 4.6: Percentage Distribution of Patients by SEC



4.2 Migration Profile of Patients

The goal of this study is to understand the impact of migration on people affected by leprosy and its consequences on treatment. This section explores the migration history of the patients and household members interviewed, covering several aspects including the reasons for migration, type of migration, frequency of movement, duration of stay, and whether they migrated alone or in a group. **Table 4.2** depicts the percentage distribution of patients' migration characteristics.

Additionally, all patients were asked who accompanied them during migration from their place of origin to their destination. About half (49%) of the patients reported that their spouse accompanied them, followed by children (41%) and other family members (28%). Less than 5% mentioned migrating with peers or friends. However, almost two-fifths (39%) of the patients indicated they travelled alone. When analysed by gender, a higher proportion of males (49%) reported migrating alone compared to females (15%).

Table 4.2: Percentage Distribution Migration Characteristics of Patients

Migration characteristics:	**Male**	**Female**	**Total**
Formation of migration $^{\delta}$			
Alone	49.4	14.5	39.3
With spouse	47.6	52.2	49.0
With children	35.9	53.6	41.0
With other family members	23.5	39.1	28.0
With peers	1.8	0.0	1.3
With friends	5.3	0.0	3.8
Total (N)	**170**	**69**	**239**

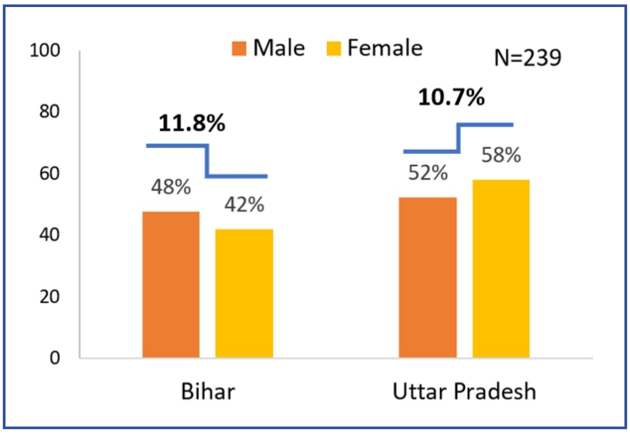
Note:
$^{\delta}$ Multiple responses possible, could not add to 100%;

Migratory Pattern of the Patients

An analysis of the migration patterns reveals that around 60% of the patients migrated to their destination and have been staying there for several years, with an average duration of 9 to 10 years. Over half (58%) of these patients migrated from Uttar Pradesh, while 42% were from Bihar (Fig. 4.7).

Further, the gender gap[37] analysis of migration patterns in Bihar reveals that female patient migration was 12% lower than male migration. In contrast, in Uttar Pradesh, female patient migration was 11% higher than male migration(Fig. 4.7). These findings suggest significant variations in migration patterns between genders in the two states, potentially reflecting differences in socio-economic factors, access to healthcare, or other underlying determinants influencing migration among people affected by leprosy. Understanding these differences can help tailor interventions and support services to better address the specific needs of male and female patients in different regions.

Figure 4.7: Gender Gap Rate (%) in migration



When asked about the districts from which they migrated, patients reported migrating from all districts in Uttar Pradesh and Bihar. However, certain districts saw a higher number of migrants than others.

On the other hand, 40% of patients reported visiting Delhi/Chandigarh solely for treatment and returning to their state of origin after receiving care (Fig. 4.8). Among these patients, 85% reported returning home on the same day they sought treatment in Delhi or Chandigarh. In qualitative interviews, 16 out of 23 patients mentioned visiting Delhi only for treatment and returning home on the same day. All these patients often mentioned the name of their native district, and this data highlights on an average these participants are traveling 1,420 km (round-trip) every month solely for treatment. Six of these patients, from Bihar, were traveling an average of 2,578 km (round-trip) to receive treatment, while 10 patients from Uttar Pradesh were covering 793 km (round-trip).

Quantitative data further suggests that the proportion of patients traveling solely for treatment is higher in Delhi (41%) than in Chandigarh (28%).

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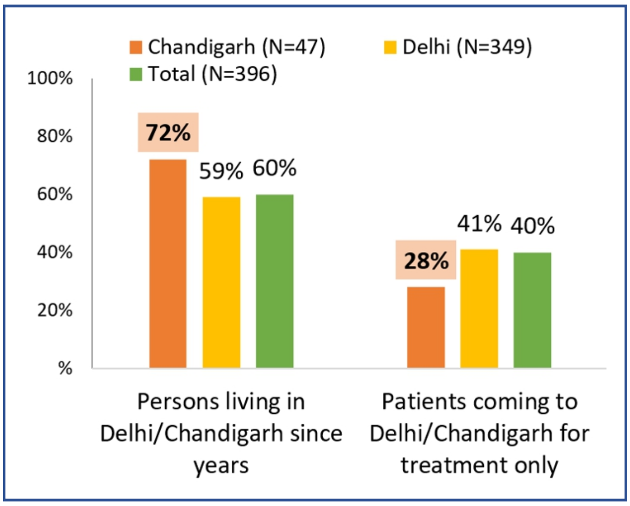
[37] Gender Gap Rate = ((Male-Female)/Male)*100

Many patients migrate due to self-stigma, as they do not want their neighbours or family members to know they have leprosy. This social stigma results in people choosing to migrate. It is crucial for the NLEP program to focus on educating the public about the common signs of leprosy, emphasizing that, while it is a communicable disease, it is not easily spread.

Figure 4.8:

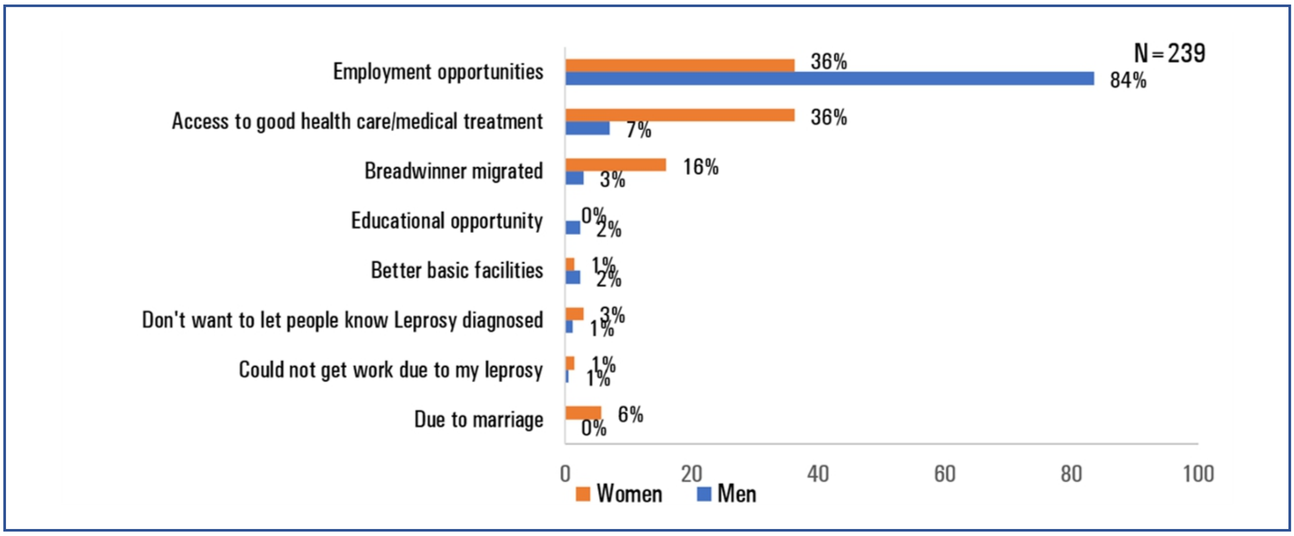


These findings underscore the extent of the effort and mobility required for patients to access essential healthcare services, highlighting the need to strengthen services in areas where leprosy treatment is lacking.

Reasons of Migration

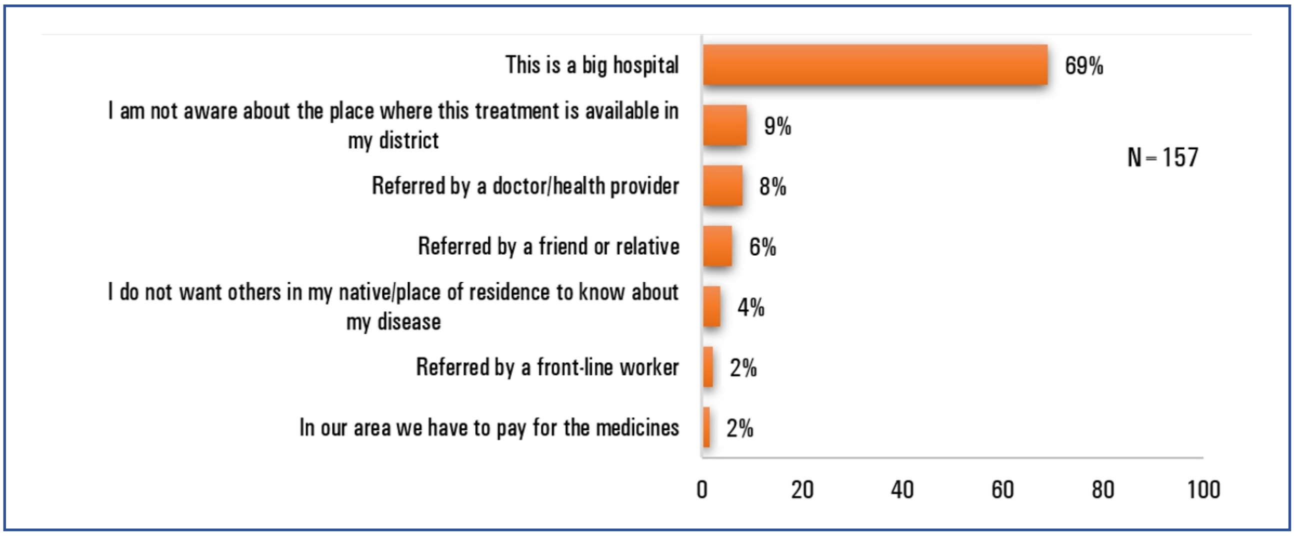
The study also examined the reasons of migration among patients residing at their destination for varying time periods (Fig.4.9). Overall, 70% of patients living at their destination migrated in search of better employment opportunities. The second most common reason (16%) for migration was access to better healthcare or medical treatment at the destination. Additionally, 20 per cent of the patients stated 'to avail better basic facilities', 'marriage', 'pursuit of better educational opportunity', 'diagnosis of leprosy', and 'could not get work due to leprosy diagnosis at place of origin' were the reasons for migration. The gender lens highlights that 84% of men and 36% of women had migrated for better employment opportunity. Similar proportion of women (36%) also migrated to access good healthcare/treatment.

Figure 4.9: Reasons of Migration for Patients Staying at Place of Destination



On the other hand, more than two-thirds (69%) of patients who travelled to Delhi/Chandigarh solely for treatment and returned to their homes reported that 'this is a big hospital'. Some of the patients (9%) also informed that they were not aware about a place where leprosy treatment is available at his/her native place. Additionally, a few patients cited being referred to these locations by doctors or healthcare providers (8%), friends or relatives (6%), and/or frontline workers (2%).Nevertheless, around 4% of patients informed that either they did not want to let other people know about their leprosy status or they needed to incur out-of-pocket expenditure for the medicines in their native place. (Fig. 4.10).

Figure 4.10: Reasons for Coming for Treatment Purposes Only



The qualitative findings highlight various reasons for patient migration. Patients choose their healthcare facility based on factors such as cost, doctor recommendations, previous treatment success, accessibility, positive feedback, unsatisfactory experiences, proximity, and self-initiated decisions. Financial considerations, affordability, and accessibility of free or low-cost healthcare services in the big hospitals at place of destination are also driving factors. Recommendations from healthcare professionals play a crucial role in guiding patients to renowned medical institutions. Additionally, some patients seeking leprosy treatment were referred from native health facilities due to reasons such as medication shortages and refusal of treatment.

The RFT patients mentioned *'the incapability of local doctors in treating their disease'*, *'lack of awareness of local doctors about leprosy treatment'*, *'unavailability of medicines across facilities in their native areas'*, *'the out-of-pocket expenditure against treatment and medicines at their native place'*, and *'good reputation of the facilities in Delhi and Chandigarh'* were the reasons for migration.

> *I took medicine for three months from the local doctors in my village, but unfortunately, I did not feel any relief from my symptoms. Someone then suggested that I visit this hospital. Here, the doctor diagnosed that I had been suffering from Leprosy. I couldn't feel the itching because the affected area had become numb.*
>
> ***– 50-years-old woman from Uttar Pradesh in Delhi***
>
> *I am already engaged, and my condition is worsening every day. My family feared that if I stayed in the village, the community might become aware of my condition. If my future in-laws found out, they could annul the engagement. So, my brother brought me to Delhi. He consulted a private doctor here, but the doctor referred me to a government facility where treatment is provided free of cost. "*
>
> ***– 22-years old woman from Bihar in Delhi***

Many patients migrated to Delhi or Chandigarh for employment opportunities. In Chandigarh, three patients undergoing leprosy treatment reported that they had moved there a long time ago and eventually settled down. One of them moved to Chandigarh in 1994, initially residing in the slums, but later received accommodation in a government rehabilitation home where he currently resides. Another patient migrated to Himachal Pradesh in 2012, and regularly visits Chandigarh for leprosy treatment. Migrants in Delhi, on the other hand, are relatively new patients, with most of them relocating to Delhi specifically to receive leprosy treatment.

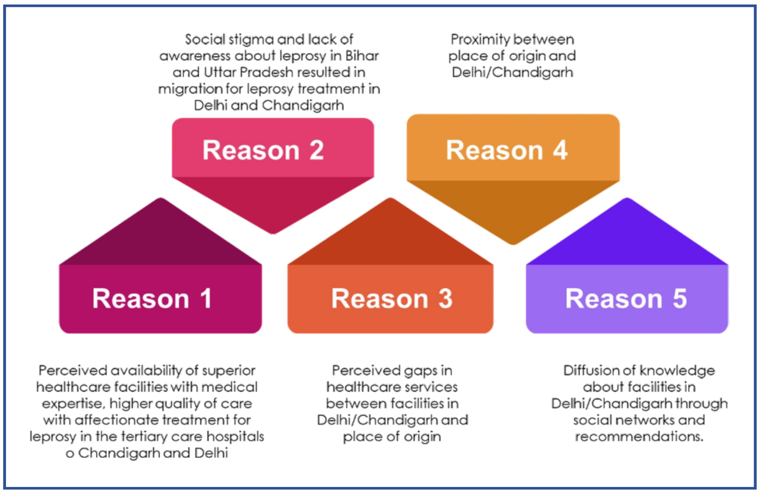
Healthcare providers and leprosy officials across the states share similar perceptions regarding the reasons for migration. Participants from Delhi indicated that employment opportunities and the perception of superior healthcare facilities are the primary drivers of migration. Job seekers are drawn to the National Capital Region due to the abundance of employment opportunities. Additionally, many migrants believe that tertiary care hospitals in Delhi offer advanced and effective healthcare services. Proximity, social networks, and economic factors also play significant roles in the decision to migrate. Some patients, identified as the sole earners in their families, support relatives who remain in their native places. Overall, migration to Delhi is influenced by a complex mix of economic, social, and health-related factors, reflecting a diverse range of motivations among the migrant population.

> *Several patients have come here from Bihar. Some come here solely for medical treatment, while others come to work after treatment. After their treatment is complete, some patients return to their hometowns. Some patients travel frequently to receive medical treatment and take medicines before returning. Additionally, some patients live with their relatives in the area. Some patients are originally from Bihar, and others are from UP.*
>
> ***– Paramedical Worker 1 Delhi***
>
> *They reach us through their relatives who already reside here in Delhi. Due to their frequent migration, they come and go and thus learn about the health treatments available here. We provide them with a self-care kit and conduct proper check-ups.*
>
> ***– Paramedical Worker 2 Delhi***

The participants in Chandigarh highlighted various reasons for migration to the Union Territory. A prominent factor is the availability of specialized medical facilities, particularly for leprosy treatment. They believe that the Government of India's provision of free treatment, along with the well-established leprosy program at Government Health Facilities, makes Chandigarh an attractive destination for medical tourism. In addition to healthcare, people migrate to Chandigarh in search of livelihood opportunities and education. A pattern is observed where the initial migration of the breadwinner leads to the entire family eventually settling in the city.

Healthcare providers from Uttar Pradesh informed that there is also significant inter-block or district migration within Uttar Pradesh, where individuals move to access leprosy treatment. Overall, migration patterns in both Delhi and Chandigarh are driven by a combination of economic, social, and health-related factors. The broad reasons for migration are highlighted in Fig. 4.11.

Figure 4.11: Reasons of Migration



In summary, the study investigated the migration patterns of individuals, uncovering a variety of reasons such as education, employment, healthcare, and family. Most of those (7 out of 23) who migrated to Delhi did so to receive treatment for leprosy, while others sought job opportunities or relocated due to marriage. The remaining 16 participants travelled only to receive treatment from Delhi or Chandigarh, citing challenges in their native areas, such as inadequate local medical services and limited awareness about leprosy treatment. Knowledge about better facilities in Delhi and Chandigarh, whether through social networks or healthcare providers, influenced migration. After receiving treatment or finding employment, most migrants either settled down over time or returned to their hometowns. In Delhi, the newer migrants primarily come for leprosy treatment, often returning to their native places after obtaining medicines.

Pattern of Migration

Examining the migration patterns of persons affected by leprosy holds significant importance for various critical aspects of leprosy control and patient care. First, understanding these patterns aids in assessing the risk of disease transmission, as frequent migration and prolonged stays with non-affected individuals can contribute to the transmission of the bacteria. Secondly, it highlights the issue of treatment adherence, as interruptions due to migration may lead to incomplete treatment and the development of drug resistance.

Data analysis of the duration of stay for the 239 patients living in Delhi/Chandigarh reveals that most patients have stayed in their place of destination for an average of 9 to 10 years. Those living in these cities for extended periods were also asked about the frequency of visits to their state of origin. The highest proportion (30%) of patients informed that they visit their place of origin *'once in a year'*, followed by *'once in six months' (27%), 'not fixed' (22%),* and *'once in three months'* (10%). This intermittent or temporary pattern of migration might be attributed to possible agricultural activities, seasonal employment opportunities, or other factors specific to certain times of the year. Though more than half of the patients (57%) indicated visiting place of origin at least once in a year, there are patients who visit their place of origin multiple times in a year (Fig. 4.12). The 157 patients who reported coming only for treatment were also asked about the duration of stay every time they come for treatment in Delhi/Chandigarh. More than four-fifths (85%) of the patients reported returning the same day to their village post receiving treatment (Fig.4.13).

Figure 4.12: Frequency of Visits to State of Origin

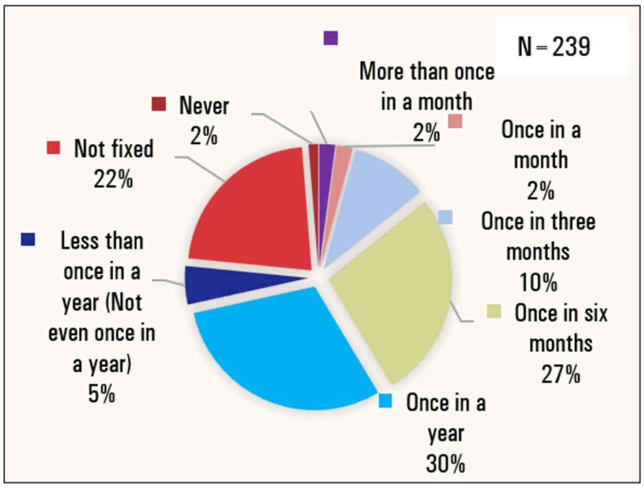
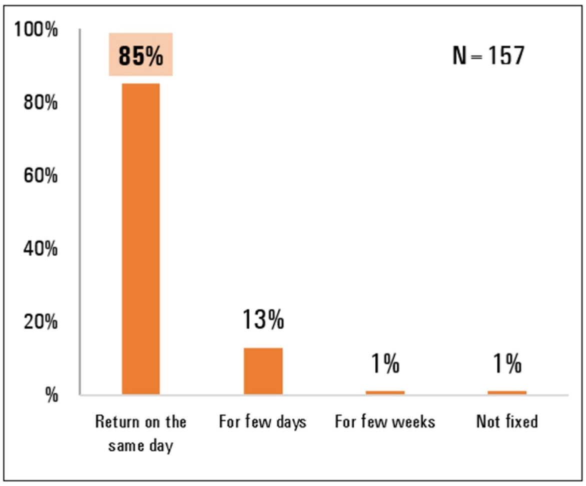


Figure 4.13: Duration of Stay of Patients Migrating Only for Treatment



To gain a deeper understanding of migration patterns, the patients were asked about their visits to their place of origin. The results showed that more than half of the patients (51%) visited their parents, followed by their spouse (17%) and in-laws (14%) (Figure 4.14). Less than one-fifth (17%) of the patients also visited other family members such as siblings, uncles, aunts, grandparents, nephews, children, and maternal family. A few patients mentioned that they frequently visit their own house. This highlights the importance of familial ties. Nonetheless, a spouse can serve as the primary support system for the patient, which can aid in treatment adherence.

Figure 4.14: Who the Patients Visits at Place of Origin

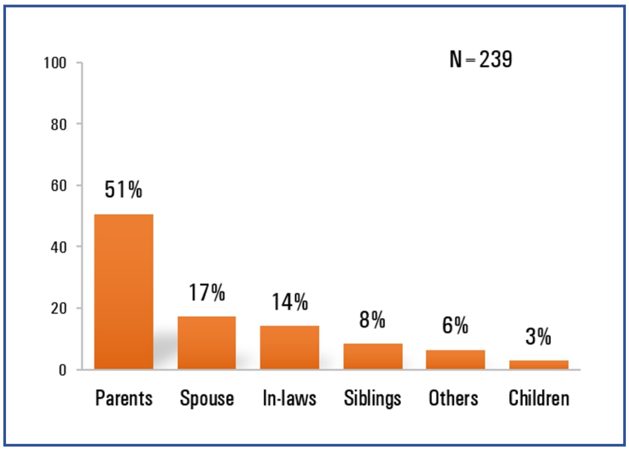


Figure 4.15: Percentage distribution of timing of migration

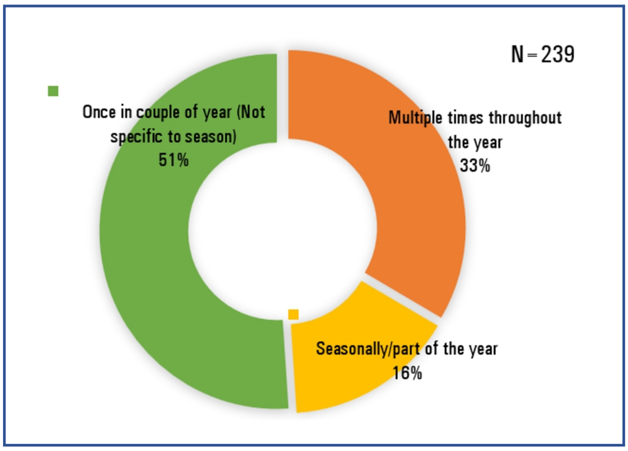


Figure 4.14 also highlights the timing and seasonality of migrant patients. Almost one-third of the patients (33%) migrate multiple times throughout the year. Considering the incubation and transmission of leprosy, this segment is very crucial for the programme. It depicts only 16 per cent of the patients migrating seasonally. On the other hand, table 4.3 illustrates that the occurrence of migration was lowest during monsoon and winter

seasons, whereas during the summer months (March–June), more than one-quarter (27%) of the patients migrate. Over two-thirds (65%) of patients reported being on 'fixed-term contact', which may be influenced by employment-related factors. Additionally, more than half (51%) of the patients migrate only once a year, while one-third (33%) migrate multiple times throughout the year (Fig. 4.15). Understanding these patterns is crucial for designing targeted healthcare interventions to ensure equitable access to care for leprosy patients.

Table 4.3. Percentage distribution migration characteristics of patients

Migration characteristics:	Total (N=239)
Season of migration*	
Summers (March- June)	27.0
Winters (Nov-Feb)	2.7
Rainy season (July-Oct)	2.7
Fixed time contract	64.9
Others	2.7
Total (N)	**100.0**

Note: *Asked to the respondents who are currently living at the place of destination.;

4.3 Disease Profile of Patients or Stage of Disease

Table 4.4 depicts the disease profile of the patients who participated in the study. This profile includes the type of leprosy diagnosed along with the disability grade at the time of diagnosis. It also highlights the percentage distribution of patients by type. Overall, most of the patients (97%) were new, with only 3% categorised as 'others'. Almost all patients (99.8%) were diagnosed at the Multibacillary (MB) stage, with a negligible proportion (0.25%) diagnosed at the Paucibacillary (PB) stage. This finding highlights the prevalence of the MB stage among migrant patients seeking leprosy diagnosis and treatment in both Delhi and Chandigarh. Furthermore, it suggests that most patients were seeking diagnosis at a more advanced stage of leprosy, which poses challenges for treatment due to the increased risk of deformity and higher risk of disease transmission.

Although about two-thirds (62%) of the patients were diagnosed with Grade 0 disability, a notable proportion (19%) were diagnosed with Grade 2 disability, and around 17% had Grade 1 disability.

Table 4.4. Percentage distribution of respondents by disease profile and state

	Total
Type of patient	
New	96.7
Other	3.3
Stage of leprosy	
PB	0.3
MB	99.7
Disability grading at the time of diagnosis	
Grade 0	62.2
Grade 1	17.4
Grade 2	19.4
Information not available	1.0
Total (N)	**396**

Note: New case patients comprise individuals who exhibit signs of leprosy but have never received treatment before, while other cases encompass patients requiring further treatment, including those experiencing relapse, re-entry into treatment, referral, or re-classification.
PB = Paucibacillary; MB = Multibacillary

This finding underlines the importance of early detection of leprosy and intervention to mitigate the risk of disability associated with leprosy. Given that considerable proportion of patients presenting with Grade 2 deformity at the time of diagnosis, there is a critical need for enhanced screening and diagnostic efforts, especially among migrant populations.

In summary, the findings of this chapter underscore that males affected by leprosy exhibit a higher propensity for migrating to seek treatment compared to their female counterparts. Most patients are married, reside with their spouses and/or children, and maintain households with an average of 4.9 members. The findings also reveal that a noteworthy proportion of patients are illiterate, with a disproportionate representation of women in this category. Many patients are engaged in the private sector or work as daily wage labourers. Despite owning smartphones, access to a smartphone is notably constrained among women.

The findings also indicate that one of the main reasons for patients migrating to Delhi or Chandigarh is exclusively in pursuit of treatment, often covering considerable distances. Several factors influence this migration, including inadequate access to healthcare for leprosy locally. Additionally, a substantial number of patients return home on the same day following treatment. Patients emphasised the compelling need to enhance local healthcare for leprosy, which would reduce the burden of travel solely for treatment, facilitate early detection, and optimise treatment outcomes. Early detection of leprosy is crucial to reduce the proportion of disability at the time of registration.

CHAPTER 5: INSIGHTS INTO DIAGNOSIS AND TREATMENT OF LEPROSY OF MIGRANT PATIENTS

Migration is an impediment to both leprosy elimination and control efforts. Prior research indicates that migration may influence the transmission of leprosy as well as other neglected tropical diseases (NTDs)[38]. Migration facilitates the spread of leprosy from endemic to non-endemic areas and remains a contributing factor to its continued incidence[39,40]. Insights into the challenges faced by migrant patients in their diagnosis and treatment is crucial for designing services that address their specific needs.

This chapter presents an analysis of the diagnosis and treatment journeys of migrant patients in Delhi/Chandigarh, categorizing the patients based on their residency and treatment purpose. The findings are based on quantitative data from 396 migrant patients and qualitative data from 23 migrant patients to understand common and differing patterns among them

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[38] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3764227/#:~:text=Migration%20has%20been%20found%20to%20be%20an%20impediment%20to%20both,17%5D%E2%80%93%5B23%5D.

[39] Rathod, S., Jagati, A., & Agarwal, P. (2019). Impact of Migration on Epidemiology and Control of Leprosy. Indian J Lepr, 91, 139-152.

[40] Bharti, O. K., Rana, R. S., & Kaushal, D. S. (2019). Investigating a Possible Linkage of Working with Migrant Workers and New Leprosy Cases among Indigenous Populations of Shimla, Himachal Pradesh, India. Indian J Lepr, 91, 117-123.

5.1 Trends in Diagnosis of Leprosy Amongst Migrant Patients

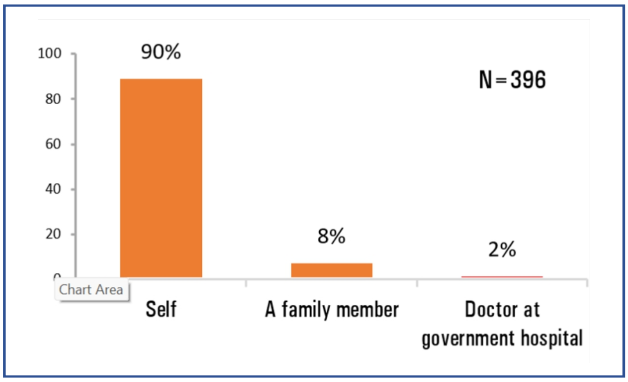
Early diagnosis and treatment of leprosy are crucial in preventing disability, deformity, and reducing stigma and discrimination Grade 2 disability (G2D) continues to be a significant public health concern globally, often resulting from delayed diagnoses. Moreover, early diagnosis and treatment reduce the risk of transmission. This section focuses on the leprosy diagnosis and highlights the gap between symptom onset and initial diagnosis, as well as the challenges faced by migrant patients in accessing treatment.

5.1.1 Insights into Identification of Signs and Symptoms of the Disease

Who First Observed Symptoms

The findings reveal that most of the patients (90%) first noticed the symptoms of leprosy themselves, followed by family members (8%) (Fig. 5.1). Additionally, 2% of the patients also reported that the symptoms were first observed by the doctor at government hospitals Respondents in the qualitative interviews also mentioned self-observation of the clinical manifestations of the condition, along with observations made by close family members and elderly members of the community. A couple of the patients also informed that healthcare providers in their state of origin diagnosed leprosy through clinical observations.

Figure 5.1: Person who saw the symptoms for the first time

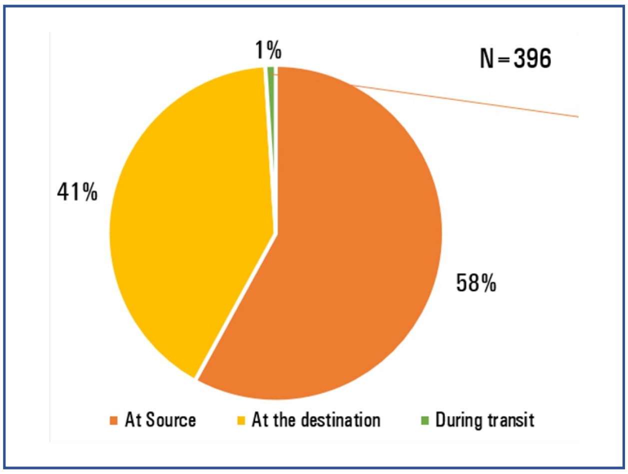


> *I went to a doctor in Kanpur for a check-up due to my problems. During the consultation, the doctor searched on his mobile and told me that I had been affected by Leprosy. He also informed me that I could receive free red-strip medicine from a Government hospital. After that, I went to other doctors in Agra and Lucknow who confirmed the diagnosis.*
>
> ***– 35-years-old man RFT from Uttar Pradesh in Delhi***
>
> *No, I had no clue about leprosy. But one elderly neighbour know these things. He told me that these are the symptoms of leprosy, even before I went to the doctor.*
>
> ***– 33-years-old man Currently on Treatment from Bihar in Chandigarh***

Place where Symptoms were Observed

The study also tried to find out the location where the symptoms were first observed, which has implication for disease management. The findings reveal that more than half (58%) of the patients noticed the symptoms for the first time at the source, while a little more than two-fifths (41%) noticed them at the destination (Fig. 5.2). Only around one per cent of the patients reported noticing the symptoms during transit. The lower identification of symptoms during transit may be attributed to the direct migration from the place of origin to the destination, with good connectivity between Delhi and Chandigarh from Uttar Pradesh and Bihar, making travelling easier and eliminating the need for a transit stay. However, the findings highlight that more women (65%) patients noticed symptoms at the source than men (52%). As can be expected, a higher proportion of the patients coming to Delhi/Chandigarh only for treatment purposes reported noticing the symptoms for the first time at the source (90%), compared to only 37% of migrant patients residing in Delhi/Chandigarh who noticed the symptoms at the source.

Figure 5.2: Places where the symptoms were seen for the first time



Type of Symptoms Observed

The symptoms of leprosy mainly affect the skin, nerves, and mucous membranes. They include discoloured patches of skin, nodules, thick or stiff skin, painless ulcers on the soles of the feet, painless swelling or lumps on the face or earlobes, loss of eyebrows or eyelashes, numbness, muscle weakness or paralysis, enlarged nerves, eye problems, stuffy nose, and nosebleeds[41].

During the case studies, patients were probed for the initial clinical manifestations, and all 23 participant patients reported various symptoms. Many participants reported experiencing multiple clinical manifestation of conditions. The various symptoms reported among patients included swelling of the hands and feet, itching, numbness in the hands, joints, and eyes, as well as ulcers on different body parts such as the hands, ears, and skin. Additional symptoms included fever, weakness, bumps on the hands and ears, blisters, facial redness and spots, and dermatological issues such as skin patches. They also experienced mobility challenges, including stiffness in the hands, musculoskeletal pain in the knees, legs, and joints, temperature sensitivity, and general discomfort.

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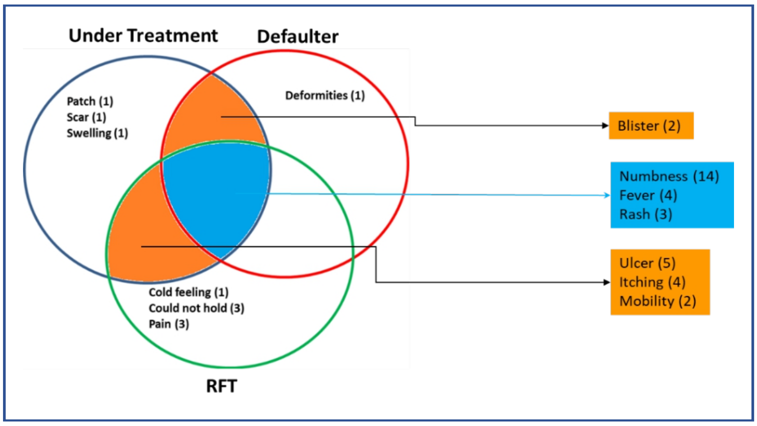
[41] https://www.cdc.gov/leprosy/signs-symptoms/index.html

> *I experience numbness in only my right hand. I am unable to feel anything if someone pinches me. My hand swells and becomes itchy at times. There have been instances when I have burnt my hand while cooking, but I didn't feel any pain. My family has been trying to find a suitable match, but people who see me often ask why my hands and feet look this way. Others wonder how I can bear it, but the truth is, I cannot feel anything.*
>
> ***– 22-years-old woman from Bihar in Delhi, RFT***

> *At one point, I faced several issues that made it difficult to carry out simple tasks. Drinking water was a challenge, and holding a bowl without spilling its contents was a struggle. Taking care of my children was also quite challenging. However, I have adapted to these challenges and can now efficiently manage these tasks. Despite this, there is one thing I am still unable to do, and that is to cook. I hope I can improve in this area with time and practice.*
>
> ***– 28-years-old woman from Uttar Pradesh in Delhi, RFT***

The most commonly reported clinical manifestation was numbness (Fig. 5.3), which was reported by the 14 participants during qualitative interviews, followed by ulcers (5), fever (4), itching (4), and rashes (3). Other clinical manifestations reported included blisters and a lack of functional mobility in the hands and feet. Nevertheless, deformities were observed in only one patient who had defaulted on treatment.

Figure 5.3: Initial clinical Manifestation of Conditions



Note1: Findings from qualitative data. Total could not add to N, due to possible multiple-responses

5.1.2 Trends in Seeking Medical Care After Seeing the Symptoms

It is crucial to detect leprosy early to prevent disability and further transmission of the bacteria. Therefore, it is essential to understand the level of awareness regarding where to seek a diagnosis for symptoms and where to seek medical help, as these factors can impact the time taken for diagnosis. To address this issue, patients were asked if they knew where to go for a diagnosis after experiencing clinical symptoms. The findings in

Fig. 5.4 reveal that more than two-thirds (64%) of the respondents were not aware of where to go for a diagnosis. However, awareness about the place of diagnosis was observed to be higher among men (71%) than women (61%).

Figure 5.4: Whether aware about where to go for Diagnosis

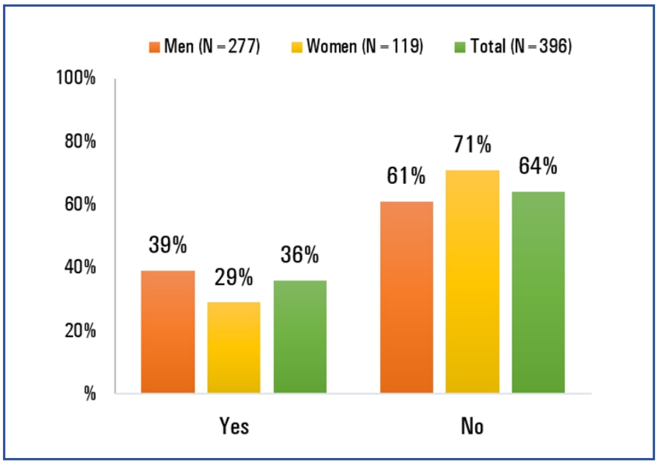
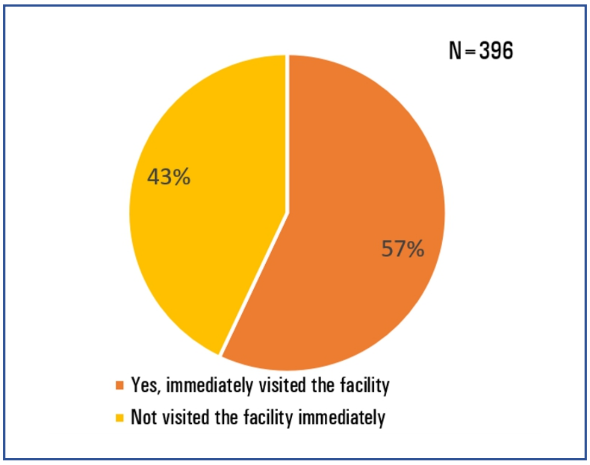


Figure 5.5: Whether visited the facility immediately post experiencing the symptoms



The patients were asked if they sought medical care immediately after noticing their symptoms to assess their treatment-seeking behaviour. The finding reveals, more than two-fifths of the patients (43%) didn't medical care right away (Fig. 5.5). Since, they perceived 'the symptoms would go on their own' (70%), 'the symptoms were not that serious'(55%), or 'they were not painful'(40%) (Fig.5.6). However, another key reason reported by patients was 'didn't have money to pay for the appointment' (11%), indicates that the patients might have thought of visiting private facilities.

Figure 5.6: Reasons for not visiting the healthcare facility immediately

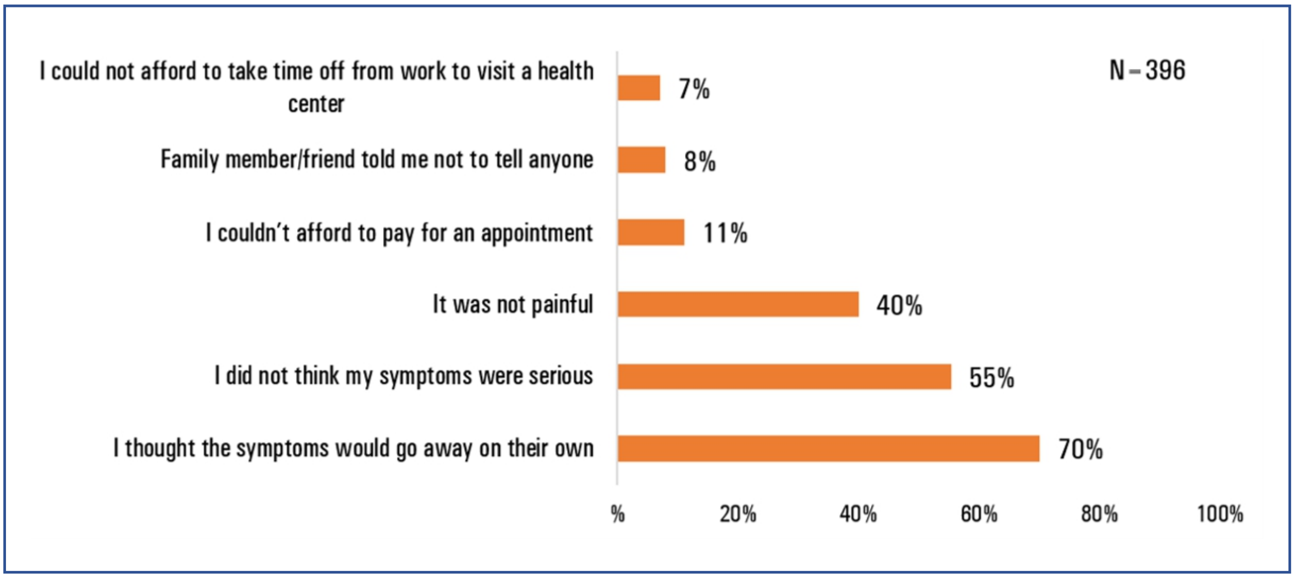


Table 5.1: Number of health facilities visited for the diagnosis

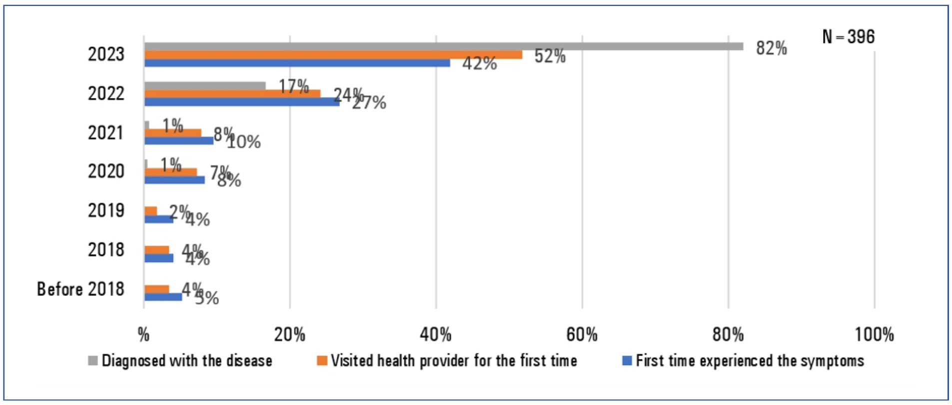
Particulars	N	%
Visited any other facility before coming to current place of treatment		
Yes	272	68.6
No	124	31.3
N (All the patients interviewed)	396	**100**
Health facilities visited (Average) $^{\delta}$	2.2	N=272
Health care providers visited (Average) $^{\delta}$	3.2	
Note: $^{\delta}$ Calculated for the patients who reported visiting other facilities		

The study also analysed whether the patients were immediately diagnosed upon reaching the health facility or if they had to visit multiple health facilities to receive the correct diagnosis. Visits to multiple health facilities and delays in seeking initial treatment after experiencing symptoms can result in delayed diagnosis, leading to a more advanced stage of the disease before treatment can begin. When asked about their healthcare journey, patients revealed that they had to visit multiple facilities and health providers before receiving the correct diagnosis. According to the data in table 3.2, almost three-fourths (69%) of the patients interviewed had visited other health facilities before coming to their current place of treatment. On average, patients reported visiting two health facilities and three healthcare providers before receiving a final diagnosis. This underscores the importance of raising awareness about where to seek treatment upon noticing symptoms of leprosy.

5.1.3 Gap Between the Symptoms First Seen vs First Time Visit to Health Provider and Diagnosis for Leprosy

The study also analysed the time taken to get the diagnosis from when the symptoms were first observed. As seen in Figure 5.7, among the current patients on treatment, slightly less than one-third (31%) of the patients noticed the symptoms before 2022, and one-fourth (25%) reported visiting a healthcare provider for the first time before 2022; however, they were all diagnosed in 2022/2023. Overall, it is observed that, on average, there was a 2-year gap between the first observation of symptoms and the first visit to a healthcare provider, and a gap of 3 years from the first visit to a healthcare provider to the diagnosis. As discussed earlier, the patients visited multiple healthcare providers before being diagnosed with leprosy, which accounts for the time taken to receive a diagnosis after symptoms were observed.

Figure 5.7: Gap between the symptoms seen, visited the health provider for the first time and diagnosis



The results of qualitative interviews show that the majority of the participants were unaware of the symptoms of leprosy before being diagnosed. They mentioned that healthcare providers at their place of origin failed to diagnose the disease and instead prescribed medicines for allergies, skin infections, and fungal infections. This may have led to a delayed diagnosis, as the patients visited multiple facilities and healthcare providers before being correctly diagnosed. Additionally, they disclosed that leprosy is not a topic openly discussed in their community. This emphasizes the need for greater awareness about leprosy among healthcare providers at the patients' place of origin.

However, a couple of participants said that they had seen some people with leprosy in their native village, which led them to recognize similarities in their own health conditions and seek medical attention. One participant mentioned that the older generation in their neighbourhood could recognize the symptoms of leprosy and advised them to see a doctor. This underscores the importance of community knowledge in leprosy diagnosis and the potential for community-based awareness programs.

> *In 2021, I had health issues like fever and ulcers in different parts of my body. I visited a local doctor nearby residence, he just told me to visit hospital for treatment. Then I visited few other doctors, tried homeopathic medicine, which didn't work. Some doctors refused to treat me and suggested visiting a bigger hospital, but I didn't know what the illness was. After a few months, the doctor advised me to visit AIIMS or Safdarjung.*
>
> ***– 33-years-old man Currently under treatment From Uttar Pradesh in Delhi***

> *I had no idea that I had leprosy. I was experiencing itching all over my body, and I assumed it was a reaction to the pesticides I used for farming. The local doctors prescribed various medications, but my symptoms kept getting worse. Whenever I went somewhere, people would tell me something was wrong. As a result, I spent a lot of money and time trying to figure out what was happening.*
>
> ***– 35-years-old man RFT from Uttar Pradesh in Delhi***

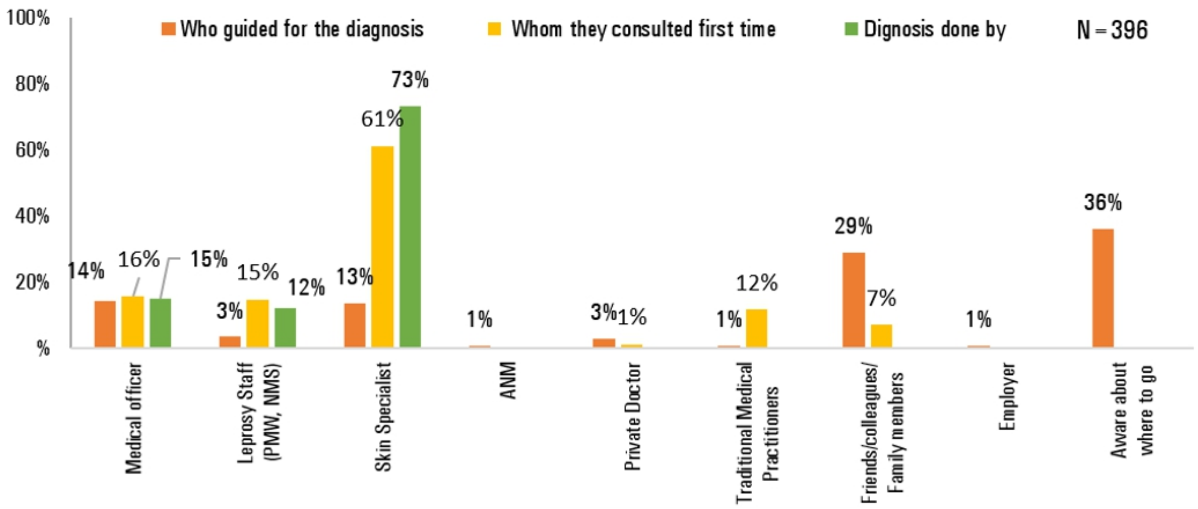
5.1.4 Place of Diagnosis

The majority of migrant patients (95%) were diagnosed at their destination, such as Delhi or Chandigarh. Even patients who first noticed symptoms at their place of origin reported being diagnosed at the destination (93%), with only a small percentage (7%) being diagnosed at their place of origin.

Friends, colleagues, family members, and healthcare professionals guided patients to seek a diagnosis. The graph below (Fig. 5.8) shows that more than one-third (36%) of the patients knew where to go to diagnose their symptoms. Over one-fourth (29%) of the patients were guided by friends, colleagues, and family members, followed by medical professionals (14%) and skin specialists (13%).

When seeking consultation, over three-fifths of patients (61%) first consulted a skin specialist for their symptoms. A smaller proportion consulted a medical officer (16%), and a similar proportion consulted leprosy staff (15%). About three-fourths of patients (73%) were finally diagnosed by a skin specialist in a government facility, highlighting the indispensable role played by skin specialists in diagnosing leprosy and the importance of their profession in the healthcare system.

Figure 5.8: Person who guided, whom they consulted first, diagnosis done by (%)



The qualitative findings also reveal the complex and varied treatment journeys of individuals affected with leprosy. Initially, many patients relied on private hospitals for medical consultation, but financial constraints often led them to seek treatment in government hospitals, where care is free. The treatment journey typically began with home remedies or consultations with local healthcare providers, followed by visits to private doctors, and eventually, government facilities. Misdiagnosis and ineffective local treatments were common, resulting in multiple consultations and prolonged periods without proper treatment.

Patients frequently switched between private and government hospitals in search of better care, with some even exploring alternative medicine such as homeopathy. Financial limitations, dissatisfaction with initial treatments, and difficulties accessing quality healthcare played significant roles in these transitions. Importantly, family influence and social networks also impacted their decisions, underscoring the role of support systems in navigating a healthcare system often lacking awareness about leprosy.

Overall, these individuals' treatment-seeking behaviours highlight the complexity of their healthcare journeys, shaped by financial, geographic, and social factors, and characterised by a persistent search for effective medical solutions.

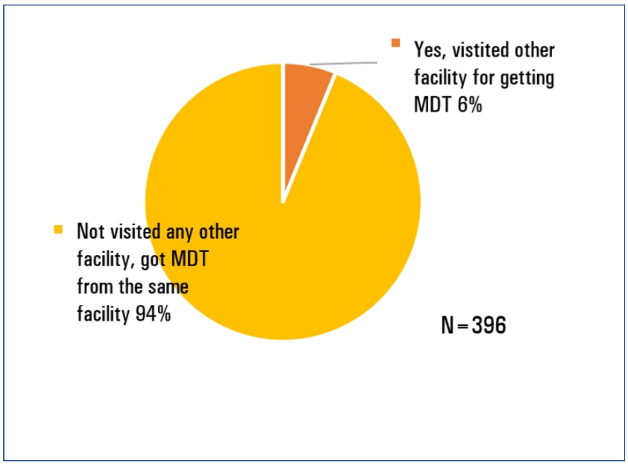
> *At first, I considered seeking treatment at a private hospital in my village. However, upon arriving in Delhi, I underwent the necessary tests, and they advised me to pursue treatment at a government facility where both treatment and medications are provided free of charge. At that moment, financial constraints were a concern, and opting for the government facility alleviated the burden of significant expenses.*
>
> ***– 22-years-old woman from Uttar Pradesh in Delhi, Currently Under Treatment***
>
> *Approximately six months ago, I experienced issues with my hands and feet, prompting me to consult a doctor in Patna. However, the prescribed medication proved ineffective, and I continued to face difficulties with my feet. Seeking a second opinion, I visited a doctor in Gorakhpur, but unfortunately, there was no noticeable improvement. It was then that my son-in-law, residing in Delhi, informed me about AIIMS. Currently, I am undergoing treatment at AIIMS.*
>
> ***– 53-years-old man from Bihar in Delhi, Currently Under Treatment***
>
> *It has been approximately two years since I began seeking medical help. Initially, I consulted 2-4 doctors in our local area, followed by a visit to a private facility. However, I found them to be primarily focused on profit. Subsequently, I sought assistance at a general hospital before finally arriving at my current location, where I have received adequate treatment. Despite previous unsuccessful attempts, I have been taking medication here for the past seven months, and I am experiencing significant improvement in my condition.*
>
> ***– 60-years-old woman from Uttar Pradesh in Delhi,***
> ***Person who defaulted the treatment***

5.2 Insights into Treatment of Migrant Patients

The currently recommended treatment regimen for leprosy consists of three drugs: dapsone, rifampicin, and clofazimine, collectively known as multi-drug therapy (MDT). The treatment duration is six months for PB cases and 12 months for MB cases. MDT kills the pathogen and cures the patient. The World Health Organization (WHO) has been providing MDT free of cost. Initially funded by The Nippon Foundation, since 2000, MDT has been donated through an agreement with Novartis[42].

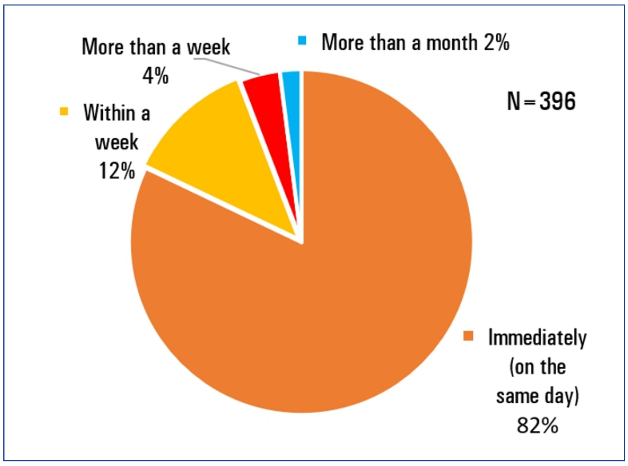
This section highlights the availability and accessibility of MDT at both the source and destination areas. As negligible numbers of patients were diagnosed while in transit, this is not discussed in detail. Figure 5.9 that most patients reported receiving MDT from the same facility where they were diagnosed with leprosy. Very few patients mentioned needing to visit another facility for MDT after diagnosis. Reasons for this included diagnoses made at private facilities, non-availability of MDT at the government facility at the time of diagnosis, or referrals to another facility for MDT.

Figure 5.9: Whether Visited any other Facility after Diagnosis for Getting MDT treatment



Post-diagnosis, patients are put on MDT treatment. According to National Leprosy Elimination Programme (NLEP) guidelines, patients should begin MDT immediately or within a week of diagnosis. Most patients (94%) started treatment immediately or within a week post-diagnosis (Fig. 5.10). This clearly highlights the adherence to the standard operating procedures (SOP) as prescribed by the NLEP by both patients and leprosy staff.

Table 5.10: Frequency of visiting health facility to get MDT



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[42] https://www.thehindu.com/news/national/health-ministry-announces-new-treatment-regimen-for-leprosy/article67772926.ece#:~:text=The%20duration%20of%20treatment%20is,via%20an%20agreement%20with%20Novartis.

The patients are expected to visit the health facility at least once a month to receive MDT. During these visits, leprosy staff assess their status, monitor the effects of the medications, and provide proper counselling. The majority of patients (94%) reported visiting the health facility at least once a month (Fig. 5.11).

Counselling is a key component of post-diagnosis care for leprosy. It is mandatory for leprosy staff to counsel patients regarding adherence to treatment. Patients should be informed about the importance of regularly continuing MDT for the prescribed duration, the potential side effects of the medication, and the necessary self-care practices.

Almost all the patients (97%) reported that someone at the health facility advised them to complete their treatment (Fig. 5.12). This guidance was primarily provided by NMS, NMA, health visitors, and para-medical workers at the facilities.

Figure 5.11: Frequency of visiting health facility to collect MDT

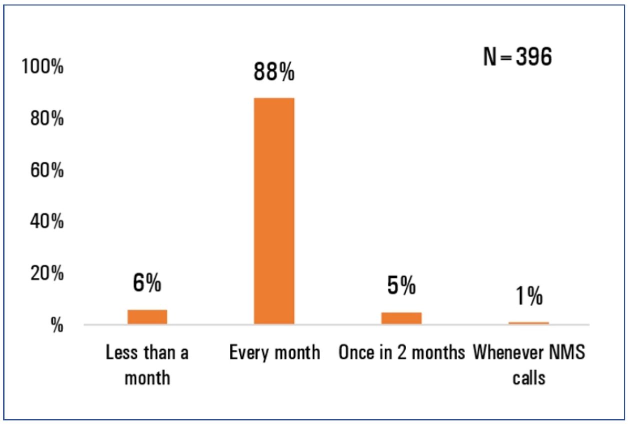
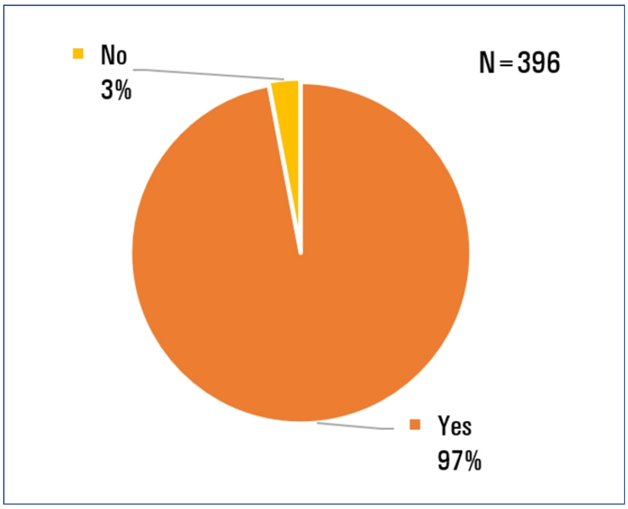


Figure 5.12: Whether someone suggested to continue the treatment



According to NLEP guidelines, patient follow-up is essential for ensuring continuity of treatment. However, only 40% of patients received a follow-up call for MDT collection, primarily made by leprosy staff. Although MDT is provided free of charge under WHO and NLEP guidelines, patients still incur other associated costs, such as travel, boarding, lodging, and food, which are out-of-pocket expenses. Around half of the participants in qualitative interviews reported spending money on transportation, with an average cost of INR 1,500 per trip.

5.2.1 Motivation for Treatment

Participants' motivation to complete treatment is influenced by several factors. These include a desire for better health, a commitment to addressing past mistakes such as neglecting symptoms or delaying medical consultation, and concerns about medication. Additionally, previous challenges with discontinuing treatment reinforce their dedication.

Participants also expressed strong personal determination and gratitude for positive outcomes, as well as concern for their family's well-being and acceptance of long-term treatment. External encouragement from doctors, friends, and family also played a significant role in their adherence to treatment.

> *Now, I am committed to finishing it. I currently do not have any ulcers or allergies, but I will continue and complete my course. In the past, I faced issues because I discontinued taking medications midway through previous instances.*
>
> ***– 25-years-old man Currently under Treatment from Uttar Pradesh in Delhi***
>
> *I completed the medicines because they told me I had a chance to recover. This illness affects the patients and takes a toll on their family members. I'm determined to spare my family from any additional suffering, which is why I diligently followed through with my medication regimen.*
>
> ***– 50-years-old man from Uttar Pradesh in Delhi, RFT***

5.2.2 Level of Satisfaction of the Treatment Received

The level of satisfaction with the treatment was found to be very high, with most patients (94%) reporting that they were either very satisfied (72%) or satisfied (22%) with the treatment they received. Since most patients were diagnosed and continue their treatment at the destination, their satisfaction is primarily reflective of the treating health facilities there. Limited information on satisfaction with treatment facilities at the source was obtained.

5.2.3 Challenges Faced During Treatment

The patients were asked about the problems they faced due to their leprosy status. More than half of them (55%) reported encountering challenges due to leprosy. Over one-fourth of the patients (27%) mentioned that they either lost their job or struggled to find a good job because of leprosy. Around one-fifth (18%) reported being unable to work due to disability. About one-tenth (9%) stated they had to migrate because of leprosy. Nearly 7% of patients shared that their community had boycotted them, or their relatives had abandoned them due to leprosy. Some patients also reported difficulties in finding a suitable marriage match, and a few had to leave their education. Financial issues were another challenge mentioned, along with the difficulty of traveling to collect medicines.

The qualitative findings revealed additional challenges during treatment, with medication management being a major issue. Many participants reported that locally, MDT was often unavailable. At times, the medicine was out of stock, or the authorized personnel refused to supply it, forcing patients to travel to Delhi or Chandigarh. Some also faced logistical challenges, such as booking train tickets and arranging accommodations. Transportation and accessibility issues, as well as long waiting times in the healthcare system, were persistent concerns. Financial constraints further complicated matters, with travel costs adding to the burden. Patients also faced social stigma and discrimination while travelling, making it challenging to find appropriate seating. Physical health problems, such as impaired mobility, created obstacles in basic activities like eating and drinking. Among women with toddlers, there was a lack of awareness about continuing breastfeeding after a leprosy diagnosis, which posed a significant challenge. Furthermore, job loss due to leprosy-related issues or the difficulty of maintaining employment while frequently taking leave for treatment added to the financial burden.

> *It would be beneficial if I could receive treatment in our area. However, medical tests won't be available. For instance, if I've been taking medication for four months and experience side effects, I won't be able to get the necessary tests done.*
>
> ***– 53-years-old man, Currently on Treatment, from Uttar Pradesh***

Patients who discontinued treatment expressed dissatisfaction with the medication's effectiveness and its side effects, highlighting the necessity for more personalised counselling during treatment. Delays and inconsistencies in receiving test reports revealed communication barriers between patients and healthcare providers, disrupting the patient's healthcare journey. Moreover, unmet transfer requests indicated a lack of responsiveness from healthcare providers in accommodating patient preferences and convenience.

> *Before coming to this facility, I went to a couple of hospitals, but I couldn't find the right doctor during those visits. Then, I heard about this facility and decided to consult the doctor here. During my first visit, I could not meet the doctor due to navigating this facility and the travel delay.*
>
> ***– 26-year-old man, RFT, from Bihar***

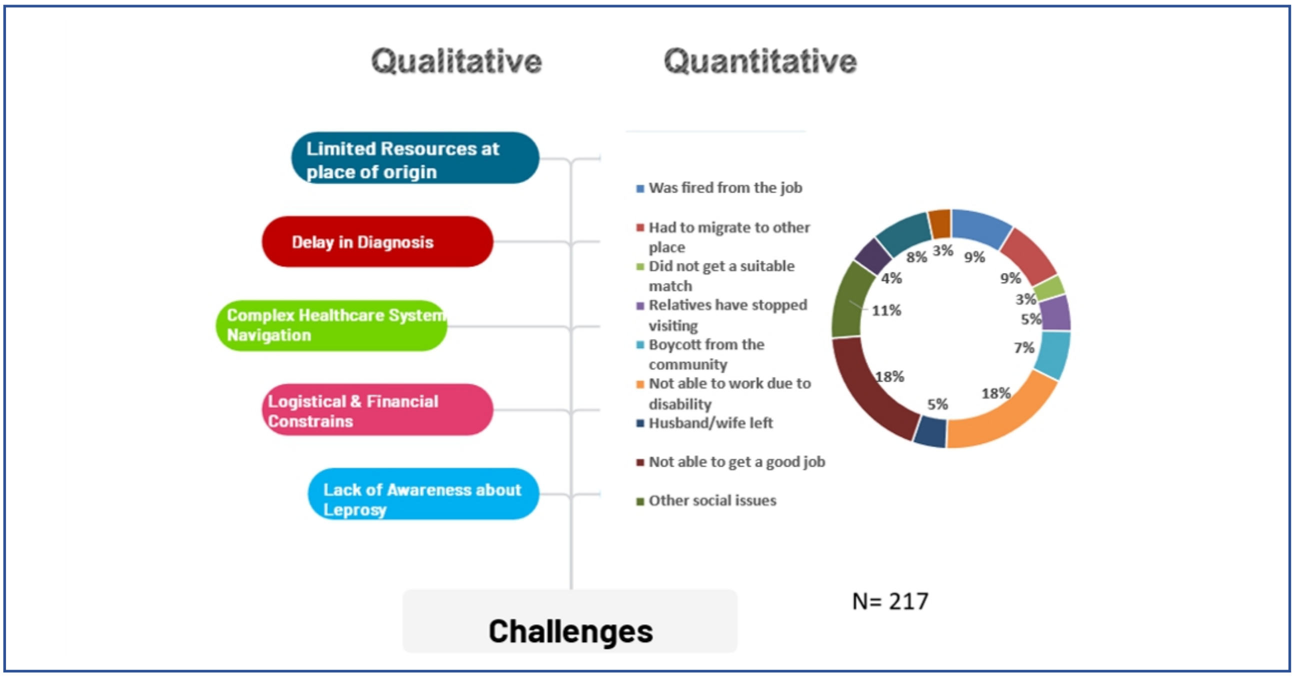
In summary, the challenges migrant patients faced at their state of origin namely Bihar & Uttar Pradesh is multiple and have been grouped into five broad categories:

- **Limited Availability and Accessibility of Affordable Leprosy Care Resources:** Patients seeking medicine and centralized treatment facilities in their native areas often face shortages due to inadequate leprosy care resources. The lack of MDT (multi-drug therapy) locally results in out-of-pocket expenditure for leprosy treatment. Additionally, healthcare providers at the village level often lack knowledge about leprosy, leading to misdiagnosis of the clinical manifestations.

- **Delay in Treatment:** Patients often waste time and resources visiting multiple healthcare providers and hospitals before finding the appropriate one. This delay exacerbates the progression of the disease.
- **Lack of Awareness:** There is a general lack of awareness about leprosy both within the community and among local healthcare providers. Patients often neglect the initial clinical symptoms, delaying their visit to healthcare providers. Healthcare providers may misdiagnose leprosy as an allergy, skin infection, or fungal infection due to insufficient knowledge.
- **Logistical and Financial Issues:** Socio-economic conditions cause concern for patients regarding the costs of travel, food, and lodging at the destination. These financial barriers further complicate access to care.
- **Complex Healthcare System Navigation:** Patients struggle with navigating the healthcare system and finding the right doctor or department to receive proper care.

The cumulative effects of these challenges at the state of origin lead patients to migrate to Delhi or Chandigarh for better diagnosis and treatment.

Figure 5.13: Challenges perceived by patients



5.2.4 Perceived Impact of Treatment

As per the RFT participants, the leprosy treatment has shown positive outcomes. Participants reported improvements in skin colour, enhanced physical mobility, and a reduction in pain, burning sensations, and boils. Social reintegration was evident, as individuals experienced greater acceptance in their communities, with invitations from neighbours and relatives. Some participants also noted temporary changes in skin colour during treatment and the successful removal of marks and ulcers.

> *After receiving treatment for leprosy, I regained the ability to walk and run. Since then, I have not experienced any pain, burning sensations, or boils. However, recently, I have encountered a new issue, which is unknown to me. I'm uncertain if the symptoms are connected to leprosy or if it is an entirely different condition.*
>
> ***– 33-years-old man from Bihar in Chandigarh, RFT***
>
> *My complexion has improved, unlike before when my face used to darken. It was a challenging period. The situation is getting better, although there are still some lingering ulcers. I can now climb stairs, and both relatives and neighbours from the village now engage with me. All these changes have occurred due to my treatment at Delhi. Earlier, people used to avoid me, but now they invite us again. I believe it's like the doctor and God collaborated for my survival, as I had a significant amount of pus, and society was shunning me.*
>
> ***– 35-years-old man from Uttar Pradesh in Delhi***

Patients who stopped treatment did so because they didn't see improvement, believed they were already cured, had other health issues, relied on alternative medicine, or didn't understand the potential complications. They may not have been adequately informed about the treatment outcome, the recovery period, or the extent of possible recovery. As a result, they stopped taking their medication when they didn't see quick results.

> *I left treatment under the assumption that I had been cured. Unfortunately, I was unaware that this decision would lead to significant problems. Upon realizing the consequences, I committed to completing the entire course of medication without missing a single day.*
>
> ***– 32-years-old man from Bihar in Delhi, Defaulted Treatment***
>
> *No, I didn't encounter any issues in the past 7-8 years, which led me to overlook the matter. However, in 2022, when I sensed some issues, I decided to pursue a comprehensive treatment.*
>
> ***– 58-years-old man from Uttar Pradesh in Delhi, Defaulter Treatment***

Patients currently on treatment exhibit diverse responses. Most participants reported positive changes in their condition due to the treatment. The level of improvement among the participants varied based on the progression of the disease. Many participants stated that the medication helped improve overall sensitivity and reduce numbness. While a couple of participants mentioned that the medication improved their overall condition, some minor issues remained. A 70-year-old male participant expressed satisfaction with the medicine, indicating substantial improvement in his condition.

> *Yes, there has been significant improvement. The wounds that were once present have completely healed, and the occurrence of ulcers have ceased. However, I still experience numbness in my right leg, and despite assurances that it will gradually subside, it persists. While walking, I continue to feel a burning sensation, and this aspect has not improved as much.*
>
> ***– 53-years-old man from Uttar Pradesh in Delhi, Currently under Treatment***

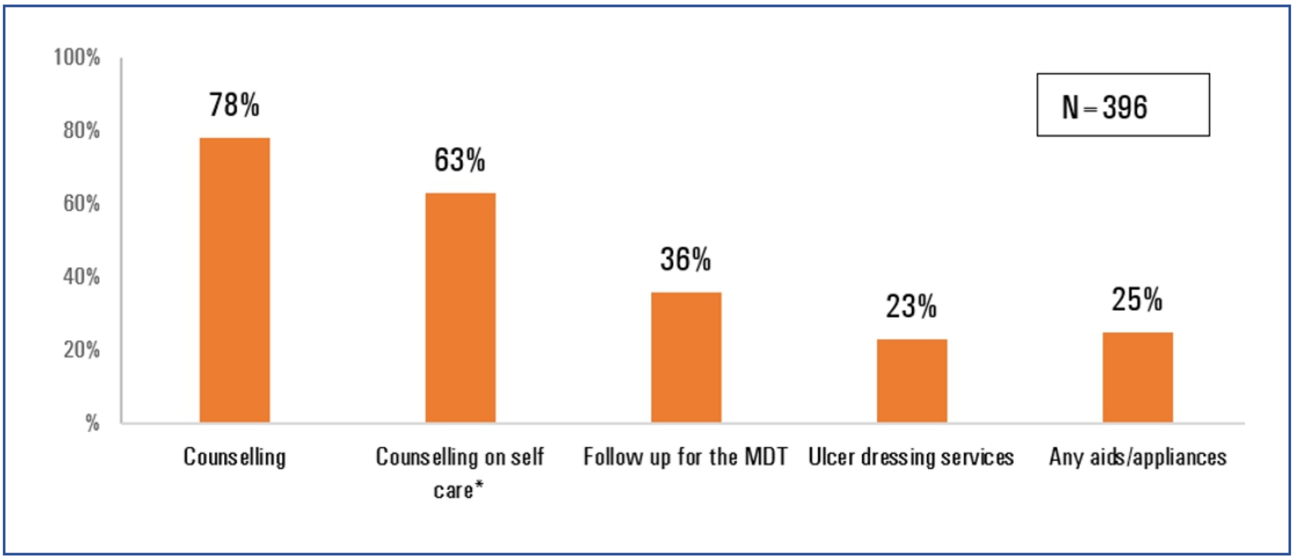
The impact of leprosy treatment is evident in the physical, mental, and social well-being of participants. Those who completed the treatment reported positive outcomes. Patients currently on treatment showed varied responses, while defaulters cited reasons such as lack of improvement. These experiences highlight the need for individualized care, regular follow-ups, and sustained support to ensure optimal health outcomes.

5.3 Availability of Support Services

The emotional well-being of individuals affected by leprosy is a crucial aspect of their overall care and should be addressed through counselling. In addition to medical treatment, counselling helps patients cope with the emotional challenges of the diagnosis and teaches self-care practices. Support services, such as follow-up care and the provision of self-care kits, are also essential for their ongoing well-being.

Almost four-fifths (78%) of patients reported receiving counselling. However, there was a decrease in the proportion of patients receiving self-care kits, MCR footwear, or counselling on self-care.

Figure 5.14: Major domains of counselling



- ***Only 1% of the patients reported ANY REACTION post-taking medicines.***
- ***Around 13% of 48 patients reported receiving ANY RECONSTRUCTIVE SURGERY (who needed).***
- ***Out of patients reporting grade 1 or grade 2 disability, 58% reported participating in any social function.***
- ***92% of the patients said that the services they received IMPROVED their ability to carry out activities required for daily living.***

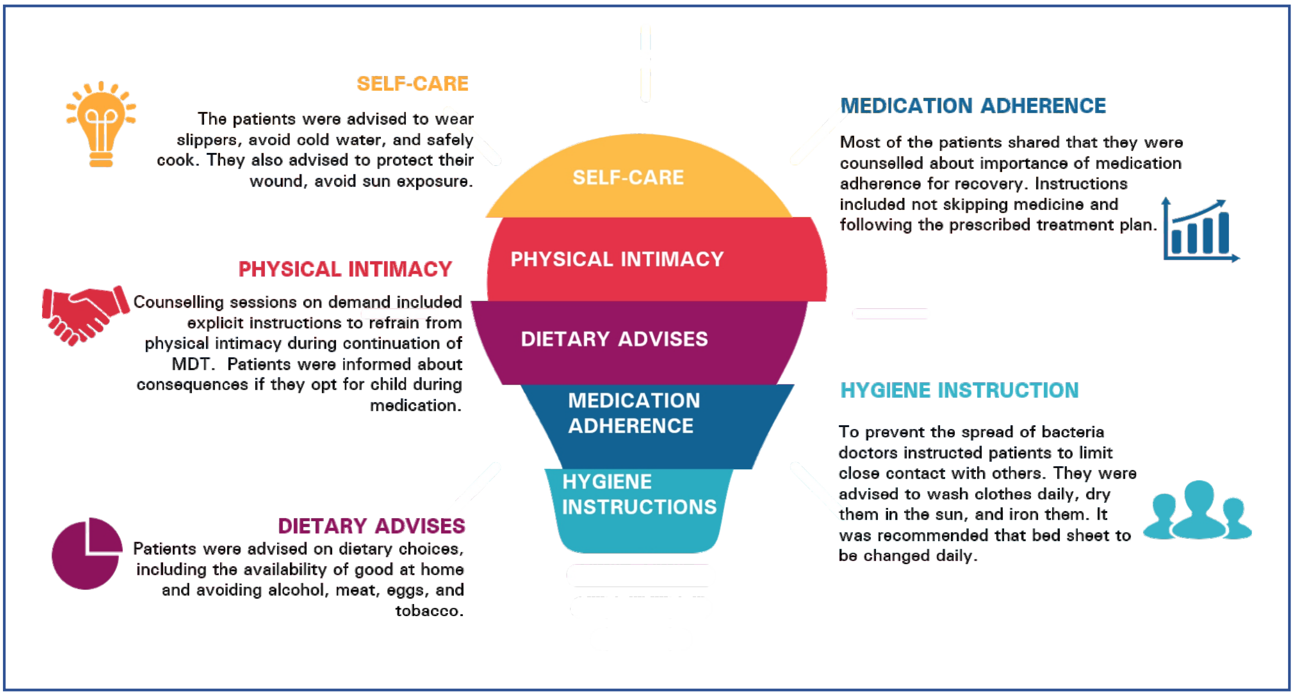
Almost all the patients reported receiving free medicines. However, very few patients received MCR footwear, self-care kits, or other aids. When asked about the topics covered during counselling, the majority of patients (99%) reported receiving guidance on the continuation of their treatment, followed by self-care (93%). This indicates that the primary focus of leprosy staff is on ensuring adherence to the treatment regimen. However, other important topics, such as side effects, self-care kits, MCR footwear, transmission of leprosy to family members, SDR (sensitive drug resistance), mental health, and others, were not discussed in detail.

In qualitative interviews, all patients stated that healthcare providers provided advice on various issues, including self-care, medication adherence, hygiene, dietary guidance, physical intimacy, and the risks associated with pregnancy during treatment. The counselling sessions primarily focused on medication adherence and self-care. Although these two areas were thoroughly addressed, a few participants mentioned that they were also informed about cleanliness and sleeping behaviour.

> *Madam told me not to worry; it would be fine. Ma'am told me two people would sleep in one room. I have to keep the bed clean. We have to stay clean, and we have to have medicine on time. We have to live nicely. We don't have to go in the sun.*
>
> ***– 22 Year old woman Currently on Treatment in Delhi***

> *They provided me with counselling. When I was admitted, the Madam came and advised me to stay away from my wife as long as I was on the red-striped medication. She explained that if my wife conceived during this time, the child could be born with disabilities, and my wife could also contract the disease. She conveyed this verbally and provided it in writing as well.*
>
> ***– 35 Year old Man RFT in Delhi***

Figure 5.15: Domains of Counselling



SELF-CARE

The patients were advised to wear slippers, avoid cold water, and safely cook. They also advised to protect their wound, avoid sun exposure.

PHYSICAL INTIMACY

Counselling sessions on demand included explicit instructions to refrain from physical intimacy during continuation of MDT. Patients were informed about consequences if they opt for child during medication.

DIETARY ADVISES

Patients were advised on dietary choices, including the availability of good at home and avoiding alcohol, meat, eggs, and tobacco.

MEDICATION ADHERENCE

Most of the patients shared that they were counselled about importance of medication adherence for recovery. Instructions included not skipping medicine and following the prescribed treatment plan.

HYGIENE INSTRUCTION

To prevent the spread of bacteria doctors instructed patients to limit close contact with others. They were advised to wash clothes daily, dry them in the sun, and iron them. It was recommended that bed sheet to be changed daily.

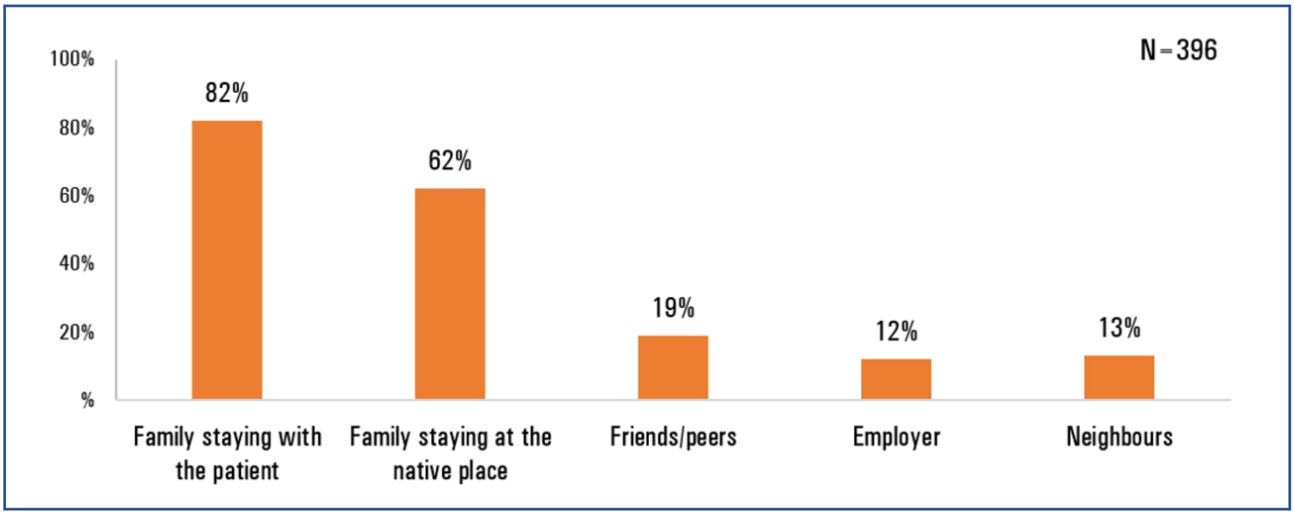
5.3.1 Additional Support Required

The patients were asked what support they needed to live a normal life following the completion of MDT treatment. The supports identified by the patients included: self-care demonstration, financial support, medicines, livelihood support, self-care kit and reconstructive surgery. While a similar question was asked to the household members, they mainly requested treatment-related support for the patient-83% followed by livelihood for any family member – 17% and financial aid – 15%. As most of the patients belong to lower or medium Socio-economic class (SEC), it is evident that they are worried about their future livelihood post treatment.

5.4 Family and Social Support Received by Patients

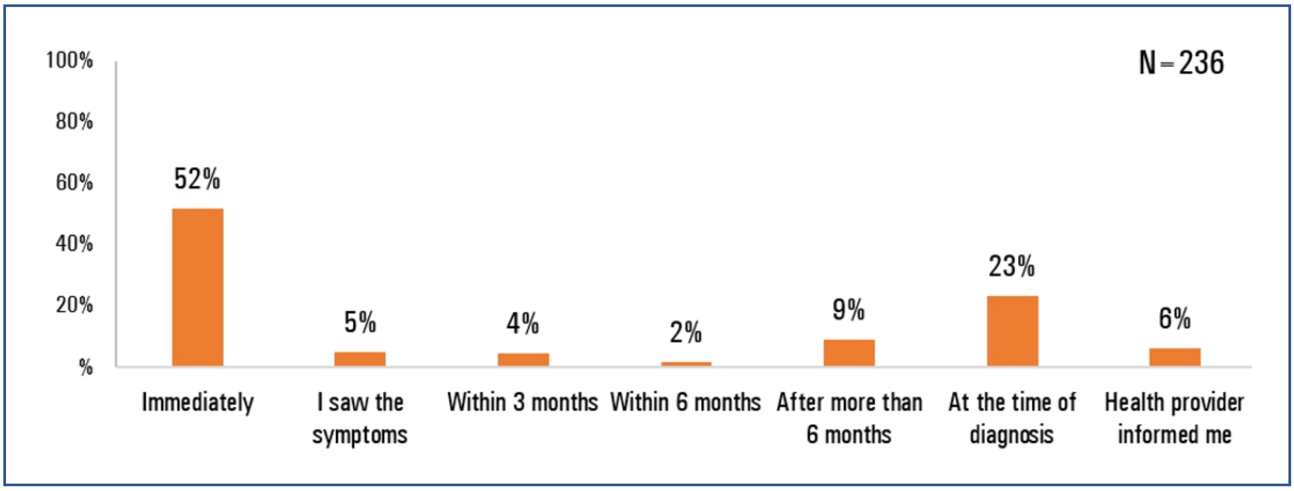
It can be seen from the following figure 5.16 that more than four-fifths of the patients (82%) reported that the family members staying with them were aware of their leprosy status. However, the family staying away from them or other outsiders were not aware about their leprosy status. This highlights the persistent fear of stigma associated with leprosy.

Figure 5.16: People who were aware about the leprosy status of the patient



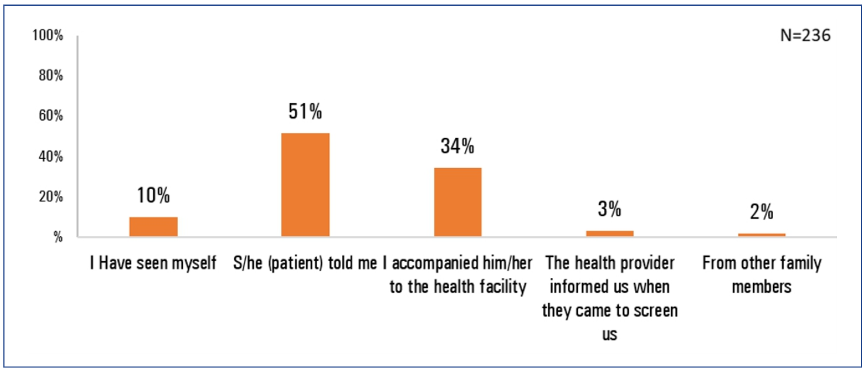
The household members were also asked when they became aware of the patient's leprosy status. Figure 5.17 clearly shows that slightly more than half (52%) of the household members learned about the leprosy status immediately, while about one-fourth (23%) were informed at the time of diagnosis.

Figure 5.17: When did the household member came to know about the leprosy status of the patient



Family support in terms of accompanying the patient to the health facility was reported by one-third of the household members interviewed. Additionally, the comfort of the patient with their family is reflected in the fact that they themselves informed their family members of their leprosy status.

Figure 5.18: Person who informed the household member about the leprosy status of the patient



The qualitative findings provided closer insights into the family support provided to patients after their leprosy diagnosis. Almost all patients indicated that their family members were aware of their diagnosis. Seven out of nine patients currently undergoing treatment reported that their family members knew about their leprosy status. Almost all participants mentioned that their family members encouraged them to seek treatment and motivated them throughout the process. Most of the participants were accompanied by family members for treatment in Delhi. One male participant shared that his spouse and sister accompanied him for treatment, helping him carry the necessary documents and complete the procedure. Another male participant expressed, *"Today I am alive because of my father-in-law, he helped me a lot to get appropriate treatment"*.

> *My daughter resides in Delhi. When my health did not improve with the treatment in my village, my son-in-law urged me to come to Delhi for better medical care. Upon my arrival, they accompanied me to various hospitals, including private ones.*
>
> ***– 68-years-old man from Uttar Pradesh in Delhi, RFT***

However, a couple of participants mentioned that some household members were sceptical about the leprosy diagnosis. One RFT participant shared that his sister-in-law left the home with her toddler, fearing they would be infected. Another participant currently on treatment was sent to her parents' home with her two children, under the pretext that 'in my marital home there was no one who could cook for them'. Another patient, who is still undergoing treatment, reported being isolated within the house, with his clothes and utensils kept separately from the others.

> *My family members did not react positively. They believed this illness might have been inherited genetically from ancestors, but we don't know the nature of the disease.*
>
> ***– 26-years-old man from Bihar in Chandigarh, RFT***

5.4.1 Social support

Patients currently on treatment reported that their family members are aware of their leprosy status, but they were sceptical about whether their neighbours or community members knew. Nearly half of the male patients stated that their friends and peers were aware of their condition, while women were more hesitant to disclose their leprosy status to anyone outside the family. Almost all women said, "I don't know if our neighbour knows about it or not. We never disclosed it". One of the patients currently on treatment informed, 'I never told anyone about my condition, since no one asked ". On the other hand, a 22-year-old betrothed woman was forced to leave her village and migrate to Delhi out of fear that her neighbours would learn of her leprosy status and her engagement would be annulled. Only one RFT participant mentioned that his entire village knew about his condition because he had been seriously ill and his condition had been critical.

> *During that interval, I found myself in a critical condition, requiring 40 days of hospitalisation. My body was covered in numerous blisters, which significantly affected my overall health. Unfortunately, this health issue led to noticeable social ostracism, as people kept their distance from me. Consequently, the information spread throughout my village.*
>
> ***– 35-years-old man from Uttar Pradesh in Delhi, RFT***

Four patients currently on treatment, two defaulters, and four RFT participants mentioned that their friends knew about their condition, but they never discriminated against them. One RFT participant shared that his friends had even helped him with money to get treatment.

> *When visiting my hometown, I reunite with friends who genuinely enjoy my company. In the early days of my leprosy diagnosis, all my friends came to see me at the hospital, providing both emotional support and financial assistance to cover the medical expenses. During that difficult time, my father refused to provide any financial aid. Whenever I meet these friends, I feel an overwhelming sense of gratitude. When I thank them, they simply express their happiness at seeing me alive and well.*
>
> ***– 33-years-old man from Bihar in Chandigarh, RFT***

5.5 Contact Tracing

As per the WHO Global Strategy Report 2021-2030, early detection through active case searches (including contact screening) and prompt treatment with MDT or post-exposure prophylaxis are crucial for containing the spread of infection and preventing disabilities. The patients and their household members were asked about contact screening among their contacts, specifically family members.

The study found that only slightly more than one-tenth (14%) of the patients reported that contact screening was conducted for their household members or close contacts (Fig. 5.19). Similarly, about 14% of the household members contacted for this study reported that contact screening was done (Fig. 5.20).

The household members cited several reasons for not undergoing screening, with the majority mentioning that "they were not informed about the screening by anyone" (89%). To confirm whether contact screening had taken place, the household members were asked if they had been given a Single Dose of Rifampicin (SDR). Around 23% of the household members reported receiving SDR. Of those, 74% noted a change in the colour of their urine after taking SDR, which was asked to confirm whether they had been given the medication. Similarly, 12 participants in the qualitative interview reported that neither their family members underwent contact screening nor received SDR. Other participants mentioned that their family members received only SDR.

> *Yes, Madam here provided a tablet for each member of my family, and they all took it. However, none of them underwent any examinations. Even though she had requested my family members to undergo tests, they did not comply.*
>
> ***– 22-years-old woman from Bihar in Delhi, Currently On Treatment***
>
> *When I received a leprosy diagnosis, I chose not to return to my family. My husband refrained from taking the prescribed medicine as he had previously abandoned treatment midway through his leprosy diagnosis. Fortunately, my children were examined for leprosy, but no signs were detected, and they are in good health.*
>
> ***– 23-years-old woman from Uttar Pradesh in Delhi, Currently On Treatment***

Figure 5.19: Whether contact screening of family members done (Patients)

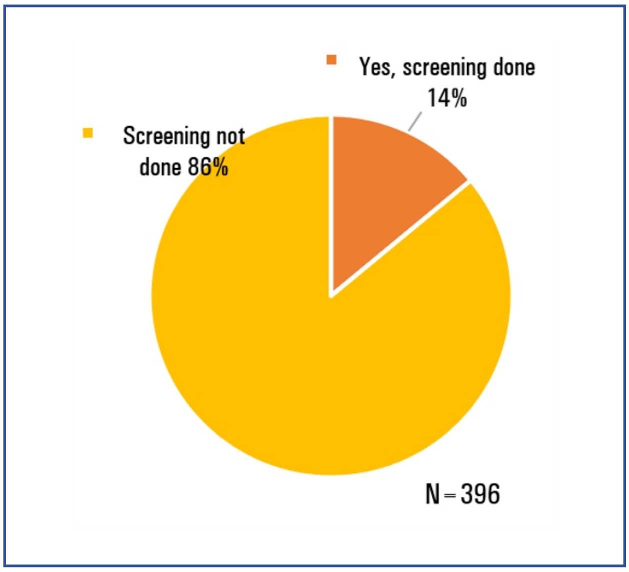
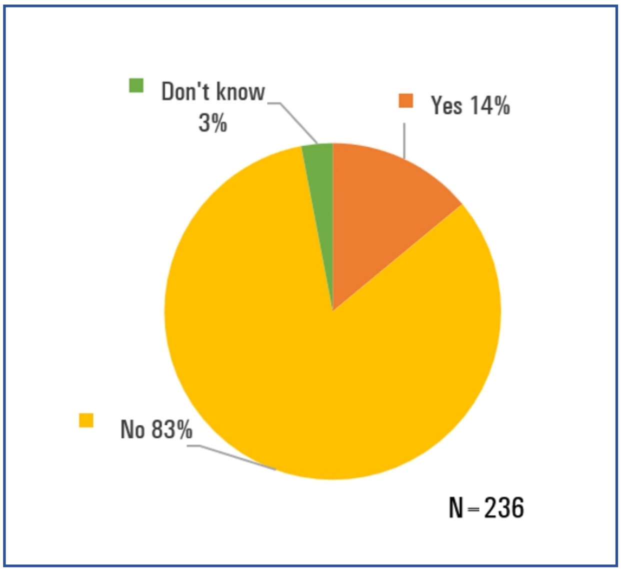


Figure 5.20: Whether screening of the respondent or other HH member was done (HH member)



Incidence of Leprosy in the family

Around 7% of the patients reported having another member in the family affected with leprosy (Fig.5.21). Most of the patients (95%) reported that they were the first one to be diagnosed with leprosy in their family (Fig.5.22).

Figure 5.21: Incidence of leprosy in the family

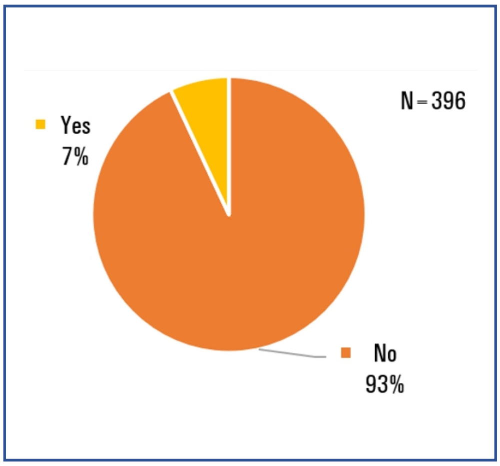
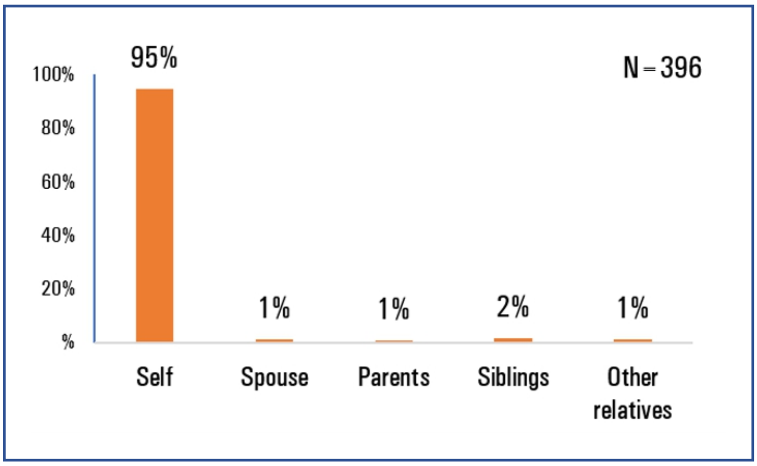


Figure 5.22: First person in the family to get leprosy



During the qualitative interviews, several participants mentioned that family members had been affected by leprosy, including siblings, nephews/nieces, and spouses. One participant expressed concern about her children, although tests showed they were not affected. Another participant's children were diagnosed with leprosy and were undergoing treatment. Additionally, one participant shared that his grandfather had leprosy but never received treatment.

> *Yes, three members of my family have been diagnosed with leprosy: my sister's daughter, my brother's daughter, and one of my brothers. The two affected nieces are aged 12 and 15 years.*
>
> ***– 22-years-old woman from Bihar in Delhi, Currently Under Treatment***
>
> *Both my elder and younger brothers suffer from this disease. My older brother went to Dwarka Sector 10. He had an operation there so he recovered. His finger was also fine. But the younger one is not receiving any treatment, he is living in our village.*
>
> ***– 26-years-old man from Bihar in Delhi RFT***

PRI Members Perception About Leprosy

Panchayati Raj Institutions (PRI) members are important stakeholders in any programme, serving as a major source of information for people in their village. They play a significant role in other health programmes, making their involvement in leprosy awareness crucial. To understand the role PRI members play or can play in addressing leprosy, interviews were conducted with 10 Pradhans, 5 other PRI members, and 20 ward councillors in an urban area. In total, 35 PRI members were interviewed. They were asked about their awareness of leprosy, its transmission, treatment, and the current status of leprosy in their village or ward.

Awareness and Myths about Leprosy

Leprosy is curable (32)

Leprosy is contagious (22)

Leprosy can happen to anyone (20)

It spreads :

- ***through sneezing and coughing (7)***
- ***due to unhygienic conditions, dirty water (6)***
- ***Living with the person affected with leprosy (3)***

Note: N for each response stated in ()

Overall, most of the PRI members had heard of leprosy. Further probing highlighted the following key issues:

Awareness About Place of Treatment and Actual Practice

All the PRI members were aware that leprosy treatment is available at government health facilities. However, their awareness about the specific level of health facility (whether PHC/CHC, etc.) providing such treatment was limited. Municipal councillors in Delhi and Chandigarh reported that treatment for leprosy is available at tertiary care hospitals such as AIIMS, Safdarjung Hospital, Hindu Rao Hospital, GTB Hospital, Swami Dayanand Hospital, Rajiv Gandhi Hospital, TLM Hospital in Delhi, and GMSH-16 and PGI in Chandigarh.

Twelve councillors stated they did not know where suspected cases could seek treatment, as there were no reported cases of leprosy in their area at the time of the interview. On the other hand, 18 PRI members reported that people visit government health facilities for treatment, while four mentioned that patients seek care at private facilities or from local private practitioners. Half of the PRI members confirmed that leprosy treatment is available at nearby PHCs/CHCs.

When asked about contact screening, half of the PRI members (17 out of 35) confirmed that contact screening for close contacts is carried out. Regarding the stigma associated with leprosy, PRI members were asked whether patients affected by leprosy could attend social functions in their community.

In response, 11 said the *'patients attend the social functions without any hesitation',* five said *'patients affected with leprosy face challenges in getting proper housing facilities in their area',* four said *'the patients affected with leprosy face challenge in keeping or obtaining new jobs',* and three PRI members said *'have a separate hamlet for the patients affected with leprosy in their area'*.

To support patients affected by leprosy, PRI members suggested several measures, including:

- Providing free treatment,
- Raising awareness and sensitizing the public to reduce stigma,
- Offering financial assistance,
- Providing livelihood options to ensure income generation.

CHAPTER 6: PERCEPTION OF HEALTHCARE PROVIDERS, LEPROSY OFFICIALS AND ILEP PARTNERS

The perspectives of healthcare providers, key officials, and ILEP) partners are vita for understanding the impact of migration on leprosy. Healthcare providers offer firsthand experience with challenges migrants face in diagnosis and treatment adherence, while officials and partners provide essential information on leprosy cases and trends. District-level officials play a pivotal role by designing tailored interventions to address specific needs of migrant populations, thereby influencing policy development and community engagement strategies. This chapter, therefore, focuses on understanding the perceptions of healthcare providers at various levels, including PHC/UPHCs, CHCs, tertiary care hospitals, private doctors, NMS, NMA, PMWs, FLWs, DLO, SLO, and ILEP partners regarding leprosy and its intersection with migration.

6.1 Roles and Responsibilities of Healthcare Providers, Leprosy Officials Towards Migrant Persons affected with Leprosy

Managing migrant leprosy patients requires coordinated efforts from key stakeholders, each playing a distinct role. Healthcare providers are at the forefront, responsible for diagnosing, planning treatments, making medical decisions, and monitoring the progress of migrant patients. Frontline workers, such as ASHA, ANM, and AWW, contribute to identifying hidden migrants within the community with symptoms of leprosy during home visits. They also maintain records, refer suspected cases to health facilities, and participate in health campaigns.

Non-Medical Supervisors (NMS) and Para Medical Workers (PMWs) are instrumental in managing migrant patients. Along with their regular responsibilities (performing clinical assessments, managing medication supplies, providing comprehensive care, and referring for reconstructive surgery), they ensure close monitoring, tracking, and follow-up with migrant patients to enhance treatment adherence and completion rates.

At the district and state levels, District Leprosy Officers (DLOs) and State Leprosy Officers (SLOs) oversee the implementation of the NLEP, including the critical task of coordinating inter-state patient transfers.

Together, these stakeholders address the unique challenges faced by migrant leprosy patients, ensuring effective care delivery and contributing to the larger objective of eradicating leprosy in India.

6.2 Insights of Key Stakeholders on Leprosy Case Detection and Diagnosis among Migrants

Case Detection

The National Leprosy Eradication Programme (NLEP) employs proactive strategies, such as house-to-house surveys, to identify cases, which are particularly crucial for reaching migrant populations. Key stakeholders, including frontline health workers (FLWs), medical officers (MOs), and public health officials, play a pivotal role in these efforts. Typically, the FLWs, like ASHAs conduct house-to-house surveys to identify individuals with leprosy symptoms, which is especially important for transient populations. . Suspected cases, including migrants, are then referred to Primary Health Centres (PHCs), Urban Primary Health Centres (UPHCs), or Community Health Centres (CHCs) for further evaluation and diagnosis.

> *Yes, we get 2-3 patients from each programme here. These programmes are organised twice a year. However, if we can do them quarterly, we have a chance to get more patients.*
>
> ***– Leprosy Official 1 Uttar Pradesh***
>
> *Yes, the awareness campaign starts on 1st February and continues for 14 days. During these days, all the ASHAs conduct home visits, talk to people, and spread awareness about leprosy. The community is mobilised to inform the ASHA if they see anyone with symptoms, and then the ASHAs work as a referral bridge between the patient and the facility. This whole program is a running activity.*
>
> ***– Healthcare Provider 5 Uttar Pradesh***

Contact Tracing for Leprosy

Contact tracing for leprosy entails examining close contacts of patients, a critical step for early case detection. However, healthcare providers, Non-Medical Supervisors (NMS), and paramedical staff in Delhi and Chandigarh highlighted the challenges in screening close contacts of migrant patients from other states. Despite frequent requests for patients to bring their close contacts to health facilities for screening, only a small number comply. Additionally, conducting contact screening in other states is beyond the scope of work for NMS, Para Medical Workers (PMWs), or healthcare providers.

Healthcare providers in Uttar Pradesh shared similar experiences . They said, patients often refuse the idea of home visits by healthcare providers for contact screening. Despite counselling, a handful of patients agreed to home visits only for family members, provided their neighbours are not informed about their leprosy diagnosis. In such scenarios, ASHAs play a vital role by incorporating contact screening into their regular home visits, leveraging their established rapport within the community.

> *The ones who are living with their family here we call their family and check them. We screen them. The patients who are coming from Bihar and Uttar Pradesh alone for treatment only, it is difficult for them. Sometimes, we ask them to bring their family members, but they refuse.*
>
> ***– Healthcare Provider 1 Chandigarh***

Diagnosis

For diagnosis, all participants reported adherence to the prescribed protocol of the National Leprosy Eradication Programme (NLEP). This protocol involves a physical examination, a biopsy or skin slit smear, and nerve examination. The process is consistently applied to both migrant and non-migrant patients across all states.

6.3 Management of Migrant Patients Affected with Leprosy

The effective management of migrant patients with leprosy is pivotal to achieving a "zero leprosy" status. Proper management ensures continuity of care, prevents duplication of records and treatments, and is expected to enhance treatment completion rates. Essential mechanisms for managing migrant patients include monitoring, follow-ups, and tracking, which require consistent and detailed record-keeping practices across states.

In Uttar Pradesh, patient records typically capture only the current address at the start of treatment, without accounting for inter-block, inter-district, or interstate migration. By contrast, Delhi and Chandigarh maintain more comprehensive registers that record both permanent and current addresses. This dual-address system enables healthcare workers to determine whether a patient has migrated from another state, with permanent addresses often verified using Aadhaar cards. Patients are recorded based on their location at the time of treatment (destination), not their place of origin. In case the patient is to be referred back to the place of origin, then a referral slip is usually provided to submit in that facility. However, there is no mechanism to confirm whether the patient continues treatment at the referred facility or drops out.

NMSs and PMWs often use registered mobile numbers to follow up with migrant patients, ensuring adherence to treatment. Healthcare providers at CHCs, PHCs, and UPHCs monitor patient progress through physical check-ups during follow-up visits and collaborate with local health workers for consistent follow-ups. Patients are also provided with emergency contact numbers for assistance.

Key stakeholders identified several challenges in tracking migrant patients, including their migratory nature, lack of motivation for treatment, social stigma, financial constraints, inaccurate contact details, language barriers, and unknown whereabouts. PMWs emphasized the need for a comprehensive digital tracking system, akin to that used for tuberculosis management, to improve patient monitoring and follow-up.

> *If a migrant patient has not come here for a month, I will know about it after looking at the register. For 8 or 10 days, they can be busy here and there, but after that, I call them. I tell them your medicines are pending. Where are you? Why did you not come to take the medicine? Also, if a patient is not coming, people often provide someone else's numbers.*
>
> ***– NMS, Chandigarh***
>
> *First, the incubation period of leprosy is too long. It takes 5-10 years to manifest the symptoms. Therefore, it is hard to identify where this patient got infected. Moreover, though Bihar or Uttar Pradesh origin person migrated to Chandigarh 20 years ago, they still visit their native place on different occasions. Hence, it's a compliance, and you must strengthen other states. Chandigarh is a concern, but you have to concentrate on Punjab, Haryana and Himachal also.*
>
> ***– Private Doctor, Chandigarh***

6.3.1 NIKUSTH

In 2017–2018, the National Leprosy Eradication Programme (NLEP) introduced NIKUSTH, a web-based system aimed at improving the reporting and management of leprosy cases. This system was designed to standardise data collection and facilitate better tracking of leprosy-related activities. The portal was expected to provide a clearer understanding of the disease's prevalence and ensure accurate reporting.

However, stakeholders have identified significant gaps in NIKUSTH, particularly regarding its utility for managing migrant patients. One critical issue is the system's inability to capture essential details about migration. If a patient relocates from one area to another, healthcare facilities at the destination may have no record of the patient's ongoing treatment from the place of origin unless the patient discloses this information. This lack of continuity can result in delays in care or, in some cases, force the patient to undergo repeated diagnostic tests unnecessarily.

Feedback from medical officers about NIKUSTH has been mixed. While they acknowledge its potential to enhance leprosy case management, they have expressed frustrations with its technical and usability challenges. Common concerns include system malfunctions, data duplication, and inadequate training for healthcare providers on how to use the platform effectively. Many feel the system is not user-friendly, which hinders its adoption and effectiveness in achieving its intended goals.

> *There is lot of work pending in NIKUSTH, they made the software but it is not that much developed, tell me one thing suppose one UP patient is there, suppose they put here UP Azamgarh, so SLO of UP must know about it that one patient was diagnosed there in Chandigarh but in software they are not able to see the patient of Chandigarh there in UP.*
>
> ***- Healthcare Provider 3 Chandigarh***

6.4 Perception on Awareness about Leprosy

Many participants highlighted a pervasive lack of awareness about leprosy within communities, which often leads to delayed diagnosis and treatment. Stigma and myths surrounding the disease persist, stemming from limited knowledge about its causes, symptoms, and treatment. Additionally, local healthcare providers and rural medical practitioners (RMPs) were reported to have insufficient understanding of leprosy's clinical manifestations. This gap in knowledge frequently results in misidentification of symptoms and incorrect treatment for patients.

Participants noted that despite challenges, community awareness about leprosy is increasing due to awareness campaigns and training. If a family member has leprosy, other members are now aware of the disease and promptly seek appropriate health facilities if similar symptoms appear.

> *The sister of my house help had hypo-pigmented patches on her skin. Both of the sisters had a wheatish complexion. The sister with the patches felt that her skin was becoming fairer. However, she was not aware of her condition. The patient had been undiagnosed for 4-5 years.*
>
> ***– Healthcare Provider 1 Uttar Pradesh***

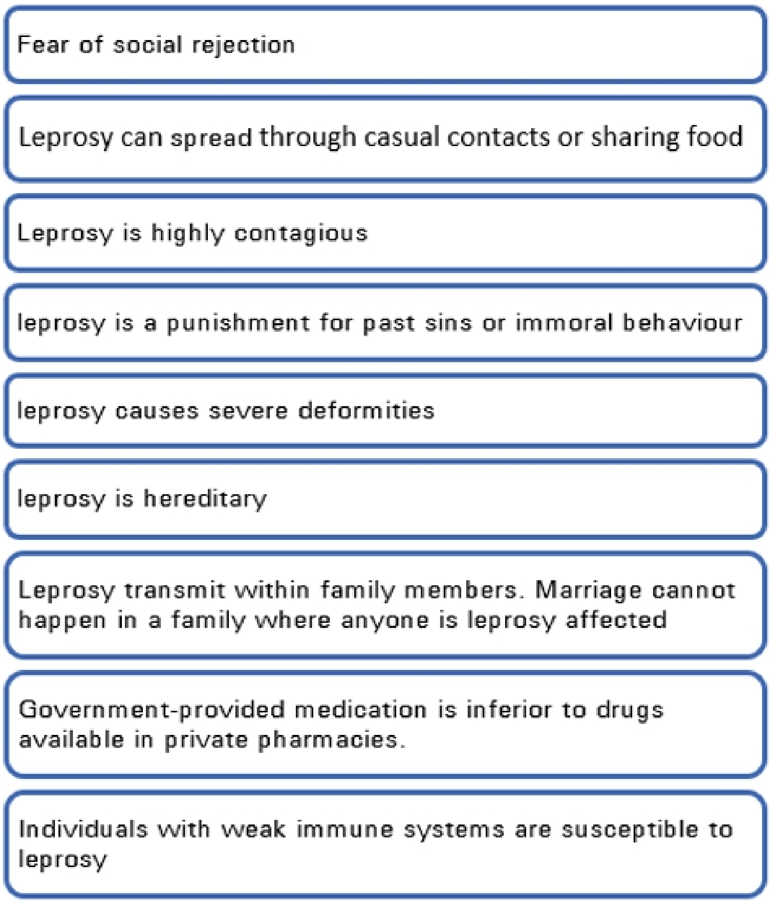
> *Patients often initially consult "jhola chhap" doctors for red patches they mistake for ringworm. These unlicensed doctors may incorrectly prescribe steroids for leprosy, worsening the condition. Eventually, patients seek proper diagnosis and treatment from us when symptoms become severe.*
>
> ***– Healthcare Provider-11, Uttar Pradesh***

6.5 Stigma and Myths Associated with Leprosy

The key stakeholders also informed that the stigma and myths associated with leprosy significantly hinder the treatment of persons affected with leprosy. Due to pervasive misconceptions, many people with leprosy choose to migrate to escape social ostracism and discrimination in their place of origin. Facing widespread rejection and the fear of public disclosure of their condition, they often relocate in search of a more accepting environment and better healthcare services.

Participants noted that deep-seated cultural beliefs, such as viewing leprosy as a curse or punishment, contribute to severe social ostracism and discrimination. This stigma discourages individuals from disclosing their condition to friends, neighbours, or employers, fearing isolation and rejection. Widespread misunderstandings about the disease's transmission perpetuate fears of contagion, further marginalising affected individuals and deterring them from seeking timely medical care. As a result, delayed treatment and discriminatory practices are common.

Figure 6.1: Common Myths & Stigma Associated with Leprosy in Society informed by Participants



Fear of social rejection

Leprosy can spread through casual contacts or sharing food

Leprosy is highly contagious

leprosy is a punishment for past sins or immoral behaviour

leprosy causes severe deformities

leprosy is hereditary

Leprosy transmit within family members. Marriage cannot happen in a family where anyone is leprosy affected

Government-provided medication is inferior to drugs available in private pharmacies.

Individuals with weak immune systems are susceptible to leprosy

Patients are often reluctant to access services due to concerns about privacy and judgment. Local health workers, such as ASHAs, face difficulties in reaching out to these patients, who frequently resist contact tracing and treatment out of fear of their leprosy status being revealed. Migration is often driven by a desire to maintain privacy and avoid the social and economic repercussions associated with their diagnosis. In some cases, individuals also migrate in search of improved economic opportunities and living conditions.

Thus, stigma not only shapes how individuals are treated within their communities but also influences their decisions to move to new regions in pursuit of a more supportive and inclusive environment.

> *Stigma around leprosy is evident in real-life situations. When I joined the department, a paramedical worker received a call from an 18-year-old patient with leprosy who refused a visit by us due to fear of job loss if his colleagues learned about his condition. We were concerned and invited him to our facility, where he explained his refusal stemmed from the fear of losing his job.*
>
> ***– Leprosy Official Delhi***

6.6 Gender Dynamics and Migration Pattern in Treatment for Leprosy: Challenges, Preferences, and Societal Perceptions

The participants highlighted significant gender-related dynamics in the treatment of leprosy and migration patterns, emphasizing the influence of societal norms, preferences, and challenges. They noted that gender roles significantly shape migration patterns among individuals affected by leprosy. Women are disproportionately impacted by societal stigma and fear, often leading to delays in diagnosis and treatment and discouraging them from seeking healthcare outside their communities. Household responsibilities and societal expectations further restrict women's mobility. In contrast, men, as primary breadwinners, are often more willing and able to migrate for healthcare or employment, creating distinct migration trends.

Participants also noted a strong preference for gender-matched interactions in healthcare. Female patients often prefer female doctors, citing greater comfort during consultations and examinations. Cross-gender examinations were identified as challenging, with male volunteers occasionally assisting in specific situations. ASHAs highlighted difficulties in examining male patients, while cross-gender counselling was identified as a barrier to discussing sensitive topics such as sexual relationships and pregnancy. Both men and women are hesitant to openly discuss these issues, underscoring the need for culturally sensitive communication approaches.

Societal stigma and fear surrounding leprosy, particularly among women patients, impact their treatment-seeking behaviour. Men often inquire about work-related issues and managing physical discomfort, while women prioritize family responsibilities and worry about disease transmission within the household. These differences reflect the impact of gender roles and cultural expectations on health-seeking behaviour.

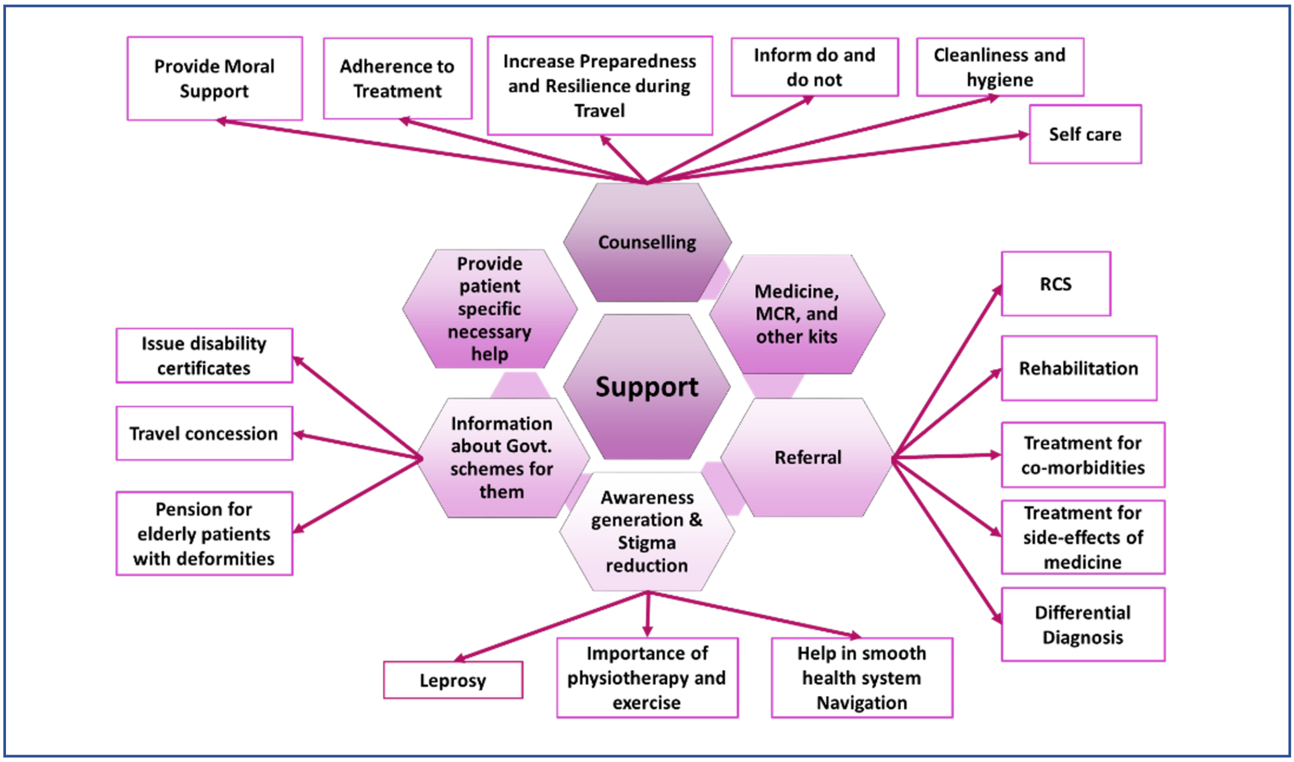
Women with family members affected by leprosy are often discouraged from interacting with others due to the stigma, resulting in delayed diagnosis and treatment. The findings underscore the need for tailored, gender-sensitive approaches to address these barriers effectively, recognizing the cultural nuances and specific needs of male and female patients.

> *Appearance for young girls is very important to get married. If they have any mark on the face then they prefer to any cream first, then visit doctors. On the other hand, attention on child health is only given if they suffer with cold, cough, or diarrhoea, no one pays attention to the marks on the body of a child.*
>
> ***– Healthcare Providers 7 Uttar Pradesh***
>
> *Resistance to home visits is common, especially for women and children. When we request visits, they refuse outright. This is especially true for women patients, who are unwilling to disclose their leprosy status to anyone other than family members.*
>
> ***– Healthcare Providers 2 Uttar Pradesh***

6.7 Support Services

Healthcare providers reported that, in addition to offering treatment and medicine, they also conduct counselling for both patients and their family members. They provide referrals, distribute medicines, Micro Cellular Rubber (MCR) footwear, and other kits. They are also involved in raising awareness about leprosy and reducing stigma. Furthermore, healthcare providers inform patients about various government schemes specifically aimed at individuals affected by leprosy and offer any additional support requested by the patients (Fig 6.2).

Figure 6.2: Support Services Participants Often Provide to the Patients



Counselling:

All participants emphasized that counselling is a crucial component of both the treatment process and post-diagnosis care for leprosy patients. Upon diagnosis, many patients experience fear and uncertainty, making counselling essential. The key areas covered in counselling include:

- Basic facts about leprosy, including how it is transmitted and prevented
- Adherence to treatment, particularly Multi-Drug Therapy (MDT)
- Self-care practices and the importance of cleanliness and hygiene management
- Addressing concerns about potential deformities
- Guidance on dietary patterns, substance consumption, and overall lifestyle behaviour

Healthcare providers also offer moral support to help alleviate the mental stress often associated with leprosy. Additionally, counselling for migrant patients is particularly important, focusing on ensuring continuity of treatment (MDT) during migration.

Figure 6.3. Reasons of Patient Referral

Side effect	• Side effects include *M. lepra* reaction, disability
Differential diagnosis	• Patients needed further diagnostic test due to confusion
Rehabilitation	• Patient who need physiotherapy or rehabilitation
Co-morbidities	• Patients with co-morbidities like cardiac situation, and other diseases
Reconstructive surgery	• For reconstructive surgery, patients are referred to Delhi, where patients receive RCS with specialized procedure

> *First of all, when we tell them that they have leprosy, they get scared. We need do counselling for them. There is nothing to be scared of, and this is a common disease like TB, Malaria, and fever. You will get well after medication, and this disease is the same like any other. The treatment is completely free. The first thing we do is put a stamp of free on their card.*
>
> ***– Paramedical Worker 1 Chandigarh***

However, focused counselling on several critical aspects is lacking, including:

- The psychological state of patients, addressing mental health concerns
- Substance abuse and its impact on treatment
- Lifestyle behaviours that could affect recovery and disease management
- Ensuring the continuation of medications during migration
- Contact tracing to identify potential new cases
- Understanding the transmission of leprosy
- Discussing the implications of physical intimacy with a partner
- Addressing pregnancy during leprosy treatment, which is a sensitive topic

Referral of Patients:

Healthcare providers identified several reasons for referring patients to other facilities. These reasons include:

- Special treatment needs, such as for M. leprae reactions or acute disability manifestations
- Referral for surgeries, steroid tapering, or other advanced treatments not available at the local level
- Differential diagnosis to ensure accurate identification of the condition through further testing
- Access to specialized services like physiotherapy, rehabilitation, or reconstructive surgery (Fig. 6.3).

Awareness Generation:

Participants emphasized that raising awareness is critical for achieving zero leprosy. They mentioned several strategies for generating awareness, such as:

- Utilizing electronic, social, and print media campaigns
- Engaging communities through village health committees and school programs
- Distributing Information, Education, and Communication (IEC) materials
- Exploring the involvement of Rural Medical Practitioners (RMPs) to enhance awareness and referral systems through partnerships with ILEP.

> *An educated person can read banners and posters. If these banners and posters are placed in schools, where educated people come from, or in our village health awareness centre, then children will read them in school. The staff and other people will read it.*
>
> **– Healthcare Provider 15 Uttar Pradesh**

> *Jhola Chap doctors are not bad. As soon as you give them the knowledge, he will consume that immediately. He would do the wrong thing when he doesn't have the knowledge and we have to get our work done from him, so we treat him or deal with him as well. They spread awareness, organise and conduct rally and they go as Pradhan's and visit villages and organise the camps there.*
>
> **– Leprosy Official 3 Uttar Pradesh**

Additional support:

The participants provide various support to leprosy patients, including informing them about government schemes, helping them avail rehabilitation, and providing moral and logistical support to those in need.

> *Patients get 75% of the railway concession. They need to fill out a form and give it to the railway. Then, the railways will give them 75% discount. I guide patients for this option. Thus, the burden of travel expenditures reduces among poor patients, and they regularly come for check-ups.*
>
> ***– Healthcare provider, Delhi***
>
> *There are schemes for the aged patients with deformities they can avail. So, we provide a deformity certificate to such patients, thus they can get pension.*
>
> ***- Healthcare provider, Uttar Pradesh***

6.8 Challenges

Healthcare professionals, key officials, and ILEP partners outlined the challenges faced by them in this study. They found that challenges for healthcare professionals, key officials, and ILEP partners were similar. They face various challenges associated with migrant patients, such as managing patient data, providing regular treatment, resistance to treatment due to stigma of public awareness about disease status, communication, and tracking and follow-up of migrant patients who provide wrong contact details. They also face challenges due to lack of resources, including human and financial resources. Coordination with the government sector and ILEP is another challenge impacting centralized and accurate patient database management. The challenges encountered by key stakeholders at different levels vary. The next section outlines the issues faced by various stakeholders.

Challenges Faced by PMWs and NMSs:

Paramedical Workers (PMWs) (health visitors and physiotherapists) and Non-Medical Supervisors (NMSs) in Delhi and Chandigarh reported significant challenges in managing patient data, exacerbated by high patient loads and the absence of a streamlined data management system. They believe the current system, which primarily identifies the location of medication intake, has limited benefits and suggests the need for a more streamlined and practical approach to data management. They felt, tracking migrant patients in particular, pose tracking challenges, especially when they fail to report changes in their contact details. This leads to communication and coordination issues, contributing to treatment non-compliance.

The paramedical workers perceived that financial difficulties, fear of unemployment, and struggle to afford basic needs among migrant patients makes treatment continuity difficult. The PMWs and NMSs also highlighted time constraints, overwhelming workloads, and additional responsibilities, such as attending camps and programs, are few other issues exacerbate their challenges. Duplication of effort in updating both Google Sheets and NIKUSTH increases the workload. Additionally, they are concerned about logistical issues like MDT stock shortages, which hamper timely and adequate treatment. Financial constraints also affect resource allocation, leading to potential lapses in recalling patient details and increasing the risk of data inaccuracies. Addressing these challenges could improve the healthcare system's efficiency and effectiveness.

> *For me, the problem is time. My posting is at various facilities in this district, and if someone suddenly asks me how many grade 2 patients I have, I start struggling with the number of patients I have in the five facilities under me. So, handling so many facilities within the stipulated time is challenging for me, but I try to do as much as possible.*
>
> ***– Paramedical Worker in Delhi***

> *The issue with migrant patients is that they often don't follow up or return for necessary medical care. It can be challenging when they need urgent treatment but are unable to come to the clinic. I've had to refer patients to facilities near their location for surgery when they were reluctant to travel to Delhi.*
>
> ***– Paramedical Worker in Delhi***

Challenges Faced by Medical Officers/In-Charge (MO/IC):

The MO/ICs also mentioned countless challenges faced by them in providing effective and adequate care to migrant patients with leprosy. As per service providers the stigma associated with leprosy plays a pivotal role in hesitancy for treatment, hindering contact tracking efforts. Lack of information, difficulty confirming addresses, and patient non-disclosure complicate healthcare delivery further. Financial barriers, such as the perceived cost of essential items like MCR shoes, also impact treatment adherence.

Diagnostic challenges, including the unavailability of test materials, add to the complexity. Timely patient engagement proves difficult, with individuals missing appointments or not seeking treatment promptly. To meet these hurdles, effective counselling and communication are crucial and will lead to patient compliance. The doctors felt that multifaceted challenges among migrant patients in seeking treatment can impact the continuity and effectiveness of their treatment. They said the challenges migrant patients face in seeking treatment are accessing prescribed medications in a new location, settling down, communication barriers, and reluctance to accept diagnoses, can impact the continuity and effectiveness of their treatment. Maintaining regular visits and navigating unfamiliar healthcare systems can be challenging for migrants, necessitating tailored interventions to address their specific needs and circumstances.

The primary issue is the lack of consistent monitoring. For example, if a patient is experiencing a reaction or undergoing steroid treatment, we need to schedule follow-up appointments within the next 2-3 weeks to ensure the correct dosage. However, if the patient is a migrant, it becomes challenging for them to visit our facility frequently.

– Healthcare Provider Chandigarh

Despite our efforts to emphasise the importance of consistency in medication, numerous patients reported discontinuation of MDT since they were visiting their native place and discontinued their medication citing unavailability. It remains crucial to consistently reinforce that completing the entire course of medication is essential.

– Healthcare Provider Chandigarh

Challenges Faced by ILEP Partners:

The ILEP partner representative also highlighted several challenges they face with respect to referral services and their mission to make India leprosy-free by 2027. These challenges include ensuring accurate patient information, particularly contact details, and addressing issues related to patient mobility and resistance to identification. Coordination difficulties between government sectors and ILEP agencies further complicate the management of centralised, accurate patient databases. Overcoming patient awareness barriers and reducing the stigma associated with leprosy remain significant challenges, requiring effective counselling. Additionally, the representative noted the inadequacy of resources, both in terms of manpower and financial support, as another critical issue.

The government and ILEP organizations need to work together to track patients mobility and understand why they might relocate for medical treatment. This involves raising awareness and eradicating stigmas about healthcare options

.– ILEP partner representative, Delhi

6.9 Suggestions of Key Stakeholders to Achieve Zero Leprosy

Key stakeholders adopted a multifaceted approach to achieving zero leprosy, with suggestions classified into four categories: awareness generation, community engagement, targeted intervention, and stakeholder engagement, as illustrated in Fig. 4.10 and discussed below.

Awareness Generation:

All participants emphasized the importance of awareness generation about leprosy, particularly through mass media, social media, and community events. Such campaigns can significantly benefit migrant patients affected by leprosy. By disseminating information about leprosy symptoms and available treatment options, these efforts ensure that migrants—who may be unfamiliar with local healthcare resources—are able to access timely medical care both at their place of origin and destination. This is essential in reducing delays in diagnosis and treatment, which are prevalent among migrant populations. Furthermore, addressing misconceptions and sharing survivor stories can help reduce the stigma surrounding the disease, fostering a more supportive environment for affected individuals. Awareness initiatives, including electronic media, helplines, and printed materials, empower migrant patients to make informed healthcare decisions and connect with appropriate medical services. These efforts not only improve health outcomes for migrants but also support the broader public health goal of zero leprosy by integrating migrant populations into the healthcare system.

> *If people were aware of the disease, they might come directly to the health facility. However, they usually visit local doctors who prescribe medicine for fungal infections. Some patients have been taking medicine for fungal infections for ten years. Those with boils and patches often buy cream from medical shops and apply it themselves. More than 20% of people here hide their condition, and unfortunately, only around one per cent of those who are aware of the disease come directly to us.*
>
> ***– Healthcare Provider, Uttar Pradesh***

Community Engagement:

Community engagement plays a crucial role in improving the lives of migrant patients affected by leprosy. By involving local communities in all stages of leprosy programs—planning, implementation, and monitoring—there is a stronger sense of ownership and sustainability, which helps to reduce stigma.

Educating communities about leprosy transmission, symptoms, and treatment, as well as addressing common misconceptions, increases the likelihood that patients will seek care at local healthcare facilities rather than migrating for treatment. Partnerships with local leaders and organizations promote inclusivity and resource mobilization, making it easier for migrants to access care within their communities. Additionally, engaging school children in leprosy education supports early detection, while providing mental health support and continuous education for frontline workers further reduces stigma and ensures timely treatment. As a result, patients are less likely to seek care elsewhere, which reduces migration for treatment and enables them to lead more stable lives in their own communities.

> *When a case is referred by ASHA, they receive Rs. 500/- incentive per month for TB. This additional incentive helps keep TB patients connected to the program and prevents dropouts. The ASHAs come in every two months to claim their money, ensuring continued engagement with the program.*
>
> ***– Healthcare Provider Uttar Pradesh***

Targeted Intervention:

The participants emphasized that the leprosy program should adopt "Targeted Interventions" similar to those in programs like TB and HIV/AIDS, focusing on high-risk areas through health camps and awareness generation activities. They highlighted the importance of identifying high-risk populations and tailoring interventions to meet their specific needs. Targeted interventions could include focused screening campaigns in regions with high leprosy prevalence, enhanced case detection strategies for vulnerable groups such as migrant workers or those living in poverty, and specialized treatment programs for communities facing barriers to healthcare access. By directing resources and efforts to areas where they are most needed, targeted interventions can accelerate progress in reducing leprosy transmission, preventing disabilities, and ultimately eliminating the disease.

Stakeholder Engagement:

Healthcare providers and leprosy officials stressed the need to engage a broad range of stakeholders, including government agencies, healthcare practitioners, NGOs, researchers, and affected communities, to tackle the challenges of leprosy. They emphasized the importance of coordinated action, evidence-based interventions, and inclusive partnerships, along with advocacy for policy changes, resource allocation, and innovation in leprosy research. Transparency, accountability, and inclusivity in stakeholder engagement were also key priorities.

Additionally, they recommended comprehensive approaches to speed up progress toward leprosy elimination goals and advocated for a unified system to track migrant patients' movements and ensure they can access treatment facilities.

> *In tuberculosis (TB) program, private healthcare providers treat TB patients but they report the cases to the government. A similar approach should be adopted for leprosy. If a private practitioner suspects a case of leprosy, they would fill out a form and refer the patient to us or provide us with the patient's name and address.*
>
> ***– Healthcare Provider, Uttar Pradesh***

> *We need better coordination between the government and ILEP partners. A database is needed to track patient mobility and reasons for seeking treatment elsewhere. Motivating patients to receive treatment at their place of origin is a challenge. It's unclear why people leave their local area for treatment when it's available nearby.*
>
> ***– ILEP Partner***

Other suggestions:

The stakeholders proposed several suggestions to achieve zero leprosy, including improving healthcare access, strengthening surveillance, empowering affected communities, integrating services into healthcare systems, investing in research and innovation, and advocating for increased commitment and public awareness. These suggestions highlight the need for a holistic and collaborative approach to address the multifaceted challenges of leprosy, such as social stigma, economic barriers, and healthcare disparities, to make sustained progress towards elimination goals.

> *We have our ICDS software for notifiable diseases, which allows us to notify the state when a patient moves from one area to another. Our goal is to ensure that the state is informed so that they can support the patient at their destination to ensure they have access to necessary medication. I'm unsure if there are existing support mechanisms in place.*
>
> ***– Healthcare Provider, Uttar Pradesh***

CHAPTER 7:
KEY FINDINGS

This chapter outlines the key findings emerging from the primary research undertaken to gain insights into the impact of migration on the treatment of patients affected by leprosy.

As outlined in Chapter 2, the study adopted a descriptive design with mixed method approach where primary data was collected using qualitative tools such as in-depth interview guidelines, case studies as well as quantitative tools, namely structured as well as semi- structured questionnaires. The study involved conducting a census of migrant patients from Bihar and Uttar Pradesh who were receiving leprosy treatment in the facilities of Delhi and Chandigarh. For patients from Uttar Pradesh who could not be contacted in Delhi and Chandigarh, follow-up was conducted in their districts of origin. A sample of six high-patient-load districts was selected[43] for follow-up. Along with the 396 patients, their household members were also contacted with the consent of the patient. Around 60% of the household members (236) of these patients were interviewed. In case of household members not physically present at the facility, telephonic interviews were conducted. Additionally, semi-structured interviews with frontline workers (FLWs), such as ASHAs, ANMs, and PRI/Municipal Council members, provided further insights. These findings highlight the need for tailored services to address the unique needs of migrant leprosy patients, ensuring continuity of treatment, rehabilitation, and referrals.

Further in-depth interviews were conducted with various stakeholders at the state, district, and block levels, along with case studies involving patients currently on treatment, defaulters, and those released from treatment (RFT). These helped provide a deeper understanding of the challenges and solutions.

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[43] Bihar is one of the study states. The patients who have migrated to Delhi and Chandigarh were interviewed in these destination state/UT. Additionally attempts were made to contact patients who could not be contacted in Delhi/Chandigarh in Uttar Pradesh. Follow up interviews in Bihar could not be conducted due to the absence of approval from the Bihar government for data collection in the state.

The key findings of the study are as follows:

i. Absence of a Standard Definition of Migrants in Context of Leprosy

One of the key gaps identified in the study was the lack of a standard definition for "migrants" within the context of the national leprosy programme. This gap was highlighted in discussions with state and district-level leprosy officials and was further emphasized during visits to health facilities in some of the study states at the exploratory stage. While a working definition was established for the purposes of this study, the need for a uniform and standard definition was clear. After brainstorming sessions at the national and state levels, with inputs from various stakeholders in the leprosy field and the technical task force, the following draft definition of "migrant" in the context of leprosy was developed. Following draft definition of migrant in context of leprosy is developed.

- Person (Men, women, transgender, children, also includes contact/cohabitants) who migrates from one location to another location temporarily or permanently– irrespective of district/state and place of diagnosis.
- A person affected by leprosy who moves outside his place of residence to another district/state for purposes of treatment** and management of conditions caused during treatment (including includes MDT, disability care, etc.).

ii. Patient Profile

A. Socio-Demographic Profile of the Patients Affected with Leprosy

The study reveals that the proportion of male migrant patients is significantly higher than female patients. Approximately 70% of the migrant patients interviewed were men, while the remaining 30% were women. This trend is consistent with the data from the master patient registers of Delhi and Chandigarh, where nearly two-thirds of migrant patients were men and only one-third were women. Most respondents (77%) were married, with 76% of the married individuals living with their spouses, and 57% having at least one child. This situation presents a significant risk for disease transmission within families, as the WHO states that "leprosy bacteria are transmitted via droplets from the nose and mouth during close and frequent contact with untreated cases.”

In terms of education, 27% of the respondents were found to be illiterate or not formally educated. Women had lower education levels than men: 23% of men and 48% of women had studied only up to class 4. The study also highlighted that 46% of the respondents were the sole earners in their households, and 61% belonged to lower socio-economic backgrounds, often working in private services, construction, or as daily wage labourers.

Additionally, when the study examined smartphone ownership, 80% of respondents owned smartphones, which could be used to send treatment reminders and other information. However, the accessibility of smartphones was lower among women (64%) compared to men (73%).

B. Medical Profile of the Patients Affected with Leprosy

The majority of patients (97%) were registered under the 'new patient' category and the remaining 3% were registered under 'others' category. 'Others' includes: re-entered, relapsed, transferred in/out patients. However, MDT register did not specify the bifurcation of others into various categories. They were just registered under "Others" category. All patients interviewed were found to be on MB treatment, and almost 37% of the patients had either Grade 1 (17.4%) or Grade 2 (19.4%) disability. Grade 1 and Grade 2 disabilities were more prevalent among men (Grade 1: 18%, Grade 2: 21%) than women (Grade 1: 16%, Grade 2: 17%).

C. Migration Profile of the Patients Affected with Leprosy

It was found during the course of the research study and during the exploratory visits, discussions with SLOs and secondary review that there was lack of a standard definition for "migrants" within the context of leprosy in India. The study followed the definition followed by Delhi, & Chandigarh when recording migrant patients in their registers. During in-depth interviews (IDIs) with key officials in Uttar Pradesh, it was noted that the state's leprosy programme does not have a formal definition for migration. The study found that 60% of the patients had been residing in Delhi or Chandigarh for an average of nine years, while 40% migrated solely for treatment and returned to their state of origin after receiving MDT. In addition to inter-state migration, patients also migrated within districts and blocks, particularly in Uttar Pradesh.

The primary reasons for migration identified in the study were better employment opportunities and access to quality healthcare. Men primarily migrated for job opportunities (84%) and treatment (7%), while women migrated mainly for access to healthcare (36%) and employment opportunities (36%). Patients who migrated solely for treatment cited the availability of large hospitals in Delhi and Chandigarh (69%) as the primary reason. Around 9% of these patients were unaware of leprosy treatment options in their district. Healthcare providers in Delhi and Chandigarh reported a high influx of migrant patients, particularly from Uttar Pradesh and Bihar, with many patients diagnosed in their home states often travelling to these cities for diagnosis and MDT.

iii. Diagnosis and Treatment of Patients

Overall, most of the patients reported getting diagnosed with leprosy at destination i.e. in Delhi or Chandigarh only. The patients reported visiting multiple health care providers as well as multiple healthcare facilities for getting the diagnosis.

The majority of patients (90%) reported noticing leprosy symptoms themselves, with 58% of them recognizing the symptoms at their place of origin. However, 95% of the patients were diagnosed at their destination (Delhi or Chandigarh). The study found that 64% of the patients were unaware of where to go for diagnosis, with women (71%) more likely than men (61%) to be unaware of treatment facilities.

Qualitative interviews revealed several factors contributing to delays in seeking treatment, including a lack of awareness about leprosy, stigma from the community and self-stigma, and myths surrounding the disease (e.g., leprosy is hereditary, spreads through coughing and sneezing, or is highly contagious). Other reasons for delayed diagnosis included the absence of pain, which led patients to disregard their symptoms. Healthcare providers and leprosy officials also reported similar reasons for delays, such as incorrect diagnoses by local health providers, social stigma and fear, perceived high treatment costs (possibly due to initial visits to private healthcare providers), limited access to healthcare during migration, confusion in navigating healthcare facilities, and a lack of awareness among local healthcare providers and traditional healers about leprosy's clinical manifestations. Most PRI members were familiar with leprosy, though few understood its transmission.

Various research studies[44,45,46] including research in endemic districts of West Bengal, Gujarat, Maharashtra, Delhi and Andhra Pradesh, study by ICMR in five states of India[47], study on Determinants of patients' delay with disability in the diagnosed leprosy cases in the three major states of India: A case-control study[48] etc. supported the fact that there is delay in the diagnosis of leprosy due to negligence at patient's end and also delays created by the health system in diagnosis.

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[44] Darlong, J., Govindasamy, K., & Daniel, A. (2022). Characteristics of children with leprosy: factors associated with delay in disease diagnosis. Indian Journal of Dermatology, Venereology and Leprology, 88(3), 337-341.

[45] Dharmawan, Y., Fuady, A., Korfage, I., & Richardus, J. H. (2021). Individual and community factors determining delayed leprosy case detection: A systematic review. PLoS neglected tropical diseases, 15(8), e0009651.

[46] Duighuisen, H. N. W., Fastenau, A., Eslava Albarracin, D. G., Ortuño-Gutiérrez, N., Penna, S., & Kamenshchikova, A. (2024). Scrutinising delay in leprosy diagnosis in Colombia: perceptions and experiences by leprosy health professionals. Global Public Health, 19(1), 2354777.

[47] https://pmc.ncbi.nlm.nih.gov/articles/PMC5230757/

[48] Govindarajulu, S., Muthuvel, T., Lal, V., Rajendran, K. P., & Seshayyan, S. (2023). Determinants of patients' delay with disability in the diagnosed leprosy cases in the three major states of India: A case-control study. Indian Journal of Dermatology, Venereology and Leprology, 89(1), 35-40. https://ijdvl.com/determinants-of-patients-delay-with-disability-in-the-diagnosed-leprosy-cases-in-the-three-major-states-of-india-a-case-control-study/

During the cases studies, the patients revealed that the treatment was often initiated with self-medication which was, followed by visiting local doctors (traditional medical practitioners, private doctors, private hospitals, and dermatologists), and government facilities. Around 69% of the patients visited multiple-facilities (on an average 3.2 healthcare providers and 2.2 facilities) before getting a correct diagnosis and initiating treatment.

Leprosy surveillance programs like LCDC, ABSULS, ACDRS were reported to be helpful in identification of the hidden leprosy cases. The frontline workers (ASHA/ANM) were aware about their role and responsibility during LCDC/ACDRS and reported keeping records of the migrant person affected with leprosy.

iv. Pathway to Care

The majority of migrant patients (94%) reported receiving treatment and medicine at the place of diagnosis. Skin specialists were primarily involved in diagnosing leprosy (73%), followed by Medical Officers (15%) and other leprosy staff (12%).

v. Diagnosis and Treatment of Patients

Almost all patients (94%) received their first dose of MDT immediately or within a week of diagnosis. It is important to note that the study focused on patients already undergoing MDT at the time of the survey. Patients diagnosed within the public health system who later shifted to private providers to complete their treatment were not included in the study. Furthermore, the majority of patients (94%) reported visiting the health facility at least once a month for MDT replenishment. Patient satisfaction with the treatment was very high, with most (94%) expressing they were either very satisfied (72%) or satisfied (22%) with the treatment they received.

More than 78% of the patients reported receiving counselling. The key areas covered in counselling included adherence to treatment, continuity of medication, and self-care. However, aspects such as MDT side effects, skin discolouration, self-care practices, the continuation of MDT during pregnancy, family planning during treatment, and physical intimacy with partners were not explicitly discussed. The counselling was often conducted by the private? skin specialists (34%) and by the leprosy staff (58%).

In addition to counselling, patients received various support services from health facilities, including MCR footwear (13%), self-care kits (13%), and reconstructive surgery (13% of 48 patients who required it). Healthcare providers and non-medical supervisors also informed patients about government schemes available specifically for leprosy patients, such as travel concessions and pension schemes for elderly disabled persons.

vi. Support System of Patients

Patients reported receiving support from family, friends, and healthcare facilities. The majority (82%) of patients indicated that their family members were aware of their leprosy status and provided both mental and financial support. However, patients were reluctant to disclose their status to neighbours or friends. Women were especially concerned about others outside the household learning of their leprosy status. Healthcare providers and leprosy staff also observed this reticence during qualitative discussions. A couple of participants in the qualitative interviews informed that their friends mentally and financially supported them for the treatment of leprosy.

vii. Contact Tracing

Overall uptake of SDR was found to be very low amongst the migrant patients interviewed. . Only 7% of patients reported that at least one member of their family was also affected by leprosy. Around 14% of patients stated that contact-screening had been conducted for their close contacts, and 23% reported that household members had received SDR. Qualitative data also showing similar findings, six of the 23 participants reported at least one family member was affected with leprosy, and half of the participants reported NO contact screening or NO SDR.

Healthcare providers and leprosy staff highlighted the challenges in contact screening for migrant patients, as close contacts often do not visit healthcare facilities at the destination. Home visits by leprosy staff were often prohibited by patients, due to fears of exposing their leprosy status within the community. Furthermore, the treating facility at the destination did not share information about the patient or their contacts at the place of origin, leaving migrants and their contacts at high risk.

viii. Monitoring and Follow-up of Persons Affected with Leprosy

Monitoring, follow-up, and tracking of migrant patients are also affected by many challenges, including the migratory nature of the patients due to work, lack of motivation of patients towards treatment due to social stigma, and financial constraints, inaccurate contact details, and lack of effective communication with patients due to language.

The monitoring of migrant patients with leprosy in India differs from other programmes like HIV and TB due to variations in disease characteristics, stigma, and infrastructure. Leprosy's long incubation period and visible symptoms contribute to higher stigma, which can delay diagnosis and treatment. The NLEP uses field-based methods like contact tracing and community outreach, with limited technology, while HIV and TB programs utilize robust digital systems for continuity of care.

HIV care focuses on lifelong treatment and viral load monitoring, whereas TB programs emphasize shorter treatment regimens with strict adherence through DOTS. While HIV and TB initiatives incorporate migrant-specific strategies Leprosy initiatives are often deprioritized, leaving them ill-equipped to address the challenges of migrant populations.

NIKUSTH

Almost all healthcare providers acknowledged the potential benefits of the NIKUSTH system for recording, monitoring, and tracking migrant patients. However, they expressed that NIKUSTH does not capture critical details related to migrant patients. This gap in the NLEP program means that if a patient migrates, the healthcare facility at the destination may not have any record of ongoing treatment unless the patient explicitly informs them. It is crucial to digitize patient information or include this aspect in NIKUSTH for better tracking.

Some participants suggested that a mobile-based NIKUSTH application would be more useful than the desktop version in remote areas as there are network issues. A mobile version would allow more accurate and timely access to patient records.

Challenges Mentioned by the Patients

Both patients and service providers faced several challenges at various levels. Challenges faced by patients due to their leprosy status included: loss of job or inability to get a job (27%), leprosy associated disability restricts working ability (18%), migrated because of leprosy status (9%). Other challenges included: community/relative boycott (7%), difficulty in getting a good match to marry, financial constrains due to leprosy, and travelling for collecting medicines.

During qualitative interviews the patients also informed about possible challenges to access treatment, and these are limited resources at place of origin, delay in treatment due to lack of healthcare providers who can provide treatment for leprosy locally, logistical and financial issues, lack of awareness, specifically among younger generation, and complex healthcare system navigation.

Healthcare providers also reported facing challenges, including administrative and logistical issues, resource limitations, uncooperative patients, increased workloads, and communication barriers. Tracking and following up with inconsistent patients was a major concern. Without dedicated trained counsellors, NMS or NMA staff had to provide counselling in addition to their regular duties, making it challenging to provide adequate support. Due to huge patient load in the tertiary care facilities in Delhi/Chandigarh it is somehow difficult for them to provide proper counselling.

The NMS and paramedical staffs also informed that due to lack of female staff in the facility, counselling a female patient about sensitive topics, such as physical intimacy, pregnancy, and breastfeeding during MDT is difficult.

An ILEP partner representative highlighted coordination challenges with the government sector, which affect the management of a centralised and accurate patient database.

CHAPTER 8: RECOMMENDATIONS

Based on the challenges faced by migrating patients identified through primary research, a set of recommendations has been developed to address these issues. These recommendations aim to ensure the availability and accessibility of treatment for migrant patients affected by leprosy, while also enhancing the well-being of their household members.

1. ADOPTION OF THE DEFINITION OF MIGRATION IN CONTEXT TO LEPROSY

The study highlighted the lack of a standard definition of "migrant" in the context of leprosy, both in India and globally. Adopting a uniform definition under the national program would enable all states to follow a consistent framework, which is essential for tracking, treating, and recording data of migrant patients. Through consultative processes, the study developed a standard definition for migrants in the context of leprosy (refer to Chapter 3 for details). It is recommended that this definition be officially adopted by the national program.

2. ROLE OF GENDER IN LEPROSY

As presented in the findings, women constitute a lower proportion of the total patients affected with leprosy (around 30%) were found. This gives rise to several questions, 1) is prevalence of leprosy among women lower compared to men or is it lack of diagnosis amongst women with symptoms?
2) are the women less likely to avail treatment for leprosy?
3) is there a lack of interest amongst women in migrating for treatment?

As highlighted by WHO, gender plays a significant role in health outcomes due to both biological and sociocultural factors. The health of women and girls is not of particular concern in many societies; they face systemic disadvantages due to discrimination rooted in sociocultural factors. Leprosy is also a health concern and considering stigma around it, the detection of leprosy amongst women may be low and may attribute to lesser proportion of women patients currently on treatment.

Other research papers also emphasizes the importance of addressing gender-specific disadvantages and, implementing measures to mitigate leprosy-related stigma and its impact, especially among women and girls[49]. To better understand and address these issues, further gender-specific research is essential.

3. UPDATION OF THE REGISTERS

The study highlighted significant gaps in recording critical patient details, which directly impact effective treatment management. All the patients were found to be registered under either “New” or “Others” category, with no specific mention of subcategories such as – Re-entered, transferred in, Relapses etc. Hence there is need to sensitize the leprosy staff to record the details of the patients under various categories at the time of initiating MDT. At this stage patient's past treatment record should be reviewed with the details of type of patient recorded accordingly in the register.

4. MIS TO TRACK THE MIGRANT PATIENTS

The study highlights that NIKUSHT, a web-based portal for leprosy case management under the National Leprosy Eradication Programme NLEP, does not have a comprehensive tracking system for migrants. The absence of such a system increases the risk of treatment defaults. It was found that the destination state/UT (Delhi/Chandigarh) recorded the migrant status of the patient, while this information was missing in the MDT registers of the source state (Uttar Pradesh). In Delhi and Chandigarh, the temporary as well as permanent address of the patients is recorded while registering them in the MDT register. This helped in identifying the migrant patients coming to these locations from other states for treatment of leprosy. However, this was absent in case of Uttar Pradesh. They only recorded their permanent address. Information related to their migration to other locations (within or outside the state) was not recorded.

Hence there is a need to integrate a migrant tracking system in NIKUSTH, ensuring a standard and uniform mechanism across all states. The potential of NIKUSTH to integrate such a system was emphasised by the healthcare providers. Specifically, it should enable:

- **Recording and sharing patient migration details** between healthcare providers, including both intra-state and inter-state movements.
- This will enable the management of migrant leprosy patients at both source as well as destination states, along with contact screening of close contacts. To address the issue of connectivity in remote areas the service providers suggested having a mobile based version of NIKUSTH.

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[49] https://www.researchgate.net/publication/324154301_Gender_and_leprosyrelated_stigma_in_endemic_areas_A_systematic_review

- Lessons from other successful management information systems (MIS), such as ***NIKSHAY*** for Tuberculosis (TB) patients in India, should be incorporated into the updated ***NIKUSHT*** system. ***NIKSHAY*** tracks migrant TB patients by maintaining treatment records across regions and states. It allows healthcare providers to update and share treatment information about migrant patients.

5. STRENGTHENING HEALTHCARE SYSTEM AND UPSKILLING OF SERVICE PROVIDERS AT SOURCE

The study highlights that many patients were diagnosed at their destination after consulting multiple healthcare providers. This highlights the need to strengthen the local healthcare system, especially in source states to enable patients to get diagnosis and treatment locally. This includes upgrading the knowledge about leprosy of health care providers including traditional healthcare providers.

The study found patients coming to Delhi and Chandigarh only for treatment purposes. Better local access to leprosy diagnosis and treatment will reduce migration that takes place only for treatment purposes. Local availability of MDT, awareness among patients, and counselling on side effects can improve treatment completion rates.

6. STANDARD OPERATING GUIDELINE FOR COUNSELLING

According to the study findings, most patients reported receiving counselling on continuation of MDT and self-care. However, various issues like transmission of leprosy, stigma, importance of contact screening, side effects, physical intimacy, issues specific to women including continuity of MDT during pregnancy and physical relations while on MDT were rarely discussed during counselling. This underscores the need for a standard operating guideline for counselling of patients affected with leprosy as well as their family members.

Strengthening/developing the Standard Operational Guidelines for counselling with special focus on areas not currently being covered under counselling will go a long way in making patient counselling effective. There is a need for the guideline to cover topics like side effects of medicines, post treatment outcomes and follow up care, transmission of leprosy, importance of contact screening etc. Additionally important issues related to stigma, contact screening and risk of transmission for the family members of the patient also need to be covered by the guideline. Further recruitment of trained counsellors is essential to provide effective counselling on leprosy and other related services.

7. COLLABORATION WITH THE INDIAN ASSOCIATION OF DERMATOLOGISTS WITH NLEP PROGRAMME

The study findings highlight the indispensable role played by the skin specialists in diagnosing leprosy. Majority of the patients indicate consulting a skin specialist (either public or private) when they first see the symptoms of leprosy. Further they also indicate being diagnosed for leprosy by the skin specialists in the government facility. Given the importance of the skin specialist in diagnosis of leprosy, a collaboration between the Indian Association of Dermatologists with NLEP Programme is essential. Such a collaboration will help in identifying key areas of support for early detection of leprosy and better adherence to treatment. A review of the Sri Lankan model reveals the important role played by dermatologists in its Anti Leprosy Campaign. Regional Skin Clinics, supervised by a consultant dermatologist, manage all patients with leprosy[50]. Key lessons on collaborating with dermatologists can be learnt from their experience.

8. CAPACITY BUILDING OF OTHER SERVICE PROVIDERS

The study findings indicate that patients visit multiple healthcare providers for getting the diagnosis. These heath care providers include traditional medical practitioners and private doctors, including those working in private hospitals. Hence it is crucial to include these health service providers in the NLEP programme. The lack of focus on leprosy during medical training and the limited exposure to the disease hinders their ability to accurately diagnose leprosy. Hence, it is essential to provide healthcare providers with regular refresher courses to enhance their diagnostic and treatment capabilities.

9. SENSITIZATION OF COMMUNITY MEMBERS

The findings highlight that family members and friends are the major source of influencers for individuals seeking diagnosis of their symptoms. In view of this, community level interventions become essential. As PRI members and ward members of Municipal Corporation play an important role as community leaders in their areas, it is very important to sensitize them. With the right knowledge they can act as change agents, promote individuals towards timely diagnosis and address stigma at the grassroot level about leprosy amongst the community members.

10. CONTACT SCREENING AT SOURCE AND DESTINATION, ALONG WITH SDR

The study revealed gaps in contact tracing, particularly for migrant patients. Contact tracing has been used in the control of infections including smallpox, tuberculosis, HIV, other sexually transmitted infections (STIs), Ebola virus and latest, COVID-19.

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[50] https://leprosycampaign.health.gov.lk/curative/regional-skin-clinics/

The objectives of contact tracing include identifying potential new cases before they might infect others (with referrals to care and social supports when indicated), detecting clusters of cases before they expand, and improving overall understanding of disease dynamics[51]. The case study of Maldives also provides valuable insights regarding the importance of organizing capacity-building, screening activities and the facilitation of internal verification for interruption of Leprosy transmission[52].

The service providers reported using various strategies for contact tracing of migrant patients including screening of accompanying household members at the facility during the treatment and providing SDR to the patients and requesting them to give it to their families. However, there is a dire need for clear guidelines to carry out the contact screening at the source (origin) for the migrant patients affected with leprosy.

Contact tracing efforts during the COVID-19 pandemic was found to be an effective tool in controlling its spread. Valuable lesson from this can be adapted in the fight against leprosy. Additionally, learnings from the management of contact screening in Tuberculosis may also provide insights to design the guidelines for contact tracing of migrant patients. Research suggests that contact tracing contributes to increased social support for the index TB case by involving household and social contacts, which is crucial for reducing loss to follow-up and promoting treatment adherence[53].

11. DEVELOPMENT OF IEC STRATEGY

Early detection of leprosy is crucial for preventing complications and for reduction of stigma. The findings revealed that around 64% of patients were unaware of where to seek diagnosis for their symptoms. Therefore, raising awareness among the general population is critical. Comprehensive IEC (Information, Education, and Communication) materials should be developed and disseminated through diverse media channels to enhance awareness about leprosy, available treatment facilities, and government schemes for patients.

Various channels for dissemination of information include personal or group counselling, use of audio-visual aid, practical visualization exercises, and social marketing like mass media campaigns, school-based education, posters, and street plays. . Additionally, as suggested by one of the service providers, engaging celebrities to promote awareness can be impactful. Jackie Shroff and Dimple Kapadia, for instance, were celebrity advocates for leprosy awareness campaigns in India decades ago. Similar campaigns leveraging social media platforms should be launched to reach wider audiences. Smartphones can also serve as vital tools for disseminating IEC messages and materials, enabling better outreach and engagement.

[51] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8847088/#:~:text=Contact%20tracing%20is%20defined%20by,%2Dexposure%20prophylaxis%2C%20and%20quarantine.

[52] https://www.who.int/maldives/news/detail/14-10-2023-maldives-inspiring-journey-towards---zero-leprosy--by-2030

[53] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9395259/

12. PEER TRAINING

The role of peer mentors in supporting positive health behaviours has been well-documented in various disease settings, such as HIV/AIDS and maternal and child health. Specifically for leprosy, peer mentors play a crucial role in reducing stigma. Individuals who have recovered from leprosy and are leading normal lives can serve as powerful role models. These "Recovered from Treatment" (RFT) patients can actively engage with others affected by leprosy, motivating them to complete their treatment and adhere to medical guidelines.

Incorporating RFT patients into awareness and support programs will not only encourage treatment completion but also provide an opportunity for patients to discuss their concerns more openly. This peer support model can strengthen mental health by reducing isolation, building self-esteem, and fostering a sense of community among those affected by leprosy.

13. ADDRESSING SOCIO-ECONOMIC IMPACTS

The study found that the majority of migrant patients affected by leprosy were from lower socio-economic backgrounds. Therefore, it is essential to develop targeted interventions to mitigate the socio-economic impacts on both the patients and their households. Introducing new social support programs and raising awareness about existing government schemes are critical steps to enhance the resilience and well-being of migrant populations affected by leprosy.

14. INCLUDING LEPROSY AS A NOTIFIABLE DISEASE

As per state government policies, currently, leprosy is a notifiable disease only in certain states of India, such as the state of Tamil Nadu[54]. To improve consistency in reporting and management, it is crucial for the central government to take necessary steps to declare leprosy a notifiable disease across all states. This would ensure uniformity in data collection, enhance early detection, and facilitate better coordination between state and national health programs. Making leprosy notifiable nationwide would also help in tracking trends, ensuring timely intervention, and reducing the stigma associated with the disease.

> *“Any health program devoid of a migrant focus is incomplete.....”*
>
> ***– John Kurian George***
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> *Swiss Emmaus Leprosy Relief Work India*

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[54] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7678510/#:~:text=There%20is%20a%20general%20impression,Division%2C%20Govt%20of%20India).

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