



TECHNICAL REPORT

**Compassion training for reducing stigma
and improving quality of care for persons
affected by leprosy**

(Experiences from Bokaro district, Jharkhand, India)



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ABBREVIATIONS

ANM – Auxiliary Nurse Midwife
AYUSH – Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homeopathy
CARE – Consultation and Relational Empathy
CBCT – Cognitively Based Compassion Training
CHC – Community Health Centre
CIT – Compassion Integrity Training
DH – District Hospital
EHF – Eyes, Hands and Feet (Disability Score)
FGD – Focus Group Discussion
FM – Family Member
G2D – Grade 2 Disability
HCP – Health Care Provider
HCW – Health Care Worker
IDI – In-Depth Interview
IRB – Institutional Review Board
MB – Multibacillary
MDT – Multidrug Therapy
NLEP – National Leprosy Eradication Programme
NMA – Non-Medical Assistant
NVivo – Qualitative Data Analysis Software
PAL – Person Affected by Leprosy
PB – Paucibacillary
PHC – Primary Health Centre
PMW – Paramedical Worker
REDCap – Research Electronic Data Capture
RBSK – Rashtriya Bal Swasthya Karyakram
SARI – Stigma Assessment and Reduction of Impact
SDS – Social Distance Scale
UHC – Universal Health Coverage
WHO – World Health Organization

EXECUTIVE SUMMARY

BACKGROUND

Leprosy remains a major public health concern in India, which contributes about 60% of global new cases. Despite effective multidrug therapy, delayed diagnosis and preventable disabilities persist. Jharkhand reports higher disease burden than the national average, with Bokaro district facing additional challenges due to migration, socioeconomic inequalities, and limited health awareness. Many persons affected by leprosy continue to experience stigma, disability, and psychosocial distress even after treatment. Compassionate, stigma-sensitive healthcare is therefore essential. However, routine training of healthcare workers (HCW) largely focuses on clinical management and overlooks compassion and psychosocial support. This study aims to develop and evaluate a compassion training for healthcare providers to improve stigma-sensitive, people-centred leprosy care in Bokaro district.

METHODS

The study used a mixed-methods before–after design in Bokaro district, Jharkhand, covering all 27 Primary Health Centres. Baseline and endline surveys included 80 healthcare providers and 80 persons affected by leprosy. Qualitative data comprised 10 in-depth interviews with HCWs and 2 focus group discussions (17 participants), 10 in-depth interviews with persons affected by leprosy and 2 focus group discussions (16 participants), and 10 in-depth interviews with family members. A compassion training programme was developed based on baseline findings and implemented for HCWs, 80 providers were trained across the district. Endline data were collected 4–5 months after training to assess changes in compassionate behaviour, stigma, and patient experiences. Quantitative data were analysed using statistical methods, while qualitative data were thematically analysed to interpret behavioural and experiential changes.

KEY FINDINGS

1. QUANTITATIVE STUDY

1.1 Study participants: Persons affected by leprosy

A total of 160 persons affected by leprosy participated in the study, with 80 respondents each at baseline and endline. Although the participants were different at the two time points, the findings provide a comparison of changes in well-being, empathy in care, and stigma experiences over time.

The socio-demographic profile showed higher female participation and a higher average age of respondents in the endline sample. Most participants were from rural areas (91%) at both time points. Educational attainment was lower in the endline sample, with the proportion of participants having no schooling being 26% at baseline and 40% at endline. Unemployment was 20% at baseline and 46% at endline, while the proportion of self-employed and students was also higher at endline. In both samples, the majority of participants were married and lived with their families in villages.

In terms of leprosy classification, the proportion of multibacillary (MB) cases was predominant in both samples (74% at baseline and 76% at endline). However, disability levels differed substantially, at baseline, 91% of participants had no disability whereas this was 71% at endline. At baseline, 4% had grade 2 disability and at endline this was 23%, showing higher visible impairments among the endline respondents.

The Human Flourishing Scale showed a significant change, with mean scores of 68.6 at baseline to 90.4 at endline ($p < 0.001$). All six domains—happiness, health, purpose, character, relationships, and financial stability—showed improvement. The regression analysis showed that at baseline, leprosy type and age significantly influenced Human Flourishing scores, with older participants and those with MB type reporting lower flourishing ($R^2 = 0.24$). At endline, higher stigma, presence of disability, and rural residence were linked with lower flourishing, while urban participants and those without impairments had higher scores ($R^2 = 0.20$). In the combined model, flourishing was negatively associated with stigma, age, disability, and MB type. The overall model explained 56% of the variance ($R^2 = 0.56$).

The Consultation and Relational Empathy (CARE) Measure also showed significant improvement, with mean scores increasing from 30.4 to 42.2 ($p < 0.001$), reflecting better patient-provider relationships and empathetic communication by HCWs. At baseline, no variables showed a significant association with CARE Measure scores, so a valid regression model could not be established. At endline, only EHF status had a significant effect ($p = 0.039$), indicating that participants without disability (EHF = 0) scored on average 1.72 points higher than those with disability. The model explained 5% of the variance ($R^2 = 0.05$). In the combined baseline–endline analysis, no statistically significant model could be derived as all variables exceeded the $p > 0.05$ threshold.

The SARI Stigma Scale revealed mixed trends. While the overall stigma score did not differ significantly, internal and anticipated stigma decreased, indicating improved self-acceptance and reduced fear of future discrimination. However, experienced stigma and disclosure concerns increased, suggesting persistent societal challenges. At baseline, no variable showed a significant association with SARI Stigma scores, and thus no valid regression model could be established. At endline, the setting (rural/urban) was the only significant predictor ($p = 0.0287$), with participants from urban areas reporting on average 5.64 points higher stigma scores than those from rural settings. The model explained 6% of the variance ($R^2 = 0.06$). In the combined baseline–endline analysis, no statistically significant model could be derived, as all variables exceeded the $p > 0.05$ threshold.

1.2 Study participants: Healthcare workers

In total, 91 HCWs were included in the study. Of the total sample, 61 HCWs (76.3%) participated at both time points. At baseline ($n=80$), 53% were female and the mean age was 40.1 years; most worked in rural areas (87%). At endline, 50% were female with the same mean age, and 93.7% worked in rural areas.

Most participants were doctors (70% at baseline; 72.5% at endline). At baseline, 66% had more than four years of medical training and 83% had received leprosy-specific training. Nearly two-thirds had over five years of work experience, and 45% had more than five years of experience

working with persons affected by leprosy. At endline, levels of training and experience were slightly higher, including 93.8% having received leprosy-specific training and 56.3% having more than five years of experience with persons affected by leprosy.

Social distance was measured using the 7-item Social Distance Scale (SDS). Median SDS scores decreased slightly from 3 (IQR 2–4) at baseline to 2.5 (IQR 1–4) at endline, suggesting a small improvement in willingness to interact with persons affected by leprosy. However, this change was not statistically significant. At both time points, respondents were most willing to accept a person affected as a colleague or neighbor, and least willing to accept them as a child's caretaker or in marriage to their child.

At baseline, significant differences in social distance were found by gender ($p=0.005$), receipt of leprosy-specific training ($p<0.001$), and years of experience with persons affected ($p<0.001$). In multivariate analysis, leprosy-specific training and experience with persons affected remained significant, explaining 18% of variance in SDS scores. At endline, no subgroup differences or significant regression model were identified. Among the 61 repeated participants, doctors and specialists showed a small but significant increase in desired social distance over time (7.9% of explained variance).

Compassion was measured using the 16-item Pommier Compassion Scale. Mean compassion scores increased significantly from 69.44 (95% CI 68.23–70.65) at baseline to 73.41 (95% CI 72.25–74.58) at endline (+3.98 points; $p<0.001$). The highest compassion scores related to attentive listening and concern for patients, while lower scores related to emotional connection and being present during suffering.

Compassion scores differed significantly by type of health worker ($p=0.025$) and years of medical training ($p=0.029$), and were associated with social distance scores ($p=0.011$). At baseline, type of health worker, experience with persons affected, and SDS score explained 15% of variance in compassion. At endline, only SDS score remained significant (14% explained variance). Among repeated participants, doctors and specialists showed a smaller increase in compassion than other health workers, explaining 7.3% of variance in change over time.

2. QUALITATIVE STUDY

This endline qualitative assessment examined the perceived impact of a stigma-informed compassion training implemented among HCWs in Bokaro District, Jharkhand State, India. Across interviews and focus groups with 59 participants – including HCWs, persons affected by leprosy, and family members – the findings reinforce the central role of compassion in shaping quality of care, patient wellbeing, and stigma reduction.

Across all participant groups, compassion was consistently described as both an inner disposition and an outward practice expressed through respectful communication, listening, reassurance, and equitable treatment. Participants repeatedly affirmed that compassionate care is “half the cure,” linking it to improved emotional relief, strengthened patient-provider trust, greater treatment adherence, and enhanced workplace morale. While healthcare settings were generally described as positive and nondiscriminatory, community-level stigma and social distancing behaviors remain prevalent, particularly in cases of visible symptoms. Fear of discrimination continues to drive concealment of diagnosis and delayed care-seeking.

HCWs reported meaningful internal and relational shifts following the training. The most salient changes centered on increased self-awareness, self-compassion, emotional regulation, and intentionality in patient interactions. Providers described improved collegial relationships and deeper attentiveness to the psychosocial burdens carried by persons affected by leprosy. Some perceived increased patient openness and strengthened mutual trust. However, because most patients sampled had not received care prior to the training period, direct before-and-after comparisons from the patient perspective were limited.

Participants emphasized that sustaining and expanding impact will require institutionalization and routinization of the training, prioritization of community-proximal workers, extension to persons affected by leprosy and broader community members, and modest structural improvements such as private consultation spaces. Strengthened longitudinal evaluation will also be critical and should be prioritized as the next phase of this work.

Overall, findings suggest that stigma-informed compassion training is both acceptable and promising in enhancing compassionate-led healthcare environments and relational quality of care. Embedding compassion more deeply within health systems and communities may be essential to achieving durable reductions in stigma and sustained improvements in care for persons affected by leprosy and other stigmatizing conditions.

CONCLUSION

The study shows that compassion training can improve the quality of interactions between HCWs and persons affected by leprosy. Quantitative findings indicate improvements in provider compassion, reduced social distance, and better patient-reported compassion and wellbeing after the intervention. Qualitative findings reinforce these results, showing greater sensitivity, respectful communication, and increased awareness of stigma among trained providers. Persons affected by leprosy reported feeling more comfortable, listened to, and respected while seeking care. However, stigma and structural barriers within communities and health systems still persist. Overall, the findings suggest that stigma-informed compassion training can strengthen people-centred leprosy services and enhance patient experience within routine public health systems.

1. INTRODUCTION

1.1 Background

Leprosy continues to be a significant public health and social concern in India despite long-standing elimination efforts under the National Leprosy Eradication Programme (NLEP) (Government of India, 2025). India accounts for nearly 60% of the global burden of new leprosy cases, making it the country with the highest reported incidence worldwide (WHO, 2025). Although multidrug therapy (MDT) has been widely successful in curing the disease microbiologically, leprosy remains closely associated with delayed diagnosis and preventable disabilities (Government of India, 2025).

Jharkhand is among the high leprosy-endemic states in India and consistently performs poor than the national average. Recent national reports from the Central Leprosy Division (CLD) highlight declining prevalence, reduced child cases, and improving disability indicators, reflecting better early detection and treatment. However, Jharkhand continues to report a substantial number of new cases annually. In the FY 2024-25, the Leprosy prevalence rate is 1.46 per 10,000 population, ANCDR is 18.63 per 100,000 population, proportion of child case is 6.44% and Grade 2 (G2D) disability 2.12% of all new cases (NLEP Annual Report, 2024-25). The persistence of G2D at diagnosis reflects systemic gaps in early case detection, community awareness, stigma-sensitive service delivery, and quality of care.

Bokaro district, an industrial and mining-intensive district of Jharkhand, presents a complex leprosy control context. Migration, informal settlements, socioeconomic inequities, and limited health literacy contribute to delayed care-seeking and interrupted follow-up. Leprosy services in Bokaro are delivered through the integrated general health system, primarily via one District Hospital (DH), 8 Community Health Centre (CHC) and 18 Primary Health Centers (PHCs). While MDT availability is high, comprehensive disability care, psychosocial support, and stigma-responsive practices remain weakly embedded within routine service delivery (Department of Health, Jharkhand, 2026).

For many persons affected by leprosy, the end of medical treatment does not mark the end of suffering. Physical impairments, activity limitations, and participation restrictions often persist for life, affecting employment, family relationships, and social inclusion (van Brakel, 2003; WHO, 2021). Despite this, district-level evidence on the quality of care, stigma experiences, and mental wellbeing of persons affected by leprosy in Jharkhand remains limited, indicating the need for focused research and intervention.

1.2 Compassion in Healthcare: Conceptual Foundations

Compassion is increasingly recognized as a core element of quality, people-centered health care. Compassion refers to the genuine motivation to alleviate the suffering of others based on a feeling of connection coupled with empathic awareness of their feelings and struggles (Negi, L. T., Harrison et al, 2025). From the perspective of patients and families, compassionate care

encompasses dignity, respect, empathetic communication, emotional responsiveness, privacy, and shared decision-making (Barker, 2023 et al., 2011; Sinclair et al., 2017).

The WHO has emphasized compassion as essential for achieving quality Universal Health Coverage (UHC), noting that health systems must move beyond technical competence to address the lived experiences, values, and preferences of people, particularly those who are vulnerable or marginalized (WHO, 2020). Empirical evidence demonstrates that compassionate care is associated with improved patient satisfaction, better adherence to treatment, enhanced trust in health systems, and improved mental health outcomes (Beach et al., 2006; Gilbert, 2014).

Compassion is equally important for HCWs. Studies show that compassion-based approaches can reduce burnout, improve job satisfaction, and strengthen professional resilience—outcomes that are especially relevant in overstretched public health systems such as those in leprosy-endemic districts (Figley, 2002; Sinclair et al., 2016).

1.3 Stigma, Compassion, and Flourishing in Chronic and Stigmatized Conditions

Leprosy is one of the most stigmatized diseases in the world, with stigma rooted in historical fears, misconceptions about contagion, and visible physical impairments (Silatham, 2003; van Brakel, 2003). In India, leprosy-related stigma continues to shape social attitudes, resulting in discrimination in marriage, employment, housing, and community participation (Rao et al., 2008).

Stigma operates at multiple levels—internalized, interpersonal, community, and institutional—and has profound consequences for mental health and wellbeing. Persons affected by leprosy experience higher levels of depression, anxiety, shame, and social withdrawal, often persisting long after completion of MDT (Somar et al., 2020). Stigma also directly undermines public health goals by delaying care-seeking, reducing treatment adherence, and weakening engagement with health services (Peters et al., 2014).

Health workers are not immune to these social norms. Evidence shows that stigmatizing beliefs and practices among HCWs contribute to disrespectful care, reduced empathy, and avoidance behaviours, thereby compromising the quality of leprosy services (van Brakel et al., 2012). Where stigma exists, compassion is obstructed; stigma objectifies individuals and erodes the sense of shared humanity that underpins compassionate and ethical care.

Cognitively Based Compassion Training (CBCT) is a research-based programme of Emory University (Atlanta, USA) that is grounded in cognitive and behavioural science, integrating psychological theory with ancient Indo-Tibetan contemplative practices to cultivate compassion, reduce bias, and promote prosocial behaviour (Ash, et al, 2019). Unlike many secular contemplative interventions, those that focus on compassion such as CBCT explicitly target systemic and interpersonal dynamics underpinning stigma, making it particularly relevant to healthcare improvement and ethical practice (Karlin & Ozawa-de Silva, 2018).

1.4 Rationale for Compassion Training for Health Care Providers (HCP) of Leprosy in Bokaro District

Under NLEP, leprosy services in Bokaro are delivered primarily by general health care (GHC) staff, whose training focuses on diagnosis, MDT delivery, and reporting. While these components are essential, compassionate care, stigma reduction, and psychosocial support are largely absent from routine training curricula. The high proportion of Grade 2 Disability in Jharkhand, as reported in the NLEP Annual Report 2024–25, signals not only delays but also deeper social and relational failures within the health system (Government of India, 2025). Fear of stigma, poor patient–provider interactions, and lack of trust discourage early reporting and sustained engagement with care.

CBCT offers a structured approach to address these gaps. In research trials, CBCT (Cognitively Based Compassion Training) has demonstrated positive effects on compassion, emotional regulation, mindfulness, and wellbeing among diverse populations, including healthcare providers (Ozawa-de Silva et al., 2012; Kirby, 2017; Ash, 2019). However, CBCT and other compassion training programs have not been adapted to address leprosy-related stigma or implemented within leprosy-endemic public health settings.

The study is closely aligned with the NLEP focus on early detection, disability prevention, and rehabilitation. Compassionate and socially sensitive approach of HCPs will address these concern making services more inclusive. The National Mental Health Programme (NMHP), which emphasizes mental wellbeing among populations affected by chronic conditions (Government of India, NHMP, 2026). The WHO’s framework emphasizes on quality, people-centered health services, highlighting dignity and compassion. Jharkhand state’s priorities focus to strengthen district health systems and address persistent health inequities (Department of Health, Jharkhand, 2026). By embedding compassion and stigma-responsiveness into routine leprosy care, the study supports national and state commitments to improving both technical quality and experiential quality of health services.

This study therefore seeks to develop, contextualize, and evaluate a stigma-informed compassion training tailored to healthcare providers delivering leprosy services in Bokaro district.

1.5 Research Question & Study Objectives

The main research question was “To what extent can compassion training that specifically addresses stigma improve compassion and quality of care offered by health workers to persons affected by leprosy and other stigmatizing health conditions”?

Primary Objective

- To study the effect of a compassion training on quality of care and stigma among healthcare providers delivering leprosy services.

Secondary Objectives

- To explore the perspectives and experiences of persons affected by leprosy and their family members regarding compassion in healthcare
- To explore healthcare providers’ perspectives on the role of compassion and stigma in leprosy care
- To identify core elements of a stigma-informed compassion training for healthcare providers
- To develop a contextualized compassion training curriculum
- To pilot and evaluate the adapted compassion training in a leprosy-endemic healthcare setting

1.6 Expected Outcomes and Impact

The project targets approximately 80 HCPs working under NLEP in Bokaro district.

Expected outcomes include:

- Improved compassion, empathy, and stigma-sensitive practices among healthcare providers
- Enhanced quality of leprosy services and patient–provider relationships
- A contextualized compassion training curriculum available for in-person and online use
- Evidence on the impact of compassion training on stigma reduction and quality of care
- Dissemination of findings and advocacy with district and state stakeholders for integration of compassionate care into routine leprosy services

Collectively, these outcomes are expected to strengthen health system responsiveness, restore dignity for persons affected by leprosy, and inform scalable approaches for addressing stigma in other chronic and stigmatized health conditions.

2. METHODOLOGY

2.1 Research design

The study followed a before-after study design with a mixed methods approach.

It was conducted in three phases, namely:

1. Baseline/ exploration phase. The baseline was conducted to explore how patients, their family members and healthcare providers understand and experience compassion. The data was captured through surveys, in-depth interviews and focus groups. The quantitative data was collected through standard tools. Appropriate guides were developed for collecting the qualitative data.
2. Intervention development and adaptation phase. During this phase, a stigma-informed compassion training curriculum was developed based on the findings of the baseline which had collected insights of the persons affected by leprosy, their family members and healthcare providers.
3. Implementation of the intervention and evaluation phase. In this phase, the healthcare providers comprising of medical officers and para medical workers across all 27 health centres of Bokaro district were trained on compassion. Post the training, evaluation was conducted to identify the post-intervention changes in compassionate behaviour amongst the healthcare providers towards the persons affected by leprosy. Opinions were also collected to address stigma. The quantitative tools were same as used in the baseline. The qualitative survey guides were revised to include probes depict specifically to get insights on the change in behaviour of the healthcare workers and experiences of the affected while seeking care.

2.2 Study population/ participants and selection criteria

The study population/participants included: 1] healthcare providers (HCP), 2] persons affected by leprosy and 3] Family members of persons affected by leprosy.

Table 1: Inclusion and exclusion criteria of study participants

Participant group	Inclusion criteria	Exclusion criteria
Persons affected by leprosy	• Diagnosed with leprosy between 1-12 months of the survey • Receiving leprosy-related services at one of the PHCs included in the study (≥ 1 visit) • Age 18 or above	• Persons unwilling or unable to give informed consent • Person has another stigmatizing condition (e.g., tuberculosis, HIV/AIDS, mental illness, etc.) • Health worker
Health workers	• Medical officers (MO), non-medical assistants (NMA), paramedical workers (PMW), Auxiliary nurse midwife (ANM), and counsellors who are involved	• Persons affected by leprosy • Persons unwilling or unable to give informed consent

	in the National Leprosy Eradication Program (NLEP) <u>and</u> interact with leprosy patients directly. • Willing and available to participate in the Compassion training • Working at a health care center included in the study for at least 6 months. • Age 18 or above	• Relocated to a different health center during the study period
Family members & caretakers	• The closest family member(s) to the person affected included in the study, or the one who provides the most supportive care to that person • Age 18 or above	• Persons affected by leprosy • Persons unwilling or unable to give informed consent • Health worker

2.4 Study Area

The study was implemented in Jharkhand state of India, in district Bokaro. Jharkhand has a population of 32,988,134 (2011 census). The state has 24 districts. The study district Bokaro is a premier industrial hub and home to the Bokaro Steel Plant, Asia's largest steel manufacturing complex. It has a population of 2,062,330, approximately 52.3% live in rural areas and 12.4% are tribal (2011 census). Jharkhand is one of the leprosy high endemic states in India; the proportion of child cases among new patients is 6.4% in the state, which is higher than the national average of 4.7%, this is an indicator of ongoing transmission (NLEP 2025 report). The annual new case detection rate of leprosy in Bokaro, the study district is 13.52 per 100,000 population. The district has 27 primary health centres (PHCs) (19 old PHCs and 8 new PHCs created in 2025) across two sub-division and eight blocks. The study included participants from all the 27 PHCs.

2.5 Sample size

Quantitative

Sample size achieved during baseline: 1] 80 HCPs and 2] 80 persons affected by leprosy. The number was achieved based on availability and consent of HCPs and affected persons. For HCPs, administrative authority has also given their input about availability.

Sample size achieved during endline: 1] 80 HCPs and 2] 80 persons affected by leprosy. During endline, attempt was made to reach the HCPs who had participated in the baseline as respondents and undergone compassion training provided by the project.

Qualitative

The planned sample size was

- In-depth interviews: 10 HCPs, 10 persons affected by leprosy and 10 family members.

- Focus group discussion: two (one male and one female members) from each of three groups namely HCPs, persons affected by leprosy and family members

Sample achieved during baseline:

Health Care Providers

A total of 19 unique HCPs participated in qualitative data collection. Of these, 8 females participated in FGDs and 9 males took part in a separate FGD, for a total of 17 FGD participants. Additionally, 8 females participated in individual IDIs and 2 males participated, for a total of 10 IDI participants. Among the participants, 6 females and 2 males engaged in *both* FGDs and IDIs. Almost all HCWs (18 of 19) provided quantitative data with the exception of 1 male FGD participant.

Persons Affected by Leprosy

A total of 24 unique PAL participated in qualitative data collection. Of these, 8 females participated in an FGD, and 8 males took part in a separate FGD, for a total of 16 FGD participants. Additionally, 2 females participated in IDIs, and 8 males participated, for a total of 10 IDI participants. Among the participants, 1 female and 1 male engaged in *both* FGDs and IDIs. All participants engaged in IDIs provided full quantitative data, while 5 of 8 male and 3 of 8 female FGD participants only provided demographic information.

Family Members of PAL

A total of 10 unique FM participated in qualitative data collection. Only IDIs were performed, no FGDs. Of the FM, 5 were female and 5 were male. Of the FM, 2 were a relative of a PAL also in the study (who provided quantitative and at least one form of qualitative data, while 8 were not. Of the 10 FM, 4 were siblings or siblings-in-law, 3 were spouses, 2 were grandchildren, and 1 was a parent. All 10 FM provided quantitative data for themselves (only demographic information).

Sample achieved during endline:

2.6 Participant Recruitment

We selected a systematic sample with a random start. Two lists were prepared: one with all health staff working at the 27 PHCs and one with all persons affected by leprosy receiving services from the health centres. In case of the HCPs, all HCPs working at the PHCs and supporting NLEP were listed; and for the persons affected by leprosy the listing began with cases registered with the PHCs within the last 1-12 months. The lists comprised of 123 HCPs and 263 persons affected by leprosy. We approached each block where a community health center (CHC) is located. From the master list, affected persons were selected from each PHC under the respective CHC based on their consent and availability. In contrast, for HCPs, the administrative authority played a role in suggesting participants, in addition to obtaining their consent and confirming their availability. The participants for the qualitative interviews were a subset of those in the quantitative sample, selected using purposive sampling. Family members were selected by the person affected (convenience sampling). All participants were recruited based on eligibility and consent.

The HCPs were interviewed at the PHCs. The persons affected by leprosy and their family members were interviewed at their homes/ a convenient location with privacy e.g. a meeting hall in a PHC.

The endline was conducted after around 4-5¹ months of training, ensuring the HCPs got a minimum period of 4 months to use their newly acquired compassion skills. During endline, the survey attempted to recruit all the HCPs who participated in the baseline and underwent training. Based on availability, we were able to recruit 61 such HCPs, the rest 19 were new. During the interim period between the baseline and endline, the persons affected by leprosy receiving services at the PHCs changed, some completed their treatment and new patients put on treatment. In order to capture the effect of intervention/ compassion training of the HCPs, the endline recruited only those persons affected by leprosy who got the opportunity to receive services from the trained HCPs.

2.7 Data collection tools

Besides a tool for collecting socio-demographic data, standard tools were used for collecting data related to compassion and stigma.

Tools/ scales used for the persons affected by leprosy

1. Human Flourishing Scale: the scale measures six different dimensions of human well-being and flourishing, which includes six domains namely happiness and life satisfaction, mental and physical health, meaning and purpose, character and virtue, close social relationships, and financial and material stability. Under each of the six domains there are two questions/ items are assessed on a scale of 0-10 with different answer options.
2. The Consultation and Relational Empathy (CARE) Measure: the scale assesses the quality of the patient-provider relationship, with a focus on the health worker's empathy as experienced by the patient. The CARE Measure consists of 10 items, each rated on a 5-point Likert scale poor to excellent. Patients are asked to rate their healthcare provider on aspects such as listening, understanding, and showing care and compassion.
3. The Stigma Assessment and Reduction of Impact (SARI) Scale: the scale measures the extent and different dimensions of stigma that persons affected by leprosy may face. This includes both internalized stigma (self-stigma) and external stigma (discrimination and social exclusion). The scale consists of 21 items and is scored using a Likert scale (Always-3, Often-2, Rarely-1, and No-0). The instrument comprises 4 sub-scales that can be used together or individually measuring experienced stigma (7 items), disclosure concerns (4 items), internalized stigma (6 items) and anticipated stigma (4 items). The item scores are summed for each sub-scale. Together they provide an overall stigma score.

Tools/ scales used for the healthcare providers

1. Social Distance Scale (SDS): the scale measures the social distance the health worker wants to keep towards a person affected by leprosy. The SDS interview starts by reading a vignette, a short description of a person with some typical characteristics of the condition, followed by 7 questions concerning the person in the vignette. The Social Distance Scale has an answer scale of 0-3 (definitely willing though definitely not willing).
2. The Pommier Compassion Scale: the scale measures an individual's level of compassion towards others, particularly in the context of healthcare professionals. The scale consists of 16 statements and responses are scored on a Likert scale on which study participants indicate how often "they feel or behave in the stated manner, ranging from "almost never" to "almost always".

¹ The trainings were conducted in multiple batches staggered over 2 months

2.8 Data analysis

1. Qualitative data were audio-recorded, transcribed and translated, from Hindi into English. NVivo software was used for detailed content analysis employing both deductive and inductive approaches. Five themes related to compassion and leprosy-related stigma were identified: (1) local perceptions and experiences of compassion, (2) views on the value of compassion, (3) knowledge and perceptions of leprosy, (4) observations of leprosy-related discrimination, and (5) suggested interventions to address discriminatory behaviors. The insights were used to explain the quantitative findings. The baseline findings were used to develop the stigma specific compassion training module for the healthcare providers. The endline evaluation determined the affect of training on the compassionate behavior of the healthcare providers.
2. For quantitative data, digital data entry was carried out using the REDCap mobile application to minimize manual errors. The data were synced daily and reviewed by the Research Coordinator to ensure timely oversight. Validation checks were conducted to assess completeness, accuracy, and consistency of the data, and unique identification numbers were assigned to each study participant to enable reliable tracking and avoid duplication. The finalized datasets were exported as CSV/Excel files and subsequently analyzed using Epi Info 7 and Stata version 15.
3. Descriptive statistics were used for demographic data and estimates of human well-being and flourishing, quality of the patient-provider relationship, the extent and different dimensions of stigma, the social distance the health worker wants to keep towards a person affected by leprosy, and an individual's level of compassion towards others.
4. Independent t-tests were conducted to identify differences between sub-groups of the study samples (both at baseline and endline), groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups. Disability scores were aggregated into two categories: disability or no disability (EHF score > 0 & 0). Similarly, marital status was sub-grouped into married & not (currently) married.
5. Regression models were used to determine the overall effect between baseline and endline data.

2.9 Ethical considerations

Informed consent was collected for all interviews, both quantitative and qualitative. The study participants were adequately explained about the risk and benefit of participating in the study and their right of withdrawal at any point of time of the study. Informed consent was also collected for including the participants in the intervention. During quantitative and qualitative data collection interviews and discussions, comfort and confidentiality of the participants was ensured. The study being focussed on training of the health workers on compassion had minimal risk of enhancing leprosy related stigma and discrimination. Special care was taken to conduct the interviews and FDGs among the leprosy affected ensured the interviews were conducted in some other closed space with confidentiality. All data was striped of the identifiers, coded and stored in password protected computer files; the study team concerned with data analysis only had access to the password.

2.10 Study Implementation

The study was launched on April 2024 through a meeting at Bokaro attended by the district leprosy office and NLR staff from Amsterdam, India Head Office and Bokaro field team.

Key events & dates

Collection of baseline data	May 2024- July 2024
Baseline data analysis & reporting	August 2024 - October 2024
Development of compassion training modules in English & Hindi – 3 English, 1 Hindi	August 2024 – March 2025
Training of healthcare providers	May 2025- June 2025
Collection of endline data	August 2025 - November 2025
Final data analysis and report writing	December 2025 - February 2026

The study was guided by a core team comprised of representatives from all the implementing partners namely Emory University, FACE, Piramal Foundation NLR India and NLR International. The team met every month. The NLR India Head office team met the project team every week. Representative of persons affected by leprosy joined the meetings as and when required particularly during data collection and interpretation of results. Periodic reports on the study progress were submitted to the state leprosy office, Jharkhand. Half yearly reports were submitted to the donor, Leprosy Research Initiative, Amsterdam. The original approved timeline was for 24 months from 1 July 2023 to 30 June 2025. No cost extension was done for 9 months in total till 31 March 2026. The delay was primarily to accommodate a longer than estimated time for acquiring ethical clearance from the Institutional Review Board (IRB) of Ranchi Medical College, administrative approval from the state leprosy office, Jharkhand; and data collection both for the baseline and endline. Dissemination of the baseline findings was done at the ECTMIH conference, Hamburg on 2nd October 2025. The final results of the study were disseminated through a state level meeting in Jharkhand on 25th March 2026 and national level meeting on 24th April 2026.

2.11 Training

The field staff consisted of the research manager and two research assistants. They received detailed training, at the start and endline.

1. Project Orientation and baseline data collection. This lasted for almost 3 weeks. A five-day in-person training was conducted with the launch of the project in April 2024. The team was oriented on the study protocol, leprosy, stigma and compassion, their roles, the procedure for recruitment of study participants, inclusion and exclusion criteria, study tools and interview techniques. Several mock interviews were conducted. The training was provided by the NLR International and NLR India Head office (HO) team. This was followed by around two weeks of mock interviews, capturing quantitative through tab in redcap software. They also conducted mock in-depth interviews and focus group discussion. The RAs transcribed the same. Each day the HO staff reviewed the data captured through tab and transcribed scripts and provided feedback.

2. Training for end-line data collection. This in-person training lasted for five days in August 2025. The team was first oriented on the importance of conducting the endline followed by data collection tools the procedure for recruitment of study participants, inclusion and exclusion criteria, study tools and interview techniques. Several mock interviews were conducted. The training was provided by the NLR International and NLR India Head office (HO) team. This was followed by around a week of mock interviews, both quantitative and qualitative. The quantitative tools were same as the baseline, but the qualitative guides were changed to include questions to determine the effect of training the healthcare providers. The focus of the training was to discuss the challenges experienced during the baseline e.g. planning travel time and appointments more efficiently. The team continued with one week of mock interviews and transcription.

3. INTERVENTION

3.1 Framework of Compassion Training

The compassion training intervention was developed as a stigma-informed, compassion-focused educational approach designed to improve healthcare providers' attitudes and behaviors toward persons affected by leprosy. The conceptual framework relies on the core principles of CBCT (cognitively based compassion training) (Ash, et al., 2019), which is the primary training modality, and augments this with tailored stigma-reduction approaches developed especially for this context.

CBCT emphasizes cultivating self-regulation, focus, emotional awareness, self-compassion, reduction in bias, and increased empathic accuracy – all in support of increasing a genuine and inclusive compassionate motivation. It includes additional modules to address structural and interpersonal stigma that may influence provider–patient relationships. By strengthening healthcare workers' capacity for emotion regulation and self-awareness, the training aims to strengthen a personal sense of centeredness and self-agency so that the intended behavioral and ethical qualities of care can be more readily learned and enacted.

The intervention was contextualized using insights from baseline research involving healthcare providers, persons affected by leprosy, and family members. Their experiences helped shape a training model that responds to real-world challenges in primary healthcare settings, particularly stigma, communication gaps, and lack of psychosocial sensitivity in routine services. The detailed baseline report has been annexed.

3.2 Training Curriculum and Modules

The compassion training curriculum was developed collaboratively by a team of international and national partners who have been trained and certified as CBCT Teachers by Emory University (Atlanta, USA). Collaborating across disciplines, this team tailored special modules for healthcare providers involved in leprosy services. The curriculum consisted of three key modules:

1. **CBCT For Leprosy Care Providers: Embracing Compassion Dissolving Stigma for Persons Affected with Leprosy and their Healthcare Provider (Facilitator Guide)** – Designed to support Emory Certified CBCT trainers in conducting experiential compassion training sessions and guiding reflective discussions to enable and foster a culture of empathy and compassion among doctors and healthcare providers who work with Persons Affected with Leprosy
2. **Embrace Compassion Dissolve Stigma – A Self Help Guide for Doctors** – The guide provides practical checklists, reflection exercises, and strategies for integrating compassion into everyday patient care, while also serving as tools for self-care and emotional well-being. The aim is to help Doctors/medical officers sustain their ability to

offer high-quality, empathetic care, while fostering resilience and maintaining a sense of balance for themselves as well

3. **Embrace Compassion and Dissolve Stigma – A Self Help Guide for Paramedics –**
The guide provides practical checklists, reflection exercises, and strategies for integrating compassion into everyday patient care, while also serving as tools for self-care and emotional well-being. The aim is to help Paramedics and Healthcare providers sustain their ability to offer high-quality, empathetic care, while fostering resilience and maintaining a sense of balance for themselves as well.

The modules included topics such as compassion and empathy in healthcare, stigma and discrimination in leprosy services, self-awareness and emotional resilience, patient-centered communication, and strategies for integrating compassionate practices into routine care. The materials were prepared in English and later translated into Hindi to ensure accessibility for frontline health workers.

3.3 Training Methodology

The training adhered to CBCT's pedagogical approach of participatory and experiential learning, moving away from conventional lecture-based formats. Sessions incorporated reflective exercises, guided discussions, role-plays, mindfulness practices, storytelling, and group activities designed to promote emotional awareness, empathy, and compassion.

Participants were encouraged to reflect on their own experiences, recognize unconscious stigma in healthcare practice, and explore ways to respond with compassion and respect. The methodology emphasized active participation, peer learning, and safe spaces for sharing personal and professional challenges.

Cadre-specific and gender-sensitive learning environments were also used to ensure that participants could express their perspectives freely. This approach helped create deeper reflection, increased openness among participants, and stronger engagement during the sessions.

3.4 Duration, Frequency, and Mode of Delivery

The compassion training was delivered through structured training workshops conducted in multiple batches during 2025. Each training batch typically lasted three days, allowing sufficient time for experiential exercises, reflection, and group discussions.

The sessions were conducted in-person to facilitate interaction and experiential learning. Four batches of training were organized for different cadres of healthcare providers, including medical officers and paramedical staff working across primary healthcare centers in Bokaro district.

The training program was implemented between March and May 2025, with participants attending sessions based on their cadre and availability. This phased approach ensured wider participation while maintaining interactive learning environments.

3.5 Participant Profile

Participants in the training included healthcare providers involved in the delivery of leprosy services within the public health system. The primary participant groups were:

- Medical Officers (MBBS), including Medical Officers-in-Charge of health facilities
- AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha, and Homoeopathy) and RBSK (Rashtriya Bal Swasthya Karyakram) medical officers
- Paramedical workers such as ANMs (Auxiliary Nurse Midwives), nurses, counselors, and support staff

These participants represented healthcare workers from multiple primary health centers across Bokaro district. Many were young professionals working within the National Leprosy Eradication Programme (NLEP). Overall, approximately 80 healthcare providers were involved in the training and subsequent evaluation.

3.6 Facilitators and Resource Persons

The training was facilitated at all times by fully-certified CBCT Teachers who were on the staff of the Piramal Foundation, and was supported by a multidisciplinary team consisting of project staff, technical experts, and other collaborators, including staff from NLR India. .

The development and facilitation of the training modules involved collaboration with organizations such as NLR International, the Piramal Foundation, FACE, and Emory University. . In addition, individuals with lived experience of leprosy contributed to the training process, providing valuable perspectives on stigma and patient experiences.

3.7 Monitoring of Training

Monitoring of the training was conducted through multiple mechanisms to ensure quality and effectiveness. These included participant feedback during training sessions, observation of engagement levels, and review meetings with facilitators and project partners, including the developer of the CBCT program.

The project team documented training attendance, participant reflections, and learning outcomes. Baseline and endline quantitative surveys were conducted among healthcare providers to measure changes in compassion, stigma, and quality of care indicators. Qualitative methods such as in-depth interviews and focus group discussions were also used to capture participant experiences and perceptions of the training.

3.8 Post-implementation Activities

Following completion of the training sessions, several activities were undertaken to sustain learning and assess the impact of the intervention. A '*Ten-Point Compassion Charter*' was developed and shared with trained healthcare providers as a practical reminder of the principles of compassionate care, including dignity, empathy, inclusivity, and teamwork.

A '*WhatsApp-based peer learning group*' was also created to enable trained participants to share experiences, discuss challenges, and support each other in applying compassionate practices in their daily work.

In addition, endline evaluation activities were conducted, including surveys and qualitative interviews with healthcare workers, persons affected by leprosy, and their family members. These activities aimed to assess changes in provider attitudes, stigma, and patient experiences following the compassion training intervention.

4. ENDLINE STUDY FINDINGS

4.1 Profile of study participants

4.1.1 Quantitative study participants

Table 2: Study participants

Participants Type	Quantitative data collected	Tools/ Scales
Persons affected by leprosy	80	1. Socio-demographic details 2. Human Flourishing Scale 3. The CARE Measure 4. SARI Stigma Scale
Health care providers	80	1. Socio-demographic details 2. Social Distance Scale (SDS) 3. The Pommier Compassion Scale

Socio-demographic profile

A total of 160 persons affected by leprosy participated in the study, with 80 respondents each at baseline and endline. The proportion of male participants differed slightly between baseline and endline, with 61% at baseline and 55% at endline. The mean age of participants was 39.9 years (range: 18–76) at baseline and 43.4 years (range: 18–77) at endline, showing a slightly older group at endline. The majority of participants were from rural areas (91%) at both time points.

In terms of caste composition, most respondents belonged to the OBC group (50% at baseline and 56% at endline), followed by SC and ST categories. The proportion of participants following Hinduism was 84% at baseline and 91% at endline. Educational attainment showed some variation between the two samples: the share of participants with no schooling was 26% at baseline and 40% at endline, while those with primary and middle schooling were less at endline. Most participants were married (75%) and lived with their families in villages (99%) at both baseline and endline.

Table 3: Socio-demographic profile of persons affected by leprosy at baseline and endline

	Baseline		Endline	
	n	%	n	%
Total	80	100%	80	100%
Gender				
Male	49	61%	44	55%
Female	31	39%	36	45%
Age (years)				
18 - 30	26	33%	22	28%
31- 45	25	31%	22	28%
46- 60	20	25%	22	28%
above 60	9	11%	14	18%
Mean (Range)	39.86 (18 - 76)		43.39 (18 - 77)	
Setting				
Rural	73	91%	73	91%
Urban	7	9%	7	9%
Caste				
Scheduled Castes (SC)	22	28%	15	19%
Scheduled Tribes (ST)	13	16%	11	14%
Other Backwards Castes (OBC)	40	50%	45	56%
General	5	6%	9	11%
Religion				
Hinduism	66	84%	73	91%
Islam	4	5%	5	6%
Sarnaism	9	11%	1	1%
Sikhism	1	1%	1	1%
Education				
No Schooling	21	26%	32	40%
Primary school (5th)	19	24%	9	11%
Middle school (8th)	16	20%	12	15%
High School (10th)	13	16%	15	19%
Higher Secondary (12th)	8	10%	8	10%
Tertiary/graduate schooling	3	4%	4	5%
Employment Status				
Unemployed	16	20%	37	46%
Home maker	21	26%	22	28%
Alms seeker	1	1%	0	0%
Self-employed	2	3%	8	10%
Service-holder	11	14%	1	1%
Student	4	5%	7	9%
Retired	2	3%	0	0%
Other	23	29%	5	6%
Marital Status				
Currently married	59	74%	60	75%
Widow(er)	6	7%	5	6%
Single/Never Married	15	19%	15	19%
Living situation				
With family in village	80	99%	79	99%
Designated colony/segregated area	0	1%	1	1%

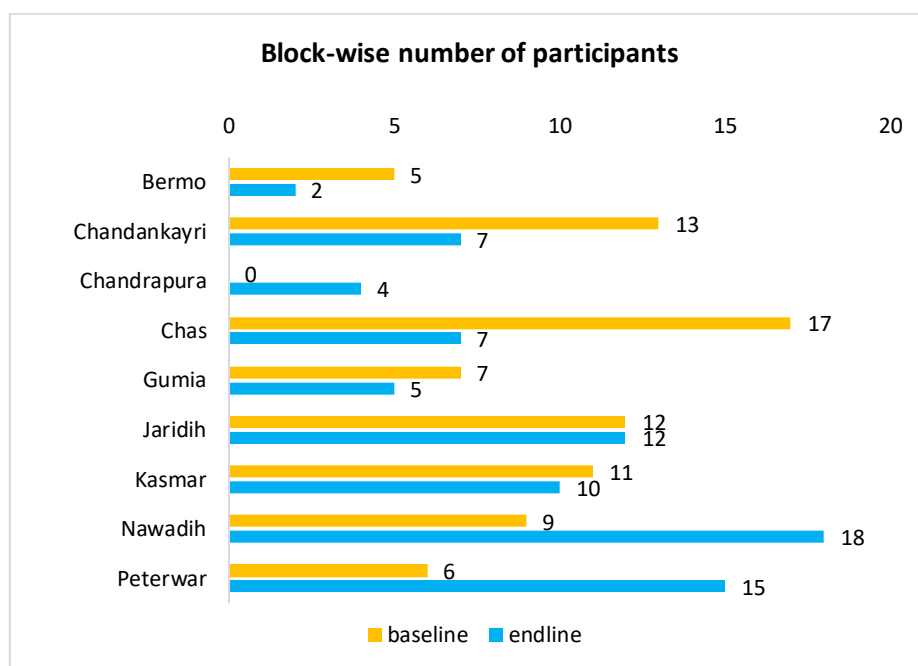


Figure 1: Block-wise number of participants at baseline and endline

4.1.2 Qualitative study participants

A total of 59 unique participants from Jharkhand State were involved in the qualitative data collection at endline, comprising Healthcare Workers (HCWs or providers), Persons Affected by Leprosy, and Family Members of persons affected by leprosy (FM). *The abbreviation of PAL is not used for persons affected by leprosy out of respect and response to advocated preference.* Unlike at baseline, no participants were involved in both a Focus Group Discussions (FGDs) and Individual In-Depth Interview (IDIs) IDI and FGD. The following table summarizes the distribution of participants:

Table 4: Overview of the qualitative study participants

Participant Group	Gender	FGD	IDI	Total
Healthcare Workers (HCWs)	Female	6	4	10
	Male	7	7	14
Persons Affected by Leprosy	Female	8	3	11
	Male	7	7	14
Family Members of Persons Affected by Leprosy (FMs)	Female	0	4	4
	Male	0	6	6
Total	All	28	31	59

Healthcare Workers

A total of 24 HCWs participated in qualitative data collection. Of these, 6 females participated in FGDs and 7 males took part in a separate FGD, for a total of 13 FGD participants. Additionally, 4 females participated in IDIs and 7 males participated, for a total of 11 IDI participants. Of the FGD participants, 1 female and 2 males participated at baseline. Of the IDI participants, 1 female participated at baseline. Due to the small sample size, a within-person analysis was not performed for repeat participants.

Persons Affected by Leprosy

A total of 25 persons affected by leprosy participated in qualitative data collection. Of these, 8 females participated in FGDs and 7 males took part in a separate FGD, for a total of 15 FGD participants. Additionally, 3 females participated in IDIs and 7 males participated, for a total of 10 IDI participants.

Family Members of Persons Affected by Leprosy

A total of 10 family members of persons affected by leprosy participated in qualitative data collection. Of these, 4 females participated in IDIs and 6 males participated, for a total of 10 IDI participants. Each participating family member is a direct relative to a person affected by leprosy who participated in an IDI. Of the 10 family members, two were siblings, one was a spouse, four were children, and three were parents.

4.2 Quantitative Study: Person Affected by Leprosy: Comparing Endline vs Baseline Findings

4.2.1 Case History

At both baseline and endline, the study sample consisted of 80 participants, with a similar distribution of leprosy types between the two samples. At baseline, 59 participants (74%) were classified as multibacillary (MB) and 21 participants (26%) as paucibacillary (PB). At endline, the number of MB cases was slightly higher: 61 participants (76%), while the number of PB cases was 19 (24%).

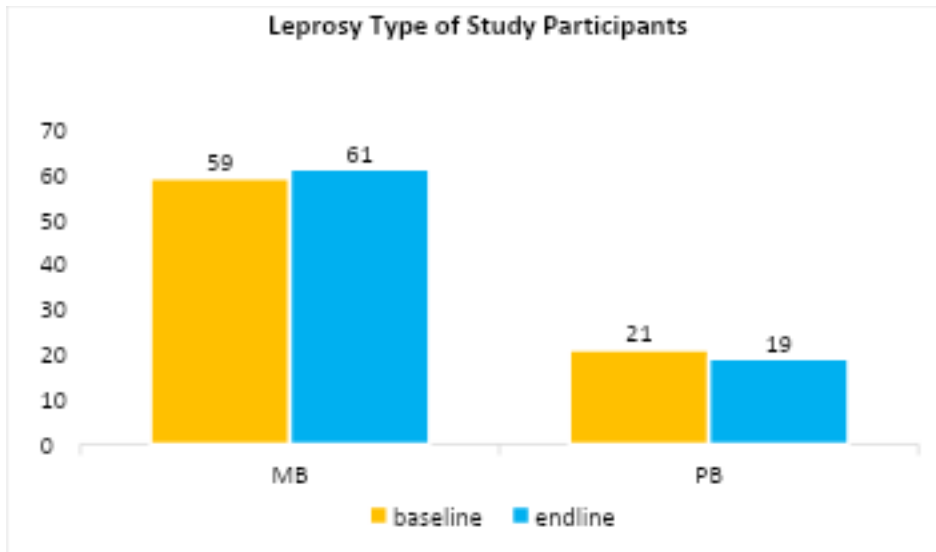


Figure 2: Leprosy type of study participants at baseline and endline

At baseline, the majority of participants (73,91%) had no disability, while 4 participants (5%) had grade 1 disability and 3 participants (4%) had grade 2 disability. At endline, the distribution was different: the number of participants with no disability was 57 (71%), those with grade 1 disability were 5 (6%), and those with grade 2 disability were 18 (23%).

Table 5: Eyes, hands, feet (EHF) scores and frequency distribution at baseline and endline

EHF Score	n (baseline)	%	n (endline)	%
0	73	91%	57	71%
1	3	4%	-	-
2	2	3%	9	11%
3	1	1%	-	-
4	-	-	9	11%
6	-	-	1	1%
8	1	1%	3	4%
10	-	-	1	1%
Total	80	100%	80	100%

Table 6: WHO disability grade and frequency distribution at baseline and endline

WHO Disability Grade	baseline	baseline%	endline	endline %
0	73	91%	57	71%
1	4	5%	5	6%
2	3	4%	18	23%
Total	80	100%	80	100%

4.2.2 Human Flourishing Scale

The **Human Flourishing Scale** is a measure designed to assess various dimensions of human well-being and flourishing, which includes various aspects of life, such as happiness, physical health, meaning and purpose, character, social relationships, and financial stability. In the Human Flourishing Scale, a total of 12 questions/ items are assessed on a scale of 0-10 with different answer options as visualized in Table 6. The total score provides an overall indication of flourishing.

Table 7: Human Flourishing Scale and its items

Domain	Q. S.No	The following questions on a scale from 0 to 10	Scale	
			0	10
<i>Happiness and Life Satisfaction</i>	1	Overall, how satisfied are you with life as a whole these days?	Not Satisfied At All	Completely Satisfied
	2	In general, how happy or unhappy do you usually feel?	Extremely Unhappy	Extremely Happy
<i>Mental and Physical Health</i>	3	In general, how would you rate your physical health?	Poor	Excellent
	4	How would you rate your overall mental health?	Poor	Excellent
<i>Meaning and Purpose</i>	5	Overall, to what extent do you feel the things you do in your life are worthwhile?	Not At All Worthwhile	Completely Worthwhile
	6	I understand my purpose in life.	Strongly Disagree	Strongly Agree
<i>Character and Virtue</i>	7	I always act to promote good in all circumstances, even in difficult and challenging situations.	Not True of Me	Completely True of Me
	8	I am always able to give up some happiness now for greater happiness later.	Not True of Me	Completely True of Me
<i>Close Social Relationships</i>	9	I am content with my friendships and relationships.	Strongly Disagree	Strongly Agree
	10	My relationships are as satisfying as I would want them to be.	Strongly Disagree	Strongly Agree
<i>Financial and Material Stability</i>	11	How often do you worry about being able to meet normal monthly living expenses?	Worry All of the Time	Do Not Ever Worry
	12	How often do you worry about safety, food, or housing?	Worry All of the Time	Do Not Ever Worry

Descriptive statistics

Table 8: Descriptive statistics of Human Flourishing Scale

	Count	Range	Minimum	Maximum	Mean	Median	95% CI
Baseline	80	58	37	95	68.61	70	66.1 - 71.1
Endline	80	75	38	113	90.41	90	87.5 - 93.3

Table 9: Independent T-test results (Human flourishing scores- baseline and endline)

Statistic	Baseline (n=80)	Endline (n=80)	Difference (Endline – Baseline)
Mean	68.61	90.41	+21.80
Standard Deviation	11.25	12.91	—
p-value (two-tailed)	—	—	< 0.001

The independent T-test of Human Flourishing scores shows a significant difference between baseline and endline. At baseline, the mean score was 68.61 (SD = 11.25), while at endline, it increased to 90.41 (SD = 12.91), representing an average increase of 21.80 points. The independent t-test indicates that this difference is highly significant ($p < 0.001$).

Across all six domains, participants surveyed at endline reported higher levels of wellbeing compared to those at baseline. In **Happiness and Life Satisfaction**, mean scores rose from 6.31 to 7.75 for life satisfaction and from 6.14 to 7.83 for happiness. **Mental and Physical Health** ratings rose from 5.79 to 7.55 and 6.10 to 7.65, indicating better self-perceived health in the endline sample. In **Meaning and Purpose**, scores rose from 6.30 to 7.98 and from 6.65 to 7.81, reflecting stronger fulfilment and direction in life in the endline sample compared to the baseline sample.

Character and Virtue scores also rose from 6.70 to 7.93 and from 5.45 to 7.09, suggesting enhanced resilience and self-control. **Close Social Relationships** strengthened significantly, with satisfaction and relationship quality improving from 6.14 to 7.95 and from 6.33 to 7.99, respectively. Finally, **Financial and Material Stability** rose considerably, as worries about expenses and security reduced, with scores increasing from 3.36 to 6.38 and from 3.35 to

6.53. Overall, the endline group demonstrated higher wellbeing and stability across emotional, social, and material aspects of life.

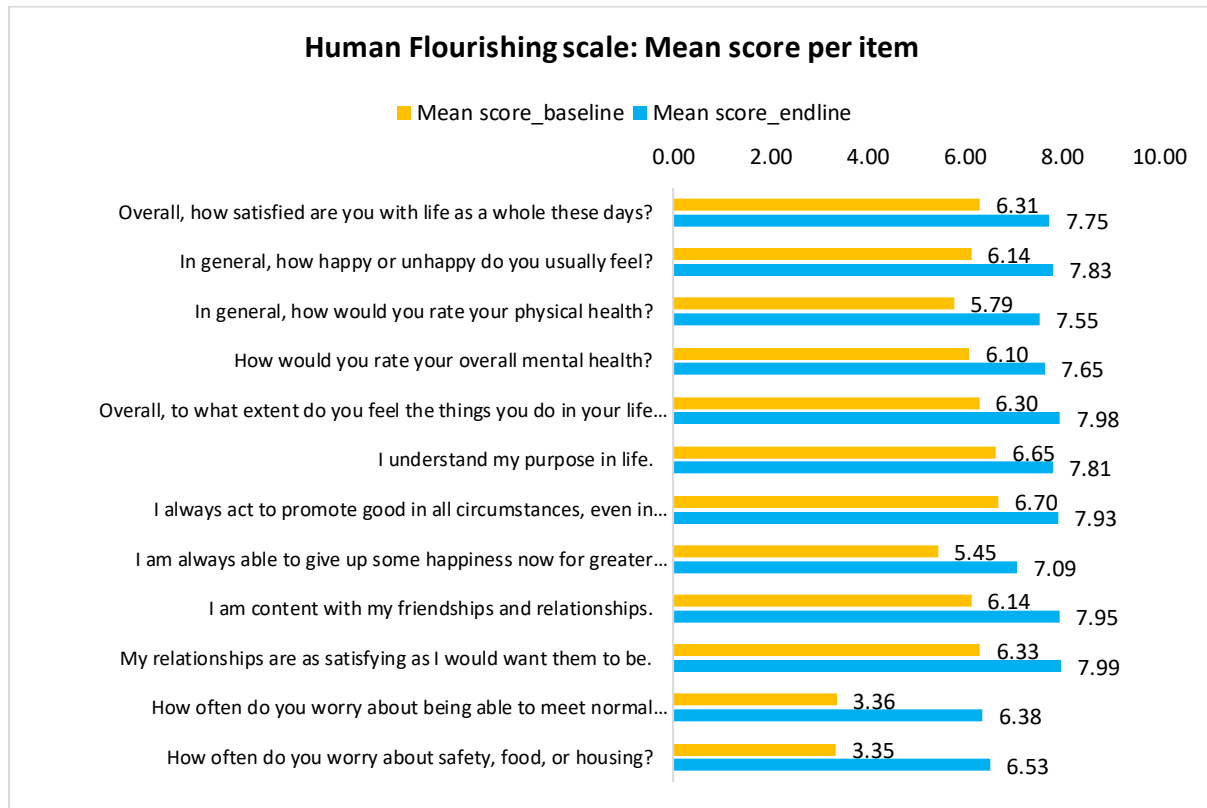


Figure 3: Human Flourishing scale: Mean scores per item at baseline and endline

Sub-group analysis (independent t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study samples (both at baseline and endline), groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups. Disability scores were aggregated into two categories: disability or no disability (EHF score > 0 & 0). Similarly, marital status was sub-grouped into married & not (currently) married.

At the baseline, a significant difference in the mean scores between PB (74.14) and MB (66.64) cases was found ($p=0.0079$). Similarly, a significant difference between age groups was indicated by a p -value of 0.0007.

At the endline, a significant difference in the mean scores between PB cases (96.32) and MB cases (88.57) was observed ($p = 0.0214$). Similarly, participants with an EHF score of 0 had a higher mean score (92.82) compared to those with EHF > 0 (84.43), with the difference being statistically significant ($p = 0.0077$). A significant negative association was also found between the SARI stigma scale score and the human flourishing score ($p = 0.0162$), indicating that higher stigma levels were associated with lower flourishing scores.

Table 10: Independent T-tests results of sub-groups (Human flourishing scale)

	Baseline				Endline		
	n (%)	Mean (95% CI)	p-value		n (%)	Mean (95% CI)	p-value
Gender							
Male	49 (61%)	67.41 (64.24-70.57)	0.2311		44 (55%)	90.07 (85.87 - 94.27)	0.7938
Female	31 (39%)	70.52 (66.62-74.41)			36 (45%)	90.83 (87.15 - 94.52)	
Setting							
Rural	73 (91%)	68.33 (65.77-70.88)	0.4699		73 (91%)	89.60 (86.68 - 92.53)	0.0696
Urban	7 (9%)	71.57 (62.00-81.14)			7 (9%)	98.86 (89.80 - 107.91)	
Age (years)							
18 - 30	26 (33%)	73.07 (68.63 -77.53)	0.0005		22 (28%)	95.59 (90.98 - 100.20)	0.1197
31- 45	25 (31%)	70.76 (67.67-73.85)			22 (28%)	90.50 (86.08 - 94.92)	
46- 60	20 (25%)	65.40 (60.88-69.92)			22 (28%)	87.41 (81.09 - 93.73)	
above 60	9 (11%)	56.89 (49.38-64.40)			14 (18%)	86.86 (79.62 - 94.10)	
Leprosy type							
PB	21 (26%)	74.14 (69.19-79.09)	0.0079		19 (24%)	96.32 (91.83 - 100.80)	0.0214
MB	59 (74%)	66.64 (63.95-69.34)			61 (76%)	88.57 (85.25 - 91.89)	
EHF							
0	73 (91%)	69.26 (66.72-71.80)	0.0966		57 (71%)	92.82 (90.14 - 95.51)	0.0077
>0	7 (9%)	61.86 (53.16-70.55)			23 (29%)	84.43 (77.67 - 91.20)	
Marital status							
Married	59 (74%)	68.37 (65.72-71.03)	0.7518		60 (75%)	89.68 (86.52 - 92.85)	0.3848
Not (currently) married	21 (26%)	69.29 (63.45-75.12)			20 (25%)	92.60 (86.41 - 98.79)	
SARI Stigma Scale score	n/a	n/a	0.2611		n/a	n/a	0.0162

Regression models at baseline and endline (Outcome variable: Human Flourishing score)

Variables showing an association with the Human Flourishing Scale mean scores at a significance level of $p \leq 0.20$ were included in the multivariate regression model. Subsequently, variables with $p > 0.05$ were sequentially removed until a statistically significant model was obtained.

At the baseline, the final model for Human Flourishing Scale outcomes includes leprosy type and the age of the persons affected with leprosy. These variables explain 24% of the variability in the Human Flourishing Scale score.

At the endline, the SARI stigma scale score, EHF score, and setting (urban/rural) were significant predictors of the human flourishing score. A one-unit increase in the sari stigma score was associated with a 0.59-point decrease in flourishing ($p = 0.0061$), indicating that higher stigma is linked with lower flourishing outcomes. Not having a disability was associated with on average 6.63 points higher on the HFS scale ($p = 0.0278$), whereas being from a rural area was associated with on average 11.55 lower scores ($p = 0.0195$). The overall model was statistically significant ($p < 0.001$), explaining about 20% of the variance in flourishing scores ($R^2 = 0.20$).

Table 11: Multivariate regression models for Human Flourishing Scale (Baseline vs Endline)

Variable	Baseline p-value	Endline p-value
Age	0.0002	–
Leprosy type (PB/MB)	0.0119	–
SARI stigma scale score	–	0.0061
EHF (0/>0)	–	0.0278
Setting (Urban/Rural)	–	0.0195
	$R^2 = 0.27$	$R^2 = 0.20$

Regression Model (Overall effect: Baseline & Endline data):

In the combined analysis of baseline and endline data, human flourishing scores were significantly influenced by social and biological factors, as well as by timepoint. Higher SARI stigma scores were associated with lower flourishing ($\beta = -0.24$, $p = 0.018$), indicating that stigma negatively impacts well-being. Older age was linked with reduced flourishing ($\beta = -0.20$, $p = 0.001$), while PB cases are associated with higher flourishing compared to MB cases ($\beta = 6.17$, $p = 0.003$).

Not having a disability was associated with higher flourishing scores ($\beta = 4.99$, $p = 0.039$). Importantly, the endline timepoint was significantly associated with higher flourishing scores approximately 23 points higher ($\beta = 23.11$, $p < 0.001$). The final model explained 56% of the variance in flourishing scores ($R^2 = 0.56$).

Endline flourishing scores were associated with on average 23.1 points higher than baseline., controlling for stigma, age, leprosy type, and EHF.

Overall, older age, higher stigma, disability and MB type are associated with lower flourishing scores.

Table 12: Multivariate regression models of Human Flourishing Scale (Overall effect)

Variable	Coefficient (β)	p-value	Interpretation
SARI Stigma Score	-0.24	0.018	Higher stigma is significantly associated with lower flourishing; each 1-point increase in stigma reduces flourishing by 0.24 points.
Age	-0.20	0.001	Older is associated with lower flourishing; each additional year reduces flourishing by 0.20 points.
Leprosy Type (PB/MB)	6.17	0.003	MB leprosy was associated with lower flourishing scores than PB cases by 6.17 points.
EHF (0/>0)	4.99	0.039	Participants with EHF >0 were associated with lower flourishing scores by 4.99 points.
Timepoint (baseline=0; endline=1)	23.11	<0.001	Endline flourishing scores were associated with on average 23.1 points higher than baseline.

4.2.3 The Consultation and Relational Empathy (CARE) Measure

The Consultation and Relational Empathy (CARE) Measure assesses the quality of the patient-provider relationship, with a focus on the health worker's empathy as experienced by the patient. The CARE Measure consists of 10 items, each rated on a 5-point Likert scale poor to excellent. Patients are asked to rate their healthcare provider on aspects such as listening, understanding, and showing care and compassion.

Table 13: The CARE Measure scale

S.No	The following questions on a scale from 0 to 5
1	Making you feel at ease
2	Letting you tell your "story"
3	Really listening
4	Being interested in you as a whole person
5	Fully understanding your concerns
6	Showing care and compassion
7	Being Positive
8	Explaining things clearly
9	Helping you to take control
10	Making a plan of action with you

Descriptive statistics

Table 14: Descriptive statistics of The CARE Measure scale

	Count	Range	Min	Max	Mean	Median	95% CI
Baseline	80	21	23	44	30.4	30	29.5 - 31.4
Endline	80	20	29	49	42.2	43	41.5 - 43.0

The independent t-test of CARE Measure scores shows a significant difference between baseline and endline. The mean score at baseline was 30.44 (SD = 4.36), whereas at endline it was 42.23 (SD = 3.39), with endline scores being higher on average than baseline scores. The independent t-test indicates that this difference is highly significant ($p < 0.001$).

Table 15: Independent T-test results (The CARE Measure scores- baseline and endline)

Statistic	Baseline (n=80)	Endline (n=80)	Difference (Endline – Baseline)
Mean	30.44	42.23	+11.79
Standard Deviation	4.36	3.39	—
p-value (two-tailed)	—	—	< 0.001

The mean scores per item indicate higher quality of interactions reported by participants at endline compared to those at baseline. Although the respondents were not the same at both time points, the consistent increase of about 1 to 1.3 points across all ten questions suggests a positive shift in how health workers engaged with persons affected by leprosy.

At baseline, the lowest mean score (2.89) was observed for “showing care and compassion,” which rose to 4.26 at endline, reflecting a stronger display of compassion among health workers. Likewise, the highest endline score (4.31) for “being positive” indicates a more encouraging and supportive attitude.

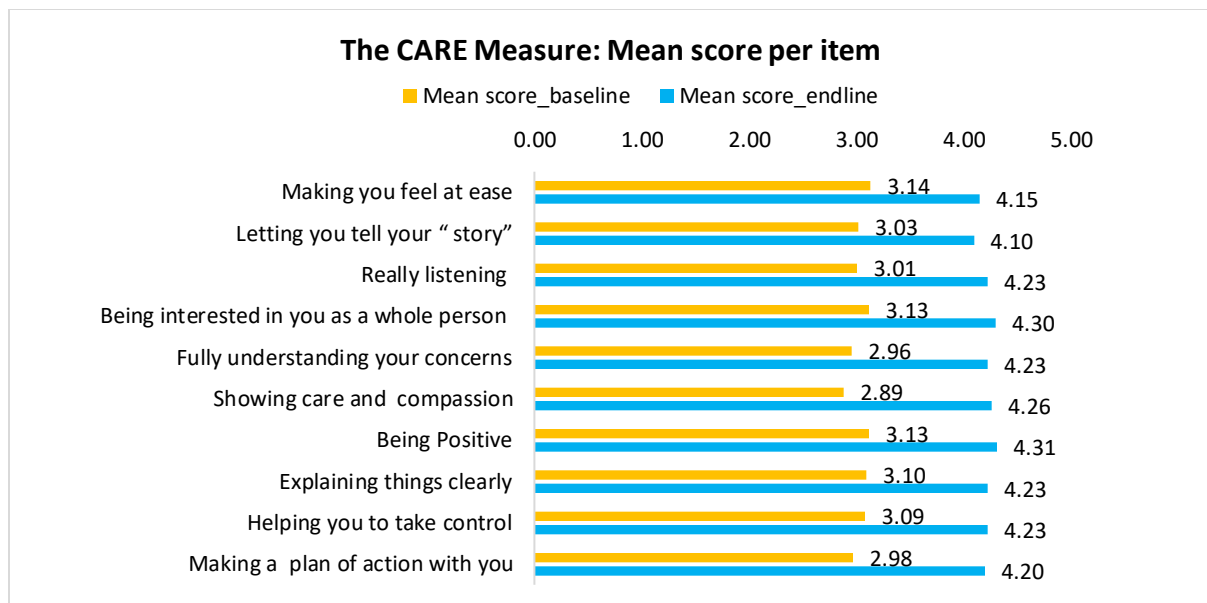


Figure 4: The CARE Measure scale: Mean score per item

Sub-group analysis (t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study samples (both at baseline and endline), groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups.

At the baseline, $p > 0.05$ in all sub-group analysis showing there is no strong evidence to suggest that the group means are significantly different.

At the endline, the participants with an EHF score of 0 had a higher mean score (42.72) compared to those with EHF > 0 (41), with the difference being statistically significant ($p = 0.0390$).

Table 16: Independent T-test results of sub-groups (The CARE Measure scale)

	Baseline			Endline		
	n (%)	Mean (95% CI)	p-value	n (%)	Mean (95% CI)	p-value
Gender						
Male	49 (61%)	30.16 (28.88-31.45)	0.4826	44 (55%)	42.14 (41.20 - 43.07)	0.7976
Female	31 (39%)	30.87 (29.46-32.28)		36 (45%)	42.33 (41.13 - 43.54)	
Setting						
Rural	73 (91%)	30.14 (29.13-31.14)	4.2733	73 (91%)	42.18 (41.39 - 42.97)	0.6917
Urban	7 (9%)	33.57 (31.62-35.52)		7 (9%)	42.71 (40.59 - 44.84)	
Age (years)						
18 - 30	26 (33%)	30.84 (28.78-32.91)	0.7132	22 (28%)	42.68 (41.40 - 43.96)	0.8944
31- 45	25 (31%)	30.76 (29.39-32.13)		22 (28%)	41.90 (40.47 - 43.35)	
46- 60	20 (25%)	29.45 (27.51-31.39)		22 (28%)	42.09 (40.60 - 43.58)	
above 60	9 (11%)	30.56 (28.39-32.73)		14 (18%)	42.21 (40.24 - 44.19)	
Leprosy type						
PB	21 (26%)	31.05 (29.28-32.81)	0.4584	19 (24%)	43.37 (42.30 - 44.44)	0.0920
MB	59 (74%)	30.22 (29.09-31.36)		61 (76%)	41.87 (40.97 - 42.77)	
EHF						
0	73 (91%)	30.53 (29.46-31.42)	0.5247	57 (71%)	42.72 (39.55 - 42.45)	0.0390
>0	7 (9%)	29.43 (26.20-32.65)		23 (29%)	41.00 (41.88 - 43.56)	
Marital status						
Married	59 (74%)	30.44 (29.46-31.42)	0.9914	60 (75%)	41.80 (40.90 - 42.70)	0.0512
Not (currently) married	21 (26%)	30.43 (28.01-32.84)		20 (25%)	43.50 (42.43 - 44.57)	
SARI Stigma Scale score	n/a	n/a	0.5823	n/a	n/a	0.4875

Regression models at baseline and endline (Outcome variable: CARE Measure score)

At baseline, all variables showing an association with CARE Measure Scale mean scores at $p > 0.20$. Therefore, a statistically significant model could not be established.

At endline, the results show that EHF has a statistically significant association with CARE Measure scores ($p = 0.039$). The positive coefficient ($\beta = 1.719$) indicates that participants with no disability (EHF=0) had, on average, 1.72 points higher CARE Measure scores compared to those with disability (EHF>0). The model explains about 5% of the variation ($R^2 = 0.05$) in CARE Measure scores.

Table 17: Multivariate regression models of The CARE Measure Scale (Baseline vs Endline)

Variable	Baseline p-value	Endline p-value
EHF (0/>0)	–	0.0390
		R² = 0.05

Regression Model (Overall effect: Baseline & Endline data):

A statistically significant model could not be established on the overall effect as all variables with $p > 0.05$ were eliminated sequentially.

Table 18: Multivariate regression models of The CARE Measure Scale (Baseline vs Endline)

Variable	Coefficient (β)	p-value	Interpretation
Timepoint (baseline=0; endline=1)	11.90	<0.001	Endline CARE measure scores were associated with on average 11.90 points higher than baseline.

4.2.4 Stigma Assessment and Reduction of Impact (SARI) Stigma Scale

The Stigma Assessment and Reduction of Impact (SARI) measures the extent and different dimensions of stigma that persons affected by leprosy may face. This includes both internalised stigma (self-stigma) and external stigma (discrimination and social exclusion).

The comparison of SARI Stigma scores between **baseline** and **endline** participants shows variations across domains reflecting different aspects of stigma experience and perception.

Descriptive statistics

Table 19: Descriptive statistics of SARI Stigma scale at baseline and endline

	Timepoint	Count	Range	Min	Max	Mean	Median	95% CI	Mean per question
SARI Stigma score	Baseline	80	63	0	63	22.25	22	19.9 - 24.6	1.06
	Endline	80	32	4	36	20	20	18.5 – 21.5	0.95
<i>Experienced stigma</i>	<i>Baseline</i>	80	21	0	21	4.53	4	3.5 - 5.5	0.65
	<i>Endline</i>	80	14	0	14	6.91	7	6.1 - 7.7	0.99

	Timepoint	Count	Range	Min	Max	Mean	Median	95% CI	Mean per question
<i>Disclosure concerns</i>	<i>Baseline</i>	80	12	0	12	6.49	7	5.7 - 7.3	1.62
	<i>Endline</i>	80	12	0	12	7.61	8	7.0 - 8.3	1.90
<i>Internal stigma</i>	<i>Baseline</i>	80	18	0	18	5.08	5	4.2 - 6.0	0.85
	<i>Endline</i>	80	12	0	12	1.48	1	1.1 - 1.9	0.25
<i>Anticipated stigma</i>	<i>Baseline</i>	80	12	0	12	6.16	6	5.7 - 6.7	1.54
	<i>Endline</i>	80	8	0	8	4	5	3.4 - 4.6	1.00

Although the overall SARI Stigma score did not differ significantly between baseline and endline participants (mean difference = -2.25 ; $p = 0.105$), the domain-level analysis showed distinct variations across groups.

Internal stigma was significantly lower among endline participants compared to baseline (mean difference = -3.60 ; $p < 0.001$). This reflects a reduction in self-stigmatizing beliefs, suggesting improved self-acceptance and confidence among endline participants.

Anticipated stigma also declined significantly (mean difference = -2.16 ; $p < 0.001$) indicating reduced fear of being stigmatized in the future, and a more positive perception of community attitudes.

In contrast, **Experienced stigma** (mean difference = 2.38 ; $p = 0.0003$) was significantly higher at endline suggesting that endline participants reported more experiences of stigma.

Disclosure concerns (mean difference = 1.12 ; $p = 0.0337$) was significantly higher at endline indicating increased hesitation or fear of disclosing one's condition, possibly due to continuing social stigma or fear of negative reactions.

The opposing directions of these domain differences likely explain why the overall SARI Stigma score difference between the two groups was not statistically significant.

Table 20: Independent T-test results (The SARI Stigma scores- baseline and endline)

	Mean Baseline (n=80)	Mean Endline (n=80)	Mean Difference (Endline – Baseline)	P-value
SARI Stigma	22.25	20	- 2.25	0.105
<i>Experienced stigma</i>	4.53	6.91	2.38	0.0003
<i>Disclosure concerns</i>	6.49	7.61	1.12	0.0337
<i>Internal stigma</i>	5.08	1.48	- 3.60	< 0.001
<i>Anticipated stigma</i>	6.16	4	- 2.16	< 0.001

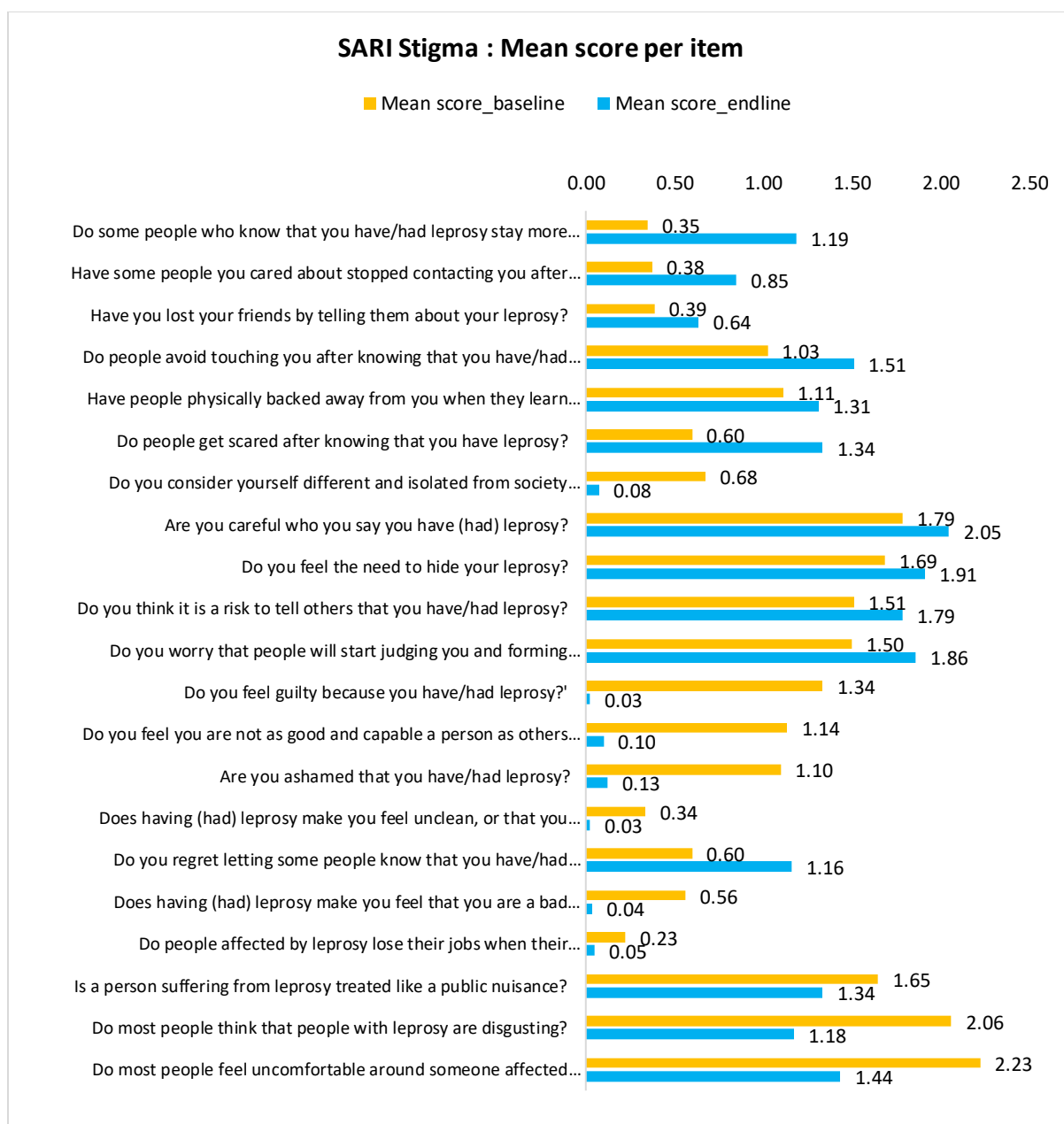


Figure 5: SARI Stigma scale: Mean score per item

Sub-group analysis (t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study sample, groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups.

At the baseline, the $p > 0.05$ in all sub-group analysis showing no strong evidence to suggest that the group means are different.

At the endline, the participants from urban settings had a higher mean score (25.14) compared to those in rural settings (19.51), with the difference being statistically significant ($p = 0.0287$).

Table 21: Independent T-test results of sub-groups (SARI Stigma scale)

	Baseline			Endline		
	n (%)	Mean (95% CI)	p-value	n (%)	Mean (95% CI)	p-value
Gender						
Male	49 (61%)	22.00 (19.55 – 24.45)	0.7901	44 (55%)	19.39 (17.43 - 21.35)	0.3576
Female	31 (39%)	22.64 (18.12 – 27.17)		36 (45%)	20.75 (18.64 - 22.86)	
Setting						
Rural	73 (91%)	22.55 (20.10 – 25.00)	0.4142	73 (91%)	19.51 (18.13 - 20.88)	0.0287
Urban	7 (9%)	19.14 (13.43 – 24.86)		7 (9%)	25.14 (17.73 - 32.56)	
Age (years)						
18 - 30	26 (33%)	22.03 (17.18 – 26.90)	0.9558	22 (28%)	19.00 (16.24 – 21.76)	0.6572
31- 45	25 (31%)	23.16 (19.15 – 27.17)		22 (28%)	20.36 (17.74 – 22.99)	
46- 60	20 (25%)	21.40 (18.37 – 24.43)		22 (28%)	19.55 (16.70 - 22.39)	
above 60	9 (11%)	22.22 (14.25 – 30.20)		14 (18%)	21.71 (18.15 - 25.28)	
Leprosy type						
PB	21 (26%)	23.62 (19.07 – 28.17)	0.4885	19 (24%)	18.58 (16.08 - 21.08)	0.2817
MB	59 (74%)	21.76 (19.10 – 24.43)		61 (76%)	20.44 (18.73 - 22.15)	
EHF						
0	73 (91%)	22.51 (20.06 – 24.95)	0.4817	57 (71%)	19.49 (17.83 - 21.15)	0.2769
>0	7 (9%)	19.57 (13.45 – 25.69)		23 (29%)	21.26 (18.44 - 24.08)	
Marital status						
Married	59 (74%)	22.78 (20.13 – 25.43)	0.4513	60 (75%)	19.72 (18.08 - 21.35)	0.5063
Not (currently) married	21 (26%)	20.76 (16.16 – 25.36)		20 (25%)	20.85 (17.83 - 23.87)	

Regression models at baseline and endline (Outcome variable: SARI Stigma score)

At baseline, no variable showed a difference with a p -value of ≤ 0.20 in the mean scores of SARI Stigma Scale. As $p > 0.05$, a statistically significant model could not be established.

At endline, the results show that setting (rural/ urban) has a statistically significant effect on SARI Sigma scores ($p = 0.0287$). The positive coefficient ($\beta = 5.636$) indicates that participants from urban settings had, on average, 5.636 points higher SARI Stigma scores compared to those in rural settings. The model explains 6% of the variation ($R^2 = 0.06$) in SARI Stigma scores.

Table 22: Multivariate regression models of SARI Stigma Scale (Baseline vs Endline)

Variable	Baseline p-value	Endline p-value
Setting (rural, urban)	–	0.0287
		R² = 0.06

Regression Model (Overall effect: Baseline & Endline data):

A statistically significant model could not be established on the overall effect as all variables with $p > 0.05$ were eliminated sequentially.

4.3 Quantitative Study: Health workers: Comparing Endline vs Baseline Findings

4.3.1 Socio-demographic profile

The baseline and endline participants for the health worker sample largely overlapped. With 61 (76.3%) of the participants being included in both the baseline and the endline study. Among the 80 health workers included in the baseline study, 53% was female. Their mean age was 40.1 years. The majority works in and came from rural areas, whereas only 13% work in and are from urban settings. For the participants included in the endline study, 50% was female. Their mean age was 40.1 years. The majority works in and came from rural areas, whereas only 6.3% work in and are from urban settings.

The study baseline sample included 56 doctors (70%), of which four are a medical specialist with two specialising in dermatology. 66% of the baseline sample had received health/medical training for over 4 years and 83% of the sample had received leprosy-specific training. 63% of the baseline sample had over five years of working experience, of which 41% had over ten years of working experience. 45% of the baseline sample had over 5 years of working experience with persons affected by leprosy, of which 25% had over ten years of working with persons affected by leprosy.

The study endline sample included 58 doctors (72.5%), of which six are a medical specialist with one specialising in dermatology. 70% of the endline sample had received health/medical training for over 4 years and 93.8% of the sample had received leprosy-specific training. 70% of the endline sample had over five years of working experience, of which 45% had over ten years of working experience. 56.3% of the endline sample had over 5 years of working experience with persons affected by leprosy, of which 35% had over ten years of working with persons affected by leprosy.

Table 23: Health workers' sociodemographic data and professional experience

baseline				Endline	
		n (n=80)	%	n (n=80)	%
Setting	Rural	70	87.50	75	93.75
	Urban	10	12.50	5	6.25
Gender	female	42	52.50	40	50
	male	38	47.50	40	50
Age (years)		mean: 40.14	95%CI: 38.06-42.22	Mean: 40.81	95%CI: 38.88-42.74
Type of health worker (doctor/non-doctor)					
	Medical specialist	4	5.00	6	7.50
	Medical doctor (not a specialist)	52	65	52	65.00
	Paramedical worker	7	8.75	9	11.25
	Physiotherapist	0	0	1	1.25
	Non-medical assistant	2	2.50	2	2.50
	Auxiliary nurse midwife	6	7.50	5	6.25
	Other	9	11.25	5	6.25
Health specialisation					
	Dermatology	2	2.50	1	1.25
	Medicine	0	0	1	1.25
	Rehabilitation	0	0	1	1.25
	None	75	93.75	71	88.75
	Other	3	3.75	6	7.50
Years of medical training received					
	No additional training (< 1 year)	7	8.75	7	8.75
	1-2 years	15	18.75	11	13.75
	3-4 years	5	6.25	6	7.50
	5-6 years	45	56.25	49	61.25
	>6 years	8	10.00	7	8.75
Leprosy specific training received					
	Yes	66	82.50	75	93.75
	No	14	17.50	5	6.25
Years of experience as a health worker					
	<1 year	4	5.00	0	0
	1-2 years	7	8.75	11	13.75
	3-5 years	18	22.50	13	16.25
	5-10 years	18	22.50	20	25.00
	>10 years	33	41.25	36	45.00
Years of experience working with leprosy patients					
	<1 year	10	12.50	6	7.50
	1-2 years	17	21.25	12	15.00
	3-5 years	17	21.25	17	21.25
	5-10 years	16	20.00	17	21.25
	>10 years	20	25.00	28	35.00

4.3.2 Social Distance Scale

The 7-item Social Distance Scale measures the social distance the health worker wants to keep towards a person affected by leprosy. The SDS interview starts by reading a vignette, a short description of a person with some typical characteristics of the condition, in this case 'Rahman', followed by 7 questions concerning the person in the vignette. The Social Distance Scale has an answer scale of 0-3 (definitely willing though definitely not willing).

Descriptive statistics

Table 24: Descriptive statistics of The Social Distance Scale

Social Distance Scale	Count	Range	Minimum	Maximum	Mean	95% CI	Median	Interquartile range
Baseline	80	15	0	15	3.14	2.47-3.80	2.5	1-4
Endline	80	10	1	11	3.21	2.79-3.64	3	2-4

To be able to compare all health workers baseline and endlines measures we chose to use an independent sample t-test to measure significance in the differences at baseline and endline. The independent t-test of the Social Distance Scale scores does not show a significant improvement from baseline to endline.

Table 25: Independent t-test results (Social Distance Scale scores- baseline and endline)

Statistic	Baseline (n=80)	Endline (n=80)	Difference (Endline – Baseline)
Mean	3.14	3.21	+0.08
95% CI	2.47-3.80	2.79-3.64	—
p-value (two-tailed)	—	—	0.850

The overall SDS outcomes have a non-normal distribution, therefore non-parametric tests were used for its analysis. For the baseline results, the median score on the Social Distance Scale is 3 (IQR: 2-4). Questions with the lowest score (most willingness) are question 2: 'How about being a worker on the same job with someone like Rahman?' and question 3: 'How would you feel having someone like Rahman as a neighbour?'. Questions with the highest scores (least willingness) were question 4: 'How about having someone like Rahman as caretaker of your children for a couple of hours?' and question 5: 'How about having one of your children marry someone like Rahman?'

The overall SDS outcomes have a non-normal distribution, therefore non-parametric tests were used for its analysis. For the endline results, the median score on the Social Distance Scale is 2.5 (IQR: 1-4). Questions with the lowest score (most willingness) are question 7: 'How would you feel about recommending someone like Rahman for a job working for a friend of yours?' and question 3: 'How would you feel having someone like Rahman as a

neighbour?'. Questions with the highest scores (least willingness) were question 5: 'How about having one of your children marry someone like Rahman?' and question 4: 'How about having someone like Rahman as caretaker of your children for a couple of hours?'

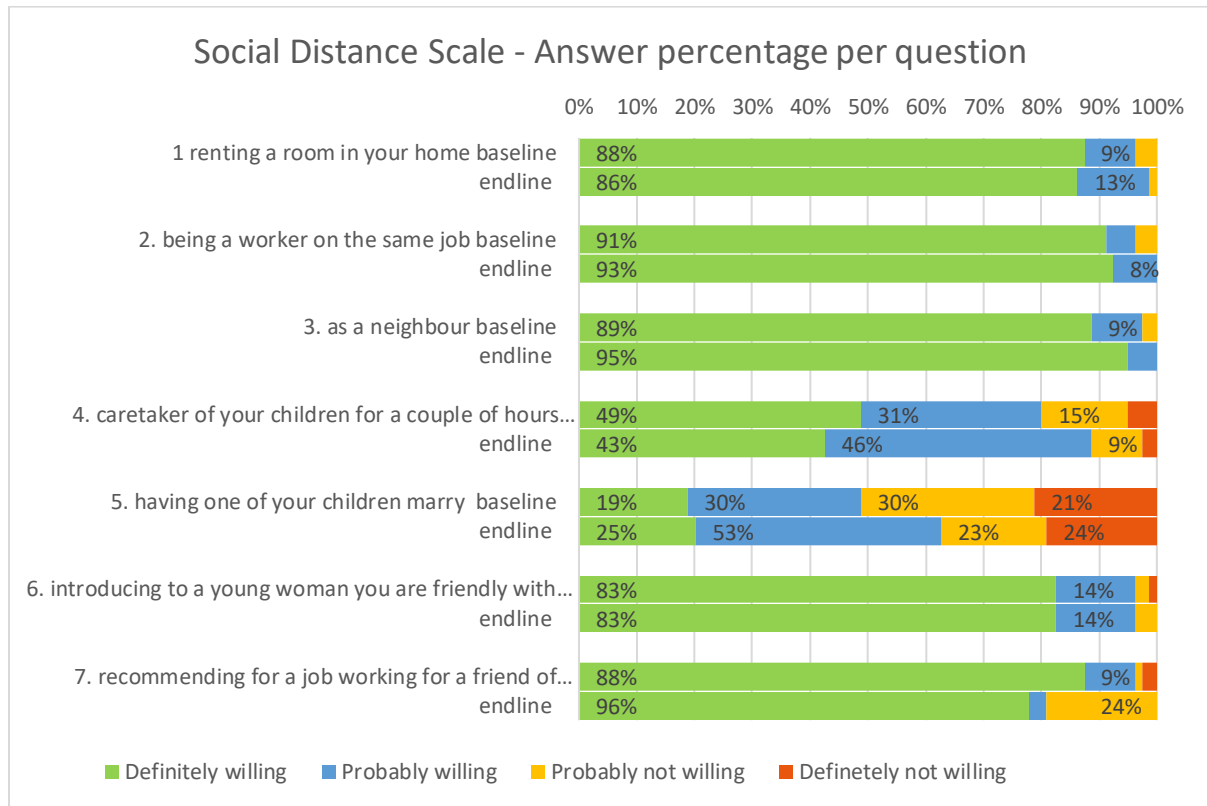


Figure 6: Social Distance Scale, answer percentage per item

Sub-group analysis (non-parametric testing)

Kruskal Wallis and Mann-Whitney U tests were used to identify differences between sub-groups of the health workers study sample. Sub-groups were formed on the basis of gender, type of health workers, years of medical training, whether leprosy training was received and the years of experience; in general and working with persons affected by leprosy.

For the baseline sample, significant differences in Social Distance Scale outcomes were found for gender ($p=0.005$), leprosy specific training received ($p<0.001$) and years of working with persons affected by leprosy ($p<0.001$).

For the endline sample, no significant differences in Social Distance Scale outcomes were found between subgroups. The sample was too small to calculate significant differences between baseline and endline for the subgroups.

Table 26: Social distance scale, sub-group scoring and associations

Baseline			Endline		
n (%)	Median (IQR)	p-value	n (%)	Median (IQR)	p-value
Total	80 (100%)	2.5 (1-4)			
Gender					0.223
female	38 (47.50%)	2 (0-3)	40 (50.00%)	2 (2-4)	
male	42 (52.50%)	3 (2-5)	40 (50%)	2 (2.5-4)	
Age	80		80 (100%)		0.111
Type of health worker					
medical doctor/specialist	56 (70.00%)	2 (1-4)	58 (72.50%)	3 (2-4)	0.451
paramedics, assistant, nurse, other	24 (30.00%)	3 (2-5)	22 (27.50%)	2 (2-4)	
Years of medical training received					
0-4 years	27 (33.75%)	3 (2-5)	24 (30.00%)	2.5 (2-4)	0.727
>4 years	53 (66.25%)	2 (1-4)	56 (70.00%)	3 (2-4)	
Leprosy specific training received					
yes	66 (82.50%)	2 (1-4)	75 (93.75%)	3 (2-4)	0.598
no	14 (17.50%)	4.5 (3-6)	5 (6.25%)	3 (2-4)	
Years of experience as a health worker					
0-5 years	29 (36.25%)	3 (2-4.5)	24 (30.00%)	3 (2-4.5)	0.124
>5 years	51 (63.75%)	2 (1-4)	56 (70.00%)	3 (2-4)	
Years of experience working with leprosy patients					
<3 years	27 (33.75%)	3 (2-6)	18 (22.50%)	3 (2-4)	0.226
3-10 years	33 (41.25%)	3 (1-4)	34 (42.50%)	3 (2-4)	
>10 years	20 (25.00%)	1 (0-2.75)	28 (35.00%)	3 (1-4)	

Note: IQR = interquartile range

Multivariate regression models (bootstrapped)

The variables that showed an association with a p-value of ≤ 0.20 with Social Distance Scale outcomes were included in a multivariate regression model. Variables with a p-value of $p > 0.05$ were excluded one by one, until a statistically significant model was established.

For the baseline sample, the final model for Social Distance Scale outcomes includes whether a health worker has received leprosy specific training and the duration of their experience with persons affected by leprosy. These variables explain 18% of the variability of the Social Distance Scale score. For the endline sample, no significant model could be derived from the data.

Table 27: Multivariate regression model for social distance scale

Variable	<i>p</i> -value	R ²
Leprosy specific training received	0.053	0.180
Years of experience working with leprosy patients	0.032	

When looking at the subsample of 61 health workers who were included in both the baseline and the endline data collection. We notice that medical doctors and specialists report a higher desired social distance than at baseline and this is a minor (7.9%) but significant explanation of the overall variability of the difference between baseline and endline outcomes.

Table 28: Associations with difference baseline vs endline outcomes Social Distance Scale

Variable	<i>p</i> -value	R ²
Health worker type (MD vs. other)	0.013	0.079

4.3.4 Pommier Compassion Scale

The Pommier Compassion Scale measures an individual's level of compassion towards others, particularly in the context of healthcare professionals. The scale consists of 16 statements and responses are scored on a Likert scale on which study participants indicate how often "they feel or behave in the stated manner", ranging from "almost never" to "almost always".

Descriptive statistics

Table 29: Descriptive statistics of Pommier Compassion Scale

Pommier Compassion Scale	Count	Range	Minimum	Maximum	Mean	95% CI	Median	Interquartile range
Baseline	80	23	57	80	69.44	68.23-70.65	70	65.5-74
Endline	80	18	61	79	73.41	72.25-74.58	75	70-78

The independent t-test of Pommier Compassion Scale scores shows a significant improvement from baseline to endline. At baseline, the mean score was 69.44 (95%CI: 68.23-

70.65), while at endline, it increased to 73.41 (95%CI: 72.25-74.58), representing an average increase of +3.98 points. The independent t-test indicates that this difference is highly significant ($p < 0.001$).

Table 30: Independent T-test results (Pommier Compassion Scale scores- baseline and endline)

Statistic	Baseline (n=80)	Endline (n=80)	Difference (Endline – Baseline)
Mean	69.44	73.41	+3.98
95% CI	68.23-70.65	72.25-74.58	—
p-value (two-tailed)	—	—	< 0.001

Highest scores, indicating most compassion, were found for questions 3 and 1: “I am unconcerned with my patients affected by leprosy problems.” And “I pay careful attention when my patients affected by leprosy talk to me about their troubles”. Lowest scores, indicating less compassion, were found on questions 15 and 6: “I can’t really connect with my patients affected leprosy when they’re suffering” and “I like to be there for my patients affected by leprosy in times of difficulty”.

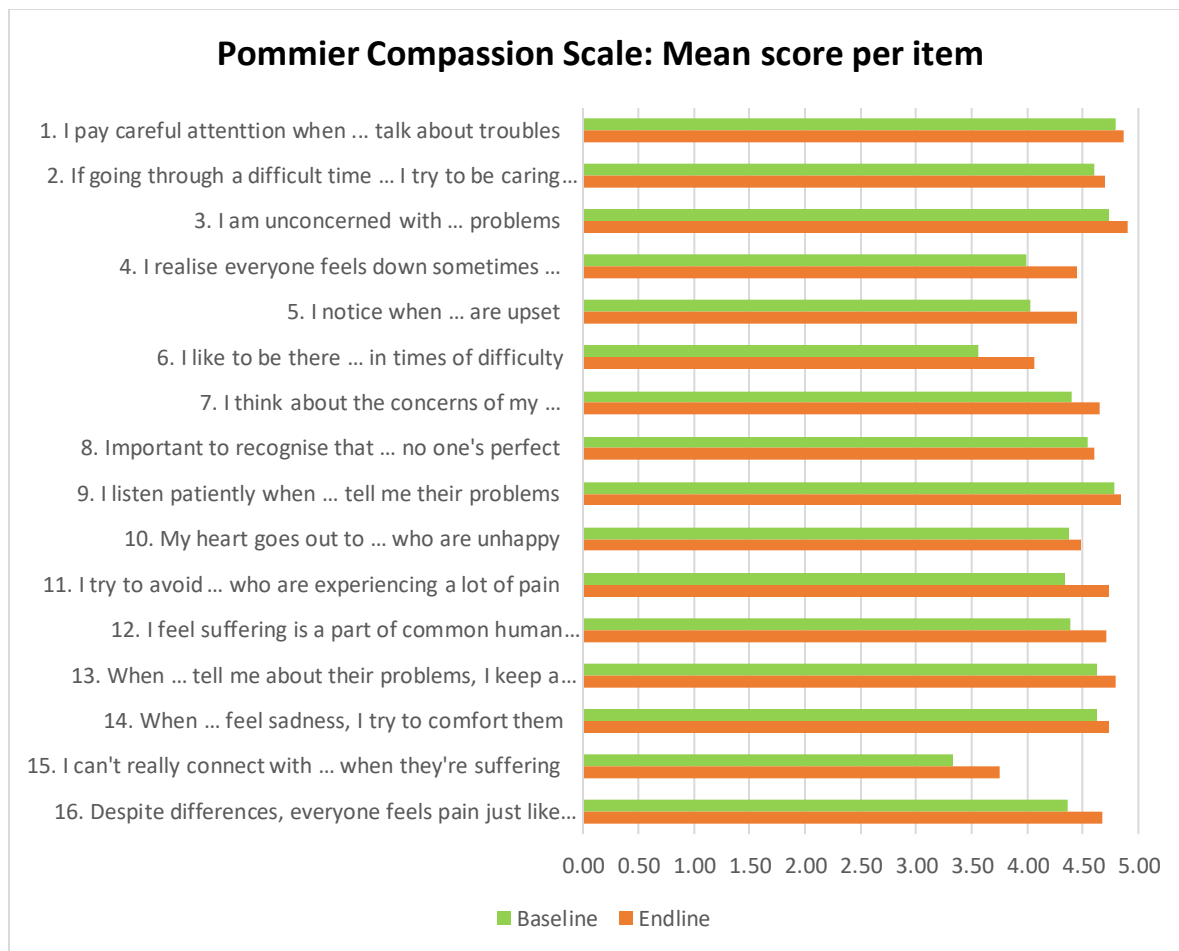


Figure 7: Pommier compassion scale, mean score per item

Sub-group analysis (t-test/ ANOVA)

The independent t-test and an ANOVA were used to identify differences between sub-groups of the health workers study sample. Sub-groups were formed on the basis of gender, type of health workers, years of medical training, whether leprosy training was received and the years of experience; in general, and working with persons affected by leprosy. In addition, a linear regression test looking for an association with the Social Distance Scale total score was also done.

Significant differences in Pommier Compassion Scale outcomes and the type of health worker ($p=0.025$) and years of medical training received ($p=0.029$) were found, also an association with the social distance scale total score ($p=0.011$) was found.

Table 31: Pommier compassion scale, sub-group scoring and associations

Baseline				Endline		
	n (%)	Mean (95% CI)	p-value	n (%)	Mean (95% CI)	p-value
Total	80 (100%)	69.44 (68.23-70.65)		80 (100%)	73.41 (72.25-74.58)	
Gender						0.882
female	38 (47.50%)	69.39 (67.52-71.28)	0.947	40 (50.00%)	73.50 (72.05-74.75)	
male	42 (52.50%)	69.48 (67.85-71.11)		40 (50.00%)	73.33 (71.43-75.22)	
Age	80		0.584			
Type of health worker						0.140
medical doctor/specialist	56 (70.00%)	70.32 (68.95-71.69)	0.025	58 (72.50%)	72.88 (71.48-74.28)	
paramedics, assistant, nurse, other	24 (30.00%)	67.38 (64.98-69.77)		22 (27.50%)	74.82 (72.70-76.94)	
Years of medical training received						0.162
0-4 years	27 (33.75%)	67.59 (65.37-69.81)	0.029	24 (30.00%)	74.67 (72.72-76.61)	
>4 years	53 (66.25%)	70.38 (68.96-71.79)		56 (70.00%)	72.88 (71.42-74.33)	
Leprosy specific training received						0.217
yes	66 (82.50%)	69.79 (68.42-71.16)	0.212	75 (93.75%)	73.60 (72.40-74.80)	
no	14 (17.50%)	67.79 (65.16-70.41)		5 (6.25%)	70.60 (64.42-76.78)	
Years of experience as a health worker						0.521
0-5 years	29 (36.25%)	70.45 (68.31-72.58)	0.211	24 (30.00%)	72.83 (70.64-75.02)	
>5 years	51 (63.75%)	68.86 (67.38-70.35)		56 (70.00%)	73.66 (72.25-75.08)	
Years of experience working with leprosy patients						0.320
<3 years	27 (33.75%)	68.22 (66.11-70.34)	0.113	18 (22.5%)	71.89 (69.08-74.69)	
3-10 years	33 (41.25%)	70.94 (69.21-72.67)		34 (42.5%)	74.21 (72.36-76.06)	
>10 years	20 (25.00%)	68.60 (65.77-71.43)		28 (35.00%)	73.43 (71.55-75.31)	
Social Distance Scale total score	n/a	n/a	0.011	n/a	n/a	<0.001

Multivariate regression model

The variables that showed an association with a p-value of ≤ 0.20 with Pommier Compassion Scale outcomes were included in a multivariate regression model. Variables with a p-value of $p > 0.05$ were excluded one by one, until a statistically significant model was established.

For the baseline sample, the final model for Pommier Compassion Scale outcomes includes the type of health worker, the duration of their experience with persons affected by leprosy and the total Social Distance Scale score. The p-value for the duration of experience with persons affected by leprosy is not ≤ 0.05 . However, it was noticed that by removing it, this results in a reduction of the R^2 of 10%. This can also be attributed to the finding of the variable's influence on the variability of the SDS total score. The final model explains 15% of the variability of the Pommier Compassion Scale score.

For the endline sample, the final model for Pommier Compassion Scale outcomes includes the only the total Social Distance Scale score. The final model explains 14% of the variability of the Pommier Compassion Scale score.

Table 32: Multivariate regression model for Pommier compassion scale

Variable	<i>Baseline</i>	<i>Endline</i>
	<i>p-value</i>	<i>p-value</i>
Type of health worker	0.030	--
Years of experience working with leprosy patients	0.112	--
Social Distance Scale total score	0.016	0.001
	$R^2=0.148$	$R^2=0.139$

Table 33: Multivariate regression overall assessment (baseline & endline)

Variable	<i>p-value</i>
Baseline / Endline	<0.001
Years of experience working with leprosy patients	0.117
Social Distance Scale total score	<0.001
	$R^2=0.233$

When looking at the subsample of 61 health workers who were included in both the baseline and the endline data collection. We notice that medical doctors and specialists report a lower increase in compassion than other health workers when comparing baseline and endline this is a minor (7.3%) but significant explanation of the overall variability of the difference between baseline and endline outcomes.

Table 34: Associations with difference baseline vs endline outcomes Pommier Compassion Scale

Variable	p-value	R ²
Health worker type (MD vs. other)	0.035	0.073

4.4 Qualitative Findings

4.4.1 Local Perceptions, Experiences, and Valuing of Compassion

"When the doctor behaves with love, you feel better." [female person affected by leprosy FGD participant]

HCWs, persons affected by leprosy, and family members alike continue to affiliate compassion with actions of helping the helpless, sick, needy, and impoverished, being of service, and for HCWs especially, going beyond their normal duties at work. By way of compassion as a feeling, they all describe empathy, pity, emotionality, kindness, and mercy, relaying these are automatic responses and innate to all. Compassion is often exhibited in medical settings, the temple, on the railways in contexts such as supporting those begging, or on the roadside for those harmed in an accident.

By way of compassion being exhibited generally in healthcare environments, persons affected by leprosy feel HCWs offer it; such behavior looks like talking lovingly and asking questions, offering assurance, helping in a way that responds relative to the patients specific needs, and explaining their disease and treatment, especially to those who are deemed more helpless. Family members proclaim less certainty, saying compassionate care is only present in medical settings sometimes, but it certainly should be consistently.

Yet all three groups agree to the distinct impact of compassion when it is present in healthcare, not just within individual interactions but within the "atmosphere." Beginning first with the HCW perspective, they offer the clearest detail as to the inner and outer workings of such compassion.

HCWs attest that compassion in caring environments improves recovery time, morale of the patient, and their emotional experience. By and large, compassion reduces patients' mental suffering, often being spoken of as "half the cure" alone, while the remaining half is medical. For example, compassionate interactions with providers are said to relieve half the pain and sorrow. This is an exchange that can become reciprocal between provider and patient, and with it the benefits become mutual too.

The power of compassion comes in connecting one to themselves and to others, generating understanding, progress, and the ability to holistically see and help another. Within spaces and interactions held by compassion, patients can openly share their experience, which relieves emotional suffering through a sense of finally being heard. When heard and encouraged by compassionate exchanges, a patient will develop self-confidence, hope and a desire to live, a sense of equality from removal of a belief in untouchability, and courage. If educated too, their misconceptions that generate internal stigma may be corrected. They will feel connected to their provider, having trust and assurance, which in turn breaks patterns of societal ostracization and may even restore their potential connection to society. They will also feel less internalized stigma and shame, knowing the true cause and accessible cure for their illness.

“It can be said that by having a feeling of compassion in a stigmatized situation, the stigma will be erased. [The patient] will have to say, there is no consequence for sin. This is a disease, if treated, it will be completely cured.” [HCW IDI participant]

Beyond a positive impact to patients in general and reciprocal relational strength between patients and providers, HCWs express compassion in caring spaces improves the working environment for HCWs too, leading to motivation, unity, harmony, engagement, collaboration, functionality, positive thinking, and desire to work. Just as with patients, HCWs can also relieve one another's suffering through offering support and understanding to their colleagues. As a whole, HCWs' wellness and moods will then improve, leading to a better ability to care for their patients by way of maintaining a positive demeanor. HCWs report a potential reduction in stress, irritation, anger, depression, and bringing personal troubles to work, as well as even discrimination against one another, if their working relationships are filled with compassion. Further, HCWs recognize they will help one another through medical challenges in new ways, again amplifying the quality of patient care. When one provider demonstrates compassion, not only do their colleagues wish to return it but patients may notice this example and also reciprocate better treatment of their providers, generating permission of and expectation for a mutual sharing of selves and personal connection.

Persons affected by leprosy paint a similar picture of the impacts and dynamics of such compassionate healthcare. They believe it can calm an angry patient, offer encouragement, and generate self-assurance, confidence, and openness. In turn, patients become happier and will return for (or even demand) further treatment. Patients will feel good both mentally and physically, and experience improved treatment and faster healing. Oppositely, persons affected by leprosy recognize that healthcare characterized by a lack of compassion generates sadness and reticence to return for further treatment, reinforcing the spread and/or progression of diseases and disability depending on why a patient presents.

“If you don't treat with love, don't talk with love, don't speak with love, it will make a lot of difference. The patient will become very sad, because he will not talk to us nicely, he will not come to the hospital, he will not want to go at all. That when the doctor does not talk to us lovingly, someone does not speak properly, we do not want to be treated, then what will he do when he goes, what will he ask? If you talk to him with love, he will feel that if he takes the medicine, he will be cured. So, if you give him medicine with love, he

will take the medicine, he will get relief and he will be cured.” [male person affected by leprosy FGD participant]

“If the doctor does not talk to the patient nicely, the patient will feel bad, he will become sad and he will not be able to get treatment. Therefore the doctor should talk to him and treat him with compassion. Treatment should be done with great love, it is very important. If he is not talked to lovingly, treatment will not be possible. This disease will spread, gradually it will spread completely and people will keep getting sick. It is important that treatment is done with love and there is no discrimination of any kind.” [female person affected by leprosy FGD participant]

Beyond direct interactions, persons affected by leprosy affirm it is crucial that a sense of a compassionate atmosphere or environment is present in care settings. They sense providers feel and operate better in such environments, being filled with love and wellness.

“Only when [healthcare workers] live well will they treat the patient well. The environment will be good, the patient will be well, and the treatment will be good. Healing will happen quickly.” [person affected by leprosy IDI participant]

In such atmospheres, similar to the proclamations of HCWs, compassion becomes reciprocal between patients and providers, or between providers themselves. persons affected by leprosy have seen a sense of friendliness, supportiveness, and openness abound.

Family members agree with the accounts of HCWs and their relatives affected by leprosy regarding the importance and impact of compassionate care. They feel when compassion is present, regardless of the diagnosis, it helps the patient mentally, promotes beneficial patient-provider relations, and also allows the providers themselves to feel good and collaborate, all leading to quick recoveries for patients.

“[A patient] will feel very good. Compassion is more effective than medicine. If people talk to them with love, it works like a balm. Their mental state will also be fine and their health will improve soon.” [FM IDI participant]

As with all others, family members also affirm that compassionate care is “half the cure.”

“Like, if you talk to him well, give him advice, give him medicine, and explain it well, then half of his illness is cured by that.” [FM IDI participant]

"Compassion is an inner feeling of a human being, which everyone should have. If there is compassion, it leads people to help each other. People can help each other and live together because its meaning is more to tell or advise than to do medicine. Its work is better than that...If there is compassion within everyone, then the disease goes away, that is, it disappears. The patient will get peace from within. If there is someone to take care of his medicine and pain, then half of his pain gets eliminated from there. Hearing compassion, everyone should have compassion." [FM IDI participant]

What this compassion looks like with patients generally is spoken to first from the HCW perspective. They believe they can demonstrate compassion via sitting near the patient, offering them a space to sit, talking nicely or properly, treating them like friends or family, listening, offering assurances, counseling, and educating them on the disease and treatment in a way they can absorb. Providers must show patience and take their time when listening to their patient's story, it may contain important details about their social determinants of health worth addressing alongside the direct disease. Even if the patient just shares about the disease, this can also help inform the provider on how to treat, leading to more accurate diagnosis, quicker delivery of medication, and faster healing.

"When the doctor talks nicely with me, and when I go to the doctor with my pain and sufferings then I am able to share openly with the doctor and when I am able to share openly and freely with the doctor then in one way that becomes a kind of treatment. When I get treatment and get better then through compassion I receive very good support/help." [female person affected by leprosy FGD participant]

When a patient has been treated with compassion in a caring environment, HCWs agree with persons affected by leprosy that they will want to return and they will also tell others affected by related maladies to come to this place they have determined to be safe. Without compassionate interactions, patients will not return to the health center and their disease will progress, possibly spreading.

Stepping beyond just healthcare or patients relations in general, HCWs and persons affected by leprosy discuss the societal impacts of compassion and compassionate care. Providers feel the healthcare sector has the opportunity, perhaps duty, to set an example for the rest of society in educating and challenging stigma, regardless of but especially if the disease is leprosy. Providers feel that if only communities had knowledge of the true source of the leprosy (e.g., not a curse), temporary safety precautions available to prevent its spread (i.e., relevance of distancing only before treatment), and the effectiveness of the cure, that stigma would go away. To this end, some providers report going into the community to offer education directly or leaving patients with their direct phone numbers to answer questions anytime. In this way, HCWs act as intermediaries between patients and the negative effects of their communities.

Relatedly, persons affected by leprosy and family members affirm that while compassion is important for treating all diseases, and also for the functioning of society, it is perhaps most important for those with stigmatizing or debilitating conditions that lead to a sense of

helplessness. They claim it supports such persons' minds to feel better and to undo some of the negative societal impact of stigma. Family members further affirm that the dynamics of compassionate healthcare are most crucial for those who are handicapped where reassurance, trust, comfort, and patient explanation are essential for a cure or improved wellness as these are not generally afforded to them in their demoralizing, daily environments.

"Compassion is essential in taking care of leprosy. When a doctor treats a disease with compassion, the mind becomes lighter. I feel that my illness will be cured when the doctor treats me with compassion because society discriminates, but when the doctor shows compassion, I believe that my illness will be cured. Compassion is very important." [female person affected by leprosy FGD participant]

4.4.2 Experiences of Persons Affected by Leprosy in and Beyond their Healthcare

Shifting from discussion of people and patients generally in Jharkhand State, into the experiences of persons affected by leprosy in and outside of care settings there, all three groups of participants brought overlapping and distinct testimony.

Most persons affected by leprosy say discriminatory behavior is present in their community context while others disagree. Predominant behaviors demonstrating this stigma include forms of distancing and ostracization such as refusal to eat or drink with a person affected by leprosy, or refusal to allow them into a temple or one's family. The more symptoms visible, the more likely one is to experience such treatment.

It is HCWs who declare with little doubt that persons affected experience significant distancing, discrimination, and stigma in their community contexts. While they agree with family members that it may be slowly improving over the decades based on clarifying the source of infection in mass media, they perceive fear is still prominent about contracting the disease. Just as persons affected by leprosy declare, HCWs expect that the more visible the disease, the greater the ostracization experienced, including distancing behaviors from one's own family.

Due to fear of ostracization, HCWs state that their patients affected by leprosy do often hide their symptoms and diagnosis from those around them, including from community health workers. They may refuse visits from health volunteers so others do not believe them to be diseased, unfortunately allowing their disease to progress and potentially transmit.

HCWs believe if you educate the patient and demonstrate the effectiveness of the cure, then they can educate the society around them and reduce patterns of stigma for future generations. Sometimes even Family members and HCWs are confirmed to discriminate, but once again, if

educated and empowered with this knowledge, HCWs share that the negative behavior often corrects.

From the person affected by leprosy perspective, most encourage other persons affected by leprosy to share their diagnosis so as to spread education (lack of which they agree with HCWs is the source of stigma) and to receive the necessary help, but they also understand there can be real consequences via discriminatory behavior that disincentivize this openness. Generally all persons affected by leprosy will share their diagnosis with their family but are hesitant to share beyond. Nevertheless, persons affected by leprosy and all other participants strongly affirm that persons affected by leprosy deserve full humanity and societal inclusion.

Their family members share similarly mixed reports on the presence and intensity of community discrimination, but they agree with HCWs that it is generally decreasing with time as lay education increases. For the time being, they affirm that distancing behaviors are a lived reality and an understandable reason to hide a diagnosis for their family members and other persons affected by leprosy. In slight contradiction to what HCWs voice and the patterns of hiding they themselves recognize, family members believe that at least families are supportive of any relative affected by leprosy. They simply wish persons affected by leprosy could more openly share to receive rapid help and spread advocacy further.

“Before, many people were afraid to go near someone with this disease, thinking they would also get it. But this kind of behavior shouldn’t happen. If you treat the sick person well, they will feel better, they will recover faster. Their family will also feel good, and the family members will also treat them well. People should be told that this disease is not that contagious, so there’s no need to be afraid. And it shouldn’t be hidden; it should be treated.” [FM IDI participant]

Regarding healthcare experiences for persons affected by leprosy, all three groups report positive interactions. HCWs voice that discriminatory behavior is now minimal. Some providers still engage in minor distancing behaviors or hold prejudices in their heart, but most focus on taking safety precautions with a new patient such as wearing gloves and express comfort treating them thereafter initial treatment. The necessity for such precautions and how they are interpreted by persons affected by leprosy is seen as controversial by providers, but unanimously supported as proper protocol for the most severe and still untreated cases. Even when safety precautions are used, providers are quick to assert they must and do apply the same compassionate behaviors of treating the patient like any other with kind talk and touch as crucial.

On the recipient end, persons affected by leprosy predominantly do feel their treatment by providers is positive, including references to such nice talk. They feel HCWs treat them equally and with the same importance as any other patient, minus a rare discriminatory doctor here and there. Their family members agree that treatment by HCWs is good and equal, with some improvements occurring over the span of decades for persons affected generally from what they have seen and heard.

To address any remaining, minor discrimination by HCWs – be it of behavior or attitude, HCWs advocate for the need for more training to reduce remaining fears about transmissibility, especially for those providers who do not have constant work with persons affected or as lengthy of educational training (e.g., community health workers).

4.4.3 Expectations and Experiences of the Compassion Training

To address remaining stigma and compromised compassionate care for persons affected by leprosy, a stigma-informed compassion training was implemented. HCWs alone then discussed their experience with this training and its perceived impacts in interviews and focus groups.

HCWs report a broadly positive experience with the training, approaching it with curiosity and caution due to the unfamiliarity of its content and lack of clarity for its purpose beforehand. They found the content to be strikingly new, bringing energy, happiness, and pleasure in their work, alongside improved collegiality, helping behavior, work atmosphere, and ability to talk to their patients affected by leprosy. They learned more about the innateness of compassion and a sense of collective duty to it.

“The training given by NLR meditation gave us energy and we become more happy while doing any work...whatever training we received is very good for the future, plus for the health department...Good relationship developed between health workers. Earlier, we used to talk with irritation and used to avoid. So, after taking this training, it has become a lot easier for the health department - or for me, in my circle, whatever - to do our work. Keep helping each other.” [HCW IDI participant]

But their biggest, and most cherished learning of all centers on self-awareness and self-compassion. Health workers repeatedly share taking time for themselves and activities like meditating, yoga, and writing were both new and welcomed concepts. And they observed that when they chose to do so, it created a positive influence on their patients and other providers.

“We liked that you told us in the training that compassion should not only be towards others but also towards ourselves, we should also pay attention to ourselves. We too definitely need compassion, it is not just the patients...First think about yourself, then take time out for yourself.” [HCW IDI participant]

“[The training] is very valuable for me, because it tells very good things about how we should see the patient and what we should do about them. That whole thing was told. Then you should take out time not only for the patient but also for yourself, take care of yourself too. We will take care of ourselves. Only then will we take care of the patient...Yes, I learned it in this training. We have to take time out for ourselves also. Earlier it did not happen that we used to take out time for ourselves or think about

ourselves, but after the training, we were told how valuable our time is, so we should take out time for ourselves.” [HCW IDI participant]

At first, they found the concepts relayed in the training to be challenging such as how to conceptualize or understand them, as well as their own emotions, but they grew more accustomed across the training days. The delivery felt simple, well-arranged, and creative, though more time to orient new meditators to the practice may be needed in future rounds so they can continue applying the skills after. Providers reported no other concerns with the training or its delivery.

Across the board, the training was seen as highly valuable, especially in evidencing compassion starts on the inside and is there when we are born. The true work is to come back to themselves and perhaps what has been forgotten across life or just needs an enhanced understanding. Once they have (re)connected to themselves, health providers report increased self-confidence and mental strength, which alongside compassion can begin to radiate outward, impacting their colleagues and patients.

“[The training] is very valuable. After knowing this, everything can be changed... During the training, I got the confidence. How to increase self-confidence? Training has played a big role in increasing self-confidence. Got a chance to know about myself, learned about how to take out time for myself.” [HCW IDI participant]

“This, which was a very important training, is helping us a lot now to make the change, as earlier we did not have compassion, now we are patient in terms of compassion. When we talk to patients and treat them, it has brought about a lot of change and will bring change in the future.” [HCW IDI participant]

Despite already being compassionate towards patients affected by leprosy, providers shared the training helped improve their behavior even further, as shown above. They report a better ability to understand their colleagues, and lower daily irritation and anger with them. Towards patients, HCWs say they may now behave better by way of listening and speaking with kindness, having more of themselves to give and a deeper motivation to help. They especially report a better understanding of the emotional weight and holistic life impacts of leprosy on their patients, which they are now more attentive to as they treat.

“The word compassion was not so involved before, not connected, but by learning it, we have become more compassionate towards the patient, we have become less angry, now we are changing our habits.” [HCW IDI participant]

“After receiving the training, patients contact us and talk to us at any time, 24 hours a day. Previously, there wasn't this kind of question, but now they call us without hesitation... There's a leprosy patient who is suffering a lot. He called at random at night

and said, 'Yes, sir, this is happening to me.' So I felt that at least the compassion training informed me enough to connect with him from a compassionate perspective...It changed both our morals and behavior." [HCW IDI participant]

The materials of the training were well-received, with the Charter being cited as a helpful daily reminder. While the guidebook was helpful during the training, it has been used less thereafter. Some have nevertheless taken to trying meditation themselves even after the training ended.

"Yes, I saw a lot of changes after the training. Like I was saying, I can understand myself well and hence I can understand others well and they can understand me well. After giving, like positivity, one who speaks with a positivity mindset, we are now working here. That is why there has been an increase. When the patient comes, we talk nicely and in a good way, because the charter given to us with the 10 points in the OPD, so we do that. There is a lot of information in it." [HCW IDI participant]

In order to continue applying the lessons of the training, providers cite an interesting observation. By interacting more compassionately with their patients affected by leprosy, patients then show a desire to open up and share more. However, the current setting for treatment takes place in public space. In order to allow patients to best respond to these compassionate interactions, providers state they need private spaces for patients with stigmatizing conditions to openly discuss despite the shame.

Beyond this discussed environment barrier, providers repeatedly highlight the need for compassion training to become routine, at least once if not twice a year, ensuring in particular that new providers receive it and that a reinforcing environment is established, especially if training can be delivered across the entire district level. Some have found a WhatsApp group supportive where they can discuss challenges in and ask questions about applying the training content of one another. Others request the establishment of a meditation room in their clinics for staff to take a moment of pause and personal replenishment for self-care.

"Look, this training can bring a lot of benefits. The feeling of compassion that was instilled in us was a very strong feeling. This feeling developed quickly. I have received a lot of training, but not one has instilled the feeling that has been instilled in us through this training. It has brought about a lot of change...Yes [more workers should receive this training]. It should be done immediately." [HCW IDI participant]

The clearest call from providers for next steps is to train all HCWs, without doing so the atmosphere of compassion will not be reinforced both for colleagues and patients. But importantly, such training must prioritize those most proximal to the community such as the ASHAs and SAHIYAs. They are the first point of contact generally with a person affected by leprosy and need to know how to approach with care and destigmatizing tactics, otherwise a patient will never even make it to receive care in a clinic, which will then prevent spread. After all the proximal workers are trained, those in outpatient settings come next including pharmacists

who provide persons affected by leprosy with medications or others in the outpatient department offering rehabilitative services. Only after this should other more specialized HCWs and those receiving their medical education be trained.

Further, HCWs urge that training must not stop with health providers of all levels, it must also be provided directly to community members. Similar to levels of health providers, they lay out a tiered plan. First it should go to persons affected by leprosy to ensure they receive proper counseling, but also to instill self-confidence, self-compassion and care tactics, trust that the disease is not their fault, and an ability to advocate for themselves and other persons affected by leprosy in society by sharing and educating. Their family members should come next, then general community members and especially schoolteachers who can amplify this information to children. Several HCWs recommend running the training with village counsels or community groups, perhaps even using creative methods like street plays. What providers make clear is that training must take a whole-society approach in order to truly reduce stigma and address misconceptions. While the currently trained providers are grateful for their training, they recognize that out of all people, they are the least likely to impart stigma due to their high level of education and exposure. In fact, it is to them persons affected by leprosy come for respite from daily discrimination.

In order to assess the level of effectiveness of this training, especially over the long-term, providers request self-evaluations they can perform to know if they are implementing the materials. Already some note a slow decline in implementation and improved atmosphere with time. And while providers believe the training is indeed helpful and impactful for persons affected by leprosy and other stigmatizing conditions, especially those with visible symptoms or disability, they feel compassion is important in all caring encounters for creating a connection, informing a treatment plan, and hastening healing.

“The biggest beneficiaries [of training] will be our leprosy patients and health workers; this will remove the stigma...Yes, [our colleagues behaviors] also changed...There will be an atmosphere of action. There will be an atmosphere of compassion.” [HCW IDI participant]

“The person most affected by this training will be the healthcare worker. And if the healthcare worker is affected, the patient will be affected. And when the patient is affected, society will be affected, and everyone in the chain from top to bottom will be affected.” [HCW IDI participant]

4.4.4 Recent Changes in Healthcare Environments

All participants were then asked about whether they perceived there to be recent changes in HCW behavior and healthcare environments. This was to assess whether any impact of the training could yet be felt – by providers themselves or by those on the receiving end, including patients affected by leprosy and their family members. Providers, having experienced the training themselves, were the only ones who could truly speak to perceived changes while accounts from recipients of caring environments could only speculate.

Providers reported possible changes in the healthcare environment as a consequence of the training. They recognize at minimum an inner transformation, especially by way of self-care. With patients, they feel they speak more sweetly, are intentionally welcoming, take more time to listen, better understand them and their role as a provider in relieving the emotional weight of the illness, ensure they reassure patients it is not their fault, and may even value the whole patient more. It is also possible, HCWs say, that the training slightly reduced remaining internal discrimination and improved their attitudes towards their patients.

"The training has brought about a significant change in our perception towards patients. We are able to understand their pain and treat them better, talk to them nicely, and we are understanding their problems better." [male HCW FGD participant]

HCWs attest that compassion was deeply present in providers before but now it is more uniform and intentional in every encounter. They feel able to hold each other accountable to a shared standard of compassionate behavior and recognize those who still have not received the training evidencing old behaviors of lower compassion and respect. The caring environment feels better as it seems like providers feel more positive, with less generalized fear and subconscious discrimination.

"Earlier, when the patients used to come, we used to have some kind of feeling towards them. We feel a little scared to see him, but now we do not have such feelings. Now we look at the face of the patient, try to see him and give him good treatment." [HCW IDI participant]

The main benefit they attest to in patients affected by leprosy as reflecting change in their own behaviors is greater openness and less hiding – of experiences, stories, and information. They feel this has improved the happiness and lives of their patients, who then return more readily but also share their experience with their friends, who may also return with them to receive care. If this is true, over time HCWs expect to see reduced numbers of untreated persons affected by leprosy and transmission rates. HCWs experience the patient-provider relationship now more as a partnership of mutual compassion and one where both feel more self-confidence in each of the roles they hold.

"Through compassion only, patients and health workers will be connected. So, compassion is very important." [female HCW FGD participant]

From the persons affected by leprosy perspective, declaration of effect cannot be certain, both because of study structure and due to the inconclusive testimony given by participants themselves. Those sampled for the interview data had generally received treatment for 5 to 6 months, while the male focus group participants generally received treatment starting 5 months

to 1 year ago, and the female focus group members began treatment between 1 to 6 months ago. This means a majority of persons affected sampled in this data did not receive any treatment prior to the start of the compassion training program to truly assess their providers behaviors and interactions before this time.

That said, some persons affected by leprosy postulate that their care may have improved recently, and relay they feel their providers act with greater friendliness and familiarity. This is evidenced via nicer talk and consistently now sitting with their patients affected by leprosy. This, however, appears to be a byproduct of simply coming to know their providers better over the course of many months of treatment and cannot be attributed to the compassion training at this time. Meanwhile, other persons affected by leprosy simply attest to unchanged treatment across their time interacting with providers with no noticeable improvement or deterioration.

To continue improving their treatment, persons affected by leprosy request providers follow up with them, offer better explanations, and ask about their experience, all with greater consistency. They affirm what HCWs believe – that they remember when and where they have received positive treatment, and will bring their friends there too, alongside returning themselves. Persons affected by leprosy also feel a sense of value and care from and appreciation for the current government program that allocates money to them for the collection of their medication monthly, or their family member who collects it. When this money is not provided as intended, however, they express distress and requests for assistance of what they feel they deserve and have been promised.

Family members agree with their relatives affected by leprosy that providers demonstrated a baseline of positive behavior in care interactions. They speculate some improvement could have occurred recently but reflect it is likely increased familiarity with their family due to the regularity of visits. If there are further ways for HCWs to improve their care, they will receive it with gratitude as they feel it not only impacts their relatives but their whole family, but they cannot specify how it would be enhanced.

4.4.5 Comparison to Baseline Data

Relative to the findings shared in the baseline data, endline results provide further detail on but in no way contradict what was identified before about (1) Local perceptions, experiences, and valuing of compassion, and (2) Experiences of persons affected by leprosy in and beyond their healthcare.

The section (3) Expectations and experiences of the compassion training, had no direct baseline comparison. Instead, participants were asked about what type of training might be helpful at baseline where they shared that it would need to extend beyond education, which could change the mind and some levels of belief but not the heart or deep-set prejudices. Training was requested to offer a positive outlook on being cured and to be offered to more than HCWs such as community members, persons affected by leprosy, and their family members –

as was reiterated at endline. In such a case, training would amplify the confidence of persons affected and their providers at once, amplifying the effect and allowing them all to become champions of changing stigma.

Similarly, section (4) Recent changes in healthcare environments did not have a comparable baseline dataset. Results align well with impacts speculated at baseline from a compassion training, except there is less discussion at the endline of a need for those being trained to have contact with persons affected by leprosy as part of the training. However, this was not directly asked about as it was not a portion of the training being evaluated since providers are already exposed to persons affected by leprosy and did not require it further. As and if training is eventually offered to new participant groups, exposure to persons affected should be strongly reconsidered as a crucial method for reducing fear.

5. DISCUSSION

Overall, the triangulated findings suggest that compassion training positively influenced health workers' attitudes and relational care, which corresponded with improved patient-reported compassion and reduced internal stigma. However, improvements in flourishing are likely partly attributable to concurrent governmental financial support. Persistent social norms, visible disability and structural factors continue to shape experienced stigma and social distance.

Human flourishing in the context of increased disability

One of the most striking findings is the significant increase in Human Flourishing Scale scores from baseline (68.6) to endline (90.4), despite a clear rise in visible disability. At baseline, 91% of participants had no disability, compared to 71% at endline, and grade 2 disability increased from 4% to 23%. Normally, one would expect higher disability levels to negatively affect wellbeing. Indeed, regression analyses confirm that disability, MB classification, age and stigma are negatively associated with flourishing. Disability is widely recognised as a determinant of reduced psychosocial wellbeing among persons affected by leprosy. Previous studies have consistently shown that visible impairments and deformities increase the risk of stigma, social isolation and diminished quality of life (van Brakel et al., 2012; Sermrittirong and van Brakel, 2014).

The qualitative findings help explain this apparent contradiction. During the study period, a government pilot programme provided direct financial contributions to persons affected at endline. Participants mentioned this support in interviews. Financial stability is one of the domains within the Human Flourishing Scale, and the improved economic situation likely contributed substantially to higher overall scores. It is therefore plausible that the increase in flourishing reflects, at least in part, reflects the impact of this financial intervention rather than the compassion training alone. Similar observations have been reported in studies showing that wellbeing among persons affected by chronic and stigmatised diseases is influenced not only by clinical outcomes but also by social relationships, dignity and economic security (VanderWeele, 2017).

In addition, qualitative data suggest that feeling valued, both through financial recognition and through more attentive listening by health workers, may have strengthened participants' sense of dignity and worth. Health workers reported being more intentional in reassuring patients and "taking away half their sorrow just by listening". This aligns with improved scores in domains such as relationships, purpose and happiness among persons affected by leprosy. Thus, even in the presence of increased disability, enhanced relational care and financial security may buffer the negative psychosocial impact of the disease. These findings highlight both the potential and limitations of provider-focused interventions in addressing stigma and wellbeing among persons affected by leprosy (Sinclair et al., 2017; Trzeciak and Mazzarelli, 2019).

Compassion, relational care and patient experience

The CARE Measure scores increased significantly (30.4 to 42.2), indicating improved patient-perceived empathy and communication. At baseline, persons affected already reported generally positive relationships with providers, a finding supported by qualitative interviews. However, at endline, participants more frequently described being treated as a “whole person” and feeling heard.

In qualitative discussions, health workers themselves reported that compassion had become more intentional. While many stated they were already compassionate before, they now felt more aware of what to label such behaviour as and how to demonstrate it. This reflects the quantitative finding of a significant increase in Pommier Compassion Scale scores (69.44 to 73.41, $p < 0.001$). Importantly, compassion was negatively associated with social distance, reinforcing the conceptual link between stigma and compassion.

At the same time, certain compassion items remained relatively low, particularly those relating to emotional connection during suffering. This echoes baseline qualitative findings that curing the disease is often perceived as easier than providing sustained psychosocial support. Compassion training may therefore have strengthened communication skills, but deeper emotional engagement, especially in complex cases, may require longer-term mentoring or reflective practice. These findings align with previous literature demonstrating that compassion-focused training can strengthen empathic communication and improve patient experience. Studies across healthcare settings have shown that compassion and empathy in clinical encounters are associated with higher patient satisfaction, improved adherence to treatment, and stronger trust in health systems (Sinclair et al., 2017; Trzeciak and Mazzarelli, 2019).

Interestingly, doctors and specialists showed a smaller increase in compassion over time and, among repeated participants, a slight increase in desired social distance. This may reflect several factors. Qualitative interviews suggest that providers may adopt more precautions when seeing visible impairments or severe symptoms. Such behaviour, while medically justified, may be perceived as distancing. It is also possible that more experienced clinicians felt they were already compassionate, limiting observable change. Both baseline and endline interviews indicated that lower-level health staff (e.g. ASHAs, sahiyas, pharmacists and outpatient staff) will benefit most from such training, as they are often the first point of contact and may have less formal education on leprosy. This may reflect structural constraints within public health systems, including time pressure, workload and limited training in psychosocial counselling. Similar barriers have been documented in other health systems where biomedical priorities dominate clinical practice (WHO, 2016).

Social distance and stigma dynamics

The Social Distance Scale showed only a small, non-significant improvement overall. As at baseline, health workers were comfortable with professional or neighbourly contact, but reluctant regarding close family relationships (marriage, childcare). This pattern strongly aligns with qualitative findings. Both persons affected and health workers reported that marriage remains a major barrier to disclosure and acceptance. This pattern is consistent with earlier studies demonstrating that stigma often persists in domains involving close social relationships (Rafferty, 2005). Community norms, such as reluctance to share food, drink or temple access,

continue to shape attitudes towards persons affected by leprosy and continues concealing of the diagnosis. Health workers' hesitation regarding familial ties may therefore reflect awareness of persistent community stigma rather than purely personal prejudice.

Urban participants reported higher stigma scores at endline. Qualitative findings provide context: people in urban settings may conceal their condition longer, often presenting later with more severe impairments. While urban areas may offer better resources, they may also involve greater social scrutiny or fear of reputational damage. The small proportion of urban participants (9%) limits firm conclusions, but the pattern warrants further investigation.

Among persons affected, stigma trends were mixed. Internal and anticipated stigma decreased, while experienced stigma and disclosure concerns increased. The rise in experienced stigma may relate to the higher proportion of visible disability at endline, as qualitative data indicate that visible impairments trigger more overt negative reactions. Conversely, reduced internal stigma may reflect increased reassurance from health workers and the empowering effect of financial support. Stigma associated with leprosy is deeply embedded in social and cultural norms and therefore difficult to change through short-term interventions alone (Sermittirong and van Brakel, 2014). Training programmes may improve attitudes within healthcare environments but may have limited influence on broader societal beliefs.

Interactions between disability, stigma and compassion

The combined regression model shows that flourishing is negatively associated with stigma, age, disability and MB type, explaining 56% of variance. Compassion, in turn, is associated with lower social distance. These relationships suggest a chain of influence: greater compassion among health workers may reduce perceived stigma and improve relational care, which can enhance wellbeing, but structural and socio-economic factors remain powerful determinants.

The increase in experienced stigma alongside improved compassion highlights the limits of provider-focused interventions in isolation. Visible disability and entrenched social norms continue to shape community responses. Compassionate care may mitigate internalised stigma and improve patient-provider relationships, but broader community engagement is needed to reduce enacted stigma. Previous research has similarly proposed that compassion can counteract prejudice and discriminatory behaviour by increasing recognition of shared human vulnerability (Goetz et al., 2010).

Implications and recommendations

First, the findings support the value of compassion-focused training for health workers. Improvements in Pommier Compassion and CARE scores, alongside qualitative reports of more attentive listening and reassurance, indicate meaningful change. However, the modest impact on social distance suggests that stigma reduction requires sustained exposure, reflection, and community-level interventions.

Second, future programmes should explicitly include lower-level health staff and frontline workers. These cadres may have greater potential for change and play a crucial role in shaping first impressions and disclosure experiences.

Third, economic empowerment appears highly influential in wellbeing outcomes. The financial pilot programme likely contributed substantially to improved flourishing and possibly reduced internal stigma. Integrated approaches combining psychosocial support, compassionate care and socio-economic assistance may therefore be most effective.

Finally, the rise in visible disability and experienced stigma underscores the need for early detection and disability prevention.

Implications for Next Steps

The endline qualitative findings identify several priority areas for strengthening and sustaining the stigma-informed compassion training. HCWs consistently described meaningful internal and relational shifts following the training, particularly through the cultivation of self-awareness and self-compassion. However, they also emphasized that without reinforcement, aspects of implementation may decline over time. Institutionalizing the training within district systems – through routine delivery, inclusion of new staff, refresher sessions, redeploying the Charter or visual reminders, WhatsApp groups or other peer supports for questions and accountability, and simple self-assessment tools – will be critical to preserving gains in workplace atmosphere and patient-provider interactions.

Providers further underscored the importance of prioritizing community-proximal workers, such as ASHAs and SAHIYAs, who often serve as first points of contact. If stigma or fear is encountered early, persons affected by leprosy may never approach further care. A tiered rollout that begins with these cadres – who are least educated by way of leprosy training, most influenced by community attitudes, and could be ideal local champions – and expands outward, may ease barriers to initial healthcare engagement and reduce concealment of symptoms. After they receive training, it should be distributed in the outpatient departments and then district-wide to all health professionals, possibly including non-clinical roles such as in the Ministry of Health where programs like the nutrition supplement occur.

Although healthcare settings were largely described as compassionate, community-level stigma remains prevalent. Participants strongly recommended extending training beyond health workers to persons affected by leprosy, family members, community leaders, and educators. Already through encouraging their friends to come to the clinic, persons affected by leprosy are becoming their own community liaison and champions. Yet without broader community engagement, healthcare-based compassion alone is unlikely to reduce societal stigma in a sustained manner. The training and associated materials will need to be tailored and simplified for such a wider range of health workers and community members who would then receive them, and will again need to be informed by thorough lived-experience assessments. Exposure to persons affected by leprosy in a fear-reducing manner should be considered for incorporation into such community-level training too as was discussed at baseline.

Further, structural supports are also necessary to reinforce relational gains. Providers noted that increased patient openness is constrained by the lack of private consultation spaces. Similarly, their self-compassion practices would be bolstered by quiet rooms and protected time in their workdays. Modest environmental adjustments, alongside reinforcement of consistent follow-up

and clearer patient communication, may help deepen trust, disclosure, and reciprocal compassion.

Finally, evaluation limitations—including no pre-training patient comparisons and potential influence of concurrent district programs—underscore the need for stronger longitudinal monitoring. A robust and larger future study that incorporates district-wide health worker and community training and evaluation should assess sustainability, referral and return patterns, and the durability of provider-level change.

In sum, the next phase of this work is well-positioned to move from a pilot study to a multi-pronged implementation and effect study with incorporated institutionalization, prioritization of first-contact workers, environmental support, community expansion, and strengthened evaluation. Embedding compassion at systems and community levels will be essential for achieving durable reductions in stigma and sustained improvements in quality of care.

Limitations of Endline Data

There are several important limitations in this study to consider when reviewing the endline results specifically, and in comparing them to the baseline study (where additional limitations were present and many of which were rectified in the endline sample).

First, the transcripts were reviewed in English after translation from Hindi to English or from Khortha to Hindi to English. This multi-step translation process may have resulted in loss or adulteration of meaning in some sections and phrases. A native Hindi speaker has re-reviewed a portion of the original recordings to correct for errors, but it is likely further discrepancies in interpretation remain. Consequently, thorough saturation is relied upon for the reporting of the endline results to reinforce strength and may thus overlook key findings coming from places where an insight was shared only a few times.

Second, the sampling method used for endline participants created an entirely separate participant group for persons affected by leprosy and their family members, and a partially distinct group for HCWs. Further, almost no sampled persons affected by leprosy were receiving treatment prior to implementation of the compassion training initiative. Thus, they and their family members cannot speak to a before-and-after effect of training on their experience of care. Further, reports of improved care from these two participant groups in the qualitative results are contradictory at times, weakening the ability to draw firm conclusions.

Third, the incorporation of a co-occurring nutrition program for persons affected by leprosy in Jharkhand State during the implementation period may have affected the level of positivity, wellness, and compassionate atmosphere perceived by participants. Given these concerns, reported results from the qualitative findings should be reviewed cautiously and in conjunction with the quantitative data.

6. CONCLUSION

This study evaluated the effect of a stigma-informed compassion training programme for healthcare providers delivering leprosy services in Bokaro district, Jharkhand. Using a mixed-methods before–after design, the findings provide evidence that strengthening compassion and stigma sensitivity among healthcare providers can contribute to improved patient experience and quality of care.

Quantitative findings indicate meaningful improvements following the intervention. Healthcare providers showed a significant increase in compassion scores and a modest reduction in social distance toward persons affected by leprosy. From the patient perspective, perceived empathy in healthcare interactions improved substantially, as reflected by higher CARE Measure scores. Persons affected by leprosy also reported significantly higher Human Flourishing scores at endline, suggesting improvements in overall wellbeing across multiple domains. Although overall stigma levels did not change significantly, reductions in internalized and anticipated stigma were observed, indicating improved self-perception and reduced fear of discrimination among affected persons.

Qualitative findings complement these results by highlighting perceived changes in attitudes and interactions among trained healthcare providers. Participants described increased self-awareness, improved listening, respectful communication, and greater sensitivity to the psychosocial challenges faced by persons affected by leprosy. Compassionate interactions were widely perceived as enhancing trust, emotional support, and treatment adherence. At the same time, community-level stigma and structural barriers within health systems were reported to persist, underscoring the need for broader stigma-reduction efforts beyond clinical settings.

Overall, the findings suggest that compassion training is a feasible and promising approach for strengthening people-centred leprosy services within routine public health systems. Integrating compassion-based and stigma-informed approaches into health worker training may improve relational quality of care, patient wellbeing, and engagement with services. However, sustained impact will require institutionalization of such training, continued supportive supervision, and complementary community-level interventions to address persistent stigma. Further longitudinal research with larger samples and longer follow-up periods would help clarify the long-term effects of compassion-based interventions on health system responsiveness and stigma reduction.

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ANNEXURES

ANNEXURE 1: BASELINE STUDY FINDINGS

1. LEPROSY AFFECTED PERSON

1.1 Socio-demographic profile of study participants

Among the 80 study participants, 61% are male and 31% are female. Age distribution shows that 36% are aged 18-30, 28% are 31-45, 25% are 46-60, and 11% are over 60. A large majority, 91%, come from rural areas, while only 9% are from urban settings.

Half of the participants (50%) belong to the Other Backward Castes (OBC)², with just 6% from the general category. The majority, 84%, follow Hinduism, while the rest adhere to other religions.

In terms of education, overall, 26% of participants, of which 14% is male and 45% is female, had never attended school. 20% of the participants are unemployed, with no significant difference between genders, while 61% of the women are homemakers. Most participants (74%) are currently married, 19% are single and never married. All participants live with their families in villages.

Table 35: Socio-demographic profile of persons affected by leprosy

		Male (n=49)		Female (n=31)		Total (n=80)	
		n	%	n	%	n	%
Total		49	61%	31	31%	80	100%
Age (years)							
	18 – 30	21	43%	8	26%	29	36%
	31- 45	12	24%	10	32%	22	28%
	46- 60	8	16%	12	39%	20	25%
	above 60	8	16%	1	3%	9	11%
Mean (Range)		39.49 (18 - 70)		40.45 (18 - 76)		39.86 (18 - 76)	
Setting							
	Rural	46	94%	27	87%	73	91%
	Urban	3	6%	4	13%	7	9%
Caste							
	Scheduled Castes (SC)	13	27%	9	29%	22	28%
	Scheduled Tribes (ST)	9	18%	4	13%	13	16%
	Other Backwards Castes (OBC)	23	47%	17	55%	40	50%
	General	4	8%	1	3%	5	6%
Religion							
	Hinduism	40	82%	26	87%	66	84%
	Islam	3	6%	1	3%	4	5%
	Sarnaism	6	12%	3	10%	9	11%
Education							
	No Schooling	7	14%	14	45%	21	26%
	Primary school (5th)	14	29%	5	16%	19	24%

² The caste system in India, while officially abolished in terms of legal recognition, continues to have a significant social and economic impact on many communities. The Indian government has implemented a system of reservations and affirmative action policies to address the historical disadvantages faced by certain groups, particularly those belonging to Scheduled Castes (SC), Scheduled Tribes (ST), and Other Backward Classes (OBC).

	Male (n=49)		Female (n=31)		Total (n=80)	
Middle school (8th)	11	22%	5	16%	16	20%
High School (10th)	10	20%	3	10%	13	16%
Higher Secondary (12th)	6	12%	2	6%	8	10%
Tertiary/graduate schooling	1	2%	2	6%	3	4%
Employment Status						
Unemployed	10	20%	6	19%	16	20%
Home maker	2	4%	19	61%	21	26%
Alms seeker	1	2%	0	0%	1	1%
Self-employed	2	4%	0	0%	2	3%
Service-holder	9	18%	2	6%	11	14%
Student	2	4%	2	6%	4	5%
Retired	2	4%	0	0%	2	3%
Other	21	43%	2	6%	23	29%
Marital Status						
Currently married	36	73%	23	74%	59	74%
Widow(er)	2	4%	4	13%	6	8%
Single/Never Married	11	22%	4	13%	15	19%
Living situation						
With family in village	49	100%	31	100%	80	100%

Among the 80 participants, the largest group (21%) comes from the Chas block, followed by Chandankayri with 16%, Jaridih with 15%, Kasmar with 14%, and Nawadih with 11%. The remaining blocks—Gumia, Peterwar, and Bermo—each contribute less than 10% of the participants.

Table 36: List of blocks and number of interviews

Block	N	%
Chas	17	21%
Chandankayri	13	16%
Jaridih	12	15%
Kasmar	11	14%
Nawadih	9	11%
Gumia	7	9%
Peterwar	6	8%
Bermo	5	6%
Grand Total	80	100%

1.2 Case History

Out of 80 total participants, 59 (74%) were diagnosed with MB leprosy. Additionally, 91% of the participants have no disabilities, 5% have Grade 1 disability, and 4% have Grade 2 disability.

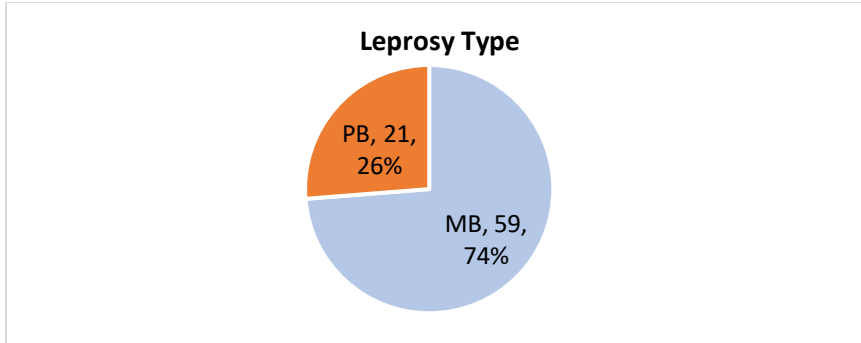


Figure 7: Leprosy type of the study participants (at the time of diagnosis)

Table 37: Eyes, hands, feet (EHF) scores and frequency distribution (at the time of diagnosis)

EHF score	N	%
0	73	91%
1	3	4%
2	2	3%
3	1	1%
8	1	1%
Grand Total	80	100%

Table 38: WHO disability grade and frequency distribution (at the time of diagnosis)

WHO Disability Grade	N	%
0	73	91%
1	4	5%
2	3	4%

1.3 Human Flourishing Scale

The **Human Flourishing Scale** is a measure designed to assess various dimensions of human well-being and flourishing, which includes various aspects of life, such as happiness, physical health, meaning and purpose, character, social relationships, and financial stability. In the Human Flourishing Scale, a total of 12 questions/ items are assessed on a scale of 0-10 with different answer options as visualized in Table 39. The total score provides an overall indication of flourishing.

Table 39: Human Flourishing Scale and its items

S.No	The following questions on a scale from 0 to 10	Scale	
		0	10
1	Overall, how satisfied are you with life as a whole these days?	Not Satisfied At All	Completely Satisfied
2	In general, how happy or unhappy do you usually feel?	Extremely Unhappy	Extremely Happy
3	In general, how would you rate your physical health?	Poor	Excellent
4	How would you rate your overall mental health?	Poor	Excellent
5	Overall, to what extent do you feel the things you do in your life are worthwhile?	Not At All Worthwhile	Completely Worthwhile
6	I understand my purpose in life.	Strongly Disagree	Strongly Agree
7	I always act to promote good in all circumstances, even in difficult and challenging situations.	Not True of Me	Completely True of Me
8	I am always able to give up some happiness now for greater happiness later.	Not True of Me	Completely True of Me
9	I am content with my friendships and relationships.	Strongly Disagree	Strongly Agree
10	My relationships are as satisfying as I would want them to be.	Strongly Disagree	Strongly Agree
11	How often do you worry about being able to meet normal monthly living expenses?	Worry All of the Time	Do Not Ever Worry
12	How often do you worry about safety, food, or housing?	Worry All of the Time	Do Not Ever Worry

Descriptive statistics

The mean score of Human Flourishing Scale is 68.61 for a total of 80 participants.

Table 40: Descriptive statistics of Human Flourishing Scale

	Count	Range	Minimum	Maximum	Mean	Median	95% CI
Human Flourishing score	80	58	37	95	68.61	70	66.11 – 71.12

The figure below presents the mean scores for each item of the human flourishing scale. The highest mean score is 6.70 for the statement, "I always act to promote good in all circumstances, even in difficult and challenging situations," followed closely by 6.65 for "I understand my purpose in life." On the lower end, the statements "How often do you worry about safety, food, or housing?" and "How often do you worry about being able to meet normal monthly living expenses?" have the lowest mean scores, at 3.35 and 3.36, respectively.

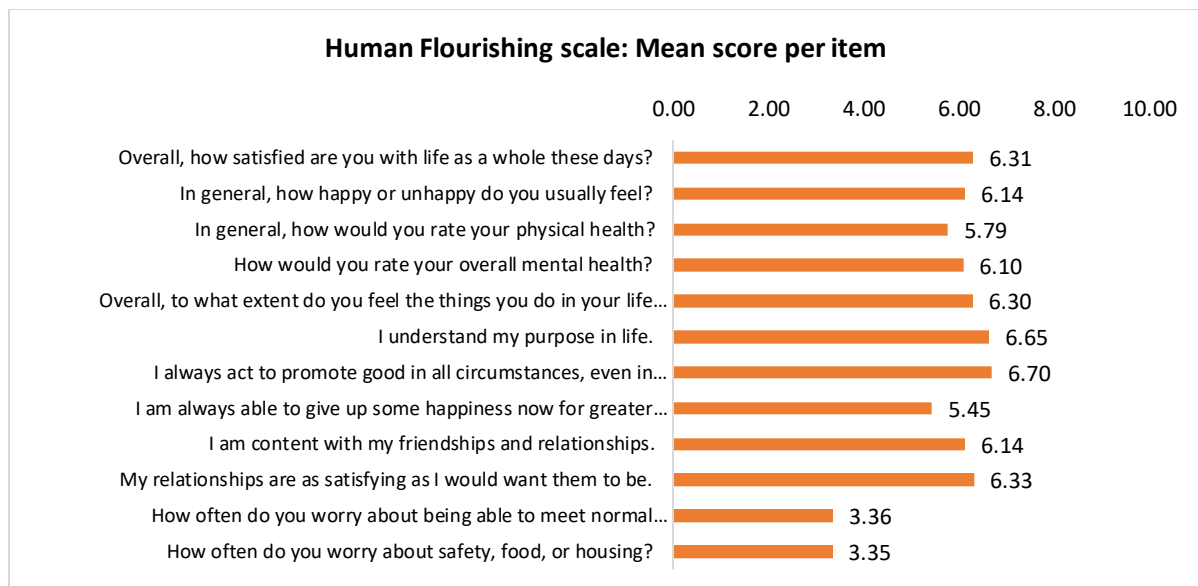


Figure 8: Human Flourishing scale: Mean score per item

Sub-group analysis (t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study sample, groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups.

A significant difference in the mean scores between PB and MB cases was found ($p=0.0079$). Similarly, a significant difference between age groups was indicated by a p -value of 0.0007.

Disability scores were aggregated into two categories: disability or no disability (EHF score >0 & 0). Similarly, marital status was sub-grouped into married & not (currently) married.

Table 41: Human flourishing scale, sub-group mean scores and p-values

	n (%)	Mean (95% CI)	p-value
Gender			
Male	49 (61%)	67.41 (64.24-70.57)	0.2311
Female	31 (31%)	70.52 (66.62-74.41)	
Setting			
Rural	73 (91%)	68.33 (65.77-70.88)	0.4699
Urban	7 (9%)	71.57 (62.00-81.14)	
Age (years)			
18 - 30	29 (36%)	71.90 (67.68-76.11)	0.0007
31- 45	22 (28%)	72.00 (68.89-75.11)	
46- 60	20 (25%)	65.40 (60.88-69.92)	
above 60	9 (11%)	56.89 (49.38-64.40)	
Leprosy type			
PB	21 (26%)	74.14 (69.19-79.09)	0.0079
MB	59 (74%)	66.64 (63.95-69.34)	
EHF			
0	73 (91%)	69.26 (66.72-71.80)	0.0966
>0	7 (9%)	61.86 (53.16-70.55)	
Marital status			
Married	59 (74%)	68.37 (65.72-71.03)	0.7518
Not (currently) married	21 (26%)	69.29 (63.45-75.12)	
SARI Stigma Scale score	n/a	n/a	0.429240

Regression (Outcome variable: Human Flourishing score)

Variables that demonstrated a significant difference ($p \leq 0.20$) in the mean scores of the Human Flourishing Scale were included in a multivariate regression model. Variables with $p > 0.05$ were systematically excluded one by one until a statistically significant model was achieved.

The final model for Human Flourishing Scale outcomes includes leprosy type and the age of the persons affected with leprosy. These variables explain 24% of the variability in the Human Flourishing Scale score.

Table 42: Multivariate regression model for social distance scale

Variable	p-value	R ²
Age	0.000195	0.24
Leprosy type	0.011875	

1.4 The Consultation and Relational Empathy (CARE) Measure

The Consultation and Relational Empathy (CARE) Measure assesses the quality of the patient-provider relationship, with a focus on the health worker's empathy as experienced by the patient. The CARE Measure consists of 10 items, each rated on a 5-point Likert scale poor to Excellent. Patients are asked to rate their healthcare provider on aspects such as listening, understanding, and showing care and compassion.

Table 43: The CARE Measure scale

S.No	The following questions on a scale from 0 to 5
1	Making you feel at ease
2	Letting you tell your "story"
3	Really listening
4	Being interested in you as a whole person
5	Fully understanding your concerns
6	Showing care and compassion
7	Being Positive
8	Explaining things clearly
9	Helping you to take control
10	Making a plan of action with you

Descriptive statistics

The mean score of the CARE measure is 30.4 for a total of 80 participants.

Table 44: Descriptive statistics of The CARE Measure scale

	Count	Range	Min	Max	Mean	Median	95% CI
The CARE Measure score	80	21	23	44	30.4	30	29.42 – 31.38

The Figure 9 presents the mean scores for each item of the CARE Measure. The highest mean score is 3.14 for the statement, "Making you feel at ease", followed closely by 3.13 for "Being interested in you as a whole person" and "Being Positive". On the lower end, the statements "Showing care and compassion" and "Fully understanding your concerns" have the lowest mean scores, 2.89 and 2.96, respectively.

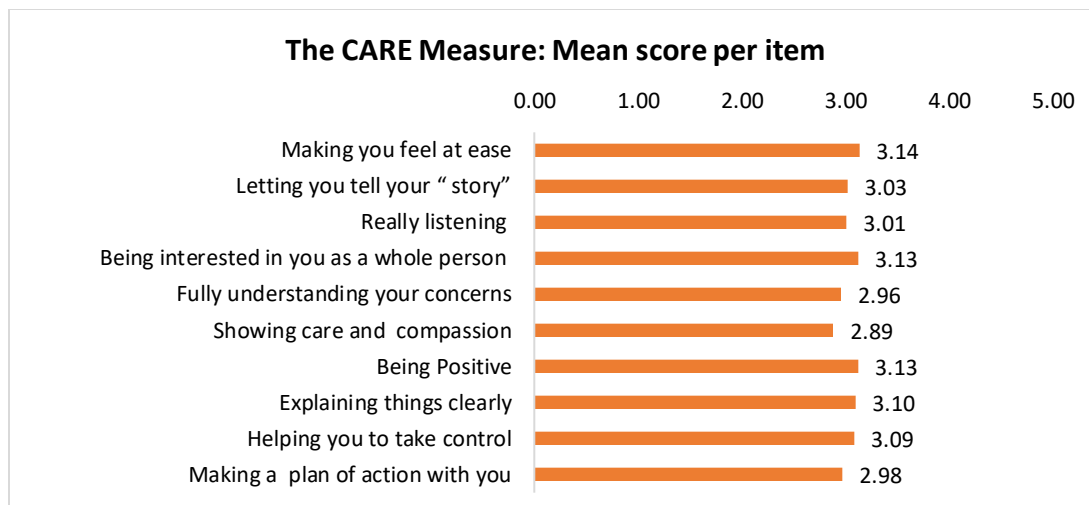


Figure 9: The CARE Measure scale: Mean score per item

Sub-group analysis (t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study sample, groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA was conducted on the defined age groups to compare the means of these groups.

Table 45 shows a p -value of over 0.05 in all sub-group analysis. This means there is no strong evidence to suggest that the group means are significantly different.

Table 45: CARE Measure scale, sub-group mean scores and p -values

	n (%)	Mean (95% CI)	p -value
Gender			
Male	49 (61%)	30.16 (28.88-31.45)	0.4826
Female	31 (31%)	30.87 (29.46-32.28)	
Setting			
Rural	73 (91%)	30.14 (29.13-31.14)	4.2733
Urban	7 (9%)	33.57 (31.62-35.52)	
Age (years)			
18 - 30	29 (36%)	30.59 (28.71-32.46)	0.6758
31- 45	22 (28%)	31.09 (29.60-32.58)	
46- 60	20 (25%)	29.45 (27.51-31.39)	
above 60	9 (11%)	30.56 (28.39-32.73)	
Leprosy type			
PB	21 (26%)	31.05 (29.28-32.81)	0.4584
MB	59 (74%)	30.22 (29.09-31.36)	
EHF			
0	73 (91%)	30.53 (29.46-31.42)	0.5247
>0	7 (9%)	29.43 (26.20-32.65)	
Marital status			
Married	59 (74%)	30.44 (29.46-31.42)	0.9914
Not (currently) married	21 (26%)	30.43 (28.01-32.84)	
SARI Stigma Scale score	n/a	n/a	0.310436

Regression (Outcome variable: CARE Measure score)

The variables did not show a significant difference ($p \leq 0.20$) in the CARE Measure mean scores. Therefore, a statistically significant model could not be established.

1.5 Stigma Assessment and Reduction of Impact (SARI) Stigma Scale

The Stigma Assessment and Reduction of Impact (SARI) measures the extent and different dimensions of stigma that persons affected by leprosy may face. This includes both internalised stigma (self-stigma) and external stigma (discrimination and social exclusion).

Descriptive statistics

The mean score of The SARI Stigma scale is 18.7 for the entire study sample.

Table 46: Descriptive statistics of The SARI Sigma scale

	Count	Range	Min	Max	Mean	Median	95% CI
SARI Stigma score	80	63	0	63	18.7	18.5	16.0 – 21.4
<i>Experienced stigma</i>	80	21	0	21	3.31	0.00	2.23 – 4.39
<i>Disclosure of concern</i>	80	12	0	12	4.50	3.50	3.48 – 5.52
<i>Internal stigma</i>	80	18	0	18	4.94	5.00	4.03 – 5.84
<i>Internal stigma</i>	80	12	0	12	5.95	6.00	5.36 – 6.54

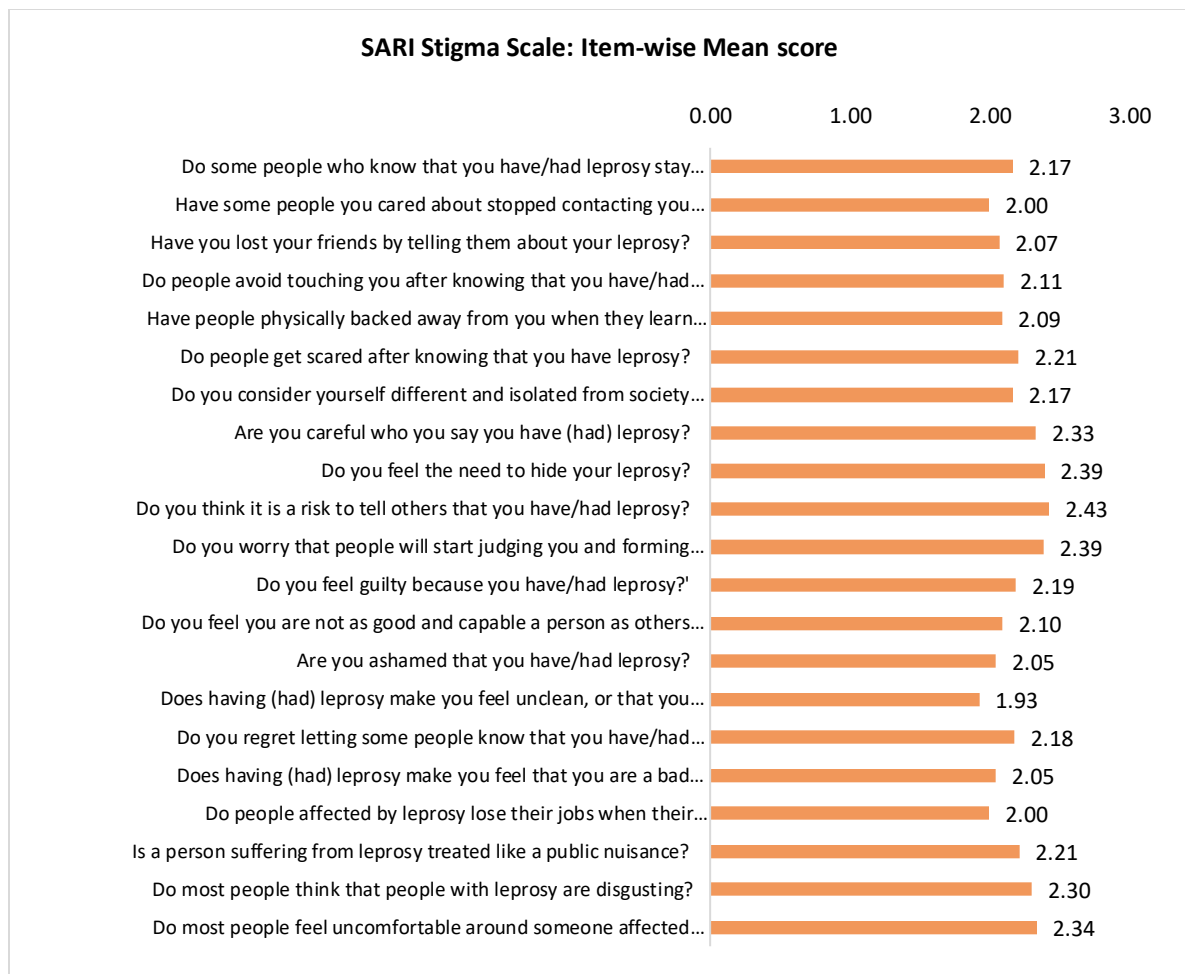


Figure 10: SARI Stigma Scale: Mean score per item

Sub-group analysis (t-test/ ANOVA)

Independent t-tests were conducted to identify differences between sub-groups of the study sample, groups were based on gender, setting, leprosy type, disability presence and marital status. Also, one-way ANOVA (analysis of variance) was conducted on the defined age groups of the participants to compare the means of these groups.

The below table shows $p > 0.05$ in all sub-group analysis. This means there is no strong evidence to suggest that the group means are different.

Table 47: SARI Stigma scale, sub-group mean scores and p-values

	n (%)	Mean (95% CI)	p-value
Gender			
Male	49 (61%)	18.84 (16.07-21.60)	0.9107
Female	31 (31%)	18.48 (13.22-23.75)	
Setting			
Rural	73 (91%)	18.73 (15.88-21.57)	0.9032
Urban	7 (9%)	18.43 (12.94-23.92)	
Age (years)			
18 - 30	29 (36%)	18.21 (13.27-23.15)	0.9601
31- 45	22 (28%)	19.91 (14.65-25.17)	
46- 60	20 (25%)	18.25 (14.66-21.84)	
above 60	9 (11%)	18.33 (9.17-27.50)	
Leprosy type			
PB	21 (26%)	21.81 (16.45-27.17)	0.1649
MB	59 (74%)	17.59 (14.60-20.58)	
EHF			
0	73 (91%)	18.93 (16.14-21.72)	0.5808
>0	7 (9%)	16.29 (8.32-24.25)	
Marital status			
Married	59 (74%)	19.51 (16.49-22.53)	0.3157
Not (currently) married	21 (26%)	16.43 (11.10-21.75)	

Regression (Outcome variable: SARI Stigma score)

Out of all the variables used, only leprosy type showed a significant difference ($p \leq 0.20$) in the mean scores of SARI Stigma Scale and was included in a linear regression model. As $p > 0.05$, a statistically significant model could not be established.

2 HEALTHCARE WORKERS

2.1 Socio-demographic profile of Healthcare Workers

Among the 80 health workers included in the study, 53% was female. Their mean age was 40.1 years. The majority works in and comes from rural areas, whereas only 13% work in and are from urban settings.

The study sample included 56 doctors (70%), of which four are a medical specialist with two specialising in dermatology. 66% of the sample had received health/medical training for over 4 years and 83% of the sample had received leprosy-specific training. 63% of the sample had over five years of working experience, of which 41% had over ten years of working experience. 45% of the sample had over 5 years of working experience with persons affected by leprosy, of which 25% had over ten years of working with persons affected by leprosy.

Table 48 - Health workers' sociodemographic data and professional experience

		n (n=80)	%
Setting	Rural	70	87.50
	Urban	10	12.50
Gender	female	42	52.50
	male	38	47.50
Age (years)		mean: 40.14	95%CI: 38.06-42.22
Type of health worker (doctor/non-doctor)			
	Medical specialist	4	5
	Medical doctor (not a specialist)	52	65
	Paramedical worker	7	8.75
	Non-medical assistant	2	2.50
	Auxiliary nurse midwife	6	7.50
	Other	9	11.25
Health specialisation			
	Dermatology	2	2.50
	None	75	93.75
	Other	3	3.75
Years of medical training received			
	No additional training (< 1 year)	7	8.75
	1-2 years	15	18.75
	3-4 years	5	6.25
	5-6 years	45	56.25
	>6 years	8	10.00
Leprosy specific training received			
	Yes	66	82.50
	No	14	17.50
Years of experience as a health worker			
	<1 year	4	5.00
	1-2 years	7	8.75
	3-5 years	18	22.50
	5-10 years	18	22.50
	>10 years	33	41.25
Years of experience working with leprosy patients			
	<1 year	10	12.50
	1-2 years	17	21.25
	3-5 years	17	21.25
	5-10 years	16	20.00
	>10 years	20	25.00

2.2 Social Distance Scale

The 7-item Social Distance Scale measures the social distance the health worker wants to keep towards a person affected by leprosy. The SDS interview starts by reading a vignette, a short description of a person with some typical characteristics of the condition, in this case

'Rahman', followed by 7 questions concerning the person in the vignette. The Social Distance Scale has an answer scale of 0-3 (definitely willing though definitely not willing).

Descriptive statistics

Table 49: Descriptive statistics of The Social Distance Scale

	Count	Range	Minimum	Maximum	Mean	Median	Interquartile range
Social Distance Scale	80	15	0	15	3.14	2.5	1-4

The overall SDS outcomes have a non-normal distribution, therefore non-parametric tests were used for its analysis. The median score on the Social Distance Scale is 2.5 (IQR: 1-4). Questions with the lowest score (most willingness) are question 2: 'How about being a worker on the same job with someone like Rahman?' and question 3: 'How would you feel having someone like Rahman as a neighbour?'. Questions with the highest scores were question 4: 'How about having someone like Rahman as caretaker of your children for a couple of hours?' and question 5: 'How about having one of your children marry someone like Rahman?'

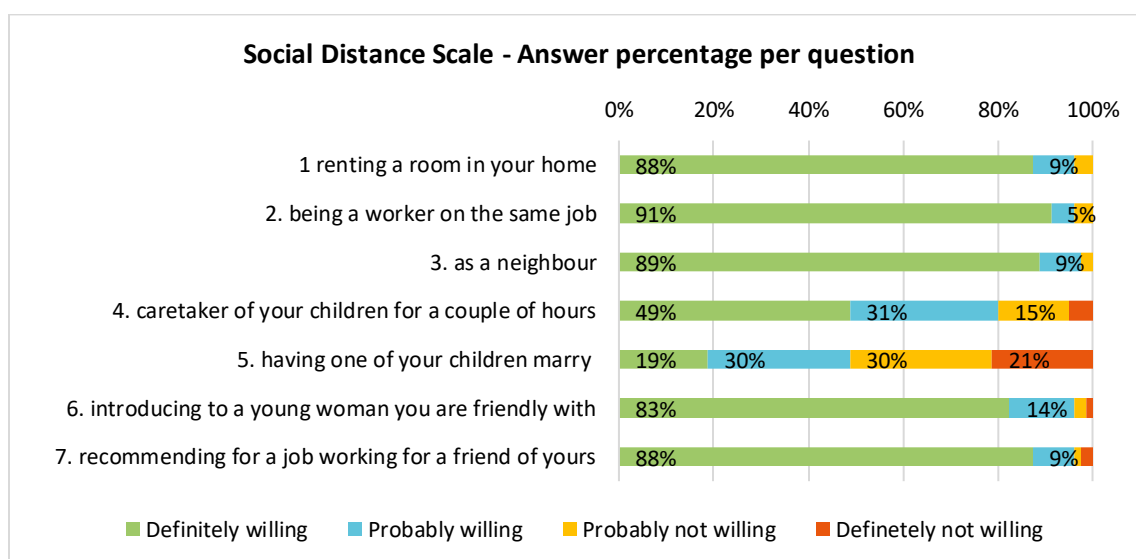


Figure 11: Social Distance Scale, answer percentage per item

Sub-group analysis (non-parametric testing)

Kruskal Wallis and Mann-Whitney U tests were used to identify differences between sub-groups of the health workers study sample. Sub-groups were formed on the basis of gender, type of health workers, years of medical training, whether leprosy training was received and the years of experience; in general and working with persons affected by leprosy.

Significant differences in Social Distance Scale outcomes were found for gender ($p=0.005$), leprosy specific training received ($p<0.001$) and years of working with persons affected by leprosy ($p<0.001$).

Table 50 - Social distance scale, sub-group scoring and associations

	n (%)	Median (IQR)	p-value
Total	80	2.5 (1-4)	
Gender			
female	38 (47.5%)	2 (0-3)	0.005
male	42 (52.5%)	3 (2-5)	
Type of health worker			
medical doctor/specialist	56 (70.00%)	2 (1-4)	0.105
paramedics, assistant, nurse, other	24 (30.00%)	3 (2-5)	
Years of medical training received			
0-4 years	27 (33.75%)	3 (2-5)	0.138
>4 years	53 (66.25%)	2 (1-4)	
Leprosy specific training received			
yes	66 (82.50%)	2 (1-4)	<0.001
no	14 (17.50%)	4.5 (3-6)	
Years of experience as a health worker			
0-5 years	29 (36.25%)	3 (2-4.5)	0.070
>5 years	51 (63.75%)	2 (1-4)	
Years of experience working with leprosy patients			
<3 years	27 (33.75%)	3 (2-6)	<0.001
3-10 years	33 (41.25%)	3 (1-4)	
>10 years	20 (25.00%)	1 (0-2.75)	

Note: IQR = interquartile range

Multivariate regression model (bootstrapped)

The variables that showed an association with a p-value of ≤ 0.20 with Social Distance Scale outcomes were included in a multivariate regression model. Variables with a p-value of $p > 0.05$ were excluded one by one, until a statistically significant model was established.

The final model for Social Distance Scale outcomes includes whether a health worker has received leprosy specific training and the duration of their experience with persons affected by leprosy. These variables explain 18% of the variability of the Social Distance Scale score.

Table 51 - Multivariate regression model for social distance scale

Variable	p-value	R ²
Leprosy specific training received	0.053	0.180
Years of experience working with leprosy patients	0.032	

2.3 Pommier Compassion Scale

The Pommier Compassion Scale measures an individual's level of compassion towards others, particularly in the context of healthcare professionals. The scale consists of 16 statements and responses are scored on a Likert scale on which study participants indicate how often “they feel or behave in the stated manner”, ranging from “almost never” to “almost always”.

Descriptive statistics

Table 52: Descriptive statistics of Pommier Compassion Scale

	Count	Range	Minimum	Maximum	Mean	Median	95% CI
Pommier Compassion Scale	80	23	57	80	69.44	70	68.23-70.65

Highest scores, indicating most compassion, were found for questions 1 and 2: “I pay careful attention when my patients affected by leprosy talk to me about their troubles” and “If I see my patients affected by leprosy going through a difficult time, I try to be caring toward them”. Lowest scores, indicating less compassion, were found on questions 6 and 15: “I like to be there for my patients affected by leprosy in times of difficulty” and “I can’t really connect with my patients affected leprosy when they’re suffering”.

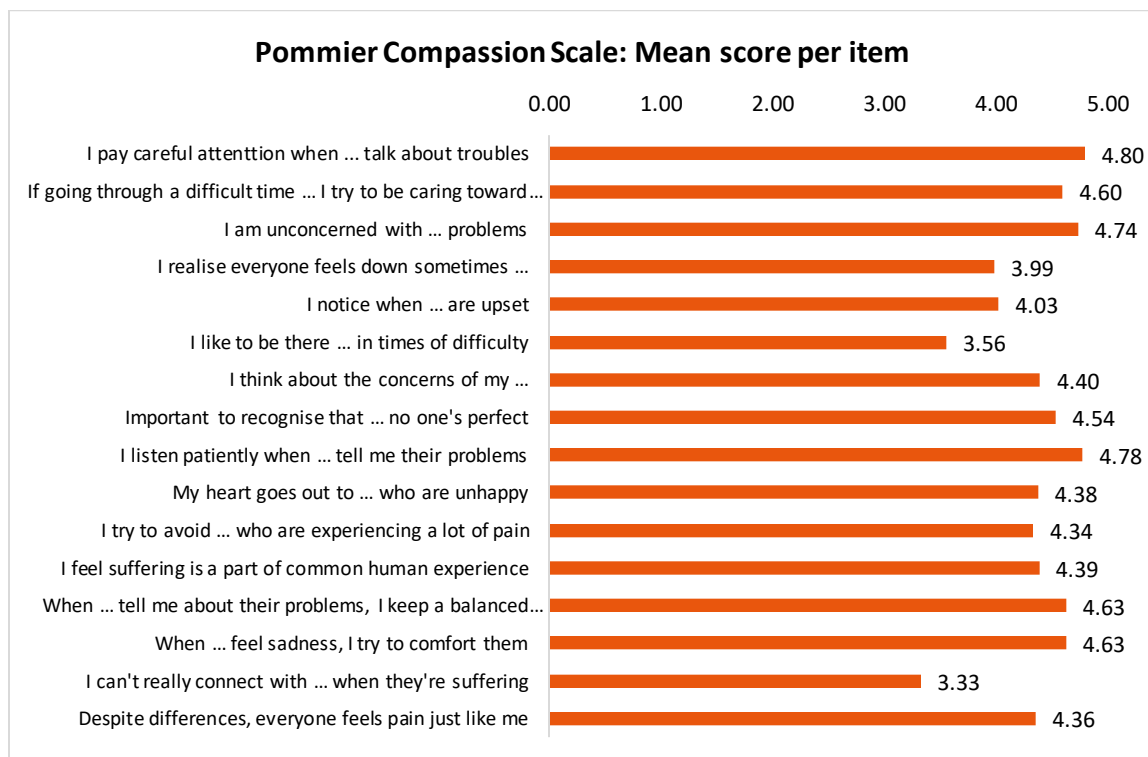


Figure 12 - Pommier compassion scale, mean score per item

Sub-group analysis (t-test/ ANOVA)

The independent t-test and an ANOVA were used to identify differences between sub-groups of the health workers study sample. Sub-groups were formed on the basis of gender, type of health workers, years of medical training, whether leprosy training was received and the years of experience; in general, and working with persons affected by leprosy. In addition, a linear regression test looking for an association with the Social Distance Scale total score was also done.

Significant differences in Pommier Compassion Scale outcomes and the type of health worker ($p=0.025$) and years of medical training received ($p=0.029$) were found, also an association with the social distance scale total score ($p=0.011$) was found.

Table 53 - Pommier compassion scale, sub-group scoring and associations

	n (%)	Mean (95% CI)	p-value
Total	80 (100%)	69.44 (68.23-70.65)	
Gender			
female	38 (47.50%)	69.39 (67.52-71.28)	0.947
male	42 (52.50%)	69.48 (67.85-71.11)	
Type of health worker			
medical doctor/specialist	56 (70.00%)	70.32 (68.95-71.69)	0.025
paramedics, assistant, nurse, other	24 (30.00%)	67.38 (64.98-69.77)	
Years of medical training received			
0-4 years	27 (33.75%)	67.59 (65.37-69.81)	0.029
>4 years	53 (66.25%)	70.38 (68.96-71.79)	
Leprosy specific training received			
yes	66 (82.50%)	69.79 (68.42-71.16)	0.212
no	14 (17.50%)	67.79 (65.16-70.41)	
Years of experience as a health worker			
0-5 years	29 (36.25%)	70.45 (68.31-72.58)	0.211
>5 years	51 (63.75%)	68.86 (67.38-70.35)	
Years of experience working with leprosy patients			
<3 years	27 (33.75%)	68.22 (66.11-70.34)	0.113
3-10 years	33 (41.25%)	70.94 (69.21-72.67)	
>10 years	20 (25.00%)	68.60 (65.77-71.43)	
Social Distance Scale total score	n/a	n/a	0.011

Multivariate regression model

The variables that showed an association with a p -value of ≤ 0.20 with Pommier Compassion Scale outcomes were included in a multivariate regression model. Variables with a p -value of $p > 0.05$ were excluded one by one, until a statistically significant model was established.

The final model for Pommier Compassion Scale outcomes includes the type of health worker, the duration of their experience with persons affected by leprosy and the total Social Distance Scale score. The p -value for the duration of experience with persons affected by leprosy is not ≤ 0.05 . However, it was noticed that by removing it, this results in a reduction of the R^2 of 10%. This can also be attributed to the finding of the variable's influence on the SDS total

score. The final model explains 15% of the variability of the Pommier Compassion Scale score.

Table 54: Multivariate regression model for Pommier compassion scale

Variable	p-value	R²
Type of health worker	0.030	0.148
Years of experience working with leprosy patients	0.112	
Social Distance Scale total score	0.016	

ANNEXURE 2 – Interview Schedules /Guides

1. Interview schedules for leprosy affected person (Quantitative)

1.1 Leprosy affected persons - sociodemographic & disability data

General			
1. Name of data collector/interviewer			
2. Date of collection			
Participant information			
3. Full name			
4. Setting	• Rural • Urban	5. Block name	☐ Nawadih ☐ Chandrapura ☐ Bermo ☐ Gumia ☐ Peterwar ☐ Kasmar ☐ Jaridih ☐ Chas ☐ Chandankiyari
6. Name of Primary Health Center (PHC)		7. Village/colony	
8. Phone Number		9. Panchayat/ward	
10. Address			
11. Sex	• Male • Female • Other	12. Age (in years)	
13. Caste		14. Religion	

● Scheduled Castes (SC) ● Scheduled Tribes (ST) ● Other Backwards Castes (OBC) ● General	● Hinduism ● Islam ● Sarnaism ● Sikhism ● Christianity ● Other: _____
15. Education (highest level completed)	16. Employment status
● No schooling ● Primary school (5th) ● Middle school (8th) ● High school (10th) ● Higher secondary (12th) ● Tertiary/graduate schooling ● Other: _____	● Unemployed ● Home maker ● Alms seeker ● Self-employed ● Service-holder ● Student ● Retired ● Other _____
17. Marital status	18. Living situation
● Currently married ● Married but Gauna Not Performed ● Widow(er) ● Divorced ● Separated/Deserted ● Single/Never Married	● With family in village ● Alone in village ● With family in isolated location ● Alone in isolated location ● Designated colony/segregated area ● Homeless ● Other: _____

19. Leprosy type			20. Diagnosis Date
● Paucibacillary leprosy (PB) (1-5 skin lesions, no bacilli in slit skin smears) ● Multibacillary leprosy (MB) (over 5 skin lesions AND/OR nerve involvement [neuritis] AND/OR bacilli in a slit skin smear)			● (DD/MM/YYYY): ____/____/____
			21. Start Date MDT ● Date (DD/MM/YYYY): ____/____/____ ● MDT not (yet) started)
Disability grade			
	Right	Left	
22. Eyes	● 0	● 0	0 - No visible or vision impairment
	● 1	● 1	1 - Vision not severely affected, can count fingers at 6 ft
	● 2	● 2	

			2 - Severe impairment, unable to count fingers at 6 ft and/or unable to close eyelid
23. Hands	● 0 ● 1 ● 2	● 0 ● 1 ● 2	0 - No sensory or visible impairment or damage 1 - Sensory impairment present but no visible impairment or damage 2 - Visible impairment or damage
24. Feet	● 0 ● 1 ● 2	● 0 ● 1 ● 2	0 - No sensory or visible impairment or damage 1 - Sensory impairment present but no visible impairment or damage 2 - Visible impairment or damage

Health centre visits

The data below needs to be obtained from the patients' health records at the respective health centre.

Name of health center: _____

Leprosy-related health centre visits <u>before baseline assessment</u>	
<i>Date of visit</i>	<i>Name of health worker</i>
Leprosy-related health centre visits <u>between baseline and endline assessments</u>	
<i>Date of visit</i>	<i>Name of health worker</i>

1.2 Human Flourishing scale

Please respond to the following questions on a scale from 0 to 10. The response scale differs for each question and will be read to you.

For the interviewer: please read the following statements to the respondent and repeat the response options.

Q#	Description	Score
<i>Domain 1: Happiness and Life Satisfaction.</i>		
1	Overall, how satisfied are you with life as a whole these days?	
	Not Satisfied At All Completely Satisfied	
	0 1 2 3 4 5 6 7 8 9 10	
2	In general, how happy or unhappy do you usually feel?	
	Extremely Unhappy Extremely Happy	
	0 1 2 3 4 5 6 7 8 9 10	
<i>Domain 2: Mental and Physical Health.</i>		
3	In general, how would you rate your physical health?	
	Poor Excellent	
	0 1 2 3 4 5 6 7 8 9 10	
4	How would you rate your overall mental health?	
	Poor Excellent	
	0 1 2 3 4 5 6 7 8 9 10	
<i>Domain 3: Meaning and Purpose.</i>		
5	Overall, to what extent do you feel the things you do in your life are worthwhile?	

	Not At All Worthwhile					Completely Worthwhile						
	0	1	2	3	4	5	6	7	8	9	10	
6	I understand my purpose in life.											
	Strongly Disagree					Strongly Agree						
	0	1	2	3	4	5	6	7	8	9	10	
<i>Domain 4: Character and Virtue.</i>												
7	I always act to promote good in all circumstances, even in difficult and challenging situations.											
	Not True of Me					Completely True of Me						
	0	1	2	3	4	5	6	7	8	9	10	
8	I am always able to give up some happiness now for greater happiness later.											
	Not True of Me					Completely True of Me						
	0	1	2	3	4	5	6	7	8	9	10	
<i>Domain 5: Close Social Relationships.</i>												
9	I am content with my friendships and relationships.											
	Strongly Disagree					Strongly Agree						
	0	1	2	3	4	5	6	7	8	9	10	
10	My relationships are as satisfying as I would want them to be.											
	Strongly Disagree					Strongly Agree						
	0	1	2	3	4	5	6	7	8	9	10	
<i>Domain 6: Financial and Material Stability.</i>												
11	How often do you worry about being able to meet normal daily living expenses?											
	Worry All of the Time					Do Not Ever Worry						
	0	1	2	3	4	5	6	7	8	9	10	

12	How often do you worry about safety, food, or housing?										
	Worry All of the Time					Do Not Ever Worry					
	0	1	2	3	4	5	6	7	8	9	

1.3 Consultation and Relational Empathy Measure (CARE)

This questionnaire asks you about your experience with compassionate care. In thinking about your healthcare providers collectively during your two most recent visits, please rate the following statements. The range of possible answers is poor, fair, good, very good, and excellent. You may also answer that a statement does not apply. Please select only one answer option for each statement and answer every statement.

For the interviewer: please read the following statements to the respondent and repeat the response options.

How were your healthcare providers at...	Poor	Fair	Good	Very Good	Excellent	Does not Apply
1. Making you feel at ease... <i>(being friendly and warm towards you, treating you with respect; not cold or abrupt)</i>	☐	☐	☐	☐	☐	☐
2. Letting you tell your "story"... <i>(giving you time to fully describe your illness in your own words; not interrupting or diverting you)</i>	☐	☐	☐	☐	☐	☐
3. Really listening... <i>(paying close attention to what you were saying; not looking at the notes or computer as you were talking)</i>	☐	☐	☐	☐	☐	☐
4. Being interested in you as a whole person... <i>(asking/knowing relevant details about your life, your situation; not treating you as "just a number")</i>	☐	☐	☐	☐	☐	☐
5. Fully understanding your concerns... <i>(communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything)</i>	☐	☐	☐	☐	☐	☐
6. Showing care and compassion... <i>(seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached")</i>	☐	☐	☐	☐	☐	☐
7. Being positive... <i>(having a positive approach and a positive attitude; being honest but not negative about your problems)</i>	☐	☐	☐	☐	☐	☐

8. Explaining things clearly... <i>(fully answering your questions, explaining clearly, giving you adequate information; not being vague)</i>	☐	☐	☐	☐	☐	☐
9. Helping you take control... <i>(exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing" you)</i>	☐	☐	☐	☐	☐	☐
10. Making a plan of action with you... <i>(discussing the next steps, involving you in decisions as much as you want to be involved; not ignoring your views)</i>	☐	☐	☐	☐	☐	☐

1.4 SARI Stigma Scale

Please respond to the following 21 questions.

The first answer options are: *yes, no, don't know, or not relevant*. If you answer yes, I will ask you how often this has happened. Then, the answer options are; *always/often, sometimes or rarely/once*.

For the interviewer: please read the following questions to the respondent and repeat the response options.

सारी लांछन (स्टिग्मा) स्केल v1.1 SARI Stigma Scale v1.1 (बर्गर के एचआईवी स्टीग्मा स्केल पर आधारित) (Based on Berger's HIV Stigma Scale)		नहीं ना No	हाँ Yes	नहीं ना जानि / Don't know	प्रास तर्क नहीं ना Not relevant	हमेश / बार - बार Always / repeatedly	कभी - कभी Sometimes	बहु कि म / एक बार Very little	स्को र Score
अनुभव किया गया लांछन Experienced stigma									
1a	क्या कुछ लोग जो यह जानते हैं कि आपको कुछ रोना है/था, आपसे ज्यादा दूरी बनाये रखते हैं? Do some people who know that you have/had leprosy stay more distance from you?	0		0	0				
b	(यदि हाँ) ऐसा कितनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
2a	यह जानने के बाद कि आपको कुछ रोना है/था, क्या कुछ लोग जो आपसे संपर्क करना बंद कर दिये हैं? Have some people you cared about stopped contacting you after knowing that you have/ had leprosy?	0		0	0				

b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
3 a	क्या दोस्ों को अपने कु ष्ट रोर के बारे में बिा कर आपने उन्हें खो तदया है? Have you lost your friends by telling them about your leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (if yes) how many times has this happened?					3	2	1	
4 a	क्या लोर यह जानने के बाद तक आपको कु ष्ट रोर है/था, आपको छू ने से बचि हैं? Do people avoid touching you after knowing that you have/had leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
5 a	क्या लोर यह जानने के बाद तक आपको कु ष्ट रोर है/था, आपसे दू री बना लेिे हैं? Have people physically backed away from you when they learn you have (had) leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
6 a	यह जानने के बाद तक आपको कु ष्ट रोर है/था, क्या लोर आपसे डर जािे हैं? Do people get scared after knowing that you have leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
7 a	यह जानने के बाद तक आपको कु ष्ट रोर है/था, क्या आप खुद को समाज से अलर् समझिे है? Do you consider yourself different and isolated from society after knowing that you have/had leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
		उप- योर (सब टोटल) Subtotal							
क ांता िा प्रिटीरिण Disclosure of concern									
8 a	आपको कु ष्ट रोर है/था, इसको तकसे बिना है, इसमें क्या आप कोई सिकग िा	0		0	0				

	बरिं हैं? Are you careful who you tell that you have (had) leprosy?								
b	(यतद हाँ) आप तकिनी बार सावधान रहें हैं? (If yes) How often are you careful?					3	2	1	
9 a	क्या आप अपने कु ए रोर को तछपाने की आवश्यकि महसूस करि हैं? Do you feel the need to hide your leprosy?	0		0	0				
b	(यतद हाँ) आप तकिनी बार अपनी स्थथति को तछपाने की ज़रूरि महसूस करि हैं? (If yes) How often do you feel the need to hide your position?					3	2	1	
1 0 a	आपको कु ए रोर है/था, दू सरो को यह बिने में क्या आपको खिरा लर्ि है? Do you think it is a risk to tell others that you have/had leprosy?	0		0	0				
b	(यतद हाँ) आपको तकिनी बार लर्ि है तक इसमें खिरा है? (If yes) How often do you think there is danger in it?					3	2	1	
1 1 a	क्या आपको तचांि होिी है तक लोर यह जानने के बाद तक आपको कु ए रोर है/था, आपके बारे में लि राय बनाने लर्ेरे? Do you worry that people will start judging you and forming negative opinions about you after knowing that you have/had leprosy?	0		0	0				
b	(यतद हाँ) आप इसके बारे में तकिनी बार तचांि करि हैं? (If yes) How often do you worry about it?					3	2	1	
		उप - योग (सब टोटल) Subtotal							
	सारी लांछन (स्टिग्मा) स्के ल v1.1 (बर्गर के एचआईवी स्टिग्मा स्के ल पर आधाररि) SARI Stigma Scale v1.1 (Based on Berger's HIV Stigma Scale)	न ही ा ं N o	हाँ Ye s	न ही ा ं जा ना / ि ी	प्रा सां त र्क न ही ा ं N ot	ह मे शा / बा र - बा र	क भी - का भी	ब हु ि क म / ए क बा र	स्को र Sc or e
अंदरूनी लांछन Internal stigma									
1 2 a	आपको कु ए रोर है/था, इसतलए क्या आप खुदको कसूरवार महसूस करि हैं? Do you feel guilty because you have/had leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
1 3 a	क्या आप खुदको दुसरे व्यस्तियों जैसा योग्य व्यस्ति महसूस नही ां	0		0	0				

	करि हैं क्योंतक आपको कु ष्ट रोर् है/था? Do you feel you are not as good and capable a person as others because you have (had) leprosy?								
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
1 4 a	क्या आप शतमिंदा हैं तक आपको कु ष्ट रोर् है/था? Are you ashamed that you have/had leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
1 5 a	क्या कु ष्ट रोर् होने से आप अशुद्ध या अपवित्र महसूस करि हैं, जैसे तक आप मांतदर में प्रवेश नही ां कर सकि हैं या पूजा (धातमगक र्तिवतथयाँ) या तववाह जैसे सामातजक कायगक्रमों में भार् नही ां ले सकि हैं? Does having (had) leprosy make you feel unclean, or that you cannot enter a temple or do Puja (religious rituals) or participate in social events like marriage?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
1 6 a	आपको कु ष्ट रोर् है/था, कु छ लोर्ोां को यह बिने का क्या आपको पछिवा है? Do you regret letting some people know that you have/had leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
1 7 a	आपको कु ष्ट रोर् है/था, क्या यह आपको महसूस कराि है तक आप बुरे व्यस्टि हैं? Does having (had) leprosy make you feel that you are a bad person?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
		उप- योर् (सब टोटल) Subtotal							
अपेकित लांछन Expected stigma									
1 8 a	मातलक को पिा चल जाने पर क्या कु ष्ट रोर् से ग्रतसि व्यस्टि की नौकरी चली जािी है? Do people affected by leprosy lose their jobs when their employers find out?	0		0	0				

b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
19a	क्या कुष्ठ रोग से ग्रस्त व्यक्ति के साथ सावगजतनक परे शानी जैसा व्यवहार तकिया जाँ है? Is a person suffering from leprosy treated like a public nuisance?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
20a	क्या अतधिकर लोग यह सोचि हैं तक कुष्ठ रोग से ग्रस्त व्यक्ति घृणा युक् होिे हैं? Do most people think that people with leprosy are disgusting?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
21a	क्या अतधिकर लोग कुष्ठ रोग से ग्रस्त व्यक्ति के पास अपने आप को असहज महसूस करि हैं? Do most people feel uncomfortable around someone affected by leprosy?	0		0	0				
b	(यतद हाँ) ऐसा तकिनी बार हुआ है? (If yes) How many times has this happened?					3	2	1	
		उप- योग (सब टोटल) Subtotal (Sub Total)							
		कुल स्कोर total score							

2. Interview schedule for Healthcare Workers (Quantitative)

2.1 Health workers - Sociodemographic data

A. General				
1. Name of data collector				
2. Date				
B. Participant information				
3. Participant name				
4. Setting	• Rural • Urban	5. Block name	☐ Nawadih ☐ Chandrapura ☐ Bermo ☐ Gumia ☐ Peterwar ☐ Kasmar ☐ Jaridih ☐ Chas ☐ Chandankiyari	
6. Name of Primary Health Center (PHC)		7. Village/Mohalla		
8. Phone no	9. Panchyat/Ward			
10. Address				
11. Sex	• Male • Female • Other	12. Age (years)		
C. Professional background				
13. Type of health worker		14. Health specialization		
• Medical specialist • Medical doctor (not a specialist) • Paramedical workers (PMW) • Non-medical supervisor (NMS) • Non-medical assistant (NMA) • Physiotherapist		• Dermatology • Rehabilitation • Medicine • Other: 		

● Staff nurse ● Auxiliary nurse midwives (ANM) ● Other:.....	● None
15. Years of medical training received (Medical or Para Medical)	16. Leprosy-specific training received
● No additional training (<1 year) ● 1-2 years ● 3-4 years ● 5-6 years ● >6 years	● Yes ● No
	17. (if answered yes) Duration of leprosy specific training
	 days/weeks/months/years (circle what applies)
18. Years of experience as a health worker	19. Years of experience working with leprosy patients
● <1 year ● 1-2 years ● 3-5 years ● 5-10 years ● >10 years	● <1 year ● 1-2 years ● 3-5 years ● 5-10 years ● >10 years

Have you received compassion training at the Health Center?	
Yes (Date)	
No	
Not Applicable	

Number of new cases detected in last six month before baseline	
Number of leprosy patients	

Number of new cases detected in <u>between baseline to endline assessment</u>	
Number of leprosy patients	

2.2 Social Distance Scale (SDS)

अनुलग्नक 4 - सामाजिक दूरी स्केल

कृपया निम्नलिखित बयान पढ़ें (कृपया देश-विशिष्ट विवरण की जांच करें)

कृपया नीचे दिए गए प्रश्नों को एसडीएस फॉर्म पर दर्ज करें

निश्चित रूप से तैयार = 0

शायद तैयार = 1

शायद तैयार नहीं = 2

निश्चित रूप से तैयार नहीं = 3

लापता मान = 4

कृपया आपके देश में मान्य सामाजिक दूरी स्केल का उपयोग करें।

कृपया निम्नलिखित कथन को इस तरह पढ़ें (पुरुषों के लिए "पुरुष", महिलाओं के लिए "महिला") ।

पुरुष

रहमान एक 23 वर्षीय आदमी है। पिछले वर्ष के दौरान कुष्ठ रोग के कारण उस का इलाज किया गया है। डॉक्टर ने उसे ठीक घोषित किया है, भले ही उसके दाहिने हाथ में कुछ उंगलियां में अभी भी विकृति हैं और उपचार के कारण उसकी त्वचा अभी भी अस्पष्ट हैं। रहमान के पास स्थानीय छोटे व्यवसाय में नौकरी है जो उसके चाचा का है। वह प्रति माह 5000 रुपये कमाते हैं और अपने काम में अच्छा कर रहा हैं। उसके हाथ में कुष्ठ रोग के प्रभाव की वजह से वह पहले की तुलना में थोड़ा सा मंदगतिवाला है, लेकिन नियोक्ता ने उस बारे में कभी शिकायत नहीं की । अपने काम पर रहमान अपने साथियों के साथ अच्छी तरह से मिलते हैं। रहमान शादी करना चाहता है। वह एक स्थानीय युवा संगठन में शामिल होने पर विचार कर रहा है, ताकि वह उसी आयु के लोगों से मिल सकें। वह अपने वर्तमान नौकरी की तुलना में अधिक कमाई करने में सक्षम होने के लिए एक बेहतर नौकरी पाने की आशा भी करता है।

महिला

रहमी एक 27 वर्षीय महिला है। पिछले वर्ष के दौरान कुष्ठ रोग के कारण उस का इलाज किया गया है। डॉक्टर ने उसे ठीक घोषित किया है, भले ही उसके दाहिने हाथ में कुछ उंगलियां में अभी भी विकृति हैं और उपचार के कारण उसकी त्वचा अभी भी अस्पष्ट हैं। रहमी के पास स्थानीय छोटे व्यवसाय में नौकरी है जो उसके चाचा कि है। वह प्रति माह 5000 रुपये कमाती हैं और अपने काम में अच्छा कर रही है। उसके हाथ में कुष्ठ रोग के प्रभाव की वजह से वह पहले की तुलना में थोड़ा सी मंदगतिवाली है, लेकिन नियोक्ता ने उस बारे में कभी शिकायत नहीं की। अपने काम पर रहमी अपने साथियों के साथ अच्छी तरह से मिलती हैं। रहमी शादी करना चाहती हैं। वह एक स्थानीय युवा संगठन में शामिल होने पर विचार कर रही है, ताकि वह उसी आयु के लोगों से मिल सके। वह अपने वर्तमान नौकरी की तुलना में अधिक कमाई करने में सक्षम होने के लिए एक बेहतर नौकरी पाने की आशा भी करती है।

	निश्चित रूप से इच्छुक	शायद इच्छुक	शायद इच्छुक नहीं	निश्चित रूप से इच्छुक नहीं	गणना
	0	1	2	3	
रहमान / रहमी जैसे किसी को अपने घर में एक कमरा किराए पर देते समय आपको कैसा महसूस होगा?					
रहमान / रहमी जैसे किसी के साथ एक ही काम पर कार्यकर्ता होने में आपको कैसा महसूस होगा?					
रहमान / रहमी जैसे किसी को एक पड़ोसी के रूप में आप कैसे महसूस करेंगे?					
रहमान / रहमी जैसे किसी को कुछ घंटों के लिए अपने बच्चों की देखभाल करने वाले होने के बारे में आप कैसे महसूस करेंगे?					
अपने बच्चों में से किसी एक की शादी रहमान / रहमी जैसे किसी से होने के बारे में आप कैसे महसूस करेंगे?					

रहमान / रहमी को अपनी एक युवा महिला दोस्त से मिलवाते समय आप कैसा महसूस करेंगे?					
आप किसी दोस्त के लिए काम करने के लिए रहमान / रहमी जैसे लोगों की सिफारिश करने के बारे में कैसा महसूस करेंगे?					
				कुल	

2.3 The Pommier Compassion Scale

		1	2	3	4	5
	<i>Please indicate how often you feel or behave in the stated manner on a scale from 1 (almost never) to 5 (almost always):</i>	Almost never	Rarely	Sometimes	Often	Almost always
1	I pay careful attention when my patients affected by leprosy talk to me about their troubles.					
2	If I see my patients affected by leprosy going through a difficult time, I try to be caring toward them.					
3	I am unconcerned with my patients affected by leprosy problems.					
4	I realize everyone feels down sometimes, it is part of being human.					
5	I notice when my patients affected by leprosy are upset, even if they don't say anything.					
6	I like to be there for my patients affected by leprosy in times of difficulty.					
7	I think little about the concerns of my patients affected by leprosy.					
8	I feel it's important to recognize that all people have weaknesses and no one's perfect.					
9	I listen patiently when my patients affected by leprosy tell me their problems.					
10	My heart goes out to my patients affected by leprosy who are unhappy.					
11	I try to avoid my patients affected by leprosy who are experiencing a lot of pain.					
12	I feel that suffering is just a part of the common human experience.					
13	When my patients affected by leprosy tell me about their problems, I try to keep a balanced perspective on the situation.					
14	When my patients affected by leprosy feel sadness, I try to comfort them.					
15	I can't really connect with my patients affected by leprosy when they're suffering.					
16	Despite my differences with others, I know that everyone feels pain just like me.					

3. Interview Guide for IDI (Qualitative)

3.1 Leprosy Affected Person

Semi-Structured Interview – Persons Affected

A. Interviewer Details

1. Name of Interviewer:
2. Date of interview:

B. Geographical Location, Contact Information, and Socio-Demographic Information

Participant ID: _____

(should be connected to quantitative survey that contains the remaining information)

C. Perceptions & Experiences of Compassion

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	When you hear the word 'compassion,' what comes to mind?	Specific actions? People? Environments? (e.g., temple, home, school, etc.)
2.	A common way to describe compassion is "a warm-hearted response to suffering and a motivation to relieve it." In other words, when we see others' challenges, we may try to help them. Do you have a word or phrase you prefer to use for this instead of compassion?	

	Questions	Follow-up Questions
3.	With this form of compassion in mind, what you may call (<i>say the participants term for compassion from above</i>), what does this look like to you?	Where have you seen it? Can you describe a person, action, or memory that you believe is compassionate?
4.	Can you share a short story or example of when you observed or experienced a compassionate act? [Probes after story is shared: How did that make you feel? Why do you believe this happened? What can be done to create more actions/experiences like this in the future?]	
5.	Where does compassion come from? [Do not read aloud] Family, faith, culture, tradition, personal values...	What do you believe motivates compassionate actions or views?
6.	What is the value of compassion?	For an individual? For a family? A community?

	Questions	Follow-up Questions
7.	~~What effect might compassion might~~ ~~might compassion have on~~ impact the care you receive?	~~What effect~~ ~~How~~ might compassion <u>have on</u> ~~impact~~ your experience of care? The quality of care you receive?
8.	~~What effect~~ ~~How~~ might compassion <u>have on</u> ~~impact~~ the treatment of conditions like Leprosy?	

D. Perceptions & Experiences of Stigma

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	Can you tell me something about the disease 'leprosy'?	What causes this (or your) disease?

2.	Can you tell me about the views/perceptions/attitudes of people in your community regarding persons with leprosy?	How do you feel about this?
3.	Do people in your community treat leprosy patients differently from other people?	<i>If necessary prompt regarding respect, gossip, discrimination, etc.</i> How do community members behave towards persons affected by leprosy? How do you feel about this?
5.	Can you share a short story or example of when you observed or experienced different behaviour from others towards persons with leprosy?	Probes <u>after</u> story is shared: How does that make you feel?

6.	Why do you believe people act in that way?	[Do not read aloud] Family, faith, culture, tradition, personal values, lack of knowledge, lack of empathy, lack of advocacy.
7.	Do you believe that this kind of behaviour can be changed?	If no, why not? If yes, how?
8.	Do health workers treat leprosy patients differently from other patients?	<u>If yes, how is this different?</u> How do health workers behave toward leprosy patients? Do you think that they give the same care to leprosy patients as to other patients? If not, how is it different?

9.	Do you ever notice negative behaviour toward persons affected by leprosy from health workers?	What do you notice? Can you give an example?
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Please document observations of interaction with the respondent in the space below

[Suggestions: level of emotion, openness, level of comfort, length of response, tone and level of voice, body posture, eye contact, facial expression]

Guidance for Semi-Structured Interviews

Location and set-up

The interview should be scheduled at a convenient time and location for the interviewee. The location should be private, ideally with a closed door or in a space without others, rather than a public place. It is helpful if there is a room where you can speak privately without interruption, and where it is quiet enough to hear and audio record the interview. Within the interview space, an arrangement with a comfortable distance between the interviewer and interviewee.

With space for materials (recorder, consent forms, questionnaires, water, and so on).

Beginning of the interview

Interviewers can start with chatting to break the ice and attempt to establish commonalities, rapport, and trust. Interviews will need to begin with a brief explanation of the research study, consent/assent procedures, rationale for talking to that particular interviewee and description of the interview format and agenda. It can also be helpful if the interviewer shares a little about who they are and why they are interested in the topic. The recording equipment should have already been tested thoroughly but interviewers may want to double-check that the audio equipment is working and remind participants about the reason for recording.

Interviewer stance

During the interview, the interviewer should adopt a friendly and non-judgmental attitude. The interviewer is to maintain a warm and conversational tone, rather than a rote (repeating same), question-answer approach. It is important to recognize the potential power differential as a researcher.

Active listening

During a face-to-face interview, there is an opportunity to observe social and non-verbal cues of the interviewee. These cues may come in the form of voice, body language, gestures and intonation, and can supplement the interviewee's verbal response and can give clues to the interviewer about the process of the interview. Listening is the key element to successful interviewing. Listening should be 'attentive, empathic, nonjudgmental, listening in order to invite, and engender talk. Silence, nods, smiles and utterances can also encourage further elaboration from the interviewee.

Continuing the interview

As the interview progresses, the interviewer can repeat the words used by the interviewee, use planned and unplanned follow-up questions that invite further clarification, exploration, or elaboration. Throughout the interview, the goal of the interviewer is to encourage the interviewee to share as much information as possible, unselfconsciously and in his or her own words. That should be recorded thoroughly. Some interviewees are more forthcoming and will offer details of their experiences without much probing required. Others will require prompting and follow-up to elicit sufficient detail.

As a result, follow-up questions are equally important to the core questions in a semi structured interview. Prompts encourage people to continue talking and they can elicit more details needed to understand the topic. Examples of verbal probes are repeating the participant's words, summarizing the main idea or expressing interest with verbal agreement.

Follow-up Question Techniques

For probing techniques and example probes we have been using in our own interviewing.

- Wait time: Interviewer remains silent after asking a question. This allows the interviewee to think about their response and often encourages the interviewee to speak.
- Echo: Interviewer repeats or summarizes the participant's words, encouraging them to go into more detail.
- Verbal Agreement: Interviewer uses affirming words to encourage the interviewee to continue speaking.
- Expansion: Interviewer asks participant to elaborate on a particular response.
- Explanation: Interviewer asks participant to clarify a specific comment.
- Leading: Interviewer asks interviewee to explain their reasoning.

3.2 Family Members of Affected Person

Semi-Structured Interview – Family Members

A. Interviewer Details

a. Name of Interviewer:
b. Date of interview:

Participant ID: _____

(should be connected to quantitative survey that contains the remaining information AND baseline study, if included at that time. Should also be connected to their family member's ID who is a person affected by leprosy)

B. Geographical Location, Contact Information, and Socio-Demographic Information

Participant information			
1. Full name of this participant		2. Participant ID	
3. Full name of family member (person affected)		4. Person Affected Participant ID	
5. Setting	• Rural • Urban	6. Block name	☐ Nawadih ☐ Chandrapura ☐ Bermo ☐ Gumia ☐ Peterwar ☐ Kasmar ☐ Jaridih ☐ Chas ☐ Chandankiyari
7. Name of Primary Health Center (PHC)		8. Village/colony	
9. Phone Number		10. Panchayat/ward	

11. Address			
12. Sex	• Male • Female • Other	13. Age (in years)	
14. Caste		15. Religion	
• Scheduled Castes (SC) • Scheduled Tribes (ST) • Other Backwards Castes (OBC) • General		• Hinduism • Islam • Sarnaism • Sikhism • Christianity • Other: _____	
16. Education (highest level completed)		17. Employment status	
• No schooling • Primary school (5th) • Middle school (8th) • High school (10th) • Higher secondary (12th) • Tertiary/graduate schooling • Other: _____		• Unemployed ☐ Retired • Home maker ☐ Other: _____ • Alms seeker • Self-employed • Service-holder • Student	
18. Marital status		19. Living situation	
• Currently married • Married but Gauna Not Performed • Widow(er) • Divorced • Separated/Deserted • Single/Never Married		• With family in village • Alone in village • With family in isolated location • Alone in isolated location • Designated colony/segregated area • Homeless • Other: _____	
20. Relationship with the affected person (participant is the ... of the affected person)		• Spouse • Child • Parent • Sibling • Grand child • Grandparent • Other: : _____	

C. Perceptions & Experiences of Compassion

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	When you hear the word 'compassion,' what comes to mind?	Specific actions? People? Environments? (<i>e.g., temple, home, school, etc.</i>)
2.	What effect might compassion have on the healthcare your relative (person affected by leprosy) receives?	What effect might compassion have on their experience of care? The quality of care they receive?
3.	What effect might this improved quality of care have on their well-being?	<i>Consider their physical, mental/emotional, social, spiritual, and economic well-being.</i>
4.	What effect might compassion have on their healthcare providers?	<i>Consider providers in different settings – at the clinic? In their village or hometown?</i>

	Questions	Follow-up Questions
5.	What effect might compassion have on the medical treatment of your loved one for conditions like Leprosy?	What effect might compassion have on the medical treatment of stigmatizing health conditions in general? How do you feel about this?

Perceptions & Experiences of Stigma

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	Do people in your community treat you or your family member affected by Leprosy differently from other people?	<i>If needed, prompt regarding disrespect, gossip, discrimination, etc.</i> How do community members behave towards you or your family member affected by leprosy? How do you feel about this?
2.	Why do you believe people act in that way?	<i>[Do not read aloud, just keep in mind possible answers like: Family, faith, culture, tradition, personal values, lack of knowledge, lack of empathy, lack of advocacy.]</i>

		Do you believe that this kind of behaviour can be changed? Why? How?
3.	How do health workers behave towards persons affected by leprosy?	Do health workers treat leprosy patients/your family member differently from other patients? If yes, how is this different? <i>Probe for negative or positive behaviors</i> Why do you think that may be? What is the source of these behaviors?
4.	Do you feel you and your family member affected by leprosy matter as much to health workers as any other patient and their family?	Why or why not? What do you notice? Can you give an example? How do you feel about that?

E. Perceptions & Experiences of Care Over Time

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	For how many months has your family member been receiving healthcare and treatment for their Leprosy?	When were they first diagnosed? Who diagnosed them?
2.	Since they began receiving care for their Leprosy, have you noticed any changes in the care they have received?	Have you noticed any changes in the behaviors or attitudes of the health workers in your community? If so, how? Have you noticed any changes in the behaviors or attitudes of health workers at the clinic? If so, how?
3.	If you have noticed any changes, how do you feel about them?	Do you want to see more of this change? Who has this change impacted most? What types of patients?

4.	What would you change, if anything, about the care your family member has received for their Leprosy?	Why is that important to you? What do you think would be the impact? <i>Probe for their or and their family member's wellbeing - social, emotional , spiritual, physical, financial</i> Do you think other patients would also value this change? If so, are there certain patients who might find this especially important? <i>Probe on stigmatizing conditions, including leprosy</i>

Please document observations of interaction with the respondent in the space below

[Suggestions: level of emotion, openness, level of comfort, length of response, tone and level of voice, body posture, eye contact, facial expression]

Guidance for Semi-Structured Interviews

Location and set-up

The interview should be scheduled at a convenient time and location for the interviewee. The location should be private, ideally with a closed door or in a space without others, rather than a public place. It is helpful if there is a room where you can speak privately without interruption, and where it is quiet enough to hear and audio record the interview. Within the interview space, an arrangement with a comfortable distance between the interviewer and interviewee.

With space for materials (recorder, consent forms, questionnaires, water, and so on).

Beginning of the interview

Interviewers can start with chatting to break the ice and attempt to establish commonalities, rapport, and trust. Interviews will need to begin with a brief explanation of the research study, consent/assent procedures, rationale for talking to that particular interviewee and description of the interview format and agenda. It can also be helpful if the interviewer shares a little about who they are and why they are interested in the topic. The recording equipment should have already been tested thoroughly but interviewers may want to double-check that the audio equipment is working and remind participants about the reason for recording.

Interviewer stance

During the interview, the interviewer should adopt a friendly and non-judgmental attitude. The interviewer is to maintain a warm and conversational tone, rather than a rote (repeating same), question-answer approach. It is important to recognize the potential power differential as a researcher.

Active listening

During a face-to-face interview, there is an opportunity to observe social and non-verbal cues of the interviewee. These cues may come in the form of voice, body language, gestures and intonation, and can supplement the interviewee's verbal response and can give clues to the interviewer about the process of the interview. Listening is the key element to successful interviewing. Listening should be 'attentive, empathic, nonjudgmental, listening in order to invite, and engender talk. Silence, nods, smiles and utterances can also encourage further elaboration from the interviewee.

Continuing the interview

As the interview progresses, the interviewer can repeat the words used by the interviewee, use planned and unplanned follow-up questions that invite further clarification, exploration, or elaboration. Throughout the interview, the goal of the interviewer is to encourage the interviewee to share as much information as possible, unselfconsciously and in his or her own words. That should be recorded thoroughly. Some interviewees are more forthcoming and will offer details of their experiences without much probing required. Others will require prompting and follow-up to elicit sufficient detail.

As a result, follow-up questions are equally important to the core questions in a semi structured interview. Prompts encourage people to continue talking and they can elicit more details needed to understand the

topic. Examples of verbal probes are repeating the participant's words, summarizing the main idea or expressing interest with verbal agreement.

Follow-up Question Techniques

For probing techniques and example probes we have been using in our own interviewing.

- Wait time: Interviewer remains silent after asking a question. This allows the interviewee to think about their response and often encourages the interviewee to speak.
- Echo: Interviewer repeats or summarizes the participant's words, encouraging them to go into more detail.
- Verbal Agreement: Interviewer uses affirming words to encourage the interviewee to continue speaking.
- Expansion: Interviewer asks participant to elaborate on a particular response.
- Explanation: Interviewer asks participant to clarify a specific comment.
- Leading: Interviewer asks interviewee to explain their reasoning.

3.3 Healthcare Workers

Semi-Structured Interview – Healthcare Providers (HCPs)

A. Interviewer Details

a. Name of Interviewer:
b. Date of interview:

B. Geographical Location, Contact Information, and Socio-Demographic Information

Participant ID: _____

(should be connected to quantitative survey that contains the remaining information AND baseline study, if included at that time)

C. Perceptions & Experiences of Compassion

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	When you hear the word 'compassion,' what comes to mind?	Specific actions? People? Environments? (<i>e.g., temple, home, school, etc.</i>)
2.	Where does compassion come from? <i>[Do not read aloud, just keep in mind possible answers like: Family, faith, culture, tradition, personal values]</i>	What do you believe motivates compassionate actions or views?

	Questions	Follow-up Questions
3.	What is the value of compassion?	For an individual? For a family? For a community? For society or a country?
4.	What effect might compassion have in a healthcare setting?	What effect might compassion have on the delivery of care? The quality of care?
5.	What effect might compassion have on patient experiences in healthcare settings?	What effect might compassion have on their wellbeing outcomes – including physical, mental/emotional, social, spiritual, and economic?
6.	What effect might compassion have on healthcare workers?	What effect might compassion have on their wellbeing – including physical, mental/emotional, social, spiritual, and economic? What effect might compassion have on their ability to do their job well? What effect might compassion have on their relationships with other healthcare workers? <i>Probe: Consider how compassion might affect your interactions with your colleagues. How might you change? How might they change?</i>

	Questions	Follow-up Questions
7.	What effect might compassion have on the medical treatment of conditions like Leprosy?	What effect might compassion have on the medical treatment of stigmatizing health conditions in general? How do you feel about this?

D. Perceptions & Experiences of Stigma

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
1.	Can you tell me something about the disease 'leprosy'?	What causes this disease?
2.	Can you tell me about the views/perceptions/attitudes of people in the places where you treat regarding persons with leprosy?	<i>If needed, prompt regarding disrespect, gossip, discrimination, etc.</i> Does it make a difference whether someone has visible signs of leprosy or not? How do you feel about this?
3.	How do health workers behave towards persons affected by leprosy?	Do health workers treat leprosy patients differently from other patients? <i>If needed, prompt initially with potentially negative behaviors – willingness to touch patients, to examine and treat persons affected by leprosy,</i>

		<i>to share a room or pass close. Secondly prompt if providers might actually treat with greater kindness, concern, care, and compassion.</i>
4.	[If they have said health workers treat patients differently from other patients in Q3]... Why do you believe health workers may behave like this?	Do you believe this kind of behavior should be can be changed? Why or why not? If you believe it <i>should</i> be changed, do you believe it <i>can</i> be changed? Why or why not? How?
5.	How do you personally feel about taking care of persons affected by leprosy?	Do you always feel comfortable being near a leprosy patient?

E. Training

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
READ TO PARTICIPANT: Over the past 6 months, many of your colleagues and possibly you too have been engaged in compassion training. These next questions are specific to your knowledge and experience of this training only.		
1.	How did you first hear about the compassion training?	Who told you? What did they tell you about it? <i>Prompt around were people excited about it, did they feel burdened by it, did they seem to value it.</i>

		What did anyone tell you about your role relative to the training (e.g., if and why you would or would not participate)?
2.	Did you participate in the training?	If yes, how much of the training were you able to attend? If no, proceed to the section F. >>
3.	How did you experience the training?	What did you like? What did you not like? Do you feel your colleagues had a similar or different experience from you? How?
4.	What challenges, if any, did you have with how the training was delivered?	Prompt: complexity (e.g., easy to understand, any difficult parts), timing, scheduling, too busy, vulnerability and safety, location, not engaging enough. Do you feel your colleagues had similar or different challenges from you? How? How do you think these challenges could be addressed in future training?

5.	How valuable, if at all, was the information you learned in the training?	Can you tell me about some of the things you learned? <i>Prompt for a few examples</i> Do you feel your colleagues have gained similar or different valuable information from the training? How so?
6.	What have you done, if anything, with the information you have learned in the training?	<i>Prompt: impact to thoughts, perceptions, attitudes, feelings, behaviors</i> Can you provide an example of a change you have noticed so far in yourself or one you plan to implement in the next month? Do you feel your colleagues have also gained this actionable information from the training? How do you know?
7.	What do you need in order to continue using the lessons and information you learned?	<i>Probe resources, supports, further training, supervisor or team culture changes, policies and norms in health center changes</i> Do you feel your colleagues have similar or different needs for support? What might they need?
8.	If you were in charge of this training, what would you plan to do with it next?	Who else might benefit? Where? When? <i>Probe: more health workers to receive it, further training, never to be trained in it again, make necessary</i>

		<i>improvements to content or delivery, clinic or district leadership to take it, patients and family members (or communities) have access, integrated into medical education or policy plans</i> Do you feel your colleagues have similar or different hopes? How so?
9.	What changes, if any, would you make to the training?	<i>Probe: changes to delivery challenges, changes to content</i> Can you suggest 3 improvements? What do you think these would help with? What, if anything, do you feel was left unaddressed by this training? Do you feel your colleagues have similar or different requests for improvement? How?

F. Perceptions & Experiences of Care Over Time

Please record the respondent's answers in the space provided after each question below.

	Questions	Follow-up Questions
2.	Have you noticed any changes to the way healthcare providers treat patients in the last 6 months?	Have you noticed any changes in your own delivery of care? Can you provide a few examples? What do you think may be contributing to these changes? <i>Probe: in yourself, in other providers</i>

	<i>Probe: behaviors, attitudes, shared norms, voiced perspectives, culture of work environment</i>	Do you believe the training you received relates to these changes? How?
c.	Who do you feel has been most impacted by these changes in treatment? (e.g., specific types of patients, health worker roles)	How do you feel about the changes you have observed in delivery of care? Would you like to see more of them? Less of them? Why
d.	Are there other changes you hope to see in the behavior of health workers or the culture of your healthcare environment?	What do you think may be required to make these changes? Who do you expect this to impact most? <i>Probe: patients with stigmatizing conditions</i> Do you think your colleagues want similar or different changes? How?

Please document observations of interaction with the respondent in the space below

[Suggestions: level of emotion, openness, level of comfort, length of response, tone and level of voice, body posture, eye contact, facial expression]

Guidance for Semi-Structured Interviews

Location and set-up

The interview should be scheduled at a convenient time and location for the interviewee. The location should be private, ideally with a closed door or in a space without others, rather than a public place. It is helpful if there is a room where you can speak privately without interruption, and where it is quiet enough to hear and audio record the interview. Within the interview space, an arrangement with a comfortable distance between the interviewer and interviewee.

With space for materials (recorder, consent forms, questionnaires, water, and so on).

Beginning of the interview

Interviewers can start with chatting to break the ice and attempt to establish commonalities, rapport, and trust. Interviews will need to begin with a brief explanation of the research study, consent/assent procedures, rationale for talking to that particular interviewee and description of the interview format and agenda. It can also be helpful if the interviewer shares a little about who they are and why they are interested in the topic. The recording equipment should have already been tested thoroughly but interviewers may want to double-check that the audio equipment is working and remind participants about the reason for recording.

Interviewer stance

During the interview, the interviewer should adopt a friendly and non-judgmental attitude. The interviewer is to maintain a warm and conversational tone, rather than a rote (repeating same), question-answer approach. It is important to recognize the potential power differential as a researcher.

Active listening

During a face-to-face interview, there is an opportunity to observe social and non-verbal cues of the interviewee. These cues may come in the form of voice, body language, gestures and intonation, and can supplement the interviewee's verbal response and can give clues to the interviewer about the process of the interview. Listening is the key element to successful interviewing. Listening should be 'attentive, empathic, nonjudgmental, listening in order to invite, and engender talk. Silence, nods, smiles and utterances can also encourage further elaboration from the interviewee.

Continuing the interview

As the interview progresses, the interviewer can repeat the words used by the interviewee, use planned and unplanned follow-up questions that invite further clarification, exploration, or elaboration. Throughout the interview, the goal of the interviewer is to encourage the interviewee to share as much information as possible, unselfconsciously and in his or her own words. That should be recorded thoroughly. Some interviewees are more forthcoming and will offer details of their experiences without much probing required. Others will require prompting and follow-up to elicit sufficient detail.

As a result, follow-up questions are equally important to the core questions in a semi structured interview. Prompts encourage people to continue talking and they can elicit more details needed to understand the

topic. Examples of verbal probes are repeating the participant's words, summarizing the main idea or expressing interest with verbal agreement.

Follow-up Question Techniques

For probing techniques and example probes we have been using in our own interviewing.

- Wait time: Interviewer remains silent after asking a question. This allows the interviewee to think about their response and often encourages the interviewee to speak.
- Echo: Interviewer repeats or summarizes the participant's words, encouraging them to go into more detail.
- Verbal Agreement: Interviewer uses affirming words to encourage the interviewee to continue speaking.
- Expansion: Interviewer asks participant to elaborate on a particular response.
- Explanation: Interviewer asks participant to clarify a specific comment.
- Leading: Interviewer asks interviewee to explain their reasoning.

4. FGD Guides (Qualitative)

4.1 Leprosy Affected Person

Focus Group Guide – Persons Affected

A. Focus Group Information

1. Name of Facilitator –
2. Name of Note Taker –
3. Date of interview –
4. Start Time – End Time –
5. Duration –
6. Name of District: - Bokaro
7. Type of Setting: Urban / Rural
8. Name of Block:
9. Panchayat/ Ward:
10. Village/ Colony:
11. Name of Primary Health Center:
12. Group make-up: Male Female (Circle One)

B. Respondent Attendance Sheet [FOCUS GROUP CODE: _____]

Name	Age	Signature	ID Number <i>*office use*</i>

C. Perceptions and Experiences of Compassion

Facilitator begins the focus group discussion with an 'icebreaker' to get everyone talking and comfortable (5 minutes), immediately following, s/he spends the next 20 minutes asking exploratory questions (sections C & D)

I would like to start by understanding what you all think about compassion. When you hear compassion, what comes to mind? *[probe: Are there specific actions, places, or people who come to mind?]*

Have you observed compassion in places where you receive healthcare? How might compassion impact the care provided? *[probe: quality of care, experience of care, experience of caregiver]*

How might compassion impact your health providers? *[probe: different settings – at the clinic? In your village or hometown?]*

What impact might healthcare delivered with compassion or by compassionate providers have on your wellbeing? *[probe: your physical, mental/emotional, social, spiritual, and economic well-being]*

What is the role of compassion in treating conditions that are stigmatizing? *Probe: Leprosy*

D. Perceptions and Experiences of Stigma

Now I'd like to talk about the social problems experienced by people affected by Leprosy.

Some people with leprosy experience social problems, for example: they are treated with less respect, they experience discrimination, they are scared to tell people they have leprosy, they are excluded. Do you know if this is the case in your community?

What have you observed? When? Where? Why do you think this might be?

How do community members behave towards you, as a person affected by leprosy? How do you feel about this?

How would you say health workers behave towards you, as a person affected by leprosy? Do you feel you matter to them as much as any other patient? *[Tell me more]*

E. Perceptions & Experiences of Care Over Time

Since you began receiving care for your Leprosy, have you noticed any changes in the care you have received? *[probe: changes in behavior or attitudes by health providers, including in the community and in the clinic]*

If you have noticed any changes, how do you feel about them? Do you want more or less of them? Who do you expect these changes impact most?

What would you change, if anything, about the care you receive for your leprosy? *[probe: for importance, for impact to wellbeing, for impact to experience of care or attrition]*

Do you think other patients would also value this change? If so, are there certain patients who might find this especially important? *Probe on stigmatizing conditions, including leprosy*

F. Wrap-up

Facilitator spends final 5 minutes revisiting a few earlier questions

Earlier in this focus group, I asked you: “what is the role of compassion in treating conditions like Leprosy?” What do you think now?

Is there anything else we should talk about related to compassion, social problems (such as disrespect, discrimination, and fear), and leprosy?

G. Facilitator Guide

4.2 Healthcare Workers

Focus Group Guide – Healthcare Providers (HCPs)

****Please note it is crucial the health worker focus group attendees have all participated in the compassion trainings. Please verify with each health worker prior to the start of the focus group****

A. Focus Group Information

1. Name of Facilitator –
2. Name of Note Taker –
3. Date of interview –
4. Start Time – End Time –
5. Duration –
6. Name of District: - Bokaro
7. Type of Setting: Urban / Rural
8. Name of Block:
9. Name of Primary Health Center:
10. Group make-up: Male Female (Circle One)

B. Respondent Attendance Sheet [FOCUS GROUP CODE: _____]

Name	Age	Signature	ID Number <i>*office use*</i>

C. Perceptions and Experiences of Compassion

Facilitator begins the focus group discussion with an 'icebreaker' to get everyone talking and comfortable (5 minutes), immediately following, s/he spends the next 20 minutes asking exploratory questions (sections C & D)

1. I would like to start by understanding what you all think about compassion. When you hear compassion, what comes to mind? *[probe: Are there specific actions, places, or people who come to mind?]*
2. Where does compassion come from? *[probe: family, faith, culture, tradition, personal values]* What do you see as its value?
3. What is the role of compassion in healthcare settings? How might compassion impact the care provided? *[probe: quality of care, experience of care, experience of caregiver]*
4. How might compassion impact health providers themselves? *[probe: consider yourself, consider your colleagues, consider different settings – at the clinic? In villages or hometowns?]*
5. What effect might compassion have on the medical treatment of stigmatized conditions? *Probe: Leprosy*

D. Perceptions and Experiences of Stigma

6. Now I'd like to talk about the social problems experienced by people affected by leprosy. Some people with leprosy experience social problems, for example: they are treated with less respect, they experience discrimination, they are scared to tell people they have leprosy, they are excluded.
7. In the communities where you treat leprosy, what are the attitudes of community members towards those people who have leprosy?
What have you observed? When? Where?
Why do you think this might be?
8. Do you think that leprosy patients deserve the same support and inclusion in their community as others?
9. Do you feel that leprosy patients prefer to hide their conditions? Can you give examples of how you know?
10. How do you each feel about providing care to persons affected by leprosy?
Do you always feel comfortable being near a leprosy patient?
11. How would you say health workers in your same role or level behave towards persons affected by leprosy? *[Tell me more]* Why do you believe health workers may behave like this?

E. Story [stigmatizing behavior/experience in healthcare environment]

Facilitator reads story and spends the following 25 minutes asking questions about the story

Story Miss Soni Kumari

I am Soni Kumari. I am 25 years old and live in Pipli village. A few months ago, I noticed that I had several spots on the skin of my neck and upper back without any sensation. I tried rubbing it with oil and vaseline for a few days but did not see any change. I was worried about what was happening to me, so I told my mother, who took me to our ASHA. When our Asha saw me, she suggested that I go to the hospital.

A senior doctor in the hospital diagnosed me with leprosy. They didn't tell me anything more but sent me to the primary health center for medicines.

It was very difficult for me to accept that I had leprosy. My spots were visible on the front of my neck. When I went to the primary health center for medicines, I was asked to wait on a chair, away from other patients! The health worker did not want to touch me. They gave me the medicine and told me how to take it, but they didn't give any additional advice on how to use it. When I asked to explain my effects, he immediately told me that if I took the medicine regularly, I would be fine.

I felt bad from this experience. A healthcare provider had never acted like this towards me. Why were people behaving like this? I don't understand why people were treating me like this.

I used to live a normal life, but not anymore. I cover my spots and I never tell anyone about my disease because when people hear about it, they treat me differently. I have lost my job and many friends too.

I have taken my medicine regularly for the last five months. There are some changes in the skin patches now, and the swelling has decreased. But I do not know if I will ever get fully better. I tried to ask the health workers again, but they told me to take the medicine regularly and said that this would cure me.

—

12. How did the story make you feel? *[Tell me more]*

13. If you could rewrite the story - what could have been done differently? *[Tell me more]*

14. What if the healthcare provider in the story could participate in a training to help him/her become more compassionate? Would that help? *[Tell me more]*

15. What impact might a compassion training for health care providers have on the person affected?

16. What about the healthcare worker? How might he/she be affected by the training?

F. Training

Over the past 6 months, many of your colleagues and you too have been engaged in compassion training. These next questions are specific to your knowledge and experience of this training specifically.

17. Were you able to attend all of the training? *Did any of you miss any of the sessions?*
18. How did you experience the training? *What did you like? What did you like less?*
19. What challenges, if any, did you have with how the training was delivered? *[probe: complexity (e.g., easy to understand, any difficult parts), timing, scheduling, too busy, vulnerability and safety, location, not engaging enough]*
20. How might these challenges be addressed in future training?
21. How valuable, if at all, was the information you learned in the training? *[probe for examples of what they learned]*
22. What have you done with the information you have learned in the training? *[probe for examples of things already changes or will change in next month. E.g, impacts to thoughts, perceptions, attitudes, feelings, behaviors]*
23. What did you think of the quality of the training materials? *[probe: review and use of the guidebook and/or the charter]*
24. What do you need in order to continue applying what you learned? *[probe: resources, supports, further training, supervisor or team culture changes, policies and norms in health center changes]*
25. If you were in charge of this training, what would you plan to do with it next? *[probe: more health workers to receive it, further training, never to be trained in it again, make necessary improvements to content or delivery, clinic or district leadership to take it, patients and family members (or communities) have access, integrated into medical education or policy plans]* Who else might benefit? Where? When?
26. What changes, if any, would you make to the training? *[probe for examples and reasons these changes may help]*. What do you feel was left unaddressed by this training?

G. Perceptions & Experiences of Care Over Time

Now we are going to move away from talking about the training specifically to discussing your recent experiences in your work environment. If you work in a clinic or lab, this relates to that setting. If you work out in the community or in villages, think about the providers you interact with either in the community or as you come to clinics.

27. Have you noticed any changes to the way healthcare providers treat patients in the last 6 months? *[probe: behaviors, attitudes, shared norms, voiced perspectives, culture of work environment]*
28. What do you think may be contributing to these changes? Do you believe the training you received relates to these changes? How?

29. Who do you feel has been most impacted by these changes in treatment? (e.g., specific types of patients, health worker roles) Would you like to see more of these changes, or less?

30. Are there other changes you hope to see in the behavior of health workers or the culture of your healthcare environment?

31. What do you think is needed to make these changes? Who do you expect these changes would benefit most? [*probe: patients with stigmatizing conditions*]

H. Wrap-up

Facilitator spends final 5 minutes revisiting a few earlier questions

32. Earlier in this focus group, I asked you: “what is the role of compassion in treating conditions like Leprosy?” What do you think now?

33. Is there anything else we should talk about related to compassion, social problems (such as stigma, disrespect, discrimination, and fear), and leprosy?

Please document observations of interaction with the respondents in the space below

[Suggestions: level of emotion, openness, level of comfort, length of response, tone and level of voice, body posture, eye contact, facial expression]

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*To know more
about our work,
kindly scan the QR
code*