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# A socio-ecological model of the management of leprosy reactions in Indonesia and India using the experiences of affected individuals, family members and healthcare providers

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## Abstract

**Background** Leprosy reactions (LR) are immune-mediated complications of leprosy that may be associated with severe and irreversible nerve damage. Non-medical aspects, such as financing, service provision, and health-care resources in the management of LR are generally overlooked as studies tend to concentrate on clinical features and treatment. Barriers to accessing care and services are a major cause of suboptimal care for people with leprosy. This study aims to explore the barriers to and facilitators of high-quality care and management of LR in two leprosy-endemic countries with different health care models – Indonesia and India – and identify areas for improvement.

**Methods** A socio-ecological model was adopted. Data were obtained from 66 interviews with individuals who experienced LR and were seeking care at the two study sites. In addition, immediate family members of individuals with LR and healthcare workers attending to people with leprosy participated in seven focus group discussions (FGDs).

**Results** This study highlights the significant impact of public health insurance regulations and uptake at the macrosystem level on the provision of healthcare services, clinical decision-making, care expenditure, and the psychological well-being of individuals with LR in Indonesia and India. Lack of specialized health professionals and communication challenges were identified in both study populations. Indonesian participants encounter additional challenges due to a fragmented information system and drug shortages. This study identifies key facilitators in providing high-quality care for LR-affected individuals, including financial assistance, availability of corticosteroid alternatives, timely provision of care, and counselling. It found that the high coverage of public health insurance cards in the Indonesian model has increased access to care among individuals affected by LR, despite the challenges. Conversely, the Indian model of care offers treatment subsidies. The advantage of the Indonesian model is its ability to provide wider access

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to high-quality care, whereas the Indian model focuses on those in most need. This study emphasizes the importance of addressing these challenges through improved communication strategies, education aimed at the affected individuals, and accessible medical care. Furthermore, variations in care-seeking behaviour and self-care practices were observed in both sites, underscoring the need for culturally sensitive and comprehensive approaches to the management of LR.

**Conclusion** The study findings demonstrate that the factors identified at the four systemic levels are interrelated and have an impact on the access, acceptability, and management of LR services. Despite its accessibility and wider coverage of public health insurance, the integrated service model in Indonesia faces challenges associated with complex regulations and the availability of medication. India's care model offers intensive, specialised care but has difficulties in ensuring sufficient health personnel, resources, and public health insurance coverage. These findings highlight the need to address these challenges to ensure timely, effective, and comprehensive care for individuals with LR.

**Keywords** Management of leprosy reactions, Universal health coverage, Person-centred care, Delivery of healthcare services, Indonesia, India

## Background

Leprosy is a neglected tropical disease, caused by the related organisms *Mycobacterium leprae* and *Mycobacterium lepromatosis* [1]. Of the 182,815 new leprosy cases reported to the World Health Organization (WHO) in 2023 71% were in South-East Asia, mainly India (125,785) and Indonesia (17,025) [2, 3]. Immune-mediated complications of leprosy ('leprosy reactions,' LR) may occur before, during, or after effective anti-microbial therapy [3–7]. The reactions are classified as Type-1 reaction (T1R) and Type 2 reaction (T2R), or erythema nodosum leprosum (ENL) [7]. There are no data reported to WHO about the incidence of leprosy reactions but a number of studies showed that T1R occurs in approximately 20%–40% of leprosy-affected individuals and ENL was found in 1–8 per 100 person-years-at-risk among individuals with multibacillary leprosy [8–15]. Leprosy reactions (LR) are a risk factor for irreversible nerve damage and are associated with disability, emotional distress, and social isolation [5, 16–20].

LR often result in a significant financial burden on the affected individual and their family [19]. Systemic symptoms of the reactions, ENL in particular, reduce the affected person's productivity and income and increase out-of-pocket (OOP) expenditure on treatment [19]. Low-income households affected by ENL are at risk of being pushed further into poverty [19, 21]. Family involvement, however, plays a crucial role in care-seeking behaviour through such moderating factors such as financial support, advice on care providers, interpretation of symptoms, response to social norms, managing the disease, and supporting the healing process [22, 23]. A study in Brazil showed that 66.7% of married participants with ENL has a better quality of life compared to those who were widowed or had no partner or spouse [21]. Families can influence the care-seeking behaviour, arrange details of therapy consultation, provide emotional support, help

maintain communication, and contribute to restoring self-confidence in individuals affected by leprosy [22, 24].

The management of LR is complex for healthcare workers because of their chronic nature, the recurrence of reactions, and adverse effects of immunosuppressive therapy (such as infections, diabetes mellitus, osteoporosis, dyspepsia, moon face, growth suppression, and adrenal insufficiency); moreover, ENL affects many organ systems, creating a wide range of symptoms [5, 25, 26]. The WHO-recommended therapeutic approach prescribes prolonged courses of high-dose corticosteroids and thalidomide for ENL, which depends on healthcare professionals having a high degree of training [6, 26, 27]. Another challenge in managing ENL is having access to research or alternatives to standard treatments such as corticosteroids [6, 27–29]. Thus, there is a need to look at healthcare systems as the overarching institutional patterns that influence the management of LR aside from the clinical guidelines. The clinical management of LR has been examined in considerable depth [8, 30–37], but to our knowledge, no publications specifically explore the management of LR from a health-system perspective.

## Management of health care resources in India and Indonesia

A systems perspective can facilitate the management of health resources, financing, and service provision in the context of illness, leading to better stewardship and generation of resources [38]. Such a perspective is important in order to make recommendations for improving the management of LR to facilitate timely access to available, affordable, safe and effective treatment. In order to gain a better understanding of how the health system works specifically for people with LR, we focus on the experiences of service providers, service users and their families in India and Indonesia.

This perspective incorporates the opinions and views of the consequences of how health services are organized for LR from affected individuals, immediate family members, and healthcare providers: in India, the National Leprosy Control Programme [39] and in Indonesia the integrated decentralized care of leprosy into general health services based in primary or secondary health facilities [39–41]. The integration in Indonesia started in 1969 [42] and in India it began in 2004 [43, 44]. India has retained more leprosy-specialized hospitals than in Indonesia, where care is mostly provided in general hospitals [43, 45]. The health ministry in both countries suggested treating and managing LR in hospitals [42, 46], which typically involves using immunomodulatory drugs, such as corticosteroids [3, 43, 44], and rehabilitation interventions, such as physiotherapy [47].

Both India and Indonesia are implementing universal health coverage (UHC) to make it easier to afford access to primary, secondary, and tertiary health facilities [40, 41]. The UHC service coverage index of Indonesia and India is similar, 59 and 61 in 2019 respectively [48]. The implementation of UHC in both countries has increased the uptake of healthcare services, but appeared particularly unequal across geographical location, sex, age, social groups in India [49, 50]. The government-sponsored health insurance scheme (GHIS) in Indonesia is governed by the state-owned health care and social security agency (BPJS-K) [51]. A similar scheme in India is the Prime Minister's People's Health Scheme (AB PM-JAY) governed by the India National Health Authority [52]. Both schemes were created to provide a comprehensive needs-based health service. The Indian scheme was launched four years later than the Indonesian one [51, 53]. Before 2018, the *Rashtriya Swasthya Bima Yojana* (the former Indian health insurance scheme) was implemented only in half (14 out of 28) of the country's states [54]. To maximise the impact of finite resources, the Indonesian government established a gatekeeping system in which BPJS-K requires insured Indonesians to provide a referral letter from primary and secondary levels to access tertiary health services [41]. In contrast, PM-JAY is still developing the protocols for gatekeeping functions within the public health system in India [55].

### Theoretical framework

Our study delves into the functioning of LR care services and the impact of the wider health system on the experiences of people with LR by using Bronfenbrenner's socio-ecological model to capture the nuanced interactions and contextual factors that influence these experiences [56]. This model was first elaborated to understand the ecology of human development, that is the relationship between individuals and their changing environments

throughout their life as a nested structure [56]. The structure consisted of four levels: microsystem (relation between a person and their immediate setting), mesosystem (interrelation between microsystems containing the developing person, such as family, healthcare provider, or support groups), exosystem (extension of the mesosystem embracing other specific social structures, such as health policies or public health campaigns in the community), and macrosystem (the overarching institutional patterns or cultural factors, including cultural beliefs, country's health system, national health legislation, or social stigma) [56]. This model has been used in many areas, such as assessing healthy lifestyles, identifying potential system interventions, the uptake of health services, and studying individual health behaviour [57–67]. The socio-ecological model can be adapted because it considers multiple levels of influence on individuals' behaviour and emphasises their social and environmental context. By considering this level of influence, this study can better understand the management of LR and develop interventions tailored to the specific needs of affected individuals and healthcare providers.

### Methods

This study is part of a larger qualitative research project on LR in Indonesia and India. In a previous article, we analysed the experiences of people with LR in these settings [17]. We examined affected individuals' perceptions of the aetiology, risk factors, diagnosis, and the impacts of LR on their physical, psychological, and social well-being [17]. This article presents the qualitative findings, focusing on the functioning of care services and the impact of the wider health system on the experiences of people with LR in these two settings.

### Study design

This study used a qualitative approach to describe barriers and facilitators in management of LR experienced by affected individuals. The study was conducted in two settings in Indonesia and India with different models of care for LR. In Indonesia, the Dr Soetomo General Academic Hospital in Surabaya uses an integrated service approach, provided on an outpatient basis in an urban general hospital. The Purulia Leprosy Home and Hospital in India provides specialist care in a dedicated rural leprosy hospital often on an inpatient basis. Both institutions act as the referral healthcare facilities with integrated services for LR in areas with high caseloads of leprosy. The Indonesian hospital is funded by the local government and the government-sponsored health insurance, whereas the Indian hospital is funded by multiple private sources of non-governmental grants.

At each study site, a research assistant with personal experience of LR assisted and transcribed the interviews and focus group discussions (FGDs). Demographic data, such as sex, age, and type of LR, were included to provide a complete description of the affected individuals and complement the qualitative data. Demographic and clinical data were collected for the individuals with LR. Clinical conditions or chronicity of the people with LR were obtained from the patients' medical records. ENL was classified as chronic when it occurred for more than 24 weeks with continuous treatment [34].

### Data collection

Purposive sampling was used to obtain a diverse sample of participants with respect to age, LR type, sex, and socioeconomic status. All participants in each group were adults or minors between 16 and 17 years of age. The exclusion criteria were anyone below 16 years, experiencing a severe LR condition, and not undergoing LR management at the study site. The participants were recruited purposively based on their direct experience in the management of LR. All data were collected by the first author, assisted by a local research assistant at each study site using semi-guided interviews, FGDs, or workshops. Five types of data collection were employed at both sites and used for triangulation to obtain a comprehensive understanding:

1. Sixty-six in-depth interviews (IDIs) with T1R- or ENL-affected individuals currently seeking care at the research sites with direct experience of LR and of its management during the data-collection period. The recruitment and IDIs took place at the hospital after the LR-affected individuals received LR management on a twice-weekly basis.
2. Five FGDs with immediate family members, such as adult children, spouses, or parents, of LR-affected interviewees. The FGD participants were recruited after the IDIs had been conducted and were invited to the FGD when their LR-affected family member was attending follow-up treatment.
3. Two FGDs with healthcare workers who had regular and direct interactions with individuals with LR. One FGD per site was based on their limited availability and the assumption that their professional experiences would provide rich, detailed insights even from a smaller number of discussions.
4. Two workshops in the Indonesia study site to validate the preliminary findings with the IDI and FGD participants.
5. Twelve phone interviews with each of the IDI participants at the India study site to validate the preliminary findings. Phone interviews were carried out due

to COVID-19 restrictions, which prohibited face-to-face meetings.

The five types of data collection took place at the study site. The data-collection tools are included in Supplementary File 1. The data were collected in the local language(s) at each site (Bahasa Indonesia, Javanese, Bengali, or Hindi). The IDIs, FGDs, workshops, and phone calls were conducted with the assistance of a trained research assistant fluent in the respective languages. To achieve data saturation, we aimed to interview at least 30 participants in each study site and conduct up to four FGDs with a maximum of six family members at each site. An FGD with up to seven healthcare workers was conducted at each site as a source triangulation. Data were collected until saturation was achieved.

IDIs and FGDs were conducted between January and June 2019 in Indonesia and from July to September 2019 in India. Interview guides were developed through several consultations with Indonesian and Indian experts, a workshop with Indonesians with LR and a personal conversation with an Indian with a prior history of LR. In the interviews, people with LR were asked about their experience in accessing services for LR and how they perceived barriers and facilitators in the provision of healthcare for their illness. The FGDs covered topics such as leprosy care and facilities provided by the hospitals, stigmatization, family support for people with LR; and elaborated on emerging issues mentioned in the IDI. Data triangulation using two validation workshops with 20 Indonesians with LR in February 2020 and 12 phone interviews with Indians with LR in September 2020 were conducted to discuss the preliminary findings. Any input in workshop or phone interviews were added in data analysis. Participants in both sites also clarified the interpretation of data.

### Data management and analysis

The IDIs, FGDs, workshops, and phone interviews were audio-recorded, transcribed verbatim, and translated into English. All identifying information was omitted from the transcripts to ensure participants' anonymity and confidentiality. All data were stored in a computer with a password-protected external hard drive accessible only by the research team. Audio files will be kept for five years and then destroyed. The transcripts were coded using thematic analysis in NVivo 12. Themes were first identified through an iterative coding process. Each code and theme were identified and located within each level of the socio-ecological framework and then classified into five main topics: health insurance, extended hospitalization, limited resources, communication barriers, and alternatives in care-seeking.



## Results

### Characteristics of participants

Sixty-six people with LR participated (33 at each site). More participants with ENL were involved than of those with T1R due to earlier data saturation of the latter group. More men participated (78.8% in Indonesia and 69.6% in India) because during the data-collection period, most people with LR at the sites were male. Table 1 provides detailed characteristics of participants with LR. Further demographic and clinical data were provided in our previous report [17].

Table 2 describes demographic characteristics of participating family members and healthcare workers. Between four and six family members and five to six healthcare workers participated in each FGD. In Indonesia, 16 Indonesian family members participated in the group discussions, of whom 12 were women. Most participants were parents of Indonesian adults with LR. In India, 22 family members participated, and the majority

**Table 1** Characteristics of participants with leprosy reactions (LR) participated in interviews

| People with LR  | Indonesia (n) | India (n)    | Total |
|---|---------------|--------------|-------|
| <b>Gender</b>   |               |              |       |
| Man   | 26            | 23           | 49    |
| Woman   | 7             | 10           | 17    |
| <b>Age</b>  |               |              |       |
| 16–17 years old   | 1             | 0            | 1     |
| 18–25 years old   | 9             | 9            | 18    |
| 26–35 years old   | 12            | 9            | 21    |
| 36–45 years old   | 5             | 10           | 15    |
| 46 years old and above  | 6             | 5            | 11    |
| <b>Type of LR</b>   |               |              |       |
| Type-1 Reactions (T1R)  | 7             | 7            | 14    |
| Type-2 Reactions (ENL)  | 26            | 26           | 52    |
| <b>Travel time to facility,</b><br>median minutes (range)                         | 53 (10–163)   | 128 (60–180) |       |
| <b>Mode of transportation</b>   |               |              |       |
| Public transportation   | 7             | 28           | 35    |
| Motorbike   | 26            | 5            | 31    |
| <b>Had in-patient (being hospitalised) experience because of leprosy reaction</b> |               |              |       |
| Yes   | 12            | 17           | 29    |
| No  | 21            | 16           | 37    |
| <b>Frequency of visits to the facility</b>  |               |              |       |
| Once weekly   | 18            | 0            | 18    |
| Once biweekly   | 4             | 3            | 7     |
| Once monthly  | 9             | 25           | 34    |
| Once per three months   | 2             | 5            | 7     |
| <b>Own a public health insurance card</b>   |               |              |       |
| Yes   | 24            | 3            | 27    |
| No  | 9             | 30           | 39    |

were spouses ( $n=10$ ) and parent ( $n=7$ ). Sixteen healthcare workers at the leprosy clinic (nine Indonesians and seven Indians) participated in FGDs. Finally, 14 Indonesians with LR participated in each workshop, and 12 Indians were interviewed via phone to validate the data.

Details of codes were categorised based on levels within the socio-ecological model and are illustrated in Fig. 1. Codes that were identified as perceived barriers are shown in yellow, the perceived facilitators in green, and factors that can be perceived as either facilitators or barriers are grouped in orange. This model dissected the interrelation of codes at each level. The research team classified the codes into four levels based on the following criteria, with validation from the participants during the workshop and phone interviews. At the microsystem level, relevant intrapersonal characteristics of the individuals affected by LR were included. The mesosystem level referred to the interconnectedness between the individuals and their close groups, such as family, neighbourhood, and friends, that affect an individual. At the exosystem level, the mesosystem expands to encompass other social structures such as healthcare providers and facilities. The macrosystem level includes institutional patterns of cultural factors and health systems that influence management of LR at lower levels.

### Health insurance

At the macrosystem level, treatment for LR was funded differently in each centre. Most affected individuals in the Indonesian study site used the BPJS-K. This scheme requires Indonesian participants at the mesosystem level to obtain a referral letter from primary and secondary health facilities before being able to obtain treatment for LR in tertiary health facilities. All insured Indonesian IDI participants considered this referral mechanism to be an issue and resulted in delays for the affected individuals in seeking help. Furthermore, publicly insured Indonesian participants in the IDIs reported that they were required to renew their referral letters periodically by revisiting primary or secondary health facilities. FGD participants corroborated this, and also said that the queue at each visit to obtain a referral letter could last from two to six hours at each tier:

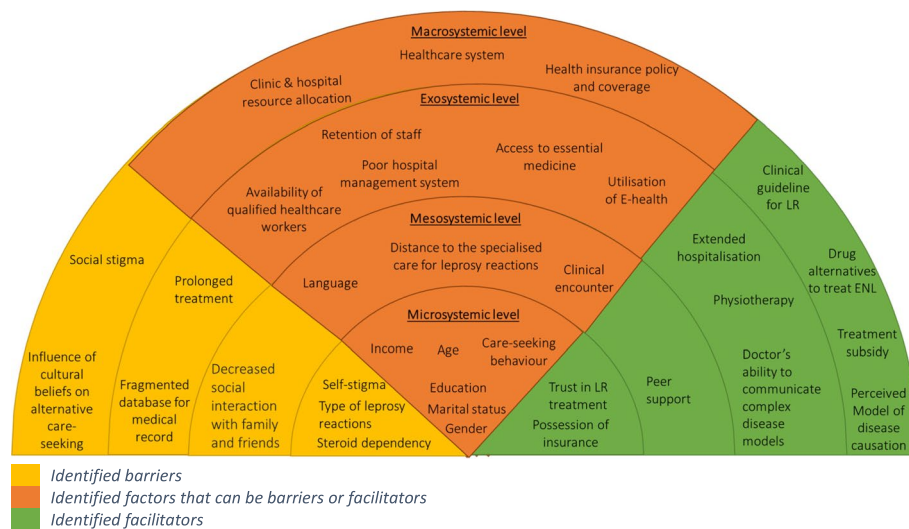
*“When I took the queue number [for the outpatient service], usually I depart from home at 4 o'clock at dawn.” (IDI-0005, ENL, Indonesia)*

*“We are sick persons, right? I'm supposed going to the referred hospital..., well, it's just impossible to visit two hospitals in a daytime.” (IDI-0004, ENL, Indonesia)*

At the microsystem level, Indonesian participants reported visiting each level of health facility before

**Table 2** Characteristics of family members and healthcare workers who participated in FGDs

| Family Members   | Indonesia (n) | India (n) | Total |
|--|---------------|-----------|-------|
| <b>Gender</b>  |               |           |       |
| Man  | 4             | 14        | 18    |
| Woman  | 12            | 8         | 20    |
| <b>Relation to the individual with LR</b>                          |               |           |       |
| Child (age 18–35 years)  | 2             | 4         | 6     |
| Parent   | 6             | 7         | 13    |
| Spouse   | 5             | 10        | 15    |
| Others (Siblings or in-laws)                                       | 3             | 1         | 4     |
| <b>Occupation</b>  |               |           |       |
| Unemployed/Retired   | 0             | 3         | 3     |
| Housewife  | 8             | 4         | 12    |
| Civil servants   | 1             | 0         | 1     |
| Manual labour (e.g., farmer, construction worker)                  | 2             | 7         | 9     |
| Others (e.g., private workers, merchants, self-employed, students) | 5             | 8         | 13    |
| <b>Healthcare workers</b>  |               |           |       |
| <b>Gender</b>  |               |           |       |
| Man  | 2             | 3         | 5     |
| Woman  | 7             | 4         | 11    |
| <b>Occupation</b>  |               |           |       |
| Doctors  | 1             | 3         | 4     |
| Residents  | 6             | 0         | 6     |
| Others (leprosy officer, nurse, administrator)                     | 2             | 4         | 6     |
| <b>Experience in leprosy program</b>                               |               |           |       |
| 1–5 years  | 6             | 2         | 8     |
| 6–10 years   | 1             | 2         | 3     |
| > 10 years   | 2             | 3         | 5     |



**Fig. 1** Socio-ecological model of management of leprosy reactions (LR)

their consultation with the dermatologist ( $n = 15$ ) and higher indirect treatment costs ( $n = 10$ ) because of this weekly outpatient visit. Before 2018, they explained that BPJS-K required renewal of their referral letter once a month to ensure specialised care continued at a tertiary hospital. The Indonesian IDI participants said that their indirect treatment cost was reduced after BPJS-K extended the validity of a referral letter was extended from one month to three months in 2018. Even so, an IDI participant with significant physical impairments still reported significant difficulties, with long queues and waiting times at each level of care because they had to be physically present to obtain the referral letter. He said, *“When the reactions occurred, I could not walk ... I had to postpone the visit [to obtain the referral letter] if no one accompanied me visiting the hospital”* (IDI-0028, T1R, Indonesia).

At the mesosystem level, other IDI participants described the time-intensive process of insurance referral procedures as exhausting when the reactions were at their peak. Healthcare workers admitted that insurance coverage regulations unduly influenced clinical decision-making in the Indonesian site. Healthcare workers reported that individuals taking corticosteroids were obliged to attend weekly for monitoring if they wanted to be covered by BPJS-K. At the macrosystem level, leprosy guidelines provided by Indonesian Ministry of Health (MoH) suggested evaluating and tapering of prednisone (the corticosteroid) prescription on severe LR every two weeks [68]. It was written that the regime starts with 40mg/day in the morning. Tapering up to 50–60 mg/day is allowed for two weeks only if there were no clinical improvements in the affected individuals [68]. Healthcare workers perceived barriers due to BPJS-K as an obstacle in administering the best course of treatment at the exosystem level:

*“BPJS only covers treatment costs on a weekly or monthly basis, which differs from the clinical recommendation. I can prescribe the [cortico]steroid for two weeks but drugs can only be covered by public insurance for one week. The remaining have to purchase by themselves [out-of-pocket].”* (FGD-01, Indonesia)

At the microsystem level, the frequent renewal of the referrals required contributed to economic hardship of ten Indonesian participants and their family members. Affected Indonesians and healthcare providers suggested two changes to public health insurance regulations to minimise exorbitant indirect health expenses: providing a longer validity period of referral letters and allowing corticosteroid monitoring and weekly consultation based on clinical judgment.

At the microsystem level, Indian participants reported no similar suggestions in interviews. However, a participant lamented the long queue at the outpatient visit: *“I felt terrible because I wait for so long, go to various rooms, and stand in a queue for medicines for five hours. It is irritating for me, but no choice because I cannot skip the queue.”* (IDI-1019, T1R, India). The doctors and healthcare workers at the FGD in the Indian site explained that they were not bound to the public insurance regulation and were able to provide care based on the patient’s clinical condition. Most of the IDI participants were not covered by the AB PM-JAY. Two-thirds of Indian participants reported not having any knowledge about AB PM-JAY or RSBY. Most Indian participants with LR did not have a public health insurance card, nor did they know the health benefits afforded to them by the card. Family members and healthcare workers confirmed this. However, three Indian participants with a public health insurance card said it provided access to public health facilities and those without a card were denied treatment. One participant said, *“The doctor [at X hospital] did not treat me because I don’t have a ration card [subsidy for food and fuel], Aadhar card [ID card], and RSBY card [public insurance card] ...”* (IDI-1004, ENL, India). Moreover, many Indian participants and healthcare workers pointed out that the uptake of AB PM-JAY is low and it only covers treatment costs in public facilities in their region of domicile. Indian participants with LR and their family members surmised that having no public insurance did not hamper the timely provision of LR care, because they had direct access to the Purulia Leprosy Home and Hospital (which is a private facility managed by a charity) and treatment costs were subsidised if necessary.

At the macrosystem level, the charity-led hospital mitigated the financial burden of Indians with leprosy. One doctor said, *“We have free medication. We try to give subsidies to those who cannot afford medicine or hospitalisation... The financial support comes from donors and other hospitals too”* (FGD-11, India). The subsidy could be given to all patients who disclosed their financial status to the hospital worker as the public hospital was not applicable to use in the study site. Family members confirmed that half the Indian participants with LR applied for a subsidy for treatment costs and paid the difference according to their financial capability.

Although care subsidies were provided or public insurance was available at macrosystem level, the affected individuals in each centre reported financial hardship due to the loss of working opportunities and travel expenses accrued to seek care at the microsystem level. The two healthcare models studied could potentially exacerbate or ameliorate financial hardship. In Indonesia, the requirement for referral letters and insurance coverage

regulations increased indirect costs and caused delay whereas the charity-led hospital in India provided subsidised care. Differences in health insurance regulations at the macro level and uptake at the micro level influenced healthcare services and clinical decision-making in both settings. BPJS-K mostly covered the care-related expenditure of Indonesian participants with its implications on care pathways at the exosystem level. Subsidised hospital care allowed for less rigid treatment decisions at the mesosystem level but was still associated with the loss of income-earning at the microsystem level.

### Extended hospitalisation

Fewer Indonesians (12 of 33) reported being hospitalised due to LR compared with more than half of the Indians (17 of 33) (Table 1). The duration of hospitalisation varied between one to two weeks for Indonesian IDI participants and ranged from a week to six months for Indian IDI participants. Indonesian healthcare providers explained that considerations for a short period of inpatient treatment depended on the individual's clinical progression coupled with the complications of a fragmented hospital reporting system, which the researcher classified as the related factors on extended hospitalisation at the exosystemic level based on the analysis of the participants' views.

This fragmented system at the exosystem level made it harder for dermatologists to obtain the patient's treatment record from other departments (such as the rehabilitation centre or dental clinic) although they were in the same hospital. Doctors based in the outpatient clinic could not fully retrieve the patient's records if they were hospitalized unless they obtained information directly from the responsible inpatient doctor. At the meso level, Indonesian doctors reported that they had to enter clinical data twice, using paper notes and an electronic system, reducing the time they had to interact with their patients. *"I never thoroughly read the paper-based report. I was confused about which should be prioritised, the paper [report] or the electronic medical record. I must write the patient's history back and forth while providing therapy. My concern was that the records are not synchronised"* (FGD-01, Indonesia).

The Indian doctors expressed their preference for extended hospitalisation at the exosystem level to monitor the use of thalidomide on ENL-affected individuals, overcome geographical and financial barriers to treatment, and improve treatment adherence and continuity of care. At the microsystem level, Indian participants with ENL described advantages to extended hospitalisation as the opportunity to participate in small group classes on self-care, receive peer support, have frequent clinical consultations, and avoid long outpatient queues.

In the validation workshop, Indonesians with ENL mentioned that the benefits of peer support were not available to them, unlike the Indian participants. Indian participants with ENL expressed optimism about being cured because of inpatient peer support group activities. The peer support at the mesosystem level reportedly occurred naturally due to group self-care practices, such as wound care under the supervision of nurses and physiotherapy. Members of the group would discuss educational messages from healthcare workers. The Indian participants felt empowered because they learned to identify their reactions and engage in appropriate self-care, and their group fostered feelings of empathy among participants and an increased sense of community.

*"We went together for exercises in [the Physiotherapist room] ... If there is a person who hardly did it, then we all helped him out. We felt more energetic during the exercise. We believed that we would get well soon... Nurses taught me to do exercises like applying oil to my hands and straightening my fingers, moving my fingers in and out."* (IDI-1003, ENL, India)

The frequent clinical consultations at the mesosystem level during hospitalisation created a sense of comfort among Indian participants. They reported receiving skin lesion and wound checks from healthcare workers. Indonesians affected by LR reported that they were initially taught about self-care practices, including applying oil or cream to dry skin, physiotherapy exercises, rest (or low-intensity activities), and maintaining their concern for illness recovery and stigma after diagnosis. However, they did not receive regular care management education and continuous support, unlike the Indian inpatients. The Indonesian healthcare workers explained in the FGD that education on self-care practice is usually given only at beginning of their leprosy treatment or when an ulcer develops.

At exosystem level, Indonesian healthcare providers preferred to limit hospitalisations whereas extended hospitalisation was a priority for Indian doctors as it allowed rest for an affected individual while their LR were at their peak [17]. Extended hospital stays also reduced travel and associated costs at microsystem level. Indonesian and Indian patients reported long journeys (see Table 1) and three to five hours in the outpatient clinic from arrival, followed by nerve function assessment, consultation with the doctor, and dispensing of prescribed drugs at the pharmacy.

Extended hospitalisation was not universally held to be a good thing at microsystem level. Seven Indonesian and 12 Indian participants highlighted negative consequences such as loss of income, isolation from their family, and



boredom. One patient said, “... *I am the only person who earns money in my family. If I get admitted, who will look after them? I prefer to have medicines instead of being admitted to the hospital.*” (IDI-1003, ENL, India). The Indian healthcare workers explained that anxieties due to loss of social contact were unavoidable. Another patient said, “*I felt bored and upset when my son was out of sight... I feel very lonely and want to cry.*” (IDI-1001, ENL, India). At the microsystem, depression associated with extended hospitalisation was not mentioned by healthcare workers in the FGD, but the challenges were confirmed in the workshop and phone interviews.

Moreover, in the Indian hospitalisation-based approach there were mesosystem issues affecting the microsystem. While extended hospitalisation adopted in India model of care provided benefits such as peer support and continuity of care, it also resulted in loss of income, isolation, and emotional upset. The predominantly outpatient care in the Indonesian model, while avoiding these issues, had its own challenges in terms of access and convenience. The care approach in both settings created diverse psychosocial challenges at the micro level due to patient preference, indirect treatment costs, and the quality of care.

#### Limited resources

Participants of IDIs and FGDs in Indonesia and India identified several resource limitations which researchers classified at exosystem level. In Indonesia, these included a lack of essential medicines for LR, no access to thalidomide, a lack of a unified, comprehensive system for maintaining and accessing patients’ medical records, high staff turnover, and a low number of skilled health professionals. In India, the main hindrance was a limited number of specialised health professionals. The personnel shortages at both sites was related to insufficient investment at the macro level. This perspective was highlighted by the hospital workers during the FGD, who pointed to a lack of funding and support from higher government bodies for LR management at both the Indonesia and the India study site. Added to this, limitations on logistical resources in the Indonesia site, which researchers classified at the exosystem level, occurred mainly due to the poor hospital management system, according to healthcare workers at the FGD.

At the exosystem level, the limited resources were attributed to the hospital’s logistical management. More than half of the Indonesian patients (covered by BPJS-K or not) reported experiencing a shortage of drugs for LR at the hospital pharmacy. Prednisone, vitamins, iron tablets, and other drugs were occasionally unavailable due to delayed supply, prompting patients to seek medications in other pharmacies resulting in additional costs. Most Indonesian participants could afford

the OOP costs incurred, however, one participant with insurance described being unable to afford medication that had to be bought during hospital shortages. She had to forgo treatment. Indonesian doctors explained in their FGD that buying drugs at an external pharmacy was a potential patient safety risk, as these often do not follow the prescriptions. In interviews and FGDs conducted with the various Indian stakeholders, it was unanimously stated there were no drug shortages. The healthcare workers explained that this was attributed to the joint support provided by the government and community service organisations to the hospital. The stakeholders felt that the collaboration ensured a well-coordinated supply chain, making medicines readily accessible at all times.

People with LR at both sites were treated with oral corticosteroids in accordance with WHO and national guidance at the macrosystemic level [26, 42, 69]. Indonesian doctors are unable to prescribe thalidomide for ENL because the drug is not included in the latest Indonesian leprosy care guidelines (Ministry of Health Decree no. 11/2019) [68] due to its teratogenicity. “*Thalidomide is not allowed for leprosy reactions here although many studies proven its efficacy*” (FGD-01, Indonesia). The hospital worker at the Indonesia study site said that thalidomide was restricted and is not available to anyone unless in a clinical trial or for those with plasma cell cancer.

Indian doctors explained that thalidomide was included in India’s National Leprosy Elimination Programme [69], claiming that it was prescribed exclusively for inpatients with chronic ENL and no women of child-bearing age were prescribed thalidomide at all. This was done to monitor its use and minimize the risk of pregnant women being exposed to the drug. In interviews, two Indian participants with chronic ENL described their experience of taking thalidomide for one week with subsequent improvement. At the mesosystemic level, an Indonesian doctor described a refractory case of ENL for whom no effective alternative to corticosteroids was available. Three Indonesian participants with ENL reported being prescribed high doses of corticosteroids for more than one year but no Indians did.

The Indian study site used an electronic record system; but there was no integrated system for patient medical records in the Indonesian site. Indonesian resident physicians noticed that the duplication of records coupled with turnover of staff in training every three months were obstacles to the management of LR which derived from the exosystem level. Some Indonesian patients explained that there was high staff turnover in the LR clinic and they were frustrated with reiterating their experiences to each physician.

This finding is based on data from participants who reported that the limited number of skilled health professionals at the exosystemic level means that there are fewer resources available for training and supervision. During the FGD, the healthcare providers added that this leads to a lack of capacity building and knowledge transfer, which further exacerbates the shortage.

The shortage of health professionals at the macrosystem level had an impact on the mesosystem and microsystem in several ways. Both sites experienced a limited number of health professionals skilled in managing LR. This shortage of health professionals skilled in managing LR affected both the microsystem and the mesosystem. At the mesosystem level, hospital workers in both sites said that the difficulty in recruiting and retaining skilled doctors in rural areas contributed to this shortage. At the microsystem level, only a minority of health professionals had the necessary skills to diagnose LR, particularly ENL. In Indonesia, two resident physicians run consultations for at least 12 patients per day. One dermatologist supervised them. At the India study site, there are three physicians, a surgeon, and a dentist who serve more than 300 people affected by leprosy and individuals with other conditions daily.

The Indonesian resident physicians explained that LR, ENL in particular, require advanced knowledge and an array of skills such as interpreting the nodules or skin abnormalities, performing a skin biopsy, excluding coinfections, and adjusting corticosteroid doses. Moreover, they reported that workers in primary care clinics had other duties such as tuberculosis and HIV control. The hospital worker added that this phenomenon was more common in rural Indonesia with an even lower number of skilled professionals.

The shortage of medical professionals in Indian leprosy hospitals was attributed by healthcare workers to their predominantly rural locations making them less desirable places for Indian doctors to work. At mesosystem level, Indian doctors reported the shortage of physicians increased their workload, the queuing times for patients, and affected communication at the outpatient clinic. The participants and their family members agreed with this.

At the mesosystem level, a few Indonesians with LR and more than half Indian participants stated they got no clear information about LR from the physician responsible for their leprosy care. Both Indonesian and Indian doctors in the FGDs described having limited time to educate affected individuals about LR. To mitigate challenges associated with high numbers of patients and limited staff numbers, the healthcare provider in the Indian study site explained in the FGD that they involved people with direct experience of leprosy and LR as volunteers in providing services and assisting with administrative tasks

at the outpatient clinic. The volunteers were remunerated with subsidised treatment costs. There was the opportunity for them to be employed there after completing the treatment.

### Communication barriers

The identified communication barriers were limitations in explaining technical or medical terms in plain language and the shortness of clinical consultations. At exosystem level, healthcare workers in both sites felt most comfortable in explaining the technical terms in their national language: Bahasa Indonesia or Hindi respectively. Indonesian resident physicians described experiencing communication difficulties when explaining diagnoses, prognoses, and treatment regimes due to their limited ability to speak local languages, such as Javanese and Madurese. Likewise, the doctors in the Indian study site found it difficult to explain LR in other local languages, such as Bengali and Urdu. The healthcare workers said that these language barriers were compounded by the educational level of the patients at microsystem level. Healthcare workers in both settings perceived communication challenges associated with the education of affected individuals and cultural understanding of illness. The doctors in both sites perceived that the education and cultural understandings of affected individuals determined their own ability to understand LR.

*"It is challenging to tell them because it depends upon... their educational background... sometimes they are not able to comprehend... the reasons for reactions." (FGD-11, India)*

*"Our community hardly disregard it [the superstitious belief]... They tried consulting the spiritual leader, although I have explained about leprosy. They keep seeking alternatives. So, this is not only about educational background but also cultural beliefs. This is hardly changed." (FGD-01, Indonesia)*

Assumptions about the affected individual's understanding, the limited consultation time, and unilateral clinical decisions exacerbated the communication barriers and are likely to make clinical consultations less successful at the mesosystem level. The Indonesian doctors are distracted by the dual set of medical records. In an FGD, the doctors at the Indonesian site said that they are completing records while consulting, making it difficult to fully address a patient's questions and concerns. Double input and fragmented system burdens in Indonesia made it difficult for the doctor to probe whether patients had correctly understood their explanations of LR. At mesosystem level, short clinical sessions could lead to misunderstandings. One doctor said,

*"I met a patient who consumed the drug not in accordance with the standard [regimen]. I found it out after reconfirming [his drug consumption habit]. He skipped the medicine several times... I thought all residents always explain the treatment clearly, but there are always patients who do not [comprehend the explanation], and we do not check their understanding." (FGD-01, Indonesia)*

A third of Indonesian participants felt that their doctor's explanation was too technical because of the unfamiliar medical terms used to describe their condition. This situation affects the quality of communication and hinders understanding of the illness and treatment at mesosystem level. Four Indonesian participants confirmed that doctors did not respond comprehensively to their queries during consultations on several occasions. One said: *"I asked 'Why is it always swollen?' They [the doctor] answered it after I kept asking"* (IDI-0012, ENL, Indonesia).

To address discomfort at the clinical consultation due to the staff turnover at mesosystem level, resident Indonesian physicians occasionally offered patients teleconsultations or through SMS if the patient had a fever or was experiencing pain. Some doctors described their efforts to address this short clinical consultation and ensure individual's understanding of LR at the Indonesia study site by providing teleconsultation for four patients with severe LR to listen to their complaints about LR symptoms and suggest first aid before making a hospital appointment. The communication difficulties were countered at the Indian centre by having a resident counsellor at the clinic. The Indian doctors highlighted the importance of having a local counsellor who could speak the local language to help identify symptoms and listen to patients' concerns before the clinical examination at mesosystem. Drawing from cases in Indonesia and hospital management practices at the Indian study site, Indonesians with LR during a participatory workshop proposed an online communication platform with doctors.

Barriers to communicating LR emerged among participants in both study sites, but the cause was considered differently between patients at the microlevel and healthcare workers at the mesosystem level. The patients primarily identified the lack of outpatient consultation time and insufficient explanations from healthcare workers as significant barriers to effective communication in both sites. For their part, healthcare workers attributed communication barriers to patients' educational backgrounds and cultural beliefs. The healthcare workers in the FGDs in both sites believed that patients' varying levels of education and differing

cultural contexts influenced their understanding and interpretation of medical information. Healthcare workers highlighted the challenge of conveying the complex causes of the disease to patients with limited health literacy and diverse cultural perspectives.

#### **Alternatives in care-seeking**

At the microlevel, Indonesian and Indian participants described a variety of care-seeking and self-care practices to manage LR, which were influenced by the duration of the condition. In Indonesia participants affected by LR said that its chronic nature prompted them to go to other healthcare facilities or seek help from shamans, faith healers, or traditional healers. Recourse to traditional medicine was attributed to cultural beliefs at the macro level but family convictions about the supernatural were also an influence on affected participants about the origins and causes of the disease. For example, an Indonesian participant described seeking alternative care whereby a traditional healer asked him to drink the blood of a wild black chicken to treat LR. He believed that drinking the chicken's blood whenever he experienced tingling sensations in his arms or legs could cure his illness. Other Indonesians with ENL who did not improve with alternative care returned to tertiary-level or leprosy-specialized hospitals for treatment. One participant said:

*"I had visited faith healers and shamans. The cleric said that it was caused by cholesterol. The shaman said I was cursed. I somewhat believed their explanations before I came to the hospital, but my illness was not improving." (IDI-1029, ENL, Indonesia)*

Indonesian participants used alternative therapies alongside medical treatment at the micro level. Indian participants used Ayurveda before visiting allopathic healthcare facilities to obtain a diagnosis. As one explained: *"I used to consume herbal medicine... because I had no information about this [diagnosis of leprosy]"*. He also mentioned that he only visited the doctor when he noticed no improvements in his health after the traditional treatment. *"My condition did not recover. Then, I stopped the herbal medicines and decided to take another treatment. I came to the hospital"* (IDI-1004, ENL, India).

At micro level, participants in both countries reported self-care practices with the potential to cause injury. The unpleasant paraesthesia of LR caused some individuals to adopt techniques to provide relief. These included the use of electric massage pads, application of hot water or stones, and even a hammer on the affected parts of the body. The stimuli provided relief but had the potential to damage tissue. Based on the researchers' analysis, it was observed that these practices at the micro level were

triggered by the desperation for relief from neuropathic symptoms.

## Discussion

This research study utilises Bronfenbrenner's socio-ecological theory to analyse the multifaceted factors affecting the functioning of LR care services and the impact of the wider healthcare system on the experiences of people with LR. As illustrated in Fig. 1, the socio-ecological framework highlights the interconnected layers of influence, ranging from the micro level (individual with LR) to the mesosystem (interactions between individuals with LR and their family, peers, or healthcare workers), and extending to the exosystem (the system of healthcare providers) and macrosystem (broader social and healthcare system contexts). This study identifies micro-level factors such as the patient's age, sex, income, care-seeking behaviour, education, marital status, trust in LR treatment, having health insurance, self-stigma, type of LR, and steroid dependency. At the mesosystem level, it examines interactions between patients, family, peers, and healthcare providers, focusing on communication barriers and support mechanisms. The exosystem considers the influence of healthcare provider's regulations and resources. Finally, the macrosystem includes the impact of social stigma, the healthcare system, cultural factors, and health insurance policies. The study examines two study sites with distinct models of leprosy care. The first study site used an integrated service model provided on an outpatient basis in a general hospital in an urban setting in Indonesia. This model has the advantage of being easily accessible to a large population due to higher coverage of public health insurance at the macrosystem level. However, it faces limitations in terms of complex regulation of public health insurance and drug availability, which can hinder the provision of timely and effective care. The second study site is based on a specialist care model provided in a dedicated hospital on a largely inpatient basis and treatment cost subsidy for leprosy care, situated in a rural setting in India. While this model allows for intensive, specialised care, it encounters challenges related to health personnel resources, public health insurance coverage and high-quality specialised care is located near to where the individual lives.

### Barriers to quality of care in management of LR

Our study highlights five main barriers to high-quality care: complex regulation of public health insurance and the gatekeeping function of primary and secondary care in managing patients' access to the specialised physician at macrosystem; availability of qualified health professionals at exosystem; paternalistic approaches in doctors' communication with patients at mesosystem;

and doctors' limited ability to explain complex disease terminology in plain language at exosystem. The concept of UHC, which is a large-scale social policy at macrosystem, is clearly seen in the Indonesia model where many patients with LR are covered by public health insurance at microsystem. This not the case in India. Compared to Indonesians affected by LR at microsystem, our participants in the Indian model of care were less aware of PM-JAY or RSBY and there was less uptake of government-sponsored health insurance at the microsystem level. One of our significant findings is that there are insurance and benefits schemes, but many Indian participants do not know about them. People may have the RSBY card but do not understand the benefits of and procedures for using it, and this puts non-literate people at a disadvantage because the registration process contains a large amount of text with minimum verbal explanation. Parisi et al. reported that only half of the eligible Indian population was aware of PM-JAY [70]. Jain and Basu emphasised that non-insured Indians from low-income households are unaware of RSBY, the state insurance [71]. Our findings are consistent with those of Parisi et al. [70] and there need to be significant efforts to increase awareness of marginalised Indian populations about PM-JAY. To ensure that Indians affected by LR have access to government-sponsored health insurance schemes, it is important to raise awareness and implement strategic plans effectively at microsystem, including educating people about the benefits of the schemes and how to use their insurance cards, as well as simplifying the process for claiming benefits at mesosystem to make the system more accessible.

The study revealed that health insurance regulations and uptake of public health insurance by LR-affected individuals at the macrosystem level greatly affect the provision of health services, clinical decision-making, care expenditure, and the psychological well-being of individuals with LR at the microsystem level in both study sites. Unlike the India model of care, the Indonesian model heavily relied on public health insurance regulation at the microsystem level. Despite the high uptake, strict regulations of Indonesia's health insurance (BPJS-K) at the macrosystem level does not allow flexibility in gatekeeping function at the primary care level, referral letters, and clinical decisions for Indonesian participants with LR in this study. Differing from the Indian model of care, we discovered in the interviews that all publicly insured Indonesian participants mentioned that they visited three levels of healthcare facilities to get the right treatment, with limited clinical decisions due to BPJS-K regulation. Our findings align with other studies that reported a significant influence of the BPJS-K on clinical decision-making in maternal care and HIV [71, 72].



Furthermore, the decision for weekly monitoring in the Indonesia model of care results in high indirect treatment expenses for individuals affected by LR, and access to healthcare in Indonesia was more time-consuming than in India.

We found that healthcare providers play a crucial role in the referral process by identifying and referring people with LR to specialized leprosy clinics or hospitals for care at mesosystem level. In both countries, the hospital with leprosy specialist care ensured that people with LR receive appropriate treatment, including anti-inflammatory drugs and rehabilitation interventions, to manage the physical and functional consequences of LR. The gatekeeping crucially influences the uptake of services, health outcomes, healthcare costs, and service-user satisfaction [72]. However, the effectiveness of the gatekeeping function depends on the availability, capacity, and quality of healthcare services to identify and refer people with LR. Our study supports the proposal made by Handayani et al. [73] to review the referral process and clinical treatment decisions in BPJS-K. Given the severity and chronicity of LR, the Indonesian government should re-evaluate the referral mechanism in BPJS-K to reduce waiting times and optimise service delivery.

Our study shows that the requirement of a referral letter for publicly insured individuals, limited coverage of public health insurance, and distance to a specialised care contribute to delays in seeking care among those with LR. The delay in individuals with LR attending integrated care services was also reported in studies from Nepal, Brazil, and India [6, 74–78]. We found that delaying an initial consultation at the microsystem level may result in disabilities or other complications in leprosy. In Sri Lanka, despite a marked delay in going for a consultation, integrating leprosy services into general health facilities at the macrosystem level has increased access to healthcare services for leprosy-affected people at the microsystem level [79]. WHO experts predicted that integrating health services might reduce costs for leprosy-affected individuals and minimise social stigma [80]. However, the integrated hospital should have a better strategy to detect hidden cases of leprosy and minimise delay in diagnosis [81, 82].

Although each country's government has made efforts to improve accessibility and quality by providing free MDT and including LR in public health insurance [83, 84], there is still a shortage of healthcare professionals, especially in rural and remote locations [85]. Our study found that the integrated healthcare model in Indonesia at the macrosystem level has limited capacity not only in diagnosing leprosy, but also in treating LR. This forces Indonesian patients to visit multiple levels of care on a monthly basis, which Indian patients do not

experience. We discovered that the delay of individuals with LR seeking specialised care and the lack of healthcare professionals at primary and higher levels of care with the appropriate training and expertise to effectively diagnose, refer suspected LR cases to other levels of the health system, and care for leprosy-affected individuals are a personnel gap in the management of LR at the exosystem level, aligning with other findings in other leprosy-endemic countries [86–89]. The shortage of qualified health professionals is a significant challenge in Indonesia and India at the exosystem level, where leprosy is endemic and the burden of LR is high [90], leading to inadequate diagnosis, treatment, and referrals, and consequently also to lower trust of affected individuals in LR treatment and leading them to seek alternative options at the microsystem level.

The relationship between the doctor and patient in managing LR is still dominated by a paternalistic approach, which is identified in unilateral clinical decisions. We discovered that the major paternalistic practices appear to relate to hospitalisation and discussing leprosy and LR with patients because of doctors' assumptions about an individual's understanding of LR. According to Gallagher, paternalism is common among clinicians, who do not consult their patients in the clinical decision-making process [91]. In our findings, this approach is reflected in clinical judgments. Most healthcare workers make decisions regarding treatment or hospitalisations based on symptoms, insurance uptake, resources, and regulations, without necessarily considering what the patient wanted.

This study reveals the communication barriers identified in the context of LR which were further compounded by the doctors' inability to explain the disease in plain language that the patients could understand at the mesosystem level. At the microsystem level, the individuals with LR found it difficult to comprehend the doctors' highly technical explanations, and specialised doctors in Indonesia and India conceded that they were limited in their ability to communicate in the local language. The lack of effective communication between patients and healthcare providers at the mesosystem level can lead to clinical decisions being made without considering the patients' preferences, and may deprive patients of the opportunity to make informed decisions about their treatment options. Improving doctors' communication skills in the clinical setting is one strategy to minimize communication barriers and improve doctor–patient relationships [92, 93]. Supporting White's findings in Brazil [94], a doctor's ability to communicate complex disease models to our participants affected by LR influences the individuals' knowledge and care-seeking behaviour. At the mesosystem level, this study suggests adding

educational activities or peer networking at outpatient clinics and developing tools for healthcare providers on how to communicate about LR and their management as additional strategies. Observational studies on HIV and mental health have shown that peer-support activities at outpatient clinics may reduce the lack of understanding of the illness among patients and increase mental well-being of the affected population [95, 96].

#### **Facilitators to quality of care in management of LR**

Our study identified five facilitators of high-quality care: financial assistance at the exosystem level, organized healthcare, availability of corticosteroid alternatives at the exosystem level, timely provision of care, and counselling at the mesosystem level. First, our study has found that the high coverage of public health insurance cards at the macrosystem level in the Indonesian model has increased access to care for individuals affected by LR, despite the challenges. By contrast, the Indian model of care offers treatment subsidies at the exosystem level. The advantage of the Indonesian model is its ability to provide wider access to quality care, whereas the Indian model is aimed those in most need. WHO reported that the Indian government is making progress in increasing the national public health insurance and establishing a gatekeeping function in healthcare [40]. The experiences of people with LR in Indonesia should be considered in India to improve the referral system at the macro level to make sure that individuals with long-term health conditions are directed to the right healthcare services more effectively and efficiently.

Our findings in India have shown that good organization in the management of LR at the exosystem level can facilitate the provision of well-coordinated care. To ensure the continuity of drug supply and prevent shortages, a synchronized information system is essential at the exo- and mesosystem levels in the India model of care. This can serve as a valuable lesson for the healthcare model in Indonesia, where an integrated information system for personal health records may improve the clinical decision-making of healthcare workers in hospitals and referral clinics. As reported by health policy and planning scholars, integrated personal health records facilitate communication between patients and health professionals and improve quality of patient data [97, 98]. Factors playing out at the exo- and mesosystem levels relating to the organisation of care such as hospitalisation time, consultations, and the organisation and management of medical records affected the microsystem of patients' experiences. Therefore, in this respect, India's site model of care at an exosystemic level seemed more aligned with the needs emerging from the microsystem than in Indonesia.

This study highlights that the management of LR with corticosteroids at the exosystem level is not effective for every individual with ENL. Others have highlighted the need for identifying effective and accessible alternatives [99, 100]. The availability of thalidomide for males played a positive role in the management of severe ENL in India but is not used in Indonesia. A retrospective study in India found that thalidomide was shown to aid in the recovery of individuals with acute or chronic ENL during or after completing MDT in an outpatient setting [101]. Leprosy specialists worldwide and WHO experts have advocated increasing access to thalidomide for individuals with ENL. However, to date, an article reported that thalidomide is only available and can be legally prescribed for individuals affected by LR in India and Brazil [102]. From a consequential perspective, the use of thalidomide could be justified if it leads to better health outcomes for those with severe ENL. The potential benefits of the drug might outweigh the manageable risks associated with its adverse effects and more equitable use for females with severe ENL [103].

Our study found that inpatient services are more commonly used and may provide more timely provision of care for LR treatment in the India site, aligning with previous research which suggests that inpatient care remains a prevalent approach in the management of LR in countries that adopted specialist care like Nepal and India [6]. We revealed that most individuals with LR in both models of care prefer outpatient services despite the extra travel costs and time spent at the microsystem level. In the India model, prolonged hospitalisation may offer some advantages but has the potential to limit an individual's agency. From the healthcare perspective, these decisions may be expedient, but they were imposed on many affected individuals by circumstances and organisations. The affected individuals' preference for outpatient care is seemingly at odds with healthcare providers' perspectives, but outpatient care is more cost-effective than hospitalisation for T1R-associated neuritis in India [104]. The costing study on the same Indian site reported that the hospital incurred an average cost per patient of INR 5,026 (IQR 180–27,079) for subsidised services to patients and placed it under considerable financial constraint [19]. The management for LR must take into account patients' preferences, indirect treatment costs, and the potential impact on their quality of care at the microsystem level.

At the mesosystem level, counselling is an important intervention in the area of leprosy and disability support, as it can help to improve the mental and emotional well-being of people with the disease and can contribute to improved treatment outcomes [105–107]. We found that the Indian study site provides counselling services

for people with leprosy and LR in the outpatient clinic. At the Indian study site, counselling can help people with LR to understand the importance of completing their treatment and preventing using alternative non-medical therapies during the clinical treatment. Therefore, guaranteeing access to an appropriate counselling service in a healthcare setting could also be important for Indonesians with LR, who do not systematically have the option of this sort of service. Yet, it should be planned well together with affected individuals [108].

### Strengths and limitations

Three strengths were identified in this study. Healthcare providers and recipients in both countries were successfully involved in gaining an overarching perspective and more nuanced perspective on the management of LR which might be generalisable for tertiary health settings. The findings were validated through member checks in which additional inputs were given by people affected by LR and the research assistants. The socio-ecological model helped to unpack the complexities of barriers and facilitators in each model of care. There were, however, five main limitations. Due to the qualitative nature of the research and the limited number of participants, the proportions and numbers in the results provide precision in reporting, rather than indicating greater accuracy or generality. First, this study did not include the experiences of people treated in primary or secondary health facilities and other specialised hospitals with a high burden of leprosy in India. We acknowledged that the reported factors in accessing LR management might differ among this population. Second, this study did not include the policy-maker's and insurance provider's perspective due to the limited period of the study. However, we tried to describe the role of insurance regulation in the management of LR from the perspective of healthcare providers. Third, there were more men with LR involved in this study. Although fewer women are represented in this study, we tried to include all women who were currently accessing care for LR during the data collection period. Fifth, this study did not explore the cultural factors which may differ in each setting. Nevertheless, we focused in depth on the interaction of barriers and facilitators at each structural level and illustrated the complexity of each factor. Last, we did not directly assess participants' prior knowledge about the existence of care services. Instead, our findings regarding the awareness and perceptions of these services emerged organically from the data collected through interviews, FGDs, and workshops.

### Research implications

These findings suggest important messages for healthcare providers, researchers, and policymakers about the

importance of having a standardised guide for management of LR, new drug development, and training for healthcare workers in both countries. It is suggested that the guide should include peer support and group activities for the affected individuals, deliberative communication between the physician and patients, tools for healthcare providers on how to communicate about LR and their management, and a sustainable supply chain of medicines. The study suggests the need for improved communication strategies, such as using counsellors or online platforms to address these barriers and enhance patients' understanding of LR. Translating knowledge about LR into local languages in the context of counselling would improve patients' understanding of the illness. This study also suggests further research on sharing lessons from countries that allow restricted use of thalidomide as a corticosteroid-sparing agent. Future research could incorporate mixed-method approaches, combining qualitative insights with quantitative measures to assess the reputation and awareness of care services more systematically. There is an urgent need to develop new drugs to reduce corticosteroid dependency in people with LR, as well as a need to recruit more healthcare workers trained in LR to increase early diagnosis of the illness, minimise the gap in service in rural and endemic areas, and communicate the clinical condition in local languages and lay terms (as opposed to medical terminology). This study recommends sharing comprehensive information about self-care and creating specific support during the treatment to prevent the use of alternative medicines and harmful pain-relief practices. It is recommended that the proposed educational activities and peer networking at outpatient services be explored as additional hospital strategies. It is also worth considering research on implementation to assess the feasibility of a community-based approach to improving the supply chain of medicines for LR, accessibility and acceptability of LR management services in the future, and acceptability of telehealth among Indonesian patients.

### Conclusion

The study findings demonstrate that the identified factors at the four systemic levels are interrelated and have an impact on the access, acceptability, and management of LR services. At the macro level, the public health system and culture largely affect the health system regulations, health insurance coverage and policy, resource allocation for clinics and hospitals, and social stigma. At the exosystemic level, the healthcare provider's management and system – such as the availability of qualified workers, access to essential medicine, and use of e-health (teleconsultations) – play a role in interactions between patients, family, peers, and healthcare

providers at the meso level. Support provided by the healthcare facility, peers, and family and access to LR specialised care at the meso level are identified as significant factors influencing the experiences of people with LR. Variations in public health insurance regulations and uptake of public health insurance at the macrosystem level significantly affect the provision of health services, clinical decision-making, care expenditure, and the psychological well-being of individuals with LR at the microsystem level in Indonesia and India. This study recommends improvements in four fundamental areas. First, simplifying the gatekeeping function and tailored public insurance regulation for Indonesians with LR merit being explored with the national health agency. Second, subsidising the travel costs for Indians with LR could be considered as a supplementary measure to minimize the number of days as an inpatient and the associated resource strains. Third, it is worth examining regulation for using thalidomide as a steroid-sparing agent in the Indonesia research site. Last, a specific counselling tool for LR in local languages and peer support is crucial at both sites.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-025-12340-5>.

Supplementary Material 1

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## Authors' contributions

AIP designed the data collection procedure and analysis, recruited participants, collected all data, performed data analysis, and wrote and revised the paper. RMHP secured the research funding and coordinated with local stakeholders for data collection, while supervising AIP in the research process and manuscript writing. Similarly, KDS coordinated with local stakeholders for preparation and data collection, and supervised AIP in the research process and manuscript writing. Both RMHP and KDS contributed equally to this paper. BSM, SLW, and MBMZ supervised AIP in writing the manuscript, reviewed the paper, and provided feedback. JD, RIA, MDA, CRSP, and MYL coordinated with local stakeholders during the data collection process and provided manuscript feedback.

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## Data availability

The results of this study were based on information that could not be disclosed publicly due to ethical considerations. To safeguard the confidentiality of the study participants, the data could not be openly shared. Approval from

the participants was to only reveal the data interpretation with pseudonyms, if cited.

## Declarations

### Ethics approval and consent to participate

This study followed the Declaration of Helsinki to ensure respect for all participants and protect their health and rights [109]. Three ethical review committees approved this study: Dr. Soetomo General Academic Hospital (070/91/301.4.2/Litb/II/2019), the Leprosy Mission Trust India (5/vii/C-37), and the London School of Hygiene and Tropical Medicine (17007). Before data collection, all participants were given a verbal explanation of the nature and purpose of the research. The participants were informed of the protocol and the consent was then obtained. Participants were informed that interview or FGD questions focused on the issues they encountered during the provision of care and may elicit unpleasant memories. Participants were also informed of their right to not answer questions and leave the study at any moment without explanation. Participants signed a consent form, and approval of minors' responsible adult was sought. Individuals gave verbal consent if they were unable to provide written consent for any reason, such as illiteracy or physical impairments that prevented them from writing, and the researcher noted it in writing before the start of the interview. A witness, such as the research assistant or a family member of the participant, observed this discussion and signed the consent form after ensuring that the participant fully understood their rights and risks. The researcher's affiliation with the hospital in Indonesia might have influenced the willingness of participants to openly share any negative experiences. Participants might have been concerned that sharing negative feedback could affect their care or work at the hospital. Despite the consent form stating that participation was voluntary and that participants could withdraw at any time without repercussions, they still had the right to decline to answer any questions that made them uncomfortable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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## References

1. WHO (World Health Organization). Global leprosy (Hansen disease) update. time to step-up prevention initiatives. *Wkly Epidemiol Rec.* 2019;2020(95):417–40.
2. World Health Organization. Global leprosy (Hansen disease) update, 2023: elimination of leprosy disease is possible—time to act. *Wkly Epidemiol Rec.* 2024;37:20.
3. World Health Organization. Guide to Eliminate Leprosy as a Public Health Problem. Guideline WHO-Geneva. 2000. <https://doi-org.vu-nl.idm.oclc.org/WHO/CDS/CPE/CEE/2000.14>.
4. Walker S, Lockwood D. Leprosy type 1 (reversal) reactions and their management. *Lepr Rev.* 2008;1:372–86.
5. Kahawita I, Walker S, Lockwood D. Leprosy type 1 reactions and erythema nodosum leprosum. *An Bras Dermatol.* 2008;83:75–82.
6. Raffe SF, Thapa M, Khadge S, Tamang K, Hagge D, Lockwood DNJ. Diagnosis and treatment of leprosy reactions in integrated services - the



- patients' perspective in Nepal. *PLoS Negl Trop Dis*. 2013. <https://doi.org/10.1371/journal.pntd.0002089>.
7. Walker SL. Leprosy reactions. In: Scollard D, Gillis T, editors. *International textbook of leprosy*. Greenville: American Leprosy Mission; 2020.
  8. Pocater L, Jain S, Reddy R, Muzaffarullah S, Torres O, Suneetha S, et al. Clinical course of erythema nodosum leprosum: an 11-year cohort study in Hyderabad. *India Am J Trop Med Hyg*. 2006;74:868–79.
  9. Saunderson P, Gebre S, Byass P. ENL reactions in the multibacillary cases of the AMFES cohort in central Ethiopia: incidence and risk factors. *Lepr Rev*. 2000. <https://doi.org/10.5935/0305-7518.20000035>.
  10. Smith WCS, Nicholls PG, Das L, Barkataki P, Suneetha S, Suneetha L, et al. Predicting neuropathy and reactions in leprosy at diagnosis and before incident events—results from the INFIR cohort study. *PLoS Negl Trop Dis*. 2009;3:e500.
  11. Hungria EM, Bühner-Sékula S, de Oliveira RM, Aderaldo LC, Pontes A de A, Cruz R, et al. Leprosy reactions: the predictive value of *Mycobacterium leprae*-specific serology evaluated in a Brazilian cohort of leprosy patients (U-MDT/CT-BR). *PLoS Negl Trop Dis*. 2017;11:e0005396.
  12. Penna GO, Bühner-Sékula S, Kerr LRS, Stefani MM de A, Rodrigues LC, de Araújo MG, et al. Uniform multidrug therapy for leprosy patients in Brazil (U-MDT/CT-BR): results of an open label, randomized and controlled clinical trial, among multibacillary patients. *PLoS Negl Trop Dis*. 2017;11:e0005725.
  13. Pönnighaus JM, Boerrigter G. Are 18 doses of WHO/MDT sufficient for multibacillary leprosy; results of a trial in Malawi. *Int J Lepr Other Mycobact Dis*. 1995;63:1–7.
  14. Ranque B, van Thuc N, Vu HT, Nguyen TH, Nguyen NB, Pham XK, et al. Age is an important risk factor for onset and sequelae of reversal reactions in Vietnamese patients with leprosy. *Clin Infect Dis*. 2007;44:33–40.
  15. Voorend CGN, Post EB. A systematic review on the epidemiological data of erythema nodosum leprosum, a type 2 leprosy reaction. *PLoS Negl Trop Dis*. 2013;7:e2440.
  16. Kar H, Gupta R. Management of leprosy reactions. In: B Kumar HK, editor. *IAL textbook of leprosy*. 2nd ed. 2016. p. 465–77.
  17. Putri AI, de Sabbata K, Agusni RI, Alinda MD, Darlong J, de Barros B, et al. Understanding leprosy reactions and the impact on the lives of people affected: an exploration in two leprosy endemic countries. *PLoS Negl Trop Dis*. 2022;16:e0010476.
  18. Peters RMH, Dadun, Lusli M, Miranda-Galarza B, van Brakel WH, Zweckhorst MBM, et al. The meaning of leprosy and everyday experiences: an exploration in Cirebon, Indonesia. *J Trop Med*. 2013;2013:507034.
  19. Chandler DJ, Hansen KS, Mahato B, Darlong J, John A, Lockwood DNJ. Household costs of leprosy reactions (ENL) in Rural India. *PLoS Negl Trop Dis*. 2015;9:1–13.
  20. de Paula HL, de Souza CDF, Silva SR, Martins-Filho PRS, Barreto JG, Gurgel RQ, et al. Risk factors for physical disability in patients with leprosy: a systematic review and meta-analysis. *JAMA Dermatol*. 2019;155:1120–8.
  21. Costa MD, Costa RD, Maria A, Dias D. Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center. 2012;87:26–35.
  22. Nasir A, Yusuf A, Listiawan MY, Makhfudli M. The life experience of leprosy families in maintaining interaction patterns in the family to support healing in leprosy patients in Indonesian society. A phenomenological qualitative study. *PLoS Negl Trop Dis*. 2022;16:e0010264.
  23. Janzen JM. Therapy management: concept, reality, process. *Med Anthropol Q*. 1987;1:68–84.
  24. Hausmann Muela S, Muela Ribera J, Toomer E, Peeters GK. The PASS-model: a model for guiding health-seeking behavior and access to care research. *Malar Rep*. 2012;2:3.
  25. Kahawita IP, Lockwood DNJ. Towards understanding the pathology of erythema nodosum leprosum. *Trans R Soc Trop Med Hyg*. 2008;102:329–37.
  26. World Health Organization. Leprosy/hansen disease: management of reactions and prevention of disabilities: technical guidance. World Health Organization; 2020. <https://iris.who.int/bitstream/handle/10665/332022/9789290227595-eng.pdf>.
  27. Becx-Bleumink M, Berhe D. Occurrence of reactions, their diagnosis and management in leprosy patients treated with multidrug therapy; experience in the leprosy control program of the All Africa Leprosy and Rehabilitation Training Center (ALERT) in Ethiopia. *Int J Lepr*. 1992;60:173–84.
  28. Naafs B. Treatment of leprosy: science or politics? *Tropical Med Int Health*. 2006;11:268–78.
  29. Rao PSSS, Sugamaram DST, Richard J, Smith WCS. Multi-centre, double blind, randomized trial of three steroid regimens in the treatment of type-1 reactions in leprosy. *Lepr Rev*. 2006;77:25–33.
  30. Antunes DE, Araujo S, Ferreira GP, da Cunha ACSR, da Costa AV, Gonçalves MA, et al. Identification of clinical, epidemiological and laboratory risk factors for leprosy reactions during and after multidrug therapy. *Mem Inst Oswaldo Cruz*. 2013;108:901–8.
  31. Walker SL, Lockwood DN. The clinical and immunological features of leprosy. *Br Med Bull*. 2006;77(1):103–21.
  32. Sampaio EP, Kaplan G, Miranda A, Nery JA, Miguel CP, Viana SM, et al. The influence of thalidomide on the clinical and immunologic manifestation of erythema nodosum leprosum. *J Infect Dis*. 1993;168:408–14.
  33. Garbino JA, Virmond M da CL, Ura S, Salgado MH, Naafs B. A randomized clinical trial of oral steroids for ulnar neuropathy in type 1 and type 2 leprosy reactions. *Arq Neuropsiquiatr*. 2008;66:861–7.
  34. Walker SL, Balagon M, Darlong J, Doni SN, Hage DA, Halwai V, et al. ENLIST 1: an international multi-centre cross-sectional study of the clinical features of erythema nodosum leprosum. *PLoS Negl Trop Dis*. 2015;9:e0004065.
  35. Pires CAA, Juca Neto FOM, de Albuquerque NC, Macedo GMM, Batista K de NM, Xavier MB. Leprosy reactions in patients coinfecting with HIV: clinical aspects and outcomes in two comparative cohorts in the Amazon Region, Brazil. *Brazil PLoS Negl Trop Dis*. 2015;9:e0003818.
  36. Walker SL, Sales AM, Butlin CR, Shah M, Maghanoy A, Lambert SM, et al. A leprosy clinical severity scale for erythema nodosum leprosum: an international, multicentre validation study of the ENLIST ENL severity scale. *PLoS Negl Trop Dis*. 2017;11:e0005716.
  37. Lockwood DNJ, Nicholls P, Smith WCS, Das L, Barkataki P, van Brakel W, et al. Comparing the clinical and histological diagnosis of leprosy and leprosy reactions in the INFIR cohort of Indian patients with multibacillary leprosy. *PLoS Negl Trop Dis*. 2012;6:e1702.
  38. Murray CJL, Frenk J. A framework for assessing the performance of health systems. *Bull World Health Organ*. 2000;78:717–31.
  39. Tiwari A, Mieras L, Dhakal K, Arif M, Dandel S, Richardus JH. Introducing leprosy post-exposure prophylaxis into the health systems of India, Nepal and Indonesia: a case study. *BMC Health Serv Res*. 2017;17:1–11.
  40. Selvaraj S, Karan KA, Srivastava S, Bhan N, Mukhopadhyay I. India health system review. New Delhi: World Health Organization, Regional Office of South-East Asia; 2022.
  41. Mahendradhata Y, Trisnantoro L, Lityadewi S, Soewondo P, Marthias T, Harimurti P, Prawira J. The Republic of Indonesia health system review. *Health Syst Trans*. 2017;7(1).
  42. Ditjen PP, Jakarta PK. *Pedoman Nasional Program Pengendalian Penyakit Kusta*. Jakarta: Kementerian Kesehatan RI Direktorat Jenderal Pengendalian Penyakit dan Penyehatan Lingkungan. 2012.
  43. National Leprosy Eradication Programme. India: Guidelines for Disability Prevention and Medical Rehabilitation. New Delhi: 2012. <http://clinicalestablishments.gov.in/WriteReadData/516.pdf>.
  44. Siddiqui MR, Velidi NR, Pati S, Rath N, Kanungo AK, Bhanjadeso AK, et al. Integration of leprosy elimination into primary health care in Orissa, India. *PLoS ONE*. 2009;4:e8351.
  45. Faizal A, Wadrianto GK. Saat Sebutan "RS Kusta" Berganti Menjadi "RS Infeksi". *Kompas.Com*. 2014. <https://regional.kompas.com/read/2014/09/24/09390051/Saat.Sebutan.RS.Kusta.Berganti.Menjadi.RS.Infeksi>.
  46. Directorate General of Health Services M of H& FWG of I. National Leprosy Eradication Programme. [https://dghs.gov.in/content/1349\\_3\\_NationalLeprosyEradicationProgramme.aspx](https://dghs.gov.in/content/1349_3_NationalLeprosyEradicationProgramme.aspx).
  47. Serrano-Coll H, Velez JD, Trochez D, Beltran JC, Suanca D, Monsalve F, et al. Effectiveness of an individual physical rehabilitation programme in a group of patients with Hansen's disease. *Lepr Rev*. 2016;87:355–67.
  48. World Bank. UHC Service Coverage Index - India, Indonesia. 2019. <https://data-worldbank-org.vu-nl.idm.oclc.org/indicator/SH.UHC.SRVS.CV.XD?end=2021&locations=IN-ID&start=2000&view=chart>.

49. Wang W, Temsah G, Mallick L. The impact of health insurance on maternal health care utilization: evidence from Ghana, Indonesia and Rwanda. *Health Policy Plan.* 2017;32:366–75.
50. Dubey S, Deshpande S, Krishna L, Zadey S. Evolution of government-funded health insurance for universal health coverage in India. *Lancet Reg Health Southeast Asia.* 2023;13:100180.
51. Government of Indonesia. UU 24 Tahun 2011 tentang Badan Penyelenggara Jaminan Sosial. 2011. <https://peraturan.bpk.go.id/Details/39268>.
52. Government of India. About NHA. 2019. [https://nha.gov.in/NHA#:~:text=National%20Health%20Authority%20\(NHA\)%20is,technological%20infrastructure%20and%20implementation%20of%20](https://nha.gov.in/NHA#:~:text=National%20Health%20Authority%20(NHA)%20is,technological%20infrastructure%20and%20implementation%20of%20). Accessed 8 Feb 2023.
53. Chandrashekar S, Agarwal VAA, Khurana R, Ashwani N. Documentation of process for customization of standard treatment guidelines Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY). 2021. <https://nha.gov.in/img/pmjay-files/STG-Manual-Booklet-final.pdf>.
54. Ministry of Health and Family Welfare of India. Increasing the Insurance Cover Under RSBY. 2017. <https://pib.gov.in/PressReleaseIframePage.aspx?PRID=1513162>. Accessed 20 Mar 2023.
55. National Health Account of India. Ayushman Bharat PM-JAY Annual Report 2020–21. 2021. <https://nha.gov.in/img/resources/Annual-Report-2020-21.pdf>.
56. Bronfenbrenner U. Toward an experimental ecology of human development. *Am Psychol.* 1977;32:513.
57. Townsend N, Foster C. Developing and applying a socio-ecological model to the promotion of healthy eating in the school. *Public Health Nutr.* 2013;16:1101–8.
58. Robinson T. Applying the socio-ecological model to improving fruit and vegetable intake among low-income African Americans. *J Community Health.* 2008;33:395–406.
59. Salihu HM, Wilson RE, King LM, Marty PJ, Whiteman VE. Socio-ecological model as a framework for overcoming barriers and challenges in randomized control trials in minority and underserved communities. *Int J MCH AIDS.* 2015;3:85.
60. Lee BC, Bendixsen C, Liebman AK, Gallagher SS. Using the socio-ecological model to frame agricultural safety and health interventions. *J Agromedicine.* 2017;22:298–303.
61. Al-Jayyousi GF, Sherbash MAM, Ali LAM, El-Heneidy A, Alhussaini NWZ, Elhassan MEA, et al. Factors influencing public attitudes towards COVID-19 vaccination: a scoping review informed by the socio-ecological model. *Vaccines (Basel).* 2021;9:548.
62. Swearer SM, Espelage DL, Koening B, Berry B, Collins A, Lembeck P. A social-ecological model for bullying prevention and intervention in early adolescence. *Handb Sch Violence Sch Saf.* 2012;333–55.
63. Hennein R, Mew EJ, Lowe SR. Socio-ecological predictors of mental health outcomes among healthcare workers during the COVID-19 pandemic in the United States. *PLoS ONE.* 2021;16:e0246602.
64. Mengesha ZB, Perz J, Dune T, Ussher J. Refugee and migrant women's engagement with sexual and reproductive health care in Australia: a socio-ecological analysis of health care professional perspectives. *PLoS ONE.* 2017;12:e0181421.
65. Ma PHX, Chan ZCY, Loke AY. The socio-ecological model approach to understanding barriers and facilitators to the accessing of health services by sex workers: a systematic review. *AIDS Behav.* 2017;21:2412–38.
66. Weisz U, Haas W, Pelikan JM, Schmied H. Sustainable hospitals: a socio-ecological approach. *GAIA Ecol Perspect Sci Soc.* 2011;20:191–8.
67. Phelan A, Kirwan M. Contextualising missed care in two healthcare inquiries using a socio-ecological systems approach. *J Clin Nurs.* 2020;29:3527–40.
68. Kementerian Kesehatan Republik Indonesia. PMK no 11/2019 tentang Penanggulangan Kusta. Jakarta; 2019. [http://hukor.kemkes.go.id/uploads/produk\\_hukum/PMK\\_No\\_\\_11\\_Th\\_2019\\_ttg\\_Penanggulangan\\_Kusta.pdf](http://hukor.kemkes.go.id/uploads/produk_hukum/PMK_No__11_Th_2019_ttg_Penanggulangan_Kusta.pdf).
69. Ministry of Health and Family Welfare. National leprosy eradication programme: training manual for medical officer. New Delhi; 2006.
70. Parisi D, Srivastava S, Parmar D, Strupat C, Brenner S, Walsh C, et al. Awareness of India's national health insurance scheme (PM-JAY): a cross-sectional study across six states. *Health Policy Plan.* 2023;38:289–300.
71. Jain N, Basu S. Understanding The Awareness and Sources of Awareness of Rastriya Swasthya Bima Yojna (RSBY)/State Scheme And Its Implication For PM-JAY Findings from A Household Survey across Seven States In India. <http://dx.doi.org.vu-nl.idm.oclc.org/10.13140/RG.2.2.26730.13761>.
72. Greenfield G, Foley K, Majeed A. Rethinking primary care's gatekeeper role. *BMJ.* 2016;354:i4803.
73. Handayani PW, Dartanto T, Moeis FR, Pinem AA, Azzahro F, Hidayanto AN, et al. The regional and referral compliance of online healthcare systems by Indonesia National Health Insurance agency and health-seeking behavior in Indonesia. *Heliyon.* 2021;7(7):e08068.
74. Feenstra P, Visschedijk J. Leprosy control through general health services - revisiting the concept of integration. *Lepr Rev.* 2002;73:111–22.
75. Visschedijk J, Engelhard A, Lever P, Grossi MA de F, Feenstra P. Leprosy control strategies and the integration of health services: an international perspective. *Cad Saúde Pública.* 2003;19:1567–81.
76. Roos BR, van Brakel WH, Chaurasia AK. Integration of leprosy control into basic health services; an example from Nepal. *Int J Lepr.* 1995;63:422–9.
77. Rao P, Gift N, Rao GS, Samuel P, Bushanam RS. Elimination of leprosy: the integration of leprosy related activities into the general health services of Tamil Nadu. *Lepr Rev.* 2002;73:123–9.
78. Barbieri RR, Sales AM, Hacker MA, Nery JA da C, Duppre NC, Machado A de M, et al. Impact of a reference center on leprosy control under a decentralized public health care policy in Brazil. *PLoS Negl Trop Dis.* 2016;10:e0005059.
79. Liyanage NR, Arnold M, Wijesinghe S. Utilization of government healthcare services by adult leprosy patients in the Western Province, Sri Lanka. *PLoS Negl Trop Dis.* 2020;14:e0008973.
80. World Health Organization. Report of an informal consultation on integration of leprosy elimination activities into general health services. Geneva: World Health Organization; 1996.
81. Kumar V, Cheng SY. Examining the factors impacting integrated service delivery in leprosy elimination programs in Bihar. *Soc Develop Issues.* 2023;45(2).
82. Siddiqui MR, Velidi NR, Pati S, Rath N, Kanungo AK, Bhanjadeo AK, et al. Integration of leprosy elimination into primary health care in Orissa. *India PLoS One.* 2009;4:e8351.
83. Kumaresan K. National Leprosy Eradication Programme (NLEP) Programmatic Management of Leprosy. 2021. [https://cltri.gov.in/AboutLeprosy/NLEP\\_Program%20Management\\_DLO.pdf](https://cltri.gov.in/AboutLeprosy/NLEP_Program%20Management_DLO.pdf).
84. Kementerian Kesehatan Republik Indonesia. Kemenkes Launching Modul Pelatihan Jarak Jauh Pencegahan dan Pengendalian Kusta. 2020. <https://www.kemkes.go.id/article/view/20090100004/moh-launched-distance-training-module-for-leprosy-prevention-and-control.html>. Accessed 23 Mar 2023.
85. Dharmawan Y, Fuady A, Korfage IJ, Richardus JH. Delayed detection of leprosy cases: a systematic review of healthcare-related factors. *PLoS Negl Trop Dis.* 2022;16:e0010756-.
86. van't Noordende AT, Korfage IJ, Lisam S, Arif MA, Kumar A, van Brakel WH. The role of perceptions and knowledge of leprosy in the elimination of leprosy: a baseline study in Fatehpur district, northern India. *PLoS Negl Trop Dis.* 2019;13:e0007302-.
87. Price VG. Factors preventing early case detection for women affected by leprosy: a review of the literature. *Glob Health Action.* 2017;10:1360550.
88. Varkevisser CM, Lever P, Alubo O, Burathoki K, Idawani C, Moreira TMA, et al. Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. *Lepr Rev.* 2009;80:65–76.
89. Peters RMH, Hofker ME, van Brakel WH, Zweekhorst MBM, Seda FSSE, Irwanto, et al. Narratives around concealment and agency for stigma reduction: a study of women affected by leprosy in Cirebon District, Indonesia. *Disability, CBR and Inclusive Development.* 2014. <https://doi-org.vu-nl.idm.oclc.org/10.5463/DCID.v25i4.389>.
90. mondiale de la Santé O, World Health Organization. Global leprosy (Hansen disease) update, 2021: moving towards interruption of transmission—Situation de la lèpre (maladie de Hansen) dans le monde, 2021: vers l'interruption de la transmission. *Wkly Epidemiol Record= Relevé épidémiologique hebdomadaire.* 2022;97(36):429–50.
91. Gallagher SM. Paternalism in healthcare decision making. *Ostomy Wound Manage.* 1998;44:22–4.

92. Dugdale DC, Epstein R, Pantilat SZ. Time and the patient–physician relationship. *J Gen Intern Med.* 1999;14(Suppl 1):S34.
93. Ha JF, Longnecker N. Doctor–patient communication: a review. *Ochsner J.* 2010;10:38–43.
94. White C. *An uncertain cure: living with leprosy in Brazil.* United States of America: Rutgers University Press; 2009.
95. Øgård-Repål A, Berg RC, Skogen V, Fossum M. Peer support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users’ experiences. *BMC Health Serv Res.* 2022;22:549.
96. Ojeda VD, Munson MR, Jones N, Berliant E, Gilmer TP. The availability of peer support and disparities in outpatient mental health service use among minority youth with serious mental illness. *Adm Policy Ment Health Ment Health Serv Res.* 2021;48:290–8.
97. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak.* 2008;8:45.
98. Rigby M, Roberts R, Williams J, Clark J, Savill A, Lervy B, Mooney G. Integrated record keeping as an essential aspect of a primary care led health service. *BMJ.* 1998;317(7158):579–82.
99. World Health Organization. Report of informal consultation on treatment of reactions and prevention of disabilities, 11–13 December 2018, Chennai, India. World Health Organization. Regional Office for South-East Asia; 2019. <https://iris.who.int/bitstream/handle/10665/325146/sea-glp-2019.1-eng.pdf>.
100. Blok D, Global partnership for zero leprosy subgroup on epidemiologic modeling and socioeconomic research. GPZL Reports on Research Priorities. *Lepr Rev.* 2019;237–89. <https://repub.eur.nl/pub/120509/Lep237-289.pdf>.
101. Upputuri B, Pallapati MS, Tarwater P, Srikantam A. Thalidomide in the treatment of erythema nodosum leprosum (ENL) in an outpatient setting: a five-year retrospective analysis from a leprosy referral centre in India. *PLoS Negl Trop Dis.* 2020;14:1–13.
102. Butlin CR, Darlong J, Mukhier M. Access to thalidomide. *Lepr Rev.* 2023;94:186–92.
103. de Jesus SM, Santana RS, Leite SN. The organization, weaknesses, and challenges of the control of thalidomide in Brazil: a review. *PLoS Negl Trop Dis.* 2020;14:1–24.
104. N RH, George R, Eapen EP, Pulimood SA, Jacob M, George R, et al. A comparison of economic aspects of hospitalization versus ambulatory care in the management of neuritis occurring in lepra reaction 1. *Int J Lepr.* 2004;7:448–56.
105. Lusli M, Peters R, van Brakel W, Zweekhorst M, Iancu S, Bunders J, Irwanto, Regeer B. The impact of a rights-based counselling intervention to reduce stigma in people affected by leprosy in Indonesia. *PLoS Neglect Trop Dis.* 2016;10(12):e0005088.
106. Dadun, Van Brakel W, Peters R, Lusli M, Zweekhorst M, Bunders J, et al. Impact of socio-economic development, contact and peer counselling on stigma against persons affected by leprosy in Cirebon, Indonesia – a randomised controlled trial. *Lepr Rev.* 2017;88:2–22.
107. Lusli M, Peters R, Bunders J, Irwanto I, Zweekhorst M. Development of a rights-based counselling practice and module to reduce leprosy-related stigma and empower people affected by leprosy in Cirebon District, Indonesia. *Lepr Rev.* 2017;88:318–33.
108. Correia JC, Golay A, Lachat S, Singh SB, Manandhar V, Jha N, et al. “If you will counsel properly with love, they will listen”: a qualitative analysis of leprosy affected patients’ educational needs and caregiver perceptions in Nepal. *PLoS ONE.* 2019;14:1–15.
109. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human participants. *JAMA.* 2025;333(1):71–4.

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