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**A single dose of rifampicin to prevent leprosy:
qualitative analysis of perceptions of persons
affected, contacts, community members and health
professionals towards chemoprophylaxis and the
impact on their attitudes in India, Nepal
and Indonesia**

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Summary

Introduction: The purpose of this study is to investigate the impact of post-exposure prophylaxis (PEP) and the education given along with PEP on knowledge about leprosy and the attitudes and reported behaviour towards people affected by leprosy. This study is a sub-study of the Leprosy Post-Exposure Prophylaxis (LPEP) programme.

Methods: Seventy-two semi-structured interviews and five Focus Group Discussions (FGDs) were conducted in India, Nepal and Indonesia. The study population consisted of i) index patients, ii) contacts, iii) community members and iv) health professionals. The participants were selected purposively. A team of four social scientists analysed the data using a thematic analysis.

Results: The participants in this study were mostly positive and sometimes very positive about the possibility to prevent leprosy in close contacts through a single dose of rifampicin. Most respondents reported that there were no changes in their views towards leprosy or people affected by leprosy after the intervention. The study revealed that the incorrect health information that was retained and the wish of some people affected to conceal the illness poses challenges for a PEP programme.

Conclusion: The LPEP programme was perceived positively and no negative effects were reported. In this analysis, PEP did not appear to have an effect on the way leprosy or people affected by leprosy were perceived. More research is needed on providing health information that is accurate and understandable for contacts, and on approaches in which disclosure of the index patient is not required.

Introduction

Close contacts of people affected by leprosy have an increased risk of contracting the disease compared to the general population.¹ One approach that can potentially contribute to the control of leprosy is chemoprophylaxis with a single dose of rifampicin (SDR) given to contacts of leprosy patients. Several studies have shown that SDR is effective in reducing the risk of leprosy among contacts (e.g. household members, neighbours and social contacts).^{2–5} The main study that tested the effectiveness of SDR was the double-blind, cluster-randomised, placebo-controlled trial conducted by Moet *et al.* in Bangladesh.² It was concluded that SDR reduces the risk of disease in contacts with 57% in the first 2 years (95% CI: 33–72%; $P = 0.0002$).

Although these results are promising, more research is needed. Effectiveness of SDR in a research setting does not mean that the treatment is also effective in the day-to-day situation of leprosy control programmes. The Leprosy Post-Exposure Prophylaxis (LPEP) programme, a multi-country study, was set up with the aim of determining the impact and the feasibility of SDR under routine programme conditions.⁶

Leprosy is a complex condition, that not only affects patients physically, but also has social and psychological implications that must be considered in a holistic view of leprosy control.^{7–12} Misunderstandings about the aetiology, treatment and prognosis have been shown to cause delay in seeking care and contribute to stigma.^{8,11} The introduction of preventive measures against leprosy, such as the distribution of SDR for contacts of leprosy patients may change perceptions regarding leprosy. People affected by leprosy who perceive leprosy as something to hide^{12–16} may change their views if they realise that they can help family members and to prevent people in the community from getting leprosy, through the distribution of Post-Exposure Prophylaxis (PEP).

Community members who are afraid of contracting the disease, may have their fears reduced if they realise that one can prevent leprosy by taking PEP. However, there may also be negative effects. Contacts will be informed that a person who lives near them is affected by leprosy and as a result they may distance themselves from this person. The primary purpose of this study is to investigate the impact of PEP and the education given along with PEP on knowledge about leprosy and attitudes and reported behaviour towards people affected by leprosy. The secondary aim is to gain insight in the perception of a variety of stakeholders concerning PEP.

Methods

STUDY DESIGN

The Perception study is a sub-study of the LPEP programme.⁶ In this paper we report the findings of the qualitative part of this study for which a cross-sectional design was selected. Perceptions regarding leprosy, people affected by leprosy and PEP were gathered through interviews and Focus Group Discussions (FGDs) after PEP or education about PEP was provided. The results of the quantitative part are described by Mieras *et al.* (in preparation).

THE STUDY AREA

The perception study was conducted in the Dadra & Nagar Haveli Union Territory in India, Jhapa District in Nepal and Sumenep District Indonesia. These countries and study sites were selected for the LPEP programme because of the endemicity, functioning leprosy control infrastructure, declared interest of Ministry of Health, and the commitment and resources to continue contact tracing - for more criteria see Barth-Jaeggi *et al.*⁶ Data were collected between April and August 2016. Table 1 provides an overview of key indicators per study area and illustrates that the study areas differ substantially from each other, for instance with regard to religion, kinship and several leprosy indicators. Several studies that focussed on perceptions towards leprosy and people affected by leprosy have been executed over the years in these three countries.^{8,10,12,15-21} These studies demonstrate the diversity of perceptions that prevail towards leprosy and people affected by leprosy. Perceptions towards leprosy are informed by culture-specific health beliefs and, for instance, ideas on causation, which ranged from bacteria to a curse. Many studies show the existence of brutal and more subtle forms of leprosy-related stigma, but occasionally there are studies that elucidate stories of inclusion and care. In all three countries, at least one study, describes the wish to conceal the disease.¹²⁻¹⁵

STUDY POPULATION, SAMPLE SIZE AND SELECTION

The study population consisted of the following participants: i) index patients, ii) contacts, iii) community members who are not contacts, but who live near the index patient and iv) health workers. To get an overview of perceptions, 24 semi-structured interviews and 1-2 FGDs were conducted per country. The participants were selected purposively, aiming for an equal number of male and female participants. Only one person per household was interviewed. Table 2 provides an overview of the study sample, the main inclusion criteria and sample size.

Table 1. Description of the three study areas (certain indicators adapted from Barth-Jaeggi *et al.*⁶ and Tiwari *et al.*²²)

Country	India	Nepal	Indonesia
Name of study area	Dadra & Nagar Haveli Union Territory	Jhapa District, Eastern Nepal	Sumenep District, East Java
Important features	Main language	Nepali	Madurese
	Urban vs. rural	Predominantly rural and a few urban areas	Rural areas
	Religion	Hindu and Christian	Mainly Muslim
	Kinship	Nuclear and joint families	Madurese families have a tradition of living together with the extended family in a place called <i>tanean lanjeng</i> . The relationships in the family are very strong.
New cases detected in 2015–16 (NCD/100,000)	99.4	18.4	43.3
New cases in 2015–16	MB (%)	26.5	76.3
	Disability Grade 2 (%)	1.8	5.5
	Women (%)	57.8	46.2
	Children (%)	23.2	6.5
Leprosy services in the study area	Structure leprosy services	Integrated into general health system	Integrated into general health system
	Case detection	Active and passive	Mainly passive
	Focal person diagnosis	Clinicians	Non-medical health professionals
	Experience SDR	No	No
			Integrated SDR since 2012 in three districts

Table 2. Study population, inclusion criteria and sample size (per country)

	Inclusion criteria	# of semi-structured interviews	# of FGDs
Index patients	i) established diagnosis of leprosy and being on MDT treatment for at least four weeks or having finished treatment in the last 2 years ii) residency in the LPEP study area iii) older than 11 years	6 (3 men, 3 women)	1–2 with 7–10 participants (mixed or separate for male and female)
Contacts	i) household member, neighbour or social contact of an index patient or as defined by the locally adopted contact definition ii) older than 11 years	6 (3 men, 3 women)	
Community members	i) never being affected by leprosy ii) living (at least one year) in the same community as the affected person iii) not household members of an index patient or eligible as a contact) iv) older than 11 years	6 (3 men, 3 women)	
Health workers	i) involved in the PEP intervention	6 (3 men, 3 women)	

Methods

Semi-structured interviews and FGDs were used to gain insight into the participants' perceptions.

SEMI-STRUCTURED INTERVIEWS

Through the semi-structured interviews we intended to establish an in-depth conversation regarding perceptions towards leprosy. A specific interview guide was developed for each type of participant. The guide provided the interviewer with a clear layout of the interview and consisted of 10–15 questions. Each research team was encouraged to adjust questions to make sure they fitted the local context. The interview started with some socio-demographic questions including age, level of education, and type of occupation. For the index patients, the type of leprosy (multibacillary (MB)/paucibacillary (PB)) and duration of illness were also obtained. Then a couple of questions on the knowledge and perceptions of the disease were asked (e.g. 'Can you tell me what you know about the disease leprosy?' 'What causes this disease?'), followed by questions about attitudes (e.g. 'Can you tell me about the views/perceptions of people in your community regarding leprosy patients?') and questions about PEP (e.g. 'Have you heard about the PEP intervention that contacts of leprosy patients can receive against leprosy?' 'What is your opinion of this new intervention?').

FGDS

The FGDs aimed to provide a broad and diverse spectrum of opinions and ideas on the topic and allowed checking of views expressed by individuals or ranking of, for example, perceived frequency of opinions about a given issue. The FGDs were held at a location that would provide a comfortable and open atmosphere. In India they were held at an Anganwadi Centre

(a centre that provides basic health care including programmes for children and pregnant women) and in a public garden, in Nepal in the health care facilities (in a room where privacy was guaranteed and health staff was not allowed to participate) and in Indonesia at the Health Department. During the focus group discussion, the facilitator used a question and topic guide to facilitate the discussion. The topic guide was developed beforehand, but facilitators were encouraged to make adjustments if necessary. Topics included perceptions towards leprosy, attitudes towards people affected and positive and negative experiences of PEP. To guide the discussions, the FGD guide suggested using body maps and post-its. Body maps were used in India, but not in the other countries. Post-its were not used because some participants were illiterate and simply sharing and discussing people's perceptions worked well and resulted in open discussions. If considered appropriate by the field team, separate FGDs for men and women were conducted.

DATA COLLECTION

The semi-structured interviews and FGDs were conducted by country field teams who were supervised by senior researchers (for details see Table 3). In each country a 2-day training in which all key aspects of social research were covered, the interview and FGDs guide were discussed and a mock interview or role play was done. Data from the interviews and focus groups was audio-recorded and afterwards transcribed and translated to English.

DATA ANALYSES

First, data were analysed in country by the main local social scientist involved. The team in India used ATLAS.ti to analyse the data, but the other countries used no specific software package at this stage. The data analysis was done using a thematic analysis. Themes (e.g. about the disease, or about PEP) and sub-themes (e.g. causes, symptoms) were created. Differences between male and female respondents were considered. Second, the country reports were shared with the first author of this paper (RP). She analysed the findings described in the reports and identified similarities and differences between countries. Third, she went through the majority of the translations of transcripts of the interviews and FGDs

Table 3. Overview data collection team

	India	Nepal	Indonesia
Supervisors/main researchers	Social scientist (HA) (anthropologist) and a social worker	Social scientist (MS) (anthropologist) and a senior staff member of the Netherlands Leprosy Relief (NLR) (NLB)	Social scientist (TK) (anthropologist)
Field team	The staff had no background in social work or social sciences. Health workers joined the field team. They had good rapport with the people and they understood the local dialect very well.	The staff was experienced in qualitative research. The interviewers were familiar with the local language, context and thematic issues.	The staff was experienced in qualitative research (as interviewer) and spoke the local language fluently.
Number of members field teams	4	2	3

using the software package ATLAS.ti 7.5.12 to get an in-depth understanding of the main themes and subthemes, before describing the findings. The overall analyses were checked and discussed with the local social scientists to ensure validity.

ETHICAL CONSIDERATIONS

National leprosy control programmes of India and Nepal submitted the country-specific LPEP protocol and data collection instruments to the relevant ethics committees for review and approval before the initiation of field work. In Indonesia the study was done under authority of the Ministry of Health. Oral or written informed consent was obtained before conducting the interviews and FGDs with the index patients, contacts, health workers and community members. Consent forms were translated into the local languages and, in case the respondent was not literate, read out loud by the interviewer. Statements and opinions of the participants were handled with confidentiality and respect.

Results

SOCIO-DEMOGRAPHICS OF INTERVIEWEES AND PARTICIPANTS OF FGDs

In most instances interviewees were courteous and welcoming; however on a few occasions respondents did not want to be interviewed. Of the 69 respondents interviewed, 35 were male and 34 female and they were between 13 and 80 years old, with an average age of 43.1.

Table 4 shows the socio-demographic information by country and by type of respondent. No major differences were seen between the index patients in the three countries in terms of division between PB and MB types, and the number of household members. Contacts were younger on average in India and community members were slightly older in Indonesia.

During this study five FGDs with a total of 40 participants were conducted; the type of respondent and number of participants differed per country. In India, one FGD with male contacts (four participants) was held and one with female contacts (11 participants). In Nepal, one FGD with people affected by leprosy (nine participants – mixed group male and female) was held and one with community members (seven participants – mixed group male and female). Finally in Indonesia, one FGD with mixed types of respondents and mixed sexes was held (nine participants).

PEP DISTRIBUTION

All three countries followed a similar procedure to distribute PEP, which normally lasted more than 1 day and involved re-visits. A team of 2–4 health workers approached an index patient and informed this person about LPEP. If the index patient was willing to participate in the study, consent for study participation was obtained and a list of close contacts was prepared. Then the contact people on the list were approached, they were informed about LPEP and if they were willing to participate, consent was obtained. Contacts were checked for eligibility. Those eligible were given SDR. A key difference between the procedures was whether the name of the index patient was disclosed to contacts or not. In India and Nepal obtaining consent to disclose the name of the index patient to the contacts was part of the procedure. However, in practice health workers regularly did not disclose the name of the index patient to the contacts. This did not mean that the contacts did not know the name of

Table 4. Socio-demographic information interviewees

		India	Nepal	Indonesia
Index patient				
Number of interviews		6	6	6
Age; average (min – max)		42.2 (15–55)	40.2 (19–68)	46.8 (13–80)
Sex	Men; number	3	3	3
	Female; number	3	3	3
# Household members; average (min – max)		5.2 (2–12)	5.2 (5–9)	4.8 (3–7)
Type of leprosy	PB; number	4	3	2
	MB; number	2	3	4
Contacts				
Number of interviews		5	6	6
Age; average (min – max)		27.2 (16–53)	40 (33–49)	41.5 (32–60)
Sex	Men; number	2	3	3
	Female; number	3	3	3
Community members				
Number of interviews		6	6	4
Age; average (min – max)		37.2 (19–53)	35.7 (27–48)	48.8 (35–70)
Sex	Men; number	3	3	3
	Female; number	3	3	1
Health workers				
Number of interviews		6	6	6
Age; average (min – max)		35.2 (25–50)	42.5 (29–58)	31.5 (25–50)
Sex	Men; number	3	3	3
	Female; number	3	3	3
Received leprosy training	Yes; number	6	5	6
	No; number	0	1	0

the index patient or did not find out later. In Indonesia the programme was designed to prevent the name of the index patient being revealed. The idea was that health workers would say something like: “someone in your neighbourhood has leprosy”. In practice, however, contacts often knew or did find out who the index patient was.

(Potential) changes in views due to PEP

In the interviews index patients were asked whether community members would think differently about leprosy or behave differently after learning about or taking the PEP medicine. Contacts, community members and health workers were asked whether there were any changes in their views (or sometimes views in the community) towards leprosy or people affected by leprosy because of PEP. First of all it should be noted that most index patients, contacts and health workers remembered the PEP intervention, but that some community members who participated in this study had not heard about the programme. Some had heard about a free medical treatment activity that was held in the village meeting hall and knew it concerned the disease leprosy, but they did not know the function of the medicine or any other details. When asked about changes, most often respondents replied that there were no changes.

Interviewer: *"After this medicine, is there any change in the behaviour towards you?"*

Respondent: *"No, there is no change."* (Nepal, index patient, female, 49 years)

Interviewer: *"So have your views about your mother in law changed after taking the medicine?"*

Respondent: *"No."*

Interviewer: *"Haven't changed? Like you should not keep her separate or nothing will happen if you stay with her."*

Respondent: *"It was as before."* (India, contact, female, 28 years)

Interviewer: *"Have you heard whether after taking this medicine, views of any community members have changed regarding such diseased persons?"*

Respondent: *"No."* (India, community member, male, age 50)

In some cases, respondents said that views were already positive and hence there has not been any change because of PEP.

"There is no change, because there is no stigma against leprosy [patients] in me."
(Indonesia, health professional, female 50 years)

"There is no change because I already knew about leprosy and its transmission."
(Indonesia, health professional, male, 32 years)

But this was definitely not always the case, as also negative views were identified especially among community members. For example, two of the three male community members in India held negative attitudes towards people affected by leprosy, even after becoming aware of PEP. One important reason was the fear for getting infected as shown by this quote:

Respondent: *"We won't go near the diseased person because it can happen to us. So that's why we won't go. . . . Many people tell that it spreads."*

Interviewer: *"Many people tell. But what do you think?"*

Respondent: *"We also feel that."* (India, community member, male, age 50)

A few times (e.g. six times in Nepal) *potential* changes in views towards leprosy or people affected by leprosy due to PEP are mentioned. The expected changes are positive i) 'people might be more familiar with the disease', or feel 'normal about the disease' and understand 'that it is only a disease'; ii) people may understand 'it will be cured' or that there is 'medicine for the control of leprosy'; iii) people might not take the disease negatively; iv) people may 'get involved with the leprosy affected' and may 'treat the leprosy affected equally'. Little evidence was collected about *actual* changes in views towards leprosy or people affected by leprosy due to PEP. The first positive change that did occur is an increased awareness about leprosy and a willingness to learn more about the disease in order to be able to share information with others. A respondent from India said: *"I like to know more about the disease so that I can tell others and prevent it spreading"* (India, contact, male, 12 years). An index patient in Nepal also underlined the importance and his willingness to share information with others. He said: *"We should also tell everyone that this disease is not dangerous, it is curable if medication is taken and that one must go to the nearby health post if they suspect about the disease"* (Nepal, index patient, male, 19 years). A second positive change that did occur because of PEP is an increased willingness to stay close to a person with leprosy. As shown by this quote from a contact in India:

Interviewer: *"If I have leprosy will you be scared that it will happen to you if you stay with me?"*

Respondent: *"No."*

Interviewer: *"Not even a little bit. Why?"*

Respondent: *"Because I have taken the pill (medicine)."* (India, contact, female, 16 years)

Positive views about PEP

Overall, index patients, contacts, community members and health workers in the three countries were positive about the distribution of PEP. Reasons why the distribution of PEP was perceived as a good intervention included the perception that PEP would reduce the risk of a contact developing leprosy, prevent the spread of the disease in the wider population, and the idea that it is better to prevent than to cure a disease. Also some more specific reasons per subgroup were identified. Some index patients were very positive about the distribution of PEP and described the intervention as *'meaningful'* and a *'good cause'*. One reason is that index patients are concerned about the health of their family members and neighbours and wish that because of PEP the disease will not spread to them.

Interviewer: *"Is it okay to give medicine like this to everyone?"*

Respondent: *"Yes, it's a million times good cause. Providing [PEP] to the public is a big deal."* (Nepal, index patient, male, 68 years)

Several contacts and community members were very positive about the distribution of PEP. Some stated that they had great confidence in the effectiveness of the medication. Also the perception that leprosy is a severe disease with possibly severe consequences was a reason why they were positive about the programme.

"The health worker came and said this medicine is for those people who are in touch with a leprosy patient so that other people will not get leprosy. They counsel in that way and we said ok. Then we all took the medicine. We are confident that we did not get leprosy after this medicine. If there is another dose of this medicine we are ready to take it too. Prevention is better than cure, we believe that. This medicine will protect us from leprosy." (Nepal, contact, female, 40 years)

"It's obviously good I don't want leprosy." (India, community member, male, 40 years)

"These types of programmes are good. It is for our benefit so that we do not get affected by the disease and this makes us feel good If we get affected by this disease we can develop wounds in our body. Then our body parts will be deformed and even our legs and hands might get decomposed and we might have to cut it off. By taking this medicine, we will not die anyhow. So, I don't feel any hesitation in taking this medicine. It is good." (Nepal, contact, male, 40 years)

Health workers were particularly positive about the distribution of PEP. They think it is a good programme and several expressed their hope that this activity is not a one-time activity. Besides reducing the spread of the disease, some other benefits of PEP were also mentioned by health workers, including more knowledge and skills among health staff, which increased self-confidence and job satisfaction. Also, aspects of the programme such as the active case finding (finding hidden cases) and the opportunity to provide counselling were appreciated by the health workers. Some mentioned that the workload did increase because of PEP, but this

was not problematic. One health worker from Nepal said *'but this [the workload] has to be taken positively since it concerns the life of the leprosy affected'*. Health workers were asked whether PEP has any disadvantages and most of the time no disadvantages are mentioned. Health workers in India and Indonesia mentioned the side effects of reddish urine, which can make contacts feel confused and anxious.

Occasionally some doubts and reluctance towards PEP were mentioned during the interviews and FGDs. One health worker said that most contacts are willing to take the medicine, but that some people have doubts. He said *"we have to make them sit with us, briefly explain to them what it is for, after that they understand"* (India, health professional, male, 22 years). When the interviewer asked what kind of explanation is provided, the respondent said *"That there is no harm in taking the medicine. If you take it, you will not get the disease"* (see also next section). Health workers and others do emphasize in the interviews and FGDs that education is important because people's knowledge about leprosy is still limited.

Three ways interviewees remembered or interpreted the information given by the health worker

The index patients and contacts were asked to recall the information about PEP given by the health worker. The interviews took place about a year after PEP was given and quite a few index patients and contacts had difficulties remembering the medicine that was given and the explanation that was provided by the health worker. Three different ways of remembering or interpreting the information given by the health worker were identified. Some say that the 'red pill' will reduce the risk of developing leprosy (which is correct). Others believed that one will not develop leprosy if the red pill is taken. This is not completely correct; PEP only reduces the risk. Again, others said that if you do not take the medicine you will get leprosy. Table 5 provides some quotes that illustrate these three different views.

WISH TO CONCEAL

The wish to conceal the illness of some people affected by leprosy poses a challenge for PEP. In this section we will address the issue of disclosure in more detail. Index patients in all three countries were asked whether they had shared the diagnosis with family, friends and neighbours. Almost all index patients had shared the diagnosis with their family, but in all three countries there were index patients who did not share the diagnosis with neighbours and or friends. Not all disclosure is voluntary or proactively done by the person affected. One

Table 5. Three perspectives towards the information given by the health worker

Perspective	Quotes	Reference
1	<i>"There is less change of leprosy"</i>	Nepal, index patient, female, 49 years
2	Interviewer: <i>"Do you know why were you given the medicine?"</i> Respondent: <i>"That I don't know. I was given the medicine with the information that the patient has got this disease but you won't get it if you take this medicine."</i>	India, contact, female, 28 years
3	<i>"If you do not take this tablet you will get this illness."</i>	India, index patient, male, 35 years
	<i>"If not eaten at that time, then it will happen."</i>	India, index patient, male, 51 years

index patient said that he did not actively inform his neighbours, but that they “*tend to find out easily about the things happening around*” (Nepal, index patient, male, 19 years). Another index patient said he felt some hesitation when sharing the diagnosis with friends and that he wondered if friends would hate him for it. They responded positively, however, as shown by this quote.

“Take your medicine on time properly and it will be cured, leprosy is nothing dangerous” he [his friend] said. I go to his home but he doesn’t discriminate me. . . . He gets angry with me if I forget to take medicine but he does not show hatred towards me.” (Nepal, index patient, male, 68 years)

This is not always the case as the example of another index patient shows.

“[When] I told my friends that I have leprosy, my friends had different reactions, some were relaxed and did not mind, some felt pity and some even bullied me, especially my friends at school. I did not go to school for three months because [I was] ashamed of being bullied by friends.” (Indonesia, index patient, male, 13 years)

Neighbours avoided and discriminated against this person. Also, one index patient from Nepal is convinced that leprosy patients do not share the diagnosis with neighbours as shown by this quote:

Interviewer: *“Do you share about the problems, difficulties with your close neighbour, relatives?”*

Respondent: *“No, I just shared [my diagnosis] with a medical person and with my family. . . . No one shares it with neighbours . . . because they don’t want to be hated by others, don’t like to be discriminated. The society runs away from the leprosy patient, they even treat leprosy patients like witches.”* (Nepal, index patient, male, 53 years)

The wish to conceal because of stigma seems to be highest among the participants in this study from Indonesia, followed by India and lastly Nepal. In Indonesia, index patients do not share the diagnosis as it is perceived to be a personal matter, but also because they are ashamed and fear to be shunned. A wish to conceal was not always a symptom of stigma. The interviews in India show that some people conceal because “*it was nothing big. And it was cured early*” (India, index patient, male, 51 years) or because it would not make a difference in their perspective “*If they don’t know or if they know what difference will it make?*” (India, index patient, male, 35 years). Table 6 provides an overview.

Table 6. Overview number of participants who disclosed and who have objection to reveal name to contacts

	Before intervention disclosed leprosy status to			Objection to disclose name to contacts for LPEP intervention			
	Nobody	Only family	Family + (a few) friends/neighbours	Yes	Some doubts	No	Unknown
Nepal		2	4	1	1	4	
India	1	3	2			4	2
Indonesia		4	2			3	3

Index patients were asked how they feel about disclosing their name to contacts for PEP. Only two had doubts or were not okay with disclosing their name and in some cases (five) the answer was not clear (see Table 6). Most said they were okay with this (11 of 18), including those who had not informed people outside their own inner circle as shown by this quote:

Interviewer: *“Do you tell [other people] that you have leprosy?”*

Respondent: *“No. Only to [name removed] and then to [health professional]. I was afraid people came to know, so I went directly to [health professional]. No one knows here even though I got this disease. Why, sir, should I tell others about my disease while it is truly my disease only?”*

. . .

Interviewer: *“In order to explain the reason why your friends and neighbours should take preventive medicine, do you feel comfortable if the health worker tells others that you are affected by leprosy?”*

Respondent: *“Yes. I will help. I’ll [tell] I had this kind of illness. . . . Poor me. I wish that all my neighbours are healthy. . . . I will help to accompany [them] to [health professional]. But, hopefully there is no one. If anyone asks me, yes, I will tell that I was affected by the disease, but I have recovered because of being treated by [health professional].”* (Indonesia, index patient, female, 50 years)

Reasons provided by index patients during the interviews for being okay with disclosing the disease to contacts include: i) already being cured; ii) the availability of MDT; iii) the idea that leprosy is a normal disease that everyone can get; iv) the belief that people will not stigmatise; v) the conviction that others would stand up against any stigma that might occur; and vi) the strong wish that family and neighbours will not get the disease. Reasons for having doubts or for not being okay with disclosing the disease include: i) a low level of knowledge about leprosy in the community; ii) the current negative perceptions in society towards leprosy; iii) the negative talking of people that might occur as a result. The extent of the challenge posed by the wish to conceal for PEP differs per research setting but seems to be highest in Indonesia, though it is an important issue in all countries.

The need for disclosure makes one index patient (Nepal, index patient, male, 53 years) critical about the programme. According to this respondent it would be better if the name of the person affected and place are not disclosed. He believes that it is more important to have an awareness programme, than a medication distribution programme. In Nepal, the need for awareness campaigns is frequently mentioned by different types of respondents. Awareness campaigns are perceived by these respondents as a requirement for PEP to be effective. Table 7 provides some quotes illustrating the reasons from being supportive of or against disclosing the disease.

It is not only the wish of the index patients to conceal, but also the procedures in certain health centres that are important for the LPEP programme. A health professional in Indonesia shared about the practice of health professionals, who decided not to mention the actual diagnosis to the patients to avoid internal and external stigma:

“[Name health centre] has its own strategy in approaching leprosy sufferers, according to informants, the status of [being affected by] leprosy will as much as possible be

Table 7. Reasons for being supportive of or against disclosing name

Reasons	Quotes	Reference
For being okay with disclosing the name	<p>Interviewer: <i>"If someone says that you are leprosy patient. . . . Do you feel uneasy in such case or not?"</i></p> <p>Respondent: <i>"No, I don't feel so. Now there is medicine. It is not like other diseases."</i></p> <p>Interviewer: <i>"So, in your close neighbourhood, if we are to say your name openly and tell them that you are a leprosy affected person and because of that they have to take the medicine during this programme, is it alright for you? Won't you feel uncomfortable with it?"</i></p> <p>Respondent: <i>"No, No. I have already taken the medicine and I don't think the society will hate me isn't it? People know me well in our village. If somebody was to throw me out from the village even after taking the medicine and getting cured, then the whole village will obviously take action to that person for sure."</i></p> <p><i>"Well we'll have contact with the neighbours very often, so if they take the medicine it will not spread to them and neither to their families too. . . . I have this disease but I don't want other to have it. I want it to stop spreading."</i></p> <p><i>"Yes, I am willing to explain to friends or neighbours to take preventive medicine, because I do not want that there are friends or neighbours who suffer from illness like me."</i></p>	<p>Nepal, index patient, female 2</p> <p>Nepal, index patient, male 68 years</p> <p>Nepal, index patient, male 19 years</p> <p>Indonesia, index patient, male, 13 years</p>
For having doubts or being not okay with disclosure	<p>Respondent: <i>"It will be not that okay at first I think. But if there are people who are in contact with our family, who come and go frequently in our house, then they should be provided the medicine so that they would not be affected because of me."</i></p> <p>Interviewer: <i>"So, they must be provided the medicine right?"</i></p> <p>Respondent: <i>"Yes."</i></p> <p>Interviewer: <i>"So, if we tell them all of these things, will be okay for you?"</i></p> <p>Respondent: <i>"It's their perception about the disease. They will obviously talk about things that had happened, but still if they get prevention from the disease after talking about the situation, then I think I should at least compromise on that. . . . It's not that my mentality is like this but I would feel a little bit hurt since I know that the people in the community will obviously think about it in a negative way. It's not that I'm tensed up because they will know about my condition but about the things they will say."</i></p> <p>Interviewer: <i>"What other people will say about it?"</i></p> <p>Respondent: <i>"Yes, because I already know what kind of thinking and mentality they have and what they might talk about."</i></p>	<p>Nepal, index patient, female, 24 years</p>

hidden from the surrounding people and from the person affected by leprosy her/himself. And it will only be told to the sufferer when [she/he] already has or will recover from leprosy, this is to prevent [the affected person's] exclusion from the surrounding community and to avoid a feeling of being inferior in the patient her/himself." (Indonesia, health professional, female, 50 years)

Discussion and conclusion

The study described in this paper aimed to understand the effect of prophylactic treatment against leprosy on perceptions towards leprosy and people affected by leprosy and to identify stakeholders' views regarding the programme. Changes in perceptions towards leprosy or people affected by leprosy were not identified in the qualitative part of this study, though participants did identify some positive changes that might occur. The preliminary findings from the quantitative data of the LPEP perception study did show perceived changes in perceptions towards leprosy or towards people affected by leprosy though they were inconsistent in the three countries and mainly seen in Nepal (Mieras *et al.*, in preparation). The quantitative perception study followed a before and after survey design. Before the implementation of the LPEP Programme knowledge, attitude and behaviour of the respondents regarding leprosy and regarding people affected by leprosy were documented. These data were compared to their perception 1–1.5 years after the start of the PEP intervention. The preliminary analysis shows that people's knowledge about leprosy increased and that they think differently about leprosy, but do not report behaving differently. Participants in this study are mostly positive and sometimes very positive about the possibility to prevent leprosy in family members, neighbours and other close contacts through prophylactic treatment. The possibility of infecting family members, neighbours and social contacts is a key concern of people affected, as was also shown in other studies executed in India, Nepal and Indonesia.^{8,12,14,23–25} Reducing the chances for this is very meaningful and important for the index patients. Likewise, the possibility of getting infected can be a worry of family members and close contacts, and reducing the risk of this they found very important.^{10,26}

The findings in this study also provide more insight into two key challenges of a PEP programme for leprosy. As expected, disclosing the disease was problematic for some index patients. Reservations of index patients concerning disclosure were respected in the LPEP programme by not including them in the study without consent. Studies in Indonesia, Bangladesh, Nepal and India have shown that some people affected by leprosy wish to conceal their disease.^{11–15,27} A key reason is the risk of being stigmatised.^{12–15} Respecting the wish to conceal is important, not only for chemoprophylaxis programmes, but for other contact-based interventions and stigma reduction interventions. For most index patients in this study disclosure was not an issue, but some would have preferred to conceal their condition, while still wanting to give their neighbours the opportunity to receive PEP. The desire to conceal the disease appeared to be the highest in Indonesia, but was also seen in India and Nepal. The study of Steinmann *et al.*, however, shows that only 48 (0.7%) of the total 6,646 index patients that were registered in six initial countries where the LPEP programme was implemented, actually refused the disclosure of their status to their contacts and hence participation in the study.²⁸

There are multiple ways to deal with this. Circumstances under which more index patients are willing to disclose could be facilitated. The reasons provided by index patients in this study for being willing or unwilling to disclose their names to contacts (e.g. knowledge about leprosy and MDT, and positive attitudes and supportive behaviour in the community) provide indicators of what is needed. Increasing knowledge about leprosy and fostering positive attitudes and behaviours is possible, as shown in several studies.^{29–32} The need for initiatives like these was very apparent in the interviews. Especially in Nepal, participants believe that PEP distribution should not be a single intervention, but that it should be combined with awareness programmes. The visits of the health workers to the index patients and contacts do indeed provide a great opportunity for creating awareness and de-stigmatising activities. Research into appropriate, feasible and effective ways to combine this with PEP-related activities is needed.

Alternatively, PEP distribution methods where disclosure is optional have been designed. Different approaches in which the identity of the index patient can be protected are currently piloted as part of the LPEP programme. For example: the extended contact tracing approach through self-screening in Sumenep district and the blanket approach in Lingat village, on Selaru island in Southeast Maluku, Indonesia. Because larger numbers of contacts were included, there is no need to disclose the identity of the index patient. It is important to realise that even if the name of the index patient is not revealed during the visit of the health workers, it is unknown what happens in the community when health workers leave. Research into these processes would be of value.

The second key challenge is the health information given to index patients and contacts by health workers and its retention. Some participants of this study, for instance, thought they would not develop leprosy if they were to take the SDR. This is problematic, in the sense that SDR only reduces the risk of developing leprosy.² We know that on the informed consent sheet specific information about PEP was provided:

. . . As you know you have been diagnosed with leprosy and are now receiving treatment for it. There is slight chance that the disease has been transmitted to your family members or neighbours also. There is now a drug called rifampicin that is effective in reducing the risk that contacts of leprosy patients get leprosy themselves. Taking only one dose is enough. This is called PEP. PEP does not give 100% protection, so it remains possible for people who have had the preventive medicines to still develop leprosy. . . .³³

No observations were, however, done during the distribution of PEP so we do not have data on how the information was provided. High quality health information including a warning that there is still a small chance of developing leprosy and instructions on where to seek care if symptoms appear, should effectively be communicated to index patients and contacts while distributing PEP. A major advantage of giving SDR is that contacts of leprosy patients are examined and through this become more aware of leprosy symptoms. So when lesions appear, contacts might recognise these as signs of leprosy and seek care at the health facilities.

These two challenges underline the importance of careful training of the staff involved in the PEP distribution. Staff should be taught high ethical standards and be able to provide accurate, clear and understandable health information about leprosy and PEP. They should be taught to de-stigmatise leprosy as much as possible.

The first limitation of this study is the difference in quality of data from the three study sites. The data from India and Nepal were of high quality, while the data from Indonesia were somewhat less rich and in-depth. Collecting data that is comparable in three very different settings by three different field teams is challenging. The impact of this is that we could not unpack some of the underlying reasons or identify contributory factors for some of the findings in Indonesia, and were restricted in comparisons between the three countries. The second limitation was that there was little information about actual changes in perception regarding leprosy. This may also be due to interviewers not probing enough to get the data, limited recall of the respondents concerning their perception before PEP was introduced and the cross-sectional nature of the study. This cross-sectional study design is the third limitation. Future studies in this area should start collecting perspectives ahead of the distribution of SDR, include observations and interviews during the distribution of SDR, and a follow-up study after the distribution after a few months (so that participants still remember the SDR) and after a year or more to assess long term effects. This would provide a more comprehensive understanding of changes in perceptions. We would also recommend a larger study sample (preferably until saturation is achieved) and think that studies in other settings and countries where SDR is introduced would provide interesting insights and comparisons.

In conclusion, the LPEP programme was perceived very positively and no negative effects were found. More experience is needed with providing health information that is accurate and understandable for contacts and with approaches in which disclosure of the index patient is not required.

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