

Towards a cross-neglected tropical disease perception study toolkit: a prototype toolkit developed in the field of leprosy

Anna T. van 't Noordende^{a,b} & Wim H. van Brakel^a

^aNLR, Wibautstraat 137K, 1094 DN Amsterdam, The Netherlands

^bErasmus MC, University Medical Center, Doctor Molewaterplein 40, 3015 GD Rotterdam, The Netherlands

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Summary

Objectives: A negative perception of leprosy and other neglected tropical diseases (NTDs) is a problem that is seen globally. It results in discrimination, social exclusion and widespread mental health problems. There is a need for a standardised toolkit to assess the different aspects of perception of leprosy or other NTDs, including essential knowledge of these conditions.

Methods: We developed the Perception Study Toolkit (PST). This toolkit consists of four measures, a Communication Needs Assessment questionnaire, Knowledge Attitudes and Practices questionnaire, the EMIC community stigma scale and the Social Distance Scale. It also comprises qualitative methods to investigate perception: the way people see leprosy, what they know about leprosy and their attitudes, beliefs and reported behaviour towards persons affected by leprosy. The PST is a toolkit and comprises separate instruments that assess different aspects of perception, it is also possible to use only one or a few of the instruments of the PST.

Results: This is not applicable because this is not a study.

Conclusions: The PST can help identify specific beliefs, knowledge gaps, misconceptions and fears to inform community education and behaviour change interventions and can be used to monitor and evaluate such interventions. Using a standard toolkit like the PST would enable assessment of the perception of leprosy or other NTDs that would allow comparison across projects and countries including monitoring of changes over time.

Keywords: Leprosy, social aspects, stigma, attitude, NTD

Introduction

Leprosy is an infectious neglected tropical disease (NTD) that primarily affects the peripheral nerves and skin. If left untreated or detected late, leprosy may lead to severe visible and permanent disabilities.^{1,2} Persons affected by leprosy often experience stigma and discrimination, especially if they have visible impairments due to their condition.^{3,4}

Health-related stigma refers to a negative social response to a disease. Stigma exists ‘when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold’.⁵ Discrimination is enacted stigma, it is acting on negative attitudes.^{5,6} Stigma does not always have to result in discrimination (e.g. people who have negative feelings or attitudes towards a person or group, but who do not act on this). Discrimination may also be caused or aggravated by other factors (e.g. fear, racism, sexism).⁶

Stigma and discrimination affect and disrupt many areas of a person’s life, such as family and social life, social participation and mental well-being.^{4,7–10} Disabilities due to the condition may cause similar effects. Leprosy causes disability and is severely stigmatised. As a result, persons affected by leprosy may suffer depression, anxiety, suicide (attempts), mental distress, low self-esteem and low quality of life.¹¹ Because of disability, stigma and poor mental health, they often experience social participation restrictions such as barriers to employment and social life, education or marriage.¹² This may impose a social and economic burden on already marginalised families.^{9,13} Family members and friends may also experience stigma and discrimination.¹¹ In addition, a negative perception of leprosy makes people reluctant to seek treatment, which may result in a delay in diagnosis or cure, increasing the risk of impairments that otherwise would have been prevented.² Stigma is also a barrier to case finding and treatment adherence, and therefore timeliness and effectiveness of treatment.^{7,14,15}

Perception is how individuals or groups “see” an object, person, event or institution.^{16–18} Perception is a broad concept; it may refer to how an individual or group “sees” others (social perception)^{16,17} but also refers to a person’s interpretation and understanding of a disease and its potential consequences (disease or illness perception).¹⁸ Perception comprises knowledge, beliefs, attitudes and emotions, which in turn influence and are influenced by personal factors (e.g. personality, experience) and environmental factors (e.g. culture, religion).^{16,17} Perceptions about leprosy, such as knowledge, attitudes and cultural beliefs, play an important role in stigma and early case finding.^{14,19–28} For example, people’s knowledge influences their awareness that signs and symptoms are due to leprosy which, if awareness is lacking, hampers early reporting of leprosy.^{29–31} In addition, community attitudes towards persons affected by leprosy are strongly influenced by local misconceptions, cultural and religious beliefs and fears that may be linked to this. For example, in some cultures leprosy is linked to supernatural causes, witchcraft, sins or immoral behaviour, or believed to be hereditary.^{19,22,26,28,29} These misconceptions and beliefs are often different in different cultures and countries. Understanding these, as well as local knowledge gaps, is crucial to understand explanatory models, attitudes and behaviour.^{29,32}

Efforts to address stigma and discrimination have focused on a number of areas including the stigmatised person, the stigmatising context and policy and systems.^{33,34} Positive outcomes in terms of reduced stigma have been reported for interventions like peer counselling,^{35–37} direct contact interventions such as community meetings, and indirect contact such as participatory videos and comics.^{37–40} For interventions to be effective, i.e. to increase positive attitudes and acceptance of persons affected by leprosy, it is important that they are culture-specific and address local beliefs and knowledge gaps.³² Only by understanding and addressing these

local beliefs and perceptions, can we design effective public messages about leprosy and other interventions. Much leprosy-related suffering can be prevented by positively influencing the perception of leprosy and by reducing or eliminating stigma.

Many knowledge, attitudes and practices (KAP) surveys and stigma studies have been conducted. These studies have used a variety of tools: in-depth interviews and/or focus group discussions, validated questionnaires or questionnaires developed specifically for the study. At least 33 studies have developed their own questionnaire to assess knowledge about leprosy^{24,41–44} or knowledge, attitudes and practices about leprosy.^{20,22,27,28,45–68} These questionnaires are often not described well or not included in the articles. The field of leprosy would benefit from having more standardised tools, also for assessing the perception of leprosy to be able to measure progress and compare between projects.

Recently, 'leprosy perception studies' were conducted in endemic districts in Brazil, India, Nepal and Indonesia.^{26,69–72} The purpose of these studies was to investigate the perceptions regarding leprosy, i.e., the way people see leprosy, what they know about leprosy and their attitudes, beliefs, fears and reported behaviour towards persons affected by leprosy. Information of these studies is used to develop context-specific community education and behaviour change interventions that are implemented to raise awareness about leprosy and to improve knowledge, attitudes and behaviour towards (persons affected by) leprosy in the context of the PEP++ project, a cluster-randomised trial to test an enhanced regimen for post-exposure prophylaxis against leprosy. The objective of this paper is to describe the Perception Study Toolkit (PST), which was used in the PEP++ project, to implement 'perception studies' for the assessment and monitoring of knowledge, attitudes and practices regarding leprosy. We propose that the PST could form the basis for developing a standard toolkit to assess perception of leprosy and, with minor adaptations, other NTDs that would enable comparison across projects, countries and would allow monitoring of changes over time. We are not aware of an alternative toolkit to measure perception that is used in the field of NTDs.

Material and methods

PURPOSE OF THE PERCEPTION STUDY TOOLKIT

The purpose of the PST is to investigate the perceptions regarding leprosy: the way people see leprosy, what they know about leprosy and their attitudes, beliefs, fears and reported behaviour towards persons affected by leprosy. With minor adaptations, the PST can also be used for other NTDs. It should be noted that the PST is a toolkit and not one instrument with different subscales (it is not intended to calculate an overall score). The PST comprises separate instruments that assess different aspects of perception, it is also possible to use only one or a few of the instruments of the PST, depending on the purpose of the study.

CONTENT OF THE PERCEPTION STUDY TOOLKIT

The PST comprises questions to assess knowledge regarding key aspects of leprosy, such as what patients were told about their diagnosis, how they would prefer to call the disease, what people believe to be early symptoms and causes of leprosy, how it transmitted, whether it can be treated, etc. Perceived attitudes, behaviours and fears regarding leprosy in the community are explored and measured using the EMIC Community Stigma Scale (EMIC-CSS) and the Social Distance Scale (SDS). In addition, semi-structured interviews and focus group discussions are held to obtain an in-depth perspective to complement and help interpret the quantitative data.

Table 1. Instruments included in the Perception Study Toolkit

Tool	Type of tool	Purpose of tool
Demographic information form	Form	To collect basic participant information such as name, age, gender, address, occupation and education
KAP Questionnaire	Questionnaire	To assesses knowledge, attitudes and beliefs of individuals regarding leprosy
Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS)	Scale	To assess perceived attitudes and behaviour towards affected persons of community members in general
Social Distance Scale (SDS)	Scale	To assess how close a contact or relationship a respondent is willing to have to a person affected by leprosy as a proxy for their attitudes
Communication Needs Assessment (CNA) questionnaire	Questionnaire	To assess what means of communication people are using, what means they are familiar with and what means they find most acceptable
Semi-structured interviews	In-depth interview	To establish an in-depth conversation and understanding regarding perceptions towards leprosy
Focus group discussions (FGDs)	Focus group discussion	To provide a broad and diverse spectrum of opinions and ideas on knowledge and perceptions towards leprosy.

Demographic data are also obtained from all participants. Each instrument is briefly described below. An overview can be found in Table 1.

Demographic information

A demographic information form can be used to collect basic participant information such as name, age, gender, address, occupation and education. It is important to collect data on factors that may influence perception of leprosy or for practical reasons such as follow-up or dissemination of results.

KAP questionnaire

The 17-item KAP questionnaire assesses knowledge, attitudes and beliefs of individuals regarding leprosy. The questionnaire consists of yes/no/don't know questions and multiple answer questions. Topics include perception regarding cause and treatment of the disease, emotions after hearing the diagnosis and the emotions and attitudes of family, friends and neighbours towards leprosy. All questions are open ended, it is therefore important not to read out the answer options. Eight items on the KAP questionnaire can be used to assess knowledge of leprosy, to calculate a total knowledge score. On some of the questions, multiple answers are possible. A total score of nine can be obtained on the KAP when considering answers correct if the correct answers were given regardless of any incorrect answers. 'Adequate knowledge' is defined as a score of six or more out of nine on the KAP (>67% correct), 'moderate knowledge'

as a score between 3 and 6 (33–67% correct) and ‘poor knowledge’ as a score of three or less (<33% correct) on the KAP questionnaire. The KAP questionnaire has been used in several leprosy studies in India, Nepal, Indonesia and Brazil between 2012 and 2019, reports of four of these studies have been published to date.^{26,69,70,72}

EMIC community stigma scale

The 15-item Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) measures perceived attitudes and behaviour towards affected persons of community members in general. The EMIC-CSS covers areas of life that may be affected by stigma, such as concealment, avoidance, pity, shame, being made fun of, respect and marriage (prospects). During the interview, the participant is asked to respond to 15 questions, offering four response options that are valued with different scores: yes (2), possibly (1), no (0) and don't know (0). The EMIC-CSS total score ranges from zero (no negative attitudes) to 30 (most negative attitudes). The EMIC-CSS has been validated among community members of persons affected by leprosy in Brazil, India, Nepal and Indonesia.^{24,73–75}

Social distance scale

The 7-item Social Distance Scale (SDS) measures how close a contact or relationship a respondent is willing to have to a person affected by leprosy as a proxy for their attitudes. The interviewee will start the SDS by reading the gender-specific vignette, a short description or word picture of a person with leprosy (separate for men and women). The vignette is followed by seven questions concerning the person in the vignette. The participant can respond to the questions by choosing one of the four options which are valued with different scores, i.e. definitely willing (0), probably willing (1), probably not willing (2) or definitely not willing (3). The SDS total score ranges from zero (no negative attitudes or fear) to 21 (most negative attitudes/fear). The SDS has been validated among community members of persons affected by leprosy in Indonesia.⁷⁴ The SDS has not been formally validated for use with persons affected by leprosy in India, but has been translated to Hindi, and partially validated and used in studies in Uttar Pradesh and Dadra & Nagar Haveli, India.^{69,70}

Communication needs assessment

The 7-item Communication Needs Assessment (CNA) questionnaire is used to assess what means of communication people are using, what means they are familiar with and what means they find most acceptable. The results are used to inform the choice of media when designing education and behaviour change interventions. All questions on the CNA are open ended. Since questions are context-specific, for example ‘what TV programmes do you usually watch?’, the answer options should be adjusted according to make them appropriate for the context they are being used in. The CNA is only used when the PTS is used to develop community education and behaviour change interventions, as input/inventory of communication preference.

Semi-structured interviews

The aim of the semi-structured interviews is to establish an in-depth conversation regarding perceptions towards leprosy. The interview guide provides the interviewer with a clear layout of the interview and, depending on type of respondent, consists of 10–15 open questions.

Focus group discussions

Focus group discussions provide a broad and diverse spectrum of opinions and ideas on knowledge, sources of knowledge and reasons behinds certain views and perceptions and

allows checking of views expressed by individuals or ranking of e.g. perceived frequency of opinions about components of perception or causative factors. During the focus group, the facilitator will use a question and topic guide as well as a timetable to conduct the discussion smoothly.

EXPERIENCES WITH ITS USE

The PST has been used in several studies in Brazil, India, Nepal and Indonesia already.^{26,69–72} The instruments can be used to investigate (gaps in) knowledge, specific fears, attitude and practices and to compare scores between participant groups, countries and in different points in time. Some examples of the use of the PST are provided below.

Investigate and assess perceptions regarding leprosy

Ballering and colleagues⁶⁹ found that community members in Chandauli district in India had a more tolerant and accepting attitude when it comes to renting out a room to, being a colleague of or living next to a person cured from leprosy. At the same time and confirming findings from elsewhere, a majority of respondents were reluctant to have a person affected by leprosy as a caretaker of their children, or have a person affected by leprosy marry one of their children.⁶⁹ The authors also report total scores on the KAP questionnaire, SDS and EMIC-CSS.⁶⁹

Interaction between knowledge, beliefs, attitudes and fears

The PST has been used in a study in Fatehpur district, Uttar Pradesh, India, to examine the interaction between knowledge, beliefs, attitudes and fears.²⁶ Using multivariate regression analysis, the authors found that health workers, participants who knew someone affected by leprosy, men, and participants with better knowledge of leprosy had more positive attitudes towards persons affected by leprosy.²⁶ The authors also determined the factors that had an independent effect on knowledge and community stigma. These findings were later used as input for developing context-specific community education and behaviour change interventions⁷⁶.

Added benefit of using a mixed methods approach

The study in Fatehpur district, India²⁶ also illustrates the complementary nature of the in-depth interviews and focus group discussions. While the EMIC and SDS scales revealed negative attitudes and stigma towards persons affected by leprosy, the interviews provided in-depth insights in the reasons for exclusion. Avoidance of persons affected by leprosy was often linked to the belief that leprosy transmits by touch and (fear of) transmission.²⁶ In addition, a study that used the PST in India, Nepal and Indonesia emphasised '(...) the importance of collecting both quantitative and qualitative data on a given topic, since results from the latter are often not generalisable'.⁷⁰

Evaluation of an intervention

Mieras and colleagues⁷⁰ used the PST to assess the impact of the Leprosy Post-Exposure Prophylaxis (LPEP) project approximately one year after the start of its implementation in India, Nepal and Indonesia. They included persons affected by leprosy, close contacts and community members in each country before and after the start of the intervention. Their study provided insight in changes in KAP questionnaire, EMIC-CSS and SDS scores in each of these groups in the three countries. They found a significant increase in knowledge of leprosy (from

4% correct to 29% correct answers on the KAP questionnaire) and a decrease in SDS and EMIC-CSS stigma scores in community members in Nepal after the intervention.⁷⁰

The implementation protocol of the PST, that comprises recommendations for using the toolkit in the field, can be found as additional information file 2.

Discussion

This paper describes the Perception Study Toolkit. The toolkit consists of qualitative and quantitative (mixed) methods to allow for triangulation and provide rich data. This allows for a comprehensive understanding of the perception of leprosy. By using a standard toolkit to assess perception of leprosy, data can be compared across projects and countries, and progress can be monitored over time. We are not aware of an alternative toolkit to measure perception that is used in the field of NTDs.

We found 33 knowledge, attitudes and practices (KAP) surveys and stigma studies that developed their own questionnaire to assess knowledge about leprosy^{24,41–44} or knowledge, attitudes and practices about leprosy.^{20,22,27,28,45–68} These questionnaires were often not described well and were not included in the articles. The KAP questionnaire used in the PST Toolkit covers eight main topics: early symptoms, cause, mode of transmission, treatment, prevention, curability, contagiousness when on treatment and prevention of disabilities. The questions about curability and prevention have been added after consultation with leprosy experts, these two questions have not yet been pilot tested. We think the field of leprosy would benefit from having more standardised tools assessing the perception of leprosy and believe the KAP questionnaire could be such a standardised tool. We called the KAP questionnaire a questionnaire, because it has not been formally validated as a scale. This should be done in a future study, but we would first like to offer it to readers of this article for further improvement. Readers are invited to suggest further improvements to the KAP questionnaire.

Standardised tools used in other KAP or stigma studies are the EMIC-CSS^{23,24,28,37,41,44,77} and de SDS.^{23,37} The EMIC-CSS and SDS are also included in the PST. Since the EMIC-CSS questions are phrased in a more general way (for example 'would leprosy be a problem for a person to get married?') and the SDS questions are directed to the responded personally (for example 'how [would *you* feel about] about having one of your children marry someone like [name of person affected]?'), using both the EMIC-CSS and the SDS allows for the exploration of community and personal attitudes towards persons affected by leprosy. Interestingly, some studies using KAP or stigma surveys among persons affected by leprosy have also included tools to assess perceived or internalised stigma or social participation. The Participation Scale,^{23,78–80} which measures social participation, an outcome directly affected by stigma, and the EMIC stigma scale for affected persons^{42,79,80} have most frequently been used, followed by the Internalized Stigma of Mental Illness scale,^{23,80} the Jacoby stigma scale,⁷⁹ Discrimination Assessment Form⁷⁹ and the Leprosy Dehabilitation Scale.⁸¹ Even though the KAP questionnaire in the PST contains five questions about stigma for persons affected, we believe the PST would benefit from adding a tool to assess internalised and/or perceived stigma. The EMIC affected persons (EMIC-AP)⁸² would allow for comparison with the EMIC-CSS, given the similarities in the questions asked in the EMIC-AP and the EMIC-CSS. An alternative would be the Anticipated stigma subscale (4 items) and Internalised stigma subscale (6 items) of the SARI Stigma Scale.⁸³

Besides assessing and monitoring knowledge, attitudes and practices regarding leprosy, the toolkit can also be used to develop culture-specific messages for health education, and to evaluate the impact of interventions. Even though low knowledge of leprosy has been

associated with high levels of stigma,^{20,24,26–28} high levels of knowledge alone do not lead to more positive attitudes and behaviour towards persons affected by leprosy.⁸⁴ Understanding the cultural belief systems in countries where leprosy is endemic is essential to understand and challenge stigma.⁸⁵ Interviews with the target group to understand where behaviour comes from are crucial when developing interventions to change behaviour.⁸⁶ A protocol that is often used to develop behaviour change interventions is intervention mapping. Intervention mapping is a six-step protocol that describes the path from problem identification to problem mitigation or problem solving.⁸⁷ The PST covers step one to three of intervention mapping: a needs assessment or problem analysis and identifying which beliefs should be targeted (KAP, EMIC-CSS, SDS and interviews) and exploring media that fit the context of the target group (CNA). To our knowledge, ‘communication needs assessments’ are not often done in the leprosy field, when designing interventions for behaviour change.⁸⁸ Step four to six of intervention mapping deal with drafting materials and designing implementation and evaluation plans.⁸⁷

Determining whether changes pre- and post-intervention can be attributed to the intervention is challenging. We have listed several strategies to best deal with this in our recommendations for implementation (additional file 2). These strategies include appropriate timing of assessments, including a control group, cluster randomisation, adding specific questions about involvement in interventions in the follow-up assessment and implementing interventions step-wise if multiple interventions are implemented. The amount of time that should have elapsed since the intervention before it is evaluated depends on the type of intervention that is evaluated. Given that long-term effects are often desired, at least one year after the intervention implementation was completed would seem a reasonable period.

Readers are invited to suggest further improvements to the toolkit. Recommendations for the implementation of the toolkit in the field can be found as additional file (S2).

Review board approval

Not applicable because this was not a separate study. However, the PST has been approved several times by ethical review boards for studies in India, Nepal, Indonesia and Brazil.

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Conflict of interest statement

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Authors’ contributions

AvtN and WB conceived the research and designed the methods. AvtN wrote the manuscript. WB edited the manuscript. Both authors read and approved the final manuscript. AvtN is guarantor of the manuscript.

Patient consent statement

No patient consent was required.

Data sharing statement

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study. The Perception Study Toolkit is available in Additional file 1. An implementation protocol is available in Additional file 2.

Supplementary data

Supplemental information for this article can be found online at <https://doi.org/10.47276/Ir.92.2.170>.

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