

Stigma and Discrimination of children affected by leprosy: PRISMA-P Protocol for a systematic review

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REVIEW TITLE AND BASIC DETAILS

Review title

Stigma and Discrimination of children affected by leprosy: PRISMA-P Protocol for a systematic review

Condition or domain being studied

Phenomena of Interest. Leprosy related stigma and discrimination as experienced by children are phenomena that are poorly understood and conceptualised. Our review is doing the groundwork in systematically exploring these phenomena of interest. We will search for and synthesise existing evidence of the stigma processes and domains of discrimination that have been reported to affect children's mental health responses and are linked to general health outcomes.

Rationale for the review

We know that the experience of stigma has profound negative impact on both physical and psychosocial well-being; stigma itself is also a health issue (van 't Noordende et al 2023; Cross, 2006). Evidence from WHO and other global mental health frameworks highlights that children affected by neglected tropical diseases, including leprosy, are at heightened risk of psychological distress, particularly when stigma, discrimination, or caregiving responsibilities are present (WHO, 2021). In the context of children, both stigma and discrimination may arise not only from a child's own diagnosis, but also from association with an affected family member, leading to psychosocial distress, social exclusion, or the assumption of caregiving responsibilities (Ministry of Health & Family Welfare, n.d.; Cruz & Deps, 2023).

To our knowledge, no global systematic review with a focus on children affected by leprosy, or on children affected by leprosy through associative stigma – and their stigma and discrimination experience or mental health response has been conducted to date. We also have insufficient evidence on the range of moderating factors. Our review therefore is intended to fill an important gap in the literature. A secondary objective is to provide input for evidence-based recommendations for practitioner guidance aiming at improving the health and well-being of children affected by leprosy.

Review objectives

Our overarching objective is to produce a systematic review that stands out for methodological rigour and synthesises exiting literature on stigma and discrimination experienced by children affected by leprosy.

Based on the conceptual framework we have developed (see Appendix 2), our main objective is to systematically review the literature for evidence on how stigma and discrimination in relation to leprosy affects children, their health and well-being.

Specifically, our review will map out the following phenomena:

- 1) The stigma experience/process, i.e. the type of stigma processes experienced by affected children will be classified.
- 2) The life domains of discrimination they experience i.e. social and community-level exclusion domains capturing the psychological, educational and social consequences of stigma on the study population.
- 3) Children's individual-level mental health experience in response to stigma and discrimination. We will examine the mental health situation and well-being mentioned in the studies related to stigma, but not pathological psychiatric states.
- 4) Any moderating factors which influence the severity of stigma and discrimination impact on health.

Keywords

Leprosy; Children and adolescents; Stigma; Discrimination; Mental health; Moderating factors

Country

United Kingdom; India; Ethiopia; Brazil

ELIGIBILITY CRITERIA

Population

Included

We will apply the PICO framework (which stands for Population, Phenomena of Interest, and Context) and is suitable for a qualitative review as suggested by Hosseini et al (2024).

P – Population: What groups of participants are study interest?

Our study population is defined as children and adolescents (aged 0-19) who are personally affected by leprosy and/or are living with an affected family member. We will include records that report on the lives of our study population from any view: including the children themselves, their caregivers, teachers or NGO's and health professionals. We will also include records on adults who are now free from leprosy but report their experiences as children with leprosy. We will include material addressing both adults and children if data provided for children is reported separately.

Excluded

We will exclude material that focuses only on adult leprosy cases, with no reference to children.

Intervention(s) or exposure(s)

Included

Phenomena of Interest. Given the lack of attention to childhood leprosy and the dearth in published sources, leprosy related stigma and discrimination as experienced by children are phenomena that are poorly understood and conceptualised. Our review is doing the groundwork in systematically exploring these phenomena of interest. We will search for and synthesise existing evidence of the stigma processes and domains of discrimination that have been reported to affect children's mental health responses and are linked to general health outcomes (see our conceptual framework in Appendix 2).

Comparator(s) or control(s)

This review does not have any comparators

Study design

Only nonrandomized study types will be included.

Context

Context. Studying the complex context is vital as it will help us further understand our three phenomena of interest. The context in which children experience stigma and discrimination is captured as 'moderating factors' in our framework (Appendix 2). These include a range of individual, environmental and social factors that can moderate the stigma/discrimination/mental health linkage in determining child health and well-being. Although the focus of the review is not on interventions amongst the study population group, there is room to capture any existing participation in anti-stigma interventions under the context of 'moderating factors'. Our study design has also drawn from existing systematic reviews on interventions to reduce leprosy related stigma in adults (Hartog et al., 2020; Sermrittirong et al., 2014).

TIMELINE OF THE REVIEW

Date of first submission to PROSPERO

07 July 2025

Review timeline

Start date: 2 June 2025. End date: 1 December 2025.

Date of registration in PROSPERO

16 July 2025

AVAILABILITY OF FULL PROTOCOL

Availability of full protocol

A full protocol has been written and uploaded to PROSPERO. The protocol will be made available after the review is completed.

SEARCHING AND SCREENING

Search for unpublished studies

Both published and unpublished studies will be sought.

Main bibliographic databases that will be searched

The main databases to be searched are *CINAHL - Cumulative Index to Nursing and Allied Health Literature*, *Embase - Embase via Ovid*, *LILACS - Latin American and Caribbean Health Sciences Literature*, *MEDLINE*, *PsycInfo* and *Scopus*.

Other important or specialist databases that will be searched

Global Health, ERIC, Web of Science, SCiELO

Search language restrictions

There are no language restrictions.

Search date restrictions

There are no search date restrictions.

Other methods of identifying studies

Other studies will be identified by: *contacting authors or experts, looking through all the articles that cite the papers included in the review ("snowballing"), reference list checking and searching conference proceedings.*

Additional information about identifying studies

Organisational websites (grey literature)

Link to search strategy

A full search strategy is available in the full protocol as described in the *Availability of full protocol* section

Selection process

Studies will be screened independently by at least two people (or person/machine combination) with a process to resolve differences.

Other relevant information about searching and screening

None

DATA COLLECTION PROCESS

Data extraction from published articles and reports

Data will be extracted by one person (or a machine) and checked by at least one other person (or machine).

Authors will not be contacted for further information.

Study risk of bias or quality assessment

Risk of bias will be assessed using:

CASP checklist for qualitative research.

AACODS checklist for critical appraisal of grey literature.

Data will be assessed independently by at least two people (or person/machine combination) with a process to resolve differences.

Additional information will **not** be sought from study investigators if required information is unclear or unavailable in the study publications/reports.

Reporting bias assessment

Risk of bias due to missing results will be assessed

Certainty assessment

We will use the CASP checklist for qualitative studies (11 questions) and the AACOD checklist for grey literature (assessing six domains) (CASP UK, 2018). This presumes that the studies we find fall into either of these two categories.

Should we find other methods than qualitative during the screening of included articles, further CASP checklists for different types of methodologies will be consulted and included in the quality assessment. We currently do not plan to exclude any studies or grey literature due to low quality assessment outcomes. We will need to reflect on how this affects the overall quality and confidence in cumulative evidence.

OUTCOMES TO BE ANALYSED

Main outcomes

Our primary outcome is a synthesis of the existing evidence on how stigma and discrimination in relation to leprosy affects children and their health and well-being. We will achieve this through capturing stigma processes, life domains of discrimination, mental health responses and moderating factors.

Our secondary outcome is to highlight research gaps and to provide evidence-based recommendations for future studies, policy development and practitioner guidance with the aim of contributing to the improvement of the health and well-being of children affected by leprosy. We will achieve this by zooming in on the moderating factors and reflecting on these from practitioner points of view. The authors who are WHO technical working group members will be crucial in translating findings of the review into practice implications.

Additional outcomes

There are no additional outcomes.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Given that our expected search results are mostly qualitative studies and grey literature, we will not have appropriate data for conducting quantitative synthesis. Instead, we will perform qualitative thematic analysis based on our conceptual framework. A systematic narrative synthesis will be provided with information presented in the text and tables to summarise and explain the characteristics and findings of the included studies. The narrative synthesis will explore the relationship and findings both within and between the included studies. The narrative will be organised under findings and discussion/implications by stigma process, life domains of discrimination, mental health response and moderating factors.

CURRENT REVIEW STAGE

Stage of the review at this submission

Review stage	Started	Completed
Pilot work	✓	
Formal searching/study identification	✓	
Screening search results against inclusion criteria	✓	
Data extraction or receipt of IPD		
Risk of bias/quality assessment		
Data synthesis		

Review status

The review is currently planned or ongoing.

Publication of review results

Results of the review will be published in English.

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

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No conflict of interest declared.

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No conflict of interest declared.

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No conflict of interest declared.

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Funding source

Review has no specific/external funding but is supported by guarantor/review team (non-commercial) institutions.

Peer review

There has been no peer review of this planned review.

ADDITIONAL INFORMATION

Review conflict of interest

Declared individual interests are recorded under team member details.. No additional interests are recorded for this review.

Medical Subject Headings

Adolescent; Caregivers; Child; Child Health; Family; Humans; Leprosy; Mental Health; Outcome Assessment, Health Care; Review Literature as Topic; Social Factors; Systematic Reviews as Topic

SIMILAR REVIEWS

Check for similar records already in PROSPERO

PROSPERO identified a number of existing PROSPERO records that were similar to this one (last check made on 7 July 2025). These are shown below along with the reasons given by that the review team for the reviews being different and/or proceeding.

- Research evidence on how to reduce stigma and discrimination related to mental and substance use disorders: umbrella review [published 28 January 2022] [CRD42022299682]. The review was judged **not to be similar**
- Stigma experienced by people with disabilities: a systematic review of self-report measures [published 27 September 2022] [CRD42022363176]. The review was judged **not to be similar**
- Exploring the impact of stigma on the health of marginalised groups: protocol for a systematic review and meta-ethnography of qualitative studies [published 1 September

2020] [CRD42020193740]. The review was judged **not to be similar**

- Stigma among family members of people with severe mental illness [published 11 July 2014] [CRD42014009244]. The review was judged **not to be similar**

PROSPERO version history

- [Version 1.0, published 16 Jul 2025](#)

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