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Measuring Care Beyond Cure: Outcome Measures in Community-Based Rehabilitation for People Affected by Leprosy

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Abstract

Leprosy is curable, yet nerve impairment, wounds, activity limitations, stigma, psychological distress and loss of livelihood can continue after multidrug therapy. Community-based rehabilitation seeks to address these wider consequences, but programmes do not always define or measure success in the same way. This structured narrative review examines outcome domains and measurement tools used in leprosy-related rehabilitation and community programmes. Relevant PubMed-indexed literature, reference lists from prior reviews, measurement studies and international rehabilitation guidance were examined. The evidence supports a multidomain approach that combines clinical indicators with measures of activity, participation, stigma, mental wellbeing, livelihood and programme implementation. Common tools include World Health Organization disability grading, the Eye-Hand-Foot score, the Screening of Activity Limitation and Safety Awareness scale, the Participation Scale and culturally adapted stigma measures. However, livelihood recovery, empowerment, sustainability and participant-defined change are less consistently measured. A practical evaluation framework should therefore use a small core of validated outcomes alongside locally relevant indicators and qualitative feedback. This approach can improve comparability without reducing rehabilitation to a single clinical or social measure. Further research should test the feasibility and cultural validity of such frameworks in community settings.

Keywords: leprosy; community-based rehabilitation; disability; participation; stigma; outcome measurement

1. Introduction

Leprosy, also called Hansen disease, is a chronic infectious disease that mainly affects the skin and peripheral nerves. Multidrug therapy can cure the infection, but delayed diagnosis and nerve damage may lead to sensory loss, weakness, wounds and lasting disability (World Health Organization [WHO], 2026). Cure therefore does not automatically end the physical or social consequences of the disease.

People affected by leprosy may experience recurrent wounds, reduced mobility, difficulty working, psychological distress, discrimination and exclusion from family or community life. These outcomes interact. A physical impairment can restrict activity; activity limitation can affect employment; stigma can intensify both social isolation and

economic insecurity. Research from Indonesia found that impairment, activity limitation, participation restriction and stigma contributed jointly to disability rather than forming one simple clinical pathway (van Brakel et al., 2012).

Community-based rehabilitation was developed to improve inclusion and quality of life for people with disabilities through locally available services and community participation. The WHO community-based rehabilitation matrix organizes this work across five components: health, education, livelihood, social inclusion and empowerment (WHO et al., 2010). This breadth is relevant to leprosy because a person may be clinically stable while still being unable to work, move safely or participate fully in society.

Existing reviews have examined community programmes and self-care interventions for people affected by leprosy, but they report substantial variation in programme design and evaluation (Ilozumba & Lilford, 2021; Martos-Casado et al., 2020). This creates a measurement problem. A study that records only ulcer healing may overlook stigma and livelihood. A programme that reports only participant satisfaction may miss preventable injury or clinical deterioration. The central question is therefore not simply whether rehabilitation "works," but whether the selected measures capture what rehabilitation is intended to change.

This review examines the outcome domains, instruments and indicators most relevant to community-based rehabilitation for people affected by leprosy. It also proposes a practical multidomain framework that can guide future programme evaluation without presenting that framework as a validated core outcome set.

2. Review Approach

A structured narrative-review approach was used because the available literature includes clinical studies, scale-development studies, programme evaluations, implementation research, international guidance and previous evidence reviews. A focused search of PubMed-indexed literature was conducted using combinations of the terms "leprosy," "Hansen disease," "community-based rehabilitation," "self-care," "participation," "stigma," "disability," "livelihood," "outcome" and "measurement." Reference lists from relevant reviews and measurement papers were also examined.

Sources were included when they described a rehabilitation outcome, evaluated or validated a measurement tool, reported community or self-care programme outcomes, or provided an established rehabilitation framework. Papers limited to antimicrobial treatment, laboratory diagnosis or case detection without rehabilitation outcomes were not prioritized. The synthesis was organized around physical health, activity, participation, stigma, mental wellbeing, livelihood, empowerment and implementation.

This was a focused narrative synthesis, not a systematic or scoping review. It did not use exhaustive multi-database screening, duplicate independent selection or formal risk-of-bias assessment. The findings should therefore be interpreted as a clinically informed framework based on relevant literature rather than a complete inventory of every published measure. Because the review used published information and did not involve participants or identifiable patient data, institutional ethics approval was not required.

3. Outcome Domains and Measurement Tools

3.1 Physical impairment and clinical safety

Physical outcomes remain essential because leprosy-related nerve damage can contribute to sensory loss, wounds and further disability after treatment. Common indicators include WHO disability grade, the Eye-Hand-Foot score, wound or ulcer status, pain, visible injury and nerve-function findings. These measures are comparatively practical and can identify clinically important change.

However, clinical indicators cannot describe rehabilitation by themselves. WHO disability grade is useful for broad classification but may be insensitive to smaller changes in daily function. An unchanged grade does not show whether a person returned to work, experienced less stigma or became more confident in community life. Clinical outcomes should therefore form one component of evaluation rather than the entire definition of success.

3.2 Activity limitation and safety

The Screening of Activity Limitation and Safety Awareness (SALSA) scale was developed for people affected by leprosy or diabetes to measure self-reported activity limitation and safety awareness (SALSA Collaborative Study Group et al., 2007). It is particularly relevant when an intervention aims to improve daily functioning rather than change impairment alone. Research in Brazil demonstrated continued activity limitations after completion of multidrug therapy, supporting the need for follow-up beyond bacteriological cure (Nardi et al., 2012).

Activity measures also require careful interpretation. A person may reduce an activity to prevent injury, which could appear as greater limitation even when it reflects better safety awareness. Evaluation should therefore consider both the score and the reason for behavioural change.

3.3 Participation, stigma and discrimination

Participation concerns involvement in work, family, education, relationships and community life. The Participation Scale was developed across Nepal, India and Brazil to measure client-perceived participation restriction, and a shortened version was later validated (Stevelink et al., 2012; van Brakel et al., 2006). Participation is distinct from attendance. A person can attend a programme without gaining greater choice, social inclusion or control over daily life.

Stigma measures examine related but different experiences, including anticipated stigma, internalized stigma, experienced discrimination and community attitudes. EMIC-based measures and the SARI Stigma Scale have been adapted for leprosy-related contexts (Dadun et al., 2017; Rensen et al., 2011). These instruments are valuable, but translation alone is not sufficient. Terms involving shame, marriage, disclosure and social status may carry different meanings across settings, so linguistic and cultural validation are necessary.

The relationship among impairment, stigma and participation is especially important. van Brakel et al. (2012) found that stigma and activity limitation were major determinants

of participation restriction. This suggests that rehabilitation evaluation should not treat physical and social outcomes as separate stories.

3.4 Mental wellbeing and quality of life

Leprosy-related stigma and disability can affect emotional wellbeing, but mental-health outcomes are often measured less consistently than physical outcomes. Instruments such as the Patient Health Questionnaire-9 and the Warwick-Edinburgh Mental Wellbeing Scale can be useful when appropriately adapted. Cross-cultural validation work in Nepal showed the importance of testing language, interpretation and measurement performance rather than assuming that a direct translation is valid (Dijkstra et al., 2024).

Broad quality-of-life measures, including WHOQOL-BREF, may capture changes across multiple domains. Their strength is breadth, but a single global score can conceal specific barriers involving wounds, employment, marriage or participation. Quality of life should complement, not replace, more targeted outcomes.

3.5 Livelihood, empowerment and social inclusion

Livelihood is central to the WHO community-based rehabilitation matrix, yet it is difficult to standardize. Relevant indicators may include work status, income security, days able to work, productivity, access to social protection or return to a valued role. These measures must be interpreted in context because work may involve formal employment, agriculture, family businesses or unpaid domestic labour.

Empowerment and social inclusion may involve group membership, decision-making, rights awareness, leadership, education and control over personal goals. These outcomes align closely with the purpose of community rehabilitation but are vulnerable to vague reporting. A programme should define the expected change before choosing an indicator. Counting the number of meetings or workshops describes delivery, not empowerment.

3.6 Implementation and sustainability

Programme outcomes cannot be understood without implementation information. Reach, attendance, retention, referral completion, acceptability, feasibility, cost and continuation help explain why an intervention succeeded or failed. Integrated programmes can widen access, but they may make leprosy-specific outcomes difficult to isolate. An implementation study from Ethiopia, for example, evaluated a holistic package for leprosy, podoconiosis and lymphatic filariasis through physical, mental-health, community and economic outcomes (Ali et al., 2025).

Engagement is also important but should not be confused with effectiveness. A programme may involve affected people in design and delivery without demonstrating improved health, participation or livelihood. Engagement processes and participant outcomes should be reported separately.

4. A Practical Multidomain Framework

No single measure captures the full purpose of rehabilitation. A practical framework should combine a small set of standardized outcomes with locally relevant indicators and participant-defined goals. Standardized measures support comparison, while local indicators

preserve meaning. The proposed domains below are a starting point for programme evaluation and require clinical and contextual review before use.

Table 1. Proposed multidomain framework for programme evaluation

Domain	Core measure or indicator	Data source	Suggested timing
Physical health	Wound or ulcer status plus disability or nerve-function indicator	Clinical assessment	Baseline and follow-up
Activity	SALSA or a validated alternative	Participant-reported	Baseline and follow-up
Participation	Participation Scale or short form	Participant-reported	Baseline and follow-up
Stigma	Context-validated EMIC- or SARI-based measure	Participant or community	Baseline and follow-up
Mental wellbeing	Culturally adapted WEMWBS or PHQ-9	Participant-reported	Baseline and follow-up; referral plan
Livelihood	Work status, income security or days able to work	Mixed indicators	Baseline and longer follow-up
Implementation	Reach, retention, referral completion and acceptability	Programme records	Continuous

A minimum framework should avoid excessive data collection. Each measure must be linked to a programme objective and a realistic decision. If a team cannot explain how it will use a measure, collecting it adds burden without improving care. Sensitive information concerning mental health, stigma, income or discrimination also requires confidentiality, informed consent where applicable and a referral plan when unmet needs are identified.

5. Implications for Project Rooh

For Project Rooh, “Care Beyond Cure” should operate as a programme theory rather than only a slogan. Equipment support, wound-care assistance, awareness work and rehabilitation referrals should not be collapsed into one beneficiary count. Each activity requires an outcome linked to its intended effect.

Assistive-device support could be evaluated through safe use, activity goals and follow-up needs. Wound-care support could track referral completion and recurrence without presenting volunteer monitoring as clinical diagnosis. Awareness programmes could assess knowledge or community attitudes, while psychosocial activities would require validated and culturally appropriate wellbeing or stigma measures. Participant feedback should be used to identify outcomes that matter locally.

Any direct evaluation involving residents must be designed with ethical oversight appropriate to the setting, accessible consent procedures, confidentiality and clear referral pathways. Programme monitoring should never become a substitute for professional care,

and research should not collect sensitive information merely to strengthen a résumé or publication.

6. Discussion

The literature supports a consistent conclusion: rehabilitation becomes distorted when programmes measure only what is easiest to count. Physical outcomes are indispensable, but they cannot establish whether a person has regained participation, security or dignity. Conversely, broad empowerment claims are weak when programmes do not monitor preventable injury, activity safety or referral completion.

The best solution is not to choose between a medical and a social model. It is to select complementary outcomes that match the intervention. Rehabilitation measurement should cover what changed, for whom, under what conditions and at what cost. Measures should also be feasible. A theoretically ideal instrument may fail in practice if it requires lengthy interviews, specialist training or repeated administration that a community programme cannot sustain.

Cultural validity is another central issue. Participation, work, family roles and stigma are shaped by language, gender, caste, disability, transport and local beliefs. Standardized scales support comparison, but scores should not erase local experience. Transparent translation, cognitive testing, interviewer training and qualitative feedback can help preserve both comparability and relevance.

A future systematic scoping review could strengthen this framework by documenting complete database searches, screening studies independently, charting measurement properties and examining which domains are most frequently neglected. Consensus work involving people affected by leprosy, clinicians, rehabilitation workers and researchers would then be needed before proposing a formal core outcome set.

7. Limitations

This review has several limitations. It is a focused narrative review and may have missed relevant studies, particularly grey literature and publications not indexed in PubMed. Study selection was based on relevance rather than a preregistered protocol, and no formal risk-of-bias assessment was performed. The included literature uses varied definitions of rehabilitation, self-care, disability prevention and social inclusion. Some interventions combine leprosy with other neglected tropical diseases, limiting disease-specific interpretation. Finally, the proposed framework has not been validated and should not be treated as clinical guidance or a universal outcome set.

8. Conclusion

Community-based rehabilitation for people affected by leprosy is multidimensional, and its evaluation must be multidimensional as well. Established measures can assess impairment, activity, participation, stigma and mental wellbeing, while livelihood, empowerment, sustainability and participant-defined change remain less consistently measured. A practical approach should combine clinical indicators, validated participant-reported measures, implementation data and locally meaningful outcomes. This balance can

make rehabilitation evaluation more accurate without losing the human realities that "care beyond cure" is intended to address.

Declarations

Author contribution: Karen Sahdev developed the review question, identified and synthesized the literature, and drafted the manuscript. Dr. Ameesha Mahajan serves as clinical reviewer for medical terminology, interpretation and patient-safety considerations.

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Competing interests: The author is the founder of Project Rooh, a community initiative related to the subject of this review. This relationship is disclosed because the review may inform future programme evaluation.

Ethics statement: This review used published sources and did not involve human participants or identifiable patient information.

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