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Community-Based Interventions for People Affected by Leprosy: A Narrative Review

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NARRATIVE REVIEW

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Keywords:
Community-Based Interventions, Hansen's Disease, People Affected by Leprosy, Socio-economic Empowerment, Stigma Reduction

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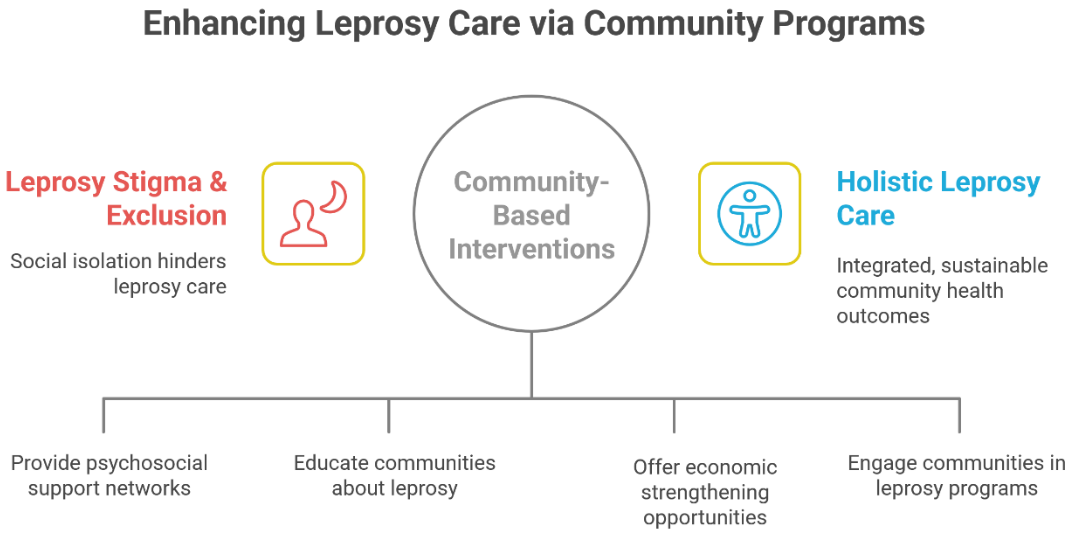
ABSTRACT

This narrative review aims to explore community-based program interventions among patients with leprosy. This study employs the PCC (Population, Concept, Context) framework and collects data from six literature reviews accessed through the PubMed database. Keywords adjusted according to Medical Subject Headings (MeSH) terms ("Community-Based Program" OR "Community Intervention" OR "Community Health Program" OR "Community Engagement") AND ("Social Support" OR "Peer Support" OR "Community Support" OR "Psychosocial Support") AND ("Leprosy" OR "Hansen's Disease"). Analysis of six articles, primarily from Asian and African contexts, reveals that community-based interventions are effective in reducing stigma, enhancing socio-economic participation, and strengthening leprosy detection and prevention strategies. These programs succeed through a multidimensional approach involving social support, education, and economic empowerment. The findings underscore that integrating psychosocial support and economic empowerment within community-led health initiatives is fundamental to achieving holistic and sustainable outcomes in leprosy care.

Key Messages:

- Community-based interventions are effective in reducing stigma and promoting social inclusion among patients with leprosy.
- These programs improve early detection and prevention strategies through active community engagement and local empowerment.
- Multidimensional approaches, incorporating social support, health education, and economic strengthening are essential to ensure long-term impact.
- Collaboration between communities, healthcare professionals, and policymakers enhances program sustainability and reach.

GRAPHICAL ABSTRACT



INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, primarily affecting the skin, peripheral nerves, upper respiratory tract mucosa, and eyes (1,2). This disease has been known since ancient times and remains a public health concern in various countries, particularly in regions with limited healthcare resources (3,4). Although leprosy can be cured with multidrug therapy (MDT), the social stigma associated with the disease remains a major challenge in eradication efforts and patient rehabilitation (4,5).

According to the World Health Organization (WHO), although the global incidence of leprosy has declined, new cases continue to be reported, particularly in developing countries such as India, Indonesia, and Brazil (6,7). The WHO identifies leprosy as a recurrent public health issue that remains prevalent across various regions worldwide (8,9). In 2022, a total of 174.087 new leprosy cases were reported globally. Furthermore, the 2022 Global Leprosy (*Hansen's Disease*) Update indicated a 23.8% increase in cases compared to the previous year, with 140.594 cases recorded in 2021 (10). These new cases were reported across six WHO regions, with the largest contribution from the South-East Asia Region (SEAR) at 71.4%, followed by the African Region (AFR) (12.6%), the Region of the Americas (AMR) (12.3%), the Eastern Mediterranean Region (EMR) (2.2%), the Western Pacific Region (WPR) (1.4%), and the European Region (EUR), which accounted for less than 1% of cases (10).

In addition to being a medical challenge, leprosy is closely associated with social stigma, which can have detrimental effects on affected individuals. Stigma against people with leprosy is often rooted in stereotypes, prejudice, and discrimination, potentially hindering their access to healthcare services, education, and social integration (11,12). As a result, many individuals with leprosy experience social isolation and difficulties in obtaining support from both the community and formal systems, further deteriorating their quality of life (13).

Stigma and discrimination against individuals with leprosy often lead to delays in diagnosis and treatment, as well as hinder their social reintegration (14). Therefore community-based approaches have gained increasing attention as a strategy to enhance early detection, treatment adherence, and social support for individuals with leprosy (15,16).

Community-based interventions in leprosy management aim to raise public awareness, reduce stigma, and strengthen social support systems for individuals affected by the disease and their families (16–18). These programs encompass various approaches, including health education, community engagement in treatment and rehabilitation processes, and improving access to inclusive healthcare services (11,17,19). Some interventions also involve leprosy survivors as agents of change, providing education to the community and assisting affected individuals in their social adaptation process.

Community-based approaches in health interventions have been proven effective in various contexts of both communicable and non-communicable diseases. In the case of leprosy, this model is expected to help address the challenges faced by affected individuals, including fear of stigma, limited access to healthcare services, and lack of social support (20–22). Various studies have demonstrated that community-based programs involving local community groups, healthcare workers, and non-governmental organizations can enhance treatment adherence and facilitate the social reintegration of individuals affected by leprosy (23–25).

Although this approach offers numerous benefits, challenges in its implementation remain. Limited resources, cultural resistance to change, and a lack of coordination among various stakeholders often hinder the success of these programs (26,27). Therefore a more comprehensive study is needed to understand the factors influencing the effectiveness of community-based interventions in leprosy management.

This study aims to provide a narrative review of community-based program interventions for people affected by leprosy, exploring community intervention models implemented in various countries, highlighting successes and challenges, and offering recommendations for future program development. While individual studies have demonstrated the effectiveness of specific interventions, a comprehensive synthesis is still needed to compare and contrast different programmatic models such as counseling, socio-economic development, and peer support and to identify common determinants of success across diverse settings. This review aims to address that gap by providing insights that are useful for both policymakers and healthcare providers seeking to improve the quality of life of people affected by leprosy. This review is guided by the following research questions: (1) What models of community-based interventions for people affected by leprosy are described in recent literature? (2) What are the documented outcomes and challenges associated with their implementation?

METHODS

This study employs the narrative literature review method, which involves comparing and analyzing existing theories while seeking references that align with the research problem. A narrative review is a process of searching for and studying a specific topic or issue by gathering data from various sources. The purpose of this method is to identify and summarize previously published articles, avoid research duplication, and explore new areas of study that have not yet been investigated. The stages undertaken in this study include: formulating research questions, determining inclusion and exclusion criteria, selecting articles, creating an extraction table, analyzing research findings and summarizing them, and reporting the results of the study.

The research object is to identify community-based intervention programs for individuals with leprosy. The selection of articles for review is conducted using the PCC (Population, Concept, and Context) approach. **Population** (Patients with Leprosy); **Concept** (Community-based intervention programs); **Context** (Programs that integrate social support mechanisms within community settings).

The data collection technique in this study employs a narrative review of six literature studies from the PubMed database. The search strategy utilizes English-language keywords adjusted according to Medical Subject Headings (MeSH) terms. Keyword PubMed: ("Community-Based Program" OR "Community Intervention" OR "Community Health Program" OR "Community Engagement") AND ("Social Support" OR "Peer Support" OR "Community Support" OR "Psychosocial Support") AND ("Leprosy" OR "Hansen’s Disease")

The author identifies six literature studies related to community-based intervention programs for individuals with leprosy (see Table 1). From these references, a detailed and comprehensive understanding of the issue can be obtained. This research method facilitates the exploration of relevant theories by utilizing a diverse range of sources. Data collected from these references are recorded and managed to ensure accurate conclusions.

The data analysis technique in this study follows the stages of a literature review, which include formulating research questions, conducting searches, identifying keywords, reviewing abstracts and articles, and documenting the findings (28). The obtained data is analyzed through these stages to generate conclusions, providing ideas or an overview of the discussed topic.

Table 1. Analyzed Article Data

No	References
1	(29) The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia
2	(30) Learning from a leprosy project in Indonesia: making mindsets explicit for stigma reduction
3	(31) Empowerment of communities in the Promotion of Prevention of Disability (POD) for persons affected by leprosy in Tanzania
4	(32) Impact of socio-economic development, contact and peer counselling on stigma against persons affected by leprosy in Cirebon, Indonesia - a randomised controlled trial
5	(33) Community intervention programmes with people affected by leprosy: Listening to the voice of professionals
6	(34) From social curse to social cure: A self-help group community intervention for people affected by leprosy in Nepal

This narrative literature review exclusively utilizes primary research. The inclusion criteria applied in this study are as follows: (1) full-text availability, (2) a focus on community-based interventions for individuals with leprosy, (3) no restrictions on the year of publication, and (4) no language limitations. The article selection process was conducted by the authors, beginning with an initial screening using a reference manager (Mendeley). Subsequently, articles were eliminated based on title, abstract, and full-text content. A critical appraisal was then performed using the Joanna Briggs Institute (JBI) checklist tools (see Table 2). JBI was chosen due to its comprehensive assessment tools, which are designed to evaluate various research designs within the existing literature.

Table 2. JBI Critical Appraisal Result

Author, Year of Publication	JBI critical appraisal tool	Study Design
Lusli et al (2016) (29)	10/10 (100%)	Mixed methods
Peters et al (2015) (30)	8/10 (80%)	A qualitative data
Mwasuka et al (2018) (31)	9/10 (90%)	A quasi-experimental
Dadun et al (2017) (32)	9/10 (90%)	A controlled trial design
Martos-Casado et al (2022) (33)	8/8 (100%)	A qualitative
Jay et al (2021) (34)	9/10 (90%)	Cross-sectional

In general, the assessment is conducted based on specific predetermined criteria. The evaluation process is carried out independently by the authors. The standard for article selection is determined by a minimum JBI score of 70%. The data extraction process was conducted independently by two researchers with expertise in their respective fields. Prior to the extraction, a data extraction protocol was developed, which included information on the author, research objectives, country, methodology, sample, and study findings.

RESULTS

Based on a literature search using the PubMed database, six relevant articles were identified that discuss community-based interventions for individuals with leprosy. In terms of country characteristics, the majority of the studies were conducted in developing countries, including Indonesia, Tanzania, India, Brazil, and Nepal. Specifically, three articles originated from Indonesia, one from Tanzania, one from India and Brazil, and one from Nepal. Various community-based interventions have demonstrated effectiveness in reducing stigma and enhancing social participation among individuals affected by leprosy.

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Studies conducted by (29,32,34) have demonstrated that counseling interventions, community contact, and group-based support contribute to reducing stigma, including internalized stigma, anticipated stigma, and stigma from the social environment. Furthermore, the social participation of individuals with leprosy has also improved, as evidenced by their reintegration into community activities, efforts to seek employment, and increased openness in interacting with the surrounding society.

Meanwhile, studies focusing on the detection and prevention of leprosy, such as those conducted study by Mwasuka et al., (2018) and Martos-Casado et al., (2022), highlight the crucial role of community engagement and healthcare workers in identifying and managing leprosy cases. Community-based education and training programs have been proven effective in increasing the detection of new cases and encouraging examinations among high-risk individuals. Furthermore, healthcare professionals involved in these programs emphasize the importance of a human rights- and gender-based approach to ensure broader and more sustainable healthcare coverage for individuals affected by leprosy.

On the other hand, the study conducted by Peters et al., (2015) highlights that stakeholders' perceptions and mindsets regarding leprosy and disability play a crucial role in the success of intervention programs. Differences in aspirations, expectations of interventions, and the values upheld by various parties may influence the effectiveness of the implemented programs. This is reflected in the data extraction (see Table 3), which summarizes various community-based interventions, including approaches, targets, and reported outcomes from previous studies.

Overall the findings of this study indicate that community-based interventions, increased social awareness, and the involvement of healthcare professionals and relevant stakeholders are key factors in reducing stigma, enhancing social participation, and supporting more effective detection and prevention of leprosy. The results from the six reviewed articles were synthesized into four primary thematic categories to guide the discussion: (1) Interventions for stigma reduction, (2) Programs for enhancing social and economic participation, (3) Strategies for community-based detection and prevention, and (3) The role of stakeholders in program implementation.

Table 3. Data Extraction

No	References	Objective	Country	Design	Instruments	Sampel	Results
1	(29)	To assesses the impact of a counselling intervention on reducing leprosy-relatedstigma in Cirebon District, Indonesia.	Indonesia	Mixed methods	Three scales were used: the SARI Stigma Scale (SSS), Participation Scale Short (PSS) and the World Health Organization Quality of Life instrument (WHO-QOL BREF).	The sample size differs per method, for example, data regarding 67 counselling clients and 57 controls from a cohort, and notes from 207 counselling clients were examined.	The notes indicate that most clients experience stigma daily, whether internalized, anticipated, or directly encountered. There was a significant reduction in the total scores of the *SARI Stigma Scale*, *Participation Scale Short*, and *WHO Quality of Life* ($p < 0.001$) after counseling. Although there was an effect in the control group, the impact was much greater in the intervention group. Qualitative data suggest that increased knowledge and awareness of rights drive change, leading clients to reconnect with neighbors, assist with household tasks, and seek employment. However, challenges remain, particularly the

No	References	Objective	Country	Design	Instruments	Sampel	Results
							desire to conceal their condition.
2	(30)	The first section discusses leprosy and stigma, emphasizing the role of mindsets. Next, the action research methodology and project phases are reviewed. An analysis of stakeholders' mindsets toward leprosy and disability follows, concluding with lessons for other development projects.	Indonesia	A qualitative data	*Interactive Learning and Action* (ILA) methodology	Sample from the Stigma Assessment and Reduction of Impact (SARI) project in Indonesia	This article has shown that exploration of different mindsets of the stakeholders, facilitated by the ILA approach, made it possible to identify differences in aspirations, attitudes to scientific validity and ethics of research, different expectations in terms of interventions and timing, conflicting intrinsic models of disability, and diverse attitudes to people affected by leprosy.
3	(31)	To reduce occurrence of leprosy related Grade 2 disabilities	Tanzania	A quasi-experimental	Manual under the supervision of District Social Welfare Officers [SWOs] and District Tuberculosis and Leprosy Coordinators [DTLCs]	12 districts were involved and 12 new POD Committees with 236 POD members were trained to be trainers	A total of 134.104 people were reached, including 65.827 students from 225 schools and 68.277 adults from 248 villages. Through sensitization activities involving various communities, 3.483 suspected leprosy cases were identified, with 531 new cases confirmed by DTLCs. Additionally, through active case finding among household contacts, 1.399 individuals were screened, and 73 new leprosy cases were confirmed.
4	(32)	To test and evaluate three interventions: counselling (involving peer counsellors), socio-economic development (SED) and contact	Indonesia	A controlled trial design	Three scales (e.g. SARI Stigma Scale, Participation scale) were applied among leprosy-affected people and two scales (e.g. Social Distance Scale) were	Sample size of 600 people affected by leprosy (150 per study area) and 200 community members (50 per study area)	The SARI Project has shown that leprosy-related stigma can be significantly reduced both within the community and among individuals affected by leprosy through structured interventions that are measurable, adaptable to various contexts, and

No	References	Objective	Country	Design	Instruments	Sampel	Results
		between community members and affected people.			used among community members pre- and post-intervention.		applicable to different target groups.
5	(33)	To explore the perceptions of health professionals regarding the development of programmes with people affected by leprosy	India and Brazil	A qualitative	An open question questionnaire	27 health professionals were interviewed	Based on the specific needs of the contexts, recommendations are suggested that, with the involvement of all parties and with sensitive approaches towards human rights and gender, they could help to guarantee universal health coverage and the sustainability of said programmes.
6	(34)	To develop a new empowered identity to re-establish access to multiple group memberships' through social participation	Nepal	Cross-sectional	• Self-help group identification • Perceived access to multiple groups • Internalized-stigma • Psychological well-being	The final sample (N = 98) was 59% (n = 58) men, 36% (n = 35) women and five who did not declare gender.	Supporting the Social Identity Model of Identity Change, we present novel evidence that group-based interventions can offer new valued identities that link to social cure resources, even in the most adverse circumstances

Abbrevation: *District Tuberculosis and Leprosy Coordinators (DTLCs), Interactive Learning and Action (ILA), Participation Scale Short (PSS), POD (Prevention of Disability), SARI Stigma Scale (SSS), Social Welfare Officers (SWOs), Socio-economic development (SED), Stigma Assessment Reduction Impact (SARI), World Health Organization Quality of Life instrument (WHO-QOL BREF)*

Table 4. Characteristics of Interventions Related to Community-Based Program Interventions Among Patients with Leprosy

Authorship	Core Intervention	Outcome	Relationship to the Topic of Discussion	Research Description
(29)	Community-Based Counseling	Reduction of stigma (internalized, anticipated, enacted), enhancement of social participation.	Reduction of Stigma and Enhancement of Social Participation	This study examines the effectiveness of counseling in reducing stigma associated with leprosy. The findings indicate that counseling interventions assist individuals with leprosy in enhancing social interactions, seeking employment, and participating in community activities.
(30)	Interactive Learning Approach (ILA) Methodology in Leprosy Programs	Identification of Stakeholder Perception Differences Regarding Leprosy and Disability	The Role of Stakeholders in Community-Based Interventions	This study reveals that stakeholders have varying understandings of leprosy interventions. The ILA approach facilitates the alignment of perceptions and enhances the effectiveness of interventions.
(31)	Community-Based Awareness and Active Screening	Enhancing Early Detection of New Leprosy Cases	Strategies for the Detection and Prevention of Leprosy in the Community	This study highlights the effectiveness of socialization programs and active screening in detecting new cases of leprosy within communities and schools.

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Authorship	Core Intervention	Outcome	Relationship to the Topic of Discussion	Research Description
(32)	A Combination of Three Interventions: Counseling, Socio-Economic Programs, and Community Contact	Reduction of Stigma, Enhancement of Social and Economic Interaction	Reduction of Stigma and Enhancement of Social Participation	This study evaluates three different interventions and finds that a combination of approaches is more effective in enhancing the social participation of individuals with leprosy.
(33)	A Human Rights and Gender-Based Approach in Leprosy Health Services	Sustainable Improvement of Healthcare Service Access	The Role of Stakeholders in Community-Based Interventions	This study highlights the importance of healthcare worker engagement in community-based programs using a gender-sensitive and human rights-based approach.
(34)	Group-Based Support and Social Identity	Strengthening New Identity and Enhancing Psychological Well-being	Reduction of Stigma and Enhancement of Social Participation	This study demonstrates that group-based interventions assist individuals with leprosy in regaining self-confidence and gaining access to broader social networks.

DISCUSSION

Community-Based Program Interventions for people affected by leprosy (see Table 4) encompass participatory approaches, active community engagement, and integration with primary healthcare services. These programs emphasize empowerment both individual and group based alongside health literacy, stigma reduction, and social support from family and the broader community. Their effectiveness is often shaped by factors such as long-term sustainability, collaboration with local stakeholders, and supportive policies that enable inclusive service delivery.

While the reviewed studies consistently report positive outcomes, these should be interpreted with caution. The evidence base primarily consists of qualitative and cross-sectional studies, which limit the ability to draw definitive causal conclusions. Therefore, observed improvements such as stigma reduction and social reintegration should be seen as associations rather than direct results of the interventions, considering potential confounders such as concurrent public health campaigns or societal shifts (29,32,34)

Reducing Stigma through Social and Psychological Interventions

Stigma remains a significant barrier to the social and psychological well-being of people affected by leprosy. Interventions such as individual and group counseling, psychosocial support, and direct community engagement have been associated with reductions in internalized and anticipated stigma. For instance, A by study Lusli et al emphasized that enhancing self-esteem and agency is crucial (29), while study by Dadun et al demonstrated that group counseling reduces social isolation (32). These interventions work not only by providing emotional support but also by creating safe environments where participants can share experiences and challenge societal narratives about leprosy.

Participation in group-based activities also plays a transformative role by fostering new, more empowered identities. A study by Jay et al noted that support groups help shift individual identities from that of a “victim” to an empowered actor with agency over their own lives (34). However, while these outcomes are positive, the mechanisms underlying such psychosocial changes are often underexplored. A more critical reading suggests that normalization of experience, social validation, and vicarious empowerment may drive these transformations. Yet, many reviewed studies offer limited elaboration on these mechanisms, signaling an area where further research is needed.

In addition the long-term sustainability of these interventions especially those using resource-intensive methods like the Interactive Learning and Action (ILA) approach has not been critically

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examined. The feasibility of replicating such approaches in severely resource-constrained environments remains unclear and should be a priority for future implementation research (29,32,34)

Enhancement of Social and Economic Participation

Socio-economic development (SED) initiatives are essential for restoring dignity and promoting community reintegration for people affected by leprosy. These programs often include livelihood training, access to credit, and community reintegration support. A study by Dadun et al reported that participation in SED programs led to improved financial independence and confidence, reducing stigma through enhanced productivity and visibility (32). Additionally, social inclusion through participation in community and religious groups strengthens bonds and reduces isolation, as shown in the findings of study by Jay et al (34).

A deeper look into the interaction between stigma reduction and economic participation reveals a layered dynamic. The reduction of internalized stigma through counseling and support seems to act as a gateway, enabling individuals to meaningfully participate in economic activities.

For example study by Lusli et al found that after engaging in psychosocial support, individuals were more motivated to seek employment (29). This reinforces the idea that psychosocial interventions not only reduce stigma but also build the internal capacity required for economic engagement.

Strategies for Detection and Prevention of Leprosy in the Community

Successful community-based leprosy programs go beyond treatment to emphasize early detection and prevention through education and outreach. Public awareness campaigns, school-based screenings, and community health volunteer involvement are widely used to promote early diagnosis. Study by Mwasuka et al documented the effectiveness of school outreach initiatives in increasing case identification (31).

The reviewed studies often lack rigorous evaluation of the scalability of these programs. Sustainability is frequently mentioned, but rarely scrutinized. For instance, programs that depend on trained volunteers or external funding may not be viable long-term in all contexts.

While applying a rights-based and gender-sensitive lens is commendable, the integration of such approaches with bottom-up participatory methods like ILA may create tensions (35). For example a centralized rights-based framework may not always align with the locally driven, consensus-building process of ILA. Future research should explore how such frameworks can complement each other in diverse implementation settings.

The Role of Stakeholders in Community-Based Interventions

The success of community-based leprosy interventions depends on the meaningful engagement of stakeholders, including communities, governments, and health systems. Programs utilizing ILA emphasize shared decision-making across five phases: problem identification, analysis, solution development, implementation, and evaluation (32). These approaches are praised for fostering mutual understanding and capacity building.

Nevertheless, most articles present stakeholder collaboration as uniformly positive, without critically examining power dynamics or institutional limitations (35). Differences in values, resources, and expectations can present substantial barriers. For example, health workers may prioritize clinical outcomes, while communities may emphasize social reintegration or spiritual healing. A more pragmatic approach would acknowledge such frictions and examine how programs negotiate conflicting priorities. It also remains uncertain whether institutional systems, especially in under-resourced settings, are equipped to support genuinely inclusive planning and co-management processes.

CONCLUSION

Community-based intervention programs for individuals affected by leprosy have demonstrated effectiveness in reducing stigma, enhancing social and economic participation, and improving case detection and prevention strategies. Their success depends on a multidimensional approach that incorporates psychosocial support, education, and economic empowerment, with active collaboration among communities, healthcare professionals, and policymakers.

These findings underscore the importance of integrating counseling, group-based support, and livelihood initiatives into leprosy control programs to foster long-term well-being and sustainable reintegration. Strengthening partnerships between local organizations, health systems, and government actors is essential to ensure accessibility, scalability, and cultural relevance.

Future investigations could address the following questions: (1) What is the sustainability of stigma reduction and improved social participation years after a community-based intervention concludes?, (2) How do specific socio-cultural and gender-related factors mediate the effectiveness of these interventions across different national or regional settings?. Answering these questions will help refine strategies that not only address the medical dimensions of leprosy but also the social determinants of health, ensuring more inclusive and equitable outcomes. Ultimately, empowering individuals affected by leprosy through holistic, community-driven efforts is key to breaking cycles of exclusion and building a more just and supportive society.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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