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## Turnitin The Role of Community Health Workers in the Control and Management of Leprosy: A Scoping Review

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SCOPING REVIEW

# The Role of Community Health Workers in the Control and Management of Leprosy: A Scoping Review

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## ABSTRACT

**Introduction:** Leprosy remains a persistent public health challenge in many endemic regions, exacerbated by delayed diagnosis and sociocultural stigma. Community Health Workers (CHWs) have emerged as pivotal actors in promoting early detection, treatment adherence, and stigma reduction.

**Methods:** This scoping review synthesizes current evidence on CHW-led leprosy interventions, drawing from articles published in PubMed, Scopus, and Google Scholar between 2000 and 2025. A total of 23 studies from countries including India, Brazil, and Indonesia were included. Data were extracted and analyzed thematically to explore CHW roles, early detection methods, and challenges encountered.

**Results:** CHWs were involved in activities such as door-to-door screening, household contact tracing, community education, and rehabilitative support. Their contributions were associated with reduced diagnostic delays and improved community engagement. However, most studies did not isolate the specific impact of CHWs, limiting causal attribution. Common barriers included inconsistent training, competing responsibilities, weak referral systems, and insufficient funding and policy support.

**Conclusion:** CHWs play a multifaceted role in enhancing leprosy control, but their effectiveness is constrained by systemic and contextual barriers. Future research should adopt more rigorous study designs, including Community-Based Participatory Research (CBPR), to better assess CHW-specific contributions and cost-effectiveness. Strengthening training, supervision, and intersectoral collaboration is essential to maximize the impact of CHW-led interventions.

**Keywords:** Community health workers (CHWs), community participation, early detection, Hansen's Disease, Leprosy

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## 2 INTRODUCTION

Leprosy, or Hansen's disease, is a neglected tropical disease (NTD) caused by *Mycobacterium leprae*, mainly affecting the skin and peripheral nerves and transmitted through prolonged contact with untreated multibacillary patients.[1] Despite progress in diagnosis and treatment, stigma and inadequate health infrastructure in low-resource regions still hamper early detection, sustaining transmission.[2,3] In 2023, 182,815 new cases were documented across 184 countries, many discovered late thereby elevating the risk of nerve damage and Grade 2 Disability (G2D).[4,5] G2D refers to visible impairments or deformities, such as claw hands or drop feet, that restrict individuals' daily activities, employment opportunities, or social interactions.[6] The African and Southeast Asian regions bear the greatest burden, with 9,729 G2D cases (2.7% among children) reported in 2023.[5]

G2D has emerged as a more reliable measure of disease burden than prevalence because it is less influenced by operational factors (e.g., control program quality) and reflects broader community awareness, as well as the capacity of local health systems to diagnose Leprosy promptly.[7] A study found that 39% of new leprosy patients had visible disabilities at the time of diagnosis, highlighting substantial delays in seeking and receiving care.[8] On the contrary, low G2D rates, for instance, 2.34%, were reported in Bargarh District, India, pointing to more effective early detection systems.[9]

The WHO's Global Leprosy Strategy 2016–2020 aimed to reduce newly diagnosed G2D cases to fewer than one per million by 2020, but this goal was not achieved. Building on those efforts, the "Towards Zero Leprosy (2021–2030)" strategy now emphasizes active case detection (ACD) to limit transmission, targeting zero disability, zero discrimination, and a 70% reduction in annual new cases.[10] Delayed diagnoses account for over half of new detections in many endemic regions.

Leprosy's delayed diagnosis frequently accounts for over 50% of new detections[6], and relying solely on passive case detection has proven insufficient due to widespread late health-seeking behavior[11,12]. Consequently, rapid diagnosis and treatment are critical for preventing further spread, minimizing medical and social consequences, and reducing the overall burden of the disease.

Community engagement is a key strategy in leprosy control, particularly in early detection efforts.[13–16] Studies highlight the role of community volunteers in reducing diagnostic delays by identifying and referring patients early (15) and demonstrate that community participation is crucial in regions with stigma and limited healthcare access.[13] Integrating community involvement into leprosy programs has shown sustainable progress toward "Zero Leprosy," even in resource-limited settings. Evidence also suggests that community participation improves health outcomes and reduces inequalities, particularly among disadvantaged populations.[14]

Within this framework, Community Health Workers (CHWs) serve as vital frontline providers, especially in remote areas.[13,17,18] Training CHWs in symptom identification and awareness campaigns significantly enhances early case detection and follow-up care, particularly in low- and middle-income countries.[13] This collaborative approach demonstrates the power of community-driven interventions in promoting awareness, ensuring timely treatment, which ultimately advances national and global leprosy eradication goals.

Recent reviews suggest that while community-based interventions can reduce stigma and improve early detection of neglected tropical diseases, the specific roles and effectiveness of CHWs in leprosy control remain insufficiently explored.[7,14,19–21] For instance, Anindhita's scoping review highlights the role of "lay supporters" in mitigating stigma and promoting adherence but does not clarify CHWs' specific tasks or training needs in leprosy-endemic settings.[19] Similarly, Dharmawan's systematic reviews[7,22] argue that individual and community determinants of delayed detection such as stigma, low knowledge levels, and limited healthcare-seeking behavior offer little insight into whether CHWs can address these barriers. Brown's focus on active case detection (ACD) methods for Leprosy also reveals a range of screening approaches (e.g., door-to-door surveys, school-based initiatives) but does not clarify how CHWs are integrated or trained within these models.[20] Hotopf's exploration of community-based groups for skin-related NTDs indicates beneficial outcomes in terms of awareness and self-care. Nevertheless, the operational challenges or day-to-day responsibilities of CHWs receive minimal attention.[21] Lastly, Likewise, Martos-Casado's research on community-based leprosy programs in priority countries reports positive health outcomes but does not specify CHWs' contributions or directly measure their impact.[14,23]

These reviews reveal two key gaps: limited clarity on CHWs' responsibilities in leprosy control and little data linking improved detection or outcomes directly to CHW-led efforts. To address this, we aim to synthesize global evidence on CHWs' roles in leprosy management, focusing on their measurable contributions and the challenges they encounter. Specifically, it seeks to address three research questions: (1) Which roles and activities do CHWs perform in community-based leprosy programs? (2) Which early detection methods and programs, involving CHWs, have been evaluated, and how effective are they? (3) What key barriers hinder CHWs' leprosy detection and management efforts? By examining international data, this review outlines best practices, identifies research gaps, and provides guidance for policymakers and public health professionals seeking earlier detection and reduced disability in leprosy-endemic communities.

## METHODOLOGY

**Study Design and Framework:** This study employed a scoping review methodology based on Arksey and O'Malley's framework, which provides a systematic approach to map existing literature, identify key concepts, and summarize evidence regarding a specific research area. To ensure transparency and methodological rigor, this scoping review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines.[24]

**Information Sources and Search Strategy:** The literature search used three databases, PubMed, Scopus, and Google Scholar, to identify relevant studies published between 2000 and 2025. Grey literature sources, including the WHO library and relevant reports, were also searched. A combination of carefully selected search terms connected with Boolean operators was used to refine search results (see Table 2).

We included all studies involving Community Health Workers (CHWs) in either professionally trained or community-recruited leprosy control and management programs. Eligible studies described CHWs' roles or activities related to early detection, prevention, clinical management, or community engagement. Our review aimed to map CHW participation broadly and did not exclusively focus on studies that formally evaluated CHW effectiveness. Studies were excluded if they did not explicitly involve CHWs or community-based volunteers, were solely limited to clinical treatment or biomedical aspects without a community-based approach, were systematic reviews without primary data, or lacked full-text availability in English.

**Data Extraction and Analysis:** Screened articles from scientific databases and grey literature were exported to Rayyan AI systematic review software. Two independent reviewers (ES, AD) screened the titles and abstracts guided by the predefined PICO framework and screened the full texts of selected articles. Any disagreements during the selection process were resolved through discussion among the reviewers to reach a consensus on inclusion or exclusion.

Relevant data from selected articles were extracted and tabulated into a Microsoft Excel database. Key variables extracted included study characteristics (author, year, country, study design), CHW terminology, CHW activities related to leprosy management programs, specific programs evaluated, early detection strategies, outcomes of CHW-led leprosy detection programs, and challenges faced by CHWs.

Extracted data were analyzed quantitatively, presented across multiple tables, and qualitatively through thematic analysis. For thematic analysis, findings were coded, categorized, and synthesized into themes related to CHW roles outcomes, and challenges and barriers were identified.

## RESULTS

**Study Characteristics:** The initial systematic search identified 361 articles, of which 59 duplicates were removed, leaving 302 articles for title and abstract screening. After this process, 244 articles were excluded, resulting in 58 articles accessed in full text. Following the full-text review, 35 additional records were excluded, leaving 23 reports included in this review, as visualized in Figure 1.

**Table 1: Search Terms**

| Database | Terms (2000-2025) | Found |
|---|---|---|
| PubMed | (((("Leprosy"[MeSH]) OR ("Hansen's disease")) OR ("Mycobacterium leprae")) OR ("Leprosy Screening")<br>AND<br>(((((("Social Participation"[MeSH]) OR ("Community-Based Participatory Research"[MeSH])) OR ("Community Health Services"[MeSH])) OR ("Community Health Workers"[MeSH])) OR ("community participation")) OR ("Community-Based Approach")<br>AND<br>(((((("Delayed Diagnosis"[MeSH]) OR ("Early Diagnosis"[MeSH])) OR ("Health Knowledge, Attitudes, Practice"[MeSH])) OR ("Social Stigma"[MeSH])) OR (diagnosis)) OR (surveillance) | 75 |
| Google Scholar | ("Community Engagement" OR "Community-Based Approach")<br>AND ("Community Health Workers" OR "CHW" OR "Health Volunteers")<br>AND ("Leprosy" OR "Hansen's Disease")<br>AND ("Early Detection" OR "Case Finding") -- | 239 |
| Scopus | (TITLE-ABS-KEY("Social Participation" OR "Community Engagement" OR "Community Participation" OR "Community-Based Approach" OR "Community Health Services" OR "Community-Based Participatory Approach"))<br>AND<br>(TITLE-ABS-KEY("Leprosy" OR "Hansen's Disease" OR "Leprosy Screening" OR "Mycobacterium leprae"))<br>AND<br>(TITLE-ABS-KEY(("("Delayed Diagnosis" OR "Early Diagnosis" OR "Health Knowledge, Attitudes, Practice" OR "Social Stigma" OR diagnosis OR surveillance) | 44 |

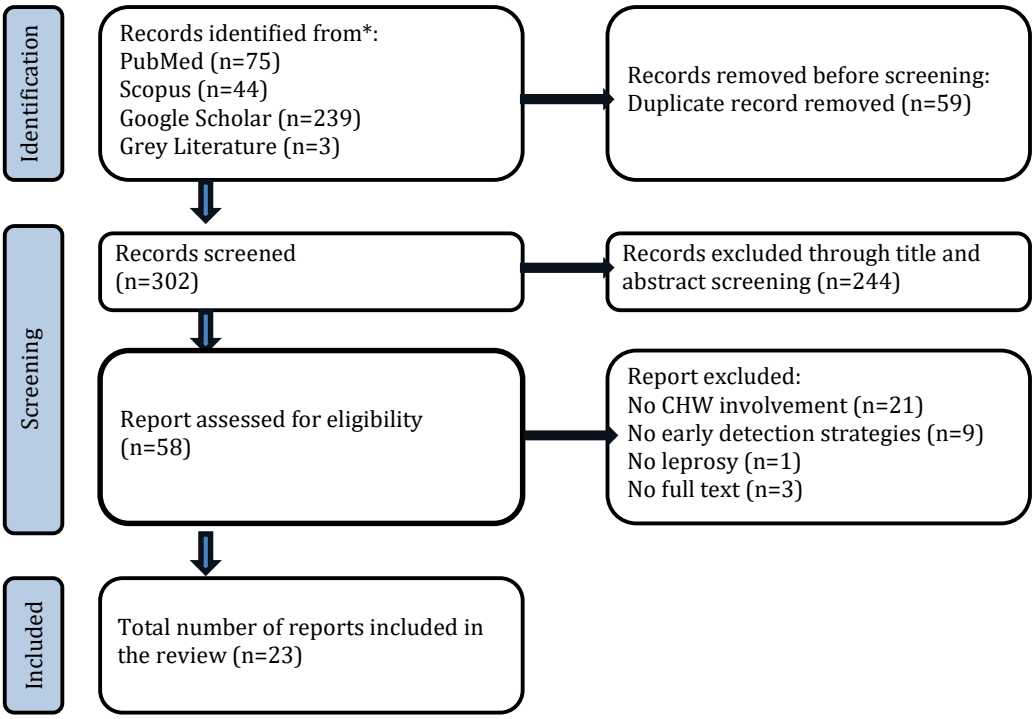


**Figure 1**: **PRISMA Flow Diagram**

As shown in Table 1, the included studies were conducted across diverse geographical settings, predominantly in India (21.7%) and Brazil (21.7%), followed by Indonesia (13.0%), Nepal and Ethiopia (each 8.7%), and multi-country studies comprising 13.0%. Additional studies came from Somalia, Uganda, and the Philippines, collectively contributing 4.3%. Regarding study design, most studies (60.9%) adopted quantitative designs, followed by qualitative studies (26.1%) and mixed methods studies (17.4%). Among the quantitative studies, several evaluated specific intervention programs, including operational research on active case detection (ACD) approaches.[12,25]

Studies used diverse terminology to describe CHWs. Several studies defined CHWs as professionally trained health personnel.[26–29] In contrast, studies by[27,30] described CHWs recruited directly from the local community. Authors use specific terms such as Accredited Social Health Activist or ASHA[28,31], Community Health Agents[13,32], Community Health Extension Workers[6], Health Cadres[33], Lay Counsellors[34,35], Community Health Volunteers[12,25,36], Multi-Purpose Workers[9,28], Volunteer Health Teams[8], or Village Volunteers[37]. Furthermore, early leprosy detection initiatives were often not standalone but integrated into broader health programs addressing multiple diseases, such as tuberculosis (TB)[6], visceral leishmaniasis[12], or other skin NDTs[37].

The findings of this scoping review are organized into thematic categories to present key aspects of CHWs' involvement in leprosy management programs. Table 2 summarizes the early detection methods and challenges encountered by CHWs in the included studies. At the same time, Figure 2 visually illustrates the interrelationships among these key themes, providing a concise overview before presenting detailed findings.

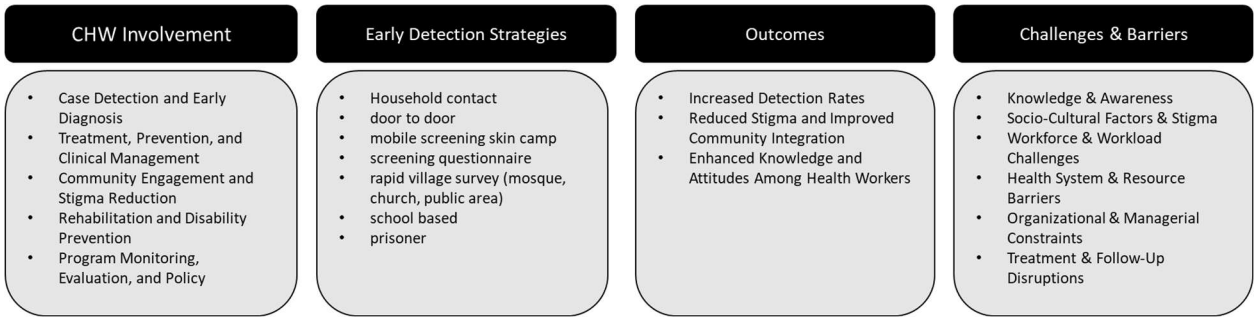


**Figure 2: Summary of CHW Roles, Early Detection Strategies, Outcomes, and Challenges in Leprosy Control and Management Program**

**Table 2: Characteristics of Included Studies, Community Health Worker Terms, and Activities in Leprosy Management Programs**

| Author, year | Country | Study Design | CHW terminology | Program's Name | CHW Involvement |
|---|---|---|---|---|---|
| Aden, 2023 [38] | Somalia | Quantitative | CHW (professional and non) | Mobile Camps | - Conduct skin camps and community outreach |
| Aquino, 2023 [26] | Brazil | Qualitative, action-research study | CHW (professional) | *Intergrahans Maranhao* | - Engage in structured discussions about Leprosy<br>- Share experiences regarding community perceptions, stigma, and misinformation<br>- Provide education |
| Baghotia, KS, 2023 [31] | India | Mixed-methods survey | Accredited social health activists (ASHA) | Not specify (under National Leprosy Eradication Programme (NLEP)) | - Conduct case detection, contact tracing, and reducing stigma<br>- Ensure medication adherence<br>- Assist in rehabilitation |
| Bernardes Filho, 2021 [32] | Brazil | Quasi-experimental, implementation research | Community Health Agents | Not specify | - Administer LSQ during home visits<br>- Health education for community members on recognizing neurological symptoms of Leprosy |
| Betru, 2023 [6] | Ethiopia | Qualitative, descriptive, and phenomenological explorative study | Community Health Extension Workers | Not specify | - Leprosy prevention and detection |
| Bhatki, 2014 [36] | India | Quantitative, Program evaluation | Community Health Volunteer | Selective Special Drive (SSD) under ALERT-INDIA's Leprosy Elimination Action Program (LEAP) | - House-to-house Information Education Campaign (IEC)<br>- Referred suspected cases to health facilities |
| Bolorino, 2024 [27] | Brazil | Quantitative | CHW (combination professional and non) | Not specify | - Identification suspected leprosy cases and guiding the community on preventive measures |
| Budiawan, 2020 [33] | Indonesia | Quantitative, program evaluation | Health cadres | Leprosy Friendly Village | - Recognize and refer suspected leprosy cases<br>- Integrate leprosy education into routine community health activities<br>- Promote to acceptance and reduce stigma |
| Fastenau, 2024 [13] | Multi-country study (Brazil, India, Nigeria) | Qualitative, case study | Community Health Agents | Not specify (under National Leprosy Eradication Programme (NLEP)) | - Outreach and early case detection<br>- Conduct screenings, and educate communities<br>- Collaborate with healthcare institutions to improve case management |
| Govindasamy, 2021 [39] | India | Quasi-experimental study | CHW (professional) | Not specify (under National Leprosy Eradication Programme (NLEP)) | - Support awareness and screening efforts<br>- Key role in referral-based case detection |
| Kengonzi, 2024 [8] | Uganda | Mixed-methods | Volunteer Health Teams | Not specify | - Assisted in case referral and community awareness<br>- Ensure medication adherence<br>- Conduct disability prevention |
| Lusli, 2015 [34] | Indonesia | Qualitative study with participatory action | Lay and Peer counsellor | Stigma Assessment and Reduction of Impact (SARI) | - Lay counsellors: Basic counselling and communication skills |

| Author, year | Country | Study Design | CHW terminology | Program's Name | CHW Involvement |
|---|---|---|---|---|---|
| | | research | | | - Peer counsellors: trained to support others |
| Lusli, 2016 [35] | Indonesia | Mixed-methods | Lay counsellor | Right-Based Counseling | - provide structured counselling to reduct stigma |
| Mahato, 2023 [25] | Nepal | Quantitative, program evaluation | Community Health Volunteer | Not specify | - conduct screenings and referrals<br>- mobilize communities<br>- identify suspected cases<br>- monitoring program |
| Mamo, 2024 [40] | Ethiopia | Quantitative, intervention | CHW (combination professional and non) | Active Case Detection (ACD) | - assist in community mobilization and screening activities<br>- preventive care<br>- Assist in rehabilitation |
| Pandapatan, 2024 [42] | Philipine | Quantitative, observational | CHW (professional) | *Kilatis Kutis Campaign* | - screening for suspected Leprosy |
| Saunderson, 2022 [11] | Multi-country review | Qualitative | CHW (combination professional and non) | Not specify | - Encourage early case detection |
| Shetty, 2009 [28] | India | Quantitative, intervention | Accredited social health activists (ASHA) | Selective Special Drive (SSD) under ALERT-INDIA's Leprosy Elimination Action Program (LEAP) | - Detect leprosy cases<br>- Conduct house-to-house visits and refer suspects for clinical examination<br>- Engage with local PHCs for diagnosis and treatment initiation<br>- Conduct monitoring and evaluation program |
| Siddiqui, 2009 [9] | India | Operational research study evaluating program integration | Multi-Purpose Workers | Not specify (under National Leprosy Eradication Programme (NLEP)) | - A key role in leprosy detection and treatment<br>- Conduct community awareness initiatives carried out through PHC outreach |
| Silva, 2020 [29] | Brazil | Quantitative, observational | CHW (combination professional and non) | Palmas Leprosy-Free Project | - Assist in early detection and prevention strategies<br>- Participate in screening activities and provide education to communities<br>- Assisted in disability prevention and self-care initiatives |
| Singh, 2019 [12] | Nepal | Quantitative, intervention | Female Community Health Volunteers (FCHVs) | Active Case Detection (ACD) | - Detect and refer suspected VL and leprosy cases<br>- Engage in community sensitization through house-to-house visits |
| Souza, 2023 [30] | Brazil | Quantitative, validation scenario | CHW (combination professional and non) | Not specify | - Provide training on simulated patient interactions |
| Tchatchouang, 2024 [37] | Cameroon, Ghana | Quantitative, observational | Village Volunteer | LAMP4YAWS project | - Identify and refer suspected cases<br>- Engage with village leaders and school-based screenings to facilitate case finding |

**Table 3: Summary of Included Studies on Early Detection Methods and Challenges in CHW-Led Leprosy Programs**

| Author, year | Country | Early Detection Method | Challenges |
|---|---|---|---|
| Aden, 2023 [38] | Somalia | Mobile screening | - Stigma<br>- Low female case detection due to social barriers<br>- Displacement due to conflict<br>- Limited access to healthcare |
| Aquino, 2023 [26] | Brazil | NA | - Social stigma and historical discrimination against leprosy patients<br>- Limited community awareness leading to misconceptions about leprosy transmission and treatment<br>- Emotional distress among CHWs in addressing community reluctance toward leprosy care |
| Baghotia, KS, 2023 [31] | India | Household contact | - High levels of stigma and misinformation about Leprosy<br>- Inconsistent training among frontline workers<br>- Inadequate infrastructure and limited availability of essential medicines<br>- Limited engagement of women and children in early detection efforts<br>- Low prioritization of contact examination and follow-up |
| Bernardes Filho, 2021 [32] | Brazil | screening questionnaire | - Low awareness of leprosy symptoms, particularly neurological signs<br>- Inconsistent training of healthcare workers in recognizing early-stage Leprosy<br>- Limited integration of leprosy detection in routine primary healthcare activities<br>- Social stigma contributing to delayed diagnosis and treatment adherence issues |
| Betru, 2023 [6] | Ethiopia | Household contact | - Lack of structured and sustainable training for health workers<br>- Insufficient community engagement and awareness programs<br>- Weak health system integration and supervision mechanisms<br>- Stigma-related barriers affecting timely diagnosis and treatment adherence |
| Bhatki, 2014 [36] | India | Door-to-door (house visit) | - Discontinuation of active surveys reduced early case detection<br>- Initial scepticism about the feasibility of involving community volunteers in leprosy detection<br>- Need for structured financial incentives to sustain volunteer participation<br>- Dependence on external funding from LEAP for training and operational costs |
| Bolorino, 2024 [27] | Brazil | Not specify | - Disparities between urban and rural Areas<br>- Many CHWs had little to no training in leprosy detection and management<br>- Limited resources and educational programs for both CHWs and the public<br>- Poor coordination between CHWs and higher levels of care for leprosy patients |
| Budiawan, 2020 [33] | Indonesia | rapid village or public survey (mosque, church) | - Finding persons affected by Leprosy willing to speak out was difficult<br>- Some health workers initially resisted engagement in leprosy programs due to fear<br>- Ongoing need for funding to sustain regular community activities |
| Fastenau, 2024 [13] | Multi-country study (Brazil, India, Nigeria) | Not specify | - Persistent stigma limiting early reporting of symptoms<br>- Gaps in healthcare accessibility and infrastructure in remote communities<br>- Sustainability issues due to funding constraints for community-led initiatives |
| Govindasamy, 2021 [39] | India | Household contact, Door-to-door (house visit), school survey | - Reluctance of CHWs to refer patients due to concerns about their informal status<br>- Stigma preventing community members from openly discussing symptoms<br>- Overlapping leprosy case detection campaigns (LCDC) by the government affected study results |
| Kengonzi, 2024 [8] | Uganda | NA | - Lack of awareness about leprosy symptoms and transmission<br>- Geographical barriers and poor infrastructure limiting healthcare access<br>- High stigma associated with Leprosy, leading to self-isolation and social exclusion<br>- Healthcare worker gaps in recognizing Leprosy, leading to misdiagnoses |
| Lusli, 2015 [34] | Indonesia | NA | - High rates of refusal to participate due to fear of social stigma<br>- Lay counsellors initially struggled with effective listening and questioning technique<br>- Family resistance to counselling due to concerns about community discrimination |

| Author, year | Country | Early Detection Method | Challenges |
|---|---|---|---|
| Lusli, 2016 [35] | Indonesia | NA | - Limited financial support and incentives for counsellors led to dropouts<br>- Some individuals refused counselling due to fear of stigma<br>- Lay counsellors (CHWs) needed additional training in active listening and engagement techniques<br>- Family members were sometimes hesitant to participate in sessions<br>- Sustainability concerns due to lack of long-term funding and integration into health systems |
| Mahato, 2023 [25] | Nepal | Household contact, Door-to-door (house visit), Prisoner survey | - Hidden leprosy cases remain undetected due to lack of awareness and delays in seeking care<br>- Prison environments pose unique challenges for leprosy detection and treatment<br>- Geographical barriers and resource limitations impact early detection efforts |
| Mamo, 2024 [40] | Ethiopia | Household contact, rapid village or public survey (mosque, church), school survey | - High staff turnover reduced post-assessment participation<br>- Limited prior training on Leprosy among healthcare workers<br>- Persistent stigma prevented some individuals from seeking care<br>- Geographical barriers made case detection and follow-up challenging |
| Pandapatan, 2024 [42] | Philipine | NA | - Lack of formal training among CHWs on leprosy identification and management<br>- Widespread misinformation about transmission and treatment<br>- Stigma and fear of contracting Leprosy affecting community interactions<br>- Limited financial incentives for CHWs , leading to low motivation |
| Saunderson, 2022 [11] | Multi-country review | NA | - Difficulties in persuading patients to list contacts for screening<br>- Convincing contacts of leprosy patients to undergo examination<br>- Lack of standardized mapping tools across different endemic regions<br>- Limited funding for active case-finding initiatives |
| Shetty, 2009 [28] | India | Door-to-door (house visit) | - Severe shortage of multi-drug therapy (MDT) supplies<br>- Missed diagnoses at CHWs due to lack of clinical expertise<br>- Difficulties in reaching patients due to transportation barriers<br>- Social stigma discouraging individuals from seeking treatment |
| Siddiqui, 2009 [9] | India | Household contact | - Validation system led to unnecessary treatment delays for newly diagnosed case<br>- Inconsistent monitoring and reporting of new case validations<br>- Limited disability and ulcer care services within Public Health Center<br>- Urban CHWs staff lacked sufficient exposure to leprosy cases, reducing their diagnostic skills |
| Silva, 2020 [29] | Brazil | Household contact, Door-to-door (house visit) | - Limited prior training among healthcare professionals, requiring continuous education effort<br>- Need for better integration of contact tracing into routine primary healthcare services<br>- Persistent stigma affecting early reporting of symptoms and care-seeking behavior<br>- Increase in newly detected cases suggests hidden prevalence rather than a rise in transmission |
| Singh, 2019 [12] | Nepal | Door-to-door (house visit) | - CHWs struggled to identify cases due to limited hands-on diagnostic training<br>- Social stigma prevented suspected leprosy patients from seeking care<br>- Lack of community trust in volunteers for disease diagnosis<br>- Operational issues in incentive-based referral system |
| Souza, 2023 [30] | Brazil | screening questionnaire, Prisoner survey | - CHWs lacked prior exposure to experiential learning methods<br>- Need for ongoing refresher training to maintain detection skills<br>- Barriers to implementing simulation training in resource-limited settings |
| Tchatchouang, 2024 [37] | Cameroon, Ghana | Door-to-door (house visit), rapid village or public survey (mosque, church), school survey, Prisoner survey | - Difficulties in accessing remote communities for case detection<br>- High levels of stigma discouraging individuals from seeking care<br>- Need for improved data reporting and integration of digital health tools |

*Notes. NA: Not available, indicating that the included study did not explicitly evaluate or describe the role or activities of CHWs in early detection; thus, no data on early detection methods were reported

**Community Health Worker Roles:** The included studies reveal diverse activities conducted by CHW in leprosy control and management programs. The majority of studies (60.9%) highlighted CHW involvement specifically in case detection and early diagnosis activities, which included identifying and referring suspected leprosy cases through various active case detection approaches.[6,9,12,13,25,27–29,31,32,37–40]

Many studies (43.5%) also highlighted CHWs' involvement in community mobilization activities, including stigma reduction, public education, and raising awareness.[12,12,13,25,26,31,33–35,40] Additionally, CHWs were actively involved in treatment, prevention, and clinical management tasks (21.7%), contributing to essential clinical aspects such as medication adherence and preventive care.[8,29,31,40] CHWs also contributed to CHWs' involvement in rehabilitation and disability prevention initiatives (17.4%), highlighting their role in addressing the long-term effects of Leprosy.[8,29,31,40] Finally, a small number of studies (8.7%) highlighted the role of CHW in program monitoring and evaluation activities[25,28], ensuring continuous oversight and improvement of leprosy detection programs.

**Specific Programs Evaluated:** Several studies in this review evaluated targeted interventions designed to enhance leprosy control and management across diverse settings. These interventions ranged from integrated case detection programs, such as the LAMP4YAWS project in Cameroon, Côte d'Ivoire, and Ghana[37], to specialized initiatives like the Palmas Leprosy-free Project in Brazil, emphasizing professional training for comprehensive patient care[29]. India's long-standing National Leprosy Eradication Programme (NLEP), initiated in 1983[41], integrated leprosy services into primary healthcare, highlighting decentralized service delivery and strengthened surveillance systems.[9,13,31] Similarly, the Selective Special Drive (SSD), under ALERT-INDIA's Leprosy Elimination Action Program (LEAP), employed community workers for door-to-door awareness and detection activities.[28,36]

In Indonesia, the Leprosy Friendly Village (LFV) initiative reduced leprosy stigma and improved early case detection through health education and community empowerment.[33] Complementing this, the Rights-Based Counselling Module (RBCM) and the Stigma Assessment and Reduction of Impact (SARI) project effectively addressed psychological, social, and stigma-related challenges by engaging trained lay and peer counselors.[34,35] These diverse yet focused approaches highlight the importance of tailored, culturally appropriate leprosy management and control strategies.

**Early Detection Strategies:** As previously mentioned, early detection was a key activity CHWs performed across most studies. The most commonly reported detection approach was door-to-door screening (26.1%), as highlighted by[12,25,29,36,37,39]. Household contact tracing was another common approach (21.7%), reported by[9,25,29,39,40]. Rapid village surveys conducted in public places including mosques and churches were reported in several studies (13.0%;[33,37,40]. School-based screenings were equally common (13.0%;[37,39,40], along with screenings conducted within prison populations (13.0%;[25,30,37]). Fewer studies reported the use of screening questionnaires (8.7%; [30,32], one of which specifically mentioned the use of the Leprosy Suspicion Questionnaire [32]. Mobile screening skin camps were the least utilized method (4.3%;[38]. Additionally, several studies (21.7%) did not specify the detection method employed[6,26,27,42].

**Outcomes of CHW-Led Leprosy Control and Management Programs:** Studies included in this review reported diverse outcomes from CHW-led interventions aimed at improving leprosy detection, reducing stigma, and enhancing overall community health. Several studies reported substantial increases in new case detection rates (NCDR) following interventions involving CHWs. For instance,[38] reported an 11-fold increase in detection rates from 2012 to 2021, while[32] NCDR was 20% among individuals who screened positive using the Leprosy Suspicion Questionnaire. Similarly,[36] observed increased detection rates of 13-34 per 100,000 compared to Mumbai's usual rate of 6 per 100,000, suggesting improved self-reporting and early detection linked to CHW-led health education. Mahato et al.[25] also demonstrated the effectiveness of contact tracing, reporting high NCDRs of up to 250 per 100,000 contacts screened, although ongoing pediatric cases and grade-2 disabilities indicated persistent transmission and delayed diagnosis. Moreover, Silva et al.[29] reported a nearly four-fold increase in general detection rates, including over a three-fold increase among children under 15.

Community-based initiatives, such as the Leprosy Friendly Village (LFV) approach evaluated by Budiawan et al.[33], significantly improved community knowledge, reduced stigma, and decreased new patient numbers from 33 to 11 between 2012 and 2017. Likewise, interventions like the Rights-Based Counselling Module[35] and SARI Project[34] in Indonesia successfully reduced stigma. They improved the quality of life, social participation, and community integration for people affected by Leprosy. Other studies reinforced these findings, indicating better health workers' attitudes, enhanced community awareness, and reduced stigma through active community engagement.[9,13,31] Nonetheless, persistent stigma and late detection were still reported in some regions, highlighting continuous challenges that require sustained CHW-driven efforts.[8,38]

**Challenges and Barriers:** Included studies consistently highlighted several challenges influencing CHW-led leprosy programs' effectiveness. A prominent barrier was inadequate knowledge and awareness among healthcare workers and communities. Many frontline staff, including CHWs, lacked formal and refresher training, preventing them from confi-

dently identifying early signs of Leprosy or conducting proper contact examinations.[26,31,36] For instance,[40] reported that prior to specific training, only 18% of healthcare workers correctly diagnosed leprosy, highlighting substantial gaps in diagnostic capabilities. Limited public understanding also hindered early detection efforts, as misconceptions about Leprosy's origins such as hereditary factors or divine punishment persisted in many rural areas.[39]

Significant sociocultural stigma was further complicated early diagnosis and treatment adherence. Patients often concealed symptoms due to fear of discrimination, exacerbated by pervasive community beliefs associating Leprosy with curses or moral failings.[39] Aden[38] specifically noted that female patients faced compounded stigma related to gender, disability, and leprosy status. Acceptability of active case detection initiatives frequently suffered, as index patients feared being stigmatized when asked to identify contacts.[11]

Operational difficulties related to workforce and workload posed another substantial challenge. CHWs, already burdened by competing healthcare responsibilities, struggled to prioritize leprosy management effectively, resulting in limited attention to necessary detection and follow-up activities.[27] Organizational challenges amplified these issues, including weak political commitment and inconsistent funding. Studies by Fastenau and Mahato[13,25] highlighted varying levels of government prioritization and limited resources allocated to leprosy control, thereby restricting program reach and sustainability.

Moreover, systemic health service and logistical barriers were typical across contexts. Weak referral pathways between primary care and specialized services created delays and disrupted continuity of care.[39] Programs heavily reliant on external funding or drug donations, as noted by Aden in Somalia, encountered severe difficulties in maintaining consistent leprosy control measures. Shortages of essential supplies, logistical bottlenecks in training and supervision, and frequent disruptions in medication supplies further weakened program effectiveness and patient adherence to treatment regimens.[25,36,42]

Lastly, disruptions in treatment and follow-up negatively impacted program outcomes. Patients frequently discontinue treatment prematurely due to misconceptions about their health status, stigma, logistical hurdles, or inadequate follow-up from healthcare workers. Scholars highlighted specific barriers to sustained engagement, noting how personal constraints and the lack of a clear national strategy hindered the integration of supportive services such as peer counseling.[34,36]

## Discussion

This review analyzed 23 studies evaluating the roles and activities of Community Health Workers (CHWs) in leprosy control and management. Most of the included studies were conducted in India, Brazil, and Indonesia, and more than 10,000 new cases have been reported as per data from 2023.[43] While the current review includes studies from other highly endemic countries (e.g., Nepal, Ethiopia, Somalia, and Philippines), several other global priority countries identified by WHO between 2014–2023[43], such as Bangladesh, Egypt, Madagascar, Mozambique, Myanmar, Nigeria, Sri Lanka, South Sudan, and Tanzania, were not represented in the included studies. This limited geographic representation may mean the review does not fully reflect the various contexts, strategies, and challenges CHWs face across all endemic regions, potentially affecting the generalizability of the findings.

Furthermore, these studies used varied terminology for CHWs, reflecting differences in local contexts, professional backgrounds, and training. For example, "lay counselors" were explicitly used for workers who received basic communication skills training rather than formal medical training. Lay counselors could be staff from non-governmental organizations, Disabled People's Organizations (DPOs), health workers, or peer volunteers.[34,35] Therefore, the variability in CHW terminology across studies reflects context-specific differences rather than mere inconsistencies. Nonetheless, this variety has several implications for implementing and comparative analysis of CHW-led leprosy management programs. It may confuse defining roles and training standards. Moreover, varied terminology makes cross-context comparisons of CHW effectiveness challenging. This may potentially obscure insights into which practices are most beneficial. Additionally, while we maintained the original terms in the narrative, we acknowledge the importance of standardization for future research. We suggest that upcoming studies adopt a minimum reporting framework for CHWs that includes role definition, training level, and degree of integration within formal health systems. This approach would enhance cross-study comparability and inform policy development across diverse implementation settings.

Our review reveals that most studies emphasize that CHWs frequently serve as the first point of contact for early leprosy detection.[6,9,12,13,25,27–29,31,32,37–40] Beyond case detection, CHWs play multifaceted roles, including community engagement, stigma reduction, treatment support, prevention, clinical management, rehabilitation, disability prevention, and program monitoring and evaluation. However, the effectiveness of these roles is often hindered by knowledge gaps and misconceptions about leprosy symptoms, emphasizing the critical need for structured training programs to enhance CHWs' capacity and impact on leprosy control and management.

Community-based approaches such as structured educational interventions, participatory learning frameworks (e.g., Paulo Freire's Culture Circle methodology), and experiential training enhanced CHWs'

abilities and community acceptance of leprosy interventions. Effective practices included culturally adapted educational initiatives, community-based screenings, and engagement with influential community figures to improve referral systems and reduce barriers to early diagnosis.

Various programs, including integrated case detection initiatives such as the LAMP4YAWS project for multiple skins Neglected Tropical Diseases (NTDs) in Cameroon, Côte d'Ivoire, and Ghana[37], as well as specialized efforts like the Palmas Leprosy-Free Project in Brazil, Leprosy Friendly Village (LFV), Stigma Assessment and Reduction of Impact (SARI), and the Rights-Based Counseling (RBC) initiative in Indonesia[33–35], have contributed to leprosy control. However, these studies do not explicitly state whether their programs operate under a national campaign.

In contrast, studies from India explicitly reference national-level implementation, particularly under the National Leprosy Eradication Programme (NLEP).[41] Initiated in 1983, NLEP integrates leprosy services into primary healthcare, emphasizing decentralized service delivery and enhanced surveillance systems. A key initiative under NLEP is the Selective Special Drive (SSD), part of ALERT-INDIA's Leprosy Elimination Action Program (LEAP), which deploys community workers for door-to-door awareness and case detection activities.[28,36] Evaluations of SSD highlight its effectiveness in improving early case detection rates, particularly in high-burden regions, although stigma and logistical constraints remain significant challenges.

In this study, door-to-door and household contact screening emerged as the predominant early detection methods, followed by public surveys. These approaches proved most effective when tailored to specific community contexts and integrated with local support systems. This result is consistent with a prior study[20], highlighting how active case detection strategies should match each setting's leprosy endemicity and sociocultural conditions. Moreover, epidemiological evidence suggests that new-case numbers plateaued once active case-finding was no longer prioritized after 2005. This demonstrates the need to renew emphasis on these approaches to achieve earlier detection and mitigate disability.[11] Contact tracing, in particular, remains the most cost-effective means of early diagnosis, given that contacts of new cases bear the highest risk of developing Leprosy. As endemicity declines, an increasingly larger proportion of new cases stems from contact-based detection, further improving the efficiency of this method over time. In addition, the recent WHO recommendation to provide post-exposure prophylaxis (PEP) to contacts reinforces the essential role of systematic screening and clinical examination, where newly identified cases are treated promptly and eligible contacts receive prophylaxis. Such measures, whether door-to-door, household-contact-based, or supplemented by broader clinical settings, underlining the need for interventions that reduce stigma, reinforce community engagement, and address both participant motivation and environmental barriers to ensure timely and successful leprosy control.

Furthermore, this review also underlines a relationship between CHW involvement and improved program outcomes, which range from increased case detection to reduced stigma, enhanced community awareness, and better treatment adherence. However, existing study designs do not allow definitive attribution of these improvements solely to CHWs. Strong community participation, supportive policies, and adequate CHW training or supervision likely contribute to these positive results.[32,33,35] Nonetheless, there are still gaps in measuring CHW-specific contributions. Our included studies have not systematically examined data that isolate CHW's impact from other program components. Rather than viewing CHWs as a standalone intervention, their work is better understood as part of a broader, community-driven process, an approach that aligns with prior studies that emphasize context-sensitive community participation for improving health outcomes.[44,45] Accordingly, future research should adopt robust methods and best-practice guidelines to clarify which CHW-led activities yield the most significant benefits, how they interact with local conditions, and how they can be effectively sustained to optimize leprosy management programs.

Nonetheless, we could not attribute improvement found solely to CHWs based on the current study designs. Since the predominantly of interventions were multifaceted and lacked comparator groups, it is difficult to distinguish CHW-specific effects from broader program activities. Therefore, future research should adopt more rigorous methodological approaches to improve causal inference. The strategies may include controlled study designs such as randomized controlled trials (RCTs), cluster-randomized trials, or stepped-wedge designs where CHW-led components are independently assessed. In addition, statistical methods such as propensity score matching, multivariable regression adjustment, or instrumental variable analysis could help control for confounding and better estimate the isolated effect of CHWs. Incorporating process evaluations or contribution analysis alongside quantitative outcomes may also help attribute specific changes to CHW-led actions.

Various challenges consistently emerged across the included studies, hindering CHW-led leprosy programs. Inadequate knowledge and awareness among frontline health workers and communities was a key barrier. With insufficient or infrequent training, many cannot recognize early symptoms or perform contact examinations effectively. Persisting misconceptions about Leprosy, coupled with widespread sociocultural stigma, further discouraged early detection and contributed to patients concealing symptoms.

Operationally, CHWs often faced competing respon-

sibilities and limited incentives, reducing their capacity to prioritize leprosy detection and follow-up. Weak political commitment and inconsistent funding compounded these issues; constraining program reach and sustainability. Systemic barriers, such as fragmented referral pathways, supply shortages, and logistical bottlenecks in training and supervision, disrupted service continuity. Treatment adherence was undermined by stigma, misinformation, and inadequate follow-up mechanisms, resulting in patients discontinuing treatment prematurely. Collectively, these interconnected challenges underscore the importance of comprehensive, context-sensitive approaches to improve leprosy control through CHW-led initiatives.

Taken together, these interlinked issues call for more robust, context-sensitive approaches that engage the community and the broader health system and policy environment. While similar challenges have been identified in previous reviews[14,19,46] on community participation in leprosy interventions, it remains unclear whether existing strategies adequately address the underlying social and structural drivers of delayed diagnosis and low adherence. Nonetheless, insufficient discussion exists on operationalizing integrated solutions that account for local norms, resource limits, and the competing demands CHWs face.

## Implications for Practice and Policy

This review presents recommendations that can be applied in a real-world setting, offering policymakers, program managers, and CHWs practical steps to enhance community-based leprosy control. A central priority involves addressing persistent knowledge gaps and misconceptions. Consistent, community-focused awareness campaigns through mass media, schools, and religious gatherings can dispel misunderstandings about Leprosy's transmission and promote recognition of early symptoms. In addition, National leprosy control programs should integrate CHWs and consider adopting successful tuberculosis (TB) strategies, such as the public-private mix (PPM) and CHW-led case detection and follow-up, to further reduce delays in diagnosis.[47]

Another critical step is strengthening the training and support provided to CHWs. Comprehensive, ongoing modules emphasizing early-symptom detection, contact tracing, and clear referral pathways enable CHWs to identify cases more accurately. Digital tools and consistent supervision sessions keep CHW skills current and prevent knowledge gaps resulting from infrequent training.

Reducing stigma in communities is also crucial. Inviting former leprosy patients to serve as health educators or advisors, sometimes called a "contact intervention," encourages empathy and fosters acceptance within families and neighborhoods.[7] Publicly visible Information, Education, and Communication (IEC) initiatives, such as radio broadcasts, pamphlets, posters, folk dances, or IEC vans, diminish fear-based beliefs and promote early care-seeking. Strengthening anti-discrimination guidelines and providing psychosocial support can amplify these efforts, ensuring patients start and remain engaged in treatment.

Because CHWs often juggle multiple tasks, clarifying role definitions and providing incentives, such as performance recognition, certification, or small stipends, is important to help them sustainably prioritize leprosy-related responsibilities. Digital data-collection tools streamline reporting processes, which allow more time for contact tracing and education. Specialized volunteers focused on awareness campaigns or counseling can further support these efforts, reducing the burden on CHWs who also address maternal health, immunizations, or TB services.

Finally, sustained political commitment is equally vital. Appropriate policy frameworks with stable funding will enable long-term planning and reliable distribution of resources, including multi-drug therapy (MDT). Collaborations with NGOs, donor agencies, and private sector partners can further diversify funding channels, supporting integrated anti-stigma campaigns alongside robust diagnostic and surveillance measures.

## Implications for Research

Future research should prioritize evaluating the specific effectiveness of CHW involvement in leprosy control, instead of focusing on broad programmatic effects. There is an urgent need to assess CHW contributions using rigorous designs that allow for causal attribution. When employing randomization design seems less feasible, using statistical methods such as matched cohort analyses, difference-in-differences models, or regression discontinuity designs may enhance causal inference.

Comparative studies should also examine the effectiveness, cost-efficiency, and sustainability of different CHW-led detection strategies to guide policy and resource allocation. Additionally, qualitative research exploring sociocultural influences on community acceptance of CHW interventions can offer insights into contextually appropriate, culturally sensitive approaches. Investigating barriers and facilitators, such as training adequacy, community trust, and systemic support, will further strengthen intervention design. Community-Based Participatory Research (CBPR) frameworks are particularly useful for enhancing community engagement, treatment adherence, stigma reduction, and early case detection while ensuring that interventions are collaboratively developed and locally relevant.[21,45]

Additionally, qualitative research exploring sociocultural influences on community acceptance of CHW-

led interventions could provide insights into culturally tailored approaches, ensuring that interventions are contextually relevant and widely accepted. Investigating barriers and facilitators to CHWs' effectiveness, such as training adequacy, community trust, and systemic support, will further enhance intervention design.

Moreover, the use of participatory research processes to support learning and strengthen district health systems should be explored as a key component of implementation research.[48] Such an approach could help identify systemic challenges, enhance CHW capacity-building, and promote the integration of CHWs into primary healthcare services. Understanding how participatory methodologies can facilitate knowledge-sharing, collaboration, and sustainable health system improvements will be essential for achieving long-term success in leprosy elimination efforts.

## Limitations

This review has several potential limitations. Firstly, restricting the literature search to articles published only in English might have excluded relevant studies from non-English speaking, endemic regions, possibly influencing the scope of findings. Secondly, given the reliance on published data, reporting bias may exist, as studies reporting negative or neutral outcomes may have been less likely to be published. Additionally, while grey literature was included, the variable accessibility and completeness of program details within these sources could have limited a comprehensive analysis. The wide variation in terminology and definitions of CHWs across studies presented challenges in accurately synthesizing roles and activities, potentially affecting the clarity and comparability of findings. Lastly, a geographical imbalance exists, with most studies conducted in India, Indonesia, and Brazil. Thus, the findings may not fully reflect the diversity of experiences and challenges in other countries with global priority. This necessitates future research to explore CHW roles and program effectiveness in a broader range of endemic settings.

Nevertheless, a key strength of this review is its comprehensive synthesis of CHW roles, intervention strategies, and associated challenges across various contexts. To strengthen future research, methodological rigor could be enhanced by including articles in additional languages or employing translation services to capture data from non-English-speaking endemic regions. Researchers should systematically seek unpublished or negative findings to address reporting bias, such as conference proceedings or non-traditional data sources. Moreover, it is important to adopt clear, standardized definitions of CHWs and documenting their training, roles, and responsibilities to improve the comparability of studies. Moreover, authors should be encouraged to provide detailed program data (e.g., participant demographics, key performance indicators, contextual factors) to yield richer comparative insights and to address the current geographical imbalance by prioritizing underrepresented regions.

## Conclusion

This scoping review emphasizes the valuable role of Community Health Workers (CHWs) in leprosy detection and management, demonstrating that their active participation mainly through strategies like household contact tracing, door-to-door screenings, and stigma-reduction initiatives can lead to earlier identification of cases and stronger community engagement. Despite these benefits, several barriers hinder the success of CHW-led efforts. Many frontline workers lack consistent training and refresher sessions, leaving them unprepared for effective symptom recognition and contact examinations. Widespread sociocultural stigma further hinders early care-seeking, as people affected by Leprosy may conceal symptoms out of fear of discrimination. Moreover, uneven health system support, characterized by limited resources, logistical constraints, and weak referral pathways, often challenges sustained program impacts and prolongs delays in case detection.

To address these challenges, future research should prioritize evaluating CHWs' effectiveness in leprosy control, using frameworks like Community-Based Participatory Research (CBPR) to improve early detection, adherence, stigma reduction, and community engagement. Comparative studies on different CHW-led methods, including cost-effectiveness and sustainability assessments, combined with qualitative inquiries into sociocultural factors, can yield evidence-based and culturally relevant strategies.

Finally, National leprosy control programs and stakeholders should strengthen CHW capacity through continuous training, supportive supervision, and incentives that acknowledge their diverse roles. Systematic health education campaigns, including those of former patients as peer educators, and policy commitments to secure funding and prevent discrimination are equally vital. Streamlined referral systems, reliable drug supplies, and better coordination with non-governmental and private stakeholders will further enhance early diagnosis and support patient adherence. By addressing these measures, CHW-led programs can more effectively reduce Leprosy's physical and social burdens and move closer to the global goal of eliminating Leprosy.

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**Availability of Data:** Data are available from the cor-

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