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Research Article

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Strengthening the Participation of Persons Affected by Leprosy in Health Services A Case Study of The Implementation of Who Guidelines in Busia County, Kenya

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Abstract

Background: *Leprosy remains a public health challenge in several regions of Kenya, with Busia County reporting a disproportionately high burden. Despite the existence of comprehensive WHO guidelines aimed at promoting the inclusion and participation of persons affected by leprosy (PALs) in health services, practical implementation remains limited in resource-constrained and decentralized health systems.*

Objective: *This case study aims to assess the current state of participation of PALs in Busia County's health services and explore how WHO guidelines can be effectively implemented to strengthen their inclusion in health system structures and service delivery processes.*

Methods: *The study employed a mixed-methods approach, combining qualitative interviews with PALs, healthcare providers, and health managers, with a review of existing health service data and policy documents. Key informant interviews and focus group discussions explored the perceptions, challenges, and facilitators of participation. Data was analysed thematically and triangulated to identify systemic gaps and opportunities for improvement.*

Results: *The study has documented barriers and enablers of PALs' participation in health service delivery. It has identified strategies for enhancing inclusion and provided recommendations for the practical application of WHO guidelines within the county health system. Findings will inform policy dialogue and guide health system strengthening initiatives targeting neglected tropical diseases (NTDs) and marginalized populations.*

Significance: *This case study contributes to the evidence base for participatory health governance in the context of leprosy and other NTDs. It offers practical insights for county health authorities, civil society, and international partners seeking to implement inclusive, rights-based approaches to health service delivery in Kenya and similar settings.*

1. Introduction

In the words of Professor T.N. Jagadisan, an Indian editor, author, teacher, social worker, and leprosy survivor: "*We should not say 'I am giving food, I am giving treatment, I am doing everything for them,' and not work for their total acceptance as we should*" [1]. Leprosy has been historically associated with deep stigma across cultures, resulting in discrimination, stereotyping, and the exclusion of affected individuals from mainstream society. A milestone in addressing these challenges was the adoption by the UN General Assembly on 21 December 2010 of the *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* [2].

In June 2010, the World Health Organization convened a seminal meeting in Manila to formalize guidelines aimed at strengthening the participation of persons affected by leprosy in health services.

Notably, half of the identified experts were individuals with lived experiences of leprosy. These guidelines were designed to assist program managers in recognizing areas for involvement of affected individuals and to outline strategies to enhance their participation in improving leprosy services in endemic countries. Integration of these efforts within broader disability and social inclusion strategies was also emphasized.

The WHO guidelines identify fourteen thematic areas. Of these, three—stigma and discrimination; equity, social justice, and human rights; and gender—are categorized as *primary issues*. The remaining eleven—information, education, and communication; advocacy; counselling; training and capacity building; referral; prevention of disability; rehabilitation; planning and management; resource mobilization; research; and monitoring and evaluation—are classified as *operational issues*. This study focuses on **stigma and discrimination** as a primary barrier to participation.

1.1. Stigma and Discrimination

Stigma is a social process that manifests through labelling, stereotyping, exclusion, rejection, fear, blame, devaluation, and marginalization. In the context of leprosy, stigma significantly hinders early diagnosis and treatment, often resulting in preventable disability and social exclusion. Women and children are especially vulnerable, warranting specific interventions.

Eliminating stigma is a critical step toward achieving full societal integration and equitable participation of affected individuals and their families. Both individuals and communities must develop a new paradigm grounded in acceptance, dignity, and evidence-based understanding.

Community participation is essential in combating neglected tropical diseases, including leprosy. Interventions must prioritize the inclusion of affected individuals, their communities, and frontline health professionals [3].

The WHO guidelines outline several key strategies to address stigma and discrimination:

- Engaging Persons Affected by Leprosy in Changing Attitudes and Practices.
  Health promotion efforts must recognize and engage the expertise of affected individuals in planning and implementation. This includes developing shared goals, clarifying roles, and encouraging respectful media representation.
- Empowerment Through Experience Sharing and Skills Development
  Empowerment workshops can help individuals overcome internalized stigma, foster mutual support, and build self-confidence. Opportunities for economic empowerment and participation in health services further enhance self-worth and social reintegration—especially for women.
- Partnerships to Repeal Discriminatory Laws
  Some countries continue to enforce outdated, discriminatory laws. Multisectoral partnerships must advocate for legislative reform aligned with international human rights frameworks, such as the UN General Assembly's 2010 resolution.
- Empowering persons affected by leprosy to collaborate with service providers improves program design and accountability. Their participation helps identify needs, increase service uptake, and ensure coordinated, inclusive care. Ultimately, this enhances health equity and upholds human rights.

1.2. The Kenyan Context

Kenya achieved the WHO leprosy elimination target of less than 1 case per 10,000 people in 1989. Cases declined from 6,558 in 1986 to 80 in 2012. However, recent trends show increasing case detection in five leprosy-endemic counties: Kwale, Kilifi, Kisumu, Siaya, Homa Bay, and Busia, which now account for over 60% of reported cases nationally [4].

Despite the low national prevalence, the disease continues to cause high morbidity. In 2013, 48% of newly reported cases had advanced disease (grade 1 or 2 disability). Most of the 133 cases reported in 2014 were multibacillary (MB), indicating delayed diagnosis and ongoing community transmission. Alarmingly, children accounted for 11% of cases in 2014 and 2% in 2015, suggesting continued transmission [4,5].

These regional variations highlight persistent risk factors and the need for context-specific strategies such as active case finding and community mobilization to sustain control gains [6].

1.3. Busia County Context

According to data from the Office of the County TB, Leprosy, and Lung Disease Coordinator, leprosy cases in Busia County are reported across all seven sub-counties, with a fluctuating trend:

- **2020** – 7 cases
- **2021** – 18 cases
- **2022** – 15 cases
- **2023** – 10 cases

Most cases are concentrated in Teso South Sub-County, with 6 cases in 2020, rising to 15 in 2022 before dropping to 8 in 2023. Affected villages include Bugengi, Angorom, and Apokor. Other sub-counties with reported cases include Teso Central, Teso North, Matayos, Nambale, Samia, Bunyala, and Butula, reflecting widespread distribution.

Despite the rising trends, no detailed epidemiological studies have been conducted to understand local transmission dynamics in the county [7].

1.4. Devolution and Service Delivery

In Kenya's devolved governance system, counties are the primary units responsible for health service delivery. Leprosy control is integrated into the national primary healthcare framework involving public, private, and faith-based health facilities.

Healthcare workers are responsible for case identification, infection control, and treatment. At the county and sub-county levels, TB and leprosy coordinators provide technical supervision, support data aggregation, and update the national surveillance system (TIBU). The National Tuberculosis, Leprosy, and Lung Health Program (NTLD-P) standardizes data collection tools and reporting across all levels [8].

1.5. Statement of the Problem

Stigma and discrimination are among the key factors contributing to the resurgence of leprosy in Kenya, despite the country achieving elimination status in 1989. As the disease continues to spread within communities, there remains a significant gap in research to inform programme development, policy formulation, and effective implementation. Although national guidelines have been developed and disseminated to promote the participation of persons affected by leprosy, there is limited evidence that such efforts are being evaluated or implemented effectively in Busia County.

Eliminating stigma is essential for the full integration and participation of persons affected by leprosy and their families within the broader community. Both the individuals affected and the community at large benefit from positive examples and the establishment of new social norms that challenge outdated beliefs and cultural misconceptions. Despite the significant advancements in leprosy control, persons affected by the disease often face systemic barriers to accessing and participating in health services. These barriers stemming from stigma, lack of awareness and limited opportunities for engagement, hinder the effectiveness of leprosy control programmes and limit the potential for positive change in the lives of affected individuals. Despite the availability of leprosy services, persons affected by leprosy are not actively involved in shaping those services, leading to a disconnect between the needs of the individual and delivery of care.

2. Objectives

- To identify and assess programmes that work with persons affected by leprosy to change negative attitudes, beliefs, and practices in Busia County.
- To document opportunities provided to persons affected by leprosy to share experiences, develop new perspectives, and acquire relevant skills.
- To appraise partnerships aimed at amending or abolishing leprosy-related discriminatory laws through the Busia County Assembly.
- To assess the methods and mechanisms through which persons affected by leprosy participate in prevention, treatment, and rehabilitation services.
- To identify gaps in knowledge, attitudes, and practices, and provide actionable recommendations for policy and programme interventions.

3. Research Questions

- Does your institution implement any programmes in collaboration with persons affected by leprosy? If so, where and when have these been implemented, and what outcomes have been achieved?
- What negative attitudes, beliefs, and practices are directed toward persons affected by leprosy and their family members?
- How are partnerships aimed at amending or abolishing discriminatory laws established and implemented? Who are the stakeholders involved in these initiatives?
- In what ways have persons affected by leprosy participated in leprosy prevention, treatment, and rehabilitation services?
- What opportunities has your programme or institution provided for persons affected by leprosy to share experiences, develop new attitudes, and acquire new skills? Please specify the dates and venues of these activities.

3.1. Justification

This study is justified on three principal grounds:

- The participation of persons affected by leprosy and their families in health services is a fundamental human right. Their involvement enhances the design, implementation, management, and outcomes of these services.
- Stigma and discrimination inflict intrinsic harm on affected individuals, creating serious barriers to early diagnosis and treatment. This harm manifests through social exclusion, hopelessness, and shame, which undermine the effectiveness of health interventions.
- Internalized stigma adversely affects self-esteem and self-efficacy, leading to a cycle of doubt, despair, and diminished socio-economic and developmental prospects.
- Therefore, this study is essential not only for generating critical data to guide evidence-based policies and interventions aimed at curbing the resurgence of leprosy, but also for contributing to a largely under-researched area of public health. The findings will support the development of inclusive, stigma-free approaches to leprosy control and rehabilitation in Busia County and beyond.

3.2. Significance

This case study contributes to the evidence base for participatory health governance in the context of leprosy and other NTDs. It offers practical insights for county health authorities, civil society, and international partners seeking to implement inclusive, rights-based approaches to health service delivery in Kenya and similar settings.

4. Methodology

4.1. Study Design

This case study employs a qualitative, exploratory research design with embedded quantitative elements, guided by a participatory health systems framework. The study aims to examine the implementation of WHO guidelines on the participation of persons affected by leprosy in health services, focusing on the county health system of Busia, Kenya.

4.2. Study Setting

The study was conducted in Busia County, a region in Western Kenya with a historically high burden of leprosy and other neglected tropical diseases (NTDs). The county has a decentralized health system comprising public health facilities at county, sub-county, and community levels. Busia also hosts community-based rehabilitation programs and local associations of persons affected by leprosy.

4.3. Target Population

The primary target populations included Persons affected by leprosy (PALs) currently or previously accessing health services in Busia County. Health care workers (HCWs) providing services at county and sub-county health facilities. County health managers and policymakers, including officials responsible for NTD and leprosy programs. Community Health Promoters (CHPs) and civil society actors engaged in leprosy-related advocacy or service delivery.

4.4. Sampling Strategy

Purposive sampling was used to identify key informants and participants with relevant experience and knowledge. A sample size of five (5) Persons Affected by Leprosy (diverse in age, gender, disability status, and engagement level); Ten (10) health care providers (including clinical officers, nurses, public health officers); six (6) county and sub-county health managers; and fifty (50) CHPs in four (4) FGDs were involved.

5. Data Collection Methods

These included Key Informant Interviews (KIIs) with county health officials, health facility managers, and representatives of CSOs. This method explored perceptions of PALs' participation, existing policies, systemic barriers, and the uptake of WHO guidelines. In-depth Interviews(IDIs) with PALs to understand their lived experiences in accessing health services, their involvement in health-related decision-making, and the perceived impact of inclusion or exclusion. Focus Group Discussions (FGDs) with CHPs, generated collective insights on participation, stigma, and proposed interventions. Document Review of the WHO guidelines, Kenya National Leprosy Strategic Plans, county health policy documents, done where available.

6. Data Management and Analysis

All interviews and FGDs were audio-recorded, transcribed verbatim, and translated where necessary. Data was analysed thematically; a coding framework was developed based on the study objectives and emergent themes. Deductive and inductive approaches guided analysis. Deductive codes were aligned with key elements of WHO guidelines (e.g., participation in planning, monitoring, evaluation), while inductive codes emerged from participant narratives. Quantitative data (e.g., demographic characteristics of participants) was analysed using descriptive statistics

7. Conclusion

This case study underscores the urgent need to operationalize the WHO guidelines in Busia County through targeted training, strategic community engagement, inclusion of leprosy in ongoing health initiatives, and support for early detection and treatment. The data reveals significant gaps in knowledge, resources, and institutional prioritization of leprosy, which must be addressed to reduce disease burden and stigma.

Ethical Considerations

Ethical approval was sought from the Alupe University Institutional Scientific Ethics Review Committee (ISERC) and the National Commission for Science, Technology and Innovation (NACOSTI). Informed consent was obtained from all participants. Measures were taken to ensure confidentiality and anonymity, including the use of pseudonyms and secure data storage. The study was conducted in a culturally sensitive manner, with attention to issues of stigma, disability, and vulnerability.

Validation and Dissemination

Overall supervision of team members was conducted by the Principal Investigator and through meetings with participants to confirm key findings and interpretations. Results were shared through a stakeholder feedback workshop in Busia County and through conference presentations and peer-reviewed publications.

Research Findings

Introduction

This case study explores the extent and nature of participation of PALs in health systems, evaluates the awareness and implementation of WHO guidelines on participation, and identifies barriers and opportunities for strengthening their involvement. This exploratory case study employed a qualitative approach involving key informant interviews (KIIs) and focus group discussions (FGDs).

Key Informants included county health officials, facility in-charges, clinical officers, and Persons affected by Leprosy (PALs). Focus Group Discussions were held with Community Health Promoters (CHPs) across five sub-counties, ensuring diversity in age, gender, and disease experience. Data were analysed thematically and triangulated to ensure validity.

• Knowledge and Awareness of Participation Rights

Low awareness of participation rights was a dominant theme. Most PALs were unaware they had the right to participate in decisions about health services. Health managers and frontline workers were similarly unaware of the WHO guidelines that promote such participation.

"There is no structured way for persons affected by leprosy to be included in decision-making." – County Health Official

"We are not told that we can be part of decisions. We just go to the clinic." – PAL

• Stigma and Discrimination as a Barrier

Stigma emerged as a key barrier. PALs reported persistent social stigma and internalized shame, while health workers acknowledged that community attitudes hinder involvement.

"Some people still believe leprosy is a curse. This keeps those affected away from public involvement." – Sub-county Public Health Officer

"Even when cured, people see us as a danger. How can we speak out?" – PAL

• Structures for Participation

There are no formal structures enabling PALs to participate in health planning or governance. While health committees exist, they rarely include PALs or actively encourage their representation.

"Our health facility board does not currently have anyone who openly identifies as having had leprosy." – Facility In-Charge

"We are not told when meetings are happening, and even if we go, we don't talk." – PAL

• Health Worker Training and Sensitization

Health workers and CHPs reported limited training on rights-based approaches and community participation. There are no existing training modules on engaging PALs beyond treatment.

"We need capacity building to understand how to engage people beyond just treating them." – Clinical Officer

"They treat us, but they don't ask us what we need." – PAL

• Attitudes Toward WHO Guidelines

Participants expressed positive attitudes once introduced to WHO guidelines. There was a strong consensus on the need to adapt and operationalize the guidelines within local systems.

"The principles are good, but we must adapt them to our local structures." – County Health Manager

"We didn't know there were such guidelines. If followed, they would change how we are treated." – PAL

• Proposed Solutions and Opportunities

Both KIIs and FGDs suggested practical interventions including focused Community sensitization to reduce stigma; Training of PALs on rights and participation; representation of PLAs in existing community health structures; and establishment of Peer-led support groups and feedback mechanisms

"We are willing to be involved, but we need support – transport, training, and respect." – PAL

"We must include this in our NTD strategy and secure funding to make it sustainable." – County NTD Focal Person

Recommendations

- Policy Integration: Domesticate WHO participation guidelines into county-level NTD and health strategies.
- Capacity Building: Train health workers and CHPs on inclusive, rights-based approaches.
- Community Engagement: Conduct awareness campaigns to reduce stigma and inform PALs of their rights.
- Structural Inclusion: Establish mechanisms for PALs' representation in facility and community health committees.
- Support Structures: Facilitate PAL-led support groups and provide logistical support for participation.
- Empowering individuals to take ownership of their health and wellbeing
- Addressing stigma and discrimination, ensuring equitable access to services and integrating leprosy services with other healthcare and social programmes.
- Promote community-based rehabilitation programmes that are accessible, affordable and culturally appropriate
- Provide vocational training and employment opportunities to support the socio- economic recovery of these individuals
- Adopting participatory approaches aligned with WHO guidelines can improve service delivery, promote dignity for PALs, and contribute to the broader goals of universal health coverage and social inclusion. Busia County can serve as a model for other leprosy-endemic regions in Kenya and beyond.

References

1. Prof. T.N. Jagadison, 1990. An Autobiography Sketch; The Indian Leprologists Look Back. Bombay, *International Leprosy Association*. 1990, pp 63-69.
2. Bam, D. D. (2010). Developing guidelines to strengthen participation of persons affected by leprosy in leprosy services: Report of the meeting, 9-10 June, Manila, Philippines. In *Developing guidelines to strengthen participation of persons affected by leprosy in leprosy services: Report of the meeting, 9-10 June, Manila, Philippines*.
3. Martos-Casado, G., Vives-Cases, C., & Gil-González, D. (2022). Community intervention programmes with people affected by leprosy: Listening to the voice of professionals. *PLoS neglected tropical diseases, 16*(3), e0010335.
4. MOH Kenya 2023. National Strategic Plan for Tuberculosis, Leprosy and Lung Health 2023/2024 – 2027/2028. The Republic of Kenya
5. Kenya National Tuberculosis Leprosy and Lung Disease Program. Annual Report 2015; 24.
6. Kenya NTD Program Annual Report, 2014.
7. County Government of Busia 2024. Busia County Leprosy Status Update 2020 - 2024. Office of the County TB, Leprosy and Lung Disease Coordinator
8. Wangara, F., Kipruto, H., Ngesa, O., Kayima, J., Masini, E., Sitienei, J., & Ngari, F. (2019). The spatial epidemiology of leprosy in Kenya: A retrospective study. *PLoS neglected tropical diseases, 13*(4), e0007329.