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Evidence-Based Interventions to Reduce Stigma and Enhance Quality of Life for People Living with Epilepsy in Shiwang'andu District, Zambia

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Abstract

This study proposes evidence-based interventions to mitigate stigma and improve the quality of life (QoL) for people living with epilepsy (PLWE) in Shiwang'andu District, Zambia, a rural area where cultural misconceptions exacerbate discrimination. Using a mixed-methods case study approach, guided by Goffman's Theory of Social Stigma and Link and Phelan's Stigma Process Model, data were collected from 62 participants via questionnaires and 18 semi-structured interviews. Findings indicate strong support for community education programs (88.7%), mobile epilepsy clinics (80.6%), and anti-discrimination policies (77.4%) to address stigma and enhance QoL. These interventions target cultural beliefs, negative community attitudes, and healthcare access barriers, aligning with global and regional strategies. The study contributes to Sustainable Development Goals 3 (Good Health and Well-Being) and 10 (Reduced Inequalities), offering a blueprint for culturally sensitive interventions to foster inclusion and improve well-being for PLWE in rural Zambia.

Keywords: Epilepsy, stigma, quality of life, community education, mobile clinics, anti-discrimination policies, Shiwang'andu, Zambia

1. Introduction

Epilepsy, a chronic neurological condition characterized by recurrent seizures, affects approximately 50 million people worldwide, with 80% residing in low and middle-income countries(WHO, 2019). Cultural misconceptions attributing epilepsy to witchcraft or spiritual possession drive stigma, leading to social exclusion, healthcare avoidance, and diminished quality of life (QoL)(Herrmann et al., 2016; Baimyrzaeva, 2018; Dusabimana et al., 2021). Stigma manifests as enacted discrimination, felt stigma, and courtesy stigma severely impacting PLWE's physical health, mental well-being, and social integration(Aranda et al., 2023).

Despite global and regional efforts to address epilepsy-related stigma, rural Zambian contexts like Shiwang'andu face unique challenges due to limited healthcare infrastructure, low literacy, and reliance on traditional healers, necessitating tailored interventions(Kaddumukasa, 2019). This study addresses this gap by proposing evidence-based strategies to reduce stigma and enhance QoL for PLWE in Shiwang'andu, contributing to Sustainable Development Goals (SDGs) 3 (Good Health and Well-Being) and 10 (Reduced Inequalities). By focusing on community-driven and policy-based solutions, the research aims to foster inclusivity and improve health outcomes in this underserved region.

2. Literature Review

The study was grounded in two complementary frameworks that inform the design of interventions to mitigate stigma and enhance QoL for PLWE, Goffman's Theory of Social Stigma and Link and Phelan's Stigma Process Model.

Goffman's theory defines stigma as an attribute that discredits an individual, reducing their social status and fostering discrimination (Aranda et al., 2023). For PLWE, stigma manifests as enacted stigma, that is, exclusion from employment or community activities, felt stigma such as shame leading to healthcare avoidance, and courtesy stigma such as family marginalization.

Link and Phelan's model outlines stigma as a process involving labeling, stereotyping, separation, and status loss/discrimination (Link, 2023). This model provides a dynamic framework for designing interventions that address the structural and social dimensions of stigma.

This section synthesizes global, Sub-Saharan African (SSA), and Zambian perspectives on evidence-based interventions to reduce epilepsy-related stigma and improve QoL, providing a foundation for strategies tailored to Shiwang'andu.

This study aimed to propose evidence-based interventions, including community education programs and policy reforms, to reduce stigma and enhance the quality of life (QoL) for people living with epilepsy (PLWE) in rural Zambia, with specific relevance to Shiwang'andu District.

Global interventions to reduce epilepsy-related stigma focus on community education, healthcare improvements, and policy reforms to address misconceptions and promote inclusion. Community education programs have proven effective in dispelling myths about epilepsy's causes, such as supernatural or contagious origins. A study in India implemented a community-based awareness campaign involving workshops and media outreach, resulting in a 25% reduction in negative attitudes toward PLWE and improved social acceptance (Singh and Gupta, 2024; Rao, 2022). These programs often involve PLWE and healthcare professionals to provide accurate information, countering stigma and encouraging treatment seeking behavior (Herrmann, 2016). Policy reforms also play a critical role globally. In some countries, anti-discrimination laws protect PLWE from exclusion in employment and education, improving their social integration and QoL. In the United Kingdom, advocacy for legal protections led to a 15% increase in employment rates among PLWE over five years, reducing economic disparities and social exclusion (Holmes, 2019). Healthcare interventions, such as training primary care providers to address stigma, have also been effective.

In Sub-Saharan Africa (SSA), where epilepsy prevalence is high (9.4 per 1,000) and where healthcare infrastructure is often limited, interventions to reduce epilepsy-related stigma focus on community engagement, healthcare system strengthening, and culturally tailored education programs (Ba-Diop, 2016). Community-based education campaigns have shown significant success in addressing cultural misconceptions, such as beliefs in supernatural causes like witchcraft or divine punishment, which are prevalent across SSA (Mélanie, 2023). In Uganda, a peer-led education campaign involving people living with epilepsy (PLWE) and community leaders reduced negative attitudes by 20% over 12 months, as measured by community surveys (Chakraborty et al., 2021). The campaign utilized local radio, village workshops, and PLWE testimonials to reframe epilepsy as a medical condition, countering myths about contagiousness and spiritual affliction (Anguzu et al., 2021). Similarly, in Tanzania, school-based education programs targeting teachers and students increased acceptance of PLWE by 15%, reducing exclusion in educational settings (Bhwana et al., 2025).

Healthcare interventions in SSA emphasize improving access to antiepileptic drugs (AEDs) and training healthcare workers to provide non-judgmental care. In Kenya, mobile epilepsy clinics staffed by trained community health workers increased AED adherence by 40% among PLWE in rural areas, as reported by (Kaddumukasa, 2019). These clinics addressed logistical barriers, such as distance to health facilities, and incorporated stigma-reduction counseling, which decreased healthcare avoidance by 25% (Kaddumukasa et al., 2018). Training programs for primary healthcare workers in Ethiopia have also proven effective, with a 30% increase in PLWE seeking biomedical care after providers were trained to address stigma and dispel myths (Molla et al., 2021). These interventions highlight the importance of integrating stigma reduction with healthcare delivery in resource-constrained settings.

Policy-level interventions in SSA are less common but show promise. In South Africa, advocacy for anti-discrimination policies in schools led to a 10% reduction in exclusion of children with epilepsy, as reported by (Kpobi, Swartz and Keikelame, 2018). Such policies protect PLWE from institutional barriers, promoting social integration and access to education. These findings suggest that interventions in SSA must combine community education with healthcare improvements and policy advocacy to address the multifaceted nature of stigma. For Shiwang'andu, these regional examples provide a blueprint for designing interventions that leverage local leaders and mobile health services to counter cultural misconceptions and improve QoL for PLWE.

In Zambia, interventions to reduce epilepsy-related stigma and improve QoL are limited, particularly in rural areas like Shiwang'andu, but pilot programs demonstrate potential for addressing cultural and structural barriers (Mambo et al., 2024). Community education programs have been piloted in rural Zambia with modest success. A study in Southern Province implemented a community awareness campaign involving traditional and religious leaders, resulting in a 15% reduction in negative attitudes toward PLWE, as measured by attitude surveys (Nkole et al., 2020). The campaign used local radio broadcasts in Bemba and community dramas to educate residents about epilepsy's medical nature, countering

beliefs in witchcraft and contagion (Mweemba, 2021). Engaging traditional healers as advocates was critical, as their endorsement of biomedical treatment increased trust in health facilities among PLWE by 20% (Patel, 2022; Mambo, 2024).

Healthcare interventions in Zambia focus on improving AED access and training Community Health Workers (CHWs). A pilot program in Lusaka Province trained CHWs to conduct home visits, provide epilepsy education, and distribute AEDs, leading to a 30% increase in AED adherence among PLWE over six months (Patel, 2019). This program also included stigma- reduction workshops, which reduced felt stigma among PLWE by 10%, as reported through self-assessments (Mambo et al., 2024).

Policy reforms in Zambia are underdeveloped but critical for long-term change. Advocacy efforts in urban areas have pushed for integrating epilepsy care into national health policies, with pilot policies in Lusaka increasing funding for AEDs by 5% (Patel et al., 2019). In rural contexts, anti- discrimination policies remain absent, but community leader endorsements could facilitate their adoption. These local interventions highlight the need for culturally sensitive approaches in Shiwang'andu, such as engaging traditional healers to dispel myths, implementing mobile clinics to improve access, and advocating for policies to protect PLWE's rights. By building on these pilot successes, interventions can address the unique challenges of rural Zambia, aligning with the study's objective to propose targeted strategies for stigma reduction and QoL improvement.

3. Research Methodology

3.1. Research Design

This study employed a mixed-methods case study approach to explore the social and cultural factors contributing to stigma against PLWE in Shiwang'andu District, Zambia. The deductive approach tested hypotheses derived from Goffman's and Link and Phelan's theories, using validated tools to ensure reliability.

A case study strategy was chosen to capture the context-specific dynamics of Shiwang'andu. Shiwang'andu, with an estimated population of 78,509 and an epilepsy prevalence of 0.4%–1.0% (314–785 PLWE), faces unique challenges due to limited healthcare infrastructure and deeply rooted cultural beliefs(Zamstats, 2022; WHO, 2024). This approach allowed for an in-depth examination of cultural and social factors within their real-life setting.

The sampling frame included PLWE, family members, community members, traditional healers, community leaders, and healthcare workers, identified through health facility records, community leader referrals, and epilepsy support groups. Purposive sampling selected 62 participants for questionnaires and 18 for interviews (8 PLWE, 4 family members, 4 community members, 1 traditional healer/community leader, 1 healthcare worker) to ensure diverse perspectives. Snowball sampling supplemented purposive sampling, addressing stigma related barriers.

3.2. Data Collection and Analysis

The research used was sequential explanatory mixed methods design where the researchers first collected quantitative data and proceeded to gather qualitative data on the same sample. The qualitative data was to confirm what the quantitative results. Quantitative data was collected through questionnaires (n=62) using the Stigma Scale of Epilepsy and WHOQOL-BREF to assess support for interventions ("Community education can reduce stigma," 1=Strongly Disagree, 5=Strongly Agree) and their feasibility ("How possible is it to implement mobile clinics?" 1=Not Possible, 5=Very Possible). Qualitative data was gathered through semi-structured interviews with 18 participants at saturation point using open-ended questions ("How can community education reduce stigma in Shiwang'andu?"). These interviews were conducted in Bemba or English.

Qualitative data were analyzed using thematic analysis (Braun and Clarke's framework), identifying themes such as Community Education, Healthcare Improvements, and Policy Reforms. Quantitative data were analyzed using descriptive statistics (means, percentages) in Excel and SPSS to quantify intervention support and feasibility. Triangulation integrated qualitative and quantitative findings to ensure robust insights.

4. Presentation of Findings and Results

4.1. Support and Feasibility of Proposed Interventions

The study identified, community education programs, mobile epilepsy clinics, and anti- discrimination policies, as three evidence-based interventions to reduce stigma and improve QoL for PLWE in Shiwang'andu. These findings are supported by quantitative (n=62) and qualitative (n=18) data.

Table 1: Support and Feasibility of Proposed Interventions

	Mean Support Support (%) (SD)		Feasibility (Mean, SD)
Community Education	88.7% (55)	4.2 (0.8)	3.8 (0.9)
Mobile Epilepsy Clinics	80.6% (50)	4.0 (0.9)	3.6 (1.0)
Anti-Discrimination Policies	77.4% (48)	3.9 (1.0)	3.4 (1.0)

Questionnaire data revealed that 88.7% (n=55) of respondents supported community education to dispel myths about epilepsy, with a mean score of 4.2(SD=0.8, 1=Strongly Disagree, 5=Strongly Agree) on the item "Community education can reduce stigma." Interviews suggested culturally tailored formats, such as radio programs in Bemba and school workshops involving PLWE. A community member noted, "Radio programs in Bemba can teach that epilepsy is not contagious," emphasizing local language and media. Feasibility was rated moderately possible (mean=3.8, SD=0.9, 1=Not Possible, 5=Very Possible), with barriers including funding and resistance to changing cultural beliefs.

Support for mobile epilepsy clinics was high, with 80.6% (n=50) of respondents endorsing their implementation (mean=4.0, SD=0.9). Of the eight PLWE interviewed, 75.0% (n=6) reported limited clinic access due to distance or stigma, with one stating, "I can't travel far for medicine; mobile clinics would help." A healthcare worker suggested, "Mobile clinics can reach remote villages monthly," aligning with improved AED adherence.

Questionnaire data indicated that 77.4% (n=48) supported anti-discrimination policies to protect PLWE's rights (mean=3.9, SD=1.0). Interviews with a healthcare worker and community leader emphasized legal protections, with one noting, "Laws should ensure PLWE can work without fear." Feasibility was moderately possible (mean=3.4, SD=1.0), with barriers including policy enforcement in rural areas and lack of awareness. Community readiness for change was rated moderately ready (mean=3.5, SD=0.9, 1=Not Ready, 5=Very Ready).

4.2. Discussion

The findings align with theoretical frameworks and literature, highlighting the feasibility and cultural relevance of proposed interventions in Shiwang'andu. Strong support for community education (88.7%) reflects Link and Phelan's model, targeting the labeling and stereotyping stages by reframing epilepsy as a medical condition (Link, 2023). This aligns with global findings, such as India's 25% reduction in negative attitudes through awareness campaigns and SSA studies, where education reduced stigma by 20% (Kaddumukasa, 2019; Misra, 2022). The emphasis on Bemba radio programs and school workshops addresses Shiwang'andu's low literacy and cultural context, unlike urban-focused interventions (Chakraborty, 2021). However, barriers like funding and cultural resistance require partnerships with local NGOs and leaders to enhance feasibility.

Support for mobile epilepsy clinics (80.6%) addresses health care avoidance (62.5% of PLWE) and aligns with Goffman's theory by reducing enacted stigma in healthcare settings (Aranda, 2023). This mirrors Tanzania's 30% increase in AED adherence via mobile clinics and Zambia's 25% improvement in Lusaka (Anguzu, 2021; Mambo, 2024). Monthly clinics counter Shiwang'andu's geographic barriers, a challenge less prevalent in urban studies. Logistical challenges necessitate collaboration with the Ministry of Health to ensure staffing and sustainability.

The 77.4% support for anti-discrimination policies supports Goffman's framework by addressing enacted stigma in employment and education. This aligns with the UK's 15% employment increase for PLWE through legal protections and urban Zambia's advocacy efforts (Holmes, 2019; Nkole, 2020). Rural enforcement challenges highlight the need for local government training and awareness campaigns to ensure policy impact. Engaging community leaders, as suggested by interviewees, leverages their influence to promote policy acceptance.

5. Conclusion and Implications

This study proposed three evidence-based interventions to reduce stigma and improve QoL for PLWE in Shiwang'andu District: community education programs (88.7% support), mobile epilepsy clinics (80.6% support), and anti-discrimination policies (77.4% support). Grounded in Goffman's and Link and Phelan's theories, these interventions address cultural misconceptions, healthcare access barriers, and systemic discrimination, aligning with global and SSA strategies. Community education targets labeling and stereotyping, mobile clinics reduce separation and improve AED adherence, and policies prevent status loss, fostering inclusion. Despite challenges like funding and rural enforcement, leveraging local leaders and partnerships enhances feasibility. These findings contribute to SDGs 3 and 10, offering a model for culturally sensitive interventions to enhance wellbeing for PLWE in rural Zambia and similar contexts.

Declaration of Competing Interests

The authors declare that they are not aware of any competing financial interests or personal relationships that may have influenced the work described in this document.

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Ethical considerations

The article followed all ethical standards appropriate for this kind of research.

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