SAARC

Print ISSN 1818-9741 Online ISSN 2091-0959 Vol.23, No 1, Year 2025

SAARC Journal of Tuberculosis, Lung Diseases and HIV/AIDS

JOL Journals online

Publishing since 2004
Free online access

SAARC TB and HIV/AIDS Centre (STAC)

SAARC Journal of Tuberculosis, Lung Diseases and HIV/AIDS

An official publication of SAARC TB and HIV/AIDS Centre

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SAARC Journal of Tuberculosis, Lung Diseases and HIV/AIDS

An official publication of SAARC TB and HIV/AIDS Centre

Vol. 23 No. 1 Year 2025

Published and distributed by:

SAARC Tuberculosis and HIV/AIDS Centre (STAC)
Thimi, Bhaktapur
G.P.O. Box 9517, Kathmandu, Nepal
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Editorial

Need for Renewed Political Commitment for TB Prevention in SAARC Member States

Globally, an estimated 10.8 million people fell ill with TB (134 per 100 000 Population) and a total of 8.4 million cases were notified in 2023. There was a 2.4 million gap between incident and notified cases and an estimated 1.25 million TB deaths in 2023. The latest treatment outcome data shows treatment success rates of 88% for TB (2022 cohort). In SAARC region, an estimated 4.0 million (206 per 100 000 Population) people fell ill with TB; and carries 37% of the Global burden of TB. A total of 3.39 million cases were notified in 2023. Regionally, there was a 0.6 million gap between the incident and the notified cases. There were an estimated 0.44 million TB deaths in 2023. The latest treatment outcome data shows treatment success rates of 90% for TB (2022 cohort). Bangladesh, India and Pakistan together notified 97% of the total cases in the region in 2023 while India alone accounted for 74% of all the total notifications.

"Political commitment" refers to the dedication and sustained effort of political leaders and actors to prioritize and address specific issues in global health such as nutrition or climate change, through actions, policies, and resource allocation. It involves mobilizing political systems, adopting policies, and ensuring long-term commitment to achieve desired outcomes. SAARC Summits held in the years 1990, 1992, 1995, 1998, 2004, 2005 and 2014 had made firm commitments on various health related agendas. The pertinent one being primary health care, education and population planning, decision to establish SAARC Tuberculosis Center in Nepal, population policy integration with health and education, health and nutritional goals, priorities on HIV/AIDS, TB, SARS, Communicable Diseases, pandemic preparedness for avian influenza, HIV/AIDS, Dengue, Malaria and the Supranational laboratory. However, there is an acute need that we look into these commitments through a new lens, especially after COVID-19 and considering the rising burden of non-communicable diseases in global and regional context. It's high time, therefore, that the leaders of the SAARC member states start building up the renewed political commitment together as a cohesive force. A fresh dedication and pledge from political leaders especially should be materialized to the earliest. Reaffirming support for existing initiatives, developing new strategies and mobilizing resources to drive meaningful change should be prioritized. The renewed commitment should focus on actions by the SAARC leaders on tackling complex challenges and ensuring the effective implementation of policies and programs to make the region free of TB.

Chief in Editor
Director, STAC

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5. 10th SAARC Summit (29 - 31 July 1998, Islamabad, Pakistan
6. 12th SAARC Summit (12 - 13 November, 2005, Dhaka Bangladesh
7. 18th SAARC Summit (26 - 27 November, 2014, Kathmandu, Nepal

Original article

SYSTEMATIC META-ANALYSIS OF TUBERCULOSIS MENINGITIS: THE BURDEN AND THE CHALLENGES IN SOUTH ASIA

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DOI: https://doi.org/10.3126/saarctb.v23i1.83799
Received: 15th Nov Accepted: 11th June Published: 31st July
This article is available at: https://www.saarctb.org/wp-content/uploads/2025/01/STAC-Journal-2025-VOL-23.pdf

ABSTRACT

Tuberculosis meningitis (TBM) is an important global health challenge. It causes significant morbidity and mortality, especially in low and middle income countries. Its early recognition, diagnosis and management, continues to pose complex and challenging issues for healthcare teams and personnel. A better understanding of the global epidemiology of TB meningitis, would help allocate appropriate healthcare resources for its management. Currently, diagnosis relies on a combination of clinical, radiological, and laboratory findings and needs to be made in timely fashion. A multidisciplinary approach is needed for optimal management and for preventing complications. Although progress has been made in recent years, several uncertain questions remain. HIV co-infection and increasing drug resistance, adds further complexity to any management decisions. This review would outline current knowledge, challenges and perspectives regarding the presentation, pathogenesis, complications, diagnosis, treatment and control of TB meningitis, especially in relation to Asian countries.

Key words: Tuberculosis Meningitis, South Asia, Sri Lanka

INTRODUCTION

Tuberculosis (TB) is a highly prevalent global human infection caused by Mycobacterium tuberculosis (MTB)[(1)(2)]. Although the causative organism of tuberculosis was discovered over a hundred years ago, this disease remains a major public health problem worldwide [(3)(4)(5)].

One-third of the world's population is infected with latent tuberculosis and these individuals are not clinically affected but carry a lifetime risk of 10% for developing the active disease [(5)(1)]. Tuberculosis meningitis (TBM) is the most severe form of extra-pulmonary tuberculosis resulting in high morbidity and mortality [(6)(3)]. In the recent past, number of immunocompromised patients has increased due to high prevalence of HIV/AIDS, increasing incidence of diabetes mellitus, growing geriatric population and increased use of immunosuppressive drugs [(7)(8)(9)(10)(11)].

Tuberculosis meningitis (TBM) still poses significant diagnostic and management challenges, especially in the developing world[(12)(13)(13)]. The incidence of TBM is on the rise with the increase in immune-deficient states such as HIV/AIDS and concomitant with an increase in the incidence of TBM. Furthermore, development of multi-drug resistance in AIDS patients is a major obstacle associated with its treatment[(14)(15)(16).] Despite modern anti-tuberculosis chemotherapy, 20% to

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50% of patients still die, and many of the survivors have significant neurological deficits [17][18]. Death from TBM is strongly associated with the delays in the proper diagnosis and management[12][13] [19] [20]. This review discusses the burden and the challenges of TBM in South Asia.

Global Tuberculosis Disease Burden

The global rise in TB cases that began during the COVID-19 pandemic has slowed and stabilized at 10.8 million cases in 2023, with most of the increase due to population growth [21]. The highest burden is in 30 countries, particularly India, Indonesia, China, the Philippines, and Pakistan. TB-related deaths declined to 1.25 million, reinforcing progress since the pandemic, but TB remains the leading cause of death from a single infectious agent [21].

Despite some progress, reductions in TB incidence (8.3%) and mortality (23%) from 2015 to 2023 remain far from WHO's 2025 targets. Post-COVID recovery in TB diagnosis and treatment has helped narrow the gap between estimated and reported cases. In 2023, 8.2 million people were newly diagnosed, reducing the backlog from previous years[21]. However, multidrug-resistant TB remains a challenge, with only 44% of estimated cases receiving treatment. Treatment success rates remain high, at 88% for drug-susceptible TB and 68% for multidrug-resistant TB[21].

Tuberculosis Meningitis burden in South Asia

Tuberculosis meningitis is a serious infection commonly found to occur in the developing countries endemic to tuberculosis[22][23]. In the developing countries with poor resources, the morbidity and mortality is high, due to poor sanitary conditions, delayed diagnosis, non-optimal treatment, and inadequate immunization by BCG [19][24][25][26].

Tuberculosis meningitis (TBM) is the most frequent form of central nervous system (CNS) tuberculosis and peak incidence is in children under 4 years of age. However, the number of adults presenting with TBM has increased as a result of the HIV epidemic [27][11][28]. The incidence of CNS tuberculosis generally reflects the incidence and prevalence of tuberculosis in the community [29]. Tuberculosis meningitis is seen in 5 to 10% of extra pulmonary tuberculosis, and accounts for approximately 1% of all TB cases. The case fatality rate of untreated TBM is almost 100% and a delay in treatment may lead to permanent neurological damage[30][31][32]. HIV infection predisposes to the development of extra-pulmonary tuberculosis, particularly tuberculosis meningitis[33][34][35]. HIV co-infection is associated with higher complication and case fatality rates [36] [37][38]. In comparison to other regions, the number of HIV-negative TBM cases remains the majority in Asia [39].

METHODOLOGY

A literature survey was conducted using Google and PubMed search engines with the keywords "tuberculosis meningitis," "South Asia," and "case reports." All case reports published in English from 2001 to 2024 and originating from South Asia were reviewed **(figure 1)**. These are summarized in **Table 1**, which provides access to the detailed case reports. No relevant case reports were identified after 2021 using the specified search criteria; therefore, the review includes case reports up to the year 2020.

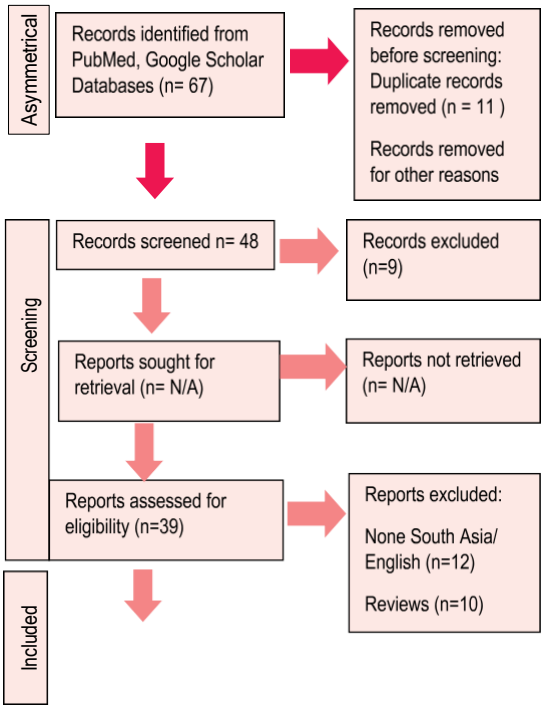

Figure 1. PRISMA flow diagram for systematic reviews

RESULTS

A total of 17 case reports on tuberculosis meningitis (TBM) published between 2001 and 2020 were identified; 4 from PubMed and 13 from Google search engine and included in the review. These reports highlight the ongoing clinical significance of TBM in South Asian countries, particularly in India, which accounted for the majority of cases. Other reports originated from Pakistan, Bangladesh, Nepal, and Sri Lanka, reflecting TBM as a regional public health Concern

Table 1:

Year	Country and the Hospital	Study population	Number and the percentage of EPTB patients	Number and the percentage of TBM patients	Gender and the affected age group of TBM patients	Reference
2005-11	**India -** University Hospital Karnataka	1267 patients registered for treatment (DOTS) of all forms of tuberculosis	528 (41.67%)	66 (12.50%)	Females 15-44 years	40
2013	**India -** University Hospital Himachal Pradesh	EPTB cases from two medical colleges and four additional randomly selected Tuberculosis Units (TUs) of Himachal Pradesh	463	24 (5.20%)	Males 20-35 years	41
2012-14	**India -** Tertiary Care Hospital in Central India	491 patients registered for treatment of all forms of tuberculosis	130 (26.40%)	3 (2.30%)	Males 0-19 years	42
2007-09	**India -** Tertiary Care Hospital in Karnataka	326 meningitis patients admitted to the paediatric department		187 (57.37%)		43
2009-11	**India -** tertiary referral center in North India	Diagnosis of intracranial tubercular infection who were admitted (from emergency, neurology outpatient department)		244	age >12 years , both male and female	44
2005-07	**Pakistan-** Tertiary Care Hospital in Karachchi	Retrospective audit of 194 patients under treatment for extra-pulmonary TB	2194	18 (9.30%)		45
2019-20	**Nepal-** Tertiary care centre in Nepal	descriptive cross-sectional study	60	39 (65.00%)	25 (64.10%)-males 14 (35.90%)-females	46
2010	**Pakistan-** Ayub Teaching Hospital, Abbottabad	500 patients admitted to medical wards from Out Patient Department with confirmed tuberculosis	120 (24.00%)	45 (9.10%)		47

2011	**Bangladesh**	A total of 152 EPTB patients from villages in Narsingdi district of Bangladesh	152	7 (4.60%)		48
2003-06	**Nepal-** Manipal college of Medical sciences	526 TB patients registered in the DOTS clinic in western Nepal	230 (48.50%)	17 (7.20%)		49
2001-10	**Bhutan**	all TB cases registered as EPTB over a period of 10 years	Varied from 30% to 40%	7 (1.00%)		50
2010-11	**Sri Lanka-** National hospital of Sri Lanka (NHSL)	all the adult cases of TB Meningitis		22 definitive cases, 46 probable cases and 21 possible cases		51
2023	**Nepal**	Case report		GeneXpert negative		52
2009-19	**Pakistan**	All TB meningitis cases reported in 10 years	25 (559)			53
2015-18	**Pakistan**	hospital	110	11 deaths		54
2018	**India**	hospital	50%			55
2017	**India**	Tertiary care hospital	209 (542)			56

Diagnosis of TBM

Early diagnosis and effective treatment are the key factors to better outcome in TBM [57][39]. In a significant number of patients, the diagnosis of TBM is empirical and is based on the clinical, laboratory and neuroimaging data[58].

Clinical diagnosis

Tuberculosis meningitis (TBM) remains a diagnostic challenge due to nonspecific symptoms and varied clinical presentations, often leading to delayed diagnosis when brain damage has already occurred [58]. TBM can present acutely but is typically a slowly progressive disease with symptoms such as fever, headache, meningeal signs, altered mental status, and cranial nerve deficits [59-63].

In adults, classic symptoms include fever, headache, neck stiffness, and focal neurological deficits [64, 65]. In children, presentation varies with age: older children commonly have fever, headache, anorexia, and vomiting, while younger children often show failure to thrive, poor appetite, vomiting, and sleep disturbances [66, 67]. In HIV-infected patients, TBM symptoms are influenced by immunosuppression, with a higher likelihood of extra-meningeal tuberculosis and systemic HIV features [38].

Several studies highlight common clinical presentations:

Sher-I-Kashmir Institute of Medical Sciences, Srinagar, Jammu and Kashmir, India. Among 38 adult TBM patients, fever, headache, and meningeal irritation were present in 78-84%; vomiting (63%) and cranial nerve palsy (36%) were also common [68].

Department of Medical Microbiology and Neurology of tertiary care referral centre in North India: Among 55 cases, fever (90.9%), headache (72.7%), neck rigidity (67.3%), altered sensorium (65.5%), and vomiting (54.5%) were frequent (69).

Aga Khan University, Pakistan: Among 46 children with TBM, fever (97%), vomiting (43%), headache

(39%), drowsiness (32%), and seizures (45%) were common findings [67].

Jinnah Postgraduate Medical Centre, Pakistan: Among 93 adults, neck stiffness was universal, while cranial nerve palsies increased with disease severity (24% in Stage I, 75% in Stage III) [73].

Civil Hospital Karachi: In 52 confirmed cases, fever (98.1%), neck stiffness (84.6%), altered consciousness (76.9%), headache (59.6%), and vomiting (36.5%) were observed. Mortality was 21.1%, with older age, advanced TBM stage, hydrocephalus, and mechanical ventilation being major risk factors [74].

Dhaka, Bangladesh: Among 30 TBM patients, fever (91.7%), headache (70%), altered consciousness (45%), vomiting (43.3%), and neck stiffness (28.9%) were predominant [75].

India (HIV-TBM Study): Among 100 HIV-positive patients with presumptive TBM, fever was the only symptom in 20%, 89% had elevated CSF protein, and 50% experienced TB immune reconstitution inflammatory syndrome (TB IRIS). The study suggested that current diagnostic criteria may not be reliable in early-stage TBM [76].

Across all studies (table 2) , fever emerged as the most common symptom, ranging from 78% to 98.1%, followed by headache (39%-84%) and neck stiffness/meningeal irritation, which was universally present in some studies (100% at Jinnah Postgraduate Medical Centre, Pakistan) but lower in others (28.9% in Dhaka, Bangladesh). Vomiting was also frequently reported, though its prevalence varied from 36.5% to 63%. Altered sensorium/consciousness was noted in 32%–76.9%, particularly in more severe cases. Cranial nerve palsies were observed primarily in adult studies, with prevalence increasing with disease severity (24% in Stage I to 75% in Stage III at Jinnah Postgraduate Medical Centre, Pakistan). The Civil Hospital Karachi study reported a mortality rate of 21.1%, with risk factors including older age, advanced TBM stage, hydrocephalus, and mechanical ventilation. The HIV-TBM study in India found that 20% of patients had fever as their only symptom, while 50% developed TB immune reconstitution inflammatory syndrome (TB-IRIS), indicating unique challenges in diagnosing TBM in immunocompromised individuals. Despite regional and demographic variations, fever, headache, neck stiffness, vomiting, and altered sensorium were the most consistent symptoms across studies, with prognosis worsening in severe TBM stages, paediatric cases, and HIV-positive individuals.

TBM Severity Classification

TBM is classified into three British Medical Research Council (BMRC) grades based on Glasgow Coma Score (GCS) [70].

Stage I: GCS 15, no focal neurological deficits.

Stage II: GCS 11-14, or GCS 15 with focal deficits.

Stage III: GCS ≤10, severe neurological impairment.

Table 2: Summary of Symptoms Reported in Case Reports Published from Asian Countries

Study	Symptoms	Reference
Sher-I-Kashmir Institute of Medical Sciences, Srinagar, Jammu and Kashmir, India.	fever, headache, and meningeal irritation, vomiting	68
Department of Medical Microbiology and Neurology of tertiary care referral centre in North India	fever, headache, neck rigidity, altered sensorium, and vomiting	69
Aga Khan University, Pakistan	fever, vomiting, headache, drowsiness, and seizures	67
Jinnah Postgraduate Medical Centre, Pakistan	neck stiffness	73
Civil Hospital Karachi	fever, neck stiffness, headache, and vomiting	74
Dhaka, Bangladesh	fever, headache, altered consciousness, vomiting and neck stiffness	75
India (HIV-TBM Study)	fever	76

TBM presents with diverse and nonspecific symptoms, making early clinical suspicion essential. Severity at presentation strongly impacts prognosis, with Stage III disease, cranial nerve involvement, and immunosuppression being significant predictors of poor outcomes. Timely empirical treatment is critical to reduce morbidity and mortality [58-76].

Laboratory diagnosis

Laboratory services are very important in the diagnosis, management and epidemiological investigation of mycobacterial diseases.

Direct smear and culture

The Ziehl-Neelsen (ZN) staining technique is the most widely used method for detecting acid-fast bacilli (AFB) in patient samples for tuberculosis (TB) diagnosis, especially in resource-limited regions [77]. However, AFB microscopy has low sensitivity (10-20%) in detecting extrapulmonary TB, particularly tuberculosis meningitis (TBM) [78]. The gold standard for TBM diagnosis is the culture of cerebrospinal fluid (CSF) to detect Mycobacterium tuberculosis [79], with a 60-70% sensitivity in adults, making it essential for drug susceptibility testing [80]. However, culture-based methods take 3 to 5 weeks [80].

Recent advances have led to faster diagnostic techniques. Broth-based cultures have reduced turnaround times compared to solid media [81]. The Microscopic Observation Drug Susceptibility (MODS) assay is an emerging cost-effective and rapid technique that is more sensitive than CSF smear microscopy and faster than conventional culture [80].

A prospective study conducted in a tertiary care hospital in New Delhi, India over two years analyzed 164 CSF samples from suspected TBM cases. ZN staining detected AFB in only 7.9% of samples. The Bactec MGIT 960 system detected M. tuberculosis in 27.4%, while LJ medium detected 10.9%. A combined approach using both increased the culture positivity rate to 29.8%. The average detection time was 18 days with MGIT 960 and 38 days with LJ medium. The study concluded that using a combination of smear microscopy, conventional culture, and automated methods (like Bactec MGIT 960) improves TBM diagnostic sensitivity compared to any single technique [81].

Nucleic acid amplification techniques (NAATs)

Nucleic acid amplification tests (NAATs) can detect fewer than 10 organisms and are useful for identifying Mycobacterium tuberculosis in clinical specimens or cultures. Polymerase chain reaction (PCR) is the most widely used NAAT method, with numerous in-house assays developed [82]. While NAATs have high specificity, their sensitivity varies. A key advantage over microscopy and culture is that DNA remains detectable for up to a month after starting anti-tuberculosis treatment. However, limitations include high cost, laboratory infrastructure requirements, trained staff, and the need for quality control to prevent contamination and assay inhibition [82, 83].

A study at a University Hospital in Varanasi, India (2009-2011) compared BacT/ALERT 3D culture medium with nested PCR for early TBM diagnosis in 50 suspected TBM patients and 20 controls. Culture positivity was 76% (38/50) in TBM patients, but 15% (3/20) of controls showed false positives with BacT/ALERT-MP. Nested PCR detected TBM in 92% (46/50) cases, with a false-positive rate of 5% (1/20) in controls. Sensitivity and specificity for BacT/ALERT-MP were 76% and 85%, while for nested PCR, they were 92% and 95%, indicating poor sensitivity of BacT/ALERT 3D culture [83].

Another study at the Central India Institute of Medical Sciences, Nagpur (2009) compared the Loop-Mediated Isothermal Amplification (LAMP) assay with nested PCR for TBM diagnosis in 27 CSF specimens. LAMP showed a sensitivity of 88.23% and specificity of 80%, whereas nested PCR had 52.9% sensitivity and 90% specificity. The study concluded that LAMP is a rapid, sensitive, and specific method superior to nested PCR, with the added benefit of being simple and suitable for rural laboratories [84].

Adenosine deaminase activity

Adenosine deaminase (ADA), an enzyme involved in purine metabolism, is elevated in the cerebrospinal fluid (CSF) of TBM patients and normalizes within 2-6 weeks of treatment. ADA estimation is a simple, rapid, and cost-effective

diagnostic test that can be conducted in basic laboratories [85].

A study in Kathmandu, Nepal (2009-2010) analyzed 28 TBM and 22 non-TBM (viral) cases. Mean ADA levels in TBM patients were 16.46 ± 6.24 U/L, significantly higher than 5.±132.96 U/L in non-TBM cases (P < 0.001). Using a CSF ADA cut-off of >10 IU/L, the test achieved 82% sensitivity and 90% specificity, making it an effective early diagnostic tool in resource-limited settings [86].

Another study in Vellore, India, assessed 40 HIV-positive meningitis patients (16 TBM, 24 non-TBM). Mean ADA levels in TBM patients were 18.1 ± 19.176 U/L, significantly higher than 2.2 ± 1.8 U/L in non-TBM cases (P < 0.001). A CSF ADA cut-off of 6 IU/L yielded 75% sensitivity and 95.8% specificity for TBM diagnosis. The study concluded that CSF ADA testing at a 6 IU/L threshold is a highly specific and moderately sensitive tool for diagnosing TBM in HIV-positive patients [87].

Interferon-gamma release assays

The Interferon-gamma (IFN-ɣ) release assay (IGRA) is an in vitro test that measures the production of IFN-ɣ release in response to stimulation with specific mycobacterial antigens and this has been used to diagnose TB infections[88] [89]. The sensitivity and specificity of this method on CSF specimens is estimated to be 89-100% and 50-82% respectively[90].

Novel Biomarkers

Novel biomarkers for TB screening, diagnosis and treatment monitoring has come to the forefront of attention in recent years [91][92][93][94][95]. These include MTB-specific antigen and antibody, with sensitivity of 84-94% and specificity of 92-94% [93]. The detection of lipoarabinomannan (LAM), a MTB cell wall lipopolysaccharide antigen, in urine, which has been proposed to be used for TBM diagnosis in immune suppressed HIV-infected patients, have been shown to have a sensitivity of 64% and a specificity of 69%[96].

Neuroimaging

Modern neuroimaging plays a crucial role in the early diagnosis of CNS tuberculosis, potentially reducing morbidity and mortality associated with delayed treatment[97,98]. Both contrast-enhanced CT and MRI are used to visualize TBM-related pathology, including tuberculomas, basal meningitis, meningeal enhancement, hydrocephalus, brain abscesses, cerebral edema, calcifications, and infarcts [99].

A prospective study in Islamabad, Pakistan (2013-2014) examined 100 TBM patients. CT abnormalities were detected in 67% of cases, with hydrocephalus (58%), edema (24%), and infarcts (5%) being the most frequent findings. MRI, performed in 62% of cases, was abnormal in 87%, revealing hydrocephalus (60%), tuberculomas (53%), leptomeningeal involvement (45%), and infarcts (13%). In 10% of patients with normal CT scans, MRI identified abnormalities, highlighting its superior sensitivity for detecting TBM complications [32].

Another study in Bangalore, India (2001-2003) examined 53 TBM patients over 50 years old, focusing on clinical, imaging, and laboratory features. Findings indicated an absence of typical TBM features such as basal meningeal enhancement, hydrocephalus, infarcts, or granulomas in most elderly patients. The study concluded that CT features in older patients are often atypical and non-contributory to diagnosis, likely due to age-related immune senescence. Therefore, strong clinical suspicion and correlation with laboratory tests are essential for early detection in elderly patients [100].

Management

The WHO and UK Guidelines recommend an initial intensive phase treatment for 2-3 months using rifampicin, isoniazid, pyrazinamide, and streptomycin (or ethambutol), followed by a continuation phase of at least 6 months with rifampicin and isoniazid [101]. Fluoroquinolones are particularly beneficial in treating multidrug-resistant tuberculosis meningitis (TBM) [102], and adjunctive corticosteroids are also recommended [103].

A study conducted at a Tertiary Care Hospital in Kerala, India (2010-2011) followed 47 TBM patients under the Revised National Tuberculosis Control Programme (RNTCP). The study found

that most patients adhered to directly observed treatment (DOTS), demonstrating good compliance with comparable mortality and morbidity rates [104].

Another study in India (2008-2011) analyzed 42 TBM patients treated under RNTCP guidelines. Of these, 83% completed the treatment, with 78% receiving actual DOTS. The study concluded that intermittent short-course chemotherapy (9-month regimen) was effective, though 16% of patients died during treatment [105].

CONCLUSION

Tuberculosis is an important public health problem in South Asia. Although the incidence of tuberculosis in South Asian countries is known, the actual incidence of TBM is uncertain. Our review outlines and discusses the findings of studies on TBM in South Asia. Despite advances in our understanding of TBM in the past few years, it continues to be the most lethal form of tuberculosis. The best way to improve survival is by rapid and accurate diagnosis and the prompt initiation of therapy. This analysis is limited by its reliance on published case reports, which may not accurately reflect the true incidence or full clinical spectrum of TBM in South Asia due to under-reporting and publication bias. The exclusion of non-English literature and potential inconsistencies in diagnostic criteria across reports further restrict generalizability. Moving forward, region-specific prospective studies, improved surveillance systems, and standardized reporting are essential to better understand the epidemiology of TBM and to guide effective diagnosis and treatment strategies.

CONFLICT OF INTEREST

None

FUNDING

None

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Original article

EPIDEMIOLOGICAL CHARACTERISTICS OF TUBERCULOSIS AND TREATMENT OUTCOME FORM 2019 TO 2023 IN GANDAKI PROVINCE OF NEPAL

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DOI: https://doi.org/10.3126/saarctb.v23i1.83800
Received: 23rd Jan Accepted: 11th June Published: 31st July
This article is available at: https://www.saarctb.org/wp-content/uploads/2025/01/STAC-Journal-2025-VOL-23.pdf

ABSTRACT

Introduction:

Tuberculosis is a one of the major public health problem globally which with rank in top ten diseases and a significant public health problem in Nepal as well as global and it continues to pose a serious threat to the health of the population and development of the country. This study aimed to assess epidemiological characteristics of tuberculosis patients and their treatment outcomes in Gandaki Province.

Methods:

A retrospective descriptive epidemiological study was conducted in the Gandaki Province of Nepal. The data were obtained from the Health Management Information System (HMIS) and the eTB system of Gandaki Province of Nepal from 2019 to 2023. Patient information from 11,532 individuals was screened, with incomplete or incorrect data excluded from the analysis. The analysis was conducted using SPSS version 22 and QGIS version 3.38.1 to understand the epidemiology of tuberculosis in the area over the past five years.

Results:

From 2019 to 2023, a total of 11,532 tuberculosis patients were reviewed in Gandaki Province, showing an increasing trend in annual TB cases. Kaski and Nawalparasi East districts reported the highest cumulative numbers, with 2,999 cases (26.01%) and 2,536 cases (21.99%) respectively. About 62.79% of the patients were male, with the most affected age group being 15 to 55 years. Nearly three-fourths of the cases were pulmonary TB. The proportion of HIV-positive TB patients increased from 0.90% in 2019 to 2.11% in 2023. March to June was peak months for TB notifications. The number of death and treatment failure cases was gradually increasing over the period. The proportion of retreatment cases of TB had increased over the period from 1.64% in 2019 to 3.48% in 2023. In the same period, there was increasing trend in proportion of DR TB cases i.e. 10.65% to 18.69% by 2023.

Conclusion:

This study highlights the increasing trend of tuberculosis cases in Gandaki Province, with over one-third diagnosed at private health facilities. A significant number of cases were reported between March and June and more than one per cent of TB patients being HIV-positive. The trend of retreatment and drug-resistant TB cases has risen from 2019 to 2023. Strengthening active case finding in rural areas, among the elderly and vulnerable groups is essential. The National TB program should effectively implement the DOTS strategy for medication adherence and adopt a public-private mix approach for early TB diagnosis.

Keywords: Epidemiological, Tuberculosis, Treatment Outcome, Gandaki Province, Nepal

INTRODUCTION

Tuberculosis is one of the most infectious diseases cause by a single infectious agent (Mycobacterium tuberculosis). It poses a significant public health problem in Nepal as well as globally and continues to pose a serious threat to the mankind.[1-3] It mainly affects poor and vulnerable populations.[4] The highest number of new TB cases occurred in the South East Asia (45%) followed by Africa (24%), Western Pacific regions (17%), Eastern Pacific (8.6%), Americas (3.2%) and Europe (2.1%) [5]. Globally in 2024, 8.2 million people were newly diagnosed with TB disease, of which 4.51 million (55%) were men, 2.706 (33%) million women and 0.98 million (12%) children. TB caused an estimated 1.25 million deaths (95% UI: 1.13-1.37 million), with 161,000 of those deaths occurring among people with HIV [1,5].

The TB burden and case notification rates in Nepal vary across provinces and regions over time. The National Tuberculosis Prevalence survey 2019 indicated that approximately 117,000 people are living with TB in Nepal. Similarly, 69,000 individuals developed TB in 2019 [6]. Drug-resistant TB (DR-TB) threatens global TB control and is a major public health concern in several countries as well as in Nepal [5,7,8]. The same report indicates that Nepal bears a high burden of drug resistance, with estimated MDR TB/RR incidence rates reaching around 28,000 in 2022 [5,6,9].

According to the National TB prevalence survey, more than 30,000 active TB cases are missing per year. It shows estimated TB cases to be much higher than what is being expected now, thus further increasing the gap between estimated cases and notified cases. In addition, 17000 people continue to die each year. According to the National Tuberculosis Program (NTP), it is estimated that 112 new TB cases occur in Nepal out of which 80 TB cases are missed daily [6,10]. In 2023/24, a total of 40,775 cases of TB were notified and registered at the National Tuberculosis Control Program in Nepal and 2766 TB cases were notified in Gandaki Province [10,11].

Older individuals have a higher risk of developing active TB, and the growing number of aging populations in both developed and developing countries may exacerbate this burden [12-14]. Additional measures should be taken to address the various risks associated with TB exposure, such as the rise in multidrug-resistant (MDR) TB [15,16], comorbidities with non-communicable diseases (e.g., HIV and diabetes mellitus) [17,18], and the impacts of alcohol and tobacco abuse [3,19]. Improving access to high-quality TB care is crucial in the effort to eradicate TB [20]. This study aimed to reflect the epidemiological characteristics of tuberculosis patients and their treatment outcomes in Gandaki Province, and to explore the scientific and effective implementation of the TB program in the Gandaki Province.

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METHODOLOGY

Study Design and Site

This is a retrospective descriptive epidemiological study was conducted in the Gandaki Province of Nepal. Gandaki Province includes three ecological zones: the southern plains (Terai), the middle mountains (Pahad), and the upper Himalayan region (Himal). These zones feature diverse characteristics, including mountainous, hilly, and plains regions, as well as both urban and rural areas, the features contribute to the areas representative significance of the study.

Figure 1: Study Map Area

Data Resource

The data were obtained from the Health Management Information System (HMIS) and the eTB system of Gandaki Province. This data included information on age, sex, district, types of TB, HIV status, smoking status, time series, referral for TB diagnosis, trends in retreatment TB cases and drug-resistant TB reported in Gandaki Province from 2019 to 2023. Patient information from 11,532 individuals was screened, with incomplete or incorrect data excluded from the analysis.

Inclusion& Exclusion Criteria

Inclusion Criteria: Tuberculosis patients with complete information, including age, sex, type of TB, HIV status, smoking status, referral for TB diagnosis, and drug-resistant TB.

Exclusion Criteria: Tuberculosis patients with missing or incomplete basic information, such as smoking status, HIV status, referral for TB diagnosis, or drug-resistant TB.

Participants and Ethical Considerations

This study utilized data from existing national HMIS and eTB systems. Since aggregated data were used, participants were not involved in setting the research question or outcome measures for the investigation. As a result, ethical approval and participant consent were not required for this study. However, administrative approval was obtained from the Health Directorate of Gandaki Province.

Statistical information

This study describes the epidemiological methods, case notification trends, and various factors such as age, sex, types of TB, HIV status, smoking status, retreatment trends, drug-resistant tuberculosis trends, time series, and treatment outcomes of reported tuberculosis patients in Gandaki Province from 2019 to 2023. The data were extracted sheet in Microsoft Excel. Data were extracted for the Nepali fiscal years FY 2076/77 BS (2019 AD), FY 2077/78 BS (2020 AD), FY 2078/79 BS (2021 AD), FY 2079/80 BS (2022 AD), and FY 2080/81 BS (2023 AD). The analysis was conducted using IBM SPSS version 22 and QGIS version 3.38.1 to understand the epidemiology of tuberculosis in the area over the past five years.

RESULTS

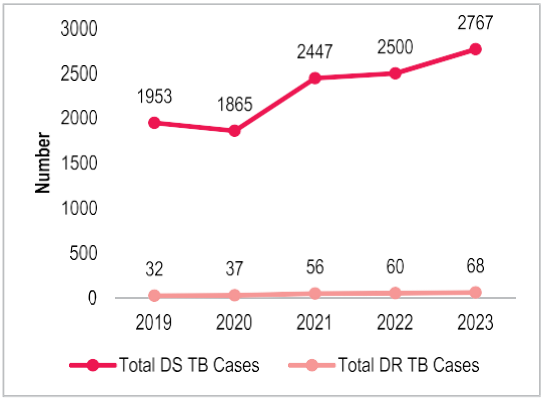

Figure 2: Number of DS and DR tuberculosis reported per year in Gandaki Province from 2019 to 2023, (n=11532)

Figure 2 shows the total number of DS TB cases reported in Gandaki province from 2019 to 2023 which was 11532 with an average annual reported incidence rate of 92.66 per 100000. The reported TB cases showed an increasing trend every year except during the COVID period when cases were slightly decreased. Immediately after post-COVID it was sharply increased in 2021.

Table 1: Basic characteristics of tuberculosis patients in Gandaki Province from 2019 to 2023 (n=11532)

Characteristics	Frequency	Proportion (%)
District		
Gorkha	1028	8.91
Manang	7	0.06
Mustang	42	0.36
Myagdi	264	2.29
Kaski	2999	26.01
Lamjung	608	5.27
Tanahu	1412	12.24
Nawalparasi East	2536	21.99
Syangja	1248	10.82
Parbat	343	2.97
Baglung	1045	9.06
Gandaki Province	11532	
Sex		
Female	4291	37.21
Male	7241	62.79
Age		
0-4 Years	104	0.90
5-14 Years	328	2.84
15-24 Years	1877	16.28
25-34 Years	1800	15.61
35-44 Years	1488	12.90

45-54 Years	1548	13.42
55-64 Years	1747	15.15
≥ 65 Years	2640	22.89
Type of TB		
PBC	6444	55.88
PCD	1700	14.74
EP	3388	29.38

Table 1 shows that during the last 5 years, the highest proportion of TB cases was reported in the Kaski district with 26% of total cases reported. The number of TB cases reported was higher in male than in female with the sex ratio of 1.67:1. Child TB cases (0-14 years) reporting was 3.74%.

Table 2: Smoking and HIV status of tuberculosis patients in Gandaki Province from 2019 to 2023 (n=11532)

Characteristics	Number of TB Patients				
	2019	2020	2021	2022	2023
Smoking Status					
Total TB Registered	1953	1865	2447	2500	2767
Total Current Smokers	128	162	194	165	224
Proportion (%) of Smokers among TB	**6.55**	**8.29**	**9.93**	**8.45**	**11.47**
HIV Status					
Total TB Registered	1953	1865	2447	2500	2767
Total HIV Tested	1562	1578	2340	2469	2744
Proportion (%) of HIV testing among TB registered	79.98	84.61	95.63	98.76	99.17
Total HIV Positive	14	25	34	25	33
Proportion (%) of HIV Positive	**0.90**	**1.60**	**2.18**	**1.60**	**2.11**

Table 2 showed that proportion of smokers among TB cases was in increasing trend from 6.55% in 2019 to 11.47% in 2023. Out of total TB cases registered, proportion of HIV testing had increased over the period (from 80% in 2021 to 99% in 2023).

Figure 3 shows that among the total diagnosed TB patients, more than 50% of TB patients were self-referral while 32.77% were referred by the private sector, 7.79% of them were referred by community and 2.58% referral through contact tracing in past 5 years period.

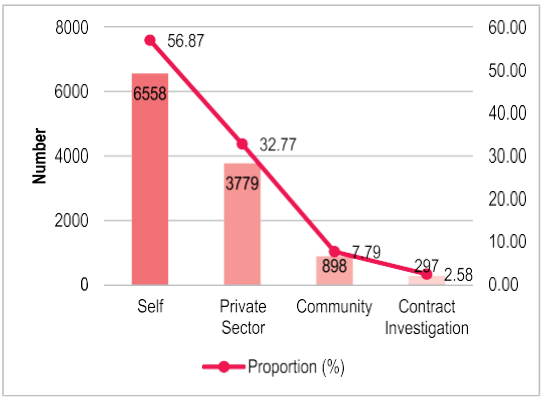

Figure 3: The cumulative reported of referral tracking status of diagnosis of tuberculosis patients in Gandaki Province from 2019 to 2023

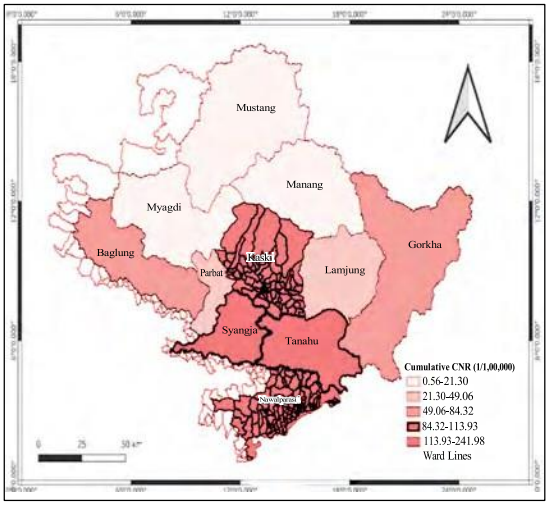

Figure 4: The geographical distribution of tuberculosis cumulative reported case notification rate in Gandaki Province from 2019 to 2023

Figure 4 shows that from 2019-2023, the cumulative reported case notification rate of TB was more than 113 per 100000 in Kaski and Nawalparasi East districts. While in Myagdi, Mustang and Manang districts, the case notification rate was below 21 per 100000 populations in the same period.

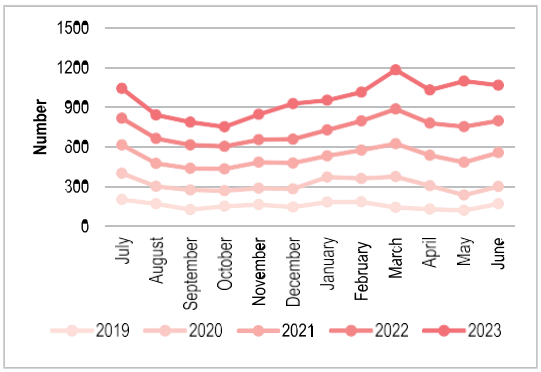

Figure 5: Time distribution of tuberculosis patients in Gandaki Province from 2019 to 2023 (n=11532)

Table 3: Treatment outcome status of tuberculosis patients in Gandaki Province from 2019 to 2023 (n=9358)							
Treatment outcome status	Number of TB Patients						
	2019	2020	2021	2022	2023	Total	Proportion (%)
Cured	8	903	829	1245	1138	4123	44.06
Completed	789	864	857	1003	895	4408	47.10
Failed	1	19	23	27	42	112	1.20
Died	14	87	91	81	106	379	4.05
Loss to follow	18	37	40	61	41	197	2.11
Not Evaluated	20	32	29	27	31	139	1.49
Total Registered	850	1942	1869	2444	2253	9358	

Figure 5 shows that TB cases were reported in all months with high notification in months of March to June. The combined cumulative numbers of reported TB cases over the 5 years showed there was up and down trend in different months throughout the year with the highest peak of disease reported was in the month of March while the lowest case reported was during September and October months.

Table 3 showed that among the total cumulative number of TB patients registered for outcome in the past 5 years, the proportion of treatment success (either cured or completed the full course of treatment) was 91.16%. The trend showed that the number of deaths, and failure cases were gradually increasing over the period.

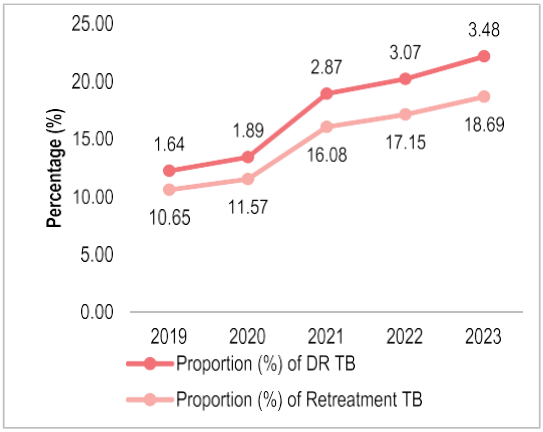

Figure 6: Trend analysis of DS retreatment TB and DR TB in Gandaki Province from 2019 to 2023

Figure 6 shows analysis of the trend from 2019 to 2023, the proportion of retreatment cases of TB had increased over the period from 1.64% in 2019 to 3.48% in 2023. During the COVID period (2019-2020) proportion of retreatment cases and DR cases were low but sharply increased in the post COVID period.

DISCUSSION

Our study reveals several important trends and emerging concerns. Over this five-year period (2019-2023), a total of 11,532 TB cases were documented, indicating a rising trend in annual case notifications. This increase could reflect either improved case detection or a genuine rise in TB incidence. Notably, Kaski and Nawalparasi East districts contributed the highest cumulative caseloads, accounting for 26.01% and 21.99% of total cases respectively. These figures may suggest localized hotspots of transmission or disparities in health service access and coverage. A gender disparity was evident, with males comprising approximately 62.79% of TB patients. This aligns with global patterns where men are generally more affected, possibly due to a combination of biological, behavioral, and socio-cultural factors. [21,22]. Other reason for the lower prevalence in female might be due to social context. Women in Nepal may face barriers to accessing TB diagnosis and treatment due to social and cultural factors like stigma, limited mobility, and a lower likelihood of seeking care as a result, women may be underdiagnosed. Similar findings were found in the study done in China which shows reveals a significantly higher incidence in males than in females[23-25]. Similar result was found in a study where the number of registered incidences was higher in men than in women [3, 26, 27,28]. The majority of cases were observed among individuals aged 15 to 55 years, highlighting the burden of TB among the economically productive age group and underlining the socio-economic impact of the disease.

TB affects all age groups, but the highest burden is often seen in adults, which is consistent with global patterns. In our study majority of the tuberculosis

patients were of above 65 years [28]. Older adults are more likely to have other chronic health conditions that can exacerbate TB and lead to higher mortality rates. The elderly population need to be screened for TB earlier considering their low immune system. In contrast to our finding, a study done by Zhan X found the highest proportion of PTB patients (20.2%) were between 40 and 50 years old [23].

Pulmonary TB remained the predominant form, comprising nearly three-fourths of the total cases, which is consistent with national and global data. However, of growing concern is the increasing proportion of TB-HIV co-infection, which rose from 0.90% in 2019 to 2.11% in 2023. This trend calls for strengthened TB-HIV collaborative activities, including routine screening and integrated care services. Seasonal variation was also noted, with a peak in TB notifications occurring between March and June. This could be influenced by environmental, occupational, or health-seeking behavior patterns and warrants further investigation to inform targeted interventions.

Moreover, the data reflect a gradual increase in TB-related deaths and treatment failure rates over the years, signaling potential gaps in treatment adherence, drug resistance, or patient follow-up mechanisms. Retreatment cases also showed a notable rise, from 1.64% in 2019 to 3.48% in 2023, indicating challenges in sustaining treatment success. Equally concerning is the upward trend in drug-resistant (DR) TB cases, which nearly doubled from 10.65% in 2019 to 18.69% in 2023. This underscores the urgent need for enhanced diagnostic capacity, drug susceptibility testing, and tailored treatment regimens to combat the spread of DR-TB. These findings emphasize the necessity for intensified TB control efforts, focused surveillance, and context-specific strategies to address the evolving TB burden in Gandaki Province. One key limitation of this study is its reliance on secondary data. As such, the accuracy and completeness of the findings depend on the quality of the original data collected and recorded by health facilities.

Regarding types of TB, the PBC cases are high; our study found that more than half (55.88%) of the patients had PBC and 14.74% had PCD and 29.38% had extra pulmonary TB. Similar evidence was found in NTC Fact sheet report where more than 70% of TB cases was pulmonary [29]. Supporting the evidence, study done by Sah SK in Nepal found four-fifth (80.9%) TB patients investigated were pulmonary positive and one-fifth (19.1%) extra pulmonary [30].

In contrast to our finding, study done by Simieneh A, et al found 49.3% had extra pulmonary TB followed by 33.3% smear negative pulmonary TB patients and 16.8% smear positive pulmonary. The differences might be that was hospital based study, so more number of extra pulmonary tuberculosis patients were detected [31].

Smoking is a significant risk factor for tuberculosis (TB) and can impact both the likelihood of developing the disease and the outcomes for those who are infected. Our study showed that the proportion of smokers among TB cases were in increasing trend from 6.55% in 2019 to 11.47% in 2023. As patient who smoke have a high chance of relapse so, it is utmost important to modify lifestyle related behaviour like smoking, tobacco-use; thus cases are increasing [15, 32] Similar finding was found in the study done in Bangladesh and Pakistan by Marshall AM shows the prevalence of smoking in the TB patient population was 8% [33]. Co-morbidity is higher among the tuberculosis patients as they have low immune system. Our study found status of HIV among tuberculosis patients was more than 1% which resembles with the study done by Ubal Leonardo which shows 1.45% of TB patients were HIV positive [24]. Similar findings were found in the study which shows 1.9% and 2.8% had HIV [30,34]. The test rate should be increased to detect the HIV status as, majority of TB patients had HIV and due to HIV; they have low immunity thus they can have had TB too. Diagnosis of HIV should be emphasized among all TB patients.

In most of the developing country where private sectors are growing and providing health services; the large number of tuberculosis patients are hold by private sectors. Our study found 32.7% TB were referred by Private HFs which corresponds with the NTCC Fact sheet which shows more than one-fourth of TB patients were referred by private sectors [29]. All the private health facilities should be emphasized, all health personnel should be provided with training for the proper diagnosis and treatment of tuberculosis [7,35]. Our study found TB

cases were increasing annually. After the COVID pandemic , the case notification rate has gradually increased worldwide and nationally which is also supported by the NTCC fact sheet 2023 and WHO global TB report which shows the TB cases increasing trend from 2020 to 2023 [5,29]

In terms of monthly distribution, the highest cumulative number of cases was reported in March and September during the survey period from 2011 to 2021, with 10.3% and 10.4%, respectively, and the lowest cumulative number of cases was reported in January during the survey period. Usually the diagnosis of TB is higher in March-June month as, in the winter season the flu and common cold symptoms resemble TB so, people refused to visit health facility for TB detection [23]. A comprehensive analysis showed that September and December were the two peak points of the disease throughout the year, with December being the highest peak (9.62% of the total) [26]. In terms of seasonality, January and February are usually the troughs each year. They peaked in March and showed a volatile downward trend, reaching a low point in October; and then rose, reaching another small peak at the end of the year, followed by a rapid decline [27].Treatment success rate is good in our study and death rate is also high. Early diagnosis and a nutritious diet should be focused to decrease the death rate.

DR TB cases are in increasing trend in Nepal [29] Retreatment cases trend was found to be increased from 1% in 2015 to 1.6% in 2017. Most of the re-treatment cases were usually converted to MDR-TB (Multi-Drug Resistant Tuberculosis) [36] greatest number of MDR/RR-TB cases identified at re-treatment resulted from initial MDR/RR-TB that was inappropriately treated as DS-TB. [37,38] Non-adhering to medication has increased drug resistant TB. It is of utmost important to properly treat during first phase to reduce drug resistant.

Policies should also prioritize the TB services to improve access in high-burden districts such as Kaski and Nawalparasi East. The seasonal peak in TB notifications may guide policymakers in allocating resources and conducting awareness campaigns during high-risk months. Finally, investment in real-time data reporting and surveillance systems is essential to improve data quality and enable evidence-based decision-making.

CONCLUSION

This study highlights an increasing trend in the number of tuberculosis patients in Gandaki Province, with the majority of reported cases being male. The highest case notification rates were observed in the Kaski and Nawalparasi East districts. Over one-third of TB patients were diagnosed at private health facilities. A significant number of TB cases were reported between March and June. More than one percent of HIV positive among TB patients and Nine out of the ten TB patients had successful TB treatment outcome in Gandaki province. The trend of retreatment and drug-resistant TB cases has increased from 2019 to 2023. The study could help identify key periods with high TB case notifications and provide a reference for timely diagnosis, prevention, and control measures.

CONFLICT OF INTEREST

None

RECOMMENDATIONS

- Active case finding should be strengthened in rural areas, among the elderly population and in other key vulnerable groups.
- The National TB program should effectively implement the DOTS strategy for medication adherence and adopt a public-private mix approach for the early diagnosis of TB.
- All TB patients should be routinely screened and tested for HIV infection.

ACKNOWLEDGEMENT

We extend our gratitude to Dr. Naveen Prakash Shah of the National Tuberculosis Control Centre, Nepal, for his assistance in developing the concept and motivating us to write this paper. We also thank Deependra Subba of the SAARC TB/HIV Centre for providing valuable information related to the publication process. Additionally, we appreciate the kind support of the Health Directorate of Gandaki Province during our study period.

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Original Article

UNDERSTANDING HEALTH INSURANCE ACCESSIBILITY FOR PEOPLE LIVING WITH HIV/AIDS IN KATHMANDU VALLEY: BARRIERS, ATTITUDES AND POLICY RECOMMENDATIONS

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DOI: https://doi.org/10.3126/saarctb.v23i1.83802
Received: 5th March Accepted: 16th June Published: 31st July
This article is available at: https://www.saarctb.org/wp-content/uploads/2025/01/STAC-Journal-2025-VOL-23.pdf

ABSTRACT

This study explores how accessibility and effectiveness Nepal's free health insurance scheme for people living with HIV/AIDS (PLHIV) in Kathmandu Valley, using a mixed-method approach with both quantitative and qualitative data. A survey of 150 PLHIV, along with 25 in-depth interviews and 4 focus group discussions (FGDs), were conducted to gather insights into participant's experiences, perceptions and the barriers they face. The findings reveal that the health insurance program provides significant financial relief, making healthcare more accessible to PLHIV by reducing out-of-pocket expenses for essential services. However, there are notable gaps in the program's coverage, particularly for mental health, chronic disease management and specialized treatments. These limitations prevent the program from fully meeting the diverse healthcare needs for PLHIV which is essential for improving their long-term well-being.

In addition to coverage gaps, the study identifies several systemic barriers that hinder the program's effectiveness. Social stigma and discrimination remain significant obstacles, with many PLHIV expressing concerns about being identified and facing negative attitudes from healthcare providers for the community. These concerns discourage participation in the program and limit access to care. Furthermore, operational inefficiencies, such as delay in service delivery, breaches of confidentiality during referrals and bureaucratic barriers to enrolment, further undermine the program's impact. The study recommends expanding the insurance coverage to include mental health and chronic disease care, improving service delivery by addressing referral system issues, streamlining enrolment processes and implementing stigma-reduction initiatives to create a more supportive healthcare environment for PLHIV. These measures could significantly enhance the program's accessibility, inclusivity and overall effectiveness.

Key words: Health Insurance, PLHIV,HIV/AIDS, Kathmandu

INTRODUCTION

HIV/AIDS remains a major global health challenge with over 39.9 million cases worldwide as of 2023 and Nepal is no exception, facing significant barriers in providing adequate healthcare and insurance coverage for People Living with HIV (PLHIV) (UNAIDS, 2024). Despite advances in treatment, PLHIV in Nepal continue to experience financial burdens related to healthcare costs, including transportation, medications, diagnostic tests and the management of HIV-related complications. While HIV testing, antiretroviral therapy (ART) and viral load testing are provided free of charge, the lack of comprehensive health insurance coverage exacerbates the challenges faced by PLHIV, particularly in accessing the full spectrum of necessary healthcare services.

As of 2023, there were 1.3 million new infections and 630,000 AIDS-related deaths. Sub-Saharan

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Africa remains the most affected region, accounting for two-thirds of global HIV cases, while Eastern Europe and Central Asia have seen rising infection rates. Women and girls represented 53% of new infections in 2023, with young women in sub-Saharan Africa particularly vulnerable. Additionally, approximately 1.4 million children were living with HIV as of 2021.

Although access to antiretroviral therapy (ART) has increased globally, 5.4 million people in need of ART remain untreated. The Joint UNAIDS aims to eliminate AIDS as a public health threat by 2030, with the goal of ensuring 95% of people living with HIV know their status, 95% of those aware are on treatment and 95% of those on treatment achieve viral suppression. As of 2023, 86% of PLHIV knew their status, 77% were on treatment and 93% achieved viral suppression.

In Nepal, HIV testing, ART and viral load testing are free but PLHIV face financial burdens from the management of HIV-related complications, including opportunistic infections and non-communicable diseases.

The Kathmandu Valley, as the economic and health care hub of Nepal, hosts a significant proportion of the country's PLHIV population. High migration rates, with individuals from rural areas seeking employment and better healthcare, contribute to this concentration. This makes understanding the accessibility of health insurance for PLHIV in the region particularly crucial, as the healthcare system here serves a large and diverse population with specific and complex healthcare needs.

In Nepal, the Government initiated free health insurance scheme for PLHIV from 2020 amid COVID 19 pandemic and so far, there are around 17,000 PLHIV enrolled in the scheme allowing a PLHIV and up to four other family members to be covered under insurance plan. The health insurance coverage includes a range of services such as outpatient department (OPD) services, emergency services, inpatient (hospitalization) services, diagnostic tests (Eg. laboratory tests, X-rays, ultrasounds, MRIs, CT scans), prescribed medications in a convenience bag, surgeries and assistive devices like spectacles, hearing aids, white canes and crutches within specified price limits. However, the coverage excludes cosmetic surgery, basic healthcare, high-cost dental treatments, artificial abortion, artificial insemination services and free drugs provided by Nepal Government.While health insurance coverage in Nepal has expanded, particularly in urban areas like Kathmandu, PLHIV often face difficulties accessing comprehensive coverage that specialized testing services. Stigma, discrimination and financial barriers further limit access to necessary care. Given the high concentration of PLHIV in the Kathmandu Valley, this research aims to identify the barriers they face in accessing health insurance and healthcare services. By exploring the perspectives of both PLHIV and healthcare providers, this study will uncover key issues within the current health insurance system and offer policy recommendations to improve accessibility and inclusivity for this vulnerable group.

Despite Nepal's efforts to provide free antiretroviral therapy (ART) and related healthcare, many PLHIV face barriers to enrolling in and utilizing health insurance. Studies suggest that health insurance can significantly reduce economic burdens among PLHIV (Alvi et al., 2020; Malik et al., 2023). This study aims to examine the effectiveness and challenges of Nepal's free health insurance program for PLHIV in Kathmandu Valley, offering policy recommendations for improving accessibility.

METHODOLOGY

Research Design

This study adopted a mixed-methods approach, integrating both quantitative and qualitative methodologies to comprehensively explore access to health insurance among people living with HIV (PLHIV) in the Kathmandu Valley.

Qualitative Design

Qualitative data were collected through in-depth interviews (IDIs) and focus group discussions (FGDs) with PLHIV, healthcare providers, policymakers, and representatives from the Health Insurance Board of Nepal. Semi-structured interview guides were used to explore participants' perceptions, attitudes, and barriers related to the health insurance scheme. All interviews and FGDs were audio-recorded, transcribed verbatim, and translated into English. A thematic analysis approach was employed using NVivo 12 Pro software for data management and coding.

Quantitative Design

A structured survey was administered to PLHIV to collect socio-demographic and socio-economic data, assess knowledge and attitudes toward health insurance, and identify barriers to enrolment and utilization of the free health insurance scheme provided by the Government of Nepal. The survey was conducted using KoBoCollect, and the data were later analysed in SPSS.

Study Sites

The study was conducted in the Kathmandu Valley, specifically in Kathmandu, Lalitpur, and Bhaktapur districts, which have a high concentration of PLHIV. These urban districts also host diverse populations, making them broadly representative of other urban settings in Nepal. Four ART (antiretroviral therapy) sites were selected for participant recruitment:

SN	Name of ART Site	Province	District
1	Bhaktapur District Hospital	Bagmati	Bhaktapur
2	Sparsha Nepal, Sanepa	Bagmati	Lalitpur
3	Bir Hospital	Bagmati	Kathmandu
4	Sukra Raj Tropical and Infectious Disease Hospital, Teku	Bagmati	Kathmandu

Study Population and Sampling

Study Population

The study population included:

- PLHIV aged 18 years and above residing in the Kathmandu Valley.
- Representatives from government bodies (e.g., Health Insurance Board, NCASC, district health offices).
- Healthcare providers and civil society members involved in HIV/AIDS-related services.

Sampling Techniques

For the quantitative component, a stratified random sampling technique was used to ensure representation across diverse subgroups of PLHIV (by age, gender, socioeconomic status, and location). Within each stratum, participants were randomly selected.

For the qualitative component, purposive sampling was employed to select key informants with relevant knowledge and experience in HIV/AIDS and health insurance service delivery.

Sample Size and Justification

Quantitative Sample

The sample size was calculated using the formula $n= z2pq/d2$ where $z = 1.96$ (95% confidence level), p = estimated prevalence of PLHIV (0.088) and d = margin of error (0.05). The calculated sample size was 123. Considering a 20% non-response rate, the final sample included 150 PLHIV, proportionately distributed across the three districts.

Qualitative Sample

A total of four FGDs were conducted at four ART centers, each involving 6-8 PLHIV. Additionally, 25 in-depth interviews (IDIs) were conducted with a diverse group of stakeholders:

- 1 official each from NCASC and Health Insurance Board
- 3 district-level HIV/AIDS focal persons (Kathmandu, Bhaktapur, Lalitpur)
- 1 municipal-level HIV/AIDS focal person
- 6 healthcare providers from ART centres
- 10 representatives from civil society organizations working in HIV/AIDS
- 3 health insurance facilitators

Data Collection Methods

Tools and Techniques

Quantitative data were collected using a structured questionnaire via KoBoCollect. Qualitative data were collected using semi-structured interview guides tailored for both FGDs and IDIs. All qualitative sessions were audio-recorded, and tools were pretested and refined prior to use.

Data Management and Analysis

Quantitative Data

Survey data were cleaned, coded, and exported from KoBoCollect to SPSS and Microsoft Excel for analysis. Descriptive and inferential statistics were computed, and results were presented in frequencies and percentages.

Qualitative Data

Thematic analysis followed a reflexive approach. Transcripts were reviewed, a coding framework was developed, and data were coded and analyzed using NVivo 12 Pro. Themes were iteratively refined and interpreted to extract meaningful insights.

Validity and Reliability

To ensure validity and reliability:

- All tools were derived from existing guidelines and pretested among 15 PLHIV residing outside Kathmandu Valley using snowball sampling.
- Necessary modifications were made post-pretest to ensure clarity and contextual relevance.
- Only those aged 18 years and older who provided written informed consent were included in the study.

RESULTS

Quantitative Findings

Table 1: Age of respondent (n=150)

Characteristics	Frequency(n)	Percentage (%)
18-24	16	10.67
24-30	15	10
30-36	23	15.33
36-43	31	20.67
43-50	32	21.33
50-57	20	13.33
57-64	12	8
64-71	1	0.67
Total	150	100

Table 1 summarizes the age distribution of participants in the research study. Out of a total sample majority of the participant were middle age. It has mean- 40.81 and median- 42.

Table 6: Main Occupation of respondents (n=150)

Characteristics	Frequency(n)	Percentage (%)
Non- government job	37	24.67
Others (Labor, Driver, Dancer, Cook, Security Guard)	34	22.67
Household work	19	12.67
Business	15	10
Self-owned	13	8.67
Unemployment	12	8
Student	8	5.33
Agriculture	7	4.67
Not willing to answer	3	2
Government job	1	0.67
Retired	1	0.67
Total	150	100

Table 6 represents the occupational distribution of the study participants. The largest group, representing 24.67%, reported working in non-government jobs. A significant portion, 22.67%, fell into "others" category. Household work accounted for 12.67%, followed by business activities at 10% and self-owned ventures at 8.67%. Unemployment was reported by 7.33%, while students and those engaged in agriculture each represented 5.33%. 2% of them were unwilling to answer and 1 participant each were government job holders and retirees.

Table 1: Di stribution of study participants by gender (n=150)

Characteristics	Frequency(n)	Percentage (%)
Male	91	60.67
Female	59	39.33
Total	150	100

Table 1 summarizes the gender distribution of participants in the research study. Out of a total sample, 60.67% were male, while 39.33% were female. This breakdown highlights the gender composition of the study population, with males representing the majority.

Table 2: Distribution of study participation by religion (n=150)

Characteristics	Frequency(n)	Percentage (%)
Hindu	105	70
Buddhist	27	18
Christian	14	9.33
Muslim	3	2
Other	1	0.67
Total	150	100

Table 2 illustrates the religious composition of participants in the study. Among the total sample, the majority identified as Hindu, comprising 70%.

Buddhists made up 18%, followed by Christians at 9.33%, Muslims at 2% and other religion 0.67%. This distribution reflects the diverse religious affiliation within the study population.

Table 3: Distribution of study population by Ethnicity (n=150)

Characteristics	Frequency(n)	Percentage (%)
Janajati	77	51.33
Bramhin/ Chhetri	60	40
Dalit	6	4
Madhesi	5	3.33
Muslim	2	1.33
Total	150	100

Table 3 illustrates the ethnic composition of the study participants. Of the sampled, the majority were Janajati, comprising 51.33%. Bramhin/ Chhetri followed with 40%, while Dalit participants accounted for 4%. Madhesi participants represented 3.33%, and Muslim participants made up 1.33%. This distribution highlights the diverse ethnic backgrounds of the study population.

Table 4: Distribution of study participation by their Marital Status (n=150)

Characteristics	Frequency(n)	Percentage (%)
Married	91	60.67
Unmarried	34	22.67
Separated	11	7.33
Widow/ Widower	10	6.67
Divorced	2	1.33
Living Together	2	1.33
Total	150	100

Table 4 represents the marital status distribution of the study participants. Out of a total of 150 participants, the majority were married, comprising 60.67%. Unmarried individuals accounted for 22.67%, while 7.33% were separated. Widow/ widower participants made up 6.67% and both divorced and living-together individuals each constituted 1.33%.

Enrolment and Awareness: 92.67% of respondents were enrolled in health insurance, with 94.67% aware of the government scheme.

Table 5: Distribution of study participation who were enrolled in free Health Insurance from Nepal Government. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	139	92.67
No	11	7.33
Total	150	100

Economic Burden: 92% believed the scheme reduced financial burdens, but 40.67% still incurred out-of-pocket expenses for services not covered by insurance.

Table 6: Distribution of study participants who felt that free Health Insurance has reduced the economic burden. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	138	92
No	12	8
Total	150	100

Table 7: Distribution of study participants who had paid the services that were not covered by Insurance. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	61	40.67
No	89	59.33
Total	150	100

Service Utilization: 78.67% had access to services, though 20% sought care from non-covered institutions due to service unavailability.

Table 8: Distribution of study participants by Utilization service through free Health Insurance. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	118	78.67
No	32	21.33
Total	150	100

Table 9: Distribution of study participants by utilization of services from other institution due to unavailability of services. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	30	20
No	120	80
Total	150	100

Challenges: 12% faced difficulties enrolling, often due to documentation issues and long waiting times. Stigma discouraged 11.33% from disclosing their HIV status during enrolment.

Table 10: Distribution of study participants who faced difficulty while being enrolled in free health insurance (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	18	12
No	132	88
Total	150	100

Table 11: Distribution of study participants who faced difficulty to identify as PLHIV while being enrolled. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	17	11.33
No	133	88.67
Total	150	100

Table 12: Feels that need to change anything in this policy. (n=150)

Characteristics	Frequency(n)	Percentage (%)
Yes	58	38.67
No	92	61.33
Total	150	100

Table 12 shows that while a majority of participants 61.33% believed that the free health insurance policy does not need any changes, 38.67% still feel that adjustments or improvements are necessary. This indicates that a significant portion of the participants believes there are areas within the policy that could be enhanced which has been presented in the qualitative findings below.

Qualitative Findings

This section presents thematic findings from Key Informant Interviews (KIIs) and Focus Group Discussions (FGDs) conducted with People Living with HIV/AIDS (PLHIV) in Kathmandu Valley. The analysis reveals interlinked domains of awareness, perceived importance, socio-structural barriers, and the perceived impacts of the government-sponsored free health insurance scheme.

Awareness, Perceptions, and Experiences with the Health Insurance Scheme

Most participants were aware of the government-sponsored health insurance scheme for PLHIV. Information about the program was primarily disseminated through ART centers, peer educators, and organizations such as the National Centre for AIDS and STD Control (NCASC) and the National Health Insurance Board. Few of the participants mentioned;

"I received this information from NCASC and the ART Centre where I go for my regular treatment." (KII_PLHIV_HI_11)"

"We were informed during meetings organized by NCASC and by various organizations working with HIV-positive individuals." (KII_PLHIV_HI_13)"

"I found out about the insurance scheme through social media and peers who had already enrolled." (FGD_PLHIV_HI_05)"

Furthermore, the scheme was widely perceived as beneficial. Participants appreciated that it covered routine laboratory tests and medications, offering financial relief and greater access to care as mentioned by the participants below;

"Health insurance gives us a sense of safety. It helps with blood tests and provides free medicines." (KII_PLHIV_HI_02)

"It is a lifeline for us–it reduces our expenses and ensures we can access essential services." (FGD_ PLHIV_HI_05)

However, many noted critical gaps in the range of services covered. Participants reported that treatments for opportunistic infections, chronic diseases, surgeries, and specialized diagnostics were not included under the scheme, as mentioned by participants below;

"Opportunistic infections and chronic illnesses like diabetes or heart problems are not covered, which limits its usefulness." (KII_PLHIV_HI_06)

"I had to purchase surgical gowns myself during my operation–the insurance didn't cover them." (KII_PLHIV_HI_13)

"Conditions like dental issues, bone diseases, and mental health problems are left out." (FGD_ PLHIV_HI_03)

Structural, Financial, and Social Barriers to Access and Utilization

Despite the program's potential, several barriers constrained effective enrolment and utilization were identified which are described below.

Financial Constraints and Employment Challenges

Though the insurance premium was waived, participants reported out-of-pocket expenses related to transportation, OPD ticketing, and medications not covered under the scheme. These costs were unaffordable for many, particularly those unemployed due to stigma or health-related limitations. Few of the participants mentioned;

"There are expenses for travel, OPD tickets, and some medicines. Even if the insurance is free, we still face financial problems." (KII_PLHIV_HI_08)

"We don't have regular income. For many, even NPR 500 or 1000 is hard to arrange." (KII_PLHIV_HI_20)

"Many PLHIV can't do labor-intensive work and struggle to find employment due to stigma." (KII_PLHIV_HI_03)

Service Limitations and Referral Process

The limited scope of covered services significantly reduced the scheme's utility. Additionally, participants found the referral system burdensome and time-consuming, especially in rural areas, and noted concerns over repeated disclosure of their HIV status during referrals, as mentioned by few of the participants below.

"Diseases like heart, liver, and cancer are excluded. So, even with insurance, we're left vulnerable." (KII_PLHIV_HI_01)

"We must go through a lengthy referral process and our status gets disclosed multiple times." (KII_PLHIV_HI_04)

Delays in medicine availability and long queues were also frequently reported, most of the participants were not happy with the time they needed to spend in the hospital for regular check-up. One of the participants mentioned;

"Even when we reach the hospital, we wait in long lines for registration, stamping, and billing." (KII_PLHIV_HI_07)

Stigma, Discrimination, and Privacy Concerns

Many participants expressed concern about using insurance services near their homes due to fear of being identified as HIV-positive. Stigma within communities and among healthcare providers discouraged service uptake. Few of the participants mentioned;

"We avoid local centers to maintain privacy. There's a fear that people will find out about our status." (KII_PLHIV_HI_05)

"Some health workers treat us differently–they use double gloves and act hesitant." (KII_PLHIV_HI_01)

Furthermore, lack of proper documents (e.g., lack of citizenship cards or birth certificates) was another frequently mentioned barrier. Due to lack of proper documentation PLHIV were facing problems in even getting registered in the system, as mentioned by one of the participants;

"People without proper documents can't register. This leaves many of us out of the insurance system." (KII_PLHIV_HI_09)

Perceived Impact of Health Insurance on PLHIV

Despite the above challenges, participants generally viewed the health insurance scheme as an important step toward improving their health and wellbeing. Those who had successfully enrolled and accessed services reported more regular health check-ups and adherence to treatment. Few of the participants mentioned;

"With insurance, we are more motivated to seek timely medical help and regular check-ups." (FGD_PLHIV_HI_04)

Participants of the study also mentioned about the relief they have felt after being enrolled in health insurance program. They mentioned that scheme also provided mental and financial relief by reducing the unpredictability of medical costs. Few of the participants mentioned;

"Now I don't have to worry about paying for every visit. That reduces my stress a lot." (KII_PLHIV_HI_07)

"It gave me peace of mind and helped me focus on my treatment." (FGD_PLHIV_HI_05)

Recommendations for Policy Improvement

Increase Coverage Limits and Scope

Participants strongly advocated expanding the scope and effectiveness of the current health insurance scheme. A major recommendation was to increase the annual coverage limit, as the existing ceiling was often insufficient to meet the comprehensive health needs of PLHIV, especially for those managing multiple co-morbidities or requiring specialist care. Few of the participants mentioned;

"The amount of NPR 1 lakh should be increased to NPR 5 lakh..." - KII_PLHIV_HI_08

"Include whole family... not just PLHIV. Chronic and costly conditions must be covered." - FGD_ PLHIV_HI_02

"Why cover only some diseases? Our needs are bigger than that." - FGD_PLHIV_HI_03

Simplify Access and Expand Service Locations

A recurring recommendation among both individual interviewees and focus group participants was the removal of the current referral system, which was widely perceived as a major procedural barrier to timely and confidential access to care. Participants described the referral requirement as burdensome-particularly for PLHIV residing in remote areas–since it necessitated travel across districts, multiple administrative steps, and, in some cases, public disclosure of their HIV status. Few of the participants mentioned;

"Remove the referral system for convenience." - KII_PLHIV_HI_01

"Patients should be allowed to choose their preferred ART Center." - FGD_PLHIV_HI_01

"Provide services at local levels–health posts and nearby hospitals." - FGD_PLHIV_HI_04

Enhance Awareness and Reduce Stigma

Participants emphasized that despite the existence of a free health insurance scheme for PLHIV, stigma, misinformation, and breaches of confidentiality continue to limit enrolment and utilization. As a response, they strongly advocated for a multi-pronged strategy involving provider sensitization, public awareness efforts, and strengthened privacy protections in service delivery. Few of the participants mentioned;

"There should be orientation... BCC materials for stigma reduction." - KII_PLHIV_HI_03

"We need health workers who treat us with dignity." - FGD_PLHIV_HI_02
"They should maintain confidentiality. Don't call out our names or show forms openly." - FGD_ PLHIV_HI_05

DISCUSSION

This study examined the accessibility and effectiveness of Nepal's free health insurance scheme among PLHIV in the Kathmandu valley. The findings reveal a mixed picture of progress and ongoing challenges. While the scheme has provided some financial relief and improved access to healthcare services, it has achieved only partial success. Persistent issues-such as limited benefit coverage, stigma, and operational inefficiencies-continue to hinder its full potential. Many PLHIV still encounter significant barriers that affect their ability to enroll in and effectively utilize the scheme.

Notably, this study adds new evidence to the body of knowledge by specifically focusing on PLHIV-a population that remains underserved and often marginalized within broader health insurance initiatives. Unlike previous studies that explored insurance access among the general population, this research offers targeted insights into the unique barriers experienced by PLHIV. By documenting their lived experiences, it underscores the need to adapt and expand insurance schemes to ensure equitable access to care in line with the principles of Universal Health Coverage (UHC).

The study's mixed-methods design, incorporating both quantitative and qualitative data, enhances the credibility and depth of the findings. Stratified random sampling ensured a diverse and representative sample, providing a more comprehensive understanding of the challenges across different subgroups of PLHIV. However, the study is geographically limited to the Kathmandu

valley, and its findings may not fully represent the experiences of PLHIV in other regions of Nepal. Additionally, reliance on self-reported data may introduce bias due to recall errors or social desirability.

The findings resonate with international literature, including studies by Alvi et al. (2020) and Chaumont et al. (2019), which emphasize the positive role of health insurance in reducing financial strain among marginalized communities. However, the study also confirms the observation of Shama et al. (2021), highlighting significant gaps in benefit coverage- particularly in areas such as mental health and chronic disease management- that limit the scheme's overall impact. Persistent social barriers such as stigma and fears of confidentiality breaches align with global findings, including those reported by Malik et al. (2023), suggesting that stigma remains a critical deterrent to insurance uptake.

Given these findings, it is plausible that the program's effectiveness could be significantly enhanced through targeted reforms. Integration of HIV-specific case management, mobile registration units, and digital platforms to streamline enrollment could address current bottlenecks while improving privacy protections. Community-based organizations could play an essential role in facilitating outreach and trust-building among hesitant populations.

The study has important implications for both policy and clinical practice. Clinically, better coordination between the insurance scheme and HIV care services could improve treatment continuity and adherence. At the policy level, expanding benefit coverage, increasing reimbursement ceilings, and implementing stronger safeguards for confidentiality should be prioritized. Although politically the program aligns with Nepal's broader commitment to UHC and social protection, scaling and reforming the scheme to be more inclusive of PLHIV will require sustained political engagement and advocacy.

Operationally, many of the recommended improvements are feasible within Nepal's existing health infrastructure. Streamlining registration, enhancing provider training, and building stronger referral systems could be achieved with targeted capacity- building investments. While these reforms will incur additional costs, they are likely to be cost-effective over time by reducing healthcare expenditures associated with untreated or advanced HIV-related conditions. Donor engagement and strategic allocation of existing resources could help manage these financial requirements.

If implemented effectively, these measures could lead to increased insurance enrollment and improved health outcomes among PLHIV. Furthermore, they would contribute to reducing HIV-related stigma, promoting social inclusion, and strengthening public trust in the health system. Such outcomes would not only improve the quality of life for PLHIV in Nepal but also offer a replicable model for inclusive health insurance design in other low and middle-income settings.

Looking forward, future research should examine the long-term effects of insurance coverage on health outcomes among PLHIV and explore disparities across urban and rural settings. Operational research focused on evaluating stigma-reduction strategies, the use of digital tools, and community engagement models will be crucial in informing the next generation of program improvements.

The study highlights progress and challenges in implementing Nepal's free health insurance for PLHIV. While the program has provided financial relief and improved access to healthcare, it also reveals limitations, including incomplete coverage, stigma and logistical barriers.

Similar studies, such as those by Alvi et al. (2020) and Chaumont et al. (2019), show the positive impact of insurance schemes in reducing economic burdens on marginalized groups. However, this study identifies gaps in coverage, particularly for mental health and chronic conditions, echoing issues found in Sharma et al. (2021) regarding limited benefits.

Social barriers like stigma and privacy concerns persist, aligning with global trends. As noted by Malik et al. (2023), fears of discrimination discourage PLHIV from enrolling, a sentiment echoed in Nepal, where breaches of confidentiality were reported. Targeted education and provider training could improve utilization.

While scheme provides financial relief, hidden costs such as transportation and uncovered medications remain significant challenges, like issues found in other countries. Improving service scope and streamlining operations could help alleviate these burdens.

Service delivery challenges, such delays and breaches of confidentiality in referral systems, further hinder the program's effectiveness. Participants suggested expanding coverage, increasing insurance limits and improving confidentiality and accessibility to enhance the program's impact.

Overall, while the free health insurance program has supported PLHIV, addressing financial barriers, stigma and service delivery inefficiencies is essential for improving healthcare access and effectiveness. Comparisons with studies from India and the Dominican Republic suggest that expanded coverage and anti-stigma initiatives could improve program efficacy (Alvi et al., 2020; Chaumont et al., 2019).

CONCLUSION AND RECOMMENDATIONS

In conclusion, while the free health insurance scheme has made significant strides in alleviating the financial burden of healthcare for PLHIV in Nepal, addressing the identified gaps and barriers is essential to realizing its full potential. By expanding the coverage to include a broader range of health services, simplifying the enrolment process, improving service delivery and referral systems, combating stigma and ensuring sufficient funding and service points, the program can be made more inclusive and efficient. These improvements will enable PLHIV to better manage their condition, improve their quality of life and ultimately achieve better health outcomes. With continued policy reforms and focus on inclusivity Nepal can develop a robust health insurance program that meets the comprehensive healthcare needs of PLHIV, ensuring they receive the support they need to live with dignity.

To enhance accessibility and effectiveness of Nepal's free health insurance scheme for PLHIV, several measures are proposed. First, expanding coverage to include essential services such as mental health care, treatment of chronic disease care and advanced treatments within the insurance package is crucial to address the comprehensive healthcare needs of PLHIV. This would ensure a more comprehensive approach to healthcare, addressing the diverse needs of PLHIV and promoting better long-term health outcomes. Given the high prevalence of mental health challenges and the need for chronic disease management among PLHIV, the inclusion of these services within the insurance package is vital to reducing the overall health burden.

Second, easing enrollment process is necessary to increase participation in the program. By streamlining documentation requirements and providing support for obtaining necessary records, enrollment barriers can be reduced, ensuring that more individuals can access the benefits of the program.

Additionally, combating stigma remains a critical issue that undermines the program's potential. Training healthcare workers in non-discriminatory practices and launching public awareness campaigns can help address the social stigma surrounding HIV. These efforts would foster a more inclusive healthcare environment, where PLHIV feel safe and supported in seeking care. Reducing stigma and discrimination would also encourage greater utilization of healthcare services, ensuring that PLHIV can fully benefit from insurance scheme.

Finally, increasing funding and service points is crucial to ensuring the sustainability and reach of the program. Establishing additional ART centers and ensuring sustained financial backing for insurance claims will improve the program's effectiveness and extend its outreach to underserved areas, particularly remote regions where access to healthcare services is limited. Expanding service points would increase geographical access and reduce travel-related financial burdens, thereby improving participation in the program.

ETHICAL CONSIDERATION

The study was approved by the Nepal Health Research Council (NHRC) (Reference No: 312). Written informed consent was obtained from all participants. Participation was voluntary, and respondents were free to withdraw at any time. Strict confidentiality was maintained. No identifying

information was collected, and unique codes were assigned to all datasets to ensure anonymity. For surveys: unique alphanumeric codes (e.g., A1, B1) were used. For interviews: anonymized codes (e.g., IDI_PLHIV_HI_01) were applied during transcription and analysis. Participants were provided with Participant information sheet prior to data collection to enable them to make informed choice.

CONFLICT OF INTEREST

There is no any financial interest or any conflict of interest related to this paper.

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Original article

TUBERCULOSIS KNOWLEDGE IN THE COMMUNITY: INSIGHTS AND GAPS FROM BELKOTGADHI, NUWAKOT DISTRICT, NEPAL

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DOI: https://doi.org/10.3126/saarctb.v23i1.83803
Received: 10th March Accepted: 11th June Published: 31st July
This article is available at: https://www.saarctb.org/wp-content/uploads/2025/01/STAC-Journal-2025-VOL-23.pdf

ABSTRACT

Introduction:

Background: Tuberculosis (TB) is a communicable disease and a major global public health challenge. The lack of knowledge about its communicable characteristics and treatment options is the main barrier to reducing its burden. This study aims to assess TB knowledge among people in Belkotgadhi Municipality, Nuwakot District.

Methods:

Data were collected from 3352 households across 12 wards of Belkotgadhi Municipality using a convenient sampling method. The data collected and stored in the Kobo Toolbox, included information on TB and sociodemographic variables. After excluding incomplete entries, 3331 households were analysed. Frequencies and percentages were calculated, and chi-square test was conducted to examine the association between TB knowledge and sociodemographic factors.

Results:

About 48.6% of respondents were unaware that TB is communicable, and 31.4% did not know it is treatable. The main prevention method identified was wearing masks in crowded areas (30%), followed by the BCG vaccine (22.7%); however, fewer than 10.0% were familiar with DOTS. The major source of health-related information was health workers. Knowledge of TB's communicability was significantly associated with gender, age, religion, literacy, family type, and health insurance status. Lower knowledge was found among illiterate, older adults, females, Hindus, those living in joint families, and those without health insurance.

Conclusion:

Knowledge of TB is low, highlighting the need to increase awareness about its communicability, treatment, and prevention. It can be enhanced through educational interventions for various sociodemographic groups, as well as by sharing information via health service providers, television, radio, and social media.

Keywords: Knowledge, Nepal, Nuwakot, Tuberculosis

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INTRODUCTION

Tuberculosis (TB) is a communicable disease and remains a critical global health issue, particularly in low- and middle-income countries(1). Despite being treatable, TB is one of the leading causes of morbidity and mortality worldwide. Pulmonary TB significantly impacts individuals by causing

chronic respiratory damage, systemic symptoms like weight loss and fatigue, as well as long-term effects including reduced lung function and increased susceptibility to infections[2].

In 2023, approximately 8.2 million people were newly diagnosed with TB, the highest number recorded since 1995, up by 7.5 million from 2022. The estimated incident rate of TB in 2023 was 134 cases per 100,000 population, indicating nearly 10.8 million individuals suffered worldwide from TB that year. Additionally, TB-related deaths were 1.25 million, making it the leading infectious disease globally, surpassing COVID-19. The number of deaths by TB was 1.6 million in 2021 [1,3].

Asia reports approximately 55% of global TB cases, with countries like India and China exhibiting the highest incidence rates. In 2021, India alone represented about 27% of the global TB burden[4]. Among those who develop TB, around 90% are adults, with a higher prevalence in men[3]. There is a gap between the expected number of TB infections and the real number of infections due to underdiagnosis and underreporting. In 2019, the estimated incidence of TB in the SAARC region was 3.7 million, and new and relapse notified cases were just 3.1 million [5].

Particularly in rural Nepal, TB remains a major health concern. A national TB survey conducted by WHO in 2018-19 estimated that over 117,000 people currently have TB, with approximately 69,000 new cases reported–about 1.6 times more than expected, and according to a report on 2021, an estimated 40,000 new active cases reported annually and 45% of the population is infected with TB [1,4]. The higher prevalence of TB is notably found among men and older populations in the hill and Terai regions, compared to the mountainous areas[6]. Despite advancements in treatment programs like Directly Observed Treatment Short Course (DOTS), 5,000 to 7,000 people die from TB annually[1].

The dynamics of TB transmission in Nepal are affected by socio-economic factors such as population density, migration, and healthcare access. The disease remains a significant public health challenge, linked to poverty, malnutrition, and inadequate healthcare infrastructure[7]. Rural populations are at higher risk of delayed diagnosis and treatment due to limited healthcare access, poor knowledge of TB, and lower health literacy compared to urban areas[4]. However, the Ministry of Health and Population has been actively working on educational campaigns to improve the importance of early diagnosis and treatment of TB and raise awareness on its transmission[8].

The lack of knowledge of TB and its transmission can delay control efforts of the disease. Belkotgadhi Municipality in Nuwakot District represents a hilly territory with residents of all castes and ethnicities. Understanding local knowledge is crucial for developing targeted health education programs to enhance awareness and reduce TB incidence in this region. This study aims to evaluate the knowledge of TB of the residents in Belkotgadhi Municipality, focusing on their understanding of its transmission, prevention strategies, and assessing the association of sociodemographic characteristics of respondents and their knowledge about the transmissible characteristics of TB.

METHODOLOGY

Study Design:

A retrospective cross-sectional study design was applied to analyze secondary data from a population-based household survey assessing community members' knowledge regarding the transmissiblity of TB and its preventive measures.

Setting:

This study was conducted in Belkotgadhi Municipality, Nuwakot District, Nepal. Nuwakot is a hilly district located in Bagmati Province. Belkotgadhi Municipality is one of the administrative divisions in Nuwakot and is characterized by predominantly rural areas with some semi-urban settlements. The region has limited healthcare facilities and health services, primarily provided through primary health care centers and local health posts.

Study Population:

The study population consisted of people over 18 years of age with clear hearing and speaking ability residing in Belkotgadhi Municipality. The primary data were collected between August and September 2024.

Variables:

The study focused on “Pulmonary TB”, which is communicable. Participants were asked questions to assess their knowledge and awareness on

TB. The dependent variable in this study was the understanding of communicable nature of TB, determined by response to the question, "What type of disease is TB?" of the respondents. Those who correctly answered “communicable” were classified as having demonstrated knowledge. A range of sociodemographic characteristics served as the independent variables.

Data Collection, Entry, and Analysis:

This study analysed secondary data collected during a one-month community health diagnosis program conducted by first-year MBBS students at Maharajgunj Medical Campus(MMC), Institute of Medicine(IOM), Tribhuvan University(TU). The academic aspect of data was fulfilled, and the ownership of the data resides with the MMC, Department of Community Medicine and Public Health(DCMPH).

For the primary data collection, the DCMPH provided a five-day orientation on tool development, data collection, and analysis to the students. They were divided into 12 groups, each assigned a ward, except one ward inaccessible due to a logistical point of view. Households were selected conveniently and conducted face-to-face interviews with the head of the household or the oldest available member capable of communication. KoboCollect, a mobile application, was used for the data collection. The questionnaire, rigorously prepared and translated into Nepali with expert support, was pre-tested in Dhunibesi Municipality, Dhading District, and refined accordingly. It included sociodemographic variables and questions on community health topics such as disease knowledge, sanitation practices, and neonatal immunization. Data related to sociodemographic and TB information were extracted for the study.

From the compiled dataset of 3352 records, 3331 were analysed after removing missing data. Descriptive statistics (frequencies and percentages) were performed, and a chi-square test was used to examine the association between sociodemographic factors and knowledge of communicable characteristics of TB.

RESULTS

Approximately 40% of respondents were aged 31-50 or above 50 years, with a mean age of 46.82(15.89) years. The age distribution of the respondents was normal, with almost similar mean and median values. The sex ratio was 108.06 males per 100 females, and the majority(84%) were Hindus. Most respondents were literate(65.42%), married (86.13%), lived in nuclear families(62.05%), and 60% belonged to relatively advantaged ethnic groups. The primary source of health information was health personnel(64%), followed by radio and television(53.6%).

Moreover, 74.93% reported that health insurance was available in their area, and only 27.74% had done it for their family. For healthcare, 76% preferred government hospitals. **(Table-1)**

Table 1. Sociodemographic characteristics and health practices of the respondents, Belkotgadhi Municipality, Nuwakot District, Nepal 2024

Variables		Frequency (n)	Percentage (%)
Age (in years)	30 and Below	578	17.35
	31 to 50	1439	43.20
	Above 50	1314	39.45
	Mean ± SD	46.8 ± 15.9	
	Min, Max	18, 80	
Sex	Male	1730	51.94
	Female	1601	48.06
Religion	Hindu	2797	83.97
	Buddhist	446	13.39
	Other	88	2.64
Ethnicity	Marginalized groups	1324	39.75
	Relatively advantaged groups	2007	60.25
Type of Family	Nuclear	2067	62.05
	Joint and extended	1264	37.95
Literacy	Illiterate	1152	34.58
	Literate	2179	65.42
Marital Status	Married	2869	86.13
	Unmarried/ single individual	462	13.87
Source of Information*	Health personnel	2133	64.03
	Radio/TV	1785	53.59
	FCHV's	1455	43.68
	Social media	1080	32.42
	School/ Educational Institutions	346	10.39
	Posters/ Pamphlets	78	2.34
	Other	76	2.28

Health Insurance in the area	Yes	2496	74.93
	No	583	17.50
	Don't Know	252	7.57
Health insurance is done for the family members	Yes	924	27.74
	No	2407	72.26
The first choice for treatment after any illness	Governmental Health Institution	2532	76.01
	Clinic/Nursing home	548	16.45
	Dhami Jhakri	186	5.58
	FCHV	43	1.29
	Others	22	0.66

#TV- Television, #FCHV- Female Community Health Volunteer

Table 2 shows, about half (51.4%) of respondents identified TB as a communicable disease, while 33.0% were unaware of its transmissible nature, and 15.6% said it is non-communicable. Among those who recognized TB as communicable, 79.6% identified coughing and sneezing as transmission modes. Notably, 14.4% admitted they did not have an idea of TB transmission.

Regarding treatment, 31.1% were unaware that TB is treatable. For prevention measures, the major was wearing masks in crowded areas (30%), followed by receiving the Bacillus Calmette-Guerin (BCG) vaccine (22.7%) and maintaining a healthy diet (22.3%). However, nearly half of the respondents admitted they did not know how to control TB infection, and most respondents (91.5%) had never heard of the Directly Observed Treatment System (DOTS).

Table 2: Knowledge regarding tuberculosis among respondents, Belkotgadhi Municipality, Nuwakot District, Nepal 2024 (n=3331)

What type of disease is TB?	**Frequency**	**Percentage (%)**
Communicable	1713	51.43
Non-communicable	519	15.58
Don't know	1099	32.99
What are the Modes of transmission of TB from one person to another (n=1713)*		
Through the coughing and sneezing of the patients	1363	79.56
Through the blood	438	25.56
By touching the patients	318	18.56
Through the urine and faeces	204	11.91
Other	37	2.15
Don't know	247	14.42
Is the TB treatable?		
Yes	2120	63.64
No	176	5.28
Don't Know	1035	31.08
How to prevent TB infection?*		
To wear a mask in a crowded area	996	29.90
Bacillus Calmette-Guerin (BCG) Vaccine	756	22.70
To take a healthy diet	744	22.34
Do not share or exchange any materials or utensils with the infected persons	655	19.66
Living in a place where the air circulates well	612	18.37
Taking care while being near the TB-infected persons	585	17.56
Washing hands regularly with soap and water	235	7.05
Don't know	1695	50.89
Heard about DOTS		
Yes	284	8.53
No	3047	91.47

* indicates multiple response type questions

Sociodemographic factors significantly influenced knowledge about tuberculosis transmission. Males showed significantly (p-value=0.010) higher TB knowledge on TB (53.58%, 95% CI: 51.27-56.01) than females (49.09%, 95% CI: 46.66-51.53). Similarly, respondents aged 31 to 50 years had significantly higher knowledge (55.59%, 95% CI: 53.09-57.95; $p < 0.001$) compared to those aged 30 years and below (53.28%, 95% CI: 49.14-57.09) and those above 50 years (46.04%, 95% CI: 43.45-48.70). Non-Hindus demonstrated better knowledge (57.30%, 95% CI: 53.18-61.24) than Hindus (50.30%, 95% CI: 48.41-52.16), with a p-value of 0.003. Also, literate individuals showed higher knowledge (58.88%, 95% CI: 56.77-60.76) compared to illiterate respondents (37.32%, 95% CI: 34.54-40.19), $p<0.001$. Additionally, nuclear families (53.55%, 95% CI: 51.48-55.78) and those with health insurance (54.65%, 95% CI: 51.51-

Table 3. Percentage Distribution of Correct Response/Knowledge about Transmission of TB, by Sociodemographic Characteristics of the respondents in Belkotgadhi Municipality, Nuwakot District, Nepal 2024

Variables		Percentage (%)	95 % CI	p-value
Sex	Male	53.58	(51.27, 56.01)	0.010
	Female	49.09	(46.66, 51.53)	
Age (years)	30 and below	53.28	(49.14, 57.09)	<0.001
	31 to 50	55.59	(53.09, 57.95)	
	Above 50	46.04	(43.45, 48.70)	
Religion	Hindu	50.30	(48.41, 52.16)	0.003
	Non-Hindu	57.30	(53.18, 61.24)	
Caste/ Ethnicity	Marginalized groups	50.67	(47.96, 53.32)	0.484
	Relatively Advantaged groups	51.91	(49.63, 54.21)	
Literacy	Illiterate	37.32	(34.54, 40.19)	<0.001
	Literate	58.88	(56.77, 60.76)	
Occupation	Agriculture	50.65	(48.55, 52.62)	0.157
	Non-agriculture	53.36	(50.22, 56.42)	
Family type	Nuclear	53.55	(51.48, 55.78)	0.002
	Non-Nuclear	47.94	(45.26, 50.63)	
First preference for the treatment	Government health institution	52.21	(50.47, 54.06)	0.106
	Other than the governmental health institution	48.93	(45.31, 52.69)	
Health insurance is done for the family members	Yes	54.65	(51.51, 57.68)	0.021
	No	50.18	(48.19, 52.05)	

57.68) had better knowledge, with p-values of 0.002 and 0.021, respectively. **(Table-3)**

DISCUSSION

The findings of this study reflect essential insights into the sociodemographic characteristics, knowledge regarding TB, and health-seeking practices among respondents in the Belkotgadhi municipality of Nuwakot District, Nepal. The results also highlight that Gender, Age, and literacy are the major factors of concern regarding the knowledge of TB.

The demographic profile indicates a predominantly(43.20%) aged between 31 and 50 years. The sex ratio of 108.06 males per 100 females indicates a slight male predominance among the respondents, possibly due to a preference for males as respondents. The majority (84.0%) of respondents were Hindu, close to the census report of Nepal 2022(9). Additionally, a major proportion (60.3%) belonged to relatively advantaged groups (A group with better access to resources, opportunities, or power in society due to higher income, education, or social status). This disparity can influence healthcare services and health education resources, potentially exacerbating health inequalities[8,10].

Health personnel were the primary source of health information, followed by radio, TV, and social media. This highlights healthcare providers' crucial role in delivering accurate information, and the growing importance of digital platforms in health-related information and communications[8].

Despite the availability of health insurance in the area, and three-fourths know this, only 27.7% reported having insurance for their family members. According to the Nepal Demographic Health Survey (NDHS) 2022, only about 10% of individuals aged 15-49 are enrolled in the health insurance program, with varying coverage by region and socioeconomic status(4). This discrepancy highlights barriers to accessing insurance coverage and suggests a need for improved outreach regarding its benefits. [11-13]

The knowledge assessment regarding TB revealed a huge gap: only 51.4% recognized TB as a communicable disease, and about one-third were unaware that TB is treatable. This contradicts the results of the NDHS 2022, indicating more than 90% had heard about TB, and only one-fifth do not recognize that TB is curable [4]. The discrepancy may be due to the geographical and demographic variability of the respondents[8,10,14]. Maybe they heard it, but the possibility is that they are unaware of its transmissible characteristics. Among those who identified TB as communicable, 79.6% recognized coughing and sneezing as transmission modes, unlike NDHS 2022, where only 50% reported it. This highlights a significant gap in understanding TB transmission. For the effective prevention, understanding the transmissible nature of TB is essential[15]. However, the observed discrepancies may be attributed to methodological variations with NDHS, like sampling technique used (nationwide representative sample vs. municipality-based), the data collection tools (standardized vs. researcher-adapted), and the target population (only ages 15-49 vs. anyone over 18), and time variations [4,16].

About 29.9% of respondents identified wearing masks as a preventive measure against TB, followed by the BCG vaccine and a healthy diet. Still, nearly half were unaware of any such methods, highlighting significant knowledge gaps. WHO also emphasizes vaccination (BCG), maintaining good ventilation to minimize airborne transmission, and practicing good hygiene to control the spread of infection [17].

There were several sociodemographic factors influencing knowledge about TB transmission. Notably, males exhibited higher correct responses compared to females, indicating potential barriers to education and access to information for women [8]. It is similar to a study conducted in Ghana[18]. Limited access to health education for females increases the risk of disease transmission for themselves and their family members, as they are the primary caregivers in the family.

Age also played a crucial role; respondents over 50 had the lowest percentage of correct knowledge. This finding is comparable to a study conducted in Saudi Arabia, where participants over 50 demonstrated significantly lower awareness levels of TB than those aged 18-28 [19]. This may be due to limited health literacy among the older age group[20].

Literacy emerged as a crucial factor; illiterate individuals were notably less aware of the transmissible nature of TB compared to their literate counterparts. According to the NDHS, the regions with lower literacy rates often report poorer awareness of TB symptoms and preventive measures[4]. A study in India mentioned, people with a high education level know the symptoms and recognize TB as a curable disease, indicating that knowledge of TB is correlated with education [21]. The result is similar to a study done in Africa and Malawi, indicating higher TB knowledge among literate compared to illiterate [22,23].

Respondents from nuclear families were significantly more aware of the spreading characteristics of TB, compared to non-nuclear families. This suggests that family dynamics influence information dissemination within households[24]. The result is supported by studies conducted in Lalitpur, Nepal, and Bangladesh, where persons from nuclear families had good knowledge about TB, compared to those from joint families. This may be due to effective communication among family members in nuclear families, better access to health education, and other factors like the income of the family and expenditure on education[14,25]. While occupation did not show significant differences in knowledge, the relationship between occupation and TB knowledge is complex and can be influenced by various factors, like specific job roles, access to training, resources, and socioeconomic conditions [14,26,27]. According to the National TB Control Program in Bangladesh, the proportion of TB infection was higher among sales and service workers (45.4%) and other non-agricultural workers (31.3%) compared to agricultural workers (13.8%)[28].

Additionally, people without health insurance exhibited a higher rate of incorrect responses compared to those with insurance. This indicates, health insurance significantly influences health-related knowledge and behaviours by enhancing access to healthcare services, interactions with service providers, and thereby improving health literacy[26]. Policies expanding health insurance are

crucial to promote equitable health outcomes for uninsured populations by bridging the knowledge gaps.

Implications for Public Health:

Enhancing public awareness can help to reduce the burden of TB. Findings highlighted the need for educational interventions to improve awareness of TB transmission, prevention, and treatment. Healthcare personnel and platforms like social media, TV, and radio can be used for sharing information. Integrating TB education into broader health promotion campaigns can bridge knowledge gaps and improve public health outcomes.

Strengths and Limitations:

This study has a sufficient sample size. But, as a secondary data analysis, it used only available information. Its cross-sectional design cannot establish cause-effect relationships, and being an academic field activity, it lacked sufficient TB-related variables.

CONCLUSION

This study reveals low knowledge of TB among respondents, influenced by various sociodemographic factors. Key information sources include health personnel, radio, TV, and social media. Educational interventions and media-based information sharing can enhance knowledge, particularly targeting females, the illiterate and older individuals, to control TB in Nepal.

ACKNOWLEDGEMENT

The authors express gratitude to Maharajgunj Medical Campus, Department of Community Medicine and Public Health, for providing secondary data and granting permission to analyze. We also appreciate the MBBS 44th Batch students for their support.

ETHICAL CONSIDERATIONS

All participation in the study was voluntary after obtaining informed consent from the participants. The anonymity and confidentiality of the participants were maintained. Ethical approval for the secondary data analysis was obtained from the Institutional Review Committee (IRC), IOM, with reference to 527-081/082.

CONFLICT OF INTEREST

None

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Original article

PREVALENCE AND CLINICAL PROFILE OF PERIPHERAL NEUROPATHY AMONG HIV PATIENTS VISITING A TERTIARY CARE HOSPITAL IN NORTH KARNATAKA: A CROSS-SECTIONAL OBSERVATIONAL STUDY

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DOI: https://doi.org/10.3126/saarctb.v23i1.83804
Received: 11th March Accepted: 11th June Published: 31st July
This article is available at: https://www.saarctb.org/wp-content/uploads/2025/01/STAC-Journal-2025-VOL-23.pdf

ABSTRACT

Introduction:

Peripheral neuropathy (PN) is one of the most common neurological complications in people living with HIV (PLHIV). The increasing life expectancy of HIV-positive patients due to combination antiretroviral therapy (cART) has led to a growing burden of chronic neurological disorders, particularly HIV-associated peripheral neuropathy (HIV-PN). Despite its high prevalence, HIV-PN remains underdiagnosed, leading to significant morbidity and poor quality of life. The objectives was to assess the prevalence of HIV-PN among HIV-positive individuals and to evaluate the demographic and clinical characteristics associated with HIV-PN.

Methods:

A cross-sectional observational study was conducted among 158 HIV-positive patients attending a tertiary care hospital in North Karnataka, India. Diagnosis of peripheral neuropathy was based on clinical symptoms, neurological examination, and nerve conduction studies (NCS). The Total Neuropathy Score (TNS) was used to grade peripheral neuropathy severity.

Results:

The prevalence of HIV-PN was 79.7%. The most common symptoms were tingling (85%), burning pain (76%), and numbness (62%), predominantly affecting the lower limbs in a length-dependent manner. Risk factors associated with peripheral neuropathy included longer HIV duration ($p<0.001$), history of tuberculosis ($p=0.002$), and exposure to older cART regimens ($p=0.001$).

Conclusion:

The study highlights the high prevalence of HIV-PN and its significant impact on patients. Routine screening, early diagnosis, and management strategies should be incorporated into HIV care programs to improve quality of life.

Keywords: HIV, peripheral neuropathy, prevalence, cART, nerve conduction studies

INTRODUCTION

Human immunodeficiency virus (HIV) is a retrovirus that progressively weakens the immune system by targeting CD4+ T lymphocytes, leading to acquired immunodeficiency syndrome (AIDS). Over the past few decades, the global response to HIV has transformed its prognosis from a fatal disease to

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a chronic, manageable condition, thanks to the widespread availability of antiretroviral therapy (ART). However, despite advancements in treatment, HIV-associated peripheral neuropathy (HIV-PN) remains one of the most prevalent and debilitating neurological complications among people living with HIV (PLHIV).

Peripheral neuropathy (PN) is a frequent yet underdiagnosed complication of HIV infection, affecting between 10% and 50% of patients globally.[1] It is characterised by distal sensory loss, burning pain, and motor dysfunction, significantly impairing patients' quality of life.[2] The pathogenesis of HIV-PN is multifactorial, involving direct viral neurotoxicity, chronic inflammation, and antiretroviral drug-induced mitochondrial toxicity. [3]

Distal sensory peripheral neuropathy (DSPN) is the most common form of HIV-PN, affecting both ART-naïve and ART-experienced individuals. It is characterised by numbness, tingling, burning pain, and sensory loss, primarily in the lower extremities. These symptoms significantly impair mobility, daily activities, and mental well-being, often leading to decreased quality of life and increased healthcare burdens. The burden of HIV-PN is particularly significant in resource-limited settings like India, where over 2.3 million people are living with HIV. Despite the availability of combination antiretroviral therapy (cART), neuropathy remains underdiagnosed and undertreated, mainly due to the absence of standardised diagnostic tools, a lack of clinician awareness, and limited access to specialised neurological assessments.

Although several studies have investigated HIV-PN prevalence and pathogenesis, many questions remain unanswered. This study aims to explore the prevalence of HIV-PN in India, where data on neuropathy among PLHIV is scarce, the impact of ART on neuropathy risk, particularly with newer ART regimens, and the effectiveness of a simple, low-cost diagnostic tool to facilitate early detection and intervention. Given that many HIV-infected individuals, especially in India, do not have access to specialized neurological care, a reliable, easy-to-use diagnostic method for non-physician healthcare workers is essential to improve early detection and management.

Significant research has shown that HIV-PN arises from multiple mechanisms, including direct viral neurotoxicity, chronic immune activation, and ART-induced mitochondrial dysfunction. Historically, older ART drugs, particularly nucleoside reverse transcriptase inhibitors (NRTIs) like stavudine (d4T), didanosine (ddI), and zalcitabine (ddC), were found to be neurotoxic, increasing the risk of neuropathy. While the phasing out of these drugs has reduced the incidence, HIV-PN continues to persist in ART-experienced patients due to cumulative neurotoxicity. Additionally, inconsistent diagnostic criteria and varied study methodologies have led to widely differing prevalence estimates, ranging from 11% to 56% globally.

In resource-limited settings such as India, the burden of HIV is substantial, with 23.48 lakh PLHIV as per the National AIDS Control Programme (NACP) released in 2019.[4] The prevalence of peripheral neuropathy in PLHIV varies widely due to differences in ART regimens, genetic factors, nutritional status, and co-infections such as tuberculosis and hepatitis C.[5]

Despite these insights, several gaps remain in our understanding of HIV-PN. There is no standardised test for diagnosing HIV-PN, and current methods, such as nerve conduction studies (NCS), lack sensitivity for detecting small fibre neuropathy, which often precedes the more apparent symptoms of DSPN. Moreover, studies investigating the prevalence of HIV-PN in India are limited, making it difficult to assess its true burden. Furthermore, there is uncertainty regarding the neurotoxic potential of newer ART regimens and their impact on the long-term risk of neuropathy in HIV patients.

Despite its high prevalence, routine screening for peripheral neuropathy in HIV clinics is not widely practised, leading to delayed diagnosis and suboptimal management. Given the chronic nature of HIV-PN, understanding its epidemiology is crucial for early intervention and targeted therapy.

This study addresses these gaps by investigating the prevalence, risk factors, and clinical characteristics of HIV-PN among PLHIV in India. Additionally, it aims to evaluate a simple, cost-effective diagnostic tool that can be used in resource-limited settings to facilitate early identification and treatment. Given the growing burden of HIV-related neurological

complications, early detection and intervention are critical in improving patient outcomes, reducing disability, and enhancing the quality of life of those affected.

By bridging the knowledge gap in HIV-PN research and introducing a practical diagnostic approach, this study aspires to make a significant contribution to the public health response to HIV in India.

Objectives

1. To determine the prevalence of HIV-associated peripheral neuropathy in a tertiary care setting and to characterise the spectrum of neuropathic symptoms among HIV-positive patients
2. To identify the demographic and clinical risk factors associated with peripheral neuropathy

METHODOLOGY

This was a cross-sectional observational study conducted at the outpatient/inpatient department in a government hospital attached to the Karnataka Medical College and Research Institute (KMCRI), Hubballi, a city in the southern Indian state of Karnatakafrom January 2023 to December 2023. A total of 158 consecutive HIV-positive adult patients attending the ART Centre and Medicine OPD were enrolled in the study, regardless of the presence or absence of symptoms suggestive of peripheral neuropathy (PN).

Patients on previously neurotoxic antiretrovirals such as stavudine were excluded, as this agent has been phased out in India following the National AIDS Control Organisation (NACO) guidelines. Concomitant drug use was documented, especially drugs known to cause neuropathy, such as isoniazid and metronidazole. Patients on anti-tubercular therapy received pyridoxine supplementation as per standard protocol. Adherence was assessed via self-reporting and pharmacy refill data, categorised as good (>95%), fair (80-95%), or poor (<80%). The study excluded those patients with pre-existing diabetes mellitus or other known causes of neuropathy (e.g., chronic alcohol use, vitamin B12 deficiency), and those with a history of neuromuscular disorders unrelated to HIV.

Detailed demographic and clinical data (age, sex, body mass index, duration of HIV infection) were collected, including ART regimen, duration of therapy, concomitant medications, adherence history, and any prior opportunistic infections (OIs). Peripheral neuropathic symptoms were assessed using a questionnaire and thorough neurological assessment was done for sensory testing – vibration sensation (128 Hz at great toe and ankle joint), temperature sensation (hot and cold testing), pain sensation (pinprick), and deep tendon reflexes (ankle, knee, wrist, and elbow joints).

Electrophysiological testing was performed in the form of nerve conduction studies (NCS) which measures the electrical conduction of peripheral nerves in upper limb (median and ulnar nerves) and lower limb (Common peroneal, tibial, and sural nerves) by measuring the parameters – Motor nerve conduction velocity (NCV), Sensory NCV, Compound motor action potential (CMAP), sensory nerve action potential (SNAP), distal latency, and F-wave latency. This helps differentiate axonal degeneration from demyelination, providing an objective confirmation of the peripheral neuropathy and classifying its severity. The gathered data was used to calculate the Total Neuropathy Score (TNS), to quantify peripheral neuropathy severity on a scale of 0 to 44.

The Total Neuropathy Score (TNS) is a composite clinical and electrophysiological scoring system used to assess the severity of peripheral neuropathy (PN) in patients. It combines symptom evaluation, clinical examination, and nerve conduction study (NCS) findings to provide a standardised measure of peripheral neuropathy severity.

Components of TNS:

1. Symptom Score (presence and severity of pain, numbness, tingling)
2. Pinprick Sensation (assessed using standard sensory testing)
3. Vibration Perception (tested with a tuning fork at 128 Hz)
4. Strength Testing (manual muscle testing of distal limb muscles)
5. Deep Tendon Reflexes (patellar and Achilles reflexes)
6. Nerve Conduction Studies (NCS) Findings (motor and sensory nerve parameters)

Scoring System:-

Mild Neuropathy:	TNS score <10
Moderate Neuropathy:	TNS score 10-20
Severe Neuropathy:	TNS score >20
Maximum Score:	44

The TNS provides a quantitative and objective assessment of neuropathy, enabling standardised comparisons and aiding clinical decision-making.

The data was coded and recorded in an MS Excel spreadsheet program, and Windows SPSS v23 was used for data analysis. The prevalence was calculated as the proportion of HIV patients diagnosed with peripheral neuropathy. Associations between clinical parameters and peripheral neuropathy were analysed using chi-square tests and logistic regression. The Mantel-Haenszel method was used to measure the strength of the association between HIV-PN and covariates, and a final model was made using logistic regression. Crude and adjusted Odds Ratios (OR), together with their 95% Confidence Intervals (95% CI), were reported. A p-value <0.05 was considered statistically significant.

The study was approved by the Institutional Ethics Committee, and informed consent was obtained from all participants.

RESULTS

Among the 158 patients, 101 (63.9%) were male and 57 (36.1%) female, with a mean age of 39.2 ± 7.4 years. Of the total study participants (n=158), 79.7% (n=126) had symptomatic peripheral neuropathy and 20.3% (n=32) were asymptomatic.

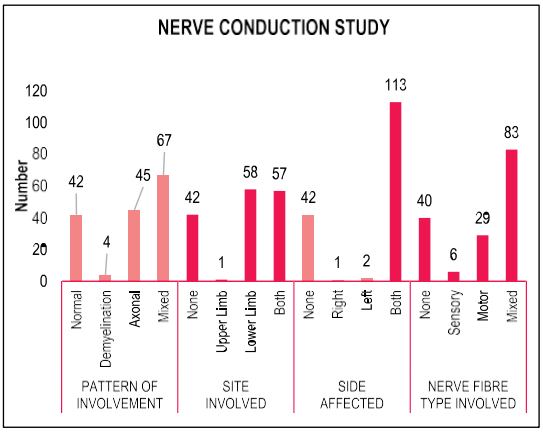

Figure 1. Summary of the NCS results in all study participants (n=158)

Among the symptomatic participants, 99.2% (n=125) had bilateral, symmetrical involvement, while one participant had unilateral (right side) symptoms. **(Figure 1)**

Among those with peripheral neuropathy, both feet were involved in 98.3%, both legs in 97.5%, both hands and fingers in 80.8%, and both the forearms and arms in 1.6% of the participants. This finding is consistent with the "stocking and glove" pattern of peripheral neuropathy involvement in 98.4% (n=124), while 1.6% (n=2) had localised neuropathy. **(Figure 1)**

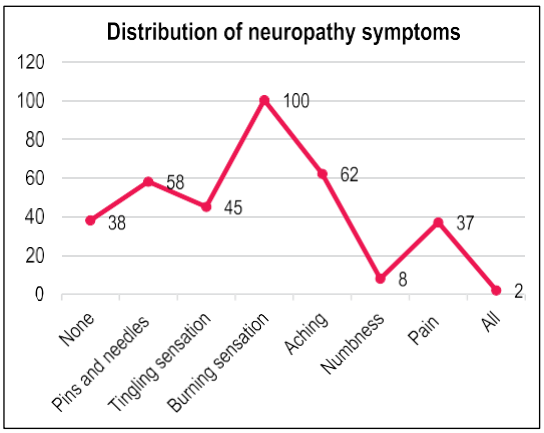

Figure 2. Distribution of peripheral neuropathy (PN) symptoms among the study participants.

Among the study participants (n=158), burning sensation was present in 63.3% (n=100) tingling sensation in 28.5% (n=45), pins and needles sensation was noted in 36.7% (n=58), aching sensation in 39.2% (n=62), numbness in 5.1% (n=8), and pain sensation in 23.4% (n=37). The rest 24% (n=32) were asymptomatic. (Figure 2)

Figure 3 summarizes the neurological examination findings among all 158 study participants. The most commonly observed abnormalities included impaired vibration sense (56 participants), impaired pinprick sensation [56], absent or areflexia [68], and mild distal muscle weakness [83]. Ankle reflexes were absent or diminished in a significant proportion [87], and gait abnormalities (mild to moderate) were noted in 65 participants. These findings reflect a predominantly sensory and areflexic pattern consistent with HIV-associated distal symmetrical polyneuropathy.

Out of 158 HIV-positive patients, 126 (79.7%) were diagnosed with peripheral neuropathy. Of these:

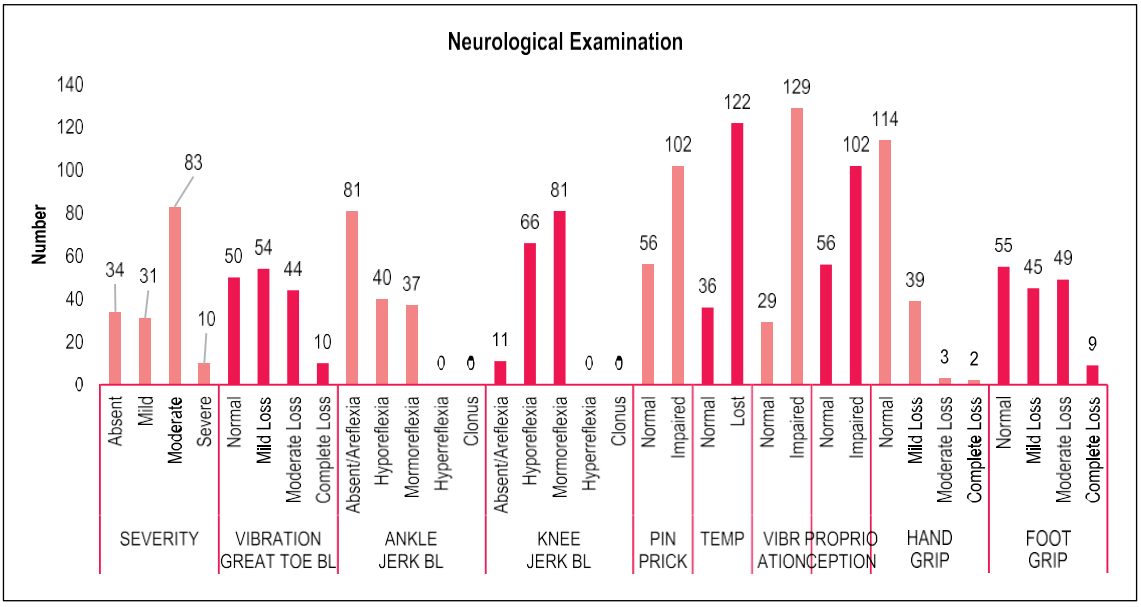

Figure 3. Summary of neurological examination in all study participants (n=158)

- Mild peripheral neuropathy: 32 patients (25.3%)
- Moderate peripheral neuropathy: 67 patients (53.2%)
- Severe peripheral neuropathy: 27 patients (21.4%)

All patients were on combination antiretroviral therapy (cART), with the most common regimens being TDF/3TC/EFV (n=101, 63.9%), AZT/3TC/NVP (n=45, 28.4%), and PI-based regimens (n=12, 7.6%). None of the patients were on stavudine-containing regimens.

Concomitant medications included cotrimoxazole (n=133, 84.1%), isoniazid (n=19, 12%)–all of whom received pyridoxine 10 mg/day–and metronidazole (n=9, 5.7%). No patients were on chemotherapy or other known neurotoxic drugs.

Adherence to ART was good in 138 (87.3%) patients, fair in 15 (9.5%), and poor in 5 (3.2%). Common co-existing opportunistic infections included tuberculosis (n=18, 11.4%), oral candidiasis (n=10, 6.3%), and one case each of cryptococcal meningitis and herpes zoster.

Electrophysiological Findings (NCS Subgroup Analysis, n=115) **(Figure 1)**

- Axonal degeneration: 67 patients (58.3%)
- Demyelination: 28 patients (24.3%)
- Mixed pattern: 20 patients (17.4%)

The factors associated with severe peripheral neuropathy included those with longer HIV duration: OR 2.1 (95% CI: 1.4-3.2, p<0.001), patients with previous exposure to stavudine: OR 3.5 (95% CI: 2.0-6.1, p=0.001) and patients with a lower CD4 count (<350 cells/mm³): OR 1.9 (95% CI: 1.1-3.4, p=0.02)

The present study revealed that patients with a longer duration of HIV (mean: 7.3 years) had a significantly higher prevalence of peripheral neuropathy (p<0.001). It was also evident that those individuals with past exposure to stavudine (d4T) and zidovudine (AZT), were strongly associated with peripheral neuropathy (p=0.001).

There was no strong correlation between current CD4 count and peripheral neuropathy severity (p=0.48) in the present study. However, patients with a lower baseline CD4 count (<350 cells/mm³) had a significantly higher risk of peripheral neuropathy. Also, the body mass index (BMI) and other metabolic factors (e.g.,diabetes, dyslipidemia) did not show a strong correlation in this study.

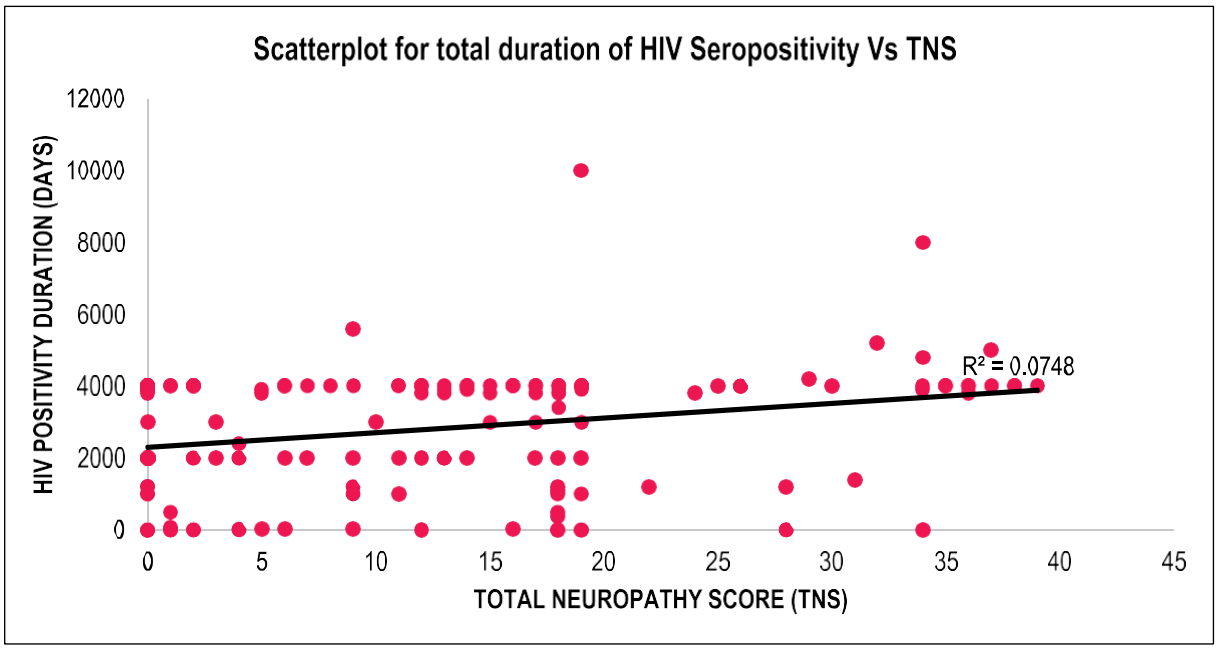

Figure 4. Scatterplot diagram for total duration of HIV Seropositivity vs TNS in the present study (r^2 = 0.07482)

The scatter plot depicts the relationship between the total neuropathy score (TNS) and the duration of HIV seropositivity (in days). The analysis revealed no significant correlation between the duration of HIV infection and the severity of peripheral neuropathy, as indicated by the low Pearson correlation coefficient (r = 0.07482). This suggests that the length of time since HIV diagnosis may not independently predict neuropathy severity in this cohort. **(Figure 4)**

Figure 5 illustrates the mean Total Neuropathy Score (TNS) across various clinical and treatment-related subgroups. Participants with peripheral neuropathy symptoms had a significantly higher mean TNS score (16.49) compared to those without symptoms (3.5). Among WHO AIDS stages, the highest mean TNS was observed in Stage 3/Staged disease (19.06/44), followed by Stage 2 (15.41/44), indicating a progressive rise in neuropathy severity with advancing immunosuppression. Patients on zidovudine-based regimens (TLE/ZLN/LE/ALE) exhibited a higher mean TNS (17.5/44) than those on TLD (13.96/44), suggesting a possible association between specific ART drugs and neuropathy severity.

DISCUSSION

This study aimed to characterise the burden of peripheral neuropathy (PN) and identify risk factors among HIV-positive patients.

The prevalence of HIV-associated PN in our cohort was 79.7%, which is consistent with reports from other low- and middle-income countries. For instance, a study from Nigeria by Adeleke et al. [15] (2022) reported a PN prevalence of 27.1%, with higher rates observed among patients on zidovudine-based regimens. Similarly, Mellors et al. [16] (2021) in South Africa noted a 32% prevalence among patients on first-line ART, linking higher risk with older age and low CD4 counts.

Mehta et al. [17] (2023) from North India reported a lower prevalence (15%), possibly due to earlier initiation of ART and absence of zidovudine use. Another study by Dube et al. [18] (2020) in Malawi found that patients with poor adherence and longer duration of HIV infection had a significantly higher risk of developing PN.

Our findings support these observations, with neuropathy more commonly seen in patients on zidovudine and those with poor adherence or co-existing TB. None of our patients were on stavudine, which has been strongly implicated in mitochondrial toxicity and is no longer recommended under NACO guidelines.

We acknowledge that isoniazid, though supplemented with pyridoxine, may still contribute to PN, especially in malnourished individuals. Cotrimoxazole and metronidazole, used by a subset of patients, are also known to occasionally contribute to neurotoxicity.

The robust association between advanced age (>40 years) and peripheral neuropathy (AOR 1.82) fulfils the objective of identifying risk factors, reinforcing age as a critical predictor. Conversely, the lack of significant links between peripheral neuropathy and gender (p=0.43) or education (p=0.328) aligns with the study's exploration of sociodemographic variables, though conflicting literature (e.g., Sindie et al. (9) on gender) underscores the complexity of these relationships.

This study introduces two novel contributions to the literature on HIV-associated peripheral neuropathy:

1. Age as a Modifiable Risk Factor: While aging is widely recognised in peripheral neuropathy pathophysiology, this study reframes advanced age (>40 years) as a modifiable risk factor in the context of modern antiretroviral therapy (ART). With HIV populations aging globally due to ART success, proactive management of age-related comorbidities like peripheral neuropathy becomes actionable rather than inevitable.

2. Context-Specific Sociodemographic Nuances: The lack of association between peripheral neuropathy and gender/education in this cohort contrasts sharply with studies from regions with pronounced socioeconomic disparities (e.g., Vecchio et al. [11], Sindie et al. [9]). This highlights that peripheral neuropathy risk mediators–such as occupational hazards, nutrition, or healthcare access–may operate differently across settings, challenging the universality of sociodemographic risk models.

These findings carry significant implications for clinical and public health practice:

1. Aging HIV Populations: As individuals with HIV live longer, the high prevalence of peripheral neuropathy (79.7%) signals an urgent need to integrate neuropathy screening into routine HIV care to prevent disability and preserve quality of life.

2. Resource Allocation: The strong age- peripheral neuropathy association suggests prioritising older patients in screening programs, optimising limited resources in high-burden regions.

3. Revisiting "One-Size-Fits-All" Assumptions: The divergent sociodemographic findings underscore that peripheral neuropathy risk factors are context-dependent. Policies must adapt to local realities rather than relying on generalised global guidelines.

The high peripheral neuropathy prevalence compared to global estimates may reflect regional differences in ART regimens (e.g., stavudine use), genetic susceptibility, or diagnostic practices. While the age-peripheral neuropathy association is consistent worldwide, conflicting sociodemographic findings highlight gaps in understanding how cultural, occupational, or economic contexts modulate risk. For instance, gender disparities in manual labour or nutrition access in certain regions might indirectly heighten peripheral neuropathy risk, masking associations in more equitable settings. Hence, it is advisable to revise the national HIV guidelines in high-prevalence regions to mandate peripheral neuropathy monitoring, aligning with WHO's focus on HIV-related comorbidities

In resource-limited settings, nutritional deficiencies, particularly vitamin B12 and folate deficiency, may exacerbate nerve damage, compounding the effects of HIV and ART-induced neurotoxicity. Additionally, the higher prevalence of tuberculosis (TB) and anti-tubercular therapy (ATT) exposure in this cohort could contribute to neuropathy, as drugs like isoniazid are known neurotoxins. Chronic immune activation and systemic inflammation due to untreated opportunistic infections or late HIV diagnosis may also accelerate neuronal degeneration. Furthermore, socioeconomic factors such as poor healthcare access, delayed ART initiation, and reliance on older neurotoxic ART regimens (e.g., stavudine) may explain the higher neuropathy burden compared to global estimates. These contextual nuances suggest that peripheral neuropathy in HIV patients is not solely a consequence of ART but a multifactorial condition influenced by broader health and economic disparities.

CONCLUSION

This study confirms a high prevalence (79.7%) of peripheral neuropathy in HIV-positive individuals, with tingling, burning pain, and numbness being the most common symptoms. Longer HIV duration, lower baseline CD4 count, and exposure to neurotoxic ART regimens (stavudine, zidovudine) were significant risk factors. Given the chronic and debilitating nature of HIV-PN, routine screening, early ART modifications, and better pain management strategies should be prioritised in HIV care programs.

While this study establishes a strong association between HIV-associated peripheral neuropathy (HIV-PN) and aging, future research should explore the longitudinal progression of peripheral neuropathy in HIV-positive individuals, particularly in the era of newer antiretroviral therapy (ART) regimens. Prospective studies could clarify whether early ART modifications or adjunct neuroprotective therapies slow peripheral neuropathy progression. Additionally, further investigations into genetic predisposition, metabolic risk factors (e.g., diabetes, vitamin deficiencies), and inflammatory biomarkers could refine predictive models for peripheral neuropathy. Cost-effectiveness analyses of routine peripheral neuropathy screening programs in resource-limited settings would also be valuable to inform scalable public health interventions.

Strengths and Limitations

Strengths include a gender-balanced cohort (68.4% male vs. 31.6% female), enhancing representativeness for similar HIV care settings, and rigorous adjustment for age-related confounders. However, the cross-sectional design precludes causal inference, and unmeasured variables (e.g., ART drug toxicity, diabetes, or vitamin deficiencies) may bias peripheral neuropathy risk estimates. Additionally, the homogeneous education levels in our sample might obscure socioeconomic gradients observed in other studies (e.g., Vecchio et al. [11]).

Key Recommendations:

1. Regular screening for peripheral neuropathy in all HIV-positive patients, especially those with longer disease duration.
2. Early switch from stavudine/zidovudine to safer ART options (tenofovir-based regimens).
3. Use of nerve conduction studies (NCS) for diagnosis in high-risk patients.
4. Further research on neuroprotective strategies to prevent or delay peripheral neuropathy progression.

CONFLICT OF INTEREST

None

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