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Original Research Article

Treatment-seeking behavior among people affected by neglected tropical diseases in Koshi Province, Nepal

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ABSTRACT

Background: Understanding the treatment-seeking behavior of individuals affected by Neglected Tropical Diseases (NTDs) is crucial for improving access to care and controlling disease spread. Identifying care-seeking barriers and facilitators enables targeted health interventions and policies for NTD-affected populations. The aim is to assess treatment-seeking behavior and associated factors among patients affected by NTD.
Methods: Community-based cross-sectional study was conducted among 102 participants (leprosy 70, Lymphatic Filariasis 32) in Koshi Province of Nepal. A standardized, pre-tested questionnaire assessed treatment-seeking behaviour, and socio-demographic and disease related characteristics. Factors associated with treatment seeking bahviour were estimated using logistic regression.
Results: Around two-thirds (65.7%) of the patients affected by NTDs sought treatment in the past 12 months. Around 12% of the patients who received treatment from health workers still needed to complete the prescribed medication regimen. Religion, financial support, and types of NTDs are significantly associated with treatment-seeking behavior.
Conclusions: NTDs affected persons from younger age groups with informal education should be targeted to improve their treatment-seeking behaviour. Expanding health insurance schemes to include NTD may reduce the out-of-pocket expenditure on receiving treatment from the health post.

Keywords: Leprosy, Lymphatic Filariasis, Nepal, NTD, Treatment-seeking behavior

INTRODUCTION

Neglected Tropical Diseases (NTDs) are a diverse group of diseases frequently affecting impoverished populations in tropical and subtropical regions, impacting over 1 billion people, according to WHO.[1] These diseases lead to significant morbidity, mortality, discrimination, and stigma in societies, particularly in Africa, Asia, and South America. Despite being curable, NTDs disproportionately burden low-income populations, particularly women, and remain a persistent public health challenge.[2] The burden of NTDs is concentrated in 16 countries, which account for 80% of the global cases. Progress toward addressing NTDs has been slower than expected in high-burden countries, with uneven advancements across the 20 diseases and their subgroups. Persistent challenges such as poverty, climate change, and rapid population growth further threaten the achievement of the 2030 targets.[3]

Over the past decade, significant progress has been made in combating NTDs. The number of people requiring interventions has decreased by 25%, with 80 million

fewer people in need between 2020 and 2021 alone. Disability-adjusted life years (DALYs) attributed to NTDs have also declined. Between 2016 and 2019, over one billion people were treated annually against NTDs, and by December 2022, 47 countries had eliminated at least one NTD.[1] Despite this advancement, conservative estimates indicate that NTDs still account for approximately 14.5 million DALYs, with the burden remaining disproportionately high in developing and tropical regions.[3]

More than a quarter of Nepalese people live below the poverty line, with limited access to timely healthcare services, making them highly vulnerable to various forms of NTDs.[2] Despite having an NTD and vector-borne disease control section in the Epidemiology and Disease Control Division (EDCD), the real burdenss of most NTDs in Nepal remain unknown. Estimating the burden of endemic NTDs and allocating appropriate resources are crucial for effective prevention, control, diagnosis, and treatment and, eventually, elimination from the country. In this context, there is a need for an evidence-informed scale-up of NTD control programs.[4] Addressing NTDs requires urgent inter-sectoral collaboration, as recommended by WHO's integrated approach, which includes five interventions on the path to universal coverage: innovative and intensified disease management; preventive chemotherapy; studies on vector ecology and management; veterinary public health services; and the provision of safe water, sanitation and hygiene. Strengthened efforts are essential to overcome the hidden burden of NTDs and accelerate their elimination in Nepal.[4]

Lymphatic filariasis (LF) and Leprosy are NTDs that present significant public health challenges, particularly among impoverished populations. LF, caused by filarial parasites, is transmitted to humans through *Wuchereria bancrofti*. As of 2020, it affected 863 million people in 50 countries and required preventive chemotherapy to stop the spread of infection. Globally, 25 million men suffer from hydrocele, 15 million individuals experience lymphoedema, and 36 million endure chronic conditions caused by LF.[5] Nepal was one of the endemic countries for LF, and the government has implemented an elimination program aligned with WHO's strategies, aiming to eliminate LF by 2020.[6] Leprosy, caused by *M. leprae*, remains prevalent in more than 120 countries, with approximately 200,000 new cases of leprosy reported annually.[7] In FY 2020/21, 2,173 new cases were detected ins Nepal, with Madhesh Province accounting for 743 cases, 34% of the total. By the end of FY 2020/21, the country had a registered prevalence rate of 0.73 cases per 10,000 populations, with 2,197 patients receiving multi-drug therapy.[8]

Nepal, a predominately mountainous country, is now endemic to several tropical diseases. However, a clear identification of NTDs specific to Nepal has not been available.[4] Early case detection and validation, complete treatment, and disability prevention are major hindrances in eliminating NTDs in Nepal. Limited programs to eliminate NTDs, POID clinics, health education, and social stigma among health workers and patients further hinder progress. Many individuals refrain from seeking support through self-help groups, excluding the burden of these diseases.[9]

Therefore, the study aims to assess treatment-seeking behavior among NTD-affected patients (e.g., Leprosy and Lymphatic Filariasis) and its associated factors. The results of this study provide valuable information that may benefit the design of programs and interventions to improve NTDs and serve as a valuable reference for future studies.

METHODS

A community-based cross-sectional study design was conducted in the Koshi Province of Nepal, focusing on Jhapa, Morang and Sunsari districts. The study targeted individuals affected by NTD, mainly Leprosy and Lymphatic Filariasis, from these districts.

Study period

The study was conducted between October 2021 and January 2022.

Inclusion criteria

Household Survey- Mothers of children under one-year age, person affected with NTDs particularly leprosy, LF, and Kalazar, person with physical disabilities, household head or adult members for general socio demographic and WASH information were included.

Health Facility Survey- Public health posts and PHCCs within selected municipalities were selected.

Qualitative study: Health mother's group members, Self-help group, marginalized group and local-level key stakeholders i.e. municipality/ward officials, health coordinators, FCHVs, traditional healers and government health authorities included.

Exclusion criteria

Households where eligible participants (mothers, persons with NTDs/disabilities) were unavailable or unreachable during study period, private health facilities of the selected municipalities, and iindividuals unable to provide informed consent were excluded.

Sampling techniques and sample size

Out of 25 NTD high-burden rural/municipalities, 12 were randomly selected for the survey. 30% of wards were randomly selected through probability proportion to size and the number of wards in selected districts. All the

individuals affected by NTDs (Leprosy and Lymphatic Filariasis) in the selected sample wards were approached through line listing, and cases were explored through household visits. A total of 102 NTDs affected persons were surveyed.

Data collection method

Data were collected through personal or face-to-face interviews using the KoBo mobile app. The questionnaire was prepared in English and translated into Nepali. It covered the socio-demographic characteristics of households and treatment-seeking patterns of NTD patients, including when and where they sought treatment, whether they had sought treatment in the last 12 months, the reasons behind not completing the treatment, and how they managed the cost. Field researchers underwent four days of training before collecting data on Android smartphones during the interviews.

Measurement of variables

Treatment sought in the last 12 months from any healthcare facility. Various socio-demographic and disease-related variables were assessed to identify the factors associated with treatment-seeking behavior. Socio-demographic variables included age, education, family type, religion, marital status, occupation, and annual household income (NPR). Other factors considered were comorbidity conditions and financial support received.

Data analysis

The e-data collected through the KoBo platform was downloaded, cleaned, and imported to Stata for analysis. Findings were analyzed using descriptive measures (mean, proportion) to describe the complication readiness distribution and predictor variables distribution. Treatment-seeking patterns for NTDs were assessed through multivariate binary logistic regression, employing a manual backward selection method for model refinement. Variables were considered significant with a p-value less than 0.05, and collinearity among the independent variables was assessed using Pearson's correlation coefficient ($r>0.50$). Field researchers explained the study objectives to participants, who provided informed consent, ensuring confidentiality and anonymity of the information collected. The e-data was securely stored on a password-protected computer/hard drive, and all safety measures recommended by the Government of Nepal and WHO, including physical distancing, hand hygiene, and mask-wearing, were strictly followed during the study.

Ethical approval

Ethical approval was obtained from the Nepal Health Research Council (NHRC) (reference No.557/2021). Informed and verbal consent was obtained from the respondents prior the data collection ensuring confidentiality and anonymity. The study respected cultural and social sensitivities and created safe spaces for vulnerable groups, including persons with disabilities, those affected by NTDs, and women. All COVID-19 safety protocols recommended by the Government of Nepal and WHO were strictly followed.

RESULTS

Socio-demographic characteristics of respondents

Table 1 represents the socio-demographic characteristics of respondents. The average age of respondents was 47.47 years (SD=14.97), with the highest proportion of sample respondents being 36-45 years (27.5%). More than half (61.8%) were male, with the proportion of males further higher (70.0%) among leprosy cases. Regarding education, 42.2% were illiterate, and another 42.2% could not read and write, while 23.5% had secondary or above. Main occupations included daily wage labor, household duties, and agriculture. Most respondents (80.4%) were married, and 36.3% reported an annual household income between 100K and 300K. A significant proportion lived in a single-family unit (63.7%), with Janajati representation and a higher incidence of leprosy and lymphatic filariasis among them. Among those with leprosy, 67.1% were from single family type, and 56.3% of those with LF exhibited the same familial structure. Similarly, over half (51%) had comorbidity, and a substantial majority (87.3%) did not receive any financial support on NTDs.

Treatment seeking behavior

Table 2 shows the treatment-seeking behavior of the respondents. Among 102 respondents, only 18.6% sought treatment when suspected of a disease, while 46.1% sought treatment after symptom onset. More than one-fourth (26.5%) sought treatment only when there was a complication because of the disease.

During the last 12 months, 65.7% sought treatment (higher among leprosy cases compared to LF), mostly from local health facilities (90.3%), followed by hospitals (55%), and traditional healers (8.1%). Nearly 60% were currently taking medicine (higher in case of Leprosy), followed by 12% (higher in case of LF), stopped taking their prescribed course before completion, primarily due to the high cost of treatment (87.5%) or believing that they have recovered (37.5%). While 53.7% felt the treatment was helpful (higher in the case of Leprosy than LF), 21% believed that the treatment was ineffective (higher in the case of LF than Leprosy). Most (62.7%) of them paid out of pocket, while 34.3% took loans and 23.9% used health insurance (higher in case of Leprosy than LF).

Table 1: Socio-demographic characteristics.

Characteristics	Leprosy (n=70)	LF (n=32)	Total (n=102)	
	%	%	N	%
Age (47.47±14.97)				
18-25	8.6	3.1	7.0	6.9
26-35	22.9	6.3	18.0	17.7
36-45	21.4	40.6	28.0	27.5
46-55	10.0	18.8	13.0	12.8
56-65	20.0	25.0	22.0	21.6
65+	17.1	6.3	14.0	13.7
Sex				
Male	70.0	43.7	63.0	61.8
Female	30.0	56.3	39.0	38.2
Education				
Cannot read and write	38.6	50.0	43.0	42.2
Literate but not enrolled in school	17.1	28.1	21.0	20.6
Primary	12.9	15.6	14.0	13.7
Secondary and above	31.4	6.3	24.0	23.5
Occupation				
Household duties/housewife	18.6	28.1	22.0	21.6
Daily wages/labors	28.6	31.3	30.0	29.4
Agriculture	20.0	15.6	19.0	18.6
Business self employ	14.3	21.9	17.0	16.7
Others (student, self-employed)	18.6	3.1	14.0	13.7
Marital status				
Unmarried	22.9	12.5	20.0	19.6
Married	77.1	87.5	82.0	80.4
Annual household income, NPR (143±161 K)				
Up to 100kK	60.0	56.3	60.0	58.8
100K+-300K	37.1	34.4	37.0	36.3
> 300K	2.9	9.4	5.0	4.9
Religion				
Hindu	92.9	81.3	91.0	89.2
Others	2.9	15.6	11.0	10.8
Caste				
Dalit	15.7	12.5	15.0	14.7
Janajati	38.6	31.3	37.0	36.3
Madheshi	25.7	34.3	29.0	28.4
Muslim	2.9	15.6	7.0	6.9
Brahmin/Chhetri	17.1	6.3	14.0	13.7
Family type				
Single	67.1	56.3	65.0	63.7
Joint and extended	32.9	43.7	37.0	36.3
Comorbidity				
Yes	44.3	65.6	52.0	51.0
No	55.7	34.4	50.0	49.0
Financial support received				
Yes	14.3	9.4	12.0	12.7
No	85.7	90.6	90.0	87.3

Table 2: Treatment-seeking behavior.

Characteristics	Leprosy	LF	Total	
	%	%	N	%
Treatment sought at first	**n=70**	**n=32**	**n=102**	
As soon as disease suspected	18.5	18.7	19	18.6
After developing symptoms	48.6	40.6	47	46.1
After complication	25.7	28.1	27	26.5
After disability and handicapped	2.9	6.3	4	3.9
Others	4.3	6.3	5	4.9
Sought treatment in last 12 months				
Yes	74.3	46.9	67	65.7
No	25.7	53.1	35	34.3
Place for treatment, (multiple response)	**n=52**	**n=15**	**n=67**	**%**
PHC/Health post/CHU	91.5	86.7	61	90.3
Hospital	55.3	53.3	37	54.8
Pharmacy	8.5	13.3	7	9.7
Traditional healers	8.5	6.7	5	8.1
Treatment course as prescribed by health worker				
Completed the prescribed dose of medicine	23.0	46.7	19	28.3
Currently taking medicine	63.5	46.7	40	59.7
Did not complete the prescribed dose of medicine	13.5	6.6	8	12
Treatment helped to improve health condition				
Yes, helped a lot	61.5	26.7	36	53.7
Yes, helped little bit	17.3	40.0	15	22.4
Did not helped at all	17.3	33.3	14	20.9
Others	3.9	0	2	3
Managed cost for treatment (multiple response)				
Own money	59.6	73.3	42	62.7
Health insurance	26.9	13.3	16	23.9
Others family members provided money	7.7	13.3	6	9
Took loan for treatment	38.5	20	23	34.3
Others	19.2	20	13	19.4

Factors affecting the treatment-seeking behavior

Multivariate analysis revealed that religion, financial support received by the patient, and types of NTDs were significantly associated with treatment-seeking behavior among affected individuals (Table 3).

Participants with income above 300K were more likely to seek treatment than those earning 100K-300K (OR=0.83,

p=0.871). Those who had completed primary education were more likely to seek treatment compared to those who cannot read and write (OR=2.85, p=0.20). For religion, non-Hindu were 9.42 times more likely to seek treatment than Hindus (p=0.05). Likewise, individuals who received financial support had a markedly higher likelihood of seeking treatment (OR=12.41, p=0.002). Lastly, those with leprosy were 5.47 times more likely to seek treatment than those with lymphatic filariasis (p=0.003).

Table 3: Factors affecting the treatment-seeking behavior among people affected by NTDs.

Variables	Odds Ratio	P value	95% CI LB	95% CI UB	Sig
Income					
Up to 100K	Ref				
100K-300K	0.70	0.506	0.25	1.97	
Above 300K	0.83	0.871	0.09	7.14	
Education					
Cannot read and write	Ref	.	.	.	
Informal education	0.70	0.57	0.20	2.38	
Primary school education	2.85	0.20	0.57	14.17	
Secondary or above	1.25	0.75	0.31	4.94	
Religion					
Hindu	Ref	.	.	.	
Others	9.42	0.05	0.96	92.01	**
Financial support received					
No	Ref				
Yes	12.41	0.002	2.59	59.34	***
Types of NTD					
Lymphatic filariasis	1	.	.	.	
Leprosy	5.47	0.003	1.79	16.70	***

*,***: significance of p value

DISCUSSION

The study aimed to assess the treatment-seeking pattern of NTD patients (i.e., leprosy and lymphatic filariasis) and factors associated with the treatment sought by NTD patients in the past 12 months. Among the respondents, 65.7% reported seeking treatment, 90.3% utilizing PHC/Health post/CHU, and 8.1% sought treatment from traditional healers. A study conducted in Ethiopia found that only 48% of respondents with leprosy sought treatment within a year, comparable to our study, where nearly half (46.9%) sought treatment in the last 12 months.[10] However, the study conducted in Yei County on different NTDs (HAT) in South Sudan stated that most respondents (97.2%) sought treatment at health facilities when they became ill with the disease.[11]

In this study, 6.7% of the LF patients sought treatment from traditional healers, while 86.7% visited health posts. In contrast, a Nigerian study stated that nearly two-thirds (60%) relied on traditional healers.[12] This highlights a greater tendency among LF patients in our study to seek care from health posts, reflecting an improved treatment-seeking behavior compared to the findings from Nigeria.

This current study identified key factors significantly influencing treatment-seeing behavior among NTD patients, including religion, financial support received, and types of NTDs. A related study conducted in northern India among 120 respondents highlighted that education was a significant factor affecting health-seeking behaviour among patients with *post Kala-azar dermal leishmaniasis.*[13] These findings align with our study, where education is also one of the significant factors in the treatment-seeking behavior of NTDs. Furthermore, the limited availability of studies analyzing the treatment-seeking behavior of individuals with NTDs underscores a significant research gap.

A study conducted in Myanmar found that household heads who view NTD, i.e., dengue fever, as fatal are more likely to seek care at public hospitals.[14] Similarly, the study conducted in Nigeria revealed that educated snakebite victims exhibit better health-seeking behavior, highlighting the need to target less educated individuals in health education programs.[15] Additionally, expanding health insurance schemes to cover a larger portion of the population is essential. Our study also showed that treatment-seeking behavior for NTDs is higher among those with formal education. These findings support the recommendation to broaden health insurance coverage, as it currently remains limited for NTD patients.

The study conducted in Nepal on LF showed that knowledge of LF transmission is influenced by various factors such as the sex of the household head, age of the respondents, place of residence, ecological belt, provinces, wealth status, migration within the past ten years, and possession of mosquito net, Radio, and TV.[16] A study conducted in South Sudan highlighted knowledge gaps in disease causes, symptoms, treatment-seeking, attitudes, and practices, emphasizing the need for tailored public health strategies and effective information channels.[11] Despite government efforts, the study conducted in Nepal on LF indicated that many groups still lack adequate knowledge of LF transmission. Based on these study's findings, knowledge-based intervention programs should prioritize vulnerable populations with limited knowledge of LF transmission.[16] Additionally, awareness programs should prioritize economically disadvantaged groups to address disparities in knowledge and promote informed practices.

Furthermore, a study conducted in Nepal on the hidden burden of NTDs reveals that the true impact of these diseases remains largely unknown.[4] To address this, it is imperative to estimate the burden of each endemic NTD

in Nepal urgently. This assessment will inform resource allocation and effective prevention, control, diagnosis, and treatment, ultimately facilitating the feasible and sustainable elimination of these diseases from the country. Consequently, there is a pressing need for evidence-based scaling up of NTD control programs.

This study provides valuable insights into the treatment-seeking behavior of patients affected by NTDs, specifically Leprosy and LF. It highlights the patterns or circumstances under which patients seek treatment, including the treatment location and cost involved. The findings show an increase in treatment-seeking behavior over the last 12 months, with most patients going to nearby health facilities, reflecting growing awareness of the importance of local healthcare access. The study also assesses patient satisfaction with the treatment received, underscoring positive shifts in treatment-seeking behavior and healthcare access.

This study has few limitations. The study only addressed two specific types of NTDs, leprosy and LF, which may not fully capture the treatment-seeking behavior of other NTDs.

CONCLUSION

The study concludes that two-thirds sought treatment in the last 12 months, with the majority visiting health posts for the treatment. However, 12% of those initiating treatment failed to complete their prescribed medicines. The primary reason for not completing the medications was the high cost of treatment, mentioned by more than two-thirds of these individuals. Additionally, only 23.9% managed their treatment cost through health insurance, while over two-thirds relied on out-of-pocket expenditure. Significant factors affecting treatment-seeking behavior included religion, financial support, and the type of NTD, with income and education demonstrating marginal significance. It is crucial to target young individuals with NTDs and those with informal education in health education programs. Additionally, expanding health insurance coverage to include NTDs is essential to reduce the financial burden and improve accessibility to care.

Recommendations

The study provides valuable insight into the treatment-seeking behavior of individuals with NTDs, which can inform policy aimed at increasing the treatment-seeking behavior on NTDs. The study also highlights the current situation regarding NTDs and treatment-seeking behavior, which is crucial for formulating plans and policies for various NTD programs. Focusing on leprosy and LF, the findings will aid government management programs for these diseases. Additionally, the results may guide future interventions to improve NTD management and serve as a reference for upcoming research. Ultimately, this study could enhance the planning and implementation of NTD control programs in Nepal, which were previously viewed as at risk or risk-free.

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