Epidemiological Characteristics and risk factors of leprosy in Terego, Koboko and Nebbi Districts in West Nile Region. A Cross sectional study.

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Abstract:

Background: Leprosy was eliminated in Uganda as public health problem for now over 30 years. However, new leprosy patients are still being reported in Uganda annually especially in West Nile region compared to other parts of the country. The study was to investigate the rise in leprosy cases in West Nile region of Uganda, understand leprosy transmission and inform the development of targeted interventions to reduce the burden of disease.

Methods: This was cross sectional study to analyse data from all leprosy patients reported in the health facilities in Koboko, Terego and Yumbe Districts. Data collection and physical examinations for all the reported leprosy reported from 2020 to 2023 was conducted. Descriptive statistics and Q-GIS v3.22.5 was used to generate maps highlighting areas of potential interest**.**

Results: A total of 525 (207 in Terego, 185 – Koboko and 133 for Nebbi) patients were reported from 2020 to 2023. Overall 66% of the case patients were females across the three districts. (69% in Koboko, 58% in Terego and 62% in Nebbi.) The mean age was 38 years (Mode 40 SD 14) and the proportion of child leprosy patients was 14.5%. Majority (93%) of the leprosy patients were Nationals peasant farmers (82%) with 96% having Multi-bacillary leprosy. The median time for symptom onset prior to diagnosis among the patients was 26 months. Terego district reported the biggest (33%) proportion of leprosy patients having grade 2 disability at the time of diagnosis. The risk factors for leprosy among the patients included poverty and being a contact. Leprosy surveillance in West Nile is mainly (86%) passive. However, targeted surveys as well as Contact surveillance is periodically done.

Conclusion: A total of 525(185- Koboko, 133- Nebbi and 207- Terego) patients were reported from 2020 to 2023. There were more females (58%) leprosy patients reported in all the three districts. The proportion of children below 15years was 14% and 33(5.3%) had grade 2 disabilities at the time of diagnosis. Majority (93%)of the patients were nationals. The sub counties with the highest number of leprosy patients reported were Angal , Lobule and Odupe for Nebbi Koboko and Terego respectively . There was limited leprosy case finding in

the communities and suboptimal integration of leprosy work into the rest of the district and health facility activities with a significant number of health care workers having limited knowledge and skills in diagnosis and Disability grading.

Recommendation:

There is need for sustained contact tracing and administration of leprosy post exposure prophylaxis to those that are eligible. Heightened health education on leprosy, provision of IEC materials and training of health workers as well as continued mentorship is also recommended. Deeper integration of leprosy into other health programs is also recommended e.g. School Health program and integrated management of Childhood Illnesses.

Key words: Leprosy, Epidemiology, investigation, West Nile.

Introduction/Background

Leprosy is an infectious chronic disease and a neglected tropical disease caused by Mycobacterium leprae, and mainly affects the skin, peripheral nerves, upper respiratory mucosa and eyes. The prolonged physical deformities associated with leprosy get progressively worse with delayed diagnosis and increasing age (1). The incubation period is long and variable; it is assumed to be five years on the average but could be up to 20 years before occurrence of symptoms. (2)

Transmission through the respiratory **route** is the main mode. (3) The frequent lack of sensation on the skin, visible hypo pigmented skin, Hypo pigmented anesthetic, and hypo esthetic skin lesion are the main clinical presentations of leprosy (4). Case detection and treatment with MDT alone have proven insufficient to interrupt transmission of Leprosy. To boost the prevention of leprosy, with the consent of the index case, WHO recommends tracing household contacts along with neighborhood and social contacts of each patient, accompanied by the administration of a single dose of rifampicin as preventive chemotherapy (5).

Leprosy remains endemic in some regions and is a global health concern. However, the possible causes and risk factors of the disease remain unclear (6). Leprosy still occurs in more than 120 countries, with more than 200 000 new cases reported every year. Elimination of leprosy as a public health problem globally (defined as prevalence of less than 1 per 10 000 population) was achieved in 2000 (as per World Health Assembly resolution 44.9) and in most countries by 2010(6). Globally, the registered prevalence of leprosy (number of cases on treatment at the end of 2021) was 16.9/1000,000 people, and the prevalence rate was 16.9 per million populations.

The number of registered cases at the end of the year was 20 960 (prevalence rate 18.0) in Africa, 25 053 (24.3), in Americas Region, 4206 (5.5) in Eastern Mediterranean Region,81 222 (39.4) in South-East Asia Region and 2360 (1.2) in Western Pacific Region (7) Diagnosis and classification are two essential points for correct patient management. Correct classification

allows proper treatment and alerts of the risk of leprosy reaction and nerve damage. The World Health Organization (WHO) classification, for therapeutic purposes, divides patients into paucibacillary (PB) and multibacillary (MB) on the basis of the number of skin lesions. PB cases have up to five skin lesions in total, whereas MB cases have six or more skin lesions. (8)

In 2022, a total of 1,812 new child cases (8.2% of total new cases) was reported in African Region, corresponding to a rate of 3.7 per million child population. Furthermore, in African region, 3 319 new cases with G2D were detected (corresponding to a rate of 2.8 per million population), accounting for 15% of all new cases detected during the year as compared to 5.6% in 2020. This increase could be linked to the resumption of activities following the COVID-19 pandemic, as well as a decrease in expertise at the country level (5). Leprosy-induced irreversible disability currently affects about one million people in the Region. The most vulnerable and high-risk populations are living in poor rural areas in the Democratic Republic of the Congo, Ethiopia, Madagascar, Mozambique, Nigeria and Tanzania (9).

Leprosy is endemic in Uganda, with 31% of the districts in the country reporting at least a patient of leprosy in 2023/2024 majority (70%) from West Nile (10). Literature suggests that the Northern region of Uganda has consistently identified more leprosy cases compared to the other regions.

The NTLP has implemented interventions to reduce the burden, such as community skin camps (community outreaches with free leprosy screening), refresher training of health workers, and contact tracing visits, particularly in areas endemic for leprosy. Despite these efforts, new cases are still being reported in Uganda. During 2023/2024 fiscal year 317 new leprosy patients were reported, a new case detection rate of 0.6/100,000. Of the 307 patients, 6% were in children < 15 years old and of those 69% were from the high burden region (Northern), indicating relatively recent spread at the community level (11)

In comparison with the previous financial year (2020/21) the data indicate that Leprosy cases have increased from 257 to 493 cases, even when there has been a decrease in the proportion of child leprosy cases from 13% to 11% in FY 2022/23, this is still much higher than the 6% National Strategic Plan (NSP) target, at the same time the proportion of grade 2 disability is on the rise, the incidence of grade 2 disability (1.72 per 1million population) is over 3 times the expected in the NSP (0.55 per 1 million population)(13).

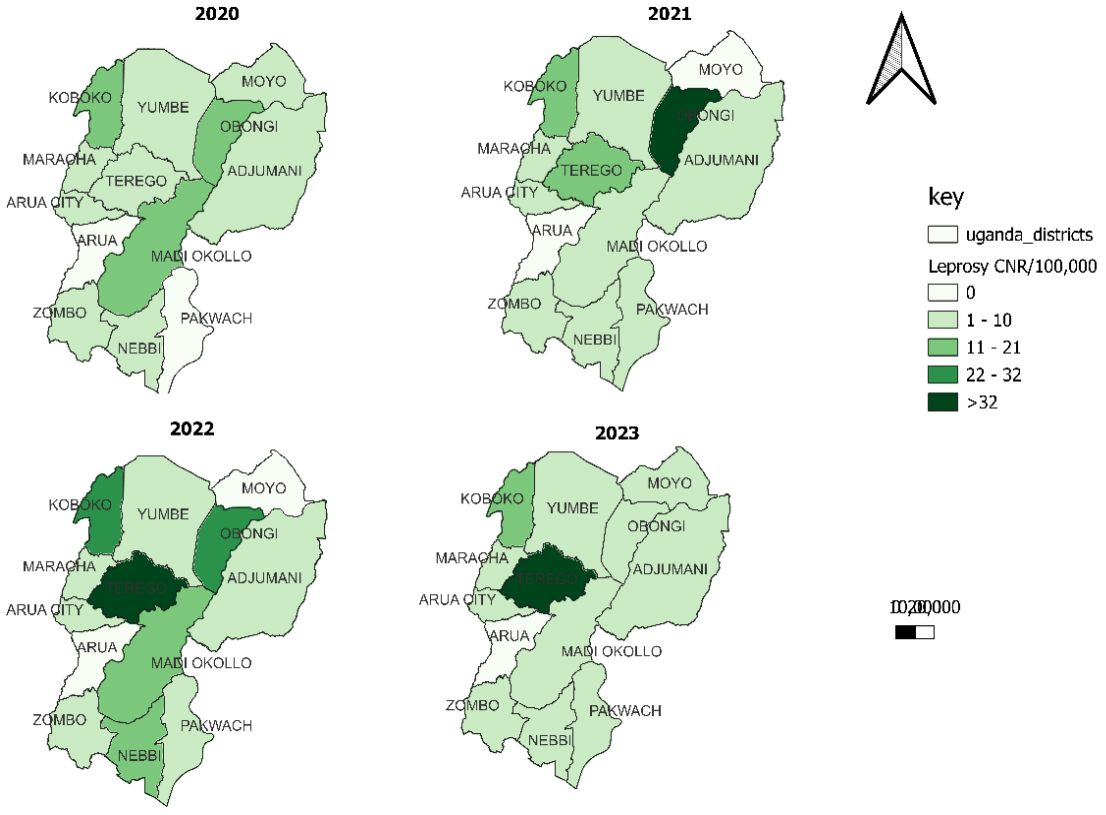
The intensive community-based activities have seen a marked improvement on patient notification. Terego, Koboko and Nebbi districts continue to register the highest case notification rate. The West Nile region still observes an increase in Leprosy cases notified compared to other parts of the country [Figure 1&2]. We therefore aimed to investigate the rise in leprosy cases in West Nile region of Uganda.

Figure 1: Table showing the number of leprosy patients notified over the last 4 Fiscal years

Region	2020/2021	2021/2022	2022/2023	2023/2024	Total Number of patients in 4 years
Acholi	2	13	26	5	46
Kigezi	0	2	0	0	2
Ankole	2	0	1	0	3

South central	0	7	5	6	18
NorthCentral	4	13	8	3	28
Bunyoro	15	6	29	10	60
Bukedi	8	7	7	4	24
Teso	6	10	12	7	35
Bugisu	4	0	6	1	7
Lango	28	20	19	13	80
Busoga	81	5	12	3	101
Tooro	12	26	27	13	78
WestNile	95	384	311	252	1042
	257	493	463	317	1621

Figure 2. Map showing the distribution of leprosy cases in West Nile Region



General Objective

To investigate the rise in leprosy cases in West Nile region of Uganda in order to understand the demographic, clinical and spatial characteristics of the disease and inform evidence based interventions for elimination**.**

Specific objectives.

1. To describe the demographic characteristics of leprosy patients reported in Kobko, Terego and Nebbi Districts between 2020 and 2023.
2. To analyze the clinical characteristics (Type of leprosy, disease severity, treatment outcomes etc. of the leprosy patients
3. To examine the spatial distribution and identify potential hotspots for targeted interventions.
4. To recommend evidence-based control measures.

Secondary objectives:

1. To assess the level of awareness and knowledge about leprosy among health care workers and the general population in Koboko, Terego and Nebbi Districts.
2. To describe the current leprosy surveillance systems in West Nile and identify areas of improvement.
3. To conduct leprosy contact management including administration of Leprosy post exposure prophylaxis to the eligible contacts.

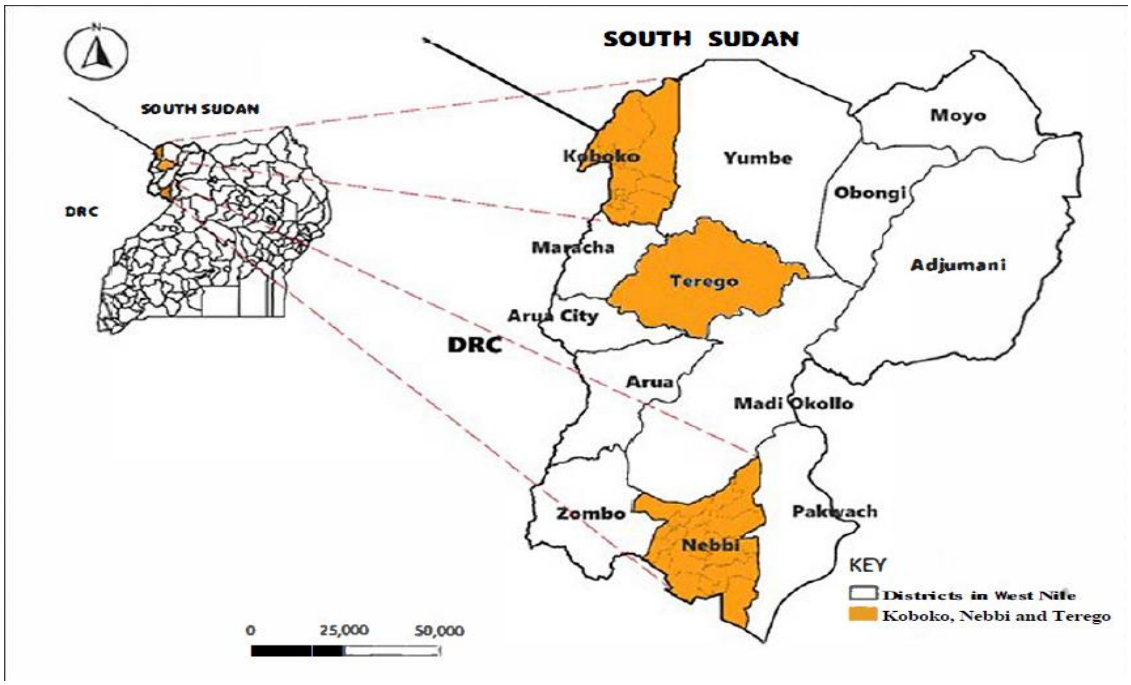
Methodology

Study Design:

This was a cross sectional study among patients with leprosy released from treatment (RFT) from 2020 and those on treatment up to June 2024 and their contacts from both households and neighbors.

Study sites: The total number of leprosy treatment sites were 36 (18 in Terego, 12 in Koboko and 6 in Nebbi Districts). Figure 3 below illustrates the sites where the investigation was carried out.

Figure:3 Inset map of Koboko Terego and Nebbi Districts



Study Population

All participants were registered in the Unit leprosy register as index patients, their Household and neighbor contacts living within a radius of about 100 meters around an index patient. The tracing status and steps of index patients and their contacts was according to the leprosy diagnostic, treatment and prevention guidelines.

Survey procedure

A team from the National Tuberculosis and Leprosy Program (NTLP) as well as epidemiologist from Uganda National Institute of Public Health, the district health team, Health Care Workers and Village Heath Teams (VHTS), performed data collection and physical examinations for all the index leprosy patients and their contacts**.**

Study procedure in details:

Before the investigation, training was conducted for all the team members, explaining the purpose and the procedures on how to complete the using a Case Investigation Form(CIF). Health facility records were reviewed. Home visits were performed for the index patients and physical examination done for both Index and Contacts of the leprosy patients. Additionally, Key Informant Interview (KII) was conducted with selected health workers

A verbally-administered case Investigation form and other tools were used to collect demographic and clinical information. The Contacts of the leprosy patients were screened and those eligible given the Leprosy post exposure prophylaxis. After confirmation of diagnoses, new patients were treated using multidrug therapy, as recommended by the WHO. For contacts without any signs of leprosy disease, only summary data was obtained (e.g. number of contacts screened). Additional activities conducted during the investigation included: Mentorship of health workers on leprosy case finding, contact management (tracing, screening, administration of Leprosy post exposure prophylaxis of those eligible and treatment with Multidrug therapy for those confirmed to have leprosy), data entry and reporting

Data obtained in the investigation was entered into the Electronic case based surveillance System (ECBSS) with the support of the Health Management Information System (HMIS) personnel in the districts.

Results:

The table below shows a summary of the demographics of the leprosy patients that were notified in the three districts of Koboko, Terego and Nebbi from 2020 t0 2023.

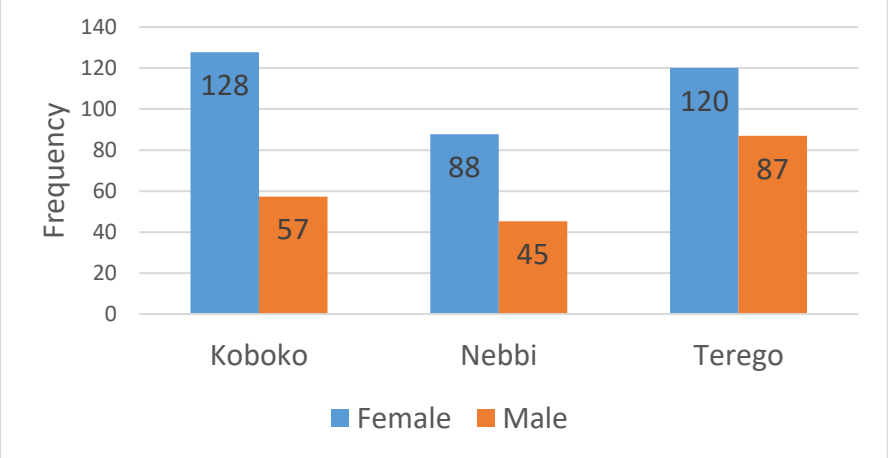
Figure 4: Demographic characteristics of leprosy patients in Koboko, Nebbi and Terego (2020-2023)

Age	0-5 years (0%)	5-15 years(14%)	>15 years(86%)	
Gender	Male : 215(42%)	Female:298(58%)		
HIV status	Positive: 5(0.9%)	Negative: 195(38%)	Unknown:313(61%)	
Occupation	Peasant: 420(82%)	Student: 40(7.7%)	Teachers: 5(0.9%)	Unemployed: :48(9.3%)
Client category	National: 488(93%)	Refugees: 37(7%)		
Level of education	Primary: 372(71%)	None: 105(20%)	Secondary:37(7%)	Tertiary: 11(2%)
Patient Type	New: 520(99%)	Relapse: 5(1%)		
Disease classification	MB:504(96.7%)	PB:21(3.3%)		
Disability grade	Grade 0:410(78%)	Grade 1:79(15.7%)	Grade 2:33(6.3%)	

A total of 525(185- Koboko, 133- Nebbi and 207- Terego) patients were reported from 2020 to 2023. The mean age was 38 and the proportion of children below 15years was 14% and 33(5.3%) had grade 2 disabilities at the time of diagnosis. Most (93%) of the patients had the more severe type of leprosy. Majority (93%)of the patients were nationals. 210(40%) of the patients reported not earning any monthly income whatsoever with majority (64%) coming from Nebbi

Gender distribution by district

Figure 5 Proportion distribution of gender by District for the leprosy patients notified from 2020-2023**.**

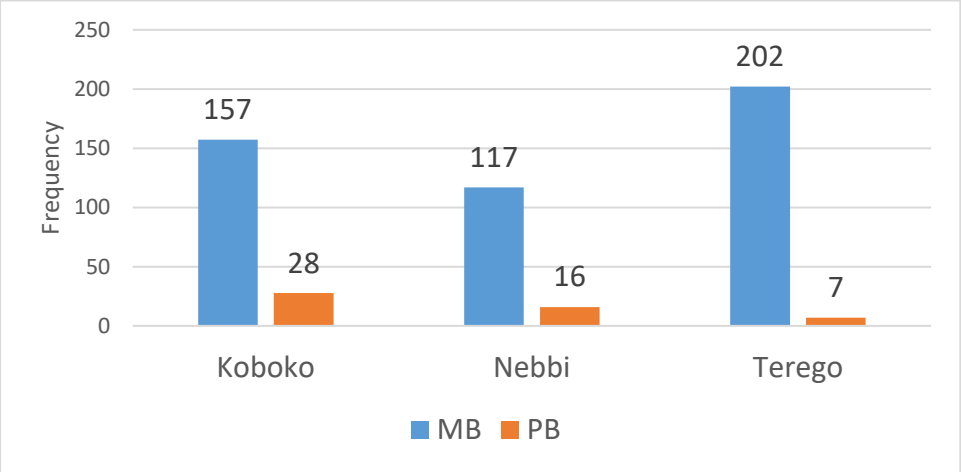


The observation is that there were more female leprosy patients reported in all the three districts.

Disaggregation by Disease classification.

The figure 5 below shows the distribution of leprosy patients by disease classification in the three districts

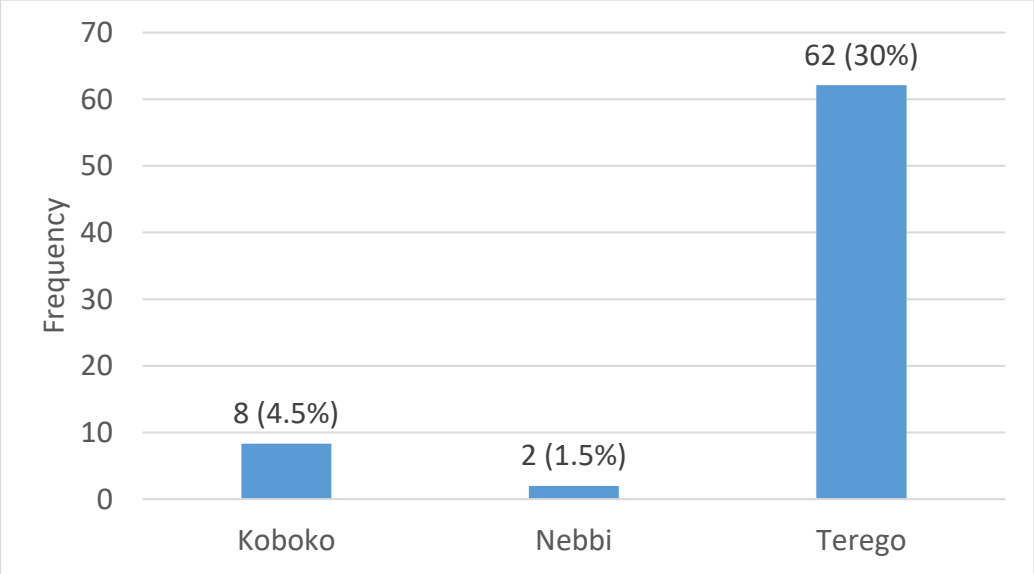
Figure 6: Distribution of leprosy -patients by disease classification.



Overall, 86% of the case patients in the three districts were multi-bacillary type of leprosy.

Grade 2 disability by district

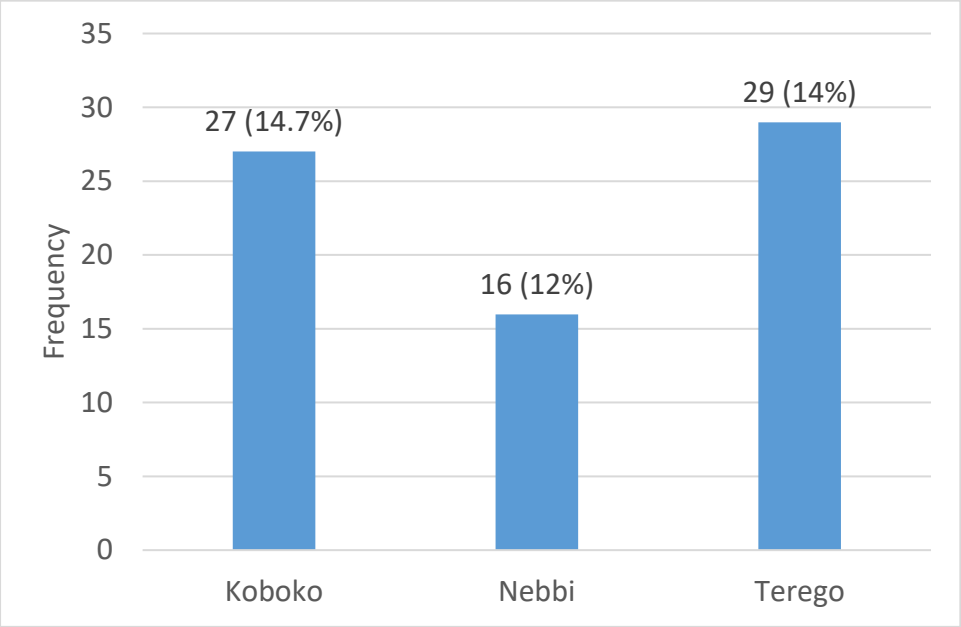
Figure 7: Grade 2 Disability at time of diagnosis



Terego district reported the biggest proportion of leprosy patients having grade 2 disability at the time of Diagnosis. All the Leprosy patients with grade 2 disability were adults above 15 years.

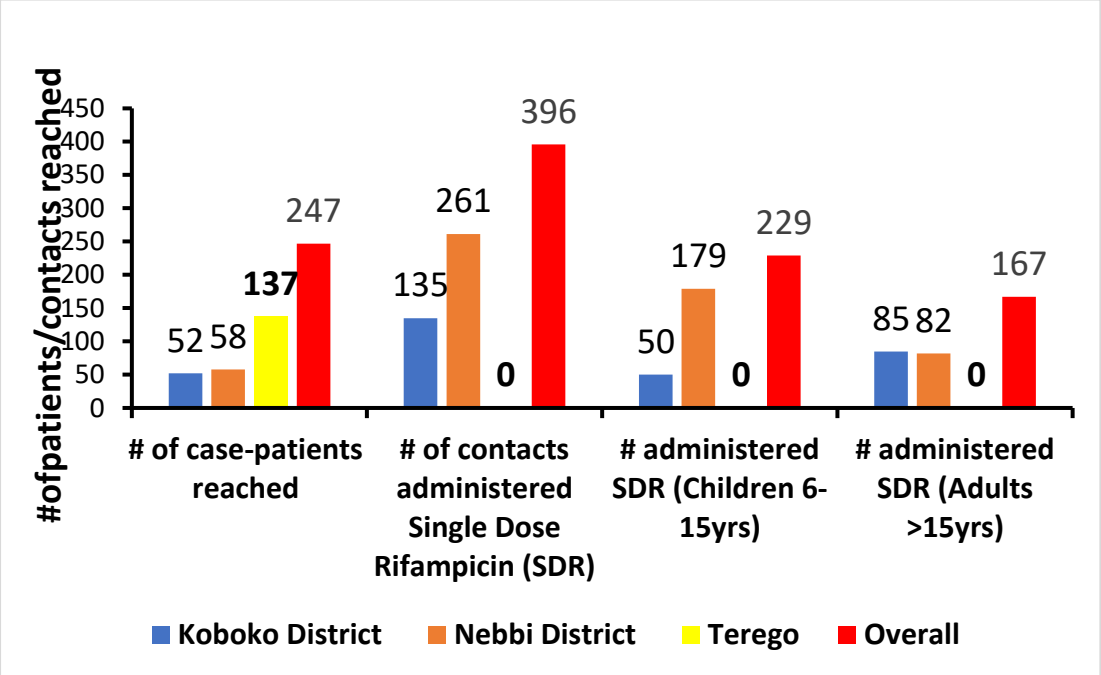
The proportion of the child leprosy patients in the three districts is shown in the Figure 7 Below.

Figure 8: Proportion distribution of child leprosy patients from 2020 - 2023



All the three districts showed a high proportion of Child leprosy cases but slightly less in Nebbi.

Figure 9: **Summary of contact screening activities**



During the investigation, the total number of contacts of leprosy patients that were screened was 427(34%). Of these 58% were children.

13 patients were diagnosed to have leprosy 10 from Terego, 2 from Nebbi and 1 from Koboko. The confirmed leprosy patients were house hold contacts. Below is a table showing the characteristics of these leprosy patients diagnosed during the contact tracing.

Figure 10: Characteristics of the leprosy patients confirmed during contact tracing

District	Age		Gender		Disability grade 2
	<15 years	>15 years	Female	male	
Terego	2	8	4	6	2
Nebbi	0	2	1	1	0
Koboko	0	1	1	0	0

Those that were eligible and received Leprosy post exposure prophylaxis were 396. 31 Contacts of leprosy patients did not meet the eligibility criteria to receive the Leprosy post exposure prophylaxis. The reasons for intelligibility are stipulated in the table below

Figure 11: Reasons for intelligibility to receive Leprosy Post exposure prophylaxis

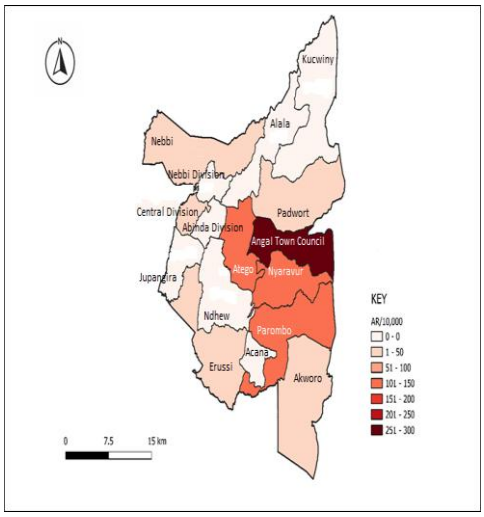
Reason for intelligibility	Number
Children below 2 years	14
Liver problems	3
Pregnancy	10
Refusal	4

Spatial distribution of leprosy patients in Koboko, Terego and Nebbi Districts

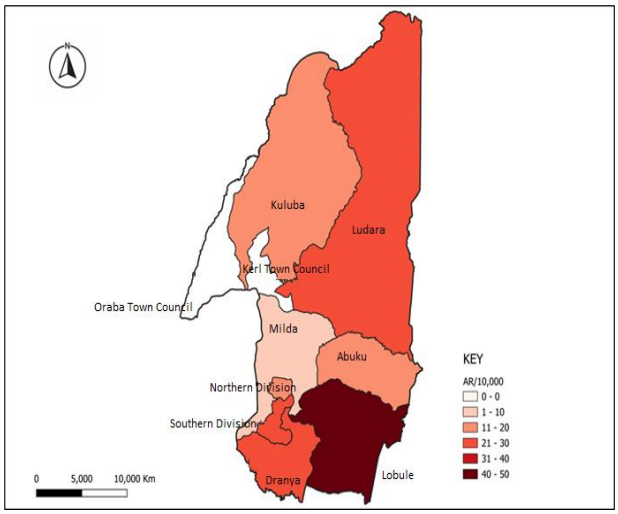
The maps in Figure 11 show the burden of leprosy in the three districts.

Figure 11: **Map showing distribution of leprosy patients in Nebbi and Koboko Districts**

Map of Nebbi

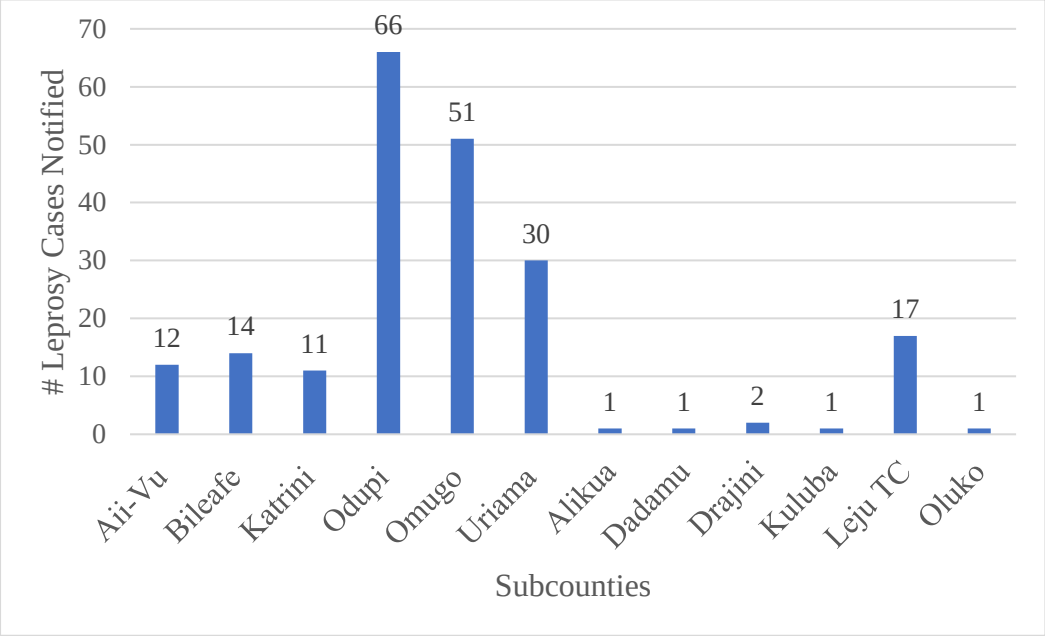


Map of Koboko



The sub counties with the highest number of leprosy patients reported were Angal and Lobule for Nebbi and Koboko Districts respectively.

Figure 12: Distribution of leprosy patient notified in Terego by geographical location

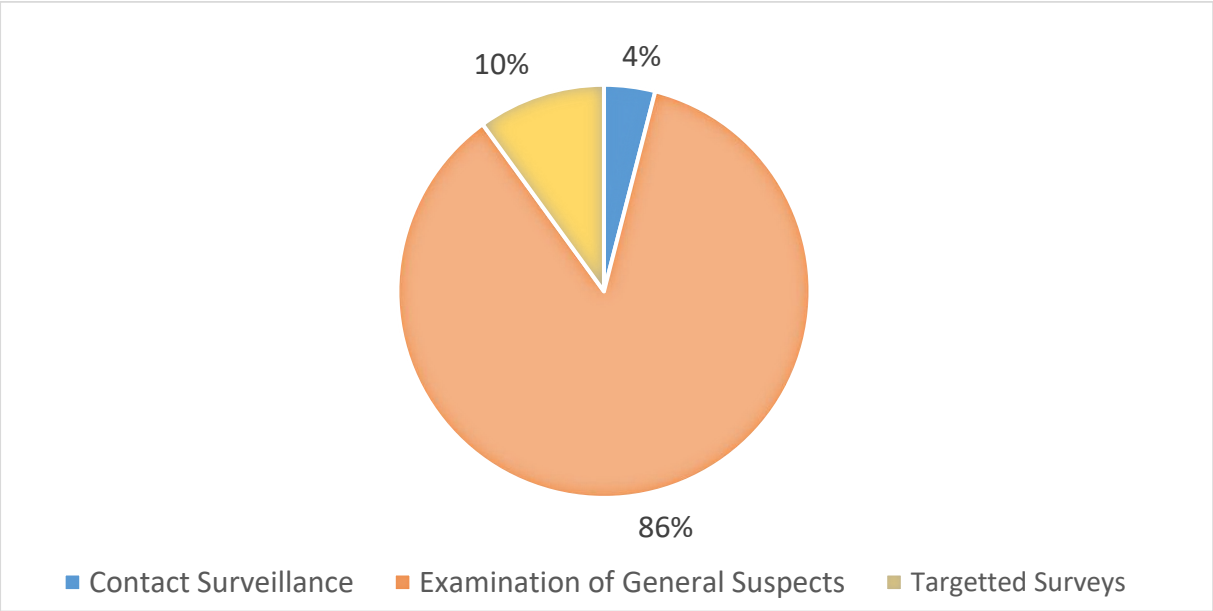


Most of the leprosy patients in Terego come from Odupi and Omugo Sub counties.

Leprosy patient detection methods

The figure 12 below summarizes the distribution of the different leprosy patient detection methods.

Figure 12: Proportion distribution of the different Patient detection methods for Koboko, Terego ans Nebbi Districts



Majority (86%) of the patients are detected through examination of patients that come to the health facilities and are suspected to have leprosy.

Possible risk factors

Hypotheses	Frequency	Number of index leprosy patients	%
History of travel to a more endemic country	19	40	48
No monthly income	15	40	40
Exposure to leprosy patient	13	40	33

Overall, 48% of the case patients in both districts reported having travelled to a more endemic country prior to their diagnosis of leprosy.

We therefore hypothesized that having a history of travel to a more endemic country was a predisposing factor for developing leprosy disease alongside poor social economic status.

Assessing the level of awareness and knowledge about leprosy among health care workers and the general population in Koboko, Terego and Nebbi Districts.

The finding was that there was a significant proportion 7 out of 15 (42%) were newly designated and recruited health workers with limited exposure to leprosy work hence limited knowledge especially on diagnosis and disability grading.

The current leprosy surveillance systems in West Nile and identify areas of improvement

Leprosy patients are reported by districts to the National Tuberculosis and Leprosy program with then compiles the data into quarterly reports. Leprosy data tools were available although some health facilities lacked Leprosy record cards. The electronic case based surveillance system is being implemented in about 30 % of the health facilities. some facilities lacking the knowledge

Discussion:

The presence of leprosy in children is a sensitive indicator for leprosy transmission. Usually, the proportion of child leprosy is closely linked with local leprosy prevalence. Among the countries with a high leprosy prevalence, such as Indonesia and Brazil, the proportion of children among new leprosy cases is high, at 11·9% and 7·9% respectively. (18) As compared with these leprosy endemic countries, Uganda is a low epidemic country. However, health worker's in Uganda still detect child leprosy cases each year with a percentage of 10% to 14%. High proportion of child leprosy patients in West Nile region signifies that the region**.**

Terego district reported the biggest proportion (33%) of leprosy patients having grade 2 disability at the time of Diagnosis as compared to Nebbi (1.5%) and Koboko (4.5%) Districts. This signifies that there is delayed diagnosis, inadequate contact tracing and limited access to leprosy related services. These findings highlight the need for context specific interventions to address grade 2disability in Terego district

Overall, 86% of the case patients in the three districts were multib-acillary type of leprosy. Consequently, numerous cases remain undiagnosed and untreated, and these individuals will act as continuing reservoirs of infection and have a profound impact on the maintenance of the chain of transmission.

Majority (86%) of the patients are detected through examination of patients that come to the health facilities and are suspected to have leprosy. The Health facility approach involves using the existing health care infrastructure to detect and manage leprosy. It is a convenient, but has limitations of dependence on patient self-reporting, and limited reach. However, studies done in Nepal revealed that the most effective approach is contact tracing (54%) followed by house to house visits (38%) in vulnerable populations and screening in prison (4%) (19). Hidden cases in the community can be identified and treated by active case detection

approaches, and these approaches are now included in the Uganda Zero Leprosy roadmap 2022-2030 (20).

Overall, 48% of the case patients in the three districts reported having travelled to a more endemic country specifically, Democratic Republic of Congo and South Sudan prior to their diagnosis of leprosy. We therefore hypothesized that having a history of travel to a more endemic country was a predisposing factor for developing leprosy disease alongside poor social economic status. The disease does not recognize borders, and thus, cooperation and coordination between neighboring countries are essential for effective elimination. Dedicating resources to shared research initiatives and implementing evidence-based strategies across borders can strengthen the drive towards a leprosy-free Uganda.

Overall, 48% of the case patients in both districts reported having travelled to a more endemic country prior to their diagnosis of leprosy. We therefore hypothesized that having a history of travel to a more endemic country was a predisposing factor for developing leprosy disease alongside poor social economic status. Other risk possible risk factors include: History of contact and poverty.

Conclusion: A total of 525(185- Koboko, 133- Nebbi and 207- Terego) patients were reported from 2020 to 2023. There were more females (58%) leprosy patients reported in all the three districts. The proportion of children below 15years was 14% and 33(5.3%) had grade 2 disabilities at the time of diagnosis. Most (93%) of the patients had the more severe type of leprosy. Majority (93%)of the patients were nationals. Most (93%) of the patients had the more severe type of leprosy. Majority (93%)of the patients were nationals. The sub counties with the highest number of leprosy patients reported were Angal and Lobule for Nebbi and Koboko Districts respectively. There was limited leprosy case finding in the communities and suboptimal integration of leprosy work into the rest of the district and health facility activities.

Recommendations: There is need for sustained contact tracing and SDR prophylaxis as well as improved cross border surveillance for leprosy. Heightened health education on leprosy, training of health workers at lower Health facilities and deeper integration of leprosy into other health programs is also recommended.

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